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Challenges in prenatal screening and diagnosis in the Netherlands

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Low uptake of the combined test in the Netherlands – which factors contribute?

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Low uptake of the combined test in the Netherlands – which factors contribute?

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Objective:

The aim of this study was to evaluate which of the following factors affect the uptake of the combined test (CT) in the Netherlands: women's socio-demographic background, attitude towards Down syndrome, attitude towards termination of pregnancy, counseling process, reimbursement policy, and knowledge on the aim of the CT.

Methods:

Cross-sectional survey in the Northwest (NW) and the Northeast (NE) region of the Netherlands.

Results:

Analyses were based on 820 questionnaires (73% response rate). Women from the NW region opted more often for the CT than women from the NE

region (52.1% and 16.5%, respectively, $p < 0.001$). Women of 36 years and older opted more often for the CT than younger women (59.4% and 28.2%, respectively, $p < 0.001$). Women's socio-demographic background and their attitude towards Down syndrome and termination of pregnancy (TOP) had contributed independently on CT choice.

Conclusion:

The uptake of the CT in this study is low. The main reason for the low uptake is the relatively positive attitude towards Down syndrome and a negative attitude towards TOP. Moreover, the perception of maternal age as strong predictor of Down syndrome risk and the inequality of access to care, due to the financial threshold for younger women, are likely to affect participation in screening.

Introduction

The aim of the combined test (CT) is to identify fetuses with an increased risk for Down syndrome, thus offering parents the possibility to opt for invasive prenatal diagnosis. In case of an affected pregnancy, parents can opt for termination of pregnancy (TOP) or prepare themselves for the birth of a child with Down syndrome.

In 2007, a national screening program has been introduced in the Netherlands with

the aim to ask all pregnant women if they want to be informed about prenatal screening. If a woman wants to receive information, she is counseled by her healthcare professional, and on the basis of the information provided, she decides whether or not she wants to opt for screening. The Dutch Department of Health has introduced an age-related system for reimbursement of the CT; women aged 36 years and older have free access to the test, whereas younger women have to pay approximately 150 euros. If women of 36 years and older decline screening, they can still opt for prenatal diagnosis based on their age.

Before 2007, the CT was offered in the Netherlands in research settings with uptake rates ranging from 53% to 86%.^{1,2} An important incentive for the present study was the observation that since the start of the national screening program the uptake of the CT is low and lower than in the past, with pronounced regional differences.^{3,1,2} The aim of this study was to evaluate which of the following factors affects the uptake of the CT in the Netherlands: women's sociodemographic background, attitude towards Down syndrome, attitude towards termination of pregnancy, counseling process, reimbursement policy, and knowledge on the aim of the CT.

Methods

DESIGN

Between March and April 2010, a cross-sectional survey was conducted at 13 ultrasound clinics in the Northwest (NW) and Northeast (NE) of the Netherlands to investigate the uptake of the CT. All pregnant women who attended the ultrasound center received an information letter and a questionnaire about the CT. The questionnaires were distributed at the time of the 20-week anomaly scan to ensure that knowledge on the outcome of prenatal diagnosis would not bias women's opinions on the CT in retrospect.

STUDY INSTRUMENT

The questionnaire used in the present study was based on a questionnaire developed in France by Seror et al.,⁴ addressing women's attitudes and decisions on screening for Down syndrome.

Our questionnaire included four sections with a total of 53 questions (see supporting information). The first section (six questions) contained questions regarding the dating scan in this pregnancy. The second section (23 questions) addressed the counseling and reasons for accepting or declining the CT. The third section (eight questions) assessed whether or not women opted for prenatal diagnosis. The final section contained questions about women's socio-demographic characteristics, attitude towards termination of pregnancy and costs of the first trimester scan. The following demographic variables were included as follows: age, parity, educational level, income status, region, and ethnicity.

