CHAPTER 7

Attitudes of Dutch primary care midwives towards the current prenatal screening and non-invasive prenatal testing

ABSTRACT

BACKGROUND

With the likely introduction of non-invasive prenatal test (NIPT) in the near future, we wanted to gain knowledge about the attitude of primary care midwives concerning current and future prenatal screening programs.

METHODS

In a cross-sectional study a digital semi-structured questionnaire was used to explore the attitudes of Dutch primary care midwives.

RESULTS

The response rate was 24% (489/2072). The background characteristics of the responders match those of the entire population of Dutch primary care midwives. The attitude of the respondents towards NIPT was positive in 72%, whereas 47% were positive towards the current FCT program. The attitudes towards NIPT were significantly influenced by religion. Advantages of NIPT mentioned were mainly the absence of iatrogenic miscarriage risk (97%), easier to understand counseling (82%), fewer referrals for invasive diagnostics (91%) and pregnancy termination in earlier gestation (77%). Disadvantages of NIPT mentioned were concern about less informed decision-making by pregnant women (70%), the test becoming a routine test (41 %), increased uptake rates (30%) and increased abortion rates (24%).

CONCLUSION

The majority of Dutch midwives responding to the questionnaire would welcome the implementation of NIPT. Specific counseling courses are recommended for all who will be counseling pregnant women on NIPT.

INTRODUCTION

In the Netherlands, the first trimester combined test (FCT) is offered to all pregnant women since 2007 as part of a national prenatal screening program. Prenatal screening aims to offer an individual risk estimate for fetal trisomies in the first trimester or early second trimester of pregnancy. FCT consists of maternal serum screening and nuchal translucency (NT) measurement, which identifies women at elevated risk for trisomy 21, 18 or 13 with a sensitivity of 80-85% for a false positive rate of 5%. The serum test is performed between 9+0 weeks and 13+6 weeks' gestation. The nuchal translucency measurement is performed between 11+0 and 13+6 weeks gestation. If the FCT shows an elevated risk (above 1:200) for trisomy invasive testing using chorion villus sampling (CVS) or amniocentesis is offered. In the Netherlands the uptake of the FCT is low (around 25%) compared to other countries.[1]

Changes in the prenatal screening program are expected with the availability of the non-invasive prenatal test (NIPT) in the Netherlands. With NIPT trisomies can be detected using cell-free fetal (cff) DNA circulating in maternal blood with a reported sensitivity and specificity of >99%, and has recently been introduced in clinical practice in many countries.[2] NIPT can be performed from 10 weeks gestation onwards and is completely safe for the fetus. With the introduction of NIPT the uptake of prenatal screening might increase because of better test characteristics and less need for invasive tests.[3] Whether NIPT should be used as primary care screening, replacing FCT, or only in case of an elevated risk as a replacement for an invasive test is subject of debate. Ethical, financial and logistic issues play a main role in this discussion, but these issues may change over time. Because NIPT is a safe test that requires only a maternal blood sample, some caregivers worry that the decision to perform NIPT might be taken to easily and good counseling will be omitted.[4,5]

In the Netherlands most pregnant women receive prenatal care by independent primary care midwives, who also do the counseling for the FCT. Until now it is not known what the attitude of primary care midwives is towards the current prenatal screening system and towards NIPT.

The aim of this study was to investigate the attitudes of primary care midwives towards the current Dutch prenatal screening program and towards the future introduction of NIPT.

METHODS

Design

In a cross-sectional design a digital semi-structured questionnaire was used. The time the respondents needed to complete the questionnaire was around 20 minutes.

Study population

The study population consisted of all primary care midwives in the Netherlands, who were members of the Royal Dutch Organization of Midwives (KNOV) in January 2012 (n=2093). In total, 95 % of all primary care midwives are KNOV members. The midwives were invited to complete an online questionnaire between February 16 and March 20, 2012. The invitation was placed both on the KNOV-website and stated in their online newsletter. After a week a postal reminder with a link to the questionnaire was sent to all primary care midwives.

Setting

At the time of the study NIPT was not yet available in the Netherlands. We provided uniform information about NIPT at the beginning of the questionnaire, including the purpose of this study, the sensitivity and specificity of the FCT, the miscarriage risk of invasive diagnostics, the characteristics of the NIPT test, the reported sensitivity and specificity of NIPT and the possible consequences of the introduction of NIPT.

