Centre for Society and Genomics

2008 – 2012

Business Plan

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Nijmegen, April 2, 2007
Foreword

This document presents the agenda of the Centre for Society and Genomics (CSG) for the period 2008-2012. During the past 2.5 years, CSG has developed a national and international programme for research and public interaction concerning the relationship between society and genomics. The plans for 2008-2012 not only include the activities of CSG as such. Rather, they involve the societal research projects and communication and education activities of all Genomics Centres funded by NGI:

Centre for BioSystems Genomics (CBSG)
Centre for Medical Systems Biology (CMSB)
Kluyver Centre for Genomics of Industrial Fermentation (Kluyver Centre)
Cancer Genomics Centre (CGC)
Ecogenomics Consortium
Netherlands Metabolomics Centre (NMC).
Netherlands Consortium for Healthy Ageing (NCHA)
Nutrigenomics Consortium
Celiac Disease Consortium (CDC)
VIRGO Consortium
Forensic Genetics Consortium Netherlands (FGCN)
Netherlands Proteomics Centre (NPC)
Netherlands Bioinformatics Centre (NBIC)
Netherlands Toxicogenomics Centre (NTC)

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4 Executive summary

Genomics is here to stay. In the years to come, society will increasingly be confronted with genomics applications. It is the ambition of the Centre for Society and Genomics (CSG) to improve the conditions for embedding genomics in society. This calls for:

- Good governance: embedding genomics applications in society in a transparent and well-informed manner and in a way that takes into account the needs and interests of (different groups of) citizens and institutions.
- Alignment of the opportunities that genomics technologies offer with the expectations and needs of society. Hence, a socially robust genomics agenda.
- Education and communication about genomics to ensure that publics and professionals are knowledgeable and well-informed in order to critically assess current and future applications.

These three objectives form the basis of our plan. They are represented in three programmes, and each of these programmes covers two major themes.

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Since 2004, the Centre for Society and Genomics (CSG) has developed an interactive programme for studying and improving the relationship between genomics and society. This programme includes 22 research projects; a series of education programmes for bachelor, master and postgraduate students; a public website and mobile DNA laboratories for upper secondary students; and numerous societal discussions, dialogue and debates. The current plan continues, but also expands and consolidates this programme. Governing the societal embedding of genomics calls for an on-going and focussed effort.

Following the advice of our international mid-term review committee, we will further develop our interactive approach. Our plan will continue to combine research with societal interaction (e.g. public communication, education, public debate and policy briefings). Thus, most of the research projects described in this plan focus on societal interaction (what can we learn from such activities and how can we improve them?), but the reverse is also true: the activities that we organise function as test-beds or input for our research. Therefore, in the context of our three programmes, research and societal interaction are presented in a comprehensive way.
This is an ambitious plan. It includes not only the work of the centre at Radboud University Nijmegen, but also the societal research and public communication activities of the Genomics Centres funded by NGI. Moreover, CSG works with a network of prominent ELSA-genomics researchers from other universities.¹ These three parties – CSG Nijmegen, the Genomics Centres and ELSA-genomics researchers – each conduct a significant part of our plan. Our interactive approach – combining research with interaction – is the basis for all research groups participating in this plan.

The collaboration of the Centre in Nijmegen with the ELSA-network and with the Genomics Centres is also built into the management structure of CSG. While the day-to-day management and programme management will be based at Radboud University Nijmegen, the six Principal investigators – who are responsible for developing our six major themes and who, together with the programme managers, form the programme committee – represent prominent research groups and/or Centres of Excellence.

The deliverables of this programme: 20 PhD thesis’s, 250 scientific articles, 50 articles in popular magazines, 55 public discussions, debates and dialogues; 120,000 hits annually at watisgenomics.nl; 200.000 visitors of one of the DNA mobile labs; the development of a virtual lab and a genomics test-lab for science centres; 2 large-scale patient information days; a genomics science festival; several modules for health professionals and much more. Ultimately, the programme aims to strengthen the governance of genomics; improve the quality of public debate (so as to prevent unnecessary adverse affects) and to further people’s knowledge about genomics as well as their ability to provide a critical assessment of genomics applications.

Genomics is here to stay, and so is CSG. In the future, however, genomics will migrate to novel emerging fields and become so firmly embedded that it no longer will be viewed as a separate research domain. After 2012, CSG will continue its programme, but no doubt it will do so in a different world in which both genomics and society have changed. Current investments will allow us to broaden our scope and to become relevant for an increasing number of partners in the life-sciences and a broad range of (international) funding schemes. The plan for the coming five years ensures that CSG by that time is well positioned, locally, nationally as well as internationally, to further develop its methods and themes in the context of research, education, policy and debate.

¹ ELSA stands for Ethical, Legal and Social Aspects.
5 Societal impact, mission and ambition

On April 2, 2020 Heather is born. Her parents are invited to subject their daughter to a Heel-prick procedure. Aided by an interactive computer programme that processes their family histories, they are requested to make their own personal selection from a list of 120 conditions. Working through a second interactive computer program, explaining the benefits and risks of all available tests, they agree (and sign informed consent) to subject Heather to genetic tests that provide risk information for 22 conditions. Not all of these are treatable, but for most of them preventive strategies are available. Some of these conditions will cause undesirable behaviour rather than physical complaints. On the basis of these tests, Heather’s parents are informed about their child’s susceptibility to heart-disease, Alzheimer, depression, ADD and several forms of cancer. Also an estimate of Heather’s life-span is disclosed. Subsequently they are referred to a life-style counsellor to obtain a personalised scheme for medication, diet and life-style advice. They are also invited to participate in counselling sessions with other couples. Finally they agree that the genetic data (in an anonymous format) may be used for further biomedical and epidemiological research (to be confirmed by Heather herself when she is 18 years old).

The above scenario depicts a world in which genomics has become an integral part of our societies and of the lives of individual men and women. Similar scenarios can be developed for bio-energy or plant genomics. In 2020, we may fill our cars with bio-fuels or spray our gardens with metagenomic solutions in order to improve soil quality. How will such scenarios affect global deforestisation or the amount of food that is available for consumption? Scenarios about the future uses of genomics science and technology trigger important questions. Are they realistic? Is it desirable for these scenarios to become reality? If so, under what conditions? How to prepare society (citizens, scientists, policy makers) for these futures? These are the issues our plan aims to address.

During the next five years, more and more genomics applications will find their way into society. This raises a broad range of questions concerning the ways in which genomics research and applications are to be meaningfully embedded. These questions can be organised under three headings. First of all, what are the implications and applications of genomics in various practices? How will genomics affect society and vice versa? Secondly, how will the agenda of genomics evolve in the near future? To what extent can this agenda be directed towards societal demands and “societal tasks”\(^2\)? Finally, how can education and communication empower citizens, students, policy-makers and researchers to assess genomics developments and applications? Investments in genomics will be wasted if we fail to address these questions in a timely and well-informed manner.

This plan concerns the *Ethical, Legal and Social Aspects (ELSA)* of Genomics, that is: the interrelatedness of genomics and society (Gaskell & Bauer 2006, Nelis et al 2006). It combines scientific research with societal interactions (e.g. education, information, communication and policy engagement). It is an indispensable part of NGI’s overall Strategic Plan because it:

1. enables timely reflection on the future promises of genomics
2. helps to shape the agenda of genomics in such a way that genomics will be relevant for society in general and for a number of societal groups and stakeholders in particular.
3. avoids polarised debates.
4. builds on and provides mass, focus and greater visibility to the achievements of ELSA genomics in the Netherlands.

There is no simple causal relationship between publications and public interactions concerning genomics on the one hand and the style or atmosphere of the public debate on the other. However, the work of social science and humanities scholars has contributed to the open-minded and balanced nature of the discussions during the past five years, in comparison to the debate over (for example) GM-food in the 1990s. Instead of asking the question “How will we profit from societal research?” we should rather ask “What damage will be done when we do not invest in studying and improving the interaction between genomics and society?”

**Mission and Scope of the programme**

This programme bridges the gap between the potentials of technological innovation on the one hand and societal demands and expectations on the other. It attunes the promises of a healthier, wealthier and more sustainable world to the needs of our societies.

The innovation potential of genomics that is studied in this programme is directly linked to the topics and themes of the research programmes of NGI’s Genomics Centres. Our programme thus focuses on topics such as cancer, target crops, proteomics, forensics, bioinformatics, multifactorial diseases, fermentation, ageing, nutrigenomics, toxicogenomics, metabolomics, infectious diseases, Celiac disease and ecogenomics. For each of these topics we will ask the question “What are the societal issues at stake?” and organise timely (public) discussion and dialogue. In this way, citizens are invited and empowered to reflect on short-term and future applications.

Although our activities focus on the topics of the Genomics Centres, they are not “technology-driven”. Rather, our strategy is to approach these issues from “both sides”. It is the aim of our plan to bring genomics research agendas and societal agendas closer together. Issues such as the assumptions
underlying genomics research or the ways in which genomics is organised in public-private constellations, for example, are explicitly addressed. Also so-called “macro” questions will be dealt with, questions that go beyond the interest of individual Centres or national boundaries. To what extent does genomics enable a fair sharing of benefits and natural resources? To what extent does it contribute to the alleviation of poverty? How can it contribute to the elimination of rare diseases?

Our programme aims to make the development of genomics science and technology more “socially robust” (Nowotny 2003) and to explore and further the conditions for the embedding of genomics in society. We borrow the term “embedding” from science and innovation studies. It refers to aligning societal demands, innovative capacities and the rules, regulations and institutions that govern these innovations.

*Our mission is to understand and improve the conditions that determine the societal embedding of genomics.*

First of all, it is our objective to *improve* the conditions for societal embedding: a dynamic process in which society and societal actors play a decisive role. These ambitions call for substantial research efforts, but always in combination with activities in the realm of public and stakeholder interaction. To improve the conditions for societal embedding, it is important to *understand* and elucidate the ways in which genomics research programs are evolving, in close interaction with their social and cultural environments. Beside, it is important to *critically assess* the conditions for societal embedding. Based on a thorough analysis of past experiences and of the dynamics of the interaction between science, technology and society, this programme aims to anticipate the (future) impacts of genomics for society.

Who is the “we” in this report? “We” refers to the Centre based at Radboud University Nijmegen. Yet, CSG is a network organisation. Our plan includes all the societal research and public interaction of the Genomics Centres of NGI. Moreover, part of our plan is carried out by ELSA groups and experts at other universities in the Netherlands. These three actors (CSG Nijmegen, Genomics Centres, the ELSA Network) all conduct a significant part of the activities described in this plan. The management of this plan is based in Nijmegen, but the Programme Committee includes representatives from all three actors. This places us in a unique position to build a strong network that combines coherence and focus with national visibility and outreach and will ensure conditions for sustaining our activities in the future.
Aims and Ambitions

In 2012 we want to have achieved:

1) That genomics governance is well organised. This requires:
   a) That citizens, genomics researchers, ELSA researchers, NGO’s and industry have more expertise about the societal aspects of genomics.
   b) That dialogue with the public on potentially controversial applications of genomics takes place at an early stage and in an open-minded and well-informed way.

2) That a durable ELSA genomics knowledge network is established.

Ad 1 Genomics science and technology will in principle affect us all. Questions concerning the application and use of genomics as well as the (future) agenda of genomics, therefore, are (or rather, should be) a matter of concern for all. We therefore need “good governance” of genomics. This implies among other things that different parties are being heard and that the decision-making process is transparent, sensitive and interactive. In 2012, professionals, scientists, citizens (including minority groups) and public interest groups must have a say in the shaping of the agenda of genomics science and technology.

More expertise means more knowledge and information about genomics as well as the ability to critically assess this information. A significant part of our programme therefore will be dedicated to capacity building. In 2012, more than 120,000 school children have used one of the mobile DNA labs, more than 200,000 people will visit watisgenomics.nl every year, and more than 20,000 people have been involved in “live” or virtual debates on genomics. A significant part of the general population will know what genomics science and technology is about and must be aware of its societal impact.

The committee responsible for the Dutch public debate on GM food (Eten en Genen), concluded that the government should develop better methods to improve timely public dialogue concerning the life sciences. We take this recommendation seriously and aim to improve the quality of the public debate on genomics. In particular, we will organise dialogue earlier, including more people, using new ways for reaching out to the public. In 2012, the concept of genomics and its implications will be a well-known topic of public discussion and dialogue.

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3 “De overheid moet betere methoden ontwikkelen om in een vroeg stadium in dialoog te kunnen treden met het brede publiek over de mogelijke toepassingen van de beschikbare kennis op het gebied van de levenswetenschappen”. Eten & Genen, een publiek debat over biotechnologie en voedsel, 2002, p.7.
Ad 2. The aim of this programme is not only to develop and conduct activities over the next five years, but to use them in order to firmly embed this type of expertise and work, by building a durable network of ELSA experts that will continue to exist after 2012. Our approach to combine research and societal interaction will be widely used and embedded both within CSG and the Genomics Centres.

The Shoulders on which we stand
This programme does not start from scratch. Rather, it integrates various initiatives and continues the development of research and interaction activities of a number of different actors. First of all, we benefit from the efforts and results of the NWO-programme “Societal Component of Genomics”. This programme has shown that in the past few years, genomics has manifested itself more and more in all layers of society: politics, care, science, industry, arts, education etc. As this process will continue, “real-time” reflection on the societal implications of genomics is needed.

Secondly, four Genomics Centres have developed a societal programme accompanying or integrated within their genomics research. CBSG, CMSB, Kluyver Centre and CGC have conducted ELSA-research and communication projects that included stakeholders, patients, professionals and genomics scientists. These programmes have been positively assessed by the different international scientific juries of the Centres.

Thirdly, CSG itself has developed a substantial programme for ELSA-research and public interactions. The 22 research projects conducted by CSG aim to understand the dynamics of genomics research and of public interactions such as policy engagement, capacity building and public dialogue. Besides, CSG organizes a number of public interaction activities, such as a public website; theatre plays; discussions; film debates etc. These activities are at the same time objects of research. Many of these activities – watisgenomics.nl, DNA-labs and Imagine – have been developed together with the Genomics Centres of NGI.

ELSA genomics: the next step
The programme 2008-2012 will use the quality and experiences of the programmes of NWO-MCG, the genomics Centres of Excellence and CSG that have been developed so far, in order to continue and consolidate, but most of all to further advance the agenda of ELSA genomics. Three aspects will be of particular importance:
1. **Interactive methods:** The effort to combine research and societal interaction will be continued. The international mid-term review committee strongly recommended CSG to further develop and improve its efforts to link research and interaction activities.\(^4\) The committee concluded that CSG has the “potential to become an international Centre of Excellence for “how to do” embedded ELSA research” (p.12). To fulfil this potential, the committee recommended CSG to a) further develop its method of embedded ELSA research and b) to strengthen in-house capacity for doing so (p.13). By developing this methodological profile, CSG uses the opportunity to increase its focus, to strengthen its “branding” as interactive ELSA centre and to intensify the relationship between research and communication activities.