STATISTICAL ANALYSIS

To compare differences in categorical variables between women who opted for the CT and those who declined, the X^2 test (or Fisher's Exact Test, if appropriate) was used. To

■ Table 1 – Socio-demographic characteristics of women opting for or declining the combined test (CT)

Variables	CT		p
	No N(%)	Yes N(%)	
<i>Age:</i>			
≤29	307 (55.1)	86 (32.7)	
30-35	209 (37.5)	117 (44.5)	
≥36	41 (7.4)	60 (22.8)	<0.001
<i>Education:</i>			
Low	57 (10.4)	25 (9.6)	
Middle	250 (45.5)	100 (38.3)	
High	243 (44.2)	136 (52.1)	0.101
<i>Income:</i>			
<1500 euros	43 (8.1)	18 (7.2)	
1500-3500 euros	375 (71.0)	129 (51.8)	
>3500 euros	110 (20.8)	102 (41.0)	<0.001
<i>Parity:</i>			
Primiparous	271 (48.7)	119 (45.2)	
Multiparous	286 (51.3)	144 (54.8)	0.370
<i>Ethnicity:</i>			
Caucasian	385 (83.9)	199 (84.0)	
Non-Caucasian	74 (16.1)	38 (16.0)	>0.99
<i>Religion:</i>			
Important	163 (29.7)	44 (16.8)	
Not important	386 (70.3)	218 (83.2)	<0.001
<i>Region:</i>			
Northeast	385 (69.1)	76 (28.9)	
Northwest	172 (30.9)	187 (71.1)	<0.001

compare differences in continuous variables between these groups, the student's *t*-test was used. Comparison by age was performed because only women aged 36 years and older receive reimbursement for the CT. Comparison by region was performed because differences between regions may reflect differences in determinants or uptake.

Associations between single co-variables and women's decision to accept or decline the CT were assessed by univariate binary logistic regression and expressed in odds ratios (ORs, 95% confidence intervals). Next, multiple binary logistic regression analysis with stepwise backward conditional inclusion of variables was performed to evaluate the adjusted impact of co-variables. Correlations and stratified tables were used to check for confounding and interaction (income education). Multiple logistic regressions were redone accordingly, taking confounding and interaction into account.

To study the relative impact of co-variables on women's decision, we distinguished six blocks of determinants: patient characteristics, women's opinions and attitudes, care characteristics, decision making and women's knowledge, reimbursement policy, and region. The relative impact of each block was evaluated by adding blocks of variables successively to the multiple binary logistic regression, and the change in 2 log likelihood

■ Table 2 – Information provided on the combined test (CT)

Information provided	CT		p
	No N(%)	Yes N(%)	
<i>Who discussed the possibility of the CT with you</i>			
General physician	14 (2.6)	2 (0.3)	
Midwife	444 (83.9)	192 (73.3)	
Gynecologist	48 (9.1)	40 (15.3)	
Sonographer	8 (1.5)	11 (4.2)	
Searched autonomously for information	15 (2.8)	17 (6.5)	<0.001
<i>Was the amount of information enough</i>			
Too much information	5 (0.9)	1 (0.4)	
Enough information	515 (95.9)	253 (96.2)	
Too little information	17 (3.2)	9 (3.4)	0.756
<i>Did you get written information in addition to oral information</i>			
Yes, a leaflet on Down syndrome screening	430 (80.7)	230 (87.5)	
Yes, information on the Decision Aid on the internet	16 (3.0)	9 (3.4)	
No, I did not receive any written information	87 (16.3)	24 (9.1)	<0.022
<i>Would you prefer to receive the written information before or after counseling</i>			
Before	213 (40.2)	159 (60.5)	
After	216 (40.8)	33 (12.5)	
I do not know	101 (19.1)	71 (27)	<0.001

was evaluated and the proportion of cases correctly predicted.

Statistical significance was defined as $p < 0.05$ (two-sided). All statistical analyses were conducted using SPSS 17.0.0.

Results

A total of 837 (73.0%) of 1140 women returned the questionnaire. Analyses were based on 820 women; 17 questionnaires were excluded from analysis because women had already opted for prenatal diagnosis and were aware whether or not their child was affected at the time the questionnaire was filled out; nine of these women had declined, and eight women had opted for the CT. Table 1 shows that 263 (32.1%) participants opted for the CT. Acceptors were on average older than decliners: 31.4 and 29.0 years, respectively ($p < 0.001$). There were no significant age differences between the NW and NE regions.

