



# **Decision-making for *participation* in screening among Turks and Moroccans in the Netherlands**

Lessons learned from chronic hepatitis B and cervical cancer

**Nora Hamdiui**

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the Netherlands**

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*If you were to rely upon Allah with reliance due to Him, He would provide for you just as He provides for the birds. They go out in the morning with empty stomachs and return full.*

[Source: Sunan al-Tirmidhī 2344]



To my dear grandfathers

May Allah bless their souls and grant them the highest state in Jannah

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# 1

General introduction

*Karima (35 years) is an English teacher who lives in Amsterdam, close to her parents. She married three years ago, has a daughter of one, and goes to the gym two times per week. She accompanies her mother every Friday to the local market for groceries. She also helps her mother with reading important Dutch letters. One day, her mother asks her to read a Dutch letter: "We invite you to the cervical cancer screening programme." Karima reads. "Screening? What is it?" "With this screening, cervical (pre)cancer can be detected early on."*

*"But I do not have any complaints." "Did you ever go?" her mother asks. "Well, no. I think it is important to take care of our health, but I am sure that Khalid (her partner) and myself did not share a bed with someone else." Karima responds.*

This hypothetical scenario illustrates multiple difficulties immigrants could face when deciding whether or not to participate in screening programmes. What to do in this scenario in which the mother has an insufficient command of the Dutch language and limited digital skills, and the invitation letter is sent in Dutch and translations are only available online? Should you only take action concerning your health if you have complaints? And if not, how do you decide if and in what manner to take action? This thesis will help in answering these questions.

### Participation of ethnic minorities in screening programmes

Over the last decades, the number of migrants in the world has grown tremendously, with a current estimation of 258 million individuals (1). Although inevitable, this rapid increase of population movement has important public health implications. While ethnic minorities sometimes reside in the host country for decades or even centuries, in general, they usually have a more unfavourable disease risk profile compared to the host population (2, 3). Furthermore, despite equal formal access to health-care services, inequalities in health-care utilisation are reported from everywhere (4). Overall, ethnic minorities have lower participation and referral rates to mammography and cervical cancer screening, more contact moments per patient with the general practitioner (GP), same or higher level of use of specialist care, and same or higher hospitalisation rates in comparison to the host population (4). More importantly, these inequalities cannot be substantially explained by differences in socioeconomic- and health status, and seem to be related to differences in need, preferences, information, (health) literacy, and formal access barriers (4, 5).

### Turkish and Moroccan immigrants in the Netherlands

In the 1960s and early 1970s, following the post-war reconstruction of the Dutch economy, the Netherlands recruited 'guest workers' (i.e. labour immigrants) for unskilled labour from mainly Mediterranean countries, starting with Italy, Greece, and Spain, later Turkey, and Morocco being the most important sending countries (6, 7). The recruitment was mainly conducted in poorer rural areas, where individuals

with no or low educational training lived. In contrast to the South European labourers who mostly returned to their home countries – especially after Spain and Portugal joined the EU – Turks and Moroccans stayed due to poor economic and political situations in Turkey and Morocco. As in early 1980s family reunification regulations were relaxed, family reunification or formation, and childbirth led to a continuing growth of the Turkish and Moroccan populations in the Netherlands. According to Statistics Netherlands' data of the period 1975-2020, the Turkish population (born in Turkey or at least one parent is born in Turkey) went from 55,639 to 416,864, and the Moroccan population (born in Morocco or at least one parent is born in Morocco) went from 30,481 to 408,864 (6, 8).

To date, 24.4% of the Dutch population has a migration background, which include both individuals that are born abroad (further referred to as first-generation immigrants) as those who have at least one parent born abroad (further referred to as second-generation immigrants) (9-11). In the four largest cities in the Netherlands, Amsterdam, Rotterdam, Den Haag, and Utrecht, there are altogether more individuals with a migration background than ethnic Dutch (51.8% versus 48.2%) (9).

Turkish and Moroccan immigrants are the largest immigrant populations with 197,446 and 172,040 first-generation immigrants, and 219,418 and 236,824 second-generation immigrants, respectively (8). Grandchildren of those of first-generation are not registered as immigrants by Statistics Netherlands, and are included in population data as not having a migration background.

In immigrant families, children and grandchildren play an important social role for – and have a close relationship with – their parents and grandparents (12, 13). They act as instructors, models, and interpreters, and provide financial, social, and/or emotional support to their parents and grandparents. At the same time, obviously parents, but also grandparents play a supportive role for children and grandchildren by helping with raising children and decision-making, serving as role models, and providing a sense of "tradition and belonging". Since children and grandchildren also frequently act as brokers for their parents and grandparents in contact with the Dutch health-care system, they are important to consider and were therefore included in this thesis for studying the health behaviour of first-generation immigrants (14).

### Informed decision-making regarding screening programmes

Previous research in Europe has shown lower participation rates for screening programmes among immigrants in comparison to non-immigrants (4). One of the most important reasons for not participating in cancer screening programmes was a lack of awareness and knowledge (15). This is especially concerning, since there is growing evidence that the burden of disease is not shared equally and differs

considerably across ethnic groups. Interventions to increase screening participation and eventually lower disease burden in these groups are thus urgently needed.

Traditionally, cancer screening programmes aim to reach a maximum uptake level and thus effectiveness (i.e. reduction of incidence and mortality) at a population level. From the perspective of the individual, however, deciding to participate in screening involves careful consideration between uncertain benefits (e.g. longer duration of life if a precursor of cancer is successfully detected and treated) and risks of adverse effects (e.g. false-positive and -negative test results, overdiagnosis and -treatment, and discomfort or pain). This entails the concept of informed decision-making (IDM) described in the Rational Decision Model (16, 17). According to this theoretical framework, individuals are entitled to individually base their decision on making maximum use of information and rationally weighing all aspects involved, considering both the pros and cons. An informed decision is commonly defined as one that is based on sufficient decision-relevant knowledge while the decision-maker's attitude (i.e. values and preferences) is consistent with his/her (intended) screening behaviour (18).

### The aim of this thesis

The aim of this thesis is to examine how Turkish- and Moroccan-Dutch immigrants can be reached and informed best on participation in preventive health-care services. To that end, we used two screening examples, i.e. for the diseases chronic hepatitis B and cervical cancer. Below, we describe why we have chosen these examples along with extra background information.

#### *Chronic hepatitis B*

The prevalence of chronic hepatitis B among individuals aged 15 years and older in the Netherlands is estimated at 0.34%, with some populations having higher prevalence (19). The largest risk group is identified as first-generation immigrants, who account for most infections (81%) (19). The most affected populations are individuals from Turkey, Somalia, and China with 18.9%, 8.3%, and 6.5% of the total chronic hepatitis B infections among immigrants, respectively (19). Although research among these three populations would be most relevant, van der Veen already studied determinants of chronic hepatitis B screening participation among Turkish-Dutch extensively (20). We choose to focus on the second largest immigrant population in the Netherlands, Moroccan immigrants, especially because the researcher (NH) has the same cultural and linguistic background. Of Moroccan immigrants in the Netherlands, 0.54% [95% CI 0.01-1.07] are estimated to be chronically infected (19). Suijkerbuijk et al. (2018) found chronic hepatitis B screening to be cost-effective for those born in a country with an endemicity of at least 0.41%, which shows sufficient relevance to target Moroccan immigrants in our studies (21). Moreover, it is important to note that the prevalence of 0.54% is based on only three small (ranging between 50 and 496 immigrants) and

local (Amsterdam and Rotterdam) Dutch studies. The scarcity of data and the degree to which they are geographically dispersed make it difficult to draw firm conclusions about the true prevalence of chronic hepatitis B among first-generation Moroccan immigrants in the Netherlands.

### Measures to control hepatitis B in the Netherlands and Morocco

Hepatitis B, caused by the Hepatitis B Virus (HBV), is one of the major global health challenges, causing both acute and chronic disease (22). Chronic HBV infection, affecting 257 million individuals globally (often without experiencing any symptoms), can lead to liver cirrhosis and liver cancer, putting individuals at high risk of premature death (22).

In the Netherlands, several measures have been taken over time to control HBV transmission, such as universal antenatal screening with subsequent free of charge HBV vaccination for new-born babies of chronically infected mothers (1989), free of charge HBV vaccination for at risk occupations (2000), behavioural high-risk groups (2002), and children of at least one parent born in an endemic country (2003), and free of charge universal infant HBV vaccination (2011) (23).

Morocco is currently reclassified as a low-endemic hepatitis B country, thanks to the measures they took to decrease the previous high prevalence of 6.29% for the period of 1957-1989 (24). After the 1980s, Morocco introduced a systematic nationwide screening of blood donors for the hepatitis B surface antigen (HBsAg: an indicator for chronic infection) (1985), a vaccination programme targeting healthcare workers (1993), and universal vaccination among infants (1999) (25, 26). Since the implementation of these measures, the chronic hepatitis B prevalence in Morocco declined to 1.08% in the period of 1990-2013 (24). As Moroccans have come to the Netherlands as labour immigrants since the 1960s and early 1970s, and could not take advantage of the measures taken in Morocco after the 1980s nor of the measures taken in the Netherlands, Moroccan first-generation immigrants have an increased risk of HBV carriage and its serious complications (i.e. liver cirrhosis and liver cancer).

### HBsAg screening in the Netherlands

Since the predominant mode of transmission in endemic countries is mother to child at birth (22), the present seropositive immigrants are most likely infected at birth and came chronically infected at arrival. Moreover, infection in infancy and early childhood leads to chronic hepatitis B in about 95% of the cases, while infection in adulthood (for example due to sexual transmission) leads to chronic hepatitis B in less than 5% of the cases (22). Therefore, in November 2016, the Dutch Health Council recommended HBsAg screening for immigrants born in countries with an endemicity of at least 2%, aimed at detecting unnoticed asymptomatic chronically infected individuals for either immediate treatment or monitoring, and preventing further transmission (27).



The Health Council proposed implementing this screening through two strategies: (1) individual case finding by the GP, and (2) local or regional screening programmes through Municipal Public Health Services (MPHS) in cities or regions with large numbers of first-generation immigrants born in countries with intermediate or high endemicity. Since no long-term hepatitis B screening programmes are implemented yet in the Netherlands, and thus, first-generation immigrants are not actively targeted for HBsAg screening, immigrants' screening behaviour cannot be studied. However, previous research has shown lower participation rates for other screening programmes among immigrants in comparison to non-immigrants (4). Hence, in order for MPHS to target immigrants adequately, evidence on determinants of intended participation in HBsAg screening and research on how to reach, invite, and inform immigrants is needed.

#### *Cervical cancer*

The risk of cervical cancer (CC) was found to be increased in immigrant populations in comparison to native Dutch. Between 1996-2009, women born in Suriname, Morocco, Antilles/Aruba, Indonesia, and Turkey were found to have standardised incidence ratios ranging from 2.1 in Surinamese women to 1.2 in Turkish women, respectively (28). Furthermore, although recent screening participation rates among these populations are lacking, Steens et al. (2013) combined data from different sources and at different levels of aggregation with screening data of 2005-2010. Based on this dataset, Steens et al. estimated lower screening participation rates for women from Morocco (53%), Antilles/Aruba (57%), Suriname (62%), and Turkey (64%) in comparison to native Dutch women (79%) (29). Since Turkish- and Moroccan-Dutch share a comparable migration status, religion, and reasons for nonparticipation in cancer screening programmes (15), we choose to target both Turkish- and Moroccan-Dutch women in our studies on IDM regarding the national CC screening programme.

#### **Cervical cancer screening in the Netherlands**

CC is ranked as the fourth most frequently diagnosed cancer in women worldwide (excluding non-melanoma skin cancer) with 569,847 cases in 2018 (30). In the Netherlands, CC ranks as the fifth most frequent cancer among women between 30 and 59 years of age (30).

CC is in almost all cases caused by an infection with one of the twelve high-risk oncogenic types of the sexually transmitted Human Papilloma Virus (HPV). Almost all sexually active women and men are infected with HPV at least once in their lifetime (80-90%) (31), but these infections are usually cleared by the immune system. However, in 3-5% (32), a chronic infection with high-risk HPV develops to invasive CC, which can take up to 20 to 30 years (33). Because of this time frame and the asymptomatic course of a chronic infection, there is a window of opportunity for

screening programmes to target precancerous cervical lesions and prevent invasive cancer.

Since 1996, the Dutch national CC screening programme has been implemented to detect CC in an early treatable stage by examining a cervical smear. Since then, mortality rates decreased (34). In 2017, the Netherlands switched from cytology-based to HPV-based screening because of substantial evidence that the latter is more effective in reducing the incidence of cervical (pre)cancer (35). Cytology examines whether there are abnormal or precancerous changes in the cells of the cervix, while HPV-based screening detects whether high-risk HPV is present in the cervix. Currently, in cases of high-risk HPV, additional cytology is performed to determine whether abnormal or precancerous changes in the cells of the cervix are present. Although an important advantage of HPV-based screening is that it can be done on a sample collected by women themselves (i.e. self-sampling), cytology can only be performed on smears collected by the GP or his/her assistant (i.e. through clinician-based sampling). In this screening programme, women aged 30 to 60 years are invited to participate every five years via a Dutch invitation letter and information brochure.

#### **Cervical cancer screening among Turkish and Moroccan women in the Netherlands**

As previously explained, Turkish- and Moroccan-Dutch women show lower CC screening participation rates compared to native Dutch women (29). It is yet unclear whether these lower participation rates are the cause of the higher CC incidence among immigrant women, as it may also be explained by various other reasons, such as differences in high-risk HPV prevalence, reflection of the incidence in the country of birth, distribution of high-risk HPV types, and differences in sexual (risk) behaviour (36). The combination of a lower CC screening participation and a higher CC incidence urges for interventions to increase (informed) CC screening participation.

Besides their screening participation, there is no evidence available regarding their decision-making process and whether or not this is informed. Previous research found that native Dutch CC screening participants regularly did not make an informed CC screening decision according to the commonly used definition described earlier. They often had insufficient decision-relevant (according to cancer experts) knowledge, especially regarding false-positive and -negative test results (37). However, earlier studies on colorectal cancer screening and bowel cancer screening found that individuals themselves often did feel informed, were satisfied with their decision, and experienced little decisional conflict (38, 39). This raises the question of how Turkish- and Moroccan-Dutch women make CC screening decisions in practice and when they consider they have made an informed and 'good' screening decision. As previous studies reported 1) lack of awareness and knowledge as main reason for nonparticipation in cancer screening programmes among Turkish- and Moroccan-Dutch women (15), and 2) lower (health) literacy levels among immigrants compared

to non-immigrants (40), IDM regarding CC screening participation is likely to be even less among Turkish- and Moroccan-Dutch women in comparison to native Dutch women. Furthermore, recent information regarding their perceived barriers and facilitators for participation in CC screening is lacking. Moreover, (non)participation in CC screening might also be influenced by the possibility of self-sampling, introduced in 2017. Native Dutch women reported self-sampling as more convenient, less embarrassing, less uncomfortable, and less painful compared to clinician-based sampling (41, 42). As self-sampling has been implemented as a possible screening method in the Netherlands only recently in 2017, it is unknown what influence it might have had on IDM regarding CC screening and its participation rates among Turkish and Moroccan women in the Netherlands.

### Research methods and frameworks

Since previous literature about decision-making regarding screening programmes among Turkish and Moroccan immigrants is scarce, we conducted both qualitative and quantitative studies. We also used and combined various statistical analyses in the field of epidemiology and social sciences to investigate the extent of and identify relevant determinants of screening intention and IDM, and to determine the presence of clustering of screening intentions.

#### *Using theoretical models explaining health behaviour*

In this thesis, a compilation of the Health Belief Model (HBM), the Theory of Planned Behaviour (TPB), and the Betancourt's Model of Culture and Behaviour was used to explore determinants of screening participation. Earlier, van der Veen et al. (2012) used this compilation as a conceptual model for her studies among Turkish-Dutch regarding HBsAg screening participation (20). Her research group found it impossible to identify one model for potential determinants of HBsAg screening participation in this population. Therefore, we followed their approach. The HBM assumes that an individual is more likely to take a 'health action' whenever s/he perceives (1) the disease as serious, (2) her/himself susceptible to the disease, (3) benefits of the 'health action', (4) limited barriers to take the 'health action', (5) self-efficacy in relation to the 'health action', and (6) s/he receives a cue to take the 'health action' (43-45). According to the TPB, intention reflects a person's readiness to perform a certain health behaviour or action, explained by attitude, subjective norm, and perceived behavioural control (43, 46). Betancourt's Model of Culture and Behaviour is more specific, as it includes culture to explain its influence on health behaviour, either directly or through psychological processes (47).

#### *Using respondent-driven sampling for sampling, studying networks, and intervention delivery*

Turkish- and Moroccan-Dutch show lower screening participation rates, are relatively hard-to-reach for researchers, and are understudied in health research in general.

As an example, in a large Dutch cohort study, targeted at six ethnic groups (residents of Dutch, South-Asian Surinamese, African Surinamese, Ghanaian, Turkish, and Moroccan ethnic origin), Turkish- and Moroccan-Dutch had the lowest response rate to an extensive research questionnaire (2).

Because of being hard-to-reach populations and having close-knit social networks (48), in this thesis, we pilot the use of respondent-driven sampling (RDS) for sampling social networks of Turkish and Moroccan immigrants in the Netherlands (49). RDS was initially developed to estimate the prevalence of disease or risk factors in hard-to-reach populations, such as injecting drug users, men who have sex with men, sex workers, and immigrants (50). With RDS, respondents are asked to complete a questionnaire and to invite individuals from their social network (i.e. peers) to do the same, creating chains of peers connected through recruitment ('recruitment trees'). In comparison to snowball sampling, unique and personal tokens are used to follow who recruited whom, and to draw the recruitment trees. Also, a statistical model can be used that weighs the sample to compensate for the fact that the sample was collected in a non-random way. Through this weighing, unbiased population estimates can be calculated (51, 52). RDS can thus be used to reach immigrants, as researchers make use of the peer-to-peer interactions to penetrate respondents' social networks, and to make unbiased population estimates on important health behaviour outcomes, such as intended screening behaviour, IDM, and its determinants.

RDS can also be used for studying network structures and dynamics (53-55) and for intervention delivery (56, 57) for so-called network interventions. The term "network interventions" describes the process of using social network data to accelerate behaviour change (56). To investigate if such a network intervention would be feasible to promote (informed) screening participation, we should first explore whether similar screening intentions cluster within social networks, which is part of this thesis.

#### *Interventions to support making informed screening decisions*

Various interventions aimed at enabling informed screening decisions were previously developed and evaluated, namely decision aids, information brochures, film or video, counselling, and a specific screening visit (58). However, as there is little empirical evidence regarding the effect of these interventions, it is unknown which strategies to enhance IDM are most effective, neither in general populations nor in specific (disadvantaged) groups (58). Previously, a Dutch research group developed an intervention in which peer educators were combined with educational films, so-called culturally sensitive educational films, which resulted in an increased IDM regarding prenatal screening among multicultural pregnant women, showing great potential for CC screening also (59). Therefore, in this thesis, we developed, used, and investigated the possible effect of culturally sensitive educational videos, distributed via RDS, on

Turkish- and Moroccan-Dutch women's IDM regarding CC screening participation, compared to the effect of the current Dutch information brochure.

Research questions

This thesis is guided by the following research questions:

- Which determinants are associated with the intention to participate in HBsAg screening among Moroccan immigrants in the Netherlands? (**Chapters 2 and 3**)
- To what extent do similar HBsAg screening intentions cluster within social networks of Moroccan immigrants in the Netherlands? (**Chapter 4**)
- What is the level of awareness and knowledge, and what are the information needs on chronic hepatitis B and HBsAg screening among Moroccan immigrants in the Netherlands? (**Chapter 5**)
- What is the performance of RDS to reach Moroccan immigrants in the Netherlands? (**Chapter 5**)
- Which determinants are associated with making an informed decision on CC screening (non)participation among Turkish and Moroccan women in the Netherlands? (**Chapter 6**)
- How can we develop a culturally sensitive educational video based on the determinants of the intention to participate in CC screening? (**Chapter 7**)
- What is the effect of a culturally sensitive educational video on IDM regarding CC screening participation among Turkish and Moroccan women in the Netherlands? (**Chapter 8**)

Outline of this thesis

Screening example: Chronic hepatitis B

In **Chapter 2**, determinants of intended HBsAg screening participation were qualitatively explored through semi-structured interviews with Moroccan immigrants in the Netherlands. In **Chapter 3**, these qualitative findings were quantitatively confirmed using offline and online RDS among Moroccan-Dutch. In **Chapter 4**, we used logistic regression analyses to investigate potential clustering of HBsAg screening intentions in social networks of Moroccan immigrants in the Netherlands. In **Chapter 5**, we conducted offline RDS to evaluate its performance to reach Moroccan-Dutch, and to make population estimates on their awareness, knowledge, and information needs on chronic hepatitis B and HBsAg screening.

Screening example: Cervical cancer

In **Chapter 6**, focus groups were conducted to explore how and why Turkish- and Moroccan-Dutch women decide to participate or not in the current Dutch national CC screening programme, and to obtain novel insights into their perceptions on self-sampling. In **Chapter 7**, we developed culturally sensitive educational videos after

selecting relevant determinants. In **Chapter 8**, the possible effect of culturally sensitive educational videos on IDM regarding CC screening participation was assessed in comparison to the effect of the current information brochure among Turkish- and Moroccan-Dutch women.

Definitions used in this thesis

<i>Decisional conflict:</i>	A state of uncertainty about which course of action to take when it involves choices on risk or uncertainty of outcomes, high stakes in terms of potential gains and losses, the need to make value tradeoffs in selecting a course of action, and anticipated regret over positive aspects of rejected options (60).
<i>Ethnic minority:</i>	There is no internationally agreed definition of what constitutes an ethnic minority. In this thesis, an ethnic minority is broadly defined as immigrants and their descendants (61).
<i>Host country:</i>	A country that is the destination for an individual or a group of individuals, irrespective of whether they migrate regularly or irregularly (62).
<i>Host population:</i>	The dominant group living in the host country (62).
<i>Immigrants</i>	Individuals who move into a country other than that of their own nationality or usual residence, so that the host country effectively becomes their new country of usual residence (62). In the Netherlands, first-generation immigrants are defined as individuals that are born abroad. Second-generation immigrants are defined as individuals who have at least one parent born abroad (11). Third-generation immigrants are regarded as not being immigrants.
<i>Informed decision-making:</i>	Decision-making based on a good understanding of the potential benefits and adverse effects of cancer screening combined with individuals' personal situation and preferences (16, 17).
<i>Migrants</i>	There is no internationally agreed definition of the term migrants. Migrants may remain in the host country ("settlers" or "immigrants"), move on to another country ("transit migrants"), or move back and forth between countries ("circular migrants") (63). In this thesis, migrants are defined as individuals born outside the Netherlands from non-Dutch parents, who have moved to live in the Netherlands on a permanent / semi-permanent basis. Otherwise referred to as "first-generation" immigrants.

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# 2

## Hepatitis B in Moroccan-Dutch: a qualitative study into determinants of screening participation

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## Abstract

### Background

Chronic hepatitis B (HBV) leads to an increased risk for liver cirrhosis and liver cancer. In the Netherlands, chronic HBV prevalence in the general population is 0.20%, but 3.77% in first generation immigrants. Our aim was to identify determinants associated with the intention to participate in HBV testing among first generation Moroccan immigrants, one of the two largest immigrant groups targeted for screening.

### Methods

Semi-structured interviews were held with first (n = 9) and second generation (n = 10) Moroccan-Dutch immigrants, since second generation immigrants frequently act as their parents' brokers in healthcare.

### Results

Most participants had little knowledge about hepatitis B, but had a positive attitude towards screening. Facilitators for screening intention were perceived susceptibility to and severity of disease, positive attitude regarding prevention, wishing to know their hepatitis B status, and to prevent potential hepatitis B transmission to others. Additional cultural facilitators included fear (of developing cancer), and existing high health care utilization; a religious facilitator was the responsibility for one's own health and that of others. Barriers included lack of awareness and knowledge, practical issues, not having symptoms, negative attitude regarding prevention, fear about the test result, and low risk perception. A cultural barrier was shame and stigma, and a religious barrier was fatalism.

### Conclusion

We identified important facilitators and barriers, which we found, can be interpreted differently. Specific and accurate information should be provided, accompanied by strategies to address shame and stigma, in which Islamic religious leaders could play a role in bringing information across.

## Introduction

Chronic hepatitis B virus (HBV) infection may progress into severe liver disease, such as liver cirrhosis and liver cancer (1). Worldwide, the prevalence of chronic HBV (measured by testing hepatitis B surface antigen (HBsAg) in blood) varies widely with the highest prevalence in countries of the African- and South-East Asian region (2). In the Netherlands, 0.2% of the general population is HBsAg positive (3) and each year an estimated 200 individuals die of sequelae of chronic HBV infection (4). Among Dutch first generation immigrants originating from intermediate- or high-endemic countries, the HBsAg prevalence was estimated as high as 3.77% (3, 5, 6).

With 385,761 individuals (2016), Moroccans represent together with Turks (397,471 individuals) the largest immigrant groups in the Netherlands. Of the total Dutch population, 2.3% is Moroccan and 2.3% is Turkish (7). There are 168,336 first generation Moroccan-Dutch of which about half live in urban areas: Amsterdam (21%), Rotterdam (12%), Utrecht (8%), and The Hague (8%) (8). In Morocco, the prevalence of HBsAg is 1.81% (9). Two small studies showed lower chronic HBV prevalences among Moroccan-Dutch (0.4% and 0%) (10, 11). However, a meta-analysis found similar chronic HBV prevalence rates in migrants compared to the prevalence of chronic HBV in their countries of origin (12). This suggests that the prevalence among first generation Moroccan-Dutch may be similar to its prevalence in Morocco.

In November 2016, the Dutch Health Council recommended blood testing of all first generation immigrants originating from countries with intermediate or high HBV endemicity to detect chronically infected individuals and refer them for monitoring or immediate treatment. Identification of infected individuals also allows measures to prevent further HBV transmission. The Council proposed two implementation strategies: (1) individual case finding by general practitioners (GPs), and (2) screening programmes in cities or regions with large immigrant numbers (13). In 1989, the Netherlands introduced antenatal HBV screening for pregnant women to prevent mother-to-child transmission (14). This means that up to now, no national HBV screening programme, specifically directed at first generation immigrants, was in place.

Because of the recent recommendation, there is no information (yet) regarding the numbers of HBV screening participation among first generation Moroccan-Dutch. What we do know, is that other health-related screening programmes reported lower attendance rates among Moroccan-Dutch compared to indigenous populations (15-19). Visser et al. (2005) reported a participation rate in breast cancer screening (1995-2001) of 37% for Moroccan women, significantly lower than the overall attendance of 76% (19). In 2007-2008, the overall attendance at breast cancer screening increased to 83%, but (again) remained significantly lower for Moroccan women (54%) (18). During

the cervical cancer screening (1998-2001), the overall attendance was 55.7%; again less Moroccan women participated (35.9%) (17).

Therefore, eliminating barriers for participation in HBV screening is demanded and requires identification of determinants of screening behaviour among Moroccan-Dutch (20). Earlier qualitative studies focusing on other preventive programmes for Moroccan-Dutch reported lack of awareness and knowledge, organizational issues (e.g. too busy), socio-cultural aspects (e.g. low level of education and fear of social isolation), perceived susceptibility, and benefits and barriers (e.g. fear of the test result) as important determinants for participation in preventive programmes (15, 21-24).

While extensive research was conducted on determinants to participate in HBV screening among Turkish-Dutch (25), no study examined these determinants among Moroccan-Dutch. Prior to implementing screening programmes as proposed by the Dutch Health Council, our aim was to identify determinants associated with HBV screening participation among first generation Moroccan-Dutch.

## Methods

### Sampling

We used purposive snowball sampling, since it may allow us to reach and study migrants (a hard-to-reach population). As a disadvantage, it may result in selection bias, as participants' social networks are not random. To limit this form of bias, we used various sources to approach possible study participants, namely community organizations (community and day care centres, mosques, interest groups, and civil support foundations) located in various cities in the Netherlands (i.e., mainly Amsterdam, Rotterdam, Utrecht, and The Hague), and assured maximum variation in our sample by including male and female participants from different places and of different ages with various levels of education and Dutch language proficiency.

Although first generation migrants (FGM) are the targeted group for screening, we also interviewed second generation migrants (SGM), since they frequently act as brokers for their (grand-)parents in contacts with the Dutch healthcare system (26). FGM were defined as individuals born in Morocco and having at least one parent born in Morocco. SGM were defined as individuals born in the Netherlands and having at least one parent born in Morocco (27). Of all study participants, we did not know their HBV screening status prior to interviewing, as we wanted to gather information, independently of their status. New study participants were recruited until data saturation was reached (i.e., no new information was found during the last interviews).

Prior to each interview, participants were verbally informed about the study and asked to sign an informed consent form. Participants received a small (non-monetary) token

of appreciation. The medical ethical committee of the UMC Utrecht approved this study [16-621/C].

### Semi-structured interviews

Semi-structured interviews were held by a native Dutch-Berber speaking female researcher in Dutch, Berber, or a combination of both, and lasted approximately one hour.

We developed a topic list consisting of questions about potential determinants of the intention to have a HBV blood test. This list was based on a compilation of the Health Belief Model (HBM), the Theory of Planned Behaviour (TPB), the Betancourt's Model of Culture and Behaviour, and literature on determinants for (non-)participating to other screening programmes (15, 21-25). Van der Veen et al. (2014) proposed this compilation as a conceptual model for her study among Turkish-Dutch regarding HBV screening participation (see Supplementary Figure S2.1) (28).

Interviews started with broad questions regarding knowledge and awareness of HBV. If participants were unfamiliar with the topic, concise verbal information about HBV, transmission, and testing was given. As sexual contact and drug use are often seen as taboo, we did not actively inform participants about these transmission routes. We informed participants about the main transmission routes among Moroccan migrants, which are perinatal transmission and blood contact between family members (5). However, if interviewees mentioned sexual contact and/or drug use by themselves, we also discussed these topics. Detailed background information was made available in Dutch through our project website ([www.rivm.nl/Onderwerpen/H/Hepatitis\\_B/MARAZ\\_onderzoek\\_hepatitis\\_B](http://www.rivm.nl/Onderwerpen/H/Hepatitis_B/MARAZ_onderzoek_hepatitis_B)).

Subsequently, we asked questions concerning potential determinants of health behaviour, including topics such as shame and stigma. At the end of each interview, socio-demographic data of the participants were recorded. Participants were also asked to score their Dutch language proficiency as 1 (poor), 2 (average) or 3 (excellent)

Interviews were audio recorded. During one interview, the tape recorder broke down at the start, and one interviewee refused to be recorded. In these two cases, notes were taken and summarized at the end of the interview.

### Data analysis

Recordings were transcribed ad verbatim, and thematically analysed through coded transcripts by NH using ATLAS.ti version 7.5.6. A random 30% of all participants was double coded by MS, MvdM, and JvS, and findings were subsequently discussed to reach consensus about their meaning. Berber interviews were directly translated into Dutch transcripts.



Results

Study participants

We included 9 first (FGM) and 10 second generation Moroccan-Dutch migrants (SGM) (see Supplementary Table S2.1). The majority was female (63%), and all participants were Muslim. FGM had a mean age of 47 years compared to 26 years for SGM. Four FGM (57% of all FGM) reported to have completed a medium level of education or higher. Of the SGM, 70% had a medium or higher level of education. FGM and SGM both reported a median Dutch proficiency score of 3.

Thematic analysis

We extracted the following themes that may influence the intention to have a HBV blood test: (1) awareness and knowledge, (2) cultural aspects and religion, (3) practical issues, (4) fear about the test result, (5) perceived benefits, (6) perceived social norm, and (7) perceived susceptibility to and severity of disease.

Awareness and knowledge

Most participants (n = 14) expressed not to know what HBV is, or having insufficient knowledge about the disease. The few participants who did know what HBV is, mentioned a general lack of medical knowledge within the Moroccan-Dutch community. FGM who were aware of HBV and did have sufficient knowledge about the disease, often associated HBV with acquired immune deficiency syndrome (AIDS), as both are sexually transmitted diseases (see Box I).

Cultural aspects and religion

Cultural aspects

Most participants (n = 15) expressed that, in general, diseases are taboo in the Moroccan culture. Some SGM participants (n = 3) mentioned high health care utilization of their (grand-)parents (FGM) as facilitator, and one SGM participant mentioned fear of developing cancer as barrier for taking the HBV test (see Box I).

Religion

Some participants introduced Islam as a topic. According to two participants, people's way to practice their religion may limit their testing behaviour. On the contrary, others mentioned that it could also stimulate people to test (see Box I).

Box I. Quotes belonging to the theme 'Awareness and knowledge', 'Cultural aspects', and 'Religion'

Theme	Corresponding quote(s)
Awareness and knowledge	<i>"It often is ignorance. You do not know what it is, you have no symptoms, and you do not know where it may lead to"</i> (R2, FGM, M, 52 years)
	<i>"It [HBV] should be more known. More information should inform people. That is necessary, because nobody talks about it"</i> (R4, FGM, F, 47 years)
	<i>"Medical knowledge is often lacking"</i> (R12, SGM, M, 20 years)
	<i>"People are not educated, so it [HBV] will be swept under the carpet. Look: Only people who know a bit more and have knowledge about the human body will think: Yes, it should go the right way, because our health comes first"</i> (R8, FGM, F, 45 years)
	<i>"I would not just do a test, just like that. As long as I feel nothing, have nothing, and perceive nothing, then I am not having a test"</i> (R2, FGM, M, 52 years)
	<i>"It's as if you are searching for a disease. If you are going to test all kind of things, you are 100% sure that you are going to find something"</i> (R4, FGM, F, 47 years)
Cultural aspects	<i>"It is basically just like AIDS and that kind of things. It [AIDS] is of course much larger and much more aggressive, much more in the media, but actually, it is all a bit the same. Our culture has a bit of shame for it [STDs]"</i> (R17, FGM, F, 46 years)
	<i>"For Moroccans, all diseases are taboo. You have cancer, it is taboo. You have diabetes, it is taboo. They do not want to express it. They do not want to tell it. It does not matter what type of disease it is. It will not be mentioned"</i> (R1, FGM, F, 45 years)
	<i>"Moroccans often like to go to the doctor. I think they would like to have the test. Especially when you tell them, you can develop cancer. What Moroccans really do not want to hear, is cancer. So, if you say cancer, they will experience stress and say: Please test me"</i> (R6, SGM, M, 21 years).

Box I. Quotes belonging to the theme 'Awareness and knowledge', 'Cultural aspects', and 'Religion' (continued)

Theme	Corresponding quote(s)
Religion	"A Moroccan who lives according to the Islam says 'Listen, I will take it all for granted. I will not have myself tested. Or I do not want any medications.' Another would say: 'Listen, Allah has created people to cure each other, so you should also accept those medications or let yourself be treated by the concerned expert'" (R16, SGM, M, age unknown)

AIDS: acquired immune deficiency syndrome, HBV: hepatitis B virus, STDs: sexually transmitted diseases

Shame and stigma

Association of hepatitis B with sexuality

We explored this theme with participants who knew that HBV can be transmitted sexually. A few female participants (n = 2) mentioned a difference between men and women regarding the sensitivity among sexuality and indicated the association of hepatitis B with sexuality as barrier (see Box II).

Association of hepatitis B with drugs

Although hepatitis B was more often associated with sexuality, two female participants mentioned the association with drugs as barrier (see Box II).

Disclosure of HBV status

Some participants (n = 3) thought people would be afraid about others' disapproving opinion if they would get to know their HBV status. If someone would be tested positive for HBV, they would only disclose this to their partner and/or a limited number of family members (see Box II).

Box II. Quotes belonging to 'Association of hepatitis B with sexuality and drugs' and 'Disclosure of hepatitis B status'

Theme	Corresponding quote(s)
Association of hepatitis B with sexuality	"Hepatitis B, you would think 'okay, how do you get that? It is sexually transmittable. That is one of the reasons, but for Moroccans it is also a reason. You can also have done that [sexual contact]. People think wrong very quickly in the Moroccan culture. People are ashamed very quickly and do not talk about such diseases [STDs]. Especially women have that" (R5, SGM, F, 23 years)  "I think it [to have a HBV test] will be more difficult for women than for men. It is just taboo. It will not be mentioned. I think that women will not have such a test so easily unless it will be mandatory or when they will notice that their liver does not work very well at a later stage" (R8, FGM, F, 45 years)
Association of hepatitis B with drugs	"Hepatitis B sounds a bit scary. I thought: 'Oh, needles'. You immediately think about a certain community. About addicts and stuff" (R19, SGM, F, 38 years)  "We, our children, they never use drugs or alcohol or whatever. They do not use each other's needles. No" (R8, FGM, F, 45 years)
Disclosure of hepatitis B status	"They would rather keep it [HBV status] for themselves. People are afraid for what would happen if the 'outside world' or doctor would know. One is also not aware of the privacy policy of different municipal organizations" (R8, FGM, F, 45 years).

HBV: hepatitis B virus, STDs: sexually transmitted diseases

Practical issues

The majority did not express any practical issues that may limit them to have a HBV test. However, a few participants (n = 2) could imagine practical issues that may impede HBV testing, such as an insufficient Dutch language proficiency. Additionally, the majority (n = 10) mentioned the costs of the test as a possible obstacle (see Box III).

Fear about the test result

Fear about the test result was frequently mentioned as a serious barrier (see Box III).

Box III. Quotes belonging to 'Practical issues' and 'Fear about the test result'

Theme	Corresponding quote(s)
Practical issues	<p>"It is just a blood test. It is not as if they [people born in Morocco] must drive far away and should take a lot of effort. Yes, you will probably go to the hospital or general practice centre once. Blood will be drawn" (R19, SGM, F, 38 years)</p> <p>"I think they [eligible people to have a HBV test] will find it [HBV test] a hassle. [...] To discuss it with the doctor I think. Many people have troubles with that [language barrier]. [...] Then they need a third person and should ask someone else. They would not do that. They will find themselves a burden, so they would let it go. I think" (R3, FGM participant, F, 45 years)</p> <p>"It is not a cure, so you are investing to know if you have something first. You can compare it to the MOT test (in Dutch: APK). If your car is riding fine, you would rather not have the MOT test, because everything is okay. You have to pay the hours that someone is looking at your car. You are losing money to know that your car is riding fine. It is comparable. However, if your exhaust is broken, and you will have the MOT test, you would pay 100 euros, 200 euros, because you know you must fix the exhaust" (R6, SGM, M, 21 years)</p>
Fear about the test result	<p>"If people would say to me: 'Come, let's have you tested for hepatitis B', I would become scared. People rather know nothing [by not testing] then to have the chance to have a bad test result" (R14, SGM, F, 18 years)</p>

HBV: hepatitis B virus, MOT: Ministry of Transport

Perceived benefits

Most participants (n = 13) had a positive attitude towards the HBV test and expressed that it will potentially benefit their health, or of their (grand-)parents. The saying "A stitch in time saves nine" (meaning: "Prevention is better than cure") was often mentioned. Preventing potential HBV transmission to others was seen as an additional benefit (see Box IV).

Perceived social norm

As for the social norm regarding HBV, many participants talked about others (including family and friends) who may avoid the ones with HBV, because of their fear to become infected as well. This social norm regarding HBV may influence the testing behaviour of FGM negatively, as people also mentioned social pressure or control. Other FGM, and to a lesser extent SGM, acknowledged the existence of social norms, but did not

want to interact in this social environment. These female participants would rather consult their partner or GP to decide whether they should take the test (see Box IV).

Perceived susceptibility to and severity of disease

A low risk perception seemed to be an important determinant of male SGM participants for not recommending the test to their (grand-)parents. This is in contrast of what female SGM participants expressed. They addressed the flawed risk perception of others while stating that this indifference should be fought (see Box IV).

Box IV. Quotes belonging to 'Perceived benefits', 'Perceived social norm', and 'Perceived susceptibility to and severity of disease'

Theme	Corresponding quote(s)
Perceived benefits	<p>"I don't think there are disadvantages. If you do not have the disease, you have nothing to lose. You did the test. If you have the disease, you will be treated. If you know you do not have the disease, it is all right. Then at least you know that you do not have it [HBV]" (R1, FGM, F, 45 years)</p> <p>"You are doing something good for common humanity. You are preventing something" (R17, FGM, F, 46 years)</p>
Perceived social norm	<p>"They will become anxious to be exposed to you. Is the disease contagious or can I come close to you or talk to you?" (R1, FGM, F, 45 years)</p> <p>"Among us [Moroccans], there is a strong social control. When people say 'It is good to have it [HBV test], because of this and that', then people will have it [HBV test]" (R11, FGM, M, 52 years)</p> <p>"I would discuss it [having a HBV test] with my partner to check what he thinks about it. That is it. I do not care about the rest. I do not care about what others think about it" (R17, FGM, F, 46 years)</p> <p>"If the GP approaches me, I will take it [HBV test]" (R4, FGM, F, 47 years)</p>

Box IV. Quotes belonging to 'Perceived benefits', 'Perceived social norm', and 'Perceived susceptibility to and severity of disease' (continued)

Theme	Corresponding quote(s)
Perceived susceptibility to and severity of disease	<p>"How great is the chance that they have it [HBV]? You also think 'If I feel good, a test is not necessary'. Even if you tell me that, they can have it without knowing and feeling something. So no, I would not recommend having the test" (R6, SGM, M, 21 years)</p> <p>"The most important argument in favour (of the HBV test) is the health risk, but that is also my most important argument against (the HBV test). How great is the risk?" (R12, SGM, M, 20 years)</p> <p>"Most people think: I don't have it [HBV]. People therefore do not have themselves tested, but I do think it is important. Especially for people who are born in Morocco" (R5, SGM, F, 23 years)</p>

HBV: hepatitis B virus, GP: general practitioner

Discussion

This is the first qualitative study identifying facilitators and barriers for participating in chronic HBV screening among first (FGM) and second generation (SGM) Moroccan-Dutch. Most participants had little knowledge about HBV, but had a positive attitude towards testing. Facilitators were perceived susceptibility to (in women) and severity of disease, positive attitude regarding prevention, the wish to know their HBV status, and to prevent potential HBV transmission to others. Cultural facilitators included fear of developing cancer and high health care utilization. A religious facilitator was the responsibility for one's health and that of others.

Barriers included lack of awareness and knowledge, practical issues, not having symptoms, negative attitude regarding prevention, fear about the test result, and low risk perception (in men). An important cultural barrier was shame and stigma as (1) diseases are taboo, (2) hepatitis B may be associated with sexual contact and drug use, and (3) disclosure of HBV status. An important religious barrier was fatalism, which is an attitude emphasizing the subjugation of all events to fate.

Some factors, such as perceived social norm or support, religion, and knowledge, seemed to act as facilitator and barrier, as seen in our proposed mechanisms (see Figures S2-S4). The label 'being different' may act as barrier, while social support may stimulate people to have themselves tested. Religion can act as facilitator if one takes responsibility of one's own health and prevents HBV transmission in the light of the Islam, but as barrier if people interpret their health as predestined and not as something they can control (i.e. fatalism).

Overall, our findings are in line with previous studies that focused on preventive behaviour of Moroccan-Dutch (15, 21-24), e.g., lack of Dutch language proficiency (15, 21, 23, 24), costs (23), and gender differences with respect to HBV risk perception (29). However, our study identified specific facilitators and barriers, such as the association of HBV with sexual contact and drugs.

Despite several differences between Moroccan-Dutch and Turkish-Dutch, such as culture (30), Dutch language proficiency (7), and screening participation (15-19), it is relevant to compare these groups because of their comparable migration status, religion, and socio-economic status. Regarding HBV specific determinants, Van der Veen et al. found in Turkish-Dutch (religious) responsibility for one's health, reputation, and social support in being tested for HBV as facilitators (31). This is similar to our findings in Moroccan-Dutch. Both in Turkish- and Moroccan-Dutch, barriers were found to be the association of HBV screening with sexual contact and fatalism. By contrast, Moroccan-Dutch also mentioned drug use as an undesirable association with HBV.



In comparison to Van der Veen et al. (31), we did not only focus on socio-cultural determinants and, therefore, found determinants that are guided by the HBM and the TPB. Turkish-Dutch mentioned perceived low efficacy of Dutch health care services as barrier and perceived obligation when being invited for screening as facilitator (31), which were not found in our study. This may be related to the low perceived quality of the Moroccan health care compared to the Dutch, while Turkish-Dutch perceive a higher quality of health care in Turkey compared to the Netherlands. Also, as we identified 'not having symptoms' as barrier, Moroccans may feel less obligated to participate in screening compared to Turkish-Dutch.

### Strengths and limitations

An important strength of our study is the inclusion of SGM, who were generally more assertive and outspoken. This led to more information on topics, such as sexual contact, drug use, and fatalism. Additionally, since SGM frequently act as brokers for their (grand-)parents in contacts with the Dutch healthcare system (26), they represent an important group to consider in programmes oriented at screening first generation Moroccan-Dutch. Second, to ensure reliability, data were double coded by a second researcher. Third, we mainly targeted cities with a high density of first generation Moroccan-Dutch, for which the Dutch Health Council also proposed HBV screening programmes.

However, there were also limitations in this study. First, we did not specifically ask participants whether they were screened for HBV. It is possible that HBV screening status influenced our study participants' opinions and the discussion at large. Second, participants did not have the opportunity to review their transcripts. This may have led to reduced internal validity. As Berber is only a spoken language, transcripts were translated and written in Dutch, which may not be easily read by most FGM participants. Third, selection bias might have occurred, as most participants were women and highly educated. The interviewer was a female Moroccan-Dutch researcher, which may have discouraged Moroccan-Dutch men to participate due to their religiousness and cultural norms. These factors may additionally have restricted men, but possibly also women, in what they expressed during the interviews. Unfortunately, it was not feasible in our time frame and budget to include a male Moroccan-Dutch researcher. Moreover, although we did not explore gender differences explicitly, our findings suggested several, as male SGM participants expressed low HBV risk perception as barrier, female participants mentioned the association of HBV with sexuality and drugs, and female participants expressed a gender difference regarding sensitivity among sexuality. These differences are only suggestive because of the qualitative nature of this study. These findings seem to imply the importance of tailored communication strategies based on gender, but further research on gender differences is needed. Furthermore, our finding of determinants acting as facilitator and barrier is challenging for communication

strategies. This dual effect shows the intrinsic limitation of choosing and labelling determinants of human behaviour. Determinants are not existing entities in the real world, but are chosen terms, used as metaphors trying to understand health behaviour. Peters and Crutzen argue not to build theories using determinants, but to establish a 'pragmatic nihilism' perspective, for which, it is essential to define theories and to develop guidelines to operationalize such determinants (32). For developing communication strategies for screening participation, this study provided sufficient information and guidance. For future studies, it would be interesting to follow the approach of 'pragmatic nihilism', and recreate and operationalize determinants. Finally, although this study provided insight into determinants of HBV testing behaviour in Moroccan-Dutch, we recommend confirming these results quantitatively in a large representative sample of this population.

### Implications and future research

As the majority of participants lacked awareness and knowledge (i.e. health literacy (33)) regarding HBV, an educational campaign is a cornerstone for participation and should by all means be introduced in Amsterdam, Rotterdam, Utrecht, and The Hague. This campaign can be tailored to the needs of Moroccan-Dutch using the obtained knowledge. Moreover, as flawed risk perceptions are present, clear and visual information on the risk of developing chronic HBV and liver cancer should be provided to aid informed decision-making among Moroccan-Dutch.

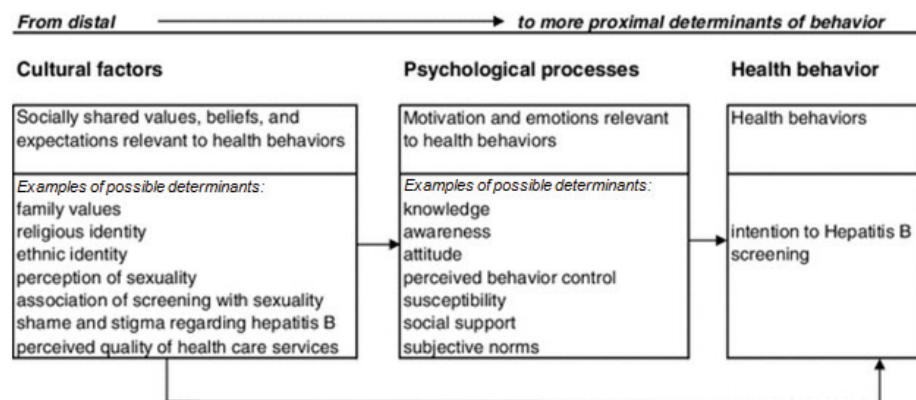
### Conclusion

This study identified important facilitators and barriers, which require careful consideration when designing and implementing communication strategies. Specific and accurate knowledge provision is important, but should be accompanied by strategies to address shame and stigma. Islamic religious leaders within the Moroccan-Dutch community should, therefore, be informed about hepatitis B and risk (1) to bring information across, (2) to decrease elements of shame and stigma, leading to more acceptance of HBV screening.

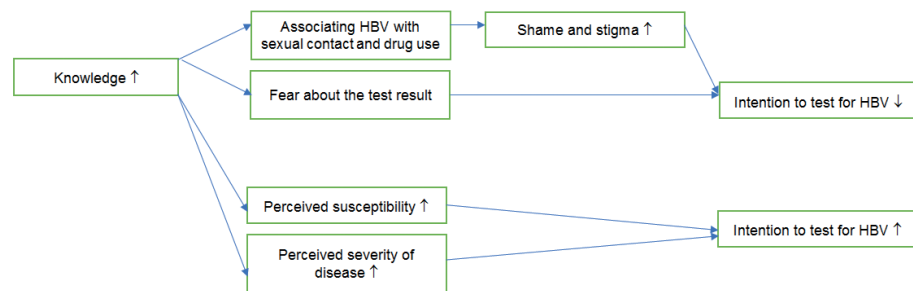
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## Supplementary Tables and Figures

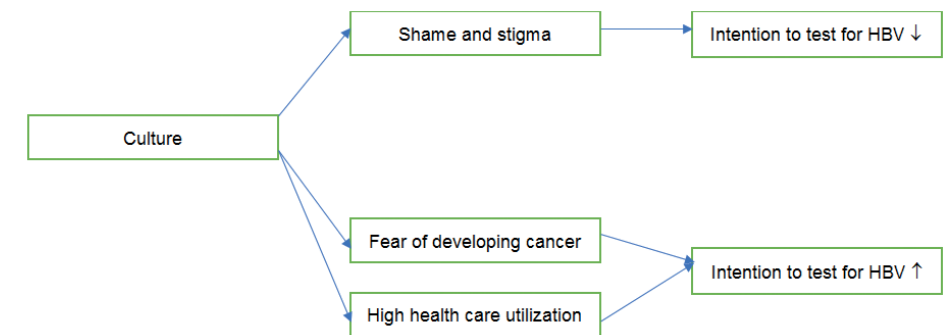


**Supplementary Figure S2.1.** Conceptual model of the relationship between social-cognitive, socio-cultural determinants, and hepatitis B-screening intention in Turkish Dutch as proposed by Van der Veen et al. (28)

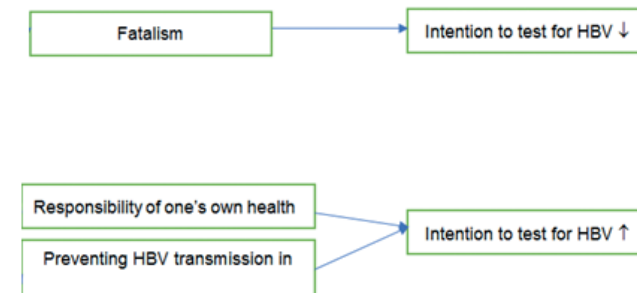


**Supplementary Figure S2.2.** Proposed mechanisms of the relationship between knowledge and intention to test for HBV

If the level of knowledge would increase and people would know that HBV may be transmitted via sexual contact or contaminated needles, this might lead to shame and stigma within the Moroccan-Dutch population and a decreased intention to test for HBV. More knowledge may also lead to an increased perceived susceptibility and severity of disease, resulting in an increased intention to test for HBV.



**Supplementary Figure S2.3.** Proposed mechanisms of the relationship between cultural determinants and intention to test for HBV



**Supplementary Figure S2.4.** Proposed mechanisms of the relationship between religious determinants and intention to test for HBV

Supplementary Table S2.1. Characteristics of the participants (n = 19)

Moroccan-Dutch interviewees	Gender (male)	Mean age, in years	Married	Religious	Mean core family size	Highest completed level of education, medium or higher	Main occupation in daily life			
							Education	Job	Retired	Household
FGM (n = 9)	3 (33)	47 <sup>a</sup>	6 (67)	9 (100)	10	4 (57) <sup>a</sup>	-	3 (43) <sup>a</sup>	-	4 (57) <sup>a</sup>
SGM (n = 10)	4 (40)	26 <sup>a</sup>	3 (33)	10 (100)	5	7 (70)	6 (60)	2 (20)	-	2 (22)

Data are reported as number of participants (%).  
<sup>a</sup>Two participants did not respond to this question.  
FGM: first generation migrant, SGM: second generation migrant



# 3

## Hepatitis B in Moroccan-Dutch: a quantitative study into determinants of screening participation

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## Abstract

### Background

In November 2016, the Dutch Health Council recommended hepatitis B (HBV) screening for first-generation immigrants from HBV endemic countries. However, these communities show relatively low attendance rates for screening programmes and our knowledge on their participation behaviour is limited. We identified determinants associated with the intention to request a HBV screening test in first-generation Moroccan-Dutch immigrants. We also investigated the influence of non-refundable costs for HBV screening on their intention.

### Methods

Offline and online questionnaires were distributed among first- and second/third-generation Moroccan-Dutch immigrants using respondent-driven sampling. Random forest analyses were conducted to determine which determinants had the greatest impact on (1) the intention to request a HBV screening test on own initiative, and (2) the intention to participate in non-refundable HBV screening at € 70,-.

### Results

Of the 379 Moroccan-Dutch respondents, 49.3% intended to request a test on their own initiative and 44.1% was willing to attend non-refundable screening for € 70,-. Clarity regarding infection status, not having symptoms, fatalism, perceived self-efficacy, and perceived risk of having HBV were the strongest predictors to request a test. Shame and stigma, fatalism, perceived burden of screening participation, and social influence of Islamic religious leaders had the greatest predictive value for not intending to participate in screening at € 70,- non-refundable costs. Perceived severity and possible health benefit were facilitators for this intention measure. These predictions were satisfyingly accurate, as random forest retrieved area under the curve scores of 0.72 for intention to request a test and 0.67 for intention to participate in screening at € 70,- non-refundable costs.

### Conclusions

By the use of respondent-driven sampling, we succeeded in studying screening behaviour among a hard-to-reach minority population. Despite the limitations associated with correlated data and the sampling method, we recommend to (1) incorporate clarity regarding HBV status, (2) stress the risk of an asymptomatic infection, (3) emphasize mother to child transmission as main transmission route, and (4) team up with Islamic religious leaders to help decrease elements of fatalism, shame, and stigma, to enhance screening uptake of Moroccan immigrants in the Netherlands.

## Background

Hepatitis B (HBV) is one of the major infectious diseases in the world, which if chronic and untreated, has an increased risk for serious complications, such as liver cirrhosis and liver cancer (1). In the Netherlands, 0.2% of the general population has a chronic HBV infection and annually an estimated 200 individuals die from chronic sequelae (2).

Countries of African and South-East Asian regions have the highest prevalence of chronic HBV (3). Dutch population-based studies showed a significantly higher prevalence of chronic HBV infection in immigrants from all intermediate or high-endemic countries (4, 5). From these areas, the two largest immigrant groups in the Netherlands are Turks and Moroccans. In 2016, there were 397,471 Turkish-Dutch individuals and 385,761 Moroccan-Dutch individuals (6).

Two small studies showed hepatitis B surface antigen (HBsAg) prevalences for Moroccan-Dutch immigrants to be 0.4% (n = 281) and 0.0% (n = 50) (7, 8). However, a systematic review and meta-analysis found similar chronic HBV prevalences for immigrants in Europe as those in their country of origin (9). This would lead to an estimated HBsAg prevalence of 1.81% among Moroccan-Dutch immigrants (10), which is nine times higher compared to the HBV prevalence in the general Dutch population.

In November 2016, the Dutch Health Council recommended HBV screening for first-generation immigrants originating from intermediate or high HBV endemic countries aiming to detect chronically infected individuals for monitoring and immediate treatment if justified, and hereby preventing further transmission. The predominant mode of transmission in the Moroccan population is mother to child at birth (1). The Council proposed two screening strategies for first-generation immigrants: (1) individual case finding by general practitioners (GPs), and (2) local screening programmes in cities or regions with large numbers of first-generation immigrants originating from countries with intermediate or high endemicity (11). Individual case finding suggests that not all patients visiting the GP will be consistently advised to test for HBV, but only high-risk individuals, which is -among others- based on the country of origin. Therefore, it is important for Moroccan-Dutch to know about this possibility to test and to enable them to request the test on own initiative. Both screening strategies start with a HBV blood test, costing € 35,- (2016). The Dutch health insurance is organised with the compulsory annual front-end deductible ("own risk") of € 385,- (2017). Therefore, the HBV blood test is not refundable for those in whom the threshold of € 385,- is not yet reached with other health care costs. The potential non-refundable costs of the test may inhibit the intention of Moroccan-Dutch individuals to test themselves for HBV.