Two possible scenarios for the introduction of NIPT were described, either NIPT for the elevated risk population, replacing invasive testing, or NIPT offered to all pregnant women, replacing the FCT. In the current situation primary care midwives receive financial compensation for prenatal counseling.

Outcome measures

The main outcome measures were the attitudes of midwives towards the current screening program and towards NIPT.

Data collection

The questionnaire included 35 closed and 4 open questions and consisted of three parts: firstly, the background variables of the midwives (*age, place of graduation, religion, urbanization of working area and function in the primary care center*); secondly the attitude towards the national screening program and thirdly the attitude towards NIPT.

The questions concerning the attitude towards the current FCT based national screening program focused on counseling and training. They addressed the capability of counseling, the difficulties in counseling (based on the following aspects: the seriousness of the disease, the

false positive result, the false negative result and the iatrogenic miscarriage risk when electing for an invasive procedure) the time required for counseling and counseling difficulties. participants were asked to indicate their attitude towards the current screening program and the influence of this attitude on their counseling. Most of the questions concerning the aspects of attitudes were measured on a 5 point Likert scale. The assumed influence of the personal attitude on counseling was measured on a "forced" 4 points scale (without neutral).

In the last part of the questionnaire, participants were asked questions about NIPT. The first question was whether they were aware of the existence of this new test. The attitude towards NIPT was addressed twice on two different moments in the questionnaire. The participants were asked to make a choice on the way of implementation of NIPT, only for high risk women or for all pregnant women. Several questions addressed the possible positive and negative influences of the introduction of NIPT for both the respondent as society.

Statistical analysis

All analyses were performed using SPSS 20.0 for windows (IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.). The answers on the open questions for the perceived needs by implementation were coded into categories, labeled and entered in SPSS.

Ethical considerations

All data were processed anonymously. Ethical review for this form of research is not required in the Netherlands.

RESULTS

A total of 489 midwives completed the questionnaires, of a total of 2086 primary care midwives, which gives a response rate of 24%. The background characteristics are listed in table 1.

Training and counseling

A total of 463 (95%) respondents were counseling patients about the FCT, and 480 (98%) answered that they had attended courses on prenatal screening, either during their initial midwifery training or during post registration courses. A majority of the respondents (98%) felt adequately trained to counsel pregnant women about the FCT and 402 (82%) of the respondents felt adequately trained to present the result of the FCT. The respondents spent a median of 10 minutes (range 3-50 min) on counseling. In total, 33/463 (7%) midwives needed more than 20 minutes per counseling. The respondents estimated that the percentage of

pregnant women electing for FCT was 25% (median, range 1-99). A minority (75/463, 17%) answered to have uptake rates of over 50%. A statistically significantly positive correlation was found between time needed for counseling and uptake rate (p=<0.001).

The respondents noted that counseling on false positive and false negative results was most difficult (respectively 59% and 52% of the respondents noted this to be hard or very hard). In contrast, 80% of the respondents considered counseling about the risk of an iatrogenic miscarriage to be easy. The severity of Down syndrome was valued easy to explain by 54% of the respondents, and 20% found it hard to explain. Most respondents commented on the complexity of the risk calculations, the difficulty of explaining the FCT in particular to people with insufficient knowledge of the Dutch language and the costs.

The attitude towards the current screening program

Of the 483 respondents, 230 (47%) reported to have a positive attitude, 84 (17%) respondents a negative attitude, and 169 respondents (35%) a neutral attitude towards the current screening program (table 2). Most midwives (89 %) answered that their personal attitude towards FCT did not affect their way of counseling. Yet, 50 respondents (10%) answered that personal attitude was certainly playing a role in their counseling. In this subgroup, no particular attitude (positive, negative or neutral) was overrepresented.

