



The role of experiential knowledge in prenatal screening decisions

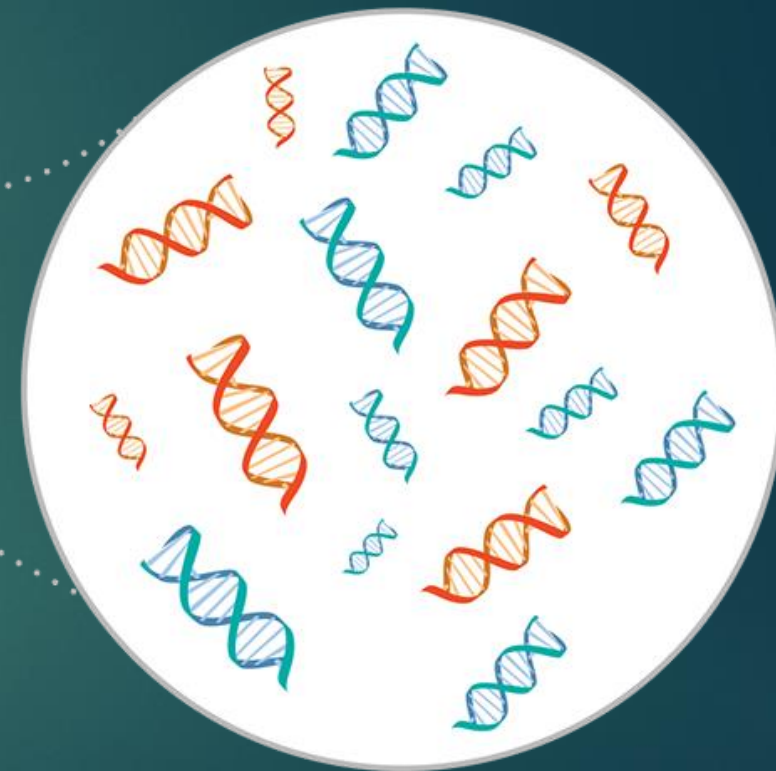
THE CASE OF NIPT IN THE
NETHERLANDS


NIPT in the Netherlands


- ▶ Recently introduced for low-risk women in the Netherlands (April 2017).
- ▶ Blood test
- ▶ Performed after 10 weeks of gestational age



Maternal blood sample



 Maternal cfDNA

 Fetal cfDNA

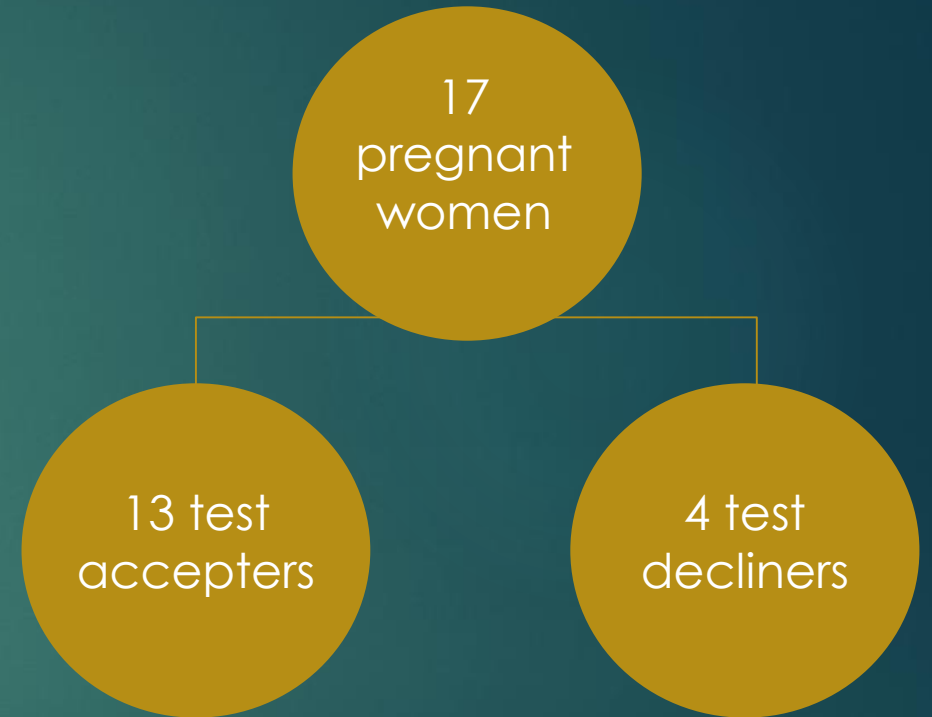
Counseling

- ▶ Informed decision-making
 - ▶ Accurate and relevant knowledge
 - ▶ In line with values
- ▶ Information provision
 - ▶ Risk rates
 - ▶ Test procedure
 - ▶ Sensitivity and specificity
 - ▶ Reporting time
 - ▶ Confirmation with invasive diagnostic testing



Research question and methods

- ▶ Research question
 - ▶ How do pregnant women decide about prenatal screening?
 - ▶ What types of information do they use when making a decision?
- ▶ Semi-structured interviews with 17 low-risk pregnant women
 - ▶ 13 test acceptors, 4 test decliners
 - ▶ Majority white, highly educated and secular.