2. **The governance of genomics applications:** Genomics will affect all levels of society. This makes the question how to **govern** genomics science and technology an urgent matter for reflection. Special attention is needed for institutional and macro-issues, international relations and comparisons, and the issue of globalisation.\(^5\)

3. **Societal tasks and trends:** Genomics applications – ideally - provide an answer to important societal issues. Societal organisations and public interest groups often stress that an inventory of pressing societal concerns should **precede** agenda setting in research. The Ministries of Agriculture, Nature and Food Quality (LNV) and Health, Welfare and Sport (VWS) likewise emphasise that the genomics agenda should be shaped to address urgent societal themes and tasks.\(^6\) What are the most important issues for the future? A number of trends can be identified already: According to an analysis drafted by COGEM\(^7\) together with CBD and the Health Council of the Netherlands, important trends in the domain of biotechnology are: (a) sustainable bio-energy, (b) blurring of boundaries between genetic modification and novel techniques for crop improvement, (c) increase of options for screening and diagnostics and (d) sub-optimal utilisation of prospects for biotechnological developments in the Netherlands. Some additional issues could be added to this list such as the role of Bio-banking.\(^8\) The Ministry of Health, Welfare and Sport also mentioned the provision of information and education about health-applications, screening, and public-private partnerships. Furthermore, both LNV and VWS emphasise that the process of setting the biotechnology or genomics agenda requires a continuous dialogue between government, citizens and scientists.

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\(^5\) Maatschappelijke Aspecten van Genomics Onderzoek: continu leren en aanpassen. Programme Commissie MCG. Concept 20 maart.


\(^7\) Netherlands Commission on Genetic Modification; Cf. Stakeholder workshop Trend Analysis Biotechnology 2007 (Utrecht March 30 2007).

\(^8\) RGO, Advies Onderzoeksagenda Medische Biotechnologie, Den Haag, April 2006.
Working together

The international mid-term review committee recommended that CSG should collaborate more closely with the other Centres of Excellence and intensify its contacts with policy and political audiences in The Hague. It is therefore not without reasons that the programme 2008-2012 is a co-effort of all Genomics Centres and focuses strongly on the issues concerning policy and governance. Besides, CSG has developed good contacts with a series of policy-networks which we want to further develop, use, inform and interact with in the future. Examples of these networks are the Forum for Biotechnology and Genetics (FBG), the Netherlands Commission on Genetic Modification (COGEM), the policy arenas of the Ministry of Agriculture, Nature and Food Quality and a number of initiatives at the Ministry of Health, Welfare and Sport.⁹

CSG also profits from collaborations with a significant number of international partners. CSG is coordinator of a large ERA-NET – ERASAGE ¹⁰ - that brings together genomics funding agencies from nine different countries including Canada, Switzerland, Germany, UK, Norway, Finland, Israel and Austria. Also, CSG collaborates with a number of well-established sister organizations such as the Centre for the Economic and Social Aspects of Genomics (CESA Gen, UK); the ESRC Genomics Policy Forum (UK), the Centre for Ethics at the University of Tartu in Estonia, the INSERM Institute in Toulouse (FR) and the Flemish Institute for Biotechnology (VIB) in Belgium. The activities of the VIB are of particular relevance because of their broad range of activities using the Dutch language.

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⁹ Notably a follow-up of the “Agenda medical biotechnology” and “Biotechnologie als Open Beleidsproces”.

In the coming years, genomics science and technology will trickle down into the fabric of our society, while society will increasingly develop ways to determine the future development of genomics. This raises the question how to govern genomics in order to benefit from its potentials without doing harm to the environment, animals or individuals.

The interactive development of genomics science and technology can be seen as an experiment from which we should learn. ELSA genomics does not provide a recipe for embedding genomics in society. Rather, ELSA genomics can be seen as a “test-bed” for studying the relationship between science and society. Rather than exposing society to new technologies in a trial-and-error manner, a test-lab is created by doing ELSA “trials” about possible effects and their assessment (Rip 2002, Krohn and Weyer 1994). By combining research with societal interaction, society becomes a laboratory that generates knowledge about the interaction between genomics and society (De Vries & Horstman 2006).

The agenda 2008 – 2012 includes three particular “test-beds”: The first and most important programme concerns the application and use of genomics. But it cannot be successfully fleshed out if we fail to address issues of agenda setting and of communication. Therefore, the second programme concerns the genomics agenda (how do scientific and societal transformations shape this agenda?), while the third programme concerns information, education and communication about genomics:

I. Genomics Applications
II. Genomics Agenda
III. Genomics Education and communication

Programme I Genomics applications
Genomics science and technology will lead to the development of new applications and products such as diagnostic tests and nutraceuticals, novel consumer products and food, alternative energy resources or new generations of fertilisers. These developments first of all pose the question to what extent innovative genomics applications and goods are deemed necessary or desirable. What are the benefits of increased testing opportunities? What do different parties – e.g. citizens, professionals, policy-makers – perceive as desirable?

Secondly, what are the conditions and prospects for both current and future genomics applications to become embedded in society? How should we govern innovative applications, particularly if such applications do not match with existing rules, regulations and (evaluation) practices? This requires more than simply “adapting” regulation and legislation. Rather, genomics challenges familiar notions and concepts such as risk, health, environment and “natural” and calls for new constellations to assess these implications. The development of nutraceuticals, for example, situated at the intersection between
medicine and life-style (choice), nicely illustrates this point. While medicines are evaluated on the basis of their effect (does it work?), food-products are evaluated in terms of risks (will it cause harm?). A useful assessment of novel products requires not just a change of practices but a new ways of thinking about health, food and what is being valued in both.

Thirdly, innovative technologies pose the question what *effects* such applications have on the environment, on markets and on individual men and women. Will it still be useful or sensible to talk about “individual choices” of consumers, patients and citizens? To what extent will the DNA chip, the use of bio-markers in screening, bio-fuels and eco-genomics change our behaviours? The programme is divided in two themes: The first theme, *Changing practices and policies*, focuses on practices and institutions. What practices emerge as a result of the co-production of genomics and society? What is or should be the role of professionals, policy-makers, producers and legislators in this process? The second theme, *Identity and behaviour*, focuses on individuals and individual behaviour. How do individual patients, consumers and citizens deal with (the promises of) genomics applications?

Programme II. Genomics agenda

Society, we have argued, will increasingly be confronted with new genomics applications. These applications concern medical tests, industrial products, food products and the environment for example. What applications will see the light and will be successfully used not only depends on “internal” scientific developments. The agenda of genomics research is shaped by a complex set of factors such as funding possibilities (e.g. 300 million for genomics research), the organisation of knowledge production (e.g. the emergence of new fields such as bio-informatics and metabolomics), institutional frameworks (e.g. a ban on human stem cells), public opinion (e.g. the GM-debate) and the role of promises and expectations in the public domain (e.g. recent commotion about the “diet-pill”). This programme focuses on the genomics agenda: what shapes this agenda and what makes this agenda “societally” robust?

Two themes will be further explored. The first theme, *Transformation of knowledge production*, studies the transformation of scientific practices and the role of genomics as a converging and enabling technology. Genomics has been described as the “informatisation” of life. Large amounts of bio-information become available in electronic formats for researcher communities worldwide. What consequences does this paradigm change within the life-sciences have for the expected applications? The second theme, *Knowledge & benefits*, focuses on ownership, benefits and private/public constellations. How is bio-information produced and exchanged? Moreover, governments, funding agencies and research institutes are developing ways for reimbursing their investments in genomics as a “big science” phenomenon. How will societies benefit from their research investments?
Programme III Genomics Education and Communication

Citizens, patients, consumers and professionals play a pivotal role both in discussions on genomics science and technology and in the acceptance and use of new genomics applications. A critical reflection on the meaning and uses of genomics applications requires knowledge and information about genomics. Preparing ourselves - and our societies – for the issues that genomics will raise, both now and in the future, requires information, communication and education. It will enable citizens, researchers, professionals and policy-makers to critically assess the implications and uses of genomics.

Our ambition to combine research with societal interaction will be most prominent in this programme. It is divided into two themes. The first theme focuses on New forms of interaction. This includes organising as well as reflecting on new forms of public information, discussion, debate and dialogue. The second theme focuses on Education and Expertise. It includes organisation of and reflection on a series of education activities for young people, scientists, citizens and professionals. Thus, both themes focus on the one hand on the development of public interaction and education activities, and on the other hand on the evaluation and improvement of these interactions, based on assessments of effect, efficiency, impact and costs.

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<td>• Consumer choices &amp; consumer behaviour</td>
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<td>II. Genomics Agenda</td>
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<td>III. Genomics Education and</td>
<td>New forms of public interaction</td>
<td>• Public debate</td>
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<td>Communication</td>
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<td>• Empowering patients, consumers and citizens</td>
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<td>• Educating young people and (young) scientists</td>
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Table 1: Programmes, Themes & Topics
These programmes organise our domain, but they must not be seen as “compartments” separated from one another by fixed boundaries. Rather, they remain closely connected, and in various ways activities in one programme can and will be made relevant for activities in the other two. Some projects explicitly build on the results of previous efforts, as the ambition to understand and improve the conditions for embedding genomics often calls for sustained efforts to ameliorate practices, update policies and inform important stakeholders.

The following paragraphs describe the three programmes in more detail. As each programme combines research and interaction, the programme describes both societal activities that are accompanied by research and research projects that include some form of societal interaction. After a short introduction of each of the six themes the text provides concise descriptions of research projects and activities. Research projects will be described in terms of question, background and deliverables, societal interactions in terms of activities, background and deliverables. Also the project manager, the organisational setting, the amount of fte’s available and the duration of the project are indicated.

Since genomics is a dynamic field in terms of pace and scope it is hard if not impossible to predict what will be important issues and themes in the public and policy arena in the next few months or years. These might be converging technologies, IP policies or genetic screening for example. Thus, although it is important to develop a focussed and coherent agenda, it is also crucial to remain responsive to new and unexpected developments and emerging issues (in research, policy or society). We therefore have reserved 12% of the overall budget for future plans and developments. The programme committee (chapter 8) will develop the focus and content of these activities.

**Programme I. Theme 1: Changing practices and policies.**

The development of genomics applications and use calls for “genomics governance”. Governance basically refers to the ways in which genomics research is “governed”, that is: made possible, developed, monitored, applied and modified in the context of contemporary knowledge societies. “Good governance” starts from the idea that governance is participatory, consensus oriented, accountable, transparent, responsive, effective and efficient, equitable, inclusive and law-abiding.

Whereas “genomics sceptics” are concerned that the available tools for monitoring and control will prove inadequate to address the novel risks genomics research entails, ranging from genetic discrimination to the creation of new organisms, genomics “believers” warn against regulatory inertia and cultural technophobia. While sceptics are concerned that genomics will reinforce a deterministic understanding of life and of ourselves (Lippman 1992, Nelkin & Lindee 1995), optimists argue that genomics information will empower individuals to manage their own health condition, and will provide patients and consumers with medicines and food products tailored to their genomic profiles. In the light of
these diverging expectations, genomics has become an important topic for governance (Gottweis 1998, 2005). How can genomics be developed in such a way that its outcomes are tailored to genuine societal interests while societal risks are adequately addressed?

The programme will compare a number of current and future applications. One of these applications is the development of new genetic tests and possibilities for screening. The recent extension of the Dutch newborn screening programme (heel-prick), from 3 to 17 diseases, can serve as exemplary case for future applications. It has been anything but a smooth process. What can be learned from the experiences of policy-makers, professionals and parents in this respect?

With respect to future applications we will investigate how genomics and society co-evolve: how do new technologies shape new practices and vice versa? Genomics applications raise new (ethical) questions and ask for different institutions to evaluate and regulate the use of such applications. This not only calls for reflection, it also requires action in political and policy settings. Bridging the gap between policy, science and the public is an important issue of concern.

### Implications and applications: the embedding of genomics

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<tr>
<th>1.1a</th>
<th>Evaluation of the Heel-prick</th>
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<tr>
<td><strong>Question:</strong></td>
<td>what can be learned from the recent extension of the newborn screening programme from 3 to 17 diseases? <strong>Background:</strong> the current extension of the newborn screening programme serves as an example for the future when genomics technologies will enable the identification of many more treatable conditions for which screening is available, either as neonatal tests or tests that take place later in life (adulthood). What are the experiences of parents, policy-makers and professionals? How to organise future testing possibilities? <strong>Deliverable:</strong> Inventory of public and professional concerns, knowledge and attitudes; Identification of good practices for introducing new forms of genetic screening.</td>
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<tr>
<td>CMSB – Dr. Symone Detmar – in collaboration with NMC, National Institute for Health &amp; Environment – 1.0 fte; 24 months</td>
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<th>1.1b</th>
<th>Screening for Haemoglobinopathy</th>
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<td><strong>Questions:</strong></td>
<td>what can be learned from the recent introduction of haemoglobinopathy (HbP) testing in the Netherlands? <strong>Background:</strong> As HbP mainly occurs in specific ethnic communities, the vision of stakeholders in migrant communities on the use of genetic screening for HbP for reproductive choices needs to be explored (religious leaders, youth workers, health care workers). What is the role and responsibility of GPs, midwives, youth care or prevention initiatives? <strong>Deliverables:</strong> Inventory of opinion of stakeholders of migrant communities; Agenda for governance of future testing and screening options.</td>
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<tr>
<td>CMSB — Dr AMC Plass - in collaboration with NMC, patient organisation (Oscar) and Erfocentrum – 1.0 fte; 48 months</td>
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### I.1c Legal framework for the implementation of new genetic screening/testing possibilities

**Question:** What is the appropriate legal framework needed for large scale applications of genomics in the domain of disease/prevention screening?

**Background:** The prospect of an increasing number of new screening programmes calls for an assessment of current legislation, such as the law on population screening (WBO) or the law that defines the relationship between patients and carers (WGBO). **Deliverable:** Roadmap for developing an appropriate legal framework for new genomics applications (health domain).

**CMSB – Prof. A. Hendriks- 1.0 fte; 48 months**

### I.1d Learning from the past. Implementation and use of genomics knowledge

**Question:** What can be learned from past experiences concerning the implementation of new genomics knowledge?

**Background 1:** Laboratory scientists, clinicians and ELSA researchers all have valuable experiences concerning genomics communication but do not necessarily share these very often. This project will bring these different groups together. **Deliverable 1:** Setting the agenda for future interaction and communication of science and society.

**Background 2:** Many industrial products and patents will never be introduced on the market. **Deliverable 2:** Inventory of the lessons and hurdles of innovation processes; Identification of good practices of innovation.