Attitudes towards NIPT

The majority, 75%, of respondents reported to be informed about the existence of NIPT, mostly by the KNOV, newspapers and training or conferences. Both the first measurement on attitude towards NIPT, in the beginning of the questionnaire, as the second measurement, after more detailed information and questions, are noted in table 2. Being religious (OR=5.30; 95%CI 2.30-12.02) was a significant determinant for having a negative attitude towards NIPT. However, religious midwives had a more positive attitude towards NIPT compared to FCT (56 % versus 40%). Working in non-urban areas was also a significant predictor for a negative attitude (OR= 2.06, 95%CI 1.10-3.85).

Uptake and consequences of NIPT

A rise in uptake of NIPT if it would replace the FCT was expected by 75% of the respondents. A rise in uptake if NIPT would replace invasive procedures was expected by 57% of the respondents. Midwives had a preference for the option that NIPT would replace the FCT in the prenatal screening program (strong preference 25%, preference 39%) as compared to the option that NIPT would replace invasive diagnostics (strong preference 9%, preference 16%). Fifty-three (11%) of the respondents noted to be neutral.
In table 3 the respondents' attitudes towards the possible consequences of NIPT are listed.

When asked about the consequences for their own practice respondents with a positive attitude reported significantly more often possible advantages of NIPT for their own practice than respondents with a negative attitude, like easier counseling (87% resp. 58%) and reduction in referrals for invasive diagnostics (90% resp. 76%). Respondents with a negative attitude valued an increase in the uptake rate of NIPT, an increase in detection T21 and an increase in selective abortion rate as disadvantages. Many midwives noted in a blank field that they believe that although NIPT would replace the FCT the first trimester ultrasound is believed to be maintained. For the society, possible advantage of NIPT noted by the respondents, respectively with a positive or a negative attitude, was the reduction of referrals for invasive diagnostics (95% resp. 87%). Disadvantages mentioned were the possible increased uptake rates (30% resp. 79%) and performing the test as a routine (43% resp. 87%) with less counseling and worse informed decision-making. Many respondents (n=45) commented on a possible increase of discrimination of people with Down syndrome, resulting in social pressure to elect for NIPT and to elect for termination of pregnancy in affected pregnancies. Also the fear of a society not accepting people with handicaps anymore is a comment made by the respondents. Some respondents (n=10) worried about the possible high costs for society with the implementation of NIPT, but are also worried about an unequal access to prenatal care if reimbursement is not available for every pregnant woman. Respondents with a negative attitude were less likely willing to participate in studies concerning prenatal screening.

DISCUSSION

This study is the first evaluation of attitudes of Dutch primary care midwives concerning NIPT. We found that 71% of the respondents were positive about NIPT, considerably more than the 47% who were positive about the current screening program. Respondents with a positive attitude towards screening reported a higher than average uptake of testing. A negative attitude towards both FCT and NIPT was significantly associated with religion.

Up to now, there is little information about the experience and the attitudes of midwives towards the current Dutch screening program and the extent to which the attitude of midwives is influencing the uptake rates of FCT. In a Dutch study in 2007, neither uptake rates, nor attitude of the pregnant women towards prenatal screening could be predicted by the counselors attitude towards prenatal screening.[6] Another study did not detect a correlation between positive attitudes of healthcare professionals towards screening and uptake rates of prenatal screening.[7] The main advantages of NIPT for pregnant women mentioned by midwives were the absence of iatrogenic miscarriage risk, easier-to-understand counseling, fewer referrals for invasive diagnostics and pregnancy termination in earlier gestation.

Reasons for concern towards NIPT were less well-informed decision making, increase in uptake rates and increase in abortion in the case of T21.

Hill et al published a study about the preferences of both women and health professionals in the United Kingdom showing that women preferred the absent risk of miscarriage whereas health professionals preferred a high accuracy.[8] Implementation of NIPT for Down syndrome into routine antenatal care will depend on many factors, including test accuracy, costs, and care pathways. In addition, preferences of the many stakeholders in prenatal care is important. In our study, the respondent midwives prefer NIPT replacing the FCT rather than NIPT replacing invasive procedures. However, policy makers or other stakeholders may prefer offering NIPT only for high-risk women. We believe successful implementation of NIPT into routine health care depends on close collaboration between all stakeholders from the earliest time of planning the changes. The majority of pregnant women (84.2% in 2010) in the Netherlands start their prenatal care with an independently working midwife. Understanding the views of the midwives is essential for planning changes in our national prenatal screening program and appears highly valuable in the interdisciplinary discussions.

