The following full text is a publisher's version.

For additional information about this publication click this link.
http://hdl.handle.net/2066/183426

Please be advised that this information was generated on 2019-02-25 and may be subject to change.
Engaging service-users in co-designing primary health care: assessing the potential of Participatory Learning & Action (PLA)

Mary O’Reilly-de Brún and Tomas de Brún
Engaging service-users in co-designing primary health-care: assessing the potential of Participatory Learning & Action (PLA)

Mary O’Reilly-de Brún and Tomas de Brún
Colophon
This thesis has been prepared by the Department of Primary and Community Care of the Radboud University Medical Centre, Nijmegen, the Netherlands. The Department of Primary and Community Care participates in the Netherlands School of Primary Care research (CaRe), which has been acknowledged by the Royal Netherlands Academy of Arts and Sciences (KNAW) in 1995.

Financial support
This thesis was made possible by funding support from:


EU Seventh Framework Programme (FP7)/2007-2013 (under Grant Agreement No: 257258) re: REsearch into Implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings (RESTORE) Project (2011-2015).

https://goo.gl/dj24Av

Cover: Mary O’Reilly-de Brún and Tomas de Brún
Design/layout: Twanny Jeiksman
Print: Ipskamp Printing, Enschede


Digital version of thesis: https://goo.gl/dj24Av

Copyright © Mary O’Reilly-de Brún and Tomas de Brún. All rights reserved.

Both authors contributed equally to the manuscript.
Engaging service-users in co-designing primary health care: assessing the potential of Participatory Learning & Action (PLA)

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.H.J.M. van Krieken,
volgens besluit van het college van decanen
in het openbaar te verdedigen op woensdag 7 maart 2018
om 14.30 uur precies

door

Mary O’Reilly-de Brún
geboren op 20 januari 1958
te Dublin, Ierland

en

Tomas de Brún
geboren op 8 september 1956
te Dublin, Ierland
Promotoren
Prof. dr. C. Van Weel
Prof. dr. A. MacFarlane, University of Limerick, Ierland
Prof. dr. M.E.T.C. van den Muijsenbergh

Copromotor
Dr. E.M. van Weel-Baumgarten

Manuscriptcommissie
Prof. dr. G.J. van der Wilt (voorzitter)
Prof. dr. M.J.F.J. Vernooij-Dassen
Dr. J. LeMaster, University of Kansas, Verenigde Staten

Paranimfen
Dr. Erik Teunissen
Edel Tierney
Engaging service-users in co-designing primary health care: assessing the potential of Participatory Learning & Action (PLA)

Doctoral thesis

to obtain the degree of doctor from Radboud University Nijmegen on the authority of the Rector Magnificus prof. dr. J.H.J.M. van Krieken, according to the decision of the Council of Deans to be defended in public on Wednesday March 7, 2018 at 14.30 hours

by

Mary O'Reilly-de Brún
born on January 20, 1958 in Dublin, Ireland

and

Tomas de Brún
born on September 8, 1956 in Dublin, Ireland
Supervisors
Prof. dr. C. Van Weel
Prof. dr. A. MacFarlane, University of Limerick, Ireland
Prof. dr. M.E.T.C. van den Muijsenbergh

Co-supervisor
Dr. E.M. van Weel-Baumgarten

Doctoral thesis committee
Prof. dr. G.J. van der Wilt (chairman)
Prof. dr. M.J.F.J. Vernooij-Dassen
Dr. J. LeMaster, MD, University of Kansas, United States of America

Paranimfen
Dr. Erik Teunissen
Edel Tierney
## Contents

**Chapter 1:** General Introduction 9

### Section I: Sub-Saharan Africa & the Republic of Ireland, 1993-2009

**Chapter 2:** The use of Participatory Learning & Action (PLA) research in intercultural health: some examples and some questions. 27

**Chapter 3a:** Own Goals and Penalties - a study of the needs of socially-excluded males in Dublin Inner City. 37

**Chapter 3b:** Hear Our Voices, Meet Our Needs: Women & Health. 101

### Section II: Exploring the use of PLA in primary healthcare research – Republic of Ireland, 2009-2011

**Chapter 4:** Using Participatory Learning & Action research to access and engage with ‘hard to reach’ migrants in primary healthcare research. 153

**Chapter 5:** Involving migrants in the development of guidelines for communication in cross-cultural general practice consultations: a participatory learning and action research project. 179

**Chapter 6:** Guideline for Communication in Cross-Cultural General Practice Consultations. 199

### Section III: Expanding the use of PLA in primary healthcare research: European application, 2011-2015

**Chapter 7:** Guidelines and training initiatives that support communication in cross-cultural primary care settings: appraising their implementability using Normalization Process Theory. 217

**Chapter 8:** Material practices for meaningful engagement: An analysis of participatory learning & action research techniques for data generation and analysis in a health research partnership. 231

**Chapter 9:** Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: An analysis of stakeholders’ experiences. 251

**Chapter 10:** Learning from doing: the case for combining normalisation process theory and participatory learning and action research methodology for primary healthcare implementation research. 281

**Chapter 11:** General Discussion 303

**Chapter 12:** Summary 321

**Samenvatting** 330

**Chapter 13:** List of Publications 339

**Curriculum Vitae – Mary O’Reilly-de Brún** 348

**Curriculum Vitae – Tomas de Brún** 351

**Acknowledgements** 353
‘If we had a keen vision and feeling of all ordinary human life, it would be like hearing the grass grow and the squirrel’s heart beat, and we should die of that roar that lies on the other side of silence.’

Mary Anne Evans (George Eliot), *Middlemarch*, 1861.
Chapter 1

General Introduction
Chapter 1

This thesis addresses the application and testing, in a variety of primary healthcare settings, of a practical, innovative research methodology intended to meaningfully engage service-users (patients) in co-designing primary health care that is responsive to their needs, expectations and values. It is based on empirical data collected in Austria, England, Greece, the Netherlands and the Republic of Ireland which assessed the feasibility and impact of the methodology as an approach for building community-based primary health care. An important aspect of this approach is the ability to include individuals and groups from communities that are considered ‘hard to reach’. In this thesis, the emphasis is on involving migrants as co-designers of their health care.

The thesis consists of three sections. Section I covers a range of participatory research projects involving vulnerable populations in sub-Saharan Africa and the Republic of Ireland over a period of years; the second and third sections cover the expansion of this early work into specifically primary health care projects. Sections II and III constitute the body of the thesis.


In this part of the thesis we describe preliminary work we conducted in sub-Saharan Africa and in the Republic of Ireland (1993 – 2009). Influenced by our anthropological background and the work of Robert Chambers, we explored the adaptation and application of participatory research methods to a range of health, education and social inclusion projects. The key aim of these projects was to help bridge the gap between the needs of communities and the provision of services at local, regional and national level. A key outcome of this preliminary work was evidence that participatory methods proved effective in eliciting, and making available to research, the perspectives of ‘hard to reach’ communities.

Section II: The Republic of Ireland 2009 - 2011

Based on this outcome, we applied participatory research methods in a project called ‘SUPERS’ (Service User PEer ResearcherS) in the Republic of Ireland (2009 – 2011). This study was based on a partnership between the national Health Services Executive’s Social Inclusion Unit, the Discipline of General Practice, National University of Ireland, Galway, and the Centre for Participatory Strategies, Galway. In response to the increase in the migrant population and challenges that arise when GPs and migrant service-users do not share language or culture, the study focussed on enhancing communication in cross-cultural general practice consultations in primary care. We trained established migrants to use participatory research methods to access and involve ‘hard to reach’ migrants in the development of a guideline to identify what communication strategies work best, for whom and in what circumstances. An innovative aspect of this study was the active inclusion of ‘hard to reach’ migrants, who, on the basis of inaccessibility, language-discordance and cultural difference, have been consistently excluded from participation in primary healthcare research. The purpose of the study was to address that gap, and to explore the feasibility of the methodology for meaningful engagement of migrant service-users in primary healthcare research. A key outcome of the study was evidence that migrants can positively influence the shape of healthcare research, expanding the

---

a Centre for Participatory Strategies (CPS), Galway, Ireland – further details are provided in Section II.
research agenda to incorporate the views and needs of ‘hard to reach’ and vulnerable populations in research that leads to innovations in health provision.

**Section III: European Union 2011 – 2015**

Following these experiences in the Republic of Ireland, the participatory research methodology was applied to a broader range of health settings and more diverse migrant populations in a European project called RESTORE (Research into implementation Strategies to support patients of different ORigins and language background in a variety of European primary care settings) from 2011 – 2015. The objective of RESTORE was to investigate and support the implementation of guidelines and training initiatives (G/TIs) to enhance communication in cross-cultural primary care consultations. The study involved migrant service-users across five diverse primary care settings: Austria, England, Greece, the Netherlands and the Republic of Ireland. In this final section of the thesis, our aim is to describe and analyse how we used the participatory methodology and practical techniques to engage migrant service-users and healthcare professionals in inter-stakeholder dialogues to co-generate and co-analyse data in order to democratically select a G/TI for future implementation at local level. The thesis illustrates the potential of a participatory methodology to enable stakeholder-centred knowledge to feed into the development of responsive community-based primary health care in a way that is congruent with its core values: collegiality, empowerment, co-responsibility and stakeholder self-efficacy.

**Anthropologists in primary health care: a personal trajectory**

In this thesis, we bring together the domains of primary health care and anthropology, specifically, participatory research methodology. As social-cultural anthropologists, we have gained an understanding of the importance of the dynamics of culture, respect for cultural diversity and an awareness of the potential of participatory research. From our engagement in primary healthcare research, we understand that the role and function of primary healthcare is to respond appropriately to the diverse and changing needs of culturally complex communities. In 2002, we established the Centre for Participatory Strategies (CPS). By 2009, through our healthcare-related work at the Centre, we had become aware of the potential of participatory research for developing responsive primary healthcare. We saw a close correspondence between core principles and pragmatics of participatory research and the core values of primary healthcare – *collegiality, empowerment, co-responsibility* and *stakeholder self-efficacy*. These values are mirrored in participatory research: *collegiality* (via inclusive and active engagement in the research process), *empowerment of all stakeholders* (by balancing asymmetrical power-relations), *co-responsibility* (via co-generation and co-analysis of data) and *stakeholder self-efficacy* (through the exercise of power in contributing to research outcomes). This indicated the significant potential of participatory research to support the ambition of building community-based primary healthcare from the ‘bottom-up’. To achieve this, the perspectives and expert knowledge of all key stakeholders (service-users and service-providers/health professionals) need to be brought into productive inter-stakeholder dialogue for the development of a responsive health care system – this is what a participatory approach can achieve. This fuelled our interest in projects such as SUPERS and RESTORE.
Chapter 1

Objective and aims of the thesis

The overall objective of this thesis was to assess the potential of using a participatory approach and methods to meaningfully involve ‘hard to reach’ or vulnerable populations in co-designing primary healthcare that is responsive to their needs, expectations and values.

In our preliminary studies in sub-Saharan Africa and Ireland, which focussed on education, social inclusion and healthcare, we set out to explore the potential of the methodology to actively engage stakeholders from vulnerable and ‘hard to reach’ populations in research that enabled their perspectives to emerge clearly in research outcomes.

In SUPERS, through a national collaboration which focussed on migrant health, we explored the possibility of meaningfully involving ‘hard to reach’ migrants from ethnically diverse communities as key stakeholders in research to co-design a specific healthcare intervention, in this instance, a ‘best practice’ guideline intended to enhance cross-cultural communication in general practice consultations.

In RESTORE, through an international collaboration which focussed on healthcare for migrants, we expanded the study across five diverse primary care settings: Austria, England, Greece, the Netherlands and the Republic of Ireland. The overall objective of RESTORE was to investigate and support the implementation of guidelines and training initiatives to enhance communication in cross-cultural primary care consultations. In this thesis, we focus on the use of participatory methods to meaningfully involve migrants as key stakeholders in inter-stakeholder dialogues designed to critically appraise and democratically select a guideline or training initiative for future implementation at local level.

Below, we summarise the essentials of primary health care, followed by a summary of key principles and pragmatics of participatory research. We describe the research context and target stakeholder group. We provide an outline of the thesis chapters and a note regarding the defence of this ‘double-book’.

The essentials of primary healthcare – a summary

Most countries experience major challenges to their health systems. Factors behind this global trend include increasing health costs and diminished returns on investment for aging populations. Where the primary health care function is formally structured in the health system, and professionals are educated for their specific tasks, the performance of the system is often optimised: better primary health care leads to better population health, fewer hospitalizations, better socio-economic equity and lower health care costs.6-10

Strengthening primary healthcare is a global strategy for overall sustainable healthcare11, based on generally accepted principles of an integrated, generalist, person-centred approach to all health problems in all stages of life for all individuals.12-15 In the ecology of medical care, primary care is the connecting point between the community and the health system, and provides care for the large
majority of health problems that individuals present. Core features include continuity of care, embedded in a lasting relationship between service-users and professionals, and empowerment, self-determination, prevention and health promotion. The rationale for the focus on the service-user’s active role is that the contribution of professional providers is limited compared to self-care and lay support: the majority of most people’s health problems are cared for (or self-cared) most of the time at home in their living environment.

A critical feature of the primary health care strategy is the adaptation of general principles to local conditions. The role and function of primary healthcare is to respond to the needs of a population-under-care, fine-tuning that care to the community level and the prevailing health challenges where it has to operate and pro-actively promoting self-efficacy in empowering that community.

This can only be achieved when primary health care is informed by the actual health needs of the population it serves. General knowledge of a population, therefore, has to be augmented by specific and contextualised knowledge of individuals, groups and communities. Efficient, robust, responsive primary healthcare depends, then, on understanding the needs, values and expectations of diverse communities, how they are affected by the social and cultural determinants of health and how this may change over time.

This understanding can, to a large extent, only be gained through involving service-users, service-providers and other key stakeholders as partners in a ‘bottom-up’ research approach oriented towards co-determining appropriate healthcare policies and practices. To realise the ambition of building community-based primary healthcare in this way, three aspects of primary health care are of particular importance for the research approach and methodology assessed in this thesis:

- **The community basis orientation**: because communities differ, even within countries and regions, and population demographics and social determinants of health may change over time, the methodology must be flexible and applicable to a broad range of populations. The capacity of the methodology to involve the most vulnerable groups and the ‘hard to reach’ is of particular importance.

- **The empowerment of populations and individuals**: in order to support communities and individuals to co-determine their health care, the methodology must be capable of involving service-users in roles that go beyond that of ‘information-providers’ or passive participants in a tokenistic consultative process. The methodology must be capable of engaging service-users in a meaningful way: involving them in a robust research process which enables their unique knowledge and perspectives to emerge, and incorporating their needs, expectations and values into the co-design of their health care.

- **Changing the perspectives of service-users and service-providers**: at the core of empowerment is positive and appropriate change. This involves ‘shifts in perspective’ wherein values, attitudes, ideas and notions undergo some alteration, or some re-orientation, and may be expressed in concrete positive action or behaviour. To achieve this, the methodology has to be capable of maintaining an environment of safety and trust.
within which meaningful inter-stakeholder dialogue can unfold, facilitating democratic co-design and co-determination of appropriate and responsive health care.

The research methodology presented in this thesis fosters reciprocal learning and ongoing dialogue between stakeholder groups (e.g., service-users and service-providers). This inter-stakeholder dialogue may prompt important ‘shifts in perspective’ for all parties, reducing barriers and increasing stakeholders’ capacity to democratically co-design and co-determine appropriate interventions. This can support the educative potential of a bottom-up approach to primary healthcare research – facilitating positive change in the perspectives, attitudes and behaviours of service-users and providers.

**Key principles and pragmatics of participatory research – a summary**

In the fields of sociology and anthropology, research methods and techniques have been developed for a ‘bottom-up’ research approach that involves diverse communities and stakeholders in active, meaningful research partnerships. By the 1980’s, we see a blossoming of participatory research methods in development studies in the global south\(^{22-25}\) and in the 1990’s, we see their application to health research in North American studies of first nation communities.\(^{26,27}\) This growing family of participatory approaches is not a monolithic body of ideas and methods, but a pluralistic orientation to knowledge-making and social change, and this is their overarching connection. ‘Family members’ include Participatory Research (PR)\(^{28-30}\) Participatory Action Research (PAR)\(^{31,32}\) Community Based Participatory Research (CBPR),\(^ {33-39}\) Participatory Rural Appraisal (PRA)\(^ {40,41}\) and Participatory Learning & Action (PLA).\(^ {42,43}\) All can be described as ways of doing research with people, not on them; they share a democratic ethos, are strongly committed to meaningful engagement by stakeholders, and promote research partnerships that, for example, strengthen relations between academy and community.\(^ {44-48}\) These participatory approaches emphasise the need for stakeholders’ active engagement across the full range of research activities, including data-generation and data-analysis.\(^ {49}\) They also share a commitment to fostering positive change, for example, stakeholders may also become actively engaged in planning and implementation of an agreed change, innovation or intervention, as illustrated in the vignette below:

**Vignette: The Gambia – how active community engagement in participatory research influenced education policy**

A participatory research process conducted across seven village communities in The Gambia, West Africa (1993/1994) actively involved ‘local experts’ (e.g., parents, teachers, young women, community leaders, entrepreneurs) as key stakeholders in the completion of a range of PLA techniques, including ‘Seasonal Calendars’. These charts identified existing socio-economic and socio-cultural barriers to girls’ education, connected with potential solutions. A key barrier was the timing of school fee payments – these fell due during the ‘hungry season’ (before the harvest), when parents did not have any spare money to invest in school fees for girls. The Seasonal Calendar data, with the potential solutions suggested by local experts, were presented by community representatives to Ministry of Education officials. The ensuing inter-stakeholder dialogue resulted in significant revisions in Ministry of Education policy: a 50% reduction in tuition fees at junior/secondary
level coupled with an agreement that other school costs (books, uniforms etc) could be paid after the harvest, when parents were better able to afford these costs. Ministry officials, who had serious concerns about the low numbers of girls attending primary school, acknowledged the effectiveness of beginning with participatory research engagement in rural communities and building on what local groups defined as important problems and workable solutions. The Ministry was able to tap into both external and internal resources and expertise in such a way that education initiatives co-designed on this integrated basis had a much greater chance of success. The Ministry was able to re-think and re-shape education policy objectives in line with the aspirations and limitations of the communities. A change in the Education Act relaxed the requirement that girls wear uniforms (thus reducing school costs) and this encouraged greater participation of girls in schooling.

Clearly, policy changes of this nature and at this level are a welcome and significant outcome of community engagement, but there were also interesting smaller-scale spin-offs: for example, reflecting insights gained from the participatory process, the new ‘relaxed uniform’ policy encouraged entrepreneurial mothers involved in the local fabric trade to design and produce ‘uniforms’ for girls based on locally-appropriate everyday dress, which were affordable and even considered ‘fashionable’, further encouraging girls’ participation in primary education.

### Participatory Learning & Action (PLA) – core principles

In this thesis, Participatory Learning & Action (PLA) was the participatory research methodology applied. Reasons for this include the fact that, as a form of action research rooted in the interpretive and emancipatory paradigms and strongly linked to social justice movements, PLA is suited to healthcare research with stakeholders whose perspectives might strongly diverge and amongst whom asymmetries of power might exist. While there is evidence of the use and impact of PLA in other contexts and disciplines, it is not commonly used in academic primary care research but shows significant promise. The core principles of PLA can be described in terms of a range of key reversals of attitude, behaviour and practice, outlined below:

<table>
<thead>
<tr>
<th>Centralised decision-making</th>
<th>De-centralised democratic decision-making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top-down research approach and design</td>
<td>Bottom-up research approach and co-design</td>
</tr>
<tr>
<td>Identifying and accessing research participants/stakeholders/groups that are almost exclusively professional, elite, powerful</td>
<td>Identifying and accessing research participants/stakeholders/groups that include and privilege the least powerful, the marginalised, ‘lay’ people</td>
</tr>
<tr>
<td>Stakeholders are perceived solely as passive beneficiaries of research</td>
<td>Stakeholders are actively involved as partners and collaborators in research as well as beneficiaries of research</td>
</tr>
</tbody>
</table>
Dominating attitudes, behaviours & practices

Empowering attitudes, behaviours & practices

<table>
<thead>
<tr>
<th>Exerting ‘power over’ others – hierarchical relationships (for example, speaking but not listening)</th>
<th>Sharing power with others – reciprocal and mutually empowering relationships (for example, listening and hearing each other’s voices/perspectives)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assuming knowledge is located solely in professional and elite groups</td>
<td>Exploring and exchanging the complex knowledges available in all stakeholder groups (because all have expertise)</td>
</tr>
<tr>
<td>Relying on verbal interactions; generally one-to-one, using questionnaires/semi-structured interview schedules designed in a top-down manner</td>
<td>Relying on combination of verbal, visual tangible interactions; group activities (mapping, charting, diagramming, discussing) using familiar physical materials</td>
</tr>
</tbody>
</table>

Analytical assumptions: reductionist

Analytical assumptions: holistic, systemic

| Research agenda is pre-set; research methods are pre-decided and linear; data-analysis is extractive. | Research agenda is open/ evolving; research methods are organic and flexible; research processes are iterative/ cyclic; data-analysis is interactive (co-analysis by and with stakeholders). |

We cannot ignore the impact of asymmetrical power relations in academic research, and these reversals acknowledge that. For example, decisions about who is included or excluded in a research project radically affect research outcomes. In order to ‘level the playing field’ we need to enact these reversals, ensuring the meaningful engagement of the most vulnerable stakeholders throughout the research process.

To capture what this means in the exercise of research activities in real time and space, we speak of a ‘PLA mode of engagement’ which promotes reciprocity, mutual respect, co-operation and dialogue. The core function of PLA is to draw stakeholders together in an ‘inter-stakeholder dialogue’ with a view to generating creative solutions to commonly-shared problems and identifying beneficial actions and/or interventions. This dialogue requires a trusting relational environment, a ‘safe space’ where stakeholders are encouraged to respect a diversity of views and experiences, and to learn from each other’s perspectives. All stakeholders are understood to possess expert knowledge about their own lives and conditions. They bring this to the ‘stakeholder table’, where implicit knowledge becomes explicit, and much that might otherwise remain hidden becomes available to the research endeavour. When stakeholders engage each other ‘at the table’, the shared, enhanced learning they gain provides the broadest possible knowledge-base for them to work with as they co-generate and co-analyse research data. Shifts in understanding and changes in perspective often occur and this sustained inter-stakeholder dialogue supports creative co-design of interventions and collaborative planning for positive action and implementation.
PLA techniques

To facilitate inter-stakeholder dialogue, we utilise a wide range of practical PLA research techniques (tools, methods) which are designed to be active, inclusive, user-friendly and democratic. These techniques help to balance asymmetrical power-relations and appeal to a wide range of stakeholder groups, ensuring that all (particularly the least powerful) become involved in a meaningful way in research. The techniques are inclusive of those who may face literacy and/or numeracy challenges, helping to ensure that they do not become disenfranchised during the research process. PLA techniques combine the visual, verbal and tangible. Stakeholders work together to generate visual maps, charts and diagrams which function as powerful reference points, or ‘data-displays’. They engage in ongoing verbal interaction – discussing, questioning, and learning from each other’s perspectives, adding new data to maps and charts. As stakeholders use PLA techniques to assess, correlate, categorise and/or prioritise data, they are also engaging in an inherently co-analytical activity. PLA techniques, therefore, have the capacity to facilitate meaningful engagement that automatically incorporates co-analysis of data. In a very practical way, then, diverse stakeholders become involved in a structured, integrated, visual-verbal-tangible process of co-generating and co-analysing data which produces visual tangible results. This may occur during a single research session, or iteratively and in successive waves of fieldwork and/or data-generation encounters. Stakeholders bring their unique knowledge and insights to bear on emerging findings; their perspectives influence the conduct and trajectory of research and research outcomes. This is a key hallmark of meaningful engagement. Meaningful engagement in inter-stakeholder dialogue through the use of PLA techniques can enable stakeholders to co-design and co-determine appropriate and responsive health care that meets their unique needs, values and expectations.

Research context and target stakeholder group

The studies presented in this thesis took place against the background of a Europe that is becoming increasingly multicultural, with recent rapid growth in the numbers of migrants with non-Western backgrounds and cultures and personal histories of stress, deprivation, conflict and violence. In 2014, there were 33.5 million migrants living in the European Union, 6.7% of its population, a number that has further increased in recent years. The capacity of host countries to cope with increasing health demands has also been negatively affected by the global financial crisis, which resulted in extensive cutbacks in health spending across Europe. These factors affected all research locations, albeit to different degrees.

In such circumstances, additional and specific challenges arise for host societies, including their health care systems, and for migrants themselves. Migrants’ health outcomes are less favourable, access to healthcare is more difficult especially for vulnerable or undocumented migrants, and many may be unaware of their rights regarding provision of healthcare services. Infectious diseases, mental health problems and non-communicable diseases are common in migrants. This makes them a vulnerable group whose needs might be poorly addressed, and this lends urgency to the task of improving health systems’ responsiveness to culturally and ethnically-diverse populations. Improving responsiveness to such populations is important in primary care, as it is the entry point to, and main provider of health care for all service-users and deals with a wide range of health
The fundamental importance of communication in general practice is amplified in cross-cultural consultations involving migrants where additional language and cultural difficulties exist. In such situations, it is often a challenge for the service-user and the GP or service-provider to surmount language and cultural barriers sufficiently to develop the necessary trusting relationship, and ensure clinical effectiveness, particularly when informal rather than professional trained interpreters are used. For that reason, international organizations have called for primary health care to be provided in a culturally appropriate way. However, we face a key problem: vulnerable groups in multi-cultural societies tend to be excluded from participation in healthcare research on a variety of grounds (e.g., inaccessibility, language discordance, cultural difference) but these grounds are not sufficient to exclude them. Rather, it presents us with an incentive to identify and explore, for example, research methodologies capable of enhancing access and promoting meaningful engagement of vulnerable groups in primary care research. These facts and concerns are central to an understanding of the research context and an appreciation of the needs of the target stakeholder groups described in this thesis.

Outline of thesis papers

Chapter 1: General Introduction

Section I: Sub-Saharan Africa & the Republic of Ireland, 1993-2009.

Chapter 2: The use of Participatory Learning & Action (PLA) research in intercultural health: some examples and some questions.
This paper is an overview of preliminary work, describing our adaptation/exploration/application of PLA methodology and techniques with various types of vulnerable groups in a range of socio-cultural contexts, across a range of research foci/topics, and in several countries.

Chapter 3a: Own Goals and penalties - a study of the needs of socially-excluded males in Dublin Inner City.
This paper is an example of a specific application of PLA in a research project with a vulnerable group of homeless men who experience social exclusion in an inner-city environment in Dublin, Ireland.

This paper is an example of a specific application of PLA in a national multi-focus research project involving women & the national strategy for women’s health in Ireland.
General introduction

Section II: Exploring the use of PLA in primary healthcare research – Republic of Ireland, 2009-2011.

In Section II, we present papers describing the use of PLA in primary healthcare research with multi-stakeholder groups in Ireland (including migrants and health professionals). These stakeholders engaged in PLA inter-stakeholder dialogues to democratically co-design a best-practice Guideline for cross-cultural communication in general practice consultations.

Chapter 4: Using Participatory Learning & Action research to access and engage with ‘hard to reach’ migrants in primary healthcare research.
Established migrants (trained in PLA techniques) facilitated a PLA inter-stakeholder dialogue with ‘hard to reach’ migrants and healthcare professionals with a view to generating a best-practice guideline for communication in cross-cultural general practice consultations.

Chapter 5: Involving migrants in the development of guidelines for communication in cross-cultural general practice consultations: a participatory learning and action research project.
This paper notes key outcomes of the multi-stakeholder PLA dialogue (Chapter 4), which fed into the Guideline mentioned below (Chapter 6).

Chapter 6: Guideline for Communication in Cross-Cultural General Practice Consultations.

Section III: Expanding the use of PLA in primary healthcare research: European application 2011 – 2015

In Section III, we present papers describing the use of PLA in a broader range of primary care settings in Europe with a greater diversity of vulnerable groups. The RESTORE project was the overall context in which our PLA work expanded; our focus is on the assessment of PLA as a methodology for meaningful engagement in inter-stakeholder dialogues where co-generation and co-analysis of data enabled stakeholders to democratically select a G/TI for future implementation at local level.

Chapter 7: Guidelines and training initiatives that support communication in cross-cultural primary care settings: appraising their implementability using Normalization Process Theory.
de Brún T, O’Reilly-de Brún M, van Weel-Baumgarten E, van Weel C, Dowrick C, Lionis C, et al. Guidelines and training initiatives that support communication in
Chapter 1


Describes the mapping process used to identify a small range of G/TIs potentially appropriate for implementation at local level in diverse primary care settings in RESTORE.

Chapter 8:  Material practices for meaningful engagement: An analysis of participatory learning & action research techniques for data generation and analysis in a health research partnership.


This paper describes the application of 2 core PLA techniques used across diverse RESTORE primary care settings to enable stakeholders to select a single G/TI for future implementation at local level.

Chapter 9:  Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: An analysis of stakeholders’ experiences.


This paper presents an analysis of stakeholders’ experiences of engaging in PLA and presents a structure describing what makes for a positive and productive PLA inter-stakeholder dialogue.

Chapter 10:  Learning from doing: the case for combining normalisation process theory and participatory learning and action research methodology for primary healthcare implementation research.


This debate paper is an account of the rationale for combining PLA with a contemporary social theory, Normalisation Process Theory (NPT) which was an important feature of the overall context of the RESTORE project. The paper expands the thesis by alerting us to the heuristic potential of PLA for the field of implementation research: how PLA (as an ‘action experiment’) may be used to practically address implementation challenges, issues, possibilities and options that may arise during an implementation ‘journey’. This use of PLA enables us to achieve deeper understandings of implementation contexts and processes.

Chapter 11:  General Discussion

Chapter 12:  Summary
Samenvatting

Chapter 13: List of Publications
Curriculum Vitae – Mary O’Reilly-de Brún
Curriculum Vitae – Tomas de Brún
Acknowledgements

Thesis Defence

This thesis is built on a joint scholarly project of which Mary O’Reilly-de Brún and Tomas de Brún are each accountable for the full content. For the defence, Mary O’Reilly-de Brún will be responsible for Chapters 3b, 4, 5, 6 and 8, while Tomas de Brún will be responsible for Chapters 2, 3a, 7, 9 and 10.

References

Chapter 1


71. O’Donnell CA, Higgins M, Chauhan R, Mullen K. “They think we’re OK and we know we’re not”. A qualitative study of asylum seekers’ access, knowledge and views to health care in the UK. BMC Health Serv Res 2007; 7: 75. 9.


Section I: Sub-Saharan Africa & the Republic of Ireland
1993-2009
Above: Villagers’ map, showing key buildings, roads and tracks, animal corrals, vegetable gardens, household compounds, male and female parents, primary school, mosque, numbers of primary school-going male and female children and household literacy levels.


Left: Villagers’ matrix of problems and solutions related to girls’ education, showing top-scored solutions.


Below: Auntie Mengeh, Headmistress, explains elements of a Seasonal Calendar to Tomas and Mary, describing levels of income, outgoings, and school fees related to wet and dry seasons.

Chapter 2

The use of Participatory Learning & Action (PLA) research in intercultural health: some examples and some questions

Translocations: Migration and Social Change
An Inter-Disciplinary Open Access E-Journal
ISSN Number: 2009-0420

O’Reilly-de Brún M
de Brún T
The Centre for Participatory Strategies (CPS)
The Centre for Participatory Strategies (CPS) was established in 2002 and is located in Galway, Ireland. CPS is an independent research and training organisation. The co-founders, Mary O’Reilly-de Brún and Tomas de Brún, are cultural anthropologists with over twenty years’ international experience in applied cross-cultural research, lecturing in cultural anthropology and participatory research methods, and the development and delivery of innovative participatory research training.

Introduction
While lecturing in the Department of Anthropology, NUI Maynooth during the 1990’s, we became interested in the work of Robert Chambers and the developing field of participatory research. Chambers identified a serious ‘gap’ in development research in the global south: local people were usually missing from the stakeholder table and many internationally-funded projects were failing to achieve their intended aims (Cernea, 1985). Chambers worked with communities to develop Participatory Rural Appraisal (PRA), a research approach which included and privileged ‘local experts’ (e.g., community representatives/service users) as key stakeholders in research. Much of Chambers’ work was applied to the field of rural appraisal. Influenced by his work, we pioneered the adaptation and application of participatory approaches and techniques to other fields of research and international development: intercultural health, gender, and development education. We now use the term Participatory Learning and Action (PLA) to describe our work.

Between 1993 and 2001, we worked closely with communities across seven countries in sub-Saharan Africa: Senegal, Mauritania, The Gambia, Guinea-Bissau, Ghana, Kenya and Tanzania. This was possible via co-operation with UNICEF and AIFA-POLOP (a local NGO in Guinea-Bissau); ACTION AID (Senegal); the WORLD BANK (Norwegian Regional Education Programme for the Sahel: Senegal, Mauritania, The Gambia) and the Danish Centre for Development Co-operation (Tanzania).

During this time, we worked in small villages, larger communities and academic institutions, focussing on bridging the gap between communities and policy-makers at local, regional and national level. We trained indigenous PLA research teams who were competent to work with local communities in local tribal languages and with cultural sensitivity. Because PLA, by its nature, is culture-sensitive and context-specific, these peer-facilitated PLA processes had the potential to make visible, rather than occlude, diverse cultural ‘knowledges’. This provided possibilities and opportunities for intercultural conversations, and, where judged appropriate or necessary, mediation and/or brokerage. This brokerage maintained communication among key stakeholders who were central to the development of sustainable local action and national policy. Solutions generated via these PLA processes were sometimes acted upon at the local level, while other solutions fed into the development of national policy. In some instances, national policies were amended because of the evidence-based research produced via these PLA processes (World Bank Report, 1995; Kane, Bruce and O’Reilly-de Brún, 1998; Kane and O’Reilly-de Brún, 2001).

By 2002, it had become clear to us that there was potential for the application of PLA approaches, methods and techniques in the Irish context, and we established the Centre for Participatory Strategies to provide research training and applied research expertise to a range of Irish
The use of Participatory Learning & Action (PLA)

organisations, individuals and communities who were interested in developing a participatory capacity.

**Key Features of Participatory Learning and Action (PLA)**

Participatory Learning and Action (PLA) is a way of doing research with people, not on them, and is best described as a growing family of approaches and methods that enable local people to share, enhance and analyse their knowledge of life and conditions in order to plan collaboratively for positive action (Chambers, 1994). By using a PLA approach and a range of PLA techniques, research activities previously appropriated by outsiders are instead carried out by local people themselves (e.g., service users) and this has significantly altered the practice of community-based research, not just the rhetoric. The practice of PLA, then, involves a range of important ‘reversals’:

<table>
<thead>
<tr>
<th>REVERSALS FROM...</th>
<th>TO...</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Speaking</td>
<td>• Listening &amp; hearing</td>
</tr>
<tr>
<td>• Assuming knowledge</td>
<td>• Sharing complex ‘knowledges’</td>
</tr>
<tr>
<td>• Dominating</td>
<td>• Empowering</td>
</tr>
<tr>
<td>• Verbal</td>
<td>• Visual</td>
</tr>
<tr>
<td>• Top-down</td>
<td>• Bottom-up and sideways in</td>
</tr>
<tr>
<td>• Participants seen solely as beneficiaries</td>
<td>• Participants seen as partners, collaborators and beneficiaries</td>
</tr>
<tr>
<td>• Service provision conceived as ‘supply-push’ from service providers towards service-users, with little or no service user involvement</td>
<td>• Service provision conceived as ‘demand-pull’ from service-users with extensive service user involvement in service design and delivery</td>
</tr>
</tbody>
</table>

- PLA encourages key stakeholders (e.g., service users, health service planners and providers, community development organisations, statutory agencies and policy makers) to focus together on issues of joint concern, to address these issues creatively and to generate positive solutions to commonly-experienced problems.

- In PLA, key stakeholders are encouraged to learn from each other’s perspectives and acknowledge each other’s expertise. Trust, rapport and mutual respect builds up in the early stages of a PLA engagement and this supports the ongoing work. Because decision-making is shared, and differentials in power are acknowledged and addressed, a balanced discussion and careful assessment is capable of generating positive interventions and actions that are likely to be sustainable over time.

- PLA is a holistic research approach; we set out to understand the research issue with reference to the wider context in which people’s lives are lived, and within which key
experiences of interest to the research are lived out.

- PLA also takes the uniqueness of a group or community into account; actions that emerge via participatory processes are likely to be culturally sensitive and appropriate.

- PLA research is organic and iterative in nature. Ideally, stakeholders engage in cycles of research, co-analysis, reflection and interaction over time in order to work out the details of recommendations for action that emerge from the research process.

- PLA practitioners are eclectic - we draw on a wide range of tools and techniques: diagramming, mapping, ranking, semi-structured interviews, case-studies, narratives (Seale, 1998; Silverman, 1993). From the field of applied anthropology, we draw on participant observation and emic and ethnographic interviewing (de Brún and O’Reilly-de Brún, 2009; Pelto and Pelto, 1970; Spradley, 1979).

- In traditional research processes, research participants are seen as ‘informants’ and research is usually designed solely by academics. In contrast, PLA often includes research participants as collaborators in the development and design of the research process itself, as co-analysts of research data and as co-authors and co-presenters of research results.

- PLA also encourages the involvement of research participants in the implementation of service planning and provision. Typically, services are designed and planned by providers with little service-user involvement. In contrast, PLA promotes user-informed service provision. Service-user involvement tends to ensure that interventions and/or actions hit the mark, and genuinely benefit those for whom they are intended (de Brún & du Vivier, 2008).

- In support of service-user involvement, PLA facilitates the building of new forms of relationship between service users, health planners and providers, statutory agencies, relevant community development organisations and policy makers. These relationships of trust create opportunities for experiences of inclusion and integration among the stakeholders involved. This promotes a strong sense of co-ownership over the entire research process and its outcomes. This commitment to the development of relationships of trust, sustained over time, characterises PLA and sets it apart as a form of engagement that goes beyond traditional forms of consultation.

- Finally, PLA is particularly suited to researching sensitive topics – for example, intercultural health, ethnicity, racism, social exclusion and issues of social integration.

Since the 1990’s, PLA approaches have developed and been applied in many countries and in many contexts, mirroring the global shift away from top-down approaches and towards genuine participation at local level. PLA can be used to explore any topic with any group in almost every context. PLA is particularly suitable for engaging with ‘hard-to-reach’ groups to develop services and strategies that are:

- fit-for-purpose
- cost-effective
• appropriate to the real needs of service users, and
• capable of contributing significantly to social inclusion and social integration.

A commitment to service-user involvement in intercultural health provision in multi-cultural Ireland

In 2002, CPS was established within the context of an increasingly multi-cultural Ireland that was rapidly coming to terms with this complex reality. While still providing participatory research training, our primary areas of interest now include a strong focus on the use of participatory strategies to improve service-user involvement in intercultural health provision. We recognise that health provision always occurs within the challenging context of social integration.

The Centre has developed a strong collaboration with the Discipline of General Practice, NUI Galway, and this collaboration has resulted in Health Research Board (HRB) funding and HSE support (Social Inclusion Unit) to engage in participatory research with a range of key stakeholders concerned about language and cultural barriers in cross-cultural General Practice consultations.

The following are examples of participatory research we have engaged in:

Communication with Asylum Seekers and Refugees (CARe) 2002-2005

The CARe (Communication with Asylum Seekers and Refugees) project, led by the Discipline of General Practice, NUI Galway, focussed on experiences of the language barrier in Irish general practice (MacFarlane, 2008, 2009). CPS collaborated by training a small group of asylum seekers and refugees to engage in participatory peer research with ethnic minority service users in Galway (2003). This training enabled the peer researchers to reach ‘hard-to-reach’ groups and to engage with them in a culturally-sensitive and language concordant manner. Clearly, this raises the comfort level for research participants, develops strong rapport between researchers and participants, and promotes greater social inclusion.

Following project completion, CPS designed a reflexive participatory evaluation with the CARe peer researchers. This involved the peer researchers as co-designers of evaluation criteria, and this brought unexpected and unanticipated ‘knowledges’ to the fore. For example, the CARe peer researchers described how their identities, and the perception of their identities by others in their communities, had altered somewhat because of their newfound status as peer researchers. In our experience, participatory evaluation enables implicit knowledge to become explicit and thus available for consideration.


The CARe project highlighted language barriers in general practice consultations in a geographical area where there was no statutory provision of interpreting services. In 2005, the former Eastern

---

* Funded by a Health Research Board Health Services Fellowship for Anne MacFarlane.

* The term ‘person seeking protection’ is now often preferred. In using the term ‘asylum seeker’ we are simply remaining consistent with the published documentation related to the CARe project.

* Data pertaining to this participatory evaluation are currently in preparation for publication.
Regional Health Authority established a pilot interpreting service for General Practitioners in the Eastern region (ERHA, 2004). This was in direct response to reports from the general practice community that language barriers posed major difficulties in general practice consultations with ethnic minority service users who had limited English-language proficiency (Crowley, 2003). In 2007, the HSE Social Inclusion Unit commissioned an evaluation of uptake of the pilot interpreting service. This was led by the Discipline of General Practice, NUI Galway in partnership with the Centre for Participatory Strategies\(^d\). The key objective of the evaluation was to inform further appropriate policy and service development in the area of safe, responsive, culturally competent delivery of care to service users from diverse ethnic, cultural and language backgrounds. This is a stated aim of the National Intercultural Health Strategy 2007-2012 (HSE 2008).

In this evaluation, a PLA mode of engagement was used with research participants wherever possible and appropriate. The researchers engaged stakeholders in an ‘educative dialogue’, acting as knowledge-brokers, sharing perspectives and insights that emerged from one stakeholder group with others. This dialogue developed in the organic iterative manner typical of PLA, enabling multi-perspectival knowledges to create a ‘thick description’ (Geertz, 1973) of the levers and barriers that encourage/discourage uptake of the interpreting service.

The report describing the findings of the evaluation of the Pilot Interpreting Service indicates that there is a clear imperative to find a balance between the needs of service users for optimal communication and the requirement of the General Practitioner or health provider to cater for the needs of all service users within a pressured environment.

The HSE expects that their current drive towards a more integrated service delivery means that the findings of this report will be widely applicable across a range of sectors within the health service.

**Health Research Board Partnership Award (2009-2011)**

In relation to the findings of the Pilot Interpreting Service described above, and in ongoing collaboration with the Discipline of General Practice, NUI Galway as lead organisation, the Social Inclusion Unit of the HSE and the Centre for Participatory Strategies (CPS) were successful co-applicants with NUIG in a recent HRB PA award (2009-2011). This award is for a participatory research project involving migrant service users, General Practitioners and practice staff, cultural mediators, interpreters, and policy makers as key stakeholders in the identification of supports for communication in cross-cultural general practice consultations.

The Project Team of academics from NUIG and CPS have initiated the engagement process with relevant key stakeholders and are currently training a cadre of peer researchers to engage with migrant ethnic service users in their own communities, in their own languages. Key stakeholder groups, by combining knowledge that is generated from their own perspectives and experiences with knowledge gained via dialogue and interaction with other stakeholders, will design and develop a set of peer-to-peer guidelines to support communication in cross-cultural general practice consultations. For example, the service-user stakeholder group will produce a guideline

\(^d\) The full Report can be downloaded at [http://www.nuigalway.ie/general_practice/research/research_reports.html](http://www.nuigalway.ie/general_practice/research/research_reports.html).
The use of Participatory Learning & Action (PLA) for other service users; general practitioners and staff will produce a guideline for other GPs and practice staff, and so on. This work is due for completion in February 2011.

**Anti-Racism & Diversity Strategy (ARDS) County Wicklow, 2009-2011**

Building on the National Action Plan Against Racism[^5] launched by the Department of Justice, Equality and Law Reform in 2006, anti-racism and diversity strategies began to be developed in many counties across Ireland. Each strategy needed to be consistent with the aims and objectives of NPAR. The emphasis in NPAR was on a 'whole-system' approach, with a particular focus on mainstreaming intercultural issues into the formulation of public policy and building on the substantial equality infrastructure already in place. One of the 5 key NPAR objectives was to accommodate diversity in service provision, including health. The County Wicklow ARDS research process remained alert to this and issues related to intercultural health service provision emerged strongly in certain groups (WCC, 2009).

In order to develop a viable Anti-Racism and Diversity Strategy (ARDS) for Wicklow County, the County Council ARDS Committee recognised that it was important to connect with a range of ethnic minority groups to explore their experiences and to elicit their suggested solutions for addressing commonly-experienced problems. The Council recognised that a participatory research approach to this task was appropriate and commissioned CPS to train a group of community development workers, service user representatives and County Council staff in PLA research techniques. This training equipped them to engage in a culturally-sensitive manner with a range of diverse ethnic groups across the County.

The team needed to have a thorough understanding of ethnicity, racism, cultural difference, integration and interculturalism, and CPS also provided intercultural awareness training. This training programme was open to all interested members of the ARDS Committee and statutory agencies, and representatives of ethnic minority groups.

CPS and the ARDS research team then co-designed a research plan which involved a series of comprehensive PLA engagement sessions with minority ethnic groups. Nine ethnic groups, seventy-one individuals in all, took part in the PLA research process, including Traveller women, West African women, representatives from the Chinese, Filipino, Polish and Turkish communities, migrant workers in the hospitality industry and people seeking protection who were accommodated in Direct Provision Centres. These representatives generated valuable data that resulted in clear recommendations in a range of areas consistent with the 5 NPAR objectives, including health.

Ethnic minority participants noted that there was a general lack of awareness among ethnic groups about the existence of the HSE National Intercultural Health Strategy (2007-2012) and recommended that this be addressed in order to support the implementation of the Strategy at local level. They also recommended that primary care teams (including social workers) be provided with information sessions about specific cultural issues that arise when dealing with specific ethnic minority groups. The HSE was identified as the appropriate lead agency for

[^5]: Available at http://www.nccri.ie/action-plan.html
both of these recommendations, with completion deadlines of December 2011 and June 2010 respectively.

**Intercultural Health: Participation and Culture?**

The Centre for Participatory Strategies has had the privilege, over twenty years and across three continents, of using participatory approaches and methods to engage meaningfully with vulnerable populations to address problems of social exclusion and to improve the design and delivery of health services, principally to ethnically diverse groups. It is our view that improving health provision and increasing social inclusion are best served by treating them holistically and seeing them as operationally interlinked. Almost by definition, increasing user-involvement via participation promotes greater social inclusion, and the genuine participation of service users can improve health outcomes and ameliorate at least some forms of social exclusion.

The discourse on health service delivery in Ireland acknowledges the desirability of engaging with service users in a participatory manner - as key stakeholders in the delivery of services (HSE, 2005; Mc Evoy et. al. 2008). But we must also acknowledge that the manner in which the discourse becomes translated into ‘on-the-ground engagement’ ranges in quality across a spectrum from high to very poor. Far too frequently, a minimal form of ‘consultation’ is offered and described as ‘engagement’, thus increasing the likelihood that service users will become research fatigued, particularly those from ethnic minority groups and other vulnerable populations. Tokenism is also a problem when service providers ‘engage’ with users but stop short at sharing some power in terms of who sets or drives the research agenda and in terms of who actually makes decisions about services. Participation and engagement have become somewhat ubiquitous terms and, at this point, would benefit from reflection, re-examination, and a more rigorous interrogation.

Our experience in participatory research applied to intercultural health in Ireland suggests that it is unwise to embark on health research projects of this nature without strong buy-in and support from the health services sector and sustainable inter-agency partnerships. When this support exists, and is coupled with the development of relationships of trust, as in some of our examples above, much of value can be achieved and definite benefits are likely to accrue to all stakeholders: service users, service planners and providers, policy makers and the academic and research communities alike.

Finally, just as ‘participation’ and ‘engagement’ need to be more rigorously interrogated, the concept of ‘culture’ also warrants our attention. Culture is often understood as a static rather than fluid reality. This does not serve us well in our attempts to engage in meaningful intercultural dialogue in order to deliver appropriate intercultural health services in Ireland. In our view, we need to be prepared to re-visit, re-examine and interrogate what we mean by culture itself.
References


Above and left: PLA research with MAIN (Men Alone in No-Man’s Land) 2007. Homeless men in inner city Dublin create Timelines describing their life experiences of social exclusion and inclusion.

In our own words, experiences of social exclusion that contributed to becoming homeless:

I loved school; school didn’t love me. The teacher called me a pleic amadán (a double fool).

It was like I was in a shadow – my childhood. I had no bond with my mother – I was a child in shadow; I was trying to prove of value to my dad but when he died, my life folded like a pack of cards.

The job took a lot out of me. My confidence was dented, deflated. It changed my personality...

I lost my job - I really lost myself, I got really low, nobody wanted to know me.

Breakthroughs into ‘inclusion’ we have experienced:

No child is born with shame...we need to be encouraged to talk about how we feel... being able to talk freely about myself with other men, that really helped.

A good GP had faith in me, and got me the right help... good kind counsel.

Going back to education and experiencing success.

Coming together here in MAIN, looking after one another, feeding ourselves, getting in touch with our spirituality.
Chapter 3a

Own Goals and Penalties - a study of the needs of socially-excluded males in Dublin Inner City.

http://hdl.handle.net/10147/296789

de Brún T  
Du Vivier E

This paper is an example of a specific application of PLA in the context of men & social inclusion/homelessness, Ireland.
Acknowledgements

We wish to thank Dublin Inner City Partnership for commissioning this research with the generous support of the Social Inclusion Unit of Dublin City Council. Pat Gates (Community Regeneration Officer, DICP) was instrumental in facilitating this study, and we wish to acknowledge his support and assistance. Thanks must also go to Trutz Haase who provided us with the Small Area Population Statistics from the 2002 Census.

The key ingredient, indeed the vital one, in this research process was provided through the life experience and expertise of the men who constituted the research group itself. We would like to register our wholehearted gratitude to the following men:

Billy
Brian
Dave B.
Dave C.
Gerry
Joe
Joe S.
J.P.
Paddy
Paul
Peter
Richard
Shay
Will

The men listed above welcomed us into their world with great honesty, integrity, and no small measure of fun. The experience was deeply enriching and will be remembered by us as an example of men’s ability to break through the ‘taboo zone’ and open up a safe space in which to share some of their vulnerabilities as well as their insights.

Finally, this research would not have been possible without the energy, commitment, and organisational abilities of Joe Murdiff and others in MAIN who worked behind the scenes to move the process forward. Thank you all.

Undoubtedly, in a report such as this we will have made mistakes in recording individual details, reporting what people said, interpreting their intentions and leaving things out. Responsibility for these shortcomings is entirely ours and we apologise in advance for any errors, omissions or oversights.

Tomas de Brún, Centre for Participatory Strategies; Ed Du Vivier, Maynooth, Co. Kildare.

MAIN logo design by Billy Polion

We wish to thank all of the above and also Bert Donlon, Event Manager Irish Film Institute (IFI) and Ian Keogh, General Manager, Jack Nealon’s of Capel Street, Dublin for the use of their premises during the Research Study.
# TABLE OF CONTENTS

1. **Executive Summary**  
   1.1 Principal Aims and Objectives  
   1.2 The Research Context  
   1.3 The Research Group: Men Alone In No-man’s-land (MAIN)  
   1.4 Participatory Learning and Action (PLA): Research that Fosters Social Inclusion  
   1.5 Gaps in Provision  
   1.6 Key Recommendations

2. **Introduction**  
   2.1 In their own words  
   2.2 Dublin Inner City Partnership (DICP)  
   2.3 Men Alone In No-man’s-land (MAIN)  
   2.4 Aims and Objectives

3. **Literature Review**  
   3.1 Social Exclusion/Social Inclusion  
   3.2 Poverty  
   3.3 Educational Disadvantage  
   3.4 Unemployment  
   3.5 Social Isolation  
   3.6 Physical and Mental Health  
   3.7 Best Practice Models

4. **Methodology**  
   4.1 Participatory Process through an In-Depth Encounter  
   4.2 Participatory Learning and Action Research  
   4.3 The Research Group  
   4.4 Taking an ‘Insider’ Perspective  
   4.5 Narrative Structure of the Research Encounter  
   4.6 Outline of Research Sessions  
   4.7 Strengths and Limitations of the PLA Approach

5. **Barriers to Social Inclusion**  
   5.1 Participants Recount Barriers in their Lives  
   5.2 Grouping of Barriers  
   5.3 Ranking of Barriers

6. **Breakthroughs towards Social Inclusion**  
   6.1 Educational Opportunity  
   6.2 Psychological Support in the form of ‘Wise Counsel’  
   6.3 Support from Friends and Family  
   6.4 Getting Involved in MAIN  
   6.5 The PLA Research Process

7. **Culturally-Appropriate Solutions**  
   7.1 Presentation and Response to Meta-Analysis  
   7.2 Suggested Solutions to Social Exclusion  
   7.3 The Way Forward
8. **Conclusions and Recommendations**

8.1 Participatory Learning and Action Research as an Innovative Model
8.2 Continuing to Build on the Good Work of MAIN
8.3 Key Recommendations

APPENDIX A: Data on Research Group
APPENDIX B: Small Area Population Statistics
APPENDIX C: Terms of Reference
APPENDIX D: Detailed Outline of Research Sessions

Bibliography
1. Executive Summary
This research was commissioned by the Dublin Inner City Partnership (DICP), with financial support from the Social Inclusion Unit of Dublin City Council, on behalf of the Men Alone In No-man’s-land (MAIN) group.

1.1 Principal Aims and Objectives
The principal aims of this research were two-fold:

1. to identify practical, locally-based and culturally-appropriate solutions that will help inner-city men experiencing social exclusion to overcome barriers and attitudes that prevent them from seeking help to tackle their social exclusion;

and

2. to identify a practical, appropriate and participatory approach to the social inclusion of vulnerable men that could be developed by MAIN and piloted in Inner City Dublin. (Terms of Reference, see Appendix C)

1.2 The Research Context
This research addresses issues raised in the DICP’s 2007 Policy Position Paper under the heading “Shaping the New Strategy”. DICP envisages a new role for itself in terms of introducing pilot approaches for innovative and tailor-made services to meet individual needs where gaps in provision have been identified. By utilising Partnership structures to support key agencies and organisations, stakeholders will be facilitated in experimenting with alternative delivery methods to meet the increasingly diverse needs of Inner City residents.

This approach . . . will ensure that the DICP is on the leading edge in relation to new thinking on quality service delivery and responding to the individual rather than operating within the constraints of the delivery system. (DICP 2007: 7)

In order to move in the direction outlined above, DICP requires a “new and fresh response”, recognizing that “many of the local residents experiencing poverty are those now ‘hardest to reach’ ” (DICP 2007: 3, 4).

1.3 The Research Group: Men Alone In No-man’s-land (MAIN)
DICP commissioned two consultants – Tomas de Brún (Director of the Centre for Participatory Strategies, CPS, in Galway) and Ed Du Vivier (an independent consultant) – to design and deliver a research study to be carried out with members of Men Alone In No- man’s-land. MAIN is a response by a number of men to what they see as an absence of social, psychological, and solidarity networks for men in Dublin.

1.4 Participatory Learning and Action (PLA): Research that Fosters Social Inclusion
This research project was designed and delivered as an in-depth, participatory process of co-inquiry, and this was integral to its outcomes. From the outset the aim of the research facilitators was to offer the men more than a series of technically-competent research sessions where information was gathered. Rather, the intention was to create a safe space where vulnerable men might actually experience the research encounter as a form of social inclusion, as well as an acknowledgment of their considerable life expertise in terms of social exclusion. The experience of participating in the research was quite transformative for a number of men, and is congruent with the approach MAIN already utilises in its work with vulnerable men in Inner City Dublin.
While the transformative dimension of this study is somewhat unique for social science research projects in general, it is quite common and often integral to a well-run Participatory Learning and Action (PLA) process. We believe that the means by which socially-excluded groups are invited to become part of research processes must serve to increase their experience of being socially included rather than furthering greater alienation and isolation. Where participation is genuinely invited, socially-excluded men can begin to experience a sense of personal and group empowerment.

1.5 Gaps in Provision

A variety of exercises were used to gather primary data during the research sessions, including: life journeys, accounts of individual barrier experiences, card-sorting, direct ranking and stories of personal breakthroughs. The research group identified twenty three barriers to social inclusion and clustered these into three distinct categories. While acknowledging that all of these barriers are important, these categories were then ranked by group members from those they considered ‘most important to progress towards solutions’ to those they considered ‘least important to progress towards solutions’. Emotional/Relational Crises and Issues ranked most highly with a score of 34, while the two other categories, Poor Inadequate Service Provision and Societal/Class Prejudice and Discrimination ranked equally with a score of 23.

The men were clear that the top-ranked category of barriers is the one where they felt existing services are particularly inadequate, representing a crucial gap in provision. With only one or two exceptions, the men felt their emotional needs were dealt with poorly when accessing ‘official’ services, because agencies tend to process clients in a more systematic and impersonal way. In many cases, the men knew what services are already provided by different agencies, organisations, and community groups. However, because of their vulnerability and an accompanying lack of confidence and low self–esteem, the matching of services to service users can be extremely problematic. The informality and ‘ethic of care’ (Gilligan 1982) inherent in the MAIN initiative is one of the key reasons men find it so helpful and meaningful to them. The men also identified ways in which they had already succeeded in breaking through various forms of social exclusion towards greater health, educational achievement, employability, relational healing and improved well-being.

Following this, the research consultants generated a meta-analysis of the experiences shared in the group in a matrix chart that was taken back to the men for consideration on our final evening together (see Chapter 7). The matrix arranged the data under five column headings:

- **Common Life Events**: Throughout our lives, we all encounter a similar set of events and relationships over which we have only limited power or control. These life events are essentially neutral. However, depending on the circumstances surrounding them, they may have either a positive or negative impact.

- **Responses**: When life events happen, others can respond to us in a variety of ways. It is how we react to these responses that may result in barriers or breakthroughs in our lives.

- **Negative Impacts on Us**: Under this heading we listed some of the ways in which these responses and our reactions have impacted negatively on us and others.

- **Saying it in Our Own Words**: Direct quotations from men in the research group are used to illustrate some of these negative impacts.

- **Interventions**: Finally, under this heading we listed some of the interventions that helped men break through these barriers towards greater social inclusion.
Each man was given a copy of the matrix chart, which was explained by the researchers, and then asked to reflect on it and offer their comments. This led to an animated discussion that resulted in the production of a series of five charts with suggestions for culturally-appropriate solutions to the social exclusion of vulnerable men in Inner City Dublin (see Appendix D).

### 1.6 Key Recommendations:

**Continue to Build on the Good Work of MAIN**

The men who took part in this research are very clear about the significance of participating in MAIN as a means of enhancing their own experience of social inclusion. It is this experiential certitude that gives them the motive power and the vision to nurture, extend and develop the work of MAIN in helping other vulnerable men like themselves. Those who took part in the co-inquiry process have been energised to share what they have achieved. They are ready and willing to work with partner agencies, organisations and groups to help shape forms of service provision that address the key needs of vulnerable men in Inner City Dublin. As one of the participants – Richard – suggests, “we must approach men in a very non-threatening way” in order to develop “a public space for exploring a private agenda”.

In order to advance the above, we recommend the following:

**A. Support MAIN to continue to come together as a group**

With great commitment the members of MAIN have given selflessly of their time and expertise. It is our view that support for the group should now be put on a more structured footing if that work is to develop and grow. Such structured support would require securing sufficient funding to assist the men to “feed” themselves, and build upon the capacities and abilities they already possess. The nature of such feeding would need to be established by the men themselves, in collaboration with relevant partner organisations. Suggestions have already been made by the group as to how MAIN might consolidate their strengths (See Chapter 7).

At the final session, the question was asked: “Can we facilitate ourselves when Ed and Tom leave?” The answer to this question depends, to some extent, on whether MAIN intends to use PLA-style participatory strategies as part of their ongoing work. If it is the intention to continue with this participatory approach, then developing a training programme tailored to the specific needs of the membership of MAIN is possible and, in our view, desirable.

**B. Foster Outreach Work through One-to-One Mentoring**

Attention ought to be paid to the desire of some members of MAIN to develop their ability to offer an outreach service to other vulnerable men in the form of one-to-one mentoring. Again, funding would need to be secured in this regard, particularly in terms of creating opportunities for further training. Such training might include elements of life-coaching, mentoring, or other forms of creative listening and talking therapies.

A case can also be made for employing one or some of the key members of MAIN in order to strengthen and develop the ability of MAIN to offer innovative services to Inner City men who experience social exclusion. The work of MAIN would progress and benefit greatly if a structured role or roles could be created in the form of a ‘coordinator’ or ‘outreach worker(s)’ from within the ranks of MAIN. These workers could be engaged on a contract basis, either full-time or part-time, or possibly through a Community Employment Scheme. Some further training should be considered here also and MAIN members need to be involved in identifying what form this should take.
C. Secure a ‘Home’ for MAIN

A key concern of the group was whether they will continue to have a place to meet in the future. Because social exclusion is often characterised by homelessness, it seems to us that MAIN would benefit greatly by having a secure ‘home’ to continue their important work.

D. DICP in Partnership with MAIN Develop an Innovative Pilot Model of Service-User-led Provision

As noted above, DICP wishes to generate tailor-made pilot services and models of delivery to address the diverse needs of its clientele. We believe that the work of MAIN fulfils these criteria. A case can be made for innovative and participative research processes, like the one used during this research, to become an integral part of “innovative creative and experimental service delivery models” like that offered by MAIN.

Service users are ‘consultation weary’. Many service providers have yet to genuinely engage with service users in the sense that this implies developing a longer-term relationship of trust, involvement and co-responsibility. What MAIN offers the men with whom they work is that longer-term relationship. In this they are already innovating and have the potential to construct a model of delivery that is ‘cutting edge’. MAIN has begun the process whereby service users can become active agents and partners in the development of more user-driven services. We believe that MAIN is an appropriate partner for DICP in further developing this innovation as a pilot model of such provision.

Once established, this model of user-led provision would benefit greatly from engagement with relevant stakeholders in an ongoing process of participatory monitoring and evaluation.

2. Introduction

2.1 In their own words

It’s been a very positive evening for me. Amazed too by the similarities. It’s been a reassuring evening for me. Much of the time you’re walking into a valley of darkness – but you know – you’re not alone! (Peter)

If you’ve never done this life map before...then that’s a barrier itself. Men don’t share together...but here...when you do share...you get great confidence. (J.P.)

You’re brought up...men don’t cry...but that song “stand up and cry, and be a man”...you know, don’t be aggressive and beat the shite out of someone because of the rage and anger in you...no...“stand up and cry, and be a man”. It’s just getting better and better, each session. All those years I thought I was alone...on my own...and now realising I’m not. (Shay)

From the outset this research has aimed to engage in a genuine way with men from Dublin’s Inner City who have experienced, or who are currently experiencing, social exclusion in any of its many forms. The above comments from the men themselves during the research process illustrate something of the quality and depth of that engagement and, in an important sense, set the tone for the rest of this report.

2.2 Dublin Inner City Partnership (DICP)

In a draft position paper, DICP acknowledges many successes since its inception in 1991 and sets out a number of discussion points for the development of a new strategic plan. This plan is emerging within a changed context at an international and national level, as well as within Dublin itself. This
Own goals and penalties

requires a “new and fresh response” from DICP which recognises that “many of the local residents experiencing poverty are those now ‘hardest to reach’ ” (DICP 2007: 3, 4.).

The issue now is to move past the approach to poverty that views it solely in terms of lack of income or consumption. We need to recognise and acknowledge the multi-dimensional aspects of the experience that reveal the linkages between depth of poverty, in terms of material and social assets... (DICP 2007: 4).

DICP envisages a new role for itself in terms of introducing pilot approaches for innovative and tailor-made services to meet individual needs where gaps in provision have been identified. By utilising Partnership structures to support key agencies and organisations, stakeholders will be facilitated in experimenting with alternative delivery methods to meet the increasingly diverse needs of Inner City residents.

This approach . . . will ensure that the DICP is on the leading edge in relation to new thinking on quality service delivery and responding to the individual rather than operating within the constraints of the delivery system.(DICP 2007: 7)

DICP commissioned this research in an attempt to hear from a group of Inner City men, a group arguably among those ‘hardest to reach’. While acknowledging the material dimensions of poverty and marginalisation, the research group has stressed the dimensions of exclusion most salient to them at this point in time as inherently social. The research project and encounter situates itself within the emerging DICP strategic plan that promotes innovation and the generation of tailor-made pilot services where a failure in existing provision has been identified. It supports experimentation and the development of new ideas and models of delivery that address the diverse needs of individuals. It also models how innovative service provision might be driven by the energies and expertise of service users themselves, in partnership and cooperation with key agencies and organisations.

2.3 Men Alone In No-man’s-land (MAIN)

DICP commissioned two consultants – Tomas de Brún (Centre for Participatory Strategies, CPS, Galway) and Ed Du Vivier (independent consultant) – to design and deliver a research study “to identify practical approaches to overcoming the social and economic exclusion of men in Dublin’s Inner City” (Terms of Reference see Appendix C). The research was to be carried out on behalf of and in conjunction with members of the MAIN group.

MAIN is a response by a number of men to what they feel is an absence of social, psychological, and solidarity networks for men. The reference to ‘no-man’s-land’ is an apt metaphor for the social isolation that many men confront on a daily basis. The dictionary definition of this term is “a land between boundaries, an unoccupied zone between opposing forces, an unclaimed piece of ground, an ambiguous area of activity or thought” (Collins 1979: 999). No-man’s-land can also be a refuge, a place to which men can beat a tactical retreat and camouflage themselves in anonymity when aspects of their lives spin out of control and threaten to overwhelm. The problem is that once a man steps beyond the boundaries and loses his place in a social network, it can be very difficult for him to get back onside.

Many men in Dublin and elsewhere find themselves alienated from their families and the wider community, experiencing feelings of hopelessness and helplessness. Social isolation can arise from a number of causes: unemployment, welfare dependency, addiction, mental and physical health issues, homelessness, marriage and relationship breakdown. Men in such situations often lack the capabilities to address their social and economic exclusion, a problem that is compounded by cultural messages that discourage men from expressing their vulnerability or seeking help from service
providers or relevant agencies.

With this in mind, MAIN set up a Steering Group which includes men who have experienced, or who currently still experience, some of the issues mentioned above. In partnership with DICP, the Steering Group decided “to explore ways in which the community and society can create social, economic and cultural space in which vulnerable males can present themselves to seek help and begin the journey back to becoming active and productive members of their community.” (Terms of Reference, see Appendix C)

2.4 Aims and Objectives
The principal aims of the research were:

• to identify practical, locally-based and culturally-appropriate solutions that will help Inner City men experiencing social exclusion to overcome barriers and attitudes that prevent them from seeking help to tackle their social exclusion; and

• to identify a practical, appropriate and participatory approach to the social inclusion of vulnerable men that could be developed by MAIN and piloted in Inner City Dublin.

A number of specific objectives were also outlined in the terms of reference, including:

• Reviewing recent empirical (both qualitative and quantitative) research studies in Ireland (and Dublin in particular) to assess the numbers of men in this category and analyse the barriers that prevent the social inclusion of vulnerable males in an urban setting. (See Chapter 3)

• Identifying the supports currently provided on an agency, interagency, voluntary or community basis to socially excluded men in Dublin’s Inner City.

• Presenting case studies of national or international projects that have been successful in overcoming barriers to the social inclusion of vulnerable males and demonstrate models of ‘best practice’. (See Chapter 3)

• Through fieldwork (survey and focus groups) with the target group, identifying a practical, appropriate and participatory approach to the social inclusion of vulnerable men that can be developed by MAIN and piloted in Inner City Dublin.

In addition to the objectives outlined above, the consultants proposed some supplementary objectives. Our goal was to assist the MAIN Group to:

• Clarify its vision, goals and possible scope of its involvement in the provision of services to marginalised men in Dublin’s Inner City;

• Develop an appreciation of both the potential and limitations of the research process;

• Build its own capacity to continue the inquiry process, while making contact and engaging with the target group;

• Gain a sense of ownership of the research process and its outcomes.

Because of the effectiveness of the participatory research process chosen, we believe that the MAIN group has been assisted to realise each of the objectives outlined above.
3. Literature Review

In 1999, the EU commissioned a research project to examine the Social Problem of Men in ten European countries. A critical review of the literature regarding the Irish situation concluded that “…academic research into men in Ireland has barely begun” (Hearn et al. 2004: 10). While this may be true in relation to theoretical studies, a growing body of policy-based research has been undertaken that provides insights into the needs of socially-excluded men. This chapter reviews some of the key studies undertaken in recent years.

3.1 Social Exclusion/Social Inclusion

Since the 1990s there has been a move away from viewing social exclusion primarily in terms of material deprivation. Instead we need to examine a range of structural and institutional processes that contribute to the production and reproduction of poverty, educational disadvantage, unemployment, social isolation, ill health and reduced well-being. These factors also have political (with a small ‘p’) consequences, rendering marginalized groups and individuals voiceless and powerless in relation to many of the decisions affecting their daily lives.

The operating definition used for social exclusion in this research encounter is one recently put forward by the Combat Poverty Agency. Social exclusion is:

... the process whereby certain groups are pushed to the margins of society and prevented from participating fully by virtue of their poverty, low education or inadequate life skills. This distances them from job, income and education opportunities as well as social and community networks. They have little access to power and decision-making bodies and little chance of influencing decisions or policies that affect them, and little chance of bettering their standard of living. (Combat Poverty Agency, 2006)

It is interesting to note that official discourses about social exclusion envisage it as a group phenomenon, apparently reflecting programme- or area-based approaches to its eradication (Saris & Bartley 2002: 14-15; Saris et al. 2002: 173-175). Until recently, there has been a tendency among policy-makers to identify groups of clients with particular characteristics and then to design specific interventions to address any deficits. Individuals who find themselves excluded from full participation in society, but who do not fit into one of these groups or live outside a designated area, are thus overlooked.

Social inclusion is conceived of as a process of increasing engagement, involvement and participation in social, economic, cultural and political structures. The Combat Poverty Agency defines social inclusion as follows:

Ensuring the marginalised and those living in poverty have greater participation in decision-making which affects their lives, allowing them to improve their living standards and their overall well-being. (Combat Poverty Agency, 2006)

The drawback of such definitions is that they paint a rather simplistic and mechanistic picture of the process. Despite the range of services available for groups experiencing social exclusion, some individuals never take part as envisaged. These apparent failures of the social inclusion paradigm lead to the suspicion that individuals who do not avail of the services available bear some responsibility for their circumstances, perhaps betraying lingering notions of the ‘deserving’ and ‘undeserving poor’ which date from the 18th and 19th centuries. Moreover, even when people become fully engaged in social and community networks, they may not experience the anticipated improvements in their standard of living or general well-being.
3.2 Poverty

Despite a broadening of the definition of social exclusion, poverty remains a key measure of social disadvantage. Whereas absolute poverty is a feature of life for many people in developing countries, being poor in high-income countries is normally defined relative to the prevailing norms of the society in question. In terms of Ireland’s National Anti-Poverty Strategy (NAPS), the problem is envisaged as follows:

People are living in poverty if their income and resources (material, cultural and social) are so inadequate as to preclude them from having a standard of living which is regarded as acceptable by Irish society generally. As a result of inadequate income and resources, people may be excluded and marginalised from participating in activities which are considered the norm for other people in society (Ireland 1997).

While there is no single and universally-accepted measure of poverty, the EC’s Social Protection Committee established a common set of indicators in June of 2006. Between 1994 and 2001, the rate of consistent poverty (DSFA-OSI 2007) in Ireland declined by two-thirds. Nevertheless, it remained relatively high in households headed by persons who are lone parents, unemployed, retired, ill and disabled (CPA 2004: 1). In general, women are at a higher risk of income poverty than men, and the risk for both sexes increases significantly with age. For example, fewer than one in five men below 65 years of age have an income less than 60% of the national median, but for men sixty-five and older this figure rises to almost three in eight.

3.3 Educational Disadvantage

Educational attainment refers to the highest level of schooling that an individual has completed, and it is normally defined in terms of the various certificates and other qualifications awarded by education and training institutions. Modern capitalist economies are stratified and segmented on the basis of a distinction between those without qualifications and those with various forms of credentials that enable access to specific trades and professions. The education system, as the principal provider of these credentials (certificates, diplomas and degrees), is deeply implicated in this process of sorting people into occupational niches (Connell 2000: 139). Educational attainment may also be seen as a key indicator of poverty and social exclusion because of a strong correlation with rates of employment and unemployment.

Nearly a quarter of all boys (24%) exit the formal education system before passing the Leaving Certificate, compared with only 6% of girls (Cleary et al. 2004: 28). A much smaller number of students (less than 4%) leave school without passing the Junior Certificate, but five out of every eight of these were male (Gorby et al. 2005: 11-12). On a national level, those leaving school without any formal educational qualifications are five times more likely to be unemployed than those who attained a leaving certificate. While male school-leavers were almost a third more likely than females to be unemployed in 2002/03, this is partly because girls tend to continue their education beyond second-level (Ibid.: 4).

Chart 3.1 below presents data from the 2002 census on participation in the labour force by males from Dublin’s Inner City, categorised on the basis of levels of educational attainment. Although those without any formal education represented only a small percentage (0.4%) of the total male population in the area, half were unemployed or still seeking their first job. By way of contrast, only one in twenty men with a third-level qualification living in the Inner City were unemployed on the night of the census in 2002. The chart clearly shows that, as a man’s level of education increases, the likelihood of his being unemployed decreases.
Adult education and training are promoted as key mechanisms for enabling the socially-excluded to lift themselves out of poverty by bettering their employment prospects, as well as increasing their engagement with social networks and participation in community decision-making (Ireland-DES 2000: 28-29, 49). In the 1970s and early 1980s, the majority of participants in adult education and training programmes were male, but in recent decades an increasing number of women have enrolled for such courses. Chart 3.2 on the following page shows how the gender balance of adult literacy learners in Ireland has changed in the last few decades. Whereas seven out of ten people taking part in adult basic education tuition in 1980 were men, this proportion had dropped to less than four in ten by the year 2000. Under the ‘Back To Education Initiative’, which was launched in 2003 to encourage hard-to-reach groups (such as disadvantaged men) to take part in adult education, over 70% of participants are women (Ireland, DJELR, c. 2006). In the vocational training sector, there has been a comparable shift in the gender of participants; by 2003, fifty-seven per cent of those taking part in FÁS courses were female (FÁS [2004]).

The changing balance of gender participation in adult education and training led to concern about a phenomenon that was referred to as the ‘Missing Men’ (McGivney 1999; Owens 2000: 3). This is perhaps a misnomer, as there has been no real decline in the number of males seeking to develop their knowledge and skills. In fact, between 1984 and 2000, the number of men taking part in provision funded under the Adult Literacy and Community Education Scheme increased almost nine-fold, while the number of women enrolled for these courses grew almost twelve times. The question, therefore, is not “Why aren’t men taking part in adult education and training?” but rather “What has made this activity so successful in attracting women?”
Much of the research on participation in adult education adopts a common-sense ‘barriers to access’ approach originally popularised by Cross (1981). Factors holding adults back from enrolling in courses are classified under five headings: institutional, informational, situational, dispositional or, latterly, contextual (Ronayne 1999: 18-19). Among others, McCaffery (1985) highlighted institutional barriers contributing to lower female enrolments during the 1970s and 80s, including the scheduling of classes at inconvenient times and the absence of childcare facilities. Once these shortcomings began to be addressed, women could take part in greater numbers. Recent studies on participation by Irish men in adult education have focused on low levels of literacy, negative experiences of school, low self-esteem, fear of embarrassment and potential loss of social welfare benefits as barriers to access (Owens 2000: Corridan 2002).

Participation has also been analysed in its social context. Levine (1987) highlighted how conceptual models of adult education adopted by providers can influence the gender balance among learners. Through ‘selective channels of publicity’ and particular arrangements for tuition, providers were able to ‘cream off’ particular categories of clients and ‘weed out’ those for whom the service was not intended. In the 1970s, many providers in the UK and Ireland promoted adult education as a means of improving the learner’s employment prospects and, given men’s traditional role as breadwinners, this approach favoured males. By the early 1980s, however, increasing attention was being paid to the needs and concerns of women. Slowey’s (1980, 1987) research in the new housing estates of North Dublin focused on the ‘vocabularies of motive’ that served to construct adult education as a legitimate ‘interest outside the home’ – something women could and should be doing for themselves. This is one possible explanation for the dramatic growth of day-time provision in Ireland from the mid-1980s onwards, which catered primarily for female learners (Inglis & Basset 1988; Inglis et al. 1993).

Increased female enrolments coupled with the predominance of women as administrators, tutors and volunteer support workers have contributed to the perception of many community-based education centres as ‘women’s space’ (Corridan 2002: 18-20). In this context, the issue of ‘male culture’ has become a focus for investigation as a factor influencing participation by men. Whereas taking an adult education course is seen as a legitimate activity for women, it is less so for men, who find it easier to justify further learning if it is called ‘training’. In addition, many men experience what Owens calls the ‘taboo zone’:

... a multi-determined oppression of the head and heart whereby one feels as powerless and meaningless as “a piece of cosmic dust” and identity is derived and directed from without rather than constructed from within the self (2000: 23).

This taboo zone is rooted in traditional norms for masculine behaviour and operates as an
internalised barrier to participation not only in adult education, but in the wider social sphere (Ibid.: 23-38).

3.4 Unemployment

Although unemployment rates have been dramatically reduced in the Celtic Tiger economy, those who find themselves unemployed are at a greater risk of poverty and social exclusion. As McGivney notes, for a man becoming unemployed involves not only the loss of a job, but also the loss of purchasing power, identity, social status, self-esteem and social interaction with workmates (1999: 35). Willot and Griffin suggest that, as the result of a loss of financial independence and a role outside the home, unemployed men can experience feelings of disempowerment and emasculation (1996:89). Thus, being out of work undermines a man’s self-image and connectedness with society in many different ways.

Table 3.3 above summarises raw data on the numbers of males and females in the Irish labour force and rates of unemployment for the last eight years. While males have been consistently more likely than women to find themselves unemployed, this may reflect higher levels of male participation in the labour force, as well as social expectations.

As the traditional breadwinners, men are expected to go out to work, and unemployment threatens this central aspect of male identity (McGivney 1999: 35). Collecting the dole is still a recognised and accepted role for a man, though clearly second best when compared to being in work. Women, on the other hand, may find it easier to classify themselves as caregivers in the home even when the opportunity of going out to work would be welcome. Those with children or elderly relatives requiring care may qualify for social welfare entitlements other than unemployment benefit/assistance, and would thus not appear on the Live Register.

As many people can weather a short period without work, a distinction is normally drawn between short-term (less than one year) and long-term (one year or more) unemployment. In this regard, men are half again more likely than women to experience long-term unemployment. For example, in October 2006 the Live Register showed that 35.7% of unemployed males had been signing on for more than twelve months, compared with 23.0% of unemployed females (Ireland-CSO 2006: Table 1, p. 2). The risk of long-term unemployment also increases with age. Compared with males under 35 years, unemployed men aged 45 to 64 years were over fifty percent more likely to have been out of work for a year or more. Once older men have been unemployed for some time, it becomes more difficult for them to re-enter the labour force. Thus, the October 2006 Live Register showed that
almost a quarter (22.9%) of unemployed males in the 45-64 year age group had been out of work for over three years. (Ibid.: Table 5b).

3.5 Social Isolation
The 2002 census showed that slightly more females than males were living on their own in Ireland. However, for nine out of twenty women (45.0%), this was the result of the death of a partner, while only one in eight men (12.4%) were classified as widowers (Ireland-CSO 2003: Table 12, p. 42). Living alone creates the potential for social isolation and poverty, though this is not always the case, as many people on their own maintain links with family members, friends, neighbours or others in their communities. Nevertheless, those living alone are at an increased risk of poverty. In 2005, for example, twenty-nine percent of adults living alone had an income less than sixty percent of the national median (Ireland-DFSA-OSI 2007: Table 5).

Changing patterns of family life over the last three decades have had a significant impact on women, but have also contributed to increased social isolation of men. Although marriage is still the dominant paradigm for couples who wish to set up home together, marriage rates have fallen, and “... marital and sexual relationships are more fluid and lack permanence” (Cleary et al. 2004: 27). The increased incidence of marital separation and divorce has also led to a sharp rise in the number of lone-parent families since the 1980s. The vast majority of these are headed by women: forty-three times more women than men received the single-parent family allowance in 2005 (Ireland-DJELR c. 2006). The current state of development with family law in Ireland is widely perceived as favouring mothers in relation to child-custody, with the result that some fathers do not have regular contact with their children. However, Ferguson notes that the absence of hard evidence makes it impossible to determine how many fathers actually apply to the courts for custody or access (Ferguson 2001: 38-40, 42).

Homelessness is a particularly acute form of social isolation, implying as it does not only the absence of stable living accommodation but also a breakdown of a person’s connectedness with a wider community. A survey undertaken in 2005 found that 954 adult males were homeless in the Dublin area, of which 129 were sleeping rough. Forty percent of homeless men were between 26 and 39 years of age, and nine out of every twenty (45%) had been homeless for over three years (Homeless Agency 2006). In recent years, there has been a considerable reduction in the problem (Homeless Agency c. 2003).

3.6 Physical and Mental Health
There is a tendency among men to ignore health problems and to delay going to a doctor for a check-up. In recent years, there has been increasing emphasis on promoting preventative measures such as health checks, self-examinations and screening for male conditions such as testicular cancer. However, consideration of general health issues for men is outside the scope of this study. Instead, this literature review focuses on a few key indicators of physical and mental health that may have a disproportionate impact on marginalised men.

Alcohol and drug abuse are two such indicators. Men drink more frequently and more heavily than women and are also more likely to drink to excess (Kelleher et al. 2003: 28-31). However, because of the cost of alcohol, men living on a limited income may not be able to drink as much or as often as those with regular wages. The data on drug abuse is more patchy, because of the illegal and hidden nature of this activity. Nevertheless, in 2004 males were twelve times more likely than females to be prosecuted for drugs offences (Connolly 2006: Figure 4.7, p. 54). Between 1998 and 2002, seven out of ten persons receiving treatment for drug abuse were male (Long, Lynn & Kelly 2005: Table 17, p. 18). Over the last decade, drug-related deaths in Ireland were between three and eighteen times
higher among males than females (Long, Lynn & Keating 2005: Figure 4, p. 39). Anecdotal evidence suggests that the vast majority of hard-drug users come from backgrounds of social and economic deprivation, and that their drug habit serves to reinforce their marginalisation.

There is also compelling evidence linking social exclusion with mental health. Although the picture with regard to the incidence of mental health problems for men and women is complex, males form the majority of psychiatric in-patients. Despite a fall in the number of residents in Irish psychiatric facilities since the 1960s, there has been little change in the gender balance of patients; the rate of hospitalisation of males is currently 25% higher for males than for females (Daly & Walsh 2006: 19-20). Single males are almost six times more likely to be in-patients than married men, while the rate of hospitalisation is three to four times higher for agricultural and unskilled manual workers than for other socio-economic groups (Ibid.: 20-21).