Previous studies (12-15) have shown lower attendance rates among Moroccan-Dutch immigrants compared to indigenous populations for screening programmes involving breast- and cervical cancer. In these studies, the most important determinants for non-participation were lack of awareness and knowledge, organizational issues, socio-cultural aspects (e.g., (health) illiteracy), perceived social norm, susceptibility, and benefits and barriers (e.g., fear of the test result). As it is unknown whether these determinants similarly influence participation in chronic HBV screening, we considered it essential to identify determinants of chronic HBV screening intention and to examine how screening can be promoted effectively in the Moroccan-Dutch community.

Therefore, our main objective was to identify determinants associated with the intention to actively request a HBV screening test (HBsAg blood testing) in first-generation Moroccan-Dutch immigrants. Since the potential costs of the screening test may discourage Moroccan-Dutch to test themselves, we also investigated the intention of first-generation Moroccan-Dutch to participate in HBV screening for non-refundable costs of € 70,-.

## Methods

### Study design

From November 2016 to February 2017, both offline-recruited and online-recruited respondents were enrolled in this study. Eligibility for participation was defined as (1) aged 16 years or older, and (2) born in Morocco and having at least one parent born in Morocco (first-generation migrants, FGM (16)) or born in the Netherlands and having at least one (grand-)parent born in Morocco (second- or third-generation migrants, STGM (16)), and (3) living in the Netherlands, and (4) not having participated in the study. The rationale for including STGM was that they frequently act as brokers for their parents and grandparents in contact with the Dutch healthcare system. They usually also have a better command of the Dutch language and are more often found online (6). Therefore, we asked STGM similar questions as FGM. STGM were requested to answer the questions for their parents or grandparents as they thought suitable.

### Respondent-driven sampling

We applied respondent-driven sampling (RDS) (17, 18), a variant of chain-referral sampling, to reach and distribute questionnaires among Moroccan immigrants in the Netherlands. RDS starts with a convenience sample of selected members of the target population. Respondents complete a questionnaire and are asked to invite "peers" from their social network to complete the same questionnaire as well. Using invitations containing unique codes, we registered who invited whom in order to follow the interactions within social networks for future analyses. We asked respondents to recruit three or more peers. We offered a gift coupon to both

offline- and online-recruited respondents, whenever someone successfully recruited three or more eligible persons of their network. The value of the gift coupon was gradually increased over time (in three steps: € 5,-, € 10,- and - € 25,-) to enhance peer recruitment. Online respondents could also see anonymous questionnaire results and their recruitment tree at the end of the questionnaire.

### Offline recruitment

Offline-recruited respondents were asked to fill in a paper-based questionnaire, which was distributed in person or via paper mail. We invited respondents at community venues, such as community centres, day care centres, mosques, interest groups, and civil support foundations. Offline-recruited respondents could invite people both offline and online. Offline, respondents could choose between receiving paper questionnaires in person (if possible) or via paper mail. If online was preferred, respondents received a specified number of invitation messages containing a personal link via email or WhatsApp, which could be forwarded to others enabling them to participate in the online questionnaire. Based on population numbers of 2004, first-generation Moroccan-Dutch immigrants mainly live in Amsterdam (21%), Rotterdam (12%), Utrecht (8%), and The Hague (8%) (19). Some other (medium-sized) municipalities, including Gouda, Almere, Leiden, Haarlem, Eindhoven and Tilburg are also cities where relatively large numbers of Moroccans of the first-generation live (19). We, therefore, targeted these cities for the start of our offline recruitment.

### Online recruitment

Online-recruited respondents were enrolled through advertisements on Moroccan-Dutch forums, Facebook, Instagram, the website of the Dutch National Institute for Public Health and the Environment (RIVM), and a Moroccan-Dutch website (20). An online RDS questionnaire system, similar to the one developed by Bengtsson and colleagues (21), was used to apply online RDS. Recruiting peers online was enabled through indirect e-mail (i.e., sending an e-mail invitation to yourself, which could be forwarded to contacts), WhatsApp, Facebook, or by sharing a hyperlink.

### Study population

First-generation Moroccan-Dutch immigrants generally speak Berber and/or Arabic. As Berber languages and Arabic dialects are solely speaking languages, no written variant is available. Therefore, respondents were invited to complete a Dutch questionnaire. To reduce possible difficulties with reading Dutch, we used simple Dutch (B1-level). Whenever respondents wanted to invite someone that did not master the Dutch language, they could provide this person's phone number in order for the researcher to contact this person to schedule a face-to-face or telephone interview in Berber. In the online questionnaire, we also provided audio recordings containing information about HBV, transmission, and testing in Dutch, Berber, and Moroccan-Arabic.

Respondents that reported to speak Berber were defined as Moroccan-Berber. A Moroccan-Arabic identity was identified whenever a respondent reported to speak Moroccan-Arabic and/or Modern Standard Arabic without the ability to speak Berber.

### Questionnaire

A questionnaire was developed and tested among both FGM and STGM. Items were based on formative qualitative research in which we discussed determinants originating from a compilation of the Health Belief Model (HBM), the Theory of Planned Behaviour (TPB), and the Betancourt's Model of Culture and Behaviour. This compilation was previously used in the Turkish-Dutch community (22) by Van der Veen, et al. This research group found it impossible to identify one model for potential determinants of HBV screening behaviour in this group. Therefore, we followed this approach. The HBM assumes that a subject is more likely to take a 'health action' whenever he perceives (1) the disease as serious, (2) himself susceptible to the disease, (3) benefits of the 'health action', (4) limited barriers to take the 'health action', (5) self-efficacy in relation to the 'health action', and (6) receives a cue to take the 'health action' (23-25). According to the TPB, intention reflects a person's readiness to perform a certain health behaviour or action, explained by attitude, subjective norm, and perceived behavioural control (23, 26). The Betancourt's Model of Culture and Behaviour is more specific, as it includes culture to explain its influence on health behaviours, either directly or through psychological processes (27).

Respondents without any knowledge or awareness of HBV were informed on the key characteristics of the virus, the disease, transmission, and testing, prior to completing the questionnaire. Detailed background information was made available in Dutch through our project website. The questionnaire included questions regarding socio-demographic factors (i.e., age, gender, country of birth, and educational level), relationship with the recruiter, social network size, knowledge about HBV, HBV vaccinating and testing history, stigma and shame regarding HBV, social influence, perceived susceptibility, self-efficacy, and severity of disease, intention to have a HBV blood test, and the perceived benefits and barriers of having this test. Supplementary Table S3.1 shows the set of outcome and predictor variables included in the questionnaire. In the Netherlands, individuals without other health care costs have to pay € 35,- (in 2017) for laboratory tests used in screening. In the questionnaire, we defined the maximum non-refundable costs at € 70,- to take a possible future cost increase into account.

### Statistical analysis

Descriptive analyses were conducted for the total group, for first-generation, and for second/third-generation Moroccan-Dutch immigrants. For our multivariate analyses, we used random forest (RF). RF is a machine learning method that uses a non-parametric algorithm to predict an outcome and to select important determinants.

RF is appropriate here, as our questionnaire consisted of a large number of possible determinants relative to the number of respondents, which leads to a high risk of overfitting and false positives (in the context of identifying important variables). Previous studies have also shown a favourable performance of RF in comparison to other variable selection methods, including those that are related to the often used logistic regression (28, 29). The RF method yields a convenient ranking of variables in terms of how predictive they are in relation to the outcome [see Supplementary information], the so-called variable importance ranking. The predictability of variables is determined through the mean decrease in accuracy. The more the accuracy of the RF model decreases by excluding a single variable, the more important the variable. Therefore, variables with a large mean decrease in accuracy are deemed more relevant for classification of the data. The RF method can also be used (as is the case with most methods) to estimate so-called marginal probabilities for a given variable. We defined a marginal probability as the average model-based probability over all individuals, given that they assume a certain value for that variable while holding all other variables constant at their original values (as is observed in the sample).

First, RF analyses were done with 'intention request' as the dependent variable and all possible determinants as independent variables, as depicted in Supplementary Table S3.1. This intention measure represents the intention for requesting a HBV test on own initiative. Second, to investigate the influence of having to pay for screening, we repeated the RF analyses using the outcome measure 'intention to participate in HBV screening for non-refundable costs of € 70,-' as dependent variable. We will further refer to this outcome measure as 'intention 70'. All possible determinants (Supplementary Table S3.1) were again included as independent variables.

Initially, we built two RF models, one with 'intention request' as dependent variable and another one with 'intention 70'. These models were trained using a subset of the individuals that responded to *all* 33 variables. A 10 times repeated 10-fold cross-validation was performed to gauge the RF models' performance (30). Furthermore, a restricted forward feature selection was used to determine how many variables are relevant for predicting the outcome (31). The selection procedure involved adding variables one by one, each time checking the model's performance. The number of relevant variables should correspond with the point at which no longer a (strong) improvement in the model's performance can be seen. The order in which variables are added follows the aforementioned variable importance ranking, i.e., starting with the single most important variable and subsequently including less important variables one by one. Subsequently, we again built two RF models with each its own dependent variable ('intention request' and 'intention 70') and the previously determined number of most important variables with their confusion matrices. The confusion matrix depicts the number of true positives (TP), true negatives (TN), false positives (FP), and false negatives (FN), classified using the training data.



Model performance was gauged by checking the model's classification accuracy (ACC), sensitivity (SENS), specificity (SPEC), and the area under the curve (AUC) [see Supplementary information]. In the Supplementary information, we also described the total RF model results for 'intention request' and the complete RF results for 'intention 70'. Furthermore, we investigated the influence of missing values on our main results by including missing values as a separate category (to increase the amount of analysable data). We decided not to use imputation, since (1) it has not been studied well for RF and it has never been shown that it is better than defining missing values as a separate category, and (2) for RF only single imputations are involved, which we found highly undesirable considering that the uncertainty of the imputation is not taken into account. Statistical analyses were conducted using R version 3.2.0. To perform RF, "randomForest" and "caret" packages were used.

## Results

### Sample characteristics

In total, we invited 350 Moroccan-Dutch immigrants, of which 143 (40.9%) were invited offline and 207 (59.1%) were invited online. Of those 350 invited individuals, 242 participated (response rate: 69.1%) in the study. These individuals recruited another 165 recruits, which resulted in 407 respondents (see Table 3.1). Respondents consisted of 193 (50.9%) first-generation Moroccan-Dutch immigrants (FGM), 186 (49.1%) second- or third-generation Moroccan-Dutch immigrants (STGM), 8 (2.0%) were born neither in the Netherlands nor in Morocco, and 20 (4.9%) had an unknown country of birth. The latter two groups of respondents were excluded, which led to a total sample of 379 Moroccan-Dutch respondents. Of these, 135 (35.6%) reported a higher educational level, 172 (45.4%) secondary school or vocational education, and 66 (17.4%) indicated no official education or primary school. Of the total sample, 79 (20.8%) self-reported to be already tested for HBV and 115 (30.3%) reported to be vaccinated against HBV.

Of FGM, 83 (43.0%) reported having a negative intention to request a HBV test on own initiative ('intention request'). Furthermore, 91 (47.2%) reported having a negative intention to participate in HBV screening for a maximum own contribution of € 70,- ('intention 70'). Of STGM, 85 (45.7%) and 85 (45.7%) reported having a negative 'intention request' and 'intention 70', respectively.

Table 3.1. Demographics and testing characteristics of Moroccan-Dutch immigrants

Characteristic	First generation (n = 193, 50.9%)	Second or third generation (n = 186, 49.1%)	Total (n = 379)
Offline/online participation	Offline	46 (24.7)	156 (41.2)
	Online	140 (75.3)	223 (58.8)
	Missing value	0 (0)	0 (0)
Moroccan-Arabic or Berber identity	Moroccan-Arabic	81 (43.5)	151 (39.8)
	Berber	105 (56.5)	227 (59.9)
	Missing value	0 (0)	1 (0.3)
Gender	Male	59 (31.7)	123 (32.5)
	Female	127 (68.3)	256 (67.5)
	Missing value	0 (0)	0 (0)
Age group	16 – 25 years	84 (45.2)	86 (22.7)
	26 – 35 years	18 (9.3)	77 (20.3)
	36 – 45 years	58 (30.1)	94 (24.8)
	46 – 55 years	63 (32.6)	64 (16.9)
	56 – 65 years	30 (15.5)	31 (8.2)
	66 years and older	12 (6.2)	14 (3.7)
	Missing value	10 (5.2)	13 (3.4)
Educational level	No official education or primary school	4 (2.2)	66 (17.4)
	Secondary school	31 (16.1)	75 (19.8)
	Vocational education	44 (22.8)	97 (25.6)
	Higher education	51 (26.4)	135 (35.6)
	Missing value	5 (2.6)	6 (1.6)

Table 3.1. Demographics and testing characteristics of Moroccan-Dutch immigrants (continued)

Characteristic	First generation (n = 193, 50.9%)	Second or third generation (n = 186, 49.1%)	Total (n = 379)
Speaking Dutch (SR)	Yes	185 (99.5)	366 (96.6)
	No	1 (0.5)	12 (3.2)
	Missing value	0 (0)	1 (0.3)
Knowledge on HBV	No	73 (39.2)	152 (40.1)
	Limited	80 (43.0)	162 (42.7)
	Sufficient	33 (17.7)	65 (17.2)
	Missing value	0 (0)	0 (0)
HBV in family or friends	Yes	25 (13.4)	77 (20.3)
	No	119 (61.7)	254 (67.0)
	I do not know	22 (11.4)	48 (12.7)
	Missing value	0 (0)	0 (0)
Tested for HBV (SR)	Yes	36 (19.4)	79 (20.8)
	No	128 (66.3)	259 (68.3)
	I do not know	21 (10.9)	40 (10.6)
Vaccinated against HBV (SR)	Missing value	0 (0)	1 (0.3)
	Yes	55 (28.5)	115 (30.3)
	No	60 (31.1)	108 (28.5)
	I do not know	78 (40.4)	156 (41.2)
Intention request	Missing value	0 (0)	0 (0)
	Yes/probably yes	100 (51.8)	187 (49.3)
	No/probably not	83 (43.0)	168 (44.3)
	Missing value	10 (5.2)	24 (6.3)

Table 3.1. Demographics and testing characteristics of Moroccan-Dutch immigrants (continued)

Characteristic	First generation (n = 193, 50.9%)	Second or third generation (n = 186, 49.1%)	Total (n = 379)
Intention 70			
Yes/probably yes	83 (43.0)	84 (45.2)	167 (44.1)
No/probably not	91 (47.2)	85 (45.7)	176 (46.4)
Missing value	19 (9.8)	17 (9.1)	36 (9.5)

Data are reported as number of respondents (%).

SR: Self-reported.

When excluding all missing values for RF analyses, 306 and 303 respondents were included in the model with 'intention request' and 'intention 70', respectively.

Multivariate associations for 'intention request'

The RF model with 'intention request' and 33 predictor variables obtained an AUC of 0.681 (see Supplementary Table S3.2). Multivariate associations to determine variable importance for 'intention request' yielded five top predictors for requesting a test, which were 'benefit clarity', 'barrier not having symptoms', 'barrier trusting Allah', 'self-efficacy', and 'risk without noticing' (see Figure 3.1).

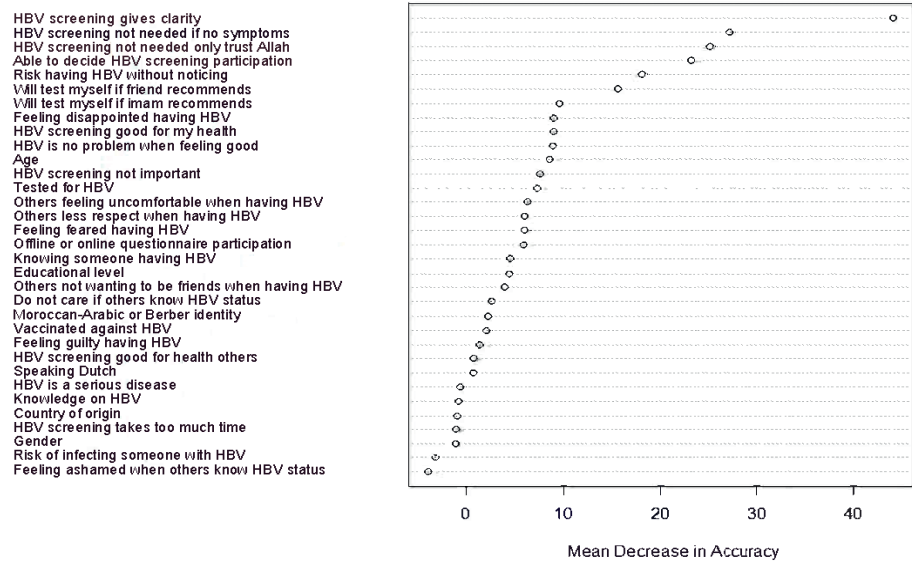
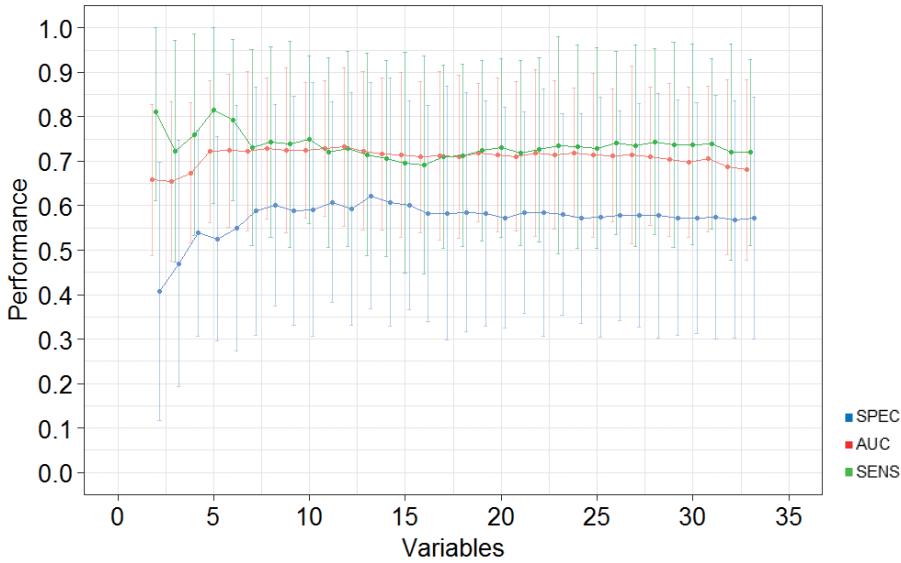


Figure 3.1. Variable importance analysis performed by RF for 'Intention request' (n = 306)

The set of 33 variables used for classification, ordered by their mean decrease in accuracy (importance) as estimated by RF.

The RF model for 'intention request' achieved the peak AUC value (0.722) after including the five most important variables (see Table 3.2 for the confusion matrix). Including more variables had a negligible effect (see Figure 3.2).



**Figure 3.2. Result of restricted forward feature selection with RF model for 'Intention request'**

This figure shows the AUC, SENS, and SPEC for 'Intention request' starting with the most important variable and adding each variable one by one to the model, following the rank obtained through calculating the mean decrease in accuracy (displayed in Figure 1).

**Table 3.2. Performance of the RF model for 'intention request' with the top five variables**

		<i>Observed intention</i>	
		Positive intention	Negative intention
<i>Predicted intention by RF</i>	Positive intention	132 (43.1%)	30 (9.8%)
	Negative intention	68 (22.2%)	76 (24.8%)

Data in this confusion matrix are presented as the numbers and percentages of observed and predicted respondents to have a positive or negative intention according to RF. Performance metrics: ACC: 0.680 (SD: 0.116); AUC: 0.722 (SD: 0.080); SENS: 0.815 (SD: 0.105) and SPEC: 0.525 (SD: 0.115).

Relative to each other, 'benefit clarity', 'barrier not having symptoms', 'barrier trusting Allah', perceived self-efficacy, and perceived risk showed distinctive estimated marginal probabilities for having a positive 'intention request' (see Table 3.3). For example, respondents who stated 'participating in HBV screening will give me clarity (i.e., a decisive answer) had a marginal probability of 0.541 of requesting a test, while respondents who answered negative on this statement had a marginal probability of 0.327 of not requesting a test. This corresponded well with the marginal probability of having a positive intention for respondents who stated 'I do not know' for their perceived risk of having HBV without noticing (0.585). In this regard, respondents who did not know their risk seemed to desire clarity regarding their HBV status and indicated to be willing to request a HBV test.

**Table 3.3. Marginal probabilities of the top five variables in relation to 'intention request'**

<i>Variables</i>	<i>Content</i>	<i>Answering options</i>	<i>Marginal probability</i>
<i>Benefit clarity</i>	Participating in HBV screening will give me clarity (i.e., a decisive answer)	Yes	0.541
		No	0.327
		I do not know	0.331
<i>Barrier not having symptoms</i>	Participating in HBV screening is not needed if I do not have symptoms or complaints	Yes	0.412
		No	0.555
		I do not know	0.498
<i>Barrier trusting Allah</i>	Participating in HBV screening is not needed as I only trust Allah	Yes	0.464
		No	0.547
		I do not know	0.512

**Table 3.3. Marginal probabilities of the top five variables in relation to 'intention request' (continued)**

Variables	Content	Answering options	Marginal probability
<i>Self-efficacy</i>	I think I am able to decide whether or not to participate in HBV screening	Yes	0.538
		No	0.429
		I do not know	0.520
<i>Risk without noticing</i>	Perceived risk of having HBV without noticing	Low	0.475
		Quite low	0.549
		Average	0.568
		Quite high	0.563
		High	0.576
		I do not know	0.585

**Multivariate associations for 'intention 70'**

The total RF model with 'intention 70' retrieved an AUC of 0.638. The top five predictors of the willingness to attend non-refundable screening for € 70,- were 'shame others', 'barrier trusting Allah', 'barrier too much time', 'offline or online questionnaire participation', and 'stigma comfort'. However, Supplementary Figure S3.2 shows that the RF model for 'intention 70' was most predictive by including the 10 most important variables. The final RF model with the 10 most important variables yielded an AUC of 0.666. Supplementary Table S3.5 shows that respondents who stated 'I would feel ashamed if I have HBV and others would know this' had an estimated marginal probability of 0.420 of having a positive 'intention 70', while respondents who answered negative on this statement had a marginal probability of 0.509 of having a positive 'intention 70'.

**Discussion**

This is the first study, to our knowledge, that investigates hepatitis B screening behaviour among Moroccan-Dutch immigrants. We found that clarity regarding HBV status, not having symptoms or complaints, fatalism (i.e., an attitude emphasizing the subjugation of all events to fate), high level of perceived self-efficacy, and perceived risk of having HBV were the strongest predictors to actively request a HBV test among Moroccan-Dutch. This information is important for the development of future HBV screening promotion in the Moroccan-Dutch community.

In our study, shame and stigma regarding HBV, fatalism, perceived burden of participating in screening, perceived severity, social influence of the imam (i.e., Islamic religious leader), and the possible health benefit had the greatest predictive value for the intention to participate in screening for a maximum own contribution of € 70,-. By using both offline and online RDS, we surveyed different individuals with different intentions to participate in screening. Offline participants (predominantly elderly) were more willing to test for HBV in comparison to those who participated online.

The large number of relevant predictors indicates a complex and diverse determination of the intention to participate in HBV screening in Moroccan-Dutch inhabitants. It was expected that knowledge of HBV would be one of the strongest predictors, as reported in previous studies on cancer screening programmes (12, 32-34). However, our data did not support this finding. This might be explained by the low percentage of individuals having sufficient knowledge before starting the questionnaire, prohibiting analyses of associations of knowledge with intention. Moreover, before respondents were surveyed on their HBV perceptions, we eliminated knowledge as a discernible determinant, as we had to bring all respondents to the same minimal knowledge level enabling participation in the questionnaire. Furthermore, we have seen that 20.8% thought to be already tested for HBV and 30.3% reported to be vaccinated against HBV. We seriously question the truthfulness of these reported data, as most of the respondents had no or insufficient knowledge on HBV prior to our introduction and without sufficient knowledge it is difficult to discern blood tests or vaccinations according causative agents. All travellers to Morocco are advised to take protection against viral hepatitis A. This might easily have caused hepatitis recall difficulties. We repeated our analysis for a sample excluding respondents who reported to be already tested or vaccinated against HBV, and found similar results for both intention measures. The most important variables were identical, less important ones differed slightly (data not shown).

### Comparison with other studies

To date, no similar research on hepatitis B screening intention has been conducted among Moroccans in the Netherlands, Morocco, or other countries. Therefore, we can only compare our study with studies on the intention of Moroccan-Dutch to participate in breast- and cervical cancer screening (12, 32, 33, 35-37). In contrast to our study, Verhoeven, et al. (1994) indicated lack of knowledge about examination, fear or shame of (results of) examination, not having received or understood the (Dutch) invitation letter, and lack of satisfaction with the GP as inhibitors within the Turkish- and Moroccan-Dutch community (12). As mentioned, we were unable to study knowledge as determinant. De Nooijer, et al. (2005) showed a higher participation rate in women born in Morocco after an invitation by the GP compared to an invitation by the Municipal Public Health Service (MPHS) (35). We have not explored how participation rate is affected by the organisation responsible for the invitation, since the Dutch Health Council advised to organise active case finding through GPs. In Denmark, perceived severity, perceived risk, and lack of emotional support were found to be associated with screening participation among migrant women, which is in accordance with our study (33, 36). Similar determinants were found in Moroccan-Spaniards (34, 38). A Moroccan study reported room for improvement when it comes to knowledge of breast cancer risk factors in female health care professionals in Morocco (32). Furthermore, a pilot cervical cancer screening programme in Morocco acquired a low compliance rate of 6.0% in 2011-2013, which was explained by a lack of a mass communication and awareness campaign regarding the screening programme (37).

Other than for Moroccan-Dutch, there is considerable more knowledge for the Turkish-Dutch population on determinants for participation in chronic hepatitis B screening. Despite several differences between Moroccan-Dutch and Turkish-Dutch immigrants, such as culture, Dutch language proficiency, and screening participation, we thought it is wise to compare these two groups because of their comparable migration status and religion. A study on the intention to participate in HBV screening in the Turkish-Dutch population identified perceived behaviour control and subjective norm of the TPB as the strongest predictors (22). Perceived behaviour control was explained by shame and stigma regarding HBV and associating HBV screening with sexuality, and subjective norm was explained by family values. We also found shame and stigma regarding HBV, and social influence of the imam as strong predictors for 'intention 70'. However, not for 'intention request', which can be explained by the fact that Van der Veen, et al. only asked for the intention to participate in HBV screening and not the intention to request a test on own initiative. We also have taken the influence of cost into account and included the GP as healthcare provider, in accordance with the Dutch Health Council's advice, and not the MPHS as Van der Veen, et al. did.

### Strengths and limitations

For the first time, we can report on important determinants for intention to participate in HBV screening among Moroccan-Dutch. Second, offline, we targeted the four big cities (Amsterdam, Rotterdam, Utrecht, and The Hague) and some other (medium-sized) municipalities, such as Leiden and Tilburg, where large numbers of Moroccans of the first generation live, and for which the Dutch Health Council also proposed local HBV screening programmes. Third, by using RDS, we were able to reach 379 respondents in only three months, which is a high number of respondents considering the challenges that come with conducting studies among migrant populations, and was higher than the number of respondents included in the single other similar study among the Turkish-Dutch population (22). Finally, we used a combined theoretical model to detect all potential predictors within the Moroccan-Dutch community.

However, a number of limitations should also be addressed. A larger percentage of respondents were female (67.5%) and reported a high(er) educational level (35.6%), compared to what was observed in the 2015 sample by Statistics Netherlands (39), which may have caused selection bias. This bias is likely to be mitigated by including education and gender as potential confounders in our models. Second, there was a moderate degree of model uncertainty, as evidenced by the large standard deviations of the ACC, AUC, SENS, and SPEC. Nevertheless, our models yielded AUC scores (0.722 and 0.666, respectively) that were still considerably higher than 0.5 (which corresponds with random guessing). Third, RDS leads to data that are correlated between respondents, whilst independence of data is one of the assumptions of RF. However, we are not aware of any machine learning approach that can deal with correlated observations, and we argue that the application of RF to such data can still yield some strong clues as to which factors are important determinants. Furthermore, RDS helped us to reach this so-called "hard-to-reach minority population" successfully, which would have been much more challenging through more traditional random sampling strategies. Fourth, missing data were not imputed and this may have introduced bias. Investigating the influence of missing values on our main results by including missing values as a separate category yielded similar findings for 'intention request' (i.e., identical top predictors, but slightly different other predictors) (data not shown). However, doing the same for 'intention 70' led to different results (see Supplementary Figure S3), as it resulted in only four of the ten identical top variables ('shame others', 'barrier too much time', 'shame guilty', and 'social influence imam'). The model's prediction accuracy and its standard deviation were not affected much by including missing values as a category. Finally, our study had several risk factors for respondents waving or refusing participation, such as language barriers and HBV associated shame and stigma. To overcome these factors, we helped respondents with filling in the questionnaire through a face-to-face or telephone interview (offline-recruited respondents) and audio recordings in Dutch,



Berber, and Moroccan-Arabic (online-recruited respondents), and focused the questionnaire on the predominance of mother to child HBV transmission.

### Implications and future research

In planning communication strategies targeting Moroccan-Dutch for HBV screening, we recommend emphasizing 'getting clarity regarding HBV status by participating in screening' in information leaflets and oral information towards Moroccan-Dutch immigrants. In an educational campaign aiming to increase the knowledge on HBV, it is also important to stress the risk of having chronic hepatitis B despite feeling healthy. The most important predictors for non-participation in 'intention 70' were shame and stigma regarding HBV. In the Netherlands, HBV is mainly transmitted sexually and is classified as a sexually transmitted disease (40). Dutch preventive programmes focus on men having sex with men and people who inject drugs, which may indeed lead to feelings of shame and stigma, as 97% of Moroccan-Dutch immigrants are Muslim prohibiting both (6). In the Moroccan epidemiology of HBV, the perinatal transmission dominates, and practically all chronically infected Moroccan-Dutch acquired their infection at birth without any relation to homosexual activity or intravenous drug use. It is therefore essential to emphasize the predominant transmission route of mother to child in an educational campaign.

Fatalism showed to be an important predictor for both 'intention request' and 'intention 70'. Therefore, Islamic religious leaders should, in our opinion, inform Muslims in mosques that the Islam also advocates health-promoting activities, and recommends those who are ill or are at risk of getting ill to strive to do anything to recover or prevent disease. These leaders would not only bring information across, help to decrease elements of fatalism, but also geared at decreasing elements of shame and stigma and so increase acceptance.

Finally, before developing and implementing HBsAg screening methods directed at Moroccan-Dutch immigrants, it would be wise to pilot these in combination with actual screening to quantify the actual risk of chronic hepatitis in this population.

### Conclusions

To enhance screening uptake of Moroccan-Dutch, promoting activities should (1) incorporate clarity regarding HBV status, (2) stress the risk of an asymptomatic infection, (3) emphasize mother to child transmission as main transmission route, and (4) team up with Islamic religious leaders to help decrease elements of fatalism, shame, and stigma.

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## Supplementary information

### Random forest

Random forest (RF) is a non-parametric method that uses a set of decision trees to make predictions in regression and classification problems, and to select important variables (1). In this study, we used RF for selecting variables in a classification context. Each tree is grown by taking a bootstrap sample of the training data, selecting a random subset of candidate predictors, and then repeatedly splitting the bootstrap sample into subsequent *partitions* based on a candidate predictor that achieves the biggest improvement in a performance metric (by default, the Gini impurity criterion). Trees are typically fully grown in classification, which means that splits are being made until all *nodes* (i.e., the partitions that are subject for a further split) contain no less than one observation, or until all candidate predictors have been exhausted for splitting purposes (whichever comes first). A tree-specific prediction for a given observation is then made taking the average over all remaining observations in the terminal node (i.e., a node that cannot be split any further) that corresponds to the observation in terms of predictors. An overall prediction is obtained by taking the average over all tree-specific predictions for the given observation.

RF can determine which variables are important as follows. Each time RF takes a bootstrap sample, it keeps track of which observations that do not fall into in the bootstrap sample (this roughly corresponds to a third of all original observations). These observations are so-called *out-of-bag* (OOB). A prediction is made for these observations using the tree that was grown on the bootstrap sample, and then an OOB error is estimated. To determine the tree-specific importance of a variable, the variable is *permuted* (i.e., randomly shuffled) in the bootstrap sample, yielding a new variant of the bootstrap sample, and a new tree is grown on the new variant. The new tree then yields a new OOB error, which then is compared with the OOB error of the original tree. The importance of this variable is gauged by taking the OOB error decrease, averaged over all trees, called the mean decrease in accuracy. A large increase in OOB error suggests that the variable is important in predicting the outcome (intention to test for HBV in our case). A ranking of variable importance is made by comparing the increase in OOB errors between variables.

The RF algorithm has several tuning parameters that need to be set by the user. The parameters that are most likely to affect the algorithm's performance are (1) the number of trees generated and (2) the size of the subset of candidate predictors for each tree. Typically, the values for these parameters are chosen such that performance is optimized. This can be done through cross-validation (2).

We pre-specified the number of trees at 5000 trees, and the random sampled number of variables (mtry) was set at the square root of the total number of variables.

## Interpreting confusion matrices

The classification accuracy is defined as the number of correct predictions (TP + TN), divided by the total number of predictions (TP + TN + FP + FN).

The sensitivity is the number of persons correctly predicted as having the outcome (TP), divided by the number of persons having the outcome (TP + FN). The specificity is the number of persons correctly predicted as not having the outcome (TN), divided by the number of persons not having the outcome (TN + FP) (3).

The area under the ROC curve represents the AUC score, which can be interpreted as the probability that a classifier assigns a higher score to a random positive sample compared to a random negative one. Thus, the higher the AUC score, the better the classification result and prediction accuracy.

## Used paper-based questionnaire (translated to English)



Rijksinstituut voor Volksgezondheid  
en Milieu  
Ministerie van Volksgezondheid,  
Welzijn en Sport

**Salaam aleikoum,**

My name is Nora Hamdiui and I study Biomedical Sciences. Regarding my Master internship within the Dutch National Institute for Public Health and the Environment (RIVM), I am conducting scientific research on the opinion of Moroccan-Dutch concerning the hepatitis B test.

Hepatitis B is more prevalent in Morocco compared to the Netherlands. Moroccan-Dutch, born in Morocco, have a higher risk to develop chronic hepatitis B compared to the general Dutch population. Therefore, there is a request to offer the blood test to these Moroccan-Dutch. I would like to know how you think about hepatitis B and the test.

With your information, we will inform the general practitioners in the Netherlands on how to offer a hepatitis B test to Moroccan-Dutch.

Would you like to fill in this short questionnaire? This will take about 10 minutes.

It is not a problem if you know little or nothing about hepatitis B. The information that you give in the study will be handled **confidentially**. Your data will be **anonymous** which means that your name will not be collected or linked to the data.

Do you need help with filling in the questionnaire? From someone who (also) speaks Berber? Call 06-57288077, or leave your phone number here:

Thanks for considering my request / Shokran for your participation!

**BarakAllahu feek.**

Kind regards,  
Nora Hamdiui

☐ Yes, I will participate

**My year of birth is:**

.....

**Signature:**

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

*If you have any questions or remarks, do not hesitate to call or e-mail me*

Version: 1

Page: 1 out of 13

The first questions concern you and the way you have been invited to this questionnaire

1. I am a...

- ☐ Male  
☐ Female

2. Where do you live?

.....

3. With how many people do you live in one household (including you)?

.....

4. What are the four digits of your postal code?

.....

5. Which languages do you speak?

*Multiple answers possible.*

- ☐ Dutch  
☐ Berber  
☐ Moroccan-Arabic  
☐ Modern Standard Arabic  
☐ Other: .....

6. What is your highest level of education completed?

- ☐ No official education  
☐ Nursery school to 8th grade  
☐ High school / Attestation du Baccalauréat  
☐ Technical or intermediate vocational education (LTS, MTS, MBO) / Diplôme de Technicien  
☐ Higher vocational education (HBO), university (WO) / Diplôme de Technicien Spécialisé, Brevet de Technicien Supérieur, Diplôme Universitaire de Technologie, Diplôme d'Ingénieur d' Application, License, Master  
☐ Other: .....

7. How are you invited for this questionnaire?

- ☐ By a family member/partner I live with
- ☐ By a family member/partner I don't live with
- ☐ By a friend, acquaintance, or colleague
- ☐ By someone else
- ☐ By an e-mail/employee of the RIVM
- ☐ Via a message on a website
- ☐ By an unknown person
- ☐ Other: .....

The next question is about hepatitis B

It is not a problem if you do not know all the answers

8. What do you know about hepatitis B?  
*Multiple answers possible.*

- ☐ I know nothing about hepatitis B
- ☐ Hepatitis B is a contagious disease
- ☐ Hepatitis B can cause liver cancer
- ☐ Hepatitis B cannot be spread by someone that looks and feels healthy

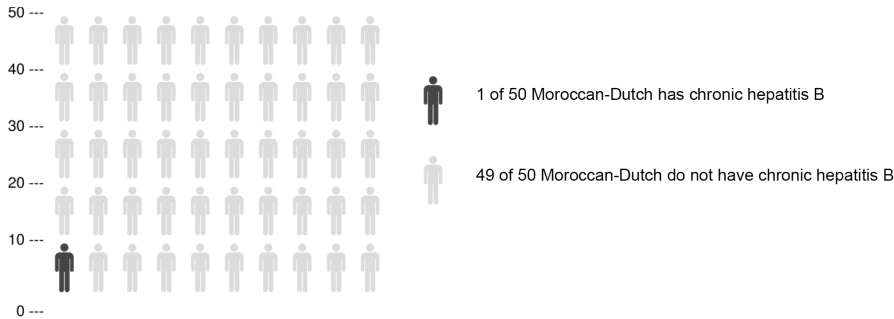
It is not a problem if you have answered the previous question incorrect. You will now get more information on hepatitis B and the hepatitis B blood test. On this page, nothing has to be filled in.

**What is hepatitis B?**  
Hepatitis B (*bousafa*) is a liver disease. You can acquire it via a virus. The hepatitis B virus is contagious. This means that others can acquire it too.

**How can you acquire the hepatitis B virus?**  
If a mother acquired the hepatitis B virus, her children can acquire it as well. In Morocco, hepatitis B predominantly spreads through this route. You can also acquire the hepatitis B virus via blood-to-blood transmission.

**What are the consequences of hepatitis B?**  
Chronic hepatitis B can cause liver damage and after a long period of time liver cancer.

**What is the risk?**  
One out of every 50 Moroccan-Dutch individuals develops chronic hepatitis B.



Often you do not feel hepatitis B. Therefore, you could have your blood tested. If the blood is good, there is no problem. If the blood is not good, you can have hepatitis B.

**How can I have my blood tested?**  
At the general practitioner, you can get a form. With this form, your blood can be drawn at a blood sample unit. The blood will be investigated thereafter. If your compulsory annual front-end deductible ("own risk") is not reached yet, you have to pay this investigation yourself.

**What if I am diagnosed with chronic hepatitis B?**  
A specialist in the hospital can treat chronic hepatitis B. You will get pills to stay healthy.

The next questions are about you and hepatitis B

9. Do you know someone who is diagnosed with hepatitis B?

- ☐ Yes
- ☐ No
- ☐ Don't know

10. Did you have yourself tested on hepatitis B?

- ☐ Yes
- ☐ No
- ☐ Don't know

11. Are you vaccinated against hepatitis B?

- ☐ Yes
- ☐ No
- ☐ Don't know

The next question concerns your country of birth to ask you the correct questions subsequently

12. What is your country of birth?

- ☐ Morocco
- ☐ The Netherlands → [go to question 22 \(page 8\)](#)
- ☐ Other: .....

The next questions are about your opinion on hepatitis B

13. How likely is it you...

Indicate the smiley you think fits the best to your answer

	low	rather low	average	rather high	high	don't know
Contracted hepatitis B in the past?						<input type="radio"/>
Will infect someone with hepatitis B?						<input type="radio"/>

Indicate whether you agree with the following statements

14. Hepatitis B is...	Agree / Yes	Disagree / No	Don't know
not a problem as long as I feel good	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
a serious disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. Imagine, you have hepatitis B and others know this, then other people would...

	Agree / Yes	Disagree / No	Don't know
still want to be friends with you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have less respect for you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel uncomfortable being around you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Imagine, you have hepatitis B and others know this, how would you feel?

	Agree / Yes	Disagree / No	Don't know
Ashamed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Guilty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disappointed in myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Don't care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next questions are about the hepatitis B blood test; indicate whether you agree with the following statements

17. I think I am...	Agree / Yes	Disagree / No	Don't know
capable of deciding whether I take the hepatitis B blood test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. I would have myself tested on hepatitis B if...	Agree / Yes	Disagree / No	Don't know
a friend, family member, or acquaintance recommends that	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
an imam recommends that	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Having a hepatitis B test...	Agree / Yes	Disagree / No	Don't know
is good for my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is good for the health of others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
gives me clarity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
cost too much time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is not important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is not necessary if I don't have any physical complaints	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is not necessary, because I only trust Allah	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Imagine, tomorrow you have to go to the general practitioner. Would you request a hepatitis B test on your own initiative?	
<input type="radio"/> Yes / probably	
<input type="radio"/> No / probably not	

21. Imagine, your general practitioner recommends you to have yourself tested on hepatitis B. Would you participate to the screening if the test...	Yes / probably	No / probably not
is free of charge?	<input type="radio"/>	<input type="radio"/>
costs € 35?	<input type="radio"/>	<input type="radio"/>
costs € 70?	<input type="radio"/>	<input type="radio"/>

CONTINUE WITH PAGE 10

CONTINUE HERE IF YOU ARE BORN IN THE NETHERLANDS

The next questions are about hepatitis B and your (grand)parent

22. How likely is it that your (grand)parent...	
Indicate the smiley you think fits the best to your answer	
	low    rather low    average    rather high    high    don't know
Contracted hepatitis B in the past?	<input type="radio"/>
Will infect someone with hepatitis B?	<input type="radio"/>

Indicate whether you agree with the following statements

23. Hepatitis B is...	Agree / Yes	Disagree / No	Don't know
not a problem as long as my (grand)parent feels good	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
a serious disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. Imagine, your (grand)parent has hepatitis B and others know this, then other people would...	Agree / Yes	Disagree / No	Don't know
still want to be friends with your (grand)parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have less respect for your (grand)parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel uncomfortable being around your (grand)parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Imagine, your (grand)parent has hepatitis B and others know this, how would your (grand)parent feel?	Agree / Yes	Disagree / No	Don't know
Ashamed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Guilty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disappointed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doesn't care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



The next questions are about the hepatitis B blood test; indicate whether you agree with the following statements

26. I think my (grand)parent is...	Agree / Yes	Disagree / No	Don't know
capable of deciding whether he/she will take the hepatitis B blood test	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. My (grand)parent would have him/herself tested on hepatitis B if...	Agree / Yes	Disagree / No	Don't know
a friend, family member, or acquaintance recommends that	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
an imam recommends that	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. Having a hepatitis B test...	Agree / Yes	Disagree / No	Don't know
is good for the health of my (grand)parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is good for the health of others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
gives my (grand)parent clarity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
cost too much time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is not important	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is not necessary if my (grand)parent doesn't have any physical complaints	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is not necessary, because my (grand)parent only trusts Allah	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. Imagine, tomorrow your (grand)parent has to go to the general practitioner. Would you recommend your (grand)parent to request a hepatitis B test?
<input type="radio"/> Yes / probably
<input type="radio"/> No / probably not

30. Imagine, your general practitioner recommends your (grand)parent to have him/herself tested on hepatitis B. Would you recommend this test too if the test...	Yes / probably	No / probably not
is free of charge?	<input type="radio"/>	<input type="radio"/>
costs € 35?	<input type="radio"/>	<input type="radio"/>
costs € 70?	<input type="radio"/>	<input type="radio"/>

It is important that as many Moroccan-Dutch as possible know that they can have themselves tested on hepatitis B. You could for example share this information with others.

Therefore, we would like to know how many Moroccan-Dutch you know

How many Moroccan-Dutch do you know?					
Place a cross in the correct column					
	0	1 – 4	5 – 14	15 – 29	30 or more
Family members					
Friends or acquaintances					
People from the mosque					
Colleagues or fellow students					

Almost done, see next page

References

1. Breiman L. Random forests. Machine learning. 2001; 45(1):5-32.

2. Hastie T, Tibshirani R, Friedman J. The elements of statistical learning, 2nd edition. New York: Springer; 2009.

3. Florkowski CM. Sensitivity, specificity, receiver-operating characteristic (ROC) curves and likelihood ratios: communicating the performance of diagnostic tests. Clin Biochem Rev. 2008; 29 Suppl 1:S83-7.

Supplementary Tables and Figures

Supplementary Table S3.1. Overview of variables measured by the questionnaire

Constructs	Variables	Short variable descriptions	Options
Intention screening	Intention request	Intention to request a HBV screening test at the GP on own initiative	Yes – No
	Intention 70	Intention to participate in non-refundable HBV screening at € 70,-	Yes – No
Perceived risk	Risk without noticing	Risk having HBV without noticing	Low – High
	Risk infecting someone	Risk of infecting someone with HBV	Low – High
Perceived severity of disease	Severity feeling good	HBV is no problem when feeling good	Yes – No – I do not know
	Severity serious disease	HBV is a serious disease	Yes – No – I do not know
Stigma regarding HBV	Stigma friends	Others not wanting to be friends when having HBV	Yes – No – I do not know
	Stigma respect	Others less respect when having HBV	Yes – No – I do not know
	Stigma comfort	Others feeling uncomfortable when having HBV	Yes – No – I do not know
Shame regarding HBV	Shame others	Feeling ashamed when others know HBV status	Yes – No – I do not know
	Shame guilty	Feeling guilty having HBV	Yes – No – I do not know
	Shame fear	Feeling feared having HBV	Yes – No – I do not know
	Shame disappointment	Feeling disappointed having HBV	Yes – No – I do not know
	Shame not caring	Do not care if others know HBV status	Yes – No – I do not know

Supplementary Table S3.1. Overview of variables measured by the questionnaire (continued)

Constructs	Variables	Short variable descriptions	Options
<i>Perceived self-efficacy</i> <i>Social influence</i>	Self-efficacy	Able to decide HBV screening participation	Yes – No – I do not know
	Social influence friends	Will test myself if friend recommends	Yes – No – I do not know
	Social influence imam	Will test myself if imam recommends	Yes – No – I do not know
<i>Perceived benefits</i>	Benefit own health	HBV screening good for my health	Yes – No – I do not know
	Benefit health others	HBV screening good for health others	Yes – No – I do not know
	Benefit clarity	HBV screening gives clarity	Yes – No – I do not know
<i>Perceived barriers</i>	Barrier too much time	HBV screening takes too much time	Yes – No – I do not know
	Barrier important	HBV screening not important	Yes – No – I do not know
	Barrier not having symptoms	HBV screening not needed if no symptoms	Yes – No – I do not know
	Barrier trusting Allah	HBV screening not needed only trust Allah	Yes – No – I do not know
<i>Knowledge on HBV</i>	Knowledge on HBV	I know nothing about HBV HBV is an infectious disease HBV can cause liver cancer Someone who is looking healthy and feeling good cannot infect others with HBV	True – False
	Moroccan-Arabic or Berber identity	-	Moroccan-Arabic – Berber

Supplementary Table S3.1. Overview of variables measured by the questionnaire (continued)

Constructs	Variables	Short variable descriptions	Options
<i>Speaking Dutch</i> <i>Knowing someone having HBV</i>	Speaking Dutch	The ability to speak Dutch	Yes – No
	Knowing someone having HBV	Knowing someone having HBV	Yes – No – I do not know
<i>Tested for HBV</i> <i>Vaccinated against HBV</i>	Tested for HBV	Tested for HBV, self-reported	Yes – No – I do not know
	Vaccinated for HBV	Vaccinated against HBV, self-reported	Yes – No – I do not know

Supplementary Table S3.2. Performance of the total RF model with 'Intention request'; confusion matrix

Observed intention			
Predicted intention by RF		Positive intention	Negative intention
	Positive intention	118 (38.6)	44 (14.4)
	Negative intention	63 (20.6)	81 (26.5)

The total RF model includes 'Intention request' as the dependent variable and all possible determinants as independent variables.  
Data are presented as the numbers and percentages of observed and predicted respondents to have a positive or negative intention according to RF.  
Performance metrics: ACC: 0.650 (SD: 0.063); AUC: 0.681 (SD: 0.102); SENS: 0.720 (SD: 0.105) and SPEC: 0.572 (SD: 0.136).

Supplementary Table S3.3. Performance of the total RF model with 'Intention 70'; confusion matrix

Observed intention			
Predicted intention by RF		Positive intention	Negative intention
	Positive intention	77 (25.4)	66 (21.8)
	Negative intention	54 (17.8)	106 (35.0)

The total RF model includes 'Intention 70' as the dependent variable and all possible determinants as independent variables.  
Data are presented as the numbers and percentages of observed and predicted respondents to have a positive or negative intention according to RF.  
Performance metrics: ACC: 0.604 (SD: 0.053); AUC: 0.638 (SD: 0.092); SENS: 0.515 (SD: 0.135) and SPEC: 0.669 (SD: 0.121).

Supplementary Table S3.4. Performance of the RF model with the top 10 variables for 'Intention 70'; confusion matrix

Observed intention			
Predicted intention by RF		Positive intention	Negative intention
	Positive intention	83 (27.4)	60 (19.8)
	Negative intention	58 (19.1)	102 (33.7)

Data are presented as the numbers and percentages of observed and predicted respondents to have a positive or negative intention according to RF.  
Performance metrics: ACC: 0.611 (SD: 0.016); AUC: 0.666 (SD: 0.092); SENS: 0.563 (SD: 0.147) and SPEC: 0.641 (SD: 0.121).

Supplementary Table S3.5. Marginal probabilities of the top 10 variables in relation to 'Intention 70'

Variables	Content	Answering options	Marginal probability
Shame others	I would feel ashamed if I have HBV and others would know this	Yes No I do not know	0.420 0.509 0.448
Barrier trusting Allah	Participating in HBV screening is not needed as I only trust Allah	Yes No I do not know	0.471 0.490 0.423
Barrier too much time	Participating in HBV screening takes too much time	Yes No I do not know	0.386 0.496 0.451
Offline or online questionnaire participation	Offline or online questionnaire participation	Offline Online	0.497 0.470
Stigma comfort	Having HBV will lead to others feeling uncomfortable having me around	Yes No I do not know	0.418 0.497 0.495
Severity serious disease	HBV is a serious disease	Yes No I do not know	0.490 0.387 0.437
Shame guilty	I would feel guilty if I have HBV	Yes No I do not know	0.444 0.485 0.488
Shame not caring	I would not care if I have HBV and others would know this	Yes No I do not know	0.530 0.477 0.475

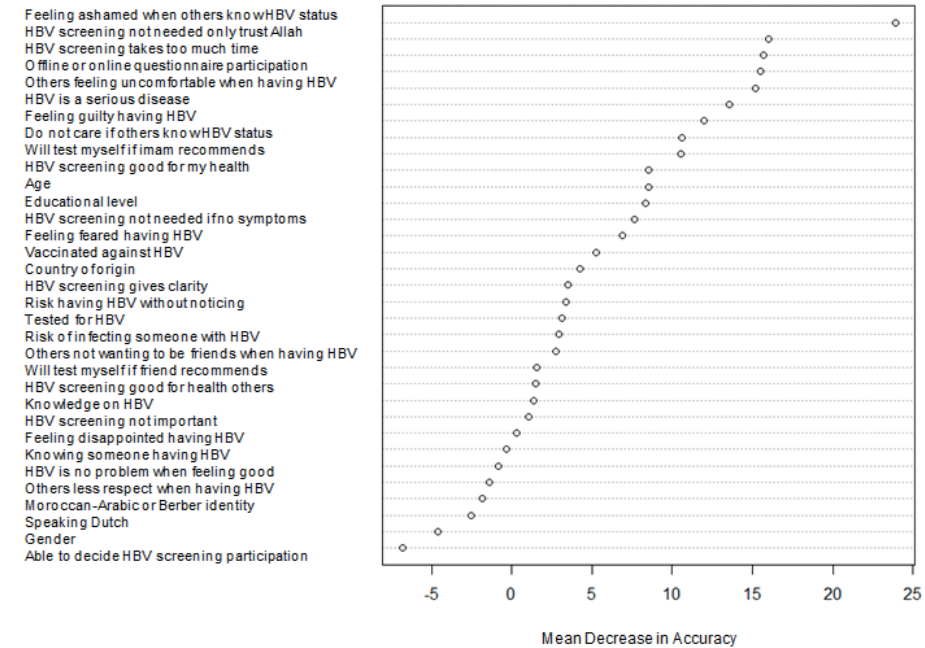
Supplementary Table S3.5. Marginal probabilities of the top 10 variables in relation to 'Intention 70' (continued)

Variables	Content	Answering options	Marginal probability
<i>Social influence imam</i>	I would have myself tested for HBV if an imam (i.e. Islamic religious leader) would recommend it to me	Yes	0.469
		No	0.513
		I do not know	0.478
<i>Benefit own health</i>	Participating in HBV screening is good for my health	Yes	0.484
		No	0.464
		I do not know	0.438

Supplementary Table S3.6. Performance metrics of all RF models

	ACC		AUC	SENS	SPEC
<b>Intention request</b>					
<i>Total model</i>	0.650 (SD: 0.063)	0.681 (SD: 0.102)	0.720 (SD: 0.105)	0.572 (SD: 0.136)	
<i>Restricted model</i>	0.680 (SD: 0.116)	0.722 (SD: 0.080)	0.815 (SD: 0.105)	0.525 (SD: 0.115)	
<b>Intention 70</b>					
<i>Total model</i>	0.604 (SD: 0.053)	0.638 (SD: 0.092)	0.515 (SD: 0.135)	0.669 (SD: 0.121)	
<i>Restricted model</i>	0.611 (SD: 0.016)	0.666 (SD: 0.092)	0.563 (SD: 0.147)	0.641 (SD: 0.121)	

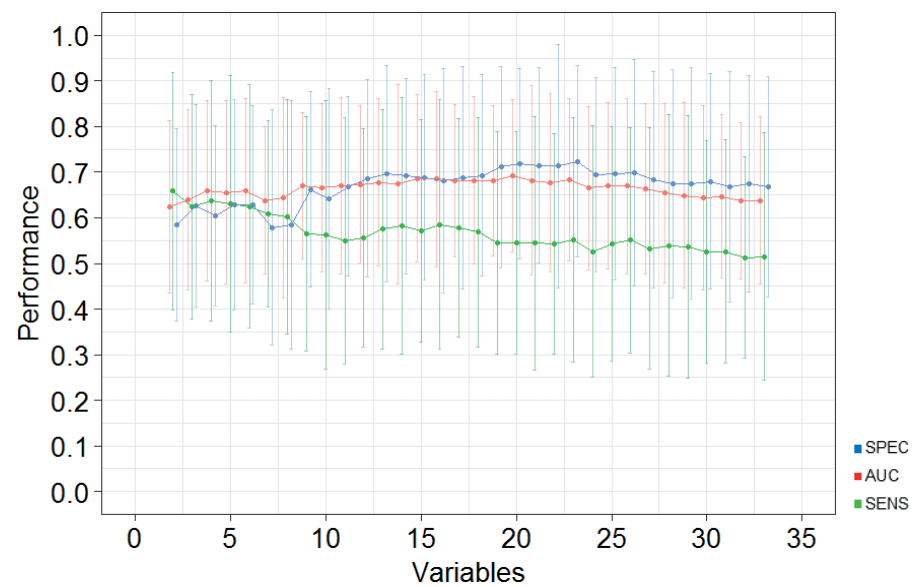
ACC: model's classification accuracy, AUC: area under the curve, SENS: sensitivity, SPEC: specificity.