Most women were counseled by their midwife ($N=636$, 80.4%), and the first visit took usually place at 7 to 8 weeks of gestation ($N=356$, 43.8%). Besides oral information, 660 (82.9%) women received the leaflet on Down syndrome screening developed by the Dutch National Screening Board, and 25 (3.1%) women used the Decision Aid on the internet. A subgroup of 111 (13.9%) women reported not to have received any written information. Most women who opted for the CT preferred to receive the information before counseling ($N=159$, 60.5%) in contrast to 40.2% of women who declined ($N=213$) ($p < 0.001$). More women who declined the CT indicated that they did not receive any written information ($N=87$, 16.3%) than women who opted for the CT ($N=24$, 9.1%)

■ Table 3 – Reasons to opt for the combined test (CT) (multiple answers possible per participant)

Reasons to opt for the CT Total acceptors = 263	Total answers N=425	<36 years answers N(%)	≥36 years answers N(%)	p	NE region N(%)	NW region N(%)	p
I want to know if there is an increased risk on Down syndrome	223 (84.8)	179 (88.2)	44 (73.3)	0.008	59 (77.6)	164 (87.7)	0.057
I will opt for all tests offered	26 (9.9)	25 (12.3)	1 (1.7)	0.013	6 (7.9)	20 (10.7)	0.649
I am of older age and I rather opt for the CT than for an invasive procedure	61 (23.2)	16 (7.9)	45 (75.0)	<0.001	25 (32.9)	36 (19.3)	0.024
I had the CT in previous pregnancy	79 (30.0)	64 (31.5)	15 (25.0)	0.423	19 (25.0)	60 (32.1)	0.300
My midwife/family/friends advised me to do the CT	14 (5.3)	7 (3.4)	7 (11.7)	0.021	2 (2.6)	12 (6.4)	0.363
Other reasons	22 (8.4)	18 (8.9)	4 (6.7)	0.792	5 (6.6)	17 (9.1)	0.627

NW = Northwest. NE = Northeast.

■ Table 4 – Reasons to decline the combined test (CT) (multiple answers possible per participant)

Reasons to decline the CT Total decliners = 557	Total answers N=1101	<36 years answers N(%)	≥36 years answers N(%)	p	NE region N(%)	NW region N(%)	p
I am young and therefore the test is unnecessary	191 (34.3)	189 (36.6)	2 (4.9)	<0.001	134 (34.8)	57 (33.1)	0.772
I want to minimize testing during this pregnancy	30 (5.4)	26 (5.0)	4 (9.8)	0.266	19 (4.9)	11 (6.4)	0.543
I think my risk on Down syndrome is low	138 (24.8)	133 (25.8)	5 (12.2)	0.060	100 (26.0)	38 (22.1)	0.341
I do not want to make a decision on TOP	123 (22.1)	111 (21.5)	12 (29.3)	0.245	80 (20.8)	43 (25.0)	0.271
Down syndrome is for me no reason to terminate a pregnancy	321 (57.6)	292 (56.6)	29 (70.7)	0.100	236 (61.3)	85 (49.4)	0.009
The test does not give any guarantees	16 (2.9)	14 (2.7)	2 (4.9)	0.332	11 (2.9)	5 (2.9)	>0.99
I have the impression that the test is not reliable	191 (34.3)	178 (34.5)	13 (31.7)	0.864	127 (33.0)	64 (37.2)	0.336
I found the test too expensive	37 (6.6)	37 (7.2)	0 (0)	0.099	20 (5.2)	17 (9.9)	0.044
Other reasons	54 (9.7)	51 (9.9)	3 (7.3)	0.786	31 (8.1)	23 (13.4)	0.062

NW = Northwest. NE = Northeast.

($p < 0.022$) (Table 2).

The vast majority of women reported to have made the decision on CT autonomously (N=648, 81.5%) and before the counseling had taken place (N=475, 59.9%). Women who opted for the CT more frequently reported having received a positive advice from the healthcare professional (N=33, 12.8%) than decliners (N=13, 2.5%) ($p < 0.001$). Similarly, women of 36 years and older were more frequently advised to opt for the CT (N=14, 14.6%) than younger women (N=31, 4.7%) ($p < 0.002$). The majority of women reported that it had been easy to decide whether or not to opt for prenatal screening (N=601, 75.4%). More acceptors found the decision easy (N=212, 81.2%) than decliners (N=389,

■ Table 5 – Attitude towards termination of pregnancy

Attitude towards TOP	Combined test		p	<36 years answers N(%)	≥36 years answers N(%)	p	NE region N(%)	NW region N(%)	p
	No N(%)	Yes N(%)							
Consider termination of pregnancy in case of Down syndrome	30 (5.6)	124 (47.3)		131 (18.7)	23 (23.2)		46 (10.3)	108 (30.6)	
Consider termination of pregnancy in case of severe structural anomaly	210 (39.2)	74 (28.2)		247 (35.3)	37 (27.4)		173 (38.9)	111 (31.4)	
I did not think termination of pregnancy was an option	172 (32.1)	52 (19.8)		201 (28.8)	23 (23.2)		133 (29.9)	91 (25.8)	
I will always carry to term	124 (23.1)	12 (4.6)	<0.001	120 (17.2)	16 (16.2)	0.572	93 (20.9)	43 (12.2)	<0.001

TOP = termination of pregnancy. NW = Northwest. NE = Northeast.

