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

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## ABSTRACT

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

**Methods** Pregnant women of 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 with 5% of the Turkish and 26% of the Surinamese women. Differences between Surinamese and Dutch women could largely 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.

## INTRODUCTION

In many Western countries, pregnant women are offered information on prenatal screening for Down's syndrome. In The Netherlands, the opportunity to participate in prenatal screening for Down's 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's 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's 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 multiethnic 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's 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 of 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's syndrome?
2. What is the contribution of background characteristics and decision-making variables to ethnic differences in informed decision-making?

## METHODS

### Participants and data collection

Pregnant women of Dutch, Turkish and Surinamese origin were recruited between September 2006 and June 2008 from 15 community midwifery practices in Rotterdam city center and the outpatient clinic of the Erasmus University Medical Center. 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 (ie, 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 1 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 of non-Dutch ethnic origin when she and at least one of her parents were born abroad or if she was born in The Netherlands with at least one of her parents having been 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<sup>11</sup>: seven items about Down's syndrome, eight items about the combined test and six items about invasive testing. Response options included 'correct,' 'incorrect' or 'don't know.' Women scored 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's 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  $\alpha$  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 categorised as 'living together with partner,' 'not living together with a partner,' or 'single.' Number of children was measured by assessing the number of children the woman cares 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 five-item instrument to measure women's identification with their religion, which included cognitive identity, emotional attachment and identification as a Muslim/Christian, etc (Cronbach  $\alpha$  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—for example, '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 five-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  $\alpha$  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 of 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  $\chi^2$  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 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.

## 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, for which 89 Dutch, 78 Turkish and 24 Surinamese agreed to make an appointment. In total, 65 Dutch, 54 Turkish and 19 Surinamese

**Table 1** Characteristics of the study population and decision-making variables

|   | Total (n = 270) | Dutch (n = 105) | Turkish (n = 100) | Surinamese (n = 65) | p Value*                |
|---|-----------------|-----------------|-------------------|---------------------|-------------------------|
| Interview method (n (%))                                      |                 |                 |                   |                     | 0.00                    |
| Telephone   | 223 (83)        | 89 (85)         | 71 (71)           | 63 (97)             |                         |
| Face-to-face  | 47 (17)         | 16 (15)         | 29 (29)           | 2 (3)               |                         |
| Gestational length (weeks)                                    |                 |                 |                   |                     |                         |
| Mean gestation at moment of booking (SD)                      | 9.5 (1.79)      | 9.2 (1.74)      | 9.7 (1.96)        | 9.5 (1.78)          | 0.25‡<br>0.62§<br>0.87¶ |
| Mean gestation at moment of interview (SD)                    | 12.5 (2.85)     | 11.6 (1.89)     | 13.1 (3.09)       | 12.9 (3.38)         | 0.00‡<br>0.01§<br>0.89¶ |
| Age (years)   |                 |                 |                   |                     |                         |
| Mean age (SD)   | 29.2 (4.83)     | 31.7 (4.28)     | 27.9 (4.24)       | 26.9 (4.75)         | 0.00‡<br>0.00§<br>0.33¶ |
| Marital status (n (%))  |                 |                 |                   |                     | 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)              |                         |
| No of children (n (%))  |                 |                 |                   |                     | 0.29                    |
| 0 children  | 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)               |                         |
| Educational level (n (%))                                     |                 |                 |                   |                     | 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)             |                         |
| Religion (n (%))  |                 |                 |                   |                     |                         |
| 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)             |                         |
| Language skills (n (%))                                       |                 |                 |                   |                     | 0.00                    |
| No problems expressing, understanding and writing Dutch       | 222 (82)        | 105 (100)       | 53 (53)           | 64 (98)             |                         |
| Problems expressing and/or understanding and/or writing Dutch | 48 (18)         | 0 (0)           | 47 (47)           | 1 (2)               |                         |
| Received information about prenatal screening (n (%))         |                 |                 |                   |                     | 0.33                    |
| No  | 39 (14)         | 11 (10)         | 17 (17)           | 11 (17)             |                         |
| Yes   | 231 (86)        | 93 (90)         | 80 (83)           | 52 (83)             |                         |
| Gender emancipation (scale 1–5)                               |                 |                 |                   |                     |                         |
| Mean gender emancipation (SD)                                 | 3.74 (0.62)     | 4.09 (0.59)     | 3.42 (0.54)       | 3.67 (0.47)         | 0.00‡<br>0.00§<br>0.01¶ |
| Subjective norm (scale-10, +10)                               |                 |                 |                   |                     |                         |
| Mean subjective norm  | −0.38           | −0.28           | −0.19             | −0.80               | 0.94‡<br>0.23§<br>0.14¶ |
| Barriers to participate in prenatal screening (n (%))         |                 |                 |                   |                     |                         |
| 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 using Pearson  $\chi^2$  tests; ethnic differences in means are tested by univariate analysis of variance.

†Two missing values among religious Turkish women.

‡p Value for mean difference between Dutch and Turkish women.

§p Value for mean difference between Dutch and Surinamese women.

¶p Value for mean difference between Turkish and Surinamese women.

**Table 2** Ethnic differences in knowledge, attitude and test uptake (n (%))

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

\*Seven missing values on test uptake.