**Background 3:** The gap between high tech production methods and consumer preferences for more natural products potentially leads to negative attitudes towards these high tech production methods. How can this be understood and addressed? **Deliverable 3:** Roadmap for the introduction and management of plant genomics products.

**CMSB – Prof. Dr. Jos van den Broek – 1 fte; 18 months**

**Kluiver Centre – Dr. Patricia Osseweijer - 1 fte; 48 months**

**CBSG - Prof. Dr Bart Gremmen- 1 fte; 48 months**

### I.1e Future testing of multifactorial diseases

**Question:** What are the ethical, legal and social issues relevant in multiple genetic testing for complex diseases?

**Background:** Multifactorial diseases such as type 2 diabetes, osteoporosis, and cardiovascular disease are caused by a complex interplay of genetic and non-genetic factors, each of which entails a minor increase in the risk of disease. However, to assess these tests, we use values and measures that are related to monogenetic disorders. But, the predictive value of multiple genetic tests and the inheritance of genomic profiles is lower than in the case of monogenic diseases. **Deliverables:** Inventory of ethical, legal and social issues concerning multiple genetic testing; Tool for evaluating these tests.

**CMSB – Dr Cecile Janssens – 1 fte; 12 months (1 additional fte funded by CMSB)**

### Government arrangements concerning new (technology) practices

### I.1f DNA databanks

**Question:** How do medical, forensic and commercial bio-banks shape and transform research practices, criminal law practice and the consumer health market?

**Background:** The storage of tissue, blood and information in medical, forensic and commercial databases challenges the ways in which we evaluate the use and necessity of medical research, forensic practices and the promises of stem-cell research for example. Of particular importance are notions concerning privacy, information, ownership, blame and bodily integrity. **Deliverable:** Agenda for the future government of DNA databanks.

**Rijksuniversiteit Groningen – Dr Hans Harbers – 1 fte; 24 months.**

**Universiteit van Amsterdam – Dr Amade M’Charek - in collaboration with Forensics Genetics Consortium Netherlands and Rathenau Institute – 1 fte; 24 months.**
### I.1g Governance of Prevention

**Question:** how should preventive genomics technologies be governed?

**Background:** Genomics applications will lead to a further expansion of preventive technologies concerning food, health, safety, and the environment. Governments tend to emphasize the benefit of prevention but prevention may include a number of tensions such as between public and private responsibilities; between risk and precaution; between have’s and have-nots and between today’s information and future hopes. **Deliverables:** Critical analyses of preventive genomic technologies; Agenda for future governance.

University & Project manager: to be assigned - 1 fte; 48 months

### I.1h Patient participation in genomics: shaping policy and research.

**Question:** to what extent do patients and patient organizations influence the governance of new genomics technologies?

**Background:** It is often claimed that patients and patient organizations are increasingly involved in agenda setting processes concerning the development and use of new genomics applications. The contribution of patients, it is often said, is unique as patients experience what it means to be ill and to live with a certain disorder or disease. **Deliverable:** Agenda for future patient participation.

CSG – Dr. Annemiek Nelis – In collaboration with VSOP - 1 fte; 48 months

### Reducing the gap between science and policy.

#### I.1i Toxicogenomics: acceptance and implementation of genomics based alternatives.

**Question:** How to align research, policy development and public debate for developing genomics-based alternatives to animal testing?

**Background:** Toxicogenomics research may significantly reduce the number of animals used in scientific research. It opens up possibilities for developing reliable in vitro and in silico (bioinformatics-based) models as alternatives to using animals in vivo. Implementation and acceptance of these tools may be hampered by current legislation and policy bodies. This project studies the gap between science, policy and public discourse, building on policy-initiatives already undertaken by the toxicogenomics consortium. **Deliverable:** Tools for ethical assessment of alternatives to animal testing; Guidelines for assessment on programme level (as opposed to project level).

CSG – Prof. Dr. Hub Zwart/Dr. Annemiek Nelis – In collaboration with NTC and the Dierenbescherming. 1 fte; 48 months

#### I.1j Viral genomics: Preventive strategies for novel respiratory virus infections

**Question:** How to bridge the gap between viral genomics, health policy and public discourse?

**Background:** Developments such as the increase of global mobility and climate change create risks for new infectious diseases and entail new challenges for viral genomics, notably in terms of respiratory infections. Are we heading for an influenza pandemic? Are these concerns phobic or realistic? And should the latter be the case: are we (the public, policy makers, GPs, researchers, etc.) ready for such an event? The project makes use of policy-initiatives that are already undertaken by the viral genomics research community. **Deliverable:** Roadmap towards a viral genomics policy.

CSG – Prof. Dr Hub Zwart/Dr Annemiek Nelis – in collaboration with VIRGO Consortium – 1 fte; 48 months

#### I.1k Informing parliamentary debate

**Activity:** organisation of projects to explore contentious issues with publics and professionals with the aim to inform Dutch Parliament. **Potential issues:** genetic screening (up-date of the citizens jury of 1993); forensic science (linking with EU project INES), influenza or alternatives for animal testing.

To be developed with Rathenau Institute – 0.1 fte; 24 months
Programme I. Theme 2: Identity and Behaviour

In the future, more and more information about individual genomes will become available. It is expected that in a not so distant future, genomics technologies will be used to sequence the genome of individuals. Consequently, individuals may receive information about their future health status, the health of their progeny, the most suitable diet and the most effective medication. Individuals may be falsely assured about their health status or they may be “empowered” to manage their own health and postpone health problems occurring later in life. How desirable are genetic testing and genetic screening? What are the perceived advantages, risks and hurdles?

Genomics information and applications bear an effect on and concerns not only human health but also individual behaviour. Knowledge about the DNA of individuals, plants or micro-organisms may affect or change the images we have of ourselves as patients, consumers or citizens. Building on the results of a number of earlier projects, this theme elaborates how genomics shapes identity. And how does the ‘genomics identity’ affect professional, public and individual responsibilities?

Genomics not only applies to genetic testing and genetic screening. Whether functional foods, bio-fuels, over-the-counter genetic tests or genomics-based food products will be used, depends to a large extent on the behaviour of (individual) consumers. European consumers have shown reluctance to accept GM-food. It is questionable whether and under what circumstances they are willing and interested to buy tasty tomato’s that are created with the help of genomics. Similar questions can be raised with regard to bio-fuels and enhanced food products that claim to respectively improve the level of sustainability and health. A further understanding of the behaviour, knowledge and values of consumers is necessary to understand and foresee the public responses to genomics, to align the genomics agenda with consumer preferences and to increase the likelihood of particular genomics applications to survive on the market.

<table>
<thead>
<tr>
<th>Genomics applications: a desirable test?</th>
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<tr>
<td>1.2a The societal demand for new genetic tests.</td>
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<td><strong>Activity:</strong> A series of virtual and real-life polls and dialogues with patients, pregnant women, parents of newborns and representatives of the general public. <strong>Question:</strong> are new genetic tests seen as desirable, comprehensible and applicable? <strong>Deliverable:</strong> Inventory of views and arguments concerning genetic testing; Evaluation of interaction and communication with women, parents and members of the public.</td>
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<td>CSG – Dr. Annemiek Nelis - in collaboration with Erfocentrum and NMC – 0.1 fte; 48 months</td>
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<td>Activity</td>
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<tr>
<td>A series of virtual and real-life polls and dialogues concerning Celiac disease.</td>
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<td>The societal demand for genetic screening</td>
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<td>Behavioural Genomics</td>
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<td>Genomic Identities &amp; human enhancement.</td>
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### Consumer behaviour

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<th>1.2i</th>
<th><strong>Consumer and Consumer Behavior</strong></th>
<th><strong>Question:</strong> what are consumer preferences concerning high-tech food such as genomic tomatoes and potatoes? <strong>Background:</strong> Consumer behaviour often is tested in particular contexts such as through surveys or questionnaires. This study focuses on the actual behaviour of consumers at home (preparing meals, cooking etc.) and while eating out. What role do concepts such as “organic food”, safety and sustainability for example have in the actual behaviour of consumers concerning genomics products? <strong>Deliverable:</strong> Contribute to agenda setting for plant genomics research.</th>
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**University of Maastricht – Prof. Dr Guido de Wert/Dr W. Dondorp- 1 fte 24 months.**

**Ageing consortium - Prof. Dr Inez de Beaufort- 1 fte; 24 months**

**CMSB – Prof. Frank Snoek – 2.0 fte; 24 and 48 months**

**CBSG – Prof. Dr Bart Gremmen – in collaboration with “The Restaurant of the Future” - 2 fte; 48 months**
Programme II. Theme 1: Transformation of knowledge production

The genomics agenda first of all is shaped by transformations of knowledge production. The Human Genome Project (HGP) symbolises the emergence of genomics as a new techno-scientific field (IHGSC 2001, 2004). In contrast to “traditional” genetics and biotechnology, and depending on evolving technologies for high throughput biochemistry and bioinformatics, genomics opts for a whole genome-oriented, rather than for a single gene-oriented approach. It has resulted in a steady stream of ever-larger and more complex genomic data sets, thus transforming the study of virtually all forms of life. In other words, genomics is not a particular branch of biology, nor simply a set of research tools for high throughput analysis. Rather, it is transforming the ways in which research in the life sciences is done (Collins et al 2003).

In various research fields, such as ecology, biomedicine and toxicology, genomics has provided researchers with new research tools and strategies that allow them to reframe and redefine some of the basic questions concerning living nature. Being a “converging field”, genomics brings together large numbers of researchers from various backgrounds. As a result, research is done on a much larger scale than in the past and in a more interdisciplinary manner. Initially, the focus was on sequencing the genomes of model organisms (worm, fly, plant, mouse and man) but by now much of the research has entered the post-sequencing phase, and this involves a shift from structural genomics (sequencing genomes), to functional genomics (understanding genomes) and related areas such as proteomics and metabolomics.

Expectations about genomics applications emerge in different forms and formats. Scientists, media, ELSA-researchers, policy makers, story-writers and representatives from industry all make promising claims about genomics, paint interesting future scenarios and organise plots and pilots that, eventually, may become irreversible. The development of personalised medicine, personalised diets, sustainable and renewable energy, tasty tomatoes and “tailored” forms of fertilisers emerge in stories, policy views and innovative networks. How do promises, expectations and scenarios help to shape future applications? The former not only describe possible futures, they actively contribute to the shaping of these future by mobilising resources, time and energy of research groups and stakeholders such as funding agencies and patient or consumer organisations (Brown & Micheal 2003).12 ELSA genomics research itself plays an active role. It questions, but also amplifies these promises.

12 The NGI initiative is a good example, producing great expectations and mobilising, on the basis of these promises, resources and researchers to fulfil them.
**Transformation of knowledge practices: implications for future use**

**II.1a Genomics profile: the bioinformation society**

**Question:** What is the role of genomics in the “informatisation” of life and of bioinformation in the genomics paradigm? What new roles and responsibilities does this imply for researchers (as producers and users of bioinformation data)?

**Background:** Genomics as a converging and enabling field symbolises increase in scale, global interdisciplinarity and exchange in the context of international networks. Notably, it is a convergence of molecular and computational approaches. Biobanks are emerging as genomics’ principal research tool.

**Deliverables:** Inventory of strategies for agenda setting; Guidelines for bio-information exchange; (3) Roadmap for empowering bioethics to address macro-issues of bio-information management.

**CSG - Prof. Dr. Hub Zwart – In collaboration with NBIC – 2.2 fte; 24 – 48 months**

**II.1b Societal profile of ecogenomics as a “new synthesis”**

**Questions:** How to assess the societal profile and prospects of ecogenomics?

**Background:** Ecogenomics as a converging field is said to represent a new paradigm and revolution in the life sciences, a synthesis of molecular (“reductionist”) and ecological (“holistic”) approaches. This “new synthesis” implies a new vision of nature, new possibilities for technological interactions with nature, more responsive to nature’s potentials, opening up possibilities for fine-grained, nature-friendly and sustainable applications.

**Deliverables:** Roadmap for a socially robust ecogenomics agenda; Tools for framing anticipatory debates; Inventory of societal implications and promises in various practices.

**CSG - Prof. Dr. Hub Zwart – In collaboration with the Ecogenomics Consortium, the Ecogenomics Platform and Prof. Dr. John Dupré (Egenis)– 1.2 fte; 48 months**

**Genomics knowledge: promises, expectations and future scenario's**

**II.1c Nutrigenomics practice beyond the laboratory.**

**Question:** How do health claims concerning nutrigenomics emerge in settings outside the laboratory and how do they effect the (future) development of genomics?

**Background:** Nutrigenomics, perhaps more than any other genomics application, is surrounded by promises and claims (“Health is the future of nutrition”). Such claims generally act as sale booster to promote new products. However, health claims are not made in laboratories. They emerge in boundary zones between (inter)national regulations, pilot studies, experimental knowledge, commercial strategies, editorials in scientific journals and reports by the media.

**Deliverables:** Guidelines for assessing health claims.

**CSG – Dr. Annemiek Nelis / Prof. Dr. Hub Zwart – In collaboration with Nutrigenomics consortium – 1 fte; 24 months**

**II.1d The changing innovation system in the area of genomics**

**Question:** How do new genomics applications (such as bio-markers and diagnostic tests) affect institutional innovation?

**Background:** Genomics involves significant changes not only of research networks but also of the various ways in which genomic knowledge and technologies are embedded in health care practices. Hospital-based networks of researchers, clinicians and funding bodies have always been pivotal in the creation of genetic knowledge and its introduction in clinical practice. **Deliverable:** Roadmap for institutional embedding of genomics.

**University of Twente - Dr. D. Stemerding – 1.0 fte; 24 months**
II.1e  Anticipatory novels as test-beds for genomics futures

**Question:** In what ways may literary sources contribute to our ability to anticipate and critically assess the genomics future? **Background:** Research-based novels may be read as literary experiments or future scenarios, as efforts to flesh out what the development of particular technologies may bring to society. Novels may function as resources for analysing the future potentials (and potential futures) of genomics, as extrapolations of laboratory developments to real-life settings. **Deliverable:** developing tools for using genres of imagination in public debate and policy development.

CSG – Prof. Dr. Hub Zwart - 1.0 fte; 48 months
University of Maastricht – 1.0 fte; 24 months

II.1f  Future scenario’s or “innovation journeys” in public health genomics

**Question:** How can scenario studies facilitate the development of future uses of genomics knowledge for a number of common disorders such as diabetes, arthritis, Alzheimer disease, cancer, asthma and multiple sclerosis? **Background:** Building on the results of current interactive scenario studies, socio-technical scenario construction will be used as a tool to explore particular “innovation journeys” in the field of genomics. **Deliverables:** Tools for assessing and developing prevention oriented practices in public health genomics.

