

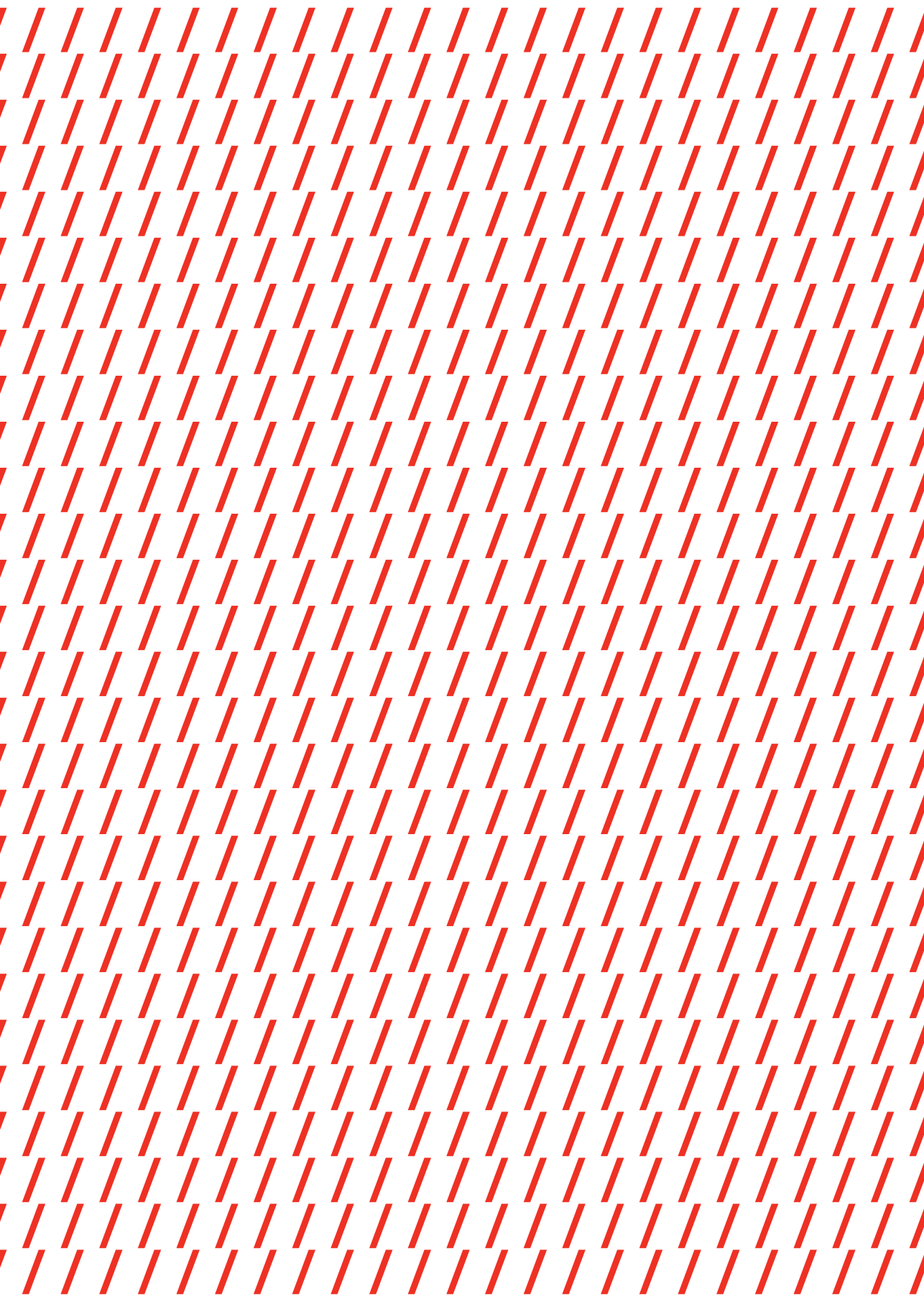


MIRJAM  
FRANSEN

# Ethnic Differences in Prenatal Screening for Down Syndrome

Information, decision-making and participation







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# Ethnic Differences in Prenatal Screening for Down Syndrome:

information, decision-making and participation

# Etnische Verschillen in Prenatale Screening op Downsyndroom:

informatie, besluitvorming en deelname

## Proefschrift

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Erasmus Universiteit Rotterdam  
op gezag van de  
rector magnificus

Prof.dr. H.G. Schmidt

en volgens besluit van het College voor Promoties.  
De openbare verdediging zal plaatsvinden op

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door  
Mirjam Petronella Fransen  
geboren te Venray



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Prof.dr. H.J. de Koning  
Prof.dr. K. Stronks

Copromotoren: Dr. M.L. Essink-Bot  
Dr. H.I.J. Wildschut

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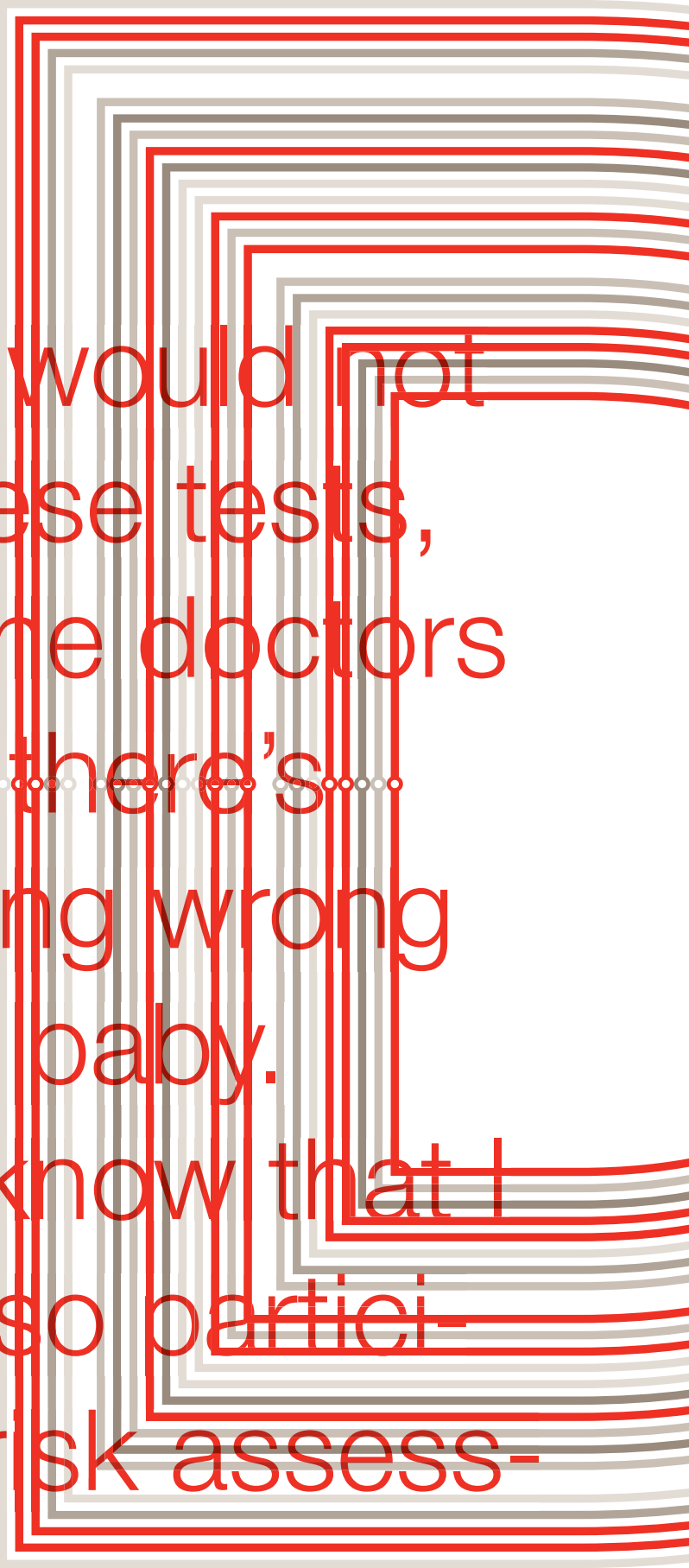




Introduction

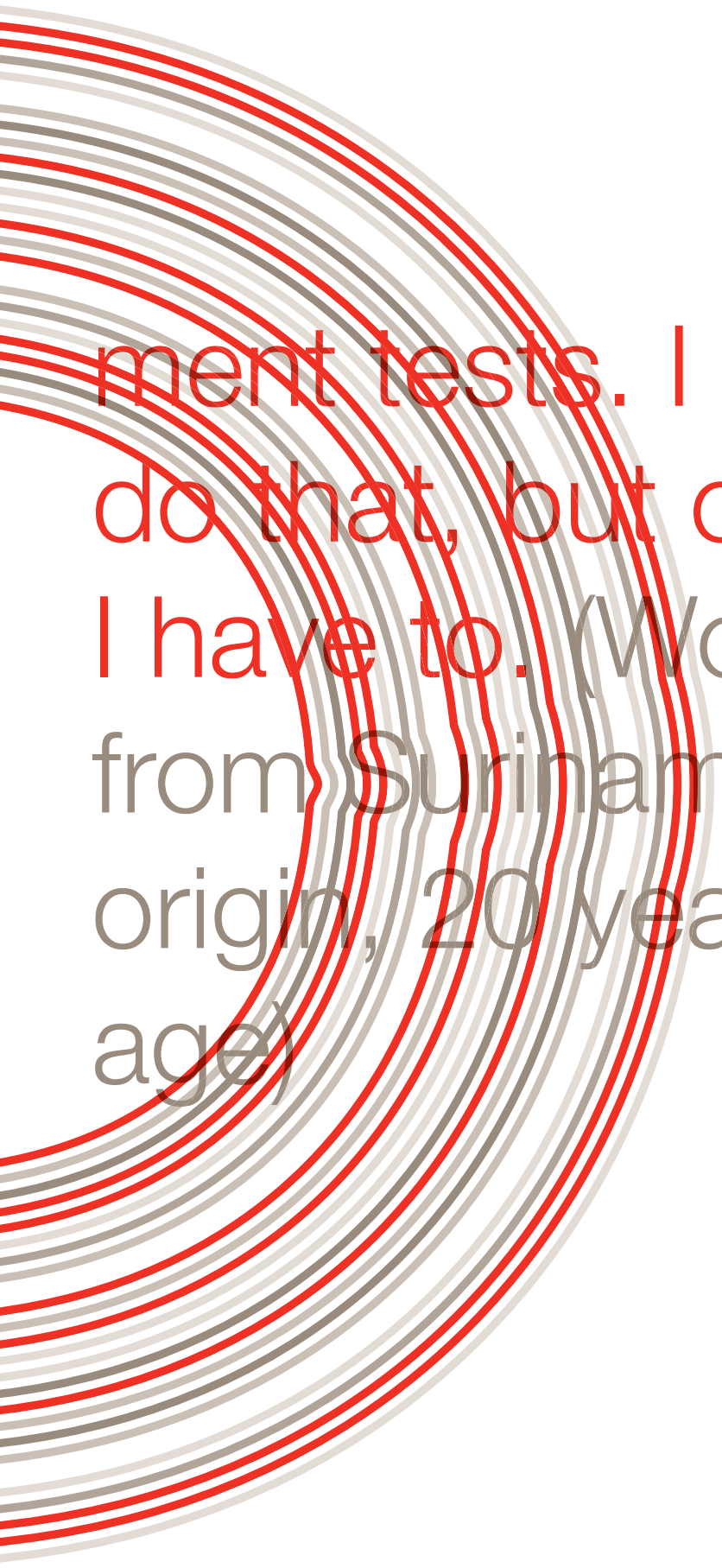
# Part

# I



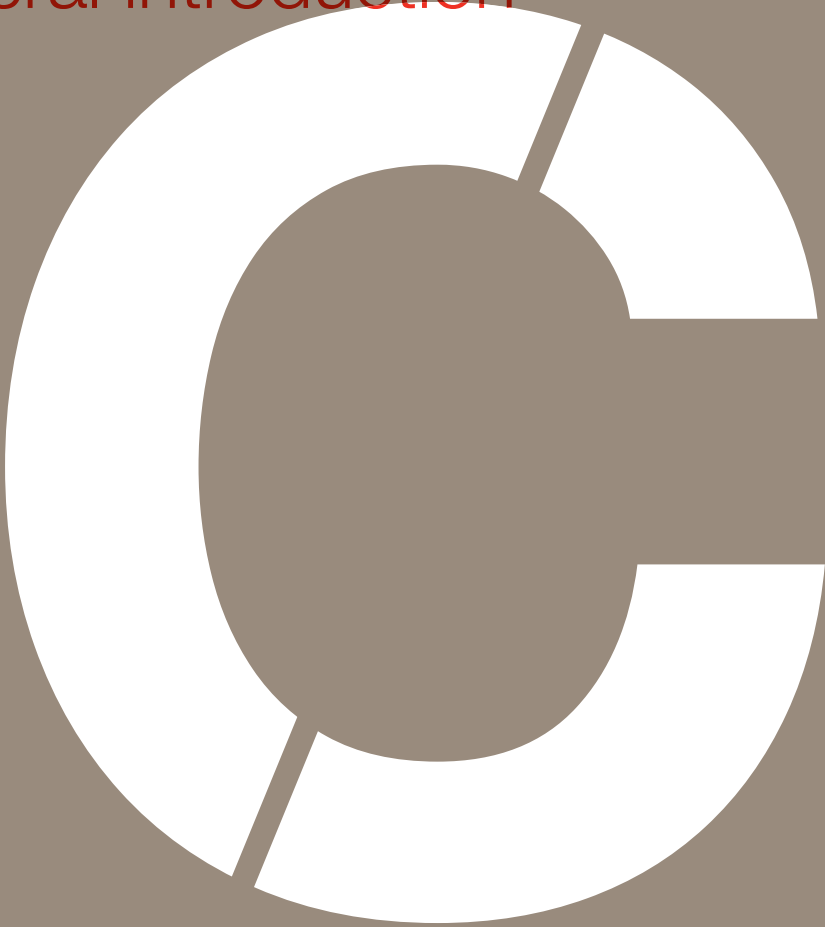
I simply would not  
want these tests,  
unless the doctors  
told me there's...  
something wrong  
with the baby.

I didn't know that I  
could also partici-  
pate in risk assess-



ment tests. I would  
do that, but only if  
I have to. (Woman  
from Surinamese  
origin, 20 years of  
age)

General introduction





Pregnant women and their partners are increasingly confronted with choices whether or not to participate in prenatal screening for structural, genetic, and chromosomal disorders, such as Down syndrome. Studies in several countries have documented ethnic differences in the provision of information about prenatal screening and Down syndrome, pregnant women's knowledge and attitude and their participation in prenatal screening for Down syndrome.<sup>1-27</sup> This thesis addresses the question whether such differences also exist in the Netherlands, where 20% of the population currently consists of individuals from non-Dutch ethnic origin.

The research as presented in this thesis reports on studies on ethnic differences in the provision of information about prenatal screening for Down syndrome, pregnant women's knowledge about prenatal screening and Down syndrome, their decision-making process and actual (non-) participation in prenatal screening for Down syndrome.

This introductory chapter first provides background information on Down syndrome, prenatal screening tests, the Dutch prenatal screening practice and the multi-ethnic population in the Netherlands.

The aim and outline of the thesis are presented at the end of this chapter.

## 1.1 Down syndrome

Down syndrome is the most common chromosomal abnormality in live born children and the most frequent chromosomal cause of intellectual disability.<sup>28</sup> It is caused by a complete or a partial trisomy of chromosome 21. The extra chromosome 21 causes characteristic physical features (epicanthic folds, flat nasal bridge, protruding tongue and open mouth) and mental retardation in people with Down syndrome.<sup>29</sup> Moreover, people with Down syndrome have an increased risk of congenital anomalies, such as congenital heart defects, and additional health-related problems, including behavioural and psychiatric problems and Alzheimer's disease.<sup>29, 30</sup> Although the life expectancy at birth of people with Down syndrome has increased from 12 years in the 1940s to 60 years in present populations in Western countries, the neonatal and infant mortality still is respectively 5 to 8 times higher in people with Down syndrome compared with the general population.<sup>31, 32</sup>

On average, 1 out of 500 live born children in the Netherlands is diagnosed with Down syndrome.<sup>33</sup> The risk of carrying a fetus with Down syndrome increases with the mother's age.<sup>34, 35</sup> The birth prevalence is not only determined by the distribution of maternal age in the general population, but also by the uptake of prenatal screening tests for Down syndrome and subsequent termination of pregnancy.<sup>36-39</sup> The birth prevalence, adjusted for fetal loss (attrition) and pregnancy termination for Down syndrome in the United Kingdom, is estimated at 1/1341 for a 25-year-old woman and increases to 1/354 at the age of 35. At the age of 45, the probability of carrying a child with Down syndrome increases to 1/36.<sup>35</sup>

## 1.2 Prenatal tests for Down syndrome

Presently available tests for prenatal screening for Down syndrome can be classified to risk assessment tests and diagnostic tests. Risk assessment tests give an estimation of the probability that the fetus has Down syndrome. The diagnostic tests provide certainty about whether or not the fetus has Down syndrome. Both types of tests can be considered as parts of the prenatal screening programme, where risk assessment tests are used to identify women with a high probability of carrying a fetus with Down syndrome, and diagnostic tests are offered in the stage of diagnostic work-up of the programme, to confirm whether or not the fetus has Down syndrome. This screening concept differs from diagnosis. Diagnostic tests are generally applied to people who actively seek healthcare services to identify the cause of their illness. Screening focus on individuals with no known symptoms and complaints related to the condition of interest and is defined as a procedure to help identify, in an organized way, a specified disease or condition among asymptomatic individuals.<sup>40</sup>

### 1.2.1 Risk assessment tests

The most commonly used risk assessment test in the Netherlands is the combined test. The combined test involves the assessment of free  $\beta$ -hCG and PAPP-A in maternal blood between 9 and 14 weeks (first trimester serum screening), and the ultrasound assessment of fetal nuchal translucency thickness between 11 and 14 weeks' gestation. The individual probability of carrying a child with Down syndrome is subsequently estimated on the basis of the biochemical and ultrasound findings, together with maternal age.<sup>41</sup> If this probability exceeds an a priori specified threshold at the time of testing, the woman is offered diagnostic testing.

In the Netherlands, the threshold of 1:200 at the time of testing is commonly used.<sup>42</sup>

### 1.2.2 Diagnostic tests

Commonly used prenatal diagnostic tests for Down syndrome are chorionic villus sampling (CVS) and amniocentesis (AMN). CVS is typically performed between the 10th and 14th week of gestation. Under ultrasound guidance, a sample of the placental tissue is obtained through the cervix or through the abdominal wall. AMN is performed in the second trimester of the pregnancy (earliest from the 15th week) and involves the aspiration of a 15-20 ml amniotic fluid through the abdominal wall under ultrasound guidance. Due to the invasive character of AMN and CVS, they are associated with an estimated procedure-related fetal loss of 0.3-0.8%.<sup>43</sup> AMN and CVS were implemented in the Netherlands since the 1970s and 1980s, respectively, and initially offered to women of advanced maternal age and to those with an increased risk of genetic and/or chromosomal abnormalities because of burdened personal or familial history. With the implementation of non-invasive risk assessment tests in standard prenatal care, the indications for AMN and CVS were extended to women of all ages whose individual risk assessment test showed a risk exceeding the threshold.

## 1.3 Prenatal screening practice in the Netherlands

In most Western countries, prenatal screening for Down syndrome, using risk assessment tests as well as diagnostic tests, has been offered as part of standard prenatal care for many years.<sup>44</sup> Women in France for example have been routinely offered prenatal screening, since a law on prenatal scree-

ning was implemented in 1997.<sup>37</sup> Also in the United States of America and Australia, women have been offered prenatal screening as part of standard prenatal care for many years.<sup>45, 46</sup> In the Netherlands, risk assessment tests have only recently been implemented in standard prenatal practice. From the 1970s to 2007, prenatal screening for Down syndrome was based on risk assessment by maternal age. Women aged 36 or above (until 1985 the threshold was 38 years or above) were initially offered AMN and CVS, because their age-related risk of carrying a child with Down syndrome was considered sufficiently high to compensate for the risk of procedure-related fetal loss associated with invasive testing methods.<sup>47</sup> The Population Screening Act (1996) stated that population screening for serious disorders that can neither be treated nor prevented is prohibited without ministerial approval.<sup>48</sup> As termination of pregnancy is considered as neither treatment nor prevention, population-based prenatal screening for Down syndrome by risk assessment tests was not allowed. After risk assessment tests became available for women of advanced maternal age, the Dutch Health Council advised the Ministry of Health to implement risk assessment tests in standard prenatal care. The Ministry of Health determined in June 2004 that all pregnant women have the right to be informed about prenatal screening for Down syndrome, whereas information should proactively be offered to pregnant women aged 36 or above and younger women should only receive information on their own demand.<sup>47, 49, 50</sup> In the following years the Ministry of Health decided that women under the age of 36 should also be offered information about prenatal screening and a national population-based screening program was developed for prenatal screening, which was officially implemented in prenatal practice since January 1st, 2007.<sup>33, 51, 52</sup> The

Ministry of Health formulated legal requirements for prenatal screening on the basis of Health Council recommendations on prenatal screening in the Population Screening Act.<sup>53</sup> It was determined that the prenatal screening programme should not be offered or financed by the government, but should be organised within the care sector. The Centre for Population Screening of the National Institute of Public Health and the Environment (RIVM) developed national guidelines for the prenatal screening programme and coordinates the organisation of prenatal screening. The first level in this organisation consists of the Central Agency that endorses requirements for national education and quality and promotes uniformity in the nationally distributed information material and agreements on national evaluations. The Central Agency is represented by patient associations, the Dutch Healthcare Inspectorate, healthcare insurers, representatives of medical specialist organisations and regional centres for prenatal screening. The Centre of Population Screening enforces decisions made by the Central Agency. The second level constitutes the regional centres for prenatal screening that conclude agreements with healthcare professionals and are responsible for safeguarding quality. The third level consists of the healthcare professionals who are responsible for adequately informing pregnant women about prenatal screening.<sup>42</sup> In fact, they are legally obliged to inform each pregnant woman about the options for prenatal screening at the booking visit. Women who express interest in screening, should be provided with further information about the nature of risk assessment tests and potential subsequent diagnostic evaluation, and should be offered counselling in decision-making.<sup>51, 53, 54</sup> Women aged 36 years or over still have an age-based indication for prenatal diagnostic testing and may directly choose for CVS or AMN. Women



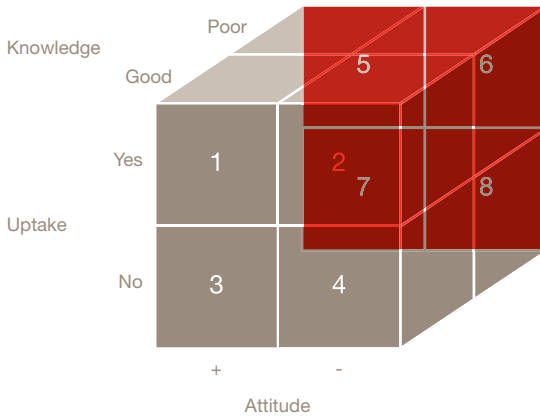


Figure 1.1  
 Multidimensional Measure of Informed Choice<sup>58</sup>

under 36 years of age are only eligible for risk assessment tests and have to pay for these tests themselves, unless they have a listed indication for diagnostic testing. If the test result indicates an increased risk of Down syndrome, the costs of diagnostic testing are reimbursed.<sup>55</sup>

### 1.4 Informed decision-making

The goal of providing information about prenatal screening to pregnant women is not to encourage uptake of prenatal screening, but to enable women (and their partners) to make an autonomous informed decision about whether or not to participate in prenatal screening for Down syndrome.<sup>33, 42, 47, 49, 50, 56</sup> According to the various definitions, an informed decision needs to be based on sufficient knowledge of relevant information about the benefits and limitations of the possible courses of action to take, and should be in accordance with the individual values and beliefs.<sup>6, 57, 58</sup> In order to quantify whether women made an informed deci-

sion about prenatal screening for Down syndrome, Marteau and Michie developed and validated a measure based on three dimensions: knowledge, attitude and behaviour, called the Multidimensional Measure of Informed Choice (MMIC).<sup>58, 59</sup> According to this measure, women make an informed decision when they have sufficient knowledge about Down syndrome and prenatal screening, and when their actual (non-) participation in prenatal screening is consistent with their attitude (Figure 1.1). It is believed that making an informed decision is associated with better psychological outcomes.<sup>6, 59</sup> A recent Dutch study among women who received a positive prenatal screening outcome (increased risk of having a child with Down syndrome) showed that women who had made an informed decision about prenatal screening for Down syndrome seemed to have a less adverse emotional reaction when confronted with the screening outcome and seemed to feel more able to make a decision about prenatal diagnostic testing than women who had not made an informed decision.<sup>60</sup> Dormandy applied the MMIC in a multi-ethnic population in the

UK and found that South Asian and Black African Caribbean women were less likely to make an informed decision on prenatal screening for Down syndrome than other women.<sup>4</sup>

## 1.5 Ethnic minority groups in the Netherlands

There are various definitions of ethnicity and measures to identify the ethnic origin of participants in healthcare research. In the studies that are presented in this thesis, we identified ethnic origin of the study population by country of birth criteria. In the Netherlands, these criteria are commonly used for the identification of ethnic groups. People are classified into ethnic groups on the basis of their country of birth and that of their parents. Someone is considered to be from non-Dutch ethnic origin when at least one of his or her parents was born abroad. In addition to these criteria, we used the method of self-identification to distinguish between different ethnic groups in the Surinamese population.<sup>61, 62</sup>

About 20% of the population in the Netherlands currently entails people from non-Dutch ethnic origin, and more than half of this group originate from non-Western countries. In the largest cities Amsterdam, Rotterdam and The Hague, 1 out of 3 individuals is from non-Western ethnic origin.<sup>63</sup> The largest non-Western groups originate from Turkey, Morocco, Surinam, the Dutch Antilles and Aruba. Turkish and Moroccan men came in the 1960s and 1970s to the Netherlands as labour migrants in order to perform unschooled jobs. From the mid-1970s on, many of them brought their families to the Netherlands and stayed permanently. In January 1st 2009, the Turkish group entailed 378330 inhabitants and is thereby the largest non-Western migrant group in

the Netherlands, being 2% of the Dutch population and 21% of all individuals from non-Western ethnic origin.<sup>63</sup> Surinam, the Dutch Antilles and Aruba are former colonies of the Netherlands and situated in northern South America. Suriname was colonised from the 17th century. The Dutch imported slaves from Africa and later contracted people from India to work at plantations. After Suriname gained independence in 1975, a large group of Surinamese people migrated to the Netherlands. In January 1st 2009, 338678 people from Surinamese origin were living in the Netherlands. Most of them are from South-Asian or Creole origin, a smaller part is from Javanese or other origin.<sup>63</sup>

Non-Western ethnic groups in the Netherlands generally have a lower income level and less often participate in the labour market than others.<sup>64</sup> Especially women from Turkish and Moroccan ethnic origin are less likely to have a paid profession for at least 12 hours per week compared to women from Dutch ethnic origin. This mostly applies to women who were not born in the Netherlands (first generation). Compared to women from Dutch ethnic origin, the likelihood (Odds Ratio, corrected for other background variables) to participate in the labour market in 2007 was 0.35 for first generation women from Turkish origin and 0.63 for the second generation in this group. For women from Moroccan origin, this was 0.28 for women in the first generation and 0.55 for women in the second generation.<sup>64</sup> In January 1st 2008, 48% of the individuals from Turkish and 45% of those from Moroccan ethnic origin belonged to the second generation ethnic minority group. First generation non-Western groups had an average age of 40 years, the second generation was on average 15 years old. People from Surinamese and Aruban/Antillean ethnic origin more often have 'mixed marriages' than people from Turkish and Moroccan ethnic origin. About 25% of the indi-

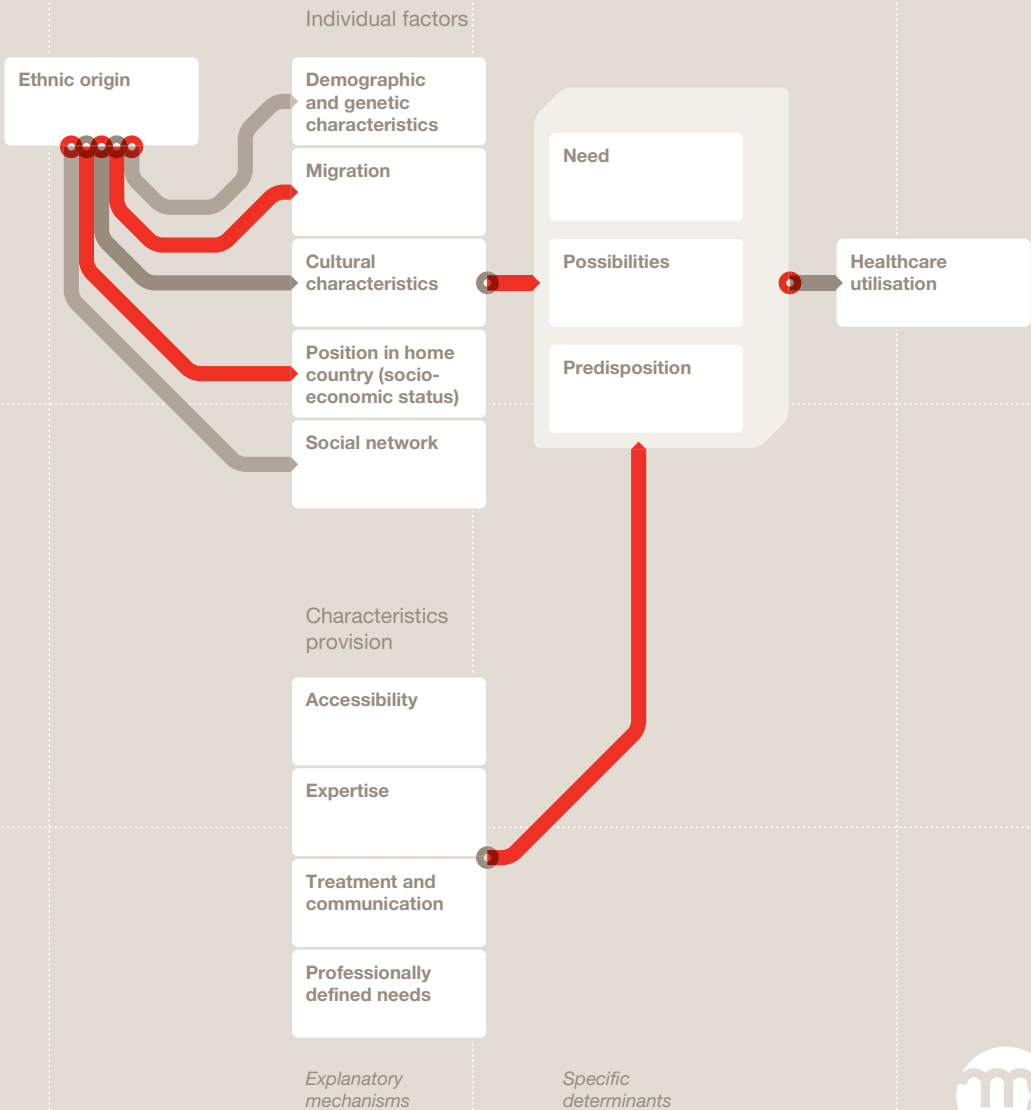
viduals from Turkish ethnic origin and 17% of those from Moroccan origin married to someone from their home country in 2006 and started a family in the Netherlands.<sup>64</sup> The average educational attainment level among non-Western ethnic minority groups in the population between 25 and 64 years old is much lower than in the Dutch group. Especially the individuals from the Turkish and Moroccan groups have a low educational attainment level. In 2006 it was found that about half of the women in the Turkish and Moroccan groups completed primary education or preparatory school at most, compared to 20% of the women from Surinamese and Aruban/Antillean origin and less than 10% among the ethnic Dutch population. More than 25% of the Dutch women completed higher professional education or university, this was respectively 22% and 21% among women in the Surinamese and Aruban/Antillean group, 10% among women in the Moroccan group and 7% among women in the Turkish group. First generation ethnic groups are generally lower educated than the second generation groups.<sup>64</sup> Since Dutch is an official language in the former colonies, individuals from Surinamese and Aruban/Antillean ethnic origin usually have less problems in speaking or understanding Dutch than those from Turkish and Moroccan origin. Only 47% of the individuals from Turkish, and 60% of those from Moroccan ethnic origin reported that they never have difficulties in speaking Dutch. Reading Dutch was no problem for 51% of the individuals in the Turkish and 63% of those in the Moroccan group. Language problems were less often reported by individuals from younger, higher educated, second-generation Turkish and Moroccan groups. More than 90% of the individuals from Surinamese ethnic origin reported never to have difficulties in speaking, reading and writing Dutch.<sup>65</sup> Almost all people from Turkish and Moroccan eth-

nic origin consider themselves as Muslims, but this does not mean that they all display religious behaviour to the same degree. Individuals from Moroccan origin more often exhibit active religious behaviour than Turkish people; i.e. they more often, fast during Ramadan, pray five times a day and follow halal diet on a daily basis.<sup>65</sup>

## 1.6 Ethnic differences in healthcare

The studies being presented in this thesis are embedded in the research area of ethnic variations in healthcare. Over the past years, research on ethnic disparities in health, healthcare utilisation and quality of healthcare has increased substantially in the Netherlands. Previous studies in this field generally showed that there are many variations in healthcare utilisation between the various ethnic groups in the Netherlands. The overall conclusion is that more research is needed to identify underlying factors of ethnic differences in healthcare utilisation and to formulate implications to improve healthcare.<sup>66</sup> A general framework to study ethnic differences in healthcare utilisation is the Behavioural Model of Utilisation, developed by Andersen, Aday and others. The model was developed in 1968 to assist in understanding why people use health services and is nowadays widely acknowledged as the most well known and most used framework for analysing factors that are associated with utilisation of healthcare services and access to healthcare.<sup>67</sup> The model suggests that utilisation is a function of a predisposition by people to use health services, factors that enable or impede such use, and people's need for care. Foets, Suurmond and Stronks adapted Andersen's model into a conceptual framework that integrates possible explanations of the relation between ethnic origin and healthcare

Figure 1.2 Conceptual framework that integrates possible explanations of the relation between ethnic origin and healthcare utilisation



utilisation and could be applied to determine ethnic differences in accessibility in healthcare and explain differences in healthcare utilisation (figure 1.2).<sup>68</sup> Ethnic differences in healthcare use could be explained by differences people have in the need, the possibilities and their predisposition to use healthcare. Possible underlying mechanisms of these three factors could be divided into individual factors and characteristics in the provision of healthcare. Individual factors include demographic and genetic characteristics (e.g. age); migration-related factors (e.g. unfamiliarity with the Dutch healthcare system); cultural factors (e.g. religion); socio-economic status (e.g. educational attainment level, poverty, housing quality); and social network (e.g. contact with the ethnic Dutch population). The provision of healthcare depends on the accessibility of healthcare (e.g. paying requirement for prenatal screening), the expertise and communication of the healthcare worker (e.g. utilisation of professional translators) and the professional defined needs (e.g. referral to specialists). These characteristics could be summarized by the term 'cultural competence' aiming at the ability of the healthcare organization to meet the needs of diverse populations and the ability of the healthcare professional to bridge cultural differences to build an effective relationship with a patient.<sup>69</sup> Cultural competence interventions at organisational and structural level have been described as efforts to ensure that the workforce of the healthcare delivery system is diverse and representative of its patient population and that the structural processes within healthcare systems guarantee full access to quality healthcare for all patients, e.g., interpreter services and culturally and linguistically appropriate health education material. Cultural competence interventions at clinical level have been described as efforts to enhance healthcare professional knowledge of the relationship between

socio-cultural factors, health beliefs and behaviours, and to equip healthcare professionals with the tools and skills to manage these factors appropriately.<sup>70</sup> Seeleman et al. distinguished cultural competencies in healthcare professionals' knowledge, attitudes and skills that can be considered essential for medical practice in an ethnically diverse setting and thereby emphasized that there are more dimensions to deliver high quality care than merely the cultural. Attitudes for example refer to healthcare professionals' awareness of the social contexts in which specific ethnic groups live and awareness of one's own prejudices and tendency to stereotype. Skills for example refer to the ability to transfer information in an intelligibly way and the ability to know when to seek external help with communication.<sup>71</sup>

## 1.7 Aim and research questions

The main aim of the research in this thesis is to assess ethnic variations in pregnant women's decision-making on participation in the prenatal screening programme for Down syndrome. This thesis addresses three central themes with the following specific research questions:

### Ethnic differences in knowledge and access to information

- 1) To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in their knowledge about Down syndrome and prenatal screening, and what is the contribution of ethnic differences in the information that is provided by midwives and gynaecologists?
- 2) To what extent do midwives experience differences and difficulties in providing information about prenatal screening for Down syndrome to pregnant women from diverse ethnic origin?

### **Ethnic differences in the decision-making process**

- 3) To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in informed decision-making on prenatal screening for Down syndrome, and what is the contribution of background characteristics and decision-making variables?
- 4) To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in uptake of prenatal screening for Down syndrome, and what considerations do they have whether or not to participate in prenatal screening?

### **Ethnic differences in the uptake of prenatal screening for Down syndrome**

- 5) To what extent did ethnic differences exist in the uptake of maternal age-based prenatal screening for Down syndrome in the Netherlands?
- 6) To what extent do ethnic differences exist in the participation in the current prenatal screening programme for Down syndrome in the Netherlands?

## **1.8 Overview of the thesis**

Table 1.1 gives an overview of the studies presented in this thesis. Part I of this thesis has started with the present chapter and continues with Chapter 2, introducing the 'Prenatal Screening Stage model' that has been developed on the basis of empirical literature and data from focus group interviews, and served as a framework to describe ethnic differences in the decision-making process regarding prenatal screening for Down syndrome. Part II describes ethnic differences in the provision of information about prenatal screening, from the viewpoint of pregnant women and healthcare

professionals. Chapter 3 describes differences in the type of information that Dutch, Turkish and Surinamese pregnant women reported to have received and its effect on their knowledge of Down syndrome and prenatal screening. Differences and difficulties that midwives experience in providing information to women from various ethnic backgrounds are described in Chapter 4.

In part III the focus is on ethnic variations in the process of deciding whether or not to participate in the prenatal screening programme. Chapter 5 presents ethnic differences in informed decision-making and describes to what extent background and decision-making variables contribute to these differences. Chapter 6 presents differences in uptake among Dutch, Turkish and Surinamese pregnant women and discusses their considerations whether or not to participate in prenatal screening.

Part IV of this thesis describes ethnic differences in participation in prenatal screening among larger populations of women in the Southwest of the Netherlands. Chapter 7 describes ethnic differences in the uptake of maternal age-based prenatal screening (AMN or CVS) in the region of Groot-Rijnmond, before non-invasive screening methods were implemented in Dutch prenatal care (2000-2004). Chapter 8 presents ethnic differences in the participation in the current prenatal screening programme for Down syndrome in the Southwest of the Netherlands in 2009.

In part V main results are put in a broader perspective and summarised. Chapter 9 provides an answer to the research questions, methodological considerations of the studies in this thesis, interpretation of the results in light of findings from other studies, and implications for further research and practice.

Table 1.1 Studies presented in this thesis

	CHAPTER	Study method	Study population	n	Focus of the study
Part I Introduction	2	Literature review and focus group interviews	Pregnant women from Dutch, Turkish and Surinamese ethnic origin in the Netherlands	27	Developing theoretical framework
Part II Ethnic differences in women's knowledge and access to information	3	Personal interviews	Pregnant women from Dutch, Turkish and Surinamese ethnic origin in the Netherlands	270*	Determining ethnic differences in information and knowledge about prenatal screening and Down syndrome
	4	Web-based questionnaire and group interview	All midwives in the region of Rotterdam	57	Assessing difficulties and differences in providing information about prenatal screening to women from diverse ethnic backgrounds
Part III Ethnic differences in the decision-making process	5	Personal interviews	Pregnant women from Dutch, Turkish and Surinamese ethnic origin in the Netherlands	270*	Determining ethnic differences in informed decision-making
	6	Personal interviews	Pregnant women from Dutch, Turkish and Surinamese ethnic origin in the Netherlands	270*	Determining ethnic differences in considerations whether or not to participate in prenatal screening
Part IV Ethnic differences in uptake of prenatal screening for Down syndrome	7	Registered-based	Pregnant women aged 36 years or over, who were living in Groot-Rijnmond between 2000 and 2004.	12340	Assessing ethnic differences in the uptake of maternal age-based prenatal screening for Down syndrome
	8	Registered-based	Pregnant women who were living in the South-West of the Netherlands between 1-1-2009 and 1-7-2009	15093	Assessing ethnic differences in the participation in the current prenatal screening programme for Down syndrome

\*Same population

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# Ethnic differences in determinants of participation and non-participation in prenatal screening for Down syndrome: A theoretical framework

Fransen MP, Essink-Bot ML, Oenema A, Mackenbach JP, Steegers EAP, Wildschut HJ. Ethnic differences in determinants of participation and non-participation in prenatal screening for Down syndrome: A theoretical framework. *Prenatal Diagnosis* 2007; 27: 938-950



# Abstract

**Objective** To develop a theoretical framework for analysing ethnic differences in determinants of participation and non-participation in prenatal screening for Down syndrome.

**Methods** We applied Weinstein's Precaution Adoption Process Model to the decision of whether or not to participate in prenatal screening for Down syndrome. The prenatal screening stage model was specified by reviewing the empirical literature and by data from seven focus group interviews with Dutch, Turkish and Surinamese pregnant women in the Netherlands.

**Results** We identified 11 empirical studies on ethnic differences in determinants of participation and non-participation in prenatal screening for Down syndrome. The focus group interviews showed that almost all stages and determinants in the stage model were relevant in women's decision-making process. However, there were ethnic variations in the relevance of determinants, such as beliefs about personal consequences of having a child with Down syndrome or cultural and religious norms.

**Conclusion** The prenatal screening stage model can be applied as a framework to describe the decision-making process of pregnant women from different ethnic backgrounds. It provides scope for developing culturally sensitive, tailored methods to guide pregnant women towards informed decision-making on participation or non-participation in prenatal screening for Down syndrome.

## 2.1 Introduction

Previous studies showed that ethnic groups in e.g., the United Kingdom, France and the United States, vary in their participation in prenatal screening for Down syndrome.<sup>1-9</sup> Women from ethnic minorities were less likely to participate in screening than Caucasian women. This was attributed to ethnic differences in knowledge of Down syndrome, attitude towards having a child with Down syndrome, influence of partner, family and health-care professionals, socio-economic factors and differences in the offer of prenatal screening.

To enable analysing such determinants systematically, we applied a theoretic behavioural stage model to participation and non-participation in prenatal screening for Down syndrome. The resulting prenatal screening stage model served as a framework in a prospective study that we initiated in Rotterdam, the Netherlands among pregnant women from Dutch, Turkish and Surinamese ethnic origin in 2006.

This paper describes the development of the prenatal screening stage model and the specification of the model by using data from a literature review and from focus group interviews with pregnant women from Dutch, Turkish and Surinamese origin. We first describe the theoretical background of the prenatal screening stage model and define the different stages in the model. Then we show how we

used results of the literature review as determinants of the transitions between the different stages, and how we tested the relevance of these stages and determinants in focus group interviews. We explain how this resulted into the final prenatal screening stage model that can be applied as a framework to describe the decision-making process of pregnant women from different ethnic backgrounds.

## 2.2 Methods

### Theoretical background of the prenatal screening stage model

We chose Weinstein's Precaution Adoption Process model to provide a theoretical framework for the decision of whether or not to participate in prenatal screening. The PAP model describes decision-making as a process and provides specific options for tailoring.<sup>10, 11</sup> This means that information and decision supporting interventions can be adapted to specific stages in the decision-making process and to the various barriers in the transition between these stages. For example, a woman who does not know anything about prenatal screening needs different information than someone who is already considering participation. The PAP model identifies several stages in any process of behaviour change (Figure 2.1).