Suicide is another issue that disproportionately impacts on men. In 2002, Irish males were 4.7 times more likely to take their own lives than females (Ireland-HO-JCHC 2006: 21). Since the late 1980s, the suicide rate in Ireland has risen considerably, though the increase has been most marked among young males between 15 and 34 years of age. When compared with the thirty member countries of the OECD, Ireland now has the second highest incidence of suicide among this age group (Begley et al. c. 2003: 38).

The available research indicates that there is no direct correlation between suicide and socio-economic deprivation, but there is a linkage with social fragmentation measured by such indicators as the proportion of single-person households, levels of transient residence and prevalence of alcohol abuse (Ireland-HO-JCHC 2006: 23). However, research by Begley and her colleagues among young men in Ireland suggests that an increased risk of suicide arises from growing anomie – “a personal feeling of not being part of, or responsible to society” (Begley et al. c. 2003: 5; Durkheim, 1952). As a result of changing economic conditions and social values in Ireland over the last two decades, young men are now experiencing dissatisfaction with their lives in terms of career opportunities, health services and social networks.

3.7 Best Practice Models

While many service initiatives, anti-poverty measures and education/training programmes have been designed to benefit males as part of larger groups of disadvantaged persons, socially-excluded men were identified as a specific target group through attempts to redress gender inequality in Irish society. The Second Commission on the Status of Women acknowledged that:

There is a real problem for men at the bottom of the social and economic pyramid, because the positive incentives that have encouraged their wives to seek change have, in many cases, passed them by. Yet their traditional role no longer exists. The automatic assumption that they controlled family finances and decision-making is gone. While children may benefit from seeing their mothers behaving more independently and confidently, men can feel threatened (1993, 86-87).

In 1994, the Department of Social Welfare implemented the Commission’s recommendation to extend funding support for men’s groups in ‘socially disadvantaged’ areas. However, eight times as many women’s as men’s groups applied for and received funding in 1996, though the average level

---

8 O’Hare and O’Connor (1987) report that there is considerable evidence from the UK and USA to suggest that the rates of mental illness are higher for women than for men. However, males exceed females in Irish psychiatric hospitals in respect of both first admissions and longterm residents. Case register morbidity, which includes all persons in receipt of some form of psychiatric care either community- or hospital-based, suggest that males are more likely to be diagnosed with mental illness in rural areas and in the West of Ireland, while females predominate in urban areas and in the East.
of grant received was similar (Ferguson 2001: Table 3.1, p. 42). Because of the difficulty of involving disadvantaged men in personal development and community work, there was a “lack of worthwhile ideas and activities coming forward for funding” (Ireland-DSW 1998: 25).

The men’s groups funded under this scheme did not follow a standard approach in working with disadvantaged men. However, the most common orientation was towards ‘personal development’, while supporting men in finding a new role for themselves in the face of long-term unemployment (Ferguson 2001: 41-42). Ferguson characterised these groups as:

... a ‘life-strategy’, a resource which vulnerable men use to gain support and to engage in life-planning to help guide them in making crucial decisions about their lives. They are a quintessentially late-modern practice in that they involve the construction by men of new kinds of relationships and communities in which self-conscious care for one another as men, self-identity and its re-constitution - rather than work, sport, or some other external reason - is the reason for the encounter (Ibid.).

Rather than directly addressing issues of gender equality in wider society, these groups focused on building self-esteem, creating a culture of care and promoting well-being for the men who took part. However, while an external review of the DSW grant scheme found that locally-based women’s groups were “very successful” in meeting their objectives, the impact of men’s groups on the wider community was found to be “limited” (Ireland-DSW 1998: 25).

Attempts have also been made to increase the involvement of men in adult education. In 1998, the Department of Justice, Equality and Law Reform launched the Women’s Education Initiative, with support from the European Social Fund. The scheme was extended to include groups working with disadvantaged men, renamed the Employment Equality Initiative (EEI) and included in Ireland’s National Development Plans for 2000-2006, as well as for 2007-2013 (Ireland-DJELR c. 2006). Since 2003 the Back To Education Initiative (BTEI), administered by the Department of Education and Science, has supported projects targeted at hard-to-reach groups, including disadvantaged men (Ireland-DES 2006). Private funding has also been set aside for initiatives designed to support socially-excluded men, though the level of uptake was described as “disappointing” (Katharine Howard Foundation 1999: 1, as quoted in Owens 2000: 13).

Despite the best efforts of community groups and educational bodies funded under these schemes, disadvantaged men remain one of the hardest to reach target groups, demanding labour-intensive approaches. In light of the lessons learnt from the EEI and BTEI experience, Brady argues that many of the methodologies and approaches developed by community-based women’s education groups in the 1980s and 90s can be adapted as models of practice for working with men (2007). However, in his review of the Department of Social Welfare grants scheme, Cousins concludes that:

Perhaps one of the weaknesses of much work in men’s development has been an assumption that models which have worked with women’s groups can simply be transferred to men’s groups. The record to date would suggest that this is not the case. (Cousins 1997a: 39, as quoted in Owens 2000: 48)

The issue of models and methods for working with men is a complex one. On the one hand, it may simply be an issue of language. For example, the men taking part in various groups at a community-based education centre in Tallaght objected to use of the words ‘personal development’ to describe such activities, referring to these instead as ‘support’ or ‘finding your own headspace’. Even the term ‘men’s group’ was problematic, as some felt that it implied that they were in need of help; the preferred terms were ‘men’s club’, ‘core team’ or simply ‘the lads’ (Du Vivier, Cox & McManus 2006: slide 6).
In light of this, we note that a key element of best practice (and a core principle of PLA) must be openness to, and encouragement of, the naming by men of their experiences and activities in a manner that is meaningful to them. Such ‘naming’ promotes ownership and avoids the pitfalls of a wholesale transfer of any model from one group to another. This caution needs to be exercised not only in relation to the gender variable, but also to a much wider range of variables including ethnicity, ability, class, economic status and sexual orientation. To avoid jettisoning what is valuable about women’s ways of working, a clear distinction also needs to be drawn between models that (a) do not or cannot enable men’s modes of expression and (b) those which are inherently adaptable and open to meaningful use and development by men.

On the other hand, at least some men resent the ‘personal development’ courses that their wives and partners take part in, as these can lead to challenges to the domestic status quo and fears of being further peripheralised in the home. If this is a key reason for men’s lack of engagement in such courses, it has nothing to do with any model because these men are not experiencing a model – they are absent. Therefore, ongoing development of best practice models of men’s work in Ireland may need to establish to what extent the problem of engagement lies with models that are not suitable for men’s work, and to what extent the problem may be a deeper and more complex one related to socio-cultural constructions of male and female gender identities in a rapidly changing social landscape.

The model and methodology employed in this research is based on the principles and pragmatics of PLA. While not explicitly a feminist research methodology, PLA is rooted in the Freirean approach and shares a great deal with both community development principles and feminist research epistemology in its commitment to emancipation, a focus on the human subject as expert in his/her own life and conditions (Chambers 1994a) and a political analysis of power differentials in society.

A number of evaluative reviews and studies of participants in adult education programmes for disadvantaged men in Ireland have been undertaken in recent years (Owens 2000; Corridan 2002; Ireland-DES c. 2004; Kavanagh 2005). These have identified several elements that are common to successful initiatives, including:

1. Outreach

   “Prolonged and target outreach” is essential in order to draw men into sustained contact with any service provided. It may take any number of forms: door-to-door visits, community consultation, peer-to-peer support groups, one-to-one mentoring, acting as a ‘gateway’ referring drop-in clients to other services or bringing activities out to potential participants in their own social settings. Nevertheless, it must be remembered that “…outreach is a protracted process which may encounter resistance from the target group; may be slow to produce quantifiable results and is highly dependent on the skills of the outreach worker (Ireland-DES c. 2004: 5).” In this regard, participants may prove to be the best outreach agents for making contact with other local men and encouraging them to take part in the project.

2. Introductory Activities

   As a complementary activity to outreach work, many successful projects have utilised introductory activities to familiarise potential participants with the location and layout of physical facilities, to meet with staff members, to demystify what is on offer, to break the ice and to build confidence. Examples of such activities include: breakfast clubs, open days/evenings, one-off talks on topics of interest, starter/taster courses, sharing of life stories and creative forms of needs assessment.
3. Threat-Free Environment

It has long been recognized that the best learning takes place in an environment where participants can take risks without fear of derision for making a mistake. However, given the competitive nature of many male-male relationships with a propensity for ‘piss-taking’, it is essential to agree and reinforce ground rules for behaviour in men’s groups. As Owens notes, “... the self-disclosure dimension of men’s development work renders participants feeling vulnerable to the threat of ridicule or slagging for engaging in ‘unmanly’ behaviour (2000: 43).” In most cases, strict confidentiality is a precondition of participation, and formal mechanisms for taking turns may need to be put in place in order to ensure that everyone gets a say.

4. Relationships of Mutual Respect and Trust

Confidentiality and other ground rules for working with groups of men help to create a climate of trust. However, a common feature of successful projects was that staff members had personal experience of working through issues surrounding the ‘taboo zone’ of male culture. As one participant in Owens’ study said: “people who’ve gone through that experience themselves have real insights on what’s involved in the process” (2000: 45). When male staff members invested themselves in their work with groups by sharing aspects of their life stories in an appropriate manner, they were able not only to establish rapport with participants, but also to create a sense of identification, mutual respect and collaboration towards common goals.

5. Real Life Context

Time and again, the available research emphasises the need to facilitate the acquisition of skills in purposeful and meaningful contexts that reflect the situations that participants encounter in their day-to-day lives. In adult education projects, this involves a creative and flexible approach to learning objectives, course content, delivery methods and assessment strategies. In all projects targeted at disadvantaged men, it is essential to find a balance between individual and group needs, between the process and content of group work, and between the affective and cognitive dimensions of development.

6. Personal Agency

Another key element in successful projects for men is their capacity to inspire a sense of personal responsibility and individual agency. Learning, whether formal or non-formal, boosts self-belief and confidence in our ability to influence the world around us. This sense of agency is critical to the process of re-engagement for men who have been disempowered through social exclusion.

7. Networking

Structured partnerships between statutory bodies, community-based groups and key individuals were found to add value to the work undertaken by projects, as well as enhancing their capacity to meet the needs of participants (Ireland-DESc. 2004: 6). Networking with other men’s groups is also essential for the exchange of ideas, broadening horizons and supporting new initiatives. As no single project is able to provide all the services participants require, it is essential for staff to maintain links with other service providers in order to facilitate referrals and make available other opportunities for education, development or employment.

Information about models of working with socially-excluded men in other countries has been difficult to come by, but what is available broadly echoes the points made above. These common elements may thus be considered best practice guidelines for planning and delivering interventions for this target group.
4. Methodology

4.1 Participatory Process through an In-Depth Encounter

Over the last decade or so, a number of bodies have sought to address the exclusion of men in Irish society. While these interventions have proved successful in meeting the needs of relatively small numbers of men, many of these projects and groups have encountered difficulty in identifying potential beneficiaries, making contact and drawing them in to avail of the services provided. Thus, while we have a good idea of what works with marginalised men once they have been brought together, much more research needs to be done to clarify how we might overcome the difficulties of contact and engagement with this target group.

Researching the needs and intentions of economically-, socially- and/or culturally-marginalised men is problematic for the following reasons:

- It is difficult to define the total number in the target group. Census data can provide statistics on social and economic status, employment, marital status, living circumstances, educational attainment and other indicators of social exclusion. While many of the men who fall into these categories may experience marginalisation, it would be erroneous to assume that all of them do.

- Like other hard-to-reach groups, it is difficult to identify men who might be categorized as marginalised. Because of their living circumstances, marginalised men are frequently under-represented in commonly-used sampling frames, such as the Register of Electors. For this reason, it is impossible to select a statistically-representative sample for a quantitative study.

- The primary goal of this research is to discover how men experience social exclusion, as well as uncovering their preferences and intentions with regard to services that might be put in place to meet their needs. Understandably, marginalised men tend to be extremely guarded in revealing such information about themselves. Under such circumstances, what respondents say is likely to represent acceptable discourse rather than real needs, and statements of intention must be seen in this light. To offset this, an atmosphere of trust and rapport needs to be built into the research encounter.

In order to achieve the objectives of this research, it was essential to engage with the target group in a genuinely inclusive way. Based on previous experience of social research, we designed the project as an in-depth encounter between ourselves and a group of men who had voluntarily agreed to engage in co-inquiry around issues of social exclusion. A variety of participatory methods were used to facilitate discussion and to produce experiential data.

4.2 Participatory Learning and Action Research

In response to the requirements of the terms of reference, and for the reasons outlined above, a quantitative survey was seen as unlikely to meet the primary goal of this research or to provide a reliable indicator of the preferences and intentions of socially excluded men in Inner City Dublin. Instead, we proposed an intensive process of qualitative co-inquiry, employing a range of Participatory Learning & Action (PLA) strategies with a relatively small number of respondents.

PLA can best be described as “a growing family of approaches and methods that enable local people to share, enhance and analyse their knowledge of life and conditions, to plan and to act.” (Chambers 1994c). It is an approach that explicitly addresses issues of power differentials between the researcher and those being researched where the researcher typically belongs to what Chambers calls ‘uppers’, while the researched belong to the category ‘lowers’ (Chambers 1997: 217). PLA is also tailored to researching ‘sensitive’ topics, such as social exclusion, particularly among a group of men,
who may often be less than forthcoming in revealing the delicate terrain of their own inner landscapes.

While a PLA research process is frequently initiated by an organisation or professional researchers, the commitment is always to move towards developing a shared responsibility for the direction that the research will take. This is achieved through fostering a team process of reflective self-awareness in terms of the political and ethical dimensions of the research. It also demands building into the research process opportunities for co-analysis, co-evaluation, and fine-tuning.

4.3 The Research Group

The great advantage of a qualitative PLA approach is that the research group constitutes a gathering of ‘local experts’ who can speak with authority and veracity about their lives and conditions. What they offer is an in-depth perspective we cannot gain by any other means, a perspective that speaks with the authority of experience and illustrates (in the manner of case-studies) the experiences of other men like themselves.

The research group for this project constituted a non-probability purposive network sample. That is, we deliberately selected men who are members of MAIN and other men who had been approached by MAIN members because they are currently experiencing forms of social exclusion. Having direct experience of social exclusion was the key criterion in the selection of men for the research process.

The value of non-probability sampling lies in the depth and quality of information generated in the research encounter. The principle of selection is the researcher’s judgment as to applicability (Robson 1993). Patton (1990) describes purposeful sampling as an effective means of obtaining ‘information rich’ material from special groups. The resulting research findings provide an important in-depth and multi-dimensional understanding of the key issues that such men experience in their daily lives. They also generate suggestions for possible interventions that would be most acceptable and appropriate for this group.

The researchers were given a list with the names of twenty men comprising all members of MAIN steering committee, along with other men from the target group identified and invited by MAIN members. Those on the list had been briefed on what the research was about and had ostensibly agreed to take part in the process. However, when contact was made by telephone, it became clear that at least some of them had reservations about becoming involved. Nevertheless, a total of fourteen men attended one or more co-inquiry sessions, while a core group of twelve men were present for three or more evenings during the course of the research.

4.4 Taking an ‘Insider’ Perspective

Key to realising the above is the commitment within PLA to taking an emic perspective. Taking an emic approach means that the researcher focuses on the participants’ own perspectives, articulated in their own language, in order to identify key categories of enquiry and analysis meaningful to them. The participants’ own lives and conditions, and their understandings become a locus of expertise. In contrast, etic approaches favour the researcher’s perspective on the issue in question, and seek to develop key categories of enquiry and analysis exclusively in the researcher’s language and categories of meaning (O’Reilly de Brún & de Brún 2007: 78). The current research takes an emic

---

b The terms etic and emic were borrowed from linguistics, but found wider application in the discipline of anthropology (Goodenough 1956). Emic research is also known as ethnoscience, the New Ethnography, ethnomethodology and componential analysis.
Own goals and penalties

approach but also brings this into conversation with the views, opinions and perspectives of the researchers. It is dialogical and collaborative in terms of the process, content and co-analysis between participants and research facilitators.

PLA also enables socially marginalised groups to find their own ‘voices’ and to ensure that these are heard. A key element in the critique of professionalized discourses of administrators and academic researchers is that they constitute a “language of power” that “…facilitates the construction of [research subjects] as simultaneously different and inferior.” (Abu-Lughod 1991: 150-151). Historically, those experiencing social exclusion have been viewed as ‘others’ who occupy a subordinate position in a hierarchy of knowledge/ power and whose ‘voices’ are generally absent from the professional, managerial and administrative structures that form the ruling apparatus of society (Ibid.: 142-144). In order to counter this mode of producing otherness, researchers must strive to bring the language of the text closer to the language used in everyday life by their research subjects.

By adopting a predominantly emic perspective, the participatory approach used for this study successfully harnessed the input and energies of the men themselves, from the early stages of co-inquiry through the research and co-analysis process:

Yes, I’m energised too, . . . I’m invigorated. Hope is rising in me. (Brian)

I want to echo what other people are saying – I found tonight very uplifting…it’s fantastic when men share together and are able to share how vulnerable we are. I love being a man. (Gerry)

You know, even the wind and the rain didn’t stop us getting here tonight. It’s working – it’s working! Men like us coming together and talking about just ourselves, being real, ordinary – the support is great. It’s working. (Joe)

Participatory research approaches also provide opportunities for experiences of inclusion, greatly increasing the likelihood of men’s ownership of the process and thus promoting sustainability of any practical actions emerging from the study. Our research process to date shows strong evidence of this:

I was looking forward to tonight – to coming back for the session. So much is happening for me here. I came in tonight and I’m leaving a better man. (Dave)

Other people kept telling me, “You will never let anybody fall”. So I now trust myself to find ways to help other men. We won’t do it on our own. ... It’s not a burden – it’s what I should be doing. This is meat and drink. Now there’s not enough time in the day. It’s great. (Joe)

Seeing how men over a short period of time, have explained some of their inner feelings and in some ways their inner demons through the confidence they gained just by being part of a group. I am also confident that we as a group can progress and reach out to other men. (J.P.)

It’s encouraging – the caring aspect. We care for each other, and I do think we’re growing. (Joe)

The level of ownership of the process is also evidenced by the fact that there was a significantly high degree of consistent attendance and engagement by the participating men.

The primary data arising from these co-inquiry sessions comprises the life stories, shared experiences, ideas, suggestions and analytic categories of the men themselves. We generated this
information through diagrams, charts, maps and written documents produced by the participants, extensive focus group discussion and sharing, and comprehensive note-taking by the facilitators. The latter data-recording technique was chosen in preference to tape/digital-recording because of concerns about the possible inhibiting effects of recording equipment as well as potential problems with sound quality. Primary co-analysis was carried out by the participants and facilitators during the sessions. Between sessions, the facilitators carried out a meta-analysis of issues that had arisen and fed this back to the group for comment, validation or amendment at the following session.

4.5 Narrative Structure of the Research Encounter

From the outset it was important to understand something of the wider cultural context of the men taking part in this study. It is only within such a context that barriers to social exclusion and culturally-appropriate solutions to those barriers can emerge. This material was accessed by inviting the men (including the research facilitators) to root the research exploration in the narratives of our unique life stories. A visualisation exercise called The Journey of My Life (Hope & Timmel 2003: 22) was chosen for this purpose. Each of us produced a life journey chart with the aid of pictorial images, words, newspaper head- lines, and written sentences which was then shared through the telling of our stories in the group.

The fact that we, as research facilitators, included ourselves in this part of the process was enriching for us, but it also served to generate trust between us and members of the group. If we hope for an honest relationship to be established with participants, it is crucially important that researchers are prepared to be vulnerable too. In receiving from these men something of their life experience, we need to be prepared to offer something of our own selves also.

Men find it easy to talk about things – depersonalising the content, stripping it of emotional undertones and distancing themselves in the process. By focusing on personal experiences through the life journey exercise we managed to foster a type of discussion that men do not normally engage in. The individual narratives shared in the group had the quality of being uniquely ‘real’ and authentic stories that conveyed feelings as well as thoughts. This metaphor of the ‘journeys of our lives’ continued to be referred to on subsequent evenings in order to assist men in identifying concrete moments when they were barred from full participation in the social life of those around them. The life journey charts were also used to map the moments when they succeeded in achieving ‘breakthroughs’ into greater social inclusion.

Through this process the men identified barriers to social inclusion, and were able to categorise them into groups meaningful for themselves. These groups were then ranked from ‘most important to progress towards culturally-appropriate solutions’ to ‘least important to progress towards culturally-appropriate solutions’. The men also identified ways in which they already had succeeded in breaking through various forms of social exclusion towards greater health, educational achievement, employability, relational healing, and improved general well-being. Finally, through a process of co-analysis, we drew on the research process itself to consider ways that these men could assist others like themselves to become more engaged with society. Several suggestions were generated for pilot interventions within Inner City Dublin to enable MAIN to reach out to socially excluded men in partnership with a relevant agency or agencies.

Each of the five sessions (of about three hours duration) concluded with a participatory co-evaluation. The final session included a formal evaluation, along with a questionnaire concerned with certain demographic variables, such as: age, educational attainment, employment status, living situation, family and marital status. The questionnaire also included a consent form where participants could indicate how they wished to be referred to (either full name, first name only or
Own goals and penalties

pseudonym) in the research report (see Appendix A for breakdown of questionnaire data). The information obtained through these questionnaires may also be compared with Small Area Population Statistics (SAPS) for Dublin Inner City, Dublin City and Ireland as a whole (Appendix B) in order to situate the research group in a broader context.

4.6 Outline of Research Sessions
The co-inquiry process was originally scheduled for a series of four sessions, each lasting about three hours. The dates had to be adjusted because one of the research facilitators fell ill, and a fifth session was added to provide additional time to complete the research. A general summary of these co-inquiry sessions is provided:

<table>
<thead>
<tr>
<th>Date</th>
<th>Theme</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Monday, 5 March 2007</td>
<td>How can we overcome these Barriers/Blockages</td>
<td>Identifying, writing up and sharing of Breakthroughs. Clarifying the factors that enable men to get past the barriers that prevent them from accessing support. Feedback from research facilitators on proposed grouping of Barriers. Direct Ranking exercise of sets of barriers. Ongoing participatory evaluation.</td>
</tr>
</tbody>
</table>

4.7 Strengths and Limitations of the PLA Approach
The results of any investigation are judged on the extent to which they satisfy three criteria: are they valid, are they reliable and are they representative of a wider social group? The ability to make more general predictions about the attitudes and behaviour of others in a particular society depends upon an evaluation of the research results in light of these criteria.

Validity refers to the truth or correctness of the findings. As the above discussion suggests, research that does not adopt an emic approach in the collection and analysis of data is in danger of producing results that participants do not recognise as a true reflection of their views. Given that we had adopted an emic approach, we wished to minimise our capacity as researchers to influence the findings. This was achieved by introducing a loose structure to elicit the experiences, attitudes and
beliefs of men in the research group; by enabling them to name the barriers they encountered and
the analytic categories for grouping and prioritising this data; and by facilitating them in suggesting
ways to address the issues that arose. For these reasons, we believe that the findings of this study
have a very high degree of face and content validity.

The second criterion – reliability – relates to the question of whether the same findings will be
obtained if other researchers were to repeat the study. Reliability is a key concern of experiments in
the physical sciences, but it is more difficult to achieve in social science research because of the
unique nature of human encounters. For example, a political pollster can record the voting intentions
of a representative sample of citizens, but there is no guarantee that the same results will be
replicated a week later, even if all the same voters are contacted, because people’s views can
change. Jones characterises qualitative research methods as “. . . a complicated, shifting, social
process occurring between... individual human beings, which can never be exactly replicated” (1985:
48).

In light of this, our study included several mechanisms to ensure the reliability of the findings. In the
first instance, it was not a once-off encounter with the research group, but took place over five
sessions spanning a period of four months. In addition, the life journey charts were brought out and
referred to repeatedly throughout the process, thus providing opportunities for participants to
confirm, clarify or correct things they had said in earlier sessions. Finally, the fact that the facilitation
of the research was shared between two consultants provided a further means of checking what
participants had said and how this could be interpreted, thus ensuring greater reliability of the
findings in this report.

The final criterion relates to whether the men who took part in the research sessions are
representative of the wider category of socially-excluded males in Dublin’s Inner City. As with all
qualitative research based on non-probability samples, we do not assert that the data derived from
this small group is representative of all marginalised men. By deliberately adopting the purposive
network sampling approach to identify and select who would be involved in the research group,
statistical rules for computing sample size and composition were no longer relevant (O’Reilly de Brún
& de Brún 2007, Robson 1993). Thus, while the findings of this study may be said to have a high
degree of validity and internal reliability, no claims can be made for their representativeness or
statistical significance.

5. **Barriers to Social Inclusion**

After each of us had shared the story of our life journey, participants were asked to consider the
barriers or blockages they have experienced throughout their lives. Barriers were defined as:

... events, things, people, organisations, anything that prevents you from being positive or moving
forward in your life. They’re like roadblocks or dams. Tonight, we want to concentrate on barriers
that prevented (people/you/us) getting help or assistance when it might have made a difference.
(Outline of Session 2)

The research facilitators illustrated this with examples of internal and external barriers they had
experienced in their own lives. Participants were then given a packet of self-adhesive labels and
asked to mark the places on their life journey charts where barriers had occurred. They were also
encouraged to write a few words about each barrier on the label in order to jog their memories when
sharing the story with the rest of the group.
5.1 Participants Recount Barriers in their Lives

Over the course of Sessions 2 and 3, the men identified and named a total of twenty-three barriers to social inclusion. These are outlined below, with a brief summary of the discussion that took place. While some of these are clearly specific to a particular individual, they do provide broader insights into how something like a long-term illness/disability can affect men in a similar position.

A. Getting Kyphos-Scoliosis

In 1999, J.P. was diagnosed with a condition known as kyphos-scoliosis – double curvature of the spine. He felt that statutory bodies, such as the Department of Social Welfare and the Health Service Executive, have not provided him with the information or help he was looking for.

B. Bias/Disability/Labeling

This was another issue identified by J.P., who saw all the red tape associated with the health and social welfare systems as an external barrier in his life. “I found myself in limbo. The medics wanted to put me on Disability [Benefit], they said I was unfit for work. But I said, ‘Hold on a minute. Surely there’s something I can do’.” Once J.P. had been labelled, the ‘system’ took over control of his life and he was given the run-around. “The system says you couldn’t sign on for Unemployment Benefit if you’re on Disability. First, you have to get through the rehabilitation system, then we’ll tell you whether you are fit to work.” The decision over J.P.’s working life – a core element of masculine identity – was effectively out of his hands.

C. Government Making Cutbacks

A number of participants felt that the problems outlined above were exacerbated by recent cutbacks in government funding to voluntary groups working in the community to provide support for those with disabilities as well as others who are disadvantaged.

D. Discrimination – Societal/Class

J.P. also recounted the difficulties he has had in finding work since being classified as ‘disabled’, despite earning a third-level qualification for himself. “They say it’s illegal to discriminate against someone for disability, but I still haven’t got any work.”

This led to a wider discussion about discrimination in society, which is often based on class distinctions. Some of the men recounted how this had affected their personal relationships with potential partners. Another participant, Will, spoke about the discrimination he experienced in trying to get a place in a ‘good’ school. Because of problems at home, he was living with his grandparents at the time. “When I gave my grandparents’ address in Ballybough, I couldn’t get into [name of an academic secondary school in city centre]. They thought I was just a skanger from the Inner City. So I went back and gave my mother’s address in Raheny and I got a place.”

E. Racial Discrimination

Paul spoke about his experience of being discriminated against because he was Irish:

I’m seventy-four and I’m talking about the time I was in England… there you’re a Paddy… They make assumptions that you’re a drunk, a rowdy because you’re Irish. Sometimes people would say bad things to you just because you might disagree with something someone said, and they would call you a bastard… but what they really meant was… you’re an Irish bastard… but they wouldn’t say the Irish bit. It’s the same though in Ireland if you’re from Sheriff Street.

Paul considered this to be a form of racial discrimination.

F. Going to College
Because of Richard’s negative experience of schooling discussed below, for much of his life he lacked confidence in his own academic skills and abilities. Nevertheless, after taking an adult education course and rebuilding some of his self-esteem, Richard decided to go on to study at third level. This was a huge step because of the fear of failure and other emotions surrounding his school experience, which acted as internal barriers to access. Nevertheless, he overcame his fears, took the chance and obtained a bachelor’s degree, followed by an honours B.A.

G.  I met a bollox of a Teacher – “He deconstructed me”
Richard remembered loving school as a boy and skipping there with joy each morning. However, this did not last, as he recalled meeting

... a bollox of a teacher. He robbed me of the joys of life. The teacher called me a ‘pleic amadán’ – a double fool. He totally ‘deconstructed’ me.

His dealings with this teacher marked him, “that was the first time I really felt hurt”. Though he didn’t have the language as a child, he now knows that he became a “child depressive”, and this proved to be a barrier to further development for much of his life.

H.  Death of my Father and Friends
Richard then went on to talk about how the death of his father had affected him.

When my father died, it was very powerful. I was alone. It was the first time I felt alone. I lost all my support systems, everything that was safe, secure and strong.

He linked this experience with the death of some friends. The experience of training together in the army as part of an armoured unit had created strong bonds between them.

[You’re] four men in an armoured box, with three other tanks looking out for you, to the back, front and side. I call it the ‘spirit of the tank’. You get very close to other men in those situations.

When these friends died, Richard felt very scared and vulnerable without the support of others looking out for and protecting him. He described these feelings as a very personal and internal barrier to moving forward in his life.

I.  All these Pubs are an Attraction
Richard described himself as “a recovering alcoholic who has been dry for the last year”. But the fact that there is “a pub on every corner” and that this is where most men in Ireland go to socialise is a problem for him. Although he has learned how to deal with it, it does present a barrier when he wants to meet, chat and celebrate with others. A number of the other men agreed that this was a problem.

J.  Taking on Someone Else’s Fear
Another participant, Dave, identified how childhood experiences had shaped certain patterns in his life.

As a baby, I had fits. That wasn’t so much a barrier, but my mother’s reaction was. Her fear, I grabbed onto it. She wouldn’t let me out to play with the other kids. If I was out playing, there always had to be somebody there, a brother [watching out for me]. Three, four, five – those are the formative years, but I didn’t get a chance to make friends.

This pattern influenced Dave’s relationships with others throughout his life.
When I was twelve, my ma ended up in hospital on or off for five years with depression. My dad worked every hour he could to keep us going. I ended up feeling very lonely. I felt really low. I guess I was depressed, but I couldn’t talk about it. I couldn’t even talk to my friends. I mean, I could talk to people, but I couldn’t talk about Dave. Eventually, I just got lost. I stopped going to school. Though I was very good in school, it became irrelevant. . .

As a result of “getting lost”, Dave developed an internal barrier that holds him back from meeting and relating to other people. “I’m afraid to commit, to let people in. All the other problems are made worse by this.”

K. 1997 – Meltdown
At an early age, Dave went out to work, but lost his job and ended up on the dole. This was an experience that drained his spirit even further: “I got really low. Nobody wanted to know me.” He then met his partner and, although the relationship was “rocky”, they got a house and moved in together. Eventually, this relationship broke up, and he lost his mother and grandmother around the same time.

I lost my house/home and hit the bottle. 1997 was the worst. Both my mother and my gran died. I couldn’t handle it. I couldn’t grieve. It took me a long time to get over the death of me ma or to go out with another girl.

Dave described this period in his life as “meltdown”. As a result of his unresolved grief, the breakdown of the relationship with his partner and the loss of house and job, Dave “took the easy way out” and started drinking.

I was stuck in a rut and drinking too much. I just hit the bottom. You drink for comfort, you drink to forget about things, but it doesn’t work.

It has taken Dave the best part of ten years to pull himself out of this situation and move on with his life.

L. Lack of Love/Affirmation
Gerry highlighted how the relationship he had with his parents had affected his life.

My mother was very manipulative, she manipulated people through her illness. My father was extremely authoritarian. Because of that, I face fear every day. Even coming here, I felt afraid. This fear of people in authority made me become the ‘quiet guy’. One of my bosses told me “You’re better than everyone here, but you don’t know it.”

In common with many of the stories recounted above, such childhood experiences are influential in shaping a man’s self-image and patterns of behaviour in later life.

M. Responsibility and Duties around Parents
Social norms and expectations can also inhibit us from reaching our full potential, as Gerry’s comments suggest:

There were a number of things I’d have liked to do with my life, like get a job abroad. But I was the eldest son, I married young and my brother and sister went away, so I was left to look after the parents. I had to stay, to be there for them. Parents can put a burden on your back. Well, at the time, I saw it as a burden, as a duty. It was only later in life that I learned to see it as a choice, my choice to stay. It took a mental shift in myself.
Many years struggling with self-awareness and personal development were required for Gerry to gain these insights into the relationship with his parents.

**N. Father not Expressing Love for You**
Because of these experiences with his parents, Gerry felt very insecure and unable to express love.

_The only time I remember either of my parents saying “I love you” was on my twenty-fifth wedding anniversary. I couldn’t handle it. My parents always used to tell me “That’s very good, but . . .”. I hated that ‘but’._

Nevertheless, Gerry was at pains to say that: “_My father did as best he could for his time._”

**O. Massive Insecurity**
Another participant, Brian, spoke about feelings of ‘massive insecurity – so big I can’t describe it’, ‘no self-belief’ and ‘lack of confidence’. He coped with this by:

_... putting on a mask, on top of another mask, on top of another. My life became a series of masks._

Brian felt that his attempts to hide away his true feelings have made it more difficult to relate to others in a real and authentic way.

**P. Grief comes to you and you don’t know how to handle it**
A number of men then spoke about the problems they had, and still have, coping with bereavement:

_When my dad died, my life folded like a pack of cards. I completely collapsed [. . .] I was totally disconnected from my heart. (Brian)_

_Eventually it [undealt-with grief] catches up with you. (J.P.)_

There was general agreement among a number of the men present about this point. The discussion seemed to suggest that we, as men, did not have role models for expressing emotions, especially grief, because our fathers and other men of that generation did not do so:

_My dad was a cloth-cap type of guy. One day he saw me crying and couldn’t cope with it. (Richard)_

In this way, barriers can be passed down from one generation to the next, from father to son. Yet, nobody wanted to point the finger of blame at this older generation of men, as that was how things were done in their day.

The men in the research group had mixed feelings about the advisability of expressing emotions openly. Brian said: “_We don’t cry when we should cry. We need to learn to cry._” However, Dave appeared to be more ambivalent: “_Not so much you don’t cry. You just get on with your life._”

**Q. Lack of Services/Facilities/ Information for Homeless/ Those in Need**
Paddy spoke about how his life fell apart and he be- came homeless. As a result of a minor injury that went untreated, Paddy had part of his foot amputated. By the time he was well enough to be discharged from hospital, he was jobless, homeless and broke. He encountered genuine difficulties obtaining assistance from the relevant state bodies.
No one wanted to take me on. Once I got into the system, you have to run around to get everything sorted. You have to keep chasing it all the time, no one really tells you.

Joe’s experience of homelessness illustrates the problems of relating to government-funded service providers and the impact on his self-image.

I became homeless. When I went down to the officer to get some help, the woman asked me was I an alcoholic or a drug addict. I mean, what was that about? . . . I was just so down, and I went down further – I eventually got completely flat.

As well as undermining a man’s sense of identity and self worth, being without a place of residence presents particular difficulties in accessing services, as Joe explained: “Without an address, you’re a non-person. Lots of men are suffering out there – just suffering in silence on their own.”

R. No One [single] Centre for Information (Department of Social Welfare/ Health Service Executive)

A number of the men spoke about the apparent lack of coordination between the DSW, HSE and other agencies, the failure to share information, and the red tape involved in accessing services. This leads to ridiculous situations like the one recounted by Paddy, who was forced to undergo a further medical examination when claiming Disability Allowance. “They had to send out a doctor to see that my foot hadn’t grown back.” A number of the men argued that what is needed is a one-stop shop, where information can be obtained about all the available services and where all of the paperwork can be easily processed.

S. No Social Architecture for Men

There followed a general discussion about the problems men encounter from middle age onwards. Housing was considered to be a major issue; many bedsits and single flats in social housing schemes are not suitable for older people or those with disabilities. Paddy noted that “. . . once you come up to fifty-five, they don’t want to know”. This appears to be a reference to DSW’s tendency to pension off people who have been unemployed for some time and are no longer contributing to the work force.

Richard argued that the problem is bigger than the absence of suitable facilities. We also need to consider the social and community dimension:

There is no social architecture for men to relate to. No male development workers (in community organisations), no outreach workers for men. The problem is so huge that working in the area is like (working with) quicksilver.

He felt that a “universal response” is needed to address the multiple problems faced by socially-excluded men.

T. Recurring Depression

Brian noted that depression seemed to be a recurring theme running throughout the discussion during the first three research sessions. Others agreed.

One word stands out – depression. (Peter)

If you have depression, it’s like shutting the door. (J.P.)
It’s part of the mix of what we are, part of our DNA. There’s five thousand years of conditioning... it’s part of the mix of the cake. (Richard)

U. Isolation
Shay spoke about the situation he found himself in after coming home from East Germany where he had lived for a number of years. The people he had grown up with hadn’t moved on in their lives, and couldn’t seem to relate to him because he had taken an alternative path. He felt that he was being forced into isolation through their begrudgery.

V. Broken Relationships
Again, a number of participants noted that this was a common experience in many of their life journeys.

W. Huge Culture of Blaming
Gerry observed that there is a culture of blame in Irish society and this can hold people back:

If something goes wrong, we get a name, we have to find a scapegoat. We live in fear of taking a chance, of making a mistake. It’s paralysing for the person.

As the barriers were identified and discussed, the research facilitators prepared a separate A5 card for each of them for use in the following exercise.

5.2 Grouping of Barriers
Because of the large number of barriers identified by the men in the research group and the apparent overlap between a number of them, the research facilitators thought it would be helpful to group them into a smaller (and more manageable) number of categories. Towards the end of third session, each of the barrier cards was read out and placed face-up on a table around which the participants were sitting. The men were then asked to sort the cards into piles based on similarities and differences between them. There was considerable discussion and debate about which card should go into which pile, and the exercise had to be concluded before all the outstanding differences could be resolved.

Before the next session, the facilitators met to consider the outcome of this card sort exercise. The participants had created four separate piles, with two barrier cards left over as agreement had not been reached on which pile they should be allocated to. While maintaining the basic structure of these categories, the facilitators felt that two of the piles could be combined because of the high degree of similarity between the barriers they contained. We also proposed that one or two barriers be allocated to different categories. In addition, we suggested labels for the category headings.

At the start of Session Four, all of these proposals were referred back to the men in the research group, who debated our suggestions and approved the final arrangement. The following are the meaningful categories of barriers that were generated through this exercise:

**Societal/Class Prejudice and Discrimination**
- Bias/Disability/Labelling
- Racial Discrimination
- I Met a bollox of a Teacher – “He deconstructed me”
- Discrimination – Societal/Class
- Huge Culture of Blaming


**Emotional/Relational Crises and Issues**
- Broken Relationships
- Father not Expressing Love for You
- Lack of Love and Affirmation
- Responsibility and Duty around Parents
- Death of my Father and Friends
- Going to College
- Isolation
- Recurring Depression
- Grief Comes to You and We don’t Know How to Handle It
- 1997 – Meltdown
- Taking on Someone Else’s Fear
- Massive Insecurity
- All These Pubs are an Attraction

**Poor/Inadequate Service Provision**
- No One [single] Centre for Information. DSW/ HSE
- Lack of Services/Facilities/Information for Homeless/Those in Need
- Getting Kyphos Scoliosis
- Government Making Cutbacks
- No Social Architecture for Men

5.3 **Ranking of Barriers**

Given the large number of barriers identified by the group, the research facilitators felt it necessary to prioritise those which needed to be addressed in the remaining sessions. We chose a simple ranking exercise and introduced this at the beginning of Session Four after agreement had been reached regarding categories of barriers. The men in the group were given the following instruction:

> Please rank these clusters of barriers according to those you consider most important to progress towards solutions to those you consider least important to progress towards solutions. (Outline of Session Four)

Each participant was given ten colour-coded match-sticks and asked to allocate these in accordance with the priority they attached to each of the three categories of barriers. This exercise produced the following ranking:

The category of Emotional/Relational Crises and Issues was ranked most highly with a score of 34, indicating clearly that these were the barriers participants wished to address and progress towards the development of culturally-appropriate solutions. There was a high degree of agreement that this category of barriers is the one where existing provision is particularly inadequate.

With the notable exception of Richard, the few men who succeeded in accessing ‘official’ services at times of emotional/relational crisis described their experience negatively. In general, they felt their emotional needs were overlooked by agencies which tend to process clients in a more systematic and impersonal way. Even if they knew what services were available and where to find them, the nature of their vulnerability with its accompanying lack of confidence and low self-esteem makes the matching of services to service users extremely problematic. The informality and ‘ethic of care’ inherent in the MAIN initiative is probably one of the key reasons men find it so helpful and meaningful.
The category referred to as Poor/Inadequate Service Provision was ranked joint second with the Societal/Class Prejudice and Discrimination group, both scoring 23. In relation to societal/class prejudice, the men in the research group acknowledged that not enough has been done in the past to address this in Ireland, but they also acknowledged that perhaps things had begun to improve in this area. In relation to inadequate service provision, when these marginalised men tried to access services, many were unhappy with the quality of the services provided. The fact that the participants identified ‘poor/inadequate service provision’ as both a barrier in itself and as a category of barriers suggests that this is a very significant issue that contributes to the creation and maintenance of social exclusion.

6. Breakthroughs Towards Social Inclusion

In addition to identifying barriers that inhibit men from moving forward in their lives, we also wished to focus on those occasions when the participants managed to breakthrough these blockages. This was important not only to provide the men in the research group with hope for the future and a sense of their own power, but also to enable them to analyse what they can do to assist others. Although one participant felt that the term ‘breakthrough’ was a bit of American psycho-babble, there was general agreement with the concept underlying this exercise.

Although we had flagged our intention to look at breakthrough moments at the beginning of Session Two, the exercise did not take place until later in the series of research sessions. The concept was introduced as follows:

BREAKTHROUGHS are great moments, events, experiences that allow us to MOVE FORWARD, sometimes to get through a barrier that has blocked us for some time. BREAKTHROUGHS can be moments when something very small happens, but on reflection, we see that it was the beginning of something much, much bigger. Breakthroughs mean our life situations and conditions improve for the better. (Outline for Session Two)

Again, the research facilitators illustrated the concept with examples of breakthroughs they had made in their own lives. Each man then received a self-adhesive star, which they used to mark the most important breakthrough moment on their life journey charts. They were also asked to write a few notes about that moment, including: what the breakthrough was, how it happened, who was involved, how it made them feel and what difference it made in their lives. These notes were then placed in envelopes and saved for later use.

During Session Four, the notes were taken out and participants were invited to share their breakthrough stories in the wider group. The researchers’ analysis of the breakthrough material in conjunction with the life journey data highlighted a number of timely supports that helped men experience greater social inclusion:

- Educational Opportunity
- Psychological Support in the form of “Wise Counsel.”
- Friends and Family.
- Being Involved in MAIN.
- The PLA Research Process.

6.1 Educational Opportunity

Even though early childhood memories of schooling were often negative, a number of men identified the importance of returning to further training or schooling up to and including third-level study. One
participant found his way into third-level education after being diagnosed with a major spinal condition:

The most important breakthrough in my life came about when I enrolled in Maynooth to initially do the Diploma in Community and Youth Work, then onto the BA Honours in Applied Social Studies. This expanded my knowledge and broadened my horizons. This however would not have been possible without the monies that I inherited from my late mother. Her death in many ways helped open a new chapter in my life. [The money] removed the burden often associated with third level study, making it easier to study to obtain my goal. (J.P.)

As a result of this breakthrough experience, J.P. describes himself as someone “who is thinking different” and who now sees himself as “an eternal optimist”.

The school experiences of another participant, Richard, were recounted in the previous chapter. In spite of such an unhelpful start in schooling, Richard returned to NUI Maynooth as an adult student and completed his degree studies there. As he says himself: “I went to College...the fool went to College. Look at the depression line...its rising!”

Shay recalls a day when his maths teacher called him “a fucking dreamer because I was watching pigeons in the yard. I was interested in nature.” He later went to a private school where he encountered an American teacher and “she was like a whole new world, and she encouraged me in art.” In spite of this positive experience, Shay took the boat out of Ireland in the 1980s and ended up in East Germany where his true education took off. The experience of learning about German language and culture, the arts and opera has remained with Shay as a key period in his life where he broke out of the confines of 1980s Ireland into the greater freedom and experience of social inclusion that East Germany offered.

On my arrival in Germany (GDR) in the 80s, I immediately became aware of artistic, educational, and sporting opportunities etc. Lectures; Theatre; Political work; Concerts, Opera; Sport. [There was] total access to these things at almost no cost! I do believe that 80% of my education today is a result of this “freedom”.

Shay concluded his input with a passionate appeal for greater opportunities for people to develop their talents. “If somebody has the wherewithal to do something, they should be allowed and encouraged to do it, at six not sixty [years of age].”

While Will was still a young man, his child died and later his relationship broke up. Like Shay, Will also felt he had to leave Ireland in order to try to escape some of his own demons. He hitched to Israel and succeeded in “sorting some things out.” After returning to Ireland, Will decided to study for a degree in education from Trinity College, Dublin. He has since become involved in MAIN.

Early experiences of schooling proved to be very influential for many of the participants. As illustrated above, some had damaging (as well as inspiring) encounters with teachers. Others were absent for lengthy periods as the result of serious illness or difficulties at home. Only a small number of men in the research group did not complete junior secondary schooling, while quite a few had pursued third-level education (see questionnaire data in Appendix A). Even when group members did not specifically mention education as a key breakthrough in their lives, many recounted how the opportunity to further their education had been important in achieving greater social inclusion. However, there are limits to this. Educational attainment serves to reduce but not entirely eliminate the experience of social exclusion. For example, of the five men in the research group who had attained third-level qualifications, only two are currently in paid employment. The remaining three men described their continued unemployment as ‘personally disturbing’ and a source of ongoing
marginalisation.

6.2 Psychological Support in the form of ‘Wise Counsel’

Richard’s story is one of making a key breakthrough after being referred by his GP to a psychotherapist for counselling. As mentioned previously, Richard suffered from depression as a child and this stayed with him into adulthood. The depression was compounded as a result of his father’s death and the deaths of some of his friends. On his life journey chart he said: “I chose the headline ‘Man of Mystery’, but I’m a mystery to myself. I’ve issues of bereavement; I’ve lost a good few friends.”

The psychotherapist helped him through the depression with talking or “wise counsel” instead of medication. “This man knows all my secrets and I’m happy that he does.” After this period of counselling, Richard says:

“I’m thinking different, beginning to feel more confident and at ease with myself. It’s like a second time round, another go at life. If this intervention had not happened, I don’t know where I’d be now. I’m fundamentally changed from that person I was fifteen years ago.”

Although Richard is the only man to identify formal counselling as the key breakthrough in his life journey, we include it here as a ‘finding’ because all of the men identified various forms of what we refer to as ‘informal counsel’. This can take the form of mentoring, compassionate listening, the experience of being part of what MAIN offers, and the support arising from participation in the research process itself. This informal counsel was central to their experiences of breaking through the barriers in their lives.

6.3 Support from Friends and Family

Brian’s story illustrates the importance of individual contact with a significant other in helping men to emerge from the no-man’s-land they find themselves in. The key breakthrough in his life came in 1971:

“I had been working in Kenya but had to return to Dublin where I isolated myself and was very depressed. I had no idea what to do. My parents with whom I stayed were tolerant but bewildered by me. I was in freefall, unable to work, totally isolated, stayed in my own room. I’d lost faith in myself, in where I could go. An old friend, also named Brian, kept coming to see me. He seemed to believe in me and accepted me where I was. He took me out many times for walks and to events. He even took me on a holiday with two other guys who had been friends. His intervention was a turning point during the worst period of my life.”

Brian stressed the importance of making meaningful connections with other men, which he later explained as a type of “life mentoring”. In relation to his own mentor, Brian said: “He had faith in me. He was a bit older than me, a bit wiser than me.” Brian now goes out looking for men who are ready to make transformative changes in their lives and offers them the opportunity to work with him as their mentor.

Billy’s story also illustrates the importance of friends and family, and the value of informal relationships as a key support for vulnerable men.

“One year out of hospital. Still feeling suicidal, lost, burnt out… family and friends showed concern and began by giving me various reading materials associated to my illness. Reading the material gave me an insight to others having similar events in their life. From there my
brother and friends encouraged me to just go out walking, or for a pint or two, so I did and after a few months found all my fears fading gradually.

Gerry maintained that: “All the breakthroughs I’ve had have been learning to accept myself a little more.” He noted that the breakthroughs all came out of periods of confusion, darkness, struggle and despair. They all involved people coming into his life and acting like “stepping stones”.

He then spoke about the most difficult period in his life. His marriage was “very rocky, nothing I could do was going right.” One of his children was sick all the time (with a disability) and he referred to her in “abusive terms”, something that shocked him at the time. He was depressed and taking medication, “one tablet three times a day, but found myself taking ten tablets at night so that I could sleep. I also used to curse all of the time.”

Gerry’s transformative moment began when two people he knew worked behind the scenes to get him transferred to another department in his workplace, where he came into contact with a third person who befriended him. After an argument with this man in a pub, Gerry was walking along Merrion Square and had a ‘transformative experience’. . . .

It was as if someone was saying, “I’ve been knocking at your door. Are you going to go ahead or stay back?” [. . .] I just knew that it was okay to be me. Before that I had no confidence in myself, I never spoke at meetings. . . . Now I know I’m good enough.

Gerry stopped cursing, his marriage started to come back “I just noticed I wasn’t taking the tablets anymore. It’s made me understand people an awful lot more. I just do what I can do and that’s okay”.

Gerry’s story highlights the involvement of other people in making a breakthrough. It also hints at the far more indefinable support of ‘spirituality’, suggesting that healing, transformation and growth for vulnerable men like him might also entail learning to accept their brokenness. Other group members affirmed what Gerry said here in terms of just learning to accept who you are, “warts and all”, while at the same time rejecting any idea that this means giving up or not trying any more.

Paddy diagnosed his condition in the following way:

For twenty years, I was a part-time friend, a part-time husband, a part-time father. I never gave anything to that relationship. After the break-up of my marriage, I found it very hard to get in relationships of any sort. I just took to avoiding situations or running away from them.

When he found out that his daughter was pregnant, he grabbed this as a second chance to be a father to her. “I decided to become a father to my daughter, and it actually worked... I was so happy.”

The hardest thing was going into the hospital to visit his daughter. He was afraid that she might reject him, and he was also nervous about meeting his ex-wife there.

I had the chance to face up to my responsibilities or run away. I decided to face up to the real world. It brought me back into the fold of my family – I got a second chance with my daughters. It worked, and all’s well that ends well.

All of the stories in this layer of the breakthrough analysis emphasise the value and importance of informal networks of friends and family in helping vulnerable men move from social exclusion towards greater social inclusion.
6.4 Getting Involved in MAIN

One of the key findings of the breakthrough stories is the significance and importance of the support that MAIN has offered these men, and continues to offer them. Dave recounted the experience like this:

The first major breakthrough was when I met Joe, Richie and JP, and was able to talk freely about myself. There was no judgment, just acceptance. It was incredible after thirty years to be able to relate my life experiences and to feel that I was accepted for the person I was and not the person I felt I should present to others. No more fear, no more lies.

At this point in his life, Dave was living on his own in a flat in Fairview, and feeling “very low”. He found it difficult meeting and talking to women, because of low self-esteem. The metaphor of Groundhog Day really struck a chord for him. This is a reference to the popular American film where the main character finds himself reliving the same day over and over again.

I was stuck in a rut, going to work, going to the pub, falling back home, going to work again. Meeting Joe and getting involved in MAIN is very positive for me. I’m doing a computer course and a Level 5 FETAC course. I’m still on the road and getting better slowly, but MAIN is really important for me.

Billy is equally clear about what MAIN has offered him:

I also bumped into Joe M — round this time and got involved with the MAIN group, and the meetings gave me an added strength. They’re not different from myself. [MAIN] allowed me to accept myself for what I am — to learn to love myself. Before this, I couldn’t see my way. . . I thought about suicide a couple of times.

Joe spoke about how the idea for MAIN came about.

One of the great things about setting up this group MAIN is that I got to know people really well [. . .] MAIN’s approach is unique, it’s a process of connection. I remember men watching football in the pub, but I noticed J.P. and Richard analysing the reactions of the crowd in the pub, and thought this was really interesting, unique. In a way, pubs aren’t that bad for some men, because at least they’re not hiding away. I much rather people go down to the pub, at least you can talk to them there. Once they stay in their flats drinking alone, they’re lost.

Joe spoke about starting up MAIN as a transformative experience in itself. “The biggest breakthrough has been setting up the men’s group. It’s only in the last year that I’ve come out of that darkness”. He also described the experience of “cleaning away things in my life, washing my clothes by hand to see the dirt coming out of them.”

Richard picked up on the value of men being able to meet not just in pubs: “It’s great we can get together and share like this. We don’t have to share only in the pub. I’m amazed by the similarity of our stories.” Brian confirmed the strength of the group and the importance of the support offered through MAIN: “For years I’ve had this lack of confidence that men could be real with each other...but this group is great...really great.”

Throughout the narration of life journeys, the consideration of barriers, and the focus on breakthroughs, a strong and clear message came through – the support offered by MAIN is of particular value to these men. MAIN is not a replacement for other informal supports such as family and friends, or for forms of professional counselling or service provision. But it is an active and vital way for vulnerable men to continue to access forms of honest and open sharing that increases their
self-confidence and self-esteem. Interestingly, the experience of being a part of MAIN effectively addresses many of the barriers that the group prioritised under the heading of Emotional/Relational Crises and Issues.

### 6.5 The PLA Research Process

In the Terms of Reference for this research project, DICP asked the research consultants to identify “a practical, appropriate and participatory approach to the social inclusion of vulnerable men that could be developed by MAIN and piloted in Inner City Dublin.”

Comments from individual men throughout the research sessions suggest that they gained from the PLA process itself and experienced it as consistent and congruent with the aims and practice of MAIN. Such a participatory research process using a PLA approach thus appears to be a practical and appropriate intervention capable of being developed by MAIN and piloted in Inner City Dublin.

Dave firmly locates his key breakthrough as “right now”, something happening during the research process itself:

> I’ve been carrying someone else’s fear. I realised this only a month ago when you asked me about barriers in my life. If I hadn’t been asked that question, I would never have seen it as a barrier[...]. I put my star major breakthrough at the end of my life-journey, which is now, really. Coming to these meetings has been the major breakthrough for me. I was always afraid, making excuses... It’s like something’s been broken, it can never grow back. The major breakthrough for me was coming to the meetings, to feel so comfortable with myself that I could look at my life and be able to accept myself. When we were talking about barriers I began to realise I was carrying a lot of fear that was not my own. With this realisation and acceptance I feel that I can deal with my own pain and fear, and try to move on with my life.

Dave’s comments were echoed by most of the other men in the group:

> I learnt how effective a structured exploration together on one’s life can encourage men to talk about deep issues that affect them. The energy, support of other men. It confirmed me in my own manhood. I want to echo what other people are saying... I found tonight very uplifting, and I’m delighted that I’ll be able to get here the next night. I wasn’t sure I would. It’s fantastic when men share together... and are able to share about how vulnerable we are... I love being a man. (Gerry)

Knowing I am not alone, and being able to interact with other males without feeling intimidated. For once in my life I have the ability and confidence to speak in front of other people. (Will)

I was waiting on the bus... very cold... and wondering to myself, why am I coming here? But the bus came anyway, and I got on, and got here. It’s been really good... I’m really glad I did come again. Improving... it’s improving all the time. Each session is better than the last. Yeah, it’s great. (Paddy)

I agree with what’s been said. There’s more hope now. When we started out we were restrained, but tonight we were a lot less restrained. Each session it gets better. We’re all willing to dance. (Shay)

My sense of it is that something is going on here... something important. It’s like ‘maleness’ [laughter in group]... no, I mean real ‘maleness’, and I have a growing sense of just what’s going on between us... it’s very powerful. (Brian)
7. Culturally-Appropriate Solutions

Before and after each session, the research facilitators met on their own to review the issues that had arisen and to finalise plans for the following session. In between sessions four and five, we met for an extended period to generate a ‘meta analysis’ that drew together the salient material from the life journeys, barriers, breakthroughs, clustering and ranking. This was intended to consolidate the issues raised throughout the co-inquiry process and to move the discussion forward towards practical solutions. We compiled a matrix chart that was taken back to the men for consideration on our final evening together.

7.1 Presentation and Response to Meta-Analysis

The matrix chart arranged the data under five column headings:

- **Common Life Events**: Throughout our lives, we all encounter a similar set of events and relationships over which we have only limited power or control. These life events are essentially neutral. However, depending on the circumstances surrounding them, they may have either a positive or negative impact.
- **Responses**: When life events happen, others can respond to us in a variety of ways. It is how we react to these responses that may result in barriers or breakthroughs in our lives.
- **Negative Impacts on Us**: Under this heading we listed some of the ways in which these responses and our reactions have impacted negatively on us and others.
- **Saying it in Our Own Words**: Direct quotations from the men were used to illustrate some of these negative impacts.
- **Interventions**: Finally, under this heading we listed some of the interventions that helped men break through towards greater social inclusion.

The matrix chart is reproduced in full below.

Each man was given a copy of the chart, which was read out and explained in detail by the researchers. We then asked participants to reflect on it and offer their comments. The response to the meta-analysis chart was very positive. A number of the men commented again about the importance of “relationships”, “emotional baggage”, and “shame”.

Yes, it’s very striking...all that about relationships, particularly because so much of masculine identity is around work and employment. It [work] is an issue, but not the dominant issue. (Richard)

A lot of this stuff is emotional baggage, and if it’s not dealt with when you get a job it just drags you down. If you don’t address the emotional baggage, you’ll never be successful in work. (J.P.)

Shame is part of something... though I do think we have it covered when we experience that ‘lack of encouragement’. The shame is felt when your self confidence is right down in the bottom of your boots. (Shay)
7.2 Suggested Solutions to Social Exclusion

The above reflection and conversation led quite logically into a consideration of practical ideas/solutions that could be developed for dealing with the social exclusion of vulnerable men like those in the research group. A number of the comments from this conversation are recorded below:

Community-based men’s groups are probably the forum for exploring some of the issues in that chart. They offer a non-threatening forum for exploring these issues. Otherwise we don’t explore these issues in a gentle way. (Richard)

Seek them (men) out, and engage them. (Joe)

Also, the ‘isolation’ strikes me...but why do we detach ourselves? If we could develop a public space for exploring a very private agenda...you must approach men in a very non-threatening way. (Richard)

It’s about listening and paying attention to each other. (Joe)

When you have a problem, it’s easier to walk away from it...the path of least resistance is easier to take...but you need support to take the other path. (Dave)

Hopefully it will come out... lots of men don’t know how to connect, or the difference between sympathy and empathy. (Joe)

I’ve a big question about building self-esteem...that it’s not just about building up an ego, and when that gets knocked then we go down. It’s about accepting ourselves as we really are...we are flawed! There is another way of coming to see ourselves. (Gerry)

We are all flawed, and we have to get back to just being human. (Shay)

The research facilitators continued to focus the conversation around specific concrete solutions:

Identifying and naming things like shame, is good, and how we move through that is with encouragement, support and empathy from other men. We need to be encouraged to talk about how we feel. We need this at the beginning, in the middle and at the end. Men need this. (Joe)

I remember the time I brought a group of ‘drug users’ to the theatre. They were delighted and amazed. We just side-stepped the social expectations that drug addicts don’t go to the theatre. We just went out and did it, and there was a great buzz from them afterwards. (J.P.)

We have to pay attention to each other; otherwise we won’t notice what we need to notice. (Joe)

We need to share, to form an ETU – an Emotional Trade Union – to come together and join up, and learn about emotions and feelings...a safe space that helps men. Small community-based men’s groups could make this happen. I don’t know how this would happen practically though! (Richard)
### Summary of Barriers and Breakthroughs

<table>
<thead>
<tr>
<th>Life Event</th>
<th>Responses</th>
<th>Negative Impacts</th>
<th>Saying it in Our Own Words</th>
<th>Breakthroughs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships with Mother/Father</td>
<td>Father not expressing love for you Lack of encouragement Authoritarian Manipulative Fearful</td>
<td>Lack of confidence &amp; self-belief Inability to express love or other feelings Massive insecurity Fear of authority Taking on someone else’s fear Responsibility/duty around parents</td>
<td>It was like I was in a shadow — my childhood. I had no bond with my mother — I was a child in shadow. (Brian) The only time I remember either of my parents saying ‘I love you’ was on my twenty-fifth wedding anniversary. I couldn’t handle it. My parents always used to tell me, ‘That’s very good. But …’. I hated that ‘but’. (Gerry)</td>
<td>Being able to talk freely about myself with other men Being accepted/no judgements We’re not to blame. No child is born with shame. We need to be encouraged to talk about how we feel.</td>
</tr>
<tr>
<td>Other Relationships Partner(s) Children Friends Other Men</td>
<td>Broken Relationships. [Note: Few references were made under Barriers, but important in many Life Journeys and Breakthroughs]</td>
<td>Feeling inadequate Fear of rejection Inability to commit isolation</td>
<td>For twenty years, I was a part-time friend, a part-time husband, a part-time father. (Paddy) I was a piece of cosmic dust, out there in the darkness. (Richard)</td>
<td>Second chance to be a father: facing up to my responsibilities Meaningful connections with other men. He had faith in me. People coming into my life — ‘stepping stones’.</td>
</tr>
<tr>
<td>Bereavement Death of my father &amp; Friends 1997 — Meltdown.</td>
<td>Lack of male role models for expressing emotions Suppressing feelings</td>
<td>Grief comes to you and we don’t know how to handle it. Inability to express grief Inability to deal with death Despair Depression</td>
<td>My dad was a cloth-cap type of guy. One day he saw me crying and couldn’t cope with it. (Richard) I was trying to prove of value to my dad. But when my dad died, my life folded like a pack of cards. (Brian)</td>
<td>Going to college Going back to education and experiencing success.</td>
</tr>
<tr>
<td>Schooling/ Education</td>
<td>I met a fellow of a teacher — he deconstructed me. Being bullied No encouragement</td>
<td>Lack of self-confidence &amp; sense of self-worth</td>
<td>I loved school, school didn’t love me. The teacher called me a plebeian vandal. (Richard)</td>
<td>Setting up PAIN Taking on a leadership role Freedom/opportunity to develop interests</td>
</tr>
<tr>
<td>Work/ Employment</td>
<td>Biased—Discrimination—Labeling. Racial discrimination Stereotyping Ageism Segregatory Blaming</td>
<td>Repressed anger Undermined self-confidence</td>
<td>[The job] took a lot out of me. My confidence was dented, deflated. It changed my personality. … I started to beat myself up. (Pat) I ended up on the dole. I really lost myself, I got really low. Nobody wanted to know me. (Dave)</td>
<td>Good kind council (counselling) Listening Encouragement Support Empathy Imagination</td>
</tr>
<tr>
<td>Our Relationship with Society</td>
<td>Bias — Disability — Labelling. Racial discrimination Stereotyping Ageism Segregatory Blaming</td>
<td>Paralyzing Isolation Putting on Masks</td>
<td>I coped with that by putting on a mask, on top of another mask, on top of another. My life became a series of masks. (Brian)</td>
<td>Deep sharing of life experiences Looking after one another Feeding ourselves Getting in touch with our spirituality</td>
</tr>
<tr>
<td>Ill Health Disability Growing Older Getting Injured Health problems</td>
<td>Poor/inadequate service provision. Lack of services/facilities/information for homeless &amp; those in need. No one-stop-shop. Government making cutbacks. No social architecture for men.</td>
<td>Disempowerment Feeling like a non-person Being put in a box</td>
<td>Life ain’t no candy. The medic wanted to put me on disability, but I said, “Hold on a minute, surely there is something I can do.” (JP) I became homeless. When I went down to the crisis to get some help, the woman asked me was I an alcoholic or a drug addict? (Joe)</td>
<td></td>
</tr>
<tr>
<td>Relationship with Ourselves (Spirit)</td>
<td>All these puts are an attraction</td>
<td>Alcohol/Substance abuse Recurring Depression Sense of Failure, Shame</td>
<td>I was stung in the gut and drinking too much. I just hit the bottom. You drink for comfort, you drink to forget about things, but it doesn’t work. (Dave)</td>
<td></td>
</tr>
</tbody>
</table>
It all comes back to supporting each other – to be able to look each other in the eye – women are great at this. (Joe)

Richard’s comments from an earlier session, and an intervention by him during this final session, sum up very well the concerns of the men:

I have doubts...Yeah, its brilliant here in the room...now...but I want it to continue to grow and happen. This is one of the strongest groups I’ve ever worked with, and I want something golden to come out of this. We need support for this. I don’t want it to end in a piece of paper.

I have a sense of fear and trepidation that MAIN can continue from tonight. I’m worried...we are actually held together by emotional strings and bandages. We need an anchor...a partner, an organisation to anchor us...this needs to be ongoing. What we need to do is set ourselves up first, and then move on to help other men.

7.3 The Way Forward

From the continuing conversation around possible interventions in response to the needs of socially-excluded men, a number of critical issues emerged. On the one hand, members of MAIN are willing to reach out to work with other men. On the other, concern was expressed about the need to look after themselves, what one participant referred to as “feeding ourselves”. The latter point was aptly illustrated by Gerry’s comment:

It’s very important if we are to work with other men that we have to resource ourselves as a group – maybe go to Glendalough or somewhere, regularly build ourselves up, get in touch with our Celtic roots and spirituality!

The facilitators remarked that the type of sharing that had been going on in the research sessions over the last few months had a special quality that seemed to have touched everyone who took part. The quality of this sharing and the willingness to be vulnerable with one another could be seen, in itself, as a type of spirituality. The challenge was to find a balance between mutual support and growth among existing members of MAIN, and the group’s goal of helping other men. As Gerry suggested:

We need to alternate between these two things. We need separate meetings for deeper sharing, and business meetings to plan the active work that we do.

In terms of consolidating MAIN as a group, participants focused on structural issues such as: clarifying its aims and objectives, ratifying a draft mission statement, finalising standing orders, appointing officers and assigning tasks/responsibilities to them. A key concern was finding a permanent ‘home’ for MAIN – a centrally-located and neutral place where the group can meet regularly. Such a ‘home’ is also essential as a contact point for outreach work with other vulnerable men in the Dublin Inner City area.

In terms of concrete suggestions for how to go about contacting and supporting other men, the responses were limited. As an introductory activity to meet with men in the area, Richard proposed holding a series of Big Breakfast events, a method that has been used with some success by the Ballymun Men’s Centre and other men’s groups. Interest was also expressed in setting up a personal mentoring service, whereby members of MAIN would be trained to work on an informal one-to-one basis with individual men in the area. Clearly, much more thought and detailed planning needs to be done before such activities can be initiated. Nevertheless, Joe was clear that the DICP was committed
“to continue to support us in this kind of work.”

8. Conclusions and Recommendations

8.1 Participatory Learning and Action (PLA) Research as an Innovative Model

The manner in which this research project was designed and delivered, as a participatory process of in-depth co-inquiry, was integral to the outcomes. From the outset, the aim of the research facilitators was to involve the men in more than a series of technically-competent sessions of information-gathering. Rather, our intention was to create a safe space where vulnerable men might actually experience the research encounter as a form of social inclusion. That the five research evenings succeeded in achieving this aim is evidenced by a selection of the participatory evaluation comments from the men themselves. When asked to name one thing they would take away from the research process, participants wrote:

That I am not alone. I now know that there people who respect me and don’t judge me. I know that if I need emotional support that I will receive it. (Dave)

[I’m] very grateful for the professional and interactive approach of the facilitators, their generosity, and the honesty of their involvement. (Joe)

This is one of the strongest groups I’ve ever worked with and I want something golden to come out of this. We need support for this – I don’t want it to end in a piece of paper. (Richard)

To the extent that Richard’s wish (echoed by all the men) is to be granted and that this piece of paper is not the only concrete outcome of our five research evenings together, it is worth noting the value of the research process itself. What strongly worked for these men was the experience of being genuinely listened to in a threat-free environment. This enabled them to be open about their vulnerabilities, the barriers to social inclusion they have encountered, and the breakthroughs they have made. In essence, the research process enabled these men to recognize all the areas of life where they possess in-depth knowledge and the capacity to effect change. It also gave them an opportunity to find their voices. Within that listening framework, even men who were initially tentative about sharing something of their stories gradually gained in confidence and grew as a result.

Seeing how men over a short period of time have explained some of their inner feelings, and in some ways their inner demons through the confidence they gained just by being part of a group. (J.P.)

These last two evenings – it’s improving my confidence. In school I’d get the shite kicked out of me…but here in this group I feel comfortable and I’m getting more and more confident. (Will)

I agree with what’s been said. There’s more hope now. When we started out we were restrained, but tonight we were a lot less restrained. Each session gets better. We’re all willing to dance. (Shay)

I’ve spent the last two weeks since the last session being fearful about being fearful. But in the last session, I realised something I had missed in the first session and that was great. . . . And tonight, I’ve taken another, a big step... just being able to talk to you about my fears. (Dave)
The fact that something transformative happened for most, if not all, of the men through the research process suggests that similar approaches could be used in future, not only with MAIN, but also with other men’s groups and vulnerable populations in Dublin’s Inner City. While this transformative dimension of the research encounter is somewhat unusual for social science research projects in general, it is quite common and often integral to a well-run Participatory Learning and Action (PLA) process. We are convinced that the means by which socially-excluded groups are invited to become part of research processes must serve to increase their experience of being socially included, rather than furthering greater alienation and isolation. Where participation is genuinely invited, socially-excluded men (and others) can begin to experience a sense of personal and group empowerment.

8.2 Continuing to Build on the Good Work of MAIN

The men who took part in this research are very clear about the significance of participating in MAIN as a means of enhancing their own experience of social inclusion. It is this experiential certitude that gives them the motive power and the vision to nurture, extend and develop the work of MAIN in helping other vulnerable men like themselves. Those who took part in the co-inquiry process are energized to share what they have achieved. They are ready and willing to work with partner agencies, organizations and groups to help shape forms of service provision that address the key needs of vulnerable men in Inner City Dublin. As one of the participants – Richard – suggests, “we must approach men in a very non-threatening way” in order to develop “a public space for exploring a private agenda”.

8.3 Key Recommendations

The review of national and international literature in Chapter 3 highlighted seven key elements of best practice when working with socially-excluded men. Interventions are likely to succeed when they:

- involve an outreach dimension
- organise introductory activities
- create a threat-free and non-competitive environment
- develop relationships based on mutual respect and trust
- relate the real-life context of participants
- inspire personal agency, and
- network with other statutory and voluntary bodies.

In order to incorporate these guidelines in advancing the proposals arising from this research, we recommend the following:

A. Support MAIN to continue to come together as a group.

With great commitment, the members of MAIN have given selflessly of their time and expertise. It is our view that support for the group should now be put on a more structured footing if that work is to develop and grow. Such structured support would require securing sufficient funding to assist the men to “feed” themselves, and build upon the capacities and abilities they already possess. The nature of such feeding would need to be established by the men themselves, in collaboration with relevant partner organisations. Suggestions have already been made by the group as to how MAIN might consolidate their strengths (See Section 7.2).

At the final session, the question was asked: “Can we facilitate ourselves when Ed and Tom leave?” The question depends, to some extent, on whether MAIN intends to use PLA-style participatory strategies as part of their ongoing work. If MAIN intends to continue with this participatory approach,
then developing a training programme tailored to the specific needs of the membership of MAIN is possible and in our view, desirable.

**B. Foster Outreach Work through One-to-One Mentoring**

Attention ought to be paid to the desire of some members to develop their ability to offer an outreach service to other vulnerable men in the form of one-to-one mentoring. Again, funding would need to be secured in this regard, particularly in terms of creating opportunities for further training and on-going support/supervision. Such training might include elements of life-coaching, mentoring or other forms of creative listening and talking therapies.

A case can also be made for employing one or some of the key members of MAIN in order to strengthen and develop the ability of MAIN to offer innovative services to Inner City men experiencing social exclusion. The work of MAIN would progress and benefit greatly if a structured role or roles could be created in the form of a ‘coordinator’ or ‘outreach worker(s)’ from within the ranks of MAIN. These workers could be engaged on a contract basis, either full-time or part-time, or possibly through a Community Employment Scheme. Some further training should be considered here also and MAIN members need to be involved in identifying what form this should take.

**C. Secure a ‘Home’ for MAIN**

A key concern of the group was whether they will continue to have a place to meet in the future. Because social exclusion is often characterized by homelessness, it seems to us that MAIN would benefit greatly by having a secure ‘home’ to continue their important work.

**D. DICP in Partnership with MAIN Develop an Innovative Pilot Model of Service-User-led Provision**

As noted above, DICP wishes to generate tailor-made pilot services and models of delivery to address the diverse needs of its clientele. We believe that the work of MAIN fulfils these criteria. A case can be made for innovative and participative research processes, like the one used during this research, to become an integral part of “innovative creative and experimental service delivery models” like that offered by MAIN.

Service users are ‘consultation weary’. Many service providers have yet to genuinely engage with service users in the sense that this implies developing a longer-term relationship of trust, involvement and co-responsibility. What MAIN offers the men with whom they work is that longer-term relationship. In this they are already innovating and have the potential to construct a model of delivery that is ‘cutting edge’. MAIN has begun the process whereby service users can become active agents and partners in the development of more user-driven services. We believe that MAIN is an appropriate partner for DICP in further developing this innovation as a pilot model of such provision.

Once established, this model of user-led provision would benefit greatly from engagement with relevant stakeholders in an ongoing process of participatory monitoring and evaluation.
APPENDIX A: Data on Research Group

At the end of the final research session, a questionnaire-cum-evaluation form was distributed to the participants present. Unfortunately, since this session had to be scheduled at the last minute to allow additional time for the research, a number of the men were unable to attend. Subsequently, attempts were made to obtain the information by telephone, but it was not possible to make contact with all the outstanding participants. In the end, data was obtained on eleven of the fourteen men who took part in one or more research sessions. Data from the 2002 Census for Dublin Inner City and for Ireland as a whole is provided for comparison.

APPENDIX B: Small Area Population Statistics
In an attempt to quantify the scale of social exclusion for men in the area, the research consultants gained access to the Small Area Population Statistics (SAPS) from the 2002 census for the thirty-nine District Electoral Divisions (DEDs) that comprise Dublin Inner City. These provide information on several key demographic characteristics of the adult male population, along with certain indicators of social exclusion. Since such statistics are aggregated at DED level, it is not possible to examine the impact of a combination of factors, except with a limited number of variables. In order to compare the Inner City area with the rest of Dublin City and with Ireland as a whole, data on the latter were also obtained.

B.1 Age
At the time the census was taken in 2002, there were over a third more boys and men living in the DIC area than those of the opposite sex. A profile of males by age is shown in Chart B.1 below, with separate bars for Dublin Inner City (blue) and the country as a whole (green).

![Chart B.1 - Males by Age](image)

The national picture shows a gentle fall and rise in the relative percentages of males with age, peaking among 20-24 year-olds and subsequently tapering towards the baseline in older age groups. However, this population bulge is much more pronounced in the Inner City. Whereas the proportion of boys and older men is lower in Dublin’s Inner City than in the country as a whole, the percentage of males from 20-34 years of age is up to twice that in the wider population. We can infer from this that young men from other parts of the country are drawn to live in the centre of the nation’s capital city by a variety of factors, including employment opportunities, further education or training, entertainment options, the availability of drugs and drugs treatment services, and hostels for the homeless.
B.2 Marital Status
Information was also obtained about the marital status of respondents, and the data for males fifteen years of age and older is summarised in Chart B.2 below:

Whereas cohabiting couples were recorded separately in the data on household composition, this was not the case in relation to marital status. Presumably, those who had previously been married and who were living with another partner at the time of the 2002 census were counted as either ‘separated’ or ‘married’ depending on their inclination when responding to this question. Caution should therefore be exercised in interpreting these statistics. Nevertheless, almost three out of every four men in Dublin’s Inner City were not in a marital relationship (i.e. either single, separated or widower) compared to only two out of four in the country as a whole.

B.3 Household Composition
The census form also included a question about the relationships between people living in private households, a category that excludes communal establishments such as hotels, hostels, hospitals, boarding schools and military barracks. The data obtained on living circumstances for both males and females of all ages is summarised in Table B.3.
The table highlights some distinctive features of the population in the Inner City area. Whereas over half of all people in Ireland lived in a traditional nuclear family (husband, wife and children), fewer than one in five persons in Dublin’s Inner City lived in such households. On the other hand, the proportion of people living in single-person households in the DIC area was twice the national average. In addition, those in the Inner City were five times more likely to share accommodation with unrelated persons than those living elsewhere in the country, a reflection of the relatively large number of rented flats in the area of Dublin between the canals. Moreover, since this data refers only to private households, it does not account for those staying in hostels for the homeless in the city centre, where males significantly outnumber females. For this reason, the percentage of men living in relative social isolation was probably higher than shown in Table B.3.

On census night in 2002, there were 7412 men (twenty-five years of age or older) recorded as living on their own in Dublin’s Inner City. However, when we focus on middle-age males – those between twenty-five and fifty-four years of age – there were significant differences between the DIC area and Ireland as a whole, as can be seen in Chart B.4. The proportion of Inner City males in this age group living on their own was more than twice the national average.

### Chart B.4 - Living Circumstances of Middle-Age Males (25 - 54 years of age)

- **Dublin Inner City**
  - Living Alone: 18%
  - Living with Others: 82%

- **Ireland as a whole**
  - Living Alone: 8%
  - Living with Others: 92%

B.4 Educational Attainment

As noted in Chapter 3, educational attainment is an important indicator of the potential for social exclusion. SAPS data was therefore obtained about the highest level of education completed among males 15 years of age and older. Although the census form included up to thirteen different options for answering this question, these have been aggregated into four categories as shown in Chart B.5.

### Chart B.5 - Males (15+ years of age) by Level of Education

- **Dublin Inner City**
  - No Formal Education: 1%
  - Primary Education Only: 21%
  - Upper Secondary or Above: 62%

- **Ireland as a whole**
  - No Formal Education: 1%
  - Primary Education Only: 23%
  - Upper Secondary or Above: 52%
Levels of education for males resident in the DIC area are comparable to those for Irish men generally, though Inner City men tend to be better educated. Almost five out of every eight men in Dublin’s Inner City had completed senior secondary school or higher, while just over four out of eight held comparable qualifications on a national level. Again, this probably reflects an in-migration of more highly qualified individuals from other parts of the country.

B.5 Employment Status
The employment status of males fifteen years of age and older at the time of the census in 2002 is summarised in the table below.

<table>
<thead>
<tr>
<th>Status</th>
<th>Ireland</th>
<th>Dublin City</th>
<th>Dublin Inner City</th>
</tr>
</thead>
<tbody>
<tr>
<td>At Work</td>
<td>63.3%</td>
<td>61.2%</td>
<td>59.2%</td>
</tr>
<tr>
<td>1st Job Seeker</td>
<td>0.8%</td>
<td>1.0%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>58%</td>
<td>72%</td>
<td>9.8%</td>
</tr>
<tr>
<td>Student</td>
<td>10.9%</td>
<td>10.6%</td>
<td>11.9%</td>
</tr>
<tr>
<td>Home Duties</td>
<td>14.4%</td>
<td>13.9%</td>
<td>11.3%</td>
</tr>
<tr>
<td>Retired</td>
<td>12.4%</td>
<td>13.0%</td>
<td>9.5%</td>
</tr>
<tr>
<td>Unable to Work</td>
<td>4.4%</td>
<td>4.1%</td>
<td>4.6%</td>
</tr>
<tr>
<td>Other</td>
<td>1.0%</td>
<td>1.6%</td>
<td>2.6%</td>
</tr>
<tr>
<td><strong>TOTAL PERSONS</strong></td>
<td><strong>100.0%</strong></td>
<td><strong>100%</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Compared with the picture for the country as a whole, men living in Dublin’s Inner City were slightly less likely to be employed, either because they were still in full-time education, looking for their first job or out of work. As noted in Section B.1 above, older men form a smaller proportion of the population in the city centre than in other parts of the country, and this is reflected in the relatively low percentage of retired males shown in Table B.6.

When data on the employment status of males fifteen years of age and older is combined with that for educational attainment a clear pattern emerges. Not surprisingly, those with higher levels of education were more likely to be in work. For example, half of all Inner City men who had not completed primary school were unemployed or still seeking their first job at the time the census was taken in 2002. As can be seen in Chart B.7, males who had completed junior secondary education or less were almost four times more likely to be out of work than those with higher levels of educational attainment.
B.6 Occupation
All persons aged 15 years of age and over in the labour force are classified by the type of work they perform, irrespective of the location or nature of the employer’s business. Those who were unemployed at the time of the census were assigned an occupation on the basis of the job they held most recently. Data for 2002 is summarised in Chart B.8.

It comes as no surprise that there were fewer farmers and agricultural workers in the Inner City than in other parts of the country. However, the higher percentages recorded for clerical workers; sales and commercial workers; and professional, technical and health workers in the DIC area are noteworthy. One possible explanation relates to the concentration of corporate offices, sales outlets and hospitals in the city centre. Despite the number of government departments located in the area bounded by Dublin’s canals, it is surprising that the percentage of male residents listing this as their occupation is lower than in other parts of the country.

B.7 Socio-Economic Group
The final piece of census data that can provide an indicator of social exclusion for males in the Dublin Inner City area is socio-economic group (SEG). A man’s SEG is largely determined by his principal occupation combined with Social Class categories, which reflect qualifications and status within the workplace. Dependents, whether adults or children, are classified in accordance with the SEG for the breadwinner in the household.

Data on the SEG classification for all males in the DIC area is presented in Chart B.9 below, along with comparable data for Ireland as a whole. To a large extent, this data mirrors that on Occupations presented above. Perhaps the most salient feature of Chart B.9 is the high percentage of males for whom the SEG was not known, presumably because this question was left unanswered when the census forms were filled in.
Chart B.9 - Males (15+ years) by Socio-Economic Group

Percentage of All Males

Socio-Economic Group

- Dublin Inner City
- Ireland as a Whole
APPENDIX C: Terms of Reference

Men Alone In No-mans Land (M.A.I.N) Research study to Identify Practical Approaches to Overcoming the Social and Economic Exclusion of Men in Dublin’s Inner City

Terms of Reference

Background
Men Alone In No-mans Land (M.A.I.N) is a response by a number of men to what they feel is the absence of social, psychological and solidarity networks for men who for various reasons including, Unemployment, Welfare dependency, Addiction, Mental and Physical Health issues and Homelessness, marriage and relationship breakdown, are experiencing helplessness, isolation, alienation and hopelessness. They have found themselves separated from family community and the wider society and excluded from the active and productive participation in ‘mainstream’ society.