72.6%) ($p=0.007$). Decliners reported more often that they were unaware a decision was being made ($N=105$, 19.6%) than acceptors ($N=28$, 10.7%) ($p=0.007$). Women from the NE region were more frequently unaware a decision was being made ($N=87$, 19.5%) in comparison to women from the NW region ($N=46$, 13.1%) ($p=0.040$).

The reasons to opt for the CT are shown in Table 3. The main reason to opt for CT was to obtain an individualized risk assessment on Down syndrome ($N=223$, 84.8%). Women of 36 years and older opted more often for the CT than younger women because others advised them to opt for the CT ($N=7$, 11.7% vs. $N=7$, 3.4%; $p=0.021$). In the NE region, older women more often opted for the CT to avoid an invasive procedure ($N=25$, 32.9%) than women from the NW region ($N=36$, 19.3%; $p=0.024$).

The main reason to decline the CT was that women would not consider TOP in case of Down syndrome ($N=321$, 57.6%) (Table 4). Younger women declined the CT more often than women of 36 years and older because they considered their age-related risk to be low ($N=189$, 36.6% vs. $N=2$, 4.9%; $p < 0.001$). Women from the NE region declined the CT more often because Down syndrome would not be a reason to consider TOP ($N=236$, 61.3% vs. $N=85$, 49.4%; $p=0.009$) and women from the NW more often declined the CT because they found it too expensive ($N=17$, 9.9% vs. $N=20$, 5.2%; $p=0.044$).

Acceptors of the CT would consider TOP in case of Down syndrome more often than decliners (Table 5). A subgroup of 210 (39.2%) women would consider a TOP in case of severe physical anomaly. Women from the NE region would consider TOP in case of Down syndrome less often than women from the NW region ($N=46$, 10.3% vs. $N=108$, 30.6%; $p < 0.001$). There were no significant differences in attitude towards TOP between the two age-groups.

■ Table 6 – Univariate and multivariate analysis – which factors influence combined test (CT) choice

Variables	Univariate logistic regression		Multiple logistic regression	
	OR (95% CI)	p	OR (95% CI)	p
BLOCK 1 – socio-demographics				
<i>Age:</i>				
≤29	1	—	1	—
30-35	2.00 (1.44 – 2.78)	<0.001	2.00 (1.17 – 3.35)	0.011
≥36	5.22 (3.29 – 8.31)	<0.001	5.61 (2.77 – 11.33)	<0.001
<i>Parity:</i>				
Primiparous	1	—		
Multiparous	1.15 (0.85 – 1.54)	<0.362		
<i>Etnicity:</i>				
Caucasian	1	—		
Non-Caucasian	0.99 (0.65 – 1.52)	0.976		
<i>Education:</i>				
Low	1	—		
Middle	0.91 (0.54 – 1.54)	0.731		
High	1.28 (0.76 – 2.14)	0.353		
<i>Income:</i>				
<1500	1	—	1	—
1500-3500	0.82 (0.46 – 1.48)	0.511	1.52 (0.52 – 4.50)	0.447
>3500	2.2 (1.20 – 4.08)	0.011	2.56 (0.80 – 8.22)	0.114
<i>Ever TOP:</i>				
No	1	—	1	—
Yes	3.25 (1.75 – 6.04)	<0.001	1.81 (0.76 – 4.34)	0.183
BLOCK 2 – attitude				
<i>Opinion TOP:</i>				
TOP in case of Down	1	—	1	—
TOP in case of anomaly	0.09 (0.05 – 0.14)	<0.001	0.14 (0.07 – 0.26)	<0.001
Never thought about it	0.07 (0.04 – 0.12)	<0.001	0.11 (0.06 – 0.22)	<0.001
Always carry to term	0.02 (0.01 – 0.05)	<0.001	0.04 (0.02 – 0.09)	<0.001
<i>Positive opinion on offer national screening:</i>				
No	1	—		
I do not know	5.83 (0.64 – 52.90)	0.117		
Yes	7.54 (0.99 – 57.43)	0.051		
BLOCK 3 – counseling				
<i>CT discussed by:</i>				
Midwife	1	—	1	—
Self	2.62 (1.28 – 5.40)	0.008	3.71 (1.07 – 12.84)	0.038
General physician	0.33 (0.07 – 1.50)	0.145	0.46 (0.04 – 5.83)	0.550
Gynecologist	1.93 (1.23 – 3.03)	0.004	1.18 (0.58 – 2.39)	0.653
Sonographer	3.20 (1.26 – 8.03)	0.014	6.47 (1.20 – 35.01)	0.030
<i>CT information:</i>				
Enough	1	—		
Too much	0.41 (0.05 – 3.50)	0.413		
Too little	1.08 (0.47 – 2.45)	0.858		