Figure 1.2 Precaution Adoption Process Model



The model has been applied to other health related behaviours, such as participation in breast-cancer screening prevention of osteoporosis or eating fruit and vegetables.<sup>12-14</sup> Modelling the decision-making process in screening behaviour differs from most other behaviours, because in screening participation is not the behaviour to be promoted as such. The aim of offering screening for Down syndrome, and also for breast cancer, is not to increase participation, but to increase informed decision-making on whether to participate in screening or not.<sup>15</sup>

### First draft of the prenatal screening stage model

In the first application of the PAP model to prenatal screening behaviour we identified five stages starting from unawareness and ending with participation or non-participation in prenatal screening for Down syndrome. We made a distinction between women's awareness of Down syndrome and awareness of prenatal screening. We considered a woman to be aware of Down syndrome if she knows what Down syndrome is, what the consequences of Down syndrome are for her child and herself and that she is personally at risk of having a child with Down syndrome. Similarly, we considered a woman to be aware of prenatal screening if she knows about the goal and procedure of the prenatal screening programme. In order to transfer from the stages of 'awareness' to the subsequent stage of 'considering whether or not to participate in prenatal screening' a woman needs to have certain beliefs (opinions or views) about her personal risk, the consequences of Down syndrome for herself and her child and the goal and procedure of prenatal screening. When a woman makes a decision, she is assigned to the stage of 'deciding whether or not to participate in prenatal screening'. In the final stage of 'acting' a woman actually participates

or does not participate in prenatal screening for Down syndrome.

### Literature study

In May 2006, we used the following groups of keywords to search the databases Medline and Science Direct for articles that were written in English, German, French or Dutch:

*Prenatal screening OR prenatal testing OR amniocentesis OR chorionic villus sampling OR maternal serum screening OR nuchal translucency measurement OR triple test OR alpha fetoprotein OR antenatal screening OR prenatal diagnostic screening OR prenatal diagnosis OR antenatal care OR prenatal care AND Down OR Down's OR Downs OR Down syndrome OR trisomy 21 OR Downsyndrome OR chromosomal AND Ethnic differences OR ethnic group OR ethnic background OR socio-demographic OR socio-economic OR inequalities OR ethnic OR racial-ethnic OR race/ethnicity OR racial OR race OR non-English OR non-native*

We also hand-searched the references in the studies we found.

Inclusion criteria were:

- Papers describing results of empirical studies on ethnic differences in determinants of participation and non-participation in prenatal screening for Down syndrome, published after 1995 and including populations of non-native (and native) pregnant women.



Exclusion criteria were:

- Papers that only described ethnic differences in uptake of prenatal screening for Down syndrome and did not report on any determinants;
- Papers that described ethnic differences in prenatal test outcomes or in rates of termination of pregnancy after a prenatal diagnosis of Down syndrome;
- Papers that reported on cost-efficacy of prenatal screening in different ethnic groups;
- Papers that focused on prenatal screening for disorders other than Down syndrome;
- Papers not reporting empirical results.

Besides the specific determinants, we recorded which prenatal tests and populations were studied, the study design and the most important results. Determinants from the literature were entered in the model as determinants of the transitions between the different stages.

### Focus group interviews

We organized focus group interviews with pregnant Turkish, Surinamese and Dutch women to evaluate the relevance of the stage model and of the various determinants in the transitions between stages. Pregnant women were recruited from midwifery practices in Rotterdam and the outpatient clinic of the Department of Obstetrics and Gynaecology of the Erasmus MC/ University Medical Centre Rotterdam, the Netherlands. Inclusion criteria were 18 years or older, confirmed pregnancy and Dutch, Turkish or Surinamese ethnic background. We defined ethnic background by the standard definition of Statistics Netherlands.<sup>16</sup> A woman is considered to be non-native when at least one of her parents is born abroad, in this case Surinam or Turkey. When both parents are born in the Netherlands, a woman is considered to be native Dutch. The main questions were:

*Have you ever thought about whether or not to participate in prenatal screening for Down's syndrome and why or why not?*

*Can you explain why you would or did participate in prenatal screening or why not?*

We conducted seven focus group interviews: two with a total of ten Surinamese pregnant women; three with a total of twelve Dutch pregnant women; and two with a total of five Turkish women. All women were between 19 and 41 years old. The interviews took place at Erasmus MC in Rotterdam. The first author (MPF/ Dutch ethnic origin) moderated the Dutch and Surinamese focus group interviews and a moderator from Turkish ethnic background facilitated the interviews with the Turkish women. All interviews were audio recorded and summarized by two independent reviewers. The data were analysed by content analysis: segments of transcribed data were categorized and coded using the Nvivo software programme.<sup>17, 18</sup>

## 2.3 Results

### Results of the literature study

The literature search identified 256 studies, 11 of which met the inclusion criteria (Table 2.1). Six studies were performed in the United States, 2 in the United Kingdom, 2 in Australia and 1 in Israel. Seven studies explicitly aimed to identify ethnic differences in determinants to explain variations in screening participation.<sup>1-3, 5-7, 9, 19-22</sup> One study explored determinants of knowledge of prenatal screening.<sup>23</sup> Three studies solely explored determinants of participation and non-participation in a specific ethnic group in their country.<sup>24-26</sup> Usually, data were obtained before prenatal testing took place

or could have taken place. Focus group interviews were performed after test uptake in one study.<sup>21</sup> Three studies retrospectively reviewed prenatal care records.<sup>20, 25, 26</sup> Five studies evaluated both invasive and non-invasive prenatal tests.<sup>1, 5-7, 21-23, 25, 26</sup> Two focused specifically on invasive prenatal testing methods such as amniocentesis or chorionic villus sampling.<sup>9, 24</sup> Four described determinants in non-invasive prenatal testing methods such as combination test or maternal serum screening.<sup>2, 3, 19, 20</sup> Nearly all studies found ethnic differences in determinants of participation and non-participation in prenatal screening. We categorized the results of the literature study using constructs of the Theory of Planned Behaviour and Informed Choice.<sup>27,28</sup> In the Theory of Planned Behaviour, attitude, subjective norms and perceived behaviour control are considered to be independent determinants of behavioural intention that predicts behaviour. An informed choice is defined as a choice that is based on relevant knowledge, consistent with the decision-maker's attitude and behaviourally implemented. This categorisation resulted in the following determinants of transitions between the stages in the prenatal screening model: availability of prenatal screening, knowledge, attitude, subjective norms, religious norms and cultural norms.

### **Availability of prenatal screening for Down syndrome**

Ethnic differences were found in the availability of prenatal screening in Australia, with women of a non-English speaking background less likely to receive an invitation than native women.<sup>25</sup> The fact that non-native women start attending prenatal care at a more advanced stage of gestation precluding prenatal testing is mentioned as a possible cause.

### **Knowledge of Down syndrome and prenatal screening**

Caucasian women in the UK had significantly better knowledge of the syndrome than Asian women.<sup>2</sup> Factors affecting knowledge included the quality of spoken English, knowing an affected child, parity and religion.<sup>2</sup> Ethnic differences were also found regarding women's knowledge of prenatal screening. Knowledge of prenatal testing was higher in Caucasian women than in non-Caucasian women.<sup>3, 9, 19</sup> Women from non-English-speaking backgrounds were less likely than those from an English-speaking background to mention Down syndrome when they were interviewed about prenatal tests.<sup>23</sup>

### **Attitude towards prenatal screening for Down syndrome**

African-American women in the US who were less likely to undergo prenatal screening, had a significantly greater faith in God, a more fatalistic attitude towards Down syndrome, and expressed less desire of testing results.<sup>5</sup> White women assigned higher values to the birth of an unaffected child than African-Americans, Latinos and Asians.<sup>6</sup> This was in accordance with Moyer's finding that African-Americans would feel less negatively about having a child with Down syndrome and would be less willing to consider abortion. However, Asians and Pacific Islanders appeared to feel more negatively about having a child with Down syndrome than other women.<sup>21</sup> Mexican-origin women in the US who refused an amniocentesis were more sceptical about the accuracy and value of scientific information and reported a higher degree of discomfort with technology, machines and needles.<sup>24</sup> Women in Israel also mentioned the possibility of false alarms.<sup>26</sup> Asian women in the US were significantly less willing to pay for invasive prenatal screening than other women, after controlling for socio-economic status.<sup>1</sup>

Table 2.1 Articles reporting on empirical studies on ethnic differences in participation and non-participation in prenatal screening for Down syndrome.

Author / year	Determinants	Population	Aim	Design	Results
Browner, 1996	Knowledge of prenatal screening	Low-risk pregnant women of diverse ethnic and social class backgrounds n=130 USA	To test the hypothesis that women who saw an information video in addition to an information booklet would retain more information about the AFP-program than those who received only the booklet.	Cross-sectional Interviews within 3 months after receiving information	All women had been given an informational booklet about the test at the time it was offered; about half also saw a video. Neither group of women retained much of the information they had received about the prenatal screening, but those who saw the video remembered more. Information-retention also varied significantly by ethnicity and level of education.
Browner, 1999	Attitude towards doctors, medicine and prenatal care Risk assessment procedure Acculturation Influence of partner	Mexican-origin women who had screened positive for AFP and were deciding whether to undergo amniocentesis. Review of 379 charts Interview 147 women and 120 partners. USA	To examine the considerations taken into account by a group of Mexican-origin women who had screened positive for AFP and were deciding whether or not to undergo amniocentesis.	Cross-sectional Semi-structured interviews after amniocentesis decisions	A woman's attitudes toward doctors, medicine, and prenatal care and her assessment of the risk and uncertainty associated with the procedure were found to be most significant. Those who accepted more had a more positive attitude.  Women born in Mexico were significantly more likely than women born in the US to refuse amniocentesis. Acculturation and length of time in the US was not predictive for deciding to undergo amniocentesis.  The hypothesis that the partner would play an important role in the decision, particularly among less acculturated women was not supported by the findings.
Chilaka, 2001	Knowledge of Down syndrome Language Knowing affected child Parity Religion	Pregnant women booking for antenatal care at Leicester General Hospital over a 3-month period. n=245 UK 48% Caucasian 35% Asian born outside the UK 13% were Asian born in the UK 4% belonged to other categories  Mean age = 29 (17-41)	To assess level of awareness and understanding of DS in a cohort of women receiving hospital antenatal care and to identify racial differences in understanding of DS, and factors responsible for the differences.	Prospective Questionnaires at two points in time (before and after consultation)	33% of the cohort had a good knowledge of Down syndrome. 51% of the Caucasians had good knowledge of DS compared to 8% in Asian women born outside the UK and 31% of Asian women born in the UK (p=0.003). Asian women born in the UK had significantly better knowledge than Asians born elsewhere.  The factors, which affected knowledge of DS, included quality of spoken English, knowing an affected child, parity and religion. The most significant factor affecting acceptance of screening was the woman's knowledge of DS. Uptake of the screening test was best in those with good knowledge (53%) compared to those with poor knowledge (23%) (p<0.02).

Table 2.1 (continued)

Author / year	Determinants	Population	Aim	Design	Results
Caughey, 2004; Kuppermann, 2000; 2004; 2006; Learman, 2003	Procedure related miscarriage versus Down syndrome affected birth	Racially / ethnically and socio economi- cally diverse pregnant women presenting to one of the 23 obstetrics clinics and practices in San Francisco Bay Area in 1997 or 1998 who are less than 20 weeks pregnant.	Kuppermann 2000: To determine how pregnant women value the procedure-related miscarriage and Down syndrome affected birth using utility as- sessment.  Learman 2003: To explore women's at- titude towards testing and the role of external influences to better understand the social, cultural and familial context of prenatal tes- ting decision-making.	Cross-sectional  Prospective	Kuppermann 2000: No consistent relationship between demograph- ic factors and preference scores. Difference scores in all racial-ethnic groups were significantly greater than zero, suggesting that on average women in each of the group found the prospect of DS-affected birth more burdensome than procedure-related miscar- riage.  Learman 2003: Ethnic differences in the views of motherhood, the acceptance of Down's syndrome by self, family and community, influence of family, faith and religion and influence of others on decision-making.  Asian women were more likely to state that their family's feelings about having a child with DS would influence their decisions.  Social and familial contexts for prenatal testing decisions differed among racial/ethnic groups even after accounting for age, marital status, and other socio-economic factors. However, racial/ethnic differences appeared to explain only a relatively modest amount of the variation in pregnant women's attitudes towards testing, disabili- ties, and degree of external influence in decision-making (15%).
(Five papers based on the same data- set)	Attitude prenatal screening  Social influences  Religion  Risk miscarriage  Willingness to pay	n= 1084  USA	Caughey 2004: To investigate the demand for invasive prenatal diagnostic testing by using estimates of wil- lingness to pay.  Kuppermann 2004: To explore how pregnant women value the potential outcomes of prenatal testing for chromosomal disorders.  Kuppermann 2006: To identify predictors of prenatal genetic testing decisions and explore whether racial or ethnic and socio-economic differences are ex- plained by knowledge, attitudes, and preferen- ces (2006).		Caughey 2004: Among women who were interested to undergo prenatal diagnostic testing, Asian Women were less willing to pay for testing, even after controlling for age, income and education.  Kuppermann 2004: Highest preference scores were assigned to outcomes resulting in the birth of a chromosomally normal infant (mean = 0.91-0.93; median = 0.99-1.00). Lower scores were ob- tained for outcomes involving pregnancy loss (mean = 0.69-0.87; median = 0.76-0.92), which were correlated with attitudes regarding miscarriage, pregnancy termination, and Down syndrome. The lowest scores were assigned to DS-affected births (mean = 0.67 - 0.69; median = 0.73-0.75), which also were correlated with attitudes toward Down syndrome. White women had higher utilities for unaf- fected birth than did women from the other groups (0.95 versus 0.90 for African-Americans and 0.91 for Latinos and Asian (p=0.001)).  Kuppermann 2006: Among women aged less than 35 years, no ra- cial or ethnic differences in test use emerged. Among women aged 35 years or older, observed racial or ethnic and socio-economic dif- ferences in testing strategy were mediated by religious and fatalistic attitudes towards screening, desirability of testing information, and perceived miscarriage risk.  Multivariable predictors of testing strategy included these 3 me- diators (P = .035, P < .001, P = .037, respectively) and health care system distrust (P = .045).

<p>Author / year                  Dormandy, 2005</p>	<p>Determinants                  Knowledge prenatal screening                  Attitude prenatal screening</p>	<p>Population                  Pregnant women attending two UK hospitals.                  n= 1499                  United Kingdom                  Black African Caribbean (n=62)                  South Asian (n=36)                  White (n=1286)                  Other (n=36)                  231 women were not invited to participate in the study because they were not literate in written English.</p>	<p>Aim                  To assess whether the lower uptake of prenatal screening for DS in women from minority ethnic groups and socio economically disadvantaged groups reflects similar or lower rates of informed choice.</p>	<p>Design                  Prospective                  Women completed questionnaires before testing did take place or could have taken place. Uptake was assessed from laboratory records.</p>	<p>Results                  Mean knowledge score in the population: 5.3 (score range 0-8, high score representing more knowledge about the test).                  Black African Caribbean mean knowledge score: 4.2 (SD 2.0)                  South Asian mean knowledge score: 3.6 (SD 2.0)                  White mean knowledge score: 5.5 (SD 1.8)                  Other mean knowledge score: 4.8 (SD 2.1)                  (Differences between groups statistically significant.)                  Rates of informed choice were higher for White women than for other women                  (56% of White women versus 20% South Asian -difference 36%, 95% CI 28-44-).</p>
<p>Jaques, 2004</p>	<p>Knowledge prenatal screening</p>	<p>Pregnant women &gt; 37 years                  n= 432                  Australia                  80 non-English speaking                  352 English speaking</p>	<p>To determine what proportion of pregnant women of advanced maternal age expected prenatal testing to give them information about whether the fetus had Down syndrome and what factors are associated with this response.</p>	<p>Cross-sectional                  Questionnaire before 24 weeks of gestation.</p>	<p>Content analysis showed that of the 432 tested women, 61.3% mentioned Down syndrome, chromosomal abnormalities or trisomies. Those from an English-speaking background were more likely to mention Down syndrome, etc. compared to women from a non-English-speaking background (adjusted OR = 3.5, P &lt; 0.001).</p>
<p>Lewando-Hundt, 2001</p>	<p>Attitude prenatal screening                  Religion                  Attitude abortion</p>	<p>Bedouin women attending Ministry of Health maternal and child health clinics in Israel.                  The data consist of a review of 537 prenatal care records, 16 in depth interviews with mothers, and four interviews with health personnel.                  Israel</p>	<p>To understand the selective uptake of prenatal screening by Bedouin women.</p>	<p>Qualitative                  Review of prenatal care records and in depth interviews.</p>	<p>The record review showed that the majority of women who attend prenatal care do not take up referrals for Maternal Serum Alpha Feto Protein (MSAFP) testing or for amniocentesis tests. Although many women interviewed talked about the value of prenatal screening, they also spoke of 'false alarms' that may result from testing. Similarly, women were aware that the socially preferred pattern of consanguinity in marriage amongst the Bedouin may cause medical problems, however test uptake was unrelated to consanguinity. There was a variety of views concerning the religious permissibility of terminating a pregnancy. This study shows that women use prenatal screening selectively in a way that helps them to balance social and medical risk.</p>

Table 2.1 (continued)

Author / year	Determinants	Population	Aim	Design	Results
Moyer, 1999	Attitude towards prenatal testing for chromosomal disorders Attitude Down's syndrome Miscarriage risk Willingness to undergo abortion	Pregnant women who varied with respect to race/ethnicity, religious background, and reproductive history, as well as in their decisions about use of prenatal screening and diagnostic testing. n=75 USA	To elucidate factors influencing women's decisions regarding prenatal genetic screening for and diagnosis of chromosomal disorders, like DS and to learn about their experiences with these tests and with the medical system.	Qualitative Focus group interviews after moment of test uptake	Substantial variation surfaced in attitudes toward testing. Factors influencing women's views included feelings about having a child with DS, moral and religious beliefs about abortion, family and social influences in the decision to participate in testing, perceptions of one's own health, the difficulty of getting pregnant, and willingness to put the fetus at elevated miscarriage risk.
Nagle, 2000	Offer of prenatal screening Intake after first trimester	Vietnamese women attending a community-based antenatal clinic in Melbourne over a two-year period. n=207 Australia	To explore lower uptake of prenatal diagnosis by Victorian women of a non-English speaking background compared to English speaking women.	Cross-sectional Review of medical charts	161 women (78%) were offered screening or diagnosis and of these women 139 (86%, 95%CI 81-92%) accepted the offer, representing 67% (95%CI 61-74%) of the entire population. Of the 127 women who had screening, rather than diagnosis, 12 (9%) had an 'increased risk' result. Eleven of these women accepted diagnosis. Almost half (44%) of these women first attended the clinic at a too advanced stage of gestation but in 25 women there were no obvious reasons.
Press, 1998	Religion Acculturation	Pregnant women who had been offered screening within the context of California's MSAFP Program. 595 obstetrical patient charts 158 pregnant women who were European-American, English-speaking Latino, or Spanish-speaking Latino. USA	To explore the effect and interaction of various factors, especially ethnicity, abortion history and attitudes, religion, and religiosity on MSAFP test decision. The intent is to describe which women are more likely to reject MSAFP screening and to understand the reasons for refusal and the meanings associated with it.	Cross-sectional Review of medical charts and semi structured interviews	Women who had never terminated a pregnancy, Spanish-speaking Latinos, and women who scored high on a religiosity scale were significantly more likely to refuse testing. However, we found that all of those factors were strongly mediated by the effects of ethnicity and acculturation, producing different patterns of association in different groups of women.

<p>Author / year                  Saucier, 2005</p>	<p>Determinants                  Knowledge prenatal screening                  Perceived susceptibility DS                  Perceived seriousness DS                  Benefits of testing                  Barriers to testing</p>	<p>Population                  Pregnant women referred for amniocentesis at Memorial Hermann Southwest Hospital Texas between August 2001 and March 2002.                  n=157                  USA                  32.7 % Caucasian                  22.8% Afro-American                  21.6% Hispanic                  19% Asian                  3.9% Other</p>	<p>Aim                  To determine the role of health beliefs in amniocentesis acceptance in a diverse racial-ethnic population.</p>	<p>Design                  Cross-sectional                  Questionnaires were completed after counseling and before ultrasound and/or amniocentesis appointment.</p>	<p>Results                  The results showed that Hispanic women were less likely to accept amniocentesis (51.5% vs. Caucasian 82.8%, African American 82.9%, Asian 82.8%). Education level was the only demographic factor higher among acceptors. Women who accepted amniocentesis scored higher on perceived seriousness, perceived susceptibility, benefits HBM and knowledge than women who declined (<math>p &lt; 0.001</math>). There was no interaction between race-ethnicity and amniocentesis decision on the Health Belief Model factor scores and knowledge scores (<math>p=0.39</math>)                  HBM scores and knowledge predicted the amniocentesis decision correctly 91.5% of the time. Individual health beliefs and knowledge play a greater role in genetic amniocentesis acceptance than do demographic factors such as race-ethnicity.</p>
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### **Subjective norms**

Learman et al. found ethnic-related differences in views of motherhood and the acceptance of Down syndrome by family and community. Caucasians were least influenced by fatalism or faith in their decision, but most likely to report that their partner influenced their decision. Asian women were most influenced by their family's feelings and were less likely to prefer a child with Down syndrome to no child at all.<sup>7</sup>

### **Religious norms**

Press et al. concluded that women who scored high on a religiosity scale were significantly more likely to refuse testing.<sup>20</sup> Lewando-Hundt described that Bedouin women in Israel are afraid that participation in prenatal testing will lead to the recommendation to terminate their pregnancy, which is against their religious principles. However other Bedouin women mentioned that pregnancy termination is acceptable under certain conditions. According to a recent Fatwa termination is allowed up to 120 days after conception if the mother's health is at risk or if the baby is deformed. This means that Islamic women could opt for termination if the anomaly is detected early in pregnancy.<sup>26</sup>

### **Cultural norms**

Press et al. found that Spanish-speaking Latinos in the US who scored as less acculturated were significantly more likely than more acculturated Spanish-speaking Latinos to refuse prenatal screening for Down syndrome.<sup>20</sup>

## **Results of focus group interviews**

### **From unawareness to awareness**

Women often mentioned that they only became aware of the opportunity to participate in prenatal screening for Down syndrome because their

midwife informed them.

*The midwife told me that I could participate in prenatal screening. I heard about it before, but did not actually think about it. Now she mentioned it, I thought 'I just do it.' Everything you can exclude is nice [Dutch woman, 34 years of age].*

### **From awareness to considering**

Beliefs about the consequences of Down syndrome and pros and cons of prenatal screening did not seem to be necessary for the transition from the stage 'awareness' to the stage 'considering'.  
*The gynaecologist referred me to the clinic for an ultrasound. She didn't tell me it was voluntary or anything like that. I thought I had to do it anyway because I was pregnant. I thought, 'OK, so I'll go' [Dutch woman, 36 years of age].*

*The midwife mentioned prenatal screening, but I didn't think about it. It simply did not come up into my mind [Surinamese woman, 20 years of age].*

Most women aged 36 years or older mentioned their increased risk of bearing a child with Down syndrome as one of the factors to start considering screening. However, hardly any of these women knew their actual risk of having a child with Down syndrome.

*I'm 39, I'm old, so I'm at increased risk. But how high is that risk? I haven't a clue, I really don't [Dutch woman, 39 years of age].*

### **From considering to deciding**

Attitude

Many women, especially the Surinamese women, mentioned personal consequences or consequences for the child as reasons to participate in screening.

*For me, it's purely a matter of not being able to take*



*care of that child. It's not a matter of wanting to, but of not being able to. I'd be angry, disappointed, and maybe unable to love the child as much [Surinamese woman, 39 years of age].*

*If your first child is unhealthy, you get isolated. There's a chance people won't understand you so well. If a child is healthy, you're socially more accepted. People also look at the child's appearance, and judge you on the basis of it [Surinamese woman, 31 years of age].*

*I think you harm your child in some way if you allow it to be born. That's why I did it.  
No, the fact that you don't want your child to suffer is more important [Surinamese woman, 40 years of age].*

Women also mentioned advantages and disadvantages of prenatal screening.  
*Why shouldn't we do it? It's without any risks and you know a little bit more than before [Dutch woman, 36 years of age].*

*On the one hand you want an amniocentesis to be sure, but then again you don't want a miscarriage. It would be much worse if the child is healthy and you lose it [Turkish woman, 30 years of age].*

*I had to consider it very well. You have to get prepared for a disabled child, you have to deal with it the whole of your pregnancy. It's your child: you feel it, it moves. You have to think all the time that it's a child with a handicap. That causes stress, and you pass that on to your child as well [Turkish woman, 25 years of age].*

*Next time, I wouldn't participate. The certainty just isn't worth the tension. What if they tell me I have*

*an increased risk? Do I have to make a decision? Would I be able to decide about it? It sounds idealistic to say I couldn't decide, because obviously you're going to think about it together, as it has such an impact on your lives. I think I'd prefer not to know. Then, if it actually happened, I'd deal with it and find out how to cope with it [Dutch woman, 34 years of age].*

One Surinamese woman said she did not know why she did not participate.  
*I didn't want those tests – I don't know why. I had only heard about amniocentesis. I thought maybe I could do it later [Surinamese woman, 38 years of age].*

#### Subjective norms

The Turkish women emphasized the role of their family in the decision-making process, because their support is very important. Dutch women said that they made the decision together with their partner. But Surinamese partners did not seem to play an important role in the decision.

*I didn't discuss it extensively with my husband – the decisions are all mine anyway. I have to carry it, so I need to know if I want it or not. I have to take care for it later. Eighty percent is your risk. If he leaves with another woman, you have to take care of the child. The father provides support, but you're 80% responsible for the child [Surinamese woman, 41 years of age].*

The gynaecologist or midwife also seemed to influence the decision.  
*I'm not in a [high-]risk group, so why would I do it? If I belonged to a [high-]risk group, my midwife would tell me. I wouldn't take the initiative [Turkish woman, 29 years of age].*

Women also expected their gynaecologist or midwife to give advice.

*I asked more than ten times, 'What shall I do? Yes or no?' He couldn't even give me any advice. He kept saying 'It's your decision' [Surinamese woman, 37 years of age].*

#### Religious norms

The Turkish women especially mentioned the role of religion in the considerations they had towards termination of pregnancy if Down syndrome would be detected.

*Although you know your child has got Down syndrome, you can't do anything about it. I wouldn't want to terminate the pregnancy, because it's a gift from God. If anything happens, which of course I hope it won't, then it is God's will [Turkish woman, 29 years of age].*

*It's different if there's also a danger to the mother's health. If they said it's either you or the baby, you wouldn't have a choice anymore [Turkish woman, 25 years of age].*

*If the mother's health is in danger, you're allowed to terminate within a certain number of weeks. I think it's 4 months, but I'd have to look it up and read carefully [Turkish woman, 29 years of age].*

*If it were a very severe disorder, I would terminate. I wouldn't mind [Turkish woman, 25 years of age].*

The Surinamese women also mentioned religious beliefs in their considerations. For some women it seemed to be difficult to find a balance between their religious beliefs and the decision to participate in prenatal screening.

*I had a religious upbringing. I kind of think 'God will judge me for that.' But I simply couldn't do it.*

*But at the back of my mind I keep thinking that it's wrong to focus on what I want. But I simply can't do it. You can participate in screening and not do anything with the outcome, but I do want to do something with it. And because of my religious background, this makes me feel guilty [Surinamese woman, 39 years of age].*

#### Cultural norms

Surinamese, Turkish and Dutch women experienced specific cultural norms in their decision to participate in screening or not.

*If you have a disabled child, people would look down on you. They'd say 'What did I tell you? She did such-and-such, and that's why she has a disabled child.' Everywhere they looked, they'd find a reason for it [Surinamese woman, 40 years of age].*

*In our culture people are a bit wary of prenatal screening. They just don't want to know. They say 'We don't want to hear about it.' Some extreme people think it's a punishment from God anyway. 'What's the use of knowing beforehand? Allah made this decision and you have to learn to cope with it. Even if it's disabled, I don't want to know, because I won't have an abortion anyway.' That's how they think about it. But you have to think what our religion says about it. It doesn't order you to distance yourself from medical care – just the opposite: you have to use medical care [Turkish woman, 25 years of age].*

*In our culture everything is perfectible. You want to control everything and decide on everything. So in a manner of speaking, nothing can happen to you [Dutch woman, 36 years of age].*

*Actually, you should justify your decision not to participate in screening at all [Dutch woman, 39 years of age].*

### **From deciding to acting**

We asked women how difficult or easy it would be for them to actually participate in prenatal screening. Most women could not immediately think of anything that would prohibit them to participate. Some said that having to pay for the test could be a possible barrier.

*I can imagine many women don't participate in screening if they have to pay for it themselves [Surinamese woman, 36 years of age].*

Language was mentioned by one woman, but she did not perceive this as a barrier.

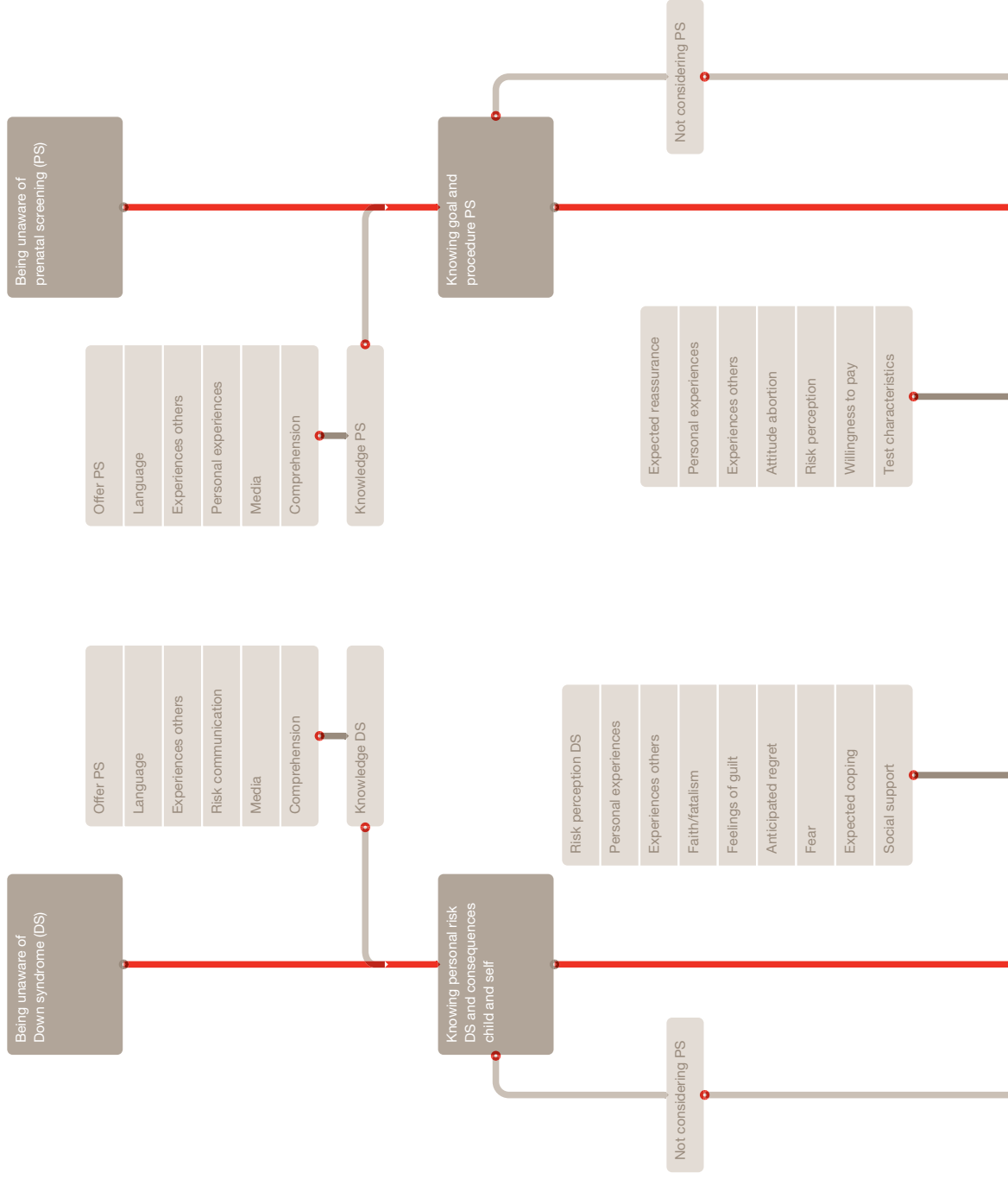
*I don't speak Dutch yet, but my family and friends support me. They go with me and translate [Turkish woman, 21 years of age].*

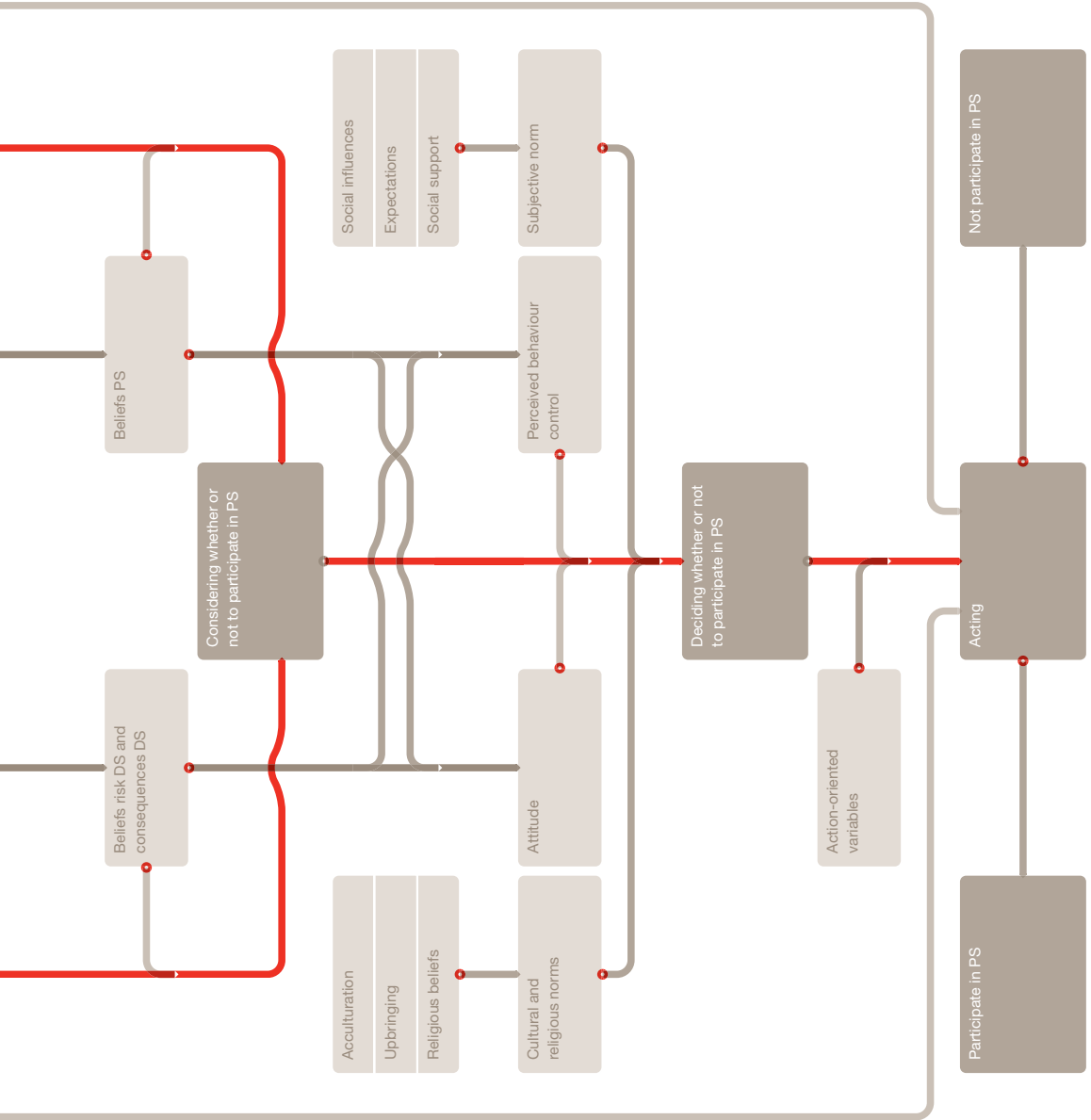
### **Adaptation of the prenatal screening stage model**

The focus group interviews largely confirmed the structure of the prenatal screening stage model. However, women did not necessarily need to have beliefs about prenatal screening, their personal risk and consequences of Down syndrome to transfer from the stage of 'awareness' to the stage of 'considering participation'. An invitation to attend prenatal screening often seemed to be sufficient to start considering whether or not to participate. So we added the offer of prenatal screening to our model as a factor determining knowledge. Other determinants of knowledge that were added to the model at this stage were: risk communication; language; personal experiences and experiences of others; media; and comprehension of information (Figure 2.2).

Beliefs seemed to directly influence women's attitude towards participating in prenatal screening. Beliefs about Down syndrome were influenced by factors including fatalism, faith, fear of having a child with Down syndrome, expected coping with a child with Down syndrome and risk perception. Beliefs about prenatal screening were influenced by attitudes towards termination of pregnancy and miscarriage risk. These factors were added to the model as determinants of beliefs (Figure 2.2). Subjective norms appeared to be relevant in women's decision to participate or not. Determinants of subjective norms as mentioned in the focus group interviews included: influence of gynaecologist or midwife; perceived expectations of society; and influences and support of partner or family. Women in our focus groups experienced different religious and cultural norms influencing their decision to participate in prenatal screening for Down syndrome or not. Especially the Surinamese women mentioned the feelings of shame they would experience if they had a child with Down syndrome. Most Dutch women stated that they almost felt socially obliged to participate in prenatal screening. Especially the Turkish women mentioned religious norms in their decision to participate in prenatal screening and consequently their considerations to terminate the pregnancy. Some women believed that termination in certain circumstances is not prohibited in Islam if it is done early in pregnancy, but they did not know the exact gestation. Except for the publication of Lewando-Hundt in 2001 we did not find other papers in our literature search that describe the role of religion in considerations to terminate for Down syndrome, probably because a first trimester test for Down syndrome is relatively new.<sup>26</sup> Studies on pregnancy termination with regard to other disorders in Islamic populations did find an association between the decision to

Figure 2.2 Prenatal Screening Stage Model





terminate a pregnancy and the week of gestation in which the disorder is detected.<sup>29, 30</sup> Significantly more Muslim women chose to terminate a pregnancy when it was detected in early diagnosis than in late prenatal diagnosis. According to Fatwa number 4 of the Islamic jurisprudence council of Mekkah Al Mukaramah, abortion is allowed within 120 days after conception provided that the fetus is grossly malformed with an untreatable severe condition.<sup>31</sup> Other studies however show this Fatwa is not familiar to all Muslims and that many think that there is a total religious ban on abortion in Islam.<sup>26, 32-34</sup>

The results of the focus group interviews also showed that it is possible that women know about Down syndrome and prenatal screening, but that they do not enter a consideration stage. They simply do not want to think about the decision to participate or not, perhaps because they have other things on their minds, or because they think that participation in screening is routine or even compulsory. Therefore we added the stage 'Not considering prenatal screening' (Figure 2.2).

## 2.4 Discussion

### Reflection on the prenatal screening stage model

We applied a theoretical stage model for health behaviour to participation and non-participation in prenatal screening. The resulting prenatal screening stage model can serve as a framework to analyse determinants in the decision-making process regarding prenatal screening for Down syndrome of women with different ethnic backgrounds. Focus group interviews showed that the first concept of our model was suitable to describe the decision-making process of pregnant women

from Dutch, Turkish and Surinamese origin. To a certain extent most considerations, stages and determinants were similarly relevant for all these women. However, we found differences between these groups, especially in women's beliefs about personal consequences and prenatal screening and in cultural and religious norms that seemed to influence women's considerations towards participation in prenatal screening and termination of pregnancy.

Foreign studies may not be directly applicable to the Dutch situation that is specific, because of the origin of the ethnic minorities living in the Netherlands, and because the organisation of prenatal care differs from other countries. Despite of this, the focus groups corroborated most of the basic determinants of prenatal screening participation found in the literature, such as knowledge, attitude, religious norms and subjective norms.

### Limitations

The limitations of this study merely refer to the inclusion of participants. Focus group interviews were conducted among women who were interested in the subject of prenatal testing and were able to come to our university to meet us. Another limitation concerns the literature search. Because first trimester Down syndrome screening is relatively new, it is possible that early detection will lead to other considerations to participate in screening.

### Implications for practice

This prenatal screening stage model and the identification of ethnically specific determinants will provide opportunities to structure the decision-making process in prenatal screening for Down syndrome. The results of the prospective study that has been initiated in 2006 in Rotterdam will offer possibilities to develop culturally sensitive, tailored methods for

offering prenatal screening for Down syndrome to pregnant women with different ethnic backgrounds and to guide them through the process of deciding whether or not they wish to participate. The offer of prenatal screening is often the start of the decision-making process: most women do not consider prenatal screening if it is not offered to them. Language barriers or intake in prenatal care after first trimester may easily cause ethnic differences in this provision. Women who do not receive an offer or who do not receive it at the appropriate time, are less likely to make an informed decision on participation. Although a timely offer is a prerequisite, it is not sufficient for informed decision making. Our results suggest that not all women go through the stage of 'considering participation' after a timely offer; misconceptions about e.g. the voluntariness of the screening need to be addressed in the counselling procedure.

### Implications for research

The development of this stage model is the first step in the currently ongoing prospective study to evaluate the determinants of participation and non-participation in prenatal screening for Down's syndrome among pregnant Dutch, Surinamese and Turkish women.