University of Twente – Dr. D. Stemerding – 1.0 fte; 48 months

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**Programme II. Theme 2: Knowledge and Benefits**

Genomics science and technology is a global enterprise. The local knowledge of indigenous people in the Andes region about wild tomato species, for example, plays a key role in the identification of genetic materials for commercial uses. To what extent do local stakeholders profit from commercial developments? How to guarantee that they will profit fairly from the benefits of genomics developments?

It is as yet unclear to what extent genomics reduces or reinforces global differences in terms of power, affluence and participation. According to the WHO, genomics knowledge is most relevant to developing countries, but these countries do not always profit from the development of this knowledge (WHO 2002, Thorsteindottir et al 2003). At the same time, the life sciences are booming in countries such as India and the Far East. The effect of the genomics “industry” on geo-political relations clearly is an issue for concern and study. Who, in other words, profits from genomics knowledge?

Knowledge production, by implication, produces and transforms power relations. Genomics is a technology with great innovative potential as it promises to produce a *better* world for all. However, different interests may be served at different moments in time. It is important therefore to ensure that the genomics agenda matches the needs of society and does so without causing harm, damage or unnecessary risks to individuals, biodiversity and the environment. To ensure that the genomics agenda is relevant for society and addresses the needs of (particular) societal groups, a critical assessment of this agenda is called for.
### Globalisation, ownership and public-private interactions

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<thead>
<tr>
<th>II.2a</th>
<th>Towards a fair and global-local just IPR (Patenting) system for genomics</th>
<th><strong>Question:</strong> How to reduce the global genomics divide between rich and poor in terms of access to knowledge? <strong>Background:</strong> Whereas patenting systems have contributed to the growth of science, it becomes increasingly clear to international actors such as FAO and NGO’s that the existing patenting system is seriously flawed with respect to global public goods, local knowledge and the use of resources. <strong>Deliverable:</strong> Tools for assessing new proposals for reducing the genomics divide.</th>
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<td>Wageningen University &amp; Research Centre (WUR) - Prof. Dr Michiel Korthals – 1.0 fte; 48 months</td>
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<td>II.2b</td>
<td>Public private partnerships: genomics governance</td>
<td><strong>Question:</strong> To what extent will public-private consortia further the innovation process? <strong>Background:</strong> Like other “big science” projects such as nanotechnology and climate change, genomics is organised in large public/private consortia that are partly funded with public money. Besides assessing these projects in terms of “return on investment”, it is important to know what the mix of public and private funding adds to the innovation process in comparison to alternative funding strategies (e.g. open innovation or full-scale public funding). <strong>Deliverable:</strong> Comparative inventory of best practices for funding innovative research.</td>
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<td>University &amp; Project manager: to be assigned – 1.0 fte; 24 months</td>
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<td>II.2c</td>
<td>Giving the tomato back to the Andes: empowering local knowledge producers in developing countries</td>
<td><strong>Question:</strong> How to improve participation of local knowledge producers (e.g. farmers) in decision making processes concerning their own agricultural products and livelihood? <strong>Background:</strong> The Prediza project aims to use existing wild tomato species to develop sustainable production technologies that can be adopted by small local farmers in developing countries. <strong>Deliverable:</strong> Roadmap for empowering farmers for agenda-setting in developing countries.</td>
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<td>CBSG – Prof. Dr. Bart Gremmen – 1 fte; 48 months</td>
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### Setting the genomics agenda

| II.2d | Identifying issues for the Genomics Agenda (1): industrial genomics | **Question:** What are the potential opportunities and bottlenecks for sustainable production, regulation and global trading of industrial genomics products? **Methodology:** A number of landmark cases related to industrial genomics products, such as the issue of land-use for biomass production, will be discussed in three international expert meetings. **Deliverable:** Roadmap for improved public interaction and regulations, specifying the responsibilities of stakeholders involved. |
|  |  | Kluyver Centre – Dr. Patricia Osseweijer – 2.0 fte; 36 months |
| II.2e | Identifying issues for the Genomics Agenda (2): Plant Genomics | **Activity:** Involving stakeholders in the development and use of genomics in a timely and anticipatory manner. **Background:** In 2005, CBSG started a Societal Interface Group (SIG) with members coming from various societal backgrounds and networks in order to allow public voices to become audible (at a stage when they can still influence research priorities) and also as a test-bed for communication strategies of the CBSG. The project will organize SIG meetings and analyze the process, comparing it with alternative attempts to involve society in innovation. **Deliverable:** Develop and assess good practices for timely stakeholder involvement in agenda setting. |
|  |  | CSBG – Prof. Dr Bart Gremmen – Societal Interface Group |
### Programme III. Theme 1: New forms of public Interaction

CSG aims to improve the public debate on genomics. The public, however, often is portrayed by scientists, media and industry as emotional (as opposed to rational), ill-informed and ill-equipped to judge the potential benefits and risk of genomics science and technology. The values, ambitions and hopes of the general public are often presented in terms of binary options: either pro or against genomics.

The idea that critical responses to or even rejection of genomics would be avoided if the public was better educated, still seems to prevail among many scientists and representatives from industry. Many still believe that if the public would know more, the public would know better. However, social scientists have repeatedly shown that this approach, known as the ‘deficit model’, is far from valid. The public simply has different reasons, different values and different types of arguments to reject, distrust or simply ignore (genomics) science and technology developments. Besides, genomics is not something that people are for or against. Most people embrace for example new possibilities that genomics has to offer for medicine and disease-prevention while they are at the same time much more critical or sceptical about the development of genomics in the field of agriculture and food production.

To improve the public debate, the life-sciences are in need of a new ‘social contract’ (Lubchenco 1998) with society to align public concerns and public stakes with the potential benefits of genomics. This programme aims to inform and involve the public in an early stage of the development of genomics so that it can assess and anticipate future uses. This requires first of all a better understanding of the public.

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<tr>
<th>Activity</th>
<th>Setting the societal agenda for genomics. <strong>Background:</strong> In the past two years CSG has organised a panel of “societal experts” (artists, politicians, scientists, medical professionals, people from industry and journalists) to define “a Societal Agenda for Genomics”. Rather than taking genomics as a starting point, these discussions will start from the question “what are the societal tasks for the future?” CSG will continue this process of critically assessing the genomics agenda from a societal point of view, focusing on issues such as globalisation, eco-genomics and medical genomics. <strong>Deliverable:</strong> Agenda for genomics research tailored to addressing urgent societal issues.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>II.2f</strong> Setting the societal agenda for genomics</td>
<td>CSG – Drs Frans van Dam – in collaboration with public interest groups and ERASAGE partners – 0.3 fte; 60 months</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>How can upstream deliberations improve the fairness and societal potentials of research agendas? <strong>Background:</strong> Research priorities are framed by partners involved in agenda setting on micro, meso and macro levels. This involves problems of inclusion (e.g. representation of non-experts) and of differential framing. The extent to which stakeholders have a voice in setting research agendas often depends on value conflicts. Moreover long-term consultations on innovative processes require learning infrastructures for both scientists as others. First, this has implications for research ethics. <strong>Deliverable:</strong> Roadmap towards fairness in agenda setting; tools for addressing value conflicts in agenda setting.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>II.2g</strong> Upstream deliberations in genomics innovation</td>
<td>WUR - Prof. Dr Michiel Korthals – 1.0 fte; 24 months</td>
</tr>
</tbody>
</table>
reactions and responses to the (perceived) promises and risks of genomics science and technology. Secondly, this requires a better understanding of the different forms of interaction that the public appreciates. While ten to fifteen years ago much discussion and debate took place in smoky cafés or similar venues, today the new media have opened a range of possibilities that allow for much larger and much more frequent interactions. These new types of interaction deserve to be tested, evaluated and explored.

<table>
<thead>
<tr>
<th>Past and current debates</th>
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<tbody>
<tr>
<td><strong>III.1a</strong></td>
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<tr>
<td>Learning from the past: debates on genetics/genomics.</td>
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<tr>
<td><strong>III.1b</strong></td>
</tr>
<tr>
<td>Public voices in life sciences</td>
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</tbody>
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<table>
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<tr>
<th>New modes of interaction</th>
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<tbody>
<tr>
<td><strong>III.1c DNA Dialogues</strong></td>
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<tr>
<td>Ageing</td>
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<tr>
<td>Animal testing</td>
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<tr>
<td>DNA-Databases</td>
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<tr>
<td>Food or Fuel?</td>
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<tr>
<td>DNA Forensics</td>
</tr>
<tr>
<td>Genetic Screening</td>
</tr>
<tr>
<td>And more…</td>
</tr>
</tbody>
</table>

CSG – Dr Annemiek Nelis / Prof. Dr. Hub Zwart – In collaboration with Prof. Dr. Brian Wynne (CESAGen UK) – 0.25 fte; 48 months

CSG – Prof. Dr Bart Gremmen – 0.5 fte; 6 months

CSG – Drs Frans van Dam & Genomics Centres – 0.2 fte; 60 months
### III.1d
**New Modes of Interaction & Communication**

**Activity:** Using new interactive technologies for public communication and interaction (e.g. SMS-polls; web-logs and chat-rooms; HYVES, virtual worlds such as *Second Life*).  

**Background:** CSG organises, studies and evaluates Web-discussions as well as the use of performing arts and bio-art and documentaries. In the period 2008 – 2012 a number of new interactive approaches will be explored, tested and evaluated. While some of these options can already be identified as possible options, others will emerge in the years to come. **Question:** what are the impact and effects of novel interactive technologies on public communication, interaction and dialogue?  

**Deliverables:** Series of public discussions; Evaluation and identification of good practices for organising interactive discussions.

<table>
<thead>
<tr>
<th>Vrije Universiteit - prof. Dr Frans Meijman – 1.0 fte; 24 months.</th>
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</thead>
<tbody>
<tr>
<td>Kluyver Centre – Dr Patricia Osseweijer</td>
</tr>
<tr>
<td>CSG – Drs Frans van Dam &amp; Genomics Centres – 0.25 fte, 48 months.</td>
</tr>
</tbody>
</table>

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### Provision of information to patients, citizens and consumers

#### III.1e
**Information day for consumers, citizens or patients.**

**Activity:** Organisation of information days for cancer patients and their families. **Background:** the Cancer consortium organised a first successful event on March 10th 2007. During this event, the cancer genomics Marktplaza attracted more than 1,300 individuals and obtained substantial media attention. **Question:** How can visualisation contribute to a better understanding of current genomics information by patients and professionals? **Deliverables:** Two large-scale information days; Assessment and development of tools for using visual representations of genomics knowledge in clinical decision making.

| CGC – Prof. Dr. Arend Jan Waarlo – 0.7 fte; 48 months. |

#### III.1f
**Consumer information & Communication**

**Question:** How to communicate genomics knowledge and information to consumers? **Background:** Public discourses on genomics often refers to “GM food” and GM crop. When being asked, many consumers refuse GM products. However, when shopping, few consumers bother to be knowledgeable about the ingredients shown on the labels of products. How desirable is it to provide more and more in-depth information to consumers? **Deliverable:** Analyses and evaluation of consumer needs; Guidelines for professionals to communicate about genomics science.

| CBSG – Prof. Dr. Bart Gremmen – 2 fte; 48 months |

#### III.1g
**Visions of Genomics**

**Question:** How do visualisations of genomics shape the understanding and normative values that individuals ascribe to genomics? **Background:** it has been suggested that visualisations of genomics enhances the understanding of genomics knowledge and information and enriches public debates while avoiding polarised positions. One project focuses on patients and professionals, a second project looks at the “visions of nature” that patients associate with genomics information. **Deliverables:** evaluation of visualisation practices; Guidelines for improving these practices.

<table>
<thead>
<tr>
<th>CGC – Prof. Dr. Arend Jan Waarlo – 0.7 fte; 48 months.</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSG – Prof. Dr Hub Zwart – 0.2 fte; 60 months.</td>
</tr>
</tbody>
</table>

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13 Several organizations, such as the broadcast corporation BNN and ABN-AMRO for example, have recently opened a branch in second life. See www.secondlife.com.
### Transformation of behavior

<table>
<thead>
<tr>
<th>III.1h</th>
<th>Social responsibility through upstream involvement in development and use of genomics applications</th>
</tr>
</thead>
</table>
| **Question:** What knowledge, emotions and visions motivate people to change their habits for example to reduce energy and change their attitudes in food choice?  
**Background:** The development of (pro-active) communication strategies requires an understanding of the effectiveness of communication activities. This project focuses on the development of novel forms of interaction (such as the Three-E-model Entertainment, Emotion, Education).  
**Deliverable:** development of tools and guidelines for communication and communication strategies.  
**Kluyver Centre – Dr. Patricia Osseweijer – 1 fte; 48 months.** |

<table>
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<tr>
<th>III.1i</th>
<th>Public Survey</th>
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</table>
| **Activity:** Organisation of a large-scale public survey among the Dutch general public.  
**Background:** NGI and CSG have twice (2002, 2005) conducted a public survey to evaluate both knowledge and attitudes of the public towards genomics. This 2-year survey will be continued as it provides an excellent opportunity to follow the development of knowledge and attitudes in the general population.  
**Deliverables:** Web-based survey on public attitudes.  
**University of Twente – Dr Jan Gutteling.** |

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**Programme III. Theme 2: Education and Expertise**

It is a broadly shared idea that the involvement of patients, consumers and citizens in decisions on science and technology will lead to more inclusive, more democratic and more robust policies, - hence good governance. However, public participation presupposes that the public has knowledge and information about the subject at hand. This is crucial for a critical understanding and assessment of genomics and its applications. Education and the fostering of expertise about genomics is therefore an important component of our programme. In the next five years, the genomics centres will organise and coordinate a broad programme, thereby linking different networks and initiatives.

In the past few years, the Genomics Centres of CBSG, CMSB, CGC, Kluyver Centre and NBIC each have developed a “mobile DNA-lab” for upper-secondary education (*DNA-labs on the Road*). These labs have proven to be an excellent tool for education and the provision of information about genomics. The labs embody an interesting mix of knowledge-transformation, hands-on-experience with genomics science and illustrations of genomics applications. Each lab consists of 4 hours in total (2 hours hands-on work with scientists) and includes tutor-instructions for teachers and students. The Genomics Centres regard the DNA-labs as the starting point for a variety of public activities that will bring genomics closer to the public.

In the period 2008-2012, the Centres will develop a (common) virtual labs and embed the mobile labs in the science centres in the Netherlands. One lab will be developed and organized together with the Forensic Genetics Consortium and Science Museum Naturalis. Also, the Genomics Centres have

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approached the organisation of the science week (Foundation NCWT) with the offer to co-organise the 2008 Science Week around “In the genes” (*Het zit in de genen*).