These men can feel extremely vulnerable and lack the capabilities to identify the means to overcome their social and economic exclusion. Well documented research has shown that cultural factors in relation to the socialisation of boys/men create barriers to vulnerable men presenting themselves to seek help and social support in times of trouble. This highlights the old stereotype of the ‘tough lonely man who works hard and suffers in silence’. This can lead to multidimensional exclusions.

The Steering Group of M.A.I.N which includes men who have experienced some of the issues mentioned above have decided to explore ways in which the community and society can create social, economic and cultural space in which vulnerable males can present themselves to seek help and begin the journey back to becoming active and productive members of their community.

Objectives of the Study
The current proposal is to carry out a qualitative and quantitative study building on the current body of practical and academic work in this area to identify practical locally based and culturally appropriate solutions that will help inner city men experiencing social exclusion to overcome barriers and attitudes that prevent them from seeking help to tackle their social exclusion. To this end, the study should provide:

1. A review of available recent empirical (quantitative and qualitative) research studies in Ireland (and Dublin in particular) to assess the numbers of men in this category and analyse the barriers that prevent the social inclusion of vulnerable males in an urban setting.

2. Identify the current agency, interagency, voluntary and community supports to socially excluded men in Dublin’s inner city.

3. Identify a number of case studies either national or international of ‘good practice’ projects that have been successful in overcoming barriers to the social inclusion of vulnerable males.

4. Through fieldwork (survey and or focus groups) with the target group, identify a practical, appropriate and participatory approach to the social inclusion of vulnerable men that could be developed by M.A.I.N and piloted in Dublin’s inner city.
Study Methodology
It is expected that the study will:

1. From a review of existing work, contain a qualitative and statistical analysis on the current barriers to male social inclusion;

2. Contain ‘best practice’ case studies on practical applications to overcoming male exclusion that could be adopted to support the social inclusion of men in Dublin’s inner city.

3. Show a critical analysis of the in-depth consultative process and field work with the target group as to the practical solutions they would support to help overcome their social exclusion.

4. Recommend a possible and appropriate solution-based initiative that could be piloted in Dublin’s inner city.

Budget
A total budget of €12,000 has been secured for the study from the Dublin Inner City Partnership and Dublin City Council.

Time Scale
The study should be completed at the latest by Mid-February 2007.

Tender Proposals
Proposals from suitable consultants are invited that will address the following issues:

Methodology
The methodology adopted must be scientific and robust with regards design, methodology and analysis.

Study Report
The findings of the study shall be presented in a well written report.

Time Scale
The proposal should set out the start date and the time scale for completing the work.

Fee
The proposal should clearly set out an all in fixed fee for all work involved in the Audit.

Experience
The proposal should clearly set out experience in carrying out similar research and the CVs of the people involved in carrying out the study.

Closing Date for receipt of proposals from interested parties is Friday 6th October 2006.

Please forward tender proposal to:
Patrick Gates
Community Regeneration Officer Dublin Inner City Partnership Equity House
16-17 Ormond Quay
Dublin 7
APPENDIX D: Detailed Outline of Research Sessions

D.1 Research Process: Session One

Structure
• Meeting together for the first time
• Building rapport
• Group formation
• Ice breaker exercise
• Introduction to the research, and the participatory research process.
• Historical Profiling: Sharing of Life Journeys and in-depth focus group discussion.
• Participatory co-evaluation.

Rationale
From the outset we wished to offer participants an opportunity to experience themselves as ‘experts’, and to begin to build up relationships of trust among the group and between the group and research facilitators. We also expected that the life journey material would yield high quality and information-rich data about the trajectories these men’s lives had taken, and material of a contextual and ‘cultural’ nature.

Findings
The data arising from this session was used in Chapters 5, 6 and 7.

D.2 Research Process: Session Two

Structure
• Concluding life journeys
• Brainstorming, and Focus Group discussion
• Identifying, naming and sharing barriers to social inclusion experienced by men
• Ongoing participatory co-evaluation

Rationale
To focus participants specifically on those times related to their life journeys where they experienced barriers to social inclusion or blockages to accessing services and supports. To continue to build rapport and support among themselves as a group of men sharing on sensitive personal issues.

Findings
The findings arising from this session form the basis for Chapter 5.

D.3 Research Process: Session Three

Structure
• Completing sharing of barriers
• Focus Group discussion
• Card-Sort technique.
• Grouping barriers into categories meaningful to the men themselves.
• Co-analysis of barrier material
• Ongoing participatory co-evaluation
Rationale
To offer participants an opportunity to discuss together in an in-depth way the type and nature of the barriers to social inclusion they encountered throughout their lives. To have men categorise the barriers generated in a way meaningful to themselves. To begin a process of reflective co-analysis on this material.

Findings
The findings arising from this session form the basis for Chapter 5.

D.4 Research Process: Session Four

Structure
Identifying, writing up and sharing moments and instances of breakthrough into greater social inclusion. Feedback from research facilitators on proposed groupings of barriers from Session Three. Direct Ranking exercise of groups of barriers. Ongoing participatory co-evaluation.

Rationale
Partly as a corrective to the exclusive focus on barriers during the previous sessions, we thought it necessary and useful to invite the men to also consider those moments and instances in their life journeys where they may have experienced breakthroughs towards greater social inclusion: an opportunity to clarify the factors that enable men to get past barriers that prevent them from accessing support.

Initial Findings
Results of the categorising and ranking of barriers are reported in Chapter 5. The findings with regard to breakthroughs are the basis for Chapter 6.

D.5 Research Process: Session Five – Final Session

Structure
- Researchers feedback the result of their meta-analysis on barriers and breakthroughs in a Matrix format for discussion.
- Researchers facilitate a Focus Group discussion on culturally appropriate interventions.
- Final participatory co-evaluation

Rationale
To offer the participating men an opportunity to consider and discuss together the outcome of our meta-analysis, and to modify or amend where necessary. Using the meta-analysis matrix to identify practical, locally-based and culturally appropriate solutions that will help Inner City men experiencing social exclusion to overcome barriers and attitudes that prevent them from seeking help to tackle their social exclusion.

Initial Findings
The principal findings of this session are reported in Chapter 7. In addition, detailed results of the Brainstorming Session are reported below:
Final Chart-work on Solutions
The research facilitators conducted a Brainstorming Exercise with the men on culturally appropriate solutions and generated five charts:

Chart One
To generate the first chart, we asked the following question:
“What would help you and other men like you, break through these barriers and move forward in your lives?”

Coming together as a group of men:

- [where it is] safe to be by yourself
- [where we can] speak about how we feel
- [where we are] engaged in doing something [for ourselves and other men like us]
- [where we can] get in touch with the spiritual
- [where we have the] time and space to be ourselves
- [and where we can continue] telling our stories. This is most important.
- Taking others to the theatre [see J.P.’s comment in Chapter 7] where sometimes it is good to offer vulnerable men a positive and unusual event outside their ‘normal’ experience.
- Pay attention to each other.

Chart Two
Here we asked the men to consider ‘specific interventions’.

- [Form an] E.T.U.M. (Emotional Trade Union Movement). This was a very honest suggestion from Richard, and found full support from other men. As mentioned before it would involve men coming together to join up, and learn about emotions and feelings. Providing a safe space that would help men. Small community-based men’s groups could make this happen. Though how ‘we’ could do this practically is still unclear.
- [Form] small, community-based men’s groups
- [By] engaging/paying attention/watching [other vulnerable men]. [Just] look and you will see
- [By establishing] one-to-one contacts
- [and] avoid competition

Chart Three
This chart focused on practical things that the participants themselves could do.

- [holding] Big Breakfasts MAIN
- Core Group (Joe, JP, Richard, Dave, Will, Aengus)
- [clarify] aims and objectives
- [ratify] mission statement
- [finalise] standing orders
- appoint tasks/responsibilities to people
- complete the research
- pay attention to ourselves as a group – feed ourselves. Not just be task or outreach focused.
**Chart Four**

This was a spill-over from Chart Three:

- [Develop, encourage and support] mentoring [among MAIN members, and between MAIN members and other vulnerable men. This would require creating training opportunities]

**Chart Five**

This chart focused on questions among the group about going forward from where they found themselves at that moment.

Concerns surfaced around the following points:
Can we facilitate ourselves when Ed & Tom leave?
[We need to] have committee meetings.
Also have meetings where we continue to share our stories, and maybe use this to complete our mission statement.
Get a place where we can meet regularly.
Bibliography


- __________ 1994. Participation in Adult Basic Education: An exploratory study of the influence of gender


- __________ Mick COX & Terry McMANUS. 2006. Support, Learning & Action for MEN in Tallaght West: An Cosán, a case study. PowerPoint presentation delivered to a workshop organised by Draiocht, the community development support agency, in Dublin on 30th March 2006.


- FERGUSON, Harry; Jeff HEARN; Øystein Gullvåg HOLTER; Lars JALMERT; Michael KIMMEL; James LANG & Robert MORGAN. [no date, c. 2005]. Ending Gender-Based Violence: A call for global action to involve men, a summary of research. Electronic document accessed on 20/05/2007 at: <http://www.sida.se/shared/jsp/download.jsp?f=SV134602.pdf&a=3108>


Section I; Chapter 3a

Office.


Own goals and penalties


- MCCORMACK, Philip & A. Jamie SARIS. No date. ‘Gender and Social Exclusion in Cherry Orchard’. Unpublished manuscript.


- __________Brendan BARTLEY; Ciara KIERANS; Colm WALSH & Philip McCORMACK. 2002. ‘Culture and the State: Institutionalizing “the underclass” in the new Ireland’. City 6 (2): 173-190.


National Women’s Council of Ireland’s *Millennium Project*, 1998-2000

PLA research materials and techniques used during the Millennium Project: *Mapping* (Violence Against Women) *Card Sort* (Women’s Health) and *Pie Charts* (as ice-breakers).
Chapter 3b

Hear our Voices – Meet our Needs: Women and Health

REPORT FROM THE NWCI MILLENIUM PROJECT

O’Reilly-de Brún M
Gilligan A L
Delaney S
Bailey N

This paper is an example of a specific application of PLA in a national multi-focus research project involving women and the National Strategy for Women’s Health in Ireland.
ACKNOWLEDGEMENTS
The NWCI Millennium Project Team would like to thank the following:
The Facilitators and Participants committed to the research.
The support of NWCI affiliate groups.
Katherine Zappone, for her initial vision for the project.
Department of Justice, Equality and Law Reform.
Department of Health and Children.
The Chairwoman, Board Members and Staff of the NWCI for securing funding for the project and supporting the Team.
Miriam Reddin Beegan.
Audry Deane.
Bridie Hughes.

THE FACILITATORS INVOLVED IN THE WOMEN AND HEALTH COMPONENT OF THE RESEARCH WERE:
Sandra Watson and Mary Sweeney, Shanty Educational Project
Sheila di Brita and Brenda Hand, Blessington Women’s Community Group
Siobhán Callan and Mary McArdle, Dóchas for Women
Aurelia Kelly and Margaret Toye, Ballybofey and Stranorlar Women’s Group
Wendy Goggin and Rose Slattery, Southhill Integrated Development Programme
Liz Waters and Toni Ryan, Community Training for Drugs Workers
Carol Heanue and Dolores Walsh, Forum Women’s Working Group
Eileen Campbell and Helena Poole-Stapleton, Strokestown Women’s Group and Connaught Rural Women’s Group
Roísin Nic Leoid and Máirín Nic Fhionghuín, NASC BAN
Margaret Harkin, Mary Margaret Parsons and Philomena Clancy, North Leitrim Women’s Resource Group
Breda O’Grady and Mary Brazil, Dublin Deaf Women’s Group
Lorraine Stack and Naomi de Rís, An Garda Síochána
Angela Hallisey and Bernadette Kennedy, South West Kerry Women’s Association
Jeanette Sheerin and Margaret O’Brien, Women Together Tallaght Network
Noreen McNamara and Mary Cunningham, Association of Baha’í Women (Cork)

THE FACILITATORS WOULD LIKE TO ACKNOWLEDGE THE FOLLOWING FOR ENABLING THEM TO DO THE RESEARCH:
Sister Margaret McConalogue and staff of the Catherine McAuley Centre
Sister Bernadette – Family Resource Centre Killinarden
Phil Funge
Community Development Project – Tralee
Joan Madden – Knockanrawley Resource Centre; Tipperary Women’s Networking Group Éigse, Dun Dealgan
Mr Con Lynch
Christa O’Brien / Fifi Smith – L.O.T. (Outhouse)
Blessington Women’s Community Group
Women’s Studies Centre NUI Galway
The views expressed in this report do not necessarily reflect the views of the National Women’s Council of Ireland.

MILLENIUM PROJECT TEAM
Mary O’Reilly de Brún - Project Manager
Ann Louise Gilligan - Research Consultant
Sarah Delaney - Research Consultant
Natasha Bailey - Researcher / Administrative Assistant
TABLE OF CONTENTS

1  Executive Summary
2  Introduction
3  Literature Review
4  Methodology
5  Results
6  Discussion
7  Conclusions and Recommendations
8  Bibliography

Appendix 1: Women and Health Back-up Sheet
Appendix 2: Case Study
1. EXECUTIVE SUMMARY

In January 1999, the National Women’s Council of Ireland (NWCI) initiated *Women Mapping the New Millennium*, a national research, analysis and action study. The research focused on six key areas of enquiry: women and health, poverty, work, education, violence against women and local development. The aim of the study was three-fold. Firstly, to provide women across the country with the necessary skills and opportunity to have their voices heard. Secondly, to obtain women’s views on each area in order to inform the NWCI’s lobbying and policy strategies in the future. Finally, to explore and evaluate a model of participatory research and analysis which might form a basis for future ongoing research of this nature.

This research could prove capable of assisting policy-makers and advisors, agencies, advocates, women and their communities with timely and appropriate information for policy formulation at local, regional and national levels.

This report presents the outcomes of the second of the above aims, that is, the views of the participants about women and health in Ireland.

1.1 RESEARCH METHODOLOGY

The study was conducted using a Participatory Learning and Action (PLA) approach, which seeks to build bridges between locals at ‘grassroots’ level and policy makers at local, regional and national levels. Researchers who use PLA emphasise the fact that engaging in participatory research is a two-way learning process for all involved; that movement towards action is a central aim of the process; that a participatory approach can work equally well in urban and rural context, and that the techniques can be adapted and applied to a wide range of issues.

In the health component of the study, 30 facilitators engaged in research with 155 women across 8 counties, urban and rural.

1.2 HEALTH BRIEF

It is recognised that there are many different understandings of health, well-being and illness which vary according to different socio-cultural factors. In order to understand the assumptions underlying health care planning and provision in Ireland, this study refers to the policy orientation outlined by the Department of Health and Children. The focus of the health discussion was to explore whether or not research participants believed that the aims and objectives of the *Plan for Women’s Health 1997-99* (Department of Health and Children, 1997) have had an impact on their own health care needs and concerns.

Also presented in this report is a case study about the research done by the Irish Deaf Women’s Group in relation to the health component of the Project. They have specific health needs in relation to being part of a linguistic and cultural minority. The experience of this group is instructive in raising our awareness of how minority groups’ health needs can shape service provision in order to make it more open, flexible and effective for service users.

1.3 CONCLUSIONS AND RECOMMENDATIONS

The following conclusions and recommendations from the health component of the Millennium Project are relevant to this concern.
1.3.1 Conclusions

- The results of the health component of the Millennium Project suggest that the Irish health system is not sufficiently decentralised or devolved, and that insufficient resources have been provided to implement enhanced services for women in their localities. In some areas services are provided and in some they are not. Childcare was still an important health need across the country despite the commitment in the Plan for Women’s Health (Department of Health and Children, 1997) to address this issue.

- The Department of Health and Children could use the four principles that guide health promotion policy in Ireland as a checklist for successful future implementation of the Plan for Women’s Health (Ibid.). These principles are:
  - Re-orienting the health service to promotion and not just acute care
  - Creating supportive environments in which to make healthy choices
  - Strengthening community action - incorporating community development approaches to health promotion
  - Developing personal skills through consultation with individuals about their needs (Department of Health and Children, 2000).

- Women across the country indicated that they could not access holistic health care, including alternative therapies, nor could they have all their health needs attended to in a one-stop shop, which was the primary ‘completely unmet’ need they identified. Thus, a biomedical model of care is still foremost in the Irish system. This is not in line with the Department of Health and Children’s acceptance of the idea of health as related to social gain.a

- The use of a biomedical model is linked to the overlooking of social, cultural and economic factors in health. For example, participants in the health component of the Millennium Project gave evidence of negative experiences in their health care due to class and gender discrimination.

- The need for health information and education was seen as the second ranking unmet health need for participants in the Millennium Project. This indicates that the plan’s commitment to increased availability and access to health information for women has not impacted upon the women involved in this research.

- There is a direct relationship between health policy and services, individual perceptions of health and well-being and the normative values of a society and culture. “Health care services, like other human service systems, closely mirror the deeply rooted social and cultural expectations of the citizenry as a whole.” (Figueras et al., 1998). Participants throughout the country indicated that they did not feel the concrete effects of promises made in the Plan for Women’s Health (Department of Health and Children, 1997). Thus, until those concrete changes are made, the Irish Government can be seen to uphold the subordinate status of women in Irish society. It may also be reasonable to assume that a tangible improvement in the state of Irish women’s health may not be felt until the policies put forward in the Plan are more thoroughly implemented.

1.3.2 Recommendations

It is recommended that the Department of Health and Children and other relevant departments and agencies, such as the Regional Health Authorities, and the Women’s Health Council:

---

a The term “social gain” refers to the idea that health has social determinants, thus, improvement in an individual’s health status can be a correlate to an improvement in their social status. There is a reflexive relationship between health status and social status.
• Fulfil the promises made in the *Programme for Prosperity and Fairness* (Department of the Taoiseach, 2000), *The Plan for Women’s Health* (Department of Health and Children, 1997) and *The National Health Promotion Strategy* (Department of Health and Children, 2000c) to consult with women about health services, their ethos and models of practice, and where they are needed.

• Commence initiatives to encourage the widespread distribution of free and accessible information about health, particularly for women’s health issues. This may mean placing the information in settings where one would not normally find health information, for instance, in rural post offices. Other innovative ways of disseminating health information should be employed using a variety of media. Participants in the Millennium Project described needing health information on a wide variety of topics, but in particular they mentioned: holistic approaches to health; cancers; reproductive health, family planning and the menopause. Information should be relevant to women’s life stages as illustrated in the results from the seasonal calendars.

• Incorporate research like the Millennium Project into the work of the *National Health Information Strategy*.

• Initiate further research to consult with women about gaps in health information provision, as well as their preferences for style, presentation and medium. Different topics and different age groups could necessitate different modes of delivery.

• Continue the decentralisation and devolution of health services, ensuring that administrative agencies and service settings are properly resourced, financially and otherwise.

• Provide awareness and sensitivity training at regular intervals to health care providers on issues of gender, ethnicity, sexuality, economic disadvantage and the relationship between social factors and health status.

• Ensure that health care providers are trained in effective communication skills and learn how to encourage client participation in their own health decisions.

• Provide free and accessible childcare, so that women can attend to their own health needs.

• Fund and resource women’s groups working with older women, Traveller women, lesbians, refugee and asylum seeking women, women from other ethnic groups living in the Republic, women with disabilities and women who are living in poverty to do research about women’s health issues. One of the most important areas of investigation would be the question of what ‘being healthy’ means to women in Ireland. This would allow for both a deeper and broader view of women’s health in Ireland. Multi-method approaches should be used in any enquiry into health for women.

• Institute a wide range of reforms in services for carers in the country as advocated by the National Women’s Council of Ireland (NWCI) in its work with health representatives in the regional women’s health committees (NWCI 2000).

• Expand the range of care options regarding models of practice, particularly alternative therapies.

• Set up free and universal provision of contraceptives, fertility treatment and information about reproductive choice and STDs (particularly HIV and AIDS).

• Initiate inter-departmental and agency links with regard to women’s health in the Republic in line with the above recommendations. For example, the Department of Health and Children
should fulfil the promise made by the Minister of Health to collaborate with NAPS on establishing health targets, measures and indicators. Health is an issue of human rights for women and should be addressed at a broad policy level.

2. INTRODUCTION

The National Women’s Council of Ireland is a non-governmental organisation (NGO) currently operating as an agent of change with and on behalf of women in Ireland facing a complex and rapidly changing society and culture. Over the past years, the work of the Council, coupled with that of other agencies and organisations, has achieved significant and life-enhancing change in ordinary women’s lives. In 1998, approaching the third Millennium, and cognisant of significant shifts in the political, economic and social landscape in Ireland, the Council recognised that new models of partnership were rapidly emerging. This indicated the need, in turn, for new models of communication and information flow between people at local ‘grassroots’ level, policy makers and the NWCI as a social partner. In seeking to develop and explore such a model, the Council proposed its Millennium Project: Women Mapping the New Millennium.

2.1 WOMEN MAPPING THE NEW MILLENNIUM

Women Mapping the New Millennium is a national research, analysis and action project that seeks to foster a process of empowerment that “has the potential to radically redesign the current paradigm that continues to produce social exclusion” (Zappone, in Kirby and Jacobsen, 1998). It is a capacity-building programme that goes beyond the traditional notion of ‘consultation’ towards an active participatory experience of research, analysis and action.

The key objectives of the project are to:

- Design and explore an innovative model for forming national and local policy through direct participation by local actors;
- Provide women across the country with the training and capacity to conduct sustained social research and analysis;
- Encourage women to analyse the social and economic implications of their activities;
- Produce ongoing, up-to-date research on key experiences of women’s lives – poverty, healthcare, work, etc.;
- Build towards sustainable development of initiatives at local level.

At time of publication, we have a partial picture as to the extent to which the last of these objectives was reached. It is the NWCI’s task to take the results of the research into the national policy arenas to which it has access. This work is ongoing. An evaluation is planned for the future in which policymakers will be asked as to the Millennium Project’s effect on Irish social policy.

We have evidence that some, but not all, of the women involved in the project have fed the results of their research into their local policy-making arenas and/or have initiated an action at local level as an outcome of their research and the skills gained through participating in the project. While this ‘action’ phase was built into the project, it was optional for facilitators and for a number of reasons,

\[b\] Agents of change or ‘change-agents’ is a term commonly used in majority-world development planning to denote organisations (governmental and non-governmental), institutions (public and private), community activists and communities themselves, policy-makers and advisors, individuals and professionals (e.g., researchers, technical experts, etc.), who seek to foster positive change in people’s lives at community, national and/or international level.
for instance, lack of time or lack of resources, not every group could progress action at local level. Also, groups may have started these initiatives long after the end of the project. A mail-out at close of the project asked facilitators to outline what ways they had used the skills gained through involvement with the project. These descriptions are available in the full reference report of the project available in the NWCI.

In many ways, the Millennium Project was a first step towards sustainable local action by the women involved. It represents the beginning of a developmental process. It illustrates the need for women to receive information, financial and training supports to pursue further projects which would enable them to investigate and challenge their environments. 

2.2 RESEARCH AREAS
Six broad areas of research enquiry were identified via consultation with Council affiliates and advisory personnel:

- Women and Poverty
- Women and Health
- Women and Work
- Violence Against Women
- Women and Education
- Women and Local Development (rural and urban)

2.3 WOMEN AND HEALTH
Attempting to provide a single definition of health is highly problematic. Sociological, anthropological and feminist discourses in this area all point to the fact that there are many different conceptualisations of health, well-being and illness (McCluskey, 1997), among women and men within and outside of the medical profession. These different conceptualisations vary according to many factors, including socio-economic background, employment, gender, and culture (Ibid.). What is essential in this context, therefore, is to focus on the voices of the women involved in this research and how they view health and well-being.

In order to understand what underlying assumptions inform health service provision in Ireland, we have adopted as our reference point the approach taken by the Department of Health and Children to health planning and service provision. Although the Department did have an explicit bias towards ‘the curative and regulatory aspects of the health services and on the need to develop the acute hospital sector during the period from 1970 to the mid-1980s’ (Department of Health and Children, 2000a), this approach changed with the publication of the health strategy ‘Shaping a Healthier Future’ in 1994. This strategy was, in fact, ‘the culmination of a reappraisal of the health services which had commenced in 1986 with the discussion document Health - the Wider Dimensions (Ibid.). In 1997, the Department of Health and Children published A Plan for Women’s Health, which was directly informed by the 1994 strategy, and was the first such plan to be formulated among the member nations of the EU. Integral to this plan was the establishment of an advisory council, the Women’s Health Council, also the first of its kind within the EU.

Shaping a Healthier Future (Department of Health, 1994) signalled a significant change in direction, with its emphasis on the achievement and measurement of ‘health gain and social gain and its commitment to organise and manage the system as an integrated whole.’ (Ibid.) This report examines whether or not the 155 women involved in this research believe that this approach to health service provision has been manifested ‘on the ground’. Do health needs as articulated by the

---

c This issue is explored in more depth in, O’Reilly-de Brún et al. (2001). The Millennium Project: Women Mapping the New Millennium Executive Summary. Dublin: National Women’s Council of Ireland.
participants parallel those set out in the *Plan for Women’s Health 1997-99* (Department of Health and Children, 1997)? Do the participants perceive those needs to have been met and, if so, to what extent?

### 2.4 PARTICIPATORY RESEARCH APPROACH

Given this brief, what shape might our research take? How research is designed, and from whose perspective, radically informs the content and results of any research project, which, in turn, informs the policies developed in response to those results. The Millennium Project utilised an emic\(^d\) approach and participatory methodology, which is described in detail in the methodology section of this report.

### 2.5 THE POLICY-INFLUENCING POTENTIAL OF THE MILLENNIUM PROJECT

The Millennium Project has the potential to address several ‘audiences’ and therefore to influence policy at various levels. Intended audiences for the results and recommendations of this study include: the National Women’s Council of Ireland and its affiliate membership, policy-makers and advisors in key Government departments, NGOs, agencies, community groups and activists concerned with the issues which formed the research agenda.

For example, since the beginning of the consultative process from which the *Plan for Women’s Health* (Department of Health and Children, 1997) emerged, the National Women’s Council of Ireland has acted in partnership with the Department of Health and Children and the eight women’s health committees around the country. We hope that our discussion of Irish women’s health will help to inform the ongoing health policy work of the Council, its affiliates and the health counterparts involved with the women’s health committees.

Through the Millennium Project, the Council has built considerable capacity within its affiliate membership (as outlined in the project objectives mentioned above). This enhanced capacity ought to further enable affiliates to address these issues at local, regional and national level, operating as agents of positive change.

Policy makers and advisors cannot develop viable policy in a vacuum. They require constant assistance from those who are the intended beneficiaries of the policies. At the same time, women cannot hope to improve their situation if their voices and expertise remains unsolicited and unheard; they need constant assistance from those who have the power and vision to seek that expertise and build it into healthy policy. A feature of the Millennium Project is the model it employs in order to bring women’s experiences, their needs, suggestions for change and potential solutions, into the heart of action and planning at local, regional and national level.

### 3. LITERATURE REVIEW

#### 3.1 THE STATE OF WOMEN’S HEALTH IN IRELAND

The life expectancy of Irish women has consistently exceeded that of men since at least 1950 (Department of Health and Children, 2000b), reflecting life expectancy patterns through the EU

\(^{d}\) To distinguish between the terms ‘emic’ and ‘etic’: etic research is conducted from the outsider’s perspective, while emic research takes the insider’s perspective on board as the framework from which to explore and understand the issue in question. The terms are drawn from anthropology (Goodenough, 1956) and were borrowed from linguistics. Emic research is also known as ethnoscience, the New Ethnography, ethnomethodology and componential analysis.
The life expectancy for women born in 1995 was 78.6 years, compared to 73 years for men. However, this life expectancy is still one of the lowest in the European Union (Department of Health, 1995).

In terms of externally reported health status, Irish women compare unfavourably to women in other EU member states:

- The standardised death rate (SDR) for Irish women aged between 0 and 64 years of diseases of the circulatory system are 42.4 per 100,000, compared to an EU average of 33.1.
- The SDR for ischaemic heart disease for Irish women is 20.8, compared to an EU average of 12.7.
- Cerebrovascular diseases (including stroke) account for 10.6 deaths per 100,000 Irish women aged between 0 and 64, compared to an EU average of 9.1.
- In 1994, 29% of Irish women aged 15 years or over were regular daily smokers, compared to 28% of Irish men. This is the third highest rate recorded in the EU, beaten only by Denmark and the Netherlands.
- This trend is repeated for the other major diseases affecting women in the EU, including cancer (of digestive organs, e.g. the colon and small intestine, and breast, lung and cervical cancer) and pulmonary conditions such as bronchitis, emphysema and asthma. Together, cancer and cardiovascular disease accounted for 65% of all deaths in women aged under 65 years in 1990.

All of this points to the fact that Irish women are at a considerable disadvantage compared to other women in the EU. However, there are some paradoxical findings emerging from the statistics gathered so far:

- Irish women perceive their health to be at a higher level than women in other EU member states (McCluskey, 1997).
- Irish women also have a low percentage of self-reported limited activity due to chronic illness but a high rate of acute illness (Directorate-General for Employment, Industrial Relations and Social Affairs, 1997).

### 3.2 THE BIOMEDICAL MODEL IN HEALTH CARE

‘Western’ approaches to healthcare are most often associated with what is known as the ‘biomedical’ model of medicine. This approach is rooted in an idea of nature ‘conceived of in mechanistic terms, which led in biology to ideas that a living organism could be regarded as a machine that might be taken apart and reassembled’ (McKeown, 1971). According to this model, illness is perceived as a failure of the ‘mechanism’ to work; in other words, a deviation from some undefined norm (Stacey, 1988). However, no system is static, and Sarah Nettleton (1995) has argued that there has been an increasing movement away from the biomedical to other models in the 1990s for a number of reasons, including:

- Medicine’s efficacy has been overplayed and over-professionalised, therefore non-medical people’s healing skills have been appropriated and healing legitimacy wholly transferred to the medical profession.

---

**Footnotes**

- Ischaemic Heart Disease, otherwise known as angina pectoris, refers to chest pain arising from the heart, usually under the breastbone, due to an inadequate supply of oxygen to the heart muscle.
- HFA Database, WHO, 1994
- World Health Statistics HFA, 1994
- Limited activity means not being able to carry out normal tasks one was previously able to do.
• Biomedicine has failed to locate the body within its socio-environmental context and therefore fails to account for the social inequalities in health.
• Biomedicine medicalises normal physiological processes such as menstruation, childbirth and menopause.

What is regarded as legitimate medical knowledge is determined more by social and political processes than knowledge about health and illness per se. These processes act to perpetuate the dominance of the medical profession and the continuation of patriarchal systems of power in the medical profession (Ibid.).

3.3 FACTORS AFFECTING HEALTH STATUS
The accusation that biomedicine does not take account of the wider socio-cultural context in which health and illness are situated has been borne out by research in this area. As Doyal (1995) says:

“**Inequalities in health between social groups are not simply inequalities in desired states of subjective well-being. They also represent objective inequalities in the capacity of individuals to play an active part in social and community life – to realise their own potential and to help others do the same.**”

Researchers have explicitly identified two main socio-cultural factors which impact on health status:

**Socio-Economic Status**
The publication of the Black Report by the National Health Service in Britain in 1988 (Black, 1988) confirmed widespread health differences linked to ‘class’ (Moore and Harrison, 1998), and Lynch et al. (2000) found a link between high levels of ill health and low socio-economic status.

**Gender**
The impact of gender on health status is far-reaching and complex. Cohen (1994) has suggested that women bear the brunt of health problems related to poverty. He also noted that women from low socio-economic backgrounds were less likely to have a cervical smear or a mammography, and that breast self-examination was also less prevalent. The danger of a ‘black box’ scenario (as with poverty, in which women become invisible) has been highlighted by Arber (1990) who cautions against using the household as the unit of measurement in determining women’s health status.

On the one hand, biomedicine has provided women with something that has empowered and liberated them in certain aspects of their lives, for example, with the provision of contraception. However, on the other hand, feminist writers such as Lorber (1997) and Kennedy and Murphy-Lawless (1998) have argued that women are doubly disempowered in the medical encounter by virtue of being both female and a patient at the same time. One example of this is the medicalisation of normal physiological processes such as pre-menstrual syndrome, menopause and childbirth.

3.4 GENDER, POWER AND KNOWLEDGE: THE ISSUE OF PATERNALISM
Sue Sherwin (1992) has argued that “…the practice of medicine serves as an important instrument in the continuing disempowerment of women in society”, and that in order to maintain this situation, a retention of ‘specialised’ knowledge is essential. This claim is justified through the construction of health and illness as part of scientific knowledge, rather than holistic, and therefore somehow outside the realm of everyday understanding. This can therefore lead to the notion that it is more appropriate for medical practitioners to take on decision-making authority over the patient, which in turn leads to a vicious circle whereby the patient is maintained in a subordinate position (see diagram below).
It should be taken into account, however, that many medical staff fear to break the vicious circle due to fear of litigation and the fact that many doctors are judged on how closely they adhere to ‘accepted policy’. This reduces room for manoeuvre and negotiation, even if practitioners wish to do so.

There has also been an increasing awareness on the part of the medical profession that treatment approaches based on purely biomedical assumptions are no longer solely adequate. According to Stacey (1988), an increasing number of general practitioners are challenging the dominant paradigm and claiming to treat their patients as whole individuals and not collections of symptoms or ‘deviations from a norm’. As far back as 1964, there was some recognition that the doctor-patient relationship itself could be therapeutic (Balint, 1964).

Paula Baraitser, a Senior Clinical Medical Officer in the central family planning clinic in Norwich, has pointed out that “…in an attempt to increase patient satisfaction [in family planning clinics] there has been a move to increase doctors’ ability to communicate sensitively and effectively by providing consultation skills training in medical schools” (Baraitser, 1995). She also goes on to acknowledge the need to understand how doctor-patient consultations are influenced by the sources of power and types of knowledge which both parties bring to the consultation (Ibid).

3.5 RESEARCH STRATEGIES IN HEALTH:
Sherwin (1992) has argued convincingly that research in the health sector should be evaluated as to whether or not it will empower women or limit their ability to make informed choices about their health care. In order to involve women in determining their own health needs and how they would like these to be catered for, an understanding of their perceptions of health and illness, and acceptable therapies, needs to be obtained. Scambler (1991) has estimated that alternative medicine is growing five times as rapidly as biomedicine, and Di Matteo et al (1985) have documented the impact of doctor-patient interactions, service users’ beliefs and their referral systems on health service utilisation, as have other researchers such as Becker and Rosenstock (1984), and Scambler and Scambler (1984).

In Ireland, a positive move would be to foster research approaches and methods which value local knowledge and enable women’s voices to be heard by policy-makers, planners and managers. The biomedical model should be equated with others as culture-specific rather than perceived as representing the ‘Truth’ about health and illness.
3.6 HEALTH PLANNING AND POLICY-MAKING IN IRELAND

Current policy in Ireland, and critiques of health promotion, both caution against the tendency to medicalise normal processes in women’s bodies. As Daykin and Naidoo (1995) point out:

“There is a need to develop policies and services which are accessible, appropriate and enhance the ability of women to resist the health-eroding pressures of their daily lives.”

International governments and NGOs are currently attempting to develop and implement models of health care that eschew assumptions based on an underlying biomedical determinist philosophy. In Ireland, the recent reappraisal undertaken by the government of the health services completed in 1994 (Department of Health, 1994) and the release of the recommendations of the Report of the Second Commission on the Status of Women (1993), resulted in the publication of a Plan for Women’s Health 1997-1999 (Department of Health and Children 1997). During the preparation for this document, extensive consultation was undertaken with Irish women on health needs and issues.

The main aims and objectives of the Plan for Women’s Health (Ibid.) reflect an increased awareness on the part of the Irish Government of the need to re-assess constructions of health, illness and well-being, and incorporate a broader view of what health and well-being actually mean. They are:

• To maximise the health and social gain of Irish women.
• To create a women-friendly health service.
• To increase consultation and representation of women in the health services.
• To enhance the contribution of the health services to promoting women’s health in the developing world.

This plan was to be implemented between 1997 and 1999. While the shift in emphasis and new recognition of the specific needs of women in health service provision is welcomed, it remains to be seen whether these aims and objectives have been implemented successfully on the ground. It also remains to be seen if the needs as articulated by the participants in this project parallel those articulated in the plan. It is essential that government stay attuned to the opinions, needs and concerns of the women living in Ireland, who are the ultimate recipients of the care provisions outlined in the Plan for Women’s Health (Ibid.).

4. METHODOLOGY

4.1 INTRODUCTION: THE DEVELOPING RELATIONSHIP BETWEEN RESEARCH METHODS AND SOCIAL POLICY

Research approaches and methods radically influence research content and, consequently, the policies designed in response to that content. Traditionally, research funding in Ireland has privileged large-scale survey-style research, and it has been a struggle to find support for smaller-scale qualitative research. The NGO sector has made strategic decisions regarding what type of research is necessary to support particular policy outcomes, but the salient question that remains is this: Is it the intention of social policy research to describe the current situation, to change it, or both? (Cantillon, 1998). What might small-scale predominantly qualitative research projects like the Millennium Project contribute to each of these objectives?

Many authors have demonstrated the inability of researchers using exclusively quantitative methods to attend to the “persistent requirement in social policy to understand complex behaviours, needs, systems and cultures” (Ritchie and Spencer, 1994; Cantillon, 1998; Hallett, 1996; Ruspin, 1999). As Irwin (1987) says, ‘Human behaviour and social existence is a subjective and wilful construction and requires drawing close to subjects in their natural contexts and understanding the fundamental human process.’ This ‘drawing close’ can best be achieved by using qualitative approaches because
they provide “an opportunity, albeit briefly, to see the world from another person’s point of view” (Schein, 1995).

This is a lesson strongly reflected by what policy-makers in ‘developing’ countries in the majority world have learned: all the components of social policy – not just the technical and economic, but also the social and cultural – have to be taken into account (Kane, 1995). All the parties involved in research and policy-making - governments, sponsors, local people and external experts - have a unique perspective to contribute (Cernea, 1991). This holistic approach to research and effective policy-formation demands that we make the best possible use of available methods and techniques, and involve local people - in our case, women accessing health services - directly in the process of research, analysis and action-planning.

4.2 FROM THE OUTSIDE IN, OR THE INSIDE OUT? CONTRASTING APPROACHES TO RESEARCH

Research is designed and approached in two main ways, which contrast strongly in terms of perspective, method and therefore outcome. The more traditional approach, and the one with which most people are familiar, might be described as doing research ‘from the outside in’. This is called the ‘etic’ (see footnote #d) approach, and is reflected in the question: “What do I see these women doing/ how will I describe their experiences?” Such research is conducted from the perspective of professional ‘outsiders’, perhaps a team of researchers, or an organisation commissioning a piece of research. The framework for the research is decided in advance, and the ‘research group’ is usually perceived as a passive participant in the process.

Feminist research methodology is similarly focused on active participation of women and others in the research process ‘stemming from a concern that existing methodologies support sexist, racist and elitist attitudes and therefore negatively effect people’s lives (Holland et al., 1995).

The feminist research project proposes not a prescriptive, distinctly feminist set of methods, but a variety of methods employed with the objective of bringing women’s experiences from the margins to the centre. The objective, in terms of research outcomes, is the development of recommendations which position women’s interests centrally in policy debates and maximize their potential for implementation into policy and practice. As such the objectives of Participatory Learning and Action as a research strategy for this project serve as an appropriate vehicle to place women and their concerns at the centre of the research process. The research strategy is outlined below.

In contrast, taking an emic approach means doing research ‘from the inside out’, and is reflected in the question: “What do these women see themselves doing/ how do they describe their experiences?” This approach sees the research group as expert in its own right, and takes that perspective on board, often placing it in positive articulation with other expert opinion. In emic research, the language and categories of analysis used by the group become the framework or lens through which the data is viewed and analysed, and the research group is involved in an active and participatory way throughout the research process.

4.3 RESEARCH STRATEGY: PARTICIPATORY LEARNING AND ACTION (PLA)

The NWCI Millennium Project was designed to respond to the challenges and concerns we have noted, and a PLA (Participatory Learning and Action) research strategy was adopted. PLA techniques are capable of accessing both qualitative and quantitative data1 and can be described as “a growing family of approaches and methods to enable local people to share, enhance and analyse their

---

1 As a research approach, PLA remains open to the integration of conventional research methods and approaches. This allows PLA to inform other research strategies, for example, a tightly-focused qualitative PLA research project is capable of usefully informing larger-scale quantitative studies.
knowledge of life and conditions, to plan and to act” (Chambers, 1994c). PLA techniques also possess the necessary flexibility to explore issues of a sensitive nature, where ‘drawing close’ to women’s actual ‘lived experience’ of health/wellbeing is essential to making visible the complex realities of those lives. This research strategy provided the women involved in the project with tools to develop analytical frameworks that make sense of their experience and articulate their vision for a more positive future.

Key features of PLA include:
• giving credence to the insights and abilities of local people to share and enhance their knowledge of the issue in question;
• using emic research to elucidate the ‘insider view’ and uncover local categories of meaning and analysis;
• avoiding the kind of biases that have characterised much research done from the outsider’s point of view (Kane, 1995), and
• ‘handing over the stick’, meaning to actively encourage local participation and development of positive action planning.

This research strategy is now in use world-wide in organisations as diverse as UNICEF, Save the Children, WorldVision, Ipas and The World Bank.

4.4 RESEARCH SCHEDULE

4.4.1 Training Programme: Training for the Millennium Project took place in two distinct phases: Phase One training spanned March to October 1999 and provided practical training in basic PLA principles and techniques. Phase Two training spanned March to May 2000 and covered more fundamental issues in PLA.

An enormous amount of material was covered in each of the training sessions in groups where women had differing levels of knowledge about research and group facilitation. Since an aim of the project was capacity-building, participants did not have to have prior experience of any of the above. Facilitation skills are extremely important in PLA research. Also important to the research is note-taking during research techniques. Both facilitation and note-taking were covered briefly in the training.

Feedback from the PLA facilitators\(^k\) indicates that a number felt that they would like more training in facilitation and note-taking: ‘[I would suggest] more in-depth training on bettering facilitation techniques – this is vital in both encouraging and energising a group to get to their full potential’ (PLA facilitator).

4.4.2 Research Schedule: At the close of each of the 13 training programmes nation-wide, facilitation teams were invited to negotiate and choose one of the six topics as their ‘national’ issue (meaning it was being researched by other teams across the country). They were also invited to devise a ‘local’ topic of their choice (‘local’ meaning it could be a topic unique to the locality). In many cases, teams preferred to select another of the six issues for their local topic because it matched their concerns and those of their research groups. The information generated for the study on health, therefore, includes 9 ‘national’ and 6 ‘local’ issues.

\(^k\) As the women involved were called after completion of the first phase of training.
Research was conducted over the period May 1999 – May 2000. Teams were provided with back-up support from one of four Millennium Project staff.

4.5 RESEARCH METHODS
The health component of the Millennium Project involved several processes:

- methods:
  - sampling
  - research outlines and selection of data-collection techniques
  - data analysis
- putting appropriate monitoring and evaluation procedures in place
- ethical issues.

4.5.1 Sampling
PLA Facilitators: The initial project design aimed to draw members from NWCI affiliate organisations to train 120 facilitators in teams of 2, giving us 60 teams nation-wide. In early 1999, the NWCI had 142 affiliates. All received information packs about the proposed Project and invitations to nationwide Information Sessions. Project information was also made available via NWCI Panel Meetings and affiliates were invited to consider nominating women for inclusion in training. 41 affiliates responded, and from this number, 9 teams from rural and 6 teams from urban-based affiliates carried out research1. Counties Cork, Donegal, Kerry, Limerick, Monaghan, Galway, Roscommon, Wicklow and Leitrim were represented, as was Dublin West (x3), North Central and South Central. In all, 15 teams conducted research on the health component, with a total of 155 participants nation-wide.

Research Participants: Intensive qualitative study of a small number of cases can lead to valuable understandings about women’s health needs and access to care. The sample of 155 participants involved in this study, therefore, is a non-probability purposeful samplem. The principle of selection is the researcher’s judgement as to applicability (Robson, 1993). The value of non-probability sampling lies in the depth and quality of information generated in the research encounter.n Facilitation teams gathered their research participants from within affiliate groups mainly via network samplingo. A basic criterion for selection was that participants needed to be able to speak from personal experiences of health-related issues.

4.5.2 Research outlines and selection of data-collection techniques
The NWCI Millennium Project Team engaged in a consultative process with affiliates, policy analysts, advisors and research consultants in the process of designing the research topics. Analysis of the data generated by this process, coupled with further input from the NWCI Policy Team, resulted in the identification of key foci for the health research component.

As one of the aims of Phase 1 was to provide data on a national scale, it was necessary to introduce some level of standardisation to the process. Therefore, a research outline comprising a range of PLA techniques and a sequence for their use was designed. Teams were asked to follow the outline closely in order to make scaling up and a level of standardisation possible. The specific questions addressed by each technique can be found in the results section of this report.

---

1 For reasons of confidentiality, participants were not asked for their address. It is therefore possible that although the facilitators may have come from an urban area, the women taking part in the research did not, especially in small urban centres. Therefore, we cannot give a precise urban/rural split.

m Types of purposeful sampling include: extreme or deviant case sampling, typical case sampling, critical case sampling and confirming and disconfirming cases (Kane, 1995).

n As our study sample is not a probability one, we are not making claims for statistical representativeness or significance of our findings.

o Network sampling is, again, a type of non-probability sampling.
It is important to stress that PLA techniques function as a focus for discussion as well as an illustration of the discussion and analysis in which the group engages.

4.5.2.1 ‘Women and Health’ – range of techniques and sequence:

- **Card Sort 1** was designed to enable participants to study a series of pre-prepared cards and decide whether all of these cards are relevant or whether some should be discarded.

- In order to access women’s own ideas of what is necessary for health and well-being, participants were asked to add any extra cards they thought should be included via a **Brainstorming Exercise**. They were asked to consider these extra cards under the research question: ‘What other key supports (needs) do you think necessary for women’s health and well-being into the year 2020?’ Participants could add up to 10 extra cards.

- Participants then proceeded to the **Seasonal Calendar**, taking all of the health needs cards and evaluating levels of intensity over the span of a woman’s life.

- The next technique, **Card Sort and Direct Ranking**, was a two-part exercise, designed to access two different things:
  - Participants were asked to divide the ‘needs’ cards into 3 categories: ‘adequately met’, ‘partially unmet’ and ‘completely unmet’. This identified which health needs and supports fell into which categories.
  - ‘Adequately met’ needs cards were set aside.
  - Then participants were asked to rank ‘partially unmet’ and ‘completely unmet’ needs cards in order of greatest to least importance for women’s health/well-being. This produced two ranked sets of cards, where participants showed how important each need or support is in relation to the others (rank order).

- The final technique to be completed was a **Double Matrix**. It was designed to correlate needs for women’s health/well-being and potential solutions. These solutions were divided into 2 categories, those that can be activated by participants themselves, and those that require outside assistance (for example, State funding).

4.5.3 **Data Analysis**

PLA was developed for use primarily at the micro or local level, the level most often ignored in policy formation. Since the Millennium Project was national in focus, it required a scaling-up of the research approach. While scaling up has been achieved in many countries, the literature attests to its problems, mainly, meeting the challenge to maintain the integrity of the PLA process in terms of its context-specific value, while attempting to make key connections across groups at the macro level.

PLA analysis is usually undertaken on-site, is of an organic formative nature and is a collaborative effort by facilitators and participants alike (Chambers, 1994b and c). Due to the limited resources at the disposal of the research team and the breadth of the project itself, this approach was not feasible for this project.

Analysis of the returned research data was, therefore, conducted in-house. It is important to stress that this does not mean participants were completely removed from the analytical process; because many of the techniques are, in and of themselves, analytical tools, participants were involved in preliminary analysis at the local level. For example, by completing matrices and direct ranking, by conducting card sorts and creating seasonal calendars, the women in this study were analysing primary data as they generated it. They made analytical decisions about proportionality; they prioritised and categorised; they showed correlation and identified bases for action planning and policy development.
The main task, therefore, facing the Project Team was to design an analytical framework appropriate for dealing with ‘scaled-up’ PLA, where the analysis was to take place in-house. This framework would have to meet a number of challenges – it would have to:

- be able to cope with a considerable bulk of data
- be able to represent as accurately as possible the voices of the women who carried out the research
- be capable of presenting themes and categories that emerged across a number of research reports, while, at the same time, preserving the depth and individuality of distinct groups’ research material.

Data arising from PLA research is often a mix of textual and numerical data, each of which are interdependent on the other. Brewer and Hunter (1989) have pointed out that qualitative research in general is inherently multi-method in focus, and this use of what is known as ‘methodological triangulation’ (Janesick, 1998) is central to the strategies employed by PLA. Four techniques (card sorts, direct ranking, seasonal calendars and matrices) were utilised for the ‘Women and Health’ component.

Multiple analytic tools were used to deal with the different forms of data. An outline of the different methods used to analyse the techniques employed in ‘Women and Health’ follows below:

<table>
<thead>
<tr>
<th>RESEARCH TECHNIQUE</th>
<th>ANALYTIC TOOL EMPLOYED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background questionnaire</td>
<td>SPSS</td>
</tr>
<tr>
<td>Facilitator evaluation forms</td>
<td>SPSS</td>
</tr>
<tr>
<td>Card Sort #1</td>
<td>Microsoft Access</td>
</tr>
<tr>
<td>Brainstorming</td>
<td>Microsoft Access</td>
</tr>
<tr>
<td>Direct Ranking</td>
<td>Microsoft Access</td>
</tr>
<tr>
<td>Card Sort ‘Categories and Characteristics’</td>
<td>Microsoft Word</td>
</tr>
<tr>
<td>Seasonal Calendar</td>
<td>Microsoft Word</td>
</tr>
<tr>
<td>Matrices</td>
<td>Microsoft Word</td>
</tr>
<tr>
<td>Accompanying observations notes</td>
<td>QSR NUD*IST</td>
</tr>
</tbody>
</table>

Finally, PLA is fundamentally conceptualised and therefore designed as a holistic, interconnected research approach. The risk of indulging in multiple methods of categorisation is that one might “lose the particularity of particular cases” (Fielding and Lee, 1998), only to be left with “…a smoothed set of generalisations that may not apply to any single case” (Huberman and Miles, 1994). This danger was tackled by including a case study of the research carried out by one of the groups in this component of the project. This group represented a group of women with special needs specifically in terms of hearing, and it was felt essential that the special health needs articulated should be studied in their own right.

Because extended co-analysis was not feasible for the project, the team became aware of questions arising from the research that could not always be answered, for instance, when observation notes from facilitators did not expand on the emic concepts being used by groups or did not clarify decisions that were made during the techniques. Research is always somewhat unpredictable and questions will arise in the research that are as important as the rich descriptions of phenomena that are present in the data. In other words, the team did not expect to present the definitive voice on each of the six issues, but to employ a way of investigating the issues that could be improved and built upon in the future. The team understood that, “no picture is ever complete... what is needed is many perspectives, many voices, before we can have deep understandings of social phenomena”
(Denzin and Lincoln, 1998). Thus, where appropriate, we have identified where information was not available and have made suggestions for future research.

4.6 DESIGNING APPROPRIATE MONITORING AND EVALUATION PROCEDURES

An essential aspect of any research project is an evaluation component. This is especially true where the research aims to encourage people to become ‘stakeholders’ in the study and to facilitate participants in making their voices heard. To this end, a framework for on-going monitoring and evaluation was designed to give facilitators the opportunity to tell us what worked well and what could be improved. Multiple data sources were employed, including:

- Observation notes accompanying the returned research.
- Evaluations of training programmes.
- Facilitators’ comments at the ‘Gathering Day’ (this was an event organised by the team in February 2000 to gather facilitators together so that we could hear about their experiences of doing research).

Facilitators’ evaluation questionnaire (this was a questionnaire designed in order to obtain facilitators’ satisfaction with the research project as a whole).

4.7 ETHICAL ISSUES

For the health component of the research, facilitators were encouraged to remain aware that women providing information on any aspect of their lives are vulnerable in a number of ways. Facilitators were aware that researching these issues requires complete confidentiality. During training, several safeguards were put in place. Confidentiality guidelines were provided in the training manuals and discussed with facilitators, as was the need to respect boundaries and assure participants of their rights during the research process. Names of participants and names of affiliate groups were not mentioned in released material without consent. If data from one affiliate group was used during training or to be released, explicit consent for this was sought from the facilitators involved.

5. RESULTS

5.1 RESPONSE RATE

15 Groups completed research on ‘Women and Health’, 9 as their national topic and 6 as their local topic. Two groups were excluded from the cross-analysis of results, as they completed the research in a manner that did not conform to the standardised outline and was therefore not amenable to cross-analysis.

The geographical distribution of groups who engaged in research in this topic were as follows (for those included in the cross-analysis):

- Dublin city and county: 4 groups
- County Monaghan: 1 group
- County Donegal: 1 group
- County Roscommon: 1 group
- County Galway: 2 groups
- County Cork: 2 groups
- County Leitrim: 1 group
- County Wicklow: 1 group
5.2 SAMPLE PROFILE

- The average age of the women who completed background questionnaires (respondents) was 42 years. Participants were asked to describe their current economic status by circling one value on a 6-point scale which consisted of: 1) extremely comfortable; 2) very comfortable; 3) comfortable; 4) not so comfortable; 5) barely comfortable, and 6) not comfortable at all.
- 53.2% of respondents described their economic situation as ‘comfortable’, and 22.8% described their economic situation as ‘very comfortable’.
- 67.6% of respondents said they worked inside the home.
- 60.5% of the women said they worked outside the home, and
- 73.1% said that their work was paid.
- 15.2% of the respondents said they left education during primary school, 12.7% during secondary school and 12.7% after the Junior or Intermediate Certificate.
- 69.6% of the respondents said that they did have daughters. The average number of daughters per respondent was 2.

5.3 CARD SORT 1

In consultation with the National Women’s Council of Ireland, a list of pre-prepared cards was drawn up which reflected current opinion on priority health needs for women in Ireland. Participants were requested to decide how many, if any, of these cards should be discarded and to give any reasons they may have had for their decision.

These needs included:
- One-stop-shop for women’s health
- Women-friendly clinics in urban and rural areas
- Respite and counselling support for women as ‘carers’
- Access to counselling and mental health care
- Easy access to women’s health/well-being information
- Equality in relationships between clients and service providers
- Access to family planning
- Access to fertility treatment
- Holistic approach to health and well-being
- Free breast screening
- Free cervical screening
- Improved maternity services.\(^p\)

This parallels those areas of concern covered in the Plan for Women’s Health 1997–99, (Department of Health and Children, 1997) although the plan goes into more detail on some areas. Below is a list of the target areas for women’s health identified by the Plan:

- Information for health
- Healthier lifestyles
- Cardiovascular disease
- Cancer (lung, breast, cervical, skin cancer)
- Promoting oral health
- Childbirth and breast-feeding
- Family Planning and reproductive health
- Violence against women
- Promoting mental health, with a specific focus on alcohol-related problems
- Creating a woman-friendly health service (Ibid.).

\(^p\) See Appendix 1 for the back-up sheet that accompanied these cards, explaining exactly what the research team meant by each card.
Of the 13 groups who were included in this exercise, 10 retained all of the pre-prepared cards. Groups H2 and H3 discarded free breast screening, although neither specified a reason for this in their accompanying observation notes.

Group H4 discarded 3 cards. ‘Easy access to women’s health and well-being information’ and ‘Women friendly health clinics in urban and rural areas’ were both felt to be covered by ‘One-Stop-Shop for women’s health’:

‘Easy access to women’s health and well-being information: when one woman said that this would be covered in one-stop-shops the group decided not to keep this card. Women-friendly health clinics in urban and rural areas...again the group felt that this need would be met in the one-stop-shop for women’s health – so threw out the card.’

‘Access to family planning’ was replaced with ‘FREE access to family planning’:

‘General belief that this was widely available, but consensus as to its need to be a free service, so changed to ‘free’ access to family planning.’

• Overall, each card raised a number of important issues for the groups involved. All the groups felt that a ‘one-stop-shop for women’s health’ was very important and should cover all of a woman’s health needs. Group H4 pointed out that an on-site crèche would be essential. ‘All agreed that it would have a crèche.’ Group H8 pointed out that women-friendly health clinics are very important, especially those located in rural areas, in terms of familiarity and privacy:

‘[A] small country town would know if you went into [the] clinic. Everything provided so no-one would know exactly what you’re going in for.’

• The need for respite and counselling support for women as carers seemed to strike a chord with most of the groups. Group H9 stressed the fact that there is often no support for women when people leave hospital, where they have had access to 24-hour care and return home. Group H5 felt that respite and support for women as carers was ‘virtually unavailable’. On the other hand, Group H13 said that in their area (Dublin) the service was improving for carers of children with special needs:

‘...they will take the child and let you have respite or give you a holiday.’

However, there did seem to be some confusion about the extent of support available, as another participant in this group felt that there was no organisation available to enable carers of people with amputations to take a break.

Group H8 said that the extent of respite care available was insufficient and that too often there was an assumption that mothers and daughters had an automatic duty to take on caring roles:

‘...with handicapped children, respite for one week only, shouldn’t presume that once a mother/daughter, [you should] put up with your lot.’

• Access to counselling and mental health care
The three groups who discussed this issue in their observation notes felt that there was a change in attitudes away from drug-based therapies for mental distress, or a denial of the legitimacy of mental distress, to a more accepting view of counselling and psychotherapy:

‘With counselling [there’s] no anti-depressants’ (Group H4).
‘...the way we were brought up was to deal with our own problems...They were not looked at as needing counselling’ (Group H13).

‘Counselling [was] seen as weakness, flaw in character... [now] becoming more...acceptable’ (Group H8).

However, when groups looked at the extent of service provision, feelings were much more mixed. Group H4 said there was difficulty accessing services, as ‘people didn’t know where to go.’ Group H8 felt that there should not be waiting lists for people trying to access counselling and that it is better to provide external rather than in-house services so as not to discourage potential clients. Group H13, however, did feel that there were easily accessible counselling services available in their area.

• Easy Access to Women’s Health and Well-being Information

Three groups recorded their discussions on this issue in their observation notes. Again, there was some contradiction between groups as to the range and current availability of such information. Group H5 felt that there was not enough

‘...information, discussion and choice offered to a woman.’

In contrast, Group H13 had a much more positive view – again they referred to the services available in their own area:

‘Information leaflets [are] good...nurses from the [various] hospitals come to the family resource centre to give talks on women’s health.’

This group said that the main stumbling block to the provision of information was in fact members of the Roman Catholic Church who had prevented talks on women’s health:

‘a family resource centre in [name withheld for reasons of confidentiality] were not allowed to have a talk on women’s health because the priest said family planning would be a part of it...[another participant] knew a group where a nun would not allow it.’

However, it is important to note here that this should be taken as anecdotal and not as evidence that this is a systematic and widespread occurrence.

Group H8 saw information and education as essential for awareness-raising, to prevent people waiting for symptoms to appear before attending for treatment for potentially serious conditions, such as cancer. They also argued for more widespread dissemination of information:

‘Is information everywhere? Should be made available rather than having to make an appointment with GP.’

• 6 groups discussed the issue of equality in relationships between clients and service providers in their observation notes. 3 of these felt that the attitude of the service provider was important in determining the quality of the interaction. Group H12 said that the friendliness of the doctor was essential:

‘...if women had a friendly doctor it would make all the difference.’

Participants in Group H13 saw a link between women having children with them during a consultation and the doctor’s attitude towards them:

‘...a mother cannot talk with the doctor when she has young children with her. Doctor’s attitude: ‘Why should he bother?’
Group H14 appeared to hold a very negative view of levels of equality between clients and service providers, especially doctors, specifically in relation to lone parents:

‘Huge lack of sympathy and respect from doctors and some nurses especially to women. Manner very bad...particularly to lone parents.’

Of the other three groups who discussed this issue in their observation notes, one (H4) discussed equality in terms of financial equality and the fact that some doctors take a different attitude to patients who use the medical card:

‘When I produce the medical card, there is an assumption and an attitude that I am not educated, that I know nothing’ (Participant quoted in observation notes).

Group H13 described a situation where levels of equality varied according to the institution and/or the particular practitioner attended (a quote here would not be appropriate as names and places are mentioned which would be prejudicial to those involved). The final group (Group H8) only mentioned this briefly in terms of the listening and communication skills of doctors during the consultation.

- **Access to family planning and access to fertility treatment**
  Family planning was not discussed by any of the groups who supplied observation notes, perhaps because it was felt that it was self-explanatory and needed no justification for inclusion on the list. Two groups mentioned access to fertility treatment, both arguing that service provision in this country was insufficient and very basic.

- **Holistic approach to health and well-being**
  Four groups expanded on their opinions about this issue in the observation notes. All supported the idea of an holistic approach to health, with even those who were reluctant to try alternative therapies supporting the right of women to choose the type of treatment they preferred:

  ‘One woman spoke of her inability to be persuaded to try ‘alternative’, but still felt others should have the choice’ (Group H4)

Group H6 felt that many ‘biomedical’ doctors still did not support alternative approaches to treatment, while Group H5 did not agree with the placing of homeopathic remedies on prescription.

Group H8 believed that there was a lack of information available on holistic approaches to health:

‘More emphasis on holistic approach if more information available. People wouldn’t only go to GP.’

- **Free Cancer Screening** (Incorporating free breast screening and free cervical screening):
  There appeared to be different opinions about whether cervical screening was in fact available free of charge. While two groups (H4 and H14) said that sometimes participants had had to pay for a cervical smear test even when on the medical card, other groups said that, although a free service was available, uptake was restricted for reasons such as privacy:

  ‘Free smear clinics but too many know you, don’t feel comfortable’ (Group H12)

  lack of smear test centres:

  ‘Local doctor sends patients [elsewhere] for smear tests’ (Group H13)

  and embarrassment:
‘Some women have hang-ups getting smear test done...’ (Group H8)

- **Improved Maternity Services**

  Only two groups discussed this issue in their observation notes, and neither went into great detail. Group H14 pointed out the need for increased choice to be given to the mother before and after childbirth:

  *Maternity – more choice before and after baby.*

  The participants in Group H4 shared different experiences of childbirth, some negative and some positive, and concluded that ‘while the service appeared to be mixed, overall the service could be improved.’

- **Summary**

  Overall, as the majority of groups included all the pre-prepared cards provided, discarding none, it can be concluded that the health needs as outlined by the NWCI are relevant and important in the daily lives of the women who took part in this research.

### 5.4 BRAINSTORMING – EXTRA CARDS ADDED

<table>
<thead>
<tr>
<th>REFERENCES</th>
<th>GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education and information</td>
<td>19</td>
</tr>
<tr>
<td>Improve state services</td>
<td>12</td>
</tr>
<tr>
<td>Reproductive Health</td>
<td>11</td>
</tr>
<tr>
<td>Community Care</td>
<td>9</td>
</tr>
<tr>
<td>Child Care</td>
<td>8</td>
</tr>
<tr>
<td>Expansion of free medical care</td>
<td>7</td>
</tr>
<tr>
<td>Women and Care^q</td>
<td>7</td>
</tr>
<tr>
<td>Abuse/Addiction</td>
<td>7</td>
</tr>
<tr>
<td>Counselling/Mental Health Care</td>
<td>5</td>
</tr>
<tr>
<td>Cancer Screening</td>
<td>4</td>
</tr>
</tbody>
</table>

The table above shows the list of additional ‘needs’ cards added by participants, by group and reference. Additional cards have been grouped together under 10 main headings for ease of analysis. As some groups created several different cards dealing with a common issue, these have been counted and the ranking of the headings is based on both the number of references and the number of groups who made those references. Topic number 1, ‘Education and Information’ is ranked number 1.

- **Education and information** has emerged as a significant issue for the groups taking part in this study. During the consultation process undertaken by the then Department of Health in drafting the *Plan for Women’s Health* (Department of Health and Children, 1997), one of the strongest messages received was that Irish women felt that a lack of information restricted their ability to evaluate their own health and the health of those closest to them, making it difficult for them to make informed decisions about their health (Ibid.). Unfortunately, it appears that there is still a perceived lack of access to education and information for the women involved in this project.

---

^q [as carers of people other than children and as recipients of care]
In the observation notes accompanying this exercise, many different points were raised about this issue. One was the impact that lack of education and/or information can have on women’s health. The following quote from Group H9 illustrates this very clearly:

‘…education on women’s health issues...is vital, women don’t have smear tests done because of ignorance.’

Another area mentioned by 2 groups was the need for more information and education on reproductive health and family planning, especially the menopause and teenage pregnancy.

A number of recommendations were put forward by groups on what could be done to improve access to education and information. Group H9 recommended that women educate themselves in order to be able to answer children’s questions:

‘Women need to be more at ease about their bodies in order to explain and answer children’s questions.’

Group H6 also put forward a number of concrete recommendations:

‘A booklet in Q+A format written in simple terms would be important...An open health programme on TV would be extremely helpful...24 hour help-line necessary.’

- Improve state services
  The second most important issue raised by groups was the need to improve state health care provision, specifically the expansion of existing services and the decentralisation and devolution of power to current services so that women in rural and isolated areas can access appropriate health care.

  For example, Group H9 discussed the need for a ‘...mobile unit for breast screening because Dublin is too far and transport is a problem.’

- Reproductive health
  This issue came third in order of importance. Two groups raised the issue of STD and AIDS awareness. Group H9 felt that clinics for STD and AIDS should be available locally, not just in major urban centres.

  ‘Sexually Transmitted Diseases, VD clinics and AIDS awareness are necessary and needed locally. Take women’s health out of the cities into the rural areas.’

  Group H8 argued that there needs to be more awareness about the risk of STDs especially those that do not manifest physical symptoms:

  ‘More awareness of STDs...can get disease not even knowing about it, i.e. no symptoms to chlamydia.’

  Interestingly, Group H12 felt that differences in the quality of contraceptive services provided and the attitudes of GPs was a real problem for them:

  ‘O: We have our female doctor and she won’t prescribe the pill, it’s her religious belief. F: Girls go to temporary doctors when full-time doctors are off, and they can get the pill.’

Prendiville and Short (1993) have documented the controversial and difficult struggle to obtain any real contraceptive services in this State, and point out that current service provision is still reliant on
private organisations like the IFPA and Well Woman Centres, as well as GPs. Much has been written about how GPs’ attitudes towards contraceptive health impacts on the quality of service they provide, if any.

- **Community Care**
  Seven groups came up with ‘needs’ cards that were grouped together under Community care – these mainly referred to the introduction of staff and services to the local community to work on behalf of the community. Group H9 wanted to see a local walk-in health clinic rather than the referral system, although they did not elaborate further in their observation notes.

- **Childcare**
  Although this issue was placed at number 5 in the ranking of overall headings in the above table, those groups that did mention it felt it to be extremely important to women’s health, especially for those women working outside the home and lone parents. Group H4 strongly recommended the setting up of communal crèches in the community: ‘...there should be communal crèches where women can drop their children if they need to.’

  Participants also linked a lack of childcare facilities to the possibility and dangers of isolation:
  ‘*Drop-in centres for mothers, get them out of the home*’ (Group H8).

- **Women and care** was a closely linked issue, ranked at number 7. This heading included women caring for dependent adults, especially elderly parents, and also women trying to access care for themselves. Group H8 argued that there is a lack of recognition on the part of the State for mothers who stay at home and for carers in general. One participant in this group recommended ‘a realistic payment for carers.’ Group H4 pointed out that improved hospice care, or home care for women who are terminally ill, is needed without means-testing. They also recommended setting up a government department for the elderly: ‘*Improved hospice/home care for women – no matter what their circumstances - for those women who are terminally ill...there should be a government department for the elderly.*’

- **Expansion of services on the General Medical Scheme**
  Most groups who mentioned this felt that certain key services should be accessible to those on a medical card. These included dental care, eye care and ENT (ear, nose and throat) care, in addition to the free cancer screening covered by the pre-prepared cards.

- **Abuse or addiction**
  Only three groups mentioned women and children experiencing domestic violence or having an addiction to substances as specific health needs. It was not clear why so few groups alluded to this issue. It is possible that both were not regarded as a health issue per se. However, those groups that did discuss violence against women and children or addiction to substances indicated that the service provided was patchy and relied very much on under-funded or voluntary organisations.
  ‘*...there is nothing...in the north-west for women experiencing violence in the home, the nearest is Enniskillen and that is a different jurisdiction*’ (Group H12).

- **Counselling/Mental Health Care**
  Relatively few groups assigned additional cards to this issue, as it had been covered in the pre-prepared cards. Those who did talked about counselling in terms of specific situations where counselling is required, such as caring for elderly parents or people with special needs, and women and children experiencing domestic violence. A demand for the provision of free or funded counselling was also voiced.

- **Cancer Screening**
Finally, 3 groups (H1, H2 and H3) added extra cards dealing with the issue of cancer screening. All three emphasised the need to ensure that all forms of cancer screening were free. One group also emphasised the importance of identifying families at high risk of developing breast cancer and providing free screening at an early age.

- **Summary**
  Although the Department of Health and Children committed itself to working with others to pilot new approaches to disseminating information and good practice guidelines in order to render health-related information more accessible, this still arose as the most important health need identified by the women themselves.

### 5.5 SEASONAL CALENDAR

The results of all the valid seasonal calendars submitted (10) were combined and an average was taken to obtain the combined trends for each health need identified. Some categories have been amalgamated to simplify the complexity of the data. ‘Free cancer screening’ was expanded to include the pre-prepared cards ‘free cervical screening’ and ‘free breast cancer screening’. ‘Access to counselling and mental health’ also incorporated the items from the relevant additional needs category. ‘Reproductive health’ now includes the pre-prepared cards ‘access to family planning’ and ‘access to fertility treatment’. ‘Women and care’ now incorporates ‘childcare’ and ‘respite and counselling support for women as carers’, in addition to the categories originally covered by this heading.

The graph illustrates a tendency for most of the health needs to peak in importance from the onset of adolescence (11-15 years) until ages 61-65. Certain categories would be expected to dominate
within this age group such as ‘free cancer screening’, ‘reproductive health’ and ‘improved maternity services’. However, other needs not directly related to child-bearing or reproductive health also followed this pattern, such as ‘women-friendly health clinics in urban and rural areas’, ‘one-stop-shop for women’s health’, ‘education and information’, and ‘expansion of free medical care’, amongst others.

However, there were some significant exceptions to this general pattern. ‘Community services’ was assigned a low but constant value throughout the life-span until about age 61-65, when it showed a small increase in assigned importance before dropping again at age 90. ‘Access to counselling and mental health’ stood out as being assigned relatively high importance throughout the life-span until its decline at around the age of 90.

‘Improve state services’ is unique in that it is assigned a particularly high level of importance from age 0-5, peaks early between the ages of 21-25 and 26-30 and falls sharply until levelling off before climbing at age 61-65. It may be that women feel that current service provision is geared more towards meeting the needs of women of child-bearing, child-rearing age, and/or sexually active women than at other points in their lives, although further research would be necessary to investigate this further.

5.6 CARD SORT CATEGORIES AND CHARACTERISTICS

13 groups divided their cards into three categories:

1. Needs adequately met by current service provision
2. Needs partially unmet by current service provision
3. Needs completely unmet by current service provision.

- **Adequately met**: 4 groups identified needs that they judged were adequately met by current service provision. While there was no overall point of commonality, 2 groups indicated that ‘Access to family planning’ was currently ‘adequately met’.

Below is a table summarising the results:

| GROUP H4               | Family planning
|                       | Supported breast-feeding
|                       | Improved maternity services
| GROUP H2               | Access to counselling/mental health care
|                       | Access to family planning
|                       | Access to fertility treatment
| GROUP H5               | Availability without prescription of natural herbal remedies
| GROUP H14              | Women’s needs not being met by the health promotion system overall
|                       | Baby nurse gives good support

- **Partially met**

---

1 This group carried out their research before the decision in late 1999 by the then Minister of Health to ban the sale of St John’s Wort without prescription.
Hear our voices – meet our needs

<table>
<thead>
<tr>
<th>NO. OF GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Counselling and Mental Health</td>
</tr>
<tr>
<td>Improved maternity services</td>
</tr>
<tr>
<td>Free breast screening</td>
</tr>
<tr>
<td>Equality in relationships between clients and service providers</td>
</tr>
<tr>
<td>Access to family planning</td>
</tr>
<tr>
<td>Respite and Counselling Support for women as carers</td>
</tr>
<tr>
<td>Access to fertility treatment</td>
</tr>
<tr>
<td>Easy access to women’s health and well-being information</td>
</tr>
<tr>
<td>Free cervical screening</td>
</tr>
<tr>
<td>Holistic approach to health and well-being</td>
</tr>
<tr>
<td>Women-friendly clinics in urban and rural areas</td>
</tr>
<tr>
<td>One-stop-shop for women’s health</td>
</tr>
</tbody>
</table>

From the above table it is clear that the majority of groups felt that counselling and mental health issues were at least partially covered by current service provision. Improved maternity services also emerged as being partially met by 7 groups. The needs that fewest groups saw as partially met by current service provision were both to do with health care services that were specifically geared towards women; the ‘one-stop-shop for women’s health’ and ‘women-friendly clinics in urban and rural areas’.

Extra cards added (coded and categorised)

<table>
<thead>
<tr>
<th>NO. OF GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education and information</td>
</tr>
<tr>
<td>Reproductive Health</td>
</tr>
<tr>
<td>Abuse/addiction</td>
</tr>
<tr>
<td>Expansion of free medical care</td>
</tr>
<tr>
<td>Improved state services</td>
</tr>
<tr>
<td>Women and care</td>
</tr>
<tr>
<td>Community services</td>
</tr>
<tr>
<td>Childcare</td>
</tr>
<tr>
<td>Counselling/mental health care</td>
</tr>
</tbody>
</table>

Caution must be exercised when interpreting the results from this table as the rank order outlined above is affected by the number of groups who named these cards in the brainstorming exercise. However, it can be said that of the 7 groups who created cards coded under ‘education and information’, 5 saw these as partially met by current service provision. Of the 6 groups who created cards coded under ‘reproductive health’, 3 saw these as partially met. On the other hand, only 1 of the 7 groups who created cards coded under ‘community care’ saw these needs as currently partially met. This situation was paralleled in ‘childcare’. Only 1 of the 4 groups who created cards coded under ‘counselling/mental health care’ felt that this need was partially met by current service provision.
• Completely unmet

<table>
<thead>
<tr>
<th>Service provided</th>
<th>NO. OF GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>One-stop-shop for women’s health</td>
<td>10</td>
</tr>
<tr>
<td>Holistic approach to health and wellbeing</td>
<td>7</td>
</tr>
<tr>
<td>Women-friendly health clinics in urban and rural areas</td>
<td>7</td>
</tr>
<tr>
<td>Respite and counselling support for women as carers</td>
<td>5</td>
</tr>
<tr>
<td>Free cervical screening</td>
<td>5</td>
</tr>
<tr>
<td>Free breast screening</td>
<td>5</td>
</tr>
<tr>
<td>Easy access to women’s health and well being information</td>
<td>3</td>
</tr>
<tr>
<td>Equality in relationships between clients and service providers</td>
<td>2</td>
</tr>
<tr>
<td>Access to fertility treatment</td>
<td>1</td>
</tr>
</tbody>
</table>

10 groups felt that ‘one-stop-shop for women’s health’ was completely unmet by current service provision. Both ‘holistic approach to health and well-being’ and ‘women-friendly clinics in urban and rural areas’ were seen as completely unmet by 7 groups.

• Cards added coded and categorised

<table>
<thead>
<tr>
<th>Service provided</th>
<th>NO. OF GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child care</td>
<td>5</td>
</tr>
<tr>
<td>Reproductive health</td>
<td>4</td>
</tr>
<tr>
<td>Community Services</td>
<td>3</td>
</tr>
<tr>
<td>Free dental/eye/E.N.T. care</td>
<td>3</td>
</tr>
<tr>
<td>Cancer screening</td>
<td>3</td>
</tr>
<tr>
<td>Women and care</td>
<td>3</td>
</tr>
<tr>
<td>Improve state services</td>
<td>3</td>
</tr>
<tr>
<td>Education, information and training</td>
<td>3</td>
</tr>
<tr>
<td>Abuse/addiction</td>
<td>3</td>
</tr>
</tbody>
</table>

Of the 7 groups who created cards coded under ‘childcare’, 5 indicated that this issue was completely unmet by current service provision. Of the 6 groups who created cards coded under ‘reproductive health’ 4 considered it completely unmet. ‘Reproductive health’ refers to issues other than those mentioned on the pre-prepared cards, specifically health needs related to the menopause. All the subsequent health needs were designated completely unmet by 3 groups.

Summary

Health care needs dealing with environments and models geared towards the needs of women, such as ‘one-stop-shop for women’s health’, ‘women-friendly health clinics in rural and urban areas’, ‘childcare’ and ‘reproductive health’ were generally seen as having the least coverage by current service provision.

‘Counselling/mental health care’ and ‘education and information’ were seen as having partial coverage by the majority of groups.
5.7 DOUBLE MATRIX

Of the 13 groups who were included in the cross-analysis, 9 returned valid double matrices. In the Double Matrix, participants were asked to identify practical actions that could be taken to ensure that their health needs could be addressed in the health service arena and more broadly in the social policy arena. They generated these actions according to two categories: first, actions that they could do something about themselves with no outside assistance and, second, actions that require outside assistance.

When analysing the double matrices, only actions that were scored as interventions that addressed the pre-prepared health needs were coded and categorised. The wide range and complexity of the added cards did not permit their inclusion in the analysis of the matrices. The observation notes for the double matrices were not as detailed for that method as for some of the others in the health process. For this reason, only the range of actions specified and a description of what each type of action entailed are included without excerpts from the observation notes.

5.7.1 Actions that could be carried out with no outside assistance

A total of 59 actions were identified by the 9 groups who produced valid double matrices. Seven of those actions could not be categorised in any way. In all, 6 types of actions were identified across the 9 groups. They are as follows:

<table>
<thead>
<tr>
<th>REFERENCES</th>
<th>GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate ourselves</td>
<td>46</td>
</tr>
<tr>
<td>Raise awareness</td>
<td>40</td>
</tr>
<tr>
<td>Lobbying work</td>
<td>30</td>
</tr>
<tr>
<td>Women supporting each other</td>
<td>20</td>
</tr>
<tr>
<td>Accessing available options</td>
<td>9</td>
</tr>
<tr>
<td>Helping carers</td>
<td>5</td>
</tr>
</tbody>
</table>

- **Educate Ourselves**
  The most popular action that participants identified as addressing the pre-prepared women’s health needs was women educating themselves about health issues and options. This education could take place in a number of settings; a local library, in a doctor’s office, or through classes. Groups also talked about women knowing their own bodies and doing their own research. The importance of this type of action is consistent with the finding that an important health need to women in the project was easy access to women’s health and well being information. Participants also suggested that providers need to be re-educated.

- **Raise Awareness**
  This category contains actions that have to do with women making others aware about the health needs of women. It also contains actions that have to do with women themselves becoming aware of, assertive and empowered about their own health issues. Some groups specified that they could start campaigns to teach women about health issues.

- **Lobbying Work**
  The third highest scoring option that participants felt they could do something about themselves was lobbying various power groups to attend to the pre-prepared women’s health needs. These groups included politicians and the health boards, but they also included the local TV station and town planners.
• **Women Supporting Each Other**
  This category included actions that identified ways of women working together collectively to meet their own health needs. Ways to do this included forming support groups, sharing experiences and putting together courses for other women.

• **Accessing Available Options**
  The fifth highest scoring action had to do with participants accessing health services that were already available in order to have the pre-prepared women’s health needs met. Options included taking an holistic approach to health, taking supplements, going for counselling and visiting the doctor or nurse and/or the local health centre.

• **Helping Carers**
  Some of the participants came up with actions around supporting women who were carers with that work and were actions that addressed the health needs for respite and counselling support for women as carers and access to counselling/mental health care.

### 5.7.2 Actions that require outside assistance

In all, a total of 87 actions requiring outside assistance were identified by the groups that produced valid double matrices. These were coded and categorised into 13 types of actions, with 8 actions that could not be categorised in any way. The 13 types of actions that were identified to require outside assistance were as follows:

<table>
<thead>
<tr>
<th>Action</th>
<th>REFERENCES</th>
<th>GROUPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government responsibilities</td>
<td>64</td>
<td>5</td>
</tr>
<tr>
<td>Education and training options</td>
<td>48</td>
<td>4</td>
</tr>
<tr>
<td>New and improved general services</td>
<td>39</td>
<td>5</td>
</tr>
<tr>
<td>Specific local services</td>
<td>18</td>
<td>4</td>
</tr>
<tr>
<td>Family planning and fertility treatment provision</td>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>Financial assistance/funding</td>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>Mental health care provision</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Services for carers</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Accessing holistic health care</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Cancer screening</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Maternity services</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Lobbying work</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Domestic violence services</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

• **Government Responsibilities**
  Actions were grouped under this heading where participants related actions that identified the State, Government or the Department of Health and Children as the site where a particular action should come from. This was by far the action that the majority of the research groups saw as addressing the pre-prepared health needs. Actions in this category ranged from funding and research to policy and legislation. An interesting facet of this category was an emphasis by participants on the Government legitimising the importance of women’s health needs. Clearly, groups felt that the State and the Department of Health and Children still had much to do in order to demonstrate a serious commitment to women’s health issues.

• **Education and Training Options**
4 groups came up with a range of actions that had to do with options for education and training around women’s health issues. This type of action ranked second in the 13 types identified. Women were not the only group that were to be in receipt of these options. 2 of these actions called for providers to be re-educated. A range of contexts, whereby women themselves could avail of education and training on health issues, were identified. They included media, antenatal clinics, schools and self-education facilities.

- **New and Improved General Services**
  This category ranked third in the types of actions identified for which the participants require outside assistance. It includes calls for improved service provision at a general or national level and also new services with a national scope as opposed to new services that would vary depending on locality. 2 of the actions called for the provision of one-stop shops for women’s health. Other groups called for new services such as mobile clinics and direct telephone links to staff in hospitals.

- **Specific Local Services**
  Actions which fell into this category involved specific groups identifying actions that were needed in their locality. These were, for the most part, changes in or provision of services. An interesting facet of this category was that these actions were indicated by groups that were either in rural areas or disadvantaged urban areas, showing that marginalised communities are not getting the services that others are receiving, and they may also have needs that are quite specific because of their marginalisation, for instance, transport in rural areas.

- **Family Planning and Fertility Treatment Provision**
  3 groups described actions that either called for accessibility to fertility treatment or the availability of family planning. With regard to family planning, participants identified the need for more clinics. The observation notes did not expand on this category.

- **Financial Assistance/Funding**
  This category ranked equally to family planning and fertility treatment provision. 2 of the actions in this grouping had to do with expanding the scope of free services in Ireland from making all services free if an individual has a medical card to the provision of free health insurance for all.

- **Mental Health Care Provision**
  4 groups came up with actions to do with provision of mental health care. For the most part, this meant the provision of counselling services. Actions dealt with rehabilitation programmes, preventative care, the need for more counsellors, further training for practising counsellors and an increased awareness of services that are already available.