Supplementary Figure S3.1. Variable importance analysis performed by RF for 'Intention 70' (n = 303)

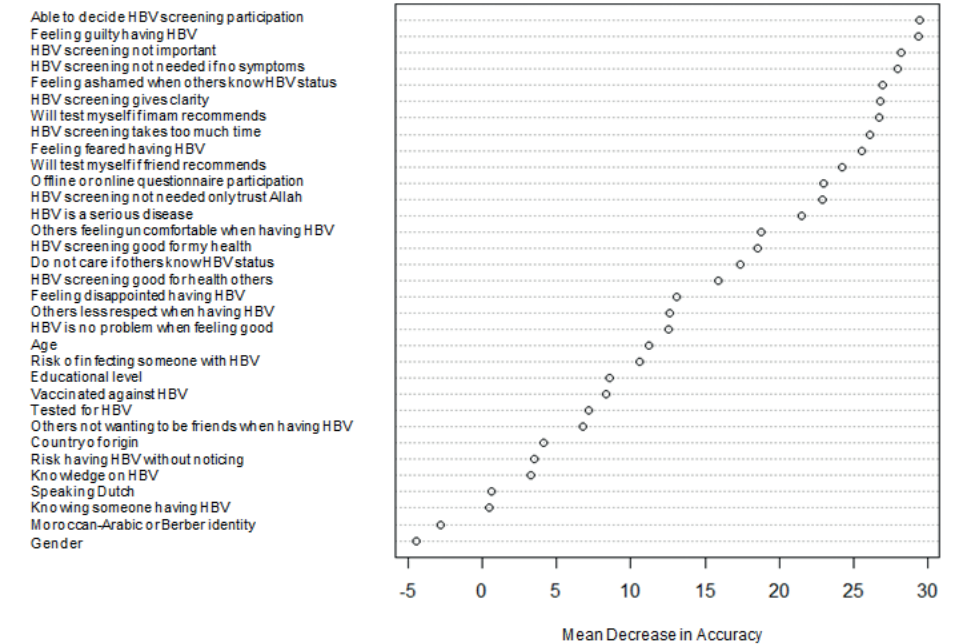
The set of 33 variables used for classification, ordered by their mean decrease in accuracy (importance) as estimated by RF.





**Supplementary Figure S3.2. Result of restricted forward feature selection with RF for 'Intention 70'**

This figure shows the AUC, SENS, and SPEC for 'Intention 70' starting with the most important variable and adding each variable one by one, following the rank obtained through the mean decrease in accuracy (See Supplementary Figure S3.1).



**Supplementary Figure S3.3. Variable importance analysis performed by RF for 'Intention 70', including missing values as category (n = 379)**

The set of 33 variables used for classification, ordered by their mean decrease in accuracy (importance) as estimated by RF.



# 4

## Clustering of chronic hepatitis B screening intentions in social networks of Moroccan immigrants in the Netherlands

**Hamdiui N**, Buskens V, van Steenbergen JE, Kretzschmar MEE, Rocha LEC, Thorson AE, Timen A, Wong A, van den Muijsenbergh M, Stein ML.

*BMC Public Health. 2020; 20(1): 344.*

## Abstract

### Background

Early detection, identification, and treatment of chronic hepatitis B through screening is vital for those at increased risk, e.g. born in hepatitis B endemic countries. In the Netherlands, Moroccan immigrants show low participation rates in health-related screening programmes. Since social networks influence health behaviour, we investigated whether similar screening intentions for chronic hepatitis B cluster within social networks of Moroccan immigrants.

### Methods

We used respondent-driven sampling (RDS) where each participant ("recruiter") was asked to complete a questionnaire and to recruit three Moroccans ("recruitees") from their social network. Logistic regression analyses were used to analyse whether the recruiters' intention to request a screening test was similar to the intention of their recruitees.

### Results

We sampled 354 recruiter-recruitee pairs: for 154 pairs both participants had a positive screening intention, for 68 pairs both had a negative screening intention, and the remaining 132 pairs had a discordant intention to request a screening test. A tie between a recruiter and recruitee was associated with having the same screening intention, after correction for sociodemographic variables (OR 1.70 [1.15 – 2.51]).

### Conclusions

The findings of our pilot study show clustering of screening intention among individuals in the same network. This provides opportunities for social network interventions to encourage participation in hepatitis B screening initiatives.

## Background

Chronic hepatitis B (HBV) is a major global health problem. If untreated, it may put people at an increased risk for chronic sequelae including liver cirrhosis and fibrosis, leading to premature death. HBV prevalence is the highest in the World Health Organization (WHO) regions Western Pacific and Africa. Here, 6.2% and 6.1% of the population is chronically infected, respectively (1).

Although the Netherlands is a low-endemic country for chronic HBV (prevalence: 0.1%) (2), several risk groups have a significantly higher prevalence of HBV carriage, the largest of which being immigrants from intermediate or high endemic countries (3, 4). Of these immigrants, an estimated 5.4% is chronically infected (2, 5). While a free of charge vaccination programme targeting behavioural high-risk groups has been introduced in 2002 (6), universal HBV vaccination has only been introduced in the Netherlands in 2011, with four vaccine doses given at the ages of 2, 3, 4, and 11 months (7). Considering the predominance of mother-to-child HBV transmission among immigrants born in endemic countries, many immigrants arriving in the Netherlands could already be infected and for them vaccination has negligible benefit. Therefore, screening for the hepatitis B surface antigen (HBsAg) as sign of chronic infection is the only option. In November 2016, the Dutch Health Council recommended HBsAg-screening for first-generation immigrants originating from intermediate (2-7%) or high ( $\geq 8\%$ ) HBV endemic countries (8). This screening for HBsAg aims to detect unnoticed asymptomatic chronically infected individuals for either immediate treatment or monitoring, and to prevent further transmission (9). Although this screening is recommended for immigrants originating from countries with a HBV endemicity of 2% or higher, it proved to be cost-effective for those originating from countries with a HBV prevalence of 0.41% or higher (10). Based on three small regional Dutch studies, the prevalence of chronic HBV among Moroccans, who form the second largest immigrant group in the Netherlands, is low (0.54% [95% CI 0.01-1.07]) but within the range targeted for screening (11). We chose to target Moroccan immigrants in our pilot study, because of the proven cost-effectiveness and having our existing infrastructure (12, 13). Following the guidelines of Statistics Netherlands, we also define first-generation Moroccan immigrants as individuals born in Morocco and having at least one parent born in Morocco, and second-generation Moroccan immigrants as individuals born in the Netherlands and having at least one parent born in Morocco (14).

The Council recommended two strategies to screen these first-generation immigrants: (1) individual case finding by general practitioners (GP), and (2) local screening programmes. Both strategies start with an HBV test (costing EUR 25 (2019)). Since the Dutch health insurance is organised with a compulsory annual amount ("front-end deductible") of EUR 385 (2019) which you have to pay for health services before your

health insurance begins to pay, the HBV test is not refundable for those for whom this threshold has not been reached yet with other health care costs (12). However, Moroccan immigrants show lower participation rates in health-related screening programmes compared to indigenous and other immigrant populations (15-18). Previous qualitative and quantitative research showed that the main reasons for this nonparticipation in HBV screening initiatives were shame and stigma, fatalism (i.e. an attitude of resignation in the face of some future event or events which are thought to be inevitable), and the perceived burden of participating in such a screening (12, 13).

However, not only characteristics of a single individual are important, as research showed that health behaviour is also influenced by the individual's social contacts (19-21). For example, an American study found an increase in breast cancer screening participation among women whose sisters were screened and in colorectal screening participation if spouses were screened (22). Higher levels of the intention to screen for cardiovascular disease were observed among Mexican-Americans when participants had at least one older-generation peer who encouraged screening (23). Encouragement by family and/or friends and the perception that screening was normative were also found to be predictive for having a mammogram among American women (24). Furthermore, studies from the United States suggest that obesity, smoking, and happiness spread in social networks through social influence (19, 20, 25). For Moroccan immigrants specifically, scientific evidence points at the crucial role of an individual's social network for coping with perceived ethnic discrimination, the use of psychosocial services, and pregnancy-related health behaviour (26-28).

However, the majority of studies investigated the role of social contacts in preventive health behaviour using egocentric data, i.e., responses of participants who were sampled independently of one another. In most cases with egocentric approaches, researchers cannot contact participant's peers directly and must rely on what participants report about their social connections' characteristics (29). There is potentially relevant information that participants simply do not know about their social connections, such as intentions to participate in screening. By contrast, few studies collected saturated network data, which includes information on all nodes and connections within a specific population. Saturated approaches can be costly, time consuming, and thus limited to very small populations (29).

In this pilot study, we used respondent-driven sampling (RDS) to sample social contacts. RDS is a variant of chain-referral sampling, which was originally developed to study hard-to-reach populations and to calculate unbiased population estimates (30). We used RDS to reach immigrants and for social network analysis where a tie between two individuals is the unit of analysis, instead of the individual itself (29, 30). This enabled us to address our hypothesis, namely that similar HBV screening

intentions among Moroccan immigrants living in the Netherlands are clustered within their close social networks (i.e. family, friends, and workmates sharing the same positive or negative screening intention) due to a strong sense of community and trust within the group. The collection and analyses of empirical network data are important first steps to help future studies in selecting appropriate network interventions to encourage participation in HBV screening initiatives (31).

## Methods

### Study population

In 2018, there were 396,539 Moroccans in the Netherlands of which 169,018 first- and 227,521 second-generation (as defined by Statistics Netherlands) (32). The children of this second generation are defined as non-immigrant and are, thus, not registered as third-generation immigrant. Of all first-generation Moroccan immigrants in the Netherlands, 21% live in Amsterdam, 12% in Rotterdam, 8% in Utrecht, and 8% in the Hague. Some medium-sized municipalities, including Gouda, Almere, Leiden, Haarlem, Eindhoven, and Tilburg, are also cities where relatively large numbers of Moroccans of the first generation live (33).

### Study design

From November 2016 to February 2017, first-generation Moroccan immigrants and their children and grandchildren were recruited throughout the Netherlands using offline and online respondent-driven sampling (RDS) to identify determinants of one's intention to participate in screening for chronic HBV, of which methods and results were described earlier (30). Although children of second-generation immigrants are non-immigrants, we included both children and grandchildren of first-generation Moroccan immigrants. In immigrant families, both children and grandchildren play an important social role for - and have a close relationship with - their parents and grandparents. They act as instructors, models, and interpreters, and provide financial, social, and/or emotional support to their parents and grandparents. Therefore, both children and grandchildren are an important group to consider when studying health behaviour of first-generation immigrants (34, 35), since they frequently act as brokers for their parents or grandparents in contact with the Dutch healthcare (36).

RDS starts with a convenience sample of the target population (so-called "seeds"). We recruited seeds offline, at community venues (such as community centres, day care centres, and mosques) and by approaching interest groups and civil support foundations in the aforementioned regions. Here, small groups of only men or only women regularly came together for cooking workshops, Dutch language courses, and Quran readings. Online, seeds were recruited through advertisements on Moroccan-Dutch forums, Facebook, Instagram, the website of the Dutch National Institute for Public Health and the Environment (RIVM), and a Moroccan-Dutch website (37). Both



offline and online questionnaires were filled in by the participants themselves with an option of translation by - or getting assistance - of a Berber-speaking researcher. Seeds ("recruiters" representing wave zero) were asked to complete a questionnaire and invite at least three Moroccans from their social network ("recruitees") to complete the same questionnaire. Initial recruitees (representing wave one) were also asked to recruit others. Therefore, they became "recruiters" too, which led to wave two, and so on. Each recruiter, who recruited at least three recruitees, received one gift coupon. The values of these coupons were EUR 5, when our study started, and were raised to EUR 10, and EUR 25, in later stages of the study in order to increase recruitment. The value was increased to stimulate peer-recruitment among all new participants. Invitations containing unique and anonymous codes (more details can be found in a previous publication (12)) enabled us to follow who invited whom and to visualise and analyse their social networks. Eligibility criteria included: (1) age  $\geq 16$  years; (2) born in Morocco and having at least one parent born in Morocco, or born in the Netherlands and having at least one (grand-) parent born in Morocco; and (3) residing in the Netherlands.

The link between each recruiter with his/her recruitee was defined as a "*tie*". A "tie" is further distinguished into "**RDS ties**" and "**venue ties**":

- Since an invitation must be physically transferred from the recruiter to the recruitee following RDS, these links are further referred to as "**RDS ties**".
- Since the majority of offline-recruited participants entailed small groups that regularly came together for a variety of activities, we assumed that all participants recruited at one community venue knew each other and thus were connected, which resulted in additional ties per community venue (further referred to as "**venue ties**").
- "RDS ties" and "venue ties" were both defined as "*having a tie*". We tested whether the assumption that these two types of ties have similar effects is reasonable.

### Questionnaire

We developed and used a questionnaire in Dutch, in which questions were based on a compilation of the Health Belief Model (HBM), the Theory of Planned Behaviour (TPB), and Betancourt's Model of Culture and Behaviour (38) following earlier studies that investigated HBV screening intention among the Turkish-Dutch population (39). The HBM assumes that a subject is more likely to take a "health action" whenever s/he perceives (1) the disease as serious, (2) herself or himself susceptible to the disease, (3) benefits of the health action, (4) limited barriers to take the health action, (5) self-efficacy in relation to the health action, and whenever (6) s/he receives a cue to take the health action. According to the TPB, intention reflects a person's readiness to perform a certain health behaviour or action, explained by attitude, subjective norm, and perceived behavioural control. Betancourt's Model of Culture and Behaviour

includes culture to explain its effect on health behaviours. The questionnaire focused on the predominance of mother-to-child HBV transmission and not on other possible transmission routes, such as sexual contact. This was to avoid feelings of shame and stigma, which were found to exist in previous studies (12, 13). To classify identity, a question regarding mother tongue was included: Dutch, Moroccan-Arabic, Berber, Modern Standard Arabic, and/or other. Those who reported to be speakers of Berber were defined as having a Berber identity, whereas those who reported to be speakers of Moroccan-Arabic and/or Modern Standard Arabic and not Berber were defined as having a Moroccan-Arabic identity. This grouping was done since these languages represent (to some extent) two social subgroups within the Moroccan community. In the questionnaire, our outcome variables (i.e. intention to request a test and intention to participate) were measured using the questions: "Imagine, you go the GP tomorrow. Would you request a HBV test?" and "Imagine, your GP advises you to have yourself tested for HBV. Would you participate in HBV screening if you would have to pay EUR 70 for this test?". We will further refer to these outcome measures as 'Intention request' and 'Intention 70'. All variables measured by the questionnaire are depicted in Supplementary Table S4.1.

### Statistical analysis

To study the distribution of similar intentions within the sampled social networks, we chose to analyse dyads (i.e. pairs of individuals), which are the smallest type of social structure in which an individual can be embedded. To obtain the dyad as the level of analysis, we first defined the set of dyads as the set of all possible pairs of participants in the sample, i.e. we constructed a set of  $n(n-1)/2$  dyads. Then, we constructed the variable "tie". This variable is coded one for pairs of participants who have either a RDS or a venue tie. The variable is coded zero for all other pairs of participants in the dataset. For each pair, we checked whether they had the same intention for requesting a HBV test on own initiative (outcome one, 'Intention request') and the same intention to participate in HBV screening for non-refundable costs of EUR 70 (outcome two, 'Intention 70'). Logistic regression was used to analyse whether tie equal to one increases the likelihood that in a pair of individuals both have the same intention.

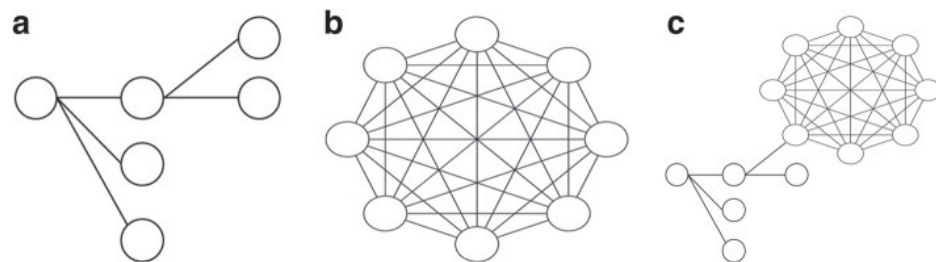
### Non-hierarchical structure

A logistic regression model assumes that observations are independent of each other, which is not the case in our sample, since participants were involved in multiple pairs (i.e. multiple times as recruiter, or as both recruiter and recruitee) and participants were also directly or indirectly linked in recruitment trees (see Figures 4.1a-c). If only RDS ties were present, a recruitment tree consisted of the seed (wave zero) and all consecutive waves with participants who all share this seed (see Figure 4.1a). If only venue ties were present, a recruitment tree consisted of all participants recruited at one community venue being connected to each other (see Figure 4.1b). If both types

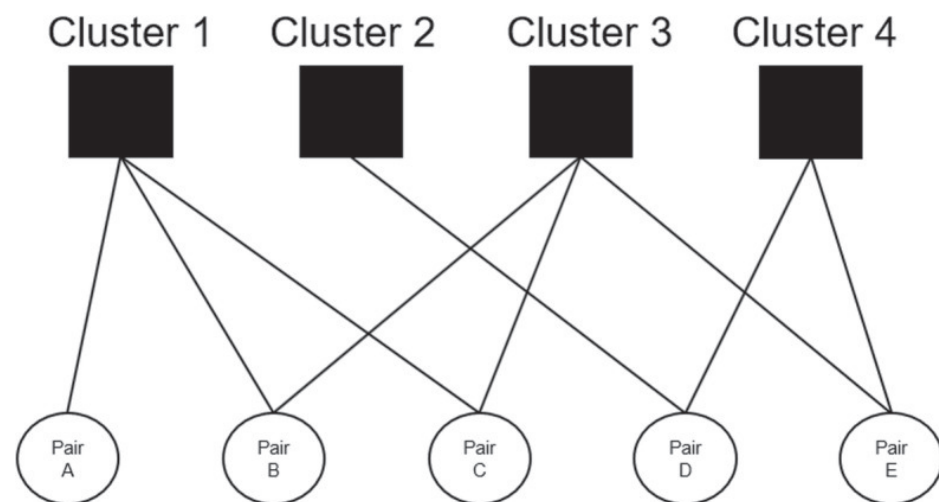


of ties were present, a recruitment tree consisted of the seed and its consecutive waves, with participants connected to each other (as a group) representing one community venue (see Figure 4.1c). These recruitment trees are further referred to as "clusters".

This creates a non-hierarchical (i.e. multi-way) nesting structure of observations of pairs each nested in one or two clusters (see Figure 4.2). We controlled for this non-hierarchical clustering by using robust standard errors adapted for multi-way clustering as suggested by Cameron et al. (40). With this method, pairs nested in overlapping clusters are considered dependent observations, whereas pairs nested in different clusters are considered independent observations. Thus, pairs are considered dependent observations if at least one node of each pair is present within the same cluster.



**Figure 4.1a.** Recruitment tree with only RDS ties,  
**4.1b.** Recruitment tree with only venue ties,  
**4.1c.** Recruitment tree with both RDS ties and venue ties



**Figure 4.2.** Data structure of clusters and pairs

By using robust standard errors adapted for multi-way clustering, pairs with at least one participant in the same cluster (see pair A and pair B for example) are considered dependent observations. Pairs without participants in the same clusters (see pair A and pair E for example) are considered independent observations.

### Logistic regression models

We constructed four models for each of the two outcomes. First, the variable "tie" was included as the single independent variable (Model I). Thereafter, we included the second independent binary variable "type of tie", with the categories: close family relationship yes/no (i.e. a family member or partner living in the same household) (Model II). Doing so, we investigated whether the association between tie and having the same screening intention differed for the type of tie studied. Subsequently, in Model III, we added several sociodemographic variables, namely: having the same gender (with the following categories: woman-woman versus man-man and man-woman versus man-man), mean age, age difference, same country of birth (with the following categories: Netherlands-Netherlands versus Morocco-Morocco and Netherlands-Morocco versus Morocco-Morocco), and the same educational level. The mean value of the pairs' educational level was added by taking the mean value of the coding values of "educational level". With a mean value of three for example, one participant may have an educational level coded as two and the other one as four. The participant's attitude towards fatalism in the context of screening was also included, since it incorporates, to some extent, one's individual religious interpretation and its influence on screening intention, which we believe is an important individual characteristic to include in the model (41). Prior to this study, determinants of individual screening intention were studied qualitatively (13) and quantitatively (12). The five most important determinants of individual screening intention (wanting clarity, fatalism, not having symptoms, self-efficacy, and risk perception) (found in this previous study (12)) were added in the final logistic regression model (Model IV) to assess whether the underlying determinants of individual screening intention are (also) concurrent between participants with a tie.

In Models III and IV, we also constructed variables at the dyad level for each sociodemographic variable and each determinant of individual screening intention. Two covariates were included for each determinant. As an example, for the sociodemographic variable "educational level" we included "having the same educational level" (1 = yes / 0 = no) and the mean educational level. This enabled us to distinguish whether a pair has the same screening intention 1) because of having the same educational level or 2) because of the educational level itself. In other words, it may be possible that having the *same* educational level is not associated with having the same screening intention, but that a *high* education level is associated with having the same *positive* screening intention. For age, we included the difference in age between pairs to incorporate its influence on having the same screening intention.

To determine associations of intention for each combination of pairs specifically (discordant, both positive, or both negative), multinomial logistic regression analyses would be needed. For the interpretability of our results, however, we chose to repeat Models I to IV, but then with the dependent variable regrouped into “having the same *positive* intention” (1 = yes / 0 = no) and “having the same *negative* intention” (1 = yes / 0 = no).

All analyses were conducted two-tailed, significance tests with  $\alpha = 0.05$ , using R version 3.4.0 and STATA version 14.2.

Results

Study participants and pairs with a tie

The study population was composed of 379 Moroccan immigrants, of which 156 (41.2%) were recruited offline and 223 (58.8%) online (see Table 4.1). Of these participants, 59.5% were seeds and 40.5% were recruited by their social contacts (recruitees). By using online RDS, we mainly reached younger second-generation immigrants and their children, with a higher educational level, compared to those recruited offline. Those recruited offline had more willingness to participate in screening for non-refundable costs of EUR 70 compared to online-recruited participants. Of the total study population, 269 (71%) would test themselves if a friend recommends having a HBV test.

Table 4.1. Sample characteristics stratified for offline/online recruitment, n = 379

Characteristic	Offline-recruited participants (n = 156, 41.2%)	Online-recruited participants (n = 223, 58.8%)	Total (n = 379)
Will test myself if friend recommends	Yes	163 (73.1)	269 (71.0)
	No	16 (7.2)	35 (9.2)
	I do not know	24 (10.8)	53 (14.0)
	Missing value	20 (9.0)	22 (5.8)
Intention request	Yes/probably yes	109 (48.9)	187 (49.3)
	No/probably not	94 (42.2)	168 (44.3)
	Missing value	20 (9.0)	24 (6.3)
Intention 70	Yes/probably yes	84 (37.7)	167 (44.1)
	No/probably not	117 (52.5)	176 (46.4)
	Missing value	22 (9.9)	36 (9.5)
Country of birth	Morocco	83 (37.2)	193 (50.9)
	The Netherlands	140 (62.8)	186 (49.1)
	Missing value	0 (0)	0 (0)
Moroccan-Arabic or Berber identity	Moroccan-Arabic	90 (40.4)	151 (39.8)
	Berber	133 (59.6)	227 (59.9)
	Missing value	0 (0)	1 (0.3)
Gender	Man	71 (31.8)	123 (32.5)
	Woman	152 (68.2)	256 (67.5)
	Missing value	0 (0)	0 (0)

Table 4.1. Sample characteristics stratified for offline/online recruitment, n = 379 (continued)

Characteristic	Offline-recruited participants (n = 156, 41.2%)	Online-recruited participants (n = 223, 58.8%)	Total (n = 379)
Age group			
16 – 25 years	22 (14.1)	64 (28.7)	86 (22.7)
26 – 35 years	16 (10.3)	61 (27.4)	77 (20.3)
36 – 45 years	34 (21.8)	60 (26.9)	94 (24.8)
46 – 55 years	35 (22.4)	29 (13.0)	64 (16.9)
56 – 65 years	25 (16.0)	6 (2.7)	31 (8.2)
66 years and older	12 (7.7)	2 (0.9)	14 (3.7)
Missing value	12 (7.7)	1 (0.4)	13 (3.4)
Educational level			
No official education or primary school	51 (32.7)	15 (6.7)	66 (17.4)
Secondary school	34 (21.8)	41 (18.4)	75 (19.8)
Vocational education	36 (23.1)	61 (27.4)	97 (25.6)
Higher education	32 (20.5)	103 (46.2)	135 (35.6)
Missing value	3 (1.9)	3 (1.3)	6 (1.6)
Speaking Dutch (SR)			
Yes	145 (92.9)	221 (99.1)	366 (96.6)
No	10 (6.4)	2 (0.9)	12 (3.2)
Missing value	1 (0.6)	0 (0)	1 (0.3)
Knowledge on HBV			
No	70 (44.9)	82 (36.8)	152 (40.1)
Limited	57 (36.5)	105 (47.1)	162 (42.7)
Sufficient	29 (18.6)	36 (16.1)	65 (17.2)
Missing value	0 (0)	0 (0)	0 (0)

Table 4.1. Sample characteristics stratified for offline/online recruitment, n = 379 (continued)

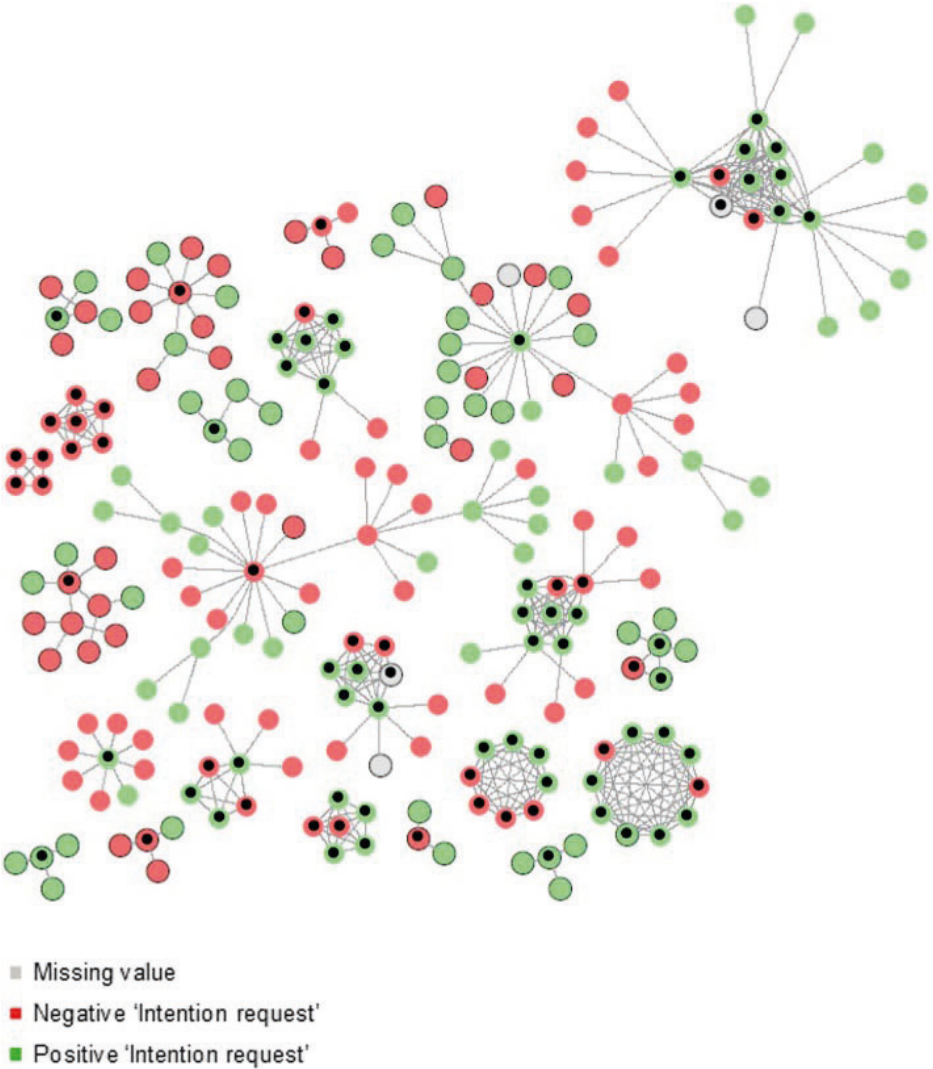
Characteristic	Offline-recruited participants (n = 156, 41.2%)	Online-recruited participants (n = 223, 58.8%)	Total (n = 379)
HBV in family or friends			
Yes	43 (27.6)	34 (15.2)	77 (20.3)
No	98 (62.8)	156 (70.0)	254 (67.0)
I do not know	15 (9.6)	33 (14.8)	48 (12.7)
Missing value	0 (0)	0 (0)	0 (0)
Tested for HBV (SR)			
Yes	30 (19.2)	49 (22.0)	79 (20.8)
No	110 (70.5)	149 (66.8)	259 (68.3)
I do not know	15 (9.6)	25 (11.2)	40 (10.6)
Missing value	1 (0.6)	0 (0)	1 (0.3)
Vaccinated against HBV (SR)			
Yes	42 (26.9)	73 (32.7)	115 (30.3)
No	61 (39.1)	47 (21.1)	108 (28.5)
I do not know	53 (34.0)	103 (46.2)	156 (41.2)
Missing value	0 (0)	0 (0)	0 (0)
Who invited you for the questionnaire?			
Family or partner	46 (29.5)	74 (33.2)	120 (31.7)
Friend, acquaintance, or workmate	40 (25.6)	60 (26.9)	100 (26.4)
Researcher of the RIVM	32 (20.5)	19 (8.5)	47 (12.4)
Via a message on a website	0 (0)	58 (26.0)	58 (15.3)
Someone else	37 (23.7)	10 (4.5)	51 (13.5)
Missing value	1 (0.6)	2 (0.9)	3 (0.8)

Data are reported as number of participants (%).  
SR: Self-reported.

The maximum number of waves was four. Of the 24 clusters, there were eight with two or more waves. The largest cluster consisted of 35 participants (see Figure 4.3). We obtained 390 recruiter-recruitee pairs: 154 pairs had a positive screening intention, 68 had a negative screening intention, 132 had a discordant screening intention, and for 36 pairs one or both individual(s) did not report their screening intention and were, therefore, not included in further analyses (see Supplementary Table S4.3). Pairs with a negative intention more often had a Berber identity and were generally younger.

**Tie in relation to screening intention**

Having a tie was associated with having the same screening intention and the association is not different for strong family ties compared to other ties (Model I-II), even after adjustment for covariates (Model III-IV) (see Table 4.2). Model IV provided the highest value of the log likelihood and thus performed the best. In this model, an OR of 1.70 [95% CI 1.15 – 2.51] was found for the association of having a tie on having the same screening intention. The greater the extent to which individuals believed that “screening gives clarity”, the higher the odds of having the same screening intention with an OR of 1.99 [95% CI 1.03 – 3.86]. Having the same educational level was negatively associated with having the same screening intention (OR 0.96 [95% CI 0.92 – 0.99]).



**Figure 4.3. Screening intention among Moroccan immigrants ('Intention request')**

*Those recruited offline are presented as nodes with a transparent border, those recruited online are presented as nodes with a black border, and seeds are nodes with a black dot in the centre.*

Table 4.2. Logistic regression analyses of having the same screening intention ('Intention request') in relation to having a tie

Variables	Model I N <sub>potential</sub> = 25651 (Log likelihood = -17767)		Model II N <sub>potential</sub> = 25493 (Log likelihood = -17657)		Model III N <sub>potential</sub> = 19175 (Log likelihood = -13226)		Model IV N <sub>potential</sub> = 18019 (Log likelihood = -12317)	
	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value
Tie	1.71 [1.25 – 2.34]	0.001*	1.70 [1.25 – 2.32]	0.001*	1.70 [1.20 – 2.40]	0.003*	1.70 [1.15 – 2.51]	0.008*
Type of tie <i>Close family relationship yes/no</i>			0.97 [0.92 – 1.02]	0.222	0.97 [0.88 – 1.06]	0.495	0.99 [0.90 – 1.08]	0.816
Same gender: W-W vs M-M					1.09 [0.96 – 1.24]	0.172	1.07 [0.95 – 1.20]	0.254
Same gender: M-W vs M-M					1.02 [0.87 – 1.20]	0.789	1.03 [0.89 – 1.19]	0.656
Mean age					1.00 [0.99 – 1.00]	0.284	1.00 [0.99 – 1.00]	0.319
Difference in age					1.00 [1.00 – 1.01]	0.370	1.00 [1.00 – 1.01]	0.316
Same country of birth: NL-NL vs MR-MR					0.85 [0.67 – 1.09]	0.199	0.89 [0.76 – 1.05]	0.170
Same country of birth: NL-MR vs MR-MR					0.82 [0.64 – 1.07]	0.143	0.86 [0.70 – 1.04]	0.127
Same educational level					0.97 [0.91 – 1.04]	0.402	0.96 [0.92 – 0.99]	0.028*

Table 4.2. Logistic regression analyses of having the same screening intention ('Intention request') in relation to having a tie (continued)

Variables	Model I N <sub>potential</sub> = 25651 (Log likelihood = -17767)		Model II N <sub>potential</sub> = 25493 (Log likelihood = -17657)		Model III N <sub>potential</sub> = 19175 (Log likelihood = -13226)		Model IV N <sub>potential</sub> = 18019 (Log likelihood = -12317)	
	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value
Mean educational level					0.99 [0.95 – 1.03]	0.634	0.99 [0.95 – 1.04]	0.780
Same response on fatalism					1.29 [0.90 – 1.86]	0.170	1.32 [0.90 – 1.93]	0.162
Mean value on fatalism					1.07 [0.93 – 1.25]	0.341	1.05 [0.95 – 1.16]	0.300
Same response on "screening gives clarity"							2.36 [0.88 – 6.30]	0.087
Mean value on "screening gives clarity"							1.99 [1.03 – 3.86]	0.042*
Same response on "screening not needed if no symptoms"							1.26 [0.96 – 1.65]	0.097



Table 4.2. Logistic regression analyses of having the same screening intention ('Intention request') in relation to having a tie (continued)

Variables	Model I N <sub>potential</sub> = 25651 (Log likelihood = -17767)		Model II N <sub>potential</sub> = 25493 (Log likelihood = -17657)		Model III N <sub>potential</sub> = 19175 (Log likelihood = -13226)		Model IV N <sub>potential</sub> = 18019 (Log likelihood = -12317)	
	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value
Mean value on "screening not needed if no symptoms"							1.06 [0.91 – 1.24]	0.447
Same response on self-efficacy							1.21 [0.84 – 1.73]	0.307
Mean value on self-efficacy							1.20 [0.95 – 1.50]	0.121
Same response on risk perception							1.10 [0.97 – 1.25]	0.146
Mean value on risk perception							1.02 [0.96 – 1.09]	0.449

\*p < 0.05  
We used the variance estimator proposed by Cameron et al, which is a robust method to correct standard errors for multi-way clustering (40).

Regrouping of screening intention

Of the 154 pairs with a positive screening intention, having a tie was associated with having the same *positive* screening intention with an OR of 1.56 [95% CI 1.11 – 2.17] (see Supplementary Table S4.4). This indicates that positive intentions on screening cluster within social networks. Same response on fatalism (OR 1.90 [95% CI 1.12 – 3.21]), same response on "screening gives clarity" (OR 4.21 [95% CI 1.25 – 14.18]), and same response on self-efficacy (OR 2.18 [95% CI 1.05 – 4.49]) were all associated with having the same *positive* screening intention. The higher a pair perceived the risk of having chronic HBV, the higher the odds of having the same *positive* screening intention (OR 1.23 [95% CI 1.01 – 1.50]).

Of the 68 pairs with a negative screening intention, having a tie was not associated with having the same *negative* screening intention (OR 1.23 [0.97 – 2.09], see Supplementary Table S4.5). Having the same response on fatalism and on self-efficacy decreased the odds of having the same *negative* screening intention with 0.69 [95% CI 0.53 – 0.89] and 0.57 [95% CI 0.36 – 0.90], respectively. The higher a pair perceived the risk of having chronic HBV, the lower the odds of having the same *negative* screening intention with 0.77 [95% CI 0.61 – 0.98], consistent with results of those having the same *positive* screening intention.

Ties also seem to reinforce the intention to participate in screening for a maximum up to EUR 70 ('Intention 70') (see Supplementary Table S4.2). Woman-woman and man-woman pairs appeared to more often have the same screening intention in comparison to man-man pairs. The results of the analyses for outcome measure "Intention 70" can be found in Supplementary Tables S4.2, S4.4, and S4.5 in the Supplementary Tables and Figures.

## Discussion

We collected empirical data to study screening intentions in social networks of Moroccan immigrants and their offspring. Having a tie was associated with having the same intention to request a HBV test, as well as with the intention to participate in screening for a maximum compensation of up to EUR 70. By making use of respondent-driven sampling (RDS), we had the advantage of studying behaviour from socially interconnected individuals (i.e. we sampled both recruiters and recruits) rather than considering responses reported by recruiters using only the persons in their own social network (i.e. ego-centric networks) as normally done in the literature (29).

A positive screening intention was clustered within the sampled social networks, while we found no indication of clustering for negative screening intention. The latter may be due to a limited number of sampled pairs with a negative screening intention ( $n = 68$ ). In our study, pairs with a negative intention were younger and more often had a Berber identity (see Supplementary Table S4.3). However, our logistic regression models did not indicate an association of these demographics with screening intention, but showed associations with determinants of individual screening intention only, which were also seen for pairs with a positive intention. Our findings suggest that interventions aimed at promoting screening participation may have benefits in the social group, beyond the individuals directly reached by these interventions, although we do not yet have a thorough understanding whether this is due to social influence. Testing this new hypothesis in an experimental setting is a future research direction.

By gradually including covariates in the model, we learned that having the same educational level had a negative association with having the same screening intention, which might be due to collinearity with some of the factors added in the final model. We also found that the more a pair thinks “screening gives clarity”, the higher the odds of having the same screening intention, which is consistent with previous work where this determinant was found as facilitator for intending to request a HBV test (12).

Pairs of woman-woman and man-woman had more often the same screening intention compared to man-man pairs for the intention to participate in screening for a maximum compensation of up to EUR 70 (‘Intention 70’). Pairs of the opposite sex will most likely be spouses or family members, since the Islam does not permit (close) social relationships with the opposite sex. Thus, spouses, family members of the opposite sex, and women more often have the same screening intention compared to men-men relationships. These findings suggest that we should not only focus on the individual when investigating (determinants of) screening behaviour, but incorporate screening behaviour of social contacts depending on sex (e.g. female spouses or friends) as well. It is necessary to approach decisions to screen (or not screen) not

only from an individual perspective but also consider the particular community in which target populations are immersed. However, whether and to what extent individuals influence each other (potentially leading to the same screening intention) should be studied using a more experimental treatment of individuals or by following social relations longitudinally. Such research could further direct on how to target communication strategies to enhance HBV screening participation.

Our results are consistent with previous work on a wide variety of behaviours and traits in social networks (42-44), such as obesity (19, 45), smoking (20, 46), happiness (25), and vaccination and cancer screening participation (47-49). In our study, having a tie was shown to play a role in the intention to screen among those with a positive screening intention. This is partly in line with previous research, where researchers found social clustering of vaccine-refusers (50). Stronger associations among pairs of women (found for ‘Intention 70’) were also observed for smoking in earlier research (46). This is possibly because women engage in stronger relationships with a higher level of intimacy and reciprocity (51, 52). Moreover, consistent with what we found for ‘Intention 70’, Christakis et al. found the highest decrease in a person's chance of smoking when a spouse quits smoking in comparison to siblings and friends quitting (20).

It is important to recognize the limitations of the presented data. First, we assumed that participants recruited at the same venue had a tie, which may have caused an invalid overrepresentation of the variable tie. We assessed whether this was reasonable by including an interaction variable (“tie x RDS/venue ties”) in our final model. No association with our dependent variable was found (data not shown), which makes our assumption plausible. Second, we obtained a limited sample size and possibly a selective group, as we reached only a maximum of four waves and no Moroccans living in the north of the Netherlands (see Supplementary Figure S4.1). A larger sample size with a better geographic coverage would provide stronger evidence to generalise our findings. Nevertheless, this study provides empirical data on screening intention within social networks among a hard-to-reach population, namely Moroccan immigrants in the Netherlands. Potential reasons for individuals to refuse participation in our study were HBV-associated shame and stigma, and language barriers. To overcome these issues, we focused the questionnaire on the predominance of mother-to-child HBV transmission, and provided the option of having a face-to-face interview (at visited community venues) or a telephone interview, in either Berber or Moroccan-Arabic. Third, since participants received an incentive whenever they recruited three individuals, we did not stimulate recruitment of their complete social network and only investigated part of this network. This recruitment restriction in combination with having sampled only a maximum of four waves could have affected our results. Moreover, RDS recruitment is biased. Participants tend to invite the “right people” (eligible and/or reliable) that they believe

would accept the invitation for the questionnaire or those that they feel will benefit from the questionnaire (53). However, we did observe that participants recruited along different types of ties (e.g., family members, friends, acquaintances, workmates), which might have increased the diversity of intentions and traits in our sample. Furthermore, we investigated screening intention rather than actual behaviour (i.e. screening participation). Since previous research reported an observed discrepancy between intention and participation (54, 55), future research should also investigate screening participation within social networks to assess potential discrepancies. Additionally, our study population included more females and was higher educated in comparison to what was reported in the 2015 sample by Statistics Netherlands (12). This bias is likely to be reduced by including gender and educational level in Models III and IV. Finally, because of the cross-sectional design of our study, we only captured a snapshot of individuals' screening intention and did not study changes over time. Our data did not allow us to identify the underlying mechanism of the observed clustering of a positive screening intention. Whether this clustering is due to social influence has yet to be studied. If so, it might be necessary to set up so-called "induction interventions" where peer-to-peer interactions are stimulated or forced to create cascades in information/behavioural diffusion using word-of-mouth, RDS, or network outreach (i.e. seeds recruit members of their personal networks to participate in an intervention together) (31).

## Conclusions

Out of all the variables considered in this study including sociodemographic characteristics, having a tie was the most important one in terms of one's screening intention. These findings emphasise the need to take the social network of individuals into account when studying individual behaviour concerning screening participation. The next step is to investigate if and how peers and/or other community members can be used to disseminate information for informed decision-making regarding screening programmes, such as chronic HBV screening.

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Supplementary Tables and Figures

Supplementary Table S4.1. Overview of variables measured by the questionnaire

Constructs	Variables	Short variable descriptions	Options
<i>Perceived risk</i>	Risk without noticing	Risk having HBV without noticing	Low Quite low Average Quite high High I do not know
	Risk infecting someone	Risk of infecting someone with HBV	Low Quite low Average Quite high High I do not know
<i>Perceived severity of disease</i>	Severity feeling good	HBV is no problem when feeling good	Yes No I do not know
	Severity serious disease	HBV is a serious disease	Yes No I do not know
<i>Stigma regarding HBV</i>	Stigma friends	Others not wanting to be friends when having HBV	Yes No I do not know
	Stigma respect	Others less respect when having HBV	Yes No I do not know
	Stigma comfort	Others feeling uncomfortable when having HBV	Yes No I do not know



Supplementary Table S4.1. Overview of variables measured by the questionnaire (continued)

Constructs	Variables	Short variable descriptions	Options
<i>Shame regarding HBV</i>	Shame others	Feeling ashamed when others know HBV status	Yes No I do not know
	Shame guilty	Feeling guilty having HBV	Yes No I do not know
	Shame fear	Feeling feared having HBV	Yes No I do not know
	Shame disappointment	Feeling disappointed having HBV	Yes No I do not know
	Shame not caring	Do not care if others know HBV status	Yes No I do not know
<i>Perceived self-efficacy</i>	Self-efficacy	Able to decide HBV screening participation	Yes No I do not know
<i>Social influence</i>	Social influence friends	Will test myself if friend recommends	Yes No I do not know
	Social influence imam	Will test myself if imam recommends	Yes No I do not know
<i>Perceived benefits</i>	Benefit own health	HBV screening good for my health	Yes No I do not know
	Benefit health others	HBV screening good for health others	Yes No I do not know
	Benefit clarity	HBV screening gives clarity	Yes No I do not know

Supplementary Table S4.1. Overview of variables measured by the questionnaire (continued)

Constructs	Variables	Short variable descriptions	Options
<i>Perceived barriers</i>	Barrier too much time	HBV screening takes too much time	Yes No I do not know
	Barrier important	HBV screening not important	Yes No I do not know
	Barrier not having symptoms	HBV screening not needed if no symptoms	Yes No I do not know
	Barrier trusting Allah	HBV screening not needed only trust Allah	Yes No I do not know
<i>Knowledge on HBV</i>	Knowledge on HBV	I know nothing about HBV HBV is an infectious disease HBV can cause liver cancer Someone who is looking healthy and feeling good cannot infect others with HBV	True False
<i>Moroccan-Arabic or Berber identity</i>	Moroccan-Arabic or Berber identity	-	Moroccan-Arabic Berber
<i>Speaking Dutch</i>	Speaking Dutch	The ability to speak Dutch	Yes No
<i>Knowing someone having HBV</i>	Knowing someone having HBV	Knowing someone having HBV	Yes No I do not know
<i>Tested for HBV</i>	Tested for HBV	Tested for HBV, self-reported	Yes No I do not know
<i>Vaccinated against HBV</i>	Vaccinated against HBV	Vaccinated against HBV, self-reported	Yes No I do not know

Supplementary Table S4.2. Logistic regression analyses of having the same screening intention ('Intention 70') in relation to having a tie

Variables	Model I N <sup>potential</sup> = 23436 (Log likelihood = -16233)		Model II N <sup>potential</sup> = 23288 (Log likelihood = -16130)		Model III N <sup>potential</sup> = 17831 (Log likelihood = -12349882)		Model IV N <sup>potential</sup> = 17085 (Log likelihood = -11832)	
	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value
Tie	1.69 [1.13 – 2.53]	0.010*	1.71 [1.15 – 2.55]	0.008*	1.71 [1.11 – 2.65]	0.016*	1.62 [1.09 – 2.42]	0.017*
Type of tie								
Close family relationship				0.624	1.03 [0.97 – 1.11]	0.335	1.05 [0.99 – 1.11]	0.084
yes/no								
Same gender:					1.03	0.615	1.03	0.076
W-W vs M-M					[0.92 – 1.15]		[1.00 – 1.07]	
Same gender:					1.04	0.019*	1.05	<0.001*
M-W vs M-M					[1.01 – 1.08]		[1.03 – 1.07]	
Mean age					1.00	0.916	1.00	0.853
					[1.00 – 1.00]		[0.99 – 1.01]	
Difference in age					1.00	0.899	1.00	0.974
					[1.00 – 1.00]		[0.99 – 1.01]	
Same country of birth:					1.01	0.965	0.97	0.850
NL- NL vs MR-MR					[0.77 – 1.32]		[0.69 – 1.36]	
Same country of birth:					1.02	0.840	0.99	0.928
NL- MR vs MR-MR					[0.88 – 1.17]		[0.84 – 1.18]	
Same educational level					1.00	0.936	0.99	0.789
					[0.92 – 1.08]		[0.91 – 1.07]	
Mean educational level					1.00	0.922	1.00	0.953
					[0.91 – 1.11]		[0.91 – 1.10]	

Variables	Model I N <sup>potential</sup> = 23436 (Log likelihood = -16233)		Model II N <sup>potential</sup> = 23288 (Log likelihood = -16130)		Model III N <sup>potential</sup> = 17831 (Log likelihood = -12349882)		Model IV N <sup>potential</sup> = 17085 (Log likelihood = -11832)	
	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value	OR [95% CI]	p-value
Same response on fatalism					0.98 [0.94 – 1.02]	0.257	0.97 [0.92 – 1.02]	0.224
Mean value on fatalism					1.00 [0.87 – 1.14]	0.962	1.00 [0.88 – 1.14]	0.960
Same response on "screening gives clarity"							0.98 [0.94 – 1.02]	0.295
Mean value on "screening gives clarity"							1.00 [0.85 – 1.18]	0.995
Same response on "screening not needed if no symptoms"							1.04 [0.94 – 1.16]	0.395
Mean value on "screening not needed if no symptoms"							1.00 [0.89 – 1.12]	0.997
Same response on self-efficacy							1.03 [0.91 – 1.16]	0.643
Mean value on self-efficacy							0.99 [0.90 – 1.10]	0.864
Same response on risk perception							1.18 [0.77 – 1.80]	0.448
Mean value on risk perception							1.21 [0.99 – 1.47]	0.059

\*p < 0.05  
We used the variance estimator proposed by Cameron et al, which is a robust method to correct standard errors for multi-way clustering (40).

Supplementary Table S4.3. Sample characteristics for pairs with a discordant, positive, and negative screening intention				
Characteristic	Discordant pairs (132 pairs with 124 unique individuals)	Positive pairs (154 pairs with 104 unique individuals)	Negative pairs (68 pairs with 67 unique individuals)	
Offline or online questionnaire participation	Offline	69 (67.6)	45 (67.2)	
	Online	34 (27.4)	33 (32.4)	
	Missing value	0 (0)	0 (0)	
Country of birth	Morocco	75 (60.5)	69 (67.6)	41 (61.2)
	The Netherlands	49 (39.5)	33 (32.4)	26 (38.8)
	Missing value	0 (0)	0 (0)	0 (0)
Moroccan-Arabic or Berber identity	Moroccan-Arabic	51 (41.1)	42 (41.2)	20 (29.9)
	Berber	72 (58.1)	60 (58.8)	46 (68.7)
	Missing value	1 (0.8)	0 (0)	1 (1.5)
Gender	Man	35 (28.2)	29 (28.4)	21 (31.3)
	Woman	89 (71.8)	73 (71.6)	46 (68.7)
	Missing value	0 (0)	0 (0)	0 (0)
Age group	16 – 25 years	23 (18.5)	14 (13.7)	16 (23.9)
	26 – 35 years	17 (13.7)	17 (16.7)	6 (9.0)
	36 – 45 years	31 (25.0)	22 (21.6)	18 (26.9)
	46 – 55 years	22 (17.7)	28 (27.5)	11 (16.4)
	56 – 65 years	17 (13.7)	11 (10.8)	10 (14.9)
	66 years and older	7 (5.6)	7 (6.9)	2 (3.0)
	Missing value	7 (5.6)	3 (2.9)	4 (6.0)

Supplementary Table S4.3. Sample characteristics for pairs with a discordant, positive, and negative screening intention (continued)				
Characteristic	Discordant pairs (132 pairs with 124 unique individuals)	Positive pairs (154 pairs with 104 unique individuals)	Negative pairs (68 pairs with 67 unique individuals)	
Educational level	No official education or primary school	32 (25.8)	28 (27.5)	13 (19.4)
	Secondary school	21 (16.9)	16 (15.7)	19 (28.4)
	Vocational education	28 (22.6)	24 (23.5)	15 (22.4)
	Higher education	39 (31.5)	33 (32.4)	18 (26.9)
	Missing value	4 (3.2)	1 (1.0)	2 (3.0)
Speaking Dutch (SR)	Yes	7 (5.6)	6 (5.9)	4 (6.0)
	No	116 (93.5)	96 (94.1)	62 (92.5)
	Missing value	1 (0.8)	0 (0)	1 (1.5)
Knowledge on HBV	No	45 (36.3)	42 (41.2)	29 (43.3)
	Limited	55 (44.4)	38 (37.3)	25 (37.3)
	Sufficient	24 (19.4)	22 (21.6)	13 (19.4)
HBV in family or friends	Missing value	0 (0)	0 (0)	0 (0)
	Yes	33 (26.6)	29 (28.4)	13 (19.4)
	No	80 (64.5)	58 (56.9)	45 (67.2)
	I do not know	11 (8.9)	15 (14.7)	9 (13.4)
	Missing value	0 (0)	0 (0)	0 (0)
Tested for HBV (SR)	Yes	31 (25.0)	20 (19.6)	13 (19.4)
	No	84 (67.7)	69 (67.6)	47 (70.1)
	I do not know	8 (6.5)	12 (11.8)	7 (10.4)
	Missing value	1 (0.8)	1 (1.0)	0 (0)

Supplementary Table S4.3. Sample characteristics for pairs with a discordant, positive, and negative screening intention (continued)

Characteristic	Discordant pairs (132 pairs with 124 unique individuals)	Positive pairs (154 pairs with 104 unique individuals)	Negative pairs (68 pairs with 67 unique individuals)
<i>Vaccinated against HBV (SR)</i>	Yes No I do not know Missing value	29 (28.4) 34 (33.3) 39 (38.2) 0 (0)	20 (29.9) 20 (29.9) 27 (40.3) 0 (0)

Data are reported as number of participants (%).  
SR: Self-reported.

Supplementary Table S4.4. Logistic regression analyses of having the same *positive* screening intention ('Intention request') in relation to having a tie

Variables	Model I N <sub>potential</sub> = 25887 (Log likelihood = -15451)	Model II N <sub>potential</sub> = 25729 (Log likelihood = -15306)	Model III N <sub>potential</sub> = 19247 (Log likelihood = -11218)	Model IV N <sub>potential</sub> = 18090 (Log likelihood = -9535)
	OR [95% CI] p-value	OR [95% CI] p-value	OR [95% CI] p-value	OR [95% CI] p-value
Tie	2.04 [1.50 – 2.76]	2.00 [1.49 – 2.69]	1.57 [1.20 – 2.06]	1.56 [1.11 – 2.17]
Type of tie				
Close family relationship yes/no				
Same gender: W-W vs M-M		0.80 [0.55 – 1.19]	0.82 [0.50 – 1.37]	0.86 [0.53 – 1.41]
Same gender: M-W vs M-M				
Mean age				
Difference in age				
Same country of birth: NL-NL vs MR-MR				
Same country of birth: NL-MR vs MR-MR				
Same educational level				
Mean educational level				

Supplementary Table S4.4. Logistic regression analyses of having the same *positive* screening intention ('Intention request') in relation to having a tie (continued)

Variables	Model I		Model II		Model III		Model IV	
	N <sub>potential</sub> = 25887 (Log likelihood = -15451)	p-value	N <sub>potential</sub> = 25729 (Log likelihood = -15306)	p-value	N <sub>potential</sub> = 19247 (Log likelihood = -11218)	p-value	N <sub>potential</sub> = 18090 (Log likelihood = -9535)	p-value
Same response on fatalism	OR [95% CI]		OR [95% CI]		OR [95% CI]		OR [95% CI]	
Mean value on fatalism								
Same response on "screening gives clarity"								
Mean value on "screening gives clarity"								
Same response on "screening not needed if no symptoms"								
Mean value on "screening not needed if no symptoms"								
Same response on self-efficacy								
Mean value on self-efficacy								
Same response on risk perception								
Mean value on risk perception								

\*p < 0.05  
We used the variance estimator proposed by Cameron et al. which is a robust method to correct standard errors for multi-way clustering (40).

Supplementary Table S4.5. Logistic regression analyses of having the same *negative* screening intention ('Intention request') in relation to having a tie

Variables	Model I		Model II		Model III		Model IV	
	N <sub>potential</sub> = 25889 (Log likelihood = -13335)	p-value	N <sub>potential</sub> = 25731 (Log likelihood = -13280)	p-value	N <sub>potential</sub> = 19252 (Log likelihood = -9238)	p-value	N <sub>potential</sub> = 18093 (Log likelihood = -8226)	p-value
Tie	OR [95% CI]		OR [95% CI]		OR [95% CI]		OR [95% CI]	
Type of tie								
Close family relationship yes/no								
Same gender: W-W vs M-M								
Same gender: M-W vs M-M								
Mean age								
Difference in age								
Same country of birth: NL-NL vs MR-MR								
Same country of birth: NL-MR vs MR-MR								
Same educational level								
Mean educational level								



Supplementary Table S4.5. Logistic regression analyses of having the same *negative* screening intention ('Intention request') in relation to having a tie (continued)

Variables	Model I			Model II			Model III			Model IV		
	N <sub>potential</sub> = 25889 (Log likelihood = -13335)	p-value	OR [95% CI]	N <sub>potential</sub> = 25731 (Log likelihood = -13280)	p-value	OR [95% CI]	N <sub>potential</sub> = 19252 (Log likelihood = -9238)	p-value	OR [95% CI]	N <sub>potential</sub> = 18093 (Log likelihood = -8226)	p-value	OR [95% CI]
Same response on fatalism							0.63 [0.52 – 0.77]	<0.001*	0.69 [0.53 – 0.89]	0.004*		
Mean value on fatalism							0.63 [0.25 – 1.57]	0.322	0.72 [0.32 – 1.60]	0.420		
Same response on "screening gives clarity"									0.92 [0.55 – 1.53]	0.738		
Mean value on "screening gives clarity"									2.47 [0.89 – 6.80]	0.081		
Same response on "screening not needed if no symptoms"									0.83 [0.66 – 1.04]	0.109		
Mean value on "screening not needed if no symptoms"									0.60 [0.34 – 1.08]	0.089		
Same response on self-efficacy									0.57 [0.36 – 0.90]	0.016*		
Mean value on self-efficacy									0.77 [0.29 – 2.02]	0.590		
Same response on risk perception									1.10 [0.89 – 1.37]	0.374		
Mean value on risk perception									0.77 [0.61 – 0.98]	0.032*		

\*p < 0.05  
We used the variance estimator proposed by Cameron et al. which is a robust method to correct standard errors for multi-way clustering (40).