The labs are anything but a stand-alone activity of the Genomics Centres. They are firmly embedded and linked to the website [www.watisgenomics.nl](http://www.watisgenomics.nl), a site with information for the general public and upper-level high school students. It contains both general lemmas and thematic issues. The site plays a pivotal role, both in informing the public about genomics and in the organisation of events, such as the mobile labs. In the near future, the site will provide more information, assignments and interactive tools for upper secondary school students. Also, the site will use more interactive tools (e.g. questionnaires) and listings of news and events. Last but not least, the site will provide more comprehensive basic theory and facts about genomics. Watisgenomics.nl is linked to and part of the “Virtueel kenniscentrum biotechnologie” of the Dutch Government, a portal that aims to improve access to information on genomics and biotechnology.

The Genomics Centres collectively are also responsible for *Imagine*. This is a school competition involving scientists, school students and the media in order to achieve tangible results in developing countries with the help of life science and biotechnology. Upper secondary school children join in this nation-wide competition to turn scientific proposals for the application of genomics technologies in developing countries into business plans. The five best groups are invited to present their business plans before a professional audience at an international conference. The best group wins the competition's grand prize: the realisation of their business plan and a visit to the country where the project will be actually carried out.

In the programme 2008-2012, the DNA labs, [www.watisgenomics](http://www.watisgenomics) and Imagine will be further embedded, developed and used in a number of public events that will be organised by CSG and the Genomics Centres. These may be the aforementioned science week but also a series of exhibitions and Festivals.

Last but not least, not only the public needs to be educated and informed about the developments within genomics, also genomics scientists, ELSA researchers, policy-makers and other professionals deserve attention. Genomics develops rapidly and generates new and unforeseen applications that require both reflection and use by scientists and professionals. Scientists have an important role to play in public interaction. Not only do we need good researchers, but also experts that are able to communicate and interact with broader audiences and stakeholders and who are well-prepared for this challenge.
## Empowerment of patients, consumers and citizens.

### III.2a Watisgenomics.nl

| Activity: | Website for upper secondary students and general public. |
| Background: | The website watisgenomics.nl was launched in 2005. The website is an initiative of CSG together with the other Genomics Centres. It offers information to a broad audience, in particular to upper secondary students and has recently been evaluated. With 13,000 hits a month, it is mainly focused on upper-secondary students and this focus should be strengthened. The site should provide more input for assignments while remaining of interest for other interested publics. |
| Deliverables: | 200,000 hits per year; 250 new articles; 15 thematic issues; 1000 news items; embedding in the science centres and the Virtual Knowledge Centre Biotechnology (VKB); Embedding in the new curriculum of upper secondary education. |

**Genomics Centres – Drs. Frans van Dam – 0.8 fte; 60 months**

### III.2b DNA Mobile Laboratories

| Activity: | Exploitation and development of 8 mobile DNA labs. |
| Background: | At the moment, five Genomics Centres have developed a Mobile DNA lab for secondary education. These labs have been one of the most successful communication activities of the Genomics Centres. Deliverables: 120,000 school children will have used the labs; Development of three new labs (Ecogenomics, Proteomics and Metabolomics); Development of virtual lab; International programme and exchange of labs; Embedding of the labs in the science centres; Courses for secondary school teachers; Courses for student-assistants; Embedding the labs, and genomics as such, in the biology curriculum and the new “Nature, Life and Technology” (NLT) course. |

**CSG, CMSB, CBSG, CGC, Kluyver, NBIC, Proteomics, Ecogenomics and Metabolomics – 1.6 fte; 60 months**

### III.2c Imagine

| Activity: | School competition concerning genomics and developing countries. |
| Background: | Imagine aims to encourage scientists in applying their expertise to pressing problems in developing countries and to increase young people’s involvement in global development issues. The potential for interesting a large audience in beneficial applications of genomics is great and will be further explored and exploited. Deliverable: Links with developing countries; Links with valorisation programmes of participating centres; Media attention; Documentary on national television; Book series on successful projects. |

**Genomic Centres & Kluyver Centre**

### III.2d Large Public Events:

| * Science week |
| * Interactive Science Exhibition |
| * Genomics Festivals |
| * Radio show |

**Activity:** Organisation of a number of large-scale Public Events. **Background:** Large public events such as those organised in collaboration with Science Museum NEMO and in the Art House LUX in Nijmegen have attracted enthusiastic audiences. The Centres aim to establish more of these events in order to prompt discussion and debate and to inform citizens about genomics. As a start of a whole series of events, the Centres have offered the organisation of the Science Seek to make “DNA” the topic for next year’s science week (p. 29). **Question:** what is the effect and impact of public events? **Background:** Events will be thoroughly assessed through surveys and small pilots. **Deliverable:** Series of events; Tools for organising dialogue, debate and communication.

**Genomics Centres – 1.2 fte; 60 months.**
### III.2e
**Forensic Science in Naturalis:**

**Activity:** Permanent interactive exhibition on Forensic science at science museum Naturalis.  **Background:** Forensic DNA research receives a lot of public attention, due to some well-known court cases and the popular TV series CSI. This area of genetics has been merging into daily life most rapidly, without much commotion or public debate. This seems to hold a major message: the clearer the public perceives the benefit the less debate. On the other hand this may also be the moment to take stock of this development. The information and education of the public concerning the actual precision in the light of advancing knowledge and technologies deserves serious attention. **Deliverable:** permanent interactive exhibition space on forensics and genomics (using a genomics lab as starting point).

Forensic Genetics Consortium Netherlands (FGCN)/ CSG- in collaboration with Naturalis Leiden – 0.2 fte; 12 months

### III.2f
**Education for (young) genomics scientists, ELSA researchers and professionals.**

#### III.2f
**Training and capacity building for young Genomics Scientists.**

**Activity:** training programme for young genomics researchers.  **Background:** Young scientists, before obtaining their PhD, should be familiar with and aware of the societal aspects of genomics. Training should include the following aspects: 1) societal aspects of genomics; 2) public communication (including media training), 3) career perspectives (outside the lab). From past experiences, we know that PhD training is most successful when it is embedded in established training and education programmes and more or less “tailor-made”. While some of our Centres already have a “society-programme” for PhD students and post-docs, others do not have such facilities available yet. **Deliverables:** Inventory of existing programmes and experiences; Training modules for genomics researchers.

GeNeYous & Genomic Centres – Prof. Dr. Arend Jan Waarlo & Drs. Terry Vrienhoek – 0,6 fte; 60 months.

#### III.2g
**Interdisciplinary training modules**

**Activity:** interdisciplinary training modules.  **Background:** a series of interdisciplinary events will be organised to bring together genomics scientists and ELSA researchers. **Deliverables:** Interdisciplinary modules for genomics and social scientists; Agenda for future interactions and events; International collaboration (for instance Marie Curie programmes)

Genomics Centres, CSG & GeNeYous – Dr. Annemiek Nelis & Drs Terry Vrienhoek. 0,2 fte; 60 months

#### III.2h
**ELSA Education**

**Activity:** training modules for ELSA genomics researchers.  **Background:** For a sustainable knowledge network of ELSA genomics, capacity building is crucial. Teaching modules concerning ELSA genomics developed by Genomics Centres will be further developed into a coherent programme. **Deliverables:** Bachelor modules for Communication studies and interdisciplinary studies; Communication courses; Summer schools (e.g. Amsterdam, Oxford); Open days; International collaboration

Genomics Centres - in collaboration with CESAGen, International School for Humanities & Social Science, University of Oxford.- 0,6 fte; 60 months
### III.2i - Educating Young people at pre-vocational school

**Activity & Question:** (how to) design suitable educational activities for pre-vocational schools. **Background:** About 60% of all secondary students attend a pre-vocational school. This school population is heterogeneous in terms of cognitive ability, learning style, ethnicity and culture. However, many educational professionals prefer to focus on other target groups they are more familiar with. As a consequence up to now little attention has been paid to involving pre-vocational students in the genomics information chain. **Deliverables:** Identifying ‘good practices’; Develop teaching modules for pre-vocational schools; Develop a hands-on lab for the science centres in the Netherlands.

**CGC - Prof. Arend Jan Waarlo – 1.0 fte; 48 months**

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### III.2j - Education of (future) Professionals

**Activity:** Developing teaching modules for genomics professionals. **Background:** Genomics is a fast developing field. Not only scientists and the public are in need of continuous education, also professionals lack knowledge of genomics that may (one day) be relevant for daily practices. Education modules days will be organised for oncology nurses (CGC) primary care workers (CMSB), (industrial) stakeholders, school teachers etc. **Deliverables:** Information days for oncology nurses; Training for school teachers; Personalised training modules (PIN/Accredidact) for primary health care workers (e.g. GP’s).

**CMSB, CGC, Kluyver Centre & CBSG. – in collaboration with professional organisations – total 0.6 fte; 60 months**

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15 VMBO: Voortgezet Middelbaar Beroeps Onderwijs
Programme IV Network Activities
Beside the three programmes, CSG also organises a number of activities that focus on the network itself and that aim to foster and strengthen the research community. In particular, this network will be fostered through the organisation of the exchange of knowledge. These activities will all be organised and developed by CSG itself.

<table>
<thead>
<tr>
<th>Strengthening the international ELSA genomics network</th>
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<tbody>
<tr>
<td><strong>IV.a</strong> International Conference ELSA Genomics</td>
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<tr>
<td><strong>IV.b</strong> EU projects coordinating actions and research</td>
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<tr>
<td><strong>IV.c</strong> Workshops and Seminars</td>
</tr>
<tr>
<td><strong>IV.d</strong> Newsletter &amp; communication</td>
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<tr>
<td><strong>IV.e</strong> Visiting Professorships</td>
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</tbody>
</table>

17 Cf. www.society-genomics.nl
Deliverables

| Deliverables |  
|---------------|-----------------------------------------------|
| Publications  | • 20 PhD Thesis’s  
|               | • 5 academic book publications  
|               | • 250 scientific articles  
|               | • 25 professional articles  
|               | • 50 articles in popular magazines, newspapers etc.  
| Watisgenomics.nl | • 50 articles from ELSA genomics researchers for watisgenomics.nl  
|               | • 200,000 hits on www.watisgenomics.nl per year  
|               | • 250 new articles, 15 new themes & 200 news items for watisgenomics.nl  
|               | • embedding of watisgenomics.nl in the science centers  
| DNA mobile labs & school education | • 120,000 school children using one of the mobile DNA labs  
|               | • development of 4 new mobile DNA-labs  
|               | • development of a Virtual Lab and a Hand-hold lab.  
|               | • embedding of the mobile DNA labs in the science centers, the new NTL curriculum and in a number of (breeding) companies.  
|               | • A permanent exhibition on Forensic DNA in Naturalis  
|               | • Annual school competition Imagine (producing book, press reports and documentary)  
|               | • embedding of genomics in the new biology curriculum  
| Teaching Modules & Courses for: | • Students at pre-vocational school level  
|               | • Bachelor & Master students  
|               | • Professionals (oncology nurses, GPs, primary care professionals, school teachers)  
|               | • PhD & Post-graduate students (genomics science and social science/humanities)  
| Public Events | • 10 large national public events (science week, festivals, radio shows)  
|               | • 2 large information days for patients  
|               | • 45 local public discussions and debates.  
|               | • 10 virtual public discussions and debates  
|               | • 30 professional and public workshops and other meetings  
| Policy Events | • 10 large policy events  
|               | • 10 policy briefs  
| Academic events | • 5 international conferences on the Societal Aspects of genomics  
|               | • 15 visits from national and international scholars  
|               | • 15 workshops for ELSA genomics researchers  

7 Composition of the Centre and its networks

Home Base

In the period 2008-2012, the Centre for Society and Genomics (CSG) coordinates and develops an (inter)national programme for societal research and interaction. The CSG management team will be the coordinator for both the NGI Genomics Centres and the Dutch ELSA community. CSG is located at the Department for Philosophy and Science Studies of the Faculty of Science, Radboud University Nijmegen.
It is part of the *Institute for Science, Innovation & Society* (ISIS), one of six research institutes of the Faculty of Science.

**Three Networks**

CSG coordinates three different networks. Firstly, it coordinates the societal activities of the *Genomics Centres* funded by NGI (table 2). Secondly, CSG coordinates the network of ELSA researchers in the Netherlands: the *ELSA-genomics network*. This network includes both participants in the MCG programme of NWO and researchers from current CSG projects. Thirdly, it coordinates and builds a local ELSA-research community at Radboud University and a platform of local genomics researchers for improving visibility and outreach. Research and educational activities of the Department of Philosophy and Science Studies are for the larger part focussed on genomics.

<table>
<thead>
<tr>
<th>Centres of Excellence</th>
<th>Innovative Clusters</th>
<th>Technology Centres</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centre for BioSystems Genomics (CBSG)</td>
<td>Ecogenomics Consortium</td>
<td>Netherlands Proteomics Centre (NPC)</td>
</tr>
<tr>
<td>Centre for Medical Systems Biology (CMSB)</td>
<td>Forensic Genetics Consortium</td>
<td>Netherlands Bioinformatics Centre (NBIC)</td>
</tr>
<tr>
<td>Kluyver Centre for Genomics of Industrial Fermentation (Kluyver Centre)</td>
<td>Netherlands (FGCN)</td>
<td>Netherlands Toxicogenomics Centre (NTC)</td>
</tr>
<tr>
<td>Cancer Genomics Centre (CGC)</td>
<td>Nutrigenomics Consortium</td>
<td>Netherlands Metabolomics Centre (NMC).</td>
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<tr>
<td>Healthy Ageing (NCHA)</td>
<td>Celiac Disease Consortium (CDC)</td>
<td>VIRGO Consortium</td>
</tr>
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Table 2, list of formal partners of CSG from NGI’s genomics network.

With these three networks, CSG aims to involve a substantial number of key experts as well as a substantial number of universities. Appendix 2 maps the (university) locations of the different groups represented in our networks. To coordinate the three networks for societal research and societal interaction, CSG has appointed six *principal investigators (PIs)* representing six different universities (table 3). During the past 2,5 years, they have developed substantial research programmes in the field of ELSA genomics and are leading figures for each of their disciplines (STS, Philosophy, Ethics, Community Genetics, Science Communication and Science Education). Together with the management team they are responsible for defining and maintaining the synergy and focus of the research programme. Each PI is responsible for one of the six themes of the programme (chapter 8). Three of these six PI’s have direct links to one of the Genomics Centres of NGI.

<table>
<thead>
<tr>
<th>Prof. Dr. Martina Cornel (VUMC / CMSB)</th>
<th>Prof. Dr Guido de Wert (UM)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Dirk Stemerding (UT)</td>
<td>Prof. Dr Michiel Korthals (WUR)</td>
</tr>
<tr>
<td>Dr Patricia Osseweijer (TUD / Kluyver Centre)</td>
<td>Prof. Dr Arend Jan Waarlo (UU / CGC)</td>
</tr>
</tbody>
</table>

Table 3: list of PI’s. See appendix 2 for CVs of each of the PI’s
In addition to these networks, CSG also has a number of strategic partnerships with public interest groups and organisations that foster and/or organise public interaction, public communication and policy engagements.