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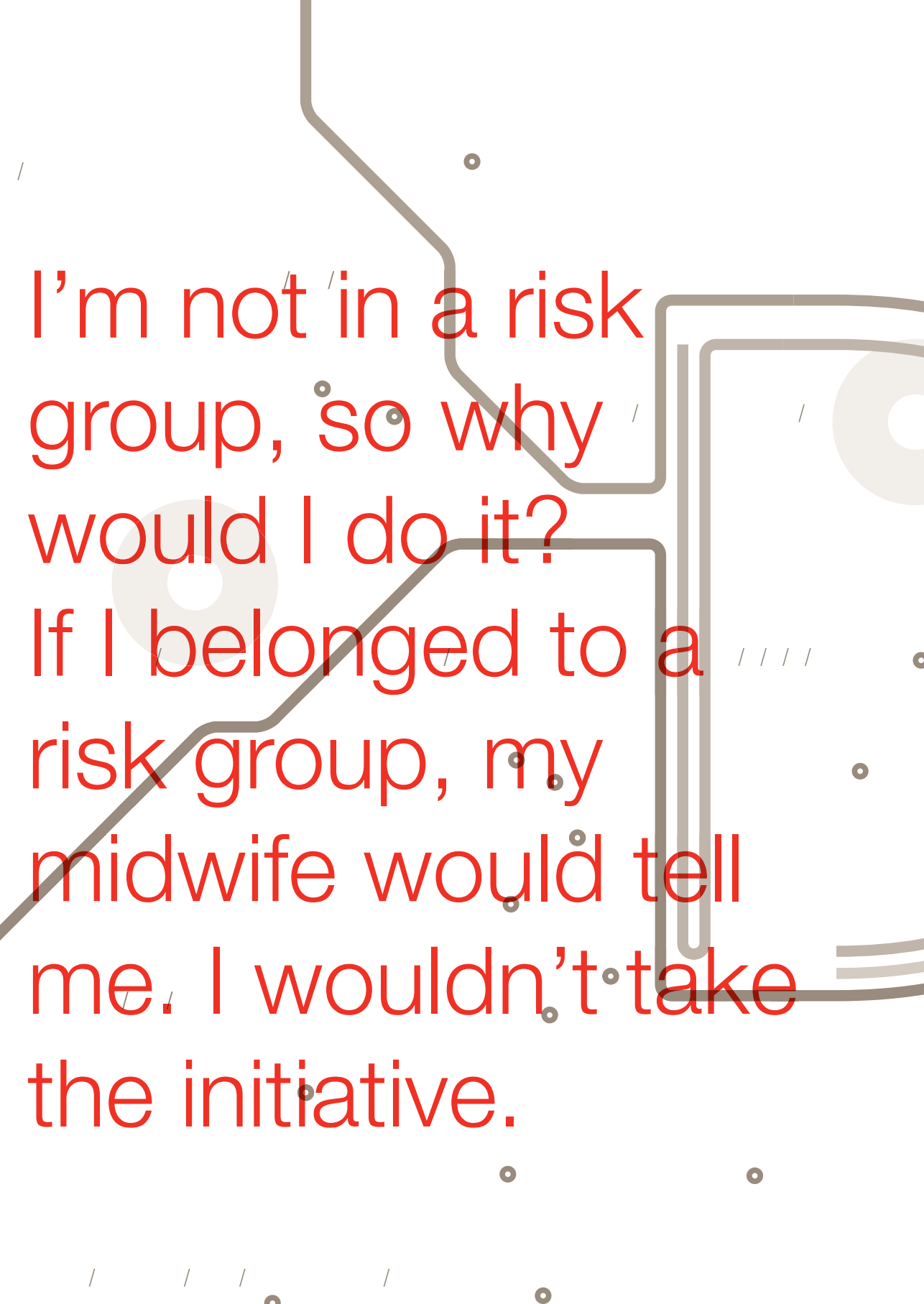




Ethnic differences in knowledge  
and access to information

# Part

# II

The background features a complex network of grey lines and dots. The lines are of varying thickness and form a grid-like structure with some irregularities. Small grey dots are scattered throughout the white space, some appearing to be at the intersections of the lines. The overall aesthetic is clean and technical.

I'm not in a risk group, so why would I do it?

If I belonged to a risk group, my midwife would tell me. I wouldn't take the initiative.

The image features a complex abstract graphic design. A prominent, thick brown line starts from the left edge, curves downwards, then moves horizontally to the right, and finally curves upwards towards the top right corner. Scattered throughout the composition are various elements: small dark brown circles, some appearing in groups or clusters; thin, light brown slashes and double slashes; and a large, faint, light brown circular shape on the left side. The overall aesthetic is clean and modern, with a monochromatic brown color palette.

(Woman from  
Turkish origin,  
29 years of age)



# Information about prenatal screening for Down syndrome. Ethnic differences in knowledge

Fransen MP, Wildschut HIJ, Vogel I, Mackenbach JP, Steegers EAP, Essink-Bot ML. Information about prenatal screening for Down syndrome. Ethnic differences in knowledge. *Patient Education and Counseling* 2009; 77: 279-288



# Abstract

**Objective** To evaluate the provision of information about prenatal screening for Down syndrome to pregnant women from Dutch, Turkish and Surinamese ethnic origins, and to examine the effects of this provision on ethnic differences in knowledge about Down syndrome and prenatal screening.

**Methods** The study population consisted of 105 women from Dutch origin, 100 women from Turkish origin and 65 women from Surinamese origin attending midwifery or obstetrical practices in the Netherlands. Each woman was personally interviewed 3 weeks (mean) after booking for prenatal care.

**Results** Most women reported to have received oral and/or written information about prenatal screening by their midwife or gynaecologist at booking for prenatal care. Women from Turkish and Surinamese origin less often read the information than Dutch women, more often reported difficulties in understanding the information, and had less knowledge about Down syndrome, prenatal screening and amniocentesis. Language skills and educational level contributed most to the explanation of these ethnic variations.

**Conclusion** Although most women from Dutch, Turkish and Surinamese origin reported to have received information from their midwife or gynaecologist, ethnic differences in knowledge about Down syndrome and prenatal screening are substantial. Interventions to improve the provision of information to women from ethnic minority groups should especially be aimed at overcoming language barriers, and targeting information to the women's abilities to comprehend the information about prenatal screening for Down syndrome.



### 3.1 Introduction

An increasing number of pregnant women are routinely offered information about prenatal screening for Down syndrome. Studies in the UK, USA and Australia have shown that this information is often not equally provided to all ethnic populations.

Pregnant women from ethnic minority groups were less likely to receive information about prenatal screening and had less knowledge about prenatal screening than other pregnant women.<sup>1-5</sup>

Our focus group interviews among pregnant women from different ethnic groups indicated that the offer of information is essential to raise pregnant women's awareness of prenatal screening.<sup>6</sup> Other studies showed that not only the offer of information, but also the type and content of the provided information, seem to be related to women's knowledge about prenatal screening.<sup>2, 7, 8</sup>

The present study evaluated the provision of information to pregnant women from Dutch, Turkish and Surinamese ethnic origin in the Netherlands, and examined its effects on ethnic differences in knowledge of Down syndrome, prenatal screening and amniocentesis. We compared groups of women from Turkish and Surinamese origin to a group of women from Dutch origin, because the former constitute the two largest non-Western ethnic minority groups in the Netherlands. In Rotterdam, 8% of the inhabitants are from Turkish and 9% from Surinamese origin.<sup>9</sup>

The study was conducted between 2006 and 2008 in the Netherlands where the offer of information about prenatal screening for Down syndrome has (since 2006) been gradually implemented in standard prenatal practice.<sup>10</sup> Midwives and gynaecologists are legally obliged to inform each pregnant woman about the options for prenatal screening at the booking visit. For those expressing

interest in screening, further information must be provided about the nature of risk assessment tests and potential subsequent diagnostic evaluation by chorionic villus sampling or amniocentesis. On the basis of test performance, acceptability and feasibility, the Dutch government recommended the combined test for the national screening program for prenatal screening of Down syndrome.<sup>11</sup> This test involves assessment of free  $\beta$ -hCG and PAPP-A in maternal blood between 9 and 14 weeks, and ultrasound assessment of the fetal nuchal translucency thickness between 11 and 14 weeks' gestation. The individual risk of carrying a child with Down syndrome is subsequently estimated on the basis of the biochemical and ultrasound findings, together with maternal age. If this risk exceeds 1:200 at the time of testing, the woman is considered to be at increased risk of having a child with Down syndrome. In that case, the pregnant woman is offered invasive testing to determine the fetal karyotype. Invasive testing is, however, associated with an estimated procedure-related fetal loss of 0.3-0.8%.<sup>12</sup> If Down syndrome is detected, women have to decide whether or not to terminate the pregnancy. In the Netherlands, termination of pregnancy is legally accepted up to 24 weeks gestation. Women aged 36 years or over, officially have a direct age-based indication for invasive testing. Women under 36 years of age, however, are only eligible for the combined test, unless they have a listed indication for invasive testing. Those who do not have a formal indication for invasive testing have to pay for the combined test themselves. If the test result indicates an increased risk of Down syndrome, the costs of invasive testing and selective termination are reimbursed.

The research questions of this study were:

- 1) From which sources do women from Dutch, Turkish and Surinamese ethnic origin report to have received information about prenatal screening for Down syndrome?
- 2) Are there ethnic differences in the information that is provided by midwives and gynaecologists in standard practice?
- 3) To what extent do women from Dutch, Turkish and Surinamese origin understand the information they received?
- 4) To what extent do women from Dutch, Turkish and Surinamese origin differ in their knowledge about Down syndrome and prenatal screening?
- 5) What is the contribution of information on ethnic differences in knowledge regarding Down syndrome and prenatal screening?

We made the explicit choice to assess the information process from the perspective of the women, because one of the goals of the information process is to increase their knowledge about prenatal screening for Down syndrome.

## 3.2 Methods

### Population

The study population consisted of women from Dutch, Turkish and Surinamese ethnic origin who were enrolled in the study between September 2006 and June 2008. Eligible women were recruited from 15 community midwifery practices in Rotterdam city centre, and from the outpatient clinic of the Erasmus University Medical Centre, Rotterdam. Midwives and gynaecologists were instructed to inform each Dutch, Turkish and Surinamese pregnant woman about this study at the booking visit, and to ask for permission to be contacted by the researcher (MF). In four midwifery practices the

researcher or research assistant recruited women immediately after the booking visit.

Women who had difficulties in understanding Dutch received translated information about the study, were contacted by a research assistant from the same ethnic background and were offered an interview in the language they preferred. Women younger than 36 years who were booked for prenatal care at a later stage (i.e. after 14 weeks' gestation) were excluded from the study because they lacked timely information on first trimester prenatal screening for Down's syndrome. Because women older than 35 years could opt directly for amniocentesis prior to 17 weeks of gestation, they were excluded from this study when their booking visit took place after 17 weeks of gestation. Women who agreed to be included in the study were contacted by telephone within one week of the booking visit. They received oral information about this study and were offered an appointment for a telephone or a face-to-face interview.

### Data collection and measures

Data collection took place through structured interviews that were conducted by the female researcher (MF) and three female research assistants that were trained to do the interviews. The interview was intended to take place before women could have participated in the prenatal screening program. Sources of information about prenatal screening were measured by one multiple-choice item with multiple answers.

Provision of information was based on women's perceptions and measured by three items. The first item assessed whether women had received the written information (in the form of a booklet) published by the National Institute for Public Health and the Environment in 2007 {Erfocentre, 2008 #35}. Pregnant women that are interested in information

about prenatal screening, receive this booklet during their booking visit. The second item assessed whether women who had received written information had actually read the booklet. The third item (Which of the following topics did your midwife or gynaecologist discuss with you at the booking visit?) measured if and what oral information women had received. Women had the following response options: the general risk of congenital disorders; the personal risk of Down syndrome; the procedure of the combined test; options for testing after increased risk; risk of iatrogenic miscarriage of diagnostic testing; no information received. These response options are adapted from Van den Berg et al.<sup>13</sup> and correspond to the national guidelines for education about prenatal screening described by the Dutch Society of Obstetrics and Gynaecology (NVOG).

In total four categories in provision of information were distinguished: 'received no information', 'received oral information only', 'received written information only', and 'received written and oral information'.

Interest in receiving information about prenatal screening was measured by the question 'Were you interested in the information that was provided by your midwife or gynaecologist?'

Comprehension of written and oral information was measured on a scale from 1 ('very easy to understand') to 5 ('very difficult to understand').

Knowledge was measured by 21 items adapted from previous studies: 7 items about Down syndrome, 8 items about the combined test, and 6 items about amniocentesis (see Appendix).<sup>13,14</sup> A summary score was calculated by summing the correct responses, resulting in a score ranging from 0-21. In accordance with Van den Berg et al. sufficient knowledge was defined based on the guess corrected midpoint (15 of 21 questions answered correctly).<sup>13</sup>

Language skills were measured by three items that assessed whether women had difficulties in speaking, understanding and reading Dutch. Socio-demographic variables (age, gestational length, marital status, religion and educational level) were assessed during the interview. Gestational length was calculated from the best obstetric estimate as reported by the woman. Marital status was categorized as 'living together with partner', 'not living together with partner', or 'single'. Religion was measured by the question whether or not a woman considered herself to be religious and, if yes, which religion. Educational level refers to the highest completed level of education and was categorised as low (primary education and preparatory secondary vocational education), medium (senior secondary vocational training, senior secondary general education or pre-university education) and high (university or higher professional education).<sup>15</sup>

Ethnic origin was assessed by country of birth of the woman and her parents. A woman is considered to be from non-Dutch ethnic origin when at least one of her parents was born abroad, in this case Turkey or Surinam.<sup>15</sup> To distinguish between Hindustani, Creole or 'other' in the Surinamese population, we used the method of self-identification as proposed by Stronks et al.<sup>16</sup>

### Analysis

Descriptive statistics were used to summarise background characteristics of the population. To test differences in knowledge regarding the type of information women received, the variables 'received written information' and 'read written information' were later combined into a new variable 'received (and read) written information'.

In the analyses for knowledge, women who received written information, but did not read it, were

categorized into the group who received no information at all. Women who received a combination of oral and written information, but did not read it, were categorized into the group of women who received oral information only. The three items 'problems speaking Dutch', 'problems understanding Dutch' and 'problems reading Dutch' were combined into a dichotomous variable '(no) problems speaking, understanding and reading Dutch'. Ethnic differences in background variables, provided information, interest in and comprehension of information were tested by chi-square tests. Mean differences in knowledge about Down syndrome, prenatal screening and amniocentesis were tested by analysis of variance (ANOVA) for ethnicity, educational attainment level, age category and type of provided information, and t-tests for religion and language skills. Differences in mean knowledge between Dutch versus Turkish, and between Dutch versus Surinamese women, were separately adjusted for variables that were significantly related to both ethnicity and mean knowledge. Each reduction in mean difference was interpreted as the contribution of these variables to the explanation of ethnic differences in knowledge.

### 3.3 Results

#### Response and characteristics of the population

In four midwifery practices, the researcher (MF) and two research assistants invited 95 Dutch, 98 women from Turkish origin and 28 women from Surinamese origin to participate in an interview, of which 89 Dutch, 78 Turkish and 24 Surinamese agreed to make an appointment. In total 65 Dutch, 54 women from Turkish origin and 19 women from Surinamese origin actually participated in an

interview. In 11 other midwifery practices and the outpatient clinic, health care professionals recruited pregnant women themselves; the exact percentage of non-response in this group is unknown. In total 64 Dutch, 72 women from Turkish origin and 54 women from Surinamese origin who were recruited by the health professionals gave permission to be contacted by the researchers. Of these women, 40 Dutch, 47 Turkish and 46 Surinamese actually participated in an interview. In total 110 of the 381 women who initially agreed to be approached by the researcher did not participate in an interview. Reasons for not participating were: not traceable in time (n=55); declined to participate after receiving information from the researcher (n=18); missed abortion (n=14); changed their mind (n=6); lack of time (n=7); and could not participate due to personal circumstances (n=10).

Table 3.1 presents the socio-demographic characteristics of the study population. Dutch women were older and higher educated than Turkish and Surinamese women. In total 47% of the Turkish women had problems expressing themselves in Dutch, and in understanding and writing Dutch. Women were interviewed 3 weeks (mean) after their booking visit. In 223 women the interview was conducted by telephone, while 46 women participated in a face-to-face interview, 60% of them being Turkish. Almost all (99%) Turkish women and most (80%) Surinamese women considered themselves to be religious, compared to only 26% of the Dutch women. Among the Surinamese women, 25 identified themselves as being Hindustani, 32 as being Creole and 8 women considered themselves to originate from a 'melting pot' of different ethnic groups. Because no significant differences in relevant outcomes were found between these two subgroups, we decided to analyse the Surinamese women as one group.

Table 3.1 Background characteristics of the study population

	Total (n=270)	Dutch (n=105)	Turkish (n=100)	Surinamese (n=65)
<b>Age category*</b>				
<25 years	73 (27)	10 (10)	33 (33)	30 (46)
26-30 years	105 (39)	33 (31)	50 (50)	22 (34)
31-35 years	70 (26)	46 (44)	12 (12)	12 (12)
>36 years	22 (8)	16 (15)	5 (5)	1 (1)
<b>Marital status [n (%)]*</b>				
Living together with partner	232 (86)	96 (91)	99 (99)	37 (57)
Not living together with partner	27 (10)	7 (7)	0	20 (31)
Single	11 (4)	2 (2)	1 (1)	8 (12)
<b>Number of children [n (%)]</b>				
0 Child	120 (45)	51 (49)	36 (36)	33 (51)
1 Child	106 (39)	42 (40)	44 (44)	20 (31)
2 Children	36 (13)	10 (9)	17 (17)	9 (14)
3 Children	6 (2)	1 (1)	2 (2)	3 (4)
4 Children	2 (1)	1 (1)	1 (1)	0 (0)
<b>Educational attainment level [n (%)]*</b>				
Low	82 (30)	11 (11)	44 (44)	27 (42)
Medium	88 (33)	20 (19)	40 (40)	28 (43)
High	100 (37)	74 (70)	16 (16)	10 (15)
<b>Religious [n (%)]*</b>				
No	92 (34)	78 (74)	1 (1)	13 (20)
Yes	178 (66)	27 (26)	99 (99)	52 (80)
<b>Language skills [n (%)]*</b>				
No problems speaking, understanding and writing Dutch	222 (82)	105 (100)	53 (53)	64 (98)
Problems speaking and/or understanding and/or writing Dutch	48 (18)	0 (0)	47 (47)	1 (2)
<b>Interview method [n (%)]*</b>				
Telephone	223 (83)	89 (85)	71 (71)	63 (97)
Face-to-face	47 (17)	16 (15)	29 (29)	2 (3)
<b>Gestational length (weeks)</b>				
Mean gestation at moment of booking in weeks (SD)	9.5 (1.79)	9.2 (1.74)	9.7 (1.96)	9.5(1.78)
Mean gestation at moment of interview in weeks (SD)	12.5 (2.85)	11.6 (1.89)	13.1 (3.09)	12.9 (3.38)

\* This characteristic differs between the ethnic groups (p-value <0.001)

Table 3.2

**Ethnic differences in sources, provision and comprehension of information about prenatal screening as reported by the study population n (%)**

	<b>Total (n=270)</b>	<b>Dutch (n=105)</b>	<b>Turkish (n=100)</b>	<b>Surinamese (n=65)</b>	<b>p- value</b>	
<b>Sources of information*</b>						
Healthcare professionals						
Midwife	206 (76)	82 (78)	70 (76)	58 (91)	0.06	
Gynaecologist	25 (9)	13 (12)	8 (9)	4 (6)	0.40	
General practitioner	16 (6)	9 (9)	2 (2)	5 (8)	0.14	
Mass media						
Internet	54 (20)	25 (24)	11 (12)	18 (28)	0.03	
Television/radio	34 (13)	19 (18)	1 (1)	14 (22)	0.00	
Magazines/newspaper	62 (23)	33 (31)	6 (6)	23 (36)	0.00	
Friends	72 (27)	48 (46)	11 (12)	13 (20)	0.00	
Family	27 (10)	7 (7)	13 (14)	7 (11)	0.23	
Study/work	17 (6)	9 (9)	6 (6)	2 (3)	0.38	
Earlier experiences	3 (1)	3 (3)	0 (0)	0 (0)	0.10	
<b>Interest in offer of information</b>						
Interested in information	201 (74)	82 (78)	69 (69)	50 (77)	0.29	
Not interested in information	69 (26)	23 (22)	31 (31)	15 (23)		
<b>Type of information</b>						
No information	46 (17)	12 (11)	20 (20)	13 (20)	0.02	
Written (and read) information	20 (7)	13 (12)	6 (6)	1 (1)		
Written (and read) and oral information	112 (42)	55 (53)	33 (33)	24 (37)		
Oral information	92 (34)	25 (24)	41 (41)	27 (42)		
General risk of congenital disorders**	106 (39)	34 (32)	43 (43)	29 (45)		
Personal risk of Down syndrome**	113 (42)	48 (46)	30 (30)	35 (54)		
Procedure prenatal screening**	122 (45)	55 (52)	37 (37)	30 (46)		
Options for diagnostic testing after increased risk**	81 (30)	42 (40)	19 (19)	20 (31)		
Risk of unintended miscarriage at diagnostic testing**	61 (23)	21 (20)	21 (21)	19 (29)		
<b>Comprehension of written information</b>						
Easy to understand information	116 (88)	68(100)	25 (64)	23 (92)		0.00
Not easy or not difficult to understand	8 (6)	0 (0)	7 (18)	1 (4)		
Difficult to understand information	8 (6)	0 (0)	7 (18)	1 (4)		

Comprehension of oral information***	Turkish		Dutch		Surinamese		0.03	
	n	%	n	%	n	%		
Easy to understand information	174	(87)	75	(96)	57	(79)	42	(84)
Not easy or not difficult to understand	15	(8)	2	(3)	9	(13)	4	(8)
Difficult to understand information	10	(5)	1	(1)	6	(8)	4	(8)

\* The total number in this section consists of women who heard about prenatal screening (n= 261).

Percentages do not sum to 100%, because multiple answers were possible.

\*\* Percentages do not sum to 100%, because multiple answers were possible.

\*\*\* Two missing reports from Turkish women, two missing reports from Dutch women, and one missing report from Surinamese women

### Sources of information about prenatal screening for Down syndrome

Only 9 women said they had not heard about prenatal screening for Down syndrome at the moment they were interviewed (8 Turkish and 1 Surinamese). Table 3.2 shows that most women heard about prenatal screening from their midwife and were interested in their offer of information; for this item there was no significant difference between the ethnic groups. Almost half of the Dutch women (46%) mentioned friends as the source of information, compared to 11% of the women from Turkish and 20% of the women from Surinamese origin. Mass media was mentioned less often by the women from Turkish origin, e.g. only 6% said they read about prenatal screening in magazines or newspapers, compared to 31% among the Dutch and 36% among the women from Surinamese origin. Only a few women mentioned their family, earlier experiences, or study/work to be an information source about prenatal screening; for these categories no significant differences were found between ethnic groups.

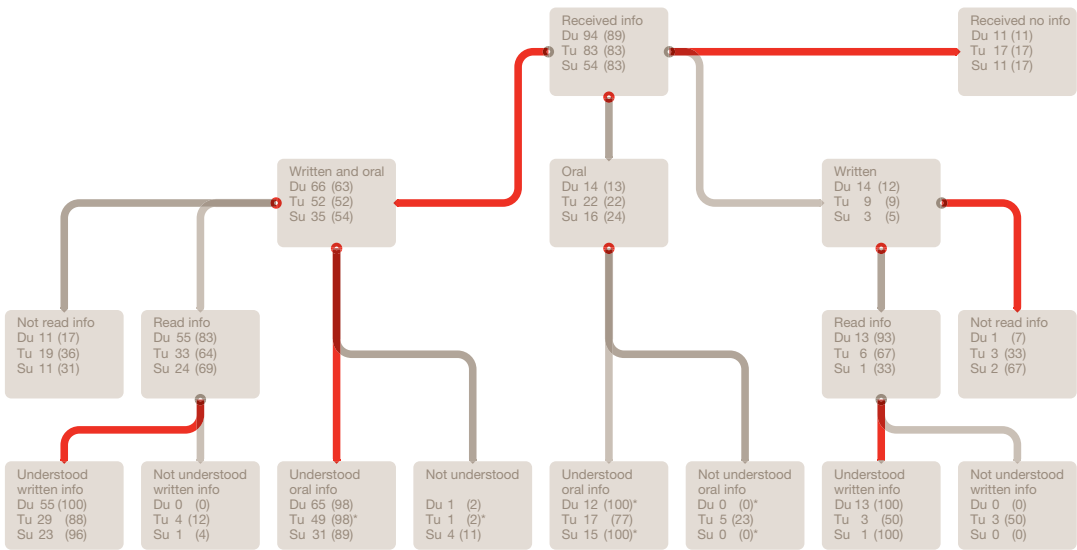
### Provision of information about prenatal screening and women's comprehension

The percentage of women who reported not to have received any information was higher among women from Turkish and Surinamese origin (Figure 3.1). Most women received a combination of written and oral information; Dutch women more often received only written information, women from Turkish and Surinamese origin more often received only oral information.

Not all women reported to have read the written information that was provided to them. The percentage non-readers was highest among women from Turkish and Surinamese origin. Language problems were not the only reason for not reading the booklet, because 32% of the Turkish and 34% of the Surinamese non-readers reported to have no problems reading Dutch (data not shown).

Table 3.2 shows ethnic differences in the type of received information, the content of oral information, and women's comprehension. Women from Turkish origin less often reported to have received oral information about the procedure of prenatal screening and options for diagnostic testing after increased risk. None of the Dutch women who

Figure 3.1 Flowchart showing the provision and comprehension of information among Dutch (Du), Turkish (Tu) and Surinamese (Su) women: data are actual numbers (%).



\*2 missing values among Turkish women  
 \*2 missing values among Dutch women  
 \*1 missing value among Surinamese women

received and read the written information reported to have difficulties in understanding the information; this was 18% among women from Turkish and 4% among women from Surinamese origin. The women from Turkish origin reported a language barrier to be the main reason for not understanding the written information. Only 1% of the Dutch, 8% of the Turkish and 8% of the Surinamese women who received oral information found it difficult to understand this information. Reasons for not understanding the oral information included: a language barrier among the women from Turkish origin; too much information about prenatal screening and other subjects; and miscommunication.

### Knowledge about Down syndrome, prenatal screening and amniocentesis

Table 3.3 shows that women who received no information from their midwife or gynaecologist had less knowledge about Down syndrome, prenatal screening and amniocentesis than women who received written and oral information, or written information only. Women who received only written information scored highest on knowledge. Women who received only oral information scored lower on knowledge than women who received written and oral information.

The lowest knowledge scores were found among women with the lowest educational level; they dif-



Figure 3.2 Ethnic differences in percentage of correct answers on knowledge items: Down syndrome

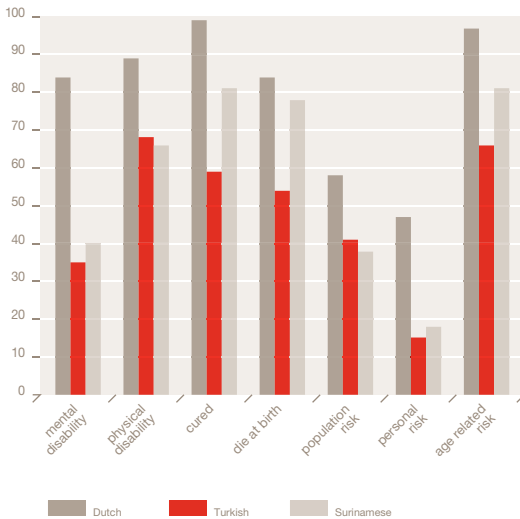
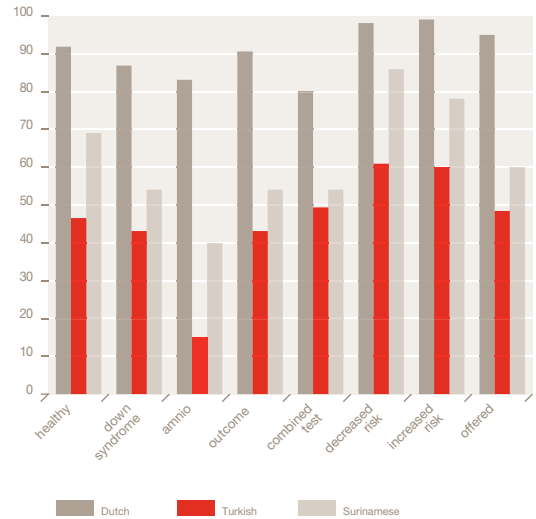


Figure 3.3 Ethnic differences in percentage of correct answers on knowledge items: prenatal screening



ferred significantly from women with a medium or high educational level. Women below 26 years of age scored lower on knowledge than women above 30 years of age. Women above 35 years of age scored highest on knowledge (16 out of 21 questions correct). Women who considered themselves to be religious scored lower on knowledge than non-religious women, and women who reported no language problems scored higher on knowledge than women with language problems.

### Ethnic differences in knowledge

In addition, Table 3.3 shows ethnic differences in all knowledge domains. The lowest number of correct answers was found among the women from Turkish origin; on average, they answered almost 10 out of 21 questions correctly, women from Surinamese origin 12.5 questions and Dutch women almost 17. Except for differences in knowledge about amnio-

centesis, all differences between the three ethnic groups were significant. The highest knowledge scores were observed among Dutch women who received written information only; they answered 18.5 of the 21 questions correctly (data not shown). Figures 3.2, 3.3 and 3.4 give an overview of the ethnic differences in knowledge about Down syndrome, prenatal screening and amniocentesis per item (see Appendix for the exact formulation of these items). Knowledge items about Down syndrome were more often answered correctly by Dutch women; in particular, they scored higher on questions about mental disability (Figure 3.2). Only 47% of the Dutch, 15% of the Turkish and 18% of the Surinamese women knew their personal risk of giving birth to a child with Down syndrome. Women from Turkish origin scored lower on all items about prenatal screening than Dutch women and women from Surinamese origin (Figure 3.3).

Table 3.3 Mean knowledge (SD) about Down syndrome, prenatal screening and amniocentesis in the study population (n=269\*)

	Knowledge Down syndrome (scale 0-7)	Knowledge prenatal screening (scale 0-8)	Knowledge amniocentesis (scale 0-6)	Total knowledge (scale 0-21)
<b>Type of information</b>				
No information	3.91 (1.63) <sup>1c</sup>	3.85 (2.56) <sup>1ab</sup>	2.87 (1.65) <sup>1bc</sup>	10.63 (4.65) <sup>1bc</sup>
Oral information	4.07 (1.64) <sup>1e</sup>	5.02 (2.43) <sup>1ae</sup>	3.11 (1.72)	12.20 (4.65) <sup>1de</sup>
Written information	4.90 (1.83)	6.20 (2.85) <sup>1b</sup>	4.10 (1.48) <sup>1b</sup>	15.20 (5.53) <sup>1bd</sup>
Written and oral information	4.90 (1.52) <sup>1ce</sup>	6.13 (2.14) <sup>1e</sup>	3.61 (1.46) <sup>1c</sup>	14.65 (4.11) <sup>1ce</sup>
<b>Educational level</b>				
Low	3.37 (1.58) <sup>2ab</sup>	3.59 (2.44) <sup>2ab</sup>	2.71 (1.56) <sup>2ab</sup>	9.68 (4.28) <sup>2ab</sup>
Medium	4.27 (1.47) <sup>2ac</sup>	5.29 (2.31) <sup>2ac</sup>	3.46 (1.54) <sup>2a</sup>	13.03 (4.29) <sup>2ac</sup>
High	5.48 (1.21) <sup>2bc</sup>	6.88 (1.62) <sup>2bc</sup>	3.77 (1.58) <sup>2b</sup>	16.13 (3.42) <sup>2bc</sup>
<b>Age category</b>				
<25 years	4.01 (1.41) <sup>3ab</sup>	4.68 (2.41) <sup>3ab</sup>	3.15 (1.56) <sup>3ab</sup>	11.84 (4.28) <sup>3ab</sup>
26-30 years	4.31 (1.77) <sup>3cd</sup>	4.95 (2.49) <sup>3cd</sup>	2.87 (1.59) <sup>3cd</sup>	12.13 (4.80) <sup>3cd</sup>
31-35 years	4.90 (1.52) <sup>3ac</sup>	6.42 (2.12) <sup>3ac</sup>	3.86 (1.46) <sup>3ac</sup>	15.18 (4.01) <sup>3ac</sup>
>36 years	5.14 (1.83) <sup>3bd</sup>	6.27 (2.86) <sup>3bd</sup>	4.68 (1.24) <sup>3bd</sup>	16.09 (5.23) <sup>3bd</sup>
<b>Religion</b>				
Not religious	5.53 (1.19) <sup>4</sup>	7.26 (1.28) <sup>4</sup>	4.03 (1.48) <sup>4</sup>	16.83 (3.10) <sup>4</sup>
Religious	3.88 (1.58) <sup>4</sup>	4.38 (2.43) <sup>4</sup>	3.00 (1.58) <sup>4</sup>	11.27 (4.36) <sup>4</sup>
<b>Language skills</b>				
No problems speaking, understanding and writing Dutch	4.80 (1.46) <sup>5</sup>	5.96 (2.17) <sup>5</sup>	3.58 (1.54) <sup>5</sup>	14.34 (4.04) <sup>5</sup>
Problems speaking and/or understanding and/or writing Dutch	2.79 (1.53) <sup>5</sup>	2.59 (2.10) <sup>5</sup>	2.28 (1.56) <sup>5</sup>	7.66 (4.01) <sup>5</sup>
<b>Ethnicity</b>				
Dutch (n=105)	5.57 (1.09) <sup>6ab</sup>	7.25 (1.41) <sup>6ab</sup>	4.02 (1.47) <sup>6ab</sup>	16.84 (2.73) <sup>6ab</sup>
Turkish (n=99)	3.38 (1.64) <sup>6ac</sup>	3.67 (2.25) <sup>6ac</sup>	2.72 (1.57) <sup>6a</sup>	9.75 (4.20) <sup>6ac</sup>
Surinamese (n=65)	4.26 (1.26) <sup>6ac</sup>	4.93 (2.21) <sup>6ac</sup>	3.25 (1.53) <sup>6b</sup>	12.45 (3.93) <sup>6ac</sup>

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\* One missing value among Turkish women

- 1a Significant difference between women who received no information and women who received oral information ( $p < 0.05$ ).
- 1b Significant difference between women who received no information and women who received written information ( $p < 0.05$ ).
- 1c Significant difference between women who received no information and women who received written and oral information ( $p < 0.05$ ).
- 1d Significant difference between women who received oral information and women who received written information ( $p < 0.05$ ).
- 1e Significant difference between women who received oral information and women who received oral and written information ( $p < 0.05$ ).
- 1f Significant difference between women who received written information and women who received oral and written information ( $p < 0.05$ ).
- 2a Significant difference between low and medium educated women ( $p < 0.05$ ).
- 2b Significant difference between low and high educated women ( $p < 0.05$ ).
- 2c Significant difference between medium and high educated women ( $p < 0.05$ ).
- 3a Significant difference between women <25 years and women of 31-35 years ( $p < 0.05$ ).
- 3b Significant difference between women <25 years and women >36 years ( $p < 0.05$ ).
- 3c Significant difference between women of 26-30 years and women of 31-35 years ( $p < 0.05$ ).
- 3b Significant difference between women of 26-30 years and women >36 years ( $p < 0.05$ ).
- 4 Significant difference between religious and non-religious women ( $p < 0.05$ ).
- 5 Significant difference between women who have language problems and women who have not ( $p < 0.05$ ).
- 6a Significant difference between Dutch and Turkish women ( $p < 0.05$ ).
- 6b Significant difference between Dutch and Surinamese women ( $p < 0.05$ ).
- 6c Significant difference between Turkish and Surinamese women ( $p < 0.05$ ).

Most of the items were answered incorrectly by more than 50% of the women from Turkish origin. In the Dutch population the percentage of incorrectly answered items in this domain was less than 20%. Smaller differences between ethnic groups were observed in knowledge about amniocentesis (Figure 3.4). Most Dutch, Turkish and Surinamese women knew that amniocentesis implies that amniotic fluid is removed by a needle through the mother's abdominal wall, but only a few knew that the risk of an abortion induced by amniocentesis is less than 1%. More than 50% of the women from Turkish and Surinamese origin incorrectly responded to the statement 'There's a risk of more than 50% of an abortion induced by amniocentesis'. Most of them answered 'Do not know' to this item, but 12% of the Turkish and 18% of the Surinamese agreed with this statement (data not shown).

Figure 3.4 **Ethnic differences in percentage of correct answers on knowledge items: amniocentesis**

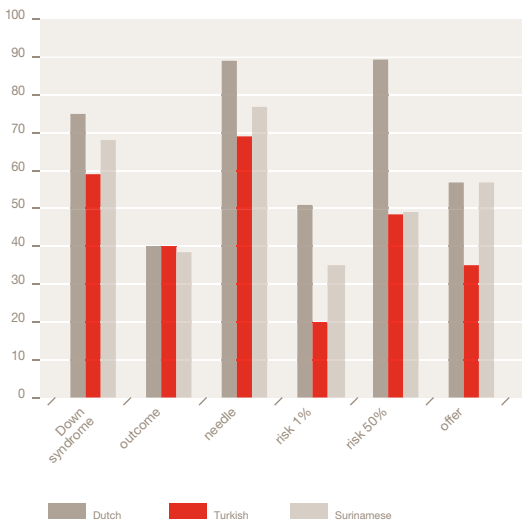


Table 3.4 shows the differences in mean knowledge scores between Dutch versus Turkish, and between Dutch versus Surinamese women, adjusted for provided information, age, education level, religion, and language skills. All adjustments significantly decreased, i.e. partly explained the ethnic differences in knowledge. Information that was provided by midwives and gynaecologists explained only a small proportion of the ethnic differences in knowledge about Down syndrome, prenatal screening and amniocentesis. Ethnic differences in knowledge about Down syndrome and prenatal screening could mostly be attributed to differences in educational level and language skills. When all variables were taken into account, the ethnic differences decreased, but remained significant. The largest ethnic differences remained in knowledge about prenatal screening, especially between Dutch women and women from Turkish origin.

Ethnic differences in knowledge about amniocentesis between Dutch women and women from Turkish origin decreased most after adjustment for language skills. The difference between Dutch women and women from Surinamese origin decreased most after adjustment for age and religion. After adjustment for all variables, the ethnic differences in knowledge of amniocentesis were no longer significant.

### 3.4 Discussion and conclusion

#### Discussion

The finding that women from ethnic minority groups less often received information about prenatal screening is in agreement with previous studies.<sup>1</sup> However, it is noteworthy that the number of women from Turkish and Surinamese origin who

reported to have received no information at all is relatively low and is almost similar to the number of Dutch women. This might be explained by the fact that we excluded all women who booked for prenatal care after 14 weeks of gestation. The finding that women from Turkish origin less often reported to have received information from friends could be related to cultural variation in

what is socially acceptable to talk about. However, it could also be related to the fact that prenatal screening is relatively new in the Netherlands and is thus a less common subject of discussion among women of ethnic minority groups. A significant ethnic difference was found in the type of information women received; women from Turkish and Surinamese origin less often reported

Table 3.4 Ethnic differences in mean knowledge about Down syndrome, prenatal screening and amniocentesis in the study population (n=269\*)

	Mean knowledge in Dutch ethnic group (SE)		Differences in mean knowledge compared to Dutch ethnic group (95%CI)			
	Dutch (n=105)		Turkish (n=99)		Surinamese (n=65)	
<b>Knowledge: Down syndrome (scale 0-7)</b>	5.57	(0.13)	-2.18*	(-2.56;-1.81)	-1.31*	(-1.73;-0.88)
Adjusted for age	5.59	(0.14)	-2.19*	(-2.61;-1.78)	-1.30*	(-1.76;-0.84)
Adjusted for educational level	5.18	(0.14)	-1.63*	(-2.04;-1.22)	-0.76*	(-1.24;-0.31)
Adjusted for religion	5.45	(0.14)	-1.82*	(-2.33;-1.31)	-1.04*	(-1.53;-0.55)
Adjusted for provided information	5.46	(0.14)	-2.07*	(-2.45;-1.69)	-1.20*	(-1.63;-0.77)
Adjusted for language skills	5.01	(0.18)	-1.66*	(-2.10;-1.23)	-1.29*	(-1.70;-0.88)
Adjusted for age, educational level, religion, type of information and language skills	4.75	(0.20)	-1.01*	(-1.58;-0.45)	-0.59*	(-1.10;-0.07)
<b>Knowledge: prenatal screening (scale 0-8)</b>	7.25	(0.19)	-3.58*	(-4.12;-3.04)	-2.31*	(-2.92;-1.70)
Adjusted for age	7.21	(0.20)	-3.49*	(-4.08;-2.90)	-2.25*	(-2.91;-1.59)
Adjusted for educational level	6.77	(0.20)	-2.90*	(-3.48;-2.31)	-1.65*	(-2.30;-1.01)
Adjusted for religion	6.97	(0.20)	-2.77*	(-3.49;-2.04)	-1.71*	(-2.41;-1.01)
Adjusted for provided information	6.99	(0.20)	-3.36*	(-3.90;-2.83)	-2.11*	(-2.77;-1.51)
Adjusted for language skills	6.24	(0.26)	-2.64*	(-3.25;-2.03)	-2.28*	(-2.85;-1.70)
Adjusted for age, educational level, religion, type of information and language skills	5.78	(0.27)	-1.46*	(-2.24;-0.69)	-1.12*	(-1.82;-0.42)

**Knowledge: amniocentesis  
(scale 0-6)**

	4.02	(0.15)	-1.30*	(-1.72;-0.88)	-0.77*	(-1.25;-0.30)
Adjusted for age	4.10	(0.15)	-1.03*	(-1.47;-0.58)	-0.54*	(-1.04;-0.04)
Adjusted for educational level	3.94	(0.17)	-1.19*	(-1.68;-0.71)	-0.68*	(-1.21;-0.15)
Adjusted for religion	3.92	(0.16)	-1.01*	(-1.58;-0.44)	-0.55*	(-1.11;-0.00)
Adjusted for provided information	3.99	(0.16)	-1.18 *	(-1.61;-0.75)	-0.63 *	(-1.12;-0.15)
Adjusted for language skills	3.60	(0.20)	-0.92*	(-1.41;-0.42)	-0.76*	(-1.22;-0.03)
Adjusted for age, educational level, religion, type of information and language skills	3.64	(0.22)	-0.23	(-0.88;0.41)	-0.18	(-0.77;0.41)

SD = standard deviation

CI= confidence interval

\* Significant ethnic difference in mean knowledge (p<0.05)

to have received written information and less often read the written information if they received it. This can easily cause disparity in knowledge because our results, and those from others, have shown that especially women who received and read written material had more knowledge about prenatal screening than women who received no information or oral information only.<sup>2, 8, 17</sup>

We do not know the exact reason why women from Surinamese and Turkish origin less often read the booklet. Translations of the booklet into English, Arabic and Turkish were not available at the time we interviewed these women; however, our findings show that language problems are not the only barrier to reading written material. Although more than 30% of the Turkish and Surinamese non-readers did not report any problems in reading Dutch, they still did not read the booklet. Perhaps this could be related to their cultural background. People with a collectivistic background often have less need for information disclosure and participation in decision-making than women with a more

individual-oriented cultural background, such as the Dutch culture.<sup>18</sup>

In the present study, the ethnic differences in knowledge about Down syndrome and prenatal screening are substantial. Others also reported less knowledge about Down syndrome and/or prenatal screening among women from ethnic minority groups.<sup>2-5, 19, 20</sup> Women from Turkish and Surinamese origin particularly knew less about the goal and interpretation of the results of the combined test. One possible explanation is that they scored much lower on these items because they were less interested in participating in the combined test. Previous analyses in our study population showed that 13% of the Turkish and 17% of the Surinamese women participated in prenatal screening versus 44% of the Dutch women. Others also reported a lower uptake of prenatal screening and testing among ethnic minorities.<sup>1, 21</sup>

Our finding that ethnic differences in knowledge can be attributed to differences in language skills is in accordance with other studies.<sup>5, 20, 22</sup> A positive

association has been reported between educational level and knowledge about prenatal screening, which underlines our finding that ethnic differences in knowledge about Down syndrome and prenatal screening can largely be explained by differences in educational level.<sup>2, 8, 13, 23, 24</sup>

The strength of our study is that we prospectively collected data in an open population among pregnant women (in early pregnancy) that had yet to decide upon prenatal screening. Women who could not express themselves in Dutch were not excluded from the study. However, a limitation is that we only know the exact response rate in the group of women who were recruited by the researchers themselves (51% of the respondents). Another limitation is the unequal distribution of educational levels among the three ethnic groups. However, these education levels reflect the education levels among the inner city population in Rotterdam.<sup>15</sup>

## Conclusion

Most Dutch, Turkish and Surinamese women reported to have received oral and/or written information about prenatal screening. However, women from Turkish and Surinamese origin less often reported to have received written information and read written information, more often reported difficulties in understanding the information, and had substantially less knowledge about Down syndrome, prenatal screening and amniocentesis. Ethnic differences in the type of information that was provided by midwives and gynaecologists explained only a small proportion of these ethnic differences in knowledge. Differences in educational level and language skills contributed most to the explanation of these ethnic differences, but could not totally explain all ethnic variation in knowledge.

## Practice implications

Since optimal knowledge scores were observed among Dutch women who reported to have received information from their midwife or gynaecologist, we think that the knowledge of women from ethnic minority groups can be improved. Our results show that interventions should especially be aimed at overcoming language barriers, and targeting information to the women's abilities to comprehend the complicated information about prenatal screening.