Supplementary Figure S4.1. The geographical distribution of our participants

This map was created using R version 3.4.0 with a shapefile (.shp file) that was extracted from GADM, an online geographic database of global administrative areas, that is freely available for academic and other non-commercial use and allowed for academic publishing (56).



# 5

## Hepatitis B screening among immigrants: how to successfully reach the Moroccan community

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## Abstract

### Introduction

Immigrants show relatively low participation rates in screening programs due to lack of awareness and knowledge. To promote screening for chronic hepatitis B, Dutch Municipal Public Health Services need evidence on how to reach and inform immigrants. Our aims were to describe the performance of respondent-driven sampling (RDS) to reach Moroccan-Dutch, and to estimate their awareness, knowledge, and information needs on hepatitis B and its screening. With this in mind, invitation and information strategies that suit Moroccan-Dutch the best can be developed adequately.

### Methods

Between February and November 2019, first- and second-generation Moroccan-Dutch were asked, using RDS, to complete paper-based questionnaires and forward them to peers. Population estimates were calculated.

### Results

We invited 21 persons ("seeds") of whom 10 were successful in peer-recruitment. We reached 14 waves and 295 Moroccan immigrants. Of all respondents, 63.7% were willing to peer-recruit, of whom 40.7% succeeded. However, support from the researchers was often needed. Of the total population of Moroccans in the Netherlands, 76.6% [95% CI 67.7 – 85.5] had ever heard of hepatitis B and 23.1% [95% CI 14.2 – 31.9] of its screening. About half (48.2% [95% CI 42.3 – 54.1]) had sufficient knowledge and 39.4% [95% CI 30.4 – 48.4] had an information need.

### Conclusions

Although extra time and efforts from the researchers were required, RDS offers a promising method for Municipal Public Health Services to reach otherwise hard-to-reach Moroccan immigrants. Knowledge on hepatitis B and its screening is limited, and there is an information need. Future information materials should focus on the asymptomatic nature of the disease, as it could potentially increase immigrants' future screening participation rates.

## Introduction

Most countries have included hepatitis B in their universal childhood vaccination program. Therefore, the challenge to reduce the hepatitis B disease burden has shifted towards finding chronically infected individuals and treating them if indicated to prevent long-term consequences, such as cirrhosis, hepatocellular carcinoma, and premature death.

In Western Europe, the overall prevalence of hepatitis B carriership is too low to warrant screening of the general population, but immigrants born in Asian and African countries have a higher prevalence and might, therefore, be targeted for screening (1). In the Netherlands, screening for the hepatitis B surface antigen (HBsAg) was calculated to be cost-effective for (sub)populations with an endemicity of 0.41% or higher (2). Moroccan-Dutch citizens constitute the second largest immigrant population in the Netherlands, and the HBsAg-prevalence in first-generation Moroccan-Dutch is 0.54% (3). The Dutch Health Council advised HBsAg-screening for immigrants born in endemic countries (i.e. first-generation immigrants), but this is not yet implemented. Anticipating the HBsAg-screening of Moroccan-Dutch, we researched the intention to participate and found it to be 44% (4). This was expected as participation rates in other screening programs are lower in comparison to indigenous Dutch, due to a lack of awareness and knowledge (5). Sampling this population for research is equally challenging. We piloted the use of respondent-driven sampling (RDS) in researching awareness and information needs on HBsAg-screening among this population. RDS starts with a convenience sample of the study population, so-called seeds (6). Seeds (wave zero) are asked to complete a questionnaire and recruit peers from their social network (wave one) for the same questionnaire, and so on. This process is repeated until the desired sample size or 'equilibrium' (i.e. when the sample characteristics are assumed to be independent from the seeds' characteristics) is reached, or if peer recruitment dies out. Unique tokens are used to follow who recruited whom and draw recruitment trees. Population estimates are made with a statistical model that weighs the sample to compensate for the non-random recruitment. In earlier published RDS studies on various topics (e.g. sexual behavior and diabetes) among immigrant populations in Europe, the reported RDS performance (i.e. reach and recruitment success) varied widely. In this short communication, we describe the successful performance of RDS to reach Moroccan-Dutch, and estimate information needs on HBsAg-screening. Our findings may help to reach and screen other minority populations in Western European countries.

## Methods

We conducted an offline cross-sectional study from February to November 2019, using RDS, to distribute paper-based questionnaires among Moroccan-Dutch aged 16 years and above. We included those born in Morocco (first-generation immigrants, FGI) and those born in the Netherlands and having at least one parent born in Morocco (second-generation immigrants, SGI). We recruited seeds at community venues such as mosques and day care centers in municipalities with relatively large numbers of Moroccan-Dutch (three large and two middle-large cities).

After questionnaire completion, respondents were asked to invite four peers (later two peers). Respondents could choose between receiving (new) questionnaires in person at the community venue, by making an appointment with one of the researchers, or to receive them by mail. We used incentives for completing the questionnaire (5 EUR voucher) and for recruiting each new respondent (2.50 EUR voucher per respondent, later 5 EUR).

Since Moroccan-Berber languages and -Arabic dialects are solely speaking languages, we developed the questionnaire in 'simple' Dutch. To check for clarity and understandability, we piloted the questionnaire among a small sample of Moroccan-Dutch. It contained 37 questions, including socio-demographic characteristics, awareness and knowledge on hepatitis B and HBsAg-screening, intention to participate in HBsAg-screening or what to advise others, and information needs. Two Moroccan-Berber speaking female researchers assisted during face-to-face questionnaire administration.

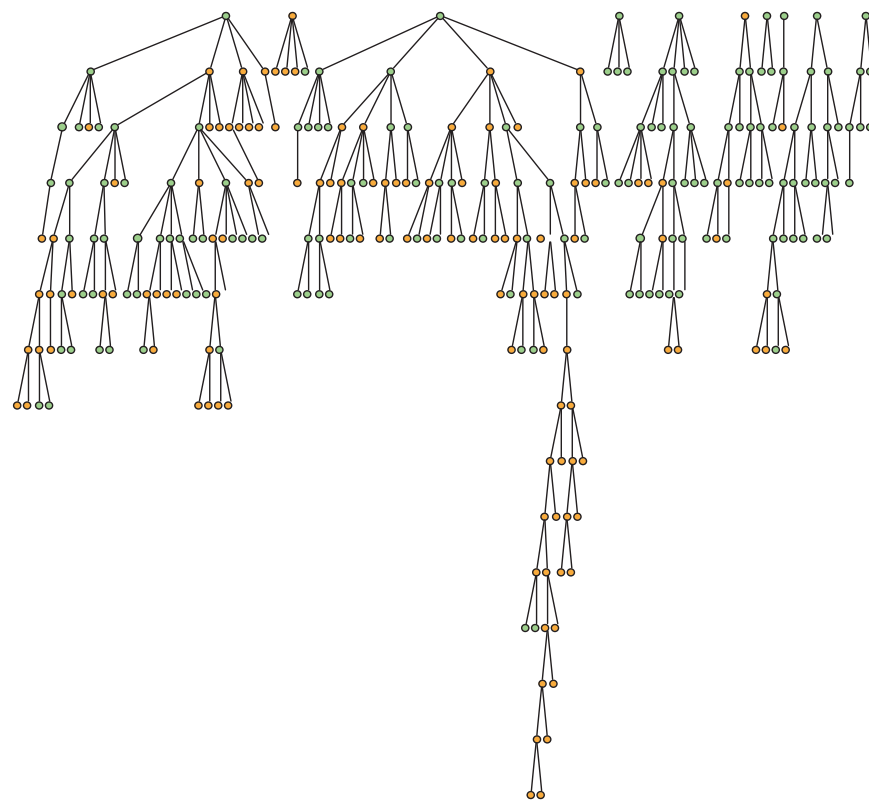
Tree visualizations and analyses were performed in R (version 3.6.0; igraph package version 1.2.5) and RDSAnalyst (version 2.2.1.0). Ethical approval was waived by the ethics committee of the University Medical Centre Utrecht, nr: 18-679/C. For compliance with the General Data Protection Regulation, we asked respondents to give their written informed consent for personal data processing before participation.

## Results

### Respondent-driven sampling performance

Of 21 seeds, 10 successfully recruited peers (see Figure 5.1) for a total sample of 295. Of this sample, 171 were FGI (58.0%) and 124 SGI (42.0%); 37.7% [95% CI 29.2 – 46.2] were male, which was lower than the national percentage of 51.0% in 2019 (see Supplementary Tables and Figures: Supplementary Tables S5.1-5.2). Fifty percent were recruited before wave 4 (see Supplementary Tables and Figures: Supplementary Figure S5.1). Two thirds (63.7%) reported willingness to recruit others, of whom the majority preferred to receive questionnaires in person (81.9%) rather than via mail. The majority (84.7%) needed assistance to successfully complete and/or forward the questionnaire to others. Researchers assisted in 52.9% of the recruitments by handing over the questionnaire via the recruiters' referral, directly contacting the peer(s) by phone, explaining the study's objectives and methodology, and for some, translating the questionnaire. Respondents were more likely to recruit peers of the same age, educational level, degree, and number of years living in the Netherlands (among FGI).

Equilibrium was reached for all characteristics, except for the average level of hepatitis B knowledge and its screening, and educational level (see Supplementary Tables and Figures: Figures S5.2-S5.12).



**Figure 5.1. Recruitment trees by country of birth**

Green: first-generation immigrants (FGI), Orange: second-generation immigrants (SGI)

#### **Awareness, knowledge, and information needs**

Few FGI (18.6% [95% CI 6.5 – 30.7]) had ever heard of HBsAg-screening (of SGI 28.1% [95% CI 11.8 – 44.4]), and 39.0% [95% CI 24.8 – 53.3] had a need for information (of SGI 39.8% [95% CI 23.6 – 56.0]) (See Supplementary Tables and Figures: Supplementary Table S5.3). There is a lack of knowledge on the asymptomatic nature of chronic hepatitis B, the possible long-term consequences of the disease, and the main transmission route of the virus in this population (i.e. mother-to-child).

Of all respondents, 74.9% did not know that one can have hepatitis B without having symptoms, and 68.1% were unaware of the cancer risk (see Supplementary Tables and Figures: Supplementary Table S5.4). Respondents wanted most frequently more

information about the risk for and possible long-term consequences of chronic hepatitis B (see Supplementary Tables and Figures: Supplementary Table S5.5).

Respondents preferred to receive information via personal contact (29.1%), or via written information (23.1%) from the general practitioner (GP) or nurse (49.5%) (see Supplementary Tables and Figures: Supplementary Table S5.6). According to 75.3%, this information should be available in Dutch. However, most FGI preferred a dual approach in both Moroccan-Arabic and Dutch.

Three quarters (73.6%) reported a positive intention to participate in screening and the majority (67.5%) would also advise their (grand)parent(s) to participate (see Supplementary Tables and Figures: Supplementary Table S5.7). Among those targeted for screening (i.e. FGI), the most frequently reported reason to not participate in screening was 'not having symptoms'.



## Discussion

This pilot demonstrated the feasibility of using RDS to sample hard-to-reach Moroccan populations in urban Netherlands. We reached 14 waves, 295 Moroccan immigrants, and equilibrium for most characteristics. This suggests that RDS might be a useful approach for targeted campaigns directed at identifying chronic carriers of the hepatitis B virus among immigrants.

Of all respondents, 77% had heard of hepatitis B and 23% of HBsAg-screening. Less than half has sufficient knowledge and information needs. SGI have heard of hepatitis B far more often than FGI. We found a lack of knowledge on the asymptomatic nature of chronic hepatitis B, which is likely to influence screening intention, as 'not having symptoms' was the main reason for not intending to participate in HBsAg-screening.

In a previous study, only 17% of the Moroccan-Dutch were found to have sufficient hepatitis B knowledge, compared to 48% in the current study (4). Since the sample composition was similar, this difference is most likely based on the variety of questions that were used to capture any existing knowledge on the disease. The 48% is in line with research among Turkish-Dutch, of whom 42% had sufficient knowledge on hepatitis B (7). Future information materials should be ideally conveyed personally by the GP in Dutch and Moroccan-Arabic. An emphasis on the asymptomatic course of the disease could potentially increase future HBsAg-screening participation rates among Moroccan FGI.

Respondents provided peer recruitments with 53% of the respondents requesting researchers' assistance. Providing assistance is not uncommon in RDS studies, as it helps to overcome barriers, speed up recruitment, and thus facilitate continuation of recruitment chains. As Moroccan-Dutch represent a hard-to-reach population, especially those with a low educational level and limited Dutch language proficiency, we consider active assistance justified to find the right answers on how to reach this population. Because of the required time and efforts, RDS should be mainly considered as an additional strategy for such hard-to-reach subgroups (e.g. low-literate).

Participation of female, younger, and higher educated Moroccan-Dutch was higher than average. This sampling bias and the fact that our sample is relatively small and geographically clustered, and did not reach equilibrium for all characteristics, implies that our population estimates should be considered with caution.

As young men have a slightly increased risk for having chronic hepatitis B (8), future RDS studies should select more male seeds aged 20-40 years (to recruit similar peers), and consider to include male researchers. We recommend to consider using

RDS to recruit immigrants for research purposes, but also for the delivery of health interventions, such as HBsAg-screening, starting at community venues where relatively large numbers of immigrants convene. Future research is needed to assess the cost-effectiveness of RDS in comparison to earlier performed outreach activities to reach immigrants for HBsAg-screening.

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Supplementary Tables and Figures

Supplementary Table S5.1. Number of respondents recruited, waves, and sample proportion per seed

<i>Seed</i>	<i>Number of respondents recruited (including seeds)</i>	<i>Maximum number of waves (including seeds)</i>	<i>% of sample</i>
1	82	7	27.8
2	16	4	5.4
3	3	1	1.0
4	4	2	1.4
5	25	6	8.5
6	7	3	2.4
7	4	1	1.4
8	5	1	1.7

Supplementary Table S5.2. Sociodemographic characteristics: sample-based, RDS-adjusted, and national data

Characteristic	Sample-based First-generation (n = 171,58.0%)	RDS-adjusted First- generation (n = 146,55.3%)	Sample-based Second- generation (n = 124,42.0%)	RDS-adjusted Second- generation (n = 118,44.7%)	Sample-based Total (n = 295)	RDS-adjusted Total (n = 264)	National* Total (n = 150,366)
Moroccan- Arabic or -Berber identity	26.3	38.7 [26.1-51.3]	31.5	29.8 [15.2-44.4]	28.5	34.4 [25.5-43.3]	
	73.7	61.3 [48.7-74.0]	68.5	70.2 [55.7-84.8]	71.5	65.6 [56.7-74.5]	
Missing value	0	0	0	0	0	0	
Gender							
Male	45.0	44.7 [30.5-59.0]	30.6	30.2 [16.2-44.1]	39.0	37.7 [29.2-46.2]	51.0
Female	55.0	55.3 [41.0-69.5]	69.4	69.9 [55.9-83.8]	61.0	62.3 [53.8-70.8]	49.0
Missing value	0	0	0	0	0	0	
Age group							
16 – 25 years	4.1	8.9 [3.4-14.4]	61.3	49.0 [33.7-64.3]	28.1	28.2 [22.2-34.1]	16.8
26 – 35 years	6.4	8.6 [0.0-19.5]	32.3	42.7 [27.7-57.8]	17.3	25.0 [17.7-32.3]	15.4
36 – 45 years	15.8	13.8 [1.1-26.5]	6.5	8.3 [4.7-11.9]	11.9	11.1 [2.9-19.4]	15.7
46 – 55 years	39.2	34.3 [25.1-43.4]	0	0	22.7	17.8 [10.8-24.8]	12.6
56 – 65 years	24.0	28.3 [19.3-37.3]	0	0	13.9	14.7 [9.4-20.1]	7.5
66 years and older	9.9	6.1 [0.0-12.3]	0	0	5.8	3.2 [0.0-8.9]	32.0
Missing value	0.6	0	0	0	0.3	0	

Supplementary Table S5.2. Sociodemographic characteristics: sample-based, RDS-adjusted, and national data (continued)

Characteristic	Sample-based First-generation (n = 171,58.0%)	RDS-adjusted First- generation (n = 146,55.3%)	Sample-based Second- generation (n = 124,42.0%)	RDS-adjusted Second- generation (n = 118,44.7%)	Sample-based Total (n = 295)	RDS-adjusted Total (n = 264)	National* Total (n = 150,366)
Educational level							
No official education or primary school	42.7	39.5 [26.1-52.9]	4.0	3.9 [0.0-11.4]	26.4	22.2 [13.8-30.7]	
Secondary school	12.9	10.3 [4.8-15.9]	35.5	30.2 [14.0-46.4]	22.4	20.0 [11.7-28.3]	
Vocational education	24.6	35.6 [23.1-48.1]	29.0	37.2 [21.6-52.9]	26.4	36.4 [29.5-43.3]	
Higher education	15.2	14.6 [2.2-26.9]	29.8	28.6 [14.4-42.9]	21.4	21.4 [13.3-29.5]	
Missing value	4.7	0	1.6	0	3.4	0	
Ability to speak Dutch (SR)							
No/barely	24.6	28.3 [16.5-40.1]	0	0	14.2	14.7 [7.6-21.8]	
Sufficient	37.4	36.8 [24.6-48.9]	3.2	3.6 [2.6-4.5]	23.1	20.8 [12.2-29.4]	
Good	37.4	34.9 [21.6-48.3]	96.8	96.5 [95.5-97.4]	62.4	64.5 [57.1-71.8]	
Missing value	0.6	0	0	0	0.3	0	
Ability to read Dutch (SR)							
No/barely	32.7	36.7 [24.1-49.2]	0.8	1.1 [0.6-1.7]	19.3	19.6 [13.0-26.2]	
Sufficient	29.8	25.6 [13.3-38.0]	4.0	4.7 [4.1-5.3]	19.0	15.6 [7.0-24.1]	
Good	36.8	37.7 [23.9-51.4]	95.2	94.2 [94.0-94.4]	61.4	64.8 [57.7-72.0]	
Missing value	0.6	0	0	0	0.3	0	

Data are reported as % (with a 95% CI for RDS-adjusted data).  
RDS-adjusted numbers are adjusted using the reported social network size (i.e. degree). For degree, we asked "How many Moroccan-Dutch (which was further defined in the questionnaire) do you approximately know?".  
SR: Self-reported.  
\*These numbers represent available data of Statistics Netherlands regarding municipalities in which recruitment was initiated.

Supplementary Table S5.3. Awareness, knowledge, and information needs on hepatitis B and its screening; sample-based and RDS-adjusted

Outcome	Categories	First-generation		Second-generation		Total
		Sample-based <sup>a</sup>	RDS-adjusted <sup>b</sup>	Sample-based <sup>a</sup>	RDS-adjusted <sup>b</sup>	
Having heard of... (i.e. awareness)	Hepatitis B	50.9	62.2 [46.8 – 77.5]	79.8	93.1 [79.5 – 100.0]	63.1 76.6 [67.7 – 85.5]
	The hepatitis B test	17.5	18.6 [6.5 – 30.7]	25.0	28.1 [11.8 – 44.4]	20.7 23.1 [14.2 – 31.9]
Level of knowledge on hepatitis B and its screening	No	8.9	15.5 [1.1 – 29.9]	11.2	8.4 [1.6 – 15.2]	12.9 12.1 [3.0 – 21.2]
	Insufficient	33.9	39.4 [25.3 – 53.6]	40.3	39.9 [26.0 – 53.8]	45.0 39.7 [30.1 – 49.2]
Information needs	Sufficient	57.3	45.0 [37.8 – 52.3]	48.5	51.7 [36.7 – 66.7]	42.1 48.2 [42.3 – 54.1]
	Yes	52.6	39.0 [24.8 – 53.3]	35.5	39.8 [23.6 – 56.0]	45.4 39.4 [30.4 – 48.4]
	No	44.4	61.0 [46.7 – 75.2]	64.5	60.2 [44.0 – 76.4]	52.9 60.6 [51.6 – 69.6]

Data are reported as % (with 95% CI for RDS-adjusted data)  
RDS-adjusted numbers are adjusted using the reported social network size (i.e. degree). For degree, we asked "How many Moroccan-Dutch (which was further defined in the questionnaire) do you approximately know?".

a: For awareness, sample size N was 171, 124, and 295 for FGI, SGI, and total, respectively. For level of knowledge, sample size N was 171, 124, and 295 for FGI, SGI, and total, respectively. For information needs, sample size N was 171, 124, and 290 for FGI, SGI, and total, respectively.  
b: For awareness, sample size N was 135, 100, and 235 for FGI, SGI, and total, respectively. For level of knowledge, sample size N was 146, 118, and 264 for FGI, SGI, and total, respectively. For information needs, sample size N was 142, 118, and 260 for FGI, SGI, and total, respectively.

Supplementary Table S5.4. Knowledge regarding hepatitis B and its screening (sample-based)

Knowledge statement	Categories	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
Hepatitis B is a contagious disease (true)	Correct	87 (50.9)	83 (66.9)	170 (57.6)
	Incorrect	37 (21.6)	14 (11.3)	51 (17.3)
	Don't know	45 (26.3)	27 (21.8)	72 (24.4)
	Missing value	2 (1.2)	0 (0)	2 (0.7)
Hepatitis B is a disease of the liver (true)	Correct	97 (56.7)	72 (58.1)	169 (57.3)
	Incorrect	12 (7.0)	12 (9.7)	24 (8.1)
	Don't know	60 (35.1)	40 (32.3)	100 (33.9)
	Missing value	2 (1.2)	0 (0)	2 (0.7)
If you have hepatitis B, you always have symptoms and complaints (not true)	Correct	40 (23.4)	45 (36.3)	85 (28.8)
	Incorrect	45 (26.3)	27 (21.8)	72 (24.4)
	Don't know	84 (49.1)	52 (41.9)	136 (46.1)
	Missing value	2 (1.2)	0 (0)	2 (0.7)
Due to hepatitis B you sometimes can get liver cancer (true)	Correct	48 (28.1)	42 (33.9)	90 (30.5)
	Incorrect	26 (15.2)	13 (10.5)	39 (13.2)
	Don't know	95 (55.6)	67 (54.0)	162 (54.9)
	Missing value	2 (1.2)	2 (1.6)	4 (1.4)
There is a vaccination against hepatitis B (true)	Correct	89 (52.0)	90 (72.6)	179 (60.7)
	Incorrect	9 (5.3)	3 (2.4)	12 (4.1)
	Don't know	71 (41.5)	31 (25.0)	102 (34.6)
	Missing value	2 (1.2)	0 (0)	2 (0.7)

Supplementary Table S5.4. Knowledge regarding hepatitis B and its screening (sample-based) (continued)

Knowledge statement	Categories	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
You can get hepatitis B through blood contact (true)	Correct	80 (46.8)	87 (70.2)	167 (56.6)
	Incorrect	29 (17.0)	14 (11.3)	41 (14.6)
	Don't know	61 (35.7)	22 (17.7)	83 (28.1)
	Missing value	1 (0.6)	1 (0.8)	2 (0.7)
You can get hepatitis B when using used needles (true)	Correct	105 (61.4)	89 (71.8)	194 (65.8)
	Incorrect	15 (8.8)	8 (6.5)	23 (7.8)
	Don't know	49 (28.7)	27 (21.8)	76 (25.8)
	Missing value	2 (1.2)	0 (0)	2 (0.7)
If a mother has hepatitis B, she can infect her children with hepatitis B during birth (true)	Correct	76 (44.4)	58 (46.8)	134 (45.4)
	Incorrect	17 (9.9)	15 (12.1)	32 (10.8)
	Don't know	77 (45.0)	51 (41.1)	128 (43.4)
	Missing value	1 (0.6)	0 (0)	1 (0.3)
The hepatitis B test is a blood test (true)	Correct	80 (46.8)	75 (60.5)	155 (52.5)
	Incorrect	6 (3.5)	5 (4.0)	11 (3.7)
	Don't know	83 (48.5)	43 (34.7)	126 (42.7)
	Missing value	2 (1.2)	1 (0.8)	3 (1.0)
There is a treatment for hepatitis B (true)	Correct	95 (55.6)	70 (56.5)	165 (55.9)
	Incorrect	12 (7.0)	9 (7.3)	21 (7.1)
	Don't know	62 (36.3)	43 (34.7)	105 (35.6)
	Missing value	2 (1.2)	2 (1.6)	4 (1.4)

Supplementary Table S5.5. Awareness, knowledge, and information needs (sample-based)

Characteristic	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)	
Having heard of... (SR, MC)	Hepatitis B	87 (50.9)	99 (79.8)	186 (63.1)
	Jaundice	135 (78.9)	84 (67.7)	219 (74.2)
	A screening	23 (13.5)	41 (33.1)	64 (21.7)
	The hepatitis B test	30 (17.5)	31 (25.0)	61 (20.7)
	- via newspaper/TV/radio <sup>a</sup>	14 (46.7)	8 (25.8)	22 (36.1)
	- via website government/RIVM <sup>a</sup>	5 (16.7)	3 (9.7)	8 (13.1)
	- via social media <sup>a</sup>	6 (0.2)	7 (22.6)	13 (21.3)
	- via GP <sup>a</sup>	5 (16.7)	2 (6.5)	7 (11.5)
	- via MPHS <sup>a</sup>	7 (23.3)	6 (19.4)	13 (21.3)
	- via family or friends <sup>a</sup>	14 (46.7)	9 (29.0)	23 (37.7)
	- via an educational meeting <sup>a</sup>	2 (6.7)	1 (3.2)	3 (4.9)
	- via my job/study <sup>a</sup>	9 (30.0)	11 (35.5)	20 (32.8)
	- via pharmacy <sup>a</sup>	0 (0)	1 (3.2)	1 (1.6)
	Hepatitis B	76 (44.4)	77 (62.1)	153 (51.9)
Having knowledge of... (SR, MC)	Jaundice	128 (74.9)	72 (58.1)	200 (67.8)
	A screening	17 (9.9)	37 (29.8)	54 (18.3)
	The hepatitis B test	26 (15.2)	27 (21.8)	53 (18.0)
	No	22 (12.9)	11 (8.9)	33 (11.2)
	Insufficient	77 (45.0)	42 (33.9)	119 (40.3)
	Sufficient	72 (42.1)	71 (57.3)	143 (48.5)
	Missing value	0 (0)	0 (0)	0 (0)



Supplementary Table S5.5. Awareness, knowledge, and information needs (sample-based) (continued)

Characteristic	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
<i>Information needs</i>			
Yes	90 (52.6)	44 (35.5)	134 (45.4)
No	76 (44.4)	80 (64.5)	156 (52.9)
Missing value	5 (2.9)	0 (0)	5 (1.7)
<i>Wanting information about...</i> <sup>b</sup>			
- what hepatitis B is	81 (90.0)	39 (88.6)	120 (89.6)
- how you can get hepatitis B	84 (93.3)	37 (84.1)	121 (90.3)
- the consequences of hepatitis B	84 (93.3)	41 (93.2)	125 (93.3)
- the prevalence of hepatitis B in Morocco and the Netherlands	82 (91.1)	37 (84.1)	119 (88.8)
- the hepatitis B mortality rate in the Netherlands	78 (86.7)	33 (75.0)	111 (82.8)
- who have the highest risk of getting hepatitis B	82 (91.1)	41 (93.2)	123 (91.8)
- why some have a higher risk than others	82 (91.1)	39 (88.6)	121 (90.3)
- what the hepatitis B test is	79 (87.8)	38 (86.4)	117 (87.3)
- where you can do the test	79 (87.8)	32 (72.7)	111 (82.8)
- the costs of the test	80 (88.9)	32 (72.7)	112 (83.6)
- why the test is implemented	80 (88.9)	28 (63.6)	108 (80.6)
- the treatment for hepatitis B	82 (91.1)	38 (86.4)	120 (89.6)

SR: Self-reported, MC: Multiple choice question, SD: Standard deviation, GP: General practitioner

<sup>a</sup>displayed for those having heard of the hepatitis B test (N = 30 (first-generation), 31 (second-generation), 61 (total))

<sup>b</sup>displayed for those having a need for information (N = 90 (first-generation), 44 (second-generation), 134 (total))

Supplementary Table S5.6. Preferences in hepatitis B (screening) information provision (sample-based)

Characteristic	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
<i>Preferred route of getting information</i>			
Personal contact	60 (35.1)	26 (21.0)	86 (29.2)
Letter/folder/brochure	45 (26.3)	23 (18.5)	68 (23.1)
Newspaper	1 (0.6)	0 (0)	1 (0.3)
TV	22 (12.9)	4 (3.2)	26 (8.8)
Radio	0 (0)	0 (0)	0 (0)
Social media	12 (7.0)	22 (17.7)	34 (11.5)
Internet	12 (7.0)	15 (12.1)	27 (9.2)
E-mail	3 (1.8)	12 (9.7)	15 (5.1)
Other	1 (0.6)	4 (3.2)	5 (1.7)
Missing value	15 (8.8)	18 (14.5)	33 (11.2)
<i>Preferred person giving the information</i>			
GP/nurse	96 (56.1)	50 (40.3)	146 (49.5)
MPHS	20 (11.7)	22 (17.7)	42 (14.2)
Islamic religious leader	11 (6.4)	5 (4.0)	16 (5.4)
Family or friend	4 (2.3)	3 (2.4)	7 (2.4)
Teacher	0 (0)	4 (3.2)	4 (1.4)
Missing value	40 (23.4)	40 (32.3)	80 (27.1)
<i>Preferred languages of the information (MC)</i>			
Dutch	106 (62.0)	116 (93.5)	222 (75.3)
Moroccan-Berber	57 (33.3)	8 (6.5)	65 (22.0)
Moroccan-Arabic	87 (50.9)	7 (5.6)	94 (31.9)
Modern Standard Arabic	11 (6.4)	4 (3.2)	15 (5.1)
Other	2 (1.2)	4 (3.2)	6 (2.0)
Missing value	7 (4.1)	8 (6.5)	15 (5.1)

Supplementary Table S5.6. Preferences in hepatitis B (screening) information provision (sample-based) (continued)

Characteristic	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
Preferred 'inviter' for hepatitis B testing (MC)			
GP	149 (87.1)	103 (83.1)	252 (85.4)
MPHS	94 (55.0)	58 (46.8)	152 (51.5)
Missing value	4 (2.3)	3 (2.4)	7 (2.4)

MC: Multiple choice question, GP: General practitioner, MPHS: Municipal Public Health Service

Supplementary Table S5.7. Intention to participate in screening and reasons for intended non-participation (sample-based)

Characteristic	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
Intention to have the test			
Yes	132 (77.2)	85 (68.5)	217 (73.6)
No	37 (21.6)	39 (31.5)	76 (25.8)
Missing value	2 (1.2)	0 (0)	2 (0.7)
Advise to have the test			
Yes	92 (53.8)	107 (86.3)	199 (67.5)
No	6 (3.5)	12 (9.7)	18 (6.1)
My (grand)parent is not born in Morocco and/or does not live in the Netherlands	66 (38.6)	4 (3.2)	70 (23.7)
Missing value	7 (4.1)	1 (0.8)	8 (2.7)
Intention to have the test for... <sup>a</sup>			
Free	68 (51.9)	38 (44.2)	106 (48.8)
Max. 20 EURO	27 (20.6)	19 (22.1)	46 (21.2)
20 – 40 EURO	23 (17.6)	12 (14.0)	35 (16.1)
40 – 60 EURO	5 (3.8)	9 (10.5)	14 (6.5)
> 60 EURO	8 (6.1)	7 (8.1)	15 (6.9)
Missing value	0 (0)	1 (1.2)	1 (0.5)
Advise to have the test for... <sup>b</sup>			
Free	32 (34.4)	28 (26.4)	60 (30.2)
Max. 20 EURO	27 (29.0)	25 (23.6)	52 (26.1)
20 – 40 EURO	16 (17.2)	23 (21.7)	39 (19.6)
40 – 60 EURO	5 (5.4)	17 (16.0)	22 (11.1)
> 60 EURO	13 (14.0)	9 (8.5)	22 (11.1)
Missing value	0 (0)	4 (3.8)	4 (2.0)

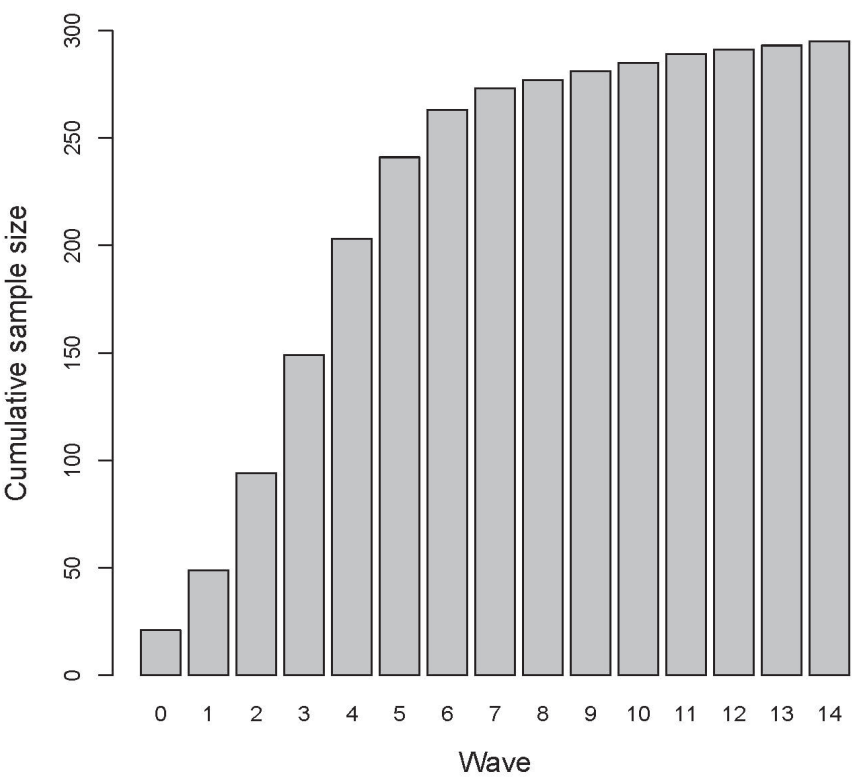
Supplementary Table S5.7. Intention to participate in screening and reasons for intended non-participation (sample-based) (continued)

Characteristic	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
<i>Reasons for not testing (MC)<sup>c</sup></i>			
Not born in Morocco	0 (0)	12 (30.8)	12 (15.8)
Already tested	5 (13.5)	6 (15.4)	11 (14.5)
Vaccinated	4 (10.8)	11 (28.2)	15 (19.7)
Hepatitis B not severe	2 (5.4)	1 (2.6)	3 (3.9)
No symptoms	13 (35.1)	7 (17.9)	20 (26.3)
Fear for the result	4 (10.8)	2 (5.1)	6 (7.9)
Shame	0 (0)	0 (0)	0 (0)
Fatalism	2 (5.4)	4 (10.3)	6 (7.9)
Not having time	2 (5.4)	3 (7.7)	5 (6.6)
First wanting to discuss the test	2 (5.4)	1 (2.6)	3 (3.9)
Other	6 (16.2)	2 (5.1)	8 (10.5)
Missing value	3 (8.1)	2 (5.1)	5 (6.6)

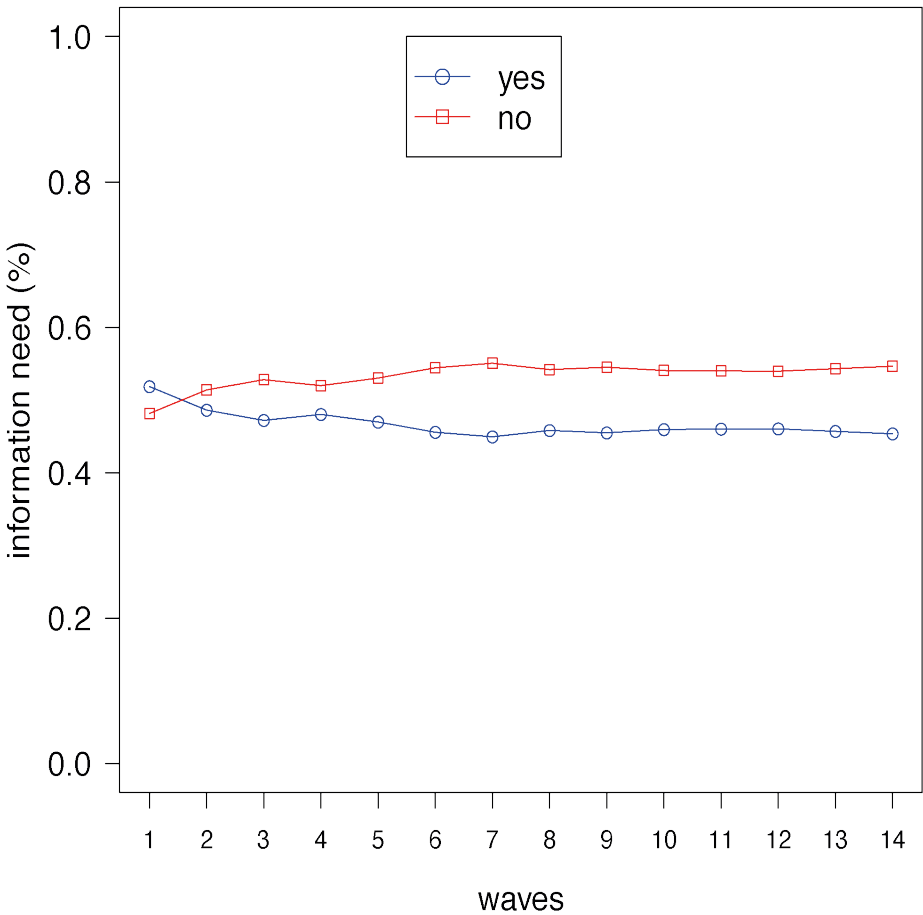
Supplementary Table S5.7. Intention to participate in screening and reasons for intended non-participation (sample-based) (continued)

Characteristic	First-generation (n = 171, 58.0%)	Second-generation (n = 124, 42.0%)	Total (n = 295)
<i>Reasons for not advising to test (MC)<sup>d</sup></i>			
Not born in Morocco	0 (0)	0 (0)	0 (0)
Already tested	0 (0)	0 (0)	0 (0)
Vaccinated	1 (16.7)	0 (0)	1 (5.6)
Hepatitis B not severe	0 (0)	0 (0)	0 (0)
No symptoms	0 (0)	4 (33.3)	4 (22.2)
Fear for the result	0 (0)	1 (8.3)	1 (5.6)
Shame	0 (0)	0 (0)	0 (0)
Fatalism	0 (0)	3 (25.0)	3 (16.7)
Not having time	0 (0)	0 (0)	0 (0)
Other	3 (50.0)	2 (16.7)	5 (27.8)
Missing value	2 (33.3)	3 (25.0)	5 (27.8)

MC: Multiple choice question, \*: Mutually exclusive  
<sup>a</sup>Displayed for those with a positive screening intention (N = 131 (first-generation), 86 (second-generation), and 217 (total))  
<sup>b</sup>Displayed for those with a positive advise to participate in screening (N = 93 (first-generation), 106 (second-generation), and 199 (total))  
<sup>c</sup>Displayed for those with a negative screening intention (N = 37 (first-generation), 39 (second-generation), and 76 (total))  
<sup>d</sup>Displayed for those with a negative advise to participate in screening (N = 6 (first-generation), 12 (second-generation), and 18 (total))

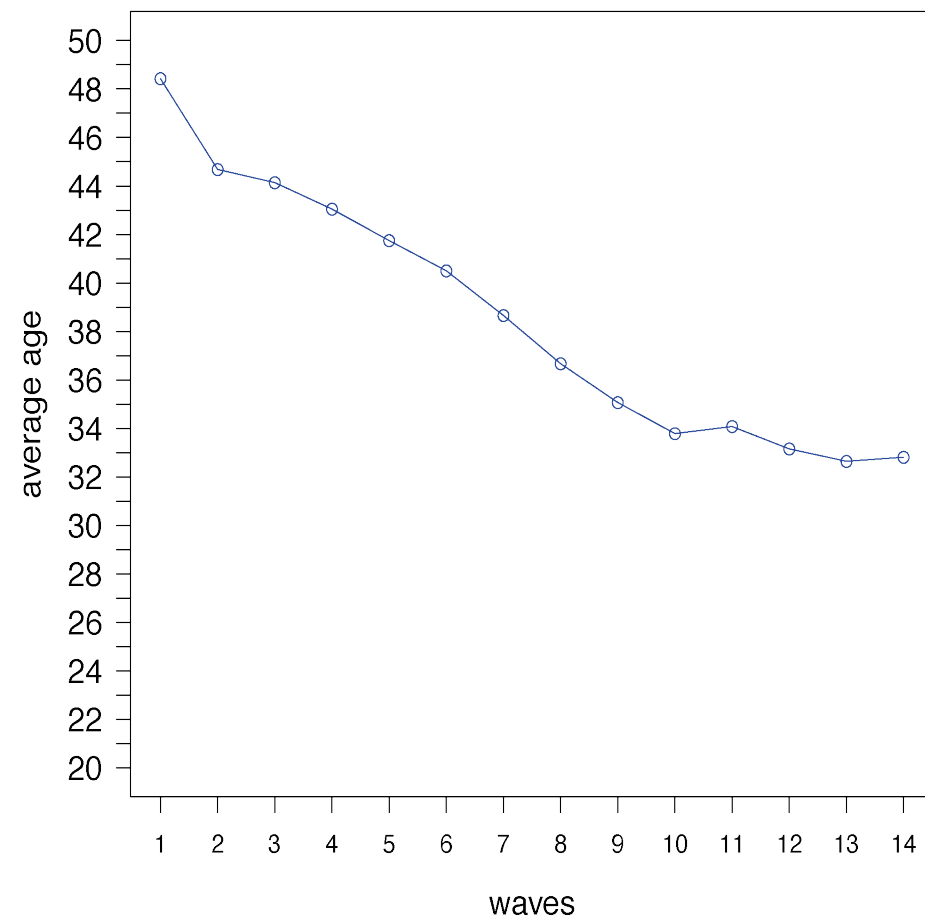


Supplementary Figure S5.1. Cumulative sample size over waves

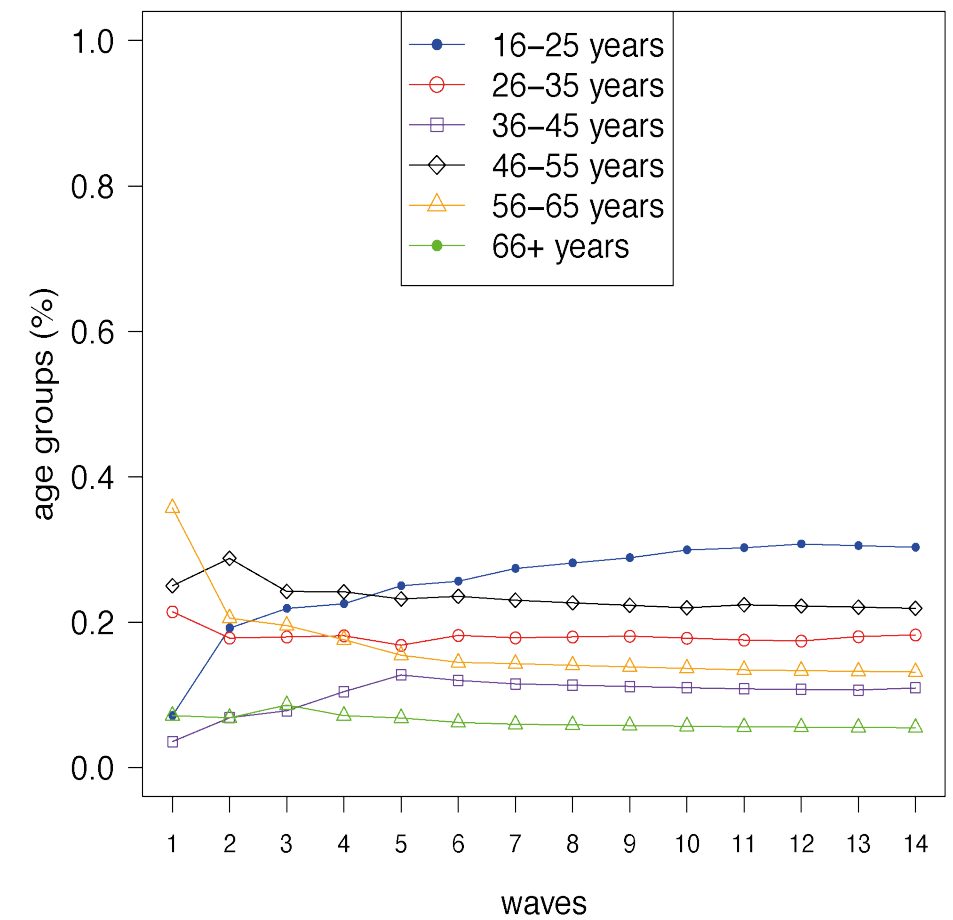


Supplementary Figure S5.2. Cumulative sample proportion of information need by waves

(excluding seeds, n = 274)

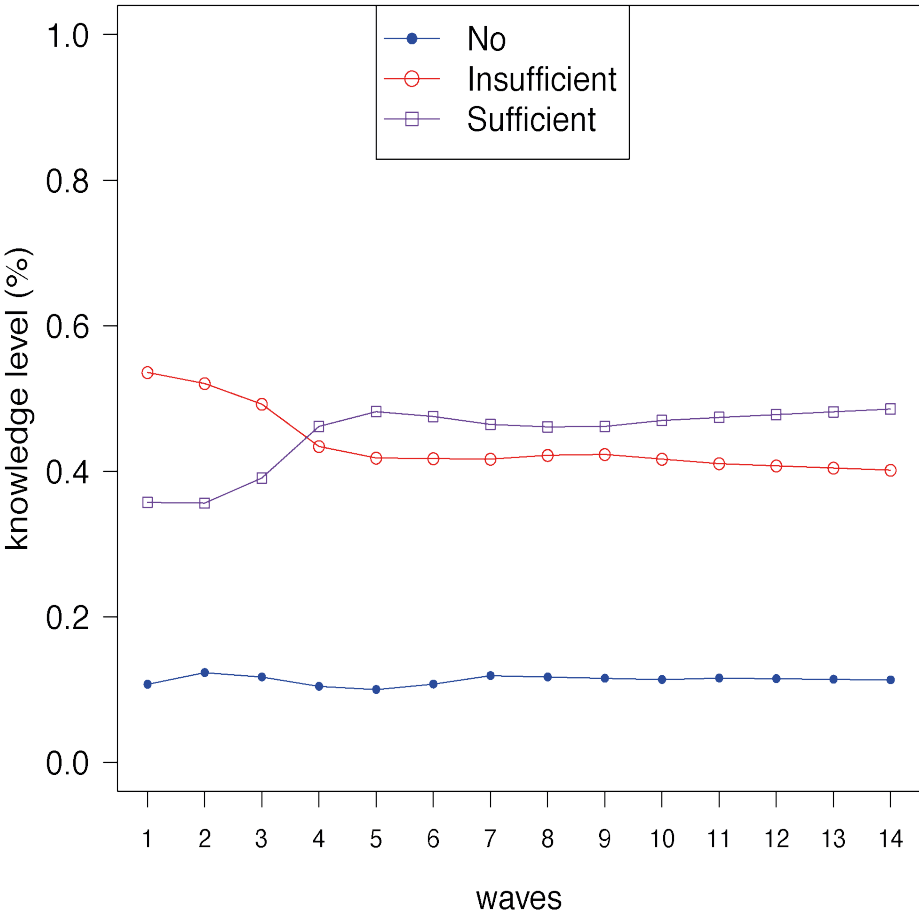


**Supplementary Figure S5.3. Average age found cumulatively by waves**  
(excluding seeds, n = 274)

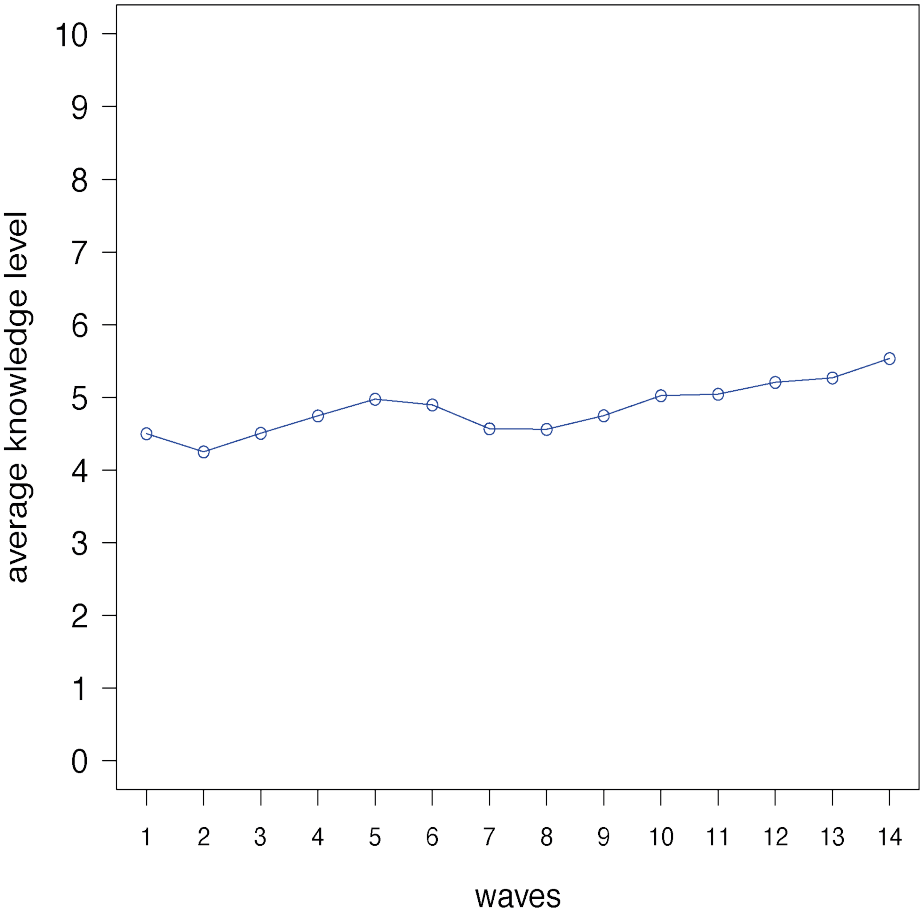


**Supplementary Figure S5.4. Cumulative sample proportion of age groups by waves**  
(excluding seeds, n = 274)

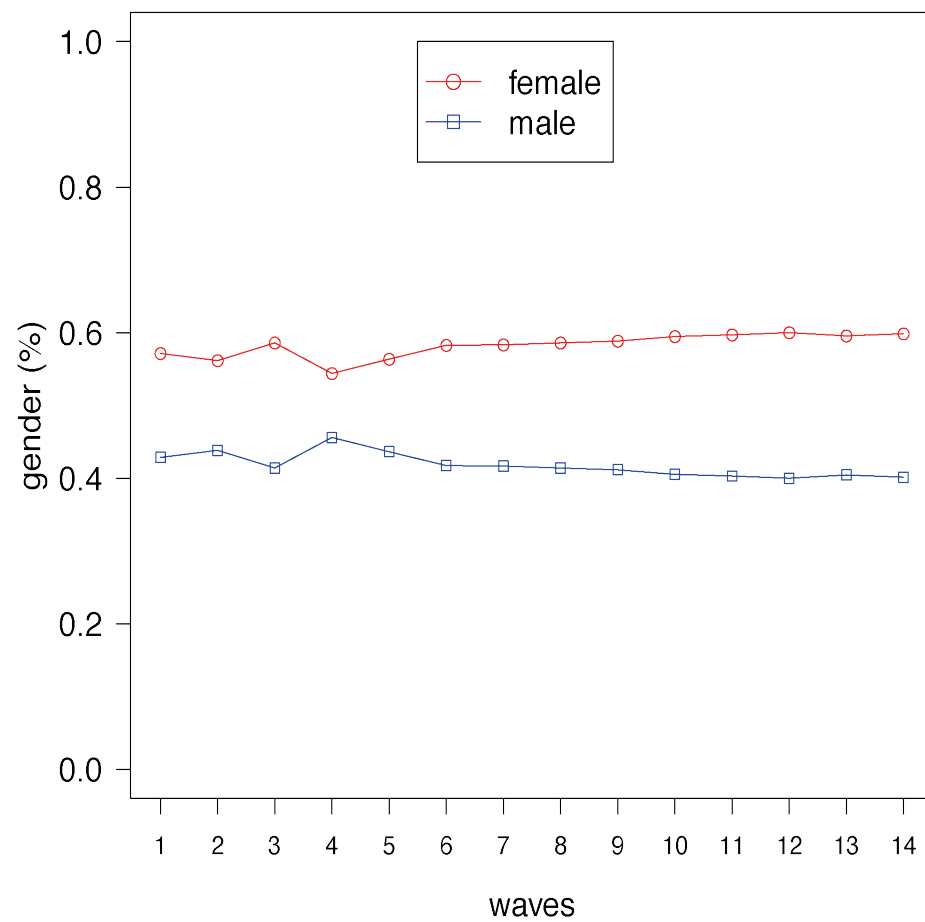




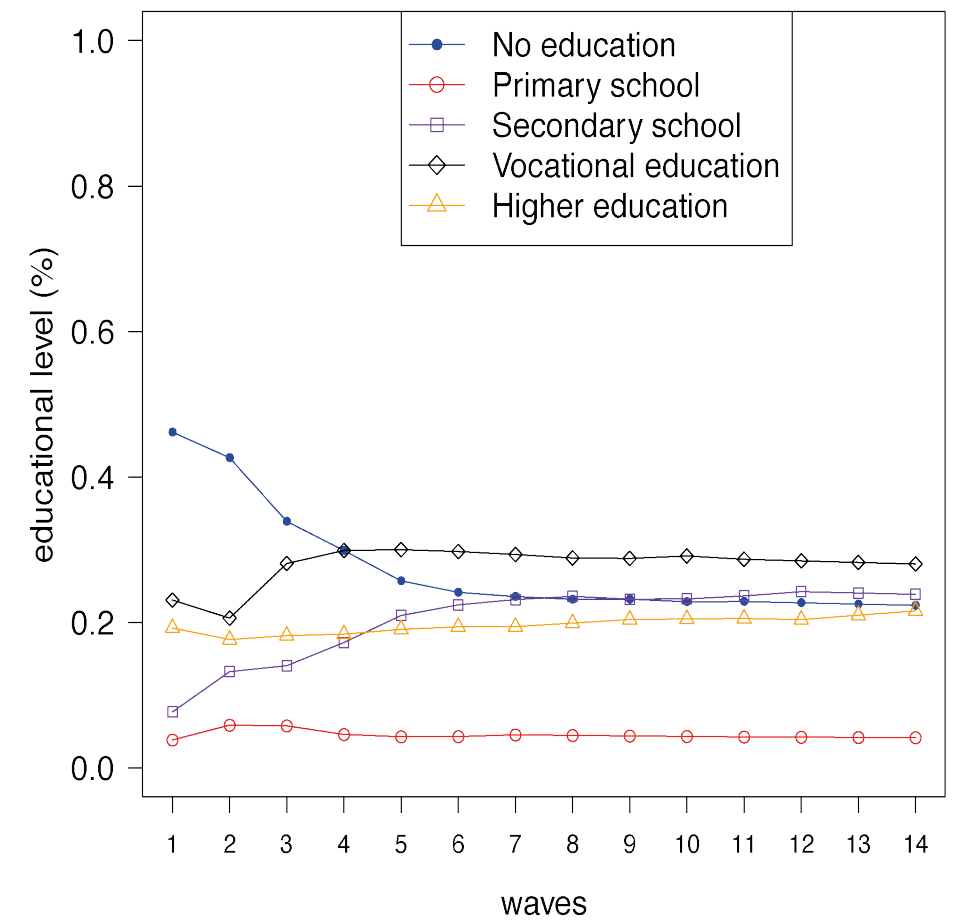
**Supplementary Figure S5.5. Cumulative sample proportion of knowledge level by waves**  
(excluding seeds, n = 274)