- **Services for Carers**
  9 references by 4 groups were made with regard to specific services provided to ease the burden on carers. Suggestions included increased options for care and financial rewards for carers. 1 group asked for more people to be trained in care for the disabled and the elderly. Another called for childminders to be registered.

- **Accessing Holistic Health Care**
  Actions addressing the need for an holistic view of health and accessibility to alternative modes of care focused on the gate-keeping by difficulties of access arising from current gate-keeping practices by the State and allopathic practitioners.

- **Cancer Screening**
  2 groups identified 2 actions to do with cancer screening. These were, “Mobile units in each county for free breast screening,” and “Screening made available.”
• Maternity Services  
2 groups came up with 4 actions addressing the need to improve maternity services in Ireland, including availability of home birth services, access to support agencies for new mothers, provision of nursing facilities in public buildings and improved neonatal services.

• Lobbying Work  
Various types of lobbying work were indicated with regard to a range of health needs.

• Domestic Violence Services  
2 groups identified 2 actions to address the prevalence of domestic violence in the country and health service provision in response to it. The actions were: “Local refuge shelter,” and “More safe houses/ funds.”

6. DISCUSSION

6.1 OVERVIEW  
The Plan for Women’s Health (Department of Health and Children, 1997) made provision for the creation of a woman-friendly health service. This was to be achieved through the implementation of the commitments in the Plan, gender-sensitivity training for staff, changes in opening times of clinics and the introduction of facilities for children at clinics. However, this study shows that women place high value on a range of new services, including: a ‘one-stop-shop for women’s health’; thorough restructuring of existing services, like ‘women-friendly clinics in urban and rural areas’; attitudinal changes among mainstream health care providers; an ‘increased acceptance of an holistic approach to health and well-being’, and ‘equality in relationships between clients and service providers’. This indicates that, while the Plan for Women’s Health (Ibid.) promoted a vision akin to that expressed by the women in this study, it did not go far enough in terms of implementation. Participants’ summaries demonstrate this through their descriptions of patchy health service provision and confusion to the extent of that provision on the ground. Adequate service provision and universal information about services were to be provided in the implementation of the Plan for Women’s Health (Ibid.).

Nonetheless, it is clear that the women who participated in this project have many strong ideas about what actions could be taken to address the gaps in service provision, ideas encompassing State responsibility as well as the need for an upgrade in service provision. These women are not passive recipients of health care policy and service provision, but people who would like to be able to collaborate actively with policy-makers and service-providers to ensure continued improvement in standards of health care.

6.2 DECENTRALISATION AND VARIABILITY OF SERVICES  
There may be a number of reasons why the directives in the Plan for Women’s Health (Department of Health and Children, 1997) have not been directly felt by women around the country. First, Ireland is among the group of countries in the EU that spend the lowest per capita on health care for its citizens (Figueras et al., 1998). A plan for health necessitates adequate financing to accomplish its goals. To add to this, Figueras et al. (Ibid.) point out that in order to maintain a decentralised and devolved system, sufficient funds have to be injected into local administration and devolution. According to the participants in the health component of the Millennium Project, adequate decentralisation and devolution has not occurred. This can be seen in the importance placed by the research groups on the improvement of service provision and the adequate funding of community care across the country.
The *Programme for Prosperity and Fairness* (Department of the Taoiseach, 2000) has made a commitment to increased health spending and enhanced services, particularly for women and marginalised groups. In 1995, the Department of Health recognised that distance from services can be a ‘major handicap for women on low incomes in rural areas’ (Department of Health, 1995). However, during this study, carried out in 1999/2000, many research groups from a range of socio-economic backgrounds and both rural and urban areas placed strong emphasis on the need for a coherent policy of decentralisation and devolution. The Department’s recognition of this problem needs to translate into concrete policies for decentralisation and devolution by the State, avoiding an over-reliance on under-funded voluntary workers.

The *Plan for Women’s Health* (Department of Health and Children, 1997) specifically referred to reproductive health and maternity services, promising to ensure that these services would be provided as recommended. However, participants in this study present a picture of patchy and variable service provision and quality across the country.

In addition, the provisions for childcare in the Plan do not seem to have had a significant impact on the women who raised this issue. They state that the fundamental importance of childcare provision, and the issue of recognition and appropriate support for the caring roles that women take on in families and social life, have not been fully addressed as yet.

### 6.3 Partnership, Promotion and Policy

Why has the implementation of the *Plan for Women’s Health* (Ibid.) not been wholly and successfully implemented? We suggest that it may be due to the differing responsibilities of various Health Boards and the Department of Health and Children, and a lack of partnership between the two. There also seems to be some disjunction between health promotion activities outlined by the Department, the actual policies devised to direct health services in the country and the variability of needs in each health region. The *National Health Promotion Strategy, 2000-2005* (Department of Health and Children, 2000c) sets out the principles for health promotion in Ireland as identified in the *Ottawa Charter for Health Promotion* (World Health Organisation, 1996). Actions to improve the health of the nation should be made on the following five fronts (Department of Health and Children, 2000c):

- Building healthy public policy
- Re-orienting the health service to promotion and not just acute care
- Creating supportive environments in which to make healthy choices
- Strengthening community action - incorporating community development approaches to health promotion
- Developing personal skills through consultation with individuals about their needs.

These principles provide a helpful guideline for health promotion programmes. One objective set out by the *National Health Promotion Strategy* (Ibid.) is a review of the implementation of the *Plan for Women’s Health* (Department of Health and Children, 1997). Data from the health component of the Millennium Project suggests that the principles of health promotion set out above could be employed as a checklist for implementing the priorities in the plan. The Department has devised a healthy policy for women’s health in Ireland, but it has not adhered to the last four principles listed. Services addressing the needs that the women in this study identified as partially or completely unmet could be improved and specific services could be more thoroughly implemented via consultation.
A community development approach would help to “ascertain the views of the public regarding their experiences of the health service” (Department of the Taoiseach, 2000), as well as attending to the geographic specificity of appropriate service provision models. The rank order of the ‘partially met’ and ‘completely unmet’ health needs show which services might constitute research priorities for the Department at national level. An ongoing process of consultation and qualitative research with women could assist in building a picture of how service providers could facilitate women to make healthier choices. This consultation process might also allow women to be active collaborators in the improvement of women’s health care in Ireland. A conduit for doing this might be further investment in and consolidation of the Women’s Health Advisory Committees by the Department of Health and Children via the Regional Health Authorities.

6.4 THE BIOMEDICAL MODEL IN HEALTH CARE

The findings of this study show that the biomedical model retains its primacy in Irish health care provision, although alternative models are clearly sought by participants. Women involved in the study consistently retained several key cards – one-stop shop for women’s health, holistic approach to health and well-being and ranked them as the first- and second-highest ‘completely unmet needs’. The importance of women-friendly health clinics in rural and urban areas is also worth noting. In other words, women from around the country are saying that they are not receiving healthcare in which holism and consideration of social factors plays a role in their health and well-being.

Because they often perceived holistic approaches as embraced by the alternative or homeopathic therapies, women referred to these in their discussions about women-friendly health clinics. Women also referred to the idea that GPs could not provide holistic care and only those who practised alternative therapies could use such a model.

The need for information about each of the three needs outlined above was also highlighted in the research and will be examined in depth below. The continued use of the biomedical model as the primary model in the provision of health care, instead of as one among many, has implications concerning whether or not the Plan for Women’s Health (Department of Health and Children, 1997) can be implemented. The one-stop shop for women’s health and the need for an holistic approach parallel the Plan’s policy for a women-friendly health service. Yet, women are frequently saying that these needs have not been met.

6.5 FACTORS AFFECTING HEALTH STATUS

Participants described different ways in which life factors intertwined with their health needs. This is in part borne out by the importance of such needs as childcare, reproductive health, support for carers and the importance of women-friendly care. All this points to the ways in which gender affects health. Women, by social arrangement, represent the majority of carers in society and need childcare and respite support so that they can attend to their own well-being. The importance placed on such needs as holistic health care, the one-stop shop and reproductive health also point to the far-reaching impact of gender on health and well-being. Further research would be needed to expand on the quality of the services to ensure that women are not being doubly disempowered in the medical encounter.

Gender and other factors are never separate from each other in terms of determining health and well-being (Moore and Harrison, 1995). This interdependence of several different social factors has

---

1 The Women’s Health Advisory Committees are currently engaged in consultation with service providers and the Department of Health and Children, in order to address such issues as information deficits, holistic health care and better family planning services. We welcome such consultation initiatives and hope that these are continued in the future.
been illustrated in the observation notes from many of the groups who participated in research for this project, including ill treatment of lone parents by medical professionals and negative assumptions about medical card users. Displacing the primacy of the biomedical model and providing information have much to do with correcting the ways in which social factors impact negatively on the health status and experiences in the medical encounter.

Health care providers have been described as moral guardians of western culture (Lupton, 1996). Their modes of practice and styles of communication have the power to shape how women think about themselves and how others perceive them, especially those women who are most marginalised. For instance, as described in the literature review, women’s physiological processes have been consistently depicted in medicine as abnormal in relation to male physiological processes. Thus, if doctors are not critical of the way in which knowledge shapes their interactions, women themselves may see those processes as negative. This could result in women being uneasy about their bodies. This was illustrated by one participant, who described how uneasiness about their own bodies could inhibit women from passing on health information to their children (see quote from Group H9 in section 5.4).

Political and ethical beliefs held by practitioners are also transferred in practice. This could limit a woman’s access to proper care, specifically with regard to reproductive health issues and availing of contraceptives (see quote from Group H12 in section 5.4).

The results from the health component of the Millennium Project also show that women are not just asking for health needs that are specifically to do with the different biological health issues they experience. They are asking for such things as childcare, counselling and information about all their health needs in the widest context. The observation notes also support a critique of health care that fails to consider social exclusion as a factor in health. There is a danger that a description of women’s health could be employed in the Irish context that reduces that description to a limited set of health problems. Eckman (1998) says that focusing on certain health priorities for women and not acknowledging others has the effect of overlooking the ways in which social factors affect their health.

The National Health Promotion Strategy (Department of Health and Children, 2000c) sets out a very limited view of the health difficulties of Irish women. They are listed as: low life expectancy compared to the rest of the EU, heart health, smoking, maternal health (neural tube defects), mental health and infant feeding (Ibid.). This is in opposition to a recent commitment in the Dáil by the Minister of Health to develop health service interventions that are matched with the strategies in The National Anti-Poverty Strategy (Department of Social, Community and Family Affairs, 1997), with health targets, policy measures and performance indicators. The Department of Health and Children must maintain its commitment to improve the health of marginalised women.

6.6 GENDER, POWER AND KNOWLEDGE, THE ISSUE OF PATERNALISM

This trend is supported in the findings by the importance of the needs for equality in the client/provider relationship, education and information and easy access to women’s health and well-being information. In the literature, these three aspects of health are linked to the paternalistic relationship between client and provider, where the provider retains decision-making power in the health encounter. When this type of relationship is maintained, a provider may assume that a woman does not ‘know anything’ and cannot make informed choices about her health. Although a trend for patient involvement in their own health care is on the rise in the EU (Figueroas et al., 1998), women are still extremely vulnerable to negative health-care encounters. The Department of Health and Children and policy-makers in general have much to do in encouraging the free distribution of health information that presents a positive image of women and respects diversity. This information should also be specific to the life stage in which women need it. As
identified in the Seasonal Calendar exercise, some needs are important at the same level throughout
the life course, while other needs peak and trough depending on life stage. Common information
about these needs should be fashioned accordingly. Information needs identified in the Millennium
Project include more information on cancers, reproductive health - particularly about STDs and HIV
and the menopause. If this information is available, women are having difficulty accessing it. The
recently established National Health Information Strategy could incorporate this research in order to
inform its work on health information for women.

Easy access to information has the potential to break the cycle of paternalism in health care and to
create a more equal playing field in the client/provider relationship. There are a number of aspects to
easy access to health information for women. Firstly, information should be readily available and
there for the taking - women should not have to ask a provider for it. Secondly, information should
be placed in a variety of settings other than just health clinics and hospitals. For instance, one
participant mentioned that rural post offices would be an ideal place for women to get health
pamphlets. Thirdly, a number of different media should be employed to get health messages across
to women.

More research needs to be done as to the types of information women need and how they would
like to see it distributed. This is backed up by the results of the double matrix, where women
suggested a number of settings where education and information dissemination could take place, for
example, in local libraries, doctors’ offices, or through classes. It should be noted that the high
ranking of the need for health information and education also links to the wider issue of social justice
for women. When women say they want information in order to make choices about their health,
they may also be saying that they want increased power for self-determination. The wider context of
women’s health issues is explored in the next and final section.

The last three themes in this discussion are linked by three detrimental assumptions that Brems and
Griffiths (1993) say underpin many of the programmes initiated around women’s health, particularly
in developing countries. They are: 1) that health can be separated from everyday life; 2) that women
cannot say what they need for their own health and 3) that the biomedical model provides the
answers to solving ill health. If the commitment to improving women’s health is not evaluated for its
real impact in Ireland, the same allegations could be levelled at Irish policy-makers.

6.7 THE RELATIONSHIP BETWEEN POLICY, WELL-BEING AND THE STATUS OF IRISH WOMEN

Health care reform is a process well-known to EU nations (Figueras et al., 1998). These reforms are
shaped by a number of trends as well as by the fundamental challenge of deciding which reform
principles fit a culture and society best. Health care reform principles have much to do with the way
health and illness are defined in a culture and the ways those definitions are intertwined with
broader socio-economic issues. Figueras et al. (Ibid.) have described a number of the trends
informing the reform of EU health care systems and the policies that direct those reforms. They are:

- Dissatisfaction with and recognised inefficiency of centralised bureaucratic systems
- Increasing interest in patient empowerment in their own health care
- Increased patient involvement in clinical decision-making.

Each of these trends manifests themselves in different ways depending on the nation state referred
to. Moreover, the ways in which health care services and policies directly affect the members of a
country say much about the way life is in that country: “Health care services, like other human
service systems, closely mirror the deeply rooted social and cultural expectations of the citizenry as a
whole. A key indicator of society’s normative values is the very nature of health care itself” (Ibid.).
The Department of Health and Children has indicated its adherence to the concept of health and social gain – that health has social determinants – in both the Plan for Women’s Health (1997) and in the recent National Health Promotion Strategy, 2000-2005 (Department of Health and Children 2000c). Health is described as a “resource for everyday life” (Ibid.). An important priority in Irish health promotion is the empowerment of people to make healthy choices, while being aware of the way in which social determinants limit or enable people to make healthy choices. The Plan for Women’s Health (Department of Health and Children, 1997) also indicated an adherence to a similar ethos and a commitment to creating a more women-friendly health system. On paper, Ireland would be seen to value and wish to encourage the good health of Irish women. What the data from the health component of the Millennium Project show is that the principles of health reform espoused by Irish policy-makers have, at best, been implemented in a sketchy way, with high variability depending on geographic location. This is in evidence from the high number of health needs identified by women in the Project as being ‘partially-’ or ‘completely unmet’. This finding is particularly borne out by the low number of ‘adequately met’ health needs of women involved in the project and the fact that there was only one common need that was perceived to have been met across the groups and their corresponding regions (see section 5.6).

The Programme for Prosperity and Fairness (Department of the Taoiseach, 2000) also reaffirmed the importance of implementing the strategies outlined in the Plan for Women’s Health (Department of Health and Children, 1997), as well as commitment to: employing models of community and primary health care that are multi-functional; encouraging a patient-focused approach in the health care services and increasing health spending over the course of the programme. It also notes that the Women’s Health Council is now properly resourced. It will be interesting to see if the ongoing evaluation of the Plan for Women’s Health (Ibid.) being carried out by the Women’s Health Council resonates with the feelings of the women in the Millennium Project.

By virtue of the fact that women in their local communities may not have felt any or very little of the changes outlined in the Plan (Ibid.) something can also be said about the value that Irish policymakers are placing on the health status of Irish women. Community care can only be effective if it is provided with full funding and support by the Department of Health and Children. It is all very well to put the commitment to good health for Irish women down on paper, but if this is not felt in real and sustained ways by women themselves, then the Government is not sufficiently committed to improving the health status and related social status of women in Irish society. There is an interconnected relationship between health policies and services, health and well-being and the actual social status of women. Doyal (1995) defines the connection between health and the social status of women: “For those who wish to improve the situation of women, physical and mental health are… strategic issues. They are important goals in their own right, but they also provide the key to women’s effective participation in attempts to create a fairer and healthier society.”

Health policies and services are integral to this relationship because policies shape the way citizens and decision-makers think about and experience society, “These individual perceptions and experiences make and yet modify the material contexts of the areas. In turn, social and industrial structure, demographic characteristics and level and quality of service provision impinge on individual consciousness and well-being” (Eyles and Donovan, 1990). Our findings clearly show that the policies published by the Department of Health and Children have not been felt by the women involved in this study, pointing to the strong possibility that measurable changes in the self-reported health status of Irish women have not occurred. Until women for the most part are satisfied with the quality of their health service, a substantial improvement in the health of Irish women may not be seen. This is of the utmost importance to policy-makers trying to cope with Irish women’s low health status compared to the rest of the EU. Health is also an issue of human rights and should be a priority for the Government in terms of its commitment to women’s health in the Beijing Platform for Action.
7. CONCLUSIONS AND RECOMMENDATIONS

7.1 CONCLUSIONS

• The results of the health component of the Millennium Project suggest that the Irish health system is not sufficiently decentralised and devolved and that inadequate resources have been provided to implement enhanced services for women in their localities. In some areas services are provided and in some they are not. Childcare was an important health need across the country despite the commitment in the Plan for Women’s Health (Department of Health and Children, 1997) to address this issue.

• In devising the Plan for Women’s Health (Ibid.) the Government has created a healthy public policy for Irish women. This is one of the five principles by which health promotion should be guided in the Republic. By using the other four principles as a checklist for future successful implementation:
  - Re-orienting the health service to promotion and not just acute care
  - Creating supportive environments in which to make healthy choices
  - Strengthening community action - incorporating community development approaches to health promotion
  - Developing personal skills through consultation with individuals about their needs (Department of Health and Children, 2000c)

The Department could make the changes to women’s health care considered necessary by women in Ireland.

• A pluralist system of health care is not in evidence in Ireland. Women across the country felt that they could not access holistic health care, including alternative therapies, and have all their health needs attended to in a one-stop shop that was the primary ‘completely unmet’ need identified by participants. Thus, a biomedical model of care is still foremost in the Irish system, leaving women with the feeling that the wider context of their lives as Irish women is not recognised as impacting on their health. This is in opposition to the Department’s commitment to the concept of health as related to social gain.

• Linked to the use of a biomedical model in health is the overlooking of the effects of social, cultural and economic factors in health. Women in the health component of the Millennium Project gave evidence of negative experiences in their health care due to class distinctions and gender. There is also a danger that a description of women’s health could be reduced to a narrow range of health difficulties such as: maternal health, heart health, smoking, mental health and infant feeding (Department of Health and Children, 2000c). This would have the effect of excluding social factors as they relate to health/well-being.

• The need for health information and education was seen as the second ranking unmet health need for participants in the Millennium Project. This demonstrates that the Plan’s commitment to increase availability and access to health information for women has not impacted positively on the women involved in this research. Easy access to women’s health/well-being information has the potential to break the cycle of paternalism in health care. That is, it has the potential to create a more equal relationship between client and provider in health care interactions.

• There is a relationship between health policy services, individual perceptions of health and well-being and the normative values of a society and culture. Women throughout the country who were involved in this study clearly indicated that they had not felt the concrete effects of promises made in the Plan for Women’s Health (Department of Health and
Hear our voices – meet our needs

Children, 1997). Therefore, it is reasonable to assume that a tangible improvement in the state of Irish women’s health is not likely to occur until the policies put forward in the Plan are more thoroughly implemented.

7.2 RECOMMENDATIONS

It is recommended that the Department of Health and Children and other relevant departments and agencies such as the Regional Health Authorities, and the Women’s Health Council:

- Fulfil the promises made in the Programme for Prosperity and Fairness (2000), The Plan for Women’s Health (Department of Health and Children, 1997), and The National Health Promotion Strategy (Department of Health and Children, 2000c) to consult with women about health services, what and where they are needed, their ethos and models of practise. Consultations should employ a multi-method approach and qualitative methods should be acknowledged as strategies that are particularly useful in finding out about women’s health issues (Brems and Griffiths, 1993).

- Commence initiatives to encourage the widespread distribution of free and accessible information about health, particularly for women’s health issues. This may mean placing the information in settings where one would not normally find health information, for instance, rural post offices. Other innovative ways of disseminating health information should be employed using a variety of media. Participants in the Millennium Project described needing health information on a wide variety of topics, but in particular mentioned: holistic approaches to health; cancers; reproductive health and family planning; menopause. Information should be pertinent to women’s life stages as illustrated in the results from the seasonal calendar technique.

- Incorporate research like the Millennium Project into the work of the National Health Information Strategy.

- Initiate further research to consult with women about gaps in health information provision and their preferences for style, presentation and medium. Different topics could necessitate different modes of delivery.

- Continue the decentralisation of health services, ensuring that administrative agencies and service settings are properly resourced, financially and otherwise.

- Provide awareness and sensitivity training at regular intervals to health care providers on issues of gender, ethnicity, sexuality and economic disadvantage, and the relationship between social factors and health status.

- Ensure that health care providers are trained in effective communication skills and learn how to encourage client participation in their own health decisions.

- Provide free and accessible childcare so that women can attend to their own health needs.

- Fund and resource women’s groups working with older women, Traveller women, lesbians, refugee and asylum seeking women, women from other ethnic minority groups living in the Republic, women with disabilities and women who are living in poverty to do research about women’s health issues. One of the most important areas of investigation would be the question of what ‘being healthy’ means to women in Ireland. This would allow for both a
deeper and broader view of women’s health in Ireland. Multi-method approaches should be used in any enquiry into health for women.

- Institute a wide range of reforms in services for carers in the country as advocated by the National Women’s Council of Ireland (NWCI) in its work with health representatives in the regional women’s health committees (NWCI unpublished, 1999), including free home help for carers, investment in respite care, co-ordination of services for carers, a non-means tested Carer’s Allowance, profiling the Homemakers Scheme and instituting uniform quality standards for all aspects of the caring services.

- Regarding models of practice, expand the range of care options, particularly alternative therapies.

- Set up free and universal provision of contraceptives, fertility treatment and information around reproductive choice and STDs (particularly HIV and AIDS).

- Initiate inter-departmental and agency links with regard to women’s health in the Republic in line with the above recommendations. For example, the Department of Health and Children should fulfil the promise made by the Minister of Health to collaborate with NAPS on establishing health targets, measures and indicators. Health is an issue of human rights for women and should be addressed at a broad policy level.
Bibliography


APPENDIX 1. WOMEN AND HEALTH BACK-UP SHEET

Please use the following notes to clarify the needs/supports described on the 12 pre-prepared cards for the Women and Health Research Statement. If your group asks you for an explanation of any of the issues, it is important that you use all or part of these explanations only so that they are standard across all the groups working on the Women and Health Research Statement.

1. **One-stop shop for women’s health** – a one-stop shop would be a health clinic or health centre where a woman could have all her health needs attended to. For instance, she would be able to see a family practitioner for general health needs; a counsellor, psychologist or psychiatrist for her mental health concerns; a homeopathic or complementary practitioner for general health needs; a masseuse for touch therapy or a variety of other alternative practitioners. A woman would also be able to have breast and cervical screening in this one-stop shop.

2. **Women-friendly health clinics in rural and urban areas** - refers to the lack of women-friendly health clinics in rural and urban areas. The term ‘women-friendly’ embraces many factors. A clinic would be ‘women-friendly’ if it had flexible opening hours, could send out staff for home visits, and if it had an in-house crèche and crèche worker. The group can think of other aspects to this but if they do, have them write them onto separate cards.

3. **Respite and counselling support for women as ‘carers’** (of people with special needs, people with disabilities, partners, children, the elderly, etc.) – this need acknowledges that women do most of the community and home care for people who are not able to do self-care for themselves. Women who do this caring should have access (time-wise, financially and so forth) to support for and time-off from their heavy workloads.

4. **Access to counselling/ mental health care** - ‘access’ to this need means access in the broadest sense of the word. That is, if a woman needs to find counselling/mental health care, it should be close to her geographically, it should be free or subsidised and it should be ‘women-friendly,’ with all that that concept embraces. There should also be more information about counselling/mental health care, its availability and choices around it.

5. **Easy access to women’s health/well-being information** – again, ‘access’ is meant in the broadest sense of the word in terms of ease of finding the information, increased production of health/well-being information and free provision of that information. The information itself should be free of sexism and should provide all the options around different women’s health needs. It should also be respectful of the differences among women in terms of class, ethnicity, sexuality and ability.

6. **Equality in relationships between clients and service providers** – aspects of equality in relationships between clients and providers include: clients and providers being on a first-name basis; clients would give fully-informed consent to procedures and prescriptions; clients would be offered all the choices and information available to them around their health needs, not just what is convenient for the provider; clients would be able to arrange exactly how they would like to manage their own health, the providers would not make those decisions for them; and providers would be respectful of the backgrounds of their clients, that is, if their client was gay or from a specific ethnic group, they would be sensitive to how background might affect a client’s needs and would never be judgmental about that.

7. **Access to family planning** – again ‘access’ is in the broadest sense of the word, particularly around choice. For instance, when a woman goes to a provider for birth control, she may not always be told of all the options available to her. True access to family planning would ensure
that a provider would be required to share all the birth control options available with her/his client. Access would also mean that these options would be widely available or that there would be no limits on obtaining them; for instance, if a woman has a medical card, she has a restricted choice of contraceptive methods ranging from certain types of the birth control pill and condoms. She would not be covered for an IUD or diaphragm, for example.

8. **Access to fertility treatment** – ‘access’ here is meant in the broadest sense of the word with particular emphasis on the financial aspects of getting fertility treatment, as well as the idea that women should be able to have fertility treatment regardless of financial position, marital status, sexuality, class, ethnicity or ability.

9. **Holistic approach to health/well-being** – often in traditional medicine (i.e. hospitals, doctors, specialists etc.), the mind is separated from the body and not seen as connected. For instance, stress could cause a physical reaction, but because stress is meant to be ‘in your head’, a provider might treat the mind and not the body. Holistic health care means that mind and body are treated together, not separately. An holistic approach to health/well-being for women would also mean that all the aspects of their lives would come into an investigation of their health/well-being because a woman’s social reality can affect her health.

10. **Free breast screening** – means that screening for breast cancer would be paid for by the State.

11. **Free cervical screening** – means that screening for cervical and endometrial cancers would be paid for by the State.

12. **Improved maternity services** – the components of improved maternity services would include improved ‘access’ to services already in place, but would also include increased options in services, for instance, that the option to have a home birth would be supported by the medical profession and could be easily accessed if a woman chose to do so. Also, that there would be respectful and equal relationships between women and maternity service providers.
APPENDIX 2: CASE STUDY: THE IRISH DEAF WOMEN’S GROUP

A2.1 INTRODUCTION

The standardised research outline for ‘Women and Health’ was not capable of fully reflecting the experiences of The Irish Deaf Women’s Group, who had specific health needs in relation to being part of a cultural and linguistic minority. In addition, they experienced unique challenges in dealing with research techniques and processes during the Millennium Project. This fact has significant implications for the future design of PLA projects for groups who have special needs related to deafness. The experience of this group is also instructive in raising our awareness of how minority groups articulate their specific health needs in order to enable health services to become more open, flexible and effective for service users.

A2.2 BRAINSTORMING – IDENTIFYING KEY HEALTH NEEDS

The group created a set of 13 ‘health needs’ cards through a Brainstorming process:

1. More awareness of deaf women’s needs required, especially around delivery/post-delivery health issues and services for mother and child.
2. Pregnancy – inability to participate in group discussions due to lack of availability of Irish Sign Language (ISL) interpreters.
3. Lack of information generally about ante- and post-natal care.
4. Ante-natal classes – cannot afford to pay for interpreter; lack of choice re male/ female doctors available to women on medical card.
5. Giving birth can be made more difficult by lack of finance for interpreter.
6. Attending out-patient departments - hospital staff and administration do not take account of specific needs of deaf women.
7. Lack of privacy and dignity in family planning clinic.
8. Feel uncomfortable having smear tests – ‘no confidence in nurses while they are busy’ and no interpreters available for General Practitioners.
9. Re: hormone replacement therapy – older women need adequate information in relation to changing health needs.
10. Re: media – lack of subtitles reduces access to information; insufficient coverage of health issues.
11. Re: genetic modification – serious lack of information – ‘deaf people are always the last to know about importance of health needs.’
12. Re: alcoholism – lack of information; lack of ISL counsellors.
13. Re: abuse – lack of awareness of needs of deaf women in relation to rape and/or domestic violence.

The group ‘bundled’ these 13 health needs into the 8 categories represented below in the Seasonal Calendar, and evaluated their levels of intensity over the span of a woman’s life.
A2.3  SEASONAL CALENDAR – KEY HEALTH NEEDS ASSESSED ACROSS THE LIFESPAN

(Please note: ‘Physical emotional’ and ‘Qualified ISL Interpreters’ follow the same trajectory in this diagram, and therefore the lines indicating these two needs across the lifespan overlap and appear as one.)

- **‘Full access’** now incorporates the need to hire interpreters for the deaf at all healthcare provision centres (rape crisis centres, hospitals, GP surgeries, cancer and gynaecology centres);
- **‘Mental health’** emphasises the need for ISL-qualified or deaf mental health counsellors and psychiatric staff;
- **‘Information’** incorporates all the areas previously indicated where information is unavailable due to barriers in communication. The group advocated the use of videos with sub-titles to supplement women’s health leaflets;
- **‘Active retirement people’** is the ‘hormone replacement therapy’ card renamed;
- **‘Physical emotional’** represents the interdependence between physiological and emotional aspects of health and well-being – incorporating the need for accessible counselling;
- **‘Qualified ISL interpreters’** emerged as one of the key areas of concern for the group – more qualified interpreters would lead to more access to information and equality;
- **‘How to be Trainer’** refers to how deaf people might act as trainers in education, healthcare, counselling and careers;
- **‘Senior Citizens (deaf women)’** overlaps with ‘active retirement people,’ but focuses on the need for general supports for older women: wheelchairs, ‘meals on wheels’ and so on.

The Seasonal Calendar indicates how certain health needs, for example, ‘Active Retirement People’ and ‘Senior Citizens’, are clearly linked to the later years of the lifespan, while ‘Information’ and ‘Mental health’ are associated with earlier years (5-55), with a dramatic peak at the 40s. ‘Full Access’ scores highly across the years from 26-50. Similarly, high scores for ‘How to be Trainer’ fall into a narrower age band, from 31-45. Two needs, ‘Physical Emotional’ and ‘Qualified ISL Interpreters’ are presented as equal in importance across the lifespan.
A2.4 MATRIX – POSITIVE ACTIONS TO HELP ADDRESS IDENTIFIED HEALTH NEEDS

The group felt that none of the health needs cards were adequately met by current service provision and proceeded to create a matrix, naming actions that would help to address their health needs.

The graph above shows the relative scores for each action according to each of the health needs listed by the group. Each vertical grid represents one of the key health needs identified by the group. Each solution identified to address key health needs has been given a certain colour bar and may address more than one health need. Thus, the solution ‘need minibus to collect deaf tutor for old people’, addresses the needs, ‘home help needs for deaf people who live alone’, and ‘Senior Deaf Citizens’.

The trend towards emphasis on the need to increase provision of ISL interpreters and recognition of the importance of ISL emerges once again in the findings of this matrix, with 3 of the top 4 scoring actions having some connection with the availability either of ISL interpreters or qualified deaf staff in health care provision.

From the observation notes, it appears as though this theme is closely linked with the increased participation of deaf people in mainstream society: ‘...nobody hears our scream. Problem is over barrier – our needs, frustrations. Interpreter would solve from problem 1 to 7.’

A2.5 KEY EVALUATION COMMENTS

Finally, in relation to the challenges this group faced using the PLA process, their evaluation included the comment that: ‘Video would be perfect solution to solve this problem. Too much hassle by writing.’

Facilitators could re-run the video to catch signing they missed during sessions, enabling them to make more complete and extensive observation notes. Although the project was described as ‘time-consuming’ and frustrating at times, the group also recognised within the process a potential for their particular voices to be heard: ‘We feel that the only way [this project] will be important [will be] because the Millennium Project will pass [it] on to the Government. It is our first step to do something like this and our turn to shout the message loud. The Millennium Project is of central importance to the women’s deaf group. We appreciate their moral support to help us to go on with [the] project by providing the interpreter’s fee/costs/patience.’
Section II: Exploring the use of PLA in primary healthcare research – Republic of Ireland, 2009-2011
SUPERS Project, Ireland 2009-2011. Our six training sessions are over. We have prepared and culture-proofed our PLA materials. We’ve co-generated a protocol document to keep all six teams on track! We want our research to be consistent, rigorous, and enjoyable for the 51 migrant stakeholders. April 17th 2010 will be our big research day!

Left: Polish migrant stakeholders completing one of seven inter-related PLA techniques, April 17th 2010, NUI Galway, Ireland.

Below: Flexible Brainstorming and Direct Ranking charts show results of 51 migrants’ perspectives about strategies for cross-cultural communication in general practice consultations.

SUPERS’ post-research reflections: ‘All the peer researchers used the same PLA techniques, so all stakeholder groups engaged in a consistent research process. Our results showed that, by using PLA, we could hear both dominant and hidden voices.’

‘Being a peer researcher with my community – I feel very powerful. When I listened to migrants’ views it gave me more energy. I feel I have done a good job for my community; I am hopeful [the outcome] will be good for the community and the problems they are facing.’
Chapter 4

Using Participatory Learning & Action research to access and engage with ‘hard to reach’ migrants in primary healthcare research


Mary O’Reilly-de Brún
Tomas de Brún
Ekaterina Okonkwo
Jean-Samuel Bonsenge-Bokanga
Maria Manuela De Almeida Silva
Florence Ogbebor
Aga Mierzejewska
Lovina Nnadi
Evelyn van Weel-Baumgarten
Chris van Weel
Maria van den Muijsenbergh
Anne MacFarlane
Abstract

**Background**

Communication problems occur in general practice consultations when migrants and general practitioners do not share a common language and culture. Migrants’ perspectives have rarely been included in the development of guidelines designed to ameliorate this. Considered ‘hard-to-reach’ on the basis of inaccessibility, language discordance and cultural difference, migrants have been consistently excluded from participation in primary healthcare research. The purpose of this qualitative study was to address this gap.

**Methods**

The study was conducted in the Republic of Ireland, 2009 – 2011. We developed a multi-lingual community-university research team that included seven established migrants from local communities. They completed training in Participatory Learning & Action (PLA) - a qualitative research methodology. Then, as trained service-user peer researchers (SUPERS) they used their access routes, language skills, cultural knowledge and innovative PLA techniques to recruit and engage in research with fifty-one hard-to-reach migrant service-users (MSUs).

**Results & discussion**

In terms of access, university researchers successfully accessed SUPERs, who, in turn, successfully accessed, recruited and retained MSUs in the study. In terms of meaningful engagement, SUPERs facilitated a complex PLA research process in a language-concordant manner, enabling inclusion and active participation by MSUs. This ensured that MSUs’ perspectives were included in the development of a guideline for improving communication between healthcare providers and MSUs in Ireland. SUPERs evaluated their experiences of capacity-building, training, research fieldwork and dissemination as positively meaningful for them. MSUs evaluated their experiences of engagement in PLA fieldwork and research as positively meaningful for them.

**Conclusions**

Given the need to build primary healthcare ‘from the ground up’, the perspectives of diverse groups, especially the hard-to-reach, must become a normative part of primary healthcare research. PLA is a powerful, practical ‘fit-for-purpose’ methodology for achieving this: enabling hard-to-reach groups to engage meaningfully and contribute with ease to academic research. PLA has significant potential to become a ‘standard’ or generic approach in building community-based primary health care. Community–university partnerships have a significant role to play in this, with capacity to radically influence the shape of healthcare research, expanding the research agenda to incorporate the views and needs of hard-to-reach and vulnerable populations.

**Keywords**

Migrants, User-Involvement, Meaningful engagement, Participatory research, Primary healthcare, Peer researchers, Guidelines
Background

Communication between professionals (service-providers) and patients (service-users) in primary care is essential in securing a full understanding of patients and their backgrounds. Communication skills are a core competency for general practitioners and necessary to build trusting relationships and achieve optimal health outcomes. Communication touches on social and cultural values, and specific communication problems arise in cross-cultural general practice consultations when service-users and general practitioners experience language and culture barriers. These problems arise particularly in the care of undocumented migrants, refugees, people seeking protection (asylum-seekers) and low-income economic migrants, and persist over time and across international settings. Guidelines have been developed to address this but uptake in daily practice is low. This may be because migrant service-users’ perspectives are seldom included in research to inform guidelines. In fact, the inclusion of all key stakeholders’ perspectives is central to the development of relevant ‘bottom-up’ health initiatives.

Participatory research (PR), participatory action research (PAR) and community-based participatory research (CBPR) are used to engage stakeholders in ‘bottom-up’ primary healthcare research. However, within this, we could not locate a detailed practical description of how to develop a guideline in partnership with migrant service-users. Recent meta-scoping reviews and a critical interpretive synthesis in the field of Public and Patient Involvement (PPI) indicate that there are many types and levels of service-user involvement in healthcare research, ranging from participants as passive subjects of a study to participants actively collaborating in research design and conduct. We were aiming for active collaboration with migrants via an accessible, inclusive research process. We chose PLA because it shares the democratic ethos of the approaches mentioned above and promotes active participation by those who might not readily perceive themselves as experts with valuable contributions to make to academic research. PLA techniques are accessible to those with literacy (reading/writing) challenges and two of the co-authors had extensive experience of adapting, developing and applying PLA in research with hard-to-reach groups across diverse cultural settings.

We designed a participatory study that aimed to produce a guideline integrating service-users’ and service-providers’ perspectives about strategies to support cross-cultural communication between GPs and migrants. The guideline, which promotes the use of professional interpreters and language-concordant GPs, is available; the study results are reported in full elsewhere.

In this paper, our focus is on method – why and how we used a PLA approach to involve migrants in primary healthcare research. Our objectives are to describe PLA methodology, mode of engagement and techniques used for enhancing migrants’ access to, and engagement in, the research process, and to report their evaluation of engagement.

Definitions and description of key terms

Our research focused on migrants known to experience communication difficulties in cross-cultural general practice consultations, e.g., the undocumented, refugees, people seeking protection and low-income economic migrants. Migrants with these profiles could be considered ‘hard-to-reach’, although this term is fluid and contested. In this study, access means identifying, contacting,
recruiting, involving and retaining hard-to-reach migrants in a research process. By meaningful engagement, we mean an experience of research that is collegial, inclusive and active for participants and which enables their perspectives to emerge clearly in research outcomes.

Methods

Study setting and rationale
The ‘SUPERS’ (Service User PEer ResearcherS) study was conducted in the Republic of Ireland (ROI) from 2009 to 2011. The study was based on a partnership between the Health Services Executive’s (HSE) Social Inclusion Unit, the Discipline of General Practice, National University of Ireland, Galway (NUI G) and the Centre for Participatory Strategies (CPS), Galway. CPS is an independent research organisation specialising in PLA research training. The HSE is the national public body responsible for the provision of healthcare to those domiciled in the State, including the increased migrant population of recent years. Between 2002 and 2011, an increase of 143% in inward migration was recorded. ROI census figures for 2011 showed that 12.6% of the total population were non-Irish nationals, with 19.4% domiciled in Galway city, making it the most multicultural city in the ROI.

The rationale for the study developed in response to an unsolved issue in the National Intercultural Health Strategy. In cross-cultural medical consultations, when general practitioners (GPs) and migrants who do not share language or culture experience communication problems, what constitutes best practice? The HSE recommended a participatory research approach to involve key stakeholders in developing a guideline to identify what communication strategies work best, for whom and in what circumstances. The intention was to identify practical solutions to everyday cross-cultural communication problems. To capitalise on the diversity of migrant groups in Galway, the HSE chose Galway city and county for the research component involving hard-to-reach migrant service-users (MSUs). The study was funded by the Health Research Board and HSE Social Inclusion Unit. Ethical approval was obtained from the Irish College of General Practitioners.

Study design: taking a PLA approach
We chose a PLA approach and methodology for this study. Rooted in interpretive and emancipatory paradigms, PLA is a form of action research. Based on the work of Robert Chambers, PLA is a practical approach to research with diverse groups where asymmetries of power may exist. Influenced by critical theory and international theories of development, PLA is strongly linked to social justice movements and, as noted above, shares the core principles of participatory action research (PAR) and community-based participatory research (CBPR).

A PLA research process brings diverse stakeholders together to engage in a process of shared, enhanced learning. A PLA ‘mode of engagement’ promotes reciprocity, mutual respect, co-operation and dialogue in research encounters within and across diverse stakeholder groups. PLA techniques are inclusive, user-friendly and democratic, generating and combining visual, verbal and tangible data. Charting, ranking, mapping and assessment techniques are combined with interviews and focus groups. This encourages literate and non-literate stakeholders alike to participate in research. They are seen as ‘local experts’ who are uniquely knowledgeable about their own lives and conditions, who bring their implicit knowledge to the ‘stakeholder table’ where, through
Using participatory learning & action research

discussion and dialogue, it becomes explicit and therefore available to the ongoing collaborative research process they are engaged in.\textsuperscript{53} Stakeholder groups or representatives engage in PLA-brokered dialogue to identify, in a democratic manner, positive solutions to shared problems, thereby achieving agreed goals.\textsuperscript{13,44,53}

PLA researchers act as facilitators, enablers and brokers, rather than directors or top-down decision-makers. This promotes strong relationships of trust and rapport with stakeholders.\textsuperscript{18,35,57} Throughout iterative cycles of research, the optimum scenario is to work effectively together to address project aims, to co-design and fine-tune research plans and processes. The democratic interactive nature of PLA allows for co-analysis of findings. Reflection and reflexivity are addressed by engaging in team debriefing, reflection and evaluation sessions.\textsuperscript{37} Evaluation criteria are co-generated and democratically agreed, and may serve as outcome measures. In essence, to adopt a PLA approach is to opt for an inclusive and active research process designed to promote and support meaningful engagement by, with and for all stakeholders, especially the least powerful.

\textbf{Study design: challenges related to access and engagement}

Several key factors may constitute insurmountable barriers to access and meaningful engagement with hard-to-reach migrants. When designing this specific PLA study, we had to take account of the following:

- The university researchers had no familiarity with the languages or cultures of the intended migrant research participants and could not, therefore, engage directly in fieldwork with them.
- Migrant service-users (particularly the undocumented) may be reluctant to participate in research that brings them into direct contact with the ‘establishment’, therefore standard recruitment strategies were unlikely to generate a participant group.
- Migrants may feel uncomfortable or threatened by research that is extractive in nature and evocative of an exercise of ‘power over’ them;\textsuperscript{58} our mode of engagement needed to reflect a very different power-sharing approach from the outset.
- Among research participants, literacy abilities may range from high to low; low literacy must be addressed sensitively.
- Appropriate evaluation tools would be required to assess migrants’ experiences of engagement, and establish to what extent these were meaningful.

\textbf{Sampling and recruitment}

We used purposeful and network sampling\textsuperscript{59,60} as is common in qualitative research; criteria used to develop sampling frame parameters are shown in Table 1. Although representativeness is not a claim qualitative studies make, our study design involved consideration of the wide range of migrants of interest domiciled in Galway city and county. As the university researchers had no familiarity with the languages and cultures of intended migrant participants, they used their community-university networks to expand the research team. They identified seven established migrants from various countries of origin, who spoke a range of languages, were also proficient in English and familiar with the host culture. Already trained as community interpreters, they were interested in training as PLA peer researchers (Table 1 left-hand column). They chose the acronym ‘SUPERs’ - Service User PEer Researchers.
Table 1 Sampling frame parameters: criteria for SUPERs and (MSUs)

<table>
<thead>
<tr>
<th>SUPERs</th>
<th>Hard-to-reach MSUs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Established migrant, well embedded in own community, and comfortable to self-select/identify as a representative of that community</td>
<td>Currently a migrant, documented, seeking protection, low income, asylum-seeker, refugee or undocumented</td>
</tr>
<tr>
<td>Domiciled in Galway city or county</td>
<td>Domiciled in Galway city or county</td>
</tr>
<tr>
<td>Have active social and professional networks in own community, from which migrant research participants who fit recruitment parameters may be recruited (purposeful, network sample)</td>
<td>Have direct social or professional contact with an established migrant from the research team; alternatively, have contact via broader migrant networks with an MSU already recruited into the study by an established migrant (purposeful, network sample)</td>
</tr>
<tr>
<td>Currently proficient in English language, but with previous or continuing (personal or professional) experience of language and culture challenges in cross-cultural primary care consultations in ROI (host country)</td>
<td>Current or previous experience of language and culture challenges in cross-cultural primary care consultations in ROI (host country)</td>
</tr>
<tr>
<td>Interested in availing of free training in participatory research techniques; prepared to commit time and energy to training as a peer researcher to progress sampling and fieldwork with other migrants in ROI</td>
<td>Willing to engage in a language-concordant participatory research study to share experiences and perspectives on language and culture challenges in cross-cultural primary care consultations in ROI</td>
</tr>
</tbody>
</table>

The SUPERs acted as ‘safe conduits’ for the recruitment of fifty-one MSUs into the study (Table 1, right-hand column). To do this, they:

- Co-generated a sampling frame
- Co-designed and translated recruitment leaflets into their own languages
- Disseminated leaflets throughout their community-based networks
- Engaged directly with MSUs’ questions and concerns about the study.

The languages spoken by SUPERs were a key determinant of sample selection: SUPERs’ and MSUs’ languages had to match for the planned data-generation encounters. Five SUPERs recruited one MSU group each; the two Nigerian SUPERs co-recruited the sixth group. MSUs came from a variety of countries of origin and coalesced into the following six language groups: Russian, Polish, Urdu, French-Lingalan, Portuguese/ Brazilian Portuguese and Edo/Igbo/Hausa/Yoruba (Nigerian participants).

Overview of research - Phases I, II and III

Below, we outline three distinct phases of research engagement in the study:39

Phase I (8 months): we focussed on capacity-building for SUPERs (4 sessions, 12 h face-to-face). Using PLA techniques and focus groups discussions, we built team trust and rapport; we explored relevant international literature and policy to expand SUPERs’ knowledge-base about cross-cultural
communication and we mapped strategies commonly used to address challenges in cross-cultural communication (Table 2, left-hand column).

**Phase II (10 months):** SUPERs completed an intensive PLA training programme (6 sessions, 28 h face-to-face, over a 3-month period). The time and effort devoted to capacity-building and training (total 40 h, Table 2, left-hand column; Table 5 was intended to enable SUPERs to become skilled language-concordant PLA facilitators, i.e., peer researchers capable of doing PLA research in the non-dominant languages of MSUs. At the close of Phase II, during an intensive research day (1 session, seven hours face-to-face) SUPERs facilitated identical sequences of 7 interlinked PLA techniques (Table 2) with MSU groups to elicit perspectives on potential guideline content.

**Phase III (6 months):** The university researchers completed an identical sequence of 7 interlinked PLA techniques with service-providers (policy makers, interpreters, general practitioners and service planners) to elicit their perspectives. Then, stakeholder working groups (SWG) comprising a sample of service-providers, all university researchers and all SUPERs engaged in a PLA-brokered dialogue, during which SUPERs represented MSUs’ perspectives and recommendations. To close the project, one year after the intensive research day, SUPERs brought the outcome of the dialogue back to MSUs to seek consensus on content. They assessed the data, noting convergences and divergences between their perspectives and those of service-providers.

**Table 2**  
**Phase I, Phase II: Methods for capacity-building, training and data generation**

*Note: PLA techniques described below combine visual, tangible materials (pictures, photographs, phrases, Post-it notes, symbols, voting tokens, etc) with verbal interactions, such as interviews, focus group discussions, and ‘on-the-spot’ co-analysis discussions.*

<table>
<thead>
<tr>
<th>PLA techniques used with SUPERs during capacity-building (4 sessions, 12 h)</th>
<th>PLA techniques used (mirrored) by SUPERs during fieldwork with MSUs (Intensive research day: 1 session, 7 h)</th>
</tr>
</thead>
</table>
| **Ice Breaker** Interactive group activity  
*Rationale:*  
- To reduce interpersonal barriers  
- To build trust and rapport in research team at outset of capacity-building processes  | **Ice Breaker** Interactive group activity  
*Rationale:*  
- To reduce interpersonal barriers  
- To build trust and rapport between SUPERs and MSUs at outset of research process  |
| **Co-generated Ground Rules** Democratic decision-making group activity  
*Rationale:*  
- To encourage active participation by SUPERs in PLA research activity  
- To promote inclusion and encourage co-ownership of PLA processes  
- To balance power dynamics between university researchers and SUPERs  
- To promote empowerment of SUPERs  | **Co-generated Ground Rules** Democratic decision-making group activity  
*Rationale:*  
- To encourage active participation by MSUs in PLA research activity  
- To promote inclusion and encourage co-ownership of PLA process  
- To balance power dynamics between SUPERs and MSUs  
- To promote empowerment of MSUs  |
Timelines (individual)
Visual map and verbal narrative of university researchers’ and SUPERS’ personal and/or professional ‘journeys’ that led to participation in the study

Rationale:
- To develop deeper trust and rapport
- To bond the community-university research team
- To promote inclusion
- To balance power dynamics

PLA-style focus group discussions
Focus group discussions using PLA ‘mode of engagement’

Rationale:
- To develop a shared knowledge-base about international literature and policy regarding cross-cultural communication
- To enhance team knowledge by mapping SUPERS’ knowledge about the range of communication strategies currently in use in cross-cultural consultations where language and culture barriers exist.

Methods used with SUPERs during PLA training
(6 sessions, 28 h)

Active, experiential ‘learning-by-doing’ training programme to equip SUPERs to facilitate a sequence of 7 interlinked PLA techniques:
1. Ice-breakers
2. Co-generated ground rules
3. Flexible Brainstorming
4. Card Sort
5. Direct Ranking
6. Mapping (visioning)
7. PLA-style focus groups

Rationale – to equip SUPERs to:
- Facilitate data generation with MSUs in a collegial inclusive manner likely to be meaningful for them
- Use visual-verbal-tangible techniques to include all MSUs, especially those who might have literacy challenges
- Promote co-analysis and co-ownership of research data by MSUs
- Highlight MSUs valuable contribution to academic research

Co-design of PLA research protocol
Community-university research team activity

Rationale:
- To produce a standardised protocol for the conduct of fieldwork
- To promote consistency and rigour in PLA process across fieldwork groups

PLA-style focus group discussions
Focus group discussions using PLA ‘mode of engagement’

Rationale:
- To surface MSUs’ common and differential knowledge and expertise
- To exchange and enhance knowledge within each MSU group during the research process
- To assist data-generation in the form of a range of charts and maps developed by MSUs (as below: Flexible Brainstorming, Card Sort, Mapping, Direct Ranking)
- To review and co-analyse data on completed charts and maps.

PLA techniques used (mirrored) by SUPERs during fieldwork with MSUs
(Intensive research day: 1 session, 7 h).

1. Ice-breakers (see above)
2. Co-generated ground rules (see above)

3. Flexible Brainstorming
Interactive knowledge exchange, knowledge generation group activity

Rationale:
- Used to map and display a range of communication strategies known to be commonly used in cross-cultural consultations where language barriers exist

4. Card Sort
Categorisation exercise

Rationale:
- To explore and analyse communication strategies in terms of those considered ‘useful’, ‘problematic’, ‘non-viable’

5. Direct Ranking
Democratic prioritisation, ranking and decision-making technique

Rationale:
- Used to identify ‘most-to-least’ acceptable communication strategies, as agreed by MSUs
### Using participatory learning & action research

- To support comparative analysis of research findings across groups.

### 6. Mapping (visioning activity) – ‘Ideal Scenario’

**Visioning activity which maps or plots data on charts**

**Rationale:**
- To visually map additional ideal strategies to create a vision for ‘best possible communication’ between GPs and MSUs, i.e. the ‘ideal scenario’.

### 7. PLA-style focus groups (see above).

---

*Methods for meaningful engagement with SUPERs and MSUs: inclusive, active, collaborative research*

The integrated nature and rigour of this study was built on an important interplay between methods used for training and capacity-building with SUPERs, and methods subsequently used by SUPERs to generate data with MSUs. All methods were designed to be collegial, inclusive, active and collaborative and to provide opportunities for meaningful engagement. Methods used with SUPERs were also designed to provide a *model* for their ‘mirroring’ engagement with MSUs. Below, we provide some examples across the three Phases of research; Table 2 provides further details.

**Phase I:** SUPERs’ capacity-building included collaborative co-design of ‘ground rules’ for respectful interaction. SUPERs’ mirrored this when, at the outset of the intensive research day, they invited MSUs to co-generate ground-rules for the day’s work.

**Phase II:** SUPERs’ PLA training was active and experiential; they ‘learned-by-doing’ how to facilitate PLA techniques for data-generation. They co-designed a research protocol to promote consistency and rigour during fieldwork. Each SUPER then used this protocol to facilitate, with his/her MSU group, identical sequences of PLA techniques, including:

- Flexible Brainstorming (knowledge-generation, knowledge-exchange)
- Card Sorts (categorisation, assessment, analysis)
- PLA-style focus groups (knowledge-sharing, knowledge-exchange, analysis)
- Direct Ranking (prioritisation, democratic decision-making)
- Mapping (visioning activity)

During the intensive research day with MSUs, these visual–verbal–tangible PLA techniques produced a range of charts, or ‘data displays’. These were arrayed on tables and walls, ready for co-analysis. SUPERs, using in-depth PLA-style focus group interviews, invited MSUs to review data, discuss emergent outcomes and offer analytical comments and insights. This collegial ‘on-the-spot’ co-analysis was possible because there were no language barriers, therefore no need for interpreters or translators. The analysis allowed clear results to emerge from each of the six MSU groups: a range of communication strategies they rejected and a range of strategies they recommended for consideration in the guideline. Following the intensive research day, SUPERs translated all data displays into English for detailed discussion with the university researchers, who recorded the data on computerized charts, enabling cross-comparison with other stakeholders’ data.
**Phase III:** The SUPERs, having co-analysed the results that emerged from MSU groups, were in a strong position to represent MSUs’ perspectives throughout the PLA-brokered dialogue with service-providers. This continued engagement ensured that ‘migrant voices’ were not lost. These examples of SUPERs’ and MSUs’ involvement, inclusion, and collaboration in activities across the full research cycle illustrate a power-sharing approach, and interactive rather than extractive research. This helps to balance power dynamics and signal that researchers are oriented towards empowerment of participants.58,61 This empowerment lies at the heart of meaningful engagement.

**Methods used to evaluate experiences of engagement**

At various points during their 2-year involvement in the project, SUPERs documented their experiences of engagement in capacity-building, training, research and dissemination via a range of qualitative methods (formative and summative). At the close of the intensive research day, MSUs documented their experiences of engagement via 3 interrelated methods (participatory evaluation, qualitative comment, Likert-type rating scales). Table 3 provides further details. The legend and codes below indicate primary data-sources:

- PE: Participatory evaluations (SUPERs, MSUs)
- QC: Qualitative comments (MSUs)
- RS: Likert-type rating scales (MSUs)
- CH: Charted processes - mapping, ranking, data displays (MSUs)
- Ph: Photographic evidence (permitted) of charts, activities, interactions (SUPERs, MSUs)
- FDB: Post-fieldwork debriefing interviews (SUPERs)
- PTAN: Project team analysis of research and evaluation data (SUPERs’ interviews, debriefings)
- CP: Conference presentation data (SUPERs)
- Tr R/D: PLA trainers’ reflection/debriefing notes

### Table 3 Methods used to evaluate experiences of engagement by SUPERs and MSUs

<table>
<thead>
<tr>
<th>SUPERs’ experiences of engagement in:</th>
<th>MSUs’ experiences of engagement:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- capacity-building</td>
<td>- attendance at fieldwork session</td>
</tr>
<tr>
<td>- PLA training</td>
<td>- active participation during fieldwork</td>
</tr>
<tr>
<td>- PLA research design and planning</td>
<td>- co-analysis during fieldwork</td>
</tr>
<tr>
<td>- facilitation of PLA fieldwork</td>
<td>- retention to end of research cycle</td>
</tr>
<tr>
<td>- project team co-analysis</td>
<td></td>
</tr>
<tr>
<td>- dissemination</td>
<td></td>
</tr>
</tbody>
</table>

**evaluated via:**

- SUPERs’ post-training participatory evaluations (PE)
- PLA trainer’s post-training reflection/debriefing notes (Tr R/D)
- SUPERs’ post-fieldwork debriefing interviews (FDB)
- Fieldwork photographs (Ph)
- PLA trainers’ post-fieldwork reflection/debriefing notes (Tr R/D)
- SUPERs’ project team analysis sessions (PTAN)
- SUPERs’ conference presentation data (CP)

- MSUs’ participatory evaluations (PE)
- MSUs’ quantitative (Likert-type) rating scales (RS)
- MSUs’ qualitative comments (QC)
- Fieldwork photographs (Ph)
- MSUs’ charts, maps, data-displays (CH)
- SUPERs’ post-fieldwork debriefing interviews (FDB)

**Evaluation criteria and analysis**

The participatory evaluations mentioned above were based on a combination of *etic* and *emic* criteria12,62: etic criteria are identified in advance by researchers. For example, our working definition
of meaningful engagement included four hallmarks: ‘collegiality’, ‘inclusion’, ‘active involvement in the research process’ and ‘emergence of participants’ perspectives in research outcomes’. We used these as core etic criteria for participatory evaluations. Emic criteria are additional criteria that participants themselves may suggest. They emerge from shared ‘insider’ experiences of the research encounter. They often contribute criteria the team could not have anticipated. In our participatory evaluations, therefore, we invited participants to suggest emic criteria and invited critical comment on the etic criteria presented. The final agreed set of criteria formed the evaluation parameters.

Evaluation data were analysed using principles of thematic analysis\textsuperscript{63,64} to identify evidence of experiences of meaningful engagement on the part of SUPERs and MSUs.

Results

Here we report on the core themes of this paper:

- Access to established and hard-to-reach migrants.
- Meaningful engagement in PLA research by established and hard-to-reach migrants.

**Accessing established migrant service-users (SUPERs)**

The access strategies used by university researchers made it possible to include seven SUPERs in the study. A profile of the SUPERs, showing gender, region of origin, languages spoken and current profession is provided in Table 4. It is based on a self-administered questionnaire SUPERs co-designed with university researchers at the outset of the project. The five female and two male SUPERs were aged between 28 and 50. All but one had third-level education. Prior to their involvement in the project, all had completed the Northern Ireland Council for Ethnic Minorities (NICEM) interpreter’s training course. They described themselves as ‘up-skilling’ towards professional interpreting and/or wishing to establish formal accreditation of their existing interpreting qualifications in the ROI. They shared a strong commitment to the professionalising of interpreting.

**Accessing hard-to-reach migrant service-users (MSUs)**

By activating their community networks, the 7 SUPERs successfully recruited 51 MSUs into the study. All 51 participated in the intensive research day and the majority returned one year later to discuss the outcome of the PLA-brokered dialogue. Complex socio-political factors limited our ability to gather socio-demographic information about MSUs. For example, educational background, literacy/numeracy abilities and other variables could not be established with precision – MSUs did not wish us to record this type of information. We were unable to establish how many were undocumented compared to those with refugee status. However, SUPERs’ observations, ‘insider knowledge’ and direct contact with MSUs during recruitment and fieldwork provided important insights into the multiple communication and access barriers these MSUs experienced: the vast majority did not speak the dominant language of the host country and were unfamiliar with the host culture. SUPERs noted that literacy abilities were mixed, and in some groups, low. Many MSUs lived in Direct Provision Centres and those without refugee status were precluded from legally entering the workforce. Some were undocumented and would not risk coming to the university for fear of
being identified; they opted to work in their homes with their language-concordant SUPER. Team observations and (permitted) photographic evidence allowed us to establish that there was an evenly balanced male–female distribution, and migrants ranged in age from early 20s to mid-60s.

### Table 4 Profile of SUPERs

<table>
<thead>
<tr>
<th>SUPERs' ID Codes</th>
<th>Gender</th>
<th>Country/region of origin</th>
<th>Languages</th>
<th>Current profession/area of interest/work</th>
</tr>
</thead>
<tbody>
<tr>
<td>#3</td>
<td>Female</td>
<td>Russia</td>
<td>Russian/English</td>
<td>Migrant support &amp; advocacy worker Community interpreter</td>
</tr>
<tr>
<td>#4</td>
<td>Female</td>
<td>Nigeria</td>
<td>Edo/Igbo/Hausa/Yoruba/English</td>
<td>Social worker Community interpreter</td>
</tr>
<tr>
<td>#5</td>
<td>Female</td>
<td>Poland</td>
<td>Polish/English</td>
<td>Healthcare assistant Community interpreter</td>
</tr>
<tr>
<td>#6</td>
<td>Male</td>
<td>Pakistan</td>
<td>Urdu/English</td>
<td>IT technician Community interpreter</td>
</tr>
<tr>
<td>#7</td>
<td>Male</td>
<td>Democratic Republic of the Congo</td>
<td>French/Lingala/English</td>
<td>Research Associate Community interpreter</td>
</tr>
<tr>
<td>#8</td>
<td>Female</td>
<td>Portugal</td>
<td>Portuguese/English/Spanish/French</td>
<td>Interpreter and translator Doctoral candidate Community interpreter</td>
</tr>
<tr>
<td>#9</td>
<td>Female</td>
<td>Nigeria</td>
<td>Edo/Igbo/Hausa/Yoruba/English</td>
<td>IT support engineer Community interpreter</td>
</tr>
</tbody>
</table>

**Meaningful engagement by SUPERs in capacity-building, PLA training and research**

SUPERs described their participation in research training, capacity-building and research as meaningful in terms of the hallmarks noted earlier. This is detailed in Table 5 (right-hand column) and illustrated by sample quotes below.

SUPERs recognised their unique power as language-concordant peer researchers who could achieve access and build rapport with MSUs:

*Our task was to be a bridge between our communities and the university. Some of the migrant service-users were hard to reach – people who were ‘seeking protection’ or were ‘undocumented’, so they were very afraid to join in anything official. [But] because each SUPER shared the language and culture of his or her group, communication was straightforward and comfortable for the service-users. We could chat about the research and explain how different [from questionnaires] it was [going to be]. SUPER #5 (FDB)*

*The anonymising codes assigned to the seven SUPERs began at #3 and ran to #9 and as shown are consistent with original project documentation.*
PLA training and capacity-building supported their development as skilled and confident peer researchers capable of facilitating a complex PLA process:

I was confident after I did the exercises with [PLA trainers]. We set up the room, [and] at that time I thought it would work, I’m equipped! So actually when I went in the field... I set up the room and everything worked for me... the pictures and the Direct Ranking... In Direct Ranking, everybody, they have their own view, and [can decide] how much they give [in votes] so they were thinking they are part of this research. SUPER #6 (FDB)

All the peer researchers used the same PLA techniques, so all stakeholder groups engaged in a consistent research process. Our results showed that by using PLA, we could ‘hear’ both dominant and hidden voices. SUPER #5 (CP)

Reflecting on their experience of the fieldwork day, SUPERs talked about empowerment and potential benefits of engagement:

[Being a peer researcher with my community,] I feel ... very powerful and ... when I listened to [MSUs’] views it gave me more energy ... I feel that I have done a good job for [my community]... I’m hopeful, that [what happens] will be good for the community and the problems they are facing. SUPER #6 (FDB)

### Table 5  Meaningful engagement by SUPERs

<table>
<thead>
<tr>
<th>Training activities by SUPERs</th>
<th>Impact/effect on SUPERs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participated in capacity-building activities:</td>
<td>• Developed trust and rapport within combined community-university research team (FDB)</td>
</tr>
<tr>
<td>- 4 sessions, 12 h face-to-face</td>
<td>• Empowered SUPERs by enhancing knowledge about cross-cultural communication in academic literature (PE)</td>
</tr>
<tr>
<td>- Timeline activity to elicit past personal experiences of language barriers confirmed value and importance of experiential knowledge in PLA research</td>
<td></td>
</tr>
<tr>
<td>Engaged in intensive PLA training:</td>
<td>• Generated a skilled multiethnic, multilingual team capable of facilitating PLA research (FDB)</td>
</tr>
<tr>
<td>- 6 sessions, 28 h face-to-face</td>
<td>• Supported development of perceived confidence and competence to act as peer researchers (FDB) (PE)</td>
</tr>
<tr>
<td>- additional piloting and practice hours</td>
<td></td>
</tr>
<tr>
<td>Research activities by SUPERs</td>
<td>Impact/effect on SUPERs</td>
</tr>
<tr>
<td>Facilitated sequence of PLA techniques in language concordant manner</td>
<td>• Empowered SUPERs as active key ‘instruments’ in PLA research (FDB)</td>
</tr>
<tr>
<td>- 1 session, 7 h face-to-face</td>
<td>• Confirmed value of language skills and cultural knowledge as means of addressing and ameliorating language and culture barriers in research (FDB)</td>
</tr>
<tr>
<td></td>
<td>• Emphasised SUPERs’ ability to create inclusive</td>
</tr>
</tbody>
</table>
Applied range of mixed visual–verbal PLA techniques
Used co-designed protocol document
Culture-proofed PLA materials for use in various techniques
Identified and trained a ‘materials manager’ to assist with use of PLA materials, data displays, photography and group management
Facilitated on-the-spot analysis with MSUs
Evaluated PLA research process
Debriefed PLA research process
Co-analysed research results

| research environment (FDB) | • Empowered SUPERs as researchers – visual nature of techniques ameliorated migrants’ literacy challenges during research process (CH) (FDB)  
| Used co-designed protocol document | • Confirmed unique value of SUPERs’ active input into co-design of protocol and culture-proofing of PLA materials (FDB)  
| Culture-proofed PLA materials for use in various techniques | • Empowered SUPERs as decision-makers (FDB)  
| Identified and trained a ‘materials manager’ to assist with use of PLA materials, data displays, photography and group management | • Confirmed SUPERs in their ability to engage in data co-analysis processes, which built confidence for subsequent team co-analysis (FDB)  
| Facilitated on-the-spot analysis with MSUs | • Highlighted the positive relational environment SUPERs succeeded in generating during research process with migrants (FDB)  
| Evaluated PLA research process | • Enabled SUPERs to identify key strengths, learning, potential improvements (re PLA process, re own skills and competencies) (FDB)  
| Debriefed PLA research process | • Allowed SUPERs to identify perceived benefits of engagement for themselves and their communities (FDB)  
| Co-analysed research results | • Confirmed SUPERs’ skills in eliciting migrant perspectives during PLA fieldwork; confirmed value of SUPERs’ continuing involvement and input into research (FDB) (CH) (PTAN)  

Meaningful engagement by SUPERs in PLA-brokered dialogue and dissemination
SUPERs’ meaningful engagement continued beyond the intensive research day when they represented MSUs’ perspectives in the PLA-brokered dialogue with service-providers. This influenced service-providers’ perspectives and informed research results, sometimes in unexpected ways. A notable example was how one GP, who considered the use of child interpreters acceptable in certain circumstances, learned (via SUPERs) about the serious negative implications of this communication strategy from MSUs’ perspectives, and revised her view. The GP then stated she would not use a child interpreter again in her medical practice. Another example was service-providers’ enhanced learning about using family members/friends as informal interpreters. Analysis of questions explored in fieldwork\(^{39}\) revealed that, while MSUs considered this a ‘useful’ strategy (family members are readily available; act as advocates) they did not find it ‘acceptable’ as best practice and emphatically challenged any assumption that the strategy was ‘ok’ because they used it. On the contrary, many migrants were forced to choose this strategy, found it burdensome, suspected that family members...
could not have sufficient ‘emotional distance’ and worried about breaches of confidentiality.\textsuperscript{38} SUPERs presented the MSU view that all stakeholders should avoid this strategy wherever possible. In the final guideline, both strategies (‘use of child interpreters’ and ‘use of family members and friends as informal interpreters’) were rejected by consensus.\textsuperscript{38,39}

One year after the intensive research day, SUPERs returned to the university to facilitate workshops with MSUs – sharing and assessing the outcome of the PLA-brokered dialogue. The final content of the guideline was then agreed via consensus or democratic majority. This consolidated SUPERs’ central roles as peer researchers throughout the project and marked the closure of their research relationship with MSUs. Most importantly, SUPERs involvement to this ‘end-point’ of research activity was further evidence of their meaningful engagement throughout the entire research cycle.

The final experience of meaningful engagement by SUPERs occurred in the public sphere when several presented research results at local, national or international conferences. The following quotes provide a flavour of SUPERs’ reflections on meaningful engagement:

\begin{quote}
To explain why I am still involved in these research projects, I have to use the word ‘passion’. If you do not have passion for these things, it will die without bringing any results. The relationships between the academic and peer researchers are not just work relationships, we are also personally connected. This makes the group very close ... when you share an interest in something, you can discuss it, improve it, bring your ideas, you know, it was all generated together. SUPER #3 [CP]
\end{quote}

\begin{quote}
Migrants are rarely perceived as people who can contribute to society in terms of solving problems – they are often seen as groups that are a problem, and this makes it difficult to persuade them that their voices matter. So we had to build people’s confidence and reassure them that their experiences of language and cultural barriers in GP consultations were truly important and necessary to the research. We explained that they represented a critical stakeholder group and we needed them on board because their voices are so often missing in research about health policies, and health policies directly affect their lives. Most important of all, we developed strong trust relationships – this meant they could tell us the truth from their perspective and we would respect it. SUPER #5 [CP]
\end{quote}

\textbf{Meaningful engagement by MSUs in PLA research}

In terms of inclusion and involvement in research (key hallmarks of meaningful engagement) we first note that 51 MSUs remained involved and actively engaged throughout the intensive sequence of PLA techniques, seven hours, face-to-face in an unfamiliar environment. They produced sets of ranked strategies, including ‘ideal scenarios’ for effective cross-cultural communication. They actively participated in on-the-spot analysis and, finally, participated in evaluations to describe their experiences. Retention, therefore, is a result worthy of note.

Evaluation results are presented in Table 6 and illustrated in the quotes below.
As asked to rate how involved and included they felt, MSUs recorded very high levels, with almost ‘perfect’ scores (RS). Their qualitative comments (QC) in response to the question ‘What was it like to be invited to participate and ‘have your say’ with regard to the research topic focused on today?’ provided further evidence:

- *It was a positive experience which may help Irish people to realise migrants’ problems.* (Polish speaker)

- *It was great to share knowledge and express my opinion.* (Russian speaker)

- *I felt important and I hope that my opinion will count while introducing the changes.* (Polish speaker)

- *I feel honoured to participate.* (Portuguese speaker)

- *I have a place; I have been taken into account.* (French–Lingalan speaker, Congolese)

No negative comments were presented under these criteria.

We expected that working with language-concordant SUPERs and using PLA techniques might enable MSUs to confidently and competently bring their perspectives to the fore in the research, another key hallmark of meaningful engagement. This proved to be the case. Asked: *What was it like to work with your peer researcher through your own language today?* positive comments included the following:

- *It was excellent working in my mother tongue.* (French–Lingalan speaker, Congolese)

- *[The peer researcher] presented information and explained everything very well.* (Russian speaker)

- *It was confidential with someone like [the peer researcher] – there was freedom [to express one’s opinions].* (French–Lingalan speaker, Congolese)

- *Secure and confident. More power.* (Portuguese speaker)

No negative comments were presented under this criterion.

**Meaningful engagement by MSUs: reflections by SUPERs**

Evaluations with MSUs took place at the close of the intensive research day, and responses were brief. We sought further clarification and confirmation of evaluation results by drawing from SUPERs’ fieldwork debriefing interviews, where they observed and reflected on MSU participation in PLA. This confirmed that the hallmarks of *inclusion* and *active involvement* were present and evident:
People [MSUs] were showing an interest in it, in the beginning, when they saw the whole thing [PLA materials/charts etc.]. [They said] ‘Oh! This is very different – this is not questionnaires, you know, it’s a completely different experience.’ SUPER #8

Table 6  Meaningful engagement by MSUs

<table>
<thead>
<tr>
<th>Research activities by MSUs</th>
<th>Impact/effect on MSUs</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSUs attended and participated in intensive language-concordant, culture-congruent PLA research fieldwork with SUPERs: 1 session, 7 hours face-to-face</td>
<td>• MSUs were empowered as active participants in fieldwork; affirmed as ‘local experts’ whose opinions and experiential knowledge were essential to the study (RS) (QC) (Ph) (FDB) (CH)</td>
</tr>
<tr>
<td>MSUs engaged in, contributed to, and completed a complex sequence of mixed visual/verbal PLA techniques</td>
<td>• Visual/verbal PLA techniques ameliorated literacy challenges and enhanced inclusion of mixed-literacy-ability migrant groups in research processes; completion of complex charts generated satisfaction among MSU participants (CH) (QC) (FDB) (Ph)</td>
</tr>
<tr>
<td>MSUs produced a set of ranked communication strategies including ‘ideal scenarios’ for effective cross-cultural communication</td>
<td>• Sharing and enhancing knowledge allowed MSUs’ implicit knowledge to become explicit; ‘ideal scenarios’ included new strategies not currently in use ‘on the ground’; created energy and excitement during fieldwork (RS) (Ph) (CH) (FDB)</td>
</tr>
<tr>
<td>MSUs actively engaged in on-the-spot co-analysis of results that emerged from their charts and maps</td>
<td>• MSUs’ analytical insights about emerging results affirmed the centrality of their expertise to the broader research endeavour; demonstrated the value and necessity of their continued participation at this stage of the research cycle – they ‘saw’ what others might not; emphasised uniqueness of their perspectives (CH) (FDB)</td>
</tr>
<tr>
<td></td>
<td>• On-the-spot co-analysis by MSUs and SUPERs enhanced collegiality (FDB)</td>
</tr>
<tr>
<td>MSUs participated in post-research evaluation</td>
<td>• This inclusive collegial process signalled that migrants’ experiences of engaging in the research process were important to the community–university team (PE) (RS) (QC)</td>
</tr>
</tbody>
</table>

I was really surprised that the people [MSUs] were so willing to take part in it, and, particularly later on [during the day] they were so engaged in everything and they were so willing to do something … to create something, and really interested in the results. SUPER #5

The fact that they [MSUs] can be part of the research, they can be so motivated … you don’t know exactly what’s there, but by seeing the person in action, thinking and trying to participate, it’s really something striking, you know. They were motivated, empowered, you know, to all the process, the [research] study, so they were really committed. I think the process itself and the topic as well [influenced this] because they would like to make their concern heard by the authorities and by people. SUPER #7
SUPERs also commented on how MSUs’ perspectives emerged clearly in the research:

*Just to see the participants, you know, coming out with the new strategies ... they come out with brilliant ideas...that was really something to be taken into account, it was a surprise!*

SUPER #7

**Meaningful engagement by MSUs – having a ‘final say’**

As noted above, a majority of MSU’s returned to the university one year later to discuss and assess, with their language-concordant SUPERs, the outcome of the PLA-brokered dialogue. The final content of the guideline was agreed via consensus or democratic majority. MSUs reported that they were satisfied their perspectives had, in the main, ‘made it through’ into the guideline. This important opportunity to have a ‘final say’ reinforced their confidence in the PLA process: their perspectives had not been submerged beneath those of other stakeholders, but had emerged clearly in the research outcome: a number of communication strategies that were acceptable to all stakeholders for inclusion in the guideline, and a number of strategies that were rejected.

**Discussion**

**Summary of findings**

In this study, our use of a PLA approach and methodology enabled migrants (SUPERs and MSUs) to engage meaningfully and contribute with ease to rigorous primary healthcare research. Our key finding regarding *access* is that expanding the research team to include and train SUPERs in PLA made it possible to bridge the ‘access gap’ to involve MSUs in the study, generating a wider-than-expected sample. SUPERs’ diverse linguistic abilities and cultural backgrounds eliminated twin barriers of linguistic and cultural dissonance. Relationships of trust and rapport stood the test of time – the majority of MSUs returned one year post-fieldwork to finalise the draft guideline. In our view, such *safe* and *sustained access* emphasises that peer researchers are an essential ‘bridge’ capable of linking hard-to-reach populations with the academy in positive, productive community–university partnerships for primary healthcare research.

Our key finding regarding *meaningful engagement* is that a PLA methodology enabled meaningful engagement on the part of SUPERs and MSUs throughout a full and complex cycle of research activities. For SUPERs, this encompassed training and capacity-building in PLA, co-design of protocol documents, fieldwork, co-analysis and representation of MSUs’ results in the PLA-brokered dialogue with service-providers. We consider it a strength of the study that meaningful engagement by SUPERs extended (post-project) to dissemination of findings at national and international conferences.

For MSUs, meaningful engagement encompassed genuine active involvement in collegial and inclusive PLA research and co-analysis. We believe this made an important qualitative difference to the study outcome. Given that language is the primary vehicle we use to express nuanced perspectives, working with language-concordant SUPERs promoted confident interaction by MSUs. This successfully empowered MSUs to share their implicit knowledge and unique perspectives about current communication strategies, encouraged them to propose innovative new strategies and
enabled them to clarify what makes for best practice, all of which informed the development of a guideline for their care.

Methodological critique – positive aspects

A major strength of this study was its innovative application of a PLA research methodology, mode of engagement, and series of techniques - rare in the field of migrant health and in primary healthcare more broadly. PLA took us beyond tokenistic inclusion of MSUs and enabled them to make a valuable contribution to a primary healthcare research project. Using PLA also had impact well beyond the immediate aim of producing a guideline: SUPERs described feeling empowered in personal and professional spheres of their lives; MSUs noted that their involvement throughout the project broke through the isolation that many experienced on a daily basis in the host country. PLA, well facilitated, can have an integrating function that prompts broader social connections and enables empowerment in other social spheres.

Another key strength of this study was the commitment and motivation of the seven SUPERs. They were:

- Temperamentally suited to PLA training and mode of engagement – this enhanced rapport between SUPERs and MSUs, making PLA fieldwork effective and productive.
- Active in co-designing protocol documentation to guide fieldwork – this ensured consistent quality and rigour across MSU groups.
- Willing to use their ‘insider knowledge’ to benefit the project and their communities – this achieved safe access and retention of MSUs.
- Willing to represent MSUs’ perspectives during the PLA-brokered dialogue and in post-project dissemination.

The study was also strengthened by:

- Availability of professional PLA trainers in the research team.
- Adequate time and resources for training and capacity-building.
- Development of a strong community-university research partnership between SUPERs and university researchers.
- Commissioning and funding organisations who committed to a multi-perspectival PLA approach to primary healthcare research.

The absence of any one of these factors could present difficulties for other researchers wishing to initiate and sustain a PLA approach in primary healthcare research.
Methodological critique – challenging aspects

- Complex socio-political factors made MSUs wary of sharing personal information; this limited the amount of socio-demographic data we could gather.

- Striving for quality and rigour while facilitating a complex sequence of seven PLA techniques in one day was demanding. SUPERs described feelings of exhaustion at the close of the day (however, they also described feelings of excitement: witnessing the positive nature of MSU participation and personal experiences of achievement as researchers).

- Pacing PLA research is an ever-present challenge: some MSUs said they would have preferred more time to complete the PLA techniques.

- We would have preferred more time for evaluation with MSUs; the brevity of their end-of-day evaluations did not produce the kind of rich illustrative quotes found in interview studies. (However, this lack was offset by SUPERs’ evaluation and debriefing data which augmented MSU data).

Perhaps the most challenging issue is the significant investment of time and resources required for PLA research. In this paper, we have tried to indicate the scale of that work and the range of tasks involved. We believe it is warranted by the quality of the outcome and the instrumental, practical and ethical gains achieved: meaningful engagement that is compliant with ethical recommendations for working with hard-to-reach groups, increased capacity for future community-engaged research, and a multi-perspectival guideline. Investment of time and resources in capacity-building may be considered overly time-consuming by some, but this notion tends to come from the academic perspective. In contrast, community participants rarely say that their investment of time and resources as PLA peer researchers is an over-commitment. In contrast, they point to experiences of enhanced learning, and meaningful engagement in research orientated towards a shared healthcare goal as adequate ‘payback’ for their investment. Furthermore, PLA training is not limited to use in a single research project; once trained, peer researchers can apply PLA to any primary healthcare research topic. Ultimately, this builds the capacity of communities to engage in rigorous participatory research hand-in-hand with the academy.

Finally, we acknowledge that migrant populations are heterogeneous in nature. This poses limitations on any qualitative study on the subject. Geo-political trends and various ‘push-pull’ factors (e.g., war, economic opportunity) also mean that migrant demographics are constantly in flux. Therefore, we are careful not to claim representativeness for the study outcomes, which took place in a particular location and socio-cultural context at a particular moment in time, with a specific group of migrants. However, in common with all qualitative studies, we suggest that the outcomes are worthy of note as a ‘depth’ insight into the research topic, which may prove valuable to other migrant groups in other situations.
Findings discussed in relation to the literature: generating relevant primary healthcare research

Much primary healthcare research is currently initiated, designed and controlled by academic institutions with little or no input from hard-to-reach populations who are the intended beneficiaries. In the literature, there are many examples of guidelines designed to address language and cultural barriers between GPs and MSUs that were developed without migrant input. There are also examples of challenges, problems and risks associated with accessing and including a range of hard-to-reach groups in healthcare research. These challenges are not sufficient reason to exclude them; rather, they are an incentive to identify methodologies capable of enhancing access and promoting meaningful engagement in healthcare research that takes account of health, socio-economic and cultural conditions. In line with the literature, our study shows that including ‘the migrant perspective’ is possible, practical and feasible and that PLA is a ‘fit-for-purpose’ methodology that produced a relevant guideline for migrant care. We believe that using PLA to ensure meaningful engagement in the ‘bottom-up’ generation of health initiatives and interventions is warranted because of the quality, breadth and relevance of the research outcome.

Our study also shows that PLA, as a brokering tool, had a powerful impact in terms of balancing asymmetrical power-relations among stakeholder groups (service-users and service-providers) and this produced a guideline qualitatively different from what would have emerged without migrants’ perspectives. These findings are reported in full in a separate paper but, in our results section, we noted some concrete examples of ‘aha’ moments whereby stakeholders altered their perspectives as a result of learning from others. Such major shifts in perspective are not readily made, but this is where PLA comes into its own – managing divergent experiences and potentially divisive views. In the transparent, democratic, dialogic PLA environment, stakeholders may gain an entirely new perspective which prompts them to shift position from long-held patterns of belief or behaviour. In keeping with the literature, PLA cleared the way in this study for stakeholders to claim ownership of the resulting democratic outcome – a guideline oriented towards optimal health outcomes. The guideline also contributes to Irish healthcare policy. It clarifies, from a multi-stakeholder perspective, what constitutes ‘best-practice’ – solving the issue identified in the HSE’s National Intercultural Health Strategy. These are powerful arguments for using PLA in research designed to solve primary healthcare problems. However, further research is required to establish whether or not the inclusion of the migrant perspective in a guideline designed for migrants’ care actually strengthens it in practice.