Midwives and gynaecologists should realize that especially women from ethnic minority groups need to be stimulated to read written material and, in case of language barriers, be provided with translated written material that explains prenatal screening and Down syndrome in a culturally sensitive way. Perhaps other types of educational materials (such as an informational video or pictures of Down syndrome and prenatal screening) could be used in addition to written material.<sup>22, 25, 26</sup> It should be further investigated why Dutch women more often reported to have received written information from their midwife or gynaecologist. Do they more often remember to have received information or is it actually more often provided to them and why? In order to increase women's comprehension of oral information, midwives and gynaecologists should provide women with appropriate and intelligible information, use an interpreter in case of language barriers, and verify whether women have understood the information that they have been provided with. Since differences in age, religion, education level and language skills could not totally explain ethnic variations in knowledge, it should be further investigated whether other factors, such as cultural differences, play a role here.

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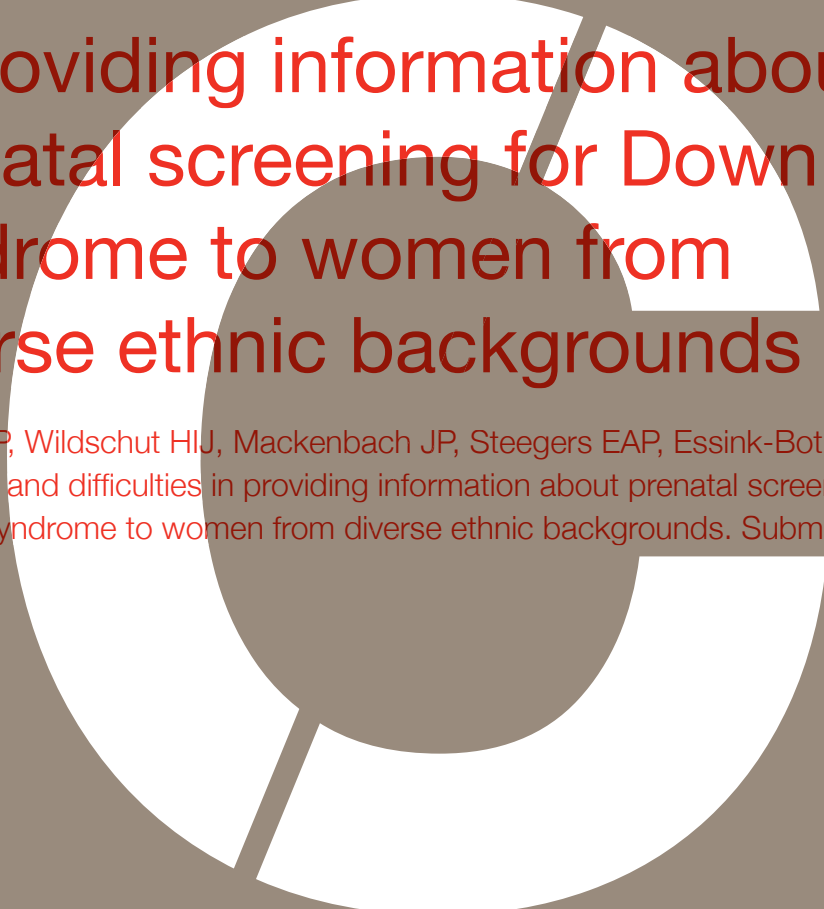


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# Differences and difficulties in providing information about prenatal screening for Down syndrome to women from diverse ethnic backgrounds

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Differences and difficulties in providing information about prenatal screening  
for Down syndrome to women from diverse ethnic backgrounds. Submitted.

4

# Abstract

**Objective** To assess differences and difficulties that healthcare professionals experience in communication with patients from diverse ethnic backgrounds, with the provision of information about prenatal screening for Down syndrome as a case study.

**Methods** We performed a case study among 24 midwifery practices in Rotterdam, the Netherlands. Midwives were requested to complete a structured web-based questionnaire. We conducted a group interview in order to obtain additional information. We used descriptive statistics to summarise ethnic differences in the provision of information and univariate analysis of variance to test differences in barriers and cultural competence between various groups of midwives.

**Results** Most midwives reported no differences in the provision of information about prenatal screening for Down syndrome to women from different ethnic backgrounds. However, when pregnant women from a non-Western ethnic background hardly speak and understand Dutch, midwives reported that they do not always offer information and feel less culturally competent in informing these women about prenatal screening. In total 58% of the midwives reported that they never use translated information materials and 88% never used professional interpreters. The main reasons for this underutilization were unawareness of the availability of translated materials and unfamiliarity with the use of professional interpreters.

**Conclusion** Although language barriers were reported to be the main difficulty in providing cultural competent care to patients from diverse ethnic backgrounds, only a minority of the midwives in this case study used translated materials or professional interpreters. Interventions should aim at increasing healthcare professionals' competences to address language barriers in the provision of information about prenatal screening for Down syndrome.

## 4.1 Introduction

Healthcare professionals in today's multicultural societies are increasingly confronted with patients from different ethnic and cultural backgrounds. This diversity has implications for healthcare systems and the professionals working in various fields of healthcare. Cultural competence has been described as the ability of healthcare organisations to meet the needs of diverse populations and the ability of the healthcare professional to bridge cultural differences to build an effective relationship with a patient.<sup>1</sup> Cultural competence interventions at clinical level have been described as efforts to enhance healthcare professionals' knowledge of the relationship between socio-cultural factors, health beliefs and behaviours, and to equip healthcare professionals with the tools and skills to manage these factors appropriately.<sup>2</sup>

In order to assess differences and difficulties that healthcare professionals in the Netherlands experience in providing cultural competent care to patients from diverse ethnic backgrounds, we performed a case study among midwives in Rotterdam, the second largest city in the Netherlands where 50% of the pregnant women belong to a non-Western ethnic group, most of them originating from Turkey, North-Africa (Morocco) and Caribbean countries (Surinam, the Dutch Antilles and Aruba). The majority of pregnant women in the Netherlands book for prenatal care at an independent community midwife practice in a decentralised primary care setting. Women are only referred to a gynaecologist in case of a complicated obstetric or medical history, or complications during pregnancy, labour or puerperium. Since 2007, midwives and gynaecologists are legally obliged to offer all pregnant women information about the options for prenatal screening with the combined

test at the booking visit. Women who express interest in screening must be provided with further information about the nature of risk assessment tests and potential subsequent diagnostic evaluation by chorionic villus sampling or amniocentesis.<sup>3-5</sup>

Our recent previous study among pregnant women in Rotterdam showed that those from Dutch, Turkish and Caribbean (Surinamese) ethnic background (n=270) reported that the midwife is the prime source of information about prenatal screening for Down syndrome.<sup>6</sup> The goal to inform pregnant women and their partners about prenatal screening is to enable them to make an informed decision whether or not to participate in prenatal screening, which is hardly reached among ethnic minority groups in various countries.<sup>7, 8</sup> Our previous study also showed that women from Turkish and Caribbean background more often reported difficulties in understanding the information that they received from their midwife and that only 5% of the 100 women from Turkish background and 26% of the 65 women from Caribbean background made an informed decision whether or not to participate in prenatal screening for Down syndrome, compared to 71% of the 105 women from Dutch ethnic background. These ethnic differences could to a large extent be attributed to differences in educational level and language barriers.<sup>6,9</sup> It is unknown to what extent midwives experience differences and difficulties, such as language barriers, in providing information about prenatal screening for Down syndrome to pregnant women from diverse ethnic backgrounds. The present study therefore aimed to answer the following research questions:

- 1) Do midwives report differences in the provision of information to women from non-Western and Dutch ethnic backgrounds?

- 2) Do midwives experience specific difficulties in providing information to women from non-Western ethnic backgrounds?
- 3) What are the determinants of possible ethnic-related differences and difficulties in the provision of information about prenatal screening for Down syndrome?

## 4.2 Methods

### Population and data collection

The study population consisted of midwives who were enrolled in the study between July and December 2008. Midwives were recruited from midwifery practices that were part of the Verloskundige Kring, the local society of midwives. Practically all midwives working in the geographical area of Rotterdam are a member of this society. Midwifery practices were visited or contacted by telephone by the researcher (MF). Representatives of the practices received information about the study and were asked whether they would participate in the study, and whether it was allowed to send an email to their colleagues with the same request. After permission, all midwives were invited to participate in the study via an e-mail letter, including a link to the web-based questionnaire. If necessary, up to five e-mail reminders were sent to each midwife, supported by telephone calls to the midwifery practices. To further explore some of the results emerging from the web-based questionnaire, the chairwoman of the society of midwives was contacted to organize a qualitative group interview at one of the meetings of the local society of midwives.

### Measures

Background characteristics of the midwives were measured by multiple-choice items. Religiosity

was measured by the question whether or not the midwife counted herself among a certain religion. Ethnic origin was assessed by country of birth of the midwife and her parents, which is in accordance with the definition applied by the Dutch Central Bureau of Statistics: i.e. someone is considered to be of non-Western ethnic origin when she or at least one of her parents was born in Turkey or countries in Africa, South America or Asia (excluding Indonesia and Japan).<sup>10</sup> Attitude towards routinely offering prenatal screening to all pregnant women was measured by one item on a scale from 1 ('totally against') to 5 ('totally in favour').

Ethnic-related differences in the provision of information were assessed by 12 multiple-choice items that measured to what extent midwives offer information to specific groups of pregnant women: non-Western women of specific age groups versus Dutch women of specific age groups; non-Western women who hardly speak and understand Dutch versus non-Western women without language barriers; religious non-Western women versus religious Dutch women; and non-Western women of higher/lower educational level versus Dutch women of higher/lower educational level. Differences in the content of the information provided to women from non-Western ethnic backgrounds and Dutch women were measured by three multiple-choice items related to informing women about choices and consequences of prenatal screening, advising women whether or not to participate in prenatal screening, and giving their own opinion on participation in prenatal screening.

Difficulties in providing information to women from non-Western ethnic backgrounds were measured by the question how often midwives experienced specific barriers in providing information about prenatal screening to women from non-Western ethnic



backgrounds. Response options ranged from 1 ('never') to 4 ('always'). A second multiple-choice item with multiple answers was provided to assess the reasons for these barriers.

Perceived cultural competence was assessed by three items on how prepared midwives believed themselves to be in providing information to women from different cultural backgrounds, women who hardly speak and understand Dutch, and those whose religious beliefs influence the decision-making process. Responses were measured on a scale ranging from 1 ('very unprepared') to 5 ('very well prepared'). These items were adapted from a previous study on preparedness in cross-cultural care.<sup>11</sup>

The use of translated written materials and professional interpreters was measured by two items on the extent of using translated written materials and professional interpreters in case of language barriers. The items were rated on a scale ranging from 1 ('never') to 4 ('always'). Reasons for not always using translations and interpreters were measured by two multiple-choice items with multiple answers and further explored in a group interview that was held at the meeting of the local society of midwives (this was attended by 23 midwives).

### Analyses

Descriptive statistics were used to summarise background characteristics of the population, provision of information to Dutch women and women from non-Western ethnic backgrounds, and the use of translated written materials and professional interpreters.

Univariate analysis of variance (ANOVA) was used to test differences in mean experience of barriers and mean cultural competence between religious and non-religious midwives, midwives with Dutch and non-Western ethnic backgrounds, midwives

with a higher or lower number of non-Western clients, and midwives with a positive, neutral or negative attitude towards routinely offering prenatal screening. Differences in the use of translated materials and professional interpreters were tested by chi-square tests.

## 4.3 Results

### Response and background characteristics of the population

All 24 midwifery practices connected with the local society of midwives participated in the study. A total of 73 midwives were sent an invitation by e-mail: 57 midwives actually filled in the web-based questionnaire (response rate 78%). In total 23 midwives, from 19 midwifery practices, participated in the group interview.

Table 4.1 presents the background characteristics of the midwives. All were female, 39% considered themselves to be religious and 16% belonged to a non-Western ethnic group. Almost all midwives worked in a group practice and had less than 10 booking visits per week, 35% of the midwives reported that the majority of their clients have a non-Western ethnic background. Not all midwives had a positive attitude towards routinely offering prenatal screening; 11% opposed the government position of informing every pregnant woman about prenatal screening.

### Ethnic-related differences in the provision of information

Fifty midwives (88%) reported that they always offer information about prenatal screening to every pregnant woman regardless of their ethnic background, language skills, religious beliefs, age or educational level.

Table 4.1 Characteristics of the midwives (n=57)

	Mean (SD)	n (%)
Age (in years)	38.5 (10.8)	
Sex		
Male		0 (0)
Female		57(100)
Religious		
Yes		35 (61)
No		22 (39)
Ethnicity		
Dutch		48 (84)
Non-Western		9 (16)
Working practice		
Solo practice		2 (3)
Group practice		55 (97)
Years of experience	12.8 (8.8)	
Number of booking visits per week		
<5		24 (42)
5-10		29 (51)
>10		4 (7)
Number of non-Western counselees		
Minority		18 (32)
Half		19 (33)
Majority		20 (35)
Attitude towards routinely offering prenatal screening		
Positive		39 (68)
Neutral		12 (21)
Negative		6 (11)

Seven midwives (12%) reported that they do not always offer information to women from non-Western ethnic backgrounds that hardly understand and speak Dutch. Three of them also reported that they generally offer information to less than half of the religious women, regardless of their ethnic background. In total, 46 midwives (81%) reported no ethnic-

related differences in providing information. Nine midwives (16%) reported to give less and two midwives (3%) reported to give more information about choices and consequences of prenatal screening to non-Western than to Dutch women. One of them reported to give more information but less advice on participation to non-Western women.

**Table 4.2 Difficulties in informing women from non-Western ethnic backgrounds about prenatal screening for Down syndrome, as reported by the midwives (n=57)**

	<b>n (%)</b>
<b>Experiences barriers</b>	
Never	3 (5)
Sometimes	39 (69)
Often	15 (26)
Always	0 (0)
<b>Reasons for experiencing barriers*</b>	
Lack of translated materials	29 (53)
Lack of time during booking visit	15 (27)
Generally lower educational level	12 (22)
Socio-economic problems	9 (16)

\* Multiple answers possible

None of the other midwives reported any differences in giving direct advice or a personal opinion on whether or not to participate in prenatal screening.

### Difficulties in informing women from non-Western backgrounds and cultural competence

Table 4.2 shows that almost all midwives (95%) experienced barriers in informing women from non-Western ethnic backgrounds about prenatal screening. Lack of translated materials, lack of time during the booking visit, and the generally lower educational level of the women were the most frequently mentioned reasons for these difficulties. In general, midwives felt competent to inform women with other cultural backgrounds and women whose religious beliefs influence their decision on screening participation. However, they felt less prepared to inform women who hardly understand and speak Dutch (Table 4.3). No significant differences in mean experience of barriers and mean cultural

competence were found between religious and non-religious midwives, midwives with Dutch and non-Western backgrounds, midwives with a higher or lower number of non-Western clients, and midwives with a positive, neutral or negative attitude towards routinely offering prenatal screening.

### Use of translated written materials and professional interpreters

Table 4.4 shows that 46 midwives (81%) reported that they never or sometimes use translated written materials when they are confronted with language barriers. Only 10 midwives (17%) reported that they mostly or always use translated materials. Most important reason for never or sometimes using translated materials was that these are not present in the midwifery practice, reported by 54% of the midwives. Other reported reasons were that translated materials are not easily available during the booking visits and that

Table 4.3 Mean cultural competence among the midwives (scale 1-5)

Competences to inform pregnant women about prenatal screening	Mean ( SD)
Readiness to inform pregnant women from a different cultural background	4.27 (0.52)
Readiness to inform pregnant women who hardly understand and speak Dutch	3.13 (0.90)
Readiness to inform pregnant women whose religious beliefs influence their decision whether or not to participate in prenatal screening	4.21 (0.65)

it is often forgotten to use translated materials, each reported by 11% of the midwives. Table 4.4 further shows that none of the midwives reported that they always or often use professional interpreters in case of language barriers, 50 midwives (88%) reported that they never and 7 midwives (12%) reported that they sometimes use professional interpreters. The most reported reason for not using professional interpreters was that midwives do not know beforehand whether there is a language problem, reported by 54% of them. Other reasons were that it takes too much time to call in an interpreter, reported by 39%, and that midwives do not know beforehand which language clients prefer, reported by 21% of the midwives. Moreover, 14% of them reported that they had no reason for not using an interpreter. No significant differences in the use of translated materials or professional interpreters were found between various groups of midwives. The group interview at the local society of midwives showed that midwives only have Dutch-language booklets about prenatal screening for Down syndrome. These booklets were developed by the Dutch 'Erfocentre' and published by the Dutch National Institute for Public Health at the start of the Dutch prenatal screening programme. Translations of the booklet were later developed and have to be downloaded from the website.<sup>12</sup> Most midwives

acknowledged the potential benefit of translated materials, but did not seem to know where to find these materials. Some midwives explained that they often download translated booklets from the website of a regional primary healthcare centre for prenatal screening. Other midwives were unaware of these kind of possibilities. Unfamiliarity also seemed to be the most important reason for not using professional interpreters. Only two midwives mentioned that they have experience with professional interpreters and were in fact very positive about it. The majority had neither positive nor negative experiences. Some of them explained that it never occurred to them to arrange a professional interpreter, but expected it to be helpful. In response to the question how the most important language barriers can be resolved, midwives mentioned that when the pregnant woman calls to make an appointment for the booking visit it is feasible to ask her whether a professional translator is needed. The midwives who had experiences with interpreters explained that interpreters are often immediately available for various languages, that it often takes only one telephone call to arrange an interpreter, and that it is free of charge. Midwives recognized that overcoming language barriers would indeed improve the provision of information about prenatal screening and seemed to be open for interventions such as the use of professional

**Table 4.4 Use of translated written material and professional interpreters in the presence of language barriers, as reported by the midwives (n=57)**

	<b>n (%)</b>
<b>Written materials*</b>	
Never uses translated materials	33 (58)
Sometimes uses translated materials	13 (23)
Mostly uses translated materials	7 (12)
Always uses translated materials	3 (5)
<b>Professional interpreters</b>	
Never uses professional interpreters	50 (88)
Sometimes uses professional translators	7 (12)

\* One missing value on the use of written materials

interpreters. The website for translated materials and telephone numbers of interpreter services were immediately included in the minutes of the meeting and were later distributed to all members of the local society.

#### 4.4 Discussion and conclusion

##### Discussion

Most midwives reported no differences in the provision of information about prenatal screening for Down syndrome to women from different ethnic backgrounds. However, when pregnant women from non-Western ethnic backgrounds hardly speak and understand Dutch, midwives do not always offer information and feel less culturally competent in informing these women about prenatal screening. Although language barriers were reported to be the main difficulty in informing these women, a minority of midwives reported to use translated materials and professional interpreters in the provision of

information about prenatal screening.

The reports of midwives on differences and difficulties in providing information to women from non-Western ethnic backgrounds are in accordance with the reports of the 270 pregnant women who participated in our previous study and were recruited from the same practices. Most pregnant women indeed reported that their midwife had told them about the possibility to participate in prenatal screening. In total, 83% of the non-Western women and 89% of the Dutch women reported to have received written and/or oral information. Non-Western women without language problems were 3.7 times more likely to have received information about prenatal screening than those who reported problems with speaking, reading and understanding Dutch (odds ratio 3.7, 95% CI 1.19-11.26).<sup>6</sup> Several studies in other countries reported on language barriers in communication with clients from ethnic minorities. For example, a study in the USA identified problems of translations as one of the sources of communication problems between

genetic counsellors and pregnant women from Mexican origin.<sup>13</sup> Multiple communication problems were described in the use of untrained or no interpreters in prenatal genetic clinics in Texas.<sup>14</sup> Language differences are also reported as a barrier to quality in healthcare organizations in general, such as the ability to understand symptoms and treating diseases among outpatient clinicians and lower rates of informed consent among hospitalised patients in the USA.<sup>15, 16-18</sup> Moreover, studies among physicians in the USA and the Netherlands showed that clients from an ethnic minority with a language barrier are less likely to receive empathic responses and involvement in the decision-making process and are more likely to have problems in understanding a medical situation.<sup>19-21</sup>

It may be questionable whether the use of translated materials and professional interpreters actually improves the provision of information when midwives are confronted with language barriers. In our previous study we were able to link midwives' reports from six midwifery practices to the reports of their clients who formed 79% of the study population.<sup>6</sup> It was found that clients from a practice that uses translated materials and professional interpreters more often reported to have received an offer of information and scored higher on knowledge about prenatal screening than clients from practices where midwives never use translated materials or professional interpreters. Unfortunately the numbers of clients per practice are too small and there is insufficient variation in the use of translated materials and professional interpreters between practices to draw conclusions about their effects on the provision of information about prenatal screening. The effect of professional interpreters has been extensively evaluated in other studies in the field of clinical care. Two reviews reported a positive impact on communication, utilization, clinical

outcomes and satisfaction with care.<sup>22, 23</sup>

Our finding that midwives often do not use professional interpreters is in accordance with studies among physicians in the USA.<sup>24, 25</sup> Physicians also reported lack of time, lack of access to medical interpreters and written materials in other languages as barriers in delivering cross-cultural care.<sup>24</sup> In-depth interviews among physicians showed that they found it easier to 'get by' without interpreters and communicate through gestures, using limited second language skills, or relying on histories obtained by other physicians.<sup>25</sup>

As far as we know this is the first study on differences and difficulties that midwives experience in providing information about prenatal screening for Down syndrome to women from diverse ethnic backgrounds. The strength of this study is that we combined quantitative and qualitative methods and were therefore able to gain more insight into reasons for the underuse of translated written material and professional interpreters, and formulate specific interventions. Despite that almost all midwifery practices in the area of Rotterdam participated in the study, the small research population could be considered a limitation of this study. Another limitation is that the data are self-reported, and we do not know the factual behaviour of the midwives.

## Conclusion

Although language barriers were reported to be the main difficulty in providing cultural competent care to patients from diverse ethnic backgrounds, only a minority of the midwives in this case study used translated materials or professional interpreters. Interventions should therefore aim at increasing healthcare professionals' competences to address language barriers in the provision of information about prenatal screening for Down syndrome. First of all, midwives should become more aware of the

availability of and access to translated materials. The availability of translated materials on the website of the Dutch National Institute for Public Health should be much more promoted among midwives and other healthcare professionals. Moreover, the group interview revealed that not all midwives are accustomed to this form of communication and prefer a booklet with various translations. To increase the use of professional interpreters, midwives and other healthcare professionals should know how to implement the use of professional interpreters in their daily practice. This not only implies that they know where to find interpreters, but also how they have to work with them. Systematic cultural competency training should therefore enclose a part of the curriculum of (future) healthcare professionals in the Netherlands. Such cultural competency training should also provide healthcare professionals with knowledge, tools and skills to better understand and manage socio-cultural issues.<sup>2</sup> An example of an intervention to increase cultural competency at organisational level is the interpreter policy of the Erasmus University Medical Centre in Rotterdam that was initiated in 2006 in order to enhance the use of professional interpreters. This policy is based on the national field norms as defined by the Netherlands Healthcare Inspectorate, prescribing the standard use of professional interpreters for communicating with clients who insufficiently speak and understand Dutch and discouraging the use of non-professional interpreters.<sup>26</sup> Erasmus MC developed a brochure and pocket-sized pamphlets with information about the interpreter policy, guidelines and advice on the use of professional interpreters, and contact information for the national interpreter service. Meetings were arranged to emphasize the importance of professional interpreters and to give instructions on the use of professional interpreters.

The present study indicates that midwives are aware of the impact of language barriers and are open for these kinds of interventions to improve the provision of information about prenatal screening for Down syndrome to women from various ethnic backgrounds.

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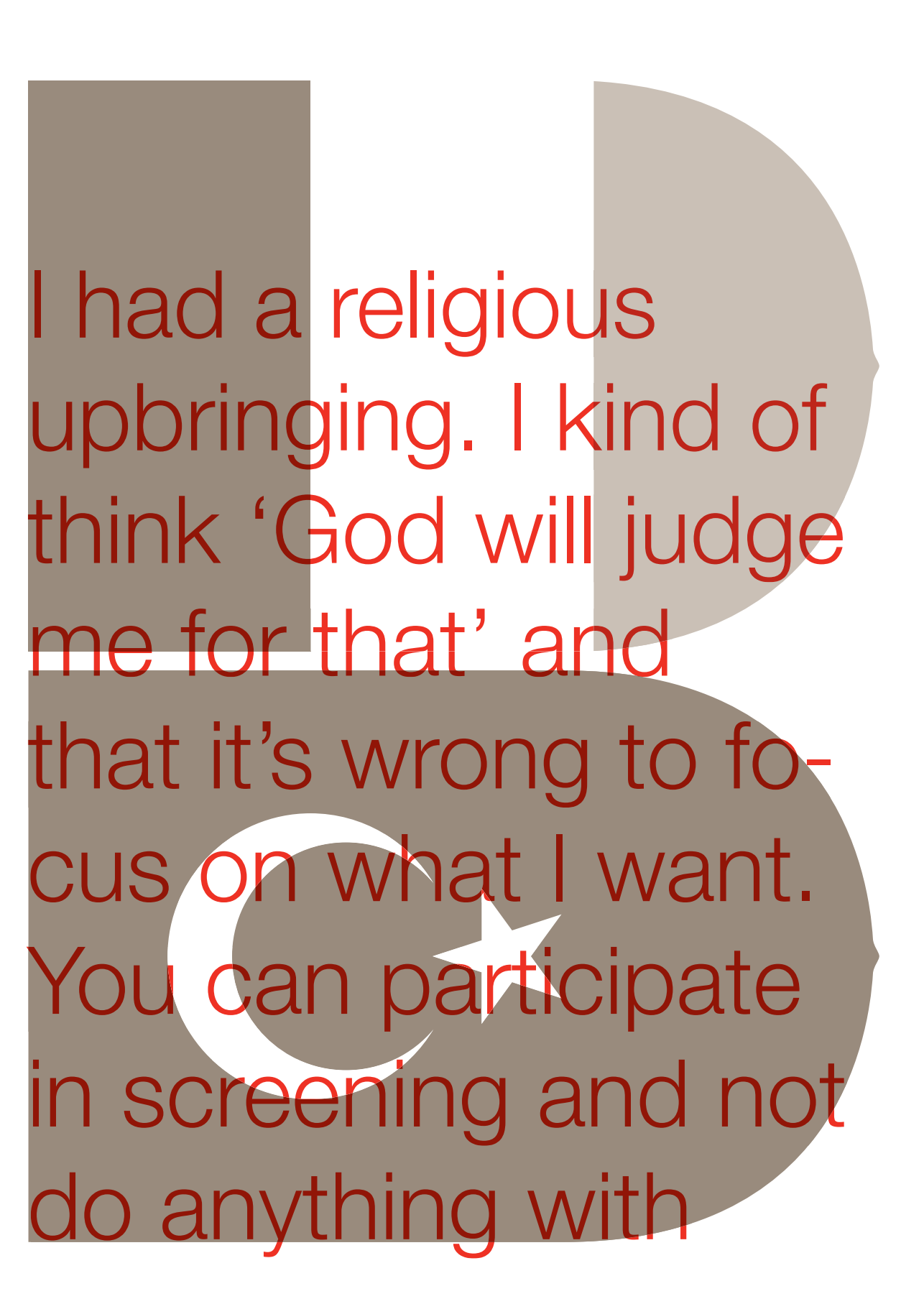




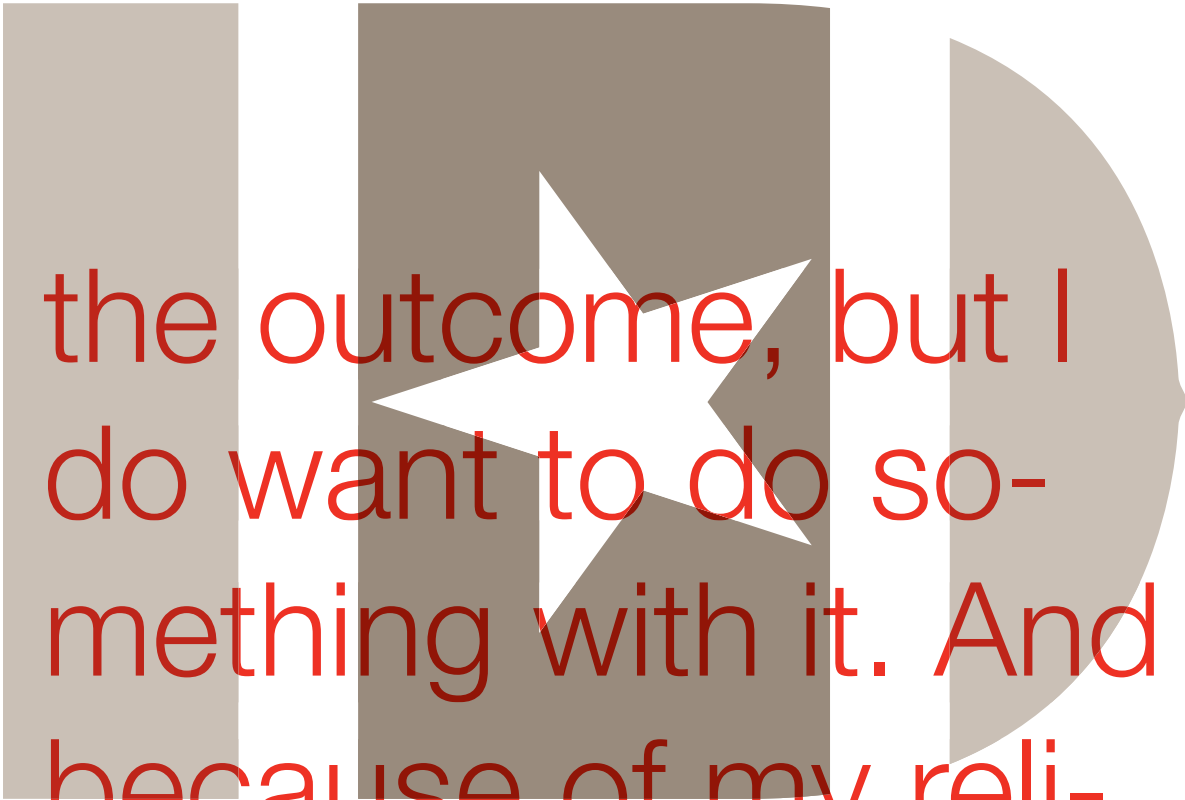
Ethnic differences  
in the decision-making process

# Part

# III



I had a religious upbringing. I kind of think 'God will judge me for that' and that it's wrong to focus on what I want. You can participate in screening and not do anything with

The background features a large, semi-transparent graphic. It consists of three vertical bars of varying heights and widths, colored in a muted taupe or brownish-grey. The tallest bar on the left contains the letter 'I'. The middle bar is shorter and contains the letter 'E'. The shortest bar on the right is a semi-circle and contains the letter 'D'. A white, five-pointed star is positioned in the center, overlapping the 'E' and 'D' bars.

the outcome, but I do want to do something with it. And because of my religious background, this makes me feel guilty. (Woman from Surinamese origin, 39 years of age).

# Ethnic differences in informed decision-making about prenatal screening for Down syndrome

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5

# Abstract

**Objective** The aim of this study was to assess ethnic variations in informed decision-making about prenatal screening for Down syndrome and to examine the contribution of background and decision-making variables.

**Methods** Pregnant women from Dutch, Turkish and Surinamese origin were recruited between 2006 and 2008 from community midwifery or obstetrical practices in the Netherlands. Each woman was personally interviewed 3 weeks (mean) after booking for prenatal care. Knowledge, attitude and participation in prenatal screening were assessed following the 'Multidimensional Measure of Informed Choice' that has been developed and applied in the UK.

**Results** In total, 71% of the Dutch women were classified as informed decision-makers compared to 5% of the Turkish and 26% of the Surinamese women. Differences between Surinamese and Dutch women could to a large extent be attributed to differences in educational level and age. Differences between Dutch and Turkish women could mainly be attributed to differences in language skills and gender emancipation.

**Conclusion** Women from ethnic minority groups less often made an informed decision whether or not to participate in prenatal screening. Interventions to decrease these ethnic differences should first of all be aimed at overcoming language barriers and increasing comprehension among women with a low education level. To further develop diversity-sensitive strategies for counselling it should be investigated how women from different ethnic backgrounds value informed decision-making in prenatal screening, what decision-relevant knowledge they need, and what they take into account when considering participation in prenatal screening.



## 5.1 Introduction

In many Western countries pregnant women are offered information on prenatal screening for Down syndrome. In the Netherlands, the opportunity to participate in prenatal screening for Down syndrome has only recently become a part of routine prenatal care. The Dutch government recommended the combined test to estimate women's individual risk of carrying a child with Down syndrome. If this risk exceeds 1:200, women are offered invasive testing to determine the fetal karyotype. Women aged 36 years or over have an age-based indication for invasive testing. Younger women are only eligible for the combined test, unless they have a listed indication for invasive testing. Those who do not have an indication for invasive testing have to pay for the combined test themselves.<sup>1-4</sup>

The goal of offering information is to enable pregnant women to make an informed decision whether or not to participate in prenatal screening. In order to quantify whether women made an informed decision about prenatal screening for Down syndrome, Marteau and Michie developed and validated a measure based on three dimensions - knowledge, attitude and behaviour - called the Multidimensional Measure of Informed Choice (MMIC). According to this measure, an informed decision is made when women have sufficient knowledge about prenatal screening and their actual (non-) participation in prenatal screening is consistent with their attitude.<sup>5, 6</sup> Dormandy applied the MMIC in a multi-ethnic population in the UK and found that South Asian and Black African Caribbean women were less likely to make an informed decision on prenatal screening for Down syndrome than other women.<sup>7</sup>

It remains unclear whether these results apply to ethnic minority groups in other countries and

to what extent variables that might influence the decision-making process contribute to ethnic differences in informed decision-making. Following the MMIC, we assessed knowledge and attitude-uptake consistency among women from Dutch, Turkish and Surinamese origin. Turkish and Surinamese people form the largest non-Western migrant groups in the Netherlands.<sup>8</sup> Possible contributing variables were derived from the prenatal screening stage model that we developed earlier to structure women's decision-making process in prenatal screening.<sup>9</sup> The specific research questions of this study were:

- 1) To what extent do Dutch, Turkish and Surinamese pregnant women differ in informed decision-making on prenatal screening for Down syndrome?
- 2) What is the contribution of background characteristics and decision-making variables to ethnic differences in informed decision-making?

## 5.2 Methods

### Participants and data collection

Pregnant women from Dutch, Turkish and Surinamese origin were recruited between September 2006 and June 2008 from 15 community midwifery practices in Rotterdam city centre and the outpatient clinic of the Erasmus University Medical Centre. Midwives and obstetricians were instructed to inform each Dutch, Turkish and Surinamese woman about this study at the booking visit, and to ask for permission to be contacted by the researcher. In four midwifery practices the researcher recruited women immediately after the booking visit. Women who were booked for prenatal care at a later stage (i.e. after 14 weeks' gestation) were excluded from the study because they lacked timely

information on first trimester prenatal screening. Women who agreed to be included in the study were contacted by telephone within one week of the booking visit. They received oral information about this study and were offered an appointment for a structured telephone or a face-to-face interview.

Data collection took place through structured interviews that were conducted by the female researcher and three female research assistants that were trained to do the interviews. The interview was intended to take place before women could have participated in prenatal screening. Women who had difficulties in understanding Dutch received translated information about the study, were contacted by a research assistant from the same ethnic background and were offered an interview in the language they preferred.

### Ethnic origin

Ethnic origin was assessed by country of birth of the woman and her parents. A woman is considered to be from non-Dutch ethnic origin when she and at least one of her parents was born abroad or if she was born in the Netherlands with at least one of her parents born abroad.<sup>8</sup> To distinguish between Hindustani, Creole or 'other' in the Surinamese population, we used the method of self-identification as proposed by Stronks et al.<sup>10</sup>

### Informed decision-making

Knowledge was measured by 21 items adapted from Marteau's MMIC and a previous Dutch study on informed decision-making: 7 items about Down syndrome, 8 items about the combined test, and 6 items about invasive testing.<sup>11</sup> Response options consisted of 'correct', 'incorrect' or 'don't know'. Women got one point for every question answered correctly. Sufficient knowledge was defined based

on the guess corrected midpoint (15 of 21 questions answered correctly).

Attitude towards prenatal screening for Down syndrome was measured by a five-item scale (see Appendix). The scale ranged from 5 to 25 and was adapted from the MMIC and Van den Berg et al.<sup>5, 11</sup> In accordance with the MMIC, the median of 15 was taken to classify women's attitudes, with scores of 15 and higher indicating positive attitudes and scores below 15 indicating negative attitudes. In our study population the five items were sufficiently correlated with a Cronbach's alpha of 0.69 (0.74 for Dutch, 0.59 for Turkish and 0.73 for Surinamese women).

(Non-) participation in prenatal screening was measured by contacting the women by telephone several months after the interview.

### Contributing factors

Age was measured by assessing women's date of birth.

Gestational length was calculated from the best obstetric estimate as reported by the woman.

Marital status was categorized as 'living together with partner', 'not living together with partner', or 'single'.

Number of children was measured by assessing the number of children the women takes care for daily.

Educational attainment level was categorised as low (primary school), medium (first and second stage secondary education) or high (vocational college or university).<sup>12</sup>

Religion was measured by the question whether or not a woman considered herself to be religious and, if yes, which religion. We used a 5-item instrument to measure women's identification with their religion, which included cognitive identity, emotional attachment and identification as a

Muslim/Christian, etc. (Cronbach's alpha 0.76).<sup>13</sup> The average score was dichotomised (above/below 4).

Language skills were measured by three items that assessed whether women reported difficulties in expressing themselves in Dutch, understanding and reading Dutch. Provision of information was based on women's perceptions and measured by two items that assessed whether women received and read written information and one item that assessed whether women received oral information about prenatal screening. Gender emancipation was measured by a scale of five items, e.g. 'Women can best be responsible for the housekeeping' and 'It's more important for boys than for girls that they can earn their own income later'. The items were rated on a 5-item Likert-type scale ranging from totally agree (1) to fully disagree (5), and the mean score formed a score for gender emancipation. High scores indicated more gender emancipation (Cronbach's alpha 0.69).

Subjective norm was measured by assessing normative beliefs and weighing the importance of these beliefs. One set of four questions measured what women assume that important others (partner, family, friends and midwife) think they should do (-2 = certainly not participate in screening; +2 = certainly participate in screening). A second set of four questions measured the importance of these beliefs (1= not at all important; 5= very important). An overall normative belief was obtained by multiplying both scores, ranging from -10 (strong subjective norm not to participate in screening) to 10 (strong subjective norm to participate in screening). Perceived barriers to participate in prenatal screening were measured by three items (agree/disagree) on considerations whether or not to participate in prenatal screening; costs; knowing where to go; and transportation.

## Analysis

Descriptive statistics were used to summarise characteristics of the population, provision of information about prenatal screening, language skills, mean knowledge and attitude scores, actual (non-) participation in prenatal screening and informed decision-making. The three items on speaking, understanding and reading Dutch were combined into one dichotomous variable.

Ethnic differences in participation in prenatal screening, attitude-uptake consistency, sufficient knowledge, age category, educational level, language skills, marital status, religion and barriers to participate in prenatal screening were tested by chi-square tests. Ethnic differences in mean age, gender emancipation and subjective norm were tested by univariate analysis of variance (ANOVA). Two sets of logistic regression analyses were conducted for insufficient knowledge and attitude-uptake inconsistency, respectively. In both models ethnicity was entered as a first block. Variables that were significantly associated with both ethnicity and the outcome were separately added to the basic ethnicity models. For each addition we calculated the percentage change in odds ratio (OR) compared with the OR in the basic model. This reduction in OR was interpreted as the contribution of the specific factors included in the model to the explanation of ethnic differences in informed decision-making. Finally we tested the full model, in which we included the variables that showed more than 10% reduction in OR in both ethnic-minority groups.

## 5.3 Results

### Response

In four midwifery practices, the researcher (MF) and two research assistants invited 95 Dutch,

98 Turkish and 28 Surinamese women to participate in an interview of which 89 Dutch, 78 Turkish and 24 Surinamese agreed to make an appointment. In total 65 Dutch, 54 Turkish and 19 Surinamese women actually participated in an interview. In 11 other midwifery practices and the outpatient clinic, health professionals recruited pregnant women themselves. The exact percentage of non-response in this group is unknown. In total 64 Dutch, 72 Turkish and 54 Surinamese women who were recruited by the health professionals gave permission to be contacted by the researchers. Of these women, 40 Dutch, 47 Turkish and 46 Surinamese actually participated in an interview. In total 110 of the 381 women who initially agreed to be approached by the researcher did not participate in an interview. Reasons for not participating were: not traceable in time (n=55); declined to participate after receiving information from the researcher (n=18); missed abortion (n=14); changed their mind (n=6); lack of time (n=7); and could not participate due to personal circumstances (n=10).

### Characteristics of the population and decision-making variables

Table 5.1 presents the background characteristics of the study population. Women were interviewed 3 weeks (mean) after their booking visit. Dutch women were significantly older and higher educated than women from Turkish and Surinamese ethnic origin. The highest percentage of women who were not living together with a partner was found among women from Surinamese origin. In total, 4% of the Dutch, 35% of the Turkish and 5% of the Surinamese women identified themselves with their religion. Among the women from Surinamese origin, 25 were Hindustani, 32 were Creole and 8 women considered themselves originating from a melting pot of different ethnic groups; because no significant

differences in relevant outcomes (knowledge and informed decision-making) were found between these three groups, we decided to analyse the women from Surinamese origin as one group. Language problems were reported by 47% of the women from Turkish origin. From the total group, 17% considered having to pay for the test as a barrier to participation in prenatal screening, 3% considered not to participate because they did not know where to go, and 2% perceived transportation problems as a barrier to participation in prenatal screening. These three barriers differed significantly between Dutch, Turkish and Surinamese women.

### Ethnic differences in informed decision-making

Table 5.2 shows that 56% Dutch, 87% Turkish and 83% Surinamese women did not participate in prenatal screening and that most women from Turkish and Surinamese origin had insufficient knowledge about prenatal screening. Women from Turkish and Surinamese origin who participated in prenatal screening did not have significant higher knowledge scores than Turkish and Surinamese non-participants. Most women (57%) had a positive attitude towards participating in prenatal screening for Down syndrome. There were no significant ethnic differences in mean attitude scores (not shown). The percentage of informed decision-makers was 71% among Dutch, 5% among Turkish and 26% among Surinamese women (Table 5.3). Uninformed decision-making was mainly due to insufficient knowledge. Almost all attitude-inconsistent decision-makers had a positive attitude, but did not participate in prenatal screening. Most of the uninformed decision-makers from Turkish origin had insufficient knowledge, a positive attitude and a negative uptake. Most uninformed decision-makers from Surinamese origin had insufficient knowledge, but made an attitude-consistent decision.