The main aim of counseling and prenatal screening is to enable pregnant women to make an informed choice. Counseling of FCT has its difficulties because the FCT only provides a risk assessment. In our study more than 40% of the primary-care midwives found false negative and positive results with risk calculations such as 1 in 250 or 1 in 400 difficult to explain. With NIPT, this will be less difficult, since the result is either highly likely abnormal (>99%), or extremely unlikely abnormal (i.e. less than 1 in 10,000). The positive and negative predictive value will be important to address in the counseling as well as the need to verify the positive result with an invasive procedure before termination of pregnancy NIPT has a potential risk for less adequate informed consent and becoming a routine diagnostic test. On the other hand, with the test becoming safer, more women will have this test performed to get informed about important aspects of the health of their baby. Similar to anomalies detected by ultrasound, also parents who would never decide to terminate the pregnancy for this condition,[9] could very well want to be informed. We need to design a robust screening program together with all stakeholders when for the implementation of NIPT, acknowledging our study outcomes. Our study data should prepare us for an increased uptake of testing once NIPT becomes available. Caregivers should be prepared so they will be able to offer good counseling.

Strengths and limitations

This study provides the first evidence that Dutch primary care midwives hold significantly different attitudes towards the current prenatal screening compared to NIPT. An important limitation is the low response rate of 24%. Despite a postal reminder to the home address of

the KNOV-members we did not receive permission of the KNOV to use email addresses of the KNOV-members. It is possible that this resulted in a lower response rate as the respondents received a paper letter and had to complete the questionnaire online. The response rate might have been higher if a personal email was send with a direct link to the online questionnaire. However, background characteristics were representable for the entire population of primary care midwives. Furthermore, in our study midwives with positive or negative attitudes towards FCT and NIPT are both represented. Obviously, the results of a survey with less than half of the targeted group of midwives actually responding need to be interpreted with caution. Our study does not claim to provide definite answers on the view of all midwives, it is however a useful starting point for discussions and collaboration between obstetric care professionals and other stakeholders in this field.

A second constraint has to do with the nature of opinion-survey. We have not only asked midwives about their attitudes but also asked for estimations of uptake rates and expectations of NIPT-consequences. Estimated numbers may very well differ from actual numbers and none of the respondents has had any real life experience with the execution of NIPT yet.

Furthermore, NIPT has not been yet implemented and attitudes are based on what is expected. If NIPT is actually implemented it would be interesting to repeat our survey and compare the data.

CONCLUSION

Dutch midwives appear to welcome the implementation of NIPT. Their attitudes towards NIPT are more positive than towards the current FCT. Main concerns for implementation are about counseling and well informed decision-making. Counseling courses specifically for NIPT are recommended for all who counsel pregnant women on NIPT.

ACKNOWLEDGEMENTS

Special thanks to A. Stiggelbout, professor in Decision Making, Department of decision making, Leiden University Medical Centre, Leiden, The Netherlands

BIJLAGE - VRAGENLIJST

Geachte collega,

Welkom bij de digitale vragenlijst over prenatale screening op Downsyndroom in het algemeen en in het bijzonder over de nieuwste ontwikkeling: Non-Invasieve Prenatale Test (NIPT).

- **Waar gaat deze vragenlijst over?**
  Het in kaart brengen van de mening van eerstelijns verloskundigen over de huidige prenatale screening op Down syndroom in het algemeen en in het bijzonder over de nieuwe ontwikkeling NIPT.
  De vragenlijst bestaat uit 3 delen:
  - Algemene vragen
  - Huidige prenatale screening
  - Non-invasieve prenatale testen (NIPT)
- **Hoe lang duurt het om de vragenlijst in te vullen?**
  Het invullen van de vragenlijst duurt ongeveer 10 minuten.
- **Tot slot**
  Heel hartelijk dank voor uw deelname.
  Heeft u vragen tijdens het invullen van deze vragenlijst? Belt u dan met
  Enja Romeijn of mail naar verloskundigenoverscreening@kpnmail.nl

Wilt u niet deelnemen, klink dan hier op 'nee'. Wij stellen het op prijs als u wel de algemene gegevens wilt invullen.