Developing community-university partnerships to support primary healthcare research

If community–university research partnerships are to develop to support primary healthcare research in the future, this study could be considered instructive as a model and also because it represents a critical case. Our use of PLA successfully overcame documented problems and issues related to including hard-to-reach groups in research. If this can be done in the relatively challenging context and circumstances of our study, it must be possible elsewhere and in all kinds of less challenging contexts and circumstances. Our study presents a practical example of how community–university research teams, trained in the application of PLA, might go about generating research oriented towards better health outcomes for communities.
Conclusions

Given the need to build primary healthcare ‘from the ground up’, the perspectives of diverse groups, especially the hard-to-reach, must become a normative part of primary healthcare research. PLA is a powerful, practical ‘fit-for-purpose’ methodology for achieving this: enabling hard-to-reach groups to engage meaningfully and contribute with ease to academic research. PLA has significant potential, therefore, to become a ‘standard’ or generic approach in building community-based primary health care.

Community–university research partnerships have a significant role to play in this; they have the capacity to radically influence the shape of healthcare research and expand the research agenda to incorporate the views and needs of hard-to-reach and vulnerable populations.

Endnotes


References


57. Sussman AL, Rivera M. ‘Be Gentle and Be Sincere about It’: A Story about Community-Based Primary Care Research. Albuquerque: Department of Family and Community Medicine, University of New Mexico; 2008.
SUPERS project, Ireland, 2009-2011
Fifty-one migrant stakeholders celebrate the completion of their PLA research day; they have contributed unique insights to the SUPERS project. Following this, their views became part of a PLA dialogue with other key stakeholders (health service planners, interpreters, doctors, policy-makers and others) resulting eventually in a migrant-informed guideline to support communication in cross-cultural general practice consultations.

SUPERS' post-research reflection comments:
The stakeholders said the atmosphere in the group was so good that if there is any need for something like this in future... they are ready to do it, because they felt so listened to! They just want to do it again! I never saw something like this happening before, because normally [migrants] are not recognised as a community or a group of people - they are only recognised as something that is creating trouble, so seeing them coming out like this and talking openly... in my experience it’s a ‘once-off’ that such a variety of disadvantaged groups were included.

Our task was to be a bridge between our communities and the university. Some of the migrant service-users were hard to reach – people who were seeking protection or were undocumented, so they were very afraid to join in anything official. But because each SUPER shared the language and culture of their group, communication was straightforward and comfortable for the service-users.
Chapter 5

Involving migrants in the development of guidelines for communication in cross-cultural general practice consultations: a participatory learning and action research project

*BMJ Open 2015;5:e007092 doi:10.1136/bmjopen-2014-007092*

Mary O’Reilly-de Brún
Anne MacFarlane
Tomas de Brún
Ekaterina Okonkwo
Jean Samuel Bonsenge Bokanga
Maria Manuela De Almeida Silva
Florence Ogbebor
Aga Mierzejewska
Lovina Nnadi
Maria van den Muijsenerbergh
Evelyn van Weel-Baumgarten
Chris van Weel
Abstract

Objective
The aim of this research was to involve migrants and other key stakeholders in a participatory dialogue to develop a guideline for enhancing communication in cross-cultural general practice consultations. In this paper, we focus on findings about the use of formal versus informal interpreters because dialogues about these issues emerged as central to the identification of recommendations for best practice.

Design
This qualitative case study involved a Participatory Learning and Action (PLA) research methodology.

Participants
The sample comprised 80 stakeholders: 51 from migrant communities; 15 general practitioners (GPs) and general practice staff; 7 established migrants as peer researchers; 5 formal, trained interpreters; and 2 service planners from the national health authority.
Setting: Galway, Ireland.

Results
There was 100% consensus across stakeholder groups that while informal interpreters have uses for migrants and general practice staff, they are not considered acceptable as best practice. There was also 100% consensus that formal interpreters who are trained and working as per a professional code of practice are acceptable as best practice.

Conclusions
Policymakers and service planners need to work in partnership with service providers and migrants to progress the implementation of professional, trained interpreters as a routine way of working in general practice.

Strengths and limitations of this study

- There is a lack of dialogue between all relevant stakeholders about the relative merits of one type of interpreting over another for communication, for whom and under what conditions.

- This study fills a gap in the literature by describing a participatory dialogue between migrants and other key stakeholders, which was used to generate a guideline for best practice for all stakeholders.

- Findings clarify an important analytic distinction between the usefulness of informal interpreters and their acceptability as best practice, and the need to emphasise the value of trained and professional formal interpreters.

- Migrants and GPs in this study were generating data based on limited experience of formal interpreted consultations and expectations of interpreted consultations with trained professionals—further research is required to explore the evidence base about the impact of high-quality professional interpreting on communication processes and health outcomes for migrants.
Introduction

Migration is a global phenomenon and many healthcare systems across the developed world face the challenge of providing culturally competent care.\(^1^2\) Migrants entering a host country often experience language and cultural barriers when accessing healthcare services. There are formal responses to this communication challenge in practice, such as the use of paid interpreters who may or may not have professional training. There is also a range of informal responses in practice, such as the use of family members, friends, mimes or gestures.\(^3\) There are policy imperatives to promote the use of formal interpreters,\(^4\) and research evidence that the use of formal medical interpreting services is the most effective strategy for ensuring accurate information exchange in cross-cultural consultations\(^5\) and that this is a cost-effective strategy.\(^6\) However, in routine practice in primary care across healthcare jurisdictions the use of formal interpreters is ad hoc and often very low.\(^7^8\)

This translational gap is under-researched,\(^9\) but the available literature indicates that there are complex challenges related to using formal interpreters in the organisational setting and existing routines of general practice surgeries.\(^7\) From this literature we know that for general practitioners the using of informal interpreters is often a pragmatic response to these organisational challenges because they are present and ‘handy’. Furthermore, while informal interpreters are considered ‘second best’ from a policy perspective and within the professional interpreting community, some service-users prefer to use family members and friends as interpreters because, in their experience, formal interpreters may align themselves with general practitioners, thus obscuring elements of the patient’s narrative.\(^10\) Therefore, evidence about advantages of formal interpreters for accuracy in interpreting is offset by evidence about advantages of informal interpreters in terms of organisational and interactional gains.

Overall, it appears that there are advantages and disadvantages for different kinds of interpreting for different stakeholders, based on their perspectives: service-user, service provider, policymaker or interpreter. Therefore, it is important to understand more about these shared and differential perspectives in order to develop robust policy and guidelines for practice. However, to date, studies in this field have not explored formal and informal strategies vis-à-vis each other, and these have either generated data with one stakeholder group only\(^6\) or with a range of stakeholders separately.\(^10\) This means that there has been no scope for dialogue between stakeholders about the relative merits of one type of strategy over another, for whom and under what conditions.

The motivation for this research is to involve migrants and other key stakeholders in a participatory dialogue about the relative merits of one type of strategy over another to inform the development of a guideline for all stakeholders for enhancing communication in cross-cultural general practice consultations. Specific objectives were to:

- Document the range of formal and informal strategies currently in use in general practice consultations
- Determine the acceptability of different strategies across stakeholder groups
- Identify, if possible, a shared view about which strategies should be recommended as best practice.
In this paper, we briefly present results about all strategies documented, but focus in particular on findings about the use of formal versus informal interpreters since dialogues about these issues emerged as central to the identification of recommendations for best practice.

Methods

Design
The theoretical basis of this research followed the interpretive paradigm and the principles of case study design,11 and involved a Participatory Learning and Action (PLA) research methodology12 based on the work of Robert Chambers.13 PLA is an adaptive strategy that enables diverse groups and individuals to learn, work and act together in a cooperative manner to share, enhance and analyse their knowledge and to plan together for positive action.12,13 PLA has been used in primary care research internationally and encourages people to focus on issues that affect them, often enabling positive service-user involvement and empowerment.12,14

Study setting
Ireland has a short history of significant inward migration which started in the late 1990s (see Mac Einri15 for an overview of this trend). Latest census shows 12% of the population are born outside of Ireland. (See http://www.cso.ie/en/census/census2011reports/census2011profile6migrationand diversity-aprofileofdiversityinireland). The national health authority—the Health Service Executive (HSE)—published a National Intercultural Health Strategy in 2008 and identified information, language and communication as priority areas for attention. A specific objective was to explore existing formal and informal practices in order to inform the nature and design of a national interpreting service.

This research was designed in partnership with the HSE to progress this objective. The research was conducted in Galway in the west of Ireland between 2009 and 2011. This region had the highest proportion of migrants living in Ireland outside of Dublin, with communities of asylum seekers living in direct provision centres, economic migrants and undocumented migrants. Previous research in the region has shown that there are problems and frustrations for migrants and GPs regarding their consultations together, with a low uptake of formal interpreters and heavy reliance on family and friends as interpreters.3,14,16 There are commercial interpreting agencies in the region who provide basic training to recruited interpreters but, as is the case elsewhere in Ireland, they do not require interpreters to be professionally trained and accredited.16

Sampling and recruitment
The sample was drawn from five stakeholder groups:
1. Established migrant service-users with capacity to become involved as peer researchers;
2. Migrant service-users with limited English who have experience of accessing and using GP services;
3. GPs and practice staff who work with migrant service-users;
4. Formal trained interpreters;
5. Service planners, social inclusion office, HSE.
Involving migrants in the development of guidelines

For all stakeholder groups, we followed the principles of purposeful sampling using a combination of network and snowball sampling strategies. Sampling and recruitment were supported by existing links and key contacts among established migrants, formal trained interpreters, general practice staff and service planners with whom we had connections through previous research and development projects in this field. Sampling for all migrants and general practice stakeholders utilised networks in Galway city, and sampling for formal interpreters and service planners utilised networks in Dublin city.

A key point about sampling and recruitment of migrants is that we involved established migrants who had the capacity to become involved as peer researchers to work in partnership with the university team to eliminate language, literacy and cultural barriers in the entire research process. The peer researchers were trained in PLA and were known as the Service-User Peer Researchers—‘SUPERs’. Through their networks, they facilitated the involvement in the project of a wider group of migrants who spoke limited English, and who had experience of accessing and using GP services in the study region.

Data generation and analysis

There were three research phases and stakeholders were involved based on the focus of activities in each phase (see table 1).

Table 1 Overview of stakeholder groups’ activities per research phase

<table>
<thead>
<tr>
<th>Stakeholder group</th>
<th>Phase I activities</th>
<th>Phase II activities</th>
<th>Phase III activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUPERs: established migrant service-users</td>
<td>Developed trust and relationships with research team</td>
<td>Trained as peer researchers</td>
<td>Dialogue and analysis with representatives of other stakeholder groups about phase II data to identify best practice strategies for guideline</td>
</tr>
<tr>
<td></td>
<td>Generated perspectives on literature and policy</td>
<td>Facilitated fieldwork with wider group of hard-to-reach migrants to review phase I mapping to explore additional strategies, uses, problems and acceptability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mapped commonly used strategies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wider group of ‘hard-to-reach’ migrant services users with limited English and limited experience of accessing and using GP services</td>
<td></td>
<td>Worked with SUPERs to review phase I mapping to explore additional strategies, uses, problems and acceptability</td>
<td>Reviewed draft recommendations for best practice strategies for guideline from completed interstakeholder dialogue</td>
</tr>
<tr>
<td>General practice staff</td>
<td>Generated perspectives on literature and policy</td>
<td>Reviewed phase I mapping to explore additional strategies, uses, problems and acceptability</td>
<td>Dialogue and analysis with representatives of other stakeholder groups about phase II data to identify best practice strategies for guideline</td>
</tr>
<tr>
<td>Formal trained interpreters Service planners</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SUPERs, Service-User Peer Researchers.
Data were generated using PLA-style interviews (n=11) and PLA-style focus groups (n=25). This means that the encounter involved a PLA mode of engagement and the use of PLA techniques to encourage interactive data generation and co-analysis to enhance learning to inform research actions (see below). Interviews were only used when there was a single participant involved/available.

**Phase I**
The purpose of phase I was to set the foundation for meaningful involvement of established migrants in a 2-year research project. The university researchers conducted five PLA-style focus groups with the established migrants over 8 months to (1) develop trust and relationships, integral to PLA partnership,\(^\text{18}\) (2) open the dialogue about communication in cross-cultural general practice consultations by sharing and discussing summaries of key policy and research knowledge prepared by the university researchers and (3) map SUPERs’ knowledge of all formal and informal strategies currently in use in daily practice. To complete phase I, the university researchers engaged in ‘matched’ data-generation (PLA style interviews: n=4; PLA style focus groups: n=2) for literature-sharing and strategy-mapping activities with GPs, practice receptionist, service planners and formal trained interpreters eliciting their perspectives on communication in cross-cultural general practice consultations.

**Phase II**
The purpose of phase 2 was to extend the dialogue about commonly used strategies to a broader number of stakeholders and to work with stakeholder groups individually to:

- Review the strategies to identify those most specifically related to, and supportive of, cross-cultural general practice consultations, with a focus on the consultation encounter;

- Explore the perceived usefulness of, and problems associated with, strategies—using a PLA Flexible Brainstorming technique;

- Determine the ‘acceptability’ of strategies to select those to be considered for inclusion in a guideline of best practice—using a PLA Direct Ranking technique;

- Generate ‘ideal scenarios’ for cross-cultural consultations, identifying ‘new’ strategies with potential to improve current practice, also to be considered for inclusion in the guideline—using a PLA Visioning technique.

These PLA techniques are described in international literature about participatory research and are used in international research settings.\(^\text{13}\) In this study, each technique was used to generate, organise and display participants’ data, and accompanying individual or focus group interviews were used to explore, synthesise and co-analyse the data. Data were generated on extensive predesigned PLA charts following protocols that ensured that verbal and visual forms of data were recorded in a consistent manner across all stakeholder groups. All PLA charts were computerised after each data generation session in order to preserve the data. Verbal data were recorded on Post-It notes in point form or short phrases rather than in full verbatim quotes. We used researchers’ debriefing notes and meeting minutes to augment the data recorded on PLA charts after all data generation sessions. We had permission to audio record data generation sessions with most stakeholder groups throughout the research phases, but migrant participants in phase II elected not to be taped.
The seven SUPERs conducted fieldwork with an extended group of ‘hard to reach’ migrants, which meant that migrants who could not speak English fluently were included in language-concordant and culture-congruent data generation encounters. There were a total of six focus groups, as two SUPERs from the same community elected to work together. A key feature of the SUPERs’ training was to use PLA techniques to ‘hear’ the voices of the migrant stakeholders and not overpower or alter migrants’ perspectives. As before, the university researchers conducted ‘matched’ fieldwork with the other stakeholder groups. (PLA style interviews n=7; PLA style focus groups n=9)

Phase III
The purpose of phase III was to have a detailed inter-stakeholder participatory dialogue about the ‘best practice’ strategies selected by individual stakeholder groups in phase II and to develop, if possible, a shared view about which strategies should be recommended as best practice for the planned guideline. In phase III, the SUPERs represented themselves and the migrant service-user data in the dialogue with representatives of the general practice; professional trained interpreters and service planner groups who had participated in phase II.
This inter-stakeholder group participated in a series of inter-related, iterative, co-analysis PLA-style focus groups (n=6) to assess phase II data over approximately a 6-month period. We used a PLA Options Assessment technique\(^\text{19}\) to:

- Explore the full range of viable strategies that were deemed in phase II to have high acceptability
- Record key comments or queries about each strategy
- Record whether each member of the inter-stakeholder group considered each viable strategy should be included or not in the guideline
- Record overall levels of agreement about inclusion of each viable strategy in the planned guideline, for example, ‘undecided’, included/excluded by democratic majority, included/excluded by consensus.

Not all members of the inter-stakeholder group could attend all meetings. The computerised data displays created from our PLA Options Assessments enabled us to readily share information at subsequent face-to-face meetings or by email. The university researchers played a major role as ‘brokers’ during this process to maintain a strong feedback loop between all stakeholders.

All data generated from phases I, II and III were analysed following the principles of thematic analysis\(^\text{20}\) during these iterative cycles of data generation and co-analysis. In addition to co-analysis with the inter-stakeholder group, the university researchers had regular team meetings and data analysis clinics to discuss and debate emergent issues, and to synthesise key findings. Finally, the university team also had co-analysis meetings with SUPERs to ensure that the SUPERs, as co-researchers, were contributing to the final analysis (n=3 PLA-style focus groups).

Findings from our analysis are presented below with a selection of illustrative examples and participant codes. As data were generated in individual and group encounters, some of our participant codes in the results section refer to stakeholder groups and others to individuals.
Results

Table 2 provides an overview of our sample (n=80). The SUPERs, migrants and general practice staff were living in Galway city (n=73), and the formal trained interpreters and HSE service planners were Dublin-based (n=7). Many stakeholders participated more than once in the process, depending on their role in the research. The SUPERs had been living in Ireland for between 6 and 12 years.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Overview of sample per research phase</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SUPERs (N=7)</td>
</tr>
<tr>
<td>Phase I</td>
<td>7</td>
</tr>
<tr>
<td>Phase II</td>
<td>7</td>
</tr>
<tr>
<td>Phase III</td>
<td>7</td>
</tr>
</tbody>
</table>

HSE, Health Service Executive; SUPERs, Service-User Peer Researchers.

The profile of the SUPERs in table 3 was drawn from the biographical details provided, and a questionnaire SUPERs co-designed during the early stages of the project. Prior to their involvement in the project, all seven SUPERs had acted as informal interpreters or advocates for members of their communities. Concerned about such informal practice, they had completed the Northern Ireland Council for Ethnic Minorities (NICEM) interpreters’ training course and were interested in improving access to and uptake of formal interpreters in the Republic of Ireland.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Profile of SUPERs</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID code</td>
<td>Gender</td>
</tr>
<tr>
<td>#3</td>
<td>Female</td>
</tr>
<tr>
<td>#4</td>
<td>Female</td>
</tr>
<tr>
<td>#5</td>
<td>Female</td>
</tr>
<tr>
<td>#6</td>
<td>Male</td>
</tr>
<tr>
<td>#7</td>
<td>Male</td>
</tr>
<tr>
<td>#8</td>
<td>Female</td>
</tr>
<tr>
<td>#9</td>
<td>Female</td>
</tr>
</tbody>
</table>
In terms of the wider sample of migrants (n=51), we could not establish migrants’ age-range, gender distribution and other variables with accuracy. This was because many in the sample were in vulnerable circumstances, for example, living as asylum seekers or undocumented migrants and had reasons to be untrusting of ‘official’ forms and documentation. However, team observations and photographic evidence indicated that there was an evenly balanced male–female distribution and migrants ranged in age from early 20s to mid-60s. The breakdown of languages spoken was:

- Polish, n=8
- Russian, n=9
- Portuguese, n=9
- French Congolese, n=8
- Urdu, n=8
- Nigerian, n=9

The general practice sample (n=15) comprised Galway-based GPs and practice staff (six males, nine females) with experience of working with refugees, asylum seekers and economic migrants. The formal trained interpreters’ sample comprised of five females, some of whom were also involved in training and research. The service planners sample comprised two females with senior roles in the HSE Social Inclusion Unit, who had been involved in the development of the Intercultural Health Strategy and were committed to exploring options for interpreting services in Ireland.

**Strategies for supporting communication in cross-cultural consultations**

Phase I mapping activities produced a set of 27 strategies commonly used to support communication in cross-cultural general practice consultations (see table 4, column 2). During phase II activity, seven of these strategies were selected by stakeholder groups as potential ‘best practice’ material, to which six distinct strategies were added on to these from ‘ideal scenarios’ that stakeholders thought could improve current practice. During phase III inter-stakeholder dialogue, these 13 strategies were grouped into categories of ‘communication support’.

We identified five core categories of support into which 24 of the 27 strategies mapping in phase I fell: formal interpreting, bilingual practice staff interpreters, family and friends as interpreters, technologies and visual aids (e.g., Google online translation; multilingual posters of body parts), and body language and gestures (see table 4, column 1). These 13 potential ‘best practice’ strategies (see table 4, column 3) became the focus of inter-stakeholder dialogue in phase III, and a total of four strategies were ultimately included in the guideline as best practice. Of these, three fell into the category ‘formal interpreting’ (see table 4, column 4).

---

*a The remaining four strategies which fell outside the core categories were carried on into the SH dialogue, and were dealt with there; for example, SHs agreed that some should be combined or subsumed into core categories, or belonged in special boxes in the guideline text.*
Table 4  Categories of support for communication in cross-cultural consultations per research phase

<table>
<thead>
<tr>
<th>Category of support</th>
<th>Strategies mapped in phase I (n=27)</th>
<th>Relevant to core categories (n=23)</th>
<th>Top-ranked strategies (from phase I) plus ‘new’ additions (from phase II) identified for consideration as ‘best practice’ (n=13)</th>
<th>Strategies identified as best practice in phase III (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal interpreting</td>
<td>3</td>
<td></td>
<td>3+2 new</td>
<td>3</td>
</tr>
<tr>
<td>Bilingual practice staff as interpreters</td>
<td>2</td>
<td></td>
<td>2+2 new</td>
<td>1</td>
</tr>
<tr>
<td>Family and friends as interpreters</td>
<td>4</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Technologies and visual aids</td>
<td>11</td>
<td></td>
<td>1+2 new</td>
<td>0</td>
</tr>
<tr>
<td>Body language and gestures</td>
<td>3</td>
<td></td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

In the next section, we elaborate on findings about the use of formal versus informal interpreters because, as previously mentioned, dialogues about interpreting issues were central to the identification of recommendations for best practice. For a summary of findings about the use of body language and gestures, and technology and other visual aids see boxes 1 and 2, respectively.

Box 1  Examples of problems with body language and gestures

- Body language is an everyday communication tool the GP may use to signal friendliness/ comfort to a service-user (GP#10, PS#12, GP#13, GP#11, Nigerian migrants, PS#14) but is unreliable as a diagnostic support (Polish migrants; GP#10, GP#13, GP#11, Russian migrants, PS#12, PS#14, Urdu-speaking migrants)

- Different cultural backgrounds can lead to misunderstanding of body language (GP#10, GP#13, PS#14, Polish migrants)

- Imprecise, incomplete form of communication (GP#11, Polish migrants, PS#12, PS#14, formal interpreters)—very difficult to explain how to take medication using body language/ gesture (PS#12)

- Stressful for all involved (Polish migrants, PS#12, PS#14)

- Frustrating/unhelpful for GP who wants service-user to get the best help possible (GP#11, GP#13—DR; PS#12)
Involving migrants in the development of guidelines

Box 2  Examples of problems with technological and visual aids

- When desperate people are under stress, it may be helpful, but a computer programme is a tool, not an ideal for best practice (SUPERS, GP#11)
- Computer programs are cold, interruptive of the intimacy of the consultation, and can be intimidating (SUPERs)
- Computer programs are open to misinterpretation (Russian migrants)
- Visual aids are perhaps useful as a basic explanatory tool or as a complementary tool alongside the use of a professional interpreter, but not best practice (service planners, GP#13, Interpreters, Portuguese migrants)
- Bilingual or multilingual materials cannot cope with psychological/mental health/social health issues (GP#11)
- Bilingual or multilingual materials are not three-dimensional, so have limited use (GP#10, service planners, Polish migrants)
- Service-user’s language may not be included in the material being used (Nigerian migrants)

Analysing usefulness and acceptability of formal and informal interpreting

Three formal interpreting strategies were identified. Two were in use—formal telephone interpreting; on-site formal face-to-face interpreting. One was considered as a potential ideal scenario—‘migrant service-user arranges formal interpreter to accompany her/him to general practice’.

Stakeholders from all groups were very vocal about the uses of formal interpreters. They discussed clinical benefits arising from the competent, effective, accurate, confidential, ethical, neutral and sensitive transmission of messages by a trained interpreter in the consultation (eg, phase II: interpreters, Polish-speaking migrants, SUPERs, Portuguese-speaking migrants, GP#11, PS#12, service planners).

Stakeholders discussed interactional benefits for the service-user–GP relationship, that is, the use of a formal interpreter promoted greater trust and satisfaction. The scope for the longer term development of trusting relationships between interpreters and GPs was also mentioned, particularly when there were opportunities to work with each other regularly (phase II: GP#10, PS#12, PS#14, Urdu-speaking migrants, Portuguese-speaking migrants, service planners and interpreters).

In terms of organisational benefits, stakeholders considered that using formal interpreters could save time and money (phase II: Polish and Portuguese-speaking migrants, interpreters). In particular, stakeholders considered that telephone interpreting provided fast access to interpreting for both the GP and the service user (phase II: Russian-speaking migrants, interpreters; phase III: inter-stakeholder working group).
Stakeholders did record problems with the use of formal interpreters; for example, the Polish-speaking migrants (phase II) recorded that there can be a lack of intimacy because of having a third person in the consulting room and that they can feel discomfort if the interpreter is of a different sex. GPs remarked that a third party intrudes on the usual doctor–patient dynamic (GP#10). Interpreters who do not follow professional codes of ethics can have prejudices that impact negatively on the consultation (phase II: formal interpreters). Finally, the practicalities of arranging for service user, interpreter and GP to meet at the same time in the one location are challenging (phase II: formal interpreters, GP#11).

However, on balance, stakeholders were more favourable than critical about this strategy. This became very apparent during phase II Direct Ranking activity, in which each individual stakeholder group ranked all strategies about formal interpreting very highly and deemed these to have high acceptability as best practice (see table 4, column 3).

Four informal interpreting strategies were identified: service-user using a child, adult family member or friend as interpreter in face-to-face consultations and service-user arranging to have own informal interpreter available over a mobile phone.

All stakeholder groups, apart from the formal, trained interpreters, considered that informal interpreters had certain uses. For example, they were considered ‘handy’ because they lived nearby (phase II: Urdu-speaking group) and could provide a measure of enhanced understanding in consultations (phase II: Russian-speaking group, Portuguese-speaking group, GP#10, GP#11); and as a service-user’s trusted choice, they provided support in the GP–service-user relationship dynamics (GP#13 and PS#12). Also, it was sometimes comforting and supportive to have a family member or friend interpreting and acting as an advocate and mentor, knowledgeable about both native and host cultures (phase II: French-Congolese-speaking migrants; Urdu-speaking migrants, service planners, GP#10, PS#12).

However, all stakeholder groups agreed that there are serious problems with informal interpreters. They discussed the intertwined problems of lack of training and lack of competency (phase II: service planners, Urdu-speaking migrants, PS#12). Family or friends who act as interpreters do not necessarily have fluency in English (PS#12, PS#14), and cannot always be available for GP appointments because of their own family or work commitments (phase II: Urdu-speaking group). Migrants also presented a counterpoint to ‘comfort and advocacy’, suggesting that this could lead to a lack of privacy for the presenting patient (phase II: French-Congolese-speaking migrants, Russian-speaking migrants, Portuguese-speaking migrants); concerns were also raised about informal interpreters pushing their own agendas (GP#10, GP#13) and abusive spouses accompanying service-users to act as informal interpreters (GP#13, service planners, PS#14).

All stakeholders had additional and strong views about problems associated with using children as interpreters (see box 3).
Box 3 Examples of problems with using children as interpreters

- A child is not a professional interpreter and is unlikely to have a medical vocabulary (Polish-speaking, Russian-speaking and Urdu-speaking migrants)
- A child may have limited English; important information could be missed (GP#11, PS#12, Nigerian migrants)
- A child may not be available (during school hours) or may be missing out on schooling (Russian migrants, service planners, Urdu-speaking migrants)
- The authority of parents may be compromised by a reliance on their child to interpret (GP#11)
- A child may be traumatised (Russian migrants), embarrassed, frightened or confused; does not have sufficient ‘emotional distance’ (Congolese and Portuguese migrants, GP#11)
- There may be fear or shame on the part of the parent and/or child—both may be embarrassed (Polish migrants, GP#10, GP#13)

The impact of missing school in order to interpret, potential for trauma and embarrassment, for example, were considered highly problematic. When ranking these strategies in terms of acceptability, the consensus across stakeholder groups was that their acceptability as best practice was low (see table 4, column 4 and table 5, column 4).

<table>
<thead>
<tr>
<th>Type of interpreting</th>
<th>Strategies identified during mapping: phase I and phase II</th>
<th>Data on usefulness from direct ranking: phase II</th>
<th>Acceptability rating from direct ranking: phase II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal interpreting</td>
<td>Formal telephone interpreting</td>
<td>Yes</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>On-site formal face-to-face interpreting</td>
<td>Yes</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>Service-user arranges formal face-to-face interpreter to accompany her/him to GP surgery</td>
<td>Yes</td>
<td>High</td>
</tr>
<tr>
<td>Family and friends as interpreters</td>
<td>Service-user uses child as face-to-face interpreter</td>
<td>Yes</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Service-user uses adult family member as face-to-face interpreter</td>
<td>Yes</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Service-user uses a friend as face-to-face interpreter</td>
<td>Yes</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Service user arranges to have own ‘informal’ interpreter on mobile phone</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5 Overview of findings about interpreting phase I and phase II

Inter-stakeholder dialogue to identify strategies for inclusion in the guideline

At the start of phase III, the inter-stakeholder group reviewed phase II data about informal interpreters. They endorsed the findings, and none of the four strategies about informal interpreting were included as best practice in the guideline. Focusing on findings from Phase II about formal
interpreting, there was 100% consensus among the inter-stakeholder group that the use of formal interpreting should be included in the guideline as best practice. However, there were long deliberations about how these data should be presented in the guideline with attention focused on emphasising the importance of training for interpreters, specific conditions that are required for high-quality professionalism among formal interpreters and implementation challenges.

Through this dialogue, stakeholders with experience of training interpreters shared their expertise with other stakeholders, focusing on specific recommendations which related to the requirements for high-quality formal, trained, professional interpreting (see box 4).

From this dialogue, all stakeholders agreed that formal, trained professional, face-to-face and telephone interpreting should be included in the planned guideline, and that details about the context and specificity of their use should also be included. The ideal scenario strategy—‘service-user arranges own formal face-to-face interpreter’—was discussed at great length, with consideration given to the potential empowerment of service users by organising their own interpreter versus the burden it might place on them and the levels of health literacy required to do so.

Overall, stakeholders concluded that a better supply of high-quality trained interpreters would need to be available in the system before this strategy could be effectively progressed. Therefore, at the end of their dialogue, the stakeholders agreed not to include this as a form of best practice at this time. Therefore, only two ‘best practice’ strategies from this category were included in the guideline (table 4, column 4).

Finally, strategies about the use of bilingual practice staff were all ruled out apart from the idea of service-users consulting with a GP who was completely bilingual and able to converse fluently in a medical consultation in the same language as the service user. At the end of phase III, over two-thirds of the migrants who had participated in phase II returned to the university to view a draft guideline. Working in small groups with their language-concordant SUPER, they assessed information about the phase III dialogue, with a focus on key deliberations, learnings and decisions. The proposed draft guideline was endorsed by all and the content was subsequently considered final.

<table>
<thead>
<tr>
<th>Box 4</th>
<th>Key recommendations from experts in training of interpreters and professionalising interpreting practice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professionalising interpreting</strong></td>
<td></td>
</tr>
<tr>
<td>• Interpreters should be formal, trained, qualified, accredited professionals, ideally well versed in medical interpreting</td>
<td></td>
</tr>
<tr>
<td>• Interpreter is ethically responsible and abides by a recognised relevant Code of Ethics</td>
<td></td>
</tr>
<tr>
<td>• Interpreter ought to possess necessary skills to coordinate the interaction (whether face-to-face or by telephone)</td>
<td></td>
</tr>
<tr>
<td>• Interpreter ought to be monitored for professional conduct and best practice</td>
<td></td>
</tr>
<tr>
<td>• Every consultation should be regarded as a potentially serious medical condition as the nature of the medical condition or seriousness of the condition cannot and should not be established by the GP or anyone else a priori</td>
<td></td>
</tr>
</tbody>
</table>
Discussion

Summary of findings

Migrants and other key stakeholders agreed that a combination of strategies was highly acceptable for inclusion as best practice in a national guideline on communication in cross-cultural consultations. The common feature among these strategies was that these related to the use of formal, trained professionals: professional interpreters for telephone and face-to-face interpreting, and bilingual GPs who are completely fluent in the language of the service-user with whom they are consulting. Strategies with low acceptability across stakeholder groups, which were not included in the guideline, related to the use of family members and friends as interpreters and other informal strategies such as the use of dictionaries or technological and visual aids. These findings are based on democratic PLA dialogues within and across stakeholder groups and reveal important differences between the usefulness and acceptability of strategies in practice. The consensus across stakeholder groups, after their dialogues, was striking.

Methodological critique

The use of a PLA methodology and a series of interactive data generation techniques are novel in the field of academic primary care. This is a major strength in this research and is in accordance with ethical guidance for research with black and minority ethnic (BME) communities. The use of PLA techniques had a consistent and positive impact on the dynamics during data generation, particularly during PLA-style focus group interviews as participants were comfortable, and engaged with each other and the researchers. The research was led by experienced PLA researchers and included significant capacity-building for established migrant participants, that is, training of SUPERs to act as peer researchers and productive efforts to meaningfully engage a relevant sample of hard-to-reach migrants and other stakeholders.

In terms of representativeness, and following qualitative understandings of representation, we consider that, overall, this was a sample with a range of socio-demographic backgrounds and a valuable range of diversity in terms of stakeholders’ expertise about the issue under investigation. For example, the sample of migrants comprised those who were well established in Ireland with considerable security (ie, the seven SUPERs) and others who had newly-arrived and were living in vulnerable circumstances, for example, in direct provision centres or as undocumented migrants (ie, the wider group of 51 migrants). Also, there was a range of English language abilities and of people who had experience of using informal and formal interpreters, and of acting as informal and formal interpreters. The GP community was represented by staff from different practices with a relatively high volume of migrants and who were, most typically, using informal interpreters in their daily practice. The health service planners had responsibility for developing HSE systems to improve communication with an open mind about what that system should be.

We acknowledge that the SUPERs had a strong commitment to developing formal interpreting services in Ireland. We have to consider whether this had an undue influence on phase II data generation. However, it is important to reiterate that their training was to use PLA techniques to ‘hear’ the voices of the migrant SHs and not to overpower or alter migrants’ perspectives. Furthermore, key decisions about the low acceptability of informal interpreters were made by
stakeholders from the wider migrant population and general practice settings and the HSE, working separately in their individual groups during phase II.

Certainly the interest of SUPERs and formal trained interpreters in formal interpreting would have influenced the inter-stakeholder PLA dialogue about strategies for inclusion in the guideline in phase III. However, this was precisely the point of the PLA dialogue: for stakeholders to share and learn from each other’s perspectives and work together to see if it were possible to develop shared views about best practice. After hearing each other’s perspectives, each member of the inter-stakeholder group had the chance to express an individual opinion as to whether a strategy should be included or not. This was the reason for recording whether final decisions about the content of the guideline during phase III were arrived at by minority, majority or consensus view.

Overall, while dialogue cannot in and of itself change the status quo in practice, the PLA dialogue was an important advance in this process of guideline development. We noted several ‘Aha moments’ during which stakeholders noted and acknowledged the ways in which they had gained enhanced learning by listening to each other’s perspectives; this led stakeholders to ‘shift position’ and alter their original perspectives. PLA is a resource-intensive process and requires both meticulous planning to ensure quality and responsiveness to the organic and iterative research process. In this project, it was particularly intensive to design effective training and capacity-building for the established migrants to work as peer researchers in their own communities. However, this is equally the strength of the research because the PLA approach enhanced recruitment of hard-to-reach migrants and eliminated language and cultural barriers from the fieldwork, which enabled meaningful participation. Therefore, the investment of resources had instrumental, practical and ethical gains.

The resultant data fill a gap in the literature by providing a democratically developed guideline for best practice that is based on a composite of learning experiences across a robust sample without comprising the individual ‘voice’ of any one stakeholder group. Guidelines arrived at in this participatory way are rare and increase the implementability of guidelines into practice.23,24

Findings discussed in relation to the literature

The findings from this study provide significant details about a wide range of strategies commonly used to manage communication in cross-cultural general practice consultations, confirming previous analysis about this translational gap25 and adding more detail about the variety of informal interpreting strategies. These findings support previous research about problems with informal interpreting, including the issue of error,5 and the complex social difficulties that can arise from informal interpreting arrangements such as the specific problems of using children26 and the burden of work on migrants to find informal interpreters whom they know and trust.14

Findings from this study also support previous research which indicates that service-users sometimes benefit from having a family member or friend present as an interpreter during a cross-cultural consultation.10,27 Also, there is an argument for case-by-case analysis of what is ‘good’ for each individual consultation so that preferences for using family members or friends can be taken into account.27 However, we argue that the analytic emphasis in this research is on acceptability rather than usefulness, and the use of a participatory dialogue to exchange perspectives across stakeholder groups is key to this research. This stimulated thoughtful discussion and debate during phase III
Involving migrants in the development of guidelines

about whether it was appropriate to put strategies involving informal interpreters into a national guideline for best practice. Thus, while stakeholders in phase II acknowledged when and why other strategies may be employed, and understood the very complex organisational challenges involved in implementing the use of formal interpreters in routine practice, the result of their dialogue was a clear consensus that informal interpreting should not be promoted as best practice for the guideline under development.

In acknowledgement of these complexities, we propose two specific areas for further research. First, a comprehensive analysis of the implementation of formal interpreting in general practice and primary care settings. Participants in this study emphasised that issues of training interpreters, monitoring professional practice, financial compensation for interpreters and the challenges of organising bookings for interpreted consultations may act as levers or barriers to implementation of existing guidelines. Other research highlights that the match between service-users and interpreters in terms of origin, religion, dialect, gender and political views will affect the implementation and that the dynamics of trust in cross-cultural consultations need careful consideration. However, apart from some exceptions, there is a lack of research in this area and this should be addressed. Second, it would be valuable to conduct further research to explore the dynamics of a four-way consultation in which a service user’s family member is present for emotional support and whether/how it impacts on the quality of the formal interpreter’s role.

Finally, it is important to note that participants in Greenhalgh et al’s study had direct experience of both kinds of interpreting and from this, they reported problems with formal interpreters. In contrast, migrants and GPs in this study were generating data based on limited experience of formal interpreted consultations and expectations of interpreted consultations with trained professionals. However, some of the problems noted in Greenhalgh et al’s work are, from some stakeholders’ perspectives, poor professional practice. It is not wise to undermine the value of formal interpreting on the basis of (perceived) poor practice. Like Greenhalgh et al, we argue that it is important to clarify the appropriate working role of interpreters and to concentrate on improving training, monitoring and evaluation so that all stakeholders are experiencing quality formal interpreting. We would not, for example, question the value of practice nurses or GPs as a healthcare provider because of poor practice, but would work to support best practice through nursing and medical organisations. We need to research a cohort of migrants, GPs and professional trained interpreters who are working to the highest professional standards to add to the evidence base about the impact of professional interpreting on communication processes and health outcomes for migrants.

Conclusion

In keeping with previous research, these findings from a participatory and inter-stakeholder research project indicate that family and friends are used as informal interpreters in general practice, and that they are sometimes useful in that role. However, we conclude that they are not acceptable as best practice. Policymakers and service planners need to work in partnership with service providers and migrants to progress the implementation of professional, trained interpreters as a routine way of working in general practice.
References

'SUPERs' (Service-User PEer researcheRS) project, Ireland, 2009-2011.
This innovative project produced a guideline designed by, with and for migrants and service-providers. Established migrants were trained in PLA techniques and acted as peer-to-peer researchers. Because they spoke the languages and understood the cultures of their own migrant communities, they were able to ‘reach’ migrants who would ordinarily be excluded from research. This had a significant impact on the outcome of the guideline.

But what motivated the peer researchers to get involved in the project?
They created PLA Timelines to describe their motivations, personal and professional, based on this question:
‘What seven key events have brought me to this room, on this night, to participate in this research project?’

‘A friend of mine died, he suffered... he was Polish and because his level of English wasn’t great, I was involved. It was quite (sigh)...quite a difficult time. The captions I chose – ‘the road hard travelled’ and ‘spiritual journey’, ‘transition’ and ‘shedding light on the dark’ describe this period and certain things then became more official. I got involved in different organisations and projects and I started helping migrants to adjust to a new culture and a new language.’
Aga Mierzejewska

‘To explain why I am here, involved in these research projects, I have to use the word ‘passion’. If you do not have passion for these things, it will die without bringing any results.’
Katya Okonkwo

This is an opportunity given to us, Congolese community and French speaking communities, to have a say in this particular issue and frame a system in which both service providers and service users would benefit! This project is vital for us and for this reason I am here tonight! Enthusiasm, challenge and high expectation is what I am feeling right now! Here I am! And let the project start!
Jean-Samuel Bonsenge-Bokanga
Chapter 6

Guideline for Communication in Cross-Cultural General Practice Consultations

Developed using a Participatory Research Approach

This project is funded by the Health Research Board and the HSE National Social Inclusion Unit through a Health Research Board Partnership Award 2009-2011

Dr. Anne MacFarlane
Ms. Mary O’Reilly-de Brún
Ms. Diane Nurse
Foreword

This research is a direct and practical response to the ongoing and distressful reality in Ireland that, on a daily basis, many service users from migrant communities and their general practitioners (GPs) face significant communication challenges in their consultations together because of language and cultural differences.

The HSE National Intercultural Health Strategy 2007-2012, developed by the HSE National Social Inclusion Unit, acknowledges the need for supports for cross-cultural communication in healthcare settings including general practice. The Strategy recommends a multi-stakeholder approach to explore the issue further, and specifically to clarify what kind of supports work best, for whom, and in what circumstances.

To progress this recommendation, and to inform best practice, the HSE National Social Inclusion Unit has worked in partnership with the Discipline of General Practice, NUI Galway and the Centre for Participatory Strategies, Galway. Funded by the Health Research Board Partnership Award, we have conducted research for this Guideline that has created opportunities for:

- Migrants to have a genuine ‘voice’ in determining what is best practice for supporting communication in cross-cultural general practice consultations in the Republic of Ireland.

- A dialogue between migrants and other key stakeholder groups about their shared and differential perspectives about best practice so that the content of the Guideline has relevance and resonance across stakeholder groups, which may act as a lever to its implementation.

The development of this Guideline is the result of an innovative, extensive and rigorous research process using Participatory Learning and Action (PLA) research methods which, we believe, renders it faithful to a diverse range of voices in our society, and we are pleased to recommend it to you.

We are committed to widespread dissemination of the Guideline. It has already been presented to representatives of migrant communities, academics, and practising GPs and interpreters, and further dissemination events with these and other audiences are planned. We are committed to investigating and supporting the implementation of this Guideline in general practice settings in order that best practice becomes routine and ‘the norm’ for service users from migrant communities and their GPs. A recent EU FP7 funding award has provided us with resources for a four-year project (2011-2015) to work with international colleagues on the implementation of guidelines like this (see www.fp7restore.eu). For effective implementation, inter-disciplinary and inter-agency dialogue and working are required and we welcome initiatives from all sectors that will support the implementation of this specific Guideline.
Development of a guideline for communication in cross-cultural general practice consultations

In 2009, the Discipline of General Practice at NUI Galway, in collaboration with the Centre for Participatory Strategies, Galway and the HSE National Social Inclusion Unit, began a participatory research project to involve migrants and other key stakeholders in the development of a Guideline for communication in cross-cultural general practice consultations. This project was funded by the Health Research Board and the HSE National Social Inclusion Unit through a Health Research Board (HRB) Partnership Award.

The development of the Guideline is a direct and practical response to the reality that service users with limited English and their GPs face significant challenges on a daily basis in their consultations together because they do not have a shared language or cultural background. This frequently results in misunderstandings and communication breakdowns, which are distressing and unsatisfactory for all involved. The National Intercultural Health Strategy 2007-2012 recognises these challenges and recommends research to clarify what supports and models of service provision are required in the Irish context.

The Guideline research was conducted in the Discipline of General Practice, NUI Galway and was led by Dr. Anne MacFarlane, Lecturer in Primary Care, with Mary O’Reilly-de Brún as the project’s Senior Researcher. Together they worked with the Steering Group that included representatives from migrant communities in the Galway region and a range of relevant organisations and agencies - the Centre for Participatory Strategies, Galway, the HSE Social Inclusion Division, and representatives of the interpreting profession in Ireland.

One of the key innovative elements of this project was that it was based on a university-community partnership: seven representatives of migrant communities in the Galway region trained as peer researchers and formed a research team with the NUI Galway researchers. The Service User Peer Researchers (SUPeRs) were Khalid Ahmed, Jean Samuel Bonsenge Bokanga, Maria Manuela De Almeida Silva, Aga Mierzejewska, Lovina Nnadi, Florence Ogbebor and Katya Okonkwo.

Mary O’Reilly-de Brún, in her capacity as co-founder of the Centre for Participatory Strategies, with co-founder Tomas de Brún, provided the Participatory Learning and Action (PLA) training to the SUPeRs. This training enabled the SUPeRs to invite participants from their wider communities to ‘have a voice’ throughout the research process, to engage in research confidently and comfortably in their own languages and culture groups, ensuring that their perspectives were included in the development of the Guideline.

Aim

The aim of this project was to inform implementation of the National Intercultural Health Strategy 2007-2012 by involving service users and other key stakeholders in the development of a guideline for enhancing communication in cross-cultural general practice consultations.
Specific objectives were to:

- Map the range of strategies currently used ‘on the ground’ to manage language and culture gaps.
- Invite stakeholders to envision potential ideal strategies that might go ‘beyond the map’.
- Determine how acceptable strategies are across stakeholder groups.
- Identify strategies appropriate for inclusion in the Guideline.

The key stakeholder groups were:

- Service users from the migrant community.
- GPs and practice staff.
- Professional, trained interpreters.
- HSE social inclusion planners.

As the diagram indicates, the project was designed to enable knowledge (data) to be generated in research encounters with stakeholder groups working separately, but also working together. Some stakeholders were able to meet face to face ‘at the stakeholder table’ to share insights from their perspectives, and to discuss their experiences and views. Some stakeholders learned about each others’ experiences and views through the university researchers who acted as ‘brokers’ – bringing PLA charts, diagrams, maps and data displays to stakeholder groups to facilitate learning across the groups about communication in cross-cultural general practice consultations.

Figure 1 Overview of Stakeholder Groups involved in the Development of this Guideline
Methodology

In order to ensure that members of migrant communities and other key stakeholder groups would be included in the development of the Guideline, we used a participatory research approach - Participatory Learning and Action (PLA). This is about doing research with, not on, people and is best described as a growing family of approaches and methods that enable service users to share, enhance and analyse their knowledge of life and conditions in order to plan collaboratively for positive action.

PLA places high value on building relationships of trust and a key feature of PLA is the recognition that building trust is a necessary condition for creating ‘safe spaces’ that enable stakeholders, particularly those from marginalised communities, to be involved in research or development projects and to speak confidently from their perspectives. PLA includes a wide range of data generation tools and techniques, including many visual techniques that make PLA accessible to literate and mixed-literacy-ability groups. For these reasons, PLA was a very appropriate methodology for this project, which involved a mixed-literacy-ability group of people living in Ireland as refugees, people seeking protection, migrant workers and undocumented migrants.

This large PLA project involved several iterative cycles of data generation and analysis across stakeholder groups.

Figure 1 shows the number of participants involved (51 migrant community service user participants and 22 service provider participants). It is important to highlight that many stakeholders participated more than once in the process, making the overall number of data generation encounters considerably higher than the actual numbers showing.

Each participating group was ‘information rich’ in its own terms, bringing relevant expertise and experience to the stakeholder table, which is central to a PLA process.

Our project had a series of inter-related activities that took place in three phases over a two-year period:

Phase I: Sharing insights from the academic literature
We shared relevant findings from national and international academic literature about communication in cross-cultural general practice consultations with our key stakeholder groups - the SUPeRs (representing migrant communities), interpreters, general practice staff (GPs and practice managers), and social inclusion service planners from the Health Service Executive.

Phase II: Fieldwork with stakeholder groups
Peer researchers (the SUPeRs) engaged in fieldwork with migrant participants from Polish, Russian, Portuguese, Urdu, Nigerian and French-Lingala-speaking Congolese communities in the Galway region. Using a consistent PLA approach and techniques, university researchers engaged in similar fieldwork with general practice staff in the Galway region, and interpreters and social inclusion service planners.

---

*a* We use this term instead of ‘asylum seeker’ to emphasise the fact that it is, in fact, protection that people are seeking.
service planners from the Health Service Executive based in Dublin. Our focus was on strategies for supporting communication in cross-cultural general practice consultations. We used PLA techniques to:

- **Map** clear details of all strategies currently in use ‘on the ground’.

- **Explore** and analyse strategies in terms of
  - Usefulness
  - Problems.

- Generate additional **Ideal Scenarios** that are not currently in use ‘on the ground’ to create a ‘vision’ for best practice.

- **Rank** all of these strategies in terms of overall acceptability

### Phase III: Co-analysis and dialogue

We used a PLA democratic dialogic process throughout the co-analysis phase to determine the strategies for inclusion in the Guideline. Representatives from all stakeholder groups worked alongside university and peer researchers using an Options Assessment process to examine charts, diagrams, data displays and visual material. In this way, they discussed and co-analysed the knowledge generated during the fieldwork phase. This extensive dialogue within and across stakeholder groups is typical of PLA, because the aim is to reach democratic (majority) agreement; in rare cases consensus may even emerge following careful co-analysis. Our dialogue allowed us to clarify which strategies were:

- **Acceptable** for recommendation as best practice in the Guideline.

- **Unacceptable** as best practice and should be discontinued in the future.

The outcome was very positive. Stakeholders arrived at a consensus view on the vast majority of strategies for recommendation as best practice (or not) in this Guideline, and achieved a democratic majority on the inclusion or otherwise of the remaining strategies.

The result is a ‘menu of options’ that all key stakeholders believe will support cross-cultural communication. We acknowledge that each specific communication encounter is, in itself, unique – it is context-specific and complex. Therefore each strategy described below, and what it offers, needs to be considered in light of the specific needs of any individual consultation.

*Remember - it is not a simple case of ‘one size fits all’ or ‘one strategy works for all consultations.’*
Findings

‘Ideal’ strategies with high acceptability included as best practice in this Guideline pertain to the use of formal, trained professionals:

• Interpreters for telephone and face-to-face interpreting.

• Bilingual GPs who are completely fluent in the language of the service user with whom they are consulting.

Strategies with low acceptability across stakeholder groups that do not constitute best practice and are not included in this Guideline relate to the use of:

• Family members and friends as informal interpreters.

• Other informal strategies, e.g. the use of dictionaries or technological and visual aids.

Details of these strategies are set out in the following pages. All strategies were generated by stakeholders during fieldwork processes, and each element of each strategy can be traced back to specific research encounters with one or more stakeholder groups.

Additional findings about communication in cross-cultural general practice consultations

Migrant service users said that it would be ideal for them if they could become fluent in English so that they could communicate directly with their GPs themselves. All stakeholders agreed that this may be an important aspiration but acknowledged that in reality, and for many reasons, it is not easy for all migrants to achieve this. For instance there is poor availability of accessible English language classes for migrants in Ireland.

Stakeholders agreed that it is important to have appropriate support for language and culture so that cultural diversity can be understood and respected. Proper attention to intercultural issues using
trained, qualified professionals would help discussions and diagnoses in general practice consultations and provide service users with security and peace of mind that their cultural and religious beliefs were being looked after. Stakeholders had many questions about what kind of model is best to address intercultural issues - internationally, there are different models in practice. Further research for the Irish context is required.

Migrants emphasised the **positive power of being listened to attentively by their GPs** – this makes for a very positive communication event.

**ACCEPTABLE STRATEGIES**

**Use of a professional interpreter for face-to-face or telephone interpreting.**

This is a crucial strategy for addressing and supporting language differences between service users and GPs.

**Under the following conditions**

- The interpreter must be a formal, trained, qualified, accredited professional who is ethically responsible and abides by a recognised relevant Code of Ethics.

- The interpreter must be adequately monitored for professional conduct and best practice.

- The interpreter must have all the necessary skills to co-ordinate the interaction (whether face to face or by telephone) during the consultation.

- Ideally, the interpreter would also have training in medical interpreting/vocabulary. Related to this is the need for the GP to brief the interpreter adequately in advance of the consultation to enable the interpreter to prepare practical terminology.

- Interpreters approach every consultation as a potentially serious medical condition as the nature of the medical condition cannot necessarily be established a priori; therefore interpreters should be used for all consultations in which there is a language difference between GP and service user.

**Rationale and Benefits**

Stakeholders emphasised that professional interpreting of this kind can:

- Provide peace of mind, satisfaction, reassurance and a sense of security and control for service users.
• Reduce stress and create a calmer consultation; the service user feels listened to, heard, understood; everyone concerned feels happy leaving the consultation.

• Relieve the service user’s family of the burden of providing informal interpreting and avoid the potential for trauma that might occur if a child is used to interpret. Professional interpreters are unlikely to be as adversely affected (traumatised) by consultations. It might be possible and useful for an adult family member to be present as well as the professional interpreter, in order to provide support and comfort to the service user.

• Ensure the competent, effective, accurate, confidential, ethical, neutral and sensitive transmission of messages between service user and provider.

• Enable clear communication and provide opportunities for clarification of problems/concerns.

• Promote GPs’ confidence in relation to treatment (medicine and dosage).

• Promote greater trust between interpreter and GP (when GPs have opportunities to work with one interpreter regularly).

• Save time and money.

• Reduce stress and pressure for nursing, administrative and other practice staff as they are not expected to struggle to accommodate and meet service users’ needs in situations where language is a major barrier and the service user may be distressed.

• Allow the interpreter to say ‘I’ve done a good job’ (because they facilitated the communication between GP and service user).

Comparing face-to-face and telephone professional interpreting:

• The physical presence of a face-to-face professional interpreter, and the use of body language and facial expressions, add to the positive quality of the communication. Telephone interpreting cannot cover human elements of the interaction that come via body language but it is useful in situations where an on-site interpreter cannot be accessed, and where service users might fear that interpreters could align themselves in a power bloc with GPs – this is less likely to occur during telephone interpreting.

• The use of face-to-face interpreting is considered more personal than telephone interpreting.

• Telephone interpreting should not be used for breaking bad news to a service user or in consultations with deaf service users.

• Telephone interpreting requires a good quality telephone connection and private surroundings.
• Telephone interpreting works best for shorter consultations.

• Telephone interpreting makes efficient use of interpreters’ time because they don’t have to travel widely from GP surgery to GP surgery and can provide fast access to interpreting for GP and service user.

**Implementation**

**Stakeholders noted that the delivery of this strategy would require:**

• Reform of the current interpreting service in Ireland so that it becomes as well developed as in other countries, for instance the UK and USA, and operates as an interpreting service that is convenient and quick to access and use.

• A service that is funded by the government/HSE and centrally organised so it is not in the control of private companies.

• The development of a business approach by the HSE to identify a cost-effective service. This business case should include attention to the risks associated with not providing an effective interpreting service.

• A service that service users do not have to pay for and that provides country-wide face-to-face professional interpreting that people can access even if they relocate to different parts of Ireland.

• A HSE-administered register of professionally trained interpreters that doctors and service users can work from to identify and choose interpreters.

• A multi-lingual call centre that service users can call 24:7 (a model like general practice out-of-hours cooperatives) and, using their own language, arrange without stress for a professional trained interpreter to accompany them to the GP practice. This implementation suggestion should complement (not replace) the responsibility on general practice staff to ensure that an interpreter is arranged for all consultations between GPs and service users with limited English. It is recognised that there may be challenges to implementing this idea in the current economic climate.

• Consideration of the development of video-conference interpreting as a potentially viable mechanism for efficiently delivering the most important benefits of face-to-face interpreting and telephone interpreting combined, given the time constraints usually involved (culture of ten-minute consultations).

• Strong encouragement from the government for GPs to use professional interpreting services - until the right to an interpreter is legislated for in the Republic of Ireland.
• Training for GPs and other health professionals about the use of interpreters.

**Bilingual GP uses service user’s language**

While having service users from one language group all accessing a GP who speaks their language might impact somewhat negatively on integration into Irish society, stakeholders considered that overall there were significant benefits to be gained from consulting with a bilingual GP because there is no language barrier and it may, on occasion, assist cultural understanding between GP and service user.

**Under the Following Conditions**

• The bilingual GP needs to be fluent in the service user’s language and the language of the host country.

**Rationale and Benefits**

*Stakeholders emphasised that this strategy can:*

• Improve the quality of the medical consultation as it builds trust and reassurance; service users can confidently explain their condition and are likely to feel fully understood and appropriately medically treated and cared for by the GP.

• Reduce the stress that might otherwise be associated with visiting the GP and put the service user at ease because s/he is able to speak freely in his/her own language.

• Promote a sense of empowerment and confidence for the service user.

• Ensure that service users are dealt with more quickly at the surgery.

• Benefit the GP because there are no communication problems.

• Ensure appropriate prescription and medical treatment by the GP, bringing the service user to a state of good health.

• Allow the GP to take account of the particular difficulties and challenging life circumstances of refugees and asylum seekers, and be sensitive to their vulnerability.

• Allow the GP to address certain cultural concepts/practices that service users may have about their health and facilitate beneficial health education.

• Create an atmosphere of welcome and comfort for GP and service user.
• Ensure the retention of intimacy between GP and service user as there is no third party, such as an interpreter, involved; this can also eliminate feelings of shame and/or embarrassment.

• Save time and money for the general practice as there is no need to hire interpreters and because bilingual GPs may also assist with filling out forms.

• Promote diversity and broadening of treatment within the Irish health system, thus promoting its credibility.

**Implementation**

**Stakeholders noted that the delivery of this strategy would require:**

- Government/HSE to support and fund the employment of bilingual GPs in the health system and engage in recruitment drives to support the creation of new, additional jobs for these GPs. This must be seen in the context of a wider strategy and policy that perceives the need for the national health service to reflect the profile of our ethnically diverse population. This would indicate commitment (on the part of health services) to the genuine integration of migrant community service users in the health service.

- Promotion, mentoring and support for bilingual GPs who take up employment in the HSE.

**STRATEGIES THAT ARE NOT CONSIDERED BEST PRACTICE AND SHOULD NOT BE USED IN GENERAL PRACTICE CONSULTATIONS**

The remaining strategies were not considered as best practice by stakeholders in this research. We know that these strategies are very commonly used and we thought it would be useful to share stakeholder perspectives on why they should be avoided.

*Agreed by consensus*

*Unacceptable strategies may continue to be utilised because, currently, the acceptable strategies are not fully available for use by all – there is important work to be done to implement the recommendations of this Guideline.*

The most common strategy used by service users and GPs in cross-cultural medical consultations is the use of family members or friends as interpreters.

*This may have certain benefits:*
- Pragmatic ‘handy’ way of managing the language gap between GP and service user.
- Can provide a measure of enhanced understanding between GP and service user.
- Service users sometimes like to have someone known to them in the consultation for comfort and advocacy.
However, there are serious problems with these strategies and stakeholders, including service users themselves and service user representatives, agreed that these do not constitute ‘best practice’ and should not be used in general practice consultations.

**Service user uses child as face-to-face interpreter:**

*Problems*

- A child is not a professional interpreter and is unlikely to have a medical vocabulary.
- A child may have limited English; important information could be missed.
- A child may not be available (during school hours) or may be missing out on schooling.
- The authority of parents may be compromised by a reliance on their child to interpret.
- A child may be traumatised, embarrassed, frightened or confused - does not have sufficient ‘emotional distance’.
- There may be fear or shame on the part of the parent and/or child – both may be embarrassed.
- How can a child tell a mother, the doctor says, ‘you have a tumour’?

**Service user uses adult family member or friend as face-to-face interpreter:**

*Problems*

- Family and friends are not trained and accredited interpreters.
- The accuracy of the interpreting may be badly compromised because of limited medical vocabulary.
- The family member or friend does not have the necessary [emotional] ‘distance’.
- The family member or friend may be embarrassed and not tell the full truth.
- Some family members, when interpreting, may try to ‘soften the blow’ and not tell the service user all they should know.
- A friend may not want to ‘lose face’ and may make something up.
- The communication is not confidential to the patient. There is a danger of breach of confidentiality to other family members and/or issues of asymmetrical gendered power relations, which compromise the safety of the patient.
- Service users are unaware that some GPs will book a formal trained interpreter if asked; if they did know, they would prefer the professional interpreter [to a family member or friend] because of issues of confidentiality and trust.

**Service user arranges to have own ‘informal’ interpreter on mobile phone:**

*Problems*

- Service users call a friend for interpreting in the surgery, then again at the pharmacy, then later at home about how to take the medicine - this may strain the relationship between them.
- Accuracy of interpreting - things may be misheard and mis-communicated via a mobile phone.
- ‘Informal’ interpreters may not always be available when needed.
- The service user may feel under obligation to the informal interpreter and the relationship can become strained.
Other strategies that are commonly used by service users and GPs in cross-cultural medical consultations are shown below, and while they may provide a small measure of enhanced understanding on occasions, there are serious problems with these strategies because they cannot represent ‘best practice’. In relation to the seriousness and complexity of cross-cultural consultations, these strategies cannot ‘stand alone’, and in particular cannot replace the use of a professional trained interpreter or a bilingual GP who speaks the language of the service user. Stakeholders agreed that the following strategies are therefore unacceptable for inclusion in this Guideline for best practice.

**GP uses body language and gestures:**

**Problems**

- Body language is an everyday communication tool the GP may use to signal friendliness/comfort to a service user, but is unreliable as a diagnostic support.
- Different cultural backgrounds can lead to misunderstanding of body language (e.g. eyes lowered – does it mean respect or avoidance?).
- Not a precise form of communication - very difficult to explain how to take medication using body language/gesture.
- Stressful for all involved.
- Frustrating for GP who wants service user to get the best help possible.

**Bilingual practice staff (receptionist/nurse/manager) use service user’s language:**

**Problems**

- Bilingual practice staff members are not trained interpreters.
- Bringing a bilingual practice staff member into the consultation to interpret raises ethical issues – could compromise the confidentiality between GP and service user.
- The presence of a practice receptionist/manager during a physical examination could create discomfort for the service user.

**Computer programmes that offer translation of words and phrases:**

**Problems**

- When desperate, when people are under stress, it may be helpful, but a computer programme is a tool, not an ideal for best practice.
- Could distract attention away from the fact that a formal trained interpreter is needed.
- Cold, interruptive of the intimacy of the consultation, can be intimidating.
- Difficult for such programmes to transmit knowledge in a culturally sensitive manner.

**Bilingual or multi-lingual materials (phrase books, dictionaries, written notes, posters):**

**Problems**

- Perhaps useful as a basic explanatory tool or as a complementary tool alongside the use of a professional interpreter, but not best practice.
• Could distract attention away from the fact that a formal trained interpreter is needed.
• Bilingual or multi-lingual materials cannot cope with psychological/mental health/social health issues.
• Bilingual or multi-lingual materials are not three-dimensional so have limited use.
• Service user’s language may not be included in the material being used.
Acknowledgements

We are very grateful for the participation of all stakeholders who engaged in this research:

Service User Peer Researchers – SUPeRs
Members of the migrant communities in Galway
GPs, practice staff and GP trainees in the Galway research site
Service planners and interpreters in the Dublin research sites.

We are particularly grateful to stakeholders who took part in the extensive cycle of data generation encounters and data analysis meetings – thank you for your sustained interest and excellent contributions.

We sincerely thank members of our Project Steering Group for their support and advice throughout the project:

Prof. Colin Bradley
Mr. Tomas de Brún
Ms. Diane Nurse
Mr. Seamus O’Leary
Ms. Ekaterina Okonkwo
Ms. Mary Phelan

Feb 26th 2011
Almost one year after engaging in initial PLA research, migrant stakeholders returned to NUI Galway, and, facilitated by ‘SUPERS’ peer researchers and University-based researchers, engaged in assessment and co-analysis of the draft content of the Guideline.
Section III: Expanding the use of PLA in primary healthcare research: European application, 2011 – 2015
**Mapping Process:** RESTORE teams in Austria, Crete, England, Ireland, The Netherlands and Scotland used a ‘Mapping Protocol’ designed and tested by the Irish Team to identify Guidances and Training Initiatives (G/TIs) for enhancing cross-cultural communication in primary care.

In the next phase of research, the task for stakeholders in each country was to evaluate several G/TIs and choose one that they considered suitable for implementation in their ‘local’ primary care setting.

20 G/TIs met the selection criteria; seven from The Netherlands, six from Ireland, five from England, two from Scotland and none from Crete or Austria, who then had the option to ‘borrow’ from other partner countries.
Chapter 7

Guidelines and training initiatives that support communication in cross-cultural primary-care settings: appraising their implementability using Normalization Process Theory


Tomas de Brún
Mary O’Reilly de-Brún
Evelyn van Weel-Baumgarten
Chris van Weel
Christopher Dowrick
Christos Lionis
Catherine A O’Donnell
Nicola Burns
Frances S Mair
Aristoula Saridaki
Maria Papadakaki
Christine Princz
Maria van den Muijsenbergh
Anne MacFarlane
Abstract

Background
Guidelines and training initiatives (G/TIs) available to support communication in cross-cultural primary health care consultations are not routinely used. We need to understand more about levers and barriers to their implementation and identify G/TIs likely to be successfully implemented in practice.

Objective
To report a mapping process used to identify G/TIs and to prospectively appraise their implementability, using Normalization Process Theory (NPT).

Methods
RESTORE is a 4-year EU FP-7 project. We used purposeful and network sampling to identify experts in statutory and non-statutory agencies across Austria, England, Greece, Ireland, Scotland and the Netherlands who recommended G/TI data from the grey literature. In addition, a peer review of literature was conducted in each country. Resulting data were collated using a standardized Protocol Mapping Document. G/TIs were identified for inclusion by (i) initial elimination of incomplete G/TI material; (ii) application of filtering criteria; and (iii) application of NPT.

Results
20 G/TIs met selection criteria: 8 guidelines and 12 training initiatives. Most G/TIs were identified in the Netherlands (n = 7), followed by Ireland (n = 6) and England (n = 5). Fewer were identified in Scotland (n = 2), and none in Greece or Austria. The majority (n = 13) were generated without the inclusion of migrant service users. All 20 were prospectively appraised for potential implementability by applying NPT.

Conclusions
NPT is useful as a means of prospectively testing G/TIs for implementability. Results indicate a need to initiate meaningful engagement of migrants in the development of G/TIs. A European-based professional standard for development and assessment of cross-cultural communication resources is advised.

Keywords
Community involvement, migrant health, Normalization Process Theory, primary care.
Introduction

Responding to the health needs of migrants is difficult and a universal issue in European primary health care where there is still important progress to be made. This problem is further marked by differences between countries in their (primary) health care systems, and their migrant health care policies. In addition, there are significant differences between countries in relation to migrant groups, in terms of cultural diversity, religious affiliation, ethnicity and country of origin. Notwithstanding these differences, primary health care is directed at the care of individuals in most countries, including the most vulnerable communities. This is why improvement of health care of migrants should be approached through primary health care. This paper focuses on improving communication between migrants and primary care providers.

Communication in primary health care

Communication skills are a core competency for GPs, and vital in achieving optimal health outcomes. The fundamental importance of communication in general practice consultations is amplified in cross-cultural consultations involving migrants where additional language and cultural difficulties exist. In such situations, it is often a challenge for patient and doctor to surmount language and cultural barriers sufficiently to develop the necessary trusting relationship, and ensure clinical effectiveness, particularly when informal rather than professional trained interpreters are used. For that reason, international organizations have called for primary health care to be provided in a culturally appropriate way.

Evidence-based guidelines and training initiatives (G/TIs) are available for students, educators and practitioners in European settings and have been reviewed and evaluated in a recent EU project, http://www.mem-tp.org. Despite the availability of these resources, they are not routinely used in day-to-day practice. Therefore, to address this translational gap, it is necessary to understand more about levers and barriers to their implementation and, ideally, to identify G/TIs that are likely to be successfully implemented in practice.

The EU RESTORE project (RESearch into implementation Strategies to support patients of different ORigins and language background in a variety of European primary care settings) in migrant health was developed to investigate and support the implementation of G/TIs to improve cross-cultural communication in primary health care delivery throughout Europe. This paper reports on a first step in RESTORE: identifying G/TIs designed to support communication in primary care settings in six European countries and prospectively appraising their potential implementability through the application of Normalization Process Theory (NPT).

Normalization Process Theory (NPT) was developed as a response to multiple failures to implement innovations in complex health care contexts. It is not a rigid conceptual framework but is designed to emphasize the realities of implementation work in real time and space, and the inter-relationships between different kinds of implementation work. There are four components in NPT (Table 1): coherence (sense-making), cognitive participation (engagement), collective action (enactment) and reflexive monitoring (appraisal). Each of these has subcomponents that are divided into a set of 16 sensitizing questions that have been successfully used by researchers as sensitizing concepts in implementation research. Our use of NPT to prospectively appraise G/TIs is a unique use of NPT.
Table 1 NPT constructs, sub-constructs and 16 sensitizing questions applied to 20 G/TIs

<table>
<thead>
<tr>
<th>NPT constructs</th>
<th>Coherence: can stakeholders make sense of the intervention?</th>
<th>Cognitive Participation: can stakeholders get others involved in implementing the intervention?</th>
<th>Collective Action: what needs to be done to make the intervention work in practice?</th>
<th>Reflexive Monitoring: Can the intervention be monitored and evaluated?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subconstructs: 16 sensitizing questions</td>
<td>Differentiation: do stakeholders see this as a new way working?</td>
<td>Enrolment: do the stakeholders believe they are the correct people to drive forward the implementation? Are they prepared to invest time and energy in it?</td>
<td>Interactional workability: does the intervention make it easier or harder to complete routine tasks?</td>
<td>Systematization: will stakeholders be able to judge the effectiveness of the intervention?</td>
</tr>
<tr>
<td>Individual specification: do individuals understand what tasks the intervention requires of them? Can they make sense of the work it might create for them in their daily routine?</td>
<td>Initiation: are they willing and able to engage others in the implementation?</td>
<td>Skill-set workability: do those implementing the intervention have the correct skills and training for the job?</td>
<td>Individual appraisal: how will individuals judge the effectiveness of the intervention?</td>
<td></td>
</tr>
<tr>
<td>Communal specification: do all those involved agree about the purpose and expected benefits of the intervention?</td>
<td>Activation: can stakeholders identify what tasks and activities are required to sustain the intervention?</td>
<td>Relational integration: do those involved in the implementation have confidence in the new way of working?</td>
<td>Communal appraisal: how will stakeholders collectively judge the effectiveness of the intervention?</td>
<td></td>
</tr>
<tr>
<td>Internalization: do all the stakeholders grasp the potential benefits and value of the intervention?</td>
<td>Legitimation: do they believe it is appropriate for them to be involved in the intervention? Do they ‘buy into’ it?</td>
<td>Contextual integration: do local and national resources and policies support the implementation?</td>
<td>Reconfiguration: will stakeholders be able to modify the intervention based on evaluation and experience?</td>
<td></td>
</tr>
</tbody>
</table>

Methods

Study context
This study is part of a 4-year EU FP-7 project, RESTORE. We were interested in working closely, meaningfully and in a democratic way with key stakeholders (migrant patients, GPs, practice staff, community interpreters, migrant representatives and policy planners) in five of the six participating countries (Austria, England, Greece, Ireland and the Netherlands. Scotland’s brief was to focus on policy-related implications of the research). The choice of these countries was directly related to the academic teams who developed and submitted the original FP-7 proposal and intentionally contains countries with diverse primary health care systems, ranging from those regarded as weak (Greece, 

and represents a significant contribution to the literature on communication in cross-cultural consultations.
and Ireland) to strong (UK and the Netherlands). Following pilot work in Ireland, a mapping process was carried out to identify G/TIs in all participating countries following the steps outlined below.

*Identification of pertinent G/TIs*

We utilized purposeful network and snowball sampling to identify agencies and individuals who we expected would be able to assist us in identifying potentially useful G/TIs in the ‘grey literature’. Those contacted included academic, policy planner, migrant service user and community interpreter colleagues. This initially involved accessing networks already known to research teams in each country, rippling outwards from these to wider networks of linked colleagues and agencies, with the initial network in each country growing to become a larger and more inclusive network. This trawl of grey literature was our primary means of identifying examples of G/TIs to include in a comprehensive portfolio.

We also conducted a literature search of peer-reviewed articles in each country to identify examples of any language-specific G/TIs that had been developed. We used a variety of databases and resources including ‘Web of Science’, within Web of Knowledge, SCOPUS plus EMBASE and Cochrane. Each country also accessed a number of databases specific to their own settings (see RESTORE website for complete databases included, www.fp7restore.eu).

The focus of our search was on primary care and followed the comprehensive definition in the Alma-Ata Declaration and the core competencies of primary care as described in The European Definition of General Practice. Although we did not actively pursue examples from secondary health care, we decided not to exclude secondary health care examples if suggested to us by our networks of colleagues—acknowledging that, in some of our settings, secondary health care refers to specialist services that may be either community or hospital-based. This meant that we allowed examples from secondary care to be included on a case-by-case basis if country teams and partner leads judged them to be of sufficient value for this primary care research project.

*Screening of identified G/TIs*

A ‘Protocol Document’ was used in each setting to help researchers in each country review their identified G/TIs in a consistent and rigorous manner. When G/TIs that lacked sufficient material were eliminated, a set of filtering criteria were then applied to the comprehensive portfolio (Table 2) in order to guide the selection of G/TIs in all countries. Seven (equally weighted) criteria were deemed to be essential in sharpening the focus for what to include when searching the grey literature and were strictly applied, that is, we only included G/TIs that comprehensively met all seven criteria. An eighth criterion was identified by RESTORE colleagues as a highly desirable one that was congruent with our project aim to involve all key stakeholders: ‘was the item generated in a participatory manner in terms of having migrant input’.

To see how implementable they were, each team appraised the included G/TIs using NPT. This ensured that the assessment process was conducted in a consistent manner across countries and that decisions were informed by knowledge related to factors that promote or impede implementation processes and thus support the normalization of the implemented G or TI in each country. We first piloted the use of NPT on a set of five G/TIs and from this developed a standardized
set of instructions for teams to appraise the remaining G/TIs. The instructions were to use the 4 NPT constructs and set of 16 NPT-based sensitizing questions to appraise the G/TIs using teams’ knowledge of their local setting and contexts. All teams were asked to give a score in an excel sheet on a five-point ‘Likert Scale’ for each. They were asked to record their decision-making processes about the scores using qualitative notes and, then, to make a judgement on the overall implementability of each G/TI.

### Table 2. Inclusion/exclusion criteria applied to remaining G/TIs after elimination of incomplete material

<table>
<thead>
<tr>
<th>Number</th>
<th>Inclusion / exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Is the focus on primary health care?</td>
</tr>
<tr>
<td>2</td>
<td>Is the focus on migrants?</td>
</tr>
<tr>
<td>3</td>
<td>Is the focus on migrants who experience language and cultural barriers?</td>
</tr>
<tr>
<td>4</td>
<td>Does the item (G/TI) aim to enhance communication in cross-cultural consultations?</td>
</tr>
<tr>
<td>5</td>
<td>Was the item generated as a guide or support for professional health-care workers?</td>
</tr>
<tr>
<td>6</td>
<td>Is the item practically shareable with stakeholders in the field?</td>
</tr>
<tr>
<td>7</td>
<td>Does the item match your health focus?</td>
</tr>
<tr>
<td>8</td>
<td>Was the item generated in a participatory manner in terms of having migrant input?</td>
</tr>
</tbody>
</table>

### Results

Across the consortium, 325 agencies were accessed through local networks in each country. These were statutory and non-statutory organizations who suggested relevant country-specific examples of G/TIs. A wide range of organization types were accessed: medical, academic, primary care, university departments, policy and health services, health care planning organizations, professional bodies, interpreting organizations, migrant support agencies, advocacy and representative organizations, equality organizations, nurse training organizations, cultural mediation and cultural competency contacts. We identified 230 examples of G/TIs from a large variety of sources and from different countries (Table 3). The results of the peer reviewed literature searches in each country yielded only one additional G/TI (included in the 230) in the Netherlands (‘Practical Assignment—Cultural Interview’: a training initiative designed to teach GP trainees how to carry out a cross-cultural interview with migrant patients).

<table>
<thead>
<tr>
<th>Country</th>
<th>Guideline</th>
<th>Training initiative</th>
<th>Information pack</th>
<th>Article</th>
<th>Report</th>
<th>Book</th>
<th>Computer application</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ireland</td>
<td>9</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>11</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>230</td>
</tr>
<tr>
<td>Netherlands</td>
<td>24</td>
<td>47</td>
<td>5</td>
<td>8</td>
<td>7</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>230</td>
</tr>
<tr>
<td>England</td>
<td>15</td>
<td>5</td>
<td>1</td>
<td>9</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>230</td>
</tr>
<tr>
<td>Greece</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>12</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>230</td>
</tr>
<tr>
<td>Austria</td>
<td>2</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>4</td>
<td>0</td>
<td>8</td>
<td>230</td>
</tr>
<tr>
<td>Scotland</td>
<td>18</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>230</td>
</tr>
<tr>
<td><strong>Subtotals by type</strong></td>
<td><strong>69</strong></td>
<td><strong>64</strong></td>
<td><strong>13</strong></td>
<td><strong>34</strong></td>
<td><strong>35</strong></td>
<td><strong>6</strong></td>
<td><strong>1</strong></td>
<td><strong>8</strong></td>
<td><strong>230</strong></td>
</tr>
<tr>
<td>Total</td>
<td>Number</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>230</td>
</tr>
</tbody>
</table>
As Table 4 shows, 97 examples of G/TI-related material were not sufficiently detailed in description to be of further use and were eliminated (n = 97). These eliminated ‘components’ of G/TI material were in the form of articles, books, information packs and applications for smart phones. After applying our filtering criteria, the remaining 133 G/TIs (guidelines, n = 69 and training initiatives, n = 64) was reduced to a set of 20 relevant examples. These consisted of 8 guidelines and 12 training initiatives. Half of the guidelines (n = 4) originated in Ireland, while half of the training initiatives (n = 6) originated in the Netherlands. The greatest number of suitable G/TIs were identified in the Netherlands (n = 7), followed by Ireland (n = 6) and England (n = 5). Fewer were identified in Scotland (n = 2), and no relevant examples were identified in Greece (n = 0) or Austria (n = 0). We also note that none of the resources identified in this European six-country mapping process has the status of being an official professional standard guideline or training initiative.

Table 4. Flow chart: elimination of G/TIs—partial material, applying filtering criteria and applying NPT prospectively

Excluded G/TIs scored low on Coherence (did not make sufficient sense to team members) and/or Cognitive Participation (teams believed they would be unable to drive through the G/TI in question to actual implementation) and/or Collective Action (teams judged the work involved in implementing G/TIs could not be sustained within the project timeframe).
All of the included 20 G/TIs addressed the well-known difficulties in cross-cultural communication, offering advices and/or training programmes to GPs and other health care providers. Only one of the G/TIs focused on ‘why migrants should communicate with health services through an interpreter’, while another directly involved migrants along with other key stakeholders to design a more inclusive guideline. Please see Supplementary Appendix in Supplementary Documentation for a more detailed description, comparison and summaries of the 20 G/TIs and in addition please see this website for links to the original sources (http://www.fp7restore.eu/index.php/en/about-restore/relevantgtis).

We also analysed how the 20 G/TIs related to the filtering criteria. It was notable that only 7 of the 20 matched criterion number 8. This points to the fact that the large majority (n = 13) of the 20 G/TIs were generated without the inclusion of migrant service users/patients, meaning that their important perspectives were missing from these G/TIs.

Following the NPT appraisal, differences between country settings were apparent. Seven G/TIs were not selected by any country as all teams considered them unlikely to have implementation potential in their specific contexts. The reason for low NPT scores (leading to elimination of G/TIs) was that in some cases, the G/TIs did not ‘make sense’ in the local context (low coherence), for example, cultural mediation was not fully understood or familiar in the Greek or English settings.

Sometimes stakeholders also excluded G/TIs because they did not believe they could drive the implementation forwards sufficiently or encourage others to do so (low Cognitive Participation). For example, the English team chose not to select some G/TIs because they were judged to be too lengthy and this would act to discourage implementation by some stakeholders. In other cases, there was a lack of essential resources to support the implementation work (low Collective Action). For example, as there are no longer state funds to pay interpreters in the Netherlands the Dutch team eliminated all G/TIs that involved the use of interpreters. The diversity of findings across settings suggests that, as expected, issues of context and cultural specificity might be influencing the appraisal process.

Discussion

Summary

In this paper, we have described a mapping process that accessed a large number of G/TIs that focused on primary healthcare for migrants. An important aspect of this study was the way NPT was then used to prospectively appraise G/TIs and therefore identify ones that had the likelihood of successful implementation.

Methodological critique

The study identified 20 pertinent G/TIs originating from four of the six participating countries. We acknowledge that there is a limited number of countries included in this study. There is, by definition, a trade-off between number of research groups involved and the depth of interaction, and, on balance, we consider the choice for in-depth interaction the correct one. We acknowledge the abundance of other G/TIs related to our own topic in EU countries who have not participated in the RESTORE project.
No relevant G/TIs were found in Austria and Greece, despite the central role of primary health care for migrants’ health in these countries. Our search strategy was directed at the most likely sources where G/TIs for primary health care professionals were published and disseminated, and national teams led this search. Therefore, it is in our view highly unlikely that methodological bias can be the reason for this result. Primary health care in Austria and Greece is therefore encouraged to develop more resources for the care of migrants.

An important aspect of this study was the way NPT was used to prospectively appraise G/TIs and therefore maximize the likelihood of successfully implementing G/TIs designed to enhance communication between GPs and migrant service users. It was important to pilot the use of NPT in this way. We acknowledge that research teams found it difficult to answer some of the 16 sensitizing questions without knowing which stakeholders or sites were going to be involved with the implementation work.

**Key findings**

We highlight the usefulness of the NPT constructs as they encouraged stakeholders to focus on issues related to the work that needed to be completed for implementation and the need to actively engage other important actors; the constructs thus worked as an effective mechanism of elimination in all countries.

There were marked differences between the six participating countries that have very different and unique histories of migration and primary health care development. Given this, it was unsurprising that the Netherlands and England, with long histories of primary health care and in-migration, identified several resources. What was more surprising was that Ireland, whose migration history had been one of net emigration until relatively recently, yielded the second highest number of G/TIs after the Netherlands.

The inclusion of stakeholders and service users in intervention development has been demonstrated to enhance the suitability of interventions in addressing health issues. Drawing on the existing knowledge of stakeholders, such as service users and community groups, ensures the suitability of intervention design and the validity of guidelines for implementation in specific contexts as well as increasing the likelihood of ‘buy in’.23-27

The mapping process showed the limited role migrants have in the development of G/TIs. Of the seven G/TIs that did involve migrants in their generation, we can be sure that only three of these are explicit about the strong involvement of migrants while the remaining four merely mention in passing that migrants contributed. This leaves the question open as to whether these four engaged in a genuinely meaningful way with migrants, or in a ‘lighter’, more consultative manner. The lack of migrant engagement in the development of G/TIs reflects a situation where primary health care remains in a mode of doing ‘for’ migrants rather than ‘with’ them, and might well be an important factor as to why G/TIs remain relatively underutilized and under-implemented.
Conclusions and recommendations

It proved very useful to prospectively apply the NPT theoretical framework to the identified G/TIs. Reporting our experiences here may be useful for other researchers considering using NPT as a predictive tool for implementation of G/TIs in primary care settings.