Table 6 (continued)

Variables	Univariate logistic regression		Multiple logistic regression	
	OR (95% CI)	<i>p</i>	OR (95% CI)	<i>p</i>
<i>Type of CT information:</i>				
No written information	1	—	1	—
Official leaflet	1.94 (1.20 – 3.13)	0.007	3.12 (1.44 – 6.75)	0.004
Decision aid on internet	2.04 (0.80 – 5.19)	0.135	0.94 (0.19 – 4.65)	0.939
<i>Timing of CT information:</i>				
Before counseling	1	—	1	—
I do not know	0.44 (0.28 – 0.68)	<0.001	0.42 (0.21 – 0.87)	0.019
After counseling	0.44 (0.31 – 0.62)	<0.001	0.40 (0.24 – 0.67)	<0.001
<i>Advice from healthcare professional:</i>				
Informed choice	1	—	1	—
Do not opt for CT	0.63 (0.20 – 0.1.93)	0.417	0.40 (0.09 – 1.77)	0.224
Opt for CT	5.58 (2.88 – 10.81)	<0.001	14.97 (4.26 – 52.60)	<0.001
<i>Follow advice health care professional:</i>				
Decide without help	1	—	1	—
Decide with help	0.88 (0.53 – 1.47)	0.624	0.53 (0.23 – 1.22)	0.141
Follow advice	1.96 (1.28 – 3.01)	0.002	1.72 (0.84 – 3.54)	0.136
BLOCK 4 – decision making				
<i>Decision difficulty:</i>				
Easy	1	—		
Hard	0.92 (0.53 – 1.60)	0.759		
Did not know a decision was being made	0.49 (0.31 – 0.78)	0.002		
<i>Decision made:</i>				
Before counseling	1	—	1	
During counseling	0.78 (0.52 – 1.17)	0.226	1.43 (0.70 – 2.91)	0.323
After counseling	0.48 (0.33 – 0.72)	<0.001	0.54 (0.30 – 0.95)	0.033
BLOCK 5 – costs and knowledge				
<i>Opinion on costs:</i>				
Alright to pay	1	—	1	—
Only opt for CT in case of reimbursement	0.26 (0.13 – 0.52)	<0.001	0.29 (0.10 – 0.89)	0.030
Only opt for CT if cheaper	0.59 (0.35 – 0.99)	0.045	1.59 (0.75 – 3.35)	0.227
<i>Knowledge on purpose of CT</i>	1.28 (1.09 – 1.51)	0.003		
BLOCK 6 – region				
<i>Region:</i>				
Northeast	1	—	1	—
Northwest	5.51 (4.00 – 7.60)	<0.001	4.86 (3.01 – 7.83)	<0.001

Block 1: 2 log likelihood 739.009, correctly predicted 67.9%.

Block 2: 2 log likelihood 618.411, correctly predicted 76.9%.

Block 3: 2 log likelihood 547.756, correctly predicted 79.7%.

Block 4: 2 log likelihood 542.302, correctly predicted 79.2%.

Block 5: 2 log likelihood 534.612, correctly predicted 79.4%.

Block 6: 2 log likelihood 489.050, correctly predicted 82.8%.

TOP = termination of pregnancy. OR = odds ratio. CI = confidence interval.

Acceptors of the CT indicated in 241 (91.6%) cases that they would also opt for the CT in a future pregnancy. Of the decliners, 366 (66.2%) women indicated that they would not consider the test in a future pregnancy, 175 women (31.6%) were uncertain, and only 12 (2.2%) stated they would opt for the CT ($p < 0.001$). If the purpose of CT would be broadened to detect also severe physical anomalies, 131 decliners (23.7%, $p < 0.001$) reported that they would opt for the CT.

The results of the multiple regression analyses, used to examine whether the decision could be predicted from background variables, are presented in Table 6. The six blocks of determinants correctly predicted participation of the CT in 82.8% of women. Women's socio-demographic background, their attitude towards Down syndrome and TOP as well as region, had a large independent impact on CT choice.