❍ Ja, ik wil deelnemen. Question Wilt u niet deelnemen, klink dan hier op 'nee'. Wij stellen het op prijs als u wel de algemene gegevens wilt invullen.

❍ Nee, ik wil niet deelnemen (door naar de algemene gegevens en alleen naar pagina 14) Wilt u niet deelnemen, klink dan hier op 'nee'. Wij stellen het op prijs als u wel de algemene gegevens wilt invullen.

Deel 1: Algemene gegevens

1 Wat is uw leeftijd?
☐☐ jaar

2 Wat is uw geslacht?
M☐V☐

3 In welke postcodegebied bent u werkzaam?
□□□□

4 In welk jaar bent u als verloskundige afgestudeerd?
□□□□

5 Waar bent u afgestudeerd als verloskundige?
- ❑ Amsterdam
- ❑ Groningen
- ❑ Maastricht/Kerkrade/Heerlen
- ❑ Rotterdam
- ❑ Overig namelijk ……

6 Wat is uw huidige functie?
- ❑ eigen praktijk/maatschap
- ❑ in loondienst van een gezondheidscentrum, STBN, etc.
- ❑ klinisch werkzaam
- ❑ in loondienst van een zelfstandig gevestigde verloskundige
- ❑ waarneemster
- ❑ anders, nl. ……..

7 In welk gebied bent u werkzaam:
- ❑ Zeer sterk stedelijk
- ❑ Sterk stedelijk
- ❑ Matig stedelijk
- ❑ Weinig stedelijk
- ❑ Niet-stedelijk

8 Leeft u vanuit een bepaalde geloofs-/levensovertuiging. En zo ja, vanuit welke geloofs/levensovertuiging?
- ❑ Nee
- ❑ (Rooms) Katholiek
- ❑ Protestants
- ❑ Anders christelijk nl…….
- ❑ Hindoeïstisch
- ❑ Humanistisch
- ❑ Anders, nl……..

9 Was counselen voor prenatale screening (PNS) een onderdeel van uw opleiding tot verloskundige?

- ❑ Ja
- ❑ Nee

10 Heeft u (al) de nascholingsmodule voor counselors prenatale screening (PNS) gevolgd?

- ❑ Ja
- ❑ Nee
- ❑ Ik ben het van plan

Deel 2: huidige prenatale screening

Sinds 1 januari 2007 wordt elke zwangere in de gelegenheid gesteld om gebruik te maken van de eerste trimester-combinatietest ter opsporing van voor onderzoek naar trisomie 21, 13 en 18. Afhankelijk van de maternale leeftijd varieert de sensitiviteit van de combinatietest van 70% -96 % en de specificiteit van 75 -97 %.
Wanneer er sprake is van een verhoogde kans op Downsyndroom trisomie 21 (of 13 of 18) is er de mogelijkheid tot invasieve diagnostiek ter vaststelling van trisomie 21. Invasieve ingrepen hebben een iatrogeen miskraamrisico tussen de 0.5 en 1%.
Het geven van voorlichting over prenatale screening en het begeleiden van zwangere vrouwen bij het keuzeproces wordt counseling genoemd.

Op iedere pagina opnieuw: prenatale screening (PNS) en vervolgens alleen PNS

11 Wat is uw houding tegenover de huidige Nederlandse Prenatale Screening (PNS)?

- ❑ Zeer positief
- ❑ Positief
- ❑ Neutraal
- ❑ Negatief
- ❑ Zeer negatief

12 In hoeverre vindt u zichzelf geschoold voor counseling PNS?

- ❑ Meer dan voldoende
- ❑ Voldoende
- ❑ Neutraal
- ❑ Onvoldoende
- ❑ Ruim onvoldoende

13 In hoeverre vindt u zichzelf geschoold voor het geven van de uitslag van de combinatietest?

- ❑ Meer dan voldoende
- ❑ Voldoende
- ❑ Neutraal
- ❑ Onvoldoende
- ❑ Ruim onvoldoende

14 Wat is u mening over de geadviseerde bedenktijd van de zwangere tussen counseling en bloedafname voor de serumtest (als onderdeel van de combinatietest)?