Table 5.1 Characteristics of the study population and decision-making variables

	Total (n=270)	Dutch (n=105)	Turkish (n=100)	Surinamese (n=65)	p- value*
<b>Interview method [n (%)]</b>					0.00
Telephone	223 (83)	89 (85)	71 (71)	63 (97)	
Face-to-face	47 (17)	16 (15)	29 (29)	2 (3)	
<b>Gestational length (weeks)</b>					
Mean gestation at moment of booking (sd)	9.5 (1.79)	9.2 (1.74)	9.7 (1.96)	9.5 (1.78)	0.25a 0.62b 0.87c
Mean gestation at moment of interview (sd)	12.5 (2.85)	11.6 (1.89)	13.1 (3.09)	12.9 (3.38)	0.00a 0.01b 0.89c
<b>Age (years)</b>					
Mean age (sd)	29.2 (4.83)	31.7 (4.28)	27.9 (4.24)	26.9 (4.75)	0.00a 0.00b 0.33c
<b>Marital status [n (%)]</b>					0.00
Living together with partner	232 (86)	96 (91)	99 (99)	37 (57)	
Not living together with partner	27 (10)	7 (7)	0	20 (31)	
Single	11 (4)	2 (2)	1 (1)	8 (12)	
<b>Number of children [n (%)]</b>					0.29
0 Child	120 (45)	51 (49)	36 (36)	33 (51)	
1 Child	106 (39)	42 (40)	44 (44)	20 (31)	
2 Children	36 (13)	10 (9)	17 (17)	9 (14)	
3 Children	6 (2)	1 (1)	2 (2)	3 (4)	
4 Children	2 (1)	1 (1)	1 (1)	0 (0)	
<b>Educational level [n (%)]</b>					0.00
Low	82 (30)	11 (11)	44 (44)	27 (42)	
Medium	88 (33)	20 (19)	40 (40)	28 (43)	
High	100 (37)	74 (70)	16 (16)	10 (15)	

<b>Religion [n (%)]</b>									
Not religious	92	(34)	78	(74)	1	(1)	13	(20)	0.00
Religious	178	(66)	27	(26)	99	(99)	52	(80)	
Islamic	104		1		98		5		
Hindu	13		0		0		13		
Christian	47		19		0		30		
No specific religion	10		7		1		2		
Other	2		0		0		2		
Religion identity**									0.00
Yes	41	(15)	4	(4)	34	(35)	3	(5)	
No	227	(85)	101	(96)	64	(65)	62	(95)	
<b>Language skills [n (%)]</b>									
No problems expressing, understanding and writing Dutch	222	(82)	105	(100)	53	(53)	64	(98)	0.00
Problems expressing and/or understanding and/or writing Dutch	48	(18)	0	(0)	47	(47)	1	(2)	
<b>Received information about prenatal screening [n (%)]</b>									
No	39	(14)	11	(10)	17	(17)	11	(17)	0.33
Yes	231	(86)	93	(90)	80	(83)	52	(83)	
<b>Gender emancipation (scale 1-5)</b>									
Mean gender emancipation (sd)	3.74	(0.62)	4.09	(0.59)	3.42	(0.54)	3.67	(0.47)	0.00a 0.00b 0.01c
<b>Subjective norm (scale-10, +10)</b>									
Mean subjective norm	-0.38		-0.28		-0.19		-0.80		0.94a 0.23b 0.14c
<b>Barriers to participate in prenatal screening [n (%)]</b>									
Have to pay	46	(17)	11	(10)	18	(18)	17	(26)	0.03
Do not know where to go	9	(3)	0	(0)	8	(8)	1	(2)	0.00
Do not have transport	5	(2)	0	(0)	5	(5)	0	(0)	0.01

\* Ethnic differences in frequencies are tested by Pearson Chi-square tests; ethnic differences in means are tested by Univariate Analysis of Variance

\*\* Two missing values among religious Turkish women

a p-value for mean difference between Dutch and Turkish women

b p-value for mean difference between Dutch and Surinamese women

c p-value for mean difference between Turkish and Surinamese women

**Table 5.2 Ethnic differences in knowledge, attitude and test uptake [n (%)]**

	<b>Total (n=263)*</b>	<b>Dutch (n=101)</b>	<b>Turkish (n=97)</b>	<b>Surinamese (n=65)</b>	<b>p-value</b>
<b>Knowledge</b>					0.00
Sufficient knowledge	115 (44)	85 (84)	10 (10)	20 (31)	
Insufficient knowledge	148 (56)	16 (16)	87 (90)	45 (69)	
<b>Attitude</b>					0.03
Positive attitude	149 (57)	55 (55)	64 (66)	30 (46)	
Negative attitude	114 (43)	46 (45)	33 (34)	35 (54)	
<b>Test uptake*</b>					0.00
Uptake	68 (26)	44 (44)	13 (13)	11 (17)	
No uptake	195 (74)	57 (56)	84 (87)	54 (83)	

\* 7 missing values on test uptake

### Contributing factors to ethnic differences in informed decision-making

Table 5.4 shows that women from Turkish origin in our population were 46 times and women from Surinamese origin almost 12 times more likely to have insufficient knowledge about prenatal screening compared to Dutch women (model 1). Following adjustment for language skills (model 5), the OR for women from Turkish origin decreased by 29%. Adjustment for gender emancipation

(model 6) showed the largest percentage reduction in OR for insufficient knowledge in women from Turkish origin (37%). Age, educational level, language skills, gender emancipation and the barrier 'have to pay' together (model 8) lowered the OR for insufficient knowledge among women from Turkish origin by 53% and among women from Surinamese origin by 54%, but the differences compared with Dutch women remained significant.

Table 5.3 Ethnic differences in informed decision-making [n (%)]

	Knowledge	Attitude	Uptake	Total (n=263)	Dutch (n=101)	Turkish (n=97)	Surinamese (n=65)
<b>Informed decisions</b>	Sufficient	Positive	Yes	45 (17)	39 (39)	1 (1)	5 (8)
	Sufficient	Negative	No	49 (19)	33 (33)	4 (4)	12(18.5)
				<b>94 (36)</b>	<b>72 (71)</b>	<b>5 (5)</b>	<b>17 (26)</b>
<b>Uninformed decisions</b>	Sufficient	Negative	Yes	2 (1)	2 (2)	0 (0)	0 (0)
	Insufficient	Positive	Yes	20 (8)	3 (3)	11 (11)	6 (9)
	Insufficient	Negative	Yes	1 (0.5)	0 (0)	1 (1)	0 (0)
	Sufficient	Positive	No	19 (7)	11 (11)	5 (5)	3 (5)
	Insufficient	Positive	No	65 (25)	2 (2)	47 (48.5)	16 (25)
	Insufficient	Negative	No	62 (24)	11 (11)	28 (29)	23 (35)
				<b>169 (64)</b>	<b>29 (29)</b>	<b>92 (95)</b>	<b>48 (74)</b>
Sufficient knowledge and attitude-uptake inconsistency				21 (12)	13 (45)	5 (6)	3 (6)
Insufficient knowledge and attitude-uptake consistency				82 (49)	14 (48)	39 (42)	29 (60)
Insufficient knowledge and attitude-uptake inconsistency				66 (39)	2 (7)	48 (52)	16 (34)
Uninformed decisions				169 (100)	29 (100)	92 (100)	48 (100)

Ethnic differences in informed decision-making are statistically significant (tested by Chi-square tests,  $p=0.00$ ).

The basic logistic model for the outcome attitude-uptake consistency (model 1) showed that women from Turkish origin in our population were almost 7 times and women from Surinamese origin almost 2.5 times more likely to have an attitude that was not consistent with (non-) participation in prenatal screening compared with Dutch women. Following adjustment for age (model 2), the OR decreased by 37.5% for the women from Surinamese origin. When the variable 'language skills' was added to the model (model 5), the largest percentage reduction in OR was seen in women from Turkish origin (24%). Age, religion identity, language skills and gender emancipation together (model 7) lowered the OR for attitude-uptake inconsistency among

women from Turkish origin by 55% and among women from Surinamese origin by 46%.

## 5.4 Discussion

We found substantial ethnic differences in informed decision-making on prenatal screening for Down syndrome. In total, 71% of the Dutch women were classified as informed decision-makers, compared to 5% of the women from Turkish origin and 26% of the women from Surinamese origin. Differences between Surinamese and Dutch women could to a large extent be explained by differences in age and educational level.



Table 5.4 Odds ratios for insufficient knowledge and attitude-uptake inconsistency

	Dutch (n=101)	Turkish (n=97)	Surinamese (n=65)
<b>Insufficient knowledge</b>	<b>OR</b>	<b>OR (95% CI)</b>	<b>OR (95% CI)</b>
Model 1: ethnicity	1.00	46.22 (19.86-107.57)	11.95 (5.65-25.31)
Model 2: ethnicity + age	1.00	36.72 (15.52-86.85)	8.61 (3.87-19.10)
		<i>-21%</i>	<i>-30%</i>
Model 3: ethnicity + educational level	1.00	34.61 (13.76-87.05)	8.55 (3.64-20.10)
		<i>-26%</i>	<i>-31%</i>
Model 4: ethnicity + religion identity	1.00	42.57 (17.43-103.97)	11.95 (5.64-25.30)
		<i>-8%</i>	<i>-0%</i>
Model 5: ethnicity + language skills	1.00	33.27 (12.91-85.69)	11.82 (5.58-25.04)
		<i>-29%</i>	<i>-1%</i>
Model 6: ethnicity + gender emancipation	1.00	29.51 (12.34-70.59)	9.12 (4.21-19.75)
		<i>-37%</i>	<i>-26%</i>
Model 7: ethnicity + have to pay	1.00	45.89 (19.66-107.13)	11.18 (5.25-23.80)
		<i>-1%</i>	<i>-7%</i>
Model 8: ethnicity + age+ educational level + language skills + gender emancipation + have to pay	1.00	22.21 (7.91-62.39)	6.03 (2.50-14.55)
		<i>-53%</i>	<i>-54%</i>
<b>Attitude-uptake inconsistency</b>			
Model 1: ethnicity	1.00	6.90 (3.50-13.61)	2.37 (1.10-5.09)
Model 2: ethnicity + age	1.00	5.75 (2.82-11.73)	1.85 (0.81-4.24)
		<i>-19%</i>	<i>-37.5%</i>
Model 3: ethnicity + educational level	1.00	6.63 (3.03-14.50)	2.29 (0.96-5.41)
		<i>-5%</i>	<i>-6%</i>
Model 4: ethnicity + religion identity	1.00	5.82 (2.85-11.87)	2.36 (1.10-5.09)
		<i>-18%</i>	<i>-0.7%</i>
Model 5: ethnicity + language skills	1.00	5.48 (2.54-11.82)	2.35 (1.10-5.05)
		<i>-24%</i>	<i>-1%</i>
Model 6: ethnicity + gender emancipation	1.00	5.74 (2.73-12.08)	2.11 (0.95-4.64)
		<i>-20 %</i>	<i>-18%</i>
Model 7: ethnicity + age+ religion identity + language skills + gender emancipation	1.00	3.66 (1.55-8.67)	1.74 (0.75-4.06)
		<i>-55%</i>	<i>-46%</i>

Percentages in italics show the percent reduction in OR compared with the basic model (ethnicity). For instance, the reduction in OR for the Turkish women when adding age into the basic model is  $[(46.22 - 36.72) / 46.22 - 1.00] \times 100 = 21\%$ .

Variables without significant contribution to ethnicity were not added to the final model.

Differences between Dutch and Turkish women could mainly be explained by differences in gender emancipation and language skills.

The strength of our study is that we prospectively collected data in an open population of pregnant women in early pregnancy that had not yet decided upon prenatal screening for Down syndrome. Women who could not express themselves in Dutch were not excluded from the study. There are, however, some limitations to the study. First, we only know the exact response rate in the group of women who were recruited by the researchers themselves (51% of the respondents). A second limitation is the unequal distribution of educational level among the three ethnic groups. However, these educational levels do reflect the educational levels of the inner-city population of Rotterdam.<sup>8</sup> The ethnic differences in informed decision-making found in our study are larger than those reported in the UK; in the latter study, 56% of the English, 20% of the South-Asians and 28% of the Black African Caribbean women made an informed decision whether or not to participate in prenatal screening.<sup>7</sup> In our study, especially the women from Turkish origin scored much lower on informed decision-making compared to the ethnic minority women in the UK. This may be related to the fact that women from in the UK were excluded from that study if they were not literate in English. In our study, 47% of the women from Turkish origin reported language problems that were subsequently identified as an important contributing factor to ethnic differences in informed decision-making. Among our women from Surinamese origin, the 26% informed decision-makers are comparable to the rates among ethnic minority women in the UK. The rate of informed decision-making among Dutch women was much higher than that among English women in the UK; this may be

related to the relatively large proportion of highly educated women in our study group. We found a significant positive association between educational level and knowledge of prenatal screening; this concurs with other studies and underlines the contribution of differences in educational level to ethnic differences in insufficient knowledge.<sup>11, 14, 15</sup> Our finding that language skills contributed to ethnic differences in knowledge of prenatal screening has been reported by others.<sup>16-18</sup> The contribution of age to ethnic differences in insufficient knowledge might be because prenatal screening for Down syndrome has only recently been introduced in the Netherlands as part of standard prenatal care for women under the age of 36 years. An earlier Dutch trial also found higher proportions of sufficient knowledge among women in higher age groups.<sup>11</sup> Our finding that most attitude-inconsistent decision-makers in our sample did not participate in prenatal screening, despite a positive attitude, is also in accordance with the findings of Dormandy; she argued that the inconsistency was more evident in women with positive attitudes, because negative attitudes are generally held more strongly.<sup>7</sup> However, we do not think this explains why younger women and women with language problems in our study were less likely to make attitude-inconsistent decisions. Because they might perceive specific barriers to participate in prenatal screening this aspect needs further investigation.

Interventions to decrease ethnic differences in informed decision-making should first of all be aimed at overcoming language barriers, for example by providing translated written material about prenatal screening and use of professional interpreters. The fact that translated written material was not available in the Netherlands at the time of this study is in conflict with the goal

of offering information about prenatal screening, which is to enable all pregnant women to make an informed decision. In order to increase comprehension among women with a low level of education, counsellors should target the information to women's abilities to understand the complicated information about prenatal screening and verify whether women have indeed understood the information.

The contribution of gender emancipation to informed decision-making found in our study could not be confirmed by other studies, nor can this be explained by our data. One explanation is that less emancipated women may not be accustomed to making an individual decision, which is a prerequisite for informed decision-making that is embedded in the Western principle of autonomy.<sup>19</sup> This raises questions about the relevance of informed decision-making for women from non-Western ethnic minority groups. Perhaps these women do not wish to make an autonomous decision, while midwives and obstetricians expect them to and try to maintain neutrality.<sup>20</sup> On the other hand, this may also apply to some women from the Western population; not all pregnant women are able to or even want to actively participate in the decision-making process.<sup>21</sup> In order to develop more effective diversity-sensitive strategies for counselling, we need to further explore to what extent women from different ethnic backgrounds value being actively involved in informed decision-making on prenatal screening, to what extent they think their partner or family should be involved in this process, what decision-relevant knowledge they need, and what they take into account when considering whether or not to participate in prenatal screening.

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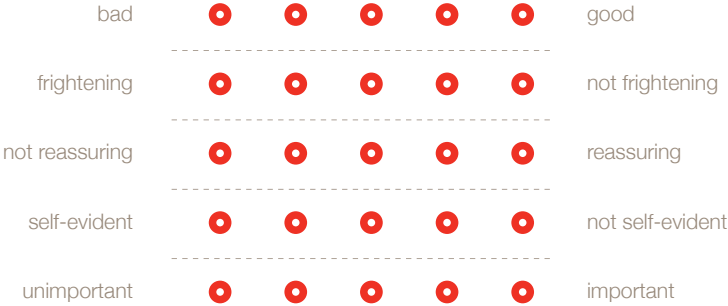
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# Appendix

**Attitude measure used in the present study.**

In my opinion, testing for Down syndrome during my pregnancy, is....



(Source: Adapted from Marteau et al., 2001<sup>5</sup> and Van den Berg et al., 2005<sup>11</sup>)





# Ethnic differences in considerations whether or not to participate in prenatal screening for Down syndrome

Fransen MP, Wildschut HIJ, Vogel I, Mackenbach JP, Steegers EAP, Essink-Bot ML. Ethnic differences in considerations whether or not to participate in prenatal screening for Down syndrome. *Prenatal Diagnosis* 2009; 29: 1262-1269.





# Abstract

**Objective** To evaluate ethnic differences in considerations whether or not to participate in prenatal screening for Down syndrome and to relate these to differences in participation.

**Methods** The study population consisted of 270 pregnant women from Dutch, Turkish and Surinamese (African and South Asian) ethnic origin, attending midwifery or obstetrical practices in the Netherlands. Women were interviewed after booking for prenatal care. Considerations were assessed by one open-ended question and 18 statements that were derived from focus group interviews. Actual participation was assessed several months later.

**Results** Women from ethnic minorities were less likely to participate in prenatal screening, which could be attributed to differences in age and religious identity. They more often reported acceptance of 'what God gives', low risk of having a child with Down syndrome and costs of screening as considerations not to participate in prenatal screening. They also reported many considerations in favour of participation, which did not differ from those of Dutch women but were less often consistent with actual participation in screening.

**Conclusion** Women from ethnic minorities should not be stereotyped as being uninterested in prenatal screening, but should be better informed about the consequences of prenatal screening and Down syndrome.

## 6.1 Introduction

In many Western countries pregnant women are offered information on prenatal screening for Down syndrome. On the basis of test performance, acceptability and feasibility, the Dutch government recommended the implementation of the combined test for prenatal screening of Down syndrome.<sup>1</sup> If the individual risk of carrying a child with Down syndrome risk exceeds 1:200 at the time of testing, the woman is offered invasive testing by chorionic villus sampling or amniocentesis to determine the fetal karyotype. Invasive testing is, however, associated with an estimated procedure-related fetal loss of 0.3-0.8%.<sup>2</sup> In the Netherlands, all pregnant women aged 36 years or over have an age-based indication for prenatal screening by the combined test and/or invasive testing; both tests are reimbursed by insurance in this age group. Women under 36 years of age are only eligible for the combined test and have to pay for this test out of their own pocket, unless they have another indication such as a previously affected pregnancy. If the test result indicates a risk of Down syndrome above the threshold value of 1:200, the costs of invasive testing are reimbursed. If Down syndrome is diagnosed by invasive testing, all women have the option for pregnancy termination before the 24th week of their pregnancy, which is legal and reimbursed by insurance, irrespective of the woman's age. Studies in the UK and the US showed that the uptake of prenatal screening for Down syndrome is lower among women of ethnic minority groups.<sup>3-7</sup> It has been proposed that ethnic differences in uptake might be explained by differences in the offer of prenatal screening.<sup>3</sup> Our previous work showed that women from ethnic minority groups less often received or read written information, had less knowledge about prenatal screening and were

less likely to make an informed decision whether or not to participate in prenatal screening.<sup>8,9</sup> These findings raised questions about their considerations whether or not to participate in prenatal screening, i.e. their balance of pros and cons. Several studies investigated women's reasons whether or not to participate in prenatal screening.<sup>10,11</sup> Only a few studied considerations of women from different ethnic backgrounds.<sup>12-15</sup>

The aim of this study is to evaluate ethnic differences in considerations whether or not to participate in prenatal screening for Down syndrome and to relate these to ethnic differences in actual participation in prenatal screening. We compared groups of women from Turkish and Surinamese ethnic origin to a group of women from Dutch origin, because the former constitute the two largest non-Western ethnic minority groups in the Netherlands. Inhabitants of Suriname, a Caribbean country mainly consist of individuals originating from Africa and South-Asia.

The specific research questions are:

- 1) To what extent do Dutch, Turkish and Surinamese women differ in participation in prenatal screening for Down syndrome and to what extent can differences be attributed to differences in demographic characteristics?
- 2) What considerations do Dutch, Turkish and Surinamese women have whether or not to participate in prenatal screening for Down syndrome and to what extent are these related to differences in actual participation?

## 6.2 Methods

### Participants and data collection

Pregnant women from Dutch, Turkish and Surinamese origin were recruited between September

2006 and June 2008 from 15 community midwifery practices in Rotterdam city centre and the out-patient clinic of the Erasmus University Medical Centre (Rotterdam). Midwives and gynaecologists were instructed to inform each Dutch, Turkish and Surinamese woman about this study at the booking visit, and to ask permission to be contacted by the researcher.

In four midwifery practices the researcher recruited women immediately after the booking visit. Women who were booked for prenatal care at a later stage (i.e., after 14 weeks' gestation) were excluded from the study because they lacked timely information on first trimester prenatal screening.

Women who agreed to be included in the study were contacted by telephone within one week of the booking visit. They received oral information about this study and were offered an appointment for a telephone or a face-to-face interview. Women who had difficulties in understanding Dutch received translated information about the study, were contacted by a research assistant from the same ethnic background and were offered an interview in the language they preferred.

### Data collection and measures

Data collection took place by structured interviews that were conducted by the female researcher (MF) and three female research assistants that were trained to do the interviews. The interview was intended to take place before women could have participated in the prenatal screening program. Ethnic origin was assessed by country of birth of the woman and her parents. A woman is considered to be from non-Dutch ethnic origin when at least one of her parents was born abroad, in this case Turkey or Surinam.<sup>16</sup>

Participation in prenatal screening was assessed several months after the interview by contacting

the women by telephone. Women were asked whether they had participated in the combined test and/or invasive tests for Down syndrome. Participation in one of these tests accounted for participation in prenatal screening in further analyses. Educational attainment level was categorised as low (primary school), medium (first and second stage secondary education) or high (vocational college or university).<sup>17</sup>

Daily care for children was measured by the question whether women have to take care for own or foster children on a daily basis.

Religious identity was measured by a 5-item instrument to measure women's identification with their religion, which included cognitive identity, emotional attachment and identification as a Muslim/Christian, etc. (Cronbach's alpha 0.76). The average score was dichotomised (above or below the point of neutrality).<sup>18</sup>

Considerations whether or not to participate in prenatal screening were measured by one open-ended question and 18 statements that were derived from focus group interviews.<sup>19</sup> Women were first asked to explain why they would or would not participate in prenatal screening and then which of the statements applied to their personal considerations.

Decisional conflict was measured by O'Connor's Decisional Conflict Scale in which decisional conflict is defined as a state of uncertainty about the courses of action to take.<sup>20,21</sup> The scale consists of 16 items ranging from 1 ('totally disagree') to 5 ('totally agree'). The items measured women's awareness about the options, advantages and disadvantages of prenatal screening, perceived difficulty and uncertainty in decision-making, perceived support from others and perceived effectiveness of the decision that has been made. The total score for each woman was divided by

the number of items. The scale was internally consistent in this study with a Cronbach's alpha of 0.85.

### Statistical analysis

Descriptive statistics were used to summarise participation in prenatal screening, demographic characteristics, and considerations whether or not to participate in prenatal screening. Answers to the open-ended question on considerations whether or not to participate in prenatal screening were categorised by the researcher and research assistant, both of whom had performed the interviews. Differences between Dutch, Turkish and Surinamese women for demographic characteristics, participation in prenatal screening and considerations were tested by chi-square tests. Multiple logistic regression analyses were conducted to assess the contribution of demographic characteristics to ethnic differences in non-participation of prenatal screening. Ethnicity was entered as a first block. Demographic variables that were significantly associated with both ethnicity and participation were separately added to the model with ethnicity. For each addition we calculated the percent change in odds ratio (OR) compared with the OR in the basic model. This reduction in OR was interpreted as the contribution of the specific factors included in the model to the explanation of ethnic differences in non-participation. Finally we tested the full model, in which we included the variables that remained statistically significant ( $p < 0.05$ ) in the model with ethnicity.

Logistic regression analyses were conducted to test whether women's considerations were significantly correlated to participation and non-participation in prenatal screening for Down syndrome. Ethnic differences in decisional conflict were tested by univariate analysis of variance (ANOVA).

## 6.3 Results

### Response

In four midwifery practices, the researcher (MF) and two research assistants invited 95 Dutch, 98 Turkish and 28 Surinamese women to participate in an interview of which 89 Dutch, 78 Turkish and 24 Surinamese agreed to make an appointment, 65 (68%) Dutch, 54 (55%) Turkish and 19 (68%) Surinamese women were actually interviewed. In 11 other midwifery practices and the outpatient clinic of Erasmus Medical Centre, healthcare providers recruited pregnant women themselves. The exact percentage of non-response in this group is unknown. In total 64 Dutch, 72 Turkish and 54 Surinamese women who were recruited by health professionals gave permission to be contacted by the researchers. Of these women, 40 (59%) Dutch, 47 (65%) Turkish and 46 (85%) Surinamese were actually interviewed. In total 110 of the 381 women who initially agreed to be approached by the researcher did not participate in the study. Reasons for not participating were: not traceable in time ( $n=55$ ); declined to participate after receiving information from the researcher ( $n=18$ ); missed abortion ( $n=14$ ); changed their mind ( $n=6$ ); lack of time ( $n=7$ ); and could not participate due to personal circumstances ( $n=10$ ).

### Characteristics of the population

Table 6.1 presents the background characteristics of the study population. Dutch women were significantly older and higher educated than Turkish and Surinamese women. In total 99% of the Turkish, 80% of the Surinamese and 26% of the Dutch women considered themselves to be religious. This was mainly Christianity for Dutch women, Islam for Turkish women, and Hinduism or Christianity for Surinamese women. 35% of the Turkish, 5% of the

Table 6.1 Characteristics of the study population according to ethnic origin and participation in prenatal screening n (%)

	Total (n=270)	Ethnic origin			Participation in prenatal screening**		
		Dutch (n=105)	Turkish (n=100)	Surinam. (n=65)	(n=68)	OR	(95% CI)
<b>Age (years)*</b>							
<25 years	73 (27)	10 (10)	33 (33)	30 (46)	5 (7)	1.0	Reference
26-30 years	105 (39)	33 (31)	50 (50)	22 (34)	16 (15)	2.5	(0.9-7.2)
31-35 years	70 (26)	46 (44)	12 (12)	12 (18)	30 (43)	10.3	(3.7-28.7)
>36 years	22 (8)	16 (15)	5 (5)	1 (2)	17 (77)	56.9	(13.8-235.2)
<b>Marital status*</b>							
Living together with partner	232 (86)	96 (91)	99 (99)	37 (57)	62 (27)	1.0	Reference
Not living together	27 (10)	7 (7)	0 (0)	20 (31)	3 (11)	1.0	(0.3-3.9)
Single	11 (4)	2 (2)	1 (1)	8 (12)	3 (3)	0.3	(0.1-2.0)
<b>Daily care for children</b>							
No	118 (44)	51 (49)	35 (35)	32 (49)	24 (20)	1.0	Reference
Yes	152 (56)	54 (51)	65 (65)	33 (51)	44 (29)	1.6	(0.9-2.8)
<b>Educational level*</b>							
Low	82 (30)	11 (11)	44 (44)	27 (42)	14 (17)	1.0	Reference
Medium	88 (33)	20 (19)	40 (40)	28 (43)	17 (19)	1.2	(0.6-2.7)
High	100 (37)	74 (70)	16 (16)	10 (15)	37 (37)	2.9	(1.4-5.9)
<b>Religious identity*</b>							
No	227 (85)	101 (96)	64 (65)	62 (95)	66 (29)	1.0	Reference
Yes	41 (15)	4 (4)	34 (35)	3 (5)	2 (5)	0.1	(0.0-0.6)

\* Differences between ethnic groups are significant for this variable (p<0.05)

\*\* In total 68 women participated in prenatal screening. There were 7 missing values on (non-) participation in prenatal screening.

Surinamese and 4% of the Dutch women actually identified themselves with their religion. In total 44% of the Dutch, 13% of the Turkish and 17% of the Surinamese women participated in prenatal screening (chi-square 27.07, p=0.00). Four Dutch and two Turkish women went directly to invasive testing. One Dutch, two Turkish and 1 Surinamese woman participated in invasive testing after the combined test. Women who participated in prenatal screening were generally older, had a higher educational level and scored lower on religious identity. Dutch women scored lowest on decisional conflict, their mean score (1.96; 95% CI 1.87-2.05) differed

significantly from the mean score of Turkish women (2.43; 95% CI 2.33-2.53) and Surinamese women (2.17; 95% CI 2.05-2.29). No significant differences in decisional conflict were found between participants and non-participants within the specific ethnic groups.

**Attributing factors to ethnic differences in non-participation in prenatal screening**

Table 6.2 shows that there were ethnic differences in participation in prenatal screening. Turkish women were 4.98 times and Surinamese women 3.79 times more likely not to participate in prenatal screening compared to Dutch women (Model 1).

Table 6.2 Odds ratios for ethnic differences in participation in prenatal screening

	Dutch (n=101)	Turkish (n=97)	(95% CI)	Surinamese (n=65)	(95%CI)
	OR	OR		OR	
Model 1: ethnicity	1.00	4.98	(2.4-10.1)	3.79	(1.7-8.1)
Model 2: ethnicity + educational level	1.00	4.40	(1.9-9.8)	3.34	(1.4-7.8)
Model 3: ethnicity + religious identity	1.00	3.57	(1.7-7.4)	3.81	(1.7-8.2)
Model 4: ethnicity + age	1.00	2.68	(1.2-6.1)	1.66	(0.7-3.9)
Model 5: ethnicity + age + educational level	1.00	2.76	(1.1-6.7)	1.77	(0.7-4.5)
Model 6: ethnicity + age + religious identity	1.00	2.00	(0.9-4.7)	1.68	(0.7-4.0)

Percentages in italics show the percent reduction in OR of non-participation compared with the basic model (ethnicity). For instance, the reduction in OR of non-participation for the Turkish women when adding age to ethnicity is  $[(4.98 - 2.68)/4.98 - 1.00] \times 100 = 58\%$ . The final model (model 6) only contains variables that remained significant in the model with ethnicity.

Ethnic differences remained significant when adjusting for educational level (Model 2) and religious identity (Model 3). Following adjustment for age (Models 4 and 5), the difference between Dutch and Surinamese women was no longer significant. When ethnicity, age and religious identity were all adjusted for (Model 6), there was no difference in uptake of prenatal screening between Dutch and Turkish women either.

**Considerations whether or not to participate in prenatal screening for Down syndrome: answers to an open-ended question**

Table 6.3 shows that 45% of the Surinamese women spontaneously mentioned their perceived

low risk of having a child with Down syndrome as a consideration not to participate in prenatal screening. The emotional difficulty or perceived impossibility to terminate the pregnancy was mentioned by 37% of the Turkish and 50% of the Dutch women. Costs of the prenatal screening test were especially mentioned by Surinamese women: 20% said this was a consideration for them not to participate in prenatal screening.

The most frequently mentioned consideration to participate among Surinamese and Turkish women was for reassurance and to exclude as many possible uncertainties about the baby’s health. Dutch women most often mentioned that they would participate because of the unfavourable conse-

**Table 6.3 Considerations whether or not to participate in prenatal screening: number (%) of women mentioning the item spontaneously in an open-ended question**

	<b>Dutch (n=105)</b>	<b>Turkish (n=100)</b>	<b>Surinamese (n=65)</b>
<b>Considerations not to participate in prenatal screening</b>			
Difficult or impossible to abort pregnancy	53 (50)	37 (37)	16 (25)
Low risk of having a disabled child	28 (27)	22 (22)	29 (45)
Disadvantages of tests	30 (29)	18 (18)	21 (32)
Prenatal screening causes stress during pregnancy	9 (9)	15 (15)	6 (9)
Costs of prenatal screening	2 (2)	3 (3)	13 (20)
<b>Considerations to participate in prenatal screening</b>			
To get reassured/exclude uncertainties about the baby’s health	15 (14)	20 (20)	18 (28)
(Increased) risk for having a disabled child	17 (16)	12 (12)	8 (12)
To gain knowledge about the baby’s health	13 (12)	13 (13)	4 (6)
Consequences of disability for the child, family and self	21 (20)	6 (6)	7 (11)
To take precautions (e.g. abortion)	10 (9)	2 (2)	1 (2)
To prepare for a disabled child	17 (16)	8 (8)	3 (5)

Ethnic differences were not analysed since these were answers to an open-ended question. Women were asked to explain why they would participate or would not participate in prenatal screening.



**Table 6.4 Ethnic differences in considerations whether or not to participate in prenatal screening for Down syndrome (DS): answers to 18 statements, data are n (%)**

	<b>Dutch (n=105)</b>	<b>Turkish (n=100)</b>	<b>Surinamese (n=65)</b>
<b>Considerations not to participate in prenatal screening</b>			
Accept what God gives	<b>28 (27)*</b>	<b>53 (53)</b>	<b>31 (47)*</b>
Child with DS can have a happy life	52 (49)*	40 (40)	29 (45)
Child with DS is welcome	51 (49)*	44 (44)	25 (38)
Participation causes increased risk of miscarriage	28 (27)*	38 (38)	23 (35)*
Not necessary: DS not in family	19 (18)	22 (22)	22 (34)
Have to pay for the test	<b>11 (10)</b>	<b>16 (16)</b>	<b>17 (26)</b>
Child with DS is punishment of God	0 (0)	2 (2)	3 (5)
<b>Considerations to participate in prenatal screening</b>			
Reassurance about the baby's health	40 (38)*	40 (40)*	27 (41)*
Possibility to prepare for a child with DS	42 (40)*	39 (39)	30 (46)*
Exclude uncertainties about the baby's health	28 (27)*	25 (25)*	23 (35)*
Possibility to end the pregnancy if child has DS	29 (28)*	24 (24)	24 (37)*
Child with DS has much pain and sadness in his/her life	<b>7 (7)</b>	<b>28 (28)</b>	<b>16 (25)</b>
Participation is part of standard prenatal care	14 (13)*	22 (22)*	13 (20)
Participation is compulsory	0 (0)	5 (5)*	2 (3)*
Unable to care for DS child	11 (10)*	14 (14)	14 (21)
Burden on other children	13 (12)*	9 (9)*	6 (9)*
Child with DS has negative effect on relationship partner	13 (12)	13 (13)	7 (11)
Others look down at me with a DS child	<b>0 (0)</b>	<b>14 (14)</b>	<b>5 (8)</b>

**Significant difference in prevalence between ethnic groups**

\* Significant correlation between consideration and uptake of prenatal screening per ethnic group

quences of Down syndrome for the quality of life of the child, their family and themselves. Some women mentioned that they would participate in prenatal screening to be able to take precautions in case the child would have Down syndrome, i.e., to terminate the pregnancy or to prepare for having a child with Down syndrome. Most of them said they did not yet know what to

decide if their foetus would be diagnosed with DS.

**Ethnic differences in considerations whether or not to participate in prenatal screening: answers to 18 statements**

Turkish and Surinamese women more often agreed with the statement 'I accept what God gives' (Table 6.4). Acceptance of 'what God gives' and

the perceived procedure related risk of having a miscarriage were significantly associated with non-participation in prenatal screening in the Dutch and Surinamese group. This means that women who agreed with these statements were less likely to participate in prenatal screening than those who did not agree with these statements. The perceived procedure related risk refers to women's perceptions of the miscarriage risk of diagnostic follow-up in the process of prenatal screening.

The belief that a child with Down syndrome is welcome and can have a happy life was relatively often reported as a consideration not to participate in prenatal screening in all three ethnic groups, but only associated with non-participation in the Dutch group. Having to pay for the test was more often reported by Surinamese women, but was not associated to non-participation in any of the three ethnic groups. Significant associations between considerations and non-participation were not found in the Turkish group.

A frequently endorsed consideration to participate in prenatal screening was to gain reassurance about the baby's health. The frequency of this consideration did not differ between Dutch, Turkish and Surinamese women and it was significantly related to participation in all three ethnic groups. Another important consideration to participate in screening was the possibility to be prepared for the birth of a child with Down syndrome. This statement was significantly associated with participation in the Dutch and Surinamese group. Compared to Dutch women, Turkish and Surinamese women more often agreed with the statement 'A child with Down syndrome has much pain and sadness in his or her life' and 'If I would have a child with Down syndrome, other people would look down at me'. These statements were not related to participation in prenatal screening.

## 6.4 Discussion and conclusion

### Discussion

Women of two non-Western ethnic minority groups in the Netherlands participated less often in prenatal screening for Down syndrome, which could be attributed to differences in age and religious identity. Compared to Dutch women, women from Turkish and Surinamese origin more often reported not to participate in prenatal screening, because they accept 'what God gives'. Costs of prenatal screening and low age-related risk of having a child with Down syndrome were especially mentioned by Surinamese women. Women from Turkish and Surinamese origin also reported many considerations in favour of participation, such as receiving reassurance about the baby's health and preparing for a child with Down syndrome. These considerations did not differ from those of Dutch women. Compared to Dutch women, considerations of Turkish and Surinamese women were less often significantly associated with participation and non-participation in prenatal screening and they experienced more decisional conflict.

The strength of the present study is that we prospectively collected data in an open population among pregnant women (in early pregnancy) who had yet to decide upon participation in prenatal screening. Most other studies on women's reasons for participation in prenatal screening assessed women's views after they had made the decision. It is likely that these views reflect women's post-choice justifications rather than their considerations when reaching the decision.<sup>10</sup> A limitation of our study is that we only know the exact response rate in the group of women who were recruited by the researchers themselves.

The contribution of differences in age to ethnic differences in actual participation in prenatal screening

ning is probably related to the finding that especially the young Surinamese women in our study mentioned their low age-related risk of having a child with Down syndrome as a consideration not to participate in prenatal screening. The fact that pregnant Surinamese and Turkish women were much younger, and therefore have a lower risk than pregnant Dutch women, is in accordance with the general age distribution of women who gave birth to a child in the Netherlands in 2007: 22% of the Surinamese women and 20% of the Turkish women was under the age of 25 years compared with only 8% among Dutch women.<sup>22</sup>

The finding that women from Turkish and Surinamese ethnic origin more often reported not to participate in prenatal screening for Down syndrome, because they accept 'what God gives' is in keeping with previous findings in other countries. A study in the USA on the societal and familial context of prenatal testing decisions also found that women from ethnic minority groups more often agreed with the statement 'In my culture we learn to accept what is given'.<sup>14</sup> Two studies in a Muslim traditional ethnic minority in Israel showed that views on the permissibility of pregnancy termination play an important role in screening participation and that some Muslim women believe that Islam totally prohibits pregnancy termination.<sup>23, 24</sup> Our study also revealed that it is not only the women who scored high on religious identity that stated they accept what God gives. Surinamese women scored much lower on religious identity than Turkish women, but just as often reported to accept what God gives. The explanatory value of this variable on ethnic differences in uptake is equal in both groups. Perhaps for many (less religious) women, accepting what God gives could also reflect a preference for a natural course of pregnancy rather than being an expression of living by religious rules. Results from a qualitative

study by Garcia et al. in the Netherlands showed that only 23% of the pregnant women who have concerns about the acceptability of intervening in the natural course of the pregnancy was actively religious.<sup>25</sup> Additionally, our study also indicated that agreement with 'accepting what God gives' does not necessarily mean that women do not consider to participate in prenatal screening. Turkish women who participated in prenatal screening also reported 'accepting what God gives' as a relevant consideration not to participate in prenatal screening. In a balance of pros and cons, other considerations, such as reassurance, might be more important to women. Another explanation is that women may not exactly realise the consequences of participating in prenatal screening. Our previous results indeed showed that especially Turkish women were less often aware of the fact that participating in prenatal screening could confront them with the decision whether or not to terminate the pregnancy.<sup>9</sup> It is noticeable that Surinamese women more often reported costs as a consideration not to participate in prenatal screening than women from Turkish and Dutch ethnic origin. This could be related to the fact that they were younger and possibly did not feel at risk. The costs could therefore be a much bigger barrier than in older women who generally feel more at risk. It should be further investigated to what extent costs play a role in uptake among various age groups. Another explanation for the role of costs on uptake of prenatal screening in the Surinamese group is the fact that Dutch inhabitants from Surinamese origin generally have a lower income at household level than the average income of the general population in the Netherlands and simply have less money to spend. However, Dutch inhabitants from Turkish origin have an even lower household income than inhabitants from Surinamese origin.<sup>26</sup> Perhaps Turkish women were

less often aware that they had to pay for this test themselves and therefore did not report costs as a relevant consideration not to participate in prenatal screening. Our previous study indeed showed that Turkish women scored very low on knowledge about prenatal screening with the combined test.<sup>9</sup> It is worrisome that Turkish and Surinamese women experienced more decisional conflict in deciding whether or not to participate in prenatal screening for Down syndrome. This is probably related to their lack of knowledge about prenatal screening and Down syndrome that we previously found.<sup>9</sup> The fact that Turkish and Surinamese women had less knowledge about the content of prenatal screening and Down syndrome, consequences of prenatal screening, options for diagnostic testing, and indicated termination of pregnancy could imply that they were less able to weigh the pros and cons and anticipate on future consequences, and less often had the feeling that they made an informed decision.

### Conclusion and practice implications

The finding that women from non-Western ethnic minority groups more often reported perceived low risk of having a child with Down syndrome and acceptance 'what God gives' as considerations not to participate in prenatal screening is in coherence with the finding that ethnic differences in participation in prenatal screening can be attributed to differences in age and religious identity. However, women from Turkish and Surinamese backgrounds also reported many considerations in favour of participation in prenatal screening, and these did not differ that much from those of Dutch pregnant women. Midwives and gynaecologists should acknowledge that considerations such as 'acceptance what God gives' could be more important for women from ethnic minority groups, but should be careful not to stereotype ethnic minority women as being uninterested in

prenatal screening. The fact that ethnic minority women more often reported costs of prenatal screening as a relevant consideration not to participate in prenatal screening adds to the discussion whether costs of prenatal screening for Down syndrome should be reimbursed to women of all ages.<sup>27</sup> The finding that considerations were less often significantly associated to actual screening participation among the women from Turkish and Surinamese ethnic origin and that they experienced more decisional conflict emphasizes the importance of informing women from ethnic minority groups about prenatal screening and Down syndrome. Since we earlier found that language problems play an important role in ethnic differences in knowledge about prenatal screening and Down syndrome, interventions in the provision of information should especially be aimed at overcoming language barriers in prenatal counseling.<sup>9</sup> Moreover, decisional aiding interventions have proven to be successful in decreasing decisional conflict and increasing informed decision-making about prenatal diagnostic testing.<sup>28</sup> It should be further investigated to what extent such interventions are also applicable and successful among pregnant women from ethnic minority groups.

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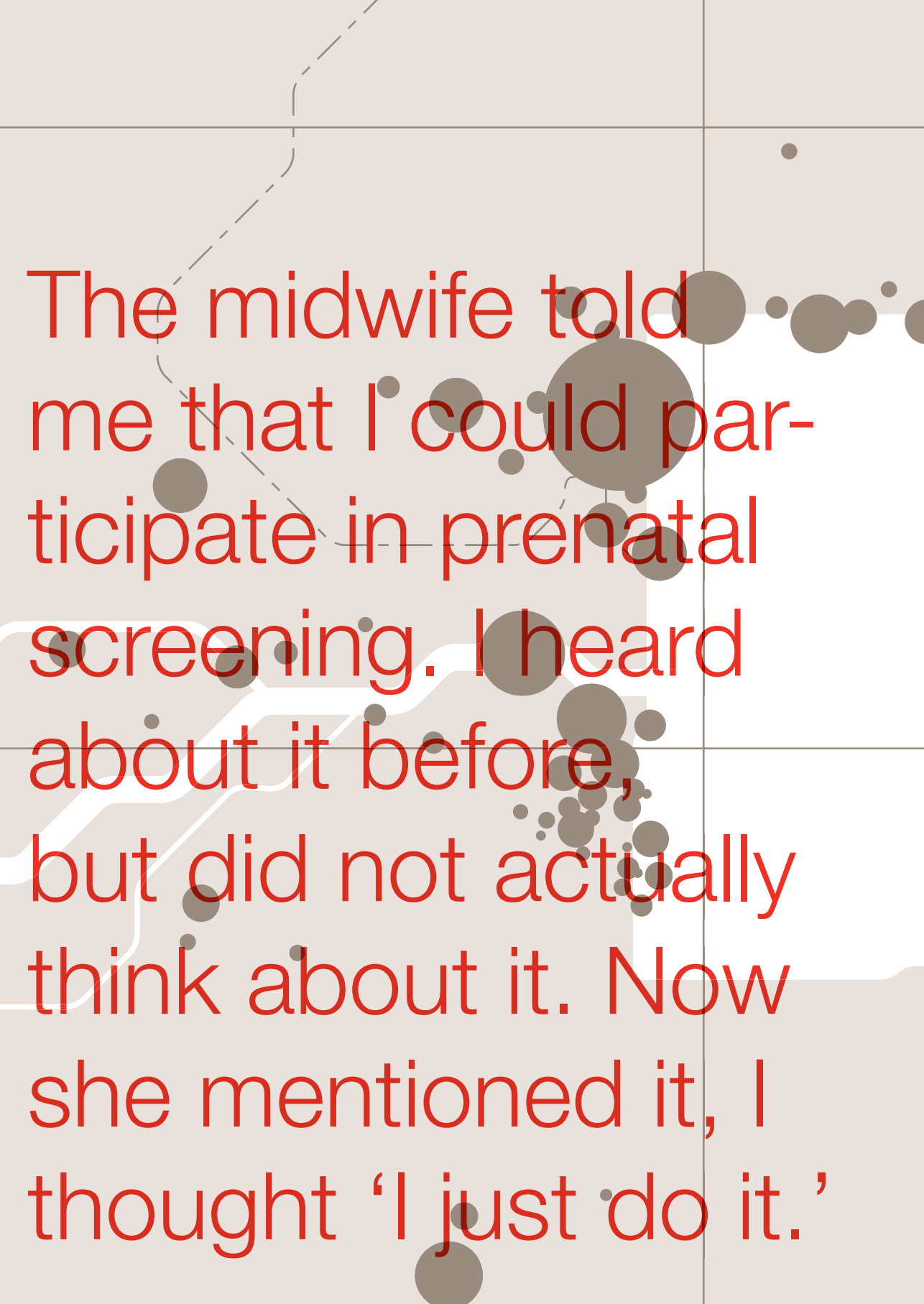




Ethnic differences in  
uptake of prenatal screening  
for Down syndrome

# Part

# IV



The midwife told me that I could participate in prenatal screening. I heard about it before, but did not actually think about it. Now she mentioned it, I thought 'I just do it.'