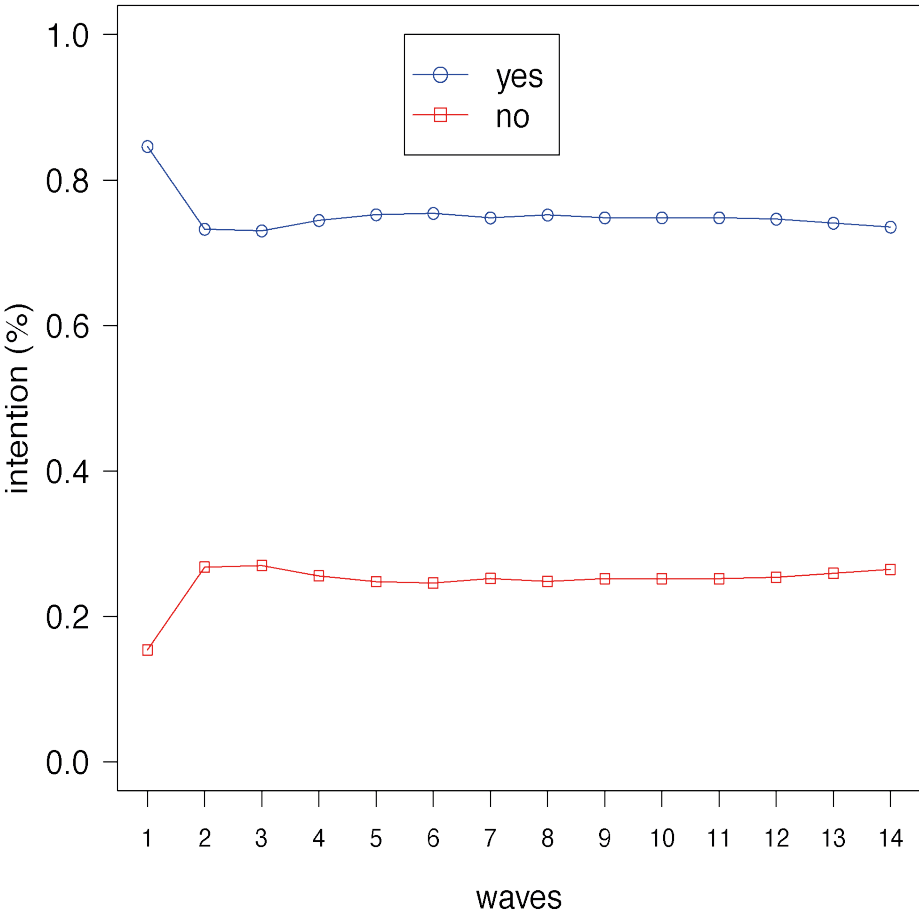
**Supplementary Figure S5.6. Average level of knowledge found cumulatively by waves**  
(excluding seeds, n = 274)



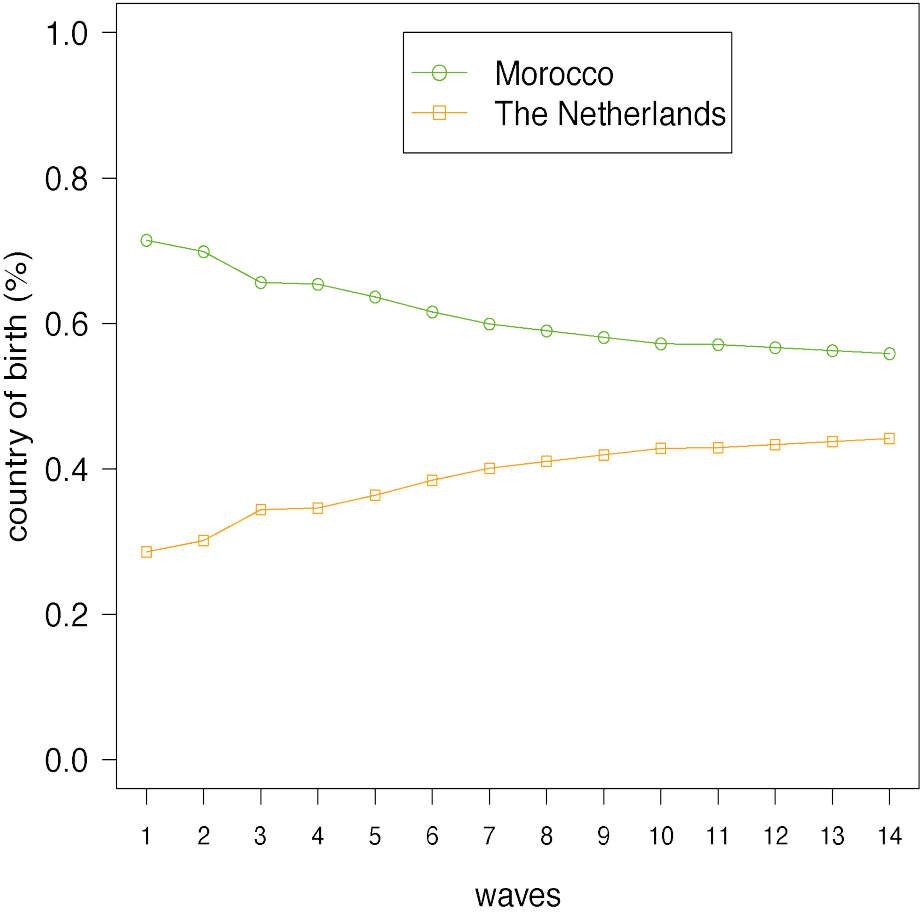
**Supplementary Figure S5.7. Cumulative sample proportion of gender by waves**  
(excluding seeds, n = 274)



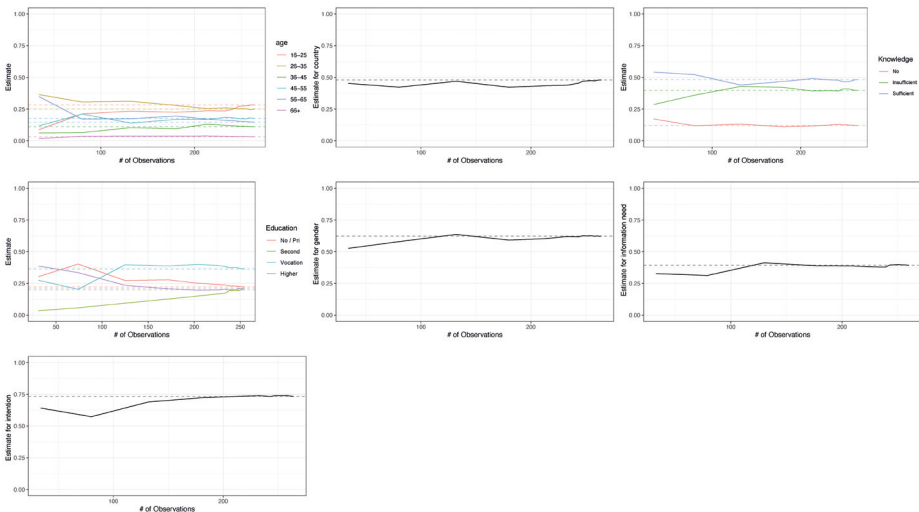
**Supplementary Figure S5.8. Cumulative sample proportion of educational level by waves**  
(excluding seeds, n = 274)



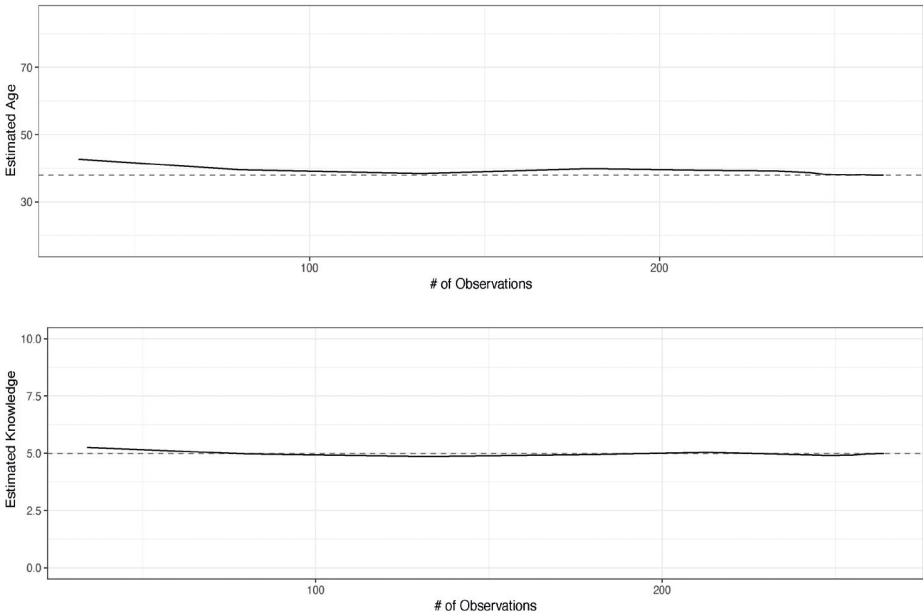
**Supplementary Figure S5.9. Cumulative sample proportion of intention by waves**  
(excluding seeds, n = 274)



**Supplementary Figure S5.10. Cumulative sample proportion of country of birth by waves**  
(excluding seeds, n = 274)



**Supplementary Figure S5.11. Cumulative RDS-adjusted proportions for age, country of birth, level of knowledge, educational level, gender, information need, and intention by sample size**  
(excluding seeds, n = 274)



**Supplementary Figure S5.12. RDS-adjusted average age and level of knowledge found cumulatively by sample size**  
(excluding seeds, n = 274)

An artistic illustration on the left side of the page. It features a light blue sky with soft, white, painterly clouds. Several black silhouettes of birds are shown in flight, scattered across the sky. Below the sky, there are rolling hills or mountains rendered in warm, golden-yellow and light brown tones, also with a painterly, textured appearance.

# 6

## Decision-making, barriers, and facilitators regarding cervical cancer screening participation among Moroccan and Turkish women in the Netherlands: A focus group study

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## Abstract

### Objectives

Whether the lower Dutch cervical cancer (CC) screening participation of Turkish- and Moroccan-Dutch women is based on informed decision-making is unknown. Our aim was to explore how and why Turkish- and Moroccan-Dutch women decide to participate or not in the current Dutch CC screening programme as well as to learn their perceptions on self-sampling.

### Design

Six focus group discussions were conducted between March and April 2019 with Turkish (n = 24) and Moroccan (n = 20) women in the Netherlands, aged 30-60 years. Questions were based on an extended version of the Health Belief Model. Discussions were transcribed verbatim and thematically analysed.

### Results

Participants lacked knowledge about CC and its screening, and seemed to be unaware of the cons of CC screening. Perceived barriers for screening were lack of a good command of the Dutch language, having a male general practitioner, fatalism, shame and taboo, and associations of CC with lack of femininity and infertility. Other barriers were fear of the test result, cancer, suffering, death, and leaving their children behind after death. Perceived facilitators were a high perceived severity of disease, social support, and short procedure time. An additional religious facilitator included the responsibility to take care of one's own health using medical options that God provided. Participants had low self-efficacy expectations towards performing correct self-sampling.

### Conclusions

Although participants' informed-decision making seems to be limited, this study showed that women do not only consider factual medical information, but also practical, emotional, cultural, and religious aspects prior to deciding to screen or not. Information materials should be tailored to these aspects, as well as translated to appropriate languages due to a lack of a good command of the Dutch language. Self-efficacy expectations towards performing correct self-sampling should be enhanced to promote informed CC screening participation among Turkish- and Moroccan-Dutch women.

## Introduction

Cervical cancer (CC) is ranked as the fourth most frequently diagnosed cancer in women worldwide (1). The most important co-factor for CC is the sexually transmitted Human Papilloma Virus (HPV), which is estimated to be contracted by 70% of all sexually active individuals worldwide (2). As the majority of HPV infections resolve within one or two years, a HPV infection does not necessarily lead to cancer development (3). A long-term infection with high-risk HPV (hrHPV), however, may develop to invasive CC, which can take up to 20 to 30 years (4). Because of this, there is a window of opportunity for screening programmes to target precancerous cervical lesions and prevent invasive cancer.

In 1996, the Dutch national CC screening programme was implemented to detect CC in an early treatable stage. Since then, women aged 30 to 60 years are invited to participate every five years via a Dutch invitation letter. Since 2017, the Netherlands switched from cytology-based to HPV-based screening because of substantial evidence that the latter is more effective in reducing the incidence of cervical (pre) cancer (5). An important advantage of HPV-based screening is that HPV testing can be done on a sample collected by women themselves (i.e., 'self-sampling').

Despite the availability of a national free of charge CC screening programme, especially Turkish- and Moroccan-Dutch women, who account for the two largest ethnic minority groups in the Netherlands, show low screening participation. Although recent screening participation rates among these populations are lacking, Steens et al. combined data from different sources and at different levels of aggregation with screening data of 2005-2010. Based on this dataset, Steens et al. estimated considerably lower screening participation rates for women born in Turkey or Morocco (64% and 53%, respectively) compared to native Dutch women (79%) (6). This is especially worrying as these populations are found to have an increased risk for CC compared to native Dutch women (7) and more than half of the diagnosed CC cases occur in women who have not participated in screening (8, 9).

Traditionally, cancer screening programmes are aimed to reach a maximum uptake level and thus effectiveness (i.e. reduction of incidence and mortality) at a population level. From the perspective of the individual, however, deciding to participate in screening involves careful consideration between uncertain benefits (e.g. longer duration of life, if a precursor of cancer is successfully detected and treated) and risks of adverse effects (e.g. false-positive and -negative test results, overdiagnosis and -treatment, and discomfort or pain). With informed decision-making (IDM) individuals are entitled to individually consider these pros and cons, and make an autonomous decision regarding their participation. Thus, nonparticipation can be an acceptable outcome whenever it is the result of IDM. Therefore, an informed decision is defined

as one that is based on decision-relevant knowledge while the decision-maker's attitude is consistent with (intended) screen behaviour (10).

There is a limited IDM regarding CC screening among the native Dutch population due to insufficient decision-relevant knowledge (11). For Turkish- and Moroccan-Dutch women specifically, no data are available regarding IDM. There is also a lack of recent information regarding their perceived barriers and facilitators for participation in CC screening. Furthermore, (non)participation in CC screening might also be influenced by the possibility of self-sampling, introduced in 2017. Previous studies among Dutch and Australian general populations show that CC screening participation increased when never- and under-screened women were offered self-sample HPV tests (12, 13). Dutch women reported self-sampling as more convenient, since they could do it in their own time and it was less time consuming (14). Additionally, previously-screened Dutch women reported self-sampling as less embarrassing, less uncomfortable, and less painful than clinician-based sampling (14, 15). A qualitative study among women in Turkey did, however, show that women thought that only a general practitioner (GP) should take a smear, and that they would be unable to use the self-sampling device themselves (16). As self-sampling has only been implemented as a possible screening method in the Netherlands in 2017, it is unknown what influence it might have on the CC screening participation rates among Turkish and Moroccan women in the Netherlands.

Therefore, our aim was to explore how and why Turkish- and Moroccan-Dutch women decide to participate or not in the current Dutch national CC screening programme as well as to learn their perceptions on self-sampling.

## Methods

### Study design

A qualitative study was conducted using focus group discussions (FGDs) to elicit information regarding the decision-making process and the perceived barriers and facilitators regarding CC screening participation among Turkish- and Moroccan-Dutch women (17). This design was chosen, since FGDs facilitate participants exploring and clarifying their knowledge, attitudes, feelings, beliefs, and experiences in ways that would be less easily accessible in individual interviews because of the interaction between participants. A focus group design enables researchers to identify group norms and shared cultural understandings and values among participants (18, 19). Focus groups were held between March and April 2019. The reporting of this study was based on the Consolidated criteria for reporting qualitative research (COREQ) checklist (20).

To avoid cultural differences to emerge and affect discussions, FGDs with Turkish and Moroccan women were conducted separately. Through telephone and email, contact persons of community organisations (e.g. community centres, mosques, and civil support foundations) were recruited and asked in which language they would like to have the FGD be conducted. Based on their reported language preference, five FGDs were conducted in Dutch and one in Turkish (for which an extra Turkish-speaking moderator was arranged). Moroccan participants may speak Moroccan-Arabic, -Berber, or both. Since the majority of Moroccans in the Netherlands speak Moroccan-Berber or both Moroccan-Berber and -Arabic, a Moroccan-Berber speaking moderator (NH) was available to translate for Moroccan-Berber speaking participants in case they had difficulties with 'finding the words' in the Dutch language.

### Study population and recruitment

Dutch women aged 30 to 60 years old (the target age groups for CC screening), born in Turkey or Morocco, were included (first generation migrants, FGM), as well as those born in the Netherlands with at least one parent born in Turkey or Morocco (second generation migrants, SGM). SGM often act as brokers for their parents in communicating with Dutch health care professionals. They act as instructors, models, and interpreters, and provide financial, social, and/or emotional support to their parents. Therefore, SGM are important to consider when studying the thoughts and perceptions of FGM (21, 22). Participants were recruited through purposive and snowball sampling, aimed at diversity in age, educational level, geography, marital status, number of children, number of years residing in the Netherlands, and command of the Dutch language (participants and non-participants in CC screening). Through telephone and email, contact persons of community organisations (e.g. community centres, mosques, and civil support foundations) in various cities in the Netherlands were recruited (Amsterdam, Arnhem, Utrecht, The Hague, and Hoofddorp). These contact persons then invited women who were actively involved within the community organisations, or who frequently visited these organisations, and/or women in their social network.

Participants received information about the study and were asked to participate in the FGD. FGDs took place at community centres or mosques where participants held weekly meetings. Recruitment for the FGDs went on until data saturation was reached for both Turkish and Moroccan woman, i.e. no new information was found during the last FGD.

### Focus group topics

The topic list was constructed based on previous literature (12-16, 23-30) and a conceptual model primarily based on the Health Belief Model (HBM) (see Figure S1) and pilot tested in the first FGD. The HBM contains the following constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers,

perceived self-efficacy, and cues to action. This model assumes that individuals are likely to engage in a 'health action' if they perceive (1) themselves susceptible to the disease in question, (2) that the disease has serious consequences, (3) that taking a 'health action' could be beneficial in reducing the susceptibility to or severity of disease, (4) that the benefits of the 'health action' outweigh the barriers, (5) that they are self-efficient in relation to performing the 'health action', and (6) that one receives cues to take the 'health action' (31, 32). Furthermore, descriptive and injunctive norm (further referred to as 'subjective norm') of the Reasoned Action Approach (RAA) was included in our conceptual model (33), since previous literature showed that the decision to participate in CC screening could be influenced by others (23, 24, 28-30, 34-36). Betancourt's Model of Culture and Behaviour assumes that health behaviour is also associated with aspects of culture, such as value orientation, beliefs, and expectations, which can either influence behaviour directly or indirectly through psychological processes (37). We incorporated 'cultural factors' to our conceptual model, since this compilation of constructs has previously been used in studies regarding screening intention among Turkish- and/or Moroccan-Dutch population(s), which resulted in valuable insights in important cultural values affecting screening intention (21, 38). Furthermore, literature shows that religious beliefs and values may influence screening intentions and were, therefore, included as well (24). At the start of each FGD, socio-demographic characteristics of the participants were collected using a short Dutch questionnaire. Educational level was categorised according to the Dutch Standard Education Format by Statistics Netherlands: (1) low when participants had no education, primary education, or had not finished secondary education, (2) medium when participants were secondary school graduates or had finished vocational education, (3) and high when participants were university or applied sciences graduates (39).

Two main subjects were discussed during the FGDs: (1) decision-making process with perceived barriers and facilitators of CC screening (non)participation and (2) perceptions on self-sampling. This was done following the conceptual model's constructs: modifying factors, cultural and religious beliefs and values, perceived susceptibility to and severity of disease, perceived benefits and barriers, perceived self-efficacy, subjective norm, and cues to action. See Table S1 for an overview of the complete topic list.

#### Data collection

Each FGD contained five to eleven participants each. A female moderator and a female assistant (NH, EM) facilitated all five Dutch-spoken FGDs. NH is a bilingual Moroccan-Dutch PhD candidate, who speaks both Moroccan-Berber and Dutch, and has a background in qualitative research including conducting and analysing interviews and FGDs. A bilingual Turkish-Dutch female GP (fluent in Turkish and Dutch) and a female assistant (NH) facilitated one Turkish-spoken FGD.

Each FGD took approximately two hours. Prior to the start of the FGDs, participants were explained again the nature of the study through a short introduction, and were then given the time to ask questions. After the introduction, open questions based on the topic list were discussed. After the discussions, participants received a gift voucher of twenty euros as a token of appreciation for their participation. All FGDs were audio-recorded and the assistant took field notes during the FGDs.

#### Data analysis

All FGDs were transcribed verbatim. The Turkish- and Moroccan-Berber spoken (parts of the) discussions were directly transcribed into Dutch by a bilingual Turkish-Dutch research assistant and NH (who also moderated all Dutch-spoken FGDs), respectively. Because of the involvement of bilingual researchers, audio recordings could be directly transcribed into Dutch, taking the meaning of what was said (in another language) into account (40). Transcripts were analysed inductively for grouping perceived barriers and facilitators using the qualitative software programme MAXQDA (version 18.0.5), based on the principles of thematic analysis (41). We used open coding, where transcripts were coded by labelling meaningful fragments of text with concepts abstracted from this text. Through systematic comparison of coded text (also called axial coding), we identified emerging themes and subthemes. These themes and subthemes were compared for several collected socio-demographic characteristics (such as being Turkish or Moroccan). To ensure reliability of the data interpretation, two researchers (EM, NH) carried out the analysis of a random sample of 40% independently. Discrepancies were discussed until consensus was reached on the labelling criteria and the coding scheme. The remaining 60% of the analysis was conducted by EM.

#### Ethics approval and consent to participate

Ethical clearance was obtained from the Medical Ethics Review Committee of the University Medical Centre Utrecht. The Committee confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply to this study (nr. 19-251). Written informed consent was obtained prior to the discussions. All transcripts were processed and stored anonymised.

Results

Study participants

A total of 24 Turkish and 20 Moroccan women were included in six FGDs (see Table 6.1). One participant was born in Bulgaria and two participants did not meet the age criteria. These participants were excluded from Table 6.1. Most Turkish and Moroccan participants were FGM (85% and 95%, respectively) and had a family history of cancer (79% and 80%, respectively). Furthermore, 75% of Turkish participants reported to participate every five years in the CC screening programme compared to 30% of Moroccan participants.

We identified seven main themes in relation to CC screening participation from our thematic analysis, including one theme regarding self-sampling. For a schematic overview of the subthemes and coding tree, see Supplementary Figure S6.2 in the Supplementary Tables and Figures. There were no distinct differences in identified themes between Turkish and Moroccan women. Also, no distinct differences were observed among the two groups related to other socio-demographic characteristics (such as age and educational level).

Table 6.1. Characteristics of the participants (n = 44)

		Turkish participants (n = 24)	Moroccan participants (n = 20)
Migrant generation (%)	First	21 (88)	19 (95)
	Second	3 (13)	1 (5)
Age group (%)	30-45 years	6 (25)	10 (50)
	46-60 years	18 (75)	10 (50)
Mean age, in years (SD)		49 (6)	46 (6)
Marital status (%)	Married	18 (75)	17 (85)
	Divorced	4 (17)	3 (15)
	Widowed	2 (8)	0 (0)
Mean number of children (SD)		3 (1)	4 (1)
Educational level (%)	Low	16 (70)	9 (45)
	Medium	4 (17)	10 (50)
	High	3 (13) <sup>a</sup>	1 (5)
Employed (%)	Yes	8 (33)	6 (30)
	No	16 (67)	14 (70)
Self-reported family history of cancer (%)	Yes	19 (79)	16 (80)
	No	5 (21)	4 (20)

Table 6.1. Characteristics of the participants (n = 44) (continued)

		Turkish participants (n = 24)	Moroccan participants (n = 20)
Self-reported command of the Dutch language: speaking (%)	Insufficient	8 (33)	3 (15)
	Sufficient	10 (42)	9 (45)
	Good	6 (25)	7 (35) <sup>a</sup>
Self-reported command of the Dutch language: reading (%)	Insufficient	8 (33)	3 (15)
	Sufficient	9 (38)	6 (30)
	Good	7 (29)	9 (45) <sup>b</sup>
Self-reported CC screening participation (%)	Every 5 years	18 (75)	6 (30)
	Not every 5 years	4 (17)	7 (35)
	Not sure how often	0 (0)	3 (15)
	Never	2 (8)	4 (20)

<sup>a</sup>One participant did not respond to this question. <sup>b</sup>Two participants did not respond to this question.

(Informed) decision-making and information need

(Informed) decision-making

Some participants expressed having difficulties with making the decision to screen or not, while others indicated it as easy and not perceiving it as a choice, but as self-evident: *'It [decision to screen or not] is easy, not difficult. It is not a choice'* (Turkish participant). Some thought that it does not hurt to participate in screening and it would rather improve their health: *'I think it [decision to screen or not] is easy, because when I get a letter at home, I think: I will go for it. [...] For me, it really is better. Why not? It can't hurt. It can only make matters better. [...] To take the matters into one's own hands.'* (Moroccan participant).

Participants thought that it is important and useful to participate in the CC screening programme, as it concerned their health. Many participants mentioned the saying *'prevention is better than cure'* and thought that timely detection of CC is a benefit of the programme. Participants often mentioned that screening meant five years of guaranteed health. However, some participants did not share this view, as they were convinced that cancer development could potentially start right after you have just been screened.

Many participants did not seem to know the cause of CC (i.e. HPV), especially not the fact that HPV is sexually transmittable: *'People think that it is a cough, a virus, they think you can get cancer from everything, and not from sexual intercourse.'* (Moroccan participant). This revelation caused some anger towards men in several FGDs, blaming

them for CC. Although most participants knew the symptoms of CC, they often did not know that having these symptoms meant that the cancer is already in a late stage. Some participants thought CC is not preventable, as they had a fatalistic approach, but they did think that it can be detected in time to be treated. Few participants knew the eligible screening age range for participation. We also observed that participants lacked knowledge about the procedure, which resulted in fear for the procedure and distrust towards health care professionals and the screening programme: *'Ignorance creates fear, because they do not know what will happen (i.e. the screening procedure). If they knew, they wouldn't be afraid.'* (Turkish participant).

### **Need for information**

Participants mentioned that there is a lack of information regarding CC. Some participants mentioned that taboo around CC contributed to this. A need for information was emphasised, especially about the cause of CC, how to prevent it, and how the procedure is performed. Participants suggested that information meetings at mosques or community centres would facilitate screening participation. These meetings would need to be provided by a female health care professional, in their own language (i.e. Turkish, Moroccan-Berber, or -Arabic), and need to incorporate Islamic beliefs and values.

### **Religious beliefs and values**

#### **Norms regarding health and illness in the Islam and fatalism**

Most participants expressed their belief that health plays an important role in the Islam. Participants mentioned that according to the Quran, it is important to take care of one's body using all available medical options, therefore facilitating CC screening participation. Participants also explained that they believe in fate and would accept whatever is God-given, including CC. Yet, for most participants this did not mean that they would not have to try to prevent it: *'God has also said, if you have something, go after it. Help exists, doctors exist, there are medicines. And if your day has arrived, correct, your day has arrived, but this doesn't mean that you don't need to do anything about it'* (Moroccan participant).

However, some participants reported cancer screening as pointless. They believed that if they would get cancer, screening would not have prevented this, and thus regarded screening as unbeneficial (i.e. fatalism). Therefore, for some, fatalism seemed to function as a barrier for screening participation: *'Even if you go every year to the cervical cancer screening programme, or every month, if it's meant to be, you will get it.'* (Moroccan participant).

### **Cultural beliefs and values**

#### **Shame and taboo around cervical cancer**

Participants mentioned frequently that Turkish and Moroccan people do not talk about CC or screening with each other. They only discussed it with very close friends or with their husbands at home, and merely when someone in the surroundings had been diagnosed with cancer, or had died from it. When asked why women did not talk about it, several reasons surfaced. First, participants explained that people in their environment believe that if you do not talk about cancer, it does not exist. Second, participants mentioned that it is not custom to talk about negative subjects, such as disease or death. Third, participants expressed that if people would know that they have a disease, they would receive pity, which was perceived as unwelcome. Another issue that frequently arose, when the cause (i.e. HPV) and transmission route of HPV was explained, was the belief that having CC meant that a woman or her partner had sexual relationships with multiple partners which would not be acceptable according to the Islam. Because of this, participants often mentioned that they would be afraid of the judgement of others, would they go to the screening programme or be diagnosed with CC, thus keeping the subject undiscussed: *'It is more like, what will they think? How did I get it, which of course is also an issue. It is an intimate piece of you. How did I get it then? And people are going to think, where did she catch that?'* (Turkish participant).

Furthermore, participants perceived CC and screening as an intimate and private matter. Talking about feminine issues at home, such as menstruation, was reportedly not customary while growing up, not even among the women in the family. Other participants supported this, claiming that there is shame around CC. The uterus was deemed the most intimate part of a woman's body, making them feel ashamed with *'spreading their legs'* during the procedure: *'It is shame. I remember the first time I went, I was thirty. I didn't know what was going to happen to me. [...] I wasn't afraid, I was ashamed to show the 'stuff''* (Moroccan participant).

Since participants associated the uterus with fertility and CC with infertility, and procreation is perceived important, participants feared that participating in screening might negatively affect their chances of a successful future (i.e. husband and children). Besides, they would feel ashamed in participating in screening, as people around them would think that they might be infertile: *'It is a very sensitive subject for women. It is something feminine. It feels as if when you have no uterus anymore, you are not a woman anymore.'* (Moroccan participant).



## Perceived threat of disease and fear of cancer and death

### Perceived susceptibility to and severity of disease

Participants perceived their overall susceptibility to developing CC as very low. This was mostly due to the belief that Muslims are not supposed to have sexual intercourse before marriage, therefore, having much fewer sexual partners compared to non-Muslims: *'I think that in our culture it [CC] is less frequent, because I think men have less often sex with several women. A woman idem ditto.'* (Moroccan participant). Participants believed that this is a reason for nonparticipation in the CC screening programme among Turkish and Moroccan women. However, others perceived that everybody is susceptible to CC, especially women with cancer in their family, as participants believed it to be hereditary, which facilitated screening participation. All participants believed CC is a very severe disease.

### Fear of cancer and death

It was often mentioned that the word *'cancer'* itself is frightening due to the frequency of people having cancer in their surroundings and due to the association of cancer with death. As CC was perceived as very severe and was associated with death, participants mentioned that they were scared of hearing the results of the screening. Many participants explained that they were very stressed and nervous until the test results would come back, especially as they experienced the waiting period as far too long. Participants explained that they did not fear death itself, but they were afraid for their children being left behind after their death: *'We all know that we are going to die. [...] But if you still have small children, it's more about your children than yourself. Even if I'm not here right now, who is going to take care of my children?'* (Moroccan participant). Some participants expressed that they did not attend the screening because of this fear of cancer and the psychological stress they would have to endure if they knew they had the disease. On the opposite, for others the fear of leaving their children behind, made them participate in the screening programme.

### Subjective norm and social support

Participants believed that the ultimate decision about participation is made by them and not by others. There were, however, several influences reported. First, participants mentioned that because of the taboo, women felt ashamed to participate in the screening programme, mostly because they were afraid of what others would think (i.e. multiple partners, infertile). However, they mostly expressed that others would provide support in participating. Their doctors and husbands acted as advisors or supporters, but did not influence their decision-making. Furthermore, close friends acted as emotional support in pushing someone to take the last steps in going to the GP when the procedure was regarded as scary. Close friends were also indicated as verbal support when women lacked a good command of the Dutch language, and were not able to make an appointment. Additionally, participants mentioned that they

made sure their mothers would participate, who did not always understand that they were being invited due to the lack of a good command of the Dutch language. Overall, participants did not feel pressure from others to (not) participate in screening, but instead, tried to influence and support others to screen themselves: *'But if someone comes to me who has to go for the first time. You go like: You have to do it, it's done very quickly, just do it. It means certainty for yourself, it's your health and you shouldn't think easily about that. That can be, especially for someone going for the first time, that last push.'* (Turkish participant).

## Practical factors

### Practical barriers and facilitators

The (expected) pain of the procedure was a barrier for some, but most participants expressed that it did not impede them to participate in screening. However, menstruation and bodily (un)cleanliness did defer participants from screening. Having a male GP contributed to nonparticipation, especially since many participants did not know it was possible to request a female doctor or assistant for the procedure. Furthermore, participants experienced difficulties with scheduling appointments due to their working schedule or because of having been pregnant: *'You can't go right after your pregnancy and around the age of thirty, many women are pregnant and having children. So it is for sure a difficult target population to contact. And then I was breastfeeding, and then I thought it was scary, and then I was pregnant again. You have to be fast.'* (Moroccan participant).

Observed facilitators for participation were that the screening is free of charge and that the procedure is quickly performed.

### Invitation letter and information brochure

Participants expressed that they feel screening participation is important because the invitation letter is sent to their homes. This created a feeling of obligation to respond to the letter and participate. Other participants expressed that the letter functioned as a reminder to make an appointment, therefore facilitating screening participation: *'If you get such a brochure, such information, you just know that it's important'* (Moroccan participant).

Participants expressed that the invitation letter and information brochure were often not (thoroughly) read or they were unable to understand it due to the lack of a good command of the Dutch language: *'I have never read it completely. I know it is an option. Then I decide whether I go or not.'* (Moroccan participant). When women did not understand that the letter was an invitation to attend the screening, they were not able to react and participate. Participants mentioned that this applied to their

mothers, unless they made an appointment to make sure that their mothers would go to the screening.

Furthermore, few participants knew of the existence of the online available Arabic and Turkish information brochures. Being available online was a barrier, especially for older Turkish and Moroccan women, who often do not know how to use the Internet. Those who had read these brochures mentioned that they are badly translated and that the language level is too complicated making them difficult to understand: *'Sometimes the translations are not even done properly. I ask myself, is it just Google Translate or something?'* (Turkish participant). Some participants were positive towards the Arabic and Turkish information brochures, as they used them in addition to the Dutch brochure in case they could not understand everything stated.

### Self-sampling

#### Practical pros and cons

The majority of the participants had not heard about self-sampling before. However, participants, who had heard of it, expressed difficulties in performing it, since instructions were complicated and difficult to understand. After explanation of the self-sampling procedure, most participants had a positive attitude towards it. Not needing to go to the GP's office and not having to *'spread their legs'* for the GP were perceived benefits. Another positive aspect was the possibility to perform it in their own time without someone else around. However, participants mentioned that there is no visual inspection of the cervix, such as at the GP's office, and that they would need to go to the GP anyway would the test result be HPV positive: *'I had received such a letter, like you said. But it also said, if it's not good, you have to go to the GP again. I thought, then I'll just go to the GP right away. I did not ask for it.'* (Turkish participant).

#### Self-efficacy

Participants regarded their ability to correctly perform self-sampling as low. Because of this low self-efficacy, they were hesitant on whether the results of the test could be trusted: *'Especially when the results are good, then you think, hmm, but what if I haven't done it properly. Then I am going to be hesitant.'* (Moroccan participant). This led to the majority of participants being hesitant towards self-sampling, preferring to go to the GP. However, participants suggested that they would be interested in self-sampling if their GP showed them how to do it or had video tutorials instead of written tutorials with pictures: *'It is written down with pictures, but it would be easy as well if you could watch a video. For example, you could go to this website and look how it should be done. [...] I find that important.'* (Moroccan participant). Participants would suggest self-sampling to others if women were determined not to go to the GP. Overall, a few participants seemed open to try self-sampling.

## Discussion

### Main findings

We explored how and why Turkish- and Moroccan-Dutch women between 30 and 60 years old decide to participate or not in the current Dutch national CC screening programme including their perceptions on the newly implemented self-sampling method.

Regarding informed decision-making (IDM), we found that many participants reported making their decision without neither being fully informed nor deliberately weighing all aspects involved. Overall, the decision was either experienced as difficult due to considering pros and cons, or as easy due to the perception that it is self-evident to participate. Prior to explaining the role and transmission route of HPV (either by the moderator or by one of the participants), many participants were not aware of HPV and did not know about its sexual transmission route. CC was thought to be hereditary and although most participants knew the symptoms of CC, they often did not know that having these symptoms meant that the cancer is already in a late stage. We also observed that participants lacked knowledge about the screening and thought that it only had advantages and could not hurt. Participants also often mentioned that screening meant five years of guaranteed health, indicating ignorance about the possibility of false-negative test results. A need for information was observed amongst participants, especially about the cause and prevention of CC. We found that having a male GP was a barrier, while women were often oblivious to the fact that it is possible to ask for a female GP or assistant. This suggests that the decision to participate (or not) is based on insufficient knowledge about CC screening.

We found several barriers to participate in CC screening, such as shame and taboo around CC, which contributed to a lack of knowledge and a low perceived susceptibility to CC, having a male GP, extra effort to schedule an appointment due to menstruation, pregnancies, and (un)cleanliness, scheduling difficulties, and lack of a good command of the Dutch language. Religion seemed to function as a barrier if people had a fatalistic approach, seeing the disease as something out of their control and God-given, and as a facilitator in regard to taking responsibility of one's own health, and using all medical options given by God. Fear of the test result, cancer, and death were also observed as both facilitating and hindering screening participation. Practical facilitators were the invitation letter, a short procedure time, and that screening is free of charge. Subjective norm was often not perceived to be influential on decision-making, but others could facilitate screening participation through emotional or verbal support.

Most participants had not heard about self-sampling before, but expressed a positive attitude towards it, especially for those who did not want to visit the GP. However, a

lack of self-efficacy towards performing self-sampling correctly was observed when self-sampling was explained. As a result, women were concerned about whether the test results could be trusted. Consequently, participants hesitated about performing self-sampling and preferred clinician-based sampling.

### Comparison with other studies

We showed that taking a fully informed and well-considered screening decision does not appear to be entirely reflective of the decision-making process in practice. Most participants reported considering not only factual medical information (i.e. detection of CC in an early treatable stage), but also practical, emotional, cultural, and religious aspects. This is in line with previous research regarding colorectal screening among the general Dutch population (42). A study of Korfage et al. reported a limited IDM among native Dutch women regarding CC screening and also showed their unawareness of the possibility of false-negative and -positive test results (11).

Many barriers and facilitators reported by this study are in line with previous research (16, 24, 27, 28, 30). A previous study also found that participants associated CC with being infertile (24). Participants in our study believed that others would think that they had multiple partners if they participated in CC screening. Studies that support this among Turkish and Moroccan women are lacking. However, two studies observed similar shame and stigma around Hepatitis B due to sexual transmission being one of the possible transmission routes (21, 38). Religion acting as both a barrier and facilitator had previously been reported by Duran (2011) in a study regarding CC screening participation among Turkish women, but was until now unknown to play a role among Moroccan-Dutch women as well (24). In contrast to previous studies, we observed that fear of cancer and death functioned as a facilitator, since women wanted to use the chance to cure the disease would they fall ill, in order to prevent leaving their children behind after death. The fear of their children being left behind appeared to overthrow the fear of the test result, cancer, and death itself, and ultimately appeared as a key reason why women would participate in screening. Although many participants reported inability to understand the invitation letter and information brochure, which is in line with other studies among Turkish-Dutch women (26, 27, 43), we found that daughters play an important role in the decision-making process of their mothers by translating the letter and brochure, and ensuring that screening appointments were made. This finding is in line with SGM frequently acting as brokers for their parents in communicating with Dutch health care professionals (22).

Previous literature showed that screening participation increased when never- and under-screened women were offered self-sampling (12, 13). In line with previous studies among the general Dutch population, we found that women lacked trust in their correct performance of self-sampling and, consequently, lacked trust in the test result (12, 24, 44). However, in contrast to these studies where self-sampling

was nonetheless preferred, Turkish- and Moroccan-Dutch women in our study were hesitant towards self-sampling and, thus, preferred clinician-based sampling. A possible reason for this discrepancy is that self-sampling instructions were deemed complicated by our populations, whereas Polman et al. (2019) showed in their study among the general Dutch population that the intelligibility of the self-sampling instructions were perceived very to extremely good (44).

### Strengths and limitations

A strength of our study is that FGDs were held at community organisations and mosques that participants frequently visited. This provided a comfortable setting for participants. Additionally, one moderator was of Moroccan origin and another of Turkish origin, which also might have contributed to participants feeling more comfortable in participating in the discussions (45). Second, our sample shows a considerably even distribution between and within the groups of Turkish and Moroccan women regarding migrant generation status, age, educational level, and employment status, which indicates that we reached a diverse sample of Turkish and Moroccan women in the Netherlands.

A possible limitation of our study was that we only arranged an extra Turkish-speaking moderator for one FGD based on what contact persons of community organisations indicated as preferred language for the FGD. In some cases, contact persons indicated that participants could participate in the discussion in Dutch. However, during the discussion itself, some Turkish participants lacked a good command of the Dutch language. Because of this, other participants in the group translated the discussion. The accuracy of these translations could not be verified, as participants could translate according to their own beliefs. Participants might also have been unable to express themselves fully during these FGDs due to this lack of a good command of the Dutch language, therefore, reducing interaction in the group and causing possible loss of information. In the future, to avoid these situations, it would be better to ask every participant what her preferred language is beforehand instead of the contact persons of the community organisations only.

### Recommendations and implications for future research

The majority of the participants lacked knowledge regarding CC and screening, which was partially caused by a lack of a good command of the Dutch language. We also found that the need for information about HPV infection, developmental stages of (pre)cancerous lesions, and prevention of CC is high. In order to increase knowledge and, therefore, IDM regarding screening participation, we suggest that female health care professionals deliver information at community-organised meetings in Turkish, Moroccan-Berber, and -Arabic. We also recommend including discussions about religious values in relation to health (care) and addressing the fear of leaving children behind whenever the mother dies due to the consequences of CC, which could

be facilitated by respected female mosque members. Furthermore, as Turkish and Arabic brochures were difficult to understand due to the advanced language level or incorrect translations, we recommend to revise these. As the online availability was also a barrier for older women in particular, we suggest to let these brochures be brought under attention by women's GPs. Our findings also suggest that when addressing self-sampling uptake among Turkish- and Moroccan-Dutch women, tailored video or face-to-face instructions are needed, which need to focus on increasing self-efficacy towards correctly performing self-sampling, and emphasise the accuracy of this sampling method. These instructions need to take the lack of a good command of the Dutch language among FGM into account. As was suggested by our sample, face-to-face instructions could possibly be provided by the GP with a translator and video instructions need to be available in several languages (Dutch, Turkish, Moroccan-Berber, and -Arabic). Furthermore, our findings reflect that by extending the traditional HBM with the RAA construct 'descriptive and injunctive norm' and 'cultural factors' from Betancourt's model of Culture and Behaviour, this model proved itself valuable in conceptualising the plausible relationships between culture and religion, psychological processes, and behaviour, and we, therefore, recommend using this model in future research among these populations. In addition, an IDM measure that is reflective of the decision-making process in practice is urgently needed. Moreover, since this study is part of a larger project, we will focus on two main interventions in the coming years. First, a blended learning approach will be developed. Part of this approach is organising several community-organised meetings in Turkish, Moroccan-Berber, and -Arabic regarding CC and screening. Second, found determinants should be selected on relevance (through a quantitative study) and targeted by using tailored communication strategies (e.g. culturally sensitive educational films) to improve IDM regarding CC screening participation among Turkish- and Moroccan-Dutch women.

## Conclusions

Turkish- and Moroccan-Dutch women lacked knowledge about CC and its screening, and seemed to be unaware of the cons of the CC screening programme. Although their IDM seems to be limited, this study showed that women do not only consider factual medical information, but also practical, emotional, cultural, and religious aspects prior to deciding to screen or not. Important barriers and facilitators for CC screening participation were identified among Turkish- and Moroccan-Dutch women. These factors need to be considered in designing tailored information materials and educational meetings. Self-efficacy about conducting self-sampling correctly should also be taken into account when addressing informed CC screening participation among Turkish- and Moroccan-Dutch women.

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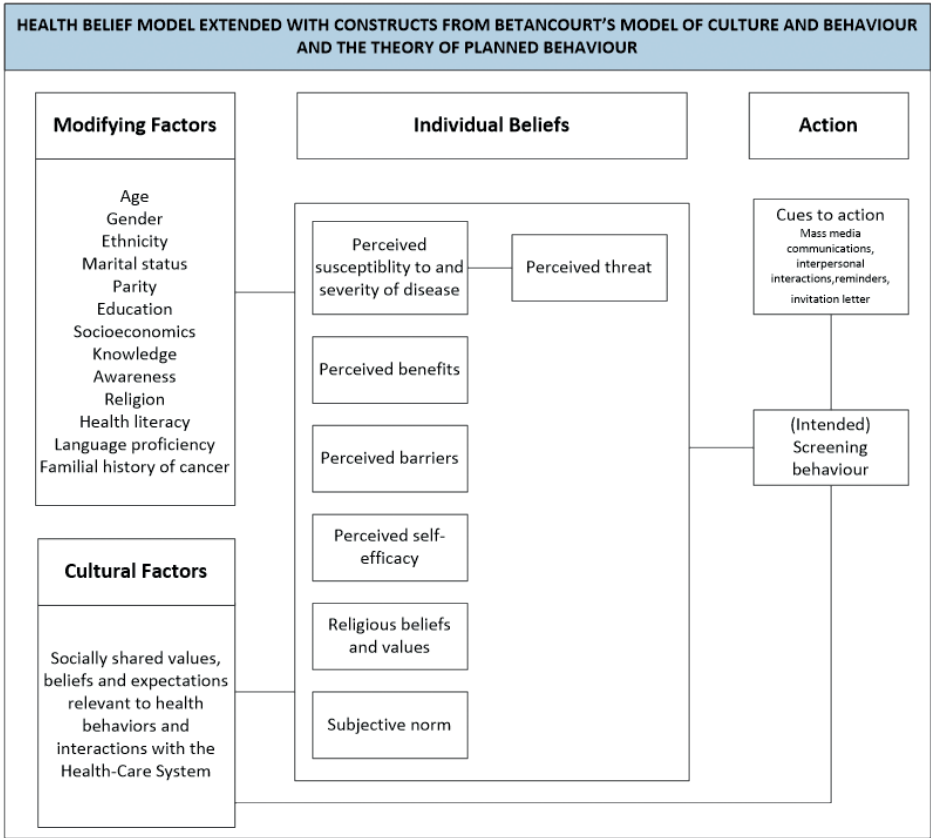
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Supplementary Tables and Figures



Supplementary Figure S6.1. Conceptual model of the relationship between modifying factors, cultural factors, individual beliefs, and (intended) screening behaviour in Turkish- and Moroccan-Dutch women

Supplementary Table S6.1. Topic list for the focus group discussions

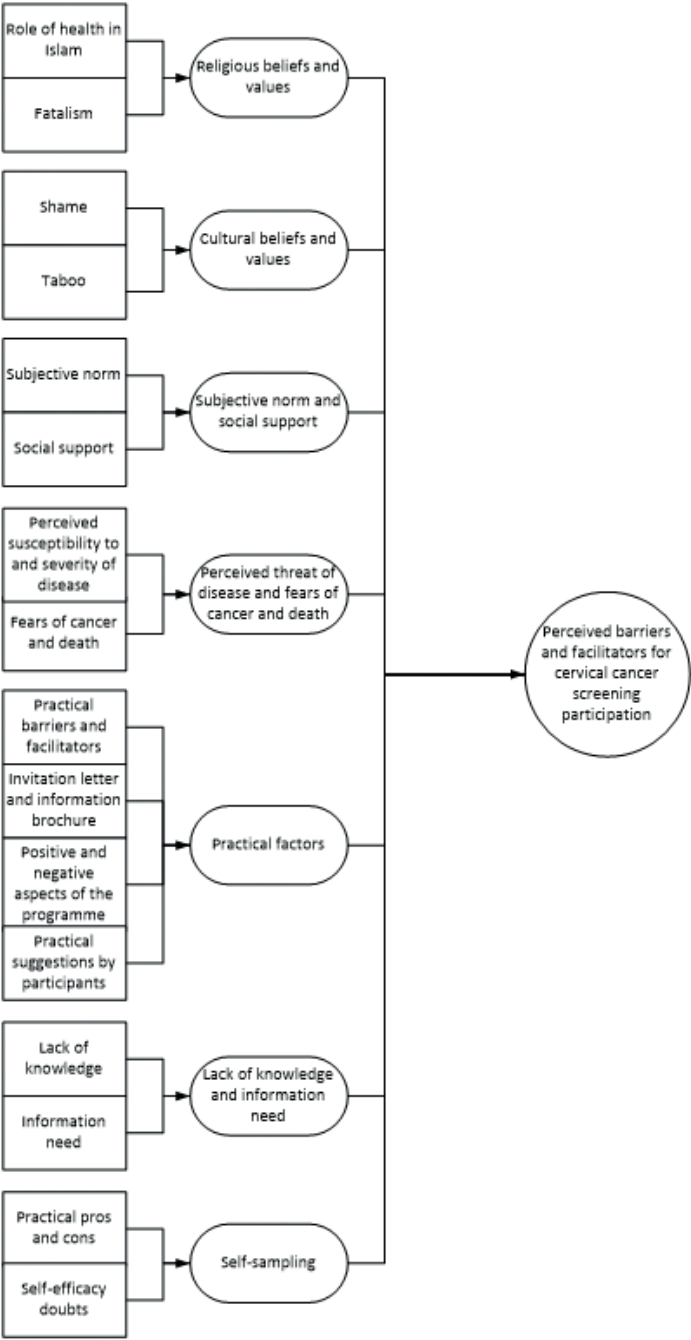
Topic	Theme	Example question(s)
Cervical cancer	Knowledge and awareness	<ul style="list-style-type: none"><li>Have you heard anything about cervical cancer before? If yes, what and where?</li><li>How could you know that you may have cervical cancer?</li><li>What do you think you could do to prevent cervical cancer?</li></ul>
	Personal experiences	<ul style="list-style-type: none"><li>Do you have personal experiences with cervical cancer? .</li><li>Do you know, for example, people in your area who have (had) cervical cancer?</li></ul>
	Cultural factors	<ul style="list-style-type: none"><li>Do you ever talk about cervical cancer?</li><li>With whom, and which words do you use?</li><li>Where and how is it discussed?</li></ul>
	Perceived susceptibility to and severity of disease	<ul style="list-style-type: none"><li>Do you find cervical cancer a serious disease? Why (not)?</li><li>Are you afraid of getting cervical cancer? Why (not)?</li></ul>
Cervical cancer screening	Knowledge and awareness	<ul style="list-style-type: none"><li>Have you heard anything about the cervical cancer screening programme before?</li><li>What do you know about how the procedure is done? Can you tell me how this (roughly) goes?</li></ul>
	Cultural factors	<ul style="list-style-type: none"><li>Do you ever talk about cervical cancer screening?</li><li>If so: With whom, and which words do you use?</li><li>Where and how is it discussed?</li></ul>

Supplementary Table S6.1. Topic list for the focus group discussions (continued)

Topic	Theme	Example question(s)
	Perceived benefits	<ul style="list-style-type: none"><li>· Why do you think this screening programme is offered by the government?</li><li>· How do you feel about being invited to participate in the screening programme? Why?</li><li>· What do you think about the screening programme?</li><li>· Do you find it useful? Do you find it important? Why yes / no?</li><li>· To what extent do you think this examination will work to prevent cervical cancer?</li></ul>
	Subjective norm	<ul style="list-style-type: none"><li>· Do you know people in your area who have participated in the screening programme? If yes: Did this affect you then? How?</li><li>· Have you spoken to others about what you could do about whether or not to participate in the screening programme?</li><li>· With whom? What was their opinion? How did this affect your decision then? And how will this affect your decision in the future?</li><li>· Do you think you are expected to participate in the screening programme?</li></ul>
	Religious beliefs and values	<ul style="list-style-type: none"><li>· What do you think religion / Quran says (if all Muslims) about whether or not to participate in the screening programme?</li></ul>
	Perceived self-efficacy	<ul style="list-style-type: none"><li>· If you receive an invitation to the screening programme, do you understand what steps you need to take to participate? Why yes/no?</li><li>· If you understand these steps, do you think you can also take these steps? Why yes / no?</li></ul>
	Perceived barriers	<ul style="list-style-type: none"><li>· I want to ask you to come up with good and less good points of the screening programme. These are good and less good points that you yourself / personally think of the screening programme.</li></ul>

Supplementary Table S6.1. Topic list for the focus group discussions (continued)

Topic	Theme	Example question(s)
	Invitational letter	<ul style="list-style-type: none"><li>· Have you ever received an invitation to the screening programme?</li><li>· What did you think of the invitation letter? And of the information brochure?</li><li>· How could these be improved?</li><li>· Do you know that the brochure can also be found in Turkish / Arabic?</li><li>· If yes: How do you know this? What do you think about this?</li><li>· Would you like to receive more information? Why yes / no?</li><li>· Would you like to receive the information differently? If yes: how and why?</li></ul>
	Self-sampling	<ul style="list-style-type: none"><li>· What do you like about the self-test?</li><li>· What do you dislike about the self-test?</li><li>· Suppose you receive an invitation to participate in the population screening tomorrow, knowing that you can also take this self-test, would you participate or not? Why yes / no?</li></ul>
	Screening behaviour	<ul style="list-style-type: none"><li>· What is most important to you when it comes to deciding whether or not to participate in the cervical cancer screening programme? Why?</li></ul>
	Suggestions	<ul style="list-style-type: none"><li>· Do you have ideas for improvements to the population screening?</li></ul>



Supplementary Figure S6.2. Coding tree

An artistic illustration of a sky with soft, white clouds against a light blue background. Several black silhouettes of birds are shown in flight, scattered across the sky. Below the sky, there are rolling hills or mountains rendered in warm, golden-yellow and orange tones, suggesting a sunset or sunrise scene.

# 7

## The development of a culturally sensitive educational video: how to facilitate informed decisions on cervical cancer screening among Turkish- and Moroccan-Dutch women

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*Submitted for publication.*

## Abstract

### Background

In the Netherlands, all women aged 30–60 years are invited to participate in the national cervical cancer screening programme, which is aimed at early detection and treatment of precancerous lesions. One fourth of the Dutch population has a migration background, with Turkish and Moroccan immigrants being the largest immigrant populations. Turkish- and Moroccan-Dutch women show lower screening participation rates, and a higher incidence of cervical cancer, compared to native Dutch women. Since current information materials are not tailored to these women's needs, we developed a short culturally sensitive educational video to facilitate informed decision-making for cervical cancer screening among Turkish- and Moroccan-Dutch women. This article describes the development process of this video and the lessons learned.

### Methods

Using the Entertainment-Education communication strategy, we collaborated with an interdisciplinary team of Turkish- and Moroccan-Dutch women, researchers, public health experts, and creative media professionals. We developed the video following the different stages of the Media Mapping model: Orientation, Crystallization, Design/Production, Implementation, and Dissemination. Each stage is described in the paper.

### Results

The video was developed in Moroccan-Arabic, -Berber, and Turkish, and emphasised three main themes: (1) more certainty about having cervical (pre)cancer, and the possibility to prevent treatment, surgery, or premature death, and because of this, being there for the children, (2) according to the Islam, a woman should take good care of her health, and (3) anxiety, shame, and privacy.

### Conclusions

A short culturally sensitive educational video, delivered as part of a larger intervention together with the current information brochure, was developed based on theory and grounded in the needs of Turkish- and Moroccan-Dutch women. The value and effectiveness of this intervention to facilitate informed cervical cancer screening decisions have yet to be evaluated in a randomised controlled trial.

## Background

Since 1996, a national cervical cancer (CC) screening programme has been implemented in the Netherlands. Although CC screening has led to a substantial decline in both early- and late-stage CC (1), Turkish- and Moroccan-Dutch women show lower screening participation rates compared to native Dutch women (2). Based on the national screening programme, regional screening organisations invite women aged 30 to 60 years every five years by sending them a Dutch invitation letter and information brochure to their home addresses. Translated information materials in other languages and additional information can be found online. We found earlier that the current invitation letter and information brochure are not tailored to the needs of Turkish- and Moroccan-Dutch women because of a lack of information on the practical, emotional, cultural, and religious aspects of CC screening (3). According to the Elaboration Likelihood Model (ELM), depending on their motivation and skills, individuals engage in high or low elaboration (i.e. level of effort to process) when encountering a message (4). Watching a short video is a relative small effort compared to reading an invitation letter and information brochure. More importantly, a video may "prime" an individual to search for and read additional information, or spark conversations about the topic with others. To date, no such video is in place. Therefore, we decided to develop a short culturally sensitive educational video to facilitate Informed Decision-Making (IDM) regarding CC screening participation. In this article, we describe the development process of this video and the lessons learned.

To create the video, an interdisciplinary team was formed consisting of members of the targeted audiences (i.e. Turkish- and Moroccan-Dutch women between 30 and 60 years old), researchers, public health experts, and creative media professionals. We will illustrate this collaborative process following the different stages of the Media Mapping model of the Center for Media & Health (5): Orientation, Crystallization, Design/Production, Implementation, and Dissemination (see Figure 7.1). Parts of this Media Mapping model are formative and summative research.



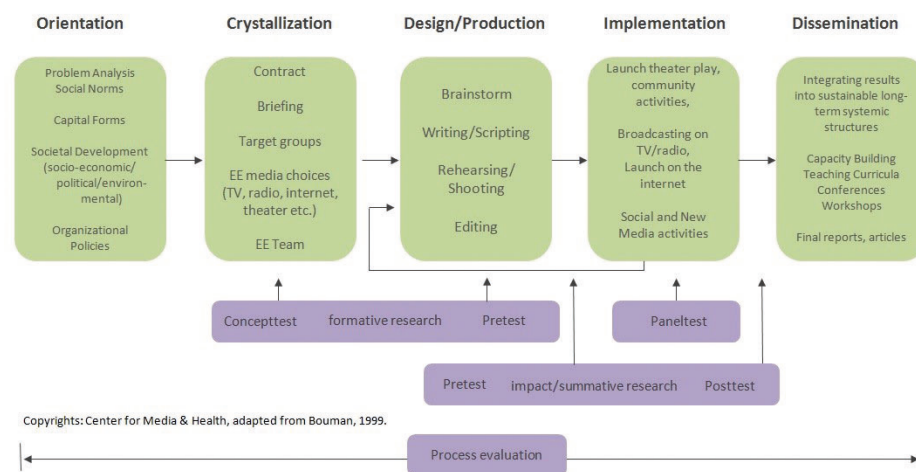


Figure 7.1. Media Mapping model (5)

## Methods

### Orientation

The current strategy in the Netherlands is to encourage women to gather information about both the advantages and disadvantages of CC screening, to ultimately make an informed decision regarding their participation. Participation in CC screening is entirely voluntary.