Zeer negatief	negatief	Neutraal	positief	zeer positief
☐	☐	☐	☐	☐

15 Doet u zelf aan counseling prenatale screening (PNS)?

- ❑ Ja
- ❑ Nee, mijn collega's in de praktijk (u kunt doorgaan naar vraag 19)
- ❑ Nee, momenteel ben ik niet werkzaam in de eerstelijns praktijk (u kunt doorgaan naar vraag 19)

16 Hoeveel tijd besteedt u gemiddeld aan counselen PNS per zwangere?

☐☐ Minuten

17 Welk percentage (schatting) van de zwangeren in uw praktijk maakt gebruik van uw aanbod voor counseling PNS?

☐☐ %

18 Welk percentage (schatting) van degenen die zich door u laten counselen maakt gebruik van prenatale screening?

☐☐ %

19 Kunt u de volgende onderdelen van de counseling rangschikken op moeilijkheid om goed uit te leggen aan de cliënt?
1= meest moeilijk, 5= minst moeilijk (gelijke scores mogen ook, dan komt u niet aan 5)

- ☐ Ernst van de afwijking(en)
- ☐ Foutpositieve uitslag
- ☐ Miskraamrisico bij invasief vervolgonderzoek
- ☐ Foutnegatieve uitslag
- ☐ Anders nl…….

20 In hoeverre heeft uw persoonlijke attitude invloed op de wijze van counselen PNS?

- ❑ Heel veel
- ❑ Veel
- ❑ Weinig
- ❑ Heel weinig

Deel 3: Nieuwe ontwikkelingen: Non-Invasieve Prenatale Test (NIPT) Met de nieuw ontwikkelde test, NIPT kan op een betrouwbare, niet-invasieve wijze het foetaal DNA in maternaal serum worden onderzocht op trisomie 21. In de toekomst zal met NIPT de bepaling van andere trisomiëen ook mogelijk zijn. Uit studies, verricht onder vrouwen met een indicatie voor een invasieve ingreep, blijkt dat NIPT een sensitiviteit heeft van bijna 100% en specificiteit van 99,3% voor het bepalen van trisomie 21. Met deze nieuwe test kan trisomie 21 vanaf ongeveer 10 weken bepaald worden waarbij de zwangere een eenduidige uitslag krijgt na ongeveer 2 weken. Hiervoor zijn 2 buisjes maternaal bloed nodig.

21a Was u voordat u deze vragenlijst ging invullen, al bekend met (Non-Invasieve Prenatale Test) NIPT?

- ❑ Ja
- ❑ Nee

21b Zo ja, op welke manier? (Meerdere opties mogelijk)

- ❑ Collega
- ❑ KNOV
- ❑ Krant
- ❑ Tijdschrift voor Verloskundigen
- ❑ Ander tijdschrift
- ❑ TV
- ❑ Radio
- ❑ Overig……..

22 Wat is uw houding ten aanzien van NIPT met de kennis die u nu hebt?

- ❑ Zeer positief
- ❑ Positief
- ❑ Neutraal
- ❑ Negatief
- ❑ Zeer negatief

Internationaal wordt er discussie gevoerd over de manieren van invoeren van NIPT binnen het prenatale screeningsprogramma.

Er zijn twee mogelijke opties:

A. NIPT vervangt invasieve diagnostiek
De combinatietest aanbieden als screeningstest en bij een verhoogde risico op trisomie 21 NIPD aanbieden ter vervanging van invasieve diagnostiek.

B. NIPT vervangt de combinatietest.
NIPT aanbieden als screeningstest aan alle zwangeren en bij een positieve testuitslag invasieve diagnostiek aanbieden ter vaststelling van trisomie 21.

23 Welke van deze 2 opties heeft uw voorkeur:

Sterke voorkeur **A**	voorkeur **A**	Neutraal	voorkeur **B**	Sterke voorkeur **B**
☐	☐	☐	☐	☐

24 Wat verwacht u dat de invoering van NIPT (als vervanging van invasieve diagnostiek, zoals bij optie A) zal betekenen voor de deelname van zwangeren aan prenatale screening?