Everything you can  
exclude is nice.

(Woman from  
Dutch origin,  
34 years of age).

# Ethnic differences in uptake of maternal age-based prenatal screening for Down syndrome

Fransen MP, Wildschut HIJ, Mackenbach JP, Steegers EAP, Galjaard RJ, Essink-Bot ML. Ethnic differences in uptake of prenatal diagnostic tests for Down syndrome. Submitted.



# Abstract

**Objective** The objective of this study was to assess ethnic differences in the uptake of maternal age-based prenatal screening for Down syndrome in 2000-2004.

**Methods** The study population consisted of 12340 women aged 36 years or over, who lived in a geographically defined region in the South-west of the Netherlands and who gave birth to a live born infant in the period 2000-2004. Data on women who had amniocentesis or chorionic villus sampling were obtained from the Department of Clinical Genetics, Erasmus MC. Data on ethnic and socio-economic background of the study population were obtained from Statistics Netherlands. Logistic regression analyses were done to assess ethnic differences in uptake of prenatal screening, adjusted for socio-economic background.

**Results** The overall uptake of maternal age-based prenatal screening was 28.5%. Women from Surinamese origin participated more often in prenatal screening than Dutch women. No differences in uptake were found between women from Dutch, Turkish and Aruban/Antillean origin. Women from North-African origin and women from low socio-economic background had a lower uptake than others. Ethnic differences in uptake could not be attributed to differences in socio-economic background.

**Conclusion** Uptake of maternal age-based prenatal screening for Down syndrome in the Netherlands was low and varied among ethnic and socio-economic groups. The finding that the uptake among Dutch women was equal or even lower compared to the uptake among other ethnic groups was unexpected and may be related to the Dutch pregnancy culture. The finding that women from North-African origin and women from low socio-economic background had a lower uptake may be related to barriers in access to prenatal screening for Down syndrome.

## 7.1 Introduction

The maternal age-based prenatal screening programme for Down syndrome involves the offer of prenatal tests to women who are at increased risk for having a child with Down syndrome because of their advanced maternal age. Commonly used tests in this programme are amniocentesis (AMN) and chorionic villus sampling (CVS). Both tests involve the examination of fetal chromosomes and provide certainty about whether or not the fetus has Down syndrome.

Since the implementation of AMN and CVS, studies in several countries have showed that pregnant women from ethnic minority groups and pregnant women from lower socio-economic background generally less often participate in AMN and CVS than others.<sup>1-10</sup> It is unknown whether the same variations exist in the Netherlands, where about 20% of the population consists of individuals from non-Dutch ethnic origin, and more than half of this group originate from non-Western countries including Mediterranean (Turkey and Morocco) and Caribbean countries (Surinam, Dutch Antilles and Aruba).<sup>11</sup> In the years 2000-2004, the period addressed in the present study, the Dutch prenatal screening programme for Down syndrome involved the offer of CVS and AMN to all pregnant women who are at increased risk for having a child with Down syndrome because of their advanced maternal (36 years or above in the 18th week of their pregnancy). Both tests were offered to women aged 36 or above, because their age-related risk of carrying a child with Down syndrome was considered sufficiently high to compensate for the risk of procedure-related fetal loss (0.3-0.8%).<sup>12, 13</sup> The costs for both tests were reimbursed by insurance. Non-invasive risk assessment tests, such as maternal serum screening and nuchal translucency measurement, were implemen-

ted in prenatal care after this study period. As in most other European countries, women of advanced maternal age still have the option to directly choose for reimbursed CVS or AMN.<sup>14, 15</sup> If Down syndrome is diagnosed, women in the Netherlands have the legal option of reimbursed pregnancy termination before the 24th week of their pregnancy.

The objective of our study was to assess ethnic and socio-economic differences in the uptake of maternal age-based prenatal screening for Down syndrome in the Netherlands.

## 7.2 Methods

### Population and data collection

We retrospectively assessed the uptake of maternal age-based prenatal screening over a 5-year period (2000-2004) in 'Groot-Rijnmond', a geographically defined region in the South-West of the Netherlands. This region includes the city of Rotterdam and 30 surrounding towns and cities. Groot-Rijnmond has 1360610 inhabitants, which is 8% of the Dutch population.

The study population consisted of all pregnant women aged 36 years or over, who lived in Groot-Rijnmond, as defined by postal codes, in the defined period. Women whose postal codes did not fit in the defined postal code area were excluded from the study. The denominator hence consisted of all women aged 36 years or over, who lived in the postal code area of Groot-Rijnmond, and gave birth to a living child between 01-01-2000 and 31-12-2004 (n=12340). They were selected on women's birth date and postal codes from the Population Register of Groot-Rijnmond.

The numerator consisted of all women aged 36 years or over, who had AMN or CVS and who lived in the postal codes belonging to Groot-Rijnmond

between 01-01-2000 and 31-12-2004 (n= 3523). They were selected on women's birth dates and postal codes from the database of the Department of Clinical Genetics, Erasmus Medical Centre. All prenatal invasive tests that are performed in the Southwest of the Netherlands are analysed by this department. Women who had more than one AMN or CVS within 9 months were counted as one case, since it is most unlikely that these pregnancies would bring forth more than one living child.

### Measures and analysis

Data on ethnic origin of the study population were obtained from the Dutch National Office of Statistics (Statistics Netherlands). They linked individual data (date of birth and address) of the women who participated in the maternal age-based prenatal screening programme (numerator) to the Population Registers of Groot-Rijnmond. These individually linked records were delivered anonymously to the researchers. Data on ethnic origin of the women who gave birth to a living child in 2000-2004 (denominator) were obtained from the Population Register of Groot-Rijnmond. Statistics Netherlands defines ethnic origin by the country of birth of a person's parents. Following their definitions, a woman is considered to be from non-Dutch ethnic origin when at least one of her parents was born abroad. A woman is considered to be from 'other-Western' (non-Dutch) ethnic origin when at least one of her parents was born in a country in Europe (excluding Turkey), North America or Oceania or Indonesia or Japan.<sup>16</sup> Data on socio-economic background of the study population were obtained via Statistics Netherlands and based on the average disposable income in the neighbourhood that women lived in. The disposable income is the total income of an individual minus contributions and taxes. The disposable income was dichotomised

into lower or higher than the average disposable income per Dutch citizen in the same year. The average disposable income in the Netherlands was 10400 euro in 2000, 11000 euro in 2001, 12000 euro in 2002, 12900 euro in 2003 and 12200 in 2004. Statistics Netherlands linked data on postal codes of the women in the study population (nominator and denominator) to neighbourhood level socio-economic background data in their electronic databank (StatLine). Linked records were delivered anonymously to the researchers. Multiple logistic regression analyses were used to assess ethnic and socio-economic differences in the uptake of prenatal screening. Two models were analysed with uptake of prenatal screening (yes/no) as dependent variable. Ethnic origin and socio-economic background were independent variables. In the first model ethnicity was entered as a first block and socio-economic background was added as potential explanatory variable. In the second model socio-economic background was entered as a first block and ethnicity was added as potential explanatory variable.

### 7.3 Results

Table 7.1 shows that 37% of the women in the study population was from non-Dutch ethnic origin. In total 54% of the women were classified as having a high socio-economic background. In the study period, the overall uptake of maternal age-based prenatal screening was 28.5%. In total 29% of the Dutch women participated in prenatal screening. Uptake was highest among 'other-Western' women (35%) and lowest among women from Moroccan ethnic origin (8%). The uptake was 25% among the women from low socio-economic background and 32% among the women from



Table 7. 1 Uptake of maternal age-based prenatal screening according to ethnic origin and socio-economic background in Groot-Rijmond, the Netherlands (2000-2004)

Ethnic origin*	n (%)	Low socio-economic background		High socio-economic background		Total	
		No test	Test	No test	Test	No test	Test
Dutch	7736 (63)	1988 (73)	715 (27)	3477 (69)	1556 (31)	5465 (71)	2271 (29)
Non-Western	3272 (26)	1968 (78)	546 (22)	506 (68)	234 (32)	2492 (76)	780 (24)
Moroccan	779 (6)	616 (93)	45 (7)	104 (88)	14 (12)	720 (92)	59 (8)
Turkish	457 (4)	284 (72)	109 (28)	40 (62)	24 (38)	324 (71)	133 (29)
Aruban/Antillean	288 (2)	170 (73)	64 (27)	32 (59)	22 (41)	202 (70)	86 (30)
Surinamese	720 (6)	355 (68)	171 (32)	124 (64)	70 (36)	479 (66)	241 (34)
Other	1028 (8)	561 (78)	157 (22)	206 (66)	104 (34)	767 (75)	261 (25)
Other Western (non -Dutch)	1332 (11)	352 (70)	150 (30)	508 (61)	322 (39)	860 (65)	472 (35)
Total	12340 (100)	4326 (75)	1411 (25)	4491 (68)	2112 (32)	8817 (71.5)	3523 (28.5)

\* Definition of ethnic origin based on country of birth, following definition rules of Statistics Netherlands (see methods section for details)

high socio-economic background.

Table 7.2 shows that women from Moroccan ethnic origin and women from other ‘non-Western’ groups were less likely to participate in maternal age-based prenatal screening for Down syndrome than Dutch women. However, uptake among women from Turkish and Aruban/Antillean origin did not significantly differ from Dutch women. Surinamese women and ‘other-Western’ women were more likely to participate in prenatal screening than Dutch women. Women from high socio-economic background were more likely to participate in prenatal screening than women from low socio-economic background. After adjustment for socio-economic background, the observed ethnic differences in uptake of maternal age-based prenatal screening remained statistically significant, indicating that the

ethnic differences in uptake were not attributable to differences in socio-economic background.

## 7.4 Discussion and conclusion

### Discussion

This study shows that the overall uptake of maternal age-based prenatal screening for Down syndrome in the Netherlands varied among the diverse ethnic and socio-economic groups. It was unexpected that women from Turkish and Aruban/Antillean origin participated equally and women from Surinamese origin participated more often in the prenatal screening programme than Dutch women. Women from North-African ethnic origin less often participated in prenatal screening.

Table 7.2 Odds Ratios (OR) for uptake of maternal age-based prenatal screening by ethnic origin and socio-economic background in Groot-Rijnmond, the Netherlands (2000-2004)

	<b>Unadjusted OR</b>	<b>(95% CI)</b>	<b>p</b>		<b>Adjusted OR</b>	<b>(95% CI)</b>	<b>p</b>
<b>Ethnic origin</b>							
Dutch	1.00	Reference			1.00	Reference	
'Non-Western'	<b>0.75</b>	<b>(0.67-0.83)</b>	<b>0.00</b>		<b>0.86*</b>	<b>(0.78-0.95)</b>	<b>0.00</b>
Moroccan	<b>0.20</b>	<b>(0.15-0.26)</b>	<b>0.00</b>		<b>0.23*</b>	<b>(0.17-0.29)</b>	<b>0.00</b>
Turkish	0.98	(0.80-1.21)	0.90		1.15*	(0.93-1.41)	0.20
Aruban/Antillean	1.02	(0.79-1.32)	0.85		1.17*	(0.90-1.52)	0.23
Surinamese	<b>1.21</b>	<b>(1.03-1.42)</b>	<b>0.02</b>		<b>1.35*</b>	<b>(1.14-1.59)</b>	<b>0.00</b>
Other non-Western	<b>0.82</b>	<b>(0.71-0.95)</b>	<b>0.01</b>		0.90*	(0.78-1.05)	0.19
'Other Western' (non-Dutch)	<b>1.32</b>	<b>(1.17-1.49)</b>	<b>0.00</b>		<b>1.33*</b>	<b>(1.18-1.51)</b>	<b>0.00</b>
<b>Socio-economic background</b>							
Low	1.00	Reference			1.00	Reference	
High	<b>1.44</b>	<b>(1.33-1.56)</b>	<b>0.00</b>		<b>1.33**</b>	<b>(1.22-1.45)</b>	<b>0.00</b>

\* Adjusted for socio-economic background

\*\* Adjusted for ethnic origin

The strength of this study is that it is the first report on ethnic differences in uptake of maternal age-based prenatal screening for Down syndrome in an unselected population in the Netherlands. Our analyses were based on all tests and births in a defined large region in the Netherlands. Only a few international studies have reported on ethnic and socio-economic differences in maternal age-based prenatal screening. Although the wide availability of non-invasive methods has changed the offer of prenatal screening, women of advanced maternal age still have the option to directly choose for CVS or AMN in most European countries.<sup>15</sup> One of the limitations of this study is that the numerator population consisted of pregnant women, while

the denominator consisted of women who gave birth to a living child in the same period. Women in the denominator who gave birth to a living child in the first months of the year 2000 could have participated in prenatal screening at the end of 1999 and were therefore not included in the numerator. Likewise, the women who participated in prenatal screening at the end of 2004, gave birth to a child after the study period and were therefore not included in the denominator. Since this time shift has comparable consequences for the numerator and denominator and we have no reason to assume that this time shift is different for specific ethnic or socio-economic groups, we do not expect that it has biased our results. Moreover, the uptake of

maternal age-based prenatal screening that we measured in our study population is comparable to the average uptake in the Netherlands in the same period. Another issue in this respect is that women who participated in prenatal screening were more likely to have a miscarriage or pregnancy termination and were therefore not included in the denominator. However, since the risk of having a miscarriage or prenatal detection of Down syndrome is about 0.5%, this probably accounts for less than 20 women who participated in prenatal screening during this study period and is therefore not a serious threat of the internal validity of our study either. The second limitation is that our data did not allow us to evaluate the effects of potential determinants of the ethnic and socio-economic differences and similarities that we found, such as parity, religion or differences in the offer of screening.

The relatively high uptake among women from Surinamese origin and the fact that women from Turkish and Aruban/Antillean origin did not differ in uptake compared to women from Dutch ethnic origin were surprising findings and not in keeping with previous studies.<sup>1-10</sup> The lower uptake among women from Moroccan origin and women from low socio-economic background is in keeping with previous French, Australian and American studies. Differences in access to information and prenatal screening, and differences in attitudes towards prenatal screening and abortion were described as possible determinants for these differences.<sup>1-8</sup> These kind of determinants may also account for the differences that we found in our study. Although differences in access of prenatal screening are not reported in the Netherlands and the costs of AMN and CVS are reimbursed, a recent Dutch study showed that women from non-Dutch ethnic origin booked for prenatal care at significantly

later stage of pregnancy than those from Dutch ethnic origin, which diminishes their possibility to decide whether or not to participate in prenatal screening. Differences in access to information could be increased by the fact that women from ethnic minority groups in the Netherlands generally have more difficulties in the command and/or understanding of the Dutch language. Previous studies showed that language barriers play a role in women's comprehension of information about prenatal screening for Down syndrome.<sup>17, 18</sup>

One of the explanations for the finding that women from Turkish and Caribbean origin equally or more often participated in prenatal screening compared to women from Dutch ethnic origin, is that the overall uptake of prenatal screening for Down syndrome in the Netherlands is generally lower than in many other countries.<sup>8, 9, 10, 19, 20, 21</sup>

This generally lower uptake may be associated with the Dutch 'pregnancy culture': in general, the natural character of pregnancy is highly valued in the Netherlands and pregnancy and delivery are generally considered as natural events that one should not 'unnecessarily' interfere with.<sup>22, 23</sup> The access to prenatal screening and considerations whether or not to participate in prenatal screening among Dutch women might differ from those of the women who originally came from North Africa, Turkey or the Caribbean, but in the end the uptake rate is low in all ethnic groups living in the Netherlands. The Dutch Working Group on Prenatal Diagnosis has collected data relating to prenatal screening in the Netherlands since 1989. Their annual reports showed that the highest uptake of maternal age-based prenatal screening in The Netherlands was 46%, as measured between 1991 and 1994.<sup>24</sup> In comparison, analysis of national datasets in Australia reported an uptake rate of 63% in 1992 and 65% in 1996.<sup>25</sup> Analysis of the

Paris Registry of Congenital Anomalies in France showed an uptake rate of 90% between 1992 and 1997.<sup>19</sup> These results were all obtained before non-invasive methods were implemented in these countries. Another explanation for the finding that Dutch women just as often or even less often participated in AMN and CVS than women from specific ethnic minority groups may be the slow but gradual increase of the use of non-invasive methods in the Netherlands.<sup>26</sup> Although the latter policy were officially implemented in 2005 and the Dutch Population Screening Act did not permit the active offer of non-invasive tests to pregnant women during our study period, a relatively small number of women already underwent maternal serum screening. This was almost 3% of all pregnant women in 1999, half of them being older than 36 years.<sup>27</sup> It is likely that women from ethnic minority groups were possibly less often aware of these alternatives and still directly participated in AMN or CVS. However, since the uptake of maternal serum screening was low before 2005, it is not very likely that this totally explains the low uptake among Dutch women of advanced maternal age.

Another interesting finding was that women from Moroccan origin had a lower uptake of AMN and CVS than women from Turkish and Caribbean ethnic origin. One of the explanations could be the difference in Dutch language proficiency that influences women's access to information. In contrast to Moroccan women, women who originate from Caribbean countries usually have no problems in speaking or understanding Dutch, as Dutch is an official language in these countries and are generally higher educated.<sup>28, 29</sup> However, the difference between Moroccan and Turkish women cannot be explained by language barriers or educational level, since these groups are comparable in these respects, but might be attributed to differences in

religious beliefs.<sup>29, 30</sup> Muslim women often believe that Islam totally prohibits pregnancy termination and are therefore more likely to refuse prenatal screening.<sup>31-36</sup> Although almost all individuals from Moroccan and Turkish ethnic origin are Muslims, Turkish people they less often exhibit active religious behaviour than Moroccan people.<sup>37</sup> It is also likely that the difference could be explained by the fact that women from Moroccan origin in the Netherlands generally book later for prenatal care than women from Turkish origin, which diminishes their possibility to participate in prenatal screening for Down syndrome.<sup>38</sup> Another explanation may be derived from the fact that Turkey is a more Western orientated country where prenatal screening is part of routine prenatal care.<sup>39</sup> The Turkish law allows early abortion on request since 1983, while the law on abortion in Morocco is more restricted.<sup>40</sup>

## Conclusion

This study shows that there were ethnic differences in uptake of maternal age-based prenatal screening for Down syndrome in the Netherlands. The variation in uptake among diverse ethnic groups was unexpected and the explanation probably complex. The findings indicate that interventions should strive for an equal access to the prenatal screening programme, for example by stimulating early attendance of prenatal care and decreasing language barriers. The aim of such interventions is not to increase uptake of prenatal screening, but to enable all women to make an informed decision whether or not to participate in prenatal screening that is based on their own values and beliefs. Culturally competent care provision is an essential condition for such interventions, at organisational as well as individual professional level.<sup>41</sup>

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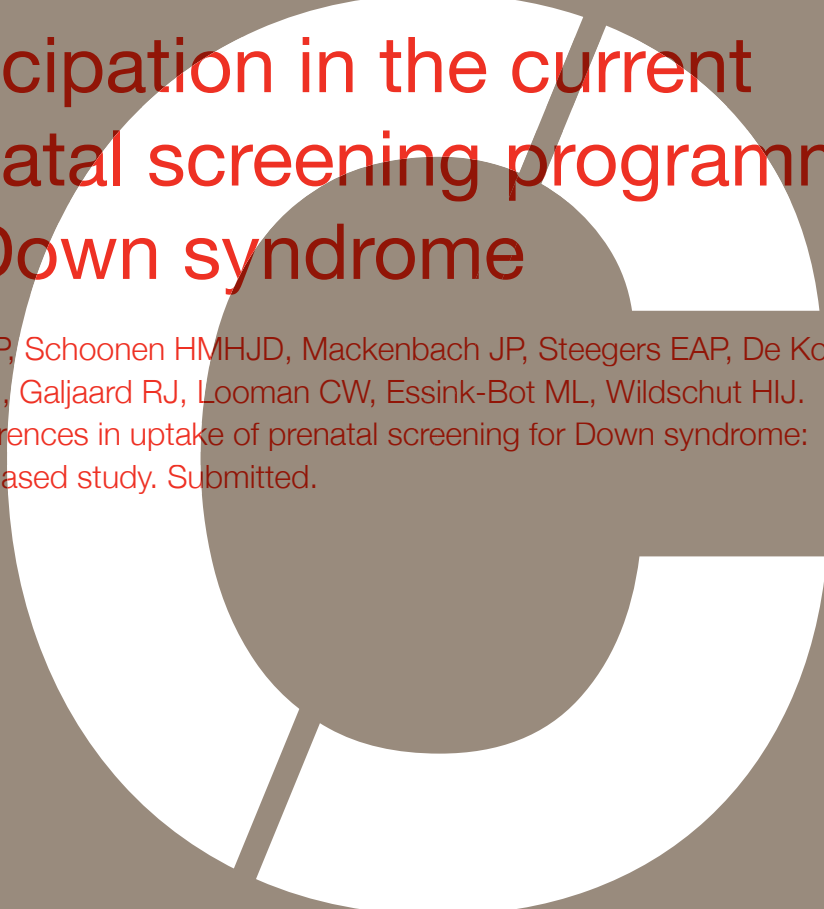
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# Ethnic differences in participation in the current prenatal screening programme for Down syndrome

Fransen MP, Schoonen HMHJD, Mackenbach JP, Steegers EAP, De Koning HJ, Laudy JAM, Galjaard RJ, Looman CW, Essink-Bot ML, Wildschut HIJ. Ethnic differences in uptake of prenatal screening for Down syndrome: a register-based study. Submitted.



# Abstract

**Objective** To assess ethnic differences in participation in the prenatal screening programme for Down syndrome for the period 1-1-2009 to 1-7-2009 in the Southwest of the Netherlands.

**Methods** Data on ethnic origin, socio-economic background and age of participants in prenatal screening were obtained from STAR Medical Diagnostic Centre and the Department of Clinical Genetics, Erasmus MC. Population data for the same postal code area were collected from Statistics Netherlands. We used logistic regression models to assess ethnic differences in participation, adjusted for socio-economic background and age.

**Results** The overall uptake of prenatal screening was 3865 out of 15093 (26%). Uptake was 28% among Dutch women, 15% among those from Turkish ethnic origin, 8% among those from North-African origin, 15% among those from Aruban/Antillean origin and 26% among women from Surinamese origin.

**Conclusion** Compared to Dutch women, those from Turkish, North-African (Moroccan), Aruban/Antillean and other non-Western ethnic origin were less likely to participate in prenatal screening, while women from Western (non-Dutch) ethnic origin were more likely to participate in prenatal screening. It was unexpected that women from Surinamese origin participated equally in prenatal screening. Since previous findings showed that pregnant women from Surinamese ethnic origin had poor knowledge about prenatal screening, it may be questioned to what extent their participation was based on informed decision-making.

## 8.1 Introduction

Studies in several countries have documented ethnic differences in uptake of prenatal screening for Down syndrome.<sup>1,2</sup> Women from ethnic minority groups are generally less likely to participate in prenatal screening. This paper addresses the question whether such differences also exist in the Netherlands, where 20% of the population currently consists of individuals of non-Dutch ethnic origin. More than half of this group originate from non-Western countries including Mediterranean (Turkey and Morocco) and Caribbean countries (Surinam, Dutch Antilles and Aruba).<sup>3</sup> Mediterranean men came in the 1960s and 1970s to the Netherlands as manual labour migrants and later brought their families to stay permanently. The Caribbean countries are former colonies of the Netherlands. After the 1980s large groups from these populations migrated to the Netherlands, mostly due to economic recession in their home country.

Presently available tests for prenatal screening for Down syndrome can be classified to risk assessment tests and diagnostic tests. Risk assessment tests give an estimate of the probability that the fetus has Down syndrome. Commonly used risk assessment tests are first trimester maternal serum screening (MSS) that involves the assessment of free  $\beta$ -hCG and PAPP-A in maternal blood between 9 and 14 weeks, and the ultrasound assessment of fetal nuchal translucency thickness between 11 and 14 weeks' gestation. The individual probability of carrying a child with Down syndrome is subsequently estimated on the basis of the biochemical and ultrasound findings, where the pre-test risk of maternal age is included in the algorithm. If this probability exceeds an a priori specified threshold at the time of testing, the woman is offered diagnostic testing with chorionic villus sampling (CVS) or

amniocentesis (AMN) that provide certainty about whether or not the fetus has Down syndrome.<sup>4</sup> The prenatal screening programme based on risk assessment has only recently (since 2007) been implemented in standard prenatal practice in the Netherlands.<sup>5,6</sup> Since then, gynaecologists and midwives are legally obliged to inform each pregnant woman about the options for prenatal screening at the booking visit.<sup>6</sup> The goal of providing information about prenatal screening to pregnant women is not to maximise uptake of prenatal screening, but to enable women and their partners to make an autonomous informed decision whether or not to participate in prenatal screening for Down syndrome.<sup>4, 7-10</sup> An informed decision needs to be based on sufficient knowledge of relevant information about the benefits and limitations of the possible courses of action to take, and should be in accordance with the individual values and beliefs.<sup>11-13</sup> Women aged 36 years or over have an age-based indication for prenatal testing and may directly choose for CVS or AMN. Women under 36 years of age are initially only eligible for risk assessment tests and have to pay for these tests themselves, unless they have a listed indication for diagnostic testing. If the test result indicates an increased risk of Down syndrome, the costs of diagnostic testing are reimbursed.<sup>14</sup> The objective of this study was to assess ethnic differences in the participation in the prenatal screening programme for Down syndrome in the Netherlands.

## 8.2 Methods

### Population and data collection

The uptake of first trimester MSS and maternal age-based CVS and AMN was assessed over the

period 1-1-2009 to 1-7-2009 in the Southwest of the Netherlands. The Southwest of the Netherlands entails 20% of the 16.5 million citizens in the Netherlands.

Data on address and date of birth of pregnant women who participated in MSS were obtained from STAR Medical Diagnostic Centre that performs MSS since 2005. Since January 1st 2009, all maternal serum screening tests that are performed in the Southwest of the Netherlands are analysed in this centre. Data of women of advanced maternal age who had AMN or CVS were obtained from the Department of Clinical Genetics, Erasmus University Medical Centre Rotterdam. Women whose postal code did not fit in the defined postal code area of the Southwest of the Netherlands were excluded from the study.

The denominator for our set of observations was estimated, because we did not have information about the number of pregnant women who were eligible to participate in the prenatal screening programme in 2009 (all women living in the assigned area in the 10th to 13th week of pregnancy). Since women are registered after giving birth, the number of women who give birth in the second half of 2009 could be used to estimate the number of pregnant women in the first half of 2009. However, the number of women who gave birth was not yet available at the time of this study. The ethnic, socio-economic and age distribution of the women who gave birth in the defined postal code area was only available for the year 2007. On the basis of the data on women who gave birth in 2007 and the total population women of fertile age (between 15 and 45 of age) in the defined postal code area in the same year, we calculated fertility rates per ethnic, socio-economic and age group. These fertility rates were applied to the population women of fertile age in the defined postal code area in 2009

in order to estimate the ethnic and socio-economic background and age of the denominator.

## Measures

Data on ethnic origin of the study population were obtained from the Dutch National Office of Statistics (Statistics Netherlands). In the Netherlands ethnic origin is defined by the country of birth of a person's parents. A woman is considered to be from non-Dutch ethnic origin when at least one of her parents was born abroad. A woman is considered to be from 'non-Western' ethnic origin when at least one of her parents was born in Turkey or countries in Africa (including Morocco), South America or Asia (excluding Indonesia and Japan). A woman is considered to be from 'other-Western' (non-Dutch) ethnic origin when at least one of her parents was born in a country in Europe, North America or Oceania or Indonesia or Japan.<sup>3</sup>

Individual data (date of birth and address) of the women who participated in the prenatal screening programme were linked to the Population Registers of the respective municipalities in the Southwest of the Netherlands in order to obtain ethnic origin of the participants in prenatal screening. These individually linked records were delivered anonymously to the researchers. Data on ethnic origin of the women who gave birth to a live born child in 2007 were obtained from the national birth records, available in the electronic database of Statistics Netherlands 'StatLine'. Data on ethnic origin of the women of fertile age in the Southwest of the Netherlands were obtained for 2007 and 2009 from the Population Registers as available in the electronic database of Statistics Netherlands.

Data on socio-economic background of the study population were obtained via Statistics Netherlands and based on the average disposable income in the neighbourhood where women lived in. The dispo-

ble income is the total income of an individual minus contributions and taxes. The disposable income was dichotomised into lower or higher than the average disposable income per Dutch citizen in the same year. Statistics Netherlands linked data on postal codes of the women who participated in the prenatal screening programme to the Population Registers in order to add neighbourhood codes to the dataset. These neighbourhood codes were then linked to the electronic databank of Statistics Netherlands 'StatLine'. Most recently available data on average neighbourhood income in this databank were obtained in 2007. Linked records were delivered anonymously to the researchers. Data on socio-economic background of the women who gave birth to a live born child were derived from the same dataset in StatLine. Data on age of the study population were obtained via Statistics Netherlands and based on women's date of birth. Age was categorised as 'younger than 26 years of age', 'between 26 and 31 years of age', 'between 31 and 36 years of age' and '36 years or age or over'.

Participation in the prenatal screening programme was first of all measured by data on women who participated in MSS. Since women above the age of 35 could also choose directly for AMN or CVS and therefore would unjustly be considered as non-participants, we also obtained data on participation in maternal age-based AMN or CVS. The numbers of women who directly chose for AMN or CVS were calculated by subtracting those who participated in both tests from the total number of participants in AMN or CVS. The women who participated in MSS as well as the diagnostic test AMN or CVS, were counted as participants in MSS. The overall participation in the prenatal screening programme was calculated by adding women who participated in MSS to those who directly participated in AMN or CVS.

## Analyses

Multiple logistic regression analyses were used to assess ethnic and socio-economic differences in the uptake of maternal age-based prenatal screening. Three models were analysed with participation in the prenatal screening programme (yes/no) as dependent variable. The first model concerned unadjusted analyses for the independent variable ethnic origin. The second model concerned unadjusted analyses for socio-economic background as independent variable. The third model contained the independent variables ethnic origin, socio-economic background and age in order to adjust ethnic differences for effects of socio-economic background and age and to adjust socio-economic differences for effects of ethnic origin and age. Since the denominator in these logistic regression models were only estimates and not real numbers of women eligible for prenatal screening, we performed a parametric bootstrap. For every replica the numbers attending and the denominators in every cell of the three-dimensional dataset were drawn from a Poisson distribution, with the observed number of women who participated in prenatal screening and the estimated number of pregnant women who were eligible for prenatal screening as parameters. Univariate and multivariate logistic regressions were performed for each of one thousand replicas and we calculated the 2.5 and 97.5% quantile of the Odds Ratios (ORs) to reach 95% Confidence Intervals (CIs) which were thereby corrected for the uncertainty of the denominator.

## 8.3 Results

Table 8.1 shows that the overall participation in the prenatal screening programme for Down syndrome in the total population was 26%. The uptake of

Table 8.1 Participation in the prenatal screening programme for Down syndrome, according to ethnic origin, socio-economic background and age n (%) in the Southwest region of the Netherlands.

	<b>Total population</b>	<b>Participation in prenatal screening</b>	<b>MSS among women of all ages</b>	<b>AMN/CVS among women above 35 years</b>
<b>Ethnic origin</b>				
Dutch	9904 (66)	2747 (28)	2620 (26)	127 (7)
Moroccan	846 (6)	71 (8)	66 (8)	5 (3)
Turkish	756 (5)	112 (15)	104 (14)	8 (9)
Aruban/Antillean	370 (2)	57 (15)	50 (14)	7 (14)
Surinamese	572 (4)	151 (26)	135 (24)	16 (16)
Other non-Western	1119 (7)	227 (20)	205 (18)	22 (13)
Other Western (non-Dutch)	1526 (10)	500 (33)	472 (31)	28 (9)
<b>Socio-economic background</b>				
Low	8509 (56)	1695 (20)	1587 (19)	108 (8)
High	6584 (44)	2170 (33)	2065 (31)	105 (8)
<b>Age</b>				
<26	2554 (17)	310 (12)	310 (12)	Not applicable
26-31	4942 (33)	1005 (20)	1005 (20)	Not applicable
31-36	4930 (32)	1429 (29)	1429 (29)	Not applicable
>36	2668 (18)	1121 (42)	908 (34)	213 (8)
<b>Total</b>	15093 (100)	3865 (26)	3652 (24)	213 (8)

MSS among women of all ages was 24% and the uptake of direct AMN or CVS among women above 35 years of age was 8%. The uptake was highest among women who originate from other (non-Dutch) Western countries (33%) and lowest among women from North-African (Moroccan) ethnic origin (8%). The uptake was 20% among the women from low socio-economic background and 33% among

the women from high socio-economic background. The highest uptake was measured among women aged 36 years or over; 42% participated in the prenatal screening programme. With the exception of Moroccan women, all women aged 36 years or over more often participated in direct age-based AMN or CVS than Dutch women of advanced maternal age. Table 8.2 shows that women from North-African



**Table 8.2 Odds Ratios (OR) for participation in the prenatal screening programme for Down syndrome by ethnic origin and socio-economic background**

	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
<b>Ethnic origin</b>		
Dutch	1.00	1.00
North African (Moroccan)	0.24 (0.18-0.31)	0.28 (0.21-0.36) <sup>1</sup>
Turkish	0.45 (0.35-0.57)	0.63 (0.48-0.81) <sup>1</sup>
Aruban/Antillean	0.47 (0.34-0.64)	0.67 (0.47-0.92) <sup>1</sup>
Surinamese	0.93 (0.73-1.16)	1.18 (0.90-1.50)
Other non-Western	0.66 (0.56-0.78)	0.83 (0.70-0.99) <sup>1</sup>
Other Western (non-Dutch)	1.27 (1.09-1.47)	1.30 (1.10-1.53) <sup>1</sup>
<b>Socio-economic background</b>		
Low	1.00	1.00
High	1.98 (1.81-2.17)	1.62 (1.46-1.79) <sup>2</sup>

<sup>1</sup> Adjusted for differences in age and socio-economic background

<sup>2</sup> Adjusted for differences in age and ethnic origin

(Moroccan), Turkish, Aruban/Antillean and other non-Western ethnic origin were less likely to participate in the prenatal screening programme than Dutch women, while those from Western (non-Dutch) ethnic origin were more likely to participate in the prenatal screening programme. Women from Moroccan origin differed most from Dutch women, followed by women from Turkish origin. No significant differences were found between women from Surinamese and Dutch ethnic origin. After adjustment for socio-economic background and age, the ORs remained statistically significant, indicating that the ethnic differences in uptake were not attributable to differences in socio-economic background or age. Women from high socio-economic background were more likely to participate in the prenatal screening programme than wo-

men from low socio-economic background. This difference remained statistically significant after adjustment for ethnic origin and age.

## 8.4 Discussion and conclusion

### Discussion

This register-based study showed that there are ethnic differences in participation in the prenatal screening programme for Down syndrome in the Netherlands. The findings of this study are in keeping with previous international studies.<sup>1, 2 15-19</sup> An unexpected finding was that women from Surinamese ethnic origin participated equally in the prenatal screening programme. As published results on uptake of the prenatal

screening programme in the Netherlands are not yet available, this provides important information for the evaluation of the recently introduced prenatal screening programme for Down syndrome. International studies on ethnic variations in uptake of first trimester prenatal screening for Down syndrome are scarce. As far as we know, this is the first study to assess ethnic differences in uptake of prenatal screening for Down syndrome in an unselected large population. Our analyses were based on all tests and births in a defined large region in the Netherlands. The total number of live born children in the first half of 2009 in the South–West of the Netherlands comprises 18% of the total population live born children in the Netherlands in the same period of time.

This study has limitations. First, we did not have exact numbers of pregnant women who were living in the Southwest of the Netherlands in the first half of 2009, because women are only registered in the Population Registers after their baby is registered after birth. The number of women giving birth in 2009 had to be estimated from the number of women who gave birth to a living child in 2007 in the same postal code area. Similarly, the distributions of their ethnic and socio-economic backgrounds had to be estimated on the basis of the ethnic and socio-economic background of the women who gave birth to a living child in 2007. Since the comparison of the population women of fertile age in 2007 and 2009 showed that the population sizes and the ethnic and socio-economic distribution did not change much in these two years, it is unlikely that the estimations for 2009 considerably deviate from the actual number and distribution in pregnant women in the first half of 2009. We therefore do not expect that the internal validity of the relative ethnic differences in uptake is biased. Second, we have to take into account that there will be diffe-

rences between the number of women giving birth and the number being pregnant at the time of the screening, as not all pregnant women will reach delivery of a live born child. Since the percentage of fetal loss generally is estimated at less than 2% and we had no reason to assume that this differs considerably per ethnic group, we do not expect this detracts from our results on ethnic differences in prenatal screening.<sup>20</sup> Since the percentage is relatively high for older women, the ORs for age may be somewhat biased, but the correction for age on the ORs for ethnicity and socio-economic background in the multivariate model will nevertheless be valid. Moreover, in the calculation of the ORs we performed a parametric bootstrap in order to reach 95% CI's which were corrected for the uncertainty of the denominator.

Third, we were unable to assess whether women who participated in first trimester maternal serum screening also had an ultrasound assessment of fetal nuchal translucency thickness, because STAR Medical Diagnostic Centre analyses all blood samples, while most ultrasound assessment take place in individual practices or hospitals. Since the results of maternal serum screening are routinely combined with nuchal translucency measurement to estimate the individual probability of carrying a child with Down syndrome, and women are offered a combination of both tests ('the combined test'), the number of women who participated in serum screening between the 10th and 13th week of gestation but did not have an ultrasound assessment between the 11th and 14th week of gestation is probably very low. Moreover, since we were interested in participation in the prenatal screening programme and maternal serum screening is the first test in this programme, lack of data on uptake of ultrasound assessment does not detract from our results.

An important finding of this study was that especially women from Turkish and Moroccan ethnic origin were less likely to participate in prenatal screening for Down syndrome, after adjustment for socio-economic and age differences. A possible explanation is that women were less often aware of this relatively new screening test for Down syndrome. Our previous interview study among pregnant women from Turkish, Surinamese and Dutch ethnic origin showed that especially women from Turkish origin were less often aware of prenatal screening tests for Down syndrome, less often read written information material and had only little knowledge about Down syndrome and prenatal screening, and less often made an informed decision whether or not to participate in prenatal screening compared to women from Dutch and Surinamese ethnic origin.<sup>21,22</sup> These ethnic differences could especially be attributed to language barriers and educational attainment level. Studies in Australia and the United States also showed that language barriers play an important role in women's comprehension of information about prenatal screening for Down syndrome.<sup>23,24</sup> Higher awareness of the recently introduced prenatal screening programme may also explain why Dutch women of advanced maternal age in our study were less likely to directly choose for diagnostic tests, but more often participated in first trimester serum screening compared to women from other ethnic origin. Moreover, a Dutch study on late booking for prenatal care showed that women from Turkish and Moroccan ethnic origin generally book later for prenatal care than women from Dutch origin, which also diminishes their possibility to participate in first trimester prenatal screening.<sup>25</sup>

An unexpected finding was that women from Surinamese ethnic origin participated equally in the prenatal screening programme. A potential

explanation is the relatively low uptake of prenatal screening among the Dutch women compared to women from other countries.<sup>17,26-28</sup> Another explanation may be that the cultural distance between women from Surinamese origin and the Dutch host population is generally smaller than between ethnic Dutch and the other non-Western ethnic minority groups. Surinamese women generally do not experience language barriers, have a higher educational attainment level than other women from non-Western ethnic origin and more often participate in the labour market.<sup>29</sup> It is therefore likely that they experience less barriers in access to prenatal screening than women from other non-Western ethnic minority groups. The results from our previous study among pregnant women from Dutch, Turkish and Surinamese ethnic origin in the Netherlands, indeed showed that women from Surinamese origin scored higher on informed decision-making than women from Turkish origin. However, compared to the level of informed decision-making among the Dutch women in our study population, other populations in the Netherlands and other countries, the level of informed decision-making among the Surinamese women that we interviewed was poor.<sup>2,30-32</sup> It is therefore questionable whether the similar uptake between Surinamese and Dutch women in this registered-based study also implies equal knowledge about Down syndrome and prenatal screening.

## Conclusion

We found that women from Turkish, North-African (Moroccan) and Aruban/Antillean ethnic origin were less likely to participate in the prenatal screening programme than women from Dutch ethnic origin. The ethnic variations that we found may be related to barriers in access to information about prenatal screening and barriers in the decision-making

process. However, solving these barriers does not necessarily imply a higher uptake among women from non-Western ethnic origin and, more importantly, that should not be the aim of providing information about prenatal screening. After all, the goal of the prenatal screening programme is to provide all pregnant women equal opportunities for an informed decision whether or not to participate in prenatal screening for Down syndrome.

### **Acknowledgements**

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Discussion

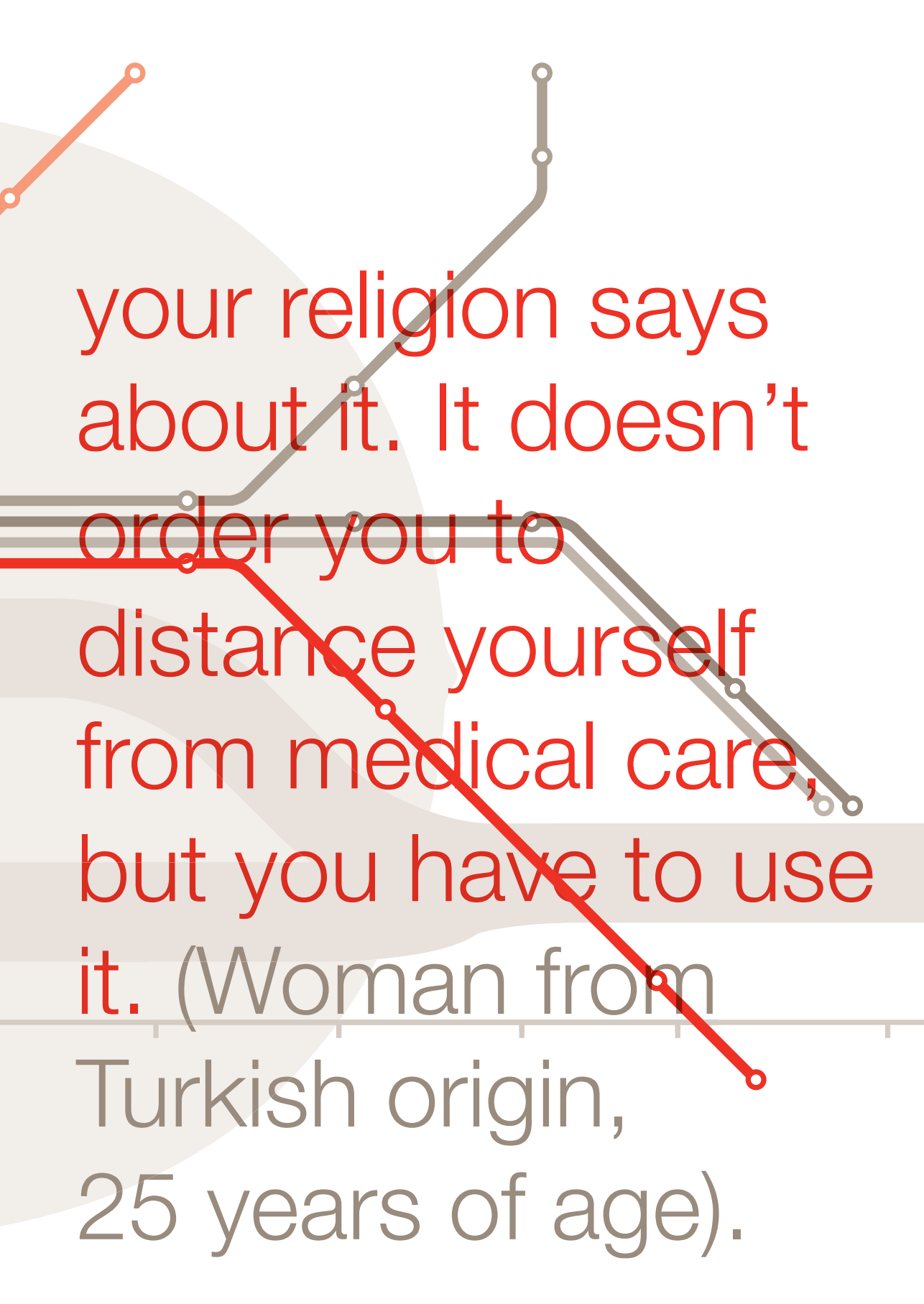
# Part V

The background features a complex network of grey and red lines with small circles at various points, resembling a circuit board or a data network. The lines are set against a light grey background with some darker grey shapes.