The mapping process allowed us to clearly establish that, in their generation, very few G/TIs in the study involved meaningful engagement with hard-to-reach migrants. The literature is clear that this is not a helpful approach, and we suggest that researchers involved in the development of such interventions involve migrants and their communities early in the design stage, throughout the ongoing development and testing of the implementation, to final evaluation and dissemination. If migrants are involved as suggested above, their involvement will constitute a ‘co-design’ and ‘co-evaluation’ process that meaningfully links resource development in primary health care with hard-to-reach communities.

Given that none of the resources identified in this European six-country mapping process has the status of being an official professional standard guideline or training initiative, we suggest that attention be given to the generation of European professional standards for the development of G/TIs in this field, similar to the CLAS (National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care) standards in the USA [http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15](http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15).

Such a standard would offer a set of clear guidelines on key ‘non-negotiable’ elements to be adhered to in the generation of such resources in all European settings, including the recommendation that the involvement of migrant service users/patients would be required in the generation of guidelines designed to enhance communication between health care providers and migrants who experience language and cultural barriers.
Acknowledgements

The RESTORE project is funded by the EU Seventh Framework Programme (FP7/2007–2013) under Grant Agreement No. 257258. RESTORE: Research into Implementation Strategies to support patients of different ORigins and language background in a variety of European primary care settings. We acknowledge contributions to the work reported in this paper of RESTORE project Consortium members: Erik Teunissen, Francine van den Driessen-Mareeuw, Wolfgang Spiegel, Katja Gravenhorst and Maria Vlahadi. The lead author has obtained permission from all of the above to be acknowledged in the acknowledgments section.

Conflict of interest: the authors declare that they have no competing interests.
References


Guidelines and training initiatives


RESTORE project 2011-2015.

Stakeholders across partner countries used two PLA techniques – Commentary Charts and Direct Ranking – to assess and democratically choose a Guidance or Training initiative (G/TI) for implementation at local level.
Chapter 8

Material practices for meaningful engagement: An analysis of participatory learning and action research techniques for data generation and analysis in a health research partnership


Mary O’Reilly-de Brún
Tomas de Brún
Catherine A. O’Donnell
Maria Papadakaki
Aristoula Saridaki
Christos Lionis
Nicola Burns
Chris Dowrick
Katja Gravenhorst
Wolfgang Spiegel
Chris Van Weel
Evelyn Van Weel-Baumgarten
Maria Van den Muijsenbergh
Anne MacFarlane
Abstract

Background
The material practices which researchers use in research partnerships may enable or constrain the nature of engagement with stakeholder groups. Participatory learning and action (PLA) research approaches show promise, but there has been no detailed analysis of stakeholders’ and researchers’ experiences of PLA techniques for data generation and co-analysis.

Objectives
To explore stakeholders’ and researchers’ experiences of PLA techniques for data generation and co-analysis.

Design
The EU RESTORE implementation science project employed a participatory approach to investigate and support the implementation of guidelines and training initiatives (GTIs) to enhance communication in cross-cultural primary care consultations. We developed a purposeful sample of 78 stakeholders (migrants, general practice staff, community interpreters, service providers, service planners) from primary care settings in Austria, England, Greece, Ireland and The Netherlands. We used speed evaluations and participatory evaluations to explore their experiences of two PLA techniques—Commentary Charts and Direct Ranking—which were intended to generate data for co-analysis by stakeholders about the GTIs under analysis. We evaluated 16 RESTORE researchers’ experiences using interviews. We conducted thematic and content analysis of all evaluation data.

Results
PLA Commentary Charts and Direct Ranking techniques, with their visual, verbal and tangible nature and inherent analytical capabilities, were found to be powerful tools for involving stakeholders in a collaborative analysis of GTIs. Stakeholders had few negative experiences and numerous multifaceted positive experiences of meaningful engagement, which resonated with researchers’ accounts.

Conclusion
PLA techniques and approaches are valuable as material practices in health research partnerships.

Keywords
Health research partnerships, migrant health, participatory research, public and patient involvement.
Introduction

Involving patients and communities in health research partnerships is consistent with international policies and is recommended for ethical and instrumental reasons. It is increasingly a requirement for research funding in many countries. There is a long-standing awareness that meaningful involvement is a genuine challenge. Recent reviews show persisting concerns that current practice is tokenistic.

Our working definition of “meaningful engagement” is an experience of partnership in research that is collegial, inclusive and active for participants. Meaningful engagement reduces asymmetries of power, encourages participants’ ownership of the project and enables participants’ authentic perspectives to emerge clearly in research outcomes.

“Material practices,” such as the types of methods and techniques that researchers use to involve stakeholders, can enable or constrain participation in research. Therefore, while there are valid concerns about a “flight to empiricism” and an overemphasis on “how to” manuals, it is important to determine what methods and techniques are used to frame the interactional and relational nature of partnerships. This will allow identification of material practices which minimize tokenism and enhance opportunities for meaningful engagement.

Research to identify the best methods to achieve meaningful engagement is currently lacking. Boote et al. reported that group meetings were the most common method used to engage the public. Workshops, meetings and focus groups were identified as common methods of engagement in three other reviews. Domecq et al. found that the most common methods in use were focus groups, interviews and surveys.

Tierney et al.’s review of service user involvement in academic primary care also found that interviews and focus groups were commonly employed. It reported examples of studies which had used methods from the field of participatory health research and found that the use of participatory methods was more congruent with stated aspirations for meaningful engagement than “standard” research methods were.

Participatory health research is an overarching term that refers to “bottom-up” research approaches specifically designed for stakeholder involvement in research partnerships. These include, among others, participatory research (PR), participatory action research (PAR), community-based participatory research, participatory rural appraisal (PRA) and participatory learning and action (PLA). All share a democratic ethos, are strongly committed to meaningful engagement by stakeholders and promote research partnerships that strengthen relations between academy and community. Participatory approaches emphasize the need for stakeholders’ active engagement across the full range of research activities, including data generation and data analysis.

Participatory approaches face challenges, such as the need to see community participation as a long-term process of implementation and support for improved health outcomes and the fact that many professional health researchers may be unprepared for the reversals of power and hierarchical relationships that a participatory approach may require. Notwithstanding these challenges, there is
consistent evidence that participatory approaches provide added value in terms of shaping the purpose and scope of research, improving research implementation and enhancing both the interpretation and the application of the research outcomes. Furthermore, participatory approaches offer a range of interesting and interactive material practices and techniques. PLA is noteworthy in this regard. This is a form of action research rooted in the interpretive and emancipatory paradigms. Based on the work of Robert Chambers, PLA is a methodology which offers a practical approach to research where asymmetries of power may exist. It involves a combination of a PLA mode of engagement and PLA techniques. A PLA mode of engagement aims to create a trusting relational environment, a “safe space” where stakeholders are encouraged to respect a diversity of views and experiences, and to learn from each other’s perspectives. All stakeholders are considered to possess expert knowledge about their own lives and conditions which they bring to the “stakeholder table” for a PLA brokered dialogue, where, using various PLA techniques, implicit knowledge becomes explicit and much that otherwise might remain hidden emerges.

**PLA techniques** evolved originally from PRA and are based on a shared stock of ideas and experiences from participatory trainers and stakeholders around the globe. They continue to be adapted to specific contexts as required. The techniques are recognizable as PLA techniques because they are explicitly designed to be active, inclusive, user-friendly and democratic. They are visual and tangible, meaning that they are used to generate physical maps, charts and diagrams (described further under Methods). Generation and co-analysis of data go hand-in-hand and are best understood as a structured, integrated process. Stakeholders’ priorities and perspectives are meant to guide the generation and co-analysis of data about the issue being explored, with researchers acting as catalysts rather than directors or top-down decision-makers.

There are some recent positive examples of PLA applied to primary care health research. These studies describe meaningful involvement of migrants and other stakeholders in the development of a guideline to improve communication in cross-cultural consultations; involvement of people with aphasia, speech and language therapy educators and students in the evaluation of community services for people with aphasia; and involvement of a variety of marginalized groups (sex workers, homeless people, Irish Travellers, migrants and drug users) in the identification of priorities for primary care team activities. However, there has been no detailed analysis of stakeholders’ or researchers’ experiences of PLA techniques for data generation and co-analysis used within a PLA-brokered dialogue. Such an analysis would provide important empirical data about the ways in which PLA techniques are experienced as material practices and how they shape interactional and relational aspects of health research partnerships.

In this paper, we describe the use of two PLA techniques (Commentary Charts and Direct Ranking) used for data generation and co-analysis, and the perceived utility of these by various stakeholders and researchers involved in a recent European primary health-care implementation project.

**Methods**

*Study setting: the RESTORE project*
RESTORE (Research into Implementation Strategies to Support Patients of Different Origins and Language Background in a Variety of European Primary Care Settings) was an EU-funded primary health-care research project that ran from 2011 to 2015. The objective of RESTORE was to investigate and support the implementation of guidelines and training initiatives (GTIs) intended to enhance communication in cross-cultural primary care consultations. This qualitative, comparative case study involved diverse stakeholders across five primary care settings: Austria, England, Greece, Ireland and The Netherlands (see File S1 for a description of the five settings). A sixth research team in Scotland focused on policy-related implications of the study. The choice of these six countries matched the academic teams who developed the proposal and intentionally included countries with diverse primary health-care systems. Ethical approval was granted by respective national committees. A detailed description of the study protocol is available elsewhere. For the purpose of this study, we emphasize that RESTORE comprised three stages of fieldwork.

1. **Stage 1.** Stakeholders were informed about RESTORE and invited to participate. Researchers mapped GTIs that were available in each RESTORE project country.

2. **Stage 2.** Stakeholders examined a set of these GTIs that showed potential for implementation in their country and selected one that they deemed most suitable or relevant for their local primary care setting.

3. **Stage 3.** Stakeholders successfully adapted their selected GTI at a local level and worked on its implementation, with evidence of some impact on daily practice.

RESTORE was the overall setting in which we explored and evaluated stakeholders’ and researchers’ experiences of two PLA techniques. These techniques were employed during Stage 2 and were intended to enable stakeholders (migrants, general practice staff, community interpreters, service providers, service planners and others) to work collaboratively and with RESTORE researchers to select a GTI for their local primary care setting.

First, we describe sampling and recruitment for RESTORE—this is the sample for the evaluation reported in this paper. We then describe the two specific PLA techniques employed in RESTORE and the methods used to evaluate stakeholders’ and researchers’ experiences of these techniques. Finally, we present our analysis of the evaluation data.

**Sampling and recruitment**

In Stage 2, we used a combination of purposeful and network sampling to identify and recruit 78 stakeholder representatives across five research sites. A geographically defined area (district) was selected in each partner country. Selection was pragmatic, based on researchers’ knowledge of groups working in the district and proximity to the research teams, to facilitate data collection. Eligible organizations/agencies were those involved in primary health-care planning and delivery (eg health-care centres, regional health authorities) as well as those addressing migrant health issues (eg non-governmental organizations focused on migrants). The aim was to identify individuals who were decision-makers (eg health authority service planners and policymakers), service providers (eg general practitioners (GPs), primary care staff, community interpreters) or service users (ie migrants using local primary care services). In line with standard ethical procedures, stakeholders in all
countries were provided with information leaflets and signed consent forms prior to participating in fieldwork sessions.

**PLA data generation and co-analysis in RESTORE**

Two members of the RESTORE consortium in the Irish team (practitioner/trainers with over 25 years’ international experience in PLA research and training in diverse cultural and social settings) led the design of PLA in RESTORE. They provided training and standardized fieldwork protocols which enabled researchers to facilitate PLA in a consistent and rigorous manner across research sites.

The PLA process for RESTORE was based on a **PLA mode of engagement and PLA techniques** in a PLA-brokered dialogue between stakeholders. One of the striking features of PLA in general is the highly visual nature of the techniques used. Stakeholders work together to generate maps, charts and diagrams which function as powerful reference points (data displays) as they engage in verbal interaction, discussing, questioning, and learning from each other’s perspectives, adding new data to maps and charts. The inherent analytical capabilities of PLA techniques aim to enable stakeholders to assess, correlate, categorize and/or prioritize data they are co-generating. PLA techniques, therefore, have the capacity to facilitate meaningful engagement that automatically incorporates co-generation and co-analysis of data “by” and “with” stakeholders.

In a very practical way, then, stakeholders using PLA techniques engage in a structured, integrated, visual-verbal-tangible process of co-generating and co-analysing data which produces visual-tangible results. This activity can appeal to a wide range of stakeholder groups, including those where literacy and/or numeracy challenges may feature, as a key aim is to ensure that stakeholders/stakeholder groups do not become disenfranchised during the research process. Data co-generation and co-analysis may occur during a single PLA session, or iteratively and in successive waves of fieldwork and/or data-generation encounters during PLA research, bringing stakeholders’ unique knowledge and insights to bear on emerging findings. This ensures that stakeholders’ perspectives influence the conduct and trajectory of research and research outcomes—a key hallmark of meaningful engagement.

The two PLA techniques we used in RESTORE in Stage 2 were Commentary Charts and Direct Ranking. A Commentary Chart is an interactive knowledge-exchange, knowledge-enhancement technique which allows stakeholders to exchange differential knowledge, expertise and perspectives. Box 1 provides information on generic steps for facilitating Commentary Charts, based on the expertise of the RESTORE project PLA trainers.

In RESTORE, PLA Commentary Charts were used to facilitate dialogue among stakeholders about the GTIs mapped in Stage 1. Full-text copies, summaries and/or PowerPoint presentations of the identified GTIs were made available to stakeholders. The Commentary Charts comprised three analytical categories—“positive aspects of the GTI,” “negative aspects of the GTI” and “questions to be checked out.” Stakeholders recorded their key deliberations, perspectives and insights about each GTI on the Commentary Chart (see Figure 1). For example, in Ireland, stakeholders met in one large group for each of five PLA sessions. They had identified a “local set” of five GTIs and co-generated five separate Commentary Charts.
Box 1 Step-by-step guidance for the use of PLA Commentary Charts and Direct Ranking Techniques

**Commentary Chart**
- Stakeholders record key data on Post-it notes about the issue of interest. This provides a visual representation of their co-generated data.
- The Post-Its are assigned to the relevant category on the chart. These categories may be determined before or during the sessions. This is the start of the co-analysis process.
- Researchers and stakeholders consider and discuss the emerging and completed Commentary Chart. This process automatically incorporates co-generation and co-analysis of data “by” and “with” stakeholders.
- Researchers and stakeholders continue the co-analysis with a visual-verbal-tangible process of “interviewing” the chart. The emphasis is on looking at the Commentary Chart and encouraging stakeholders to share their unique knowledge and insights, to exchange differential knowledge by asking: Does the Commentary Chart make sense? Are stakeholders comfortable with their data display? Is there anything striking/odd about the data display? Are diverse views sufficiently and accurately represented? Does anything need to be added as we reflect on the Chart? Are stakeholders willing and content to “sign off” on the Chart? Can it now be presented to another stakeholder group (as needs be) for discussion and development?

**Direct Ranking**
- Physical objects and/or images are selected to represent the issues/entities being ranked. This provides a visual focus for the co-analysis process.
- Stakeholders place the selected images randomly on a large flipchart sheet, to give each image equal visual “weight” and importance.
- Stakeholders engage in co-analysis and clarify what the ranking criterion will be.
- Stakeholders discuss each object/image in relation to the agreed ranking criterion, listening, learning, questioning, reflecting and assessing, thus continuing the integrated processes of data generation and analysis.
- When discussion is complete, each stakeholder is provided with an equal number of “votes” (e.g., paper clips, coins, matches).
- Stakeholders distribute their votes across the images.
- Stakeholders count the number of votes assigned to each image.
- Results are double-checked, recorded in numerical form on “Post-It” notes and attached to the relevant images.
- Stakeholders draw a line down the centre of the flipchart sheet and place the images on the line: highest scoring image at the top, lowest at the bottom, others in between in positions dictated by number of votes accrued.
- Researchers and stakeholders continue the co-analysis with a visual-verbal-tangible process of “interviewing” the results of the Direct Ranking process. The emphasis is on looking at the Direct Ranking chart and encouraging stakeholders to share their unique knowledge and insights, to exchange differential knowledge by asking: does it make sense? Do stakeholders feel comfortable with the outcome? Is there anything striking/odd about the result? Having been decided by democratic vote, is the result definitely acceptable? Are stakeholders willing and content to “sign up” to the result?
Where several stakeholder groups met separately (eg Austria) or were geographically dispersed (eg The Netherlands), charts were computerized and circulated around stakeholder groups by email, iteratively accruing additional data. On occasion, researchers took physical charts from one stakeholder group to the next, and data were added incrementally. As Commentary Charts “travelled” around stakeholder groups, the knowledge-exchange and knowledge-enhancing process continued.

The intended practical outcome expected of Commentary Charts in RESTORE was that they would present a visual, tangible data display of stakeholders’ knowledge, expertise and perceptions about the sets of GTIs. Stakeholders could then review the data display and continue their co-analysis activity as they began to use Direct Ranking to select a single GTI for implementation at local level.

Direct Ranking is an interactive technique for identifying priorities or preferences in a democratic manner. It yields a visual result in chart form. Box 1 provides a summary of the generic steps for this technique. In RESTORE, the specific application of Direct Ranking was to produce a clear, documented democratic result—a single GTI for implementation that stakeholders are willing to “sign up to” for Stage 3. The images selected to represent each GTI were photographs of the front covers of GTIs. The agreed ranking criterion was “Prioritize the GTIs in terms of the most-to-least suitable for implementation in our general practice setting and context.” Stakeholders had equal voting power as they had 20 paper clips each (see Figure 2). The intended practical outcome expected of Direct Ranking Charts in RESTORE was that they would present a visual, tangible data display of stakeholders’ decision about which GTI was considered most suitable for implementation in their setting. Across research sites, the majority of PLA sessions involving Commentary Charts and Direct Ranking were each 2-3 hours in duration. The completed paper-based charts were computerized to preserve them and to make them readily available for further analysis.
Evaluation of the use of PLA techniques in RESTORE

Stakeholders at all sites participated in qualitative “speed” evaluations (SEs) to document their experiences of involvement in their PLA sessions. A “speed evaluation” is a brief verbal (digitally recorded) or written evaluation, which provides an opportunity for stakeholders to describe experiences in their own words and suggest areas for improvement. It allows researchers to “take the temperature” of the group, to build on positives, and, where possible, to plan suggested improvements for forthcoming PLA sessions. Speed evaluations usually occur at the close of a PLA process or session. Participants respond to an open-ended question in a rapid, interactive and spontaneous way. For example, on completion of Commentary Charts, the question was as follows: “During this session, we worked together in a participatory way: listening, learning, creating our Commentary Charts. In a word or phrase, please comment on your experience of this.”

Stakeholders at the Irish site also completed a participatory evaluation (PE) because the facilitators there had extensive experience of this technique. This form of more in-depth collaborative evaluation is judgement-based and may be formative or summative. Stakeholders responded to questions focused on Direct Ranking and their experiences of engagement in the PLA process. An “open category” question also invited stakeholders to comment on any aspect of their experience, especially if there were any improvements and/or changes that could be made. Speed and participatory evaluations were either noted or audio-taped and transcribed at each site, and collated as reports by the researchers. We had ethical approval to include data from all of these reports in the analysis for this paper, apart from the data from the English site.

All academic researchers involved in PLA fieldwork participated in in-depth reflection interviews (R Int), conducted by the PLA trainers, at the close of Stage 2 fieldwork (n=16). Interviews were conducted face-to-face or by Skype; interview length ranged from 50 minutes to 1 hour 45 minutes, depending mainly on the number of researchers involved (eg Austria - 1 interviewee; The Netherlands - 4). The interview schedule was circulated to all teams in advance. They were asked to reflect on the use of Commentary Charts and Direct Ranking with reference to their experiences of the techniques and their observations of stakeholders’ experiences of them (see File S2 for this topic guide). Interviews were audio-taped and professionally transcribed. All evaluation data were collated and analysed following the principles of thematic analysis in qualitative research. The PLA researchers at the Irish site, who have more than 25 years’ experience of qualitative interviewing, generated a “start list” of codes derived from participatory research literature describing meaningful engagement (eg active inclusion, collaboration/colllegiality, power-sharing) and its opposite (eg exclusion/passivity, researcher-controlled, powerlessness). This, augmented by repeated readings of researchers’ and stakeholders’ data, generated a final set of 33 codes. Each code was understood to incorporate its mirror or binary opposite. Data were collated under these codes to identify emerging themes. The researchers also conducted a basic content analysis to establish the relative weighting of “positive” to “negative” evaluation comments in the final set of themes. In keeping with our comparative case study design, the analysis of all evaluation data explored shared and differential findings across the five contexts. Using different enquiry techniques (speed and participatory evaluations, focus group discussions and team “reflection” interviews) to explore researchers’ and stakeholders’ perspectives about their experiences of the same events (PLA sessions), we achieved a measure of triangulation, or cross-validation.
As per Lincoln and Guba,49 prolonged involvement of researchers in fieldwork for “trust-building” and “knowing the culture,” coupled with persistent observation of stakeholders’ reactions to PLA methods and peer debriefing by research teams when producing regular field reports, contributed to study depth. This, in conjunction with the triangulation or cross-validation mentioned above, contributed to and enhanced the trustworthiness, credibility and dependability of the study. 49,53

Results

Study sample
There was appropriate representation of stakeholders at each site by gender, age group, country of origin and type of stakeholder group (see Table 1), thus validating the purposefulness of the sample.

Table 1 Stakeholders’ socio-demographic characteristics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Austria</th>
<th>England</th>
<th>Greece</th>
<th>Ireland</th>
<th>Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>6</td>
<td>2</td>
<td>6</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>7</td>
<td>10</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>31-55</td>
<td>9</td>
<td>7</td>
<td>11</td>
<td>11</td>
<td>20</td>
</tr>
<tr>
<td>56 plus</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Country of origin</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chile</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Congo</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Ireland</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Nigeria</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Poland</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Portugal</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Russia</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Netherlands</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td>Morocco</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Indonesia</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Philippines</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Greece</td>
<td>-</td>
<td>-</td>
<td>13</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Syria</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Albania</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>UK</td>
<td>-</td>
<td>6</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Pakistan</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Austria</td>
<td>7</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Croatia</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Turkey</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ghana</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Benin</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Undefined</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Stakeholder Group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Migrant community</td>
<td>8</td>
<td>7</td>
<td>2</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Primary care doctors</td>
<td>5</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Primary care nurses</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Primary care admin/management staff</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Interpreting community</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Health service planning and/or policy personnel</td>
<td>5</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>
Material practices for meaningful engagement: An analysis of participatory learning and action research techniques

We monitored attendance at each session and over time. There was good, sustained involvement of stakeholders across settings for the duration of Stage 2, which involved six PLA sessions. Specifically, there were only minor variations in the sample, for example if a stakeholder could not attend due to work or personal commitments. Only two stakeholders dropped out (both from the English setting) during the fieldwork period (September 2012 to May 2013).

There was strong representation of the academic research team, as 16 of 18 individuals participated in PLA fieldwork and its evaluation (see Table 2).

### Table 2 Description of RESTORE researchers trained in PLA

<table>
<thead>
<tr>
<th>Country of origin</th>
<th>Austria</th>
<th>England</th>
<th>Greece</th>
<th>Ireland</th>
<th>Netherlands</th>
<th>Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-30</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>31-55</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>56 plus</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Country of origin</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Emergent themes**

We identified five interrelated themes of stakeholders’ experiences that elucidate their positive perspective on the PLA techniques (see Table 3). Findings were relevant across countries and participant groups unless otherwise specified.

Stakeholders described their overall involvement in the PLA process of co-generation and co-analysis in ways that speak powerfully of (1) meaningful engagement in a “safe space”: active inclusion, collegiality, collaboration. They reported that group dynamics were positive. The working environment was considered safe, allowing stakeholders to readily and safely express diverse views in a relaxed and enjoyable manner. This was also noted and commented on by researchers.

Stakeholders described how there was (2a) enhanced learning throughout the process of using Commentary Charts and Direct Ranking. The Commentary Charts facilitated exposure to each other’s perspectives about the GTIs and contributed to positive experiences of enhanced learning. Researchers considered that this placed stakeholders in a more informed position from which to prioritize GTIs during Direct Ranking. For example, in Ireland, details about time demands in general practice surgeries were described by the general practice stakeholders. This enhanced other stakeholders’ understanding of the clinical setting and impacted on their assessment and ranking of the GTIs that they were examining (see File S3 for a detailed example from the Irish setting). It was clear that (2b) enhanced learning led to important new understandings and, on occasion, resulted in
shifts away from long-held positions and towards new possibilities. This suggests that the sharing of diverse perspectives during co-analysis enabled stakeholders to broaden their horizons. Researchers’ comments reflected stakeholders’ sense of the “flow” between the two techniques. Researchers noted the interactive energy of stakeholders’ involvement in a PLA process that generated a “win-win” outcome. Furthermore, the visual nature of Direct Ranking allowed stakeholders to engage in a nuanced decision-making process which was demonstrably democratic. This indicated (3) democracy-in-action. Stakeholders enjoyed positioning GTIs and Post-It notes (stickies) and distributing their 20 “paper clip” votes on the chart. Asymmetrical power relations were balanced in part by the fact that 20 votes per stakeholder meant equal voting power and equal opportunity to influence the outcome. Finally, by arranging the GTI images according to the vote count, the democratic outcome was immediately accessible to all and the chart showed the important result stakeholders had achieved. Researchers noted the equalizing power of PLA, “levelling the playing field,” and that stakeholders with a lower level of language skills were not disenfranchised—they could “see” the result; the presence (density) compared to absence (paucity) of paper clips visually expressed what a numerical count confirmed. Stakeholders recognized that their choice represented a fundamental input into the progress and trajectory of the research. Exercising power in this way contributed to a genuine sense of “ownership” of the research project: (4) power, ownership. Researchers commented on the genuineness/authenticity of stakeholders’ interactions—the willingness of some stakeholders to put others before themselves. This was even the case where the vested interests of typically powerful stakeholders might be expected to win the day, but where choices inclusive of all stakeholders actually won out. An important outcome was (5) sustained engagement. Direct Ranking provided opportunities for stakeholders to experience “positive power,” and researchers noted that they often linked this to the “light” side of PLA: energy, enjoyment, fun and achievement. This “lightness” seemed to offset research fatigue and contributed to sustained meaningful engagement of stakeholders in Stage 2 research.

### Table 3 Positive experiences of involvement

<table>
<thead>
<tr>
<th>Analytical themes</th>
<th>Supporting quotes from stakeholders (SH) and researchers (R)</th>
</tr>
</thead>
</table>
| 1. Meaningful engagement in “safe space” | Great feeling of safety within the group. I felt comfortable to express my views and suggestions. IRL Migrant and Community interpreter PE  
It is not necessarily always the case to work with different professionals in this relaxed way. AUS academic SE  
Interaction gives the participant an opportunity to express his/her views. NL Nurse SE  
Service users at the other end of the [power] spectrum, if you like, who maybe are used to having little power in that type of situation, felt very protected and safe. I think it’s a testimony to the process as well as everything else. IRL Researcher #1 R Int |
| 2a. Enhanced learning | Brilliant process. Couldn’t have predicted the variety of viewpoints and perspectives. IRL GP SE  
The participatory approach was very interesting as well as how we exchanged ideas and knowledge … GR academic SE  
The most interesting [thing] for me was that we also had the opportunity to talk to each other about our own experiences. I did not know that so many people do have the same—or at least familiar—experiences, like me. AUS Migrant SE  
It is definitely useful, fascinating and, to my idea, effective to analyse trainings [GTIs] together. NL Practice Nurse SE |
| 2b. Enhanced learning | I suddenly recognised that those essential contents do not only affect migrants, or people with a migratory background, but also [other] patients. AUS GP SE  
Evaluating trainings with other disciplines is nice and inspiring (leads to out of the box thinking). NL GP SE |
| Material practices for meaningful engagement:  
| An analysis of participatory learning and action research techniques |

**generated new understandings**  
Usually, in these sessions, I think of the interpreting point of view and then of the view of the migrant service-user but then I said, “No, I also have to [think] from the point of view of someone that helps migrants a lot [referring to another stakeholder]”—it’s three hats I have to put on all of the time and then decide for each one which is the more relevant thing! Today was a challenge because I was saying to myself I have to use the three hats and do it quick. I was happy with the way I was managing that today. Migrant and Community interpreter IRL SE  
Our continuing session [Direct Ranking]... flowed together with this methodology used, because we did not forget our previous commentary [charts] based on this participatory approach. GR Primary care nurse SE  
It [Direct Ranking] was just wonderful, it was the high point of the whole research [process in Stage 2]... it flowed, everybody was enjoying it [and] everybody got absolutely involved in the whole business. ENG Researcher #1 R Int  
The ranking was interactive. It was an important thing we found as we saw that people during the ranking were already interacting—“hey, what are we going to do?”—and that was quite a natural process. It was not a process of winning and losing, I found out. That was surprising to me. NL Researcher #1 R Int

| 3. Democracy-in-action | 20 votes rather than one—very interesting! Colour-coded voting [was] excellent. [A] visual as well as numeric result! IRL Health service planner PE  
The best part for me was the voting process, everything was equal. GR Migrant SE  
The process of voting [during Direct Ranking] and the result itself... I think this really helped them to [have] trust in the technique. AUS Researcher #1 R Int  
This was a qualitative technique which resolved into a quantitative technique, kind of... you can also really give them a number. You can say, okay, out of 10 people, eight liked that [GTI] the most... and I really think our stakeholders, and especially I have to say our GP, really liked this also the most. AUS Researcher #1 R Int  
And it was fantastic I think to see how well the voting process actually worked and you know when the final figures were tallied that in fact all of the stakeholders were very, very happy with the outcome. That was striking... a very positive outcome because it needn’t have gone that way. IRL Researcher #1 R Int  
Yeah, it’s also good for people with less language skills, it’s a good system for them to be part of the process... it’s about working with paper clips and it’s visual and I thought especially the ranking process made them [migrant stakeholders] part of the whole group, because in the beginning it was difficult for some migrants to express themselves. And then, they were, you know, standing next to each other and doing it by themselves and it [the process] was really helpful to get them committed, in my opinion. NL Researcher #1 R Int

| 4. Power, ownership | I feel like we have accomplished so much and this methodology shows it! GR GP SE  
It gave me a feeling of importance to participate here. AUS Migrant SE  
Yes, it [choosing the GTI] matters! We looked at options, positive/negative, and together we came up with a decision. It is important as we go to the next stage [Stage 3 of research] that we “own” the option chosen. IRL Health Service Planner PE  
But there was another training [GTI] that was exclusively for GPs that could be very good and strong training [which] was not appropriate for other parties, so the GPs, although they would have liked that one themselves, they chose the other one, which they could be involved in as well. NL Researcher #2 R Int  
Both of our [stakeholder] groups were very enthusiastic... we explained it [voting system] and they felt that they had power, it’s kind of like how you taught us... it’s giving them power, the votes, so we saw that. And what else? They were excited. GR Researcher #2

| 5. Sustained engagement | And also I think they found it fun, the stakeholders around the table—they were also a bit surprised but they considered it fun. NL Researcher #2 R Int  
The process worked so well... every stakeholder was happy with the chosen GTI. That was amazing... it’s a great testament to the process. [There] was a great sense of achievement, personal achievement, team achievement and stakeholder group achievement, fantastic. And then... an eagerness to move on to the next stage as well. IRL Researcher #1 R Int  
We also think the [PLA] system will work ... because people like these methods, they will go further on with this. NL Researcher #1 R Int |
Negative comments were also identified. Speed evaluation data from The Netherlands comprised a total of 21 stakeholder comments. Of these, there were five negative responses. Speed and participatory evaluation data from Ireland, where evaluations were more extensive, generated 80 stakeholder comments. There were two negative responses. No negative comments were recorded in data from Greece or Austria. However, our content analysis showed that five of 15 stakeholders in Austria chose not to offer evaluation comments of any nature.

Analysis of the negative comments about the PLA techniques shows that the process was considered overly time-consuming by some Dutch clinical stakeholders. There was also a reduced sense of inclusion for some stakeholders in The Netherlands due to the inter-stakeholder representation in the PLA sessions.

1. ‘Slow, too labour-intensive.’ Netherlands (NL) Nurse SE
2. ‘Useful meeting, the presentation can be done faster.’ NL General Practitioner SE
3. ‘Learning-full, but I felt a little like an outsider not involved in daily practice.’ NL Practice Manager SE
4. ‘Nice! Maybe without migrant participants there might be more space for interaction.’ NL SH#76 SE

The other negative comments were RESTORE-specific (rather than about the PLA processes per se) and came from The Netherlands and Ireland, early in Stage 2. They related to the view that the summaries of the GTI were too brief and needed to be longer to make better judgements, and a degree of uncertainty about what the objective of the process was.

1. ‘I am not sure of the potential benefits of assessing GTIs.’ Ireland (IRL) Community Interpreter SE
2. ‘Not clear on the outcome of the session/what we want to achieve by assessing GTIs?’ IRL Community Interpreter SE

Discussion

In this paper, we have explored the perceived utility of two PLA techniques—Commentary Charts and Direct Ranking—for data generation and analysis with a diverse sample comprising migrants, general practice staff, community interpreters, service providers, service planners and academic researchers.

Summary of findings

Our findings show that Commentary Charts and Direct Ranking techniques, with their visual nature and inherent analytical capabilities, were experienced by stakeholders from both community and health-care settings as powerful tools for collaborative decision making. There was consensus among stakeholders and researchers that there were few negative experiences, and numerous multifaceted positive experiences of meaningful engagement: PLA created a “safe space” and a trusting environment in which they learned from each other’s perspectives, gained enhanced knowledge via the co-generation of Commentary Charts and used these data to inform their co-analysis during Direct Ranking. Using these two PLA techniques involved stakeholders in an experience of
“democracy-in-action” which was empowering and energizing, promoting a sense of ownership and sustained engagement in the research project.

**Contribution to existing literature**

There is limited knowledge about suitable methods for involving stakeholders in a meaningful (rather than tokenistic) way in health research partnerships.\(^3\)\(^{11}\) There is evidence that participatory learning and action research approaches and methods seem promising.\(^5\)\(^{32-36}\) In line with this, our findings show that the application of specific PLA techniques in RESTORE proved fit for purpose. Taken together, the five themes show that academic researchers and stakeholders from community and health sector backgrounds reported that it facilitated collaborative decision making and meaningful engagement, automatically incorporating co-generation and co-analysis of data by diverse stakeholders operating in diverse primary care settings.

Furthermore, we provide new evidence about how PLA techniques are capable of delivering this— their combined visual, verbal and tangible nature and inherently analytical capabilities involved stakeholders in structured, integrated co-generation and co-analysis of research data, which delivered practical democratic results at all five sites. This empirical evidence about the capacity of PLA to “deliver” meaningful engagement in data generation and co-analysis is a significant addition to a literature that calls for methodological innovation in this sphere. These findings provide important empirical data about *experiences of participation* that are lacking in the literature.\(^3\) They support Kothari’s assertion\(^9\) that the types of techniques used by researchers can constrain or enable stakeholder involvement (eg findings from Theme 1 that the use of PLA created a safe and meaningful space for engagement and from Theme 5 that it led to sustained engagement for the duration of the fieldwork). They are also in line with Brett et al.,\(^1\) elucidating that involving stakeholders in data analysis ensures a broader interpretation of data (eg findings from Theme 2 about enhanced learning).

In keeping with Tierney et al.,\(^5\) we actively explored both positive and negative experiences. In line with Domecq et al.’s review,\(^11\) stakeholders were predominantly positive about their experiences. In particular, themes 3 and 4 (Democracy-in-action; Power, ownership) reveal the ways in which power imbalances were reduced and that experiential learning, rather than reiteration of professional concepts, became the *common ground* upon which democratic decision making took place. This is an important function of PLA: to “level the playing field” where asymmetric power relations between stakeholders/stakeholder groups may exist.\(^7\)

Our results show that this levelling also occurred between stakeholders and researchers: throughout the Commentary Charts and Direct Ranking, it was stakeholders who exercised power and took on the key responsibility of selecting a GTI for implementation, thereby “setting the agenda” for the final stage of RESTORE fieldwork. Researchers, in their capacity as catalysts, facilitated but did not control this process. This shared ownership and agenda-setting takes us firmly beyond tokenism and towards a “shared power” approach, enhancing the research partnership.

The rare, negative experiences reported by stakeholders in this study warrant attention: the time and pace of research, the need for comprehensive information to facilitate equitable participation, and the possibility that bringing different types of stakeholders together may, on occasion, actually
reduce a sense of active inclusion for a minority. While concerns about time demands and tokenistic participation have been reported previously, the empirical findings about disadvantages of interactions in mixed stakeholder groups are new. Therefore, this analysis of two PLA techniques to support such dialogues is an important contribution to the literature.

**Methodological critique and suggestions for future research**

We were unable, for site-specific ethical reasons, to include the use of stakeholder evaluation comments from the English site in our thematic and content analyses. However, we were able to ameliorate this by including comments from researchers’ reflection interviews. We cannot claim representativeness of findings for the qualitative study data presented here. However, we emphasize that in this comparative case study, spanning five European countries with very different primary care systems, the same PLA techniques were used and successfully involved diverse stakeholders in data generation and co-analysis.

Regarding the PLA techniques employed, there was variation in our use of PLA Commentary Charts: stakeholders reviewed the Commentary Charts together at the same time in some settings, while some were physically removed from one another and reviewing the Commentary Charts after others had done so. This may have created variation across the sites and this possibility would be worth exploring in future work.

Regarding evaluation methods employed: speed evaluations are efficient and the key messages recorded were similar to those in the additional participatory evaluation conducted at the Irish site. However, the brevity of speed evaluations does not encourage rich, lengthy, in-depth stakeholder responses. The additional participatory evaluation conducted did provide richer data, while researchers’ reflections also added to the quality and depth of evaluation data. Therefore, we suggest using an array of PLA evaluation techniques in future projects to explore all stakeholders’ experiences of involvement in greater depth.

RESTORE ended before our thematic analysis of stakeholders’ evaluation data took place, and we did not, therefore, benefit from their contribution to the development of codes and categories for thematic analysis, nor from their potential insights about the relevance and veracity of evaluation results. While we are confident that data saturation was achieved as the analysis reached a point where the codes and themes were comprehensive, we acknowledge the lack of member checking. In future projects, it would be apposite to invite stakeholders to co-generate evaluation criteria and to co-analyse the results of evaluation data, thus closing the circle of “involvement.”

To add to the evidence base, we need further research and evaluation to explore whether and how PLA techniques might work when applied in projects with very different research foci and stakeholder groups to those in RESTORE. The specifics of involving community and health sector partners in analysis of other qualitative methods, such as interviews and focus groups, would also be valuable.
**Conclusion**

PLA Commentary Charts and Direct Ranking techniques, with their distinctive visual, verbal and tangible nature and inherently co-analytical capabilities, are rated very positively by stakeholders and researchers. The positive benefits gained from the PLA process in this study (knowledge sharing, knowledge enhancement, levelling the playing field, new knowledge impacting on collaborative decision making) outweighed the negatives. The significant additional investment of resources was impactful and was worth the time and effort. Therefore, we recommend the use of these two PLA techniques as material practices to enable collaborative decision making and meaningful engagement in health research partnerships.

**Acknowledgements**

We thank all stakeholders who were involved in the RESTORE project for their time commitment and contribution of knowledge. We thank our RESTORE project consortium members for their involvement and support with this research: Ciaran Clissmann, Francine van den Driessen Mareeuw, Frances Mair, Christine Princz, Erik Teunissen and Maria Vlahadi.
References


Material practices for meaningful engagement:
An analysis of participatory learning and action research techniques


34. McMenamin R, Tierney E, MacFarlane A. Who decides what criteria are important to consider in exploring the outcomes of conversation approaches? A participatory health research study *Aphasiology.* 2015;29:914-938.


47. Mukherjee N. *Participatory Learning and Action, with 100 Field Methods.* New Delhi: Concept Publishing; 2001.


RESTORE Project  
2011-2015  

Stakeholders (even the smallest) are warmly welcomed to an evening of PLA research activities.

Inter-stakeholder dialogue in action:

Stakeholders use a Seasonal Calendar technique to discuss and plot a timeframe and range of tasks related to implementing their chosen Guidance/ Training Initiative: ‘Working with an Interpreter is Easy’.

But as the chart develops, it reveals a heavy burden of tasks on the practice staff, who are now looking concerned. This uneven workload is a serious problem. It could negatively affect their implementation plans. The other stakeholders suggest re-negotiating the allocation of tasks to lighten the burden on practice staff. Community interpreters say they will handle advertising posters. Other stakeholders take on other tasks. This small leap of generosity is a ‘transformative moment’ for the group.
Chapter 9

Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: An analysis of stakeholders’ experiences


de Brún T
O’Reilly- de Brún M
Van Weel-Baumgarten E
Burns N
Dowrick C
Lionis C
O’Donnell C
Mair FS
Papadakaki M
Saridaki A
Spiegel W
Van Weel C
Van den Muijsenbergh M
MacFarlane A
Plain English summary

It is important for health care workers to know the needs and expectations of their patients. Therefore, service users have to be involved in research. To achieve a meaningful dialogue between service users, healthcare workers and researchers, participatory methods are needed. This paper describes how the application of a specific participatory methodology, Participatory Learning and Action (PLA) can lead to such a meaningful dialogue. In PLA all stakeholders are regarded as equal partners and collaborators in research.

During 2011 – 2015, a European project called RESTORE used PLA in Austria, Greece, Ireland, The Netherlands and the UK to investigate how communication between primary health care workers and their migrant patients could be improved.

78 migrants, interpreters, doctors, nurses and other key stakeholders (see Table 2) participated in 62 PLA sessions. These dialogues (involving discussions, activities, PLA techniques and evaluations) were generally 2-3 hours long and were recorded and analysed by the researchers.

Participants reported many positive experiences about their dialogues with other stakeholders. There was a positive, trusting atmosphere in which all stakeholders could express their views despite differences in social power. This made for better understanding within and across stakeholder groups. For instance a doctor changed her view on the use of interpreters after a migrant explained why this was important. Negative experiences were rare: some doctors and healthcare workers thought the PLA sessions took a lot of time; and despite the good dialogue, there was disappointment that very few migrants used the new interpreting service.

Abstract

Background

In order to be effective, primary healthcare must understand the health needs, values and expectations of the population it serves. Recent research has shown that the involvement of service users and other stakeholders and gathering information on their perspectives can contribute positively to many aspects of primary healthcare. Participatory methodologies have the potential to support engagement and dialogue between stakeholders from academic, migrant community and health service settings. This paper focuses on a specific participatory research methodology, Participatory Learning and Action (PLA) in which all stakeholders are regarded as equal partners and collaborators in research. Our research question for this paper was: "Does the application of PLA lead to meaningful engagement of all stakeholders, and if so, what elements contribute to a positive and productive inter-stakeholder dialogue?"

Methods

We explored the use of PLA in RESTORE, a European FP7-funded project, during 2011 – 2015 in 5 countries: Austria, Greece, Ireland, the Netherlands and the UK. The objective of RESTORE was to investigate and support the implementation of guidelines and training initiatives (G/TIs) to enhance communication in cross-cultural primary care consultations with migrants. 78 stakeholders (migrants, interpreters, doctors, nurses and others – see Table 2) participated in a total of 62 PLA sessions (discussions, activities, evaluations) of approximately 2-3 hours’ duration across the five sites. During the fieldwork, qualitative data were generated about stakeholders’ experiences of engagement in
this dialogue, by means of various methods including participatory evaluations, researchers’ fieldwork reports and researcher interviews. These were analysed following the principles of thematic analysis.

**Results**

Stakeholders involved in PLA inter-stakeholder dialogues reported a wide range of positive experiences of engagement, and very few negative experiences. A positive atmosphere during early research sessions helped to create a sense of safety and trust. This enabled stakeholders from very different backgrounds, with different social status and power, to offer their perspectives in a way that led to enhanced learning in the group – they learned with and from each other. This fostered shifts in understanding – for example, a doctor changed her view on interpreted consultations because of the input of the migrant service-users.

**Conclusion**

PLA successfully promoted stakeholder involvement in meaningful and productive inter-stakeholder dialogues. This makes it an attractive approach to enhance the further development of health research partnerships to advance primary healthcare.

**Background**

Concerns about increasing health care expenditure with diminished health-related returns on investment are the driving factor behind many health reforms. In parallel with this, there is a paradigm shift towards person-centred care that is responsive to individuals, groups and communities.\(^1\)\(^2\) Responsive, effective primary healthcare systems are an important element of this development.\(^3\)\(^4\) In order to be effective, primary healthcare must be informed by an accurate understanding of the diverse health needs, values and expectations of the populations they serve, and how these are affected by the social and cultural determinants of health.\(^3\)\(^6\) This requires an exchange and information gathering process between primary healthcare professionals and patients/service-users in individual encounters, as well as in research and service planning. This paper relates to patient and public engagement in primary healthcare research partnerships\(^7\)\(^12\) and our specific focus is on migrant health. There are increasing imperatives for involving patients and members of the public in health research. There is international support for Public and Patient Involvement (PPI) in the form of legislation and policy directives\(^13\) and it is increasingly advocated by health funding agencies and Government health departments.\(^7\)\(^9\)\(^11\)\(^12\)\(^14\)

The first international evidence about the impacts of PPI at all stages of research from design to dissemination is well-documented in the PIRICOM study, a recent systematic review of 66 PPI studies. PIRICOM indicated that the involvement of stakeholders (see Table 1) can make positive practical contributions to many aspects of primary healthcare research, for example, fostering greater honesty in the flow of information during data-generation and a broader interpretation of data during data-analysis.\(^15\) Pearson et al also note the positive value of stakeholders’ insights regarding, for example, service-design, quality and safety.\(^16\)
Table 1. Definitions and descriptions of key terms

<table>
<thead>
<tr>
<th>Definitions and descriptions of key terms</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Researcher/catalyst</strong></td>
</tr>
<tr>
<td>Researchers who adopt a PLA approach, techniques and mode of engagement act as catalysts – their primary role and responsibility is to elicit diverse stakeholders’ perspectives and facilitate collaborative inter-stakeholder dialogue/action. The researcher/catalyst facilitates, rather than controls, the direction that stakeholder’s perspectives provide to the research process. <strong>60</strong></td>
</tr>
<tr>
<td><strong>PLA ‘mode of engagement’</strong></td>
</tr>
<tr>
<td>A PLA ‘mode of engagement’ is the essential attitudinal disposition a researcher/catalyst adopts to promote participation, learning and positive action by and with diverse stakeholder groups; the researcher/catalyst listens, enables, supports stakeholder/inter-stakeholder dialogues, which are ideally reciprocal, mutually respectful, co-operative and productive. <strong>19,31</strong> Where necessary and appropriate, researchers may act as knowledge-brokers, sharing perspectives and insights that emerge from one stakeholder group with the next, thus ‘brokering’ an educative inter-stakeholder dialogue. <strong>19,20</strong></td>
</tr>
<tr>
<td><strong>PLA research methods and techniques</strong></td>
</tr>
<tr>
<td>The broad range of qualitative, participatory activities typical of PLA research which combine the verbal, visual and tangible. Verbal activity includes focus groups, interviews, dialogues, debate and negotiation, story-telling, oral histories, role-play and drama. These are usually combined with visual and tangible activity – generating physical maps, charts, diagrams (e.g., Commentary Charts, Direct Ranking, Seasonal Calendars). Stakeholders’ priorities and perspectives guide this participatory engagement process. <strong>19,20,31,55,60</strong></td>
</tr>
<tr>
<td><strong>Meaningful engagement</strong></td>
</tr>
<tr>
<td>We draw from the work of Cornwall and Jewkes, <strong>18</strong> Gaventa <strong>21</strong> and Chambers <strong>22</strong> in defining ‘meaningful engagement’ as an experience of partnership in research that is collegial, inclusive and active for participants, reduces asymmetries of power and enables participants’ authentic perspectives to emerge clearly in research outcomes. A PLA mode of engagement, research methods and techniques are intended to support and facilitate meaningful engagement in inter-stakeholder dialogues.</td>
</tr>
<tr>
<td><strong>Stakeholder</strong></td>
</tr>
<tr>
<td>Drawing from McMaster Health Forum (2015) we describe a stakeholder as an individual, group or organisation that has an interest in the organisation and delivery of healthcare and will have an interest in the content or outcome of a guideline.</td>
</tr>
<tr>
<td><strong>Inter-stakeholder dialogue</strong></td>
</tr>
<tr>
<td>Drawing from the work of McMaster <strong>81</strong> regarding ‘stakeholder dialogue’, and Pronk <strong>82</strong> and Ashraf <strong>83</strong> regarding ‘multi-stakeholder dialogue’ we describe inter-stakeholder dialogue as a multi-directional dialogue that occurs between/among diverse stakeholders. Diverse stakeholders may coalesce into a single group, or be dispersed across several groups. Inter-stakeholder dialogues focus on a shared goal (e.g. a health issue or problem all stakeholders have a vested interest in addressing/solving). By learning from each other’s perspectives, stakeholders may develop unique understandings or uncover insights related to the issue or problem at hand, generating creative solutions regarding key implementation considerations. This can only come about when relevant stakeholders who are involved in, or affected by decisions related to the issue, work through it together, charting an agreed course of action towards their shared goal.</td>
</tr>
<tr>
<td><strong>Transformative moments</strong></td>
</tr>
<tr>
<td>During PLA research, transformative moments can occur when stakeholders (working in a group or across several groups) face a seemingly intractable problem and, through dialogue, some stakeholders make a small leap of generosity towards others, thereby resolving the impasse. <strong>65,84</strong></td>
</tr>
</tbody>
</table>

However, as early as 2002, Beresford warned that increasing pressures for stakeholder involvement from a wide range of sources could lead to it being seen as a ‘must-do, virtuous activity’ which can lead to a ‘tick-box’ tokenistic approach, simply going through the motions, but failing to go beyond a consumerist approach. He emphasises the value of a democratic approach which involves...
Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue

stakeholders in powerful decision-making roles in research to enable them to improve the quality of their lives. The current literature on PPI in research indicates that involvement spans a continuum from inclusion of stakeholders as passive subjects of a study (tokenistic involvement) to the inclusion of stakeholders as active participants, collaborators and contributors to many aspects of research activity (meaningful engagement – see Table 1). For some patient groups, active participation is even more challenging than for others. For instance, migrants, the focus of RESTORE, are less often included, let alone actively participate in research, due to communication barriers and unfavourable socio-economic living conditions. Domecq, Prutsky et al reviewed 142 studies that described a spectrum of engagement and concluded that, while engagement seems feasible in most cases, both service-users and researchers had overarching concerns about tokenism. Their review is consistent with previous reviews in the field of PPI and they conclude that there is limited knowledge about particular methods for enacting meaningful engagement and that research dedicated to identifying the best methods for this is lacking and clearly needed.

Similarly, following Jagosh et al who emphasise the importance of partnerships for health research, it is clear we need to know more about effective methods for developing research partnerships that can facilitate meaningful dialogue between stakeholders from academic, community and health service settings. These need to be supported by a relational environment of trust and mutual respect, generating ‘safe spaces’ where stakeholders feel secure and empowered to actively participate. The challenge is not to subsume differences of opinion and knowledge, but to enable stakeholders to deal positively with differences and to seek mutually acceptable outcomes. At its best, then, inter-stakeholder dialogue (see Table 1) has the potential to empower diverse stakeholders to contribute their unique insights to the co-generation of knowledge in research processes. This challenging task of engaging stakeholders (who may hold diametrically opposing views) in productive inter-stakeholder dialogue requires a research approach, methodology and techniques suited to the task. To address these problems and challenges of PPI, it is valuable to draw on a ‘bottom-up’ participatory research methodology that is inherently dialogic in nature.

There is a range of participatory methodologies including, among others, Participatory Research (PR), Participatory Action Research (PAR), Community Based Participatory Research (CBPR), Participatory Rural Appraisal (PRA) and Participatory Learning & Action (PLA). All share a democratic ethos, are strongly committed to meaningful engagement by stakeholders, and promote research partnerships that strengthen relations between academy and community. Participatory approaches emphasise the need for stakeholders’ active engagement across the full range of research activities.

This paper focuses on PLA because recent research studies in primary healthcare indicate the scope for meaningful research partnerships with migrants which can be realised by PLA, and warrant further investigation.

PLA is a form of action research, rooted in interpretive and emancipatory paradigms and influenced by the work of Robert Chambers. It is a practical approach to research with diverse stakeholders where different world-views pertain and asymmetries of power may exist and need to be balanced. An important principle of PLA is the reversal from a perception of stakeholders (see Table 1) solely as beneficiaries to a perception that stakeholders are also partners and collaborators.
Researchers use a PLA ‘mode of engagement’, and act as catalysts to support an inclusive atmosphere and positive tone with and among stakeholders. A key aim is to create ‘safe space’ and trusting relationships in which stakeholders can feel sufficiently secure to risk sharing diverse perspectives and opinions. Researchers actively encourage stakeholders to recognise that they are ‘experts’ in their own right, possessing unique implicit knowledge of their lives and conditions. They bring their valuable knowledge to the ‘stakeholder table’, where, by participating in a range of PLA techniques, they engage in iterative cycles of discussion and dialogue which makes their knowledge explicit and therefore available to the research. The inclusive, user-friendly and democratic nature of PLA techniques also encourages stakeholders to co-operatively assess, generate and analyse data, to create workable solutions to problems that may arise during research, and to plan for change and/or implementation.

In practical terms, stakeholders achieve this through the generation of maps, charts, diagrams (visual and tangible data) while engaging in one or other form of discussion/dialogue, e.g., focus groups, interviews, story-telling, drama, role-plays (verbal data). The production of maps and charts is not the primary goal – the knowledge-exchange, knowledge-enhancing process that goes on among stakeholders as they work together on these tasks is key to the inter-stakeholder dialogue and the research outcomes. As inter-stakeholder dialogues develop, the knowledge-exchange, knowledge-enhancement process can lead to learning the new or the unexpected and stakeholders may experience shifts and changes in their understanding. This occurs in a relational environment that tends to be characterised by co-operation rather than competition. While the use of PLA in primary healthcare research is growing and migrants’ experiences of the methods have been reported, there has been no detailed analysis to date of the use of PLA methods for inter-stakeholder dialogues with migrants in health research. The sharp rise in migration (especially of refugees) to the European Union in recent years lends an urgency to addressing this gap in knowledge.

In this paper, our objective is to address this knowledge gap by exploring the use of a Participatory Learning & Action (PLA) research methodology for inter-stakeholder dialogue in a recent European primary healthcare implementation project – the RESTORE project. We use empirical evidence of stakeholders’ experiences of, and researchers’ reflections on this type of dialogue to develop and present an analysis intended to enhance our understanding of what makes for positive and productive inter-stakeholder dialogue. Our main research question to be answered in this paper was: "Does the application of PLA lead to meaningful engagement of all stakeholders, and if so, what elements contribute to a positive and productive inter-stakeholder dialogue?"

In Table 1 we present definitions and descriptions of key terms used throughout this paper.

**Methods**

**Study setting and design – the RESTORE project**

RESTORE (REsearch into implementation STRategies to support patients of different ORigins and language background in a variety of European primary care settings) was an EU FP7-funded project running from 2011-2015. The objective of RESTORE was to investigate and support the implementation of guidelines and training initiatives to enhance communication in cross-cultural
primary care consultations. This was a qualitative, comparative case-study informed by Normalisation Process Theory (NPT) and PLA.

RESTORE involved diverse stakeholders across five primary care settings with diverse primary healthcare systems: Austria, England, Greece, Ireland and The Netherlands. A sixth research team in Scotland focussed on policy-related implications of the study. The choice of countries matched the academic teams who developed the original FP7 proposal and intentionally included countries with diverse primary health care systems. Ethical approval was granted by the respective national committees.

RESTORE was designed as part of a series of participatory research studies with migrant community involvement exploring communication in cross-cultural consultations. The design and governance of RESTORE was led by an academic consortium but, following the principles of PLA, the research process (recruitment, fieldwork and data analysis) was inclusive of migrants and other stakeholders with significant ownership of decision-making about methods, pace of work and the implementation work in hand. There were three stages to RESTORE (see Figure 1).

A detailed description of the study protocol and the rationale for combining NPT and PLA is published elsewhere. Details of the implementation process and its outcomes are also available, and these analyses highlight the central role that the PLA methodology had on both process and outcome.

Figure 1 The three stages of RESTORE

Therefore, our focus in this paper is on our use of PLA as a methodology and range of techniques used to engage stakeholders in inter-stakeholder dialogue as they undertook parallel, but distinctive, implementation journeys during stage 2 and 3 of RESTORE. RESTORE was the overall setting in which we explored the use of PLA for inter-stakeholder dialogue.
Sampling and recruitment of stakeholders

The primary care setting in each country determined the make-up of the stakeholder groups (see Table 2) we were able to access and engage in inter-stakeholder dialogues in each country.

In this paper we focus on RESTORE Stakeholders (SH):

- Migrant service user (MSU)
- Interpreter (Int)
- General Practitioner/Family Physician (GP)
- Practice Nurse (PN) (in Austria referred to as Doctor’s surgery assistant)
- Practice Manager (PM)
- Researcher (Res)

Table 2 Stakeholders’ socio-demographic characteristics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Austria</th>
<th>England</th>
<th>Greece</th>
<th>Ireland</th>
<th>Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>6</td>
<td>2</td>
<td>6</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>7</td>
<td>10</td>
<td>8</td>
<td>19</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Austria</th>
<th>England</th>
<th>Greece</th>
<th>Ireland</th>
<th>Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>18–30</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>31–55</td>
<td>9</td>
<td>7</td>
<td>11</td>
<td>11</td>
<td>20</td>
</tr>
<tr>
<td>56 plus</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Country of origin</th>
<th>Austria</th>
<th>England</th>
<th>Greece</th>
<th>Ireland</th>
<th>Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chile</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Congo</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Ireland</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>3</td>
<td>–</td>
</tr>
<tr>
<td>Nigeria</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Poland</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Portugal</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Russia</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Netherlands</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td>Morocco</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>Indonesia</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td>Philippines</td>
<td>2</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td>Greece</td>
<td>–</td>
<td>–</td>
<td>13</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Syria</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Albania</td>
<td>–</td>
<td>–</td>
<td>1</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>UK</td>
<td>–</td>
<td>6</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Pakistan</td>
<td>–</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Austria</td>
<td>7</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Croatia</td>
<td>2</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Turkey</td>
<td>2</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Ghana</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Benin</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Undefined</td>
<td>–</td>
<td>1</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stakeholder group</th>
<th>Austria</th>
<th>England</th>
<th>Greece</th>
<th>Ireland</th>
<th>Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td>Migrant community</td>
<td>8</td>
<td>7</td>
<td>2</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Primary care doctors</td>
<td>5</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Primary care nurses</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Primary care admin/management staff</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Interpreting community</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Health service planning and/or policy personnel</td>
<td>5</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>
Purposeful and network sampling\textsuperscript{70} was used to identify and recruit 78 stakeholder representatives in primary care settings across the five sites for Stages 2 and 3 research (see Table 2 for details). Stakeholders included migrant service-users, general practitioners/family physicians (GPs), primary care nurses, practice managers and administrative staff, interpreters and cultural mediators, service planners and policy-makers. They participated in a total of 62 PLA sessions, spread over a period of 15 to 19 months, the majority of which were 2-3 hours in duration. The extensive nature of participation in terms of the number of months anticipated for fieldwork and the intention to have 2-3 hour PLA sessions at regular intervals was discussed explicitly during recruitment.

RESTORE researchers were trained in a PLA mode of engagement and series of techniques to facilitate and support inter-stakeholder dialogues. The Irish team (MacFarlane, O’Reilly-de Brun and de Brun) had previous experience with PLA.

The PLA training programme was provided by two members of the RESTORE consortium (1\textsuperscript{st} and 2\textsuperscript{nd} author) who are PLA practitioner/trainers, with over 25 years’ international experience in PLA research and training in diverse cultural and social settings.\textsuperscript{19,20,32,67,71-73}

The extensive nature of the time commitment for stakeholders and researchers was known at the outset and was explicitly discussed during recruitment and consortium meetings respectively. This issue was re-visited during consortium meetings which were held every 6 months in order to be responsive to emergent challenges. However because of the participatory nature of PLA it was not possible to predict precisely at the start how much time would be needed.

**PLA techniques used in RESTORE**

The uniqueness of the location, context and differing primary care systems, coupled with the Guideline or Training Initiative chosen, meant that each country followed its own unique implementation ‘journey’, or trajectory. These specifics meant that different combinations of PLA techniques were used to suit individual local settings. It is not possible to do justice to this complexity in this paper, but to gain a sense of what PLA ‘looks like’ in action during an inter-stakeholder dialogue, please see Table 3 and Figure 2, which provide brief descriptions of the PLA techniques used in stage 2 and 3 of RESTORE fieldwork, and Table 4 which presents a practical description of a PLA session that took place at the Irish site.

**Table 3** Stage 2 and 3 Fieldwork: Description of PLA techniques

<table>
<thead>
<tr>
<th>Stage 2 fieldwork: Description of PLA techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Co-generated Ground Rules</strong></td>
</tr>
<tr>
<td>A democratic decision-making group activity that usually occurs at the outset of a PLA research cycle or process.</td>
</tr>
<tr>
<td><strong>Aim &amp; Rationale:</strong></td>
</tr>
<tr>
<td>Generates a set of agreed rules for stakeholders’ and researchers’ co-participation, interaction, dialogue, and joint activity during a PLA research cycle or process.</td>
</tr>
<tr>
<td>Encourages active inclusion and early co-ownership by stakeholders of PLA research activities, promoting empowerment.</td>
</tr>
<tr>
<td>Helps to balance asymmetrical power relations in and between stakeholder groups where these may exist.</td>
</tr>
</tbody>
</table>
Commentary Charts

An interactive, highly-visual charting or diagramming technique promoting knowledge-exchange and knowledge-enhancement during stakeholder/inter-stakeholder dialogues.

**Aim & Rationale:**
Enables stakeholders to learn from each other’s differential knowledge, expertise and perspectives, broadening horizons and advancing stakeholder dialogue.
Generates visual ‘data displays’ of stakeholders’ perspectives and knowledge about the issue being explored, including ‘positive’ and ‘negative’ aspects of each as described from diverse stakeholders’ perspectives, in their own words. Commentary Charts are useful ‘data displays’ and aide-memoires that all stakeholders can review prior to engaging in Direct Ranking.

Direct Ranking

A democratic ranking/prioritization technique.

**Aim & Rationale:**
Enables stakeholders to democratically and transparently prioritise a set of items.
Generates visual outcome of stakeholders’ democratic decision.
Advances inter-stakeholder dialogue towards the task in hand.

<table>
<thead>
<tr>
<th>Stage 3 fieldwork: Description of PLA techniques</th>
</tr>
</thead>
</table>

Flexible Brainstorming

An interactive knowledge-generation and knowledge-exchange technique.

**Aim & Rationale:**
Enables stakeholders to rapidly generate and share data in a co-operative manner, using visual materials which are flexibly arranged and re-arranged and often brought forward into subsequent techniques.

Card Sort

A categorization technique.

**Aim & Rationale:**
Enables stakeholders to generate analytical categories that are meaningful to them and to arrange data within these categories. Particularly useful for stakeholder’s assessment and co-analysis of data.

Seasonal Calendar

A grid-based diagram involving co-operative stakeholder/inter-stakeholder dialogue, action-planning and decision-making – the diagram includes a stakeholder-informed timeframe and set of identified actions necessary for an implementation process.

**Aim & Rationale:**
Enables stakeholders to dialogue, assess and negotiate assignment of responsibilities (activities, tasks) as they co-plan their work.
Seasonal Calendars are useful as a ‘running record’ of stakeholders’ fine-tuning of action-planning, and a record of emerging outcomes of implementation/action over time. Diagrams can be computerized, readily shared among dispersed stakeholder groups, and populated with revisions, additions, deletions and updates.

Speed Evaluation (SE)

A brief verbal (digitally recorded or written) evaluation, usually conducted at the close of a PLA process or session. Stakeholders respond to open-ended questions, in a rapid, interactive and spontaneous way.

**Aim & Rationale:**
Provides stakeholders with an opportunity to describe experiences in their own words, affirming positives and suggesting areas for improvement.
Allows researchers to ‘take the temperature’ of the group, to build on positives, and, where possible, to plan suggested improvements for forthcoming PLA sessions. Coming at the close of a PLA session, speed evaluations can be as short as ten minutes, are not unduly demanding, yet yield valuable formative evaluation data.
Participatory Evaluation (PE)

A form of in-depth collaborative evaluation (formative or summative) which is based on a combination of etic and emic criteria. Etic criteria are identified in advance by researchers, whose experience enables them to suggest valuable ‘outsider’ criteria. Emic criteria emerge from shared ‘insider’ experiences, are identified by participants themselves and enable them to suggest valuable ‘insider’ criteria. The final democratically-agreed set of emic and etic criteria forms the evaluation parameters.

Aim & Rationale:

Provides stakeholders with an opportunity to suggest evaluation criteria which are important and meaningful to them. Stakeholders emic criteria are capable of yielding evaluation data about the the affective dimension of their experience, which often drives behaviour, but might otherwise remain ‘invisible’ and ‘unheard’. Researchers often note that emic criteria contribute to an evaluation in ways they could not have anticipated or planned.

Table 4 Description of inter-stakeholder dialogue, Stage 2 fieldwork - Direct Ranking PLA technique

<table>
<thead>
<tr>
<th>Description of inter-stakeholder dialogue, Stage 2 fieldwork: Direct Ranking PLA technique</th>
</tr>
</thead>
</table>
| On the evening of 6th February 2013, eleven people who are stakeholders in the RESTORE research project about migrant health gather for the seventh time in a meeting room in the National University of Ireland, Galway. Having come from various workplaces, they are greeted with culturally-appropriate refreshments. Aged between 31 and 55, eight are female, three male. Of these, eight represent migrant communities from six different countries and cultures, and five of them have experience in community interpreting. Also present are a policy planner, a practice manager and a doctor. These stakeholders make up an ‘inter-stakeholder group’ as they represent various and diverse backgrounds and fields of stakeholder expertise; they all have a vested interest in participating in the research and all have unique knowledge to contribute. All are fluent in English which is the conversation language. Two researchers from the university, who are conversant with Participatory Learning & Action (PLA) research, are facilitating this PLA session, which is one among many in a two-year-long research process. In previous meetings, these stakeholders engaged in PLA techniques to assess a range of Guidances and Training Initiatives (G/TIs) related to improving communication between migrants and healthcare professionals. They identified strengths and weaknesses of each G/TI as they perceived them. They exchanged very diverse perspectives and views, learning from and with each other, and co-generated Commentary Charts to record their findings. The atmosphere in this inter-stakeholder group is relaxed, open and trusting, which is essential because the task they face this evening is to use another PLA technique (Direct Ranking) to democratically select a single Guidance or Training Initiative for implementation in a local healthcare setting. First, they review their Commentary Charts and discuss and co-analyse them in relation to the research question asked: ‘Please rank the Guidances and Training Initiatives in terms of ‘most suitable’ to ‘least suitable’ for implementation at local level’. Having listened carefully to all perspectives, they use visual and tangible materials (images, photographs, Post-its, markers, flipchart paper, paper clips) to complete a Direct Ranking chart which clearly shows their voting result. They check their outcome, and the researchers invite them to confirm their result by engaging in continued discussion, asking key questions such as ‘Is everyone comfortable with the decision you have reached as a group?’ ‘Is there anything of concern to anyone?’ ‘Is there anything surprising about your result?’ By the end of the three-hour PLA session, eleven very diverse stakeholders have generated a transparent democratic outcome, based on their co-generation and co-analysis of data. They now know which of the G/TIs they agree to proceed with on their ‘implementation journey’; in future PLA sessions, they will use other PLA techniques to work together, fine-tuning their chosen Guidance for use in the primary care practice where the doctor and practice manager work.
Evaluation of stakeholders’ experiences of PLA

During Stages 2 and 3 fieldwork, data were generated about stakeholders’ experiences of using PLA techniques to support inter-stakeholder dialogue. A range of data sources provided information for this evaluation of experiences:

(a) qualitative speed evaluations of the sessions (minuted or audio-taped and transcribed)

(b) stakeholders at the Irish site completed an in-depth participatory evaluation which provided rich data, augmenting briefer speed evaluations

(c) researchers at all sites completed extensive post-fieldwork ‘team reflection’ interviews, either face-to-face or by Skype. These included in-depth data from researchers’ perspectives about stakeholders’ experiences of inter-stakeholder dialogue. The team interviews also documented researchers’ reflections on practice as researcher-catalysts (see Table 1) who facilitated inter-stakeholder dialogues. These interviews were audio-taped and transcribed

(d) research teams completed information-rich fieldwork reports, consistently using the same template, containing qualitative evaluation commentaries. Fieldwork reports and team interviews contained explicit questions designed to evoke rich data about both positive and negative experiences, and potential improvements that might be made. Email correspondence describing researchers’ reflections on transformative moments provided additional data.

In addition, we drew on the following data sources:

- Visual charts, e.g., Commentary Charts, Direct Ranking (all five sites); Seasonal Calendars computerized after fieldwork for analysis and evaluation purposes (all sites but Austria)
- photographic evidence of fieldwork activity and charts (all sites but Austria)
- research team post-fieldwork session debriefing notes which were audio taped and transcribed (Irish site).

Data analysis of stakeholders’ experiences of PLA

We followed the principles of thematic analysis in qualitative research to analyse our data. Two experienced PLA researchers at the Irish site (O’Reilly-de Brun and de Brun) independently generated a ‘start list’ of codes derived from participatory research literature describing a continuum from positive to negative aspects of inter-stakeholder dialogue. Collectively, these authors identify positive aspects of stakeholder engagement in terms of active inclusion of stakeholders, building trust and rapport, supporting collaboration/collegiality, promoting shared and enhanced learning and balancing asymmetrical power-relations among stakeholders. They also identify ‘negatives’ – for example, exclusion/passivity, researcher-controlled process, and stakeholder powerlessness.

The ‘start-list’ of codes developed, via repeated readings of researcher and stakeholder data sources, into a final list of thirty-three codes. Each code was understood to incorporate its mirror or binary opposite. Data were coded, then collated to identify emerging themes. Twenty-seven codes
containing positive data coalesced into six themes (e.g., collegiality/collaboration); six codes containing negative data coalesced into three themes. (e.g., time commitment). A basic content analysis established the relative weighting of ‘positive’ to ‘negative’ evaluation comments (positive far outweighed negative). The six themes (Table 5) which contained data about stakeholders’ positive experiences of dialogue, researchers’ positive experiences of dialogue and researchers’ observations and comments about stakeholder’s positive engagement offered a measure of richness and triangulation to our analysis and provided the scaffolding for a three-level analysis of what makes for positive and productive inter-stakeholder dialogue (Figure 2).78

Table 5. Three levels of dialogue

<table>
<thead>
<tr>
<th>Level</th>
<th>Names of Themes A-F</th>
</tr>
</thead>
</table>
| 1.    | A. Trusting relationships in safe space  
       | B. Collegiality and collaboration  
       | C. Balanced asymmetrical power-relations |
| 2.    | D. Enhanced learning leading to shifts in understanding  
       | E. New relational environments fostering creative problem-solving |
| 3.    | F. Small leaps of generosity leading to transformative moments/events. |

Results

Positive experiences

Stakeholders reported a wide range of positive experiences of engagement in PLA inter-stakeholder dialogue that were confirmed by researchers’ reports and reflections. The analysis revealed that PLA inter-stakeholder dialogue processes are complex, multi-layered and multi-levelled and unfold in an incremental manner. Six key themes emerged in three levels of dialogue as shown in Table 5. Figure 2 (Flow Chart) provides an overview of fieldwork stages, the PLA techniques used, and how they related to the three levels of inter-stakeholder dialogue identified in Table 5. Each of the levels is porous and should be understood to have ‘soft boundaries’, meaning that there is interplay between levels, and they are not to be understood as self-contained ‘silos’. For example, key basic components of Level 1, e.g. ‘development of trusting relationships in safe space’ typically flow into Levels 2 and 3. Level 2 (a deepening of Level 1) is unlikely to occur if key components of Level 1 are absent or skipped (e.g., balancing asymmetrical power relations).

Level 1 – Basic components of PLA inter-stakeholder dialogue

Stakeholders reported positive experiences of enjoyment and interaction during the early stages of inter-stakeholder dialogue. All findings were relevant across settings, unless stated otherwise below. The comments below give a flavour of their initial experiences of the PLA dialogic process, highlighting the newness of this approach for them:

- It was a nice and very special experience. I have never done this before in that kind of way. (AUST, SH 01, GP)
- A new experience and a way of sharing ideas. (GR, SH03, MSU)
**Figure 2**: Flow Chart: Overview of Stages of research in RESTORE project related to levels of successful Inter-stakeholder Dialogue

**Stage 1**: Recruitment of Stakeholders at all sites (n=78)
- Mapping Process: Completed in all sites; yielded a small set of Guidance and Training Initiatives (G/TIs) in each country (≤6)

**Stage 2**: Fieldwork
- Stakeholders select a single G/TI (from the small set) for implementation in each country
- PLA ‘mode of engagement’ and techniques used for inter-stakeholder dialogue to select one G/TI in all countries:
  - Co-generation of Ground Rules;
  - Flexible Brainstorming;
  - Commentary Charts;
  - Direct Ranking.

**Stage 3**: Fieldwork
- Stakeholders implement a single G/TI in each country.
- 5 x unique implementation trajectories

**Level 1 requires**
*Basic components of PLA inter-stakeholder dialogue*
- Developing trusting relationships
- Creation of safe participatory space
- Active inclusion of stakeholders
- Stakeholders listen and learn to/from each other’s perspectives
- Relaxation, enjoyment, fun
- Collegiality & collaboration
- Balancing asymmetrical power-relations

**Level 2 requires**
*Additional necessary components of PLA inter-stakeholder dialogue, for deeper engagement*
- All of Level 1 above, plus:
  - Enhanced learning
  - Shifts in understanding
  - New relational environment (co-operative rather than competitive)
  - Creative and innovative problem-solving
  - Sustained positive engagement of stakeholders in research process.

**Level 3 requires**
*Optimal components of PLA inter-stakeholder dialogue which may lead (i.e. not automatically) to ‘Transformative Moments’*
- All of Level 1 and 2 above, plus:
  - Potential to resolve intractable problems;
  - Willingness to reduce organisational or inter-group territorialities, e.g., small leap of generosity across boundaries.
Very interesting research method. I am very much enjoying the experience, and hoping to learn a lot in the process. (IRL, SH10, MSU) 

I love that everyone is putting in the work, there’s a lot of material there and I like also to say thank you because sometimes I feel everyone can be putting their voice in the task, we are all involved, I feel that. It’s good. (IRL, SH11, MSU) 

This positive tone and atmosphere was the foundation for the development of trusting relationships and safe participatory spaces. RESTORE researchers, who, apart from the Irish researchers were all new to this form of dialogic process, reflected on their early experiences as researcher-catalysts facilitating a PLA inter-stakeholder dialogue. English and Austrian teams described achieving genuine engagement with stakeholders and the impact this had on them as stakeholders’ voices began to emerge:

What I found was how easy it was to get people to engage with the process. (ENG, Res)

With the group...we have to be respectful and everybody has his or her own voice. It was really... so fascinating - (AUST, Res)

It worked and people engaged and there seemed to be enjoyment. And we evolved. (ENG, Res)

A Dutch researcher was impressed that the PLA process allowed stakeholders from multi-disciplinary backgrounds to collaborate successfully at the early stage of co-designing ground-rules:

Yeah, what I found remarkable (and I was quite optimistic about the PLA method)... it was a system that people from different multidisciplinary groups were able to get involved in - the whole system, at an early stage already. So they became co-designers a bit ... by this way of working. I think it was very valuable of PLA when you want to implement a strategy or implementation project to do it in this way. I had a very good feeling about it. (NL, Res)

Greek researchers were surprised to note that high-status medical staff new to this form of engagement became easily involved in it:

We were also very surprised with how some other medical doctors [got] involved in this PLA process, which was something completely new for the health care staff. (GR, Res)

Researchers noted how PLA techniques operated as vehicles for generating safety in stakeholder groups, and how trusting relationships and positive networking developed through active engagement and teamwork:

We noticed that the flexible brainstorm technique was a very safe technique for the migrants. It was not too difficult and gave them the opportunity to associate and discuss with each other in a natural way. We had the impression that this technique facilitated the contact between the migrants and the researchers. What was interesting was that
SH16 felt safe enough to tell to the other migrant and researchers that he was undocumented. (NL, Res)

Each PLA technique achieved what we hoped for; every exercise produced lots of information and was very interactive, the techniques assisted in untangling issues by talking through them and breaking down ideas into tasks. Above all, it is still achieving... engagement of the stakeholders. (GR, Res)

At the English and Dutch sites, which involved very diverse stakeholder groups, researchers noted how rewarding inter-stakeholder dialogue appeared to be – how ‘safe space’ made it possible for stakeholders to begin to offer their perspectives in a collegial and collaborative manner; this helped to balance asymmetrical power-relations in a new group where some stakeholders possessed more social capital and/or professional power than others:

As researchers we have found it very rewarding working with the group, who all appear to get on well and have been willing and able to work in a democratic and inclusive manner, respectfully listening to each other and bringing an impressive degree of knowledge and expertise to the stakeholder table. It has been encouraging witnessing a great level of networking taking place within the group, which suggests that stakeholders are benefiting from the meetings in ways that go beyond the RESTORE project. (ENG, Res)

Additionally, we [researchers] noticed that the mixed groups really stimulated interaction of all ‘sorts’ of staff members, we saw in depth [PLA focus group] discussions in which all group members were participating. (NL, Res)

**Level 2 – Deeper engagement: Additional necessary components of a PLA inter-stakeholder dialogue**

Level 2 dialogue was a continuation and ‘deepening’ of the trust and safety developed at Level 1. As described previously, the practical tasks for stakeholders during Stage 2 fieldwork were to review and assess G/TIs relevant to their primary care setting, using PLA techniques (Commentary Charts and Direct Ranking, as per Table 3) to select a single G or TI for actual implementation. Stage 3 fieldwork involved fine-tuning, planning and implementation activities (using Seasonal Calendars and Flexible Brainstorming techniques, among others). The comments below illustrate the key necessary components (see Figure 2) of Level 2 inter-stakeholder dialogue – sharing of diverse perspectives, which led to enhanced learning, which fostered shifts in understanding:

I really liked the fact of being heard among those people – my voice had the same weight as all the others. (AUS, SH07, MSU)

The participatory approach was very interesting as well as how we exchanged ideas and knowledge and especially the cohesion of the group. (GR, SH10)

Very democratic and led to better understanding of the G/TIs and other stakeholder’s views and input. (IRL, SH01, GP)
Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue

Researchers echoed this Level 2 engagement in their reflective comments about stakeholders’ continued active inclusion and the balancing of asymmetrical power-relations:

> And they [stakeholders] were on different levels, I mean there was a doctor, a GP and another one, a local administrator, so they would have differences... Yes, but they were accepting, the one was accepting the other. (GR, Int)

An exchange between Dutch researchers during a post-fieldwork team reflection interview highlights their concern and relief about balancing asymmetrical power relations:

> Yes, it worked, we were a little afraid that working in a multidisciplinary setting with different groups...[might not work] (NL, Res 1)

> Certainly in groups with hierarchical differences.... (NL, Res 2)

> Yes, which would be difficult... there would be a group dynamic... the participants with the highest educational levels would dominate the discussion or say, okay, I’m not saying anything because I want to give... migrants more opportunity to say something. But it worked quite naturally and that was surprising. (NL, Res1)

At Level 2, ‘shifts in understanding’ occurred, even though this involved ‘hard work’ – this was articulated in particular by the stakeholders in the Irish setting:

> I find this experience very enjoyable. Because we are doing some work here, it’s hard work but it’s very, very enjoyable and I think it really broadens your perspective on things, and new horizons. When I reflect back on the first meeting we had, I remember when I was reading the first, em, Guidance I could only see it from my own perspective as an interpreter, and now, when I was reading it today, I could really, I started seeing it from other perspectives and I think that shows that we’re really learning things for ourselves as well, so it’s great. (IRL, SH07, Int)

The incremental nature of the inter-stakeholder dialogue, the co-operative relational environment and enhanced learning enabled stakeholders to shift to new positions or understandings:

> It’s been team work, people from different backgrounds coming together for a bigger purpose but actually having a great time doing it. I think the trust and openness and everything has been phenomenal and I learnt so much along the way. I would have my own fixed ideas, you know, about consultations and interpreted consultations, and the good/bad and indifferences associated with that. But to have it cracked wide open every time and hearing all the different perspectives, I think, in particular, from the service users, but also from the community interpreters, and to see the different slants – I learnt so much about the interpreting [process] that I would never have known. (IRL, SH01, GP)
It’s a marvellous way to learn... You [indicating other stakeholders] have changed my mind on subjects that I thought I was entrenched in, that I had an entrenched view on.

(Irl, SH05, PM)

Another component of Level 2 inter-stakeholder dialogue is creative problem-solving. This tended to occur because a new relational environment (based on co-operation and collaboration rather than competition) generated co-operative discussion which stakeholders linked to the ability to creatively solve problems together:

The only truly group discussion I’ve ever been part of – a properly democratic process that actually solves problems. (Irl, SH02, PM)

Level 3 – Optimal components of a PLA inter-stakeholder dialogue: potential for ‘Transformative Moments’

The context and pre-condition for Level 3 dialogue (see Figure 2) is when stakeholders encounter a seemingly intractable problem. This may or may not happen during a PLA dialogue, but should an intractable problem surface, the groundwork laid during Levels 1 and 2 dialogue tends to create the necessary environment in which stakeholders may reach across boundaries (e.g., organisational, lay/professional, status/power) to generate a creative solution to the problem. This outcome is what we coin a ‘transformative moment’ or event. It is important to emphasise that such an event is not a required or necessary component of PLA inter-stakeholder dialogues, which are successful and complete in themselves without this, therefore we do not expect a transformative event to occur in all PLA dialogues. In RESTORE, three countries reported experiences of transformative moments (England, Ireland, The Netherlands.) The Irish example below illustrates how Level 3 inter-stakeholder dialogue can carry forward all that is experienced and achieved in Levels 1 and 2, providing a platform for Level 3 to unfold.