Discussion

Although the majority of women in this study appreciated to receive information on the CT, only 32% actually opted for it. The main reason to opt for the CT corresponded with the primary aim of the screening test, that is, to obtain an individualized risk assessment on Down syndrome. Almost half of the women who opted for CT would consider TOP in case of Down syndrome. Women's motivations to decline the CT were diverse; two thirds indicated that Down syndrome would not be a reason to terminate a pregnancy, one third indicated that they considered their prior risk to be low and a quarter of all women indicated that they had doubts about the reliability of the screening test. Exclusion of the 17 women who opted for prenatal diagnosis is unlikely to have biased our results. It was a small group, with heterogeneous reasons to opt for or decline the CT and heterogeneous opinions on prenatal diagnosis and TOP. Furthermore, the incidence of congenital anomalies is low.

The CT uptake in this study (32%) is considerably lower than uptake rates reported in Denmark (>90%) and France (88%).^{4,5} In England, the uptake rates vary per region, ranging from 98% in the London area to 20% in Lancaster.⁶⁻¹⁰ The CT uptake in the present study is lower than uptake rates previously reported in research settings in the Netherlands (86% and 53%, respectively) prior to introduction of the national screening program.^{1,2} A similar decreasing trend was seen in the UK, where uptake rates over the years decreased from 83% to 41% (1993-2005).⁷

What are the reasons behind this decreasing trend? Our study shows that most women declined the CT because they would not consider TOP in case of Down syndrome. Moreover, 23.4% of the decliners would opt for the CT if it was not only aimed at detecting Down syndrome, and 39% of the decliners would consider TOP in case of a severe physical anomaly, suggesting that disease perception also plays a role. In the Netherlands, good specialized medical care, family support, and special education contribute to a high societal acceptance of children with Down syndrome. Although this may explain the overall low uptake, it does not explain the difference in uptake between the NE and NW regions as good facilities for children with Down syndrome are available throughout the country. Our results indicate that in the Netherlands, there are substantial inter-regional differences in attitudes toward Down syndrome and TOP. Similar findings were reported by Shanta et al. who concluded that attitude towards the CT and TOP had a larger im-

pact on the uptake of screening than knowledge on the CT despite similar information and counseling.⁹ In our study, women's age and parity did not differ by region. These determinants are therefore unlikely to explain the regional inequalities. An Australian study related differences in uptake to inequality in access to screening for women living in remote areas.^{11,12} Although the NW of the Netherlands is more densely populated than the NE region, these differences do not compare with the Australian situation. In summary, not only different attitudes towards TOP but also different attitudes towards Down syndrome are likely the reasons for the low and variable uptake rate.⁹

Our study indicates that Dutch women still perceive maternal age as a strong and reliable predictor of Down syndrome risk. In the national information leaflet on Down syndrome screening, substantial emphasis is put on the age-related risk, and it is suggested that the CT performs better in older than in younger women.¹³ This belief is strengthened by the age-related CT reimbursement policy which undermines equal access and may give the impression that the CT in younger women is unnecessary. In our study, one in 14 young women declined the CT because they found this test too expensive. The effect of reimbursement could be more substantial than our results suggest, because respondents probably are reluctant to mention costs as main reason to decline the CT. Furthermore, women seem to fail to make a distinction between the age-related risk and their individual risk, and fail to realize that the age-related risk is only one of the constituting elements of the individual risk.^{14,15} Only unbiased counseling can adjust these assumptions. Our results suggest that some of the healthcare professionals in the two regions may not have counseled without bias. This is unlikely to explain the difference in CT uptake because the increase in predictive power is less than 3% (see block 3, Table 6). However, on the basis of our data, it is impossible to conclude if they truly deviated from value neutrality or rather made a shared decision without affecting women's autonomy. In order to improve counseling and informed decision making, we propose that both in the national information leaflet and during the counseling, it is emphasized that maternal age is part of the risk assessment and not an independent determinant of risk. Moreover, a more objective explanation of the performance of the CT to younger women and abolishment of the financial threshold would stimulate equal access.

Conclusion

The uptake of the CT in this study is low, especially among younger women and women from the NE region of the Netherlands. The main reason for the low uptake is the relatively positive attitude towards Down syndrome and a negative attitude towards TOP. Moreover, the perception of maternal age as strong predictor of Down syndrome risk and the inequality of access to care, due to the financial threshold for younger women, are likely to affect participation in screening.

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