- ❑ deelname neemt sterk toe
- ❑ deelname neemt toe
- ❑ deelname blijft gelijk
- ❑ deelname neemt af
- ❑ deelname neemt sterk af

25 Wat verwacht u dat de invoering van NIPT (als vervanging van de combinatietest, zoals bij optie B) zal betekenen voor de deelname van zwangeren aan prenatale screening?

- ❑ deelname neemt sterk toe
- ❑ deelname neemt toe
- ❑ deelname blijft gelijk
- ❑ deelname neemt af
- ❑ deelname neemt sterk af

Enerzijds zal NIPT naar verwachting de counseling makkelijker maken. De zwangere krijgt een betrouwbare uitslag in plaats van een kansbepaling. Bij een positieve uitslag op trisomie 21 zal dit in eerste instantie nog worden bevestigd met invasieve diagnostiek. Uitsluiting van het miskraamrisico zal ook een belangrijke factor zijn in het maken van een keuze. De verwachting is dat meer vrouwen zullen kiezen voor NIPT dan voor de CT.
Anderzijds is een veelgenoemde stelling dat invoering van NIPT zal leiden tot een minder weloverwogen keuze van de zwangere over mogelijke deelname aan prenatale screening en diagnostiek.

26 Hieronder volgen mogelijke consequenties van invoering van NIPT voor de zwangere. Beschouwt u, als verloskundige, ieder van deze consequenties voor de zwangere overwegend als een voordeel, nadeel of neutraal?

Mogelijke consequenties	groot voordeel	voordeel	neutraal	nadeel	groot nadeel
Geen miskraamrisico	☐	☐	☐	☐	☐
Begrijpelijkere counseling voor de zwangere door eigen zorgverlener	☐	☐	☐	☐	☐
Daling aantal verwijzingen voor counseling naar de 2e lijn	☐	☐	☐	☐	☐
Daling aantal verwijzingen voor invasieve ingrepen	☐	☐	☐	☐	☐
Toename deelname test(en) op trisomie 21	☐	☐	☐	☐	☐
Toename opsporing trisomie 21	☐	☐	☐	☐	☐
Weloverwogen keuze neemt af	☐	☐	☐	☐	☐
Zwangerschapsafbreking bij kortere amennorroeduur	☐	☐	☐	☐	☐
Totaal aantal zwangerschapsafbrekingen neemt toe na vaststelling trisomie 21	☐	☐	☐	☐	☐
Er vindt een echo (nekplooimeting) minder plaats	☐	☐	☐	☐	☐

Overige opmerkingen .....

27 Hieronder volgen mogelijke consequenties van invoering van NIPT voor uzelf. Beschouwt u, als verloskundige, ieder van deze consequenties voor uzelf overwegend als een voordeel, nadeel of neutraal?

Mogelijke consequenties	groot voordeel	voordeel	neutraal	nadeel	groot nadeel
Eenvoudigere counseling	☐	☐	☐	☐	☐
Minder onzekere cliënt	☐	☐	☐	☐	☐
Daling aantal verwijzingen voor counseling naar de 2e lijn	☐	☐	☐	☐	☐
Toename deelname test(en) op trisomie 21	☐	☐	☐	☐	☐
Toename opsporing trisomie 21	☐	☐	☐	☐	☐
Daling aantal verwijzingen voor invasieve ingrepen	☐	☐	☐	☐	☐
Totaal aantal zwangerschapsafbrekingen neemt toe na vaststelling tisomie 21	☐	☐	☐	☐	☐
Er vindt een echo (nekplooimeting) minder plaats	☐	☐	☐	☐	☐

Overige opmerkingen .....

28 Hieronder volgen mogelijke consequenties van invoering van NIPT voor de maatschappij. Beschouwt u, als verloskundige, ieder van deze consequenties voor de maatschappij overwegend als een voordeel, nadeel of neutraal?

Mogelijke consequenties	groot voordeel	voordeel	neutraal	nadeel	groot nadeel
Testen op trisomie 21 wordt vanzelfsprekender	☐	☐	☐	☐	☐
Toename deelname test(en) op trisomie 21	☐	☐	☐	☐	☐
Toename opsporing trisomie 21	☐	☐	☐	☐	☐
Totaal aantal zwangerschapsafbrekingen neemt toe na vaststelling trisomie 21	☐	☐	☐	☐	☐
Counseling door eigen zorgverlener is goedkoper	☐	☐	☐	☐	☐
Daling aantal verwijzingen voor counseling naar de 2e lijn	☐	☐	☐	☐	☐
Daling aantal verwijzingen voor invasieve ingrepen	☐	☐	☐	☐	☐

Overige opmerkingen .....