Finally, CSG is committed to expanding and strengthening its international networks, both on a European and on a global level, through joint activities (such as EU projects, conferences, dissemination) and exchange (such as visiting scholars, newsletter, education). FP7 offers good prospects and opportunities for continuing and up-scaling our activities. Our involvement in ERASAGE and other European initiatives places us in a most promising position to achieve these goals.

8. Management and organisation

To fulfil our aims and ambitions and to create a sustainable knowledge network, the organisation- and management structure of CSG will guarantee:

- Management of a coherent, focussed programme
- Strong collaboration with Genomic Centres
- Strong collaboration with ELSA researchers (CSG as platform)
- Further development of international networks
- Strong embedding of CSG at Radboud University

The organisation of CSG is based on the three programmes described above (Genomics Applications, Genomics Agenda and Genomics Education and Communication), subdivided into six themes. Every programme is managed by a Programme Manager, and every theme by a Principal Investigator (PI). The core of CSG thus consists of three teams involving one programme manager and two PIs.

Moreover, every programme combines research and interaction. All three teams have a joint responsibility to develop a coherent set of activities in accordance with the general programme and profile of CSG and the financial framework set out by the management team. While the three programme managers are positioned at Radboud University, the PIs are prominent ELSA experts. Besides prominent research groups, they represent relevant disciplines and collaborate with Genomics Centres (as was already outlines above). Their names and affiliations are shown below (CVs in Appendix 3).
Dr. Annemiek Nelis is manager of Programme 1 (Genomics applications). Prof. Dr. Hub Zwart is manager of Programme 2 (Genomics agenda). A programme manager for Programme 3 (Education and Communication) will be appointed. This will be a non-academic with a high-public profile and expertise in the field of education, industrial relations, arts or public debate. Together, Programme Managers and Principal Investigators form the Programme Committee, responsible for the annual update of the overall programme.

The Programme Managers, together with the Business Director, constitute the CSG management team. Thus, programme managers are linking pins between the scientific and managerial level. As scientific director, Hub Zwart will chair the programme committee. The management team will be based at the RU in Nijmegen.
As general director, Annemiek Nelis is responsible for all CSG activities. She is the chair of the management team. Hub Zwart is scientific director and responsible for the scientific quality of the programme, and (as chair of the department and director of the research institute ISIS) also for the embedding of CSG at the Radboud University and the Faculty of Science. Business tasks (financial management and organisation) are the responsibility of the General Director and will be delegated to the business director. Managerial tasks (monitoring, planning and control) are handled by the management team. All members of the management team are based at Radboud University. The management team determines the financial framework for the programme committee. It is supported by a staff bureau for finances and administration. Overall communication activities (public website, corporate communication, etc.) are also Nijmegen-based.

CSG’s international Scientific Advisory Board will assess the scientific quality and relevance of each research project. This committee consists of: Prof. Dr. George Gaskell (chair, London School of Economics), Prof. Dr. Ruth Chadwick (Cardiff, CESAGen), Prof. Dr. Herbert Gottweis (Vienna,
Department of Political Science) and two members yet to be appointed: a genomics expert of international renown and an international expert on genomics communication and/or education.

The Foundation CSG is the legal entity under which the Centre functions. The board of the foundation is based in Nijmegen. The supervisory board of the Foundation consists of the following persons: Prof. Dr. J van Eijndhoven (Erasmus University Rotterdam), Dr E. Meijer (Unilever), Prof. Dr. H. Thijssen (Radboud University), Prof. Dr. R.Hoppe (Twente University), Mr. M.Buchel (science museum NEMO). The CSG management reports to the supervisory board twice a year.

9. Breakdown of costs

Budget
The strategic plan CSGII aims at a total budget of 25 million €, 15 million € for research, 7 million € for societal interaction, 3 million € for organisation and management. All activities are financed on the basis of the NGI Strategic Plan. No matching is required. Yet, the Radboud University is strongly committed to CSG and will continue to support the activities of CSG. It will facilitate embedding CSG in the Radboud University both now and in the future and provide additional costs for the research time of the general director (0.4 fte), the scientific director (0.6 fte), the director communication and education (0.2) and the communication officer (0.2 fte). Also, the research efforts of researchers and assistant professors of the Department of Philosophy and Science Studies will be dedicated to genomics research (2.0 fte). The total matching of the RU amounts to 3.4 fte per year which is the equivalent of 410 K€ annually (2050 K€ in total for 5 years). Moreover, building on our results so far, substantial additional funding will be acquired through EU projects. This will become increasingly important. Indeed, building a solid infrastructure on the basis of NGI funding, resulting in a robust set of firmly embedded local and international activities and networks, will be of key importance for continuation of our activities after 2012. The breakdown of costs of the programme is presented in the following tables.

Costs have been calculated on the basis of core costs + 50% per 12 months\textsuperscript{18}:

\begin{itemize}
  \item PhD students $62.5 \text{ K€}$
  \item Support staff $75 \text{ K€}$
  \item Post-doc $100 \text{ K€}$
  \item Lecturer $100 \text{ K€}$
  \item Professor $150 \text{ K€}$
\end{itemize}

\textsuperscript{18} These are the budgets that are being used by the Radboud University. For some of the projects of the Centres of Excellence, slightly different budgets have been used.
<table>
<thead>
<tr>
<th>Nr</th>
<th>Project Title</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>Personnel</th>
<th>Facilities/</th>
<th>Total</th>
<th>Costs fte 5 yrs</th>
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<td>yrs</td>
<td>other costs</td>
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<td>Evaluation of the heelpick</td>
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<td></td>
<td>175</td>
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<td>100</td>
<td>100</td>
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<td></td>
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<td>175</td>
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<td>Legal Framework</td>
<td>80</td>
<td>100</td>
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<td></td>
<td></td>
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<td></td>
<td>200</td>
<td>4</td>
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<td>160</td>
<td>160</td>
<td>150</td>
<td>630</td>
<td>160</td>
<td>790</td>
<td>9,5</td>
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<td>Future testing of multifactorial diseases</td>
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<td>100</td>
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<td>1.1f</td>
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<td>120</td>
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<td>400</td>
<td>400</td>
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<td>1.1g</td>
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<td></td>
<td>80</td>
<td>120</td>
<td>120</td>
<td>80</td>
<td>400</td>
<td>400</td>
<td>4</td>
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<td>1.1h</td>
<td>Patient participation in genetics</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>50</td>
<td>250</td>
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<td>1.1i</td>
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<td>50</td>
<td>50</td>
<td>50</td>
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<td>1.1j</td>
<td>Viral genomics: preventive strategies</td>
<td>50</td>
<td>50</td>
<td>50</td>
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<td>50</td>
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</tr>
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<td>1.1k</td>
<td>Informing Parliamentary debate</td>
<td></td>
<td></td>
<td></td>
<td>40</td>
<td>40</td>
<td>40</td>
<td>20</td>
<td>100</td>
<td>120</td>
</tr>
<tr>
<td>1.1l</td>
<td>A conversation on Genomics</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>60</td>
<td></td>
<td>80</td>
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2.1a The societal demand for new genetic tests  
2.1b The societal demand for genetic screening  
2.1c Ageding  
2.1d Behavioural Genomics  
2.1e Genomic Identities & human enhancement  
2.1f Individualized choice in prenatal screening?  
2.1g Estimating Risk: Ageing & Longevity  
2.1h Tailored intervention strategies  
2.1i Consumer and consumer behavior  
2.2a Towards a fair and global-local just IPR system  
2.2b Public private partnerships  
2.2c Empowering local knowledge producers  
2.2d Identifying issues for the Genomics Agenda (1)  
2.2f Setting the societal agenda for genomics  
2.2g Upstream deliberations

3.1a Learning from the pas  
3.1b Public Voices in the life sciences.  
3.1c The DNA dialogues  
3.1d New Modes of Interaction  
3.1e Information days  
3.1f Consumer information & Communication  
3.1g Visions of Genomics  
3.1h Social responsibility  
3.1i Public Survey  
3.2a watusigenomics.nl  
3.2b DNA Mobile laboratories  
3.2c Imagine  
3.2d Large Public Events  
3.2e Forensic science in Naturalis  
3.2f Training and capacity building scientists  
3.2g Interdisciplinary training modules  
3.2h ELSA education  
3.2i Education at pre-vocational schools  
3.2j Education of (future) professionals

4a International conference ELSA Genomics

4b EU Projects coordination

4c Workshop and Seminars

4d Newsletter /communication

4e Visiting Professorship

4f Dissemination

4g Publications

5 Management

6 Reservation

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
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<tr>
<td>5237</td>
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<td>4387</td>
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<td>3897</td>
<td>16410</td>
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Table 4 Total Costs Programme 2008-20012 (K€)
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<tr>
<th>Programme</th>
<th>Theme</th>
<th>Requested from NGI (k€)</th>
<th>Personnel (k€)</th>
<th>Personnel Fte</th>
<th>Other (k€)</th>
</tr>
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<tr>
<td>I. Genomics applications</td>
<td>Changing practices and policies</td>
<td>3240</td>
<td>2870</td>
<td>40,9</td>
<td>370</td>
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<tr>
<td></td>
<td>Identity and Behaviour</td>
<td>2310</td>
<td>2100</td>
<td>26,8</td>
<td>210</td>
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<td>II. Genomics Agenda</td>
<td>Transformation of knowledge production</td>
<td>2000</td>
<td>2000</td>
<td>26</td>
<td>0</td>
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<td></td>
<td>Knowledge &amp; Benefits</td>
<td>1795</td>
<td>1520</td>
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<td>275</td>
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<td>III. Education, Communication</td>
<td>New forms of public interaction</td>
<td>2825</td>
<td>1915</td>
<td>21,8</td>
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<td></td>
<td>Education and Expertise</td>
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<td>2860</td>
<td>36,2</td>
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<td>IV. Network</td>
<td>Management</td>
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<td></td>
<td>Reservation</td>
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<td>3000</td>
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<td>Totals</td>
<td></td>
<td>2500</td>
<td>16410</td>
<td>173,15</td>
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Table 5 Total Budget per Programme (K€)

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<tr>
<th>Partner</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>Total Research</th>
<th>Total Interaction</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>CSG (RU)</td>
<td>655</td>
<td>655</td>
<td>490</td>
<td>475</td>
<td>475</td>
<td>2750</td>
<td>2750</td>
<td>2750</td>
</tr>
<tr>
<td>CMSB</td>
<td>580</td>
<td>625</td>
<td>295</td>
<td>250</td>
<td>150</td>
<td>1500</td>
<td>400</td>
<td>1900</td>
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<tr>
<td>CGC</td>
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<td>505</td>
<td>305</td>
<td>305</td>
<td>505</td>
<td>1500</td>
<td>380</td>
<td>1880</td>
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<tr>
<td>Kluyver</td>
<td>395</td>
<td>385</td>
<td>375</td>
<td>375</td>
<td>385</td>
<td>1500</td>
<td>415</td>
<td>1915</td>
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<tr>
<td>CBSG</td>
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<td>372</td>
<td>347</td>
<td>342</td>
<td>327</td>
<td>1500</td>
<td>260</td>
<td>1760</td>
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<td>Ageing</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>400</td>
<td>100</td>
<td>500</td>
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<tr>
<td>ELSA</td>
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<td>890</td>
<td>730</td>
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<tr>
<td>Collective</td>
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<td>989</td>
<td>989</td>
<td>989</td>
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<td>4026</td>
<td>4041</td>
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</table>

Table 6 Contribution of NGI to CSG (Radboud), Genomics Centres and ELSA network.

19 Including management costs (3000 K€) & Reservation (2900 K€)
Societal Valorisation

CSG first of all contributes to societal valorisation of genomics. Good governance will stimulate conditions for innovation and valorisation and to evidence-based policies in this area. Although the impact and significance of societal research and interaction for society is an important item of concern for CSG, impact in terms of financial benefits will be difficult to measure and define. Rather, valorisation (prospects, benefits, role of valorisation in government funding) is an object for research (theme 2) and in this way CSG can be expected to contribute to overall strategies of valorisation. It is clear that a societal programme is necessary to ensure or strengthen impact and benefits of genomics research and embedding of this research in a societally meaningful way. Therefore CSG’s activities constitute an indispensable component of NGI’s overall Strategic Plan, on the condition that our activities are organised in close interaction with the Genomics Centres, and this is what our programme aims to achieve. Finally, there is evidently a valorisation aspect on our objective to build a sustainable knowledge structure. Utilisation of CSG’s output is a relevant concern for all three programmes.

<table>
<thead>
<tr>
<th>Managerial positions</th>
<th>Name</th>
<th>Management time</th>
<th>Research time</th>
<th>NGI</th>
<th>Matching Radboud University</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Fte per year</td>
<td>(K€) for 5 years</td>
<td>(K€)</td>
<td>(K€)</td>
</tr>
<tr>
<td>General Director</td>
<td>dr. A. Nelis</td>
<td>0,6</td>
<td>450</td>
<td>0,4</td>
<td>300</td>
</tr>
<tr>
<td>Scientific Director</td>
<td>Prof. H. Zwart</td>
<td>0,2</td>
<td>150</td>
<td>0,6</td>
<td>450</td>
</tr>
<tr>
<td>Business Director</td>
<td>vacancy</td>
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<td>750</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Programme manager Communication</td>
<td>vacancy</td>
<td>0,2</td>
<td>150</td>
<td>0,2</td>
<td>150</td>
</tr>
<tr>
<td>Office manager</td>
<td>M.Cantore</td>
<td>1</td>
<td>375</td>
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<tr>
<td>Financial support</td>
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<td>0,8</td>
<td>300</td>
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<tr>
<td>Communication officer</td>
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<td>200</td>
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<tr>
<td>Business Director</td>
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<td></td>
<td></td>
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<tr>
<td>Administrative</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Management Costs &amp; Capacity</td>
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</tr>
<tr>
<td>Managerial capacity</td>
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<td>5</td>
<td>3000</td>
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<td>2050</td>
</tr>
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</table>

Table 7 Management Costs & Contribution Radboud University

Societal Valorisation

CSG first of all contributes to societal valorisation of genomics. Good governance will stimulate conditions for innovation and valorisation and to evidence-based policies in this area. Although the impact and significance of societal research and interaction for society is an important item of concern for CSG, impact in terms of financial benefits will be difficult to measure and define. Rather, valorisation (prospects, benefits, role of valorisation in government funding) is an object for research (theme 2) and in this way CSG can be expected to contribute to overall strategies of valorisation. It is clear that a societal programme is necessary to ensure or strengthen impact and benefits of genomics research and embedding of this research in a societally meaningful way. Therefore CSG’s activities constitute an indispensable component of NGI’s overall Strategic Plan, on the condition that our activities are organised in close interaction with the Genomics Centres, and this is what our programme aims to achieve. Finally, there is evidently a valorisation aspect on our objective to build a sustainable knowledge structure. Utilisation of CSG’s output is a relevant concern for all three programmes.
10. Embedding after 2012
Science and society are changing rapidly. As a converging and enabling field, genomics is a dynamic research area by definition. In the coming years, genomics will disseminate to new domains and increasingly become embedded in various forms of knowledge production. This is already happening. New fields such as ecogenomics, toxicogenomics and metabolomics are becoming increasingly important. Our knowledge society is changing as well. There is an increasing demand for sustainable energy and new materials, for tailored medicines and more reliable knowledge concerning the causes of disease and the relationships between food, lifestyle and health. Genomics is part of this globalising world in which the use and exchange of information (e.g. “biobanking”) becomes increasingly important. In other words, genomics is here to stay, but it will migrate to novel fields and often become so firmly embedded that it no longer will be viewed as a separate research approach. Genomics will increasingly be used and applied to address emerging societal demands. This means that CSG’s mission, expertise and infrastructure will remain relevant beyond 2012.