In our culture people are a bit wary of prenatal screening.

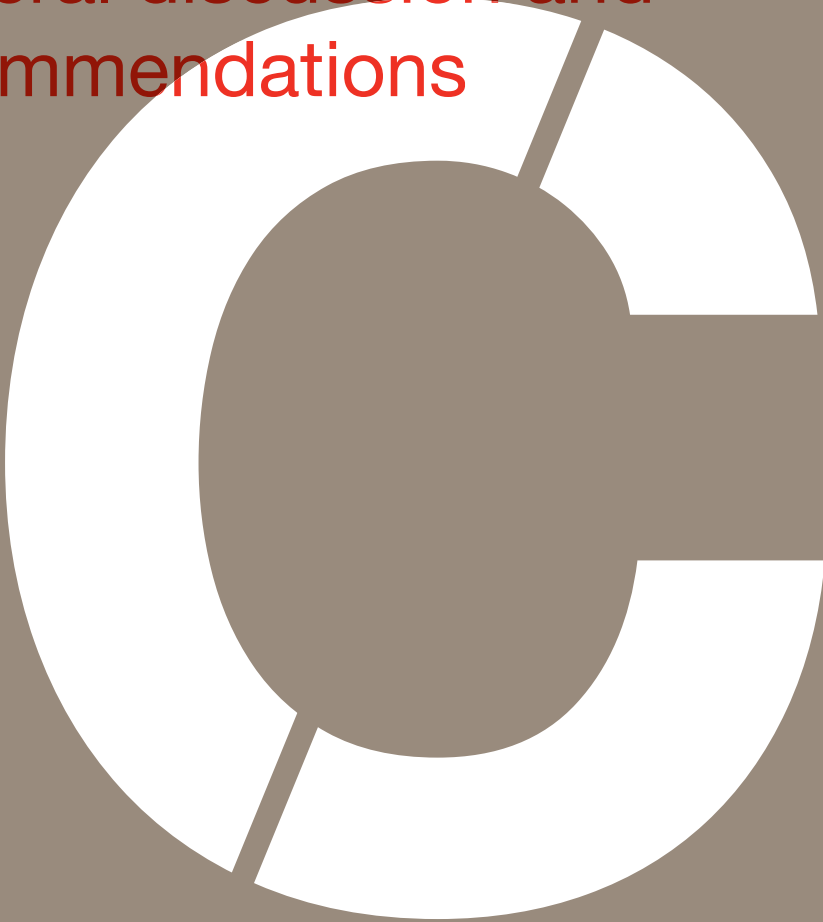
They say 'What's the use of knowing beforehand? It's Allah's decision'.

In my opinion, you have to think what



your religion says  
about it. It doesn't  
order you to  
distance yourself  
from medical care,  
but you have to use  
it. (Woman from  
Turkish origin,  
25 years of age).

# General discussion and recommendations





# General discussion

The main aim of the research in this thesis was to evaluate ethnic differences in pregnant women's decision-making on prenatal screening for Down syndrome. The three central themes were: ethnic differences in the provision of information and women's knowledge, ethnic differences in the decision-making process and ethnic differences in the uptake of prenatal screening for Down syndrome. In this chapter the results will be summarised by answering the research questions (paragraph 9.1), followed by some comments on the methodological issues (paragraph 9.2) and a discussion of the results in light of findings from other studies (paragraph 9.3). The chapter ends with a general conclusion (paragraph 9.4) and implications and recommendations for future research and practice (paragraph 9.5).

## 9.1 Answers to the research questions

The main findings of the studies that are presented in this thesis are described per research question and ordered in the Prenatal Screening Stage model (Figure 9.1). This model was described in Chapter 2 of this thesis and served as a framework for data collection among pregnant women and midwives. The results of the personal interviews are presented per ethnic group for the examined stages and determinants in the decision-making process. The results of the web-based questionnaires among midwives are incorporated in the model as well.

### 9.1.1 Ethnic differences in knowledge and access to information

**Question 1** To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in their knowledge about Down syndrome and prenatal screening, and what is the contribution of ethnic differences in the information that is provided by midwives and gynaecologists?

**Question 2** To what extent do midwives experience differences and difficulties in providing information about prenatal screening for Down syndrome to pregnant women from diverse ethnic origin? Although most women reported to have received information about prenatal screening from their midwife or gynaecologist and said they were interested in this information, not all women were aware of Down syndrome and prenatal screening at the time they were interviewed (Figure 9.1). Women from Turkish and Surinamese origin less often reported to have received written information and read written information, more often reported difficulties in understanding the information and had significantly less knowledge about Down syndrome and prenatal screening compared to Dutch women (Chapter 3). Women from Turkish origin scored

lowest on knowledge. The ethnic differences in knowledge could mainly be attributed to differences in educational level among Surinamese women and to language barriers among Turkish women (Chapter 3). Although language barriers were also reported by midwives as the main difficulty in informing women from non-Western ethnic origin, only a minority of the midwives reported to use translated materials and professional interpreters in the provision of information about prenatal screening (Chapter 4 and Figure 9.1). Unawareness of the availability of translated materials and unfamiliarity with the use of professional interpreters seemed to be the main reason for this underutilization (Chapter 4).

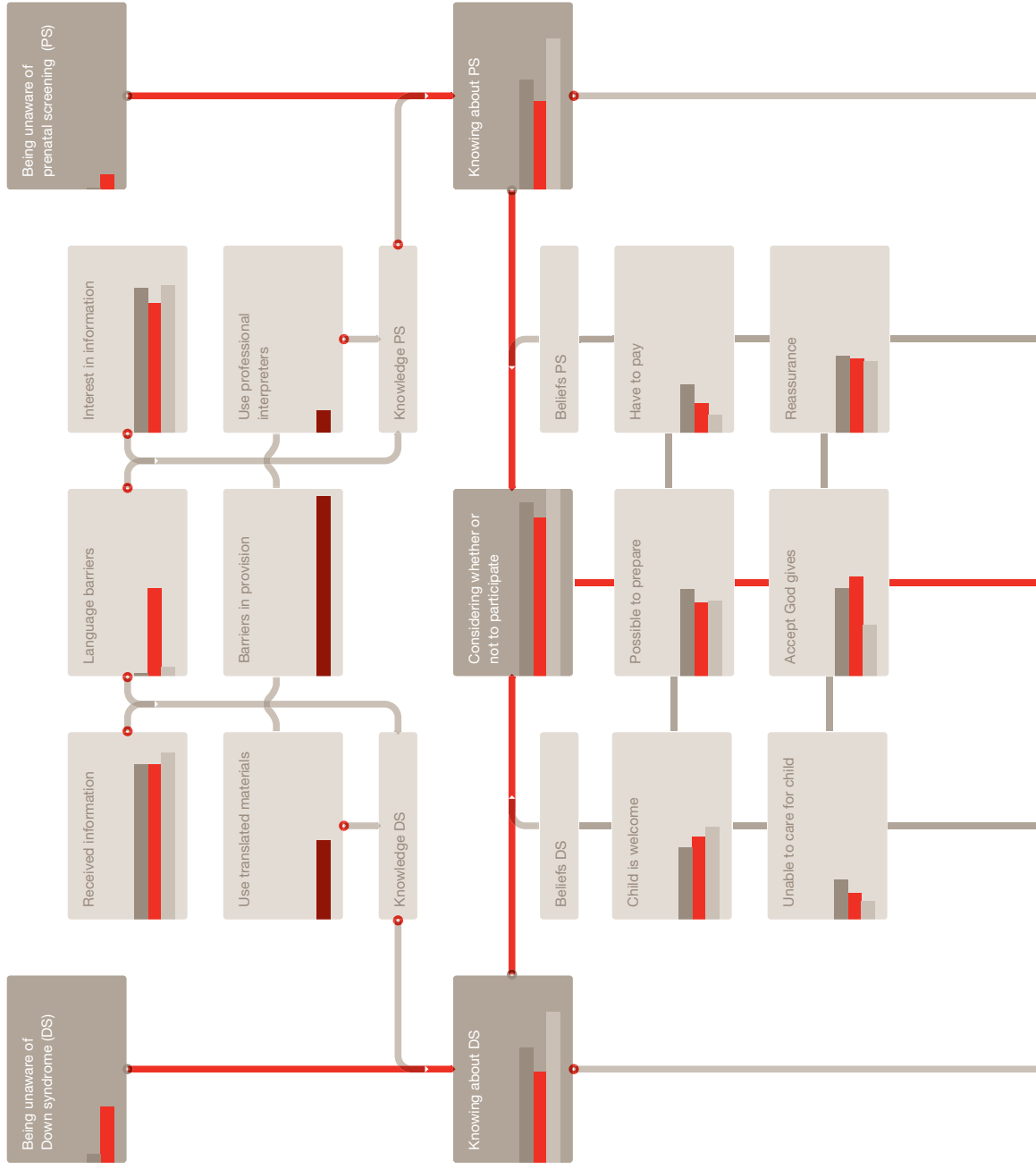
### 9.1.2 Ethnic differences in the decision-making process

**Question 3** To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in informed decision-making on prenatal screening for Down syndrome, and what is the contribution of background characteristics and decision-making variables?

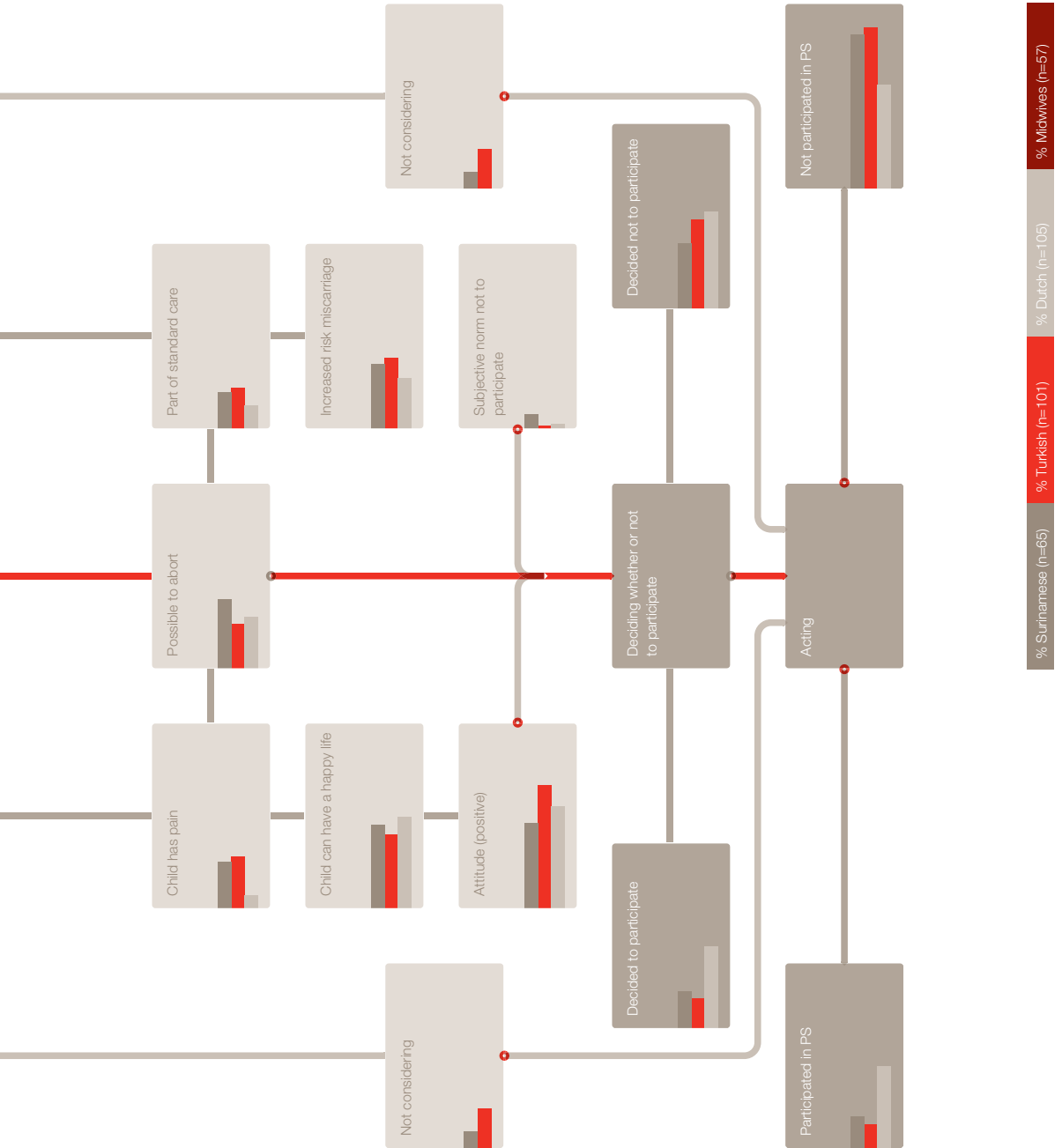
**Question 4** To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in uptake of prenatal screening for Down syndrome, and what considerations do they have whether or not to participate in prenatal screening?

In total, 71% of the Dutch women were classified as informed decision-makers, meaning that they had sufficient knowledge about prenatal screening and that their actual (non-) participation in prenatal screening was consistent with their attitude. By contrast, only 5% of the women from Turkish origin and 26% of the women from Surinamese origin made an informed decision whether or not to participate in prenatal screening. Most Turkish women who made an uninformed decision had insufficient

Figure 9.1 Prenatal Screening Stage Model







knowledge, a positive attitude and a negative uptake. Most Dutch and Surinamese uninformed decision-makers had insufficient knowledge, but made an attitude consistent decision. Differences in informed decision-making between Dutch and Turkish women could mainly be explained by differences in language skills and gender emancipation. Differences in informed decision-making between Surinamese and Dutch women could to a large extent be explained by differences in age and educational level (Chapter 5).

Figure 9.1 shows that not all women had considered whether or not to participate in prenatal screening at the time of the interview. Six women from Surinamese origin and 21 women from Turkish origin reported not to have considered whether or not to participate in prenatal screening. Most of these women reported that they had not thought about prenatal screening, since they did not know that they could participate in prenatal screening, their midwife did not talk about prenatal screening, or because they did not belong to a high-risk group. Ten women from Surinamese origin, ten women from Turkish origin and four women from Dutch origin did not yet know what to decide at the moment they were interviewed. Except for two women from Turkish origin, none of them participated in prenatal screening. Seven women from Turkish origin and three women from Surinamese origin decided to participate in prenatal screening, but eventually did not. Two women from Turkish origin and one woman from Surinamese origin decided not to participate, but participated after all. The total uptake of screening was 13% among the Turkish, 17% among the Surinamese and 44% among the Dutch women. The lower uptake among Surinamese women in the study population could be attributed to differences in age. The lower uptake among Turkish women could be attributed

to differences in age and religious identity (Chapter 6). Turkish and Surinamese women more often reported acceptance of 'what God gives' as a consideration not to participate in prenatal screening. Surinamese women especially mentioned their low risk of having a child with Down syndrome and the costs of screening. Turkish and Surinamese women also reported many considerations in favour of participation, such as gaining reassurance about the baby's health or preparing for the birth of a child with Down syndrome. These considerations did not differ from those of Dutch women but were less often consistent with actual participation in prenatal screening (Chapter 6).

### 9.1.3 Ethnic differences in uptake of prenatal screening for Down syndrome

**Question 5** To what extent did ethnic differences in uptake of maternal age-based prenatal screening for Down syndrome exist in the Netherlands?

**Question 6** To what extent do ethnic differences in participation in the current prenatal screening programme for Down syndrome exist in the Netherlands?

The overall uptake of maternal age-based prenatal screening for Down syndrome (AMN or CVS) was 28.5% in the period between 2000 and 2004, before risk-assessment tests were implemented in standard prenatal care in the Netherlands (Chapter 7). Compared to Dutch women, women from Surinamese and Western (non-Dutch) origin had a higher uptake, women from Turkish and Antillean/Aruban ethnic origin had a comparable uptake and women from Moroccan and other non-Western ethnic origin had a lower uptake of AMN or CVS. Women from low socio-economic background had a lower uptake than women from high socio-economic background. Ethnic differences in uptake could not be attributed to differences

in socio-economic background.

The overall participation in the current prenatal screening programme (first trimester serum screening for all women or direct AMN or CVS for women of advanced maternal age) was measured in the first half of 2009 and showed an overall uptake rate of 26% (Chapter 8). Compared to Dutch women, those from Turkish, Moroccan, Aruban/Antillean and other non-Western ethnic origin were less likely to participate in the prenatal screening programme, while those from Western (non-Dutch) ethnic origin were more likely to participate in the programme. No significant differences were found between women from Surinamese and Dutch ethnic origin. Women from low socio-economic background were less likely to participate in the prenatal screening programme than women from high socio-economic background. Ethnic differences remained statistically significant after adjustment for differences in socio-economic background and age. Except for women of advanced maternal age from Moroccan ethnic origin, all women of advanced maternal age were more likely to participate in direct age-based AMN or CVS than Dutch women in this age group.

## 9.2 Methodological issues

Strength of this study is that we combined large-scale epidemiological studies on ethnic differences in uptake of prenatal screening with interview studies that assessed ethnic differences in the decision-making process. In the interview study we combined qualitative and quantitative (mixed) methods in order to evaluate ethnic differences in pregnant women's decision-making on prenatal screening for Down syndrome. Possible variables that may play a role in pregnant women's decision-

making process whether or not to participate in prenatal screening were derived from literature and explored in focus group interviews (Chapter 2). Quantitative interview data was collected in an open population of pregnant women who had yet to decide upon prenatal screening (Chapter 3, 5 and 6). Most other studies on women's reasons for participation in prenatal screening assessed women's views after they had made the decision. It is likely that these views reflect women's post-choice justifications rather than their considerations when reaching the decision. Besides the viewpoints of the pregnant women, we also assessed the opinions of the midwives that were working in the practices where these pregnant women were recruited. Unfortunately we were unable to evaluate and compare their views over the same information process (Chapter 4). In order to assess ethnic differences in uptake of prenatal screening on a larger scale, population-based studies were performed in region Southwest of the Netherlands (Chapter 7 and 8). Our analyses were based on all tests and births in a defined large region in the Netherlands. Ethnic differences in uptake of prenatal screening were not assessed in an unselected population in the Netherlands before. We not only assessed ethnic differences in maternal age-based prenatal screening, but also assessed very recent data (2009) on uptake of maternal serum screening as part of the prenatal screening programme that was implemented in standard prenatal care in 2007. Specific limitations of the studies that are included in this thesis were discussed in previous chapters. However, in the interpretation of our study findings some general issues need to be acknowledged that may have threatened the internal validity (i.e., whether applied methods measured what they purport to measure) and external validity (i.e., whether results may be generalised to other

populations or settings than our research sample) of the results. These issues will be discussed in the next paragraph.

### 9.2.1 Internal validity

#### **Design interview study among pregnant women**

Deciding whether or not to participate in prenatal screening is a process and usually not one moment in time. In order to exactly map this process, a longitudinal design should be used where women are interviewed at several moments during the decision-making process. Since there usually is little time between booking for prenatal care and the moment of participation in prenatal screening, and the process of decision-making varies between women, we decided to interview each woman once before she could participate in prenatal screening and later assess whether she participated in prenatal screening or not. As the main aim of our study was to assess ethnic differences in pregnant women's knowledge and considerations whether or not to participate in prenatal screening for Down syndrome, we believe this was the best design at this moment and does not detract from our conclusion.

#### **Non-response**

A limitation of the interview study among 270 pregnant women is that we only know the exact non-response rate of the women that were recruited by the researchers (51% of the respondents). We were unable to map the non-response of women who were recruited by midwives and gynaecologists (49% of the respondents), because the number of women who did not want to be contacted by the researcher was not completely registered by midwives and gynaecologists. However, since women who were recruited by researchers did not significantly differ in relevant outcomes from women who were recruited by midwives and

gynaecologists and the drop-out of women who initially agreed to make an appointment to be interviewed was almost the same, we have no reason to assume that the recruitment was threatened by selection bias.

#### **Self-reported data**

One of the limitations of the measures that we used in the quantitative studies among pregnant women and midwives is that the data is self-reported. Self-reported data have the advantage that they are relatively easy to obtain and are the only possible means to measure subjective variables such as attitude and considerations whether or not to participate in prenatal screening. However, self-reports have the disadvantage that several types of reporting bias may take place that threaten the internal validity of the data.

Although questionnaires for midwives were filled in anonymously and the questions were neutrally formulated, midwives could have had the tendency to fill in questions towards perceived desirable standards. The data could therefore have been biased by social desirability. However, the finding that almost all midwives reported never to use professional translators and not always use translated materials indicates that social desirability was low. Social desirability could not have had an impact on knowledge measurements among pregnant women, since women could not provide the correct answer if they do not have sufficient knowledge about the subject. Regarding the measurement of attitudes, it is possible that some women, perhaps especially women from non-Western ethnic minority groups, have difficulty expressing themselves negatively towards prenatal screening when they are interviewed upon this subject by an employee of Erasmus MC. Another outcome that might have been biased by social desirability is the importance

of out-of-pocket payment of prenatal screening. Stating that costs are the reason for not participating in a test for the health of your baby may not be easy for many women. It is possible that costs play a more important role among women who have less money to spend. However, the relatively small socio-economic differences in the uptake of prenatal screening that we found among the population in the Southwest of the Netherlands do not confirm this supposition.

Language skills of the pregnant women were measured by self-reported data as well. Since we also asked for the opinion of the interviewer on this subject, we were able to compare the data on language skills. Unfortunately we were unable to make this comparison for the women who requested an interview in Turkish, since the Turkish interviewer did not communicate in Dutch with these women and, therefore, could not evaluate their Dutch language skills. We found that the Dutch language skills, as reported by the women from Turkish origin that reported no language barriers in speaking and understanding Dutch, were also positively evaluated by the interviewer. We therefore have no reason to assume that the self-reported data on language skills provide biased results.

### Confounding

Since various background variables could influence the association between ethnic origin of the pregnant women and relevant outcomes, the internal validity of results from the analyses could potentially be threatened by confounding. Educational attainment level could for example be a possible confounder in measuring ethnic differences in pregnant women's knowledge, since educational attainment level is associated with both knowledge and ethnic origin. To minimise confounding bias, we performed our analyses controlling for most im-

portant confounders. These potential confounders were selected on the basis of literature (Chapter 2) and univariate analyses and later incorporated as confounders in the analyses that measured ethnic differences in women's knowledge (Chapter 3), informed decision-making (Chapter 5) and uptake of prenatal screening (Chapters 7 and 8). Nevertheless, we cannot exclude residual confounding in these studies.

### Appropriateness of measurements

Another issue that may have threatened the internal validity of the interview study is that the measures that we used among women from non-Western ethnic minority groups are embedded in Western concepts. Future research should consider that people in less individualistic cultures are less tended to disagree with for example opinions or statements that they are confronted with. The cross-cultural appropriateness of the methods that we used to measure women's attitude, subjective norms and considerations should be evaluated in order to develop more culturally sensitive measures for specific research populations. Difficulties in answering statements do not specifically count for individuals from ethnic minority groups, but for those with low literacy in general. The personal pronoun 'I' can cause confusion, since respondents think the interviewer is talking about him or herself. Since we personally interviewed the women, we could extensively explain the method to answer the statements and asked for clarification if the answer was not in line with previous ones. In possible guidelines for methodological problems in quality of life research among Turkish and Moroccan cancer patients, Hoopman et al. suggest to change statements into the second person singular form.<sup>1</sup> We think that another important guideline is to use open-ended questions. The single open-ended question that we

used in addition to the statements was very useful. Future research might consider this as an addition to personal interviews or questionnaires among multi-ethnic and low literacy populations.

### 9.2.2 External validity

#### **Generalisability of the results to the Netherlands**

Although the interviews were carried out in Rotterdam, we expect that our general findings on ethnic variations in the provision of information by midwives, pregnant women's knowledge about prenatal screening and Down syndrome, attitude-uptake consistency, and considerations whether or not to participate in prenatal screening for Down syndrome are representative for at least the majority of the Dutch, Turkish and Surinamese population and midwives in other large cities in the Netherlands. The multi-ethnic populations in the largest cities have comparable background characteristics and the working environment for midwives is established by national guidelines and shaped by their comparable client population. The unequal distributions of educational attainment levels and age in the study population reflect the educational attainment levels and age of pregnant women in Rotterdam and other large cities and approximate the distributions in the general multi-ethnic population in the Netherlands.<sup>2</sup> The relatively low number of women above age 35 is in agreement with the general age distribution among women who gave birth to a living child in the Netherlands in 2008 as well, although the number of women in that age group was relatively low among all three ethnic groups in our sample, especially among the Surinamese women.<sup>3</sup> The Turkish and Surinamese women from the first and second generation were equally represented in our study population. Since there are relatively more first than second-generation Turkish and Surinamese women of child bear-

ing age in the Netherlands, the second generation was overrepresented in our study population.<sup>4</sup> It is unlikely that the findings can be generalised to specific subgroups, such as highly educated women from Turkish and Surinamese origin and the lowest educated women from Dutch ethnic origin, since these groups were rather small in our study population. Moreover, we do not believe that the specific findings on knowledge, informed decision-making and considerations can be generalised to other ethnic groups in the Netherlands. The registered-based studies showed that ethnic groups vary in uptake of prenatal screening. Especially the women from Moroccan ethnic origin participated less often in prenatal screening and differ from Turkish women in this respect. However, the fact that the findings in this thesis indicate that there are ethnic differences in access and quality in the provision of prenatal screening concerns the total Dutch society. For example, the finding that midwives hardly use any translated materials or professional interpreters raises questions about the cultural competence among other healthcare professionals and institutions in the Netherlands. We believe that the ethnic and socio-economic differences in uptake that we found in the registered-based studies can to a certain extent be generalised to other parts of the Netherlands. We assume that the provision of prenatal screening does not differ per region, since the prenatal screening programme is recently implemented in all regions of the Netherlands. The government has set out legal requirements for prenatal screening in the Population Screening Act.<sup>5</sup> The Central Agency that coordinate the prenatal screening programme, has established national education requirements and quality requirements that each practice and hospital has to follow in order to receive a certificate to provide prenatal screening for Down syndro-

me.<sup>6</sup> Moreover, the total number of live born children in the first half of 2009 in the South–West of the Netherlands comprises 18% of the total population live born children in the Netherlands in this period of time. However, we should take into account that the proportion of mothers from non-Dutch ethnic origin in the South–West of the Netherlands is 7% higher compared to the total population of mothers in the Netherlands and that the population from Dutch ethnic origin in the South–West of the Netherlands generally has a higher socio-economic background than the population from Dutch ethnic origin in the North of the Netherlands.<sup>2</sup>

### **Generalisability of the results to other countries**

Some issues should be taken into account when generalising the findings of the studies that are described in this thesis to other Western countries. Most important in this respect is the specific prenatal care and prenatal screening practice and policy in the Netherlands. In contrast to most other countries, prenatal care in the Netherlands is provided outside the hospitals. The majority of pregnant women in the Netherlands book for prenatal care at an independent community midwife practice in a decentralised primary care setting. Women are only referred to an obstetrician in case of a complicated obstetric or medical history, or complications during pregnancy, labour or puerperium. In general, the natural character of pregnancy is highly valued in the Netherlands and pregnancy and delivery are generally considered as natural events that should not be interfered. In most Western countries, prenatal screening for Down syndrome with the combined test has been part of standard prenatal care for decades. In the Netherlands, it has become part of standard prenatal care since 2007. Women under 36 years of age, who do not have a formal indication for invasive testing, have to pay

for the combined test themselves. If the test result indicates an increased risk of Down syndrome, the costs of invasive testing and selective termination, where requested, are reimbursed. In contrast to most other countries where prenatal screening is perceived as something self-evident, prenatal screening has not yet become accepted as a normal affair in pregnancy.

Another issue in the generalisability of the results to other countries is that the multi-ethnic population in the Netherlands is not comparable to those in other countries. The ethnic minority groups differ in ethnic origin, migration history, culture, religion and socio-economic status, not only within, but also between countries. As proposed in the conceptual framework in the introduction of this thesis (Figure 1.2), these individual factors influence the need, possibilities and predisposition of healthcare utilisation. Although our results confirmed many of the previous international results, studies from other countries generally showed a higher uptake of prenatal screening compared to the women in our study population 7–13. Moreover, the ethnic differences in knowledge that we found in our study population were more extensive than the knowledge differences that were reported in studies from other countries.<sup>7, 14–17</sup>

In conclusion, these issues lead to the remark that results may be generalised to other countries, though with caution. The conclusion that there are ethnic differences in the provision of the prenatal screening programme and uptake of prenatal screening can for example be generalized to other countries. Specific results on e.g. informed decision-making are probably most applicable to countries that are comparable to the Netherlands with regard to ethnic minority groups and prenatal screening practice.

## 9.3 Discussion of the results

The results that are presented in this thesis provide insight into ethnic variations in pregnant women's decision-making on prenatal screening for Down syndrome. In the following paragraph, the findings will be discussed per central theme and interpreted in light of findings from other studies.

### 9.3.1 Ethnic differences in knowledge and access to information

The ethnic variations that we found in pregnant women's knowledge about Down syndrome and/or prenatal screening (Chapter 3) are in agreement with the results from several other studies, performed in the United States of America, United Kingdom, and Australia.<sup>7, 18, 15-17</sup> According to our results ethnic differences in knowledge could mainly be attributed to differences in educational attainment level among Surinamese women and language barriers among Turkish women. The role of language barriers in knowledge has been frequently reported by other studies in prenatal care.<sup>15, 17, 19, 20</sup> Other studies also reported a positive association between educational attainment level and knowledge about prenatal screening.<sup>14, 21-24</sup> Since the information on prenatal screening and the offer itself are rather complex, a probable explanation for these associations is that women from low educational level and women who hardly speak and understand Dutch have a lower health literacy. This implies that they have a lower capacity to access, understand and use health information to make informed decisions regarding participation in prenatal screening.<sup>25</sup>

The current provision of information on prenatal screening does not seem to compensate for this low health literacy among women from ethnic minority groups. Although midwives recognised the difficulty of providing information on prenatal

screening to women who hardly speak and understand Dutch, only a minority used translated materials or professional interpreters (Chapter 4). Language barriers are also reported by healthcare professionals in other fields of healthcare, as well as the underuse of translated materials and professional interpreters.<sup>26-28</sup> This indicates that the findings of this study are not restricted to the field of prenatal screening. Low health literacy and language barriers and their possible interrelation raise serious communication problems between healthcare professionals and clients and, as the conceptual framework that has been described in the introduction of this thesis (figure 1.2) proposes, thereby diminishes the possibilities for healthcare utilisation.<sup>29-33</sup>

### 9.3.2 Ethnic differences in the decision-making process

The finding that women from non-Western ethnic minority groups more often reported a low perceived risk of carrying a child with Down syndrome and acceptance 'what God gives' as considerations not to participate in prenatal screening is in agreement with the finding that ethnic differences in participation in prenatal screening can be attributed to differences in age and religious identity. However, women from Turkish and Surinamese origin also reported many considerations in favour of participation in prenatal screening (Chapter 6). This implies that women from non-Western origin should not be stereotyped as being uninterested in prenatal screening. The finding that the considerations from Turkish and Surinamese women did not differ that much from those of Dutch pregnant women, but were less often associated with actual participation and their higher levels of decisional conflict indicates that they may experience more difficulties in deciding whether or not to participate



in prenatal screening than Dutch women. The ethnic differences in informed decision-making that we found are in line with the results of a previous study that applied a similar measure of informed choice (MMIC) in a multi-ethnic population in the United Kingdom (Chapter 5).<sup>7</sup> Since most Turkish and Surinamese women did not participate in prenatal screening, it was unexpected that 66% of the Turkish and 46% of the Surinamese women had a positive attitude towards participating in prenatal screening. As described in the methodological issues in this thesis, one of the explanations for this inconsistency is that the MMIC may be less appropriate to measure the attitude of women from non-Western ethnic groups. In addition to this, it is possible that the inconsistency is related to the fact that many of them were not aware about the options, advantages and disadvantages of prenatal screening, consequences of Down syndrome and perceived more difficulty and uncertainty in decision-making. Further analyses in our study population showed that women who made an attitude-consistent decision generally had higher levels of knowledge. However, when the analyses were performed per ethnic group, this association was only significant for women from Surinamese ethnic origin. A previous study in the United Kingdom did not find any significant associations between attitude-consistency and knowledge.<sup>34</sup>

Another issue that needs to be kept in mind when interpreting the findings of the study on ethnic differences in informed decision-making and women's considerations whether or not to participate in prenatal screening is the relevance of these concepts among women who originate from non-Western cultures. Informed decision-making is embedded in the Western principle of individual autonomy and may not be just as

relevant to women who originate from non-Western, more collectivistic cultures.<sup>35</sup> In collectivistic cultures the interest of the group is considered to be more important than the individual interest. Since individual decision-making is less common in non-Western, collectivistic cultures, it is possible that weighing pros and cons in the process of considering whether or not to participate in prenatal screening simply is not an issue when the group has already decided on a certain subject. Perhaps women from non-Western ethnic minority groups do not wish to make an autonomous decision, while midwives and obstetricians expect them to and try to maintain neutrality.<sup>20</sup> A recent qualitative study in the Netherlands showed that women who originated from non-Western countries would participate in prenatal screening if their midwife or gynaecologist would recommend this to them.<sup>36</sup> Our focus group interviews showed similar results and indicated that women expect a direct advice from their midwife (Chapter 2). Women in the questionnaire study were also asked to what extent they agreed with the statement 'My midwife or gynaecologist has to decide whether I should participate in prenatal screening'. In total 5% of the Dutch women did not disagree with this statement. This was 16% among women of Turkish origin and 9% among women among Surinamese origin. This indicates that not all pregnant women are able or even want to participate actively in the decision-making process.<sup>37</sup> This may also apply for parts of the Western population. A recent study in France for example showed that 42% of the women who were offered prenatal screening were passively involved in the decision-making process and unaware of the possibility of having to make decisions about invasive testing and/or termination of pregnancy.<sup>38</sup>

### 9.3.3 Ethnic differences in uptake of prenatal screening for Down syndrome

The studies that are described in Chapter 7 and 8 of this thesis showed that the uptake of prenatal screening with risk assessment tests and diagnostic tests was relatively low in the Netherlands and varied among ethnic groups.

The finding that women from non-Western ethnic origin and women from low socio-economic background less often participated in maternal age-based prenatal screening was in keeping with previous studies (Chapter 7).<sup>9, 13, 19, 39-43</sup> However, the finding that Dutch, Turkish and Aruban/Antillean women did not differ in uptake of AMN and CVS and that women from Surinamese origin even had a higher uptake was unexpected. One of the explanations for these unexpected findings is that the uptake of maternal age-based prenatal screening for Down syndrome in the Netherlands is generally lower than in many other Western countries.<sup>43, 44</sup> This lower uptake may be associated with the Dutch 'pregnancy culture': in general, the natural character of pregnancy is highly valued in the Netherlands and pregnancy and delivery are generally considered as natural events that one should not 'unnecessarily' interfere with. Another explanation may be the slow but gradual increase of the use of first trimester risk assessment tests in the Netherlands.<sup>45</sup> Although the Dutch Population Screening Act did not permit the active offer of first trimester screening to pregnant women during our study period, a relatively small number of women had maternal serum screening already.<sup>46</sup> It is likely that women from non-Western ethnic origin were possibly less often aware of these alternatives. Moreover, women from non-Western origin generally book later for prenatal care than women from Dutch origin, which diminishes their possibility to participate in first trimester prenatal screening.<sup>47</sup>

The same reasoning probably explains why most women from non-Western origin of advanced maternal age were more likely to participate in direct AMN or CVS and less often participated in first trimester serum screening in the current prenatal screening programme than Dutch women (Chapter 8). Although risk assessment tests are implemented in standard prenatal care for more than two years, it seems that these women were less often aware of the possibility to participate in these tests first. Not only non-Western women of advanced maternal age, but also younger women from non-Western ethnic origin, especially those from Moroccan and Turkish ethnic origin, were less likely to participate in first trimester prenatal screening compared to Dutch women. These ethnic variations in participation in the current prenatal screening programme are in keeping with previous studies from other countries.<sup>7, 9, 13, 17, 48, 49</sup> However, the finding that women from Surinamese ethnic origin did not differ from Dutch women in uptake of maternal serum screening was unexpected. Again, a possible explanation is the relatively low uptake among the Dutch women compared to women from other countries.<sup>9, 12, 48, 50</sup> Another explanation is that women from Surinamese origin generally do not experience language barriers, have a higher educational attainment level than other women from non-Western ethnic origin and more often participate in the labour market.<sup>4</sup> It is therefore likely that they experience less barriers in access to prenatal screening than women from other non-Western ethnic minority groups. The results from our interviews indeed showed that, compared to Turkish women, Surinamese women scored higher on knowledge, uptake or attitude-consistency. However, compared to the level of informed decision-making among the Dutch women in our study population,

Table 9.1 Overview of main outcomes personal interviews

	Pregnant women in the study population		
	Dutch origin	Turkish origin	Surinamese origin
Interested in receiving information	↑	↑	↑
Received information	↑	↑	↑
Sufficient knowledge	↑	↓	↓
Attitude-uptake consistency	↑	↓	↓
Informed decision-making	↑	↓	↓
Decisional conflict	↓	↑	↑

other populations in the Netherlands and other countries, the level of informed decision-making among the Surinamese women that we interviewed was poor.<sup>7, 21, 22, 34</sup> It is therefore questionable whether the equal uptake between Surinamese and Dutch women in our registered-based study in 2009 also implies equal knowledge about Down syndrome and prenatal screening.

### 9.4 Conclusion

The findings that are presented in this thesis give insight into ethnic variations in pregnant women’s decision-making on participation in the prenatal screening programme for Down syndrome. Our interview study showed that women from Turkish and Surinamese origin were interested in information about prenatal screening, but had difficulties in understanding this information and less often made an informed decision whether or not to participate in the prenatal screening programme compared to Dutch women (Table 9.1).

Ethnic differences in informed decision-making could especially be attributed to language barriers

and low educational attainment level. Although language barriers were also reported by midwives as a difficulty in the provision of information, only a few of them reported to use professional translators or translated written materials. The registered-based studies indicated that ethnic variations also exist in actual participation in the prenatal screening programme. The ethnic differences in uptake of first trimester serum screening and diagnostic tests might be related to barriers in access to information about prenatal screening and barriers in the decision-making process. However, solving these barriers does not necessarily imply a higher uptake among women from non-Western ethnic origin and, more importantly, that should not be the aim of providing information about prenatal screening. After all, the goal of the prenatal screening programme is to enable all pregnant women to make an informed decision whether or not to participate in prenatal screening for Down syndrome. The findings that are described in this thesis have demonstrated that this aim is certainly not achieved and indicate that there are ethnic differences in access and quality of prenatal screening.

## 9.5 Implications

### 9.5.1 Implications for future research

#### Address barriers in access to information

The finding that ethnic differences in pregnant women's knowledge about prenatal screening for Down syndrome are mainly caused by language barriers and a lower capacity to access, understand and use the information on prenatal screening, indicates that there are problems in the current provision of information by midwives and gynaecologists. Future research should analyse these problems in order to develop structural interventions to improve the access to information for all pregnant women.

Since our interview study only assessed data from the viewpoint of pregnant women and midwives, an observational study is preferable to start with in order to assess how midwives and gynaecologists actually communicate with clients from non-Western ethnic origin, how they deal with language barriers (e.g. interpreter and translated material use), how they offer information about prenatal screening and whether they check if the information is properly understood. Since Turkish and Surinamese women less often read the written material they received, it would also be interesting to assess how they are offered the written material. Is it for example provided together with ten other booklets, is the content explained, are women advised to read the booklet? Furthermore, it should be investigated to what extent pregnant women from various ethnic backgrounds read the translated material and to what extent they understand it.

#### Further research informed decision-making

In order to develop more effective diversity-sensitive strategies for counselling in prenatal screening, we need to further explore to what extent indivi-

duals from non-Western ethnic origin value being actively involved in informed decision-making on prenatal screening and further discuss to what extent healthcare professionals should always strive for informed decision-making. Further research should assess how midwives and gynaecologist cope with women who are not able to consider whether or not to participate in prenatal screening or women who expect that the midwife will decide for them. Further studies are needed to assess whether alternatives for informed decision-making are possible. Irwig et al. for example propose that all pregnant women should be aware of the prenatal screening programme and receive an agreed minimum of information about benefits and harms of the procedure so that they can decide whether to follow the advice of an authoritative health body or make an individual choice. The decisions and behaviour of the women who prefer to follow advice should be consistent with the recommendation.<sup>51</sup> Following this proposal, Entwistle et al. suggested the 'consider an offer approach' as a new approach to communicate about screening. This approach is designed to respect personal autonomy without overburdening people with unwanted information and decision-making tasks. Within this approach, counsellors should either recommend or offer screening or help people to consider recommendations or offers from others.<sup>37</sup> It should be further investigated whether these kind of approaches would be a good alternative to offer prenatal screening for Down syndrome to pregnant women from various ethnic background.

#### Further research decision-making process

According to the Prenatal Screening Stage Model (Figure 9.1), the decision-making process whether or not to participate in prenatal screening is influenced by women's attitude and subjective norm.

Measurement of these variables and results are described in Chapters 5 and 6. In contrast to our expectation, subjective norm (what women assume that their partner, family, friends or healthcare professional think they should do and how important this opinion is for them) did not differ between ethnic groups (Chapter 5). As described in the methodological issues, the measurement of subjective norm could be less appropriate for women from Turkish and Surinamese origin. We therefore recommend to evaluate other techniques to assess social influences among multi-ethnic study populations that could be used in future research in this area.

Moreover, further research is needed on possible interventions to support pregnant women in their decision-making process. Decisional aiding interventions have proven to be successful in decreasing decisional conflict and increasing informed decision-making about prenatal diagnostic testing.<sup>14</sup> It should be further investigated to what extent such interventions are also applicable and successful among pregnant women from non-Western ethnic origin.