29 Stel dat NIPT wordt geïmplementeerd in het Nederlands screeningsprogramma, wat is volgens u het belangrijkste aandachtspunt?

.....

.....

30 Wat is uw mening over NIPT na de informatie die u hebt gelezen in deze vragenlijst:

- ❑ Zeer positief
- ❑ Positief
- ❑ Neutraal
- ❑ Negatief
- ❑ Zeer negatief

Het Nederlandse NIPT consortium en de NITRO-studie

In het voorjaar van 2011 is het NIPT-consortium opgericht waarin alle academische ziekenhuizen, het RIVM, de KNOV, de NVOG, de VSOP en Sanquin deelnemen met als doel een grootschalige studie op te zetten. De voorbereidingen worden getroffen voor de zogenaamde **Non-Invasief Trisomie Onderzoek (NITRO) studie** waarbij in het huidige studiedesign de combinatietest zal worden vergeleken met de nieuwe NIPT. De counseling voor de NITRO-studie zal voornamelijk bij de verloskundigen plaatsvinden.

31 Bent u bereid in de toekomst vrouwen te counselen voor de NITRO-studie?

- ❑ Ja
- ❑ Nee, om de volgende reden(en)

.....

Hartelijk dank voor het invullen van de vragenlijst!

Variables	Median(Range)	N (%)*	National data **
Gender			
Female		473 (97)	98%
Male		9 (2)	2%
Age	33 (21-63)		
<25		55 (11)	7%
25-34		208 (42)	41%
35-44		106 (22)	22%
45-54		83 (17)	15%
>54		36 (7)	7%
Years since graduation	9 (1-41)		
Urbanization of working area			
no		165 (34)	7%
little		65 (13)	22%
moderate		70 (14)	22%
strong		42 (9)	29%
very strong		141 (29)	20%
Religion			
religious/belief		199 (40.7)	58%
non-religious/belief		283 (57.9)	42%
Estimation by midwife of clients:			
wish to receive information FCT	90% (2-100)		91% (84-94)
elect FCT	25% (1-99)		27% (14-49)
Time required for counseling interview	10min (3-50)		23min

Table 1. *Background characteristics of primary care midwives*
**Responses to some questions were missing, thus total values may not add to 100%.*
***National data 2011(primary care midwives)*

Variables	*N (%)**
Attitude towards current FCT	
positive	230 (47)
neutral	169 (35)
negative	84 (17)
Assumed influence personal attitude on counseling FCT	
very little	138(28)
little	280 (57)
strong	49 (10)
very strong	1 (0.2)
Attitude towards NIPT (first measurement)	
positive	322(68)
neutral	119 (25)
negative	31(7)
Attitude towards NIPT (second measurement)	
positive	347 (71)
neutral	95 (19)
negative	38 (8)

Table 2. *Attitudes of primary care midwives towards FCT and NIPT*

** Responses of some questions were missing, thus total values may not add to 100%*

	Advantage (%)	*Neutral (%)*	*Disadvantage (%)*
Absence of iatrogenic miscarriage risk	97	1	0.2
More understandable counseling	82	17	0.4
Reduction counseling consultations in hospital	42	57	0.2
Reduction referrals invasive diagnostics	91	7	0.4
Increased uptake rate NIPT	11	58	30
Increased detection DS	47	40	11
Less well-informed decision	2	27	70
Abortion at earlier gestation	77	17	4
Increase of abortion in case of DS	7	67	24
One ultrasound investigation less (NT)	23	60	16
Routinisation of testing	13	35	41

Table 3. *Attitudes of primary care midwives towards the possible consequences of NIPT NIPT: non-invasive prenatal test; DS: Down syndrome; NT: nuchal translucency*

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E.J.T. Verweij ● D. Oepkes ● E.S.A.van den Akker
M.A. de Boer ● R.E. Hellemondt ● D.P. Engberts

NTOG oktober 2013