Three stages can be distinguished in societal research and interaction concerning genomics. During the first stage (CSG I 2004-2007) genomics was still basically a laboratory phenomenon. Societal research and interaction was often of an exploratory and anticipatory nature. During the coming years (CSG II 2008-2012), more and more genomics applications will become available, and genomics research will become relevant for various societal practices. In other words, genomics is rapidly migrating from the sphere of promises to the sphere of implementations, albeit not in a straightforward or technology-driven way. On the contrary, genomics applications will be adopted and adapted in a dynamic and creative manner by various stakeholders, and society will increasingly influence the ways in which genomics research will evolve. This means that, more than in the past, our research will have to be relevant for policy development and societal organisations.

As for the future we expect that, after 2012, genomics research will have contributed to numerous research fields and societal practices so that CSG will have to broaden its scope. We will use the expertise, networks and infrastructures developed in order to address broader areas of concern. Or, to put it differently, our expertise and networks will become relevant for a much large group of stakeholders and for newly evolving research and societal agendas. New application-oriented initiatives have already been established. Top Institutes such as Pharma (TIP), Green Genetics (TTIGG), the Top Institute for Food and Nutrition (TIFN) and the Centre for Translational Molecular Medicine (CTMM) are examples of this trend. CSG’s agenda will become increasingly relevant for such initiatives.

After 2012, CSG will continue to exist. First of all, on the local level, the Radboud University has committed itself to ensure CSG’s continuity in the form of tenures for key personnel (general director, scientific director, communication officer and office manager). This implies that CSG’s management team
will remain in place and that our three core programmes, and the six themes they encompass, will be further developed in the future. And indeed, we believe that after 2012, issues concerning genomics applications (dissemination of genomics to novel areas), the genomics agenda (emergence of new constellations and research fields) and genomics education and communication (for instance bèta-gamma interaction) will remain relevant. Moreover, on the national level, the Genomics Centres have committed themselves to continuing their collaboration with CSG after 2012. This means that CSG will continue to play a crucial role in the development of their societal activities (research and interaction). Building on established collaborations with Genomics Centres and the ELSA genomics network, in line with our programmes and themes, sufficient critical mass will have been established for extending our activities into the future. Yet, besides continuation, there will be new challenges as well. Instead of relying on NGI funding, CSG will have developed experience and robust networks for acquiring substantial additional funding, notably in the form of EU projects. During the past few years, we already established promising international networks. By further developing them through joint international activities (EU projects, conferences, dissemination) and by using the full potential of ERASAGE (ERANET initiative of funding agencies coordinated by CSG) will ensure a solid basis for international research and coordinating activities. Moreover, new alliances will have to be developed on the national level as well, with the Top Institutes mentioned above, but also with policy makers en societal partners.

In the future, building on our networks and expertise, the CSG approach (systematically combining research and interaction) will be applied to other areas (bionanoscience, new materials, molecular medicine, etc.) in interaction with a broader range of interested partners, including more intensive collaborations with policy makers and governmental bodies, but also with a broader range of research organisation (expanding our scope beyond the genomics network). In other words, CSG will use the funding for developing a sustainable, prominent and visible source or expertise for conducting interactive research concerning the future developments and impacts of the life sciences.

In short, after 2012, CSG will remain important as an experienced and prominent booster (both nationally and internationally) of academic reflection on the ways in which genomics research (or life science research more generally) are evolving as well as on the ways in which the process of agenda setting can be more strongly oriented towards emerging societal trends and needs. At the same time, CSG will further public visibility of this research, thereby allowing various stakeholders but also civil society at large to co-shape the embedding of genomics. CSG will continue to contribute to the process of interdisciplinary research, that is: the interaction between the sciences, social sciences and humanities. Finally, CSG will be well positioned (in terms of mass, focus and visibility) to play a leading role in further developing the emerging European and global networks for ELSA research, education and policy development in the life sciences in general and genomics in particular.
Appendix 1: References


Appendix 2: Curriculum vitae of management and principal investigators

Prof. Dr. H.A.E. Zwart

Function: Full professor of Philosophy, Faculty of Science, Radboud University Nijmegen, Department of Philosophy & Science Studies (Chair), Institute for Science, Innovation & Society (Director), Centre for Society & Genomics (Scientific director)

Address: P.O. Box 9010, 6500 GL Nijmegen, The Netherlands, zwart@society-genomics.nl

Hub Zwart (1960) studied philosophy (cum laude) and psychology (cum laude) at Radboud University Nijmegen. He worked as research associate at the Centre for Bioethics (Maastricht, 1988-1992) and defended his thesis on consensus formation in a pluralistic society in 1993 (cum laude). He was appointed as research director of the Centre for Ethics (Nijmegen, 1992-2000) and acted as editor-in-chief of the Dutch Journal Tijdschrift voor Geneeskunde en Éthiek. In 2000 he became full professor of philosophy at the Faculty of Science. He was European lead of the EU Canada exchange program Coastal Values (1999-2003). In 2004 he became director of the Centre for Society & Genomics, funded by the Netherlands Genomics Initiative and established at his department. The focus of his research is on epistemological and ethical issues in the life sciences: biomedicine (1988-1996), research with animals (1996-2003), environmental research (1998-2003) and genomics (2003-present). His current research concerns: the epistemological profile of genomics; philosophical implications of the Human Genome Project; epistemological profile of ecogenomics; challenges of macro-ethics (the ethics of bio-information); scientific authorship and comparative epistemology (literary imagination as a research tool). Hub Zwart teaches Introduction to philosophy and ethics of life sciences; Introduction to philosophy and ethics of science; Visible Scientists; and Science and literature.

Key publications


Memberships
Co-editor of the journal Genomics, Society & Policy
Editorial Board of the journal Environmental Values
Editorial Board of the journal Tailoring Biotechnologies
Partner in the EU FP6 Science & Society program Institutionalisation of Ethics in Science Policy
Chair of the Dutch Association of Animal Ethics Committees
Member of the subcommittee on ethical and societal aspects of genetic modification of COGEM (Netherlands Commission on Genetic Modification)
Member scientific advisory board Ecogenomics Consortium
Affiliated Principal Investigator Nijmegen Centre for Molecular Life Sciences (NCMLS)
Dr. Annemiek Nelis

Function: General Director of the Centre for Society and Genomics

Address: Centre for Society and Genomics, Radboud University Nijmegen. P.O. Box 9010, 6500 GL Nijmegen, The Netherlands; nelis@society-genomics.nl

Annemiek Nelis (1970) is sociologist of science and technology. She wrote her Ph.D. on the development of clinical genetics and DNA –technology in the Netherlands and has been studying the societal aspects of genetics and genomics for nearly 15 years. After receiving her PhD from the University of Twente, Annemiek worked subsequently in Cambridge (UK) and Amsterdam (VU & UvA). During this period she also was responsible for the Ph.D. education programme of the research school Science, Technology and Modern Culture (WTMC). Since September 2004 she has been working at the Centre for Society and Genomics. She started at the CSG as deputy director. March 2007 she became general director of the CSG. Together with the scientific director, Hub Zwart, Annemiek has been responsible for the scientific and interactive programme of CSG. Annemiek is coordinator of a large ERA- network called ERASAGE. ERASAGE brings together 11 funding organisations concerned with the Ethical, Legal and Social aspects of genomics in Europe and Canada. Her current research concerns the role of patient organisations in decision-making on genomics technologies; ethnographic laboratory research; and the institutional organisation and method of ELSA genomics.

Key Publications


Memberships
Member College van Advies Chronisch Zieken en Gehandicaptenraad (2001 -2004)
Associated Fellow of the Science & Technology Studies Unit (SATSU), University of York (2000 -)
Member of the Jury of the genomics school competition Imagine (2006 -)
Prof. Dr. Martina Cornel

Function: Full professor of Community Genetics

Address: VU Medical Centre. Postbus 7057, 1007 MB Amsterdam. M.C.Cornel@vumc.nl

Martina Cornel, M.D, Ph.D. (1959) has been appointed as a professor of community genetics at the VU University Medical Center in Amsterdam in 2002. She is a physician and epidemiologist. In recent years she was involved in research on genetic screening criteria, a pilot on preconception screening for cystic fibrosis and hemoglobinopathy, research on genetic education and the international database for rare diseases (Orphanet). She teaches medical students and health science students in the areas of health promotion and large scale applications of genetics & genomics and is involved in postgraduate training in these areas.

She was a member of the Health Council Committee on Neonatal Screening and is now chair of the program committee Neonatal Screening. In 2006/2007 she contributed to public discussions on screening on radio (AVRO), in Volkskrant, Bionieuws, Medisch Contact and various magazines for public health and ESTA (a womens magazine). She participated in debates at the Radboud University Nijmegen, VSOP/Erfocentrum, Genomics Momentum, CESAGEN/CSG conference, RIVM and VUMC.

Key publications


Memberships
Member of the Public and Professional Policy Committee (PPPC) of the European Society for Human Genetics (ESHG), chair from summer 2007 onwards.

Chair of Dutch Association for Community Genetics

Chair of Dutch Program committee Neonatal Screening

Associate editor Community Genetics

Chair of working party on societal aspects of genomics, CMSB, Leiden

Core Group member of the Center for Society and Genomics, CSG, Nijmegen.
Prof. Dr. Guido de Wert

Function: Professor of Biomedical Ethics at the Faculty of Health, Medicine and Life Sciences, Maastricht University, The Netherlands.

Address: Maastricht University, Faculty of Health, Medicine and Life Sciences, Dept. Health, Ethics and Society, P.O. Box 717, 6100 MD Maastricht, The Netherlands; g.dewert@zw.unimaas.nl

The main research interest of Guido de Wert (1959) regards the ethics of genomics (including community genetics, clinical genetics, and behavioral genomics). In 1999, he defended his thesis Looking ahead. Reproductive technologies, genetics and ethics at the Erasmus University Rotterdam (cum laude).

De Wert teaches biomedical ethics, especially the ethics of reproductive medicine and genetics/genomics in the curricula of both Medicine and Life Sciences at Maastricht University. Furthermore, he contributes to various post-academic courses in Biomedical Ethics in The Netherlands.

He is consultant of various patient organizations, especially the VSOP (an umbrella organization). He regularly writes about bio-ethical (genomics-related) issues in Dutch papers.

Key publications


Memberships
Guido de Wert is Crown-appointed member of the Health Council of the Netherlands, member of both the Council’s Standing Committee on Medical Ethics and Health Law and the Standing Committee on Genetics, member of the Ethics Committee of International Stem Cell Forum, and member of the Task Force Ethics & Law of the European Society of Human Reproduction and Embryology.
Dr. Dirk Stemerding

**Function:** Assistant professor, Department of Science, Technology, Health and Policy Studies

**Address:** School of Management and Governance, University of Twente, PO box 217, 7500 AE Enschede, The Netherlands, d.stemerding@utwente.nl

Dirk Stemerding (1951) was trained in biology at the University of Groningen. He graduated at the University of Maastricht with a dissertation on the history of biology. General theme of his research at the University of Twente is the study of societal embedding of technology. In the past ten years he has published on a range of subjects, including (1) the introduction of new forms of genetic (DNA-) diagnosis in clinical genetics as well as other clinical practices (especially cancer genetics), (2) emerging practices of prenatal screening and related processes of social learning, (3) issues of government regulation in the field of the new genetics and biotechnology. He was one of the partners in a EU Concerted Action Programme on Genetic Services in Europe (led by prof. Rodney Harris, University of Manchester, 1995-1997). As principal investigator of the Dutch Centre for Society and Genomics he is currently involved in an interactive scenario study focussing on the dynamics and implications of the shift from established practices of clinical genetics to emerging practices of community genetics. He is also participating in a collaborative project Developing scenarios of moral controversies concerning new biomedical technologies (funded by the Dutch National Research Council) which aims at the development of a methodology assisting policy-making in this field. He lectures in the fields of Health Science and Technology Assessment, and has contributed to the Genomics and Society course of the Life Sciences master programme at the University of Nijmegen and the Dutch DNA-dialogues, organised by the CSG. He is member of an advisory committee of the Dutch Health Council which prepares a report on preconception care.

**Key publications**


**Memberships**

Society for the Social Study of Science
European Society of Science, Technology and Society
Prof. Dr. Michiel Korthals

**Function:** Professor Applied Philosophy, Chair of Chairgroup Applied Philosophy, Chair Wageningen Ethics Centre, Wageningen University

**Address:** Hollandseweg 1, 6706 KN Wageningen, michiel.korthals@wur.nl

Michiel Korthals (1949) studied Philosophy, Sociology, and Anthropology at the University of Amsterdam (UvA) and the Karl Ruprecht Universität in Heidelberg. He graduated at the UvA with a dissertation on the Frankfurt School. His academic interests include bioethics and ethical problems concerning food production and environmental issues, deliberative theories, and American Pragmatism. With respect to genomics he is in particular interested in deliberative theories that can enhance the embedding of (nutri-)genomics in dynamic and globalizing situations. He published and lectured on the relationship of genomics with food and agriculture. Korthals is member of various ethics councils of international genomics projects. As a member of the Dutch Consumentenplatform he advises the Dutch Government on new technologies with respect to food, agriculture, environment and nature. Korthals participated in the management of various GELS-genomics education programs.

**Key publications**


**Memberships**
- International Library of Agricultural and Food ethics (M. Korthals, Editor in Chief)
- Science Committee, Genome Canada (2002/2005)
- Centre for Society and Genomics, NWO/Radboud University, Core Group member
- Ethical Panel, EU-commission, FP6 and FP7
- NWO: Program Ethics, Research, Policy (2004-)
- NWO: Societal Responsible Innovation, Theme Committee (2006-)
- Member of Ethics Council, AQUAMAX, Sustainable Aquafeeds to Maximize the Health Benefits of Farmed Fish for Consumers, IP Project, EU, 6th Framework, 2006-2010;
- Member of Ethics Platform, EARNEST, Early Nutrition Programming Project, IP Project, EU, 6th Framework, 2006-2010;
- Member of the International Advisory Board of GE3LS Architecture, Genome Canada, Mike Burgess (UBC, Vancouver), 2005-2010;
- Reviewer for Genome Canada, Genome Espana, and for various journals and publishers.
Dr. Patricia Osseweijer

**Functions:** Managing Director Kluyver Centre for Genomics of Industrial Fermentation; Programme Leader Industrial Genomics for Society.