#### **Further research among other ethnic groups**

Another important remaining question is to what extent women from other ethnic origin, such as Moroccan or Aruban/Antillean women differ from Dutch women in access to information about prenatal screening, knowledge and decision-making. An interesting question for example is how often Moroccan women, who least often participate in the prenatal screening programme, make an informed decision whether or not to participate in prenatal screening. Since they more often exhibit active religious behaviour than Turkish women, it would also be interesting to assess to what extent their religion plays a role in the decision whether

or not to participate in prenatal screening. Furthermore, it should be investigated whether other women from non-Western ethnic origin experience problems in decision-making, such as attitude-uptake inconsistency and decisional conflict and what are determinants of these problems in decision-making. It would be interesting to study what considerations women from non-Western ethnic origin have when they have more knowledge about prenatal screening for Down syndrome and whether their uptake increases with knowledge. In this future research, qualitative research methods are advisable, quantitative methods should be used in addition. Special effort should be paid to cultural-sensitive questionnaires that are comprehensive for women from ethnic minority groups and women with low literacy. For example by adapting statements into second person singular form and avoiding lengthy questions, many response options and negatively formulated questions.<sup>1</sup>

#### **Further evaluation of ethnic differences in uptake of prenatal screening**

The study on ethnic differences in uptake of first trimester serum screening is the first study on this subject in the Netherlands and conducted over only a small period of time. Once the exact distribution of ethnic origin and socio-economic background of the women who were pregnant in the first half of 2009 are available, the data should be evaluated again.

We recommend that comparable studies will be carried out among the total population pregnant women in the Netherlands, and on regular basis to assess trends in ethnic differences in prenatal screening for Down syndrome in the Netherlands. Since we were unable to assess whether the serum screening was combined with nuchal translucency measurement, it is advisable for the Centre for Po-

pulation Screening of the National Institute of Public Health and the Environment (RIVM) that coordinate the organisation of the prenatal screening programme, to develop a well-thought evaluation system that can be applied in various research designs.

### **Develop research infrastructure for midwifery practices**

Since most pregnant women in the Netherlands are recruited for scientific research via midwifery practices, it would be advisable to develop a research infrastructure for midwifery practices, for example through academic employment practices. This infrastructure should focus at implementing ethnic data collection and developing specific quality measurements for diverse patient populations. Further research is also needed in order to improve the general recruitment among ethnic minority groups in the Netherlands. Many researchers in the Netherlands have reported difficulties in recruiting ethnic minority respondents, due to illiteracy, concern about immigration status, mistrust of institutions, lack of familiarity and distrust of research, inaccurate or unregistered home addresses, private telephone numbers and extended stays in the country of origin.<sup>1</sup>

### **9.5.2 Implications for prenatal screening practice and policy**

The findings that are described in this thesis call for improvements in access and quality of prenatal care for all pregnant women. Interventions at individual, organisational and governmental level should aim at the provision of information about prenatal screening for Down syndrome and the counselling of women from non-Western ethnic origin in the process of deciding whether or not to participate in prenatal screening. Specific implications will be discussed below.

### **Overcome language barriers**

Since ethnic differences in pregnant women's knowledge could mainly be attributed to poor Dutch language skills, interventions to improve the provision of information should be aimed at overcoming language barriers. It is recommended that healthcare professionals first of all learn how to recognize language barriers. Pregnant women who apparently have no problems in everyday communication do not necessarily have sufficient Dutch language skills to understand the complicated information about prenatal screening. Moreover, it is advisable to increase healthcare professionals' awareness of the availability of and access to translated materials and professional interpreters. The availability of translated materials on the website of the Dutch National Institute for Public Health should be much more promoted. To increase the use of professional interpreters, it is suggested that healthcare professionals should know how to implement the use of professional interpreters in their daily practice. This not only implies that they know where to find interpreters, but also how they have to work with them. Systematic cultural competency training should therefore enclose a part of the curriculum of student midwives, gynaecologists trainees, general practitioners and genetic counsellors, and should be implemented in the national education and quality requirements that are established by the Central Agency of the prenatal screening programme. The regional centres for prenatal screening address healthcare professionals about working with these requirements.<sup>6</sup> Other possibilities to decrease language barriers can be found in the practice environment itself. An example of an initiative to enhance the use of professional interpreters is the interpreter policy (started in 2006) of the Erasmus University Medical Centre in Rotterdam. This policy is based on the

national field norms as defined by the Netherlands Healthcare Inspectorate, prescribing the standard use of professional interpreters for communicating with clients who insufficiently speak and understand Dutch and discouraging the use of non-professional interpreters.<sup>52</sup> Erasmus MC developed a brochure and pocket-sized pamphlets with information about the interpreter policy, guidelines and advice on the use of professional interpreters, and contact information for the national interpreter service. Meetings were arranged to emphasize the importance of professional interpreters and to give instructions on the use of professional interpreters. On the other hand, interventions to decrease language barriers should not only be aimed at healthcare professionals and organisations, but also at the (pregnant) women themselves. Although people are obliged to follow a language course when they migrate to the Netherlands, our results suggest that the Dutch government should more actively stimulate these women to learn and speak Dutch and keep up their language skills. In June 2008, the Dutch government started a national campaign 'Het begint met taal'. The message of this campaign is that taking part in Dutch society begins with speaking Dutch and that it is extremely important that people understand, speak, read and write Dutch. The campaign is not only aimed at individuals. Municipalities and organisations are invited to join and adopt the campaign at local level. The start of this promising campaign shows that the government recognise the problem of language barriers and acknowledge the urgency of interventions to improve Dutch language skills of the multi-ethnic population in the Netherlands.

#### **Increase comprehension of information**

Since educational level played an important role in ethnic differences in women's knowledge and

informed decision-making, interventions should be aimed at targeting information to the women's abilities to comprehend the complicated information about prenatal screening. It is therefore strongly recommended that healthcare professionals are provided with guidelines how to provide intelligible and appropriate information to women from low literacy, to stimulate these women to read written material and to verify whether women have understood the information that they have been provided with. Such guidelines could also be implemented in the curriculum of student midwives, gynaecologists, general practitioners and genetic counselors, as well as in the national education and quality requirements that are established by the Central Agency of the prenatal screening programme.<sup>6</sup> Another recommendation is to evaluate the national written material on comprehension in groups of low educated pregnant women from various ethnic origin, including Dutch low educated women. It could be considered whether other types of educational materials (such as an informational video or pictures of Down syndrome and prenatal screening) must be used in addition to written material.<sup>53-55</sup>

#### **Improve counselling in the decision-making process**

The studies presented in this thesis show that the aim of the prenatal screening programme to enable all pregnant women and their partners to make an informed decision is not achieved in the Netherlands by far, especially not among women from non-Western ethnic origin. The finding that women from most non-Western ethnic groups less often participate in prenatal screening does not have to be a problem if their decision is based on sufficient knowledge and consistent with their attitude. However, our findings indicate that this is not the case for most pregnant women. Since knowledge is a

prerequisite for informed decision-making, interventions should first of all be aimed at overcoming language barriers and increasing comprehension of information, as described above. However, interventions should also aim at the remaining process of decision-making. The findings from our personal and focus group interviews indicate that many women from non-Western ethnic origin are interested in considering whether or not to participate in prenatal screening, but experience more difficulties in their decision-making process. Healthcare professionals should be careful not to stereotype these women as being uninterested in prenatal screening, but try to assist them in the process of deciding whether or not to participate in prenatal screening. Possible tools to support healthcare professionals are so-called 'decision aids'. Decision aids have proven to be successful in decreasing decisional conflict and increasing informed decision-making about prenatal screening for congenital defects, such as Down syndrome.<sup>56-58</sup> The independent research organisation TNO and Leiden University Medical Center have developed a decision aid to support pregnant women in the Netherlands in their decision whether or not to participate in the current prenatal screening programme. Women and healthcare professionals can use this decision aid on the public healthcare portal website 'KiesBeter.nl', developed by the Dutch National Institute for Public Health.<sup>59</sup> Unfortunately the decision aid is not translated or adapted to other ethnic groups in the Netherlands and it is questionable to what extent the decision aid is easy to understand and use by all pregnant women and healthcare professionals. On the basis of our findings, we recommend to translate the present decision aid and evaluate whether it is applicable and successful among pregnant women from diverse populations in order to implement such decision aids in prenatal care.

However, it should be kept in mind that it is also possible that not all women are able or even want to participate actively in the decision-making process. The national quality requirements do not provide clear guidelines for healthcare professionals how to deal with these kind of situations and need further elaboration.<sup>6</sup>

### **Implications in conclusion**

The implications of the findings as presented in this thesis and interventions to improve access and quality of prenatal screening require efforts by the Dutch government, the Centre for Population Research of the National Institute of Public Health and the Environment (RIVM), the Central Agency of prenatal screening, regional prenatal screening centres and healthcare professionals. It is necessary that the barriers in providing good quality prenatal care to all pregnant women in the Netherlands receive political attention in order to create better conditions for the organisation of the prenatal screening programme. It is also recommended for the Central Agency of prenatal screening to develop guidelines to support healthcare professionals in the provision of information about prenatal screening to women from various ethnic origins and in counselling these women in their decision-making process.





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# Summary

## Part I: Introduction

Several studies abroad have documented ethnic differences in the provision of information about prenatal screening for Down syndrome, the level of knowledge and attitude of pregnant women, and uptake of prenatal screening for Down syndrome. This thesis addresses the question whether such differences also exist in the Netherlands, where 20% of the population consists of individuals from non-Dutch ethnic origin. The Dutch prenatal screening programme for Down syndrome consists of risk assessment tests to identify pregnant women with a high probability of carrying a fetus with Down syndrome, and diagnostic tests to confirm whether or not the fetus has Down syndrome. Healthcare professionals are obliged to inform each pregnant woman about the options for prenatal screening. Women who express interest should be provided with further information and counselling in decision-making as to whether or not to participate in prenatal screening. The goal of providing information about prenatal screening to pregnant women is not to encourage uptake of prenatal screening, but to enable women (and their partners) to make an informed decision about whether or not to participate in prenatal screening for Down syndrome (Chapter 1).

The main aim of the research in this thesis was to assess ethnic variations in pregnant women's decision-making on participation in the prenatal screening programme for Down syndrome. Since no theoretical framework was available to analyse ethnic variations in the decision-making process, the first goal was to develop such a framework. We therefore applied Weinstein's 'Precaution Adoption Process Model' to the decision of whether or not to participate in prenatal screening for Down

syndrome. The model was specified by reviewing the literature and by data from seven focus group interviews with pregnant women from Dutch, Turkish and Surinamese ethnic origin (Chapter 2). This resulted in the 'Prenatal Screening Stage Model' that we used to guide data collection and to describe the decision-making process of pregnant women from different ethnic backgrounds. The following research questions were formulated and classified in three central themes:

### Ethnic differences in knowledge and access to information

- 1) To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in their knowledge about Down syndrome and prenatal screening, and what is the contribution of ethnic differences in the information that is provided by midwives and gynaecologists?
- 2) To what extent do midwives experience differences and difficulties in providing information about prenatal screening for Down syndrome to pregnant women from diverse ethnic origin?

### Ethnic differences in the decision-making process

- 3) To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in informed decision-making on prenatal screening for Down syndrome and what is the contribution of background characteristics and decision-making variables?
- 4) To what extent do women from Dutch, Turkish and Surinamese ethnic origin differ in uptake of prenatal screening for Down syndrome and what considerations do they have whether or not to participate in prenatal screening?

### Ethnic differences in uptake of prenatal screening for Down syndrome

- 5) To what extent did ethnic differences exist in the uptake of maternal age-based prenatal screening for Down syndrome in the Netherlands?
- 6) To what extent do ethnic differences exist in the participation in the current prenatal screening programme for Down syndrome in the Netherlands?

### Part II: Ethnic differences in pregnant women's knowledge and access to information

**Chapter 3** provides an answer to the first research question. The study population consisted of 105 women from Dutch ethnic origin, 100 women from Turkish origin and 65 women from Surinamese origin (total=270). We recruited these women between September 2006 and June 2008 from community midwifery practices in Rotterdam and from the outpatient clinic Erasmus MC. Women were personally interviewed in the language they preferred, a mean of 3 weeks after booking for prenatal care. We asked the women whether they had received oral and/or written information from a healthcare professional and whether they had read the written information. Women's knowledge was measured and evaluated by 21 questions about Down syndrome and prenatal screening. The results showed that the midwife is the prime source of information about prenatal screening for Down syndrome, and that most pregnant women received oral and/or written information at booking for prenatal care. However, women from Turkish and Surinamese ethnic origin less often read the written information than Dutch women, more often reported difficulties in understanding the information, and had signifi-

cantly less knowledge about Down syndrome and prenatal screening tests. Differences in language skills and educational level contributed most to these variations.

**Chapter 4** describes to what extent midwives experience differences and difficulties (such as language barriers) in informing pregnant women from diverse ethnic backgrounds about prenatal screening for Down syndrome (research question 2). All 24 midwifery practices that were part of the 'Verloskundige Kring' (the local society of midwives) participated in a web-based survey, 57 midwives (78% response rate) completed a structured questionnaire. Most midwives reported no differences in informing women from diverse ethnic backgrounds. However, when pregnant women hardly speak and understand Dutch, midwives reported that they do not always offer information and feel less culturally competent in informing these women about prenatal screening. Although language barriers were reported to be the main difficulty, a minority of midwives used translated materials or professional interpreters. We explored the reasons for this underutilization in a group interview. Most midwives acknowledged the potential benefit of translated materials, but were unaware of the availability of these materials. Unfamiliarity seemed to be the most important reason for not using professional interpreters in communication with pregnant women who hardly speak and understand Dutch.

### Part III: Ethnic differences in the decision-making process

**Chapter 5** addresses the research question to what extent women from Dutch, Turkish and Surinamese ethnic origin make an informed decision about

whether or not to participate in prenatal screening, and to what extent background characteristics and decision-making variables contribute to ethnic differences in informed decision-making (research question 3). Data on informed decision-making were assessed among the population of 270 pregnant women, by the 'Multidimensional Measure of Informed Choice'. According to this measure, an informed decision is made when women have sufficient knowledge about prenatal screening and their actual (non-) participation in prenatal screening is consistent with their attitude. In total 5% of the women from Turkish origin, 26% of the women from Surinamese origin and 71% of the women from Dutch origin were classified as informed decision-makers. Differences between Dutch and Turkish women could mainly be attributed to differences in language skills and gender emancipation. Differences between Surinamese and Dutch women could to a large extent be attributed to differences in educational level and age.

**Chapter 6** concerns the same population pregnant women and describes to what extent these women differ in uptake of prenatal screening, and what considerations they have whether or not to participate in prenatal screening (research question 4). Women's considerations were measured by means of one open-ended question and 18 statements that were derived from the focus group interviews. Uptake of prenatal screening was assessed several months after the interview by contacting the women by telephone. The uptake of screening was 13% among the Turkish, 17% among the Surinamese and 44% among the Dutch women. These differences between ethnic groups could mainly be attributed to differences in age and religious identity. Women from Turkish and Surinamese origin more often reported acceptance of

'what God gives' as a consideration not to participate in prenatal screening. Surinamese women especially mentioned their low risk of having a child with Down syndrome and the costs of screening. Women from Turkish and Surinamese origin also reported many considerations in favour of participation, such as 'gaining reassurance about the baby's health' or 'preparing for the birth of a child with Down syndrome'. Women from Turkish and Surinamese origin experienced more decisional conflict in deciding whether or not to participate in prenatal screening and their considerations were less often consistent with actual participation in prenatal screening. The findings indicate that women from non-Western ethnic origin should not be stereotyped as being uninterested in prenatal screening, but that they should be better informed about the consequences of prenatal screening and Down syndrome.

#### **Part IV: Ethnic differences in uptake of prenatal screening for Down syndrome**

**Chapter 7** describes a register-based study in Groot-Rijnmond, a geographically defined region in the Southwest of the Netherlands. The aim of this study was to assess ethnic differences in the uptake of maternal age-based prenatal screening for Down syndrome for the period 2000-2004, before risk-assessment tests were implemented in standard prenatal care (research question 5). We found an overall uptake rate of 28.5%. Compared to Dutch women, women from Surinamese and Western (non-Dutch) origin had a higher uptake, women from Turkish and Antillean/Aruban ethnic origin had a comparable uptake, and women from Moroccan and other non-Western ethnic origin had a lower uptake of prenatal screening. Women from low socio-economic



background had a lower uptake than women from high socio-economic background. Ethnic differences in uptake could not be attributed to differences in socio-economic background.

**Chapter 8** describes a register-based study that we performed in 2009 to assess ethnic differences in participation in the current prenatal screening programme (research question 6). We assessed the uptake of first trimester serum screening (for women of all ages), and direct diagnostic testing (for women of advanced maternal age) over the period 1-1-2009 to 1-7-2009 in the Southwest of the Netherlands. The overall participation in the prenatal screening programme was 26%, which is low compared to other countries. Compared to Dutch women, those from Turkish, Moroccan, Aruban/Antillean and other non-Western ethnic origin were less likely to participate in the prenatal screening programme, which might be related to barriers in the decision-making process. The differences between women from Dutch origin versus women from Moroccan and Turkish origin remained significant after adjustment for socio-economic background and age. We did not find significant differences between women from Surinamese and Dutch ethnic origin. However, in light of our previous findings, it is questionable to what extent the participation of the Surinamese group was based on an informed decision.

## **Part V: Discussion**

**Chapter 9**, the general discussion, begins with a summary of the main findings per research question, followed by some comments on the methodological issues that should be acknowledged when interpreting the results. Threats to the internal

validity related to study design, non-response, self-reported data, confounding, appropriateness of measurements, and estimations of the denominators in the register-based studies, and threats to the external validity of the main findings, are all discussed. The ethnic variations we found in pregnant women's knowledge and informed decision-making, and the contribution of language barriers and educational level, are in agreement with the results from other international studies on prenatal screening for Down syndrome. Language barriers are also reported by healthcare professionals in other fields of health care, as well as the underutilization of translated materials and professional interpreters, indicating that the findings of our studies are not restricted to the field of prenatal screening. The ethnic variations we found in pregnant women's knowledge, decision-making and uptake of prenatal screening demonstrate that the goal of the prenatal screening programme to enable all pregnant women to make an informed decision whether or not to participate in prenatal screening for Down syndrome is certainly not achieved, and indicate that there are ethnic differences in access and quality of prenatal screening. The interventions to improve access and quality of prenatal screening require additional efforts by the Dutch government, the Centre for Population Screening of the National Institute of Public Health and the Environment (RIVM), the Central Agency of prenatal screening, regional prenatal screening centres and healthcare professionals. Better conditions should be created for the organisation of the prenatal screening programme. It is also recommended to develop specific national guidelines to support healthcare professionals in the provision of information about prenatal screening to women from various ethnic origins, and in counselling these women in their decision-making process.

# Samenvatting

## Deel I: Introductie

Uit diverse buitenlandse studies komt naar voren dat er etnische verschillen zijn in het aanbod van informatie over prenatale screening op Downsyndroom, in de kennis en attitude van zwangere vrouwen en hun deelname aan prenatale screening. De vraag die in dit proefschrift centraal staat is of zulke verschillen ook voorkomen in Nederland, waar 20% van de bevolking behoort tot een etnische minderheid.

Het landelijk programma voor prenatale screening op Downsyndroom bestaat uit kansbepalende en diagnostische testen. Aan de hand van kansbepalende testen wordt vroeg in de zwangerschap onderzocht of de kans op een kind met Downsyndroom verhoogd is. Als er sprake is van een verhoogde kans, kunnen vrouwen een vlokkentest of vruchtwaterpunctie laten verrichten om vast te stellen of er al dan niet sprake is van Downsyndroom. Voor vrouwen van 36 jaar of ouder en vrouwen met erfelijke of aangeboren afwijkingen in de familie is het mogelijk direct te kiezen voor diagnostische testen. Zorgverleners zijn wettelijk verplicht elke zwangere vrouw te informeren over het huidige prenatale screeningsaanbod. Vrouwen die hiervoor interesse tonen, behoren nader te worden geïnformeerd over prenatale screening en eventueel geholpen te worden bij hun besluit al dan niet op het screeningsaanbod in te gaan. Het informatieaanbod is daarbij niet zozeer gericht op deelname van zoveel mogelijk zwangere vrouwen aan het prenatale screeningsprogramma, maar op geïnformeerde besluitvorming van de betrokkene vrouwen om al dan niet deel te nemen aan prenatale screening op Downsyndroom (Hoofdstuk 1).

Het belangrijkste doel van het onderzoek dat in dit proefschrift wordt beschreven is het achterhalen

van etnische verschillen in het besluitvormingsproces van zwangere vrouwen ten aanzien van deelname aan prenatale screening op Downsyndroom. Om etnische verschillen in kaart te kunnen brengen, moest allereerst een theoretisch raamwerk worden ontwikkeld. We baseerden het raamwerk op Weinstein's 'Precaution Adoption Process Model' en vulden het in aan de hand van bevindingen uit wetenschappelijke literatuur. De relevantie van het raamwerk werd getest in focusgroep interviews met zwangere vrouwen van Nederlandse, Turkse en Surinaamse herkomst. Dit alles resulteerde in het 'Prenatal Screening Stage Model' dat kon worden gebruikt bij de dataverzameling en de beschrijving van het besluitvormingsproces van zwangere vrouwen (Hoofdstuk 2). De volgende onderzoeksvragen werden geformuleerd en behandeld in drie centrale thema's:

### Etnische verschillen in kennis en toegang tot informatie

- 1) In hoeverre verschillen vrouwen van Nederlandse, Turkse en Surinaamse herkomst in kennis over Downsyndroom en prenatale screening en in welke mate spelen etnische verschillen in de informatie die door verloskundigen en gynaecologen wordt verstrekt hierin een rol?
- 2) In hoeverre ervaren verloskundigen verschillen en moeilijkheden bij het aanbieden van informatie over prenatale screening op Downsyndroom aan zwangere vrouwen van diverse etnische herkomst?

### Etnische verschillen in het besluitvormingsproces

- 3) In hoeverre verschillen vrouwen van Nederlandse, Turkse en Surinaamse herkomst in het nemen van een geïnformeerd besluit met betrekking tot prenatale screening op Downsyndroom

en in welke mate spelen achtergrondkenmerken en besluitvormingsvariabelen hierin een rol?

- 4) In hoeverre verschillen vrouwen van Nederlandse, Turkse en Surinaamse herkomst in deelname aan prenatale screening op Downsyndroom en wat zijn hun afwegingen om wel of niet deel te nemen aan prenatale screening?

### Etnische verschillen in deelname aan prenatale screening op Downsyndroom

- 5) In hoeverre bestonden er in Nederland etnische verschillen in deelname aan prenatale screening op leeftijdsindicatie?
- 6) In hoeverre bestaan er in Nederland etnische verschillen in deelname aan het huidige landelijk programma voor prenatale screening op Downsyndroom?

## Deel II: Etnische verschillen in kennis van zwangere vrouwen en toegang tot informatie

**Hoofdstuk 3** geeft antwoord op de eerste onderzoeksvraag. De onderzoekspopulatie bestond uit 105 Nederlandse vrouwen, 100 vrouwen van Turkse herkomst en 65 vrouwen van Surinaamse herkomst (totaal=270). Deze vrouwen werden tussen september 2006 en juni 2008 geworven via verloskundigenpraktijken in Rotterdam en de polikliniek Verloskunde van het Erasmus MC. Wij namen gemiddeld 3 weken na het intakegesprek een persoonlijk interview af bij deze vrouwen in een door hen gewenste taal. Aan hen werd gevraagd of ze van hun zorgverlener mondelinge en/of schriftelijke informatie hadden ontvangen en of ze de schriftelijke informatie hadden gelezen. Kennis werd gemeten aan de hand van 21 vragen over Downsyndroom en prenatale screening.

De resultaten lieten zien dat de verloskundige wordt beschouwd als de belangrijkste bron van informatie over prenatale screening op Downsyndroom en dat de meeste zwangere vrouwen tijdens het intakegesprek mondelinge en/of schriftelijke informatie ontvingen. Echter, Turkse en Surinaamse vrouwen lazen deze schriftelijke informatie minder vaak dan Nederlandse vrouwen, rapporteerden vaker problemen met het begrijpen van informatie en hadden significant minder kennis over Downsyndroom en prenatale testen. Hierin speelden verschillen in Nederlandse taalvaardigheid en opleidingsniveau een belangrijke rol.

**Hoofdstuk 4** beschrijft in hoeverre verloskundigen problemen (zoals taalbarrières) en verschillen ervaren bij het informeren van zwangere vrouwen van verschillende etnische herkomst over prenatale screening (onderzoeksvraag 2). Alle 24 verloskundigenpraktijken van de Verloskundige Kring Rijnmond namen deel aan een vragenlijstonderzoek via internet, 57 verloskundigen (78% respons) vulden de vragenlijst in. De meeste verloskundigen gaven aan geen verschillen te ervaren in het informeren van zwangere vrouwen. Zij gaven echter wel aan dat ze zich minder cultureel competent voelen en niet altijd informatie aanbieden als de vrouw niet of nauwelijks Nederlands spreekt en verstaat. Hoewel taalbarrières werden gerapporteerd als het voornaamste probleem, maakt een minderheid van de verloskundigen gebruik van vertaalde schriftelijke materialen en zetten slechts een paar verloskundigen professionele tolken in. De redenen hiervoor werden geëxploreerd in een groepsinterview. De meeste verloskundigen erkenden de mogelijke voordelen van vertaalde folders over prenatale screening, maar waren zich niet bewust van het bestaan van deze materialen. Het beperkt inzetten van professionele tolken kon met name

toegeschreven worden aan de onbekendheid met professionele tolken in de verloskundigenpraktijk.

### **Deel III: Etnische verschillen in het besluitvormingsproces**

**Hoofdstuk 5** gaat over de populatie vrouwen zoals beschreven in hoofdstuk 3 en beschrijft in hoeverre zij verschillen in het nemen van een geïnformeerd besluit (onderzoeksvraag 3). We achterhaalden de mate van geïnformeerde besluitvorming aan de hand van de 'Multidimensional Measure of Informed Choice'. Volgens dit meetinstrument is er sprake van een geïnformeerd besluit als iemand voldoende kennis heeft over prenatale screening en wanneer wel of geen deelname aan prenatale screening overeenkomt met de attitude die iemand heeft ten aanzien van persoonlijke deelname. In totaal nam 71% van de Nederlandse, 26% van de Surinaamse en 5% van de Turkse vrouwen een geïnformeerd besluit om wel of niet deel te nemen aan prenatale screening. De verschillen tussen Nederlandse en Turkse vrouwen konden vooral worden toegeschreven aan verschillen in Nederlandse taalvaardigheden en mate van vrouwenemancipatie. Verschillen tussen Nederlandse en Surinaamse vrouwen konden grotendeels worden toegeschreven aan verschillen in opleidingsniveau en leeftijd.

**Hoofdstuk 6** gaat over dezelfde onderzoekspopulatie en behandelt de vraag in hoeverre vrouwen van Nederlandse, Turkse en Surinaamse herkomst verschillen in deelname aan prenatale screening en welke afwegingen zij hebben om wel of niet deel te nemen aan prenatale screening (onderzoeksvraag 4). Tijdens het persoonlijke interview stelden we een open vraag over redenen om wel of niet deel

te nemen aan prenatale screening en legden we deze vrouwen 18 stellingen voor. Deze stellingen waren ontwikkeld op basis van de resultaten uit de focusgroep interviews die beschreven zijn in het tweede hoofdstuk van dit proefschrift. Deelname aan prenatale screening werd enkele maanden na het persoonlijke interview achterhaald door telefonisch contact op te nemen met de vrouwen. In totaal nam 44% van de Nederlandse, 17% van de Surinaamse en 13% van de Turkse vrouwen uiteindelijk deel aan de screening. De etnische verschillen konden voornamelijk worden toegeschreven aan verschillen in leeftijd en religieuze identiteit. In vergelijking met Nederlandse vrouwen, rapporteerden Turkse en Surinaamse vrouwen vaker dat 'accepteren wat God geeft' een afweging is om niet deel te nemen aan prenatale screening. 'Een kleine kans op een kind met Downsyndroom' en 'kosten van prenatale screening' werden vooral door Surinaamse vrouwen genoemd. Turkse en Surinaamse vrouwen noemden ook veel afwegingen om wel deel te nemen, zoals 'gerustgesteld worden over de gezondheid van de baby' of 'voorbereiden op de komst van een kind met Downsyndroom'. In vergelijking met Nederlandse vrouwen, rapporteerden zij echter meer problemen bij het nemen van een beslissing om wel of niet deel te nemen en hun afwegingen waren minder vaak in overeenstemming met de feitelijke deelname. De resultaten geven aan dat vrouwen van niet-westerse etnische herkomst niet gestereotypeerd moeten worden als ongeïnteresseerd in prenatale screening, maar dat zij beter geïnformeerd moeten worden over prenatale screening en Downsyndroom.

## Deel IV: Etnische verschillen in deelname aan prenatale screening op Downsyndroom

**Hoofdstuk 7** geeft een beschrijving van een studie in Groot-Rijnmond, een geografisch vastgestelde regio in het zuidwesten van Nederland. Het doel van deze studie bestond uit het achterhalen van etnische verschillen in deelname aan prenatale screening in de periode 2000-2004 (onderzoeksvraag 5). Het programma voor prenatale screening op Downsyndroom bestond in deze periode uit het aanbieden van een vlokkentest of vruchtwaterpunctie aan zwangere vrouwen van 36 jaar of ouder. Kansbepalende testen waren nog niet geïmplementeerd in de standaard prenatale zorg. In totaal nam 28,5 % van alle vrouwen deel aan prenatale screening. In vergelijking met vrouwen van Nederlandse herkomst, was de deelname hoger onder vrouwen van Surinaamse en Westerse (niet-Nederlandse) herkomst, hetzelfde onder vrouwen van Turkse en Antilliaanse/Arubaanse herkomst, en lager onder vrouwen van Marokkaanse en niet-Westerse herkomst. Vrouwen met een lagere sociaal-economische achtergrond namen minder vaak deel aan prenatale screening dan vrouwen met een hogere sociaal-economische achtergrond. Etnische verschillen in deelname konden niet worden toegeschreven aan verschillen in sociaal-economische achtergrond.

**Hoofdstuk 8** geeft antwoord op de vraag in hoeverre er etnische verschillen bestaan in deelname aan het huidige programma voor prenatale screening op Downsyndroom (onderzoeksvraag 6). Deelname aan eerstetrimester-serumscreening (voor vrouwen van alle leeftijden) en directe prenatale diagnostiek (voor vrouwen van 36 jaar of ouder) in de periode 1-1-2009 tot 1-7-2009 werd voor

alle etnische herkomstgroepen in het zuidwesten van Nederland achterhaald. De totale deelname aan het landelijk programma was 26%, wat lager is dan in de meeste andere landen. In vergelijking met Nederlandse vrouwen, namen Turkse, Marokkaanse, Arubaanse/Antilliaanse en andere vrouwen van niet-westerse herkomst minder vaak deel aan het programma. De verschillen tussen Nederlandse versus Marokkaanse en Turkse vrouwen bleven significant na correctie voor socio-economische achtergrond en leeftijd. Er werden geen significante verschillen gevonden tussen Nederlandse vrouwen en Surinaamse vrouwen. Gezien onze eerdere bevindingen (zie hoofdstuk 5 van dit proefschrift) is het echter de vraag in hoeverre deze Surinaamse vrouwen deelnamen op basis van een geïnformeerd besluit.

## Deel V: Discussie

**Hoofdstuk 9**, de algemene discussie, begint met een samenvatting van de hoofdbevindingen per onderzoeksvraag, gevolgd door enkele opmerkingen over de methodologische kwesties die in acht moeten worden genomen bij het interpreteren van de resultaten. Potentiële beperkingen van de interne validiteit naar aanleiding van onderzoeksupzet, non-respons, zelfgerapporteerde data, confounding, geschiktheid van meetinstrumenten, schatting van de noemer in de studies naar etnische verschillen in deelname aan screening, en potentiële beperkingen van de externe validiteit van de hoofdbevindingen worden bediscussieerd. De etnische verschillen die we hebben gevonden in kennis en geïnformeerde besluitvorming van zwangere vrouwen en de rol die taalbarrières en opleidingsniveau hierin spelen, komen overeen met resultaten van vergelijkbare internationale studies. Taalbar-

rières worden tevens gerapporteerd door zorgverleners in andere velden van de gezondheidszorg, evenals het ondergebruik van vertaalde materialen en het onvoldoende inzetten van professionele tolken. Dit wijst erop dat onze bevindingen zich niet alleen beperken tot het terrein van prenatale screening. De etnische verschillen die wij vonden in kennis, besluitvorming en deelname aan prenatale screening laten zien dat het doel van het landelijk programma om alle zwangere vrouwen in staat te stellen een geïnformeerde keuze te maken om wel of niet deel te nemen aan prenatale screening nog lang niet is behaald, en wijzen erop dat er etnische verschillen in de toegankelijkheid en kwaliteit van prenatale screening bestaan. De interventies om de toegankelijkheid en kwaliteit van prenatale screening te bevorderen, vragen om extra inspanningen van de Nederlandse overheid, het Centrum voor Bevolkingsonderzoek van het RIVM, het Centraal Orgaan prenatale screening, de regionale centra voor prenatale screening en de zorgverleners. Er moeten betere voorwaarden worden gecreëerd voor de organisatie van het programma prenatale screening op Downsyndroom. Het verdient aanbeveling specifieke landelijke richtlijnen te ontwikkelen ter ondersteuning van zorgverleners in het aanbieden van informatie over prenatale screening aan zwangere vrouwen van diverse etnische achtergronden, en in het begeleiden van deze vrouwen bij de besluitvorming.



# Recht uit mijn hart...

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*Mirjam*



PhD Portfolio Summary  
Summary of PhD training and teaching activities



Name PhD student:	Mirjam P. Fransen
Erasmus MC Department:	Public Health
PhD period:	2004-2009
Promotor:	Prof. dr. J.P. Mackenbach
Supervisors:	Dr. M.L Essink-Bot Dr. H.I.J. Wildschut

	Year	Workload (Hours/ECTS)
<b>1. PhD training</b>		
<b>General academic skills</b>		
Biomedical English Writing and Communication	2006	4 ECTS
<b>Research skills</b>		
Master of Public Health, Netherlands Institute for Health Sciences (Nihes) Rotterdam, the Netherlands	2004-2006	30 ECTS
<b>Presentations at national and international conferences</b>		
Bijeenkomst Nederlandse Associatie voor Community Genetics en Public Health (NACGG) - <i>Etnische verschillen in deelname aan prenataal onderzoek (poster presentation)</i>	2004	20 hours
Onderzoeksdag Verloskunde & Vrouwenziekten - <i>Etnische verschillen in deelname aan prenatale onderzoeken naar Downsyndroom (oral presentation)</i>	2006	20 hours
International Down's Syndrome Screening Group (IDSSG), 7th International Congres, Amsterdam, the Netherlands - <i>Ethnic differences in uptake of prenatal screening for Down syndrome: determinants of participation and non-participation. An explorative study (oral presentation)</i>	2006	40 hours
Workshop Erasmus Centre for Migration, Ethnicity and Health (ECMEH) - <i>Etnische verschillen in deelname aan prenataal onderzoek (oral presentation and discussion)</i>	2006	10 hours

<p>Minisymposium</p> <p>- <i>Prenatale screening bij etnische minderheden</i> (oral presentation)</p>	2008	10 hours
<p>Nederlands Congres Volksgezondheid 2008, Groningen, the Netherlands</p> <p>- <i>Informatie over prenatale screening naar Downsyndroom: Kennis en besluitvorming van zwangere vrouwen</i> (poster presentation)</p>	2008	20 hours
<p>Referaat AMC/Universiteit van Amsterdam, afdeling Sociale Geneeskunde, Amsterdam, the Netherlands</p> <p>- <i>Etnische verschillen in deelname aan prenatale screening op Downsyndroom</i> (oral presentation)</p>	2008	10 hours
<p>9th World Congress of Perinatal Medicine, Berlin, Germany</p> <p>- <i>Information about prenatal screening for Down syndrome: Ethnic differences in pregnant women's knowledge</i> (poster presentation)</p> <p>- <i>Ethnic differences in informed decision-making about prenatal screening for Down syndrome</i> (poster presentation)</p> <p>- <i>Ethnic differences in deciding whether or not to participate in prenatal screening for Down syndrome</i> (poster presentation)</p>	2009	40 hours
<b>Seminars and workshops</b>		
<p>Attending seminars of the Department of Public Health, Erasmus MC Rotterdam</p>	2004-2009	100 hours
<p>Attending and organizing meetings of the 'Risk perception-Informed decision making -Quality of life -club' at the department of Public Health, Erasmus MC, Rotterdam</p>	2004-2009	50 hours
<p>Attending meetings of the Erasmus Centre for Migration, Ethnicity and Health (ECMEH), Erasmus MC, Rotterdam</p>	2006-2009	10 hours
<p>Symposium on the occasion of the inauguration of Prof. T. Marteau 'Individual choices in health care', VU Medical Centre, Amsterdam</p>	2005	8 hours
<p>Symposium verloskundige zorg en etniciteit; Stichting Obstetrische en Gynaecologische Research, Rotterdam</p>	2005	8 hours
<p>Nederlands Congres Volksgezondheid 2005, Rotterdam</p>	2005	16 hours
<p>'Couleur Locale' bijeenkomst over kindergeneeskundige zorg in een kleurrijke samenleving; Sophia Kinderziekenhuis Erasmus MC, Rotterdam</p>	2005	8 hours

'Botsende waarden', middag over ethiek en multiculturele gezondheidszorg;  
Commissie Medische Ethische Vraagstukken, Erasmus MC, Rotterdam

2006 4 hours

Eerste Landelijke Conferentie Pre- en Neonatale Screening; Centrum voor  
Bevolkingsonderzoek RIVM and Nederlandse Associatie voor Community  
Genetics (NACG), Utrecht

2007 8 hours

Workshop Improving health and preventing disease and the role of family  
history information; EMGO instituut, Amsterdam

2007 8 hours

Attending meetings of 'Cultuur & Gezondheid', an initiative of the Department  
BMG Erasmus MC Rotterdam and ZonMW, Den Haag

2007 10 hours

Minicursus methodologie van patiëntgebonden onderzoek en voorbereiding  
van subsidieaanvragen, Erasmus MC Rotterdam

2009 8 hours

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## 2. Teaching activities

### Lecturing

Two lectures on qualitative research among ethnic minorities for the  
Netherlands Institute for Health Sciences (Nihes), Course HS17  
'Ethnicity Health and Health Care'

2008- 2009 20 hours

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## List of publications

**First authorships**

- Fransen MP, Schoonen HMHJD, Mackenbach JP, Steegers EAP, De Koning HJ, Laudy JAM, Galjaard RJ, Looman CW, Essink-Bot ML, Wildschut HIJ. Ethnic differences in uptake of prenatal screening for Down syndrome. A register-based study. Submitted.
- Fransen MP, Wildschut HIJ, Mackenbach JP, Steegers EAP, Galjaard RJ, Essink-Bot ML. Ethnic differences in uptake of prenatal diagnostic tests for Down syndrome. Submitted.
- Fransen MP, Wildschut HIJ, Vogel I, Mackenbach JP, Steegers EAP, Essink-Bot ML. Differences and difficulties in providing information about prenatal screening for Down syndrome to women from diverse ethnic backgrounds. Submitted.
- Fransen MP, Essink-Bot ML, Vogel I, Mackenbach JP, Steegers EAP, Wildschut HIJ. Ethnic differences in informed decision-making about prenatal screening for Down syndrome. *Journal of Epidemiology and Community Health* 2010; in press (doi:10.1136)
- Fransen MP, Wildschut HIJ, Vogel I, Mackenbach JP, Steegers EAP, Essink-Bot ML. Ethnic differences in considerations whether or not to participate in prenatal screening for Down syndrome. *Prenatal Diagnosis* 2009; 29(13):1262-1269
- Fransen MP, Wildschut HIJ, Vogel I, Mackenbach JP, Steegers EAP, Essink-Bot ML. Information about prenatal screening for Down syndrome. Ethnic differences in knowledge. *Patient Education and Counseling* 2009; 77(2): 279-288
- Fransen MP, Essink-Bot ML, Oenema A, Mackenbach JP, Steegers EAP, Wildschut HIJ. Ethnic differences in determinants of participation and non-participation in prenatal screening for Down syndrome: a theoretical framework. *Prenatal Diagnosis* 2007; 27(10):938-50.
- Fransen MP, Meertens RM, Schrande-Stumpel CTRM. Communication and risk presentation in genetic counseling. Development of a checklist. *Patient Education and Counseling* 2006; 61(1): 126-133.
- Fransen MP, Meertens RM, Schrande-Stumpel CTRM. Communicatie over genetische risico's in de gezondheidszorg. *TSG* 2004; 82(7): 442-449.
- Fransen MP, Meertens RM, Schrande-Stumpel CTRM. Communicatie over genetische risico's. *Tijdschrift Kanker* 2004; 28:20-23.

**Co-authorships**

- Van Kesteren N, Meertens RM, Fransen M. Technological innovations and the promotion of energy conservation: satisfaction with, and effectiveness of an in-business control system. In: Verbeek PP, Slob A, ed. *User behaviour and technology development: shaping sustainable relations between consumers and technologies*. Dordrecht: Springer, 2006; 159-172.

- Meertens R, Schaalma H, Fransen M. The receiver's point of view: effect hierarchies and the underlying social-psychological processes. In: Bartels G, Nelissen W, ed. *Marketing for sustainability: towards Transactional Policy-Making*. Amsterdam: IOS Press, 2002; 163-175.





### About the author

Mirjam Fransen was born on February 5, 1976 in Venray, the Netherlands. After completing her secondary education at Elzendaal College in Boxmeer, she studied Nursing at HAN University of Applied Sciences in Nijmegen and received a Bachelor degree in 1997. After working for a short period as a nurse in the Netherlands and the United Kingdom, she started a Master of Health Education at Maastricht University in 1998. During her time as a student she worked as a nurse in mother and child care. In 2000 she obtained a Master degree in Health Sciences.

After graduation she worked at the Department of Health Education, Maastricht University. In August 2004 she started a PhD-study at the Department of Public Health, Erasmus MC, University Medical Center Rotterdam, which resulted in this thesis. She obtained a Master degree in Public Health at the Netherlands Institute for Health Sciences in 2006. Since November 2009, she is appointed as a postdoc researcher at the Department of Social Medicine, Academic Medical Centre, University of Amsterdam.

Mirjam is married to Pepijn Roelofs and they have four children: Bente (2000), Elin (2002), Isen (2004) and Liva (2007).

### Over de auteur

Mirjam Fransen werd geboren op 5 februari 1976 te Venray. Na het afronden van haar middelbare school aan het Elzendaal College in Boxmeer, studeerde zij Verpleegkunde aan de Hogeschool van Arnhem en Nijmegen en behaalde haar Bachelor diploma in 1997. Nadat ze voor een korte periode als verpleegkundige in Nederland en Engeland had gewerkt, startte ze in 1998 met de studie Gezondheidsvoorlichting aan de Universiteit van Maastricht. Tijdens haar studententijd werkte ze als verpleegkundige in de ouder- en kindzorg. In 2000 behaalde zij haar Doctoraal diploma Gezondheidswetenschappen.

Na haar afstuderen werkte zij bij de capaciteitsgroep Gezondheidsvoorlichting, Universiteit Maastricht. Vanaf augustus 2004 werkte zij aan haar promotieonderzoek op de afdeling Maatschappelijke Gezondheidszorg van het Erasmus MC in Rotterdam, wat resulteerde in dit proefschrift. In 2006 behaalde ze haar Doctoraal diploma Maatschappelijke Gezondheidszorg bij het 'Netherlands Institute for Health Sciences'. Sinds november 2009 is ze werkzaam als postdoc onderzoeker bij de afdeling Sociale Geneeskunde, Academisch Medisch Centrum, Universiteit van Amsterdam.

Mirjam is getrouwd met Pepijn Roelofs en samen hebben zij vier kinderen: Bente (2000), Elin (2002), Isen (2004) en Liva (2007).