In the Netherlands, 24.4% of the population has a migration background, which includes both individuals who were born abroad (further referred to as first-generation immigrants) as those who have at least one parent born abroad (further referred to as second-generation immigrants) (6-8). Overall, Turkish and Moroccan immigrants are the largest immigrant populations with 422,030 persons and 414,186 persons, respectively, each accounting for 2.4% of the total population in 2021 in the Netherlands (9).

Steens et al. (2013) estimated that in the Netherlands 64% of women born in Turkey, and 53% of women born in Morocco participated in CC screening, compared to 79% of women born in the Netherlands (2). These lower CC screening participation rates are worrisome, especially because these populations also show higher CC incidence ratios of 1.2 (Turkish) and 1.7 (Moroccan) compared to native Dutch women (with a reference incidence ratio of 1.0) (10).

Multiple factors can play a role in women's decision-making process regarding cancer screening, such as lack of awareness and knowledge, organisational issues, and

socio-cultural aspects (11). According to the concept of IDM based on the Rational Decision Model, screening decisions are based on making optimal use of information, and rationally weighing all aspects involved, considering both the pros and cons (12-14). This means that uncertain benefits (e.g. longer duration of life if a precursor of cancer is successfully detected and treated), and risks of adverse effects (e.g. false-positive and -negative test results, overdiagnosis and -treatment, and discomfort or pain) should be considered in the individuals' decision-making process (12-14). In a previous study using focus group discussions and a follow-up questionnaire among Turkish- and Moroccan-Dutch women, we found that they do not only consider factual medical information, but also practical, emotional, cultural, and religious aspects prior to deciding to screen or not (3). Next to medical information (e.g. risk factors of CC), practical, emotional, cultural, and religious aspects play a significant role in the decision-making process of these women. That is why we decided to combine an informative approach with a more affective approach.

Since the current invitation letter and information brochure include mostly factual medical information, practical, emotional, cultural, and religious aspects need to be added. Moreover, Turkish- and Moroccan-Dutch women often indicated to not (thoroughly) read the invitation letter and information brochure, or simply being unable to understand these materials due to a lack of a good command of the Dutch language (3). Moreover, Turkish- and Moroccan-Dutch make less use of printed media, and more use of audio-visual media (30% versus 75%, and 34% versus 72%, respectively) (15). A previous study showed that culturally competent educational films improved IDM regarding prenatal screening among Dutch multicultural pregnant women (16).

Therefore, in accordance with the ELM, and to further stimulate IDM for CC screening among Turkish- and Moroccan-Dutch women, we developed a short culturally sensitive educational video in the women's own languages (Turkish, Moroccan-Arabic, and -Berber), to complement the currently used information brochure. The narrative in this video focused on practical, emotional, cultural, and religious aspects.

### Theoretical framework

To develop a short culturally sensitive educational video to facilitate IDM, we made use of the Entertainment-Education (EE) communication strategy (17, 18). This strategy can be defined as "the process of purposively designing and implementing a mediating communication form with the potential of both entertaining and educating people, in order to enhance and facilitate different stages of behaviour change" (17). This strategy allows for a better alignment with the lifestyles and culture of audiences who lack a "reading culture". Since Turkish- and Moroccan-Dutch make less use of printed media, and more use of audio-visual media (15), we chose to create a video based on the EE strategy. The EE strategy is characterised by a more affective approach, and applies



storytelling to present (new) knowledge, ideas, norms, and practices, with the aim of stimulating conversations with family, friends, and acquaintances about the issues raised in the video (17-20). Based on the Social Cognitive Theory (19, 21), individuals may learn by observing the behaviour of role models seen in real life, or by characters seen in films, which contribute to storylines effectively conveying specific knowledge, ideas, norms, and practices (20). To facilitate recognisability for all women watching the video, we chose to portray three types of role models in the video: one who has a positive attitude towards CC screening participation; one who has a negative attitude towards CC screening participation; and one who has an ambivalent attitude towards CC screening participation.

### Crystallization

Upon completion of the orientation phase, we approached several video production companies. We selected the company called Zouka Media who had proven experience and expertise in producing videos for and by Turkish- and Moroccan-Dutch women. The ideas of the researchers and Zouka Media aligned well in approaching and informing these women through a short culturally sensitive educational video (e.g. type and content of the storyline, recruitment and type of actresses, and the setting of the video), and Zouka Media showed great willingness to work in an interdisciplinary team. Subsequently, a contract was negotiated between the partners.

We conducted formative research as input for the development of the briefing document. We held six focus group discussions among 24 Turkish- and 20 Moroccan-Dutch women during which seven main themes emerged (3). These themes were (1) (informed) decision-making and information need, (2) religious beliefs and values, (3) cultural beliefs and values, (4) perceived threat of disease and fear of cancer and death, (5) subjective norm and social support, (6) practical factors, and (7) self-sampling. To identify the most relevant themes to include in our video (as including all seven themes would result in a too lengthy video), we developed a follow-up questionnaire, and distributed this via offline and online snowball sampling. In total, this questionnaire was completed by 248 Turkish- and 234 Moroccan-Dutch women. During analyses, we used the Confidence-Interval Based Estimation of Relevance (CIBER) approach to select the most relevant determinants of IDM, and inform the focus of the video (22). As a result, we identified four relevant determinants, i.e. beliefs about (1) preventing treatment or surgery, (2) reducing the chance of dying from CC, (3) shame regarding the cervical smear test performed by the general practitioner, and (4) privacy regarding the smear test. Based on the findings of this formative research, we developed a briefing document in close collaboration with the video producer. This document contained information on the background, target groups, objectives, planning, organisation, format, themes, and final delivery.

Thereafter, an EE team was formed, consisting of representatives of the targeted audiences, the health communication field, and the media field. In the end, the team consisted of eight Turkish- and Moroccan-Dutch women (who later figured as the main characters in the videos), a health communication expert, three cancer screening and public health experts (with Turkish and Moroccan cultural and linguistic backgrounds), and a video producer and -director (both with a Moroccan cultural and linguistic background).

We developed the video in three languages, namely Turkish, Moroccan-Arabic, and -Berber (all with Dutch subtitles). Depending on the age, educational level, and migration generation, Moroccans in the Netherlands generally speak Dutch, Moroccan-Arabic, and/or -Berber. Since Berber languages are for them solely speaking languages, Moroccan-Berber women with a limited command of the Dutch language will have difficulties with reading the Dutch information brochure. They will, however, be able to watch the Moroccan-Berber video. The same holds for Moroccan women who speak solely Moroccan-Arabic and Turkish women; they are able to watch the Moroccan-Arabic and Turkish video, respectively.

## Results

### Design/Production

We identified four relevant determinants, and decided to choose for three main themes, since shame and privacy (i.e. determinant 3 and 4) could easily be discussed in the video jointly. As a result, the short video emphasised the following themes: (1) "more certainty about having cervical (pre)cancer, and the possibility to prevent treatment, surgery, or premature death, and because of this, being there for the children", (2) "according to the Islam, a woman should take good care of her health", and (3) "anxiety, shame, and privacy". To facilitate IDM, it was important to ensure balanced content in terms of potential benefits and adverse effects of CC screening. We also wanted to emphasise the ease and reliability of self-sampling, as since 2017, women are able to participate in CC screening by collecting a sample by themselves (i.e. self-sampling). As many women indicated not having heard of self-sampling before (3), the possibility of self-sampling was introduced in the video.

Thereafter, we incorporated two main themes regarding self-sampling. The first theme was "it is easy and not painful to perform self-sampling". This was incorporated in the script: *"I also did it [self-sampling] at home. It was so easy. It was done in a heartbeat."* The second theme was "trust in oneself to correctly perform self-sampling, and trust in the test result". This was illustrated in the script by one of the actresses saying: *"Did you know that you can also request a self-sampling kit? Then you can do it at home without someone else being around. The doctor told me that it's just as reliable as the*

*one performed by the doctor.*". In Supplementary Table S7.1, examples of quotes from the video can be found for each theme.

Because of the respective age range of 30–60 years, we decided to cast three semi-professional actresses aged 30, 40, and 50 years approximately. We chose to work with semi-professional actresses to facilitate a natural look and feel of the video, and also due to our time frame and budget. The youngest actress (aged approximately 30 years) would be the doubting character: the one who was not sure what to decide, since she received the invite to participate in CC screening for the first time. The oldest actress (aged approximately 50 years) would represent the positive role model; she is the most experienced one, as she already participated in CC screening a couple of times. The actress aged approximately 40 years would represent the negative role model.

Since nonparticipation can also be an outcome of an informed decision, we decided that the video would end with the character in doubt saying that she will search for more information to make her decision. The goal of the short video is to stimulate women to make an informed decision, by searching for information, or talking about the subject with others or the general practitioner. The pay-off, therefore, included *"Get well informed. Talk about it with a friend or call your general practitioner. Would you like to know more? Go to..."*.

We instructed the actresses to act as close friends with whom you can discuss this (intimate) subject, since we know that close friends can act as emotional support in stimulating someone to take the last steps in going to the general practitioner when the CC screening procedure is regarded as scary (3). Close friends can also give verbal support when women lack a good command of the Dutch language, and are not able to make an appointment (3). In addition, we chose to film the video in a hair salon of one of the friends after closing time, as the EE team thought that these kinds of subjects may then be discussed (in a safe environment) with only women. It is also possible to talk about other subjects (e.g. hair) in between to make it entertaining, and less formal and educational.

After having multiple brainstorming sessions with the EE team and the research team to share professional knowledge as input for the video script, we started the production. Because of the different languages, we worked with three different main characters per video. One of the main characters was a Moroccan woman who spoke both Moroccan-Arabic and -Berber, and played a main character in both the Moroccan-Arabic and -Berber versions of the video. Each team of actresses had two sessions prior to the shooting day with a health communication professional, and two creative media professionals to get familiar with the Dutch script. During the first session, we discussed the goal of the video, how they were expected to interact

with each other, how to translate some words used in the script, and what they were expected to wear during the shooting day (i.e. no or neutral make-up, and neutral and matching colours of their clothing). At the end of this first session, we asked the three teams of actresses to practise and rehearse with each other, and play out the script during the second session. During this second session, the two Moroccan teams performed the storyline very well, and were given only small additional comments for the shooting day. Unfortunately, the Turkish team had insufficient preparation time due to illness in the team and scheduling difficulties, and proved to be not well adjusted to each other during the performance. They were, therefore, asked to meet (virtually) again to get familiar with the script, and practice the lines and interactions with each other. To help the team do this, one of the creative media professionals offered to be present during this practice session for guidance and support.

Unfortunately, because of lockdown measures to control the COVID-19 pandemic, the initially planned shooting days (March 2020) were cancelled. After these measures were lifted, we held two days of shooting under strict restrictions in June 2020 (see Figures 7.2 and 7.3). These restrictions included a maximum of 10 persons at the filming location, as few movements of the actresses as possible, social distancing (i.e. maintaining a distance of 1.5 metres) between all persons at the filming location (the hairdresser and the client were exempted, since contact-based professions were allowed again), and, although not nationally compulsory, face masks covering the nose and mouth had to be worn by all persons at the filming location (actresses were exempted). Additionally, general hygiene measures had to be taken into account (e.g. regularly and thoroughly washing hands, avoiding touching eyes, nose, and mouth, covering mouth and nose with the bent elbow when coughing or sneezing, and cleaning and disinfecting surfaces frequently).



Figure 7.2. Shooting day 1: Moroccan-Arabic group



Figure 7.3. Shooting day 2: Turkish group

After the production and before the final editing, we invited a convenience sample of Turkish- and Moroccan-Dutch women to watch the raw footage to verify whether the content and presentation matched their needs and requirements. Meetings were also organised with various experts on CC, health communication, public health, and Turkish and Moroccan languages/culture (e.g. gynaecologist, general practitioner, psychologist, cancer screening programme expert, health communication experts, public health experts, and key community informants) to provide feedback. We asked them for detailed comments and suggestions on its content and presentation, and to assess its understandability and cultural appropriateness. Although their feedback was overall positive, the following changes were suggested: (1) to add culturally appropriate background music, (2) to add certain shots, delete redundant information, shorten the video (e.g. the first shot of the hair salon), or replace certain shots (e.g. when one of the jokes did not work out), (3) to speed up the Turkish conversation in the editing, and (4) to use voice records in the pay-off of the video.

After three editing rounds, three short videos (of 3-4 minutes) were delivered in July 2020. Each can be found through <https://youtu.be/e8m3vz7OHzo> (Turkish), <https://youtu.be/QMWwWc4gS4o> (Moroccan-Arabic), and <https://youtu.be/VP8Gl2Na4nl> (Moroccan-Berber). An overall making-of video (in Dutch) can be found via <https://youtu.be/uwq1yhRmKV4>.



## Implementation

We studied the video's effectiveness on the women's IDM through a two-arm randomised controlled trial (RCT) (see the Netherlands Trial Register, nr NL8453). In this trial, respondents either received the current Dutch information brochure (that is normally sent to their home addresses every five years, and can be considered 'usual care') (control condition), or this brochure combined with our short video (intervention condition). We were particularly interested to find out whether a combination of an information brochure (informative approach) and a video (affective approach) would better support IDM regarding CC screening participation among Turkish- and Moroccan-Dutch women. The report including the results of this trial is in preparation.

All respondents were asked several questions on socio-demographic characteristics and IDM prior to accessing one of the conditions through our online questionnaire software. Afterwards, respondents in the intervention arm were asked to study the brochure that was visualised using an image per page. The 20 images could be studied through a 'slider' on our questionnaire webpage. Thereafter, Moroccan women could indicate which language they preferred; Moroccan-Arabic or -Berber. By clicking 'Next', a YouTube video in the preferred language could be played (and if preferred, a full-screen viewing modus could be chosen). Respondents in the intervention arm were also asked what they thought about this video. Overall, most women (both Turkish and Moroccan) scored the video as entertaining, informative, clear, and good. Some Turkish respondents found the video offensive to women wearing headscarves:

*"The video is so offensive to women wearing headscarves. [In the video] the women with headscarves are ignorant, and the western-looking [without wearing a headscarf] woman will help them get rid of that ignorance."* and *"The framing where the woman without a headscarf explains everything to the young ignorant women with headscarves is biased and derogatory."*

## Dissemination

After the end of the trial, the three short culturally sensitive educational videos were made publicly available on the website of the National Institute for Public Health and the Environment: <https://www.rivm.nl/bevolkingsonderzoek-baar-moederhalskanker/videos-marokkaans-turks>. Currently, the invitation letter that is sent to women aged 30 to 60 years includes a hyperlink that refers to all additional information materials including these videos.

The videos have also been distributed via the Dutch expertise centre called Pharos. Pharos has ample experience with adapting and disseminating health-promoting materials among immigrants in the Netherlands. The videos can be found on the Pharos

website: <https://www.pharos.nl/kennisbank/filmpjes-over-bevolkingsonderzoek-naar-baar-moederhalskanker-voor-en-door-marokkaans-nederlandse-en-turks-nederlandse-vrouwen/>, and the website for general practitioners that Pharos hosts together with the Dutch college of general practitioners: <https://www.huisarts-migrant.nl/filmpjes-over-bevolkingsonderzoek-naar-baar-moederhalskanker-voor-en-door-marokkaans-nederlandse-en-turks-nederlandse-vrouwen/>.

## Discussion

In this article, we describe the development of a short culturally sensitive educational video for Turkish and Moroccan women in the Netherlands. This video (affective approach) together with the current Dutch information brochure (informative approach) aims to facilitate informed CC screening decisions among Turkish- and Moroccan-Dutch women. In agreement with earlier calls for full disclosure of intervention development and content (23), this article provides an overview of the development process and the content that was produced. Other similar video productions and studies may learn from our systematic approach and our lessons learned when developing health-related videos for immigrant populations.

Our participatory EE strategy using the Media Mapping model provides a framework that is both grounded in theory and practice, and involved both members of the intended audiences and various experts. Both the EE strategy and the Media Mapping model proved to be valuable tools to guide the development of a short culturally sensitive educational video. We, therefore, recommend designing and developing such an intervention in a systematic manner (using for example the Media Mapping model) with an interdisciplinary team of members of the targeted audiences, researchers, public health experts, and creative media professionals to ensure the quality and cultural appropriateness of such an intervention.

During this intervention development process, we have learned a few important lessons.

First, although Turkish- and Moroccan-Dutch women were closely involved in the development process, comments were made by a few Turkish respondents about specific role models wearing a headscarf or not. In the Turkish video, there was one woman who did not wear a headscarf (in real life), and she was coincidentally the positive role model with the most CC screening experience and knowledge. We based the distribution of the role models solely on the actresses' age. We used age as an indicator for the number of times invited for screening, and thus, the number of times that a decision had to be made. The more times invited, the more a woman may have read, talked, or thought about or have experiences with the screening. In the future, next to age, one's physical appearance (e.g. wearing a headscarf or not) should be thoroughly considered when assigning role models, to minimize stereotyping

as much as possible. It is important to note, however, that it is very challenging to develop a single video tailored to the needs of a diverse range of individuals (e.g. young/old, first/second generation, with a low/high educational level). Having said this, efforts should be made to ensure content and image appropriateness for the majority of the targeted audience.

Second, and in line with the previous lesson, due to costs, we could only develop a single video (in three different languages), while a broad age range of 30-60 years might require multiple videos, as women in this age group differ greatly in sociodemographic characteristics, such as Dutch language proficiency, educational level, and migration generation. During our previous studies in this project (on which we based the content of the video), we included mostly first-generation immigrant women aged 46-60 years with a low or medium educational level that came together at community venues (3). As a result, the themes in the video may be more directed to these women, and may not address the majority of Turkish- and Moroccan-Dutch women between 30 and 60 years old. In line with this, some Moroccan respondents mentioned that the video seems to be directed at those not able to understand the Dutch language. We expect that our randomised controlled trial can reveal whether or not the effect of the video differs for several subgroups.

Third, because of our affective approach, the idea was to portray the characters in the video as close friends who talk about intimate matters, and give each other advice and emotional support. Because of the COVID-19 related restrictions during the shooting days, the three actresses were, however, not able to act as close friends. The actresses could not sit close to each other, and could not touch, hug, or kiss each other. We think that this explains why some of the respondents could not imagine that such a conversation would take place in real life. They might have looked like three random strangers, which makes it indeed unlikely that they would discuss such an (intimate) subject with each other.

Fourth, the acting skills in the Turkish video had a lower quality than in the Moroccan video, caused by insufficient preparation time to feel comfortable acting with each other, as we already observed during our second session with the actresses prior to the shooting day. Although we kindly asked the Turkish actresses after the second session to put in more time and effort to get a smooth storyline on the shooting day, it remained difficult for them to remember the lines and act naturally. A great advantage in the Moroccan teams of actresses was that they already knew each other (and some were even actual close friends). We, therefore, advise allowing for sufficient time to practise acting with each other, especially if actresses do not already know each other.

Furthermore, differences in work culture, expectations, and the way of thinking between representatives of the health communication field and the media field can result in misunderstandings and challenges to combine and balance entertainment and education. To avoid misunderstandings, we invited all team members to articulate their ideas and views, and explain their importance and relevance for the final product. As both fields (i.e. health communication and media) are responsible for a balanced mixture of entertainment and education, we made agreements on the roles and responsibilities of both fields, in each stage of the development process. We invested time to create mutual understanding and to reach consensus about the final product's form, content, and presentation.

Finally, the approved original script may change due to technical or practical production matters (e.g. COVID-19 related restrictions), casting, and costs. As an example, due to the restrictions on the filming location, we were not able to visualise a safe nor homely environment in which close friends discuss intimate subjects, such as cancer and the smear test performed by the general practitioner. Time to prepare the shooting days was also limited, since we had to wait for COVID-19 related measures to be lifted and quickly plan the shooting days due to the upcoming summer break and other upcoming film projects of the video producer. Such adjustments need to be discussed, agreed upon, and made during the ongoing production process, keeping in mind that, in culturally sensitive educational videos, alterations might have a stronger effect on the impact, than in written, factual information provision.

## Conclusions

A short culturally sensitive educational video, delivered as part of a larger intervention together with the current information brochure, was developed based on theory and grounded in the needs of Turkish- and Moroccan-Dutch women. The value and effectiveness of this intervention to facilitate informed CC screening decisions have yet to be evaluated in a RCT. These results will be used to improve future information materials in the Dutch CC screening programme, coordinated by the Dutch National Institute for Public Health and the Environment.



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**Supplementary Table S7.1. Corresponding quotes per theme, included in our developed short video**

Theme	Examples of corresponding quotes in the video
More certainty about having cervical (pre)cancer and the possibility to prevent treatment, surgery, or premature death, and because of this, being there for the children	<i>"I think it's wise to participate in screening. Prevention is better than cure, right? It's a small effort and you can save yourself a lot of misery."</i> <i>"Well, what do you prefer? Finding out that you are sick to get treated? Or to eventually (Allah may forbid) leave Salma [her daughter] all by herself?"</i>
According to the Islam, a woman should take good care of her health	<i>"Everybody should know for themselves, but Allah does urge you to take good care of your health."</i>
Anxiety, shame, and privacy	<i>"Well, I am not spreading my legs for a man, not even for a doctor. That's so embarrassing. I have also heard that it [sampling procedure] hurts."</i>
It is easy and not painful to perform self-sampling	<i>"I also did it [self-sampling] at home. It was so easy. It was done in a heartbeat."</i>
Trust in oneself to correctly perform self-sampling and trust in the test result	<i>"Did you know that you can also request a self-sampling kit? Then you can do it at home without someone else being around. The doctor told me that it's just as reliable as the one performed by the doctor."</i>



# 8

## Evaluation of a culturally sensitive educational video to facilitate informed cervical cancer screening decisions among Turkish- and Moroccan-Dutch women: A randomised intervention study

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*Submitted for publication.*

## Abstract

### Background

In the Netherlands, especially Turkish- and Moroccan-Dutch women show low cervical cancer (CC) screening participation and limited informed decision-making (IDM) in this regard. To meet the needs of these women, a Culturally Sensitive Educational Video (CSEV) was developed. The objective was to evaluate the effect of the CSEV on IDM regarding CC screening participation among Turkish and Moroccan women aged 30-60 years in the Netherlands.

### Methods

Initial respondents were recruited via several social media platforms and invited to complete an online questionnaire. Following respondent-driven sampling, respondents were asked to recruit a number of peers from their social network to complete the same questionnaire. Respondents were randomly assigned to the control (current information brochure), or intervention condition (brochure and CSEV). We evaluated the added effect of the CSEV on knowledge, attitude, intention, and IDM using intention-to-treat analyses.

### Findings

The final sample included 686 Turkish- and 878 Moroccan-Dutch women. Among Turkish-Dutch women, 33.1% of the control respondents and 40.5% of the intervention respondents consulted the brochure (not statistically significant). Among Moroccan-Dutch women, these percentages were 28.2% and 37.9%, respectively ( $p = 0.0028$ ). Of all intervention respondents, 96.1% (Turkish) and 84.4% (Moroccan) consulted the CSEV. The CSEV resulted in more positive screening attitudes among Moroccan-Dutch women, in comparison to the brochure (74.3% versus 68.4%,  $p = 0.065$ ).

### Interpretation

Our short, easily implementable CSEV resulted in more positive screening attitudes in Turkish- and Moroccan-Dutch women, and can thus contribute to informed CC screening decisions.

## Introduction

Cervical cancer (CC) is ranked as the fourth most frequently diagnosed cancer in women worldwide (1). After the introduction of widespread screening programmes, there has been a decline of early- and late-stage CC (2).

In the Netherlands, since 1996, a national CC screening programme has been implemented for women aged 30 to 60 years. Regional screening organisations send an invitation letter and information brochure in Dutch, to the home addresses of targeted women every five years. Screening is free of charge and is carried out by the general practitioner (GP) or his/her practice assistant, who samples a cervical smear (i.e. clinician-based sampling). The smear is initially tested on the presence of the Human Papilloma Virus (hrHPV), a risk factor for developing CC (3). If hrHPV is present, cervical cells in the smear are assessed for abnormal or precancerous lesions. An important advantage of HPV-based screening is that it can also be done by self-sampling. If this self-sample tests positive for hrHPV, a cervical smear for cytological examination is sampled at the GP.

From the perspective of the individual, deciding to participate in screening involves careful consideration between uncertain benefits and risks of adverse effects. This consideration is pivotal in informed decision-making (IDM): the process in which individuals base their decision on making optimal use of information and weighing all aspects involved. IDM is only possible when a woman has adequate decision-relevant knowledge and her attitude towards participating is consistent with her (intended) (non)participation (4).

In the Netherlands, especially Turkish- and Moroccan-Dutch women, representing the largest immigrant populations, show low screening participation and limited IDM regarding participation (5, 6). Earlier research indicated an overall lack of knowledge and nonfamiliarity with the possible disadvantages of CC screening (5).

In decision-making, Turkish- and Moroccan-Dutch women not only take factual medical information into account, but also consider practical, emotional, cultural, and religious aspects prior to deciding to screen or not (5). However, the current invitation letter and information brochure contain predominantly factual medical information. Turkish- and Moroccan-Dutch women often indicated to not (thoroughly) read the invitation letter and brochure, or simply being unable to understand these materials due to a lack of a good command of the Dutch language (5). These women were also shown to make less use of printed media and more of audio-visual media (7). As a Culturally Competent Educational Film, developed with peer educators, was successful in improving IDM for prenatal screening among pregnant ethnic minority women, we considered this beneficial for IDM in CC screening participation as well.



(8). Thus, we developed a Culturally Sensitive Educational Video (CSEV) incorporating more effective information and distributed it via respondent-driven sampling (RDS).

In this study, we evaluated the effect of this CSEV on IDM regarding CC screening participation among Turkish- and Moroccan-Dutch women. We hypothesised that adding a CSEV to the current Dutch information brochure would increase the IDM on participation in CC screening of these women.

## Methods

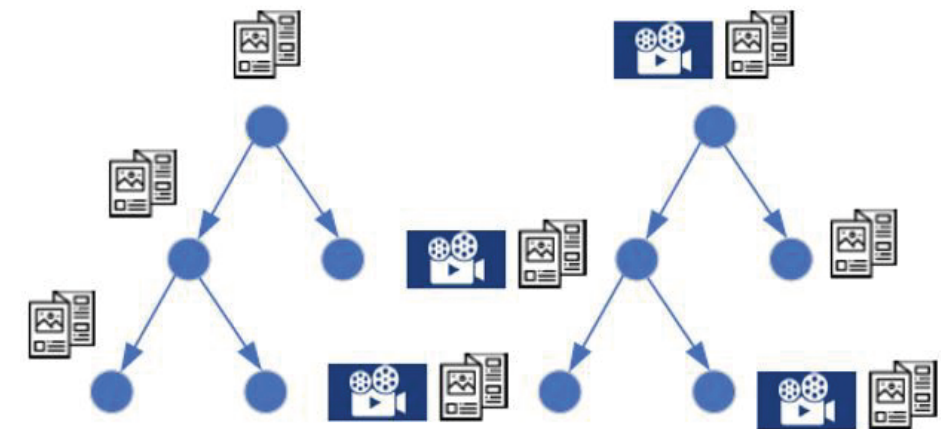
### Study design

Between 23 November 2020 and 6 August 2021, a randomised intervention study was conducted with a control and an intervention group. We used web-based respondent-driven sampling (RDS) to recruit Turkish- and Moroccan-Dutch women, as previous attempts learned that traditional random sampling methods were not effective to reach these populations effectively (9). Their close-knit social networks also enable respondents to easily recruit each other (10). The reporting of this study adheres to the CONSolidated Standards Of Reporting Trials (CONSORT) guideline.

### Randomisation and masking

Respondents were asked to complete an online questionnaire, in which questions on IDM were asked before and after the control or intervention condition. The control group was asked to read the information brochure regarding the screening programme that is currently sent with the screening invitation. The intervention group was asked to read the same brochure and watch the CSEV. This request was shown on one webpage. By clicking 'Next', they first received the brochure, and subsequently on the next page, the CSEV was displayed.

RDS starts with a convenience, ideally diverse, sample of members of the population, which are called seeds (11). Seeds are asked to complete a questionnaire and to recruit a number of their peers to complete the same questionnaire. Successfully recruited peers are then also asked to recruit a number of peers. This recruitment was continued until the calculated sample size was reached. Unique tokens were used to follow who recruited whom and draw recruitment trees. Each new respondent was randomly assigned to either the control or intervention condition (i.e. individual level randomisation) (see Figure 8.1).



**Figure 8.1. Study design: respondent-driven sampling where each new respondent was randomly assigned to either the control or intervention condition**

### Study population and recruitment

Inclusion criteria for respondents were: 1) women being 30 to 60 years old, and 2) being born in Turkey or Morocco, and having at least one parent born in Turkey or Morocco (first-generation immigrants), or being born in the Netherlands, and having at least one parent born in Turkey or Morocco (second-generation immigrants), and 3) living in the Netherlands.

Seeds were recruited via several social media platforms, such as (1) public and private women's groups on Facebook, (2) the LinkedIn pages of the involved researchers, (3) the foundation called the Association Moroccan Doctors Netherlands (AMAN), and (4) the participating video producer Zouka Media. We also (5) contacted several influencers on Instagram with many Turkish- and/or Moroccan-Dutch female followers and asked them to share the questionnaire via their story or bio. Throughout the study, we used paper- and web-based flyers and an online infographic to promote and share the link to the questionnaire. The flyers and infographic were spread among offline community organisations, foundations, and mosques, as well as online platforms, such as LinkedIn and Facebook.

After completion of the questionnaire, respondents were asked to invite - through WhatsApp, e-mail, platforms as Instagram, and/or SMS - a maximum of 20 women from their social network to complete the same questionnaire. In case of e-mail, reminders were sent to complete and/or forward the questionnaire, and to encourage respondents to remind their peers to complete the questionnaire (after one week of no participation of at least one peer). To prevent respondents potentially influencing each other's answers, respondents were explicitly requested not to discuss their answers or watch the CSEV with others. Initially, an incentive of 10 EUR was awarded



to every respondent that completed the questionnaire herself and peer-recruited two other women that also completed the questionnaire. From 3 March 2021, to further stimulate peer recruitment, an incentive of 15 EUR was awarded to every respondent that completed the questionnaire herself and peer-recruited one other woman that also completed the questionnaire.

### Questionnaire

We developed a questionnaire for measuring informed decision-making (IDM) based on the Rational Decision Model, that supposes that decision-making is based on a proper understanding of the potential benefits and adverse effects of cancer screening (decision-relevant knowledge) in the context of their personal situation and preferences (attitude) (12). The questionnaire contained 52 questions regarding socio-demographic characteristics, previous CC screening participation, knowledge regarding CC screening, attitude towards CC screening, and intention to participate in the next CC screening round. Questions regarding knowledge, attitude, and intention were asked for clinician-based sampling, whereas for self-sampling, we included questions on awareness, perceptions, and intention. The rationale for this difference was that the self-sampling method was only introduced in 2017, which means that not every woman is aware of its existence. Therefore, instead of assessing knowledge and attitude, we questioned their awareness and perceptions on self-sampling. Knowledge regarding CC screening was measured using three questions about the subsequent steps following a test result and the possibility of false-positive test results, with a score ranging from zero to four. Attitude towards CC screening was measured using ten questions, with a score ranging from zero to ten. These scores were transformed to zero to 100 scores to facilitate interpretation, following an earlier study of Korfage et al (13). In agreement with Van den Berg et al. (14) and Korfage et al. (13), we classified scores in the range of 45 to 55 as a neutral attitude. Scores below 45 were classified as a negative attitude, and scores above 55 as a positive attitude. Intention was measured by asking respondents whether they intended to participate in the next CC screening round. All questions regarding attitude and intention had three response options, namely 'Yes', 'I do not know', and 'No'.

Following earlier research, we combined knowledge, attitude, and intention to calculate IDM (yes/no) (4, 8). An informed decision was defined as having adequate knowledge (total score  $\geq 3.0$ ), either a positive attitude (total score  $> 55.0$ ), and a positive intention, or a negative attitude (total score  $< 45.0$ ), and a negative intention. All other combinations were defined as an uninformed decision.

The questionnaire was made available in Dutch, Turkish, and Moroccan-Arabic. Since first-generation Turkish- and Moroccan-Dutch immigrants have low reading abilities, audio recordings in Dutch, Turkish, Moroccan-Arabic, and Moroccan-Berber

(a spoken language) were available. To ensure understandability, the questionnaire was extensively pre-tested among low-literate Turkish- and Moroccan-Dutch women.

### Culturally Sensitive Educational Videos

We developed three Culturally Sensitive Educational Videos (CSEVs) in collaboration with the video producer, and eight Turkish- and Moroccan-Dutch peer educators and actresses. Since all respondents received the brochure containing cognitive information on CC screening, we focused the video on affective information related to CC screening (i.e. experiences and fears). Turkish- and Moroccan-Dutch women especially need information on practical, emotional, cultural, and religious aspects of CC screening (5). Therefore, the CSEVs emphasised three themes regarding clinician-based sampling, and ensured balanced content in terms of possible benefits and adverse effects. The themes included "more assurance regarding health and the ability to prevent treatment, surgery, or death, and because of this, being there for their children", "according to the Islam, a woman should take good care of her health", and "anxiety, shame, and privacy". For self-sampling, two themes were included, namely "it is easy and not painful to perform self-sampling" and "trust in themselves to correctly perform self-sampling and trust in the test result". The CSEV was available in Turkish, Moroccan-Arabic, and Moroccan-Berber (all with Dutch subtitles). Moroccan-Dutch respondents could choose between a Moroccan-Arabic-spoken or Moroccan-Berber-spoken video.

To verify whether the CSEVs were understandable and culturally appropriate, online discussions were held between experts on language, communication, culture, and CC (screening). The CSEVs were also pilot tested in a small sample of Turkish- and Moroccan-Dutch women to verify whether the feasibility, content, and lay-out matched their needs and requirements. Through automatic registration by the questionnaire software, we measured whether and how long respondents consulted the brochure (in both the control and intervention group), and whether the intervention group actually watched the CSEV.

All CSEVs are available via <https://www.rivm.nl/bevolkingsonderzoek-baar-moederhalskanker/videos-marokkaans-turks>. Further details about the development and tailoring of the CSEVs will be reported elsewhere.

### Sample size calculation

We used a two-sided test and assumed a binomial distribution, a 95% confidence interval, 80% power, and an absolute change of 10% in IDM. Therefore, 776 Turkish- and 794 Moroccan-Dutch women (in total; both the control and intervention group) were needed. This absolute change of 10% in IDM was based on a previously reported increase of 11% in IDM regarding prenatal screening among pregnant ethnic minority women in the Netherlands due to a developed CSEV (8).

### Statistical analysis

The flow of inclusion of respondents was visualised. Possible insincere respondents (i.e. those that probably participated for many incentives only) were excluded from the data, and were not eligible for an incentive, whenever one of the following criteria was met: (1) the respondent *and* her recruitee completed the questionnaire in less than five minutes, or (2) the respondent *or* her recruitee completed the questionnaire in less than five minutes, *and* there was less than five minutes between the start of the two participations. Respondents who indicated no migration background, another migration background than Turkish/Moroccan, or did not indicate their country of birth and/or those of their parent(s), and those aged younger than 30 or older than 60 were also excluded.

Descriptive statistics were used to provide an overview of the sample characteristics and the proportion of respondents who viewed the brochure and the CSEV. To analyse the potential additional effect of the CSEV compared to that of the brochure only, we conducted intention-to-treat (ITT) analyses (16). We assessed the differences in knowledge (or awareness in case of self-sampling), attitude (or perceptions in case of self-sampling), intention, and IDM (only for clinician-based sampling) between the control and intervention group after the control or intervention condition using Chi-square tests or Fisher's exact tests.

As a post-hoc analysis, we explored the open-field comments stated by respondents at the end of our questionnaire, to explain differences found between Turkish- and Moroccan-Dutch women. A two-sided p-value smaller than 0.05 was considered statistically significant. All analyses were performed in the statistical software R, version 4.0.2.

### Ethical considerations

After the Medical Ethics Review Committee of the University Medical Centre Utrecht confirmed that the Medical Research Involving Human Subjects Act does not apply to this study (nr: 20/105), we registered the trial at the Netherlands Trial Register (nr: NL8453). Respondents were informed about the study (but did not know there was a control and an intervention group), and asked to give their digital informed consent.

### Role of the funding source

The funder of this study had no role in the study design, data collection, data analysis, data interpretation, or writing of the report.

## Results

### Flow of the inclusion of respondents

Of the 2948 respondents that started the questionnaire, 1931 (65.5%) completed it (see Figure 8.2). After excluding 367 respondents (19.0%), 686 Turkish- and 878 Moroccan-Dutch women were included for analysis: 793 in the control group (350 Turkish and 443 Moroccan), and 771 in the intervention group (336 Turkish and 435 Moroccan).

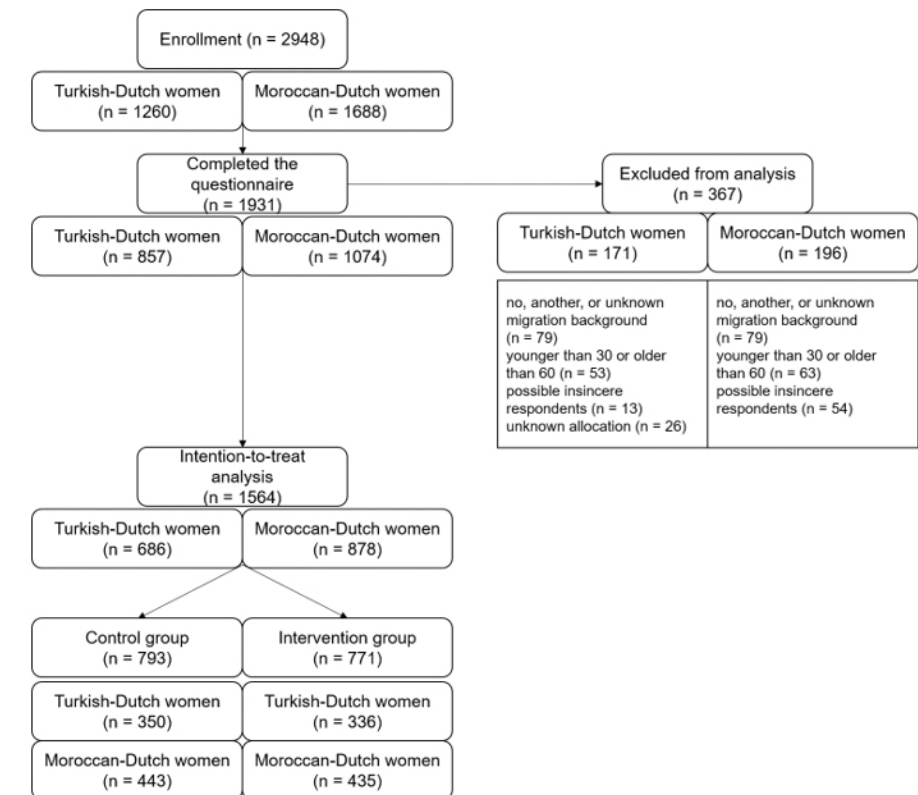


Figure 8.2. Flow diagram of the recruitment and response of respondents

### Sample characteristics

The final sample consisted of 686 Turkish- and 878 Moroccan-Dutch women (see Table 8.1). The majority in both groups was aged between 30 and 39 years, highly educated (43.0% and 51.7%, respectively), and 7.7% and 12.0% had respectively no official or primary education. Of Turkish women 59.9% and of Moroccan 56.4% were second-generation immigrant. The online social network (i.e. other Turkish- or Moroccan-Dutch women aged 30-60 years) was for the majority between 11 to 49, and nearly 3% had no online social network.

In total, 40.1% (Turkish) and 36.4% (Moroccan) indicated to have never participated in CC screening, 44.5% (Turkish) and 49.3% (Moroccan) reported to participate every five years in CC screening, and 15.5% (Turkish) and 14.2% (Moroccan) participated irregularly. Respondents represented a wide geographic area across the Netherlands (see Supplementary Figures S8.1a and S8.1b).

Among Turkish-Dutch women, 33.1% of the control respondents and 40.5% of the intervention respondents viewed the brochure (not statistically significant). Of the intervention respondents, 96.1% viewed the CSEV. Among Moroccan-Dutch women, 28.2% of the control respondents and 37.9% of the intervention respondents viewed the brochure ( $p = 0.0028$ ). Of the intervention respondents, 84.4% viewed the CSEV.

### Knowledge of CC screening

Turkish-Dutch respondents with sufficient knowledge of CC screening increased from 54.6% to 68.3% in the control group (+ 13.7% absolute change) ( $p = 0.00026$ ), and from 49.1% to 63.7% in the intervention group (+ 14.6%) ( $p = 0.00019$ ). Moroccan-Dutch respondents with sufficient knowledge increased from 61.4% to 78.8% in the control group (+ 17.4%) ( $p < 0.0001$ ), and from 65.7% to 77.5% in the intervention group (+ 11.8%) ( $p = 0.00017$ ). In terms of knowledge, the CSEV did not show a significant effect above the information brochure for both groups (see Supplementary Tables S8.1a and S8.1b).

### Attitude towards CC screening

Turkish-Dutch respondents with a positive attitude towards CC screening decreased from 70.0% to 67.1% in the control group (- 2.9%) (not statistically significant), and from 66.7% to 66.4% in the intervention group (- 0.3%) (not statistically significant). Moroccan-Dutch respondents with a positive attitude increased from 64.6% to 68.4% in the control group (+ 3.8%) (not statistically significant), and from 65.1% to 74.3% in the intervention group (+ 9.2%) ( $p = 0.00403$ ). Overall, there was no added effect of the CSEV on the attitude towards CC screening among Turkish-Dutch women ( $p = 0.89$ ) (see Supplementary Table S8.2a). We found that Moroccan-Dutch women in the intervention group had more often a positive attitude towards CC screening compared to the control group, although this difference was not statistically significant ( $p = 0.065$ ) (see Supplementary Table S8.2b). Moroccan-Dutch women in the intervention group who had never participated in CC screening had significantly more often a positive attitude towards CC screening, compared to the control group ( $p = 0.012$ ).

**Table 8.1. Sample characteristics of Turkish- and Moroccan-Dutch respondents**

Characteristic	Turkish N = 686	National data proportions (Turkish) 17-19	Moroccan N = 878	National data proportions (Moroccan) 17-19
<b>Age (years)</b>				
30 - 39	418 (60.9%)	36%	455 (51.8%)	40%
40 - 49	189 (27.6%)	37%	328 (37.4%)	37%
50 - 60	92 (13.4%)	27%	95 (10.8%)	23%
Missing value	0 (0%)		0 (0%)	
<b>Educational level</b>				
No official education, or primary school	82 (12.0%)	44%*	68 (7.7%)	43%*
Secondary school	110 (16.0%)	33%	136 (15.5%)	39%
Vocational education	198 (28.9%)	23%	219 (24.9%)	18%
Higher education	295 (43.0%)		454 (51.7%)	
Missing value	1 (0.1%)		1 (0.1%)	
<b>Generation</b>				
First	275 (40.1%)	72%	383 (43.6%)	73%
Second	411 (59.9%)	28%	495 (56.4%)	27%
Missing value	0 (0%)		0 (0%)	
<b>Size of their online social network</b>				
0	17 (2.5%)	NA	24 (2.7%)	NA
1 - 10	180 (26.2%)		160 (18.2%)	
11 - 49	273 (39.8%)		412 (46.9%)	
50 - 99	96 (14.0%)		157 (17.9%)	
100 - 249	74 (10.8%)		91 (10.4%)	
250 - 499	33 (4.8%)		29 (3.3%)	
≥ 500	13 (1.9%)		5 (0.6%)	
Missing value	0 (0%)		0 (0%)	
<b>Language questionnaire completion</b>				
Dutch	432 (63.0%)	NA	758 (86.3%)	NA
Turkish/Arabic	234 (34.1%)		2 (0.2%)	
Missing value (due to technical failure)	20 (2.9%)		118 (13.4%)	

Table 8.1. Sample characteristics of Turkish- and Moroccan-Dutch respondents (continued)

Characteristic	Turkish N = 686	National data proportions (Turkish) 17-19	Moroccan N = 878	National data proportions (Moroccan) 17-19
Previous CC screening participation	Every five years	305 (44.5%)	433 (49.3%)	NA
	Not every five years	106 (15.5%)	125 (14.2%)	
	Never	275 (40.1%)	320 (36.4%)	
	Missing value	0 (0%)	0 (0%)	

CC: cervical cancer, NA: not applicable, \*includes no official education, primary school, and secondary school

Intention and informed decision-making regarding CC screening participation

Both the control and intervention group had more often a positive intention after consulting the brochure or the brochure and CSEV, in both Turkish- and Moroccan-Dutch women (see Table 8.2). An increase was observed among Turkish-Dutch women from 78.3% to 82.6% in control respondents (+ 4.3%) (not statistically significant), and from 79.2% to 84.5% in intervention respondents (+ 5.3%) (not statistically significant). The same holds for Moroccan-Dutch women: from 79.9% to 86.0% in control respondents (+ 6.1%) (p = 0.0202), and from 80.0% to 86.9% in intervention respondents (+ 6.9%) (p = 0.0082). However, the CSEV did not have a statistically significant added effect above the brochure in terms of intention.

Furthermore, more women made an informed decision after the corresponding condition in both the control and intervention group among Turkish- and Moroccan-Dutch women (see Table 8.2). Of the control respondents, IDM increased from 38.6% to 44.3% in Turkish-Dutch women (+ 5.7%) (not statistically significant), and from 43.8% to 53.7% in Moroccan-Dutch women (+ 9.9%) (p = 0.0039). The same holds for intervention respondents: we saw an increase of IDM from 34.5% to 42.9% in Turkish-Dutch women (+ 8.4%) (p = 0.032), and from 44.6% to 58.9% in Moroccan-Dutch women (+ 14.3%) (p < 0.0001). However, the CSEV did not have a statistically significant effect above the brochure in terms of IDM (see Tables 8.2 and 8.3).

Table 8.2. Intention and informed decision-making regarding CC screening participation in the control and intervention groups, before and after the brochure (control) or the brochure and CSEV (intervention)

Population		Turkish-Dutch women		Moroccan-Dutch women	
Characteristic		Control group	Intervention group	Control group	Intervention group
		N = 350	N = 336	N = 443	N = 435
Intention to participate in CC screening Before	Positive	274 (78.3%)	266 (79.2%)	354 (79.9%)	348 (80.0%)
	Neutral	60 (17.1%)	58 (17.3%)	65 (14.7%)	68 (15.6%)
	Negative	16 (4.6%)	12 (3.6%)	24 (5.4%)	19 (4.4%)
Intention to participate in CC screening After	Positive	289 (82.6%)	284 (84.5%)	381 (86.0%)	378 (86.9%)
	Neutral	48 (13.7%)	41 (12.2%)	45 (10.2%)	41 (9.4%)
	Negative	13 (3.7%)	11 (3.3%)	17 (3.8%)	16 (3.7%)
IDM before	Yes	135 (38.6%)	116 (34.5%)	194 (43.8%)	194 (44.6%)
	No	215 (61.4%)	220 (65.5%)	249 (56.2%)	241 (55.4%)
IDM after	Yes	155 (44.3%)	144 (42.9%)	238 (53.7%)	256 (58.9%)
	No	195 (55.7%)	192 (57.1%)	205 (46.3%)	179 (41.1%)

CC: cervical cancer, IDM: informed decision-making

Table 8.3. Informed decision-making regarding CC screening participation in the control and intervention groups, after the brochure (control) or the brochure and CSEV (intervention)

Population		Turkish-Dutch women		Moroccan-Dutch women	
Characteristic		Control group	Intervention group	Control group	Intervention group
		N = 350	N = 336	N = 443	N = 435
Age (years)	30 – 39	124 (35.4%)	112 (33.3%)	107 (24.2%)	89 (20.5%)
	40 – 49	47 (13.4%)	52 (15.5%)	72 (16.3%)	62 (14.3%)
	50 – 60	24 (6.9%)	28 (8.3%)	26 (5.9%)	28 (6.4%)
Educational level	No official education or primary school	23 (6.6%)	32 (9.5%)	18 (4.1%)	25 (5.7%)
	Secondary school	29 (8.3%)	39 (11.6%)	34 (7.7%)	25 (5.7%)
	Vocational education	62 (17.7%)	54 (16.1%)	54 (12.2%)	44 (10.1%)
	Higher education	80 (22.9%)	67 (19.9%)	99 (22.3%)	85 (19.5%)
Generation	First	74 (21.1%)	89 (26.5%)	96 (21.7%)	87 (20.0%)
	Second	121 (34.6%)	103 (30.7%)	109 (24.6%)	92 (21.1%)
Previous CC screening participation	Every five years	58 (16.6%)	71 (21.1%)	70 (15.8%)	56 (12.9%)
	Not every five years	37 (10.6%)	31 (9.2%)	26 (5.9%)	31 (7.1%)
	Never	100 (28.6%)	90 (26.8%)	109 (24.6%)	92 (21.1%)

CC: cervical cancer





### Self-sampling

There were no statistically significant differences found in awareness, perceptions, and intention regarding self-sampling when comparing the control and intervention group among Turkish-Dutch women (see Supplementary Table S8.4a).

More Moroccan-Dutch respondents thought that self-sampling is easy to perform in the intervention group compared to the control group (65.3% versus 56.9%,  $p = 0.038$ ). Additionally, fewer respondents in the intervention group thought that self-sampling would be painful, compared to the control group (13.6% versus 18.5%,  $p = 0.048$ ) (see Supplementary Table S8.4b).

### Discussion

This study evaluated the effect of a Culturally Sensitive Educational Video (CSEV) on knowledge, attitude, intention, and informed decision-making (IDM) regarding CC screening among Turkish- and Moroccan-Dutch women aged 30-60 years. The CSEV was watched far more often than the brochure when both were offered, and the intervention group who watched the video also studied the brochure more often than the control group. The brochure has a significant positive influence on IDM, while the CSEV has an added effect on the attitude towards CC screening in especially Moroccan-Dutch women. These women had more often a positive attitude towards CC screening compared to the control group with only the brochure. This was especially the case among women who had never participated in CC screening. Based on the open-field comments of Turkish-Dutch respondents, we think we can explain why this effect was not visible in this group. It appeared that some of the Turkish-Dutch respondents were offended by the fact that in the Turkish video the actress who played the negative screening attitude was wearing a headscarf.

### Comparison with previous research

In line with our results in the control group, a previous study among Dutch women invited for breast cancer screening also found that the brochure enhanced IDM (20). Earlier randomised controlled trials that strived to enhance IDM regarding cancer screening often developed a decision aid (DA), in which information was presented differently in comparison to the standard letter and/or brochure (21-25). These studies tend to target knowledge instead of attitudes that we aimed for. In line with our study, an earlier randomised controlled trial in Germany among all targeted women without a Turkish migration background also compared the standard information brochure for breast cancer screening with a newly developed DA (26). In contrast with our study, more intervention respondents were knowledgeable in comparison to the control group. This seems to be related to the fact that the same information was presented in both groups, but only visually instead of textually in the intervention group versus control group. We, on the other hand, did not include any factual medical information

in the CSEV and did not target the women's knowledge. In the United Kingdom, a similar intervention study regarding participation in lung cancer screening among smokers also used a video, and found that it improved knowledge and reduced decisional conflict (27). However, this video was also targeted at increasing knowledge instead of improving screening attitudes.

### Implications for practice and policy

We recommend to develop videos that incorporate information provided in the current brochure, as many Turkish- and Moroccan-Dutch women do not read the brochure (thoroughly) or are simply not able to read it (5). In line with this current study, a video has shown to be more engaging and attractive than textual information (28). Considering that about one third of the control group consulted the brochure, the effect of the brochure on IDM might be greater if the brochure was studied more often and in more detail. We expect that in the context of this study, respondents were more likely to read the brochure (intensively) than those who receive it with the invitation (i.e. the Hawthorne effect). Therefore, we recommend to present the CSEV to all women through the invitation letter, e.g. using a weblink or a QR code, so that the CSEV and all other online-provided materials can be accessed easily. We propose to consider using the CSEV in mosques, community centres, and educational meetings regarding (women's) health for those women with limited digital skills. Other options are to distribute the CSEV in women's groups on Facebook or to broadcast the CSEV on a loop in the waiting room at the GP's office.

Women are invited for CC screening every five years, and might not be interested to search for or gather information every time they are invited. Therefore, next to evaluating different modes of delivering visual information, we recommend to research the use of different distribution channels to reach uninformed women, such as was done in this present study, namely social media and involving influencers, key figures, informants, and close-knit community groups.

In October 2021, the Dutch Health Council recommended to offer self-sampling as an equivalent alternative to clinician-based sampling, and to send the self-sampling kit together with the invitation (29). Due to the CSEV, more Moroccan-Dutch respondents thought that self-sampling is easy to perform, and fewer respondents thought that self-sampling would be painful. Therefore, sending the self-sampling kit with the invitation should go hand in hand with implementing our CSEV. Overall, being a short intervention that is easily implemented, our CSEV represents an efficient way of enhancing screening attitudes and facilitating IDM among immigrant women.

### Strengths and limitations

One major strength of this study was its design as a randomised intervention study. Worldwide, this study also has one of the largest samples successfully recruited

using web-based RDS (30). Additionally, our CSEVs were systematically developed and based on extensive qualitative and quantitative research among Turkish- and Moroccan-Dutch women (5). The brochure that we used during our study is sent to all women aged 30-60 years by the regional screening organisations. This brochure is 'usual care', has been used in practice since November 2016, and openly discusses potential benefits and harms of CC screening. We, therefore, deliberately used the CSEV as an addition to the brochure to facilitate one's individual thinking process and/or discussion with other women, and not as a replacement intervention. Our CSEV can now easily be added to the existing invitation materials. More importantly, our CSEV includes other more affective aspects, which are not incorporated in the brochure, but are needed for Turkish- and Moroccan-Dutch women to be able to make a conscious decision on their CC screening participation (5).

However, a number of limitations should also be addressed.

First, due to the online delivery, we sampled more 30-39 year olds, those of second generation, and highly educated Turkish- and Moroccan-Dutch women, compared to the national dataset of 2020 of Statistics Netherlands (17-19). Still, the two randomised groups were comparable, and 12% and 8% of the Turkish- and Moroccan-Dutch respondents reported no official education or completed primary school, respectively. Also, regarding previous CC screening participation, we did find similar rates of at least one participation in CC screening of 60% and 64% of Turkish- and Moroccan-Dutch women versus 64% and 53%, respectively, in previous reports (6).

Second, the time elapsed between the previous screening invitation and the questionnaire administration, which varied largely among our respondents, might have impacted the experienced relevance of the decision-making questions and the previously existing knowledge. However, this heterogeneity is likely to play a similar role (if it does at all) in both the control and intervention group because of the performed randomisation.

Third, women participating in our study might have been different from those not participating. They could, for example, be more interested in CC screening as a topic, and thus be more informed about the screening than non-participating women. Nevertheless, since we used incentives for successful peer recruitment, this might also have been the reason for some respondents to participate in the study, rather than being interested in CC screening. In addition, this possible selection bias is likely to be present in both the control and intervention group and should not affect the evaluation of the CSEV.

Fourth, our knowledge construct contained only some facts about CC screening (i.e. process after a negative/positive test result and the possibility of false-positive test results). Although these have been carefully selected, they do not cover the entire spectrum of decision-relevant information (e.g. hrHPV as the causative agent of CC and its transmission route) and could only indicate some deficits. Because of the use of RDS, and thus requesting women to successfully recruit others, we aimed to

burden the respondents as less as possible and, therefore, keep the questionnaire as short as possible.

Finally, we based the content of the CSEVs on our earlier conducted focus groups among offline-recruited Turkish- and Moroccan-Dutch women (5). Because of the measures for the ongoing COVID-19 pandemic (e.g. nationwide lockdowns), we were unable to approach potential respondents face-to-face and recruit them offline. The respondents, as well, were unable to recruit peers offline unless they were household members. This resulted in an online-only, relatively young, mostly second-generation sample of Turkish- and Moroccan-Dutch women. It would be highly relevant to evaluate the CSEVs in an offline setting, comparable with our previous study (5). We believe the CSEVs could affect IDM (greater) in such a setting, for which the CSEVs were tailored during the development process.