**Address:** Delft University of Technology, Department of Biotechnology, Julianalaan 67, 2628 BC Delft, The Netherlands; P.Osseweijer@tudelft.nl

Patricia Osseweijer (1958) has a degree in Molecular Biology, a PhD degree in Science Communication at the Free University of Amsterdam (2006), and professional experience in curriculum development, management of fund acquisition and management of (inter)national research and education projects. In 1999 she was appointed Managing Director of the Department of Biotechnology and Executive Secretary for the Research School Biotechnological Sciences Delft Leiden. She initiated and presently co-chairs a new research group on ethics and society issues in biotechnology and has organised many international workshops and courses in this field. In 2002 Patricia was involved in the initiation of the Kluyver Centre for Genomics of Industrial Fermentation and appointed Managing Director. She developed the Genomics and Society Programme and has been responsible, as Programme Leader, for the coordination of societal research projects in several universities, which were integrated in the communication strategy of the Kluyver Centre.

**Key publications**


**Memberships**

Redactieraad Netherlands Genomics Initiative (2003-2006)
SBN (Stichting Biotechnologie Nederland) Board member (1999-), treasurer (2002-2007)
NBV (Netherlands Biotechnology Society) Board member (1997-2001)
NBV Working Group on Society Aspects of Biotechnology (1995-)
Raad van Wetenschappelijk Directeuren Delftse Onderzoekscholen (secretaris, 1999-2004)
EFB (European Federation of Biotechnology) Section on Biochemical Engineering Science (First Secretary, Board member)(1996-2001)
EFB Task Group on Education (Chairman Working Group on Short Courses)(1991-)
EFB Task Group on Public Perceptions of Biotechnology (Convenor Working Group on Research and Higher Education)(1993-)
Prof. Dr. Arend Jan Waarlo

Function: Professor of Genetics & Health Communication

Address: Princetonplein 5, 3584 CC Utrecht, The Netherlands; A.J.Waarlo@phys.uu.nl

Arend Jan Waarlo (1949) is senior lecturer in biology education and communication and holds a special VSOP-chair in genetics & health communication at the Freudenthal Institute for Science and Mathematics Education, Utrecht University. His PhD thesis was on ‘Biology teaching and health education’. In 1999 and 2000, he was also employed at the University for Humanistics in Utrecht. He has trained biology teachers, life-stance and moral education teachers, professionals in health and environmental education, and is currently engaged in the Utrecht Master’s Degree Programme ‘Science Education and Communication’. He participated in various curriculum development and research projects.

Key publications


Memberships
From 2000 to 2004 he was a member of the Academic Committee of the European Researchers in Didactics of Biology (ERIDOB). His current research interest is in acquiring genomics-related opinion-forming competence. He is manager of the CSG project ‘DNA labs for citizenship: learning for understanding and valuing genomics in upper-secondary education’. He collaborates with the Dutch Genetic Alliance VSOP since about 15 years. He regularly lectures interactively on ‘predicting and tinkering with DNA’ for laymen. He is a member of the editorial board of the Electronic Journal of Biotechnology.
Appendix 3: Consulted organisations

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
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</thead>
<tbody>
<tr>
<td>Ir. M. van den Bosch</td>
<td>Ministerie van EZ</td>
</tr>
<tr>
<td>Dhr. J. Breekveldt</td>
<td>Werkplaats Biopolitiek</td>
</tr>
<tr>
<td>Mw. A.M. van Dam</td>
<td>Nederlands Gesprek Centrum</td>
</tr>
<tr>
<td>Drs. R. Dekker</td>
<td>Ministerie van VROM</td>
</tr>
<tr>
<td>Dhr. R. Gude</td>
<td>Internationale School voor Wijsbegeerte</td>
</tr>
<tr>
<td>Mw. Drs. J. Hensing</td>
<td>Ministerie van OCW</td>
</tr>
<tr>
<td>Drs. C. Hogenhuis</td>
<td>Stichting Oikos</td>
</tr>
<tr>
<td>Mw. Drs. S. Homsma</td>
<td>Nederlandse Bond voor Verzekeraars</td>
</tr>
<tr>
<td>Ir. M. Horning</td>
<td>Ministerie van EZ</td>
</tr>
<tr>
<td>Prof. Dr. M.J. van den Hoven</td>
<td>TU Delft</td>
</tr>
<tr>
<td>Drs. R.T.A. Janssen</td>
<td>Nederlandse Biotechnologie Associatie NIABA</td>
</tr>
<tr>
<td>Mw. Drs. J. Kuil</td>
<td>Dierenbescherming</td>
</tr>
<tr>
<td>Mw. Drs. M. van de Meent-Nutma</td>
<td>NWO Geesteswetenschappen</td>
</tr>
<tr>
<td>Dr. C. Oosterwijk</td>
<td>VSOP</td>
</tr>
<tr>
<td>Mw. G. Roebeling</td>
<td>WECF Nederland</td>
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<tr>
<td>Mw. Dr. S. Schalk</td>
<td>Greenpeace Nederland</td>
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<tr>
<td>Dr. J.T.C.M. Sprangers</td>
<td>Ministerie van LNV</td>
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<tr>
<td>Mr. Drs. J. Staman</td>
<td>Rathenau Instituut</td>
</tr>
<tr>
<td>Dr. C.M. Vos</td>
<td>Ministerie van VWS</td>
</tr>
<tr>
<td>Prof. Dr. P.A.Th.J. Werrij</td>
<td>Wageningen Universiteit</td>
</tr>
<tr>
<td>Dhr. H. van Wietmarschen</td>
<td>Werkplaats Biopolitiek</td>
</tr>
<tr>
<td>Drs. J.B. van den Wijngaard</td>
<td>Ministerie van VWS</td>
</tr>
</tbody>
</table>
Appendix 4: Letters of support

Centre for BioSystems Genomics (CBSG) – Prof. Dr. Willem Stiekema (Director)
Centre for Medical Systems Biology (CMSB) – Prof. Dr. Gert-Jan B. van Ommen (Director)
Kluyver Centre for Genomics of Industrial Fermentation (Kluyver Centre) – Prof. Dr. Jack Pronk (Scientific director), Dr. Patricia Osseweijer (Managing director)
Cancer Genomics Centre (CGC) - Dr. J.E. Speksnijder (Managing Director)
CSG Scientific Advisory Board – Prof. Dr. George Gaskell (Chair), Prof. Dr. Ruth Chadwick
Dear Dr Nelis,

With great interest we have received the business proposal of the Centre for Society and Genomics (CSG) for the period 2008-2012. We acknowledge that a societal programme as proposed by CSG is of utmost importance, especially since science and society are changing rapidly. This is clearly illustrated by the increasing demand for sustainable food production, energy and new materials, for tailored medicines and more reliable knowledge concerning the causes of disease and the relationships between food, lifestyle and health.

In the coming years, genomics will further disseminate to new domains and one can expect even more societal issues to arise. We therefore believe that the development of genomics science and technology, especially when one considers the speed at which these developments are taking place, requires to be well embedded in society. A programme that bridges the gap between the potentials of technological innovation on the one hand and societal demands and expectations on the other is what we need. Therefore we fully support the programme that the Centre for Society and Genomics had set out for the period 2008-2012 and we look forward to a valuable collaboration over the next 5 years.

The CSG programme is very well linked to the topics and themes of our research programmes that focus on Brassica vegetables, tomato and potato. The CSG programme enables us to continue with our dedicated research cluster on societal research that will provide results such as communication strategies and consumer preferences that CBSG needs to become successful in the years to come and in which our industrial partners have expressed great interest.

After 2012 the scope of genomics and thus its societal programme may need further broadening. For our centre we then think of developments such as plant systems biology and synthetic biology that both have the potential to influence plant breeding and farming practices and the use of crops and their products. Because of these developments we will continue to make our expertise and networks available for newly evolving research in both natural and social sciences. Therefore our centre has the firm intention to continue our support for and collaboration with CSG.

With kind regards,

Prof. Dr. Willem J. Stiekema
Leiden, March 30 2007-03-29

Centre for Society and Genomics
Dr. A. Nelis, General Director
Postbus 9010
6500 GL Nijmegen
the Netherlands

Leiden, March 28th 2007

Dear dr. Nelis, dear Annemiek

We have wholeheartedly contributed to the business proposal of the Centre for Society and Genomics (2008-2012) for our field field of multifactorial diseases, and read with agreement the last version of it. It expresses the need for societal research and public interaction concerning genomics now that applications increasingly affect different levels of society, identifies many issues worth addressing and outlines suitable trajectories for their study.

In our own field this includes the realization that the players are not only the researchers and patients but also caretakers, insurance companies, other health professionals and a wide scala of decision making and funding bodies, not least NGI and its commissioning ministries, and most importantly the public at large.

The Centre for Medical Systems Biology (CMSB) therefore fully supports the programme that the Centre for Society and Genomics has set out for the period 2008-2012 and is happy to be part of this programme. The CMSB particularly looks at bridging the gap between research developments and the broader use and application of results in society. Also after 2012, we see a further need for societal research and communication on this topic, a need that we hope to further develop and fulfill in collaboration with CSG. We intent to continue to bridge, together with CSG, the gap between research and societal use and it is the stated intention of CMSB to continue collaboration with CSG also after 2012.

Wishing you every success,

Prof. dr. Gert-Jan B. van Ommen
Director CMSB
Dear Dr. Nelis,

Thank you very much for sending us the draft Business Proposal for the Centre for Society and Genomics (CSG) for the period 2008-2012.

The mission of the Kluvyer Centre for Genomics of Industrial Fermentation is to provide scientific excellence in microbial genomics for quantum-leap innovations in industrial biotechnology, aimed at improving sustainability and quality of life. It fully recognises that this mission requires thorough investigation of the processes that determine societal implementation of our research outputs.

The importance that the Kluvyer Centre assigns to societal research is reflected by the inclusion of a dedicated societal research programme in its business plans for 2002-2007 and 2008-2012. This investment is strongly supported by our Industrial Platform and by the Kluvyer Centre consortium members. This is, for example, exemplified by the setting up of a new research group Biotechnology and Society at the Delft University of Technology. Since, in the future, genomics-driven industrial biotechnology finds its way into ever more aspects of daily life, we continue to see societal research as vital.

We are pleased that the Business Plan of the Centre for Society and Genomics acknowledges the Kluvyer Centre's plans and ambitions and has allocated financial support for the Kluvyer Centre's proposed activities in this area. Even more importantly, we welcome the added value that integration of our societal programme in the Centre for Society and Genomics' overall strategy will bring, in terms of expertise and outputs.

We fully support the programme that the Centre for Society and Genomics has proposed for the period 2008-2012 and we look forward to continuation of our productive collaboration. The Kluvyer Centre is committed to continue its mission beyond 2012 and,
based on positive evaluations of our joint scientific activities, fully intends to also continue collaborating with the Centre for Society and Genomics consortium beyond a next NGI funding term.

We thank you for the pleasant and constructive discussions that led to the definition of our joint research plans and hope for a positive evaluation of your Business Plan!

Yours sincerely,

Prof. Dr. Jack Pronk
Scientific Director

Dr. Patricia Osseweijer
Managing Director
April 1, 2007

Dear dr. Nelis,

Thank you for sending us the business proposal of the Centre for Society and Genomics (CSG) for the period 2008-2012. We agree that a strong societal programme linked to genomics research is of great importance, since science and society are changing rapidly. This is illustrated by the increased knowledge concerning the genetic changes that turn a normal cell into a cancer cell and realistic opportunities for a better diagnosis and treatment of this terrible disease that soon will be the number one killer in the Netherlands due to ageing of the population.

The mission of the Cancer Genomics Centre (CGC) is to strengthen cancer genomics research in the Netherlands striving for better understanding of the cancer process so as to form a basis for the development of novel diagnostic and prognostic tools and the development of new therapeutic modalities; to strengthen the knowledge chain to commercialize results obtained so as to add economic value to society; to improve communication with relevant societal stakeholders; to establish a platform for cancer research, valorisation and communication to be continued after 2012.

For the CGC, informing those in society who are directly affected by the developments in cancer genomics, e.g. cancer patients and professionals, is of utmost importance. Furthermore, we feel that future citizens, genomics researchers and professionals should receive proper education concerning genomics and its impact on society, and we therefore strive for a better embedding of genomics at various educational levels. In part 6 of our Business Plan, we have described a number of concrete outreach activities combined with social research that the Cancer Genomics Centre will perform in the context of CSG programme III: ‘Genomics Education and Communication’ in order to fulfil this ambition.
The Cancer Genomics Centre supports the programme that the Centre for Society and Genomics had set out for the period 2008-2012. As described in our mission statement, the Cancer Genomics Centre will continue as a platform for cancer research, valorisation and communication after 2012, and within that context, will continue its collaboration with the Centre for Society and Genomics.

Sincerely yours,

[Signature]

Dr. J.E. Speksnijder
Managing director
Cancer Genomics Centre
30 March 2007.

Prof. Dr H.A.E. Zwart
Dr A.P. Nelis
Centre for Genomics and Society
Nijmegen University
Netherlands

Re: Centre for Society and Genomics 2008-2112: Business Plan

Dear Hub and Annemiek

I read your Business Plan with great interest. Here you set out a strategic research programme for the Centre for the coming five years. You outline an integrated, proactive and provocative programme, bringing together a wide range of expert contributors from the Netherlands. While the research addresses a number of significant issues that will confront society as genomics develops, it does so in the context of a number of important objectives; the pursuit of societal embedding of genomics, practical measures for effective public engagement and education, and a commitment to scholarship, drawing upon the humanities and the social sciences.

I am impressed by your comprehensive vision and by your success in engaging with the NGI Genomics Centres and other institutions and groups in the Netherlands. I have observed similar attempts in the UK, the USA and Canada and come to the conclusion that the CSG is the model for others to follow.

Yours sincerely

George Gaskell BSc PhD
Dear Annemiek

Re: Centre for Society and Genomics 2008-12

Thank you for sending me a copy of your Business plan for the period 2008-12. I have pleasure in writing in support of this plan, which I am sure will ensure future work of utmost importance in the field. As Director of the ESRC Centre for Economic and Social Aspects of Genomics I look forward to co-operating with you during this period.

With every good wish

Ruth Chadwick

RUTH CHADWICK B.Phil., M.A., D.Phil. (Oxon)
Director of CESAGen