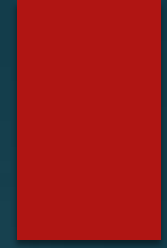


Expert vs experiential knowledge

- ▶ Expert knowledge
 - ▶ Good understanding
 - ▶ Not decisive in final decision
- ▶ Experiential knowledge
 - ▶ Obtained through observation or experience
 - ▶ Embodied
 - ▶ Empathetic



Reproductive history



Reproductive history

Because I found the miscarriages rather intense, I thought, 'What if I get a child with one of these syndromes [Edwards' syndrome or Patau's syndrome]?' These children have a life span of about 6 weeks. (...) I felt like I was not able to deal with that again. I thought, if that happens... I cannot cope with that. I wanted to rule that out for myself.
– Robin, 32, test accepter



Family history



Family history

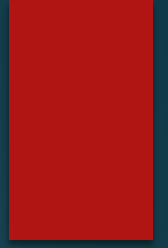
When you look at them, you can see that their lives are seriously restricted by their son. And you can see that the child is struggling in life as well. And of course there is happiness sometimes, but there are very difficult moments too in which you... In which your child doesn't understand anything about the world at all. That is something you just don't wish for your child. If you could make a wish, you would wish that your child wouldn't suffer from those syndromes. Quirine, 33, test accepter. – Quirine, 33, test accepter



Other people's test experiences



Other people's test experiences



The wife of my colleague regretted that she did not accept it [prenatal screening]. Because she could see that people who had done it felt relieved, so she felt like: "I would have liked to get that relief or certainty. Or that you can prepare when it is negative." Birgitte, 26, test accepter. – Birgitte, 26, test accepter



Conclusion

- ▶ Experiential knowledge more prominent in decision-making than expert knowledge
- ▶ Experiential knowledge as an 'assistive resource'
 - ▶ Meaning of losing a child during pregnancy
 - ▶ Imagine life with a disabled child
 - ▶ Give meaning to technical aspects of screening tests
- ▶ Concrete, current and commonsensical
- ▶ Experiential knowledge not used to undermine expert knowledge

Recommendations for counseling

- ▶ Attend to individual information needs
- ▶ Enable women to raise their own doubts and concerns
- ▶ Exploration of experiential knowledge

Point of discussion

- ▶ Should counselors actively provide experiential knowledge?


van mijn ongeboren kind

ing op down-, edwards- en patausyndroom 20 wekenecho Meer informatie

ing op down-, edwards- en patausyndroom > Keuzehulp

en anderen?

Meer over de aandoeningen Kosten Veelgestelde vragen **Keuzehulp**



den van hoe zwangeren (en hun partners) een keuze maken over prenatale screening.

st ons betreft welkom. Maar als onze tweede downsyndroom zou hebben, dan zou dat niet alleen heel veel betekenen voor Stefan en mij, maar in daarom besloten om wel onderzoek te laten doen. Mocht er iets zijn, dan zouden we ons daar in elk geval goed op voor kunnen bereiden. Uit was met het kindje. We hebben toen gekozen voor verder onderzoek in het ziekenhuis. Gelukkig kregen we daar een goede uitslag.”

en op deze kleine gewacht, het kindje is meer dan welkom. Een test zou mij denk ik juist stress geven tijdens de zwangerschap, omdat het geen you als je net die ene bent? Mijn man begrijpt mijn gevoel hierover. Wij doen daarom geen test, dit stond voor ons eigenlijk al vast. Het gesprek e hierin alleen nog maar sterker gemaakt.”

e van mijn vriendinnen die zwanger is, dus ik wist eigenlijk niet dat er zoveel vragen zouden komen over ‘wel of geen onderzoek’, ‘welke test’ en en’. Gelukkig nam de verloskundige alle tijd om de verschillende mogelijkheden toe te lichten. We hebben uiteindelijk gekozen voor de NIPT m zou komen, zou ik het zeker verder laten onderzoeken. Ik weet het wel hoor, echte zekerheid krijg je nooit, er kan altijd iets gebeuren. Maar de r

Extra: Reproductive history II

I did not do it [accept a prenatal screening test] with the other three [children] either. Maybe it sounds a bit stupid, but I just assume, because I already experienced three good pregnancies, that this time all will be fine as well. – Melissa, 34, test decliner