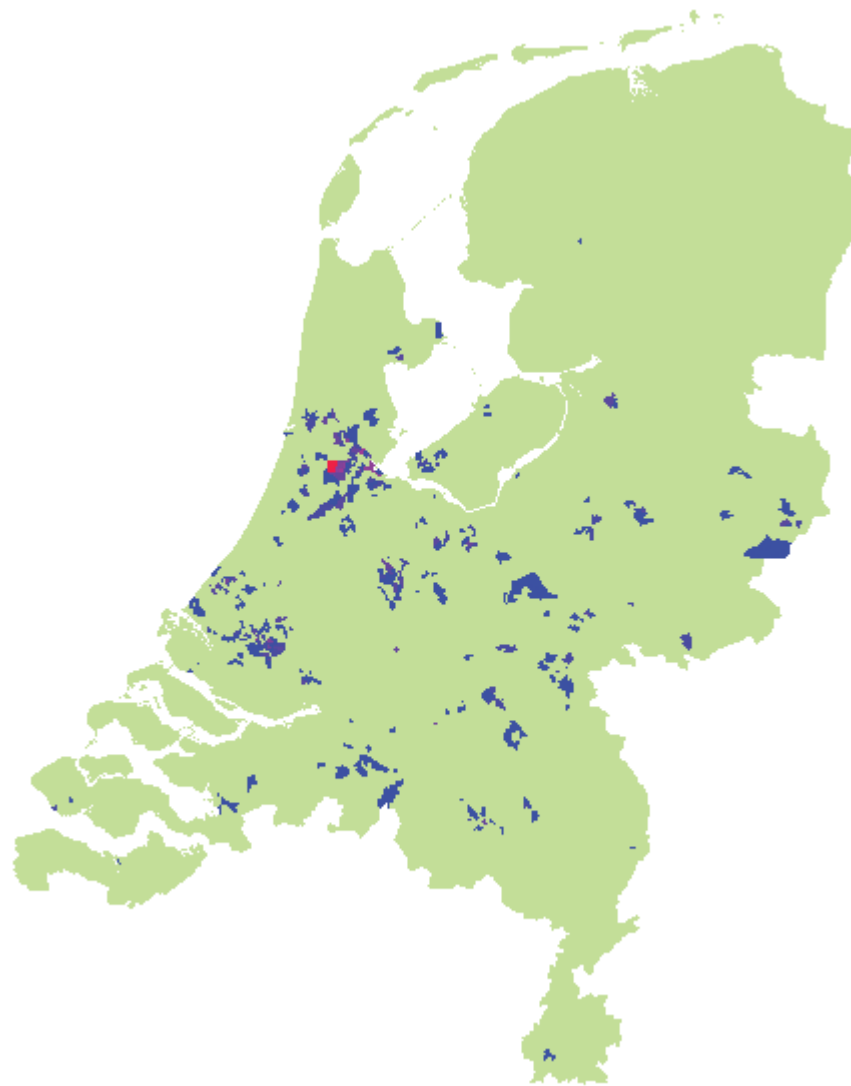
## Conclusions

This randomised intervention study has demonstrated that a CSEV positively impacted CC screening attitudes, especially among Moroccan-Dutch women. Women who were offered both the brochure and CSEV, consulted the brochure more often than those who received the brochure only. The CSEV was also watched far more often than the brochure. The CSEV can, therefore, be widely distributed through offline and online channels, additional to the current information materials.

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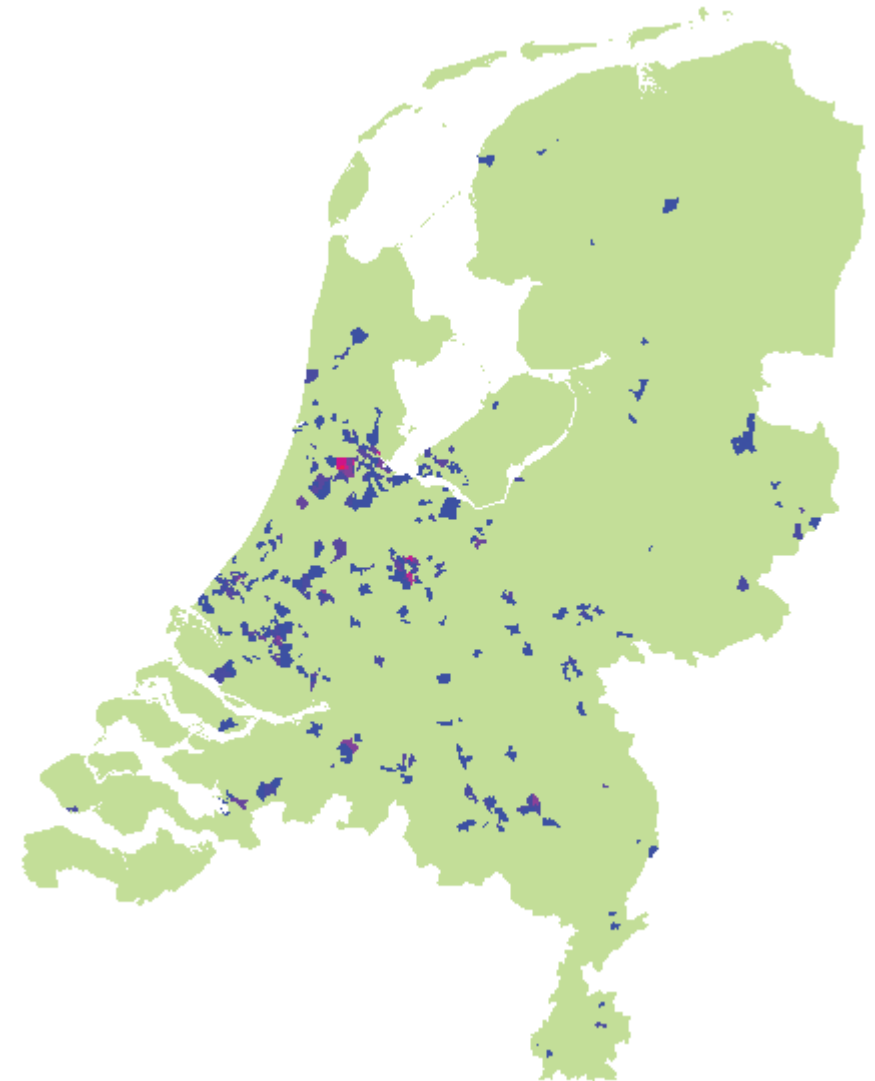
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## Supplementary Tables and Figures



**Supplementary Figure S8.1a. Geographical distribution of Turkish-Dutch respondents**

A map showing the geographical area of respondents was created with a shapefile that was extracted from GADM, an online geographic database of global administrative areas.<sup>15</sup>



**Supplementary Figure S8.1b. Geographical distribution of Moroccan-Dutch respondents**

A map showing the geographical area of respondents was created with a shapefile that was extracted from GADM, an online geographic database of global administrative areas.<sup>15</sup>

Supplementary Table S8.1a. Knowledge of CC screening among the control and intervention Turkish-Dutch respondents, after the brochure (control) or brochure and CSEV (intervention)

Characteristic	Control group		Intervention group		P value
	N = 350		N = 336		
	Sufficient knowledge		Sufficient knowledge		
Total group	239 (68.3%)		214 (63.7%)		0.23
Age (years)	30 – 39	141 (40.3%)	121 (36.0%)		0.28
	40 – 49	68 (19.4%)	60 (17.9%)		0.67
	50 – 60	30 (8.6%)	33 (9.8%)		0.66
Educational level	No official education or primary school	19 (5.4%)	26 (7.7%)		0.29
	Secondary school	32 (9.1%)	32 (9.5%)		0.97
	Vocational education	72 (20.6%)	63 (18.8%)		0.61
	Higher education	115 (32.9%)	93 (27.7%)		0.16
Generation	First	85 (24.3%)	81 (24.1%)		>0.999
	Second	154 (44.0%)	133 (39.6%)		0.27
Previous CC screening participation	Every five years	121 (34.6%)	107 (31.8%)		0.50
	Not every five years	36 (10.3%)	27 (8.0%)		0.38
	Never	82 (23.4%)	80 (23.8%)		0.98

CC: cervical cancer

Supplementary Table S8.1b. Knowledge of CC screening among the control and intervention Moroccan-Dutch respondents, after the brochure (control) or brochure and CSEV (intervention)

Characteristic	Control group	Intervention group	P value
	N = 443	N = 435	
	Sufficient knowledge	Sufficient knowledge	
Total group	349 (78.8%)	337 (77.5%)	0.70
Age (years)	30 – 39	182 (41.8%)	0.86
	40 – 49	130 (29.3%)	>0.999
	50 – 60	30 (6.8%)	28 (6.4%)
Educational level	No official education or primary school	16 (3.7%)	0.65
	Secondary school	45 (10.3%)	0.66
	Vocational education	78 (17.9%)	0.83
	Higher education	195 (44.0%)	197 (45.3%)
Generation	First	126 (29.0%)	0.29
	Second	211 (48.5%)	0.55
Previous CC screening participation	Every five years	173 (39.8%)	0.18
	Not every five years	55 (12.6%)	0.25
	Never	109 (25.1%)	0.88

CC: cervical cancer





Supplementary Table S8.2a. Attitude towards CC screening participation among the control and intervention Turkish-Dutch respondents, after the brochure (control) or brochure and CSEV (intervention)

Characteristic	Control group N = 350	Intervention group N = 336	P value
	Positive attitude	Positive attitude	
<b>Total group</b>	235 (67.1%)	223 (66.4%)	0.89
<b>Age (years)</b>			
30 – 39	143 (40.9%)	127 (37.8%)	0.46
40 – 49	62 (17.7%)	62 (18.5%)	0.88
50 – 60	30 (8.6%)	34 (10.1%)	0.57
<b>Educational level</b>			
No official education or primary school	25 (7.1%)	24 (7.1%)	>0.999
Secondary school	30 (8.6%)	36 (10.7%)	0.41
Vocational education	70 (20.0%)	60 (17.9%)	0.54
Higher education	110 (31.4%)	103 (30.7%)	0.89
<b>Generation</b>			
First	94 (26.9%)	97 (28.9%)	0.62
Second	141 (40.3%)	126 (37.5%)	0.50
<b>Previous CC screening participation</b>			
Every five years	119 (34.0%)	123 (36.6%)	0.53
Not every five years	36 (10.3%)	36 (10.7%)	0.95
Never	80 (22.9%)	64 (19.0%)	0.26

CC: cervical cancer

Supplementary Table S8.2b. Attitude towards CC screening participation among the control and intervention Moroccan-Dutch respondents, after the brochure (control) or brochure and CSEV (intervention)

Characteristic	Control group N = 443	Intervention group N = 435	P value
	Positive attitude	Positive attitude	
<b>Total group</b>	303 (68.4%)	323 (74.3%)	0.065
<b>Age (years)</b>			
30 – 39	155 (35.0%)	173 (39.8%)	0.16
40 – 49	118 (26.6%)	119 (27.4%)	0.87
50 – 60	30 (6.8%)	31 (7.1%)	0.94
<b>Educational level</b>			
No official education or primary school	22 (5.0%)	20 (4.6%)	0.92
Secondary school	52 (11.7%)	49 (11.3%)	0.91
Vocational education	77 (17.4%)	81 (18.6%)	0.70
Higher education	152 (34.3%)	172 (39.5%)	0.13
<b>Generation</b>			
First	134 (30.2%)	132 (30.3%)	>0.999
Second	169 (38.1%)	191 (43.9%)	0.096
<b>Previous CC screening participation</b>			
Every five years	180 (40.6%)	172 (39.5%)	0.79
Not every five years	44 (9.9%)	42 (9.7%)	0.98
Never	79 (17.8%)	109 (25.1%)	0.012*

CC: cervical cancer, \* p < 0.05



**Supplementary Table S8.3a. Pre- and post-IDM in the control group, among Turkish-Dutch women**

Characteristic		IDM after brochure			P value
		Yes, participation N = 152	Yes, no participation N = 3	No N = 195	
<b>Baseline IDM</b>	Yes, participation	110 (72.4%)	1 (33.3%)	20 (10.3%)	<0.001***
	Yes, no participation	0 (0%)	1 (33.3%)	3 (1.5%)	
	No	<b>42 (27.6%)</b>	<b>1 (33.3%)</b>	172 (88.2%)	

IDM: informed decision-making, \* p &lt; 0.05, \*\* p &lt; 0.01, \*\*\* p &lt; 0.001

**Supplementary Table S8.3b. Pre- and post-IDM in the intervention group, among Turkish-Dutch women**

Characteristic		IDM after brochure and film			P value
		Yes, participation N = 140	Yes, no participation N = 4	No N = 192	
<b>Baseline IDM</b>	Yes, participation	90 (64.3%)	0 (0%)	25 (13.0%)	<0.001***
	Yes, no participation	0 (0%)	1 (25.0%)	0 (0%)	
	No	<b>50 (35.7%)</b>	<b>3 (75.0%)</b>	167 (87.0%)	

IDM: informed decision-making, \* p &lt; 0.05, \*\* p &lt; 0.01, \*\*\* p &lt; 0.001

**Supplementary Table S8.3c. Pre- and post-IDM in the control group, among Moroccan-Dutch women**

Characteristic		IDM after brochure			P value
		Yes, participation N = 234	Yes, no participation N = 4	No N = 205	
<b>Baseline IDM</b>	Yes, participation	172 (73.5%)	0 (0%)	19 (9.3%)	<0.001***
	Yes, no participation	1 (0.4%)	2 (50.0%)	0 (0%)	
	No	<b>61 (26.1%)</b>	<b>2 (50.0%)</b>	186 (90.7%)	

IDM: informed decision-making, \* p &lt; 0.05, \*\* p &lt; 0.01, \*\*\* p &lt; 0.001

**Supplementary Table S8.3d. Pre- and post-IDM in the intervention group, among Moroccan-Dutch women**

Characteristic		IDM after brochure and film			P value
		Yes, participation N = 256	Yes, no participation N = 0	No N = 179	
<b>Baseline IDM</b>	Yes, participation	175 (68.4%)	0 (0%)	14 (7.8%)	<0.001***
	Yes, no participation	0 (0%)	0 (0%)	5 (2.8%)	
	No	<b>81 (31.6%)</b>	0 (0%)	160 (89.4%)	

IDM: informed decision-making, \* p &lt; 0.05, \*\* p &lt; 0.01, \*\*\* p &lt; 0.001

**Supplementary Table S8.4a. Awareness, perceptions, and intention regarding self-sampling, after the brochure (control) or brochure and CSEV (intervention), among Turkish-Dutch women**

Characteristic		Control group N = 350	Intervention group N = 336	P value
<b>Aware of the option of self-sampling</b>	Yes	242 (69.1%)	254 (75.6%)	0.071
	No	108 (30.9%)	82 (24.4%)	
<b>Ease of performance</b>	Yes	157 (44.9%)	169 (50.3%)	0.36
	Do not know	140 (40.0%)	120 (35.7%)	
	No	53 (15.1%)	47 (14.0%)	
<b>Painful</b>	Yes	56 (16.0%)	51 (15.2%)	0.38
	Do not know	156 (44.6%)	135 (40.2%)	
	No	138 (39.4%)	150 (44.6%)	
<b>Able to perform correctly</b>	Yes	152 (43.4%)	154 (45.8%)	0.51
	Do not know	126 (36.0%)	107 (31.8%)	
	No	72 (20.6%)	75 (22.3%)	
<b>Trust in the test result</b>	Yes	171 (48.9%)	168 (50.0%)	0.53
	Do not know	137 (39.1%)	120 (35.7%)	
	No	42 (12.0%)	48 (14.3%)	
<b>Intention to self-sample</b>	Yes	163 (46.6%)	156 (46.4%)	0.24
	Do not know	59 (16.9%)	72 (21.4%)	
	No	128 (36.6%)	108 (32.1%)	

**Supplementary Table S8.4b. Awareness, perceptions, and intention regarding self-sampling, after the brochure (control) or brochure and CSEV (intervention), among Moroccan-Dutch women**

Characteristic		Control group N = 443	Intervention group N = 435	P value
Aware of the option of self-sampling	Yes	386 (87.1%)	390 (89.7%)	0.29
	No	57 (12.9%)	45 (10.3%)	
Ease of performance	Yes	252 (56.9%)	284 (65.3%)	0.038*
	Do not know	135 (30.5%)	106 (24.4%)	
	No	56 (12.6%)	45 (10.3%)	
Painful	Yes	82 (18.5%)	59 (13.6%)	0.048*
	Do not know	160 (36.1%)	147 (33.8%)	
	No	201 (45.4%)	229 (52.6%)	
Able to perform correctly	Yes	255 (57.6%)	272 (62.5%)	0.30
	Do not know	115 (26.0%)	96 (22.1%)	
	No	73 (16.5%)	67 (15.4%)	
Trust in the test result	Yes	261 (58.9%)	279 (64.1%)	0.28
	Do not know	128 (28.9%)	110 (25.3%)	
	No	54 (12.2%)	46 (10.6%)	
Intention to self-sample	Yes	217 (49.0%)	231 (53.1%)	0.26
	Do not know	76 (17.2%)	79 (18.2%)	
	No	150 (33.9%)	125 (28.7%)	

\* p < 0.05



# 9

General discussion

## The aim of this thesis

Over the last decades, there has been a rapid increase of migrants in the world because of economic, social, political, or environmental reasons (1). Being a minority group in a new country of residence, even if it is for decades or centuries, immigrants (and their descendants) usually have a more unfavourable disease risk profile compared to the host population (2, 3). Although formal access to health-care services is equally established, inequalities in health-care utilisation are reported from everywhere (4). More specifically, compared to the host population, several reviews reported that immigrant populations have lower participation rates to preventive health-care services, such as vaccination and screening for disease (4, 5). Differences in socioeconomic- and health status can only partially explain these disparities, which seem to be more related to differences in need, preferences, information, (health) literacy, and formal access barriers (4, 6). In this thesis, we focused on Turkish- and Moroccan-Dutch immigrants, the two largest immigrant populations in the Netherlands.

The aim of this thesis was to examine how Turkish- and Moroccan-Dutch immigrants can be reached and informed best on participation in preventive health-care services. To that end, we used two screening examples, i.e. for the diseases chronic hepatitis B (HBsAg screening) and cervical cancer (CC screening). Therefore, we opted to answer the following research questions:

- Which determinants are associated with the intention to participate in HBsAg screening among Moroccan immigrants in the Netherlands? (**Chapters 2 and 3**)
- To what extent do similar HBsAg screening intentions cluster within social networks of Moroccan immigrants in the Netherlands? (**Chapter 4**)
- What is the level of awareness and knowledge, and what are the information needs on chronic hepatitis B and HBsAg screening among Moroccan immigrants in the Netherlands? (**Chapter 5**)
- What is the performance of respondent-driven sampling to reach Moroccan immigrants in the Netherlands? (**Chapter 5**)
- Which determinants are associated with making an informed decision on CC screening (non)participation among Turkish and Moroccan women in the Netherlands? (**Chapter 6**)
- How can we develop a culturally sensitive educational video based on the determinants of the intention to participate in CC screening? (**Chapter 7**)
- What is the effect of a culturally sensitive educational video on informed decision-making regarding CC screening participation among Turkish and Moroccan women in the Netherlands? (**Chapter 8**)

In the following paragraphs, the main findings of our studies are discussed in relation to previous research and literature. The scope of our findings is also discussed in relation to relevance for other immigrant populations and other preventive health-care services. Next, we reflect on several methodological considerations, and end this chapter with recommendations for future research and implications for policy and practice.

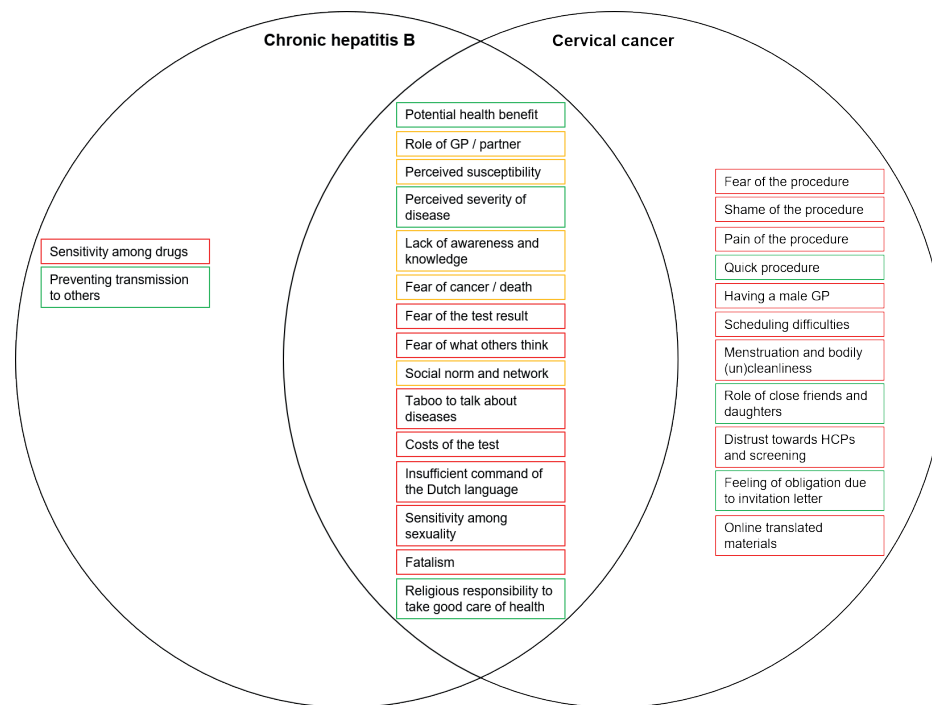
## Discussion of main findings

### Facilitators and barriers for participation in screening programmes

This thesis has looked into facilitators and barriers for participation in screening for chronic hepatitis B and CC. In contrast to a national free of charge screening programme for CC (since 1996), not all Dutch citizens with an increased risk for chronic hepatitis B are invited for screening. In November 2016, the Dutch Health Council recommended screening of the hepatitis B surface antigen (HBsAg) for immigrants born in countries with an endemicity of at least 2%, aimed at detecting unnoticed asymptomatic chronically infected individuals for either immediate treatment or monitoring, and preventing further transmission (7). Although the Council proposed individual case finding by the general practitioner (GP) and local or regional screening programmes through Municipal Public Health Services (MPHS), to date, no screening programme is established. Therefore, respondents in our studies were asked hypothetically on how and what they would decide on their HBsAg screening participation would they be invited in the future. For CC screening, on the other hand, women aged 30 to 60 years are invited to participate every five years via a Dutch invitation letter and information brochure, sent to their home addresses.

In Chapters 2, 3, 4, and 6, we investigated which determinants are associated with participation in screening for chronic hepatitis B and CC. To understand Turkish and Moroccan immigrants' behaviour on preventive health-care services overall, in Figure 1, we categorised all identified determinants and found a great overlap in determinants reported for chronic hepatitis B and CC. In general, the figure shows a mixture of many different determinants that work in multiple directions, both facilitating and hindering screening participation. The figure highlights the complexity of immigrants' health behaviour and the possibility of interactions between determinants, resulting in different effects on screening participation among immigrant populations.





**Figure 9.1. Facilitators and barriers for participation in chronic hepatitis B and CC screening among Turkish- and Moroccan-Dutch**

Green: facilitator, Red: barrier, Orange: facilitator and barrier; GP: general practitioner, HCPs: healthcare professionals

Figure 9.1 reveals that most of the identified determinants play a role in both screening initiatives. This suggests that preventive health-care utilisation involves equal facilitators and barriers among immigrant populations. The number one reason why Turkish and Moroccan immigrants reported to participate in screening initiatives was the potential health benefit. If they would participate in screening, they would get clarity on whether or not they have an increased risk for disease, and could act upon this test result by monitoring and/or treatment. The perceived disease severity also played a facilitating role, especially when respondents understood that a positive test result could mean (slow) development of cancer (i.e. liver cancer after being tested HBsAg positive, and CC after being tested human papillomavirus (HPV) positive). To prevent cancer, but more importantly, a deteriorating health and death, Turkish and Moroccan immigrants would opt for screening participation. More specifically, mothers of (small) children reported not to fear death per se, but would fear leaving their children behind, and therefore, felt the responsibility (as a mother) to participate in screening (Chapter 6). Others, however, feared the test result and the possibility of having or developing cancer, and would rather not know this result. Although the fear of cancer could act in both directions (facilitating and hindering), fear of the test

result was a clear barrier found for both HBsAg screening and CC screening. Another determinant that worked in both directions was perceived susceptibility. Based on whether an individual perceived the susceptibility to be low or high, this determinant worked either hindering or facilitating. The same holds for the role of the GP and the spouse. The GP and the spouse were highly valued and were considered to be the go-to advisors. Depending on the advice given by these advisors, individuals stated that they would (almost) always follow this advice; whether it be hindering or facilitating. Overall, lack of awareness and knowledge resulted in multiple barriers. As an example, Moroccan-Dutch expressed that if they do not have any symptoms, they would not test themselves for chronic hepatitis B (Chapters 2, 3, and 5), showing a lack of knowledge on the asymptomatic nature of the disease. Another example is that Turkish- and Moroccan-Dutch women did not know they could request a female GP or assistant for having the cervical smear taken (Chapter 6), which hindered their screening participation. Some believed that CC is hereditary (Chapter 6), indicating again a lack of knowledge, but this belief acted as a facilitator for CC screening. Shame regarding their test result and fear of what others would think played an important hindering role. In case of chronic hepatitis B, Moroccan immigrants feared avoidance (because of being contagious) and disapproval (since associated with sexuality and drug use), while Moroccan- and Turkish women feared receiving pity from others, and others' thoughts when knowing they attended CC screening, such as having multiple partners and being infertile (Chapters 2 and 6). Overall, there is a taboo in the Turkish and Moroccan community to talk about diseases, while simultaneously, adherence to the social norm and do what others do (mirror one's social network) are perceived necessary to not be stigmatised. Previous literature shows that this is common for all sexually transmitted diseases and is not only limited to immigrant populations (8).

In terms of religious beliefs, two determinants played a role for both screening initiatives: fatalism and the religious responsibility to take good care of one's own health. The largest religion in both Turkey and Morocco is the Islam. Turkish- and Moroccan-Dutch reported that their Islamic beliefs also influenced their health behaviour. For some, their Islamic beliefs resulted in the belief that all events are predetermined, and, therefore, inevitable (i.e. fatalism). Fatalism was found to be a hindering determinant, as screening participation would not prevent the event of developing a disease, if that would be one's faith. This has also been found among Latinas (9). Others also acknowledged that a disease would be God-given, but that it is also one's religious responsibility to use all medical options given by God and take good care of one's own health.

A lack of a good command of the Dutch language is a known barrier for access to healthcare for immigrants in general. Information materials cannot be read (thoroughly), and are, therefore, not understood. Translated information materials

provided did not meet the needs of Turkish- and Moroccan-Dutch women, because of a too difficult (academic) level of writing and/or because of their only-online availability (Chapter 6). Sensitivity among sexuality was a barrier for both HBsAg screening and CC screening. When looking into previous literature on other preventive health-care services, we found a systematic literature review among European adolescents and their parents regarding the HPV vaccine. This review reported doubts about HPV vaccine safety and the belief that the vaccine may encourage sexual activity as barriers to accept the HPV vaccine (10). On the other hand, a systematic review among immigrant parents reported the exact same barriers, but found an additional barrier, namely a cultural and religious belief that abstinence from sexual contact before marriage would provide protection from CC (11). This suggests that in general barriers and facilitators for preventive health-care behaviour do not differ between immigrants and non-immigrants, although the extent of their influence might be greater in immigrants. Additional factors in relation to language, culture, and religion play a specific role in immigrants, especially when it involves certain sensitive or disapproved behaviours, such as sexual contact and drug use. Furthermore, depending on the disease, invitation strategy, and procedure in question, other barriers and facilitators can be found. First, whether the disease or the causative agent of the disease can be transmitted to others and through which transmission route(s) can lead to additional aspects that underlie preventive health-care behaviour. Second, whether or not someone receives a cue to action (i.e. invitation), which cue (e.g. personal invitation letter, general poster), and by whom (e.g. GP or MPHS) are factors that determine an individual's attitude and intention to participate in screening. As an example, a previous Dutch study showed that an invitation by the GP led to an 8% higher CC screening participation rate than an invitation by the MPHS (12). Third, whether the procedure is a blood test (in the case of chronic hepatitis B) or a cervical smear (in the case of CC), may shape different perceptions and thus determinants, such as shame of the procedure in case of a cervical smear taken by the GP.

The specific screening in question, however, seems to have little influence on the decision-making process of Turkish- and Moroccan-Dutch. Only one aspect, sensitivity for drug use, was specifically found to be a barrier for HBsAg screening participation (not for CC screening, since drug injection is not a risk factor for CC). Similarly, preventing transmission to others was a facilitator for HBsAg screening participation, but not for CC screening. This might be explained by the fact that the hepatitis B virus (HBV) can be transmitted via sexual contact, sharing needles, syringes, or other drug-injection equipment, and from mother to child at birth, while the route of HPV transmission is primarily through sexual contact. This would mean that HPV can only be transmitted to their husband, as according to the Islam, Muslims are not supposed to have sexual contact before marriage or with someone other than their spouse. Another explanation might be that being chronically infected with HBV means that one is chronically infectious for others, while having CC is not a factor in

the transmissibility of the virus causing CC (i.e. HPV). Since a national CC screening programme has been implemented, numerous practical barriers and facilitators were mentioned for this screening, while this was not the case in the hypothetical scenario of HBsAg screening. In line with an earlier scoping review among migrant women in Europe, we also found that having a male GP, fear, shame, and pain of the procedure were barriers to participate in CC screening (13).

There were no differences found between Turkish- and Moroccan-Dutch women in their reasoning of (non)participation in CC screening. Furthermore, our findings regarding chronic hepatitis B among Moroccan-Dutch were also in line with the main findings of an earlier thesis of Van der Veen (2012) among Turkish-Dutch (14). Her thesis aimed to study the effect of cultural tailoring in promoting HBsAg screening in Turkish immigrants in Rotterdam, the Netherlands. To that end, she studied the importance of several socio-cultural determinants. Religious responsibility of one's own health, the perceived obligation when being invited for screening, and the association of HBsAg screening with sexual activity were also found to be important determinants in her focus group discussions (15).

This raises the question whether there are differences in determinants of screening behaviour between immigrant populations at all. Overall, Turkish- and Moroccan-Dutch immigrants referred regularly to their religion and their corresponding beliefs that influenced their screening behaviour. Many of the by us identified determinants might, therefore, also be expected among other Muslim immigrant populations, such as for the Somali. A previous study among Somali women in the Netherlands explored perceptions about preventing CC (16). This study found similar perceptions, such as lack of knowledge (e.g. not familiar with the possibility of having a smear taken by a female practitioner), distrust towards the Dutch healthcare, shame about the procedure (i.e. having a cervical smear taken), having a male GP, insufficient command of the Dutch language, low perceived susceptibility (since premarital sex is religiously forbidden), fatalism, and the religious responsibility to take good care of one's own health. Additionally, in line with our findings, a double sexual standard is mentioned, where men are (culturally) 'allowed' to have premarital sex, while the Islam forbids premarital sex for both men and women. An important difference, however, was that Somali women were embarrassed of what their vaginas look like because of female genital mutilation, a common practice in Somalia. Earlier, socio-psychological determinants of HPV vaccination intention and uptake were studied among four ethnic groups in the Netherlands, namely (1) Dutch, (2) Surinamese, Netherlands Antillean, and Aruban (SNA), (3) Middle-Eastern and North-African (MENA) (including Turkish), and (4) Other (17). Both the identified determinants as well as the direction and strength of association of the determinants were similar across all non-Dutch groups. It is important to note, however, that the scope of this study did not include language barriers and cultural and religious aspects.

To conclude, overall, similar socio-psychosocial determinants can be targeted for all ethnic groups (including for native Dutch individuals) in promoting preventive health-care behaviour, but extra efforts should be taken to search for possible additional determinants related to language, culture, and religion in different immigrant populations. This also means that interventions and the mode of delivery should be tailored to the needs of different ethnic groups.

### **Making (informed) decisions in healthcare**

Today, the northern European society and culture emphasises individualism, personal happiness, and self-actualisation. This concept of autonomy urges personal responsibility and autonomous decision-making, which is also reflected in the approach in fields of medicine and public health (18, 19). Making an informed decision in healthcare, based on individual preferences and values, is increasingly recognised as important, and promoted in supporting patient autonomy, and ensuring no coercion or deception (20). In cancer screening particularly, there has been a shift from only promoting the benefits of screening to stimulate individuals to participate in screening towards providing comprehensive information, including both the benefits and harms of screening, to enable individuals to make an informed decision (20).

Currently, in the Netherlands, there are three national screening programmes implemented i.e. for breast, cervical, and colorectal cancer. Traditionally, these cancer screening programmes aim to reach a maximum uptake level, and thus effectiveness (i.e. reduction of incidence and mortality) at a population level. From the perspective of the individual, deciding to participate in screening involves careful consideration between uncertain benefits and risks of adverse effects. This entails the concept of informed decision-making (IDM) described in the Rational Decision Model (21, 22). According to this theoretical framework, individuals are entitled to individually base their decision on making optimal use of information and rationally weighing all aspects involved. An informed decision is commonly defined as one that is based on sufficient decision-relevant knowledge while one's attitude (i.e. values and preferences) is consistent with his/her screening behaviour (23). In general, this concept of IDM is viewed by experts in the field of cancer screening as making a 'good' screening decision (24-26).

While about half of Turkish- and Moroccan-Dutch women in our studies made an informed decision according to the expert-defined concept, the other half did not, which was mainly due to a lack of knowledge (Chapter 8). Although Turkish- and Moroccan-Dutch women were often aware of the possible advantages of CC screening, possible disadvantages were rarely acknowledged (Chapter 6). Despite that experts would define such a decision as uninformed, overall, Turkish- and Moroccan-Dutch women reported to experience little decisional conflict and feel certain about making their decision. This finding is not limited to Turkish and Moroccan

immigrants and also not to CC screening in particular. Previous research found that native Dutch CC screening participants also do not make informed decisions regularly. They often had insufficient expert-defined decision-relevant knowledge (27). Furthermore, similar to our results, how individuals make their decision for cancer screening (e.g. colorectal), but also for other screening initiatives, such as prenatal screening, has shown to not fully correspond with the expert-defined concept of IDM (28, 29). Nevertheless, also in line with our findings, multiple studies on different cancer screening programmes found a low decisional conflict among a diverse range of populations. Although invitees lack factual medical knowledge, after consideration of a (limited) number of different aspects, they feel certain about their decision on cancer screening (non)participation (30, 31). Furthermore, Turkish- and Moroccan-Dutch women in our studies stressed the need for including also practical, emotional, cultural, and religious aspects, next to medical factual information (Chapter 6). Similarly, in the context of colorectal cancer screening, native Dutch individuals also use experiences of their own and of individuals close to them (e.g. those who had cancer in the past) as a source for factual, social, and affective information, and these individuals also indicated that certain emotions (e.g. fear of cancer) play a role in their decision-making process (32).

Thus, uninformed decision-making combined with little decisional conflict has been reported for a range of screening initiatives among diverse populations. Rather than only focusing on factual medical information included in the cancer screening programme's information materials, a diverse range of individuals, both immigrants and non-immigrants, expressed the need for including practical and emotional aspects as well. Yet, our findings reveal that Turkish- and Moroccan-Dutch need an additional inclusion of both cultural and religious aspects when informing them about screening for disease (Chapter 6). Our studies also highlight a higher degree of uninformed decision-making among Turkish- and Moroccan-Dutch immigrants (Chapter 8) compared to native Dutch (27), which suggests that the circumstances for making an informed decision are not optimal nor equal for all individuals. Since IDM requires invited individuals to apply information to their own situation and values, it is obvious that the degree to which individuals have the capacity to obtain, process, and understand health information (i.e. health literacy) is highly influential (33). As immigrants have lower health literacy levels compared to non-immigrants (34), immigrants are less capable of applying IDM. Correspondingly, in Chapter 6, Turkish- and Moroccan-Dutch women reported that the invitation letter and information brochure for CC screening were often not (thoroughly) read or understood due to the lack of a good command of the Dutch language. To access and read online available translated information materials, a number of barriers were mentioned: (1) being incorrectly translated, (2) written in a too complicated language level, and (3) being online available only, because of their self-reported limited digital skills. As circumstances indeed seem to be not optimal nor equal for all individuals, policy

intending to foster IDM may unintendedly enlarge differences in access to care, and eventually, also health disparities among different immigrant populations.

Health literacy skills are crucial to make informed decisions in healthcare. To illustrate this, our thesis reports several barriers based on incorrect or insufficient knowledge on CC screening and the way the programme is organised. As an example, cervical smears are sometimes sampled by a male healthcare worker. In these cases, women have the option to request a female GP or assistant. Since 2017, women could also opt for the possibility to perform self-sampling for the initial test on high-risk HPV presence. As 91% of all women are tested HPV negative, in most cases clinician-based sampling is not required (35). To overcome the often reported shame of being physically examined by a male GP or by anyone at all (Chapter 6), women may choose these alternative options. However, after the researchers had informed the participating women about the possibility of self-sampling, Turkish- and Moroccan-Dutch women expressed concerns about its ease of use and whether or not their sampling competency could be trusted (Chapter 6). As a result, women were found uncertain about the trustworthiness of the test result (following self-sampling) and still preferred clinician-based sampling. Although this lack of trust was also reported among native Dutch women, contrarily, these women still preferred self-sampling (36-38). This discrepancy might be explained by the fact that self-sampling instructions were deemed complicated by Turkish- and Moroccan-Dutch women (due to a lower level of health literacy), whereas native Dutch women scored the exact same self-sampling instructions as very to extremely good (37).

To date, there is no consensus on which information is relevant and what level of knowledge is needed to be regarded as being 'sufficiently informed'. There is also no consensus on who should determine what 'relevant knowledge' is; experts or invited individuals themselves. Although by experts common acknowledged pros and cons (e.g., longer duration of life versus false-positive and -negative test results, overdiagnosis and -treatment, and discomfort or pain) were mentioned by the participating women, these women defined their perceived pros and cons more broadly in terms of practical issues (e.g., scheduling difficulties), emotions (e.g., fear of leaving children behind), culture (e.g., judgement of others due to the virus' sexual transmission route), and religion (e.g., taking responsibility to take care of own health, or by contrast, subjugating all events (i.e., cancer development) to fate and thus not taking own preventive measures (i.e., participation in cancer screening)) (Chapter 6). Similarly, earlier, experts viewed IDM as a result of deliberately weighing all aspects involved, considering both the pros and cons, while most invited individuals (as also found in this thesis; Chapter 6) expressed screening participation to be self-evident (39). More importantly, invited individuals even expressed concerns about reporting potential adverse effects of the screening in the information materials, as it could hinder screening participation (Chapter 6). Literature also reports that experts found

the standard information materials sufficient to make informed decisions, while invited individuals expressed the need to search for additional information (39).

### **The role of social networks in making screening decisions**

In contrast to the Dutch culture that views 'personhood' from the perspective of autonomy and individual rights, many other cultures, such as the Turkish and the Moroccan, define 'personhood' in the context of one's community, where personal interconnectedness and the social and moral meaning of relationships play a vital role (40). Conformingly, in deciding to participate in screening for disease, Turkish- and Moroccan-Dutch immigrants consult their partner, close friends, daughters, and GP (Chapters 2 and 6). Their partner and GP act as supporters or advisors, while close friends and daughters provide emotional and verbal support and ensure that screening appointments are made. We also found clustering of similar screening intentions in social networks of Moroccan immigrants in the Netherlands (Chapter 4). This finding may suggest that individuals prefer to participate in the common decisions of the community and to consider the common interest and values of the community, instead of making a fully autonomous decision. This may also suggest that one's social network, rather than the individual, takes a primary role in making screening decisions, and that peers surrounding the individual who is making the screening decision should also be taken into account when informing about and inviting to screening programmes.

Although experts in the field of cancer screening may state that a fully autonomous decision is necessary for IDM, decisions made in conjunction with others, within communities, may not diminish one's autonomy if one is dependent on those who he or she identifies with (40). In addition, although there is a rather strong family life in most segments of the Turkish and Moroccan culture, others may still be rather independent from their families and prefer more autonomy. Therefore, this thesis highlights that healthcare and health education professionals should be aware of different types of self-perception and the role of one's social network to promote informed screening behaviour, with family involvement if necessary.

### **The use of respondent-driven sampling**

Immigrant populations are often not or barely included in population-based research and are understudied in health research overall. Because of this, researchers and experts tend to classify these populations as 'hard-to-reach' groups. In essence, these populations are not necessarily hard to reach, but require a number of considerations to be taken into account. First, research materials, such as an interview guide or questionnaire, should be translated in their mother languages and considered simple and comprehensible by the populations targeted. This calls for pre-testing of these materials among a diverse range of individuals, rather than a convenience sample that has adequate (health) literacy levels. Simple and comprehensible information



will benefit both low and adequate (health) literacy populations. Second, especially among first-generation immigrants, who may not be familiar with scientific research, distrust Dutch governmental/health institutes, and have a lack of a good command of the Dutch language, a personal face-to-face approach with researchers or key figures with the same cultural and/or linguistic background may help in gaining trust, properly explaining the aim and methodology of the study, and eventually, recruiting these individuals to participate in the study. Third, making use of the connectedness and trust within one's social network, individuals may be recruited through snowball sampling methods.

We used respondent-driven sampling (RDS) in Chapters 3, 4, 5, and 8 for sampling social networks of Turkish and Moroccan immigrants in the Netherlands, both offline with paper-based questionnaires and online with web-based questionnaires. RDS starts with a convenience sample of the target population (so-called 'seeds'); respondents are asked to complete a questionnaire and to invite individuals from their social network (i.e. peers) to do the same. This is also done with snowball sampling, but with RDS, unique and personal tokens are used to follow who recruited whom and to draw recruitment trees. Respondents are also asked to report their personal network size (so-called 'degree'). Using a statistical model that incorporates respondents' degree, the sample can be weighed to compensate for the fact that it was collected in a non-random way.

RDS can be used for multiple purposes, namely (1) to reach so-called 'hard-to-reach' groups (such as immigrants) for participation in research, but also for the delivery of health interventions, (2) to make population estimates taking respondents' degree into account for weighing the obtained sample, and (3) to study the sampled social networks. For all three purposes, it is a great challenge to motivate respondents to recruit their peers to participate in the study. In Chapters 3 and 4, researchers did not provide extra assistance to enable successful peer recruitment, which resulted in 379 respondents, with a limited number of four waves, and 60% of the sample consisting of seeds. In Chapter 5, however, researchers assisted in more than half of the recruitments by handing over the questionnaire via the recruiters' referral, directly contacting the peer(s) by phone, explaining the study's objectives and methodology, and for some, translating the questionnaire. As a result, we reached 295 respondents, with an impressive number of 14 waves, and only 7% of the sample being seeds. Although providing assistance is not uncommon in RDS research, our studies show that assistance is crucial to generate long recruitment chains among immigrant populations. It is important to note, however, that it is highly labour intensive, and requires time and efforts of (preferably bilingual) researchers.

Especially if the research objective is to make population estimates, and, thus, 'equilibrium' (i.e. when the sample characteristics are assumed to be independent

from the seeds' characteristics) is necessary, peer-to-peer recruitment should be encouraged and researchers' help is recommended. Especially for immigrant populations, this help should not only be restricted to contacting their peers, handing over the questionnaire, and explaining the study's objective and methodology verbally (which is commonly provided in RDS studies), but should also include translation of the questionnaire, and culturally sensitive explanation of what scientific research constitutes, and how data are stored and managed, which will help in gaining trust of the targeted community. In addition, in studies aimed at making population estimates, respondents' degree are required for weighing the obtained sample. It is, however, challenging for respondents to indicate their degree adequately and precisely, and often no degree or only an approximation is given. Therefore, it remains questionable whether the weighing of the sample fully compensates for its non-random collection. In line with this, previous research found that several most common assumptions about peer recruitment, essential for the validity of estimators, were not supported by their data (41). These assumptions included that peer recruitment occurs between the recruiters' direct peers, those recruited are a random selection of these direct peers, and that the probability of being recruited and included in the sample is proportional to their degree.

Furthermore, this thesis, in line with previous research (42), reports that respondents are more likely to recruit similar peers, such as having the same age, educational level, degree, and number of years living in the Netherlands (Chapter 5). Therefore, by making use of certain seeds in combination with appropriate incentives, specific subgroups (e.g. low-literate) can be recruited. As an example, in all of our RDS studies, immigrants with a high educational level (i.e. higher professional education or university, in Dutch: HBO or WO) were overrepresented, but we were also successful in reaching considerable percentages of those with no official education and that stopped education after completing primary school (18% in Chapter 3 and 4, and 27% in Chapter 5), and those with limited Dutch language proficiency (14% in Chapter 5). This illustrates that, although not totally generalisable (further discussed under 'Sample size and generalisability') and being very labour intensive, RDS is able to recruit social networks of especially low-literate immigrant populations. In Chapter 8, we were even able to recruit 686 Turkish- and 878 Moroccan-Dutch women aged 30-60 years in an online-only RDS study. Of this sample, of Turkish- and Moroccan-Dutch women respectively, 12% and 8% did not attain school or completed primary school only, and 40% and 36% had never participated in CC screening before. Since we found that both HBsAg screening intentions and IDM regarding CC screening participation cluster in immigrants' social networks (Chapter 4), and that individuals are likely to recruit peers similar to themselves (Chapter 5), RDS has an added value in reaching uninformed or nonparticipating individuals, facilitating thus the health promotion efforts of preventive health-care services. Therefore, to conclude, making



use of one's social network enables penetration into Turkish and Moroccan immigrant (sub)groups.

### Interventions to aid in (informed) decision-making

There has been a growing body of evidence showing that a diverse range of interventions and tools (e.g. decision aids) help in improving knowledge or decisional self-efficacy, promoting informed decisions, and reducing anxiety or decisional conflict (43-45). In line with this literature, especially Moroccan-Dutch women who were offered both the current standard information brochure and our developed culturally sensitive educational video made significantly more often an informed CC screening decision compared to those who were offered the brochure only (Chapter 8).

Current information materials regarding the three Dutch cancer screening programmes can be considered traditional non-narrative health education materials that tend to rely on facts, figures, and statistics. Narrative health education materials are story-based and can be defined as *"a representation of connected events and characters that has an identifiable structure, is bounded in space and time, and contains implicit or explicit messages about the topic being addressed"* (46). As mentioned earlier, Turkish- and Moroccan-Dutch expressed the need for information on practical, emotional, cultural, and religious aspects, rather than only medical factual information (Chapter 6). In addition, Turkish- and Moroccan-Dutch make less use of printed media and more use of audio-visual media (47). We, therefore, developed, used, and evaluated a narrative-based culturally sensitive educational video aimed at facilitating informed CC screening decisions among Turkish- and Moroccan-Dutch women aged 30-60 years (Chapters 7 and 8). Narrative health education materials are increasingly being used to communicate health information and prompt health behaviour change. To date, earlier research and literature indicates that, in comparison to non-narrative health education materials, narrative-based materials are as effective, if not more effective, in improving knowledge and promoting behaviour change (46, 48-52). In an earlier project by others, a non-narrative and a narrative film were developed, which contained facts regarding the cause of CC, HPV vaccination, and CC screening (53, 54). The narrative film starred a Mexican-American family and used the Latino cultural tradition and the value of 'familism', while the non-narrative film used a traditional style featuring doctors and women presenting facts and information. Among a sample of African-American, Mexican-American, and non-Hispanic white women in Los Angeles, the narrative film was more effective in increasing knowledge, improving attitudes, and increasing CC screening participation than the non-narrative one (54). Although the baseline knowledge was lower in women with low health literacy, the increase in knowledge and the measured acceptability was independent of one's health literacy level (55). This finding indicates that narrative health communication materials are well suited for individuals with low health literacy, and importantly, do

not exacerbate existing health inequalities. Moreover, although the film was targeted towards and featured Latina women, all positive effects were seen for all ethnic groups, while being more evident for Mexican-American women (54). As already discussed earlier in this Chapter, since immigrants have lower health literacy levels compared to non-immigrants, these populations tend to be less capable of making informed health decisions (34). Combined with a lack of a good command of the Dutch language, this suggests that immigrant populations benefit less from the current non-narrative-based health communication materials (56, 57), and that it is crucial that (future) information materials equitably serve low and adequate (health) literacy populations, including immigrants.

In regards to the mode of delivery, audio-visual versus printed, our developed culturally sensitive educational video was watched far more often than the information brochure by both Turkish- and Moroccan-Dutch intervention respondents to which both were offered (Chapter 8). This might be explained by a previous finding where authors found that watching a narrative film was associated with more cognitive and emotional involvement than when the same printed narrative was studied (58). Despite that one might say that audio-visual materials are, thus, superior with respect to printed materials, literature reports that a film was more often found to be a persuasive attempt and induced resistance in comparison to the printed version (58). Additionally, compared to audio-visual media, individuals have more control on the pace of exposure in case of printed media (59, 60), and have the ability to read the text non-linearly, which may lead to readers skimming and choosing (relevant) text, pausing, and thinking of counterarguments. To give viewers more control on the pace of exposure and the content watched, a narrative film could be structured in clear fragments, allowing viewers to pause and fast forward the film. Another possibility is to develop an interactive narrative, enabling viewers to make choices at key plot points and switch between different scenes of different characters (61). Likewise, printed narratives may embed (more) emotional cues to increase cognitive attention and emotional involvement. Therefore, depending on the aim of the communication material at hand (e.g. increasing uptake, facilitating informed decisions), one might arguably choose for one or the other.

## Methodological considerations

In Chapters 2 to 8, we have addressed several limitations which each of our studies faced. In this paragraph, we will highlight three overall methodological considerations.

### Qualitative and quantitative research methods in offline and online settings

We used both qualitative and quantitative methods to gain insight into Turkish and Moroccan immigrants' perspectives and decision-making process for two screening initiatives. While qualitative methods proved to be able to retrieve rich and detailed information on how and why immigrants participate in screening or not, quantitative methods enabled quantification of important qualitative findings, analysis of potential clustering of screening intentions, and performing an effect evaluation of culturally sensitive educational videos. This thesis also used both offline and online recruitment methods to include Turkish and Moroccan immigrants in our studies. These two modes of recruitment were found to complement each other, as online respondents were mainly younger, higher educated, second-generation immigrants, while offline respondents were mainly older, lower educated, first-generation immigrants (Chapter 4).

### Sample size and generalisability

The sample sizes of our quantitative studies (except for Chapter 8) are relatively small and not sufficiently powered to find potential subgroup differences. We are, however, pleased with the diversity of the samples reached and the impressive number of Turkish- and Moroccan-Dutch women aged 30-60 years recruited in Chapter 8. At the time of conducting the study described in Chapter 8, the Coronavirus Disease 19 (COVID-19) pandemic and its control measures (e.g. nationwide lockdowns and thus community centres and mosques being closed) disabled us to approach potential respondents face-to-face and recruit them offline. The respondents, as well, were not able to recruit peers offline unless they were household members. We would always recommend to combine both online and offline methods for reaching a representative sample of Turkish- and Moroccan-Dutch immigrants. The generalisability of our findings could also be limited by the fact that individuals with a high educational level (i.e. higher professional education or university, in Dutch: HBO or WO) were overrepresented in our samples. On the contrary, Steens et al. combined data from different sources and at different levels of aggregation with CC screening data of 2005-2010, and estimated that 36% and 47% of Turkish- and Moroccan-Dutch women do not participate in CC screening, respectively (62). In Chapter 8, although this was an online-only sample, we found similar non-participation rates of 40% and 36% among Turkish- and Moroccan-Dutch women, respectively.

### Cross-sectional studies

All studies included in this thesis had a cross-sectional study design. Therefore, respondents had already decided about their CC screening (non)participation, which may have influenced their answers in the focus group discussion or questionnaire study. Also, some respondents might have participated in one of our studies long before the next CC screening invitation, while others might have been invited only very recently. The experienced relevance of our questions regarding decision-making might have been heterogenous, and thus answered differently, depending on the time between the invitation to screen and the invitation to participate in our study. We have also found clustering of chronic hepatitis B screening intentions (Chapter 4), but due to the cross-sectional study design, we are unable to identify its underlying mechanism. It remains to be researched whether immigrants influence each other to jointly decide for (non)participation in screening or that individuals with similar screening intentions seek and incorporate each other in their social networks.

## Recommendations for future research

Based on the studies included in this thesis, we provide four recommendations for future research related to decision-making in preventive healthcare among immigrant populations.

### 1. There is a need of a (validated) measure for informed or deliberate decision-making for cancer screening programmes

The current measure of IDM is based on the Rational Decision Model and constitutes of decision-relevant knowledge, attitude, and one's (intentional) screening behaviour. An important drawback of this measure is that knowledge items are defined by experts, without taking into account the target population's own needs for information relevant for decision-making. Chapter 6 of this thesis has resulted in rich detailed information on how Turkish- and Moroccan-Dutch women make real-life decisions for CC screening. These data could be used as a starting point for developing a new measure for decision-making for especially Turkish- and Moroccan-Dutch women. It is also essential that this new measure is not only validated among native Dutch women, but among Turkish- and Moroccan-Dutch women too.

### 2. Make use of different methods, both offline and online, to reach diverse immigrant populations

This thesis reports on different methods, such as snowball sampling and RDS, in both offline and online settings, while collaborating with a diverse range of key figures (e.g. contact persons of community organisations and mosques, Instagram influencers, women's Facebook groups). Offline and online methods proved to be complementary to each other and the use of the social network yielded immigrants with lower educational and (health) literacy levels. In Chapter 8, for example, we conducted an online-only RDS study and found that 37% and 47% of the Turkish- and Moroccan-Dutch respondents were recruited through peer recruitment, respectively. It is important to note, however, that peer-to-peer recruitment does not happen by itself and requires extra time, efforts, and formative research to initiate and keep the peer recruitment going. This recommendation is also applicable for policy and practice.

### 3. Pilot studies should be conducted to assess whether a specific immigrant population differs in deciding for (non)participation in preventive health-care behaviour (e.g. vaccination, screening) from the host population or from other immigrant populations, depending on the available evidence base

As already reflected earlier in this Chapter, there are small – but important – differences, mostly related to language, culture, and religion, between the decision-making processes of immigrants and non-immigrants for preventive health-care behaviour (e.g. vaccination, screening). This is also the case for determinants associated with

(intentional) preventive health-care participation. Moreover, various immigrant populations may especially differ in the role of culture and religion. Consequently, there is no “one size fits all” approach, but in general, it is not necessary to start from scratch to investigate another immigrant population. Therefore, depending on the available evidence, there is a need to conduct a (small-scale), often qualitative, pilot study to assess whether a specific immigrant population differs from the host population, or from other immigrant populations in deciding for (non)participation in preventive health-care behaviour.

### 4. Researching the effectiveness of (audio-visual) narrative health communication materials in especially immigrant populations is highly needed to decide for a possible shift in the future Dutch information provision

Narrative health communication materials seem to be well suited for individuals with low health literacy including immigrant populations, without disadvantaging individuals with adequate health literacy levels (55). To help overcome knowledge gaps and health disparities between individuals with low and adequate health literacy levels, more research is needed on the effectiveness of narrative health communication materials in immigrant populations. Although audio-visual materials are not necessarily superior with respect to printed materials, we know that Turkish- and Moroccan-Dutch make less use of printed media and more use of audio-visual media (47). To that end, it is worth investigating the effect of audio-visual versus printed information materials to better reach and inform these populations on various health matters.

## Recommendations for policy and practice

Based on our studies in relation to previous literature and research, we provide six recommendations for policy and practice.

### 1. It remains crucial to register ethnicity to identify and reduce possible health (care) disparities among immigrant populations

During multiple studies performed in this thesis, we faced difficulties in accessing Dutch data on screening participation rates for different ethnic or migrant backgrounds. There is a persisting view of some healthcare providers, directors, policy makers, and researchers that registering ethnicity is unnecessary, undesirable, or forbidden by the law (63). While the European General Data Protection Regulation (GDPR) forbids processing personal data on race or ethnic background, processing such data for research is allowed under certain conditions, such as an informed consent. These data should also be carefully secured and handled to avoid any stigmatisation (63). There should be a reasonable balance between privacy and data protection on the one hand, and doing important research on the other hand (64, 65). If we do not collect any data on ethnicity, important health (care) disparities remain hidden, and neither research nor interventions aimed at reducing these disparities will be initiated (66).