While collaborating on their Seasonal Calendar, Irish stakeholders noticed an emerging problem: the practice staff had assigned themselves a large number of key implementation tasks which needed to be completed at the outset of the implementation of the G/TI. This left them with a very daunting and overwhelming workload early on in their implementation journey. Irish researchers’ post-PLA session team reflection captured a sense of the burden this generated for practice staff stakeholders:

I think our GP staff tonight felt heavily burdened... they probably felt a fair responsibility that they’ve a lot to do. One of them kept saying: ‘There’s all that stuff [practice staff tasks] there on the top line - that should have been done yesterday, and there’s a lot there...’ (Irl, Res)

Practice staff took on the tasks in the belief that they were the only stakeholders who could complete them. However, other stakeholders noticed the dispiriting effect of this burden on the practice staff. A lively and compassionate conversation ensued: community interpreters, migrant service-users and the policy planner offered to lift some of the workload burden from the shoulders of practice staff. They negotiated and re-positioned tasks on the Calendar, redistributing them more evenly across all stakeholders. This brought a great sense of relief to practice staff:
Yeah, it seems a bit more in control now, I was worried about that top line [of practice staff tasks] so much to do! Once we’ve broken it down into what we need to do now, and when, and who’s going to help us [to] do it, it’s cool, grand, I’m good. (IRL, SH02, PM)

Likewise – yeah, I think I’ve also been a bit concerned about the fact that so much of it now would revolve around us [practice staff] trying to recruit people, and how are we going to do this, oh god, will we do it wrong? I think it’s become obvious that it’s very much shared and we have help from all the excellent resources, be it from the service-users or interpreters - there’s a lot of input there, which means it won’t be all down to us. (IRL, SH01, GP)

This example of a ‘transformative moment’ for stakeholders highlighted the impact of the deepening of relationships of trust. The increasingly co-operative and collaborative nature of the PLA inter-stakeholder dialogue and engagement made it possible for some stakeholders to take a small leap of generosity towards others. This directly and effectively resolved the potentially intractable problem. It allowed the inter-stakeholder group to resolve this potentially significant barrier to continued implementation.

Post-PLA session debriefing notes by the Irish researchers confirmed this:

...it became very clear that the community interpreters, while they had highlighted only three [tasks for themselves] were quite willing to get involved in [the] pink ones [tasks], which were the practice-assigned ones. And I could visibly see... a relaxation coming over the practice staff. Because they were hearing, unambiguously, from the community interpreters that: ‘No, we are very willing to collaborate and work with you to work [this] out.’ The service-users, policy person, and community interpreters were... generously saying: ‘Don’t worry, you are not on your own; we’ll help you, we’ll translate the posters, we’ll look at the names, we’ll help you to identify service-users with these languages’, etc, etc. I could see that happening, I could see that moment when things began to not look so frightening and so burdensome for the practice staff. They are the locus of so much of what happens in [this part of] the project. It’s a tough one for them in that way. (IRL, Res)

Negative experiences
In contrast to the ‘positives’ noted above, negative experiences reported coalesced into three key analytical themes: time commitment, research fatigue and uptake of implemented service. GP and clinical stakeholders reported experiencing time challenges because of the commitment involved in a lengthy and intensive research engagement:

But I still do think as a GP it’s hard to adjust to spending so much time on this, but very worthwhile obviously. As always, I think the project is fascinating.’ (IRL, SH1, GP)

Researchers had time challenges related to fitting in all the planned PLA processes in fieldwork sessions, while at the same time not over-burdening stakeholders, and also in terms of having insufficient time to reflect on fieldwork:
We have noticed that we always run short of time at our sessions. For example at our 2nd [Stage 3 fieldwork] session we had planned to start the seasonal calendar and we did not have time for this, and in our 3rd session the discussion was flowing so well and again we did not start the seasonal calendar. We worked around the schedule always and found other ways and time to complete the PLA techniques. (GR, Res)

A major inhibiting factor often mentioned is the fact that the GP practice is always in shortage of time. As research team, we really have to be careful not to overload the practice with too many questions or tasks. (NL, Res)

It has been very challenging to protect sufficient time to fully reflect on and analyse the session transcripts which emerge from [fieldwork] sessions... there is a constant tension and an art to finding the balance: we sense the need to slow down the research process to ensure that, as the field researchers, we don’t overlook and ignore important information from stakeholders, thereby missing opportunities to generate solutions to genuine problems of local adaptation, and concomitantly compromising our PLA values of respect for stakeholders’ expertise and experience. On the other hand, we know how important it is to maintain momentum, so that stakeholders feel they are advancing and progressing. (IRL, Res)

While rare, there were reported instances of research fatigue on the part of both researchers and stakeholders:

As researchers, we too can burn out and find our energy for the project compromised as meetings build up in both intensity and number... The Irish stakeholder group can have up to 12 lively vocal people engaging all at once and can be demanding in terms of facilitation, group management and time management skills. (IRL, Res)

Another challenge... was the heavy workload that the stakeholders had these past few months. We felt that we were becoming quite exhausting [for them]. They did not express this towards us, but at times we felt that they just need a break! They appreciated that we did not bother them during their August holiday and they came back rejuvenated, and that was great. (GR, Res)

In two countries (Ireland and Greece), as a result of the RESTORE implementation journey in local settings, a new interpreting service was introduced into primary care practices but uptake was low. This contributed to a sense of research fatigue and frustration on the part of stakeholders and researchers alike:

...We feel that the stakeholders are burned out in general with their position and extra work loads they have now [in their work-lives] and they are bummmed [very disappointed] that this implementation isn’t going as well as they thought. Likewise for the researchers, we are surprised that it is going so ‘slow.’ (GR Res)
Discussion

Summary of findings

Our findings show that using a PLA mode of engagement and techniques for inter-stakeholder dialogue in a recent European primary healthcare implementation project led to a meaningful engagement of stakeholders who came from diverse backgrounds with significant power asymmetries. It provided opportunities for stakeholders to share, in an open and democratic manner, their diverse expert ‘knowledges’ about the suitability or otherwise of guidelines and training initiatives. This allowed them to select one for implementation and to contribute in practical terms to the implementation process at a local level. Stakeholders reported predominantly positive, but also a few negative experiences of inter-stakeholder dialogue. This was true across stakeholder groups in all study centres. Researchers’ fieldwork reports and interviews confirmed these results. We have presented the elements contributing to a positive and productive inter-stakeholder dialogue in terms of three levels of dialogue which develop incrementally. The development of trusting relationships in safe space fosters collegiality and co-operation (Level 1) moving towards enhanced learning across stakeholder groups/interests. This can lead to shifts in understanding and generates a relational environment of collaboration (Level 2) which may lead to experiences of compassionate co-responsibility in the face of seemingly intractable problems (Level 3). In such instances, the key experience is one of burden-sharing, prompting a ‘small leap of generosity’ from some stakeholders towards others which resolves the impasse or problem. The outcome is what we have coined a ‘transformative moment’ for the stakeholders involved. This can be a pivotal moment in an implementation journey – where there is a danger that an intractable problem might threaten progress, but a small leap of generosity re-energises stakeholders and impels them, and the research, forward. Negative experiences were relatively few and related to time commitment, research fatigue and disappointment regarding lack of uptake of implemented services.

Findings discussed in relation to the literature

There is limited knowledge about suitable methods for involving stakeholders in a meaningful (rather than tokenistic) inter-stakeholder dialogue. Tierney et al note that participatory approaches and methods seem promising and call for further research and methodological innovation. In line with this, our findings show that, in RESTORE, the use of a PLA ‘mode of engagement’ and series of PLA techniques for inter-stakeholder dialogue about implementation went beyond what Beresford describes as a ‘consumerist approach’ and proved effective as a democratic method of facilitating positive and productive dialogue among diverse stakeholders in diverse primary care systems.

The empirical data show that PLA provided a ‘safe space’ and promoted trusting relationships in which stakeholders felt sufficiently secure to share their diverse perspectives and opinions. Researchers, as a function of their training in PLA, had skills to actively encourage stakeholders to recognise that they are ‘experts’ in their own right and encouraged them to bring their unique implicit knowledge to the stakeholder table, making it explicit to the research process through dialogue.

There were also some differences across stakeholder groups: the challenges of clinician engagement in primary care research in general, in particular related to the time involvement, is well documented and our experience was similar in that regard. However, we acknowledge an
important distinction - clinician's involvement in PLA fieldwork in RESTORE was longer than in studies using more traditional methods, e.g., interviews or focus groups, and was sought over an extended period of time (20 months for fieldwork). Interestingly, we observed that clinicians who were engaged gave more time than they thought they could, and were willing to explore creative ways of being involved in a time efficient way (we described this in more detail in Lionis et al. 2016 and Teunissen et al.). Negative experiences related to policy circumstances that could not be influenced by the stakeholders are similarly reflected in the literature.

**Methodological critique and suggestions for future research**

We have documented and discussed key methodological strengths of our study above. Here, we note some areas for improvement and make some suggestions about how future research studies could be strengthened.

**Limitations of our study.**

1. We were unable, for site-specific ethical reasons, to include the use of stakeholder evaluation comments from the English site in our thematic analysis. However, we were able to ameliorate this by including data from researcher’s reflection interviews and fieldwork reports from this site.

2. Our thematic analysis about the use of PLA was conducted after the RESTORE project ended. This precluded us from incorporating stakeholders’ evaluation criteria into the analysis, as we would prefer and recommend for all PLA projects. However, the numerous and detailed stakeholder verbatim quotes included by researchers in their fieldwork reports, and researchers' own insights offered during post-fieldwork reflection interviews, provided valuable pointers for identifying appropriate evaluation criteria, analytical codes and themes and supported interpretation of findings.

3. Evaluation methods: ‘speed evaluations’ are time-efficient but brief. A practical way of eliciting immediate responses from stakeholders at the close of PLA sessions, they allow researchers and stakeholders to hear how an inter-stakeholder dialogue is developing, what is working well and what requires improvement. Improvements can then be worked into the next PLA session. However, speed evaluations should ideally be augmented by participatory evaluations (as was the case in the Irish site) to give stakeholders adequate time and opportunity to engage in more in-depth evaluation, and to collaboratively include criteria stakeholders consider appropriate and valuable. This often fills ‘evaluation gaps’ the researchers are unaware of, and generates unanticipated results which are highly beneficial to the progress of the research.

4. In common with all qualitative studies, we do not claim generalizability of findings for the study data presented here but suggest that our results about using a PLA ‘mode of engagement’ and PLA techniques to meaningfully engage stakeholders in inter-stakeholder dialogue across five European countries with very different primary care systems are promising and that PLA may be transferrable to other countries, topic areas and community or population groups.
**Recommendation for future research**

To add to the evidence base, we need further research and evaluation to explore if and how PLA techniques might work when applied in projects with very different research foci and stakeholder groups than those in RESTORE.

Two of the three negative themes identified (time commitment, workload/research fatigue) are important issues for careful consideration in future PLA projects. In RESTORE, we provided clear information at the outset, on-going reflection on the process and support for the workload. Nevertheless, the time commitment, as it evolved, became challenging for both clinical stakeholders and researchers. However, we have noted that, overall, those involved thought the time commitment was worth it. For future PLA projects, wherever funding, bureaucratic and/or other circumstances allow, we recommend extensive collaborative discussion between representative stakeholders and researchers at the *very earliest stages of project design* to develop and discuss ideas for managing time, acknowledging ‘upfront’ that the organic and iterative nature of a PLA project may affect this, and agreeing (as we did in RESTORE) that alterations in timeframe will be negotiated and re-negotiated where possible.

The critical importance of the researchers as catalysts and facilitators of participatory behaviour in research settings is clear. This was skilled work and the researchers were trained by two of their group who already had the skills and knowledge. Further, there was a continual learning feedback loop into the researcher group from the fieldwork as to application of the methodology. A key question, therefore, is how participatory learning and action can be replicated without those skills and without the funding to support their purchase? Arguably this question is about building capacity in the academic primary care community for PLA research. Also, it is about advising that PLA research is not undertaken by those without the necessary skills set, no more than a randomized controlled trial would be conducted without the required skill set.

**Conclusions**

PLA, with its mode of engagement and range of techniques, is capable of involving stakeholders in a meaningful, positive and productive inter-stakeholder dialogue across diverse primary health care systems. PLA attends to power differentials within and between stakeholder groups, making it particularly effective for facilitating equity between differing and conflicting perspectives as they emerge in inter-stakeholder dialogues. This makes PLA a valuable approach to be used in the further development of community-based primary healthcare.

PLA inter-stakeholder dialogue processes are complex. Our analysis describes three levels of dialogue which develop incrementally. This analytical framework may prove useful to researchers interested in developing and supporting meaningful stakeholder engagement through inter-stakeholder dialogues in primary healthcare research.
List of abbreviations
CBPR = Community Based Participatory Research
GP = General Practitioner
GUIDELINES AND TRAINING INITIATIVE = Guideline / Training Initiative
Int = Interpreter
MSU = Migrant service user
NPT = Normalisation Process Theory
PAR = Participatory Action Research
PLA = Participatory Learning and Action
PM = Practice Manager
PN = Practice Nurse
PO = Practice Operator
PPI = Public and Patient Involvement
PR = Participatory Research
PRA = Participatory Rural Appraisal
Res = Researcher
SH = Stakeholder

Acknowledgements
We would like to thank our RESTORE research colleagues who contributed to the fieldwork, but not to this paper: Francine Van den Driessen Mareeuw, Katja Gravenhorst, Christine Printz, Erik Teunissen.

Ethical approval
The national committees that granted ethical approval:
UL Education and Health Sciences Faculty research ethics committee; Ethics Committee of Medical University of Vienna; Liverpool Local Research Ethics Committee; Ethical Committee at the University Hospital of Heraklion, Crete and National Drug Organization (EOF); the Irish College of General Practitioners; Research Ethics Committee Radboud University Nijmegen Medical Centre.

Consent for publication
All participants to the meetings have given oral and written consent to publication of the anonymised data. Consent forms are stored at the different sites, according to existing university rules and regulations.

Competing interests
The authors declare they have no competing interests.
References

19. O’Reilly-de Brún M, de Brún T, Okonkwo E, Bonsenge-Bokanga JS, De Almeida Silva MM, Ogbebor F, Mierzjewska A, Nnadi L, van Weel-Baumgarten E, van Weel C, van den Muijsenbergh M, MacFarlane A. Using Participatory Learning & Action research to access and engage with ‘hard to reach’ migrants in...


60. MacFarlane A, O’Reilly-de BM. Guideline for communication in cross-cultural general practice consultations. NUI G: Galway; 2012.


Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue


Left: RESTORE Project, NPT training, Vienna 2012. NPT colleagues provide input.

Research teams use PLA techniques (Flexible Brainstorming, Card Sort and Mapping) to explore NPT constructs.

Below: RESTORE Project, NPT analysis, Niguelas, Granada, Spain 2014. Research teams discuss outcomes of NPT analyses.
Learning from doing: the case for combining normalisation process theory and participatory learning and action research methodology for primary healthcare implementation research


Tomas de Brún
Mary O’Reilly-de Brún
Catherine A. O’Donnell
Anne MacFarlane
Abstract

Background
The implementation of research findings is not a straightforward matter. There are substantive and recognised gaps in the process of translating research findings into practice and policy. In order to overcome some of these translational difficulties, a number of strategies have been proposed for researchers. These include greater use of theoretical approaches in research focused on implementation, and use of a wider range of research methods appropriate to policy questions and the wider social context in which they are placed. However, questions remain about how to combine theory and method in implementation research. In this paper, we respond to these proposals.

Discussion
Focussing on a contemporary social theory, Normalisation Process Theory, and a participatory research methodology, Participatory Learning and Action, we discuss the potential of their combined use for implementation research. We note ways in which Normalisation Process Theory and Participatory Learning and Action are congruent and may therefore be used as heuristic devices to explore, better understand and support implementation. We also provide examples of their use in our own research programme about community involvement in primary healthcare.

Conclusions
Normalisation Process Theory alone has, to date, offered useful explanations for the success or otherwise of implementation projects post-implementation. We argue that Normalisation Process Theory can also be used to prospectively support implementation journeys. Furthermore, Normalisation Process Theory and Participatory Learning and Action can be used together so that interventions to support implementation work are devised and enacted with the expertise of key stakeholders. We propose that the specific combination of this theory and methodology possesses the potential, because of their combined heuristic force, to offer a more effective means of supporting implementation projects than either one might do on its own, and of providing deeper understandings of implementation contexts, rather than merely describing change.

Keywords
Primary healthcare, Participatory learning & action research, Normalisation process theory, Implementation research, Theoretical frameworks
Learning from doing: the case for combining normalisation process theory and participatory learning and action research methodology

Background

The development and implementation of research findings is not a straightforward matter. There are substantive and recognised gaps in the process of translating research findings into practice and policy.\(^1\) One well-recognised translational gap is between the development of new treatments and implementation of these in practice with the intended service users/patient or population groups, the so-called ‘know-do’ gap. Another relates to using the results of health services research to inform wider health-related policy and to influence research-policy-practice links.\(^3\) However, before such implementation reaches a stage of action, that is ‘doing’, the individuals and groups involved frequently have to go through a process of consideration about the nature and complexity of implementation work. It is important that individuals and groups engage in a comprehensive consideration of these issues so as to better inform their actions. However, often individuals and groups are not supported through this process. We refer to this as the ‘think-do’ gap in implementation projects.

In addressing these translational gaps, implementation researchers are encouraged to consider greater use of theoretical approaches\(^1\) and a more diverse and innovative range of methodological approaches from health services and community-based research, such as qualitative methods and participatory approaches\(^2\) to improve the outcome of implementation projects. In addition, Davis et al’s systematic review of the use of theory in implementation research\(^6\) suggests that researchers give careful consideration to their choice of theory and provide a rationale for that choice. Another key issue is to develop knowledge about how theories, generally designed as heuristic devices to stimulate thinking, can be operationalised as action in an implementation journey. For example, the success of guidelines is often limited when they are applied in primary care settings because of their disease orientation and lack of focus on patients’ and communities’ needs. Primary care could benefit from methods that involve people and ‘community centeredness’ in a systematic way, and this is where the combination of NPT and PLA might be of benefit.\(^7\) This would build on the success observed in other fields when participatory methods and theoretical frameworks are brought together, for example in the implementation of e-health interventions.\(^8\)

In this paper we respond to the above proposals. We consider, in brief, the current use of theory and diverse methods in the field of implementation science generally, before focussing on a combination of theory and method that we have experience of from our programme of research about community involvement in primary healthcare: Normalisation Process Theory (NPT) and Participatory Learning and Action (PLA). We will describe NPT and our rationale for its completed and planned use in our research. We will highlight the need to explore effective methodological partners, particularly for the prospective use of NPT and, from there, describe PLA, its relevance for implementation research and the apparent congruence between NPT and PLA for investigating and supporting the implementation of innovation in primary healthcare settings. We conclude that, taken together, they may offer a potent heuristic for prospective, implementation research, a heuristic with which to ‘think-do’ which may have greater potential to improve implementation processes than if they were to be used separately.
Discussion

The value of theory for implementation science

Eccles et al.\(^1\) have argued that in order to overcome translational gaps in implementation research we need to see greater use of theoretical approaches, on the basis that this will offer (i) generalisable frameworks that can be applied across different settings and individuals, (ii) an opportunity for the incremental accumulation of knowledge, and (iii) an explicit framework for analysis. Approaching this from our inter-disciplinary perspectives, we see theory as sets of assumptions or concepts, or a relatively abstract inquiry that is distinguished from empirical research or practical recommendations. At this ‘high’ level, theory is generally abstract and broadly applicable.\(^10\) The term theory is, however, also used interchangeably with, and as an analogue for, model or framework\(^11,12\) particularly when it operates at the mid-level, namely where it is less abstract and addresses specific phenomena that can be translated into testable propositions.\(^10\) In this situation, theory is understood as a heuristic device to ‘think through’ research questions, data acquisition and analysis. As with most applied empirically-based social science work, we believe that actual real life situations and contexts should inform theory making and theory use, so that theory may be enabled to speak effectively and usefully across a spread of different situations or clusters of settings that share sets of key characteristics.\(^1\) We believe that if theory is developed, used and interrogated critically\(^13\) so it doesn’t ‘flatten out’ the specificity and contextual factors encountered in different organisational settings, then it certainly has the scope to impact positively on implementation science.\(^14\)

There is growing interest in the use of cognitive, behavioural and organisational theories in implementation research.\(^15\) There are a range of theories and conceptual frameworks in use that offer different foci for researchers, each offering a particular perspective, often influenced by the disciplinary background of the researchers who have developed and used it.\(^16\) A recent review identified over 60 different theories or frameworks applicable to implementation research.\(^12\) A more careful critique of these found that the focus varied from dissemination of research findings, through dissemination and supported implementation, to a principal focus on the conditions and actions required for implementation. Other approaches used in implementation research focus more on the organisational conditions than on the work required of individuals within the organisations. These include the Diffusion of Innovations Theory,\(^17-19\) theories of collective and individual learning and expertise,\(^20-22\) the Theory of Reasoned Action,\(^23\) and Actor-Network Theory.\(^24,25\)

Each of these theoretical approaches has their own utility and value and it is not within the scope of this article to provide a comprehensive critique of each one. However, it is worth noting that the Theory of Reasoned Action lacks attention to social contexts and influences and, thus, has been criticised for being overly individualistic; Diffusions of Innovation Theory is excellent in understanding the introduction and spread of innovations but less helpful in terms of understanding the implementation work leading to routinisation in daily practice. Theories of collective and individual learning are overly focused on internalisation of innovations and Actor Network Theory is contentious because of its focus on inanimate objects and its lack of explanatory power.\(^26\) In implementation research it is imperative that we understand how individual and collective action is required to implement new innovations and to understand more about how innovations become embedded in daily routine to such an extent that they become part of that daily routine – namely,
how new ways of working become normalised. A recently developed contemporary social theory, Normalisation Process Theory, offers a comprehensive conceptual framework in this regard.

**Rationale for using normalisation process theory**

NPT was developed as a response to multiple failures to implement innovations in complex healthcare contexts.\(^{15}\) It is not a rigid model but is designed to emphasise the realities of implementation work in real time and space, and the inter-relationships between different kinds of implementation work. There are four components in NPT (Table 1): coherence (sense-making), cognitive participation (engagement), collective action (enactment) and reflexive monitoring (appraisal). Each of these has subcomponents that can be used by researchers as sensitising concepts in implementation research.\(^{26-28}\) A recent review\(^ {29}\) found that NPT has been used across a number of international settings and for analysis of implementation of innovations in primary and secondary healthcare settings. NPT is most frequently used retrospectively as an organizing framework for analyses and reporting findings. It has also been used to inform study/intervention design, to generate research questions for fieldwork and to create tools for investigating and supporting implementation.\(^ {29}\) The review concludes that NPT offers opportunities for incremental knowledge gain over time and an explicit framework for analysis, which can explain and potentially **shape** implementation processes. It was recommended that, in future NPT research, researchers should, where possible, involve multiple stakeholders including *service users* in order to enable analysis of implementation from a range of perspectives.\(^ {29}\) In terms of drawbacks or challenges associated with the application of NPT, the review notes that researchers involved in coding data under NPT constructs might have some difficulty with apparent overlaps between constructs. In an earlier paper,\(^ {30}\) researchers noted some concern about correctly understanding the intended conceptual meaning of NPT constructs, as they wished to ensure that their analysis would be congruent with the theory. However, the benefits of using NPT clearly outweighed any such drawbacks.

We have chosen to use NPT in our research programme primarily for three reasons. First, because we are concerned with the *work* that individuals and groups have to do for a new technology or practice to become embedded and sustained in routine practice. Based on a social action approach to implementation, NPT has been developed through paying close attention to the concrete dynamics of actual implementation situations. From this, it has elucidated the individual and collective work involved in implementation processes. Second, it appeals to our sensibilities about theory because NPT is designed to be used as a heuristic device to critically interrogate data and we have used its precursor, the Normalisation Process Model, in this way retrospectively with good effect in prior research.\(^ {31,32}\) Finally, we are particularly interested in the idea of using NPT prospectively to shape implementation processes and involve *service users* in the analysis of implementation processes.\(^ {29}\) The application of NPT to the prospective collection of data raises the opportunity to critically interrogate the usefulness of NPT and to explore what unique perspectives service users may have for analysing implementation processes.

We are therefore interested in advancing knowledge and understanding about the ways NPT might be applied or ‘operationalised’ in practice to support implementation work, particularly when its components refer to dynamic, complex and inter-related actions and interactions between individuals and organisational structures that are not open to manipulation. This specific challenge
for NPT relates to the more general literature about the need for effective methodology to explore and support implementation research.

### Table 1 NPT constructs and sub-constructs

<table>
<thead>
<tr>
<th>NPT Constructs</th>
<th>Coherence</th>
<th>Cognitive Participation</th>
<th>Collective Action</th>
<th>Reflexive Monitoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can stakeholders make</td>
<td>Can stakeholders get others involved in implementing the intervention?</td>
<td></td>
<td></td>
<td>Can the intervention be monitored and evaluated?</td>
</tr>
<tr>
<td>sense of the intervention?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do stakeholders see this</td>
<td>Do the stakeholders believe they are the correct people to drive forward</td>
<td>Does the intervention</td>
<td>Will stakeholders</td>
<td></td>
</tr>
<tr>
<td>as a new way of working?</td>
<td>the implementation?</td>
<td>make it easier or harder</td>
<td>be able to judge</td>
<td></td>
</tr>
<tr>
<td>Do individuals understand</td>
<td>Are they willing and able to engage others in the implementation?</td>
<td>to complete tasks?</td>
<td>the effectiveness</td>
<td></td>
</tr>
<tr>
<td>what tasks the intervention</td>
<td></td>
<td></td>
<td>of the intervention?</td>
<td></td>
</tr>
<tr>
<td>requires of them?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do all those involved</td>
<td>Can stakeholders identify what tasks and activities are required to sustain</td>
<td>Do those involved in the</td>
<td>How will stakeholders</td>
<td></td>
</tr>
<tr>
<td>agree about the purpose</td>
<td>the intervention?</td>
<td>implementation have the</td>
<td>collectively judge</td>
<td></td>
</tr>
<tr>
<td>of the intervention?</td>
<td></td>
<td>correct skills and training</td>
<td>the effectiveness</td>
<td></td>
</tr>
<tr>
<td>Do all the stakeholders</td>
<td>Do they believe it is appropriate for them to be involved in the</td>
<td>Do local and national</td>
<td>Will stakeholders</td>
<td></td>
</tr>
<tr>
<td>grasp the potential</td>
<td>intervention?</td>
<td>resources and policies</td>
<td>be able to modify</td>
<td></td>
</tr>
<tr>
<td>benefits and value of the</td>
<td></td>
<td>support the intervention?</td>
<td>the intervention</td>
<td></td>
</tr>
<tr>
<td>intervention?</td>
<td></td>
<td></td>
<td>based on evaluation and experience?</td>
<td></td>
</tr>
</tbody>
</table>

**Operationalising NPT in implementation research: the need for an effective methodology to explore and support implementation science**

Randomised controlled trials (RCTs) are regarded as a gold standard in the domain of health services research focused, as they are, on the question of “does this intervention work”? While explanatory trials measure efficacy, i.e. the benefit a new treatment or intervention can produce under ideal conditions, pragmatic trials answer questions of effectiveness, namely the benefit of a new treatment or intervention in the ‘real’ world. Even then, pragmatic trials are often less sensitive to the dynamics of healthcare settings as complex systems that are characterised by non-linear interactions shaped by organisational culture.
Social and cultural anthropologists have researched societies, groups and organisations for over 100 years in an effort to better understand ‘culture’. One of the insights gained from that research is that much of what we call culture is non-linear, shadowed, and deeply embedded in the realm of the non-rational; expressive of differing notions of what constitutes rational thinking and behaving, including differing rationalities. The issue of culture is germane here in that a number of authors within the implementation science domain have alluded to the fact that implementation settings are complex adaptive systems that have the capacity to self-organise, and that they have shadow systems within them that inhibit implementation. These shadow systems are often poorly understood. We acknowledge that in implementation contexts we frequently have different cultural influences and rationalities layered onto and embedded within organisational cultures and rationalities. For example, primary care research relies on professions with diverse cultural norms, expectations and values, where there may or may not be the experience or structures to support professionals in their work together as inter-disciplinary teams. This is further complicated in that primary care professionals need to respond to culturally diverse communities, aiming to include all populations in their research, a core value of primary healthcare research. Implementers often fail to recognise and acknowledge these inter-related realities, leading to implementation failure. NPT draws attention to both individual and collective views of implementation, but is not itself a methodology. It therefore requires to be operationalised through appropriate methodological approaches.

Researchers need to develop methods and approaches that allow them to explore organisational cultures and settings as adaptive systems where the non-rational or different rationalities play a significant part in implementation in healthcare settings. The authors are fully aware that the concept of ‘culture’ is a highly contested one and a difficult and complex area to approach for the non-specialist. Researching culture, therefore, ideally requires the specialist skills and background of social scientists as part of multi-disciplinary research teams in implementation research. This is particularly important in primary healthcare which operates in communities where cultural diversity is an important and dynamic characteristic.

To meet this aim of description, exploration and analysis of culture in implementation research, there is, therefore, an obvious need to utilise qualitative research methods, and in particular ethnographic-style research. These are appropriate tools for uncovering some of the non-rational/differently rational and culture-related dimensions inherent in implementation situations and contexts. Brown and McCormack highlight that, in a previous ethnographic study they conducted the use of ethnography was successful in identifying contextual issues that needed to be addressed or changed but provided no opportunity to enact change. This means that, while deploying research methodologies that help us understand the shadow side and complexities of organisations is important and necessary, for implementation to actually work such ‘understanding’ only takes us so far. We need to consider methodologies that offer not only the possibility of understanding and deepening our knowledge, but also provide a mechanism for exploring and facilitating the enactment of change—the doing side of the ‘know–do’ gap.

Therefore we propose that, in conjunction with other qualitative research methodologies including ethnographic research, implementation research might profit from enlisting the assistance of participatory and action research methodologies as a means of more effectively understanding and supporting the ‘know–do’ gap and implementation work. This view is supported by Greenhalgh et
al.’s important review of the diffusion of innovations in service organisations\textsuperscript{15} where one of the recommendations for future research was that implementation research should be participatory, engaging ‘on-the-ground’ practitioners as partners in the research process:

‘Because of the reciprocal interactions between context and program success, researchers should engage ‘on-the-ground’ service practitioners as partners in the research process. Locally owned and driven programs produce more useful research questions and data that are more valid for practitioners and policymakers’.\textsuperscript{15}(pp 581-562)

Below we focus on one such methodology – Participatory Learning and Action (PLA) research.

**Participatory Learning and Action (PLA) research**

PLA is a form of action research. It is a practical, adaptive research strategy that enables diverse groups and individuals to learn, work and act together in a co-operative manner, to focus on issues of joint concern, identify challenges, and generate positive responses in a collaborative and democratic manner.\textsuperscript{44,45} Its roots are in the global south where it was explicitly designed to address the introduction of planned change in international development contexts. Robert Chambers identified a serious ‘gap’ in development research where local people were usually missing from the stakeholder table and many internationally funded projects were failing to achieve their intended aims.\textsuperscript{46} Chambers worked with communities to develop Participatory Rural Appraisal (PRA), a research approach that included and privileged ‘local experts’ (e.g. community representatives/service users/patients) as key stakeholders in research. Much of Chambers’ work was applied to the field of rural development. Under modernisation theory, which was the dominant international development theory at the time, local people (the so-called beneficiaries of change) were considered to be the factor in change situations that constituted a barrier to introducing an innovation. They were considered to be backward, largely uneducated and overly traditional in their thinking; all features that putatively impeded the implementation of change and innovation. PRA was successful in helping to deconstruct the conceit within modernisation theory that local populations are the problem, and refigured them as a resource for research and development projects – experts in their own right, along with those others more commonly identified as experts (for example, development professionals, service providers and planners). Influenced by Chambers’ work, two of the authors of this paper (de Brún and O’Reilly-de Brún) pioneered, over the past 25 years, the adaptation and application of participatory approaches and techniques to other fields of research in international development throughout sub-Saharan Africa (gender, development education, female education) and in Europe, to intercultural and migrant health. We use the term Participatory Learning and Action (PLA) to describe our work.\textsuperscript{47}

The healthcare literature contains many examples of a broad, growing family of ‘bottom-up’ participatory research approaches. This growing family is not a monolithic body of ideas and methods but a pluralistic orientation to knowledge-making and social change, and this is their overarching connection. A core shared principle is the inclusion of ‘local experts’ as active participants who provide their unique insights to the research endeavour. These approaches include, among others, Participatory Research (PR)\textsuperscript{48-50} Participatory Action Research (PAR)\textsuperscript{51-53} Emancipatory Action Research (EAR)\textsuperscript{54,55} Community Based Participatory Research (CBPR)\textsuperscript{56-59} and Participatory Learning & Action (PLA).\textsuperscript{47,60} Major reviews and comparisons of a wide range of participatory
approaches and methods are also available in the literature.\textsuperscript{54,61,62} Critiques of participatory methodologies alert us to important challenges, for example, the need to see community participation as a long-term process of implementation and support for improved health outcomes\textsuperscript{50}, the need to develop funding streams for participatory research to ensure that local health priorities influence the research agenda\textsuperscript{52} and the fact that many professional health researchers may be unprepared for the reversals of power and hierarchical relationships a participatory approach may require.\textsuperscript{49} Notwithstanding these challenges, the great strength of participatory approaches lies in the democratic inclusion of locals as ‘experts in their own right’ – the reconfiguring of locals as stakeholders capable of providing unique insights to healthcare research. PLA is noteworthy in that it employs a range of highly-visual research techniques which are readily accessible to diverse stakeholder groups where asymmetries of power may exist.\textsuperscript{60} PLA, when well-facilitated, ‘levels the playing field’ and the transparently democratic processes and techniques help to balance power differentials (e.g., within multi-disciplinary teams in primary care settings). To understand the potential of PLA to balance asymmetries of power, it is important to understand a series of key reversals\textsuperscript{45,47,63-65} of attitude and practice that underpin its use in research and development projects (Table 2). PLA also highlights the ways that learnings are achieved across such diverse groups, and where and how such learnings are oriented towards co-designed action planning and implementation.

For example, in previous work, we successfully used PLA to develop a multi-perspectival guideline to support cross-cultural communication in primary healthcare consultations. We formed a combined community-university research team, including seven established migrants whom we trained as peer PLA researchers. Their diverse linguistic abilities, cultural backgrounds and PLA training enabled them to safely access and meaningfully engage with hard-to-reach migrant service-users from six different language groups, representing diverse cultural and ethnic backgrounds. A significant proportion of the migrant service-users had low literacy, and our use of a wide range of PLA techniques enabled them to participate effectively in the research process, allowing their perspectives and those of health service-providers to come together in a PLA dialogue which resulted in a democratically generated and agreed guideline for cross-cultural communication. PLA was instrumental in generating safe spaces and sustained engagement of stakeholders over a two-year period and linked a hard-to-reach population with the academy and service-providers in a positive, productive community-university partnership for primary healthcare research.\textsuperscript{60,66}

PLA is highly relevant for the field of implementation research because it employs a pragmatic, multi-perspectival research methodology. We would argue that PLA is relevant to the field of implementation research because of its iterative and organic nature, and the ways it encourages diverse stakeholders to engage in cycles of research, co-analysis, reflection and evaluation over time. This highly reflexive process enables stakeholders to address issues of joint concern creatively in order to arrive at positive strategies to achieve goals, implement agreed actions and influence national and/or local policy.\textsuperscript{67} Importantly, possible solutions to problems can be considered heuristically – ‘tried out’ and ‘fine-tuned’ through various iterations towards workable and sustainable outcomes for all stakeholders.
Table 2  Key reversals in participatory learning & action research methodology

<table>
<thead>
<tr>
<th>Reversal from...</th>
<th>to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assuming knowledge...</td>
<td>exploring and exchanging complex ‘knowledges’</td>
</tr>
<tr>
<td>Hierarchical relationships among stakeholders...</td>
<td>reciprocal and mutually empowering relationships</td>
</tr>
<tr>
<td>Viewing stakeholders as passive beneficiaries...</td>
<td>viewing stakeholders as active partners and collaborators who benefit differentially from research outcomes</td>
</tr>
<tr>
<td>Viewing stakeholders as problem makers...</td>
<td>to engaging with them as problem-solvers</td>
</tr>
</tbody>
</table>

**NPT and PLA: working together to incrementally increase knowledge in implementation contexts**

NPT and PLA both have relevance, as theory and method respectively, for the field of implementation research.68 Through NPT’s framework, the various layers of activity and work inherent in innovation and implementation can be made explicit and available for investigation. NPT can enhance researchers’ knowledge of the implementation process, shaping data generation and analysis, and providing conceptual density.39 However, as mentioned earlier, that alone may not be sufficient to support the *action* required to achieve implementation, i.e. to make it happen. It is interesting to think about closing the ‘know-do’ gap between knowing about implementation processes/problems and doing something about them. Through PLA’s specific problem-solving orientation, attention is paid to generating knowledge and understanding of implementation processes as well as the actions required for implementation. PLA is interested in engaging social actors to identify and report problems, and to work individually and collectively to identify potential solutions to those problems. In this way, PLA offers a significant added dimension in supporting implementation processes and exploring the enactment of implementation through PLA dialogue.

As well as their scope to impact on the field separately, we are interested in the ways in which there is congruence between NPT and PLA. In terms of their origins, PLA and NPT are congruent in that they have both been developed in response to multiple failures to implement innovations (albeit in quite distinct settings and contexts). Moreover, as we highlight here, NPT and PLA are epistemologically compatible because both are located within the broad social science constructivist paradigm, which acknowledges that reality is defined, and meaning is conveyed for members of groups and organisations, through a range of socio-cultural means. Such socio-cultural factors can be both explicit (mission statements, sets of formal rules, sets of guidelines) and implicit (‘non-rational’ and non-linear influences).35,39-41 Given this congruence, we are interested in the ways a complementary partnership between NPT and PLA may offer exciting possibilities to better understand and support, theoretically and practically, the dynamics and pragmatics of implementation processes.

When we consider areas where NPT and PLA may lack congruence, we note that NPT has focused in the main on the perspectives of ‘professionals’ (service-providers, planners, policy-makers). This meant that service-users’ unique perspectives were missing from analysis of implementation processes.29 Also, NPT does not explicitly consider issues of inclusivity and power. This potential drawback may, however, be balanced by PLA’s emphasis on inclusion of the least powerful at the
Learning from doing: the case for combining normalisation process theory and participatory learning and action research methodology

stakeholder table. Conversely, a potential drawback of PLA may be that being rooted so strongly in the experiential world of stakeholders, a PLA research process might ‘miss’ important implementation questions or topics that NPT alerts us to. Taken together, then, NPT and PLA may enhance each other, offering a potentially stronger heuristic than either on their own might otherwise provide. Such a heuristic can help researchers to explore more adequately ‘think-do’ gaps in the emerging field of implementation science, and also have a positive impact on the ‘know-do’ gaps that are currently evident in practice and policy. Below, we provide a concrete example (Table 3) of the use of NPT and PLA in the development of a framework for implementation of community participation in primary healthcare.68 NPT constructs and sub-constructs (Table 1) alert researchers to a range of important factors that promote or inhibit implementation.

Table 3 Community participation in primary healthcare: identifying actions to improve implementation using normalisation process theory and participatory learning and action research

<table>
<thead>
<tr>
<th>NPT Construct</th>
<th>NPT informed questions re community participation in primary healthcare explored in PLA fieldwork</th>
<th>Problems in the practice of community participation in primary healthcare identified with stakeholders during PLA fieldwork that impact on implementation</th>
<th>Recommended actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coherence</td>
<td>How is service user involvement defined?</td>
<td>Multiple terms are in use. People use the same terms to mean different things. There is lack of shared understanding about the work involved across stakeholders.</td>
<td>All stakeholders clarify their own understanding of community participation in primary healthcare and, through dialogue with each other, arrive at a shared understanding of community participation in primary healthcare with other stakeholders at the start of a community participation project.</td>
</tr>
<tr>
<td>Cognitive Participation</td>
<td>Why do stakeholders get involved?</td>
<td>There is a lack of clarity about why different stakeholders get involved. People get involved for different reasons and there is a lack of understanding about the roles that people play.</td>
<td>Stakeholders work together to clarify who needs to be involved and agree to work together to drive the implementation of a community participation in primary care project forward.</td>
</tr>
<tr>
<td>Collective Action</td>
<td>What methods are used?</td>
<td>Involvement can be tokenistic. There is often a lack of adequate resources and skills to do the work meaningfully. Stakeholders are not clear about their individual roles</td>
<td>All stakeholders should have appropriate organisational support, skills and training, trust in the work and the ability to perform all tasks involved in order to make an activity or process take place.</td>
</tr>
<tr>
<td>Reflexive Monitoring</td>
<td>What are the outcomes?</td>
<td>It is difficult to evaluate the impact of community participation in primary healthcare. Evaluation is often ad hoc and/or anecdotal.</td>
<td>Stakeholders will appraise their work, using formal and informal systems, so that they can learn about what is working well and can modify work practices to maximize community participation in primary healthcare.</td>
</tr>
</tbody>
</table>

For the Framework, NPT was used to develop a comprehensive set of research questions designed to enhance understanding (retrospectively) about what affected implementation processes in a variety of community participation projects in primary healthcare across rural and urban locations in Ireland. For example, the NPT construct ‘collective action’ which relates to ‘enactment’ or ‘getting the work done’ generated research questions about stakeholder involvement: was it tokenistic or meaningful? Were adequate resources and skills available to stakeholders to enable them to do the implementation work meaningfully? Using a PLA approach and techniques, researchers explored these and other NPT-derived questions during data generation and empirical fieldwork with diverse stakeholders. This combined use of NPT and PLA ensured that all NPT constructs were covered and that a range of stakeholders’ perspectives on these key implementation issues were elicited and represented. Key benefits of this application of NPT and PLA included (a) a more developed understanding of the complex interplay that existed between individual, organisational and social factors, (b) clarification of the ideal conditions for implementing community participation in primary healthcare in the Irish primary care context and (c) a set of recommendations which, given the use of NPT as a theoretical framework, may have transferability and relevance across a variety of contexts for projects that have, as their core objective, meaningful community involvement. The Framework is an example of the use of NPT as a heuristic device to stimulate thinking and of PLA as the methodological process through which ‘NPT thinking’ was operationalised as ‘action’ with stakeholders: stakeholders identified levers and barriers to implementation and participated in the development of recommendations for future action to ensure meaningful community participation. It is this interplay between NPT and PLA which allows their combined heuristic potential to unfold. Essentially, NPT is a theory capable of supporting the individual or group to think through issues involved in implementation, thereby addressing the ‘think-do’ gap. PLA offers a methodology capable of translating thinking into concrete action – operationalising ‘thinking’ into ‘doing’/action.

**Engaging social actors in complex adaptive systems**

In its commitment to investigating organisations as whole systems, or complex adaptive systems, NPT is rooted in the need to attend to the role of social actors, in terms of individual and collective action, in any organisation where change or innovation is to be introduced. As mentioned above, working with the four NPT constructs encourages researchers to pay attention to the full range of actors involved in implementation work and the nature of their reciprocal, interdisciplinary and interprofessional relationships. Similarly PLA, influenced as it has been by social and cultural anthropology, understands the methodological need to approach organisations holistically and/or dialectically, paying due attention to the full range of social actors (participants/stakeholders) within organisations charged with implementing innovations, and to exploring complex social and cultural processes. Through a PLA dialogue, key stakeholder groups are encouraged to listen to, and learn from, each other’s knowledge and perspectives. Trust, rapport and mutual respect builds up in the early stages of engagement and this supports the ongoing cycles of work (i.e. research, co-analysis, reflection and evaluation).

PLA also encourages stakeholders to be questioning of, and exercise control within their context as far as is practically possible – to think and reflect about the ways PLA processes and other stakeholders’ perspectives and knowledge can be used to challenge the seemingly ‘fixed’ elements of the ‘real world’ of their particular organisational setting. For example, one way of facilitating this might be to invite stakeholders to imagine ideal solutions and scenarios that could challenge or
change their organisational context, if this is deemed desirable by them in terms of implementing an innovation. PLA thus promotes the active engagement of all stakeholders in such processes and can support actors to make even small ‘transformative leaps of generosity’ towards each other and away from familiar and ‘precious’ territorialities that can inhibit implementation. Building trust is a necessary prerequisite in creating the conditions for such leaps of generosity to occur. Brown and McCormack allude to the importance of creating psychologically safe spaces through the use of an action research methodology in the effective management of pain among older people. Given that PLA is broadly a form of emancipatory research, it explicitly seeks to articulate the voice of marginalised or underserved groups, communities and populations.

However, we should not forget that PLA also has the power to engage in an emancipatory way with other more professionally-orientated stakeholder groups in implementation settings, in terms of creating ‘conditions of safety’ within which to explore issues of professional territoriality, and other areas of tacit knowledge and practice that can inhibit implementation of innovation. This is illustrated in research carried out with homeless men in Dublin’s inner city in 2008. In addition to generating culturally appropriate knowledge about the experience of social exclusion among homeless men, and surfacing culturally appropriate solutions to that experience, the PLA process had the added and unintended outcome of galvanising the men as a group to begin the development of a new form of service provision offered by themselves to other homeless men in Dublin. The group is known as MAIN (Men Alone In No-man’s land) and the PLA process was the catalyst for these men to rethink their self-perceptions as relatively powerless individuals towards becoming a resource for other homeless men in inner-city Dublin. Through the experience of the PLA research, the men of MAIN began a process of recasting and rethinking their ascribed role as service users towards the more innovative and powerful one of service provider. To enable them to achieve this transformation they sought and received the support of statutory and non-statutory agencies to begin an outreach programme among their peers.

We propose that this heuristic possibility of PLA is not merely confined to the service user group as has so far been discussed in this illustration, but also to other key stakeholder groups. The key challenge for the commissioning agency in the example above was to allow its own practice and thinking to be touched by this heuristic possibility. As a statutory service provider organisation it was more used to receiving sets of recommendations from researchers that would clearly indicate what the provider organisation needed to do in order to answer the needs of the men of MAIN. What it found new and somewhat disconcerting, at least initially, was the shift in its organisational self-perception that was called for by the men in the PLA research process. A brokered conversation took place, through the researchers, between the men of MAIN and the service provider organisation. This eventually led to the organisation re-thinking at least some aspects of how it normally considered and practiced the delivery of services to homeless men in Dublin’s inner city. This balance of attention to all social actors and stakeholders as well as organisational cultures is crucial, because for change to occur in culturally distinct organisations the creation of safety for all is a precondition that allows for the possibility of a transformational moment occurring.

**Exploring implementation as a reflexive engagement**

In keeping with their underlying epistemological stance, both NPT and PLA emphasise the importance of co-assessments and reflexive processes for all stakeholders engaged in
implementation work. The NPT construct ‘Reflexive Monitoring’, is about reflecting on the implementation work itself, monitoring how the work is assessed by different stakeholders, tracking progress, and monitoring the effect of the implementation. PLA is essentially a sustained reflexive process that is rooted in the experience of all stakeholders in terms of monitoring and evaluating the detail and overall effects of any innovation. PLA dialogues can be used to promote and foster self-reflection and self-evaluation as well as bringing differing knowledges and perspectives into conversation with each other. Related to this, PLA is always inherently about the generation of emic perspectives and approaches where insider knowledge is valued and surfaced.  

PLA researchers/practitioners can engage with key stakeholders to enable what is often expert but implicit knowledge to become explicit and therefore available for exploration and analysis in an ongoing and respectful dialogue. Emic perspectives were developed by cognitive anthropologists as a way of accessing deep cultural knowledge through linguistic analysis, and therefore lend themselves to helping surface some of the already mentioned seemingly non-rational or shadow systems within individual organisational cultures. However, precisely because of PLA’s interest in bringing different forms of knowledge into articulation with each other across stakeholder groups, it can also acknowledge the role and importance of knowledge generated in an etic manner that either informs, or emerges during PLA dialogues. Examples of ‘etic knowledges’ will include those of different professions who have a stake in implementation, including researcher knowledge and community-based forms of knowledge; though we point out that professionals and researchers also possess emic forms of knowledge. Paying attention to both emic and etic perspectives may be particularly useful in fostering conversations in implementation settings between diverse stakeholders whose differing knowledges and perspectives are brought to the fore by the use of the theoretical framework. PLA approaches can help interrogate the theory, to identify which elements of the theory are relevant to a specific context or setting, and which elements of the implementation work in that specific context or setting may not be addressed or covered by the theory. This attention to, and management of, etic and emic perspectives requires a specific attitudinal disposition on the part of the researcher/participatory research practitioner towards stakeholders, which is based on the key reversals involved in PLA and underpins a PLA mode of engagement. In the context of bringing together NPT and PLA so as to better understand implementation in diverse contexts we emphasise the crucial importance of providing high quality training for researchers in PLA research methodology as well as in NPT.

Importantly, the use of PLA approaches has the potential to ensure that emic perspectives are not ‘lost’ through the use of NPT as an etic theoretical framework. NPT and PLA used together could help ‘keep in touch’ with the changing nature and dynamics of implementation work as defined and shaped by those involved in the work, using theory to explain, understand and support that work. This approach is underpinning new research into the implementation of guidelines and training initiatives designed to support cross-cultural communication in primary care. Additional file 1: Figure S1 highlights an example of our current research, the RESTORE project (REsearch into implementation STRategies to support patients of different ORigins and language background in a variety of European primary care settings) which was conducted across five European primary care settings. The involvement of migrant service-users, along with other key stakeholders (general practice staff, primary care nurses, community interpreters, healthcare service planners) was core to the participatory design of RESTORE, and a key component of the rationale for combining NPT and
PLA was that both are inherently adaptive and responsive to diverse primary healthcare contexts. A PLA dialogue was developed around NPT constructs to prospectively inform the implementation of guidelines and/or training initiatives to support communication in cross-cultural general practice consultations. Essentially, RESTORE is the empirical ‘testing-ground’ for the proposals in this paper about the potential combined heuristic force of NPT and PLA to offer a more effective means of supporting implementation projects than either one might do on its own. RESTORE presents the opportunity to explore how to operationalise NPT and PLA prospectively and to ask in what ways NPT and PLA proved to be congruent or lacking in congruence. RESTORE may also provide insights about what it may mean, practically and methodologically, to use both NPT and PLA at the same time. How does it change data collection and analysis? This analysis is underway and results will be reported in separate papers. A detailed description of the study protocol has been published and is available.75

Conclusions

Implementation researchers are interested in bridging the ‘know-do’ gap. For this, we need to develop implementation strategies that are up to the task of enhancing knowledge and enacting change. Building on calls for the use of theory and action-oriented methodologies, this paper advances knowledge in the field of implementation research by exploring the combination of theory and method. We argue that NPT is a unique and sophisticated heuristic device for understanding and supporting implementation work. PLA is an action-oriented research methodology that also possesses heuristic power. Taken together, they potentially present an effective and potent heuristic to ‘think-do’ with. We shall monitor carefully the impacts and implications of testing this combination in our ongoing empirical work in the RESTORE project. We note that NPT on its own has, to date, been successful in offering explanations for why implementation projects have or have not worked post-implementation. Combining NPT and PLA also offers the possibility of prospectively demonstrating the effectiveness of this combination to actively foster change in implementation settings, rather than merely describing or commenting on change. This combination of theory and method also places us in a better position to continually refine and develop the theory.

Finally, we note that there may be potential for a broader view and practice of collaborative learning communities or networks that go beyond single implementation studies. For daily practice, NPT and PLA could serve as a method for primary health care to plan and review its responsiveness to community priorities. Its application in this context might benefit from an adaptation of the methodology to the time and staffing constraints of the health system. In addition, while potential challenges might emerge regarding different foci and priorities of research and health service and systems, we might also look toward establishing, over time, implementation science organizational research cultures. Here, researchers and researched could occupy a shared platform, with equal status and power to participate in the full continuum of research and research utilization.
Additional file

Additional file 1: Figure S1. Combining NPT and PLA to involve migrant service users and other stakeholders in the implementation of guidelines and/or training initiatives to support communication in cross-cultural general practice consultations in five EU countries: The RESTORE project.

Abbreviations
FUSION, Framework for implementation of USer InvOlvemeNt in Primary Care; 
MAIN, Men Alone In No-man’s land; 
NPT, Normalization Process Theory; 
PLA, Participatory Learning and Action; 
PRA, Participatory Rural Appraisal; 
RCT, Randomized Control Trial; 
RESTORE, REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings

Acknowledgments
We wish to acknowledge the excellent contributions made to the development of this paper by Evelyn van Weel-Baumgarten (Radboud University Medical Centre, Nijmegen, The Netherlands) and Maria van den Muijsenbergh (Radboud University Medical Centre, Nijmegen, The Netherlands, and Pharos, Centre of Expertise on Health Disparities, Utrecht, The Netherlands).

Authors’ contributions
TdeB and MORdeB (as joint first authors and equal contributors) conducted the literature review that informed this manuscript and developed the key intellectual content and rationale. AMacF and KOD contributed significantly both intellectually and practically to the paper to warrant co-authorship. All authors have commented and agreed on the manuscript.
References


32. May C. A rational model for assessing and evaluating complex interventions in health care. BMC Health Serv Res. 2006;6:86.


58. Baptiste DR, Mathis J. Working with community women as partners to prevent HIV among youth: implications for training. Paper presented at the Women and HIV Conference: May 1997; Pasadena California, USA.


63. O’ Reilly-de Brún M, de Brún T. Participatory Learning and Action (PLA) Training Manual. Galway: Centre for Participatory Strategies (CPS); 2011.


Additional file

Figure 1: Combining NPT and PLA to involve migrant service users and other stakeholders in the implementation of guidelines and/or training initiatives to support communication in cross-cultural general practice consultations in five EU countries: The RESTORE project.

- RESTORE is concerned with optimising the delivery of primary health care to European citizens who are migrants who experience language and cultural barriers in host countries. We focus on the implementation of evidence-based health information (e.g. guidelines to enhance communication in cross-cultural consultations) and interventions (e.g. training initiatives on interculturalism and the use of paid interpreters) designed to address language and cultural barriers in primary care settings.

- In RESTORE, NPT and PLA are being used in combination with each other as a ‘know-do’ tool to investigate and support this implementation work. We will facilitate a PLA-brokered dialogue with key stakeholders – NGOs and service users from migrant communities, general practice staff, interpreting and/or cultural mediator staff, service planners and policy makers in five European countries: Austria, England, Greece, Ireland, and The Netherlands.

- The PLA-brokered dialogue is being developed as a mode of engagement whereby relationships of trust, mutual respect and rapport are fostered and encouraged within and across stakeholder groups so that data can be generated to elicit stakeholder explicit and hidden ‘knowledges’ for discussion and co-analysis.

We will facilitate a PLA-brokered dialogue to operationalise the NPT constructs described below:

1. **Coherence** – whether evidence-based health information and/or interventions designed to address communication in cross-cultural general practice consultations ‘make sense’ (or not) to stakeholders and whether they see the point of them (or not) for their work.

2. **Cognitive Participation** – whether there is engagement from stakeholders with some/one of the guidelines and/or training initiatives and whether there is ‘buy-in’ to actually engage in an implementation project.

3. **Collective Action** – participants’ experience of implementing their chosen guidelines and/or training initiative in their local setting with a focus on co-designing potential solutions to arising problems that can be tested by participants. Taken together, these two tasks create an iterative loop between analysis of initial experiences with the intervention and the work related to its implementation, exploration of potential solutions to any experienced problems, and testing of identified potential solutions by participants.

4. **Reflexive Monitoring** – mapping out how participants themselves appraise the implementation they have engaged with in their local settings and exploring the ways in which experiences of implementation work may shape and re-shape ‘coherence’, ‘cognitive participation’ and ‘collective action’.
History teaches us that societal challenges do not have a single answer... that there is no single solution to the problems we face, that there is no single truth.

We need to be curious in order to discover... we need to listen in order to understand. If we’re biased, we won’t see the other side to the story.

Shaping society requires a broad view and an understanding that many things in life are inter-related.

*Extract from Radboud University Mission Statement*
Chapter 11

General Discussion
Using PLA in primary healthcare research – discussion of key findings

Overview

Vulnerable groups in multi-cultural societies tend to be excluded from healthcare research on a variety of grounds. Barriers cited include inaccessibility, language discordance and/or cultural difference. Without doubt, there are challenges associated with accessing and including vulnerable groups in a meaningful way but, in our view, this is not sufficient reason to exclude them; rather, it is an incentive to identify research methodologies capable of enhancing access and promoting meaningful engagement in healthcare research that takes account of health, socio-economic and cultural conditions.

In this thesis, our preliminary work (1993-2009) focused on the use of a participatory methodology with a wide range of vulnerable and ‘hard to reach’ groups, to explore a variety of research topics (e.g., education, social exclusion, health). The body of the thesis (SUPERS and RESTORE projects) focuses specifically on primary healthcare and migrant engagement. Migrants who do not share in the culture/s and language/s of their host country, and who may also be vulnerable because of personal histories of stress, deprivation, conflict and violence present unique challenges to the primary care systems of host societies. This makes them a vulnerable group whose needs might be poorly addressed, and this lends urgency to the task of improving health systems’ responsiveness to culturally and ethnically-diverse populations. Improving responsiveness is important in primary care, as it is the entry point to, and main provider of health care for all service-users and deals with a wide range of health problems.

In light of this, the overall objective of this thesis was to assess the potential of using a Participatory Learning & Action (PLA) research approach and methods to meaningfully involve ‘hard to reach’ and vulnerable populations in the co-design and co-determination of primary healthcare that is responsive to their needs, expectations and values.

Section I: Preliminary work – sub-Saharan Africa and the Republic of Ireland, 1993 – 2009

Chapters 2, 3a, 3b

In our early studies in Africa and the Republic of Ireland (1993-2009) we set out to explore the potential of PLA to actively engage ‘hard to reach’ and vulnerable groups in research. We worked with ethnically, culturally and linguistically diverse groups: low-income women, young girls, homeless men, and ethnic minorities. We invited them to use PLA techniques to share their unique perspectives, with a view to identifying solutions that could bridge the gap between their perceived needs and service-provision at local, regional and/or national level. A key outcome of this preliminary work was evidence that PLA proved effective in eliciting, and making available to research (and to policy-makers) the perspectives of vulnerable and ‘hard to reach’ communities. PLA also showed promise as an approach capable of involving vulnerable groups in the development of initiatives to
General discussion

improve their lives and conditions: women suggested changes to national health strategies, young
girls identified constraints to school attendance which prompted policy changes to improve access to
education, homeless men suggested innovative approaches to enhance social inclusion and ethnic
minorities designed anti-racism interventions.

Section II: Exploring the use of PLA in primary healthcare research - Republic of Ireland, 2009 – 2011

Chapters 4, 5, 6

The outcomes of our early studies encouraged us to use PLA for a collaborative project located in the
Republic of Ireland which focused specifically on primary health care for migrants (Service User Peer
ResearcherS – ‘SUPERS’). The project set out to address an unsolved issue in the National
Intercultural Health Strategy. With a growing migrant population, general practitioners and migrant
service-users who did not share a common language and culture were experiencing significant
challenges in the consultation room: there were concerns and questions about what communication
strategies worked best, for whom, and in what circumstances? Migrants’ perspectives had rarely
been included in primary healthcare research oriented towards developing guidelines to address
such questions; challenges cited in the literature as barriers to their inclusion included inaccessibility,
language discordance and cultural difference. We set out to explore the possibility that a PLA
approach could overcome these barriers, and, if so, could PLA techniques be used to establish a
sufficiently meaningful engagement with migrants such that they were empowered to act as co-designers
of a practical guideline for best practice in cross-cultural consultations? In order to address
these questions, we trained seven established migrant service-users as peer PLA researchers. Using a
PLA approach and techniques, they accessed, recruited and facilitated research with 51 ‘hard to
reach’ migrants from their culturally and linguistically diverse local communities. A ‘mirror’ PLA
process conducted with healthcare professionals, followed by a brokered PLA dialogue, resulted in
the democratic co-design of a guideline to enhance cross-cultural communication in general practice
consultations. The guideline was published and disseminated by the Health Services Executive of
the Republic of Ireland. These outcomes confirmed our expectations that PLA has many strands of
potential that are critical for building community-based primary healthcare from the ‘ground up’.

Access

By training established migrants as peer PLA researchers we were able to expand the academic
research team to bridge the ‘access gap’: a larger than anticipated sample of ‘hard to reach’
migrants, with a broad mixture of ethnic and socio-cultural backgrounds and languages were
recruited as study participants. At a deeper level of ‘access’ - in terms of eliciting migrants’ unique
perspectives and knowledge - the peer researchers’ familiarity with their languages and cultures
eliminated the twin barriers of linguistic and cultural dissonance. In these respects, PLA overcame
barriers that usually exclude ‘hard to reach’ migrant groups from primary healthcare research.

Trust and retention of ‘hard to reach’ migrant research participants

The peer researchers generated a safe and secure environment which allowed ‘hard to reach’
migrants to actively and confidently participate in PLA research. The relationships of trust and
rapport thus established stood the test of time: one year after first engaging in PLA, a majority of migrant participants returned to finalise the draft guideline.

**Meaningful engagement**

The peer researchers’ PLA training allowed them to facilitate a complex research process, using a range of PLA techniques capable of including both literate and non-literate. These techniques enabled the ‘hard to reach’ migrants to bring their unique knowledge and perspectives to the fore, to co-generate and co-analyse data. This user-friendly, democratic PLA process resulted in experiences of meaningful engagement which took migrants well beyond roles as ‘information-providers’ or passive participants in a tokenistic consultation. They contributed with ease and competence to a rigorous, robust research process and evaluated their engagement as positive and empowering.

**Inter-stakeholder dialogue delivers a practical democratic outcome**

The peer researchers strongly represented the ‘hard to reach’ migrants’ perspectives during inter-stakeholder dialogues with key healthcare professionals and service-providers. This strengthened the overall representation of migrants in the study and ensured that their voices were not lost or subsumed beneath those of healthcare professionals. The inter-stakeholder dialogues continued the democratic decision-making typical of PLA and produced clear recommendations for best practice in cross-cultural primary care consultations: the use of professional interpreters constituted best practice; the use of family members and friends as interpreters, and technological and visual aids, while deemed ‘useful’, were not considered acceptable as best practice and were excluded from the guideline. The ability to reach consensus across stakeholder groups was a striking finding, considering the range and diversity of perspectives. Where consensus was not reached, the transparently democratic PLA process enabled stakeholders to agree that the majority view about the acceptability (or not) of a particular communication strategy should prevail. The consistent involvement of migrants throughout the study had a profound impact on the resulting practical outcome: a co-designed guideline for best practice in cross-cultural primary care consultations that was responsive to ‘hard to reach’ migrants’ needs, expectations and values.

**Empowerment of groups and individuals**

Migrants’ experiences of PLA during the SUPERS project also illustrated how they were empowered. ‘Hard to reach’ migrants engaged in robust academic research and contributed to a best-practice guideline, thus co-determining healthcare policy and practice; their engagement in PLA research also broke through the isolation that many experienced on a daily basis in the host country. This demonstrates that PLA can have an integrating function that prompts broader social connections and enables empowerment in other social spheres. For the peer researchers (SUPERS), their experiences of PLA empowered them in personal and professional spheres of their lives. They now represent a cohort of trained PLA researchers who constitute a valuable and unique resource for building primary care research for and within their communities.

**Building research capacity in the community**

An important aspect, then, of empowerment is the building up of research capacity in the community. The SUPERS’ training in a PLA ‘mode of engagement’ equipped them to act as facilitators and brokers (rather than as directors or top-down decision-makers) with their ‘hard to reach’ migrant groups. Their training provided them with a ‘basket’ of practical PLA techniques for research
fieldwork and co-analysis. They co-designed fieldwork protocols to ensure consistency and rigour, and their training also promoted reflexive practice, included post-fieldwork evaluation and co-analysis with academic team members, all of which contributed to increased skill levels. This culminated in public roles, presenting research findings at national and international conferences. Taken together, this represents significant research capacity-building of community members.

Section III: Expanding the use of PLA in primary healthcare research – European Union, 2011 – 2015

Chapters 7, 8, 9, 10

Following these experiences and results in the Republic of Ireland, a European project called RESTORE (REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings) provided an opportunity to expand the application of PLA across a broader range of primary healthcare settings in countries with different histories of migration (Austria, England, Greece, the Netherlands and the Republic of Ireland) and to engage with more diverse migrant populations under a variety of socio-economic and cultural conditions. The overall objective of RESTORE\textsuperscript{21,22} was to investigate and support the implementation of guidelines and training initiatives (G/TIs) to enhance communication in cross-cultural consultations. We used a mapping process to identify a range of G/TIs that might prove suitable for implementation at local level in the five primary care settings.\textsuperscript{23} We trained small teams (2-5 social scientists/clinicians) from each country in a PLA ‘mode of engagement’ and PLA techniques which they then used to engage migrant service-users and healthcare professionals in inter-stakeholder dialogues.

In Section III of the thesis, we describe and analyse diverse stakeholders’ experiences of using PLA to co-analyse G/TIs and to democratically select one that they considered likely to enhance communication in cross-cultural primary care consultations. Evaluations confirmed that stakeholders’ involvement in the PLA research process was both positive and productive. Stakeholders had few negative and numerous positive experiences of meaningful engagement: PLA supported a safe, trusting environment in which stakeholders listened to and learned from each other’s perspectives, gained enhanced knowledge (which informed co-analysis) and experienced active, meaningful collaboration. The combined visual, verbal, tangible nature of PLA techniques (e.g., Commentary Charts and Direct Ranking) facilitated involvement of mixed-literacy-ability groups and reduced language and (health) literacy barriers; the inherently analytical capabilities of the techniques enabled stakeholders to produce a transparently democratic outcome. In these respects, PLA proved to be a powerful tool for decision-making; the iterative PLA process was described by stakeholders as empowering and energizing – promoting ownership, shared power and co-responsibility.\textsuperscript{20,21}

Our study also shows that PLA, as a brokering tool, had a powerful impact in terms of balancing asymmetrical power-relations among stakeholder groups (service-users and service-providers) during inter-stakeholder dialogues. This is where PLA comes into its own – managing divergent experiences and potentially divisive views.\textsuperscript{25,26} In the transparent, democratic, dialogic PLA environment, stakeholders may gain an entirely new perspective which prompts them to shift position from long-
held patterns of belief or behaviour and to identify ‘common ground’ on which to base positive action.\textsuperscript{19,20} This is illustrated in the vignettes below:

**Vignette 1: Should children be used as interpreters?**

*Service-users influence the perspective of a service provider.*

In the SUPERS project, during an inter-stakeholder dialogue about cross-cultural communication strategies, a general practitioner (GP) expressed the view that using child interpreters was useful and acceptable in certain circumstances. Migrant service-users asked the GP to consider potential negative implications of this strategy (as they perceived and experienced it): children may be burdened by hearing about a parent’s symptoms and/or illness; children might struggle to adequately interpret adult language and medical terms, and in some cases, be traumatised by having to relay ‘bad news’ to their parents. Having listened openly to the migrant service-users, a shift in perspective was clearly evident on the part of the GP when she stated that she would not use a child interpreter again in her medical practice.

**Vignette 2: Why should we use professional interpreters?**

*Service-users and service-providers learn from each other’s perspectives.*

During the RESTORE project, service-user representatives in the Irish setting influenced the perspective of a GP who described herself as having ‘very fixed ideas about interpreting’. She had no experience of using professional interpreters for cross-cultural medical consultations, and imagined that doing so would be a difficult and tiresome process. During a role-play with service-users and a community interpreter, the GP had the opportunity to experience, in ‘safe space’, what an interpreted consultation was actually like. Her end-of-project evaluation included comments about her shift in perspective: ‘I had my own fixed ideas, you know, about interpreted consultations, and the good/bad associated with that, but to have it cracked wide open...and to hear all the different perspectives, in particular from service-users, but also from community interpreters, to see the different slants, I learned so much about interpreting that I would never have known.’

As part of her ongoing involvement in RESTORE, the same GP went on to work with migrant representatives and community interpreters to advertise the availability of a new interpreting service at her medical practice. From previous research, we knew that many migrants in Ireland were unaware that they could request the services of an interpreter, while others assumed that it would be intrusive or would reduce their trust level to have a ‘third person’ (stranger) in the consulting room. However, service-users who availed of the new interpreting service learned that having an interpreter present was helpful and clarifying: ‘It was helpful – without the interpreter I wouldn’t have been able to say what I wanted to say to the doctor.’ ‘I’d prefer to do a consultation with an interpreter [present] because it’s easier for me to tell some stuff to the doctor.’ ‘It was very, very good, there weren’t any misunderstandings.’ Service-users also described how having an interpreter was supportive and promoted confidence in diagnosis and treatment: ‘Actually, I think I got all answers what I wanted to get.’ ‘I came out with high confidence [in my diagnosis].’ One service-user seemed to gain immediate trust in the interpreter: ‘I definitely would have no problem with the professional interpreter; [next time] I would like the one I had [just now] rather than a different one, it’s just that I trust her now.’ Clearly, service-providers (in this case, the GP and the community interpreter) influenced service-users’ behaviour and contributed to important ‘shifts in perspective’. 
On occasion, shifts in perspective extended to what we call ‘transformative moments’: stakeholders (faced with a seemingly intractable problem) made a ‘small leap of generosity’ across territorial boundaries, opening up new possibilities for solving the problem. This illustrates the heuristic potential of PLA:

| Vignette 3: How can we solve this seemingly intractable problem? |
| Stakeholders (service-users & service-providers) share the burden... |

During the RESTORE project, while creating a PLA ‘Seasonal Calendar’ chart to assign and visually ‘plot’ responsibility for key G/Ti implementation tasks, stakeholders at the Irish site noticed an emerging problem. Practice staff had assigned themselves a large number of tasks which needed to be completed imminently, believing ‘in good faith’ that they were the only stakeholders who could complete them. However, the chart clearly showed that they had taken on a very daunting and burdensome workload. Noticing this, and its dispiriting effect on practice staff, other stakeholders addressed it. A lively and compassionate conversation ensued: community interpreters, migrant service-users and the policy planner offered to lift some of the workload burden from the shoulders of practice staff. Together, they negotiated and re-positioned tasks on the Calendar, redistributing responsibilities more evenly across all stakeholders. This brought a great sense of relief to practice staff and enabled the implementation process to proceed. What appeared to be an intractable problem was resolved by a small leap of generosity, generating a disproportionately positive impact.

The results of our studies confirm that PLA is an effective, ‘fit-for-purpose’ approach and methodology which can ensure that stakeholder-centred knowledge feeds into the development of evolving primary healthcare in a way that is responsive to stakeholders’ changing needs and health priorities. This builds primary healthcare in a way that is consistent with its core values: collegiality, empowerment, co-responsibility and stakeholder self-efficacy.27

Using PLA in primary healthcare research – challenges and ‘pressure points’

**Investing time, energy and resources in PLA training and research – PLA researchers**

The effectiveness, potential and achievements of PLA that we outline above did not come about without a significant investment of time, energy and resources. To do PLA well requires appropriate training of researchers, meticulous planning and co-design of research protocols, preparation and culture-proofing of physical research materials as well as time devoted to fieldwork and PLA processes with stakeholders. Researchers commit to teamwork, reflexivity, reflection, debriefing, evaluation and, in many cases, to co-presentation of findings and co-authorship of research papers.19,20 PLA projects may be of short or long duration; PLA researchers may be unpaid volunteers (as in SUPERS) or paid professionals (as in RESTORE). These and many other factors demand ‘more’ or ‘less’ of PLA research teams, and ought to be taken into account when assessing researchers’ experiences of engagement in PLA.

In SUPERS, the peer researchers were unpaid volunteers. They completed 28 hours of PLA training: learning core techniques, co-designing the research protocol and culture-proofing research materials. They then engaged in a single day (7 hours) of intensive research, facilitating a complex
sequence of seven interlinked PLA techniques with migrant stakeholder groups. Striving for quality and rigour under such time constraints is challenging and the peer researchers described feelings of exhaustion at the close of the day; however, they also described feelings of excitement: they enjoyed witnessing the positive nature of migrant service-users’ participation and they had personal experiences of achievement as researchers. In RESTORE, the paid professional researchers also faced time challenges as they attempted to balance fitting in all the planned PLA processes while not over-burdening stakeholders. They felt they had insufficient time to reflect on fieldwork, and they reported rare (though important to note) instances of research fatigue. Pacing PLA research is an ever-present challenge—we place a high value on ‘not rushing’ but the circumstances and demands of the overall research project often clash with this value. When using PLA in primary healthcare research, adequate time, energy and resources for training and research and the pacing of research itself will be a ‘pressure point’ that demands careful attention, in order to maintain the congruent core values of primary care and participatory research.

Stakeholders’ investment of time, energy and resources in PLA research: health professionals
Healthcare professionals tend to be reluctant to commit time and energy to primary care research in general, and this is well-documented. For some who do, it may come at a cost. Clearly, engaging in research is an added pressure on an already-full agenda, with no certainty about benefits or gains for clinicians. In RESTORE, while we encountered some evidence of reluctance, this usually proved to be an initial resistance which gave way as clinicians experienced what it was like to engage in PLA and what it could deliver. Given that involvement in PLA inter-stakeholder dialogues was sought over an extended period of time (20 months) it was interesting to observe that most clinicians committed more time than they initially thought they could (or intended to) and even explored creative ways of being involved in a time-efficient way. Vignettes 1 and 2 above are examples of other clear benefits and gains for clinicians: achieving important insights into service-user concerns regarding child interpreters, and realizing how interpreted consultations could support appropriate diagnosis and treatment. Vignette 3 illustrates another type of gain for healthcare professionals: the experience of ‘sharing the burden’. In the collaborative environment of PLA inter-stakeholder dialogues, clinicians realised they did not have to shoulder all the responsibility for decision-making, and that democracy-in-action was the order of the day when choosing a guideline for implementation. Overall, our evaluations provided ample evidence that the PLA process, as an experience in itself, and what it is capable of delivering, ‘captured’ the attention and sustained interest of many clinicians, and connected with their core primary healthcare values. The ‘pressure point’ for primary healthcare research, then, is to attract healthcare professionals in the first instance, and ensure that their experiences of engagement in PLA are sufficiently meaningful to guarantee their continued involvement. This is in line with Dutch experiences of health care reform, which noted the importance of stimulating primary care professionals to ‘exert their passion and expertise’ through participation in primary care research and development.

Stakeholders’ investment of time, energy and resources in PLA research: migrant service-users and migrant representatives
In contrast to healthcare professionals, community-based participants (migrant service-users, migrant representatives) rarely, if ever, considered the time energy and resources that they contributed to PLA research to be an over-commitment, or over-demanding. Evaluations of the SUPERS project revealed that migrant service-users considered their involvement in research
oriented towards a shared health goal to be more-than-adequate ‘payback’ for their investment. They also noted that engaging together in PLA broke through the isolation that many experienced on a daily basis in the host country. This suggests that PLA, well-facilitated, can have an integrating function that prompts broader social connections and enables empowerment in other social spheres. A ‘small engagement’ in PLA may have a disproportionately ‘large’ positive impact on the most vulnerable in our communities.

Evaluations from RESTORE revealed that migrant service-users sometimes experienced research fatigue but this was offset by the exercise of positive power they experienced during democratic PLA processes; they recognised that their input clearly influenced the progress and trajectory of the research – this gave them a sense of ownership of the research project.

However, we find ourselves wondering if ‘hidden’ pressure points existed in our projects, which might emerge more clearly were we to engage in extended PLA primary care research on a regular basis with community members. For example, can we continue to offset research fatigue by experiences of meaningful engagement, or do we need to explore new and more effective ways of pacing research? What are appropriate ways to compensate community-based stakeholders and participants? Is it sufficient to depend on their goodwill and generosity? There are ethical and practical issues embedded in these questions. When considering using PLA in future primary healthcare research, it would be valuable to explore how current participatory research partnerships that actively involve community members are operating in this regard.

Building research capacity in communities

From our preliminary projects right through to SUPERS and RESTORE, we built ‘research capacity’ – training and supporting indigenous teams in Africa, migrant peer researchers in Ireland, clinicians and social scientists in Europe. We believe this investment of time, energy and resources is warranted when we consider the quality, breadth and relevance of research outcomes. In addition, a PLA approach, mode of engagement and application of techniques facilitates meaningful engagement that is compliant with ethical recommendations for working with vulnerable groups. It is also important to point out that PLA training is rarely limited to use in a single research project; our experience suggests that, once trained, researchers are able to apply PLA to many research topics, with many groups, under a variety of conditions. (Interestingly, some researchers have also applied their PLA training in fields other than research, for example, adapting it for co-development in education and teaching practice.)

This capacity-building makes community-based PLA research teams an invaluable resource for the development of responsive healthcare in communities-under-care. However, a pressure point for future primary care research will be to build PLA research capacity in such a way that the community is truly ‘doing it for itself’ in a long-term, sustained and sustainable way, with adequate funding and appropriate supports. Training and resourcing small PLA teams comprising community-based peer and co-researchers alongside interested local practice staff and/or academics is a strong model for achieving this. We believe it is critically important to develop such research partnerships to champion and drive primary care research into the future.
**Time constraints and evaluation**

The literature includes many studies which describe efforts to use a participatory approach in a research project but do not provide any evaluation by stakeholders of their experiences of engagement.³⁹ We recognise that time constraints may often limit evaluations. In SUPERS and RESTORE, at the close of PLA research sessions, there was little time for lengthy evaluations; to ensure we captured at least the basics of stakeholder’s experiences of engagement, we used ‘speed evaluations’. Speed evaluations are time-efficient but brief, and do not produce the kind of rich, illustrative quotes found in in-depth evaluations. To offset this, we augmented our speed evaluation data by drawing on researchers’ post-PLA session in-depth reflection interviews, where they recorded observations and comments about stakeholders’ engagement. This provided a measure of richness and triangulation. Additional in-depth PLA participatory evaluation (conducted with stakeholders at the Irish RESTORE site only) was a good example of high-quality evaluation which provided many insights into stakeholders’ experiences of engagement. In order to build a stronger sense of positive and negative experiences of stakeholders’ involvement in PLA, we propose that, in future primary healthcare projects, researchers use a full array of evaluation tools and ensure that PLA processes are evaluated from the perspectives of all stakeholders involved in the study. This would be a significant addition to the evidence base.

**Generalisability and transferability**

In common with qualitative and participatory studies, we do not claim representativeness for, or generalizability of our findings. However, our studies demonstrated the successful application of PLA across many countries in relation to various topics. In most instances, PLA was being applied in relatively challenging contexts and circumstances, and, in SUPERS and RESTORE, in a period when primary healthcare was experiencing the strains of an economic crisis, resulting in diminished health funding and increased demands for health care. Given this, we consider that our studies represent ‘critical cases’: if we can use PLA successfully in these circumstances, it must be possible to do so elsewhere and in all kinds of less challenging contexts and circumstances. This confirms that PLA is a highly transferable methodology, mode of engagement and set of techniques.

**Addressing power asymmetries – from ‘local’ to ‘global’ and back again**

Our studies showed that PLA is effective in addressing power differentials among stakeholders involved in primary care research at a local level. However, we must acknowledge that macro-level structural inequalities and major geopolitical forces continually impact on migrant health and limit what can be achieved. For example, in RESTORE, we discovered that implementation of G/TIs was inhibited due to factors outside stakeholders’ control, such as lack of an appropriate funding stream, or the absence of practical services required to fully support implementation.⁴⁰ Notwithstanding this, we believe PLA is a powerful methodology for building the capacity of primary healthcare to respond to many consequences of these forces as they are experienced at local level within communities-under-care. An ongoing challenge for primary healthcare research will be to continue to manage power asymmetries, bringing together powerful and influential ‘uppers’ and the most vulnerable in our communities⁴¹-⁴³ in sustained inter-stakeholder dialogues, to achieve ‘win-win’ situations⁴⁴ which may, in time, effect change beyond the local.
General discussion

Overarching conclusions

Our conclusions, as set out below, show that PLA can ‘deliver’ in relation to three key aspects of primary healthcare that are essential to the task of developing responsive primary healthcare:

- addressing the community basis orientation
- enabling the empowerment of populations and individuals, and
- facilitating positive change in the perspectives of service-users and service-providers.

**Conclusion 1: PLA is capable of involving vulnerable, ‘hard to reach’ migrants and other stakeholders in primary healthcare research and is a highly transferable methodology**

The *community basis orientation* of primary care acknowledges that communities are heterogeneous and that population demographics and social determinants of health may change over time. To build responsive health care ‘from the ground up’, therefore, requires a research approach and methodology that is inclusive, flexible and widely applicable, capable of accessing and involving many types of vulnerable groups in primary healthcare research. This thesis, to the best of our knowledge, is the first to study the use of PLA to involve vulnerable, ‘hard to reach’ and undocumented migrants as key stakeholders in co-designing primary healthcare that is responsive to their needs, expectations and values. In this respect, the work can be regarded as ‘proof of concept’: using PLA made it possible to involve vulnerable migrants and to bridge the barriers that culture, language, literacy challenges and (health) literacy pose. It was instructive to discover that PLA could be successfully applied across a broad range of primary healthcare settings and systems in five European countries, and that, despite significant cultural, socio-economic and contextual variations within and among migrant stakeholder groups, the use of PLA resulted in meaningful engagement of migrants as co-analysts and co-designers in all settings. This, coupled with our preliminary work, which documented the successful application of PLA across very different populations and research topics, leads us to conclude that PLA is a highly transferable methodology, widely applicable to diverse groups and research topics in the community-under-care.

**Conclusion 2: PLA facilitates meaningful engagement beyond tokenism and enables co-determination of primary healthcare practice & policy**

The *empowerment of populations and individuals* is a core aspect of responsive healthcare. In this thesis, it was important to assess the level and nature of migrant’s involvement - would it be possible to establish engagements that were sufficiently meaningful and empowering such that migrants would act as co-designers of healthcare? A key outcome of the SUPERS and RESTORE projects was evidence that PLA enabled vulnerable, ‘hard to reach’ and undocumented migrants to engage meaningfully in healthcare research as co-analysts and co-designers. They contributed with ease and competence to rigorous, robust research processes. Their engagement throughout PLA inter-stakeholder dialogues with healthcare professionals ensured that their perspectives were incorporated in research outcomes and they described their engagement as positive, energising and empowering. We conclude that PLA is a powerful, practical ‘fit-for-purpose’ methodology capable of
meaningfully engaging ‘hard to reach’ migrants in the co-design and co-determination of healthcare that is responsive to their needs, expectations and values.

**Conclusion 3: PLA addresses asymmetries of power, enabling changes in stakeholders’ perspectives on primary healthcare issues**

The third key aspect of primary healthcare is *facilitating positive change in the perspectives of service-users* (e.g., migrants) and *service-providers* (e.g., healthcare professionals). In this thesis, it was important to explore and assess how PLA facilitated this. Our studies show that PLA proved effective in creating and maintaining trusting environments within which meaningful inter-stakeholder dialogues unfolded. This was possible because the methodology was capable of managing power asymmetries – very diverse stakeholders interacted in a collegial and co-operative manner, respectfully sharing knowledge and insights. This led to enhanced learning and shifts in perspective during dialogues which increased stakeholders’ capacity to democratically co-design and co-determine appropriate healthcare interventions. We conclude that a PLA methodology is capable of addressing asymmetries of power, enabling changes in stakeholders’ perspectives, leading to the co-determination of appropriate and responsive healthcare.