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 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 more highly educated than Turkish and Surinamese women. The highest percentage of women who were not living together with a partner was found among the Surinamese women. In total, 4% of the Dutch, 35% of the Turkish and 5% of the Surinamese women identified themselves with their religion.

Among the Surinamese women, 25 were Hindustani, 32 were Creole, and eight 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 Surinamese women as one group.

Language problems were reported by 47% of the Turkish women. 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 2 shows that 56% Dutch, 87% Turkish and 83% Surinamese women did not participate in prenatal screening and that most Turkish and Surinamese women had insufficient knowledge about prenatal screening. Turkish and Surinamese women who participated in prenatal screening did not have significantly higher knowledge scores than Turkish and Surinamese non-participants (not shown). Most women (57%) had a positive attitude towards participating in prenatal screening for Down's 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 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 Turkish uninformed decision-makers had insufficient knowledge, a positive attitude and a negative uptake. Most Surinamese uninformed decision-makers had insufficient knowledge but made an attitude-consistent decision.

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

Table 4 shows that Turkish women in our population were 46 times and Surinamese women almost 12 times more likely to have insufficient knowledge about prenatal screening compared with Dutch women (model 1). Following adjustment for language skills (model 5), the OR for Turkish women decreased by 29%. Adjustment for gender emancipation (model 6) showed the largest percentage reduction in OR for insufficient knowledge in Turkish women (37%). Age, educational level, language skills,

**Table 3** Ethnic differences in informed decision-making (n (%))

|                      | Knowledge  | Attitude | Uptake    | Total<br>(n=263) | Dutch<br>(n=101) | Turkish<br>(n=97) | Surinamese<br>(n=65) |
|----------------------|--|----------|-----------|------------------|------------------|-------------------|----------------------|
| Informed decisions   | Sufficient   | Positive | Yes       | 45 (17)          | 39 (39)          | 1 (1)             | 5 (8)                |
|                      | Sufficient   | Negative | No        | 49 (19)          | 33 (33)          | 4 (4)             | 12 (18.5)            |
|                      |  |          |           | 94 (36)          | 72 (71)          | 5 (5)             | 17 (26)              |
|                      | 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)                |
| Uninformed decisions | 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)              |
|                      |  |          |           | 169 (64)         | 29 (29)          | 92 (95)           | 48 (74)              |
|                      | 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)              |
|                      |  |          | 66 (39)   | 2 (7)            | 48 (52)          | 16 (34)           |                      |
|                      |  |          | 169 (100) | 29 (100)         | 92 (100)         | 48 (100)          |                      |

Ethnic differences in informed decision-making are statistically significant (tested by  $\chi^2$  tests,  $p=0.00$ ).

gender emancipation and the barrier 'have to pay' together (model 8) lowered the OR for insufficient knowledge among Turkish by 53% and among Surinamese women by 54%, but the differences compared with Dutch women remained significant.

The basic logistic model for the outcome attitude-uptake consistency (model 1) showed that Turkish women in our population were almost seven times and Surinamese women 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 Surinamese women. When the variable 'language skills' was added to the model (model 5), the largest percentage reduction in OR was seen in Turkish women (24%). Age, religion identity, language skills and gender emancipation together (model 7) lowered the OR for attitude-uptake inconsistency among Turkish women by 55% and among Surinamese women by 46%.

**DISCUSSION**

We found substantial ethnic differences in informed decision-making on prenatal screening for Down's syndrome. In total, 71% of the Dutch women were classified as informed decision-makers, compared with 5% of the Turkish and 26% of the Surinamese women. Differences between Surinamese and Dutch women could to largely be explained by differences in age and educational level. 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 who had not yet decided upon prenatal screening for Down's 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 Turkish women scored much lower on informed decision-making compared with 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 Turkish women reported language problems that were subsequently identified as an important contributing factor to ethnic differences in informed decision-making. Among our Surinamese women, the

**Table 4** Odds ratios for insufficient knowledge and attitude-uptake inconsistency

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

Percentages in italics show the percentage 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]x100=21%. Variables without significant contribution to ethnicity were not added to the final model.

26% informed decision-makers are comparable with 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 significantly 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's 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 these 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 explore further 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.

### What is already known on this subject

- ▶ Informed decision-making about prenatal screening for Down's syndrome is considered to be essential in good quality of prenatal care.
- ▶ Women from ethnic minority groups in the UK were less likely to make an informed decision about prenatal screening for Down's syndrome.
- ▶ It is unknown to what extent variables that might influence the decision-making process contribute to ethnic differences in informed decision-making.

### What this study adds

- ▶ Ethnic differences in informed decision-making could to a large extent be attributed to differences in language skills, educational level, age and gender emancipation.
- ▶ Interventions 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 and what they take into account when considering participation in prenatal screening.

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**APPENDIX**

Attitude measure used in the present study.  
In my opinion, testing for Down's syndrome during my pregnancy, is....

| Bad            |                          |                          |                          |                          |                          | Good             |
|----------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|------------------|
| Frightening    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Not frightening  |
| Not reassuring | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Reassuring       |
| Self-evident   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Not self-evident |
| Unimportant    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | Important        |

Source: adapted from Marteau *et al*<sup>5</sup> and Van den Berg *et al.*<sup>11</sup>