### 2 Face-to-face educational meetings in different languages, led by trusted, valued, and competent speakers, are needed to bridge knowledge gaps

In Chapter 6 of this thesis, Turkish- and Moroccan-Dutch women expressed the need for face-to-face educational meetings in their own languages in a safe and comfortable setting, while being able to ask questions. These respondents were mostly women of older age, those of first generation, and with a lower educational level. To meet this need, we held multiple educational meetings and will remain doing so in our current follow-up implementation project (2021-2022) in collaboration with an important key institute, namely the Association Moroccan Doctors Netherlands (in Dutch: Associatie Marokkaanse Artsen Nederland, AMAN). We recommend to organise face-to-face educational meetings in different languages, led by trusted, valued, and competent speakers, to bridge existing knowledge gaps on health-related issues. To overcome distrust and practical barriers, it is important to organise these meetings at trusted locations nearby, such as a mosque or community centre in the city where the targeted population lives. Furthermore, our studies show that Turkish- and Moroccan-Dutch women with a lower educational level and those who have never participated in CC screening before make less often informed screening decisions. These educational meetings should, therefore, target especially these women. Based on our previous experiences with organising such meetings and offline data collections at community centres and mosques, we are convinced that particularly these women can be reached through these organisations.

### 3. Integrated education is needed to better comprehend the link between primary and secondary prevention

To our experience, Turkish- and Moroccan-Dutch found it confusing to hear about HPV as the cause of CC, and consequently, to understand the relationship between HPV vaccination and CC screening. Instead of informing women solely about one of the two preventive measures, it is recommended to discuss both measures jointly, to make clear what the link is between vaccination and screening, and what this means in practice for women invited for one or both of these programmes.

### 4. Extra attention should be paid to the accessibility and understandability of current health information materials

Mass communication through standard Dutch invitation letters and information brochures do not sufficiently reach Turkish- and Moroccan-Dutch due to the perceived difficulty level of the language used and being only available in Dutch (offline). Our thesis shows that women with a low educational level (i.e. no education or completed primary school only) make less often informed screening decisions compared to women with a high educational level (i.e. higher professional education or university, in Dutch: HBO or WO). In the Netherlands, 29% has limited health literacy levels, among which elderly, lower educated individuals, and immigrants are overrepresented (67, 68). As mentioned earlier, this suggests that IDM is hampered by limited health literacy. It is, therefore, essential to develop information materials that have been tested for comprehensibility among individuals with limited health literacy. We also recommend to always rewrite information materials in A2 level as much as possible, which can be understood by 95% of the Dutch population (69). Translated information materials, as well, need to be extensively tested for understandability among the targeted immigrant populations. Additionally, translated information materials are presently often only available online. In Chapter 6 of this thesis, especially older first-generation Turkish and Moroccan immigrant women experienced a barrier due to the lack of digital skills. To increase current materials' accessibility, we recommend to disseminate these materials to community centres, mosques, and GP practices with a relatively large number of Turkish and/or Moroccan patients.

### 5. Additional (audio-visual) tailor-made information materials should be developed to meet individuals' information needs

Currently, health education materials are often non-narrative and rely mostly on facts, figures, and statistics. Rather than only focusing on factual medical information, a diverse range of individuals, both immigrants and non-immigrants, have the need for including practical and emotional aspects as well. This thesis also shows that Turkish- and Moroccan-Dutch need extra inclusion of cultural and religious aspects when informing them about screening for disease. Therefore, additional tailor-made and narrative-based information materials should be developed to meet these information needs. As an example, we developed three narrative-based culturally sensitive

educational videos in Turkish, Moroccan-Arabic, and -Berber (all subtitled in Dutch), which were found to increase IDM in especially Moroccan-Dutch women. Likewise, during our follow-up implementation project, we have developed a cartoon with the same content as in our videos to study its effectiveness on IDM among Turkish- and Moroccan-Dutch women. Next to distributing these materials via community centres, mosques, and GP practices, online routes through Facebook groups and Instagram should also be incorporated to reach especially younger, second-generation, and higher educated Turkish- and Moroccan-Dutch. Because our videos were viewed by a higher percentage than the information brochure was read, we propose to make future information materials more audio-visual rather than textual.

#### **6. Offering the possibility of self-sampling to all women can facilitate participation in CC screening**

To overcome the often reported shame of being physically examined by a male GP or by anyone at all (Chapter 6), self-sampling can be an attractive alternative, and, thus, facilitate participation in CC screening. In October 2021, the Dutch Health Council recommended, in line with our findings, to include self-sampling as an equivalent alternative to clinician-based sampling and to send the self-sampling kit together with the invitation letter (70). As described in Chapter 6, however, Turkish- and Moroccan-Dutch women expressed concerns about the self-sampling's ease of use and whether or not their sampling competency could be trusted. In Chapter 8, in comparison to the current information brochure, watching our developed culturally sensitive educational video resulted in an increase in the perceived self-efficacy of Moroccan-Dutch respondents in performing self-sampling. Therefore, sending the self-sampling kit together with the invitation should ideally be accompanied by implementing our culturally sensitive educational video. In addition, materials and other interventions to inform Turkish- and Moroccan-Dutch women on self-sampling should pay extra attention to women's self-efficacy expectations towards performing correct self-sampling to enhance informed CC screening participation among Turkish- and Moroccan-Dutch women.

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## Appendix

## Summary

Over the last decades, there has been a rapid increase of migrants in the world because of economic, social, political, or environmental reasons. Being a minority group in a new country of residence, even if it is for decades or centuries, immigrants usually have a more unfavourable disease risk profile and poorer outcomes of care compared to the host population. Even in case of equal formal access to health-care services, inequalities in the utilisation and quality are reported from everywhere. As such, compared to the host population, immigrant populations have lower participation rates to preventive health-care services, such as vaccination and screening programmes. Differences in socioeconomic- and health status can only partially explain these lower participation rates, which seem to be more related to differences in need, preferences, information, (health) literacy, and access barriers. In this thesis, we focused on the participation in preventive health-care services among Turkish- and Moroccan-Dutch immigrants, the two largest immigrant populations in the Netherlands. The aim of this thesis was to examine how Turkish- and Moroccan-Dutch immigrants can be reached and informed best on preventive health-care services for informed decision-making on participation. To that end, we used two examples, namely screening for chronic hepatitis B (HBsAg screening) and preliminary stages of cervical cancer (CC screening).

In **Chapter 1**, the background and aim of this thesis are described. This thesis answers the following **research questions**:

- Which determinants are associated with the intention to participate in HBsAg screening among Moroccan immigrants in the Netherlands? (**Chapters 2 and 3**)
- To what extent do similar HBsAg screening intentions cluster within social networks of Moroccan immigrants in the Netherlands? (**Chapter 4**)
- What is the level of awareness and knowledge, and what are the information needs on chronic hepatitis B and HBsAg screening among Moroccan immigrants in the Netherlands? (**Chapter 5**)
- What is the performance of the recruitment method *respondent-driven sampling* (RDS) to reach Moroccan immigrants in the Netherlands? (**Chapter 5**)
- Which determinants are associated with making an informed decision on CC screening (non)participation among Turkish and Moroccan women in the Netherlands? (**Chapter 6**)
- How can we develop a culturally sensitive educational video based on the determinants of *informed decision-making* (IDM) regarding participation in CC screening? (**Chapter 7**)
- What is the effect of a culturally sensitive educational video on IDM regarding CC screening participation among Turkish and Moroccan women in the Netherlands? (**Chapter 8**)

**Chapter 1** describes the background of the chosen preventive health-care services. In November 2016, the Dutch Health Council recommended screening (HBsAg screening through a blood test) for the chronic liver inflammation hepatitis B for immigrants born in countries with a chronic hepatitis B endemicity of at least 2%. This recommendation was aimed at detecting asymptomatic chronically infected individuals for immediate treatment or monitoring, and to prevent further transmission of this disease. Although the Council also proposed local or regional screening programmes through Municipal Public Health Services (MPHS) in addition to individual case finding by the general practitioner (GP), to date, no screening programmes (after a series of pilots) have been established specifically for Turkish- or Moroccan-Dutch immigrants. Since no HBsAg screening programme is established, respondents in our studies were asked hypothetically on how and what they would decide on their HBsAg screening participation would they be invited in the future.

The other preventive health-care service concerns the national CC screening programme that has been implemented since 1996 to detect (pre-stages of) cervical cancer in an early treatable stage. To this end, a cervical smear is collected by the GP or doctor's assistant, or by the women themselves (this self-sampling by means of the self-sampling kit has been possible since 2017). For CC screening, women aged 30 to 60 years are invited to participate every five years via a Dutch invitation letter and information brochure, sent to their home addresses. The participation of Turkish- and Moroccan-Dutch women is lower than that of women from the host population.

**Chapter 2** describes our qualitative study into determinants of HBsAg screening participation among first- and second-generation Moroccan-Dutch immigrants. Our participants had little knowledge about (chronic) hepatitis B, but had a positive attitude towards the screening. Facilitators for intending to screen were perceived susceptibility to and severity of disease, positive attitude towards prevention, wishing to know their hepatitis B status, and to prevent potential hepatitis B transmission to others. A religious facilitator was the responsibility to take good care of one's own health and that of others. Barriers to participate included lack of awareness and knowledge about hepatitis B, practical issues, not having symptoms, negative attitude towards prevention, fear about the test result, and a low perceived susceptibility. Possible cultural barriers were shame and stigma due to the association of (chronic) hepatitis B with sexual contact and drugs, and a religious barrier was fatalism (i.e. an attitude emphasising the subjugation of all events to fate). Different determinants, such as religious beliefs, can work in multiple directions, both facilitating and hindering screening participation. These determinants should be carefully considered when designing and implementing communication materials and strategies. Specific and accurate knowledge provision is important, but should be accompanied by strategies to address shame and stigma. Islamic religious leaders within the Moroccan-Dutch community should, therefore, be informed about the risks of hepatitis B to bring



information across and to decrease elements of shame and stigma, leading to more acceptance of HBsAg screening.

To quantify the qualitative findings and identify which determinants have the greatest impact on screening intention, we investigated determinants associated with the intention to request a blood test for HBsAg screening in first-generation Moroccan-Dutch immigrants (**Chapter 3**). We also researched the influence of non-refundable costs for this screening on their screening intention. This shows that about half of the respondents intends to request a blood test at the GP, while about 44% is willing to attend HBsAg screening for EUR 70. Clarity regarding their own infection status, not having symptoms, fatalism, perceived self-efficacy, and perceived risk of having chronic hepatitis B were the strongest predictors to request a test. If the test would cost 70 EUR, perceived disease severity and the possible health benefit were found as facilitators for this intention. Shame and stigma, fatalism, perceived burden of screening participation, and social influence of Islamic religious leaders had the greatest predictive value for not intending to participate in screening at EUR 70 non-refundable costs. Based on this study, we recommend that information about HBsAg screening (1) incorporates clarity regarding the infection status, (2) stresses the risk of an asymptomatic infection, (3) emphasises mother-to-child transmission as the main transmission route, and (4) is developed in collaboration with Islamic religious leaders to help decrease elements of fatalism, shame, and stigma to enhance screening uptake of Moroccan immigrants in the Netherlands.

For several studies described in this thesis, we used *respondent-driven sampling* (RDS) as a method to approach and involve people in our studies. With RDS, initial respondents ('seeds') are asked to participate in research by completing a questionnaire and inviting individuals from their social network (i.e. peers) to do the same, creating chains of peers ('waves') connected through peer recruitment ('recruitment trees'). Because of the use of RDS in Chapter 3, we were also able to investigate whether similar HBsAg screening intentions among Moroccan immigrants living in the Netherlands are clustered within their close social networks (i.e. family, friends, and workmates sharing the same positive or negative screening intention) due to a strong sense of community and trust within the group (**Chapter 4**). More importantly, out of all the variables considered in this study including sociodemographic characteristics, 'social relationship' was found to have the most important influence on one's screening intention. These findings emphasise the need to take the social network of individuals into account when studying individual behaviour concerning screening participation. The next step could be to investigate if and how peers and/or other community members can be used to disseminate information regarding screening programmes.

In **Chapter 5**, we describe the successful performance of RDS to reach Moroccan-Dutch immigrants, and estimate their information needs on HBsAg screening. Using RDS, we reached 14 waves and 295 respondents with only 21 seeds recruited by the researchers. Of all respondents, 77% had heard of hepatitis B and 23% of HBsAg screening. Less than half had sufficient knowledge about hepatitis B and the need for information. We found a lack of knowledge on the asymptomatic nature of chronic hepatitis B, which is likely to influence screening intentions, as not having symptoms was the main reason for not intending to participate in HBsAg screening. Respondents wanted most frequently more information about the risk for and possible long-term consequences of chronic hepatitis B.

RDS appears to be a good method to recruit so-called "hard-to-reach" groups, such as immigrants, to participate in research, but also for the delivery of health interventions, such as HBsAg screening, starting at community venues where relatively large numbers of immigrants convene (e.g. mosques and community centres). Future research is needed to assess the cost-effectiveness of RDS in comparison to earlier performed outreach activities to reach immigrants for HBsAg screening.

In the focus group study (**Chapter 6**), we investigated how and why Turkish- and Moroccan-Dutch women decide to participate or not in the current Dutch CC screening programme as well as their perceptions on self-sampling. Participants were found to lack knowledge about CC and its screening, and seemed to be unaware of the possible cons of CC screening. They often indicated to not (thoroughly) read the Dutch invitation letter and information brochure, or simply being unable to understand these materials due to a lack of a good command of the Dutch language. According to them, this was an important barrier to participating in the screening. Other barriers were having a male GP, fatalism, shame and taboo, associations of CC with lack of femininity and infertility, fear of the test result, and fear of cancer, suffering, death, or leaving their children behind after death. Perceived facilitators were a high perceived severity of disease, social support, the short amount of time it takes to have a cervical smear taken, and the religious responsibility to take good care of one's own health using all medical options that God provides. Participants regarded their ability to correctly perform self-sampling as low. Because of this low self-efficacy, they were hesitant on whether the results of the screening could be trusted. This study shows that Turkish- and Moroccan-Dutch women do not only consider factual medical information, but also practical, emotional, cultural, and religious aspects prior to deciding to participate in screening or not. Therefore, information materials should be tailored to these aspects as well as translated to appropriate languages (due to the lack of a good command of the Dutch language) to promote informed decision-making (IDM) regarding CC screening participation among Turkish- and Moroccan-Dutch women. It is also essential to enhance women's self-efficacy towards performing self-sampling correctly.



As described in Chapter 6, Turkish- and Moroccan-Dutch women stress their need to include information on the practical, emotional, cultural, and religious aspects of CC screening. The current Dutch invitation letter and information brochure are often not (thoroughly) read or understood and include mostly factual medical information. We, therefore, developed a short culturally sensitive educational video to facilitate IDM for CC screening participation among Turkish- and Moroccan-Dutch women. **Chapter 7** describes the development process of translating research data into a culturally sensitive educational video in Moroccan-Arabic, -Berber, and Turkish. Using the *Entertainment-Education* communication strategy and following the *Media Mapping* model, we developed the video in collaboration with Turkish- and Moroccan-Dutch women, researchers, public health experts, and creative media professionals. The added value and effectiveness of this intervention to facilitate informed CC screening decisions are evaluated in a randomised intervention study (reported on in Chapter 8).

In this study among Turkish- and Moroccan Dutch women aged 30-60 years, respondents were randomly assigned to the control (current information brochure) or intervention condition (current information brochure and culturally sensitive educational video) (**Chapter 8**). The results suggest that the video was more appealing to consult in comparison to the current information brochure, and that the information brochure is also more often studied when the video is also offered. While in the intervention group no increase was found for knowledge, intention to participate, or IDM, the intervention (adding the video) did result in more positive screening attitudes among Moroccan-Dutch women. This was especially the case for Moroccan-Dutch women who never have participated in CC screening before. Having developed a short intervention that can be easily implemented, it can help Turkish- and Moroccan-Dutch women in making informed CC screening decisions. We, therefore, recommend to widely distribute this intervention through offline and online channels, additional to the current information materials.

In **Chapter 9**, we discuss the main findings of our studies in relation to previous research and literature, but also in relation to the relevance for other immigrant populations and other preventive health-care services:

#### **Facilitators and barriers for participation in screening programmes**

Our found socio-psychosocial determinants for participation in preventive health-care services will generally apply to *all* ethnic groups (including for native Dutch individuals), but extra efforts are needed to search for possible specific additional determinants related to language, culture, and religion in different (immigrant) populations. For example, our Turkish- and Moroccan-Dutch respondents appeared to have a need for specific information on CC screening related to cultural and religious aspects. This means that interventions and the mode of delivery should

be developed together with representatives of the target group, so that they are tailored to their needs.

#### **Making (informed) decisions in healthcare**

Our studies indicate a lower degree of IDM among Turkish- and Moroccan-Dutch immigrants in comparison to native Dutch individuals, which suggests that the circumstances for making an informed decision are not optimal nor equal for all individuals. The capacity to obtain, process, and understand health information (i.e. health literacy) seems to be highly influential.

#### **The role of social networks in making screening decisions**

In deciding to participate in screening for disease, Turkish- and Moroccan-Dutch immigrants consult their partner, close friends, daughters, and GP. We also found *clustering* of similar screening intentions in social networks of Moroccan immigrants in the Netherlands. This suggests that one's social network, rather than the individual, takes an important role in making screening decisions, and that peers surrounding the individual who is making the screening decision should also be taken into account when informing about and inviting to screening programmes.

#### **Interventions to aid in (informed) decision-making**

Current information materials regarding the three Dutch cancer screening programmes can be considered traditional non-narrative health education materials that tend to rely on facts, figures, and statistics. Our study shows that adding a culturally sensitive educational video enables more positive screening attitudes towards CC screening in comparison to the current information brochure. How information is delivered clearly makes a difference. Turkish- and Moroccan-Dutch make less use of printed media and more use of audio-visual media. This is confirmed by our finding that the video was watched far more often than the current information brochure by both Turkish- and Moroccan-Dutch intervention respondents to which both were offered, and that the brochure was consulted more often by the intervention group (with the video). Depending on the aim of the communication material at hand (e.g. increasing uptake, facilitating informed decisions), policy makers and communication professionals might arguably choose for printed or audio-visual media, considering the pros and cons of each mode of delivery.

In addition, this chapter provides several methodological considerations, and ends with recommendations for future research and implications for policy and practice.

#### **For future research related to decision-making in preventive healthcare among immigrant populations, we recommend:**

- to develop and validate a new measure for informed or deliberate decision-making for cancer screening programmes

- to make use of different methods, both offline and online, to reach diverse immigrant populations
- to conduct pilot studies assessing whether a specific immigrant population differs in (IDM in regards to) deciding for (non)participation in preventive health-care services from native Dutch individuals or from other immigrant populations
- to research the effectiveness of (audio-visual) narrative-based health communication materials in different populations to consider a possible shift in the nature of the information provision

**Finally, we recommend for policy and practice:**

- to register ethnicity to identify and act upon possible health (care) disparities among immigrant populations
- to organise face-to-face educational meetings in different languages, led by trusted, valued, and competent speakers, to bridge knowledge gaps
- to provide integrated education to different (immigrant) populations to better comprehend the link between primary and secondary prevention (e.g. HPV vaccination and CC screening)
- to pay extra attention to the accessibility and understandability of the current health information materials, especially for so-called "hard to reach" groups
- to develop additional (audio-visual) tailor-made information materials together with the target group to meet their information needs
- to offer self-sampling as a standard offer of CC screening enabling more women to participate in this screening

## Samenvatting

In de afgelopen decennia is het aantal migranten vanwege economische, sociale, politieke of ecologische redenen sterk toegenomen. Als minderheidsgroep in een nieuw land van verblijf, ook al is dat voor tientallen jaren of eeuwen, hebben immigranten meestal een ongunstiger ziekerisicoprofiel en slechtere uitkomsten van zorg dan de leden van de meerderheidsbevolking. Toegang tot en kwaliteit van de gezondheidszorg voor hen is slechter dan voor anderen, ook bij formeel gelijke toegang. Zo is er onder immigrantenpopulaties, vergeleken met de meerderheidsbevolking, een lagere deelname aan de preventieve gezondheidszorg zoals vaccinaties en screeningsprogramma's. Verschillen in sociaaleconomische en gezondheidsstatus kan deze lagere deelname slechts gedeeltelijk verklaren; deze lijkt meer verband te houden met verschillen in behoefte, voorkeuren, informatie, gezondheidsvaardigheden, geletterdheid alsmede met barrières in de toegang. In dit proefschrift hebben we ons gericht op deelname aan preventieve gezondheidszorg van Turks- en Marokkaans-Nederlandse immigranten, de twee grootste immigrantenpopulaties in Nederland. Het doel van dit proefschrift was om te onderzoeken hoe Turks- en Marokkaans-Nederlandse immigranten het beste kunnen worden bereikt en geïnformeerd over preventieve gezondheidszorgprogramma's, zó dat zij tot een geïnformeerde keuze over deelname kunnen komen. Hiervoor hebben we twee voorbeelden gebruikt, namelijk het opsporen van chronische hepatitis B (HBsAg-screening) en voorstadia van baarmoederhalskanker (het bevolkingsonderzoek naar baarmoederhalskanker).

**In Hoofdstuk 1 worden de achtergrond en het doel van dit proefschrift beschreven. Dit proefschrift geeft antwoord op de volgende onderzoeksvragen:**

- Welke determinanten hangen samen met de intentie om deel te nemen aan HBsAg-screening onder Marokkaanse immigranten in Nederland? (**Hoofdstukken 2 en 3**)
- In hoeverre clusteren vergelijkbare HBsAg-screeningsintenties binnen sociale netwerken van Marokkaanse immigranten in Nederland? (**Hoofdstuk 4**)
- Wat zijn het bewustzijn, kennisniveau en informatiebehoefte ten aanzien van chronische hepatitis B en HBsAg-screening onder Marokkaanse immigranten in Nederland? (**Hoofdstuk 5**)
- Hoe goed werkt de rekruteringsmethode *respondent-driven sampling* (RDS) voor het bereiken van Marokkaanse immigranten in Nederland? (**Hoofdstuk 5**)
- Welke determinanten zijn geassocieerd met het nemen van een geïnformeerde beslissing over deelname aan het bevolkingsonderzoek naar baarmoederhalskanker van Turkse en Marokkaanse vrouwen in Nederland? (**Hoofdstuk 6**)

- Hoe kunnen we een cultuur sensitieve educatieve video ontwikkelen op basis van determinanten van geïnformeerde besluitvorming over deelname aan het bevolkingsonderzoek naar baarmoederhalskanker? **(Hoofdstuk 7)**
- Wat is het effect van een cultuur sensitieve educatieve video op geïnformeerde besluitvorming met betrekking tot deelname aan het bevolkingsonderzoek naar baarmoederhalskanker onder Turkse en Marokkaanse vrouwen in Nederland? **(Hoofdstuk 8)**

**Hoofdstuk 1** beschrijft de achtergrond van de gekozen preventieprogramma's. In november 2016 adviseerde de Gezondheidsraad screening (HBsAg-screening door middel van bloedonderzoek) voor de chronische leverontsteking hepatitis B onder immigranten geboren in landen waar chronische hepatitis B endemisch voorkomt onder ten minste 2% van de bevolking. Dit advies was gericht op het opsporen van chronisch geïnfecteerde personen zonder symptomen, zodat zij onmiddellijk behandeld of gemonitord kunnen worden en verdere transmissie van de ziekte voorkomen kan worden. Hoewel de Raad naast individuele *case finding* door de huisarts ook lokale of regionale screeningsprogramma's via de GGD voorstelde, zijn er tot op heden na een serie pilots geen screeningsprogramma's opgezet specifiek gericht op Turks- of Marokkaans-Nederlandse immigranten. Aangezien er geen HBsAg-schermingsprogramma is opgezet, werden de respondenten in onze onderzoeken hypothetisch gevraagd hoe en wat ze zouden beslissen over hun deelname aan HBsAg-scherming als ze in de toekomst zouden worden uitgenodigd.

Het andere preventieprogramma betreft het sinds 1996 ingestelde landelijke bevolkingsonderzoek om (voorstadia van) baarmoederhalskanker in een vroeg behandelbaar stadium op te sporen. Hiertoe wordt een uitstrijkje van de baarmoedermond afgenomen door de huisarts of doktersassistent(e), of door de vrouwen zelf (deze zelfafname door middel van de zelfafnameset is mogelijk sinds 2017). Voor het bevolkingsonderzoek worden vrouwen tussen de 30 en 60 jaar om de vijf jaar uitgenodigd om deel te nemen, via een Nederlandstalige uitnodigingsbrief en informatiebrochure die naar hun huisadres worden gestuurd. De deelname van Turks- en Marokkaans-Nederlandse vrouwen is lager dan van vrouwen uit de meerderheidsbevolking.

**Hoofdstuk 2** beschrijft onze kwalitatieve studie naar determinanten van deelname aan HBsAg-scherming onder Marokkaans-Nederlandse immigranten van de eerste en tweede generatie. Onze respondenten bleken weinig kennis te hebben van (chronische) hepatitis B, maar stonden wel positief tegenover de scherming. De bereidheid om deel te nemen aan scherming was groter wanneer zij de vatbaarheid voor en de ernst van de ziekte als hoog inschatten, een algemeen positieve houding ten opzichte van preventie hadden, graag hun hepatitis B-status wilden weten of de mogelijke overdracht van hepatitis B naar anderen wilden voorkomen. Ook de

religieus geïnspireerde verantwoordelijkheid om goed voor de eigen gezondheid en die van anderen te zorgen, verhoogde de bereidheid om deel te nemen aan de scherming. Barrières om deel te nemen, waren onder meer het gebrek aan bewustzijn en kennis over hepatitis B, praktische problemen, het niet hebben van symptomen, een negatieve houding ten opzichte van preventie, angst voor de testuitslag en een laag gepercipieerde vatbaarheid. Mogelijk cultureel bepaalde barrières bleken schaamte en stigma vanwege de associatie van (chronische) hepatitis B met seksueel contact en drugs en het religieus geïnspireerd fatalisme (d.w.z. een houding die de onderwerping van alle gebeurtenissen aan het lot benadrukt). Verschillende determinanten, zoals bijv. religieus bepaalde opvattingen, kunnen zowel screeningsdeelname vergemakkelijken als belemmeren. Deze determinanten moeten zorgvuldig worden overwogen bij het ontwerpen en implementeren van communicatiematerialen en -strategieën. Specifieke en accurate kennisvoorziening is belangrijk, maar moet gepaard gaan met strategieën om schaamte en stigma aan te pakken. Islamitische religieuze leiders binnen de Marokkaans-Nederlandse gemeenschap zouden daarom moeten worden geïnformeerd over de risico's van hepatitis B zodat ook zij informatie kunnen overbrengen en de elementen van schaamte en stigma kunnen verminderen, wat zal leiden tot meer acceptatie van HBsAg-scherming.

Om de kwalitatieve bevindingen te kwantificeren en te identificeren welke determinanten de grootste impact hebben op de screeningsintentie, hebben we determinanten onderzocht die samenhangen met de intentie om een bloedtest voor HBsAg-scherming aan te vragen bij Marokkaans-Nederlandse immigranten van de eerste generatie **(Hoofdstuk 3)**. Ook onderzochten we de invloed van kosten voor deze scherming (het bloedonderzoek valt onder het eigen risico) op hun screeningsintentie. Hieruit blijkt dat ongeveer de helft van de respondenten van plan is om een bloedtest bij de huisarts aan te vragen, terwijl ongeveer 44% bereid is om voor 70 euro deel te nemen aan HBsAg-scherming. Duidelijkheid over hun eigen infectiestatus, het niet hebben van symptomen, fatalisme, de gepercipieerde zelfeffectiviteit en het gepercipieerd risico op chronische hepatitis B waren de sterkste voorspellers om een test aan te vragen. Wanneer de test 70 euro zou kosten, werden de gepercipieerde ernst van de ziekte en het mogelijke gezondheidsvoordeel gezien als faciliterende determinanten. Schaamte en stigma, fatalisme, ervaren last van deelname aan scherming en sociale invloed van islamitische religieuze leiders hadden de grootste voorspellende waarde voor het niet voornemens zijn om deel te nemen aan scherming wanneer deze 70 euro zou kosten. Op basis van deze studie raden we aan om in de voorlichting over HBsAg-scherming (1) duidelijkheid over de infectiestatus te includeren, (2) het risico op een asymptomatische infectie te benadrukken, (3) de moeder-op-kind transmissie te benadrukken als de belangrijkste transmissieroute, en (4) samen te werken met islamitische religieuze leiders om

elementen van fatalisme, schaamte en stigma te helpen verminderen om de screeningsdeelname van Marokkaanse immigranten in Nederland te verhogen.

Voor verschillende onderzoeken die in dit proefschrift worden beschreven, hebben we gebruik gemaakt van *respondent-driven sampling* (RDS) als methode om mensen te benaderen voor en te betrekken in onze studies. Met RDS worden initiële respondenten ('seeds') gevraagd aan het onderzoek mee te doen door een vragenlijst in te vullen en personen uit hun sociale netwerk (d.w.z. kennissen) uit te nodigen om hetzelfde te doen, waardoor ketens van kennissen ('golven') worden gecreëerd die verbonden zijn via onderlinge werving ('rekruteringsbomen'). Door het gebruik van RDS in Hoofdstuk 3 konden we tevens vaststellen dat vergelijkbare HBsAg-screeningsintenties onder Marokkaanse immigranten in Nederland geclusterd zijn binnen hun hechte sociale netwerken (d.w.z. familie, vrienden en collega's die dezelfde positieve of negatieve screeningsintentie delen) vanwege een sterk gemeenschapsgevoel en vertrouwen binnen de groep (**Hoofdstuk 4**). Sterker nog, van alle variabelen die in deze studie zijn overwogen, inclusief sociaal demografische kenmerken, bleek 'sociale relatie' de belangrijkste invloed te hebben op iemands screeningsintentie. Deze bevindingen benadrukken de noodzaak om rekening te houden met het sociale netwerk van personen bij het bestuderen van individueel gedrag met betrekking tot screeningsdeelname. Een volgende stap zou kunnen zijn om te onderzoeken of en hoe kennissen en/of andere leden van de gemeenschap kunnen worden ingezet om informatie te verspreiden over screeningsprogramma's.

In **Hoofdstuk 5** beschrijven we de succesvolle toepassing van RDS om Marokkaans-Nederlandse immigranten te bereiken en schatten we hun informatiebehoefte ten aanzien van HBsAg-screening. Met behulp van RDS bereikten we 14 golven en 295 respondenten met slechts 21 seeds die door de onderzoekers werden gerekruteerd. Van alle respondenten had 77% gehoord van hepatitis B en 23% van HBsAg-screening. Minder dan de helft van hen had voldoende kennis over hepatitis B en de behoefte aan informatie. We vonden een gebrek aan kennis over de asymptomatische aard van chronische hepatitis B, die waarschijnlijk de screeningsintenties beïnvloedt, aangezien het niet hebben van symptomen de belangrijkste reden was om niet voornemens te zijn aan HBsAg-screening deel te nemen. Respondenten wilden het vaakst meer informatie over het risico op en mogelijke langetermijngevolgen van chronische hepatitis B.

RDS blijkt een goede methode om zogenaamd "moeilijk bereikbare" groepen als immigranten te rekruteren voor deelname aan onderzoek en mogelijk ook voor het aanbieden van gezondheidsinterventies, zoals HBsAg-screening, te beginnen op locaties waar relatief grote aantallen immigranten samenkomen (zoals moskeeën en buurthuizen). Toekomstig onderzoek is nodig om de kosteneffectiviteit van RDS

te beoordelen in vergelijking met eerder uitgevoerde "outreach"-activiteiten om immigranten te bereiken voor HBsAg-screening.

In de focusgroep-studie (**Hoofdstuk 6**) hebben we onderzocht hoe en waarom Turks- en Marokkaans-Nederlandse vrouwen besluiten om wel of niet deel te nemen aan het huidige bevolkingsonderzoek baarmoederhalskanker en hoe zij denken over de zelfafnameset. De deelnemers bleken weinig kennis te hebben over baarmoederhalskanker en het bevolkingsonderzoek, en leken niet op de hoogte van de mogelijke nadelen van het bevolkingsonderzoek. Zij gaven aan de Nederlandstalige uitnodigingsbrief en informatiebrochure niet (goed) te lezen of deze materialen simpelweg niet te begrijpen door een gebrekkige beheersing van de Nederlandse taal. Dit was volgens hen een belangrijke barrière om deel te nemen aan het bevolkingsonderzoek. Andere barrières bleken te zijn: het hebben van een mannelijke huisarts, fatalisme, schaamte en taboe, associaties van baarmoederhalskanker met gebrek aan vrouwelijkheid en onvruchtbaarheid, angst voor de testuitslag, en angst voor kanker, lijden, de dood of het achterlaten van hun kinderen na de dood. Factoren die volgens hen bijdragen aan deelname zijn een hoge gepercipieerde ernst van de ziekte, sociale steun, de korte tijdsduur die nodig is om een uitstrijkje te laten maken en de religieus geïnspireerde verantwoordelijkheid om goed voor de eigen gezondheid te zorgen met behulp van alle medische opties waarin God voorziet. Deelnemers beoordeelden hun vermogen om de zelfafnameset correct uit te voeren als laag. Vanwege deze lage zelfeffectiviteit twijfelden ze of de resultaten van het bevolkingsonderzoek te vertrouwen waren. Deze studie toont aan dat Turks- en Marokkaans-Nederlandse vrouwen niet alleen feitelijke medische informatie in overweging nemen, maar ook praktische, emotionele, culturele en religieuze aspecten voordat ze beslissen om wel of niet deel te nemen aan het bevolkingsonderzoek. Daarom moet voorlichtingsmateriaal op deze aspecten worden afgestemd en in de juiste talen worden vertaald (vanwege de moeite met de Nederlandse taal) om geïnformeerde deelname aan het bevolkingsonderzoek onder Turks- en Marokkaans-Nederlandse vrouwen te bevorderen. Het is ook essentieel om de zelfeffectiviteit van vrouwen te vergroten bij het correct uitvoeren van de zelfafnameset.

Zoals beschreven in Hoofdstuk 6, benadrukken Turks- en Marokkaans-Nederlandse vrouwen hun behoefte aan informatie over de praktische, emotionele, culturele en religieuze aspecten van het bevolkingsonderzoek naar baarmoederhalskanker. De huidige Nederlandstalige uitnodigingsbrief en informatiebrochure worden vaak niet (goed) gelezen of begrepen en bevatten vooral feitelijke medische informatie. Daarom ontwikkelden we een korte cultuur sensitieve educatieve video om de geïnformeerde besluitvorming voor deelname aan het bevolkingsonderzoek onder Turks- en Marokkaans-Nederlandse vrouwen te vergemakkelijken. **Hoofdstuk 7** beschrijft het ontwikkelingsproces van het vertalen van onderzoeksgegevens naar een cultuur

sensitieve educatieve video in het Marokkaans-Arabisch, -Berbers en Turks. Met behulp van de communicatiestrategie *Entertainment-Education* en volgens het *Media Mapping*-model hebben we de video ontwikkeld in samenwerking met Turks- en Marokkaans-Nederlandse vrouwen, onderzoekers, volksgezondheidsexperts en creatieve mediaprofessionals. De toegevoegde waarde en effectiviteit van deze interventie om geïnformeerde screeningsbeslissingen te vergemakkelijken, zijn geëvalueerd in een gerandomiseerde interventiestudie die beschreven is in Hoofdstuk 8.

In dit onderzoek onder Turks- en Marokkaans-Nederlandse vrouwen tussen de 30 en 60 jaar werden respondenten willekeurig toegewezen aan de controle- (huidige informatiebrochure) of interventieconditie (huidige informatiebrochure en cultuur sensitieve educatieve video) (**Hoofdstuk 8**). De resultaten suggereren dat de video aantrekkelijker was om te raadplegen dan de huidige informatiebrochure en dat de informatiebrochure vaker wordt bestudeerd als ook de video wordt aangeboden. Hoewel in de interventiegroep geen toename werd gevonden van kennis, intentie om deel te nemen of geïnformeerde besluitvorming, leidde de interventie (de toevoeging van de video) wel tot een meer positieve houding ten opzichte van het bevolkingsonderzoek bij Marokkaans-Nederlandse vrouwen. Dit was vooral het geval voor Marokkaans-Nederlandse vrouwen die nog nooit eerder aan het bevolkingsonderzoek hadden deelgenomen. De korte interventie die wij hebben ontwikkeld, kan gemakkelijk worden geïmplementeerd en kan Turks- en Marokkaans-Nederlandse vrouwen helpen bij het nemen van een geïnformeerde beslissing over deelname aan het bevolkingsonderzoek. We raden daarom aan om deze interventie breed te verspreiden via *offline* en *online* kanalen, aanvullend op het huidige voorlichtingsmateriaal.

In **Hoofdstuk 9** bespreken we de belangrijkste bevindingen van onze studies in relatie tot eerder onderzoek en literatuur, maar ook in relatie tot de relevantie voor andere immigrantenpopulaties en andere preventieve gezondheidsprogramma's:

#### **Faciliterende en belemmerende factoren voor deelname aan screeningsprogramma's**

De door ons gevonden sociaal-psychosociale determinanten voor deelname aan preventieve programma's zullen in het algemeen gelden voor *alle* etnische groepen (ook voor Nederlanders *zonder* een migratieachtergrond), maar er zijn extra inspanningen nodig om te zoeken naar mogelijke specifieke aanvullende determinanten in relatie tot taal, cultuur en religie binnen verschillende (immigranten) populaties. Zo bleken onze Turks- en Marokkaans-Nederlandse respondenten behoefte te hebben aan specifieke informatie over het bevolkingsonderzoek naar baarmoederhalskanker gerelateerd aan culturele en religieuze aspecten. Dit betekent dat interventies en de wijze waarop deze worden aangeboden, moeten worden

ontwikkeld samen met vertegenwoordigers van de doelgroep, zodat zij afgestemd zijn op hun behoeften.

#### **(Geïnformeerde) beslissingen nemen in de zorg**

Onze studies wijzen op een lagere graad van geïnformeerde besluitvorming onder Turks- en Marokkaans-Nederlandse immigranten in vergelijking met Nederlanders zonder een migratieachtergrond, wat suggereert dat de omstandigheden voor het nemen van een geïnformeerde beslissing niet optimaal of gelijk zijn voor alle individuen. Het vermogen om gezondheidsinformatie te verkrijgen, te verwerken en te begrijpen, d.w.z. gezondheidsvaardigheden, lijken hierbij van grote invloed.

#### **De rol van sociale netwerken bij het nemen van screeningsbeslissingen**

Turks- en Marokkaans-Nederlandse immigranten overleggen bij de beslissing om deel te nemen aan screening op ziekte met hun partner, goede vrienden, dochters en huisarts. We vonden ook *clustering* van vergelijkbare screeningsintenties in sociale netwerken van Marokkaanse immigranten in Nederland. Dit kan er op wijzen dat iemands sociale netwerk, in plaats van het individu, een belangrijke rol speelt bij het nemen van screeningsbeslissingen en dat ook rekening moet worden gehouden met kennissen rond de persoon die de screeningsbeslissing neemt bij het informeren over en uitnodigen voor screeningsprogramma's.

#### **Interventies ter ondersteuning van (geïnformeerde) besluitvorming**

Huidige informatiematerialen met betrekking tot de drie Nederlandse bevolkingsonderzoeken naar kanker kunnen worden beschouwd als traditioneel niet-narratieve gezondheidsvoorlichtingsmaterialen die overwegend gebaseerd zijn op feiten, cijfers en statistieken. Onze studie laat zien dat de toevoeging van een cultuur sensitieve educatieve video tot een meer positieve houding ten opzichte van het bevolkingsonderzoek mogelijk maakt in vergelijking met de huidige informatiebrochure. Hoe informatie wordt aangeboden, maakt duidelijk verschil. Turkse en Marokkaanse Nederlanders maken minder gebruik van gedrukte media en meer gebruik van audiovisuele media. Dit wordt bevestigd door onze bevinding dat de video veel vaker werd bekeken dan de huidige informatiebrochure door zowel Turks- als Marokkaans-Nederlandse interventierespondenten aan wie beide werden aangeboden en dat de brochure door de interventiegroep (met de video) vaker werd geraadpleegd. Afhankelijk van het doel van het communicatiemateriaal (bijv. het verhogen van de deelname, het vergemakkelijken van geïnformeerde beslissingen), kunnen beleidsmakers en communicatieprofessionals beargumenteerd kiezen voor gedrukte of audiovisuele media, rekening houdend met de voor- en nadelen van elke wijze van aanbieden.



Daarnaast geeft dit hoofdstuk een aantal methodologische overwegingen en eindigt het met aanbevelingen voor toekomstig onderzoek en implicaties voor beleid en praktijk.

Voor **toekomstig onderzoek** met betrekking tot besluitvorming in de preventieve gezondheidszorg onder immigrantenpopulaties, bevelen we het volgende aan:

- ontwikkel en valideer een nieuwe maat voor geïnformeerde of weloverwogen besluitvorming voor bevolkingsonderzoeken naar kanker
- maak gebruik van verschillende methoden, zowel *offline* als *online*, om diverse immigrantenpopulaties te bereiken
- voer pilotstudies uit om te beoordelen of een specifieke immigrantenpopulatie verschilt in (geïnformeerde besluitvorming tot) deelname aan preventieve gezondheidsprogramma's vergeleken met Nederlanders zonder een migratieachtergrond of andere immigrantenpopulaties
- onderzoek de effectiviteit van (audiovisuele) narratief-gebaseerde gezondheidscommunicatiematerialen bij verschillende populaties om een mogelijke verschuiving in de aard van de informatievoorziening te overwegen

Tot slot adviseren wij voor **beleid en praktijk**:

- etniciteit te registreren om mogelijke gezondheids(zorg)verschillen onder immigrantenpopulaties te identificeren en hierop te kunnen handelen
- persoonlijke voorlichtingsbijeenkomsten te organiseren in verschillende talen, geleid door vertrouwde, gewaardeerde en competente sprekers, om kennislacunes te overbruggen
- geïntegreerd voorlichting te bieden aan verschillende (immigranten)populaties om het verband tussen primaire en secundaire preventie te verduidelijken (bijv. HPV-vaccinatie en het bevolkingsonderzoek naar baarmoederhalskanker)
- extra aandacht te besteden aan de toegankelijkheid en begrijpelijkheid van de huidige gezondheidsvoorlichtingsmaterialen, met name voor zogenaamd "moeilijk bereikbare" groepen
- aanvullend (audiovisueel) op maat gemaakte informatiematerialen te ontwikkelen samen met de doelgroep om aan hun informatiebehoeften te voldoen
- de zelfafnameset als standaardaanbod aan te bieden bij het bevolkingsonderzoek naar baarmoederhalskanker zodat het meer vrouwen mogelijk wordt gemaakt om deel te nemen aan dit bevolkingsonderzoek

## Curriculum vitae

Nora Hamdiui was born on 15 July 1992 in Arnhem, the Netherlands. After completing her secondary education at the Beekdal Lyceum in Arnhem in 2009, she obtained her bachelor degree Biology and Medical Laboratory Research at the Hogeschool van Arnhem en Nijmegen in Nijmegen in 2013. After working for a year at the Radboudumc as a Diagnostic Molecular Scientist, she was eager to study the master Biomedical Sciences. After a pre-master of a year, she started her master Biomedical Sciences with a specialisation in Epidemiology at the Radboud University in Nijmegen and graduated with honours in 2017.

During her last internship at the National Coordination Centre for Communicable Disease Control (LCI) of the National Institute for Public Health and the Environment (RIVM), she studied the determinants of the intention to participate in chronic hepatitis B screening among Moroccan immigrants in the Netherlands (that later became part of her thesis).

After this internship, she started working in 2017 as a junior researcher at the LCI of the RIVM and followed up on her earlier performed studies. She also wrote a ZonMw grant application on informed decision-making regarding cervical cancer screening among Turkish- and Moroccan-Dutch women. By receiving this grant, she started her PhD in 2019 at the department of Primary and Community Care of the Radboudumc and the LCI of the RIVM, resulting in this thesis. The aim of her PhD thesis was to examine how Turkish- and Moroccan-Dutch immigrants can be reached and informed best on preventive health-care services for informed decision-making on participation. To that end, she used two examples, namely screening for chronic hepatitis B (HBsAg screening) and preliminary stages of cervical cancer (CC screening).

Since 2021, Nora works as a postdoctoral researcher at the LCI of the RIVM. Her research continues to focus on decision-making regarding preventive health-care services among several hard-to-reach populations in the Netherlands (including immigrants), with, at current, a specific focus on COVID-19 contact tracing and the COVID-19 vaccination.

## List of publications

### Published papers

**Hamdiui N**, Stein ML, van der Veen YJJ, van den Muijsenbergh METC, van Steenbergen JE. Hepatitis B in Moroccan-Dutch: a qualitative study into determinants of screening participation. *European Journal of Public Health*. 2018; 28(5):916-922.

**Hamdiui N**, Stein ML, Timen A, Timmermans D, Wong A, van den Muijsenbergh METC, van Steenbergen JE. Hepatitis B in Moroccan-Dutch: a quantitative study into determinants of screening participation. *BMC Medicine*. 2018; 16(1): 47.

**Hamdiui N**, Buskens V, van Steenbergen JE, Kretzschmar MEE, Rocha LEC, Thorson AE, Timen A, Wong A, van den Muijsenbergh M, Stein ML. Clustering of chronic hepatitis B screening intentions in social networks of Moroccan immigrants in the Netherlands. *BMC Public Health*. 2020; 20(1): 344.

**Hamdiui N**, van Steenbergen J, Rocha LEC, Meiberg A, Urbanus A, Ait Hammou N, van den Muijsenbergh M, Timen A, Stein ML. Hepatitis B screening among immigrants: How to successfully reach the Moroccan community. *Journal of Viral Hepatitis*. 2021; 28(12): 1759-1762.

**Hamdiui N**, Marchena E, Stein ML, van Steenbergen JE, Crutzen R, van Keulen HM, Reis R, van den Muijsenbergh METC, Timen A. Decision-making, barriers, and facilitators regarding cervical cancer screening participation among Turkish and Moroccan women in the Netherlands: a focus group study. *Ethnicity & Health*. 2021: 1-19.

Helms YB, **Hamdiui N**, Kretzschmar MEE, Rocha LEC, van Steenbergen JE, Bengtsson L, Thorson A, Timen A, Stein ML. Applications and Recruitment Performance of Web-Based Respondent-Driven Sampling: Scoping Review. *Journal of Medical Internet Research*. 2021; 23(1): e17564.

Helms YB, **Hamdiui N**, Eilers R, Hoebe C, Dukers-Muijrers N, van den Kerkhof H, Timen A, Stein ML. Online respondent-driven detection for enhanced contact tracing of close-contact infectious diseases: benefits and barriers for public health practice. *BMC Infectious Diseases*. 2021; 21(1): 358.

### Submitted papers (Under Review)

**Hamdiui N**, Bouman MPA, Stein ML, Crutzen R, Keskin D, Afrian A, van Steenbergen J, van den Muijsenbergh METC, Timen A. The development of a culturally sensitive educational video: how to facilitate informed decisions on cervical cancer screening among Turkish- and Moroccan-Dutch women.

**Hamdiui N**, Stein ML, van Steenbergen J, Crutzen R, Bouman MPA, Khan A, Çetin M, Timen A, van den Muijsenbergh METC. Evaluation of a web-based culturally sensitive educational video to facilitate informed cervical cancer screening decisions among Turkish- and Moroccan-Dutch women aged 30 to 60 years: A randomised intervention study.

## PhD portfolio

**Name PhD candidate:** N. Hamdiui

**Department:** Primary and Community Care

**Graduate School:** Radboud Institute for Health Sciences

**PhD period:** 01-09-2017 – 03-12-2021

**Promotors:** Prof. dr. M.E.T.C. van den Muijsenbergh, Prof. dr. A. Timen

**Copromotors:** Dr. M.L. Stein, Dr. J.E. van Steenberghe

Training activities	Hours
<b>Courses</b>	
- RIVM - Begin-R cursus (2018)	8.40
- RIVM - Gebruik-R cursus (2018)	8.40
- RIVM - Exp-R cursus (2018)	8.40
- RIVM - Vis-R cursus (2018)	8.40
- INSNA - Conducting a Network Study from Start to Finish (2018)	11.20
- RIVM - Introductie workshop Kwalitatief onderzoek (2018)	11.20
- RIVM - Realist Evaluation workshop (2018)	11.20
- RIVM - Participatory Action Research Workshop (2018)	5.60
- RIVM - Radboudumc - Scientific integrity (2019)	20.00
- RIHS - Introduction course for PhD candidates (2019)	15.00
- Centre for Business Network Analysis - Sampling of hard-to-reach Populations with SNA (2019)	11.20
- Centre for Participatory - Participatory Learning & Action Techniques (2019)	44.80
- RIVM - Learn-R cursus (2019)	8.40
- EMWO - BROK (2019)	42.00
- Scientific Writing for PhD candidates (2019)	84.00
- Qualitative Research Methods and Analysis (2019)	84.00
- RU - Loopbaanmanagement voor Promovendi (2020)	28.00
- RIVM - Q-Methodology: An introduction (2020)	2.50
- RU - Writing a peer review (2021)	1.50
<b>Seminars</b>	
- RIVM - Journal Club (2019)	28.00
- RIVM - Journal Club (2020)	28.00
- EBM Refereerbijeenkomst (oral) (2020)	10.00
- Alliantie - Bijeenkomst onderzoeksgroep Gezondheidsverschillen (oral) (2021)	10.00
- Gezondheidsvaardigheden en ACHC - Online netwerkbijeenkomst - Gezondheidsvaardigheden en misinformatie (2021)	3.00

Training activities	Hours
<b>Conferences</b>	
- 7th Games for Health Europe Conference - Transformation (2017)	14.00
- Virology Education - Nationale Hepatitis Dag 2017 (2017)	7.00
- ICT&health Conferentie 2018 (2018)	7.00
- UU - Symposium "Complex dynamics of infectious diseases" (2018)	2.80
- Radboudumc - Symposium 'Persoonsgerichte, integrale eerstelijnszorg' en oratie van Maria van den Muijsenbergh (2018)	5.60
- VvE werkgroep Junior epidemiologen - Symposium: Your Epidemiological Career Your Future (2018)	5.60
- Nederlands Congres Volksgezondheid – Preventie is een mindset (oral) (2018)	14.00
- RIVM - Dutch Epidemiology Conference (WEON) (poster) (2018)	14.00
- NHG - Wetenschapsdag - Bruggen bouwen tussen onderzoek en praktijk (oral) (2018)	14.00
- INSNA - XXXVII Sunbelt Conference (oral) (2018)	42.00
- Stichting Gezondheid Allochtonen Nederland - Symposium "Allochtonen en gezondheid" (2018)	7.00
- 8th Games for Health Europe Conference – Prove and Move (oral) (2018)	28.00
- BIN NL - Dag van het gedrag 2018: 'Nederland loopt voorop' (2018)	7.00
- Pre-conference 11th European Public Health Conference: Winds of change in health promotion to improve public health (2018)	7.00
- 11th European Public Health Conference – Winds of change: towards new ways of improving public health in Europe (oral) (2018)	42.00
- Amsterdam UMC - Symposium on HPV-induced cancers: new developments in prevention and treatment (2019)	5.60
- UvA - 'Health, Behaviour and Society' - FMG conference 2019 (2019)	7.00
- Promovendi Netwerk RIVM (Proneri) PhD retreat (2019)	14.00
- RIVM - 2e Nederlandse HPV-onderzoeksdag: Future perspectives of HPV prevention: vaccination and screening (2019)	7.00
- 12th European Public Health Conference – Building bridges for solidarity and public health (oral) (2019)	42.00
- European Scientific Conference on Applied Infectious Disease Epidemiology 2019 (poster) (2019)	35.00
- Radboud University Network on Migrant Inclusion (RUNOMI) Conference 2020 (oral) (2020)	14.00
- RIVM - Online congres 'Bevolkingsonderzoeken in beeld (en geluid)' (oral) (2021)	42.00

Teaching activities	Hours
<b>Supervision of internships / other</b>	
- RIVM - Review abstracts Dutch Epidemiology Conference (WEON) (2018)	2.80
- Review scientific publication (2018)	3.00
- RIVM - Co-organizing a 1-2 day PhD retreat (2019)	56.00
- Yannick Helms VU MSc Global Health (2019)	49.00
- Eline Marchena VU MSc Health Sciences (2019)	49.00
- Nadia Ait Hammou VU MSc Health Sciences (2019)	49.00
- Loussi Bedrosian HAN BSc Biologie en Medisch laboratoriumonderzoek (2020)	49.00
- Damla Keskin VU MSc Health Sciences (2020)	49.00
- Amina Afrian VU MSc Health Sciences (2020)	49.00
- Abresham Khan VU MSc Biomedical Sciences (2021)	49.00
- Miyase Cetin VU MSc Health Sciences (2021)	49.00
- Review scientific publication (2021)	3.00
<b>Total</b>	<b>1,333.60</b>

## Research data management

This page contains information on how research data were collected, stored, and protected during the course of this PhD. The term **research data management** is defined as *"the organisation of research data, meta-data, and documentation throughout the scientific life-cycle, from planning and creation up to dissemination and long-term archiving, to ensure data quality, minimize risks, save time, and comply with legal, ethical, institutional, and funders' requirements regarding prescribed standards of research integrity and data reusability"*.

All digital data obtained during this PhD are stored at a secured server of the National Institute for Public Health and the Environment (RIVM), department National Coordination Centre for Communicable Disease Control (LCI). To ensure reproducibility of the analyses performed, transcripts (qualitative), raw data (quantitative), coding files (ATLAS.ti and MAXQDA), and scripts (R and STATA) are stored at a secured server of the RIVM/LCI.

In Chapters 2 and 6 of this thesis, qualitative data were collected through semi-structured interviews and focus group discussions, respectively. These studies were conducted in accordance with the principles of the Declaration of Helsinki, for which ethical clearance was obtained from the Medical Ethics Review Committee of the University Medical Centre Utrecht. The Committee confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply to these studies (Chapter 2 – nr. 16-621/C, Chapter 6 – nr. 19-251). Written informed consent was obtained prior to the interviews and discussions. All transcripts were processed and stored anonymised. Contact details of the participants, necessary to conduct the study, were stored separately from the other data during data collection, and have been destroyed afterwards.

In Chapters 3, 4, 5, and 8 of this thesis, quantitative data were collected through paper- and/or web-based questionnaires. These studies were conducted in accordance with the principles of the Declaration of Helsinki, for which ethical clearance was obtained from the Medical Ethics Review Committee of the University Medical Centre Utrecht. The Committee confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply to these studies (Chapters 3 and 4 – nr. 16-621/C, Chapter 5 – nr. 18-679/C, Chapter 8 – nr. 20/105). Respondents were asked to give their written or digital informed consent prior to their participation. Since we used respondent-driven sampling (RDS) (i.e. respondents were asked to forward paper- or web-based questionnaires to peers) and also incentives to stimulate peer recruitment, respondents were asked to give their e-mail address and/or postal address to receive questionnaires for their peers and/or to receive an incentive. These personal data were stored separately from their questionnaire answers during data collection.

These data have been destroyed after data collection for all respondents, except for those that have indicated willingness to participate in similar future studies. For these latter respondents, their contact details are stored securely (located in a folder on a secured server of the RIVM/LCI that only a limited number of involved researchers have access to and are also requested to enter a password). Anonymous paper-based questionnaires will be handed over to the archive department of the RIVM and saved in accordance to the Dutch regulations conform organisational guidelines.

In Chapter 7 of this thesis, we developed a culturally sensitive educational video. Turkish- and Moroccan-Dutch women portrayed in this video gave their written informed consent to publish and reproduce all photo- and film materials produced for this research project in the media for an indefinite period of time.

An existing web-based RDS platform was used to collect web-based questionnaire data. Access to the Operator interface of this platform is secured with two factor authentication. An Operator must log in with an e-mail address and a password with a minimum length and a combination of symbols, and this password should be renewed every 50 days. A unique and temporary code should additionally be entered using Google Authenticator. The RDS software is hosted on secured servers and the database is encrypted. The software has been extensively tested against the Open Web Application Security Project (OWASP) guidelines by an external penetration tester. The RDS platform meets the EU General Data Protection Regulation (GDPR).

## Dankwoord

Na het afstuderen had ik nooit gedacht dat ik zou gaan promoveren. Het leek mij een langdurig proces waarvan je van tevoren zeker moet weten dat je het een lange tijd leuk blijft vinden. Toch voelde ik tijdens het schrijven van de subsidieaanvraag dat dit onderwerp mij raakt en veel voldoening geeft, en wist ik zeker dat ik graag een promotieonderzoek zou willen doen. Terugkijkend op het proces is het bijzonder en enorm leerzaam geweest. Ik kijk er met veel trots op terug, maar zonder de steun en hulp van mijn begeleiders, collega's, familie en vriendinnen was het nooit gelukt.

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Aura, ik heb veel bewondering voor hoe je als hoofd van de LCI (ook tijdens de coronacrisis) oog had voor mijn (leer)proces en mij de ruimte bood om te reflecteren. Ik ben jou enorm dankbaar voor je scherpe blik, vertrouwen en alle kansen die je mij gegeven hebt. Laten we, ondanks dat je nu in Nijmegen zit, elkaar niet uit het oog verliezen en samen mooie projecten voortzetten.

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Dit proefschrift was er nooit geweest zonder de vele geweldige stichtingen, buurthuizen, moskeeën en andere organisaties die geholpen hebben bij het werven



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