**Recommendations**

**Recommendation 1**

Given the need to build primary healthcare ‘from the ground up’, the perspectives of diverse groups, especially the ‘hard to reach’, must become a normative part of primary healthcare research. PLA is a powerful, practical ‘fit-for-purpose’ methodology for achieving this. As community needs and social determinants of health change over time, PLA engagement should be a continuous process rather than a one-off event. *We therefore recommend the use of PLA as a methodology of choice (a generic approach) in primary health care research* for sustained meaningful engagement with communities-under-care.

**Recommendation 2**

In recommending that PLA become a methodology of choice for primary healthcare research, we acknowledge the time constraints on healthcare professionals and the energy, expertise and commitment that community members are prepared to invest in primary healthcare research. In light of this, and the core primary healthcare values of collegiality, empowerment, self-efficacy and co-responsibility, *we recommend embedding PLA training primarily in the ‘practice community’ to build participatory research capacity at local level*. Why? Because ‘the practice community’ includes service-users (e.g., patients/carers) and service-providers (e.g., practice staff, clinicians, local policy-planners) who are key stakeholders with vested interests in re-designing healthcare to meet prevailing circumstances. Embedding PLA training in the practice community would involve training community members, interested general practice staff and other relevant experts (e.g., academics) who regularly interact with the general practice and/or the community-under-care, as PLA research teams. These small, modest PLA research partnerships would co-design research agendas from a collaborative starting point and jointly facilitate PLA research engagements in the community-under-care. The power-sharing at the heart of good PLA practice would help stakeholders to understand each other’s limitations as well as identify opportunities for change that can realise a better primary
healthcare outcome, especially for the vulnerable in the community. Such modest collaborative interventions may have disproportionally positive effects; also, PLA would serve as a method for primary health care to incrementally review and plan its responsiveness to community priorities. In terms of putting these recommendations into practice, it may be useful to:

- start with a modest plan: identify a practice community interested in using PLA; train community members and one or more practice staff as a PLA team (partnership)

- collaboratively ‘set the research agenda’ - identify a modest project of mutual interest and relevance to the general practice and the practice community; ensure the project is within the power of the new PLA team to deliver, and provide adequate support for the application of PLA to the project in question

- ensure there is protected time for in-depth participatory evaluation from all stakeholders’ perspectives of (a) the PLA training and (b) of any PLA research project undertaken; maintain the emic dimension of stakeholders’ experiences by collaboratively incorporating evaluation criteria they consider appropriate and valuable

- arrange for PLA team members who have gained experience in PLA primary care research projects to provide short introductory ‘PLA information sessions’ to healthcare professionals (e.g., at conferences) to attract them to, and familiarise them with PLA

- introduce a core PLA research training module into GP training and CPD (continuing professional development) programmes to provide GPs and practice staff with initial exposure to the methodology and its potential

- introduce a PLA module into academic research training programmes, particularly in academies/departments closely connected to/oriented towards primary healthcare research

- use existing community-based networks (formal and informal) where vulnerable groups regularly gather (e.g., shelters, support and advocacy groups, churches and mosques, sporting organisations) to raise awareness within the broader community about the nature of PLA research, stressing its potential to meaningfully involve diverse groups in addressing healthcare issues of concern to them; this initial engagement could serve as a ‘building block’ towards gaining access and building trust in subsequent research projects

- develop a network among practice communities that are engaging in PLA research; the network would share research results, processes, issues and plans, with a view to generating data about best-practice in PLA primary healthcare research and also
to explore potential approaches to larger-scale or macro healthcare issues that affect many communities in common

- ensure that, over time, strong and supportive connections are forged between PLA primary care research teams/partnerships/networks and relevant powerful and influential individuals, groups and organisations within and beyond the community (e.g., academic and philanthropic foundations and individuals, local, national and international policy-makers, educators, media figures, responsible social media, etc). PLA teams are bound to be affected by factors outside their control (e.g., funding, bureaucracy, current policies, social disturbance, political change) which may limit what they can achieve on their own; connecting with influential personnel to identify and cultivate potential champions may strengthen and support the ongoing development of PLA-based primary care research, and the implementation of emergent findings

- recognise that primary healthcare has open borders with all other fields of society (economics, social inclusion, etc). As PLA is not disease-restricted, but open to exploration of, for example, well-being and pro-active research for better health outcomes, this broadens the field of engagement for PLA teams engaging in primary healthcare research and opens up extensive opportunities to exercise PLA’s potential to reduce biases, soften boundaries, and invite stakeholders to emerge from their silos.

Finally, if the only interface between service-users and service-providers is the general practice surgery, this asks too much – responsive primary healthcare cannot be delivered in this way. Therefore, we emphasise that, for those of us with any influence, expertise or say in the matter, we must ensure that ‘the community does it for itself’; that we share methods and tools that enable communities-under-care to engage in a fully-empowered manner in their own healthcare development.
General discussion

References:

Chapter 11


My heart is moved by all I cannot save; so much has been destroyed. I have to cast my lot with those who, age after age, perversely, with no extraordinary power, reconstitute the world.

Adrienne Rich, from ‘Natural Resources’.
Chapter 12

Summary / Samenvatting
Summary

The overall objective of this thesis was to apply and assess the potential of Participatory Learning and Action (PLA) as a research approach and methods to meaningfully involve ‘hard to reach’ and vulnerable populations in the co-design and co-determination of primary healthcare that is responsive to their needs, expectations and values. We describe the application and testing of PLA in a variety of primary healthcare settings: empirical data was collected in Austria, England, Greece, the Netherlands and the Republic of Ireland. Our assessment focuses on three key aspects of primary care – the community basis orientation, the empowerment of groups and individuals and the potential for positive change in the perspectives of service-users and service-providers – which are critical to realising the ambition to build community-based primary healthcare from the ‘bottom-up’.

The emphasis in this thesis is on involving migrants as co-designers of their health care.

The thesis consists of three sections:

**Section I** *(Chapters 2, 3a, 3b)* covers a range of participatory research projects involving vulnerable populations in sub-Saharan Africa and the Republic of Ireland.

**Section II** *(Chapters 4, 5, 6)* covers the application of PLA to a primary healthcare research project concerning migrant health in Ireland (the ‘SUPERS’ project).

**Section III** *(Chapters 7, 8, 9, 10)* covers the expansion of the application of PLA across a broader range of healthcare settings in Europe (the RESTORE project).

Sections II and III constitute the body of the thesis.

In **Chapter 1 (General Introduction)**, we note that strengthening primary healthcare is a global strategy for overall sustainability of healthcare systems. We summarise the essentials of primary healthcare: to respond to the needs of a population-under-care, fine-tuning that care to the community level and prevailing health challenges. This means that responsive primary healthcare depends on understanding the needs, values and expectations of diverse communities, how they are affected by the social and cultural determinants of health and how this may change over time. We point out that general knowledge of a population, therefore, has to be augmented by specific and contextualised knowledge of individuals, groups and communities. To access and elicit this knowledge requires the involvement of service-users, service-providers and other key stakeholders as partners in a ‘bottom-up’ research approach oriented towards co-determining appropriate healthcare policies and practices. Essentially, all key stakeholders need to be ‘at the table’. However, ‘hard to reach’ and vulnerable populations are consistently excluded from participation in primary healthcare research on the basis of inaccessibility, language-discordance and cultural difference. To close this gap, we need a research methodology capable of eliciting and balancing the perspectives of all stakeholders, especially the least powerful and most vulnerable. We therefore outline the key principles and pragmatics of PLA, noting the close connection between the core values of primary healthcare and participatory research. PLA, with its attention to balancing power differentials, and its use of practical research techniques specifically designed to be inclusive, user-friendly and democratic, encourages reciprocal learning and ongoing dialogue between stakeholder groups (e.g., service-users and service-providers) and enables stakeholders to participate in the full range of
research activities, including data-generation and data-analysis. The key function of PLA is to actively engage stakeholders in inter-stakeholder dialogue with a view to the co-generation of creative solutions to commonly-shared problems, and the identification and implementation of beneficial actions or interventions. PLA ensures that stakeholders’ perspectives, especially those of the ‘voiceless’, influence the conduct and trajectory of research and research outcomes, which is a hallmark of meaningful engagement, an essential ingredient for the co-design and co-determination of appropriate and responsive healthcare. Finally, we note that, against a background of a Europe that is becoming increasingly multi-cultural, with health systems under pressure because of a global financial crisis, and with increasing numbers of non-Western migrants requiring health services, we urgently need to improve health systems’ responsiveness to culturally and ethnically-diverse populations. Although we face the key problem of migrants’ traditional exclusion from primary healthcare research, this is a gap we believe can be addressed, and it provides us with an incentive to identify and explore research methodologies capable of enhancing access and promoting the meaningful engagement of vulnerable groups in primary healthcare research.

**Section I: Chapters 2, 3a, 3b**

**Chapter 2**
In our early studies in sub-Saharan Africa and Ireland (1993-2009), which focussed on education, social inclusion and healthcare, we applied a participatory research approach and adapted participatory techniques to actively engage stakeholders from vulnerable and ‘hard to reach’ populations in community-based research. In Africa, to overcome barriers associated with language and cultural diversity, we trained indigenous teams (familiar with local tribal languages and cultural nuances) to use PLA with community groups. This enabled locals to participate in the research process, ensured that their perspectives emerged clearly in research outcomes and encouraged inter-stakeholder dialogues that ‘bridged the gap’ between the needs of communities and service-provision at local, regional and national level.

**Chapter 3a**
This participatory research study was conducted with disadvantaged homeless men in Dublin, Ireland (2007). The men used PLA techniques to identify barriers to social inclusion, and co-generated creative culturally-appropriate solutions. Based on this, they designed a practical plan to assist homeless men like themselves to overcome barriers and attitudes that prevent them from seeking help to tackle their social exclusion. The study demonstrated the potential of PLA to actively engage vulnerable stakeholders from a ‘hard to reach’ population in research oriented towards improving their lives and conditions. A key finding was the ‘changed perspective’ of these men during the PLA research process: they moved from seeing themselves as passive service-users to seeing themselves in active mentoring and support roles, operating as peer service-providers for other homeless men, an interesting expression of self-efficacy and empowerment.

**Chapter 3b**
This study was the first application of PLA in the Republic of Ireland (1998-2001). 120 women across 26 counties were trained as PLA ‘peer researchers’ and they facilitated research with almost 500 women. The aim of the health component of the study (presented here) was to explore whether or
not the aims and objectives of the Irish Government’s *Plan for Women’s Health 1997-1999* had impacted on their health and well-being, needs and concerns, and if so, in what manner. Women used PLA techniques to identify a range of serious gaps and omissions in the plan, and identified potential solutions that could positively inform future health policy and strategies.

Taken together, these studies indicated that PLA methodology and techniques could be applied to a range of research topics, with many types of vulnerable populations, in diverse socio-cultural contexts, and in several countries. PLA showed promise as an approach capable of involving vulnerable and ‘hard to reach’ groups in robust research to identify creative solutions to problems and to work with other key stakeholders to develop initiatives to improve their lives and conditions.

**Section II: Chapters 4, 5, 6**

**Chapter 4**
In this Section, we introduce a primary healthcare project called ‘SUPERS’ (*Service User Peer ResearcherS*), conducted in the Republic of Ireland (2009-2011). In response to communication difficulties that arose in cross-cultural general practice consultations when general practitioners and migrant service-users did not share language or culture, the project explored the capacity of PLA to meaningfully involve ‘hard to reach’ migrants as key stakeholders in the co-design of a specific healthcare intervention, in this instance, a ‘best practice’ guideline intended to enhance cross-cultural communication in general practice consultations. Migrants’ perspectives have rarely been included in the development of such guidelines; considered ‘hard-to-reach’ on the basis of inaccessibility, language discordance and cultural difference, they have been consistently excluded from participation in primary healthcare research. The purpose of the study was to address this gap. We trained seven established migrants from local communities as PLA ‘peer researchers’; they used their access routes, language skills, cultural knowledge and PLA training to recruit and engage in research with 51 hard-to-reach migrant service-users (MSUs) from ethnically diverse communities. The peer researchers facilitated a complex series of seven interrelated visual/verbal/tangible PLA techniques in a language-concordant and culturally-sensitive manner. This fostered meaningful engagement on the part of the MSUs and ensured that their perspectives were included in a subsequent inter-stakeholder dialogue with service-providers to identify which communication strategies worked best, for whom, and in what circumstances. This dialogue produced a practical guideline for improving communication between service-providers and MSUs in Ireland. SUPERs evaluated their experiences of capacity-building, training, research fieldwork and dissemination as positively meaningful for them. MSUs evaluated their experiences of engagement in PLA fieldwork and research as positively meaningful for them. This study indicated that, given the need to build primary healthcare ‘from the ground up’, the inclusion of diverse groups, especially the hard-to-reach, must become a normative part of primary healthcare research. PLA is a powerful, practical ‘fit-for-purpose’ methodology for achieving this: enabling ‘hard to reach’ groups to engage meaningfully in, and contribute with ease to academic research.

**Chapter 5**
In this chapter, we continue to explore the use of PLA in the SUPERS project, focusing on the inter-stakeholder dialogue between service-providers (health professionals) and service-users (MSUs). The
sample comprised 80 stakeholders: 15 general practitioners/general practice staff; 5 formal, trained interpreters; 2 service planners and the 51 migrant service-users (MSUs) and 7 peer researchers mentioned in the previous chapter. The inter-stakeholder dialogue continued the democratic decision-making typical of PLA and produced clear recommendations for best practice in cross-cultural primary care consultations: it was agreed that the use of professional interpreters constituted best practice; the use of family members and friends as interpreters, and technological and visual aids, while deemed ‘useful’, were not considered acceptable as best practice and were excluded from the guideline. The ability to reach consensus across stakeholder groups was a striking finding, considering the range and diversity of perspectives. Where consensus was not reached, the transparently democratic PLA process enabled stakeholders to agree that the majority view about the acceptability (or not) of a particular communication strategy should prevail. The consistent involvement of migrants throughout the study had a profound impact on the resulting practical outcome: a co-designed guideline for best practice in cross-cultural consultations that was responsive to ‘hard to reach’ migrants’ needs, expectations and values. Guidelines for best practice that are co-generated in this participatory manner are rare and fill a significant gap in the literature. The use of PLA, while resource-intensive, was equally the very strength of the research, producing an inclusive guideline which, because of its resonance with ‘many voices’, is likely to have a greater chance of being implementable in practice. This chapter also emphasises the need for policy-makers and service planners to work in partnership with service-providers and migrants to progress implementation of agreed best-practice strategies.

**Chapter 6**

This chapter presents the ‘Guideline for Communication in Cross-cultural General Practice Consultations’ which was the key practical output from the ‘SUPERS’ project. The result of an innovative, extensive and rigorous PLA process, the Guideline was a concrete response to an unsolved issue in the HSE (Health Service Executive) National Intercultural Health Strategy 2007-2012. The Strategy acknowledged the need for supports for cross-cultural communication in healthcare settings including general practice consultations, but was unable to specify what communication strategies constituted best practice. The Strategy recommended a multi-stakeholder approach to explore the issue further. The SUPERS project achieved this by the application of PLA, and the Guideline is important as an example of collaborative co-design and co-determination of a primary healthcare initiative. The Guideline was published and disseminated by the Health Services Executive of the Republic of Ireland. The study outcomes confirmed our expectations that PLA has many strands of potential that are critical for building community-based primary healthcare from the ‘ground up’.

**Section III: Chapters 7, 8, 9, 10**

In this Section, we examine the RESTORE project (REsearch into implementation STRategies to support patients of different ORigins and language background in a variety of European primary care settings, 2011-2015). This international collaboration, which focussed on healthcare for migrants, provided an opportunity to expand the application of PLA across a broader range of primary healthcare settings in countries with different histories of migration (Austria, England, Greece, the Netherlands and the Republic of Ireland) and to engage with more diverse migrant populations under
a variety of socio-economic and cultural conditions. The overall objective of RESTORE was to investigate and support the implementation of guidelines and training initiatives to enhance communication in cross-cultural primary care consultations. Our intention was to use PLA to meaningfully involve migrants as key stakeholders in inter-stakeholder dialogues designed to critically appraise and democratically select a guideline or training initiative for implementation at local level.

Chapter 7 provides a detailed account of the mapping process we used to identify a range of guidances and training initiatives (G/TIs) that might prove suitable for implementation at local level in the diverse primary care settings of RESTORE. We used purposeful and network sampling to identify experts in statutory and non-statutory agencies across Austria, England, Greece, Ireland, Scotland and the Netherlands who recommended G/TI data from the grey literature. In addition, a peer review of literature was conducted in each country. Resulting data were collated using a standardized Protocol Mapping Document. G/TIs were identified for inclusion by (i) initial elimination of incomplete G/TI material; (ii) application of filtering criteria; and (iii) application of a contemporary theory of implementation – Normalisation Process Theory (NPT). 20 G/TIs met the selection criteria: Netherlands (n=7), Ireland (n=6), England (n=5), Scotland (n=2); none were identified from Greece or Austria. The majority (n=13) were generated without the involvement of migrant service-users. The research teams in each country used NPT to prospectively appraise all 20 G/TIs for potential implementability in their cultural and primary care settings. This was necessary in order to reduce the 20 to a more feasible number to present to stakeholders, who, through PLA inter-stakeholder dialogues, were to critically appraise and democratically select a single guideline or training initiative for implementation at local level. We established that NPT was useful as a means of prospectively testing G/TIs for implementability. We also established that very few G/TIs were generated via meaningful engagement with hard-to-reach migrants. This reflects a situation where primary healthcare remains in a mode of ‘doing for’ rather than ‘collaborating with’ migrants, and might well be an important factor in understanding why G/TIs remain relatively under-utilised and under-implemented. Our results indicated a need to initiate meaningful engagement of migrants in the future development of G/TIs. To support this, a European-based professional standard for the development of G/TIs in this field would be advised, similar to CLAS (National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care) in the USA.

Chapter 8 describes the application of 2 core PLA techniques used across diverse RESTORE primary care settings to enable stakeholders to select a single G/TI for implementation at local level. While we have established that PLA research approaches and techniques show promise, and we know that the material practices used by researchers may foster or constrain the quality and efficacy of engagement with stakeholder groups, there has been no detailed analysis of stakeholders’ and researchers’ experiences of using PLA techniques for data-generation and co-analysis. This chapter addresses that gap. Our purposeful sample of 78 stakeholders included migrants, general practice staff, community interpreters, service providers, and service planners from primary care settings in Austria, England, Greece, Ireland and The Netherlands. We used speed evaluations and participatory evaluations to explore their experiences of engaging in two PLA techniques – Commentary Charts and Direct Ranking. They used these techniques to co-generate and co-analyse data about G/TIs, critically appraising them and democratically selecting one they considered suitable for implementation at local level. We used in-depth interviews to evaluate 16 RESTORE researchers’ observations and comments about stakeholders’ engagement, which provided a measure of
triangulation. We conducted thematic and content analysis of all evaluation data. Our findings showed that Commentary Charts and Direct Ranking techniques, with their visual nature and inherent analytical capabilities, were experienced by stakeholders from both community and healthcare settings as powerful tools for collaborative decision-making. There was consensus among stakeholders and researchers that there were few negative experiences, and numerous multifaceted positive experiences of meaningful engagement: PLA created a ‘safe space’ and a trusting environment in which they learned from each other’s perspectives, gained enhanced knowledge via the co-generation of Commentary Charts and used these data to inform their co-analysis during Direct Ranking. Using these two PLA techniques involved stakeholders in an experience of ‘democracy-in-action’ which was empowering and energizing, promoting a sense of ownership and sustained engagement in the research project. We concluded that these PLA techniques are valuable material practices for collaborative decision-making, and that PLA can support meaningful engagement in primary healthcare research partnerships.

Chapter 9 presents further analysis of stakeholders’ experiences of engaging in PLA during their participation in RESTORE and presents an analytical framework describing what makes for a positive and productive PLA inter-stakeholder dialogue in primary healthcare research. Our sample of 78 stakeholders (migrants, general practice staff, community interpreters, service providers, and service planners as described in Chapter 8) participated in a total of 62 PLA inter-stakeholder dialogue sessions across the five research sites (Austria, England, Greece, Ireland and The Netherlands). During the PLA fieldwork, special attention was given to assessing stakeholders’ experiences of these dialogues by means of various qualitative and participatory evaluation techniques. Data sources included stakeholders’ visual charts and evaluations, and researchers’ fieldwork reports and post-fieldwork team reflection interviews. These data sources were analysed following the principles of thematic analysis. Stakeholders reported predominantly positive and relatively few negative experiences; this was confirmed by researchers’ reports and reflections. Our analysis revealed that PLA inter-stakeholder dialogue processes are complex, multi-layered and multi-levelled: we describe three levels of dialogue which unfold in an incremental manner, providing an analytical framework for understanding how essential components of Level 1 PLA inter-stakeholder dialogue (e.g., trust, collegiality, balancing asymmetrical relations) can promote development into additional necessary components of Level 2 dialogue (e.g., enhanced learning, shifts in understanding, creative problem-solving). When Levels 1 and 2 are reached in an inter-stakeholder dialogue, this may, on occasion, initiate Level 3. This involves stakeholders’ willingness to operate outside their traditional ‘silos’ in order to resolve intractable problems, which might otherwise halt implementation in its tracks. We concluded that, in RESTORE, the use of PLA proved effective as a democratic method of facilitating positive and productive inter-stakeholder dialogues, enabling diverse stakeholders across diverse primary care settings and systems to offer their perspectives, and to experience meaningful engagement despite significant differences in social capital and power. This makes PLA an attractive and effective approach for enhancing the development of health research partnerships to advance primary healthcare.

Chapter 10: This chapter (a debate paper) is an account of the rationale for combining PLA with a contemporary social theory, Normalisation Process Theory (NPT) which was an important feature of the overall context of the RESTORE project. The paper expands the thesis by alerting us to the heuristic potential of PLA for the field of implementation research: how PLA (as an ‘action
experiment’) may be used to practically address implementation challenges, issues, possibilities and options that may arise during an implementation journey. This use of PLA enables us to achieve deeper understandings of implementation contexts and processes.

Chapter 11 (General Discussion): In this chapter, we discuss the key findings drawn from our early work in Africa and the SUPERS and RESTORE projects in Ireland and Europe. We highlight a number of ‘pressure points’ that may be important to consider when using PLA in primary healthcare research in the future. We present our over-arching conclusions and key recommendations, with some practical suggestions for implementing these recommendations.

Conclusions

Our conclusions, as set out below, show that PLA can ‘deliver’ in relation to three key aspects of primary healthcare essential to the task of developing responsive primary healthcare:

- addressing the community basis orientation
- enabling the empowerment of populations and individuals, and
- facilitating positive change in the perspectives of service-users and service-providers.

1. PLA is capable of involving vulnerable, ‘hard to reach’ migrants and other stakeholders in primary healthcare research and is a highly transferable methodology.

2. PLA facilitates meaningful engagement beyond tokenism and enables co-determination (by diverse stakeholder groups) of primary healthcare practice & policy, which empowers populations and individuals.

3. PLA addresses asymmetries of power, enabling shifts in understanding and positive change in stakeholders’ perspectives on primary healthcare issues.

Recommendations

1. Given the need to build primary healthcare ‘from the ground up’, the perspectives of diverse groups, especially the ‘hard to reach’, must become a normative part of primary healthcare research. PLA is a powerful, practical ‘fit-for-purpose’ methodology for achieving this. As community needs and social determinants of health change over time, PLA engagement should be a continuous process rather than a one-off event. We therefore recommend the use of PLA as a methodology of choice (a generic approach) in primary health care research for sustained meaningful engagement with communities-under-care.

2. In recommending that PLA become a methodology of choice for primary healthcare research, we acknowledge the time constraints on healthcare professionals and the energy, expertise and commitment that community members are prepared to invest in primary healthcare research. In
light of this, and the core primary healthcare values of collegiality, empowerment, self-efficacy and co-responsibility, we recommend embedding PLA training primarily in the ‘practice community’ to build participatory research capacity at local level.
Samenvatting

Het doel van dit proefschrift was er op gericht om te onderzoeken of *Participatory Learning and Action* (PLA) als onderzoeksmethode zou helpen om moeilijk bereikbare en kwetsbare groepen op een zinvolle manier te betrekken bij het mede-vormgeven van hun eerstelijns gezondheidszorg. Dit vanuit het streven om deze zorg te laten beantwoorden aan hun behoeften, en hun waarden en verwachtingen ten aanzien van gezondheidszorg. We beschrijven toepassing en onderzoek van PLA in verschillende stelsels van gezondheidszorg: empirische gegevens werden verzameld in Oostenrijk, Engeland, Griekenland Nederland en de Ierse Republiek. Ons onderzoek richt zich op drie kernaspecten van eerstelijns zorg – de *wijkgerichtheid*, *empowerment* van individuen en groepen, en de mogelijkheid om verwachtingen van hulpvragers en hulpverleners in *positieve zin te veranderen*. Deze aspecten zijn van belang bij het realiseren van de ambitie om wijkgerichte eerstelijnszorg vanuit de lokale omstandigheden op te bouwen. In dit proefschrift gaat het concreet om het betrekken van migranten als medeontwerpers van hun gezondheidszorg.

Het proefschrift bestaat uit drie delen:

**Deel I** (*Hoofdstukken 2, 3a, 3b*) beschrijft een aantal participerend onderzoeken met kwetsbare groepen in sub-Sahara Afrika en de Ierse Republiek.

**Deel II** (*Hoofdstukken 4, 5, 6*) beschrijft de toepassing van PLA in een gezondheidsonderzoek met migranten in Ierland (het ‘SUPERS’ project).

**Deel III** (*Hoofdstukken 7, 8, 9, 10*) beschrijft de uitbreiding van de toepassing van PLA in verschillende stelsels van gezondheidszorg in Europa (het ‘RESTORE’ project).

De delen II en III vormen de kern van dit proefschrift.

In *Hoofdstuk 1* stellen wij vast dat versterking van de eerstelijnsgezondheidszorg wereldwijd als strategie wordt gehanteerd bij het realiseren van duurzame gezondheidszorg. We vatten de kernpunten van eerstelijnsgezondheidszorg samen: het kunnen inspelen op de behoeften van de populatie-in-zorg, het toespitsen van zorg op wijk niveau en de daar spelende gezondheidsbedreigingen. Dit betekent dat het voor responsieve eerstelijnsgezondheidszorg noodzakelijk is om inzicht te hebben in de gezondheidsbehoeften in de betreffende populatie, en de waarden en verwachtingen die er ten aanzien van de te bieden gezondheidszorg leven; hoe dit samenhangt met sociale en culturele determinanten van gezondheid; en hoe dit in de loop van de tijd kan veranderen. We stellen dat algemene kennis over populaties derhalve dient te worden uitgebreid met specifieke en met kennis-in-context van individuen, groepen en gemeenschappen onder zorg. Het vergaren van deze kennis vraagt om een onderzoekbenadering van onder af (‘*bottom-up*’), waarin hulpvragers, hulpverleners en andere belanghebbenden gezamenlijk de gewenste gezondheidszorg vormgeven. Het is daarbij essentieel dat alle betrokkenen ‘aan tafel’ zitten. Moeilijk te bereiken en kwetsbare groepen zijn echter als regel uitgesloten van eerstelijnsgezondheidsonderzoek, als gevolg van ontoegankelijkheid, taal barrières en culturele verschillen. Om hieraan het hoofd te kunnen bieden is een onderzoeksmethode nodig die er toe in staat is om de perspectieven van alle belanghebbenden naar voren te laten komen en met elkaar in evenwicht te brengen, in het bijzonder van diegenen met de ‘minste macht’ en meest kwetsbaren. Om die reden beschrijven wij de kern principes en pragmatiek van PLA, waarbij we vaststellen dat eerstelijnsgezondheidszorg en participatief onderzoek belangrijke waarden delen. PLA nodigt uit tot
een dialoog tussen belanghebbenden (zoals hulpvragers en hulpverleners) waarbij betrokkenen van elkaar leren. Dit wordt mogelijk gemaakt met praktische onderzoeksmethoden speciaal ontworpen om iedereen gebruiks vriendelijk en democratisch in het proces te betrekken en verschillen in macht en kracht te verevenen. Dit maakt het mogelijk voor belanghebbenden deel te nemen aan een scala van onderzoeksactiviteiten met inbegrip van het verzamelen en analyseren van gegevens. De kernfunctie van PLA is het actief betrekken van diverse belanghebbenden in gezamenlijk overleg met het oog op het gezamenlijk komen tot creatieve oplossingen van gedeelde problemen, en het benoemen en tot stand brengen van daarop gerichte acties of interventies. PLA draagt er zorg voor dat de visies van belanghebbenden, en in het bijzonder van diegenen zonder krachtige stem, het beloop van het onderzoek en de resultaten ervan beïnvloeden. Dit is het keurmerk van *zinvolle betrokkenheid*, een essentieel onderdeel van het samen ontwerpen en samen bepalen van gepaste en responsieve gezondheidszorg. Tenslotte stellen wij vast dat er urgente behoefte bestaat aan een verbeterde responsiviteit van de gezondheidszorg op de culturele en etnische diversiteit van de bevolking – gegeven Europa’s toenemende multiculturele samenstelling, de toename aan niet-Westere migranten die een beroep doen op de gezondheidszorg en de financiële druk op gezondheidsvoorzieningen tijdens een internationale financiële crisis. Alhoewel migranten doorgaans uitgesloten zijn van eerstelijnsgezondheidsonderzoek, kan aan dit probleem naar onze mening worden tegemoet gekomen door het beproeven van onderzoekmethoden die ons in staat stellen om kwetsbare groepen zinvol te betrekken in eerstelijnsgezondheidsonderzoek.

**Deel I: Hoofdstuk 2**

In onze eerste onderzoeken over onderwijs, sociale inclusie en gezondheidszorg in Afrika en Ierland (1993-2009) pasten wij een onderzoeksbenadering toe en pasten participatie technieken aan om belanghebbenden uit moeilijk bereikbare en kwetsbare populaties actief te betrekken in onderzoek in hun gemeenschap. In Afrika leidden wij inheemse groepen die bekend waren met de lokale stamtalen en cultuur op om PLA toe te passen en daarmee taal en cultuur barrières te slechten. Dit maakte het mogelijk om de lokale bevolking in het onderzoek te betrekken, droeg er zorg voor dat hun visie duidelijk in de resultaten van het onderzoek naar voren kwam en stimuleerde overleg tussen verschillende belanghebbenden om het gat te dichten tussen de voor de lokale bevolking noodzakelijke en feitelijk geboden zorg op plaatselijk, regionaal en landelijk niveau.

**Deel I: Hoofdstuk 3a.**

Dit participatief onderzoek werd gedaan met kansarme dakloze mannen in Dublin, Ierland (2007). De mannen gebruikten PLA technieken om barrières te achterhalen bij sociale betrokkenheid, en droegen bij aan creatieve, cultureel acceptabele oplossingen. Op basis hiervan ontwikkelden zij een praktisch plan dat daklozen zoals zij zelf in staat stelde deze barrières te overwonnen en om hulp in te roepen om hun sociale uitsluiting te boven te komen. Dit onderzoek toonde aan dat PLA in staat was kwetsbare belanghebbenden uit een moeilijk bereikbare populatie *actief te betrekken* bij onderzoek om hun levensomstandigheden te verbeteren. Een kern bevinding was het ‘veranderde perspectief’ van deze mannen gedurende het PLA onderzoek: zij zagen zichzelf veranderen van passieve gebruikers van zorg tot het vervullen van een rol in actieve ondersteuning en raadgeving aan andere dakloze mannen – een interessante blijk van zelfverantwoordelijkheid en ‘empowerment’.

**Deel I: Hoofdstuk 3b**
Chapter 12

Dit onderzoek was de eerste toepassing van PLA in de Ierse Republiek (1998-2001). 120 vrouwen uit 26 verschillende provincies werden opgeleid tot PLA ‘co-onderzoekers’, die onderzoek met bijna 500 vrouwen mogelijk maakten. In dit manuscript is het onderdeel opgenomen dat betrekking had op gezondheidszorg en als doel had vast te stellen in hoeverre het Ierse regeringsplan voor de Gezondheid van Vrouwen (1997-1999) een effect had gehad op hun gezondheid, welzijn, behoeften en zorgen; en indien dit het geval was – in hoeverre. De vrouwen stelden door het gebruik van PLA technieken een reeks ernstige tekortkomingen in het plan vast, alsmede mogelijke oplossingen waarmee toekomstig gezondheidsbeleid en strategie kon worden verbeterd.

Samengevat wezen deze onderzoeken er op dat PLA methoden en technieken toepasbaar waren bij een scala aan onderzoeksonderwerpen, met uiteenlopende kwetsbare groepen in verschillende sociaal-culturele omstandigheden en in diverse landen. PLA vormde daarmee een aantrekkelijke benadering, in staat om kwetsbare en moeilijk bereikbare groepen te betrekken in solide onderzoek, dat is gericht op het vinden van creatieve oplossingen voor problemen en het samen met andere belanghebbenden ontwikkelen van plannen om hun levensomstandigheden te verbeteren.

Deel II: Hoofdstuk 4

In dit deel presenteren wij een eerstelijnsgezondheidsonderzoek ‘SUPERS’ (Service User Peer ResearcherS), uitgevoerd in de Ierse Republiek (2009-2011). Dit onderzoek werd gedaan naar aanleiding van communicatie problemen die zich in transculturele consulten voordeden in de huisartspraktijk wanneer huisartsen en de migranten hulpvragers geen gemeenschappelijke taal of cultuur deelden. PLA werd gebruikt om moeilijk bereikbare migranten op een zinvolle manier te betrekken in het samen ontwikkelen van een ‘best practice’ richtlijn voor transculturele communicatie in consulten in de huisartspraktijk. Het gezichtspunt van migranten werd tot nog toe zelden betrokken in de ontwikkeling van dit soort richtlijnen. Omdat zij als gevolg van ontoegankelijkheid, taalproblemen en culturele verschillen als moeilijk te bereiken te boek stonden, werden zij systematisch uitgesloten van deelname in eerstelijnsgezondheidsonderzoek. Het doel van dit onderzoek was om dit gat te dichten. Wij leidden zeven migranten uit lokale gemeenschappen op tot co-onderzoekers. Zij gebruikten hun toegang, talvaardigheid en culturele kennis en PLA vaardigheden om 51 moeilijk bereikbare migranten hulpvragers (MHVs) uit etnisch verschillende gemeenschappen te reconstrueren en in het onderzoek op te nemen. Deze migrant co-onderzoekers voerden, zonder taal barrière en op een cultureel passende wijze een complexe reeks van zeven samenhangende visuele/verbale/tastbare PLA technieken uit. Dit leidde ertoe dat MHVs uit zinvolle wijze werden betrokken bij het onderzoek en dat hun gezichtspunten vervolgens werden betrokken in het overleg met de andere belanghebbenden – hulpverleners om vast te stellen welke communicatie strategieën het beste werkten, voor wie en onder welke omstandigheden. Dit leverde een praktische richtlijn op ter verbetering van communicatie tussen hulpverleners en MHVs in Ierland. De migranten-onderzoekers evauueerden hun opleiding, het uitvoeren van het onderzoek en het verbreiden van de daarbij opgedane kennis als positief en betekenisvol voor hen. MHVs evalueerden hun ervaringen van betrokkenheid in het veldwerk en onderzoek als positief en betekenisvol voor hen. Dit onderzoek bevestigt dat, gegeven de noodzaak om eerstelijnsgezondheidszorg van onderaf op te bouwen, het betrekken van verschillende groepen, en in het bijzonder groepen die moeilijk te bereiken zijn, regel zou moeten zijn in eerstelijnsgezondheidsonderzoek. PLA is een krachtige, praktische, geëigende methode om dit te realiseren: het maakt het mogelijk dat moeilijk bereikbare groepen op een zinvolle manier worden betrokken, en gemakkelijk kunnen bijdragen aan academisch onderzoek.
Deel II: Hoofdstuk 5

Dit hoofdstuk is een verdere exploratie van PLA in het SUPERS onderzoek, gericht op overleg tussen verschillende belanghebbenden: professionals-hulpverleners en hulpvragers-MHVs. De onderzoeksgroep bestond uit 80 belanghebbenden: 15 huisartsen/praktijk medewerkers; 5 professionele vertalers; 2 beleidsmakers; en de 51 MHVs en 7 migranten-co-onderzoekers uit het vorige hoofdstuk. Het overleg tussen verschillende belanghebbenden zette het democratisch besluitvormingsproces voort zoals passend bij PLA en leidde tot duidelijke aanbevelingen voor ‘best practice’ in transculturele eerstelijns consulten: overeengekomen werd dat het gebruik van professionele vertalers een ‘best practice’ vormde; het gebruik van familieleden en vrienden als vertalers, en technologische en visuele hulpmiddelen, alhoewel ‘bruikbaar’, werden niet als ‘acceptabele praktijk’ beoordeeld en werden uitgesloten van de richtlijn. Dat hierover consensus kon worden gebruikt tussen de verschillende groepen belanghebbenden was een opvallende bevinding, gezien de wijd uiteenlopende visies. Daar waar geen consensus werd bereikt stelde de transparante democratische PLA werkwijze belanghebbenden in staat om te besluiten dat een in meerderheid gedragen opvatting over het al dan niet acceptabel zijn van een bepaalde communicatie strategie zou moeten worden gevolgd. De consequente betrokkenheid van migranten gedurende het gehele onderzoek had een wezenlijke invloed op het praktische resultaat: een samen ontwikkelde richtlijn voor ‘best practice’ in multiculturele consultaties die tegemoet kwam aan de behoeften, verwachtingen en waarden van moeilijk bereikbare migranten. Richtlijnen die op deze participerende manier zijn ontwikkeld, zijn zeldzaam en vormen een belangrijke aanvulling op de beschikbare literatuur. De inzet van PLA vormde de kracht van dit onderzoek, alhoewel het een beslag op mensen en middelen legt: omdat de richtlijn recht doet aan de opvattingen van verschillende partijen, maakt dit de kans groter dat deze in de dagelijkse praktijk zal worden ingevoerd. Dit hoofdstuk benadrukt ook de noodzaak van beleidsmakers en anderen die zorgvoorzieningen ontwerpen, om hun werk in samenspraak met hulpverleners en migranten in te richten, om zo het invoeren van overeengekomen praktische werkwijzen te bevorderen.

Deel II, Hoofdstuk 6

Dit hoofdstuk presenteert het belangrijkste praktische resultaat was van het ‘SUPERS’ project: de ‘Richtlijn voor Communicatie in Transculturele Huisartsen Consultaties’. Als resultaat van een innovatief, omvangrijk en solide PLA proces vormde de Richtlijn een concreet antwoord op een onopgelost probleem in de Nationale multicul turele Gezondheidsstrategie (2007-2012) van de Directie Gezondheidszorg (HSE) van de Ierse Republiek. De Gezondheidsstrategie erkende de noodzaak voor een ondersteuning van multiculturele communicatie in gezondheidsvoorzieningen, met inbegrip van huisartsen consulten, maar was niet in staat om aan te geven welke communicatie benaderingen ‘best practice’ vormden. Op grond hiervan deed het de aanbeveling om dit met inzet van betrokken belanghebbenden nader te onderzoeken. In het SUPERS project werd dit door het toepassen van PLA gerealiseerd en de Richtlijn is belangrijk als een voorbeeld van het gezamenlijk ontwerpen en definiëren van een eerstelijnsgezondheidszorg initiatief. De Richtlijn werd gepubliceerd en verspreid door de Directie Gezondheidszorg van de Ierse Republiek. De onderzoeksresultaten bevestigden onze verwachtingen dat PLA diverse mogelijkheden biedt die van belang zijn om eerstelijnsgezondheidszorg vanuit de lokale gemeenschap op te bouwen.

Deel III: Hoofdstukken 7, 8, 9, 10
Chapter 12

In dit deel onderzoeken wij het RESTORE project (REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings, 2011-2015). Deze internationale samenwerking, die zich richtte op gezondheidszorg voor migranten, bood de gelegenheid om de toepassing van PLA uit te breiden naar verschillende gezondheidsstelsels in landen met verschillende voorgeschiedenis ten aanzien van migratie (Oostenrijk, Engeland, Griekenland, Nederland en de Ierse Republiek), en om te werken met meer uiteenlopende populaties migranten en diversiteit aan sociaaleconomische en culturele omstandigheden. Het doel van RESTORE was in essentie om de implementatie te onderzoeken en bevorderen van richtlijnen en trainingsinitiatieven, ten behoeve van de communicatie in consulten met migranten in de eerstelijnsgezondheidszorg. Daarbij wilden wij PLA gebruiken om migranten als essentiële belanghebbenden, op een zinvolle wijze te betrekken bij overleg met andere betrokkenen om een richtlijn of trainingsinitiatief kritisch te analyseren en langs democratische weg te selecteren.

Hoofdstuk 7 geeft een gedetailleerd verslag van het proces dat wij gebruikten om een reeks richtlijnen en training initiatieven (G/TIs) in kaart te brengen, die mogelijk geschikt zouden zijn om in de eerstelijnsgezondheidszorg bij de verschillende RESTORE deelnemers in te voeren. Via een sleepnet procedure stelden wij een gerichte selectie samen van experts uit formele en informele organisaties uit Oostenrijk, Engeland, Griekenland, Nederland en de Ierse Republiek en Schotland, die G/TIs uit de grijze literatuur aanbevolen. Aansluitend werd in ieder land een beoordeling van de literatuur verricht. De bevindingen werden verzameld en met behulp van een gestandaardiseerd protocol. G/TIs werden geïdentificeerd voor inclusie door (i) het verwijderen van onvolledig G/TIs materiaal; (ii) de toepassing van selectie criteria; en (iii) de toepassing van een actuele theorie voor implementatie – Normalisation Process Theory (NPT). Twintig G/TIs werden daarmee geïncludeerd: 7 uit Nederland, 6 uit Ierland, 5 uit Engeland, en 2 uit Schotland. In Oostenrijk en Griekenland werden er geen gevonden. De meerderheid (13) was tot stand gekomen zonder betrokkenheid van migranten – hulpvragers. De onderzoeksgroepen in ieder land gebruikten NPT om prospectief alle 20 G/TIs te beoordelen op invoerbaarheid in de eerste lijn in het betreffende land. Dit was nodig, om de 20 G/TIs te reduceren tot een hanteerbaar aantal en vervolgens middels PLA overleg tussen verschillende belanghebbenden tot een kritische analyse te komen en daarop langs democratische weg één richtlijn of training initiatief ter plaatse in te voeren. Wij stelden vast dat NPT een waardevolle methode was om op voorhand G/TIs te testen op hun invoerbaarheid. Wij stelden ook vast dat slechts weinig G/TIs tot stand waren gekomen met een zinvolle betrokkenheid van moeilijk bereikbare migranten. Dit weerspiegelt de situatie waarin eerstelijnsgeneeskunde zich presenteert als ‘werken voor’ in plaats van ‘in medewerking met’ migranten en verklaart waarschijnlijk het geringe gebruik en de beperkte invoering van G/TIs. Onze bevindingen geven aan dat het nodig is om migranten op een zinvolle wijze te betrekken bij de toekomstige ontwikkeling van G/TIs. Om dit verder te ondersteunen zouden wij een Europese professionele standaard voor de eerstelijnsgezondheidszorg willen adviseren voor de ontwikkeling van G/TIs, vergelijkbaar met de CLAS (National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care) in de Verenigde Staten.

Hoofdstuk 8 beschrijft twee kern PLA technieken, die in de diverse eerstelijnsvoorzieningen in RESTORE werden gebruikt om belanghebbenden in staat te stellen om een G/TI te selecteren voor implementatie in hun praktijk: Commentaar Kaarten en Direct Rangschikken. Wij hadden vastgesteld dat PLA technieken en werkwijzen veelbelovend zijn, en wij wisten dat het materiaal dat praktijken

Hoofdstuk 9 beschrijft de verdere analyse van de ervaringen van belanghebbenden, van hun betrokkenheid in PLA gedurende hun deelname aan RESTORE. Het biedt een analytisch kader over wat zorgdraagt voor een positief en productief PLA overleg tussen belanghebbenden in eerstelijnsgezondheidszorg onderzoek. Onze onderzoeksgroep van 78 belanghebbenden (migranten, tolken, medewerkers uit huisartspraktijken en andere hulpverleners en beleidsmakers zoals beschreven in hoofdstuk 8) namen deel aan in totaal 62 PLA overleg sessies in de vijf landen (Oostenrijk, Engeland, Griekenland, Ierland en Nederland). Gedurende het PLA veldwerk werd door middel van kwalitatieve en participatieve evaluatie technieken speciale aandacht geschonken aan de ervaringen van belanghebbenden. Gegevens bestonden uit door belanghebbenden zelf ingevulde visuele kaarten en evaluaties, veldwerk rapporten van onderzoekers, en interviews waarin met de onderzoeksteams op hun dataverzameling werd gereflecteerd. Deze gegevens werden thematisch geanalyseerd. Belanghebbenden vermeldden bovenal positieve en weinig negatieve ervaringen, wat werd bevestigd door de onderzoekers in hun rapporten en reflecties. Onze analyse bracht aan het licht dat het overleg tussen belanghebbenden meerlagig en complex is: wij beschrijven drie niveaus van dit overleg, die zich stap voor stap ontwikkelen. Op grond daarvan kan worden begrepen hoe essentiële onderdelen van niveau 1 PLA overleg tussen belanghebbenden (vertrouwen, collegialiteit, het in evenwicht brengen van ongelijke verhoudingen) de ontwikkeling kunnen stimuleren van eveneens essentiële onderdelen van niveau 2 overleg (een versterkt leerproces, veranderingen in onderling begrip, creatieve oplossing van problemen). Wanneer overleg tussen belanghebbenden
Hoofdstuk 12

voldoet aan de niveaus 1 en 2 kan niveau 3 worden bereikt, waarin belanghebbenden bereid zijn om buiten hun gebruikelijke grenzen te treden om weerspannige problemen op te lossen die anders het implementeren van plannen zouden verhinderen. Onze conclusie is dat in RESTORE het gebruik van PLA effectief was om op democratische wijze positief en productief overleg tussen belanghebbenden tot stand te brengen. Dit stelde belanghebbenden uit diverse eerstelijns praktijken en stelsels in staat om hun visies te geven en zinvol betrokken te zijn bij overleg, in weerwil van wezenlijke verschillen in sociaal kapitaal en macht. Dit maakt PLA een aantrekkelijke en effectieve benadering voor het tot stand brengen van gezondheidsonderzoek samenwerking om eerstelijnsgezondheidszorg verder te ontwikkelen.

Hoofdstuk 10: Dit hoofdstuk (een discussie artikel) is een verslag van de motivering om PLA gelijktijdig te combineren met een sociale theorie, Normalisation Process Theory (NPT), hetgeen een belangrijk aspect was van het RESTORE project. Het artikel ontwikkelt de stelling over de waarde van het heuristische potentieel van PLA voor het domein van implementatie onderzoek: hoe PLA (als een experiment-in-actie) gebruikt kan worden om de uitdagingen, kwesties, mogelijkheden en opties die naar voren komen in de loop van het implementatie proces het hoofd te bieden. Door PLA op deze manier in te zetten wordt een dieper begrip mogelijk van het proces en de specifieke omstandigheden van implementatie.

Hoofdstuk 11: In dit hoofdstuk bespreken wij de kernbevindingen van ons eerste werk in Afrika en van het SUPERS en RESTORE project in Ierland en Europa. Wij benadrukken een aantal problemen die belangrijk zijn om in ogenschouw te nemen bij het inzetten van PLA in toekomstig eerstelijnsgezondheidszorg onderzoek. Wij presenteren vervolgens onze algemene conclusies en kern aanbevelingen met een aantal praktische adviezen voor het verwerken van deze aanbevelingen.

Conclusies

Onze conclusies, zoals hieronder verwoord, tonen aan dat PLA kan bijdragen aan drie kern aspecten van eerstelijnsgezondheidszorg, die wezenlijk zijn om te komen tot responsieve eerstelijnsgezondheidszorg:

- De oriëntatie op de samenleving waarin de zorg zich afspeelt;
- Het bevorderen van de eigen kracht van groepen en individuen om bij te dragen aan ontwikkelingen;
- Het bewerken van een positieve verandering in de meningen en visies van hulpvrager en hulpverleners.

1. PLA is in staat om kwetsbare, moeilijk bereikbare migranten en andere belanghebbenden in eerstelijnsgezondheidszorg onderzoek te betrekken.

2. PLA brengt een zinvolle betrokkenheid tot stand, die uitstijgt boven het plichtmatige uitnodigen, wat leidt tot door verschillende belanghebbenden samen ontworpen plannen voor eerstelijnsgezondheidszorg praktijk en beleid. Dit vergroot de kracht van individuen en van groepen.
3. PLA pakt ongelijkheid in macht aan, waardoor een verhoogd onderling begrip tot stand komt, en leidt tot een positieve verandering in de visie van diverse belanghebbenden op eerstelijnsgezondheidszorg zaken.

**Aanbevelingen**

1. Gegeven de noodzaak om eerstelijnsgezondheidszorg vanuit de populatie onder zorg op te bouwen, dient het betrekken van de meningen en visies van diverse groepen, en vooral van de meest moeilijk te bereiken, een norm te worden in eerstelijnsgezondheidszorg onderzoek. PLA is een hiervoor geschikte, krachtige, praktische, methode. Daar de noden en sociale determinanten van gezondheid van gemeenschappen door de tijd veranderen, dient dit een continu en niet een éénmalig proces te zijn. *Wij bevelen daarom het gebruik van PLA aan als de generieke methode in eerstelijnsgezondheidszorg onderzoek voor duurzame uitwisseling en overleg met de populatie-in-zorg.*

2. Wij bevelen PLA aan als preferente methode in eerstelijnsgezondheidszorg onderzoek. Daarbij onderkennen wij de grote tijdsbelasting ervan op hulpverleners en de hoeveelheid energie, deskundigheid en betrokkenheid die de gemeenschap hierin moet investeren. Daar staat tegenover dat collegialiteit, empowerment, self-efficacy en medeverantwoordelijkheid belangrijke waarden zijn in de eerstelijnsgezondheidszorg, *en daarom bevelen wij aan om opleiding in PLA in te bedden in de eerstelijns praktijk populatie, om zo een participatieve onderzoekscapaciteit op lokaal niveau op te bouwen.*
History says, Don’t hope
On this side of the grave,
But then, once in a lifetime
The longed-for tidal wave
Of justice can rise up,
And hope and history rhyme.

Seamus Heaney, from The Cure at Troy:
Chapter 13

List of publications

Curriculum Vitae

Acknowledgments
List of Publications

Peer reviewed publications


Thesis

Section I: Sub-Saharan Africa & the Republic of Ireland – 1993-2009


Section II: Exploring the use of PLA in primary healthcare research – Republic of Ireland 2009-2011


O’Reilly-de Brún M, MacFarlane A, de Brún T, Okonkwo E, Bonsenge-Bokanga JS, De Almeida Silva MM, et al. Involving migrants in the development of guidelines for communication in cross-cultural
Section III: Expanding the use of PLA in primary healthcare research – European application 2011-2015


Non-peer reviewed publications


## Presentations & Workshops

<table>
<thead>
<tr>
<th>PRESENTER(S)/ CO-AUTHORS</th>
<th>CONFERENCE / VENUE/ TITLE</th>
<th>DATE / FORMAT</th>
</tr>
</thead>
<tbody>
<tr>
<td>MacFarlane A, O'Donnell C, Mair F, Gravenhorst K, <strong>de Brún T</strong>, Lionis C, van den Muijsenbergh M, <strong>O’Reilly-de Brún M</strong>, Spiegel W, van Weel-Baumgarten E, Dowrick C., on behalf of the RESTORE Consortium.</td>
<td>SAPC Dublin, Ireland (Society for Academic Primary Care) <em>What is the impact of public and patient involvement in implementation research?</em></td>
<td>July 2016 ORAL PRES</td>
</tr>
<tr>
<td><strong>O’Reilly-de Brún M</strong>, <strong>de Brún T</strong>, Mair F.</td>
<td>RESTORE University of Limerick, Ireland <em>Combining theory (NPT) and method (PLA) in implementation research</em></td>
<td>Mar 2015 WORKSHOP</td>
</tr>
<tr>
<td>Wilczynska M, Okonkwo E, <strong>O’Reilly-de Brún M</strong>, <strong>de Brún T</strong>, McMenamin R, MacFarlane A.</td>
<td>IIRNPC Canberra, Australia (International Implementation Research Network in Primary Health Care) Australian Primary Healthcare Research Conference <em>How do we better involve stakeholders in primary health care research? An example of the use of PLA in a six-country European project, RESTORE</em></td>
<td>July 2014 DVD</td>
</tr>
<tr>
<td>Dowrick C, MacFarlane A, Mair F, O’Donnell C, Lionis C, <strong>de Brun T</strong>, <strong>O’Reilly-de Brún M</strong> et al, on behalf of the RESTORE Consortium</td>
<td>SAPC Edinburgh, Scotland (Society for Academic Primary Care) <em>Supporting communication in cross-cultural primary care consultations: how to implement guidelines and training initiatives across Europe</em></td>
<td>July 2014 WORKSHOP</td>
</tr>
<tr>
<td>van den Muijsenbergh M, Cooper L, Teunissen E, Lionis C, <strong>de Brun T</strong>, <strong>O’Reilly-de Brún M</strong> et al - on behalf of the RESTORE Consortium</td>
<td>WONCA Lisbon, Portugal (World Organisation of Family Doctors) <em>Supporting communication in cross-cultural primary care consultations: how to implement guidelines and training initiatives across Europe</em></td>
<td>July 2014 WORKSHOP</td>
</tr>
<tr>
<td>Murphy S, Taylor A, <strong>de Brún T</strong>, <strong>O’Reilly de Brún M</strong>, MacFarlane A - on behalf of the RESTORE Consortium</td>
<td>ICGP Kilkenny, Ireland (Irish College of General Practitioners) <em>Supporting communication in cross-cultural primary care consultations: implementing guidelines and training initiatives</em></td>
<td>June 2014 ORAL PRES</td>
</tr>
<tr>
<td>Title</td>
<td>Event</td>
<td>Date</td>
</tr>
<tr>
<td>-------</td>
<td>-------</td>
<td>------</td>
</tr>
<tr>
<td>4th Community Interpreting Conference</td>
<td>Dublin City University, Ireland</td>
<td>June 2014</td>
</tr>
<tr>
<td>Nurse D, O'Reilly de Brún M, de Brún T, Quilty T, Okonkwo E, MacFarlane A</td>
<td>EUPHA</td>
<td>April 2014</td>
</tr>
<tr>
<td>O'Reilly-de Brún M, de Brún T, MacFarlane A</td>
<td>WONCA</td>
<td>June 2013</td>
</tr>
<tr>
<td>de Brún T, O'Reilly-de Brún M, Papadakaki M, Vlahadi M, Saridaki A, Prinz C, Teunissen E, van den Driessen Mareeuw F, Gravenhorst K, Burns N and MacFarlane A</td>
<td>WONCA</td>
<td>June 2013</td>
</tr>
<tr>
<td>Lionis C, Papadakaki M, Vlahadi M, A Saridaki A, Maltezis K, O'Reilly-de Brún M, de Brún T, MacFarlane A, et al</td>
<td>WONCA</td>
<td>June 2013</td>
</tr>
<tr>
<td>O'Reilly-de Brún M, de Brún T, MacFarlane A</td>
<td>ICGP Annual Conference</td>
<td>June 2013</td>
</tr>
<tr>
<td>O'Reilly-de Brún M, de Brún T, MacFarlane A</td>
<td>AUDGPI</td>
<td>Mar 2013</td>
</tr>
<tr>
<td>O'Reilly-de Brún M, de Brún T, MacFarlane A</td>
<td>AUDGPI Annual Scientific Meeting</td>
<td>Mar 2012</td>
</tr>
</tbody>
</table>
### Chapter 13

**General Practice in Ireland**

<table>
<thead>
<tr>
<th>Event Title</th>
<th>Location</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Evaluation of participatory research training provided to an international, interdisciplinary team of primary healthcare researchers.</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MacFarlane A, de Brún T, O’Reilly-de Brún M.</td>
<td>York Action Research Conference York St. John University, England</td>
<td>User involvement in primary care: Combining contemporary social theory with participatory learning &amp; action research</td>
</tr>
<tr>
<td>June 2011</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>O’Reilly-de Brún M, Bradley C, Waters C, de Brún T, MacFarlane A.</td>
<td>ICGP 2nd Research and Audit Conference Kilkenny, Ireland (Irish College of General Practitioners)</td>
<td>Are family and friends acceptable as interpreters in cross-cultural general practice consultations? An analysis using Participatory Learning &amp; Action research methods</td>
</tr>
<tr>
<td>June 2011</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>O’Reilly-de Brún M, Mierzejewska A, Ahmed K, Bonsenge-Bokanga JS, Nnadi L, Okonkwo K, Ogbebor F, De Almeida Silva MM, de Brún T, MacFarlane A.</td>
<td>3rd Community Interpreting Research Seminar, Trinity College, Dublin</td>
<td>Are family and friends acceptable as interpreters in cross-cultural general practice consultations? Participatory research methods and user involvement provide insights for a guideline of best practice</td>
</tr>
<tr>
<td>Feb 2011</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>MacFarlane A, O’Reilly-de Brún M, de Brún T.</td>
<td>ADEGS/AUDGPI Scientific Meeting</td>
<td>Are family and friends acceptable as interpreters in cross-cultural general practice consultations? An analysis using participatory learning and action research methods</td>
</tr>
<tr>
<td>Jan 2011</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>MacFarlane A, O’Reilly-de Brún M, de Brún T.</td>
<td>NUI Galway, Galway, Ireland. Discipline of General Practice</td>
<td>Community engagement/user involvement in primary healthcare research projects in Galway, Ireland, using a Participatory Learning &amp; Action (PLA) approach</td>
</tr>
<tr>
<td>Nov 2010</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>July 2010</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>MacFarlane A, O’Reilly-de Brún M.</td>
<td>2nd Community Interpreting Research Seminar NUI Galway, Ireland</td>
<td>User involvement in the development of guidelines for communication in cross-cultural general practice consultations: The use of Participatory Learning and Action (PLA) research</td>
</tr>
<tr>
<td>June 2010</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>June 2010</td>
<td>ORAL PRES</td>
<td></td>
</tr>
<tr>
<td>MacFarlane A, O’Reilly-de Brún M</td>
<td>AUDGPI ASM Dublin, Ireland (Association of University Departments of General Practice in Ireland)</td>
<td></td>
</tr>
</tbody>
</table>
### List of Publications

<table>
<thead>
<tr>
<th>Authors</th>
<th>Event/Conference</th>
<th>Location</th>
<th>Title</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>de Brún T, O'Reilly-de Brún M.</td>
<td>NORFACE Seminar Series</td>
<td>Dublin, Ireland</td>
<td>Service user involvement in debates about supports for communication in cross-cultural consultations: a qualitative analysis</td>
<td>Mar 2009</td>
</tr>
<tr>
<td>O'Reilly-de Brún M, MacFarlane A, O'Flynn A, Nurse D.</td>
<td>AU&amp;DGPI Annual Conference</td>
<td>Royal College of Surgeons in Ireland (RCSI), Dublin, Ireland</td>
<td>Pilot Interpreting Service for General practices in the HSE Eastern Region: A Quantitative analysis of uptake levels and patterns of use</td>
<td>Feb 2009</td>
</tr>
<tr>
<td>MacFarlane A, O'Reilly-de Brún M, O'Flynn A, Nurse D.</td>
<td>AU&amp;DGPI Annual Conference</td>
<td>Royal College of Surgeons in Ireland (RCSI), Dublin, Ireland</td>
<td>Uptake of language interpreters in general practice: an analysis using the Normalisation Process Theory</td>
<td>Feb 2009</td>
</tr>
<tr>
<td>de Brún T.</td>
<td>HSE Heart Failure Implementation Group</td>
<td>Galway, Ireland</td>
<td>Development of a comprehensive heart-failure service in Ireland – towards a structured, integrated approach</td>
<td>Sept 2009</td>
</tr>
<tr>
<td>de Brún T.</td>
<td>Dublin City Council, Social Inclusion Unit</td>
<td>Dublin, Ireland</td>
<td>Men Alone in No-Man’s Land (MAIN) a participatory research study of the needs of socially-excluded males in Dublin Inner City - presentation of findings</td>
<td>May 2008</td>
</tr>
<tr>
<td>de Brún T, O'Reilly-de Brún M, MacFarlane A.</td>
<td>Combat Poverty Agency (CPA)</td>
<td>Dublin, Ireland</td>
<td>‘Having Your Say’ – the case of the missing voice. 3 PLA case-studies from Ireland</td>
<td>Nov 2007</td>
</tr>
</tbody>
</table>

Presentations prior to 2007 are not included in the above.
Chapter 13

Curriculum Vitae – Mary O’Reilly-de Brún

1958-1986: Mary O’Reilly-de Brún was born on 20th January 1958 in Dublin, Ireland. Her parents, Kevin and Carmel O’Reilly, had four daughters – Mary is third among her sisters Claire, Geraldine and Jacinta. While working as a civil servant, she studied fine art (painting) part-time at the National College of Art & Design, Dublin. She and her life-partner, Tomas de Brún, married in 1980. Having worked as an art teacher and graphic designer, she had the opportunity to attend Maynooth University as a mature student in 1986.

1986-1989: B.A.Th., Anthropology and Theology (double first), Maynooth University, Ireland.

1989-1995: Lecturer, Department of Anthropology, Maynooth University, Ireland.
Courses: Introduction to Anthropology; Practicing anthropology; Qualitative and participatory research.

1992: M. Th., (first class honours), Maynooth University, Ireland. Thesis title: From Silence to Sacred Speech. A participatory research study of women’s journeys to feminist consciousness, voiced ‘in their own words’.

1993-1995: Lecturer, Department of Anthropology, Maynooth University, Ireland.
Courses: Introduction to Anthropology; Practicing anthropology; Qualitative and participatory research.
Invited Lecturer, Ushaw College, Durham University, England.
Course: Culture, communities and change.
Invited Lecturer, Milltown Institute of Theology and Philosophy, Ireland.
Courses: Dynamics of culture; Anthropological research methods.

- Participatory Learning & Action (PLA) practitioner, trainer, project designer and co-ordinator
- Mary pioneered the adaptation and application of participatory research methods to the field of female education in sub-Saharan Africa.
- With Tomas, Mary co-designed and delivered innovative PLA research training programmes to indigenous teams in Senegal, Mauritania and The Gambia.
- These research projects involved inter-stakeholder dialogues between communities, government departments and international agencies (Aifa-Polop, Senegal; Ministry of Education, The Gambia; Action Aid, The Gambia, Ministry of Education, Mauritania). This research helped to ‘bridge the gap’ between the needs, values and expectations of communities and regional and national-level policy makers, planners and officials.

1999-2001: Project Co-ordinator & PLA trainer: National Women’s Council of Ireland’s (NWCI) Millennium Project. The Millennium Project involved training 120 women across the
Republic of Ireland in a PLA approach and techniques; these ‘peer researchers’ then facilitated PLA research with almost 700 women on topics ranging from women’s health, to poverty, domestic violence, education, employment and local development, generating important policy reports for the Irish Government.

2002: Co-founder (with Tomas de Brún) of the Centre for Participatory Strategies (CPS), Connemara, Galway, Ireland. CPS offers innovative PLA research training programmes. Since 2002, Mary and Tomas have trained and supported teams to engage in PLA research applied to health, poverty alleviation, drug addiction and homelessness, ethnicity and anti-racism, community development, health needs assessment and other research topics, working closely with academics, community development workers, psychologists, clinicians, Travellers, people seeking protection (asylum-seekers/refugees) and personnel from NGOs and statutory agencies.

2004-2008: Lecturer: annual 30-hour PLA research training programme for international students of global development, Kimmage Development Studies Centre, Dublin.


2007-2008: Member of the Expert Round Table on Evidence-Based Practice in Integration Policy & Research, Migration & Citizenship Research Initiative, University College Dublin, Ireland.

2009-2015: Senior Researcher, Discipline of General Practice, National University of Ireland, Galway (NUI G). During this period, Mary and Tomas co-designed and delivered participatory research training and support to researchers involved in the ‘SUPERS’ and ‘RESTORE’ projects. Mary and Tomas also facilitated the RESTORE project’s PLA research and analysis at the Irish site, 2011-2015.

2013: Radboud University Medical Centre, Nijmegen, The Netherlands. Mary registered as a candidate for this ‘double-book’ PhD (National Centre for Evidence-Based Practice, NCEBP) at Radboud. The overall objective of this collaborative thesis (which draws on the ‘SUPERS’ and ‘RESTORE’ projects and earlier work in Africa) is to assess the potential of using a PLA approach and methods to meaningfully involve ‘hard to reach’ and vulnerable populations in co-designing primary healthcare that is responsive to their needs, expectations, and values. This continues Mary and Tomas’ focus on ‘bridge-building’: using a PLA approach and techniques to support communities to build primary care ‘from the bottom up’ via inter-stakeholder dialogues between service-users and service-providers, thereby advancing collegiality, empowerment, co-responsibility and stakeholder self-efficacy in primary healthcare research.

2015-to date: In her capacity as co-founder and co-director of CPS, Mary continues to pursue her strong commitment to the use of PLA approaches and methods in the emerging
fields of user-involvement, community-engaged research, inter-stakeholder dialogue, and peer research. The Centre’s aim is to continue to share methods and tools that support meaningful engagement by service-users and service-providers, enabling the least powerful and the most vulnerable to become key actors in research and action to improve their lives and conditions. Most importantly, the Centre is dedicated to a power-sharing approach that embeds PLA research capacity in the community, ensuring that ‘the community does it for itself’.

Mary has retained her connection with the National University of Ireland, Galway, as an Honorary Senior Researcher in the Discipline of General Practice.
Curriculum Vitae – Tomas de Brún

1956-1986: Tomas de Brún was born on 8th of September 1956 in Dublin, Ireland. His parents, Thomas and Maureen Browne (de Brún) had four children, and Tomas is fourth among his siblings Harry, Jay and Veronica. He studied fine art and sculpture at the National College of Art and Design for two years. He and his life-partner, Mary O’Reilly-de Brún, married in 1980. Having worked for some time as a graphic designer, he returned to university as a mature student in 1986.

1986-1989: B.A.Th., in Anthropology (1.1) and Theology (2.1) Maynooth University, Ireland.

1989-1996: Lecturer, Department of Anthropology, Maynooth University, Ireland. Courses: Biological Anthropology – human evolution, ‘race’ & ethnicity; Anthropology of Art; Anthropology of Religion.

1992: M. Th., Maynooth University, Ireland.


- Participatory Learning and Action (PLA) practitioner, trainer, project co-ordinator.
- With Mary, co-designed and delivered innovative PLA research training programmes to indigenous teams in Senegal, The Gambia, Guinea-Bissau.
- These research projects involved inter-stakeholder dialogues between communities and government departments and international agencies (Aifa-Polop, Senegal; Ministry of Education, The Gambia; UNICEF, Guinea-Bissau; Action Aid, The Gambia). This research helped to ‘bridge the gap’ between the needs, values and expectations of communities and regional and national-level policy makers/planners and officials.

2000: M. Phil (Ethnic and racial studies), Department of Sociology, University of Dublin, Trinity College. Thesis title: ‘Masculinity and irishness: emerging identities, diverging trajectories?’ Ethnically Irish heterosexual men voiced how their life experiences converged and diverged from hegemonic norms of masculinity and Irishness.


2002: Co-founder (with Mary O’Reilly-de Brún) of the Centre for Participatory Strategies (CPS), Connemara, Galway, Ireland. CPS offers innovative PLA research training programmes. Since 2002, Tomas and Mary have trained and supported teams to engage in PLA research applied to health, poverty alleviation, drug addiction and homelessness, ethnicity and anti-racism, community development, health needs assessment and other research topics, working closely with academics, community
development workers, psychologists, clinicians, Travellers, people seeking protection (asylum-seekers/refugees) and personnel from NGOs and statutory agencies.

**2007-2009:** Irish representative (one of four) - NORFACE European Seminar Series on the use of evidence-based research in policy (Dublin, Edinburgh, Oslo).

**2007-2008:** Member of Expert Round Table on Evidence-Based Practice in Integration Policy & Research, Migration & Citizenship Research Initiative, University College Dublin, Ireland.

**2009:** Kimmage Overseas Development Education Programme (KODE). Tomas designed and developed the ‘Anthropology of Development’ core component of this online education Master’s Degree in Development. He was appointed ‘subject specialist’, a role he holds to date.

**2010-2015:** Senior Researcher, Discipline of General Practice, National University of Ireland, Galway (NUI G). During this period, Tomas and Mary co-designed and delivered participatory research training and support to researchers involved in the ‘SUPERS’ and ‘RESTORE’ projects. Tomas and Mary also facilitated the RESTORE project’s PLA research and analysis at the Irish site, 2011-2015.

**2013:** Radboud University Medical Centre, Nijmegen, The Netherlands. Tomas registered as a candidate for this ‘double-book’ PhD (National Centre for Evidence-Based Practice, NCEBP) at Radboud. The overall objective of this collaborative thesis (which draws on the ‘SUPERS’ and ‘RESTORE’ projects and earlier work in Africa) is to assess the potential of using a PLA approach and methods to meaningfully involve ‘hard to reach’ and vulnerable populations in co-designing primary healthcare that is responsive to their needs, expectations, and values. This continues Tomas’ and Mary’s focus on ‘bridge-building’: using a PLA approach and techniques to support communities to build primary care ‘from the bottom-up’ via inter-stakeholder dialogues between service-users and service-providers, thereby advancing collegiality, empowerment, co-responsibility and stakeholder self-efficacy in primary healthcare research.

**2015-to date:** In his capacity as co-founder and co-director of CPS, Tomas continues to pursue his strong commitment to the use of PLA approaches and methods in the emerging fields of user-involvement, community-engaged research, inter-stakeholder dialogue and peer research. The Centre’s aim is to continue to share methods and tools that support meaningful engagement by service-users and service-providers, enabling the least powerful and the most vulnerable to become key actors in research and action to improve their lives and conditions. Most importantly, the Centre is dedicated to a power-sharing approach that embeds PLA research capacity in the community, ensuring that ‘the community does it for itself’.

Tomas has retained his connection with the National University of Ireland, Galway, as an Honorary Senior Researcher in the Discipline of General Practice.
Acknowledgements

Chris van Weel
Dear Chris, our deepest appreciation for your interest in, and enthusiasm for exploring the potential of PLA for the field of primary healthcare research. As we explored this terrain, we benefitted greatly from your immense professional experience in the field of primary care and research capacity-building. Your skill in guiding us through the ‘highs and lows’ of our PhD journey was paramount. We will always remember how you kept faith with us, and we will always be grateful for the ‘lightness’ you bring, your gentleness and humour. Special memories for us: dinner with you and Evelyn in a little restaurant in Rethymno during the RESTORE consortium meeting in Crete where we talked about our histories, about PLA, primary care and our hopes for the future. Chris, we are inspired by your integrity and compassion, your deep commitment to the person-centred ideal of care, and the professional and personal manner in which you live that out.

Anne MacFarlane
Dear Anne, our journey together began in 2004. Little did we realise then that a shared excitement about using PLA in primary healthcare research would lead to a whole range of innovative projects, among them SUPERS and RESTORE. We have always appreciated your willingness to take a step ‘outside the box’, to try something new, and to rigorously explore possibilities and challenges. That provided interesting opportunities to push the ‘edge of the envelope’ regarding healthcare research. A special memory for us: our early ‘fur-ball’ meetings, where we brainstormed ideas and conceived of them as a big fur ball which we could later untangle, organise, re-configure. Anne, our deepest appreciation for the energy, time and professional expertise you generously shared over many years and most recently throughout our PhD journey. We appreciate your commitment to the underserved.

Evelyn van Weel-Baumgarten
Dear Evelyn, we have been inspired by your interest in the role PLA might have in enhancing communication between service-users and service-providers. Throughout our RESTORE PLA training workshops, and fieldwork, reflection and evaluation, we enjoyed the insights, questions and suggestions you continually offered from a trainer/practitioner perspective. Over the course of the PhD you have brought your extensive professional expertise and tenacity to bear, to our benefit. We will always appreciate your strength of purpose and your clarity. We remember your many kindnesses, and a special memory for us is the hilarity you brought to the ‘circus tent’ exercise during the PLA training in Vienna. Evelyn, your commitment to your inspiring work with EACH (International Association for Communication in Healthcare) will continue to encourage us in our future work.

Maria van den Muijsenbergh
Dear Maria, our deepest appreciation for sharing and enhancing a vision of what PLA might contribute to healthcare research in a society where the marginalised seem to be increasingly silenced. We are constantly inspired by your work – your commitment to reducing disparities in
healthcare access for migrants and socially-vulnerable service-users. Throughout our PhD journey, you have brought an extraordinary balance of ‘head and heart’ to bear – we have benefitted greatly from your professional insights into the world of the least powerful, and we have been greatly refreshed by your personal warmth, advice and support. A special memory for us: when we first met for the RESTORE project in Glasgow, we shared an exciting and unforgettable evening, telling stories about our respective work, and our hopes. That evening we sensed that we ‘spoke a common language’ that is neither English nor Dutch but is the language of hope and compassion for a more equitable world. Maria, you continue to inspire us.

Members of RESTORE
Nicky Burns, Ciaran Clissman, Chris Dowrick, Francine van den Driessen-Mareeuw, Katja Gravenhorst, Christos Lionis, Frances Mair, Anne MacFarlane, Maria van den Muijsenbergh, Catherine O’Donnell, Maria Papadakaki, Christine Princz, Aristoula Saridaki, Wolfgang Spiegel, Erik Teunissen, Maria Vlahadi, Evelyn van Weel-Baumgarten.

Thank you for the great enthusiasm with which you engaged in the PLA training we provided throughout RESTORE. We learned so much with you and from you during those four years; as RESTORE developed, we enjoyed how creatively you adopted and adapted PLA for different countries, cultures and primary care contexts, doing an amazing job! We have wonderful memories of working with you – energetic discussions, bright ideas, creative problem-solving, all leavened by laughter and evenings of dance and good food! We send you an ancient Gaelic toast: ‘Sláinte an bhraidein chugat, croí folláin agus gob fluich’ - the health of the salmon to you, a full heart and a wet mouth!

Paranimfen (two colleagues who support us during the defence)
Erik Teunissen
Erik, your support and practical information was invaluable. Thank you for being a pioneer, forging your PhD path, encouraging us to follow. We so enjoyed your warmth and humour through all the years of RESTORE and it is wonderful to have your support on this special day.

Edel Tierney
We value your friendship beyond words. Your encouragement supported us when we needed it most. We have watched the extraordinary ways in which you have applied PLA in your research field, breaking new ground. You engage in PLA with such heart and expertise. Thank you for being here to support us today.

Stakeholders and support staff in sub-Saharan Africa & Ireland 1993-2009
Our experiences as PLA trainers and practitioners in Africa were the foundation on which we built subsequent work. We owe a debt of gratitude to many:
Auntie Mengeh, Musu Faye, Ousman Dibba, Lamin Fatty, Haddy Sissoho and other researchers in The Gambia, West Africa, the first teams we trained in PLA who took it ‘to the ground’ – literally. How could we ever forget watching you work with villagers – using sticks, leaves, seeds and ash to
generate enormous village maps and complex diagrams in the fine red sand? Or analysing our results by candlelight when evening fell? We had no electricity, no Internet, no mobile phones but we shared incredible goodwill and passion for the innovative work we were doing together. We remember how patient you were: helping us to become culturally-aware, teaching us how to greet people in several languages, advising how many ‘kola nuts’ to bring as gifts to Alkalos (village chiefs).

To the townspeople and villagers who participated so wholeheartedly in the early research: the Mandinka, Wolof, Acu, Serer, Fula and Jola peoples of Busura, Kataba, Kumdam Mandinka, Soma, Missera, Kora Jula Kunda and Kerr Auldi. We loved the energy and precision you brought to the research: ‘No, no, there are only five girls in that compound, not six, and just 1 goes to school! And don’t listen to Mamadou; he has three wives, not two!’ Laughter was always part and parcel of learning, a wonderful confluence.

Our deep appreciation to the World Bank ‘Heads of Mission’ who supported our early PLA work, to UNICEF in Guinea-Bissau and to Ministry of Education staff in Senegal, Mauritania and The Gambia, especially Lawrence Bruce and Therese Cardos. You were willing to take a risk, to try something new, to approach research with an open mind. You ensured that key research results influenced positive policy change.

**Stakeholders and peer researchers in Ireland 1998-2007**

What we learned in West Africa travelled home to Ireland with us. My warm thanks to Katherine Zappone, whose vision for the NWCI Millennium Project (1998-2000) initiated an extraordinary experience of training 120 ‘local’ women as peer PLA researchers. They facilitated PLA research across the Republic of Ireland on women’s health, education, work, local development and, with immense care and insight, on sensitive issues such as violence against women and women’s poverty. This brought the voices and experiences of 492 women in Ireland forward into the policy arena. To all of you, who participated with honesty, verve and humour – thank you. You were courageous pioneers.

Using PLA with the homeless men of MAIN in inner city Dublin (2007) was striking – the deep listening within the group generated a new and powerful energy – you saw yourselves as more than vulnerable stereotypes – ‘socially-excluded men in need of services’ – and began to experience yourselves as men capable of connecting with and supporting others. You took positive power; no longer willing to be seen as part of the problem, you acted as part of the solution. To see you become established as a peer-to-peer service provider in Dublin city, offering ‘counselling and support services to men that find themselves feeling isolated, alienated, helpless or hopeless’ is inspiring. Bravo!

**Stakeholders in SUPERS Project 2009-2011**

We express heartfelt thanks and appreciation to the ‘SUPER’ researchers: Khalid Ahmed, Jean-Samuel Bonsenge-Bokanga, Maria Manuela De Almeida Silva, Aga Mierzejewska, Lovina Nnadi, Florence Ogbebor and Ekaterina Okonkwo. You did something extraordinary – using your own languages, cultural knowledge and six PLA training sessions, you facilitated professional-level primary
care research which ‘broke the mould’; you have shown that, as members of the local community, you can go where academics may not, eliciting the perspectives of community members who would otherwise be excluded from research. The old excuses for such exclusion can no longer hold. To all the stakeholders, from migrant service-users to general practitioners, interpreters and Health Service Executive service planners who participated in this project, our gratitude for your energy, time and determination to have a say in improving health services for migrants. That determination should power us all forward!

**Stakeholders in RESTORE project 2011-2015**
To the many diverse and fascinating stakeholders in Austria, England, Greece, The Netherlands, and the Republic of Ireland who engaged in the RESTORE project with such commitment and generosity – migrants and migrant representatives, general practitioners, practice staff, interpreters, policy planners and many others – our thanks and deep appreciation. Research depends so strongly on people like you who are willing to share life stories, expertise, insights, ideas – your views and your participation make all the difference.

**Secretariat ELG**
Transforming a selection of articles into this highly professional ‘double book’ is no easy task. It demands great skill, energy and attention to detail. For this, we warmly thank Twanny Jeijsman-Rouwhorst. We always felt we were in the safest of hands. Our warm appreciation also to Tilly Pouwels; her help and support were invaluable during our registration and in the early stages of our engagement with Radboud University.

**Radboud University**
Our sincere thanks to Radboud University, where a ‘double-book’ such as this is possible, welcomed and supported. We deeply appreciate the opportunity to present our shared body of work, a collaborative endeavour spanning almost thirty years, in this manner.

**To people who inspired us and supported our educational path, in the broadest sense:**

**To primary care practitioners:**
Dr. Michael Casey and staff, Carna, Co Galway, Ireland.
Dr. Joe Curran and staff, Clonbur, Co, Galway, Ireland.
Our sincere thanks for the person-centred manner in which you have cared for our well-being.
**Students and colleagues:**
Over the years, we have been privileged to learn with and from many students and colleagues, exploring anthropological research and development in the global south at the Danish Centre for Development Co-operation, Tanzania and, in Ireland, at Kimmage Development Studies Centre. We enjoyed developing innovative applications of PLA with students in the Department of Anthropology, Maynooth University, and later in the Discipline of General Practice, NUI Galway. We also acknowledge with thanks our colleagues in the Health Services Executive (HSE) Ireland.

**Families of Origin**
Our thanks and love to our late parents Carmel and Kevin O’Reilly, Maureen and Thomas Browne (de Brún). You stood proudly with us when we were awarded our bachelors’ and masters’ degrees. We know you would love to share this day with us, and we believe you are with us in spirit. Joyful thanks are due to our much-loved siblings and in-laws: Claire, Owen, Geraldine, Patrick, Jacinta, Ray, Harry, Maureen, Veronica, Jay and, too numerous to mention, other family members across three generations who have supported us in so many ways – our warmest appreciation.

**Friends**
So many people come to mind, and we thank you all. For particular reasons, we mention here Máirín and Gearóid Breathnach, Gary and Eleanor Browne-Travers, Doc Gilbert, Rob and Susan, Eley and Kieran, Mike and Clare. Bernard and Deirdre Kelleghan, Albert and Catriona Larkin, Teresa and Tim McCarthy, Emer McDermott, Ruth McMenamin, Ang and Joe O’Shea, Hans Pieper, Miriam and Derek Reddin-Beegan, Edel Tierney, Melanie Vaughan-Smith and Brigitte and Charlie Winter-Bangard. You yourselves know the many ways in which you have enlivened and enriched our lives: long conversations, picnics on Connemara beaches, adventures in Germany, gentle advice in hard times, compassionate listening always. From our hearts to yours – deepest appreciation for the unparalleled gift of friendship you have shared with us over the decades.

**Centre for Participatory Strategies (CPS) – workshop participants**
Since 2002, we have provided PLA training programmes to wonderfully diverse groups of participants in Ireland and abroad – anthropologists, architects, community development workers, farmers, geographers, health services staff, human rights activists, migrant advocacy groups, policy-makers, psychologists, Travellers, sisters in religious congregations, sociologists and others! We especially recall the energy and excitement on ‘de-briefing’ days when participants would return to the workshops with sheaves of intricate charts and diagrams, enthusiastically showing us the PLA techniques they had practiced with friends, families and unsuspecting neighbours! You have all enriched the development of the Centre and informed our ethos and direction. We thank you.

**Contact details:**
*Centre for Participatory Strategies,*  
Ross Wood, Clonbur, Co. Galway, Ireland. F12 P298  
++ 353 86 0637800  email: cps.actionresearch.ireland@gmail.com
Finally, we express our thanks to each other:

For Tomas:

This journey has been traced in coral and glass
on windswept Connemara shores;
waves breaking from stillness
before pen touches page.

Close your eyes.

The beat of a steadfast heart
marks time with a blessed rage.

Mary, Dec 2017.

For Mary:

Roots - deep
anchor us in the heart
from where we have journeyed forth

Along routes, pathways and small migrations
through realms and understandings

We hold fast to roots and routes
and travel onwards.

Tomas, Dec 2017.