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Stimulating Informed Decisions in Prenatal Screening: Exploring Initiatives to Aid Parental Decision-Making

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Abstract

Informed decisions concerning non-invasive prenatal testing (NIPT) seem contingent on health professionals and expectant parents (1) having access to multifaceted information about the procedure of NIPT and the subsequent choices; and (2) actively reflecting about what prenatal screening means beyond the medical level (including personal values and beliefs). International studies show that many pregnant women do not make informed decisions about prenatal testing (Beulen et al. 2016). Interviews we conducted with various stakeholders in Belgium show similar tendencies.

Based on transdisciplinary research (Dehens et al. 2017)—which included stakeholder interviews, and a review of academic literature, current prenatal screening guidelines, and good practices—we propose three initiatives that can help stimulate informed choices. The initiatives are: (1) a decision aid that encourages expectant parents to think about NIPT, its possible outcomes, and the conditions NIPT screens for (see e.g. Smith et al. 2018; Carslon et al. 2019); (2) the creation of a nation-wide protocol (*draaiboek*) for prenatal screening outlining what information should be provided at what point during a pregnancy, in what way, and by whom (see for instance the *Draaiboek Prenatale screening down-, edwards- en patausyndroom en structureel echoscopisch onderzoek versie 9.0* in the Netherlands); and (3) an online platform featuring a balanced representation of testimonials about various experiences with the main conditions NIPT screens for taking Braverman (2008) as a starting point. These initiatives were discussed (conceptually) at a round table discussion with a broad range of stakeholders (May 8, 2019). A concluding poll showed

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a strong consensus concerning the need to develop a prenatal screening protocol and a decision aid in order to help health professionals and expectant parents, navigate through prenatal screening programs in Belgium. Anticipating the widening scope of genetic tests, a general plan of action is necessary to ensure counseling possibilities and informed decisions.

Key words

NIPT, genetic counseling, informed decisions, transdisciplinary research, Down syndrome

Original Challenge Statement (see Supplement 1)
To find "a way to provide gynecologists and general practitioners with the tools to counsel in a non-directive manner, thereby assisting expecting parents to make informed decisions about their pregnancies."

1. Background

Two pre-conditions for informed decisions in prenatal screening are fulfilled when expectant parents have "adequate decision-relevant knowledge" and when their decisions for or against prenatal testing reflect their values about and attitudes toward prenatal testing (Beulen et al. 2016: 1410) and, we would add, disability. Genetic counseling is a crucial element in this decision-making process (see for instance Carlson et al. 2019). The goal of genetic counseling is "to provide the risk assessment, support, education and resources needed to facilitate patient decision making that best supports the individual patient's personal needs and values." (Fonda Allen, Stoll & Bernhardt 2016: 56).

The issue of genetic counseling in Belgium gained momentum when the federal government decided to reduce the cost of NIPT to €8.68 for all women who have public health insurance in Belgium, but additional resources for counseling did not follow (Costan et al. 2018). This decision, and the speed with which the policy was implemented in July 2017, sparked societal discussion. No country had at that date made NIPT more accessible to pregnant women than Belgium. As a result, a large majority of pregnant women opt for NIPT. However, to our knowledge, no additional budget has been made available for genetic counseling.

In non-invasive prenatal testing (NIPT) the placental cell-free DNA circulating in the maternal blood is analyzed. Today it is the most accurate screening test for trisomy 21, 13, and 18, with a detection rate that varies between 94.4% and 100% and a false positive rate that varies between 0% and 0.94% for trisomy 21 (Gil et al. 2017), though we need to take into account that detection options and accuracy depend on the source and the variations of NIPT.[1] NIPT can also detect the sex of the fetus and sex chromosome aneuploidies (Gil et al. 2017). The (current) goal of NIPT is to generate information for expectant parents about possible fetal chromosomal abnormalities, and in this way enable them to make autonomous and informed reproductive decisions.[2] If NIPT indicates a fetal abnormality, expectant parents can choose to continue with invasive prenatal testing, to continue the pregnancy, or to terminate.

In Belgium, NIPT is routinely used but expectant parents are not always prepared for the difficult choices that the test potentially confronts them with (Costan et al. 2018). Studies from other countries confirm that many pregnant women do not make informed decisions about prenatal testing (see for instance Beulen et al. 2016). Numbers about informed decisions among pregnant women in Belgium are limited, yet those available indicate that 30–40% of women are insufficiently informed about NIPT and Down syndrome (Buyle, 2018). This quantitative study in Belgium found that women's knowledge about prenatal screening is characterized by "a discrepancy between the knowledge about what Down syndrome entails (44.74%) and the knowledge about prenatal testing (65.15%)." (Buyle 2018: 11). In her study, which included 549 women, Buyle (2018) found that age, literacy, socio-economic situation, and the provision of information brochures were factors that influenced women's attitudes towards and knowledge of prenatal tests and Down syndrome. Other factors the literature reports to influence pregnant women's informed decisions about prenatal screening include: (health) literacy (Delanoë et al. 2016; Smith et al. 2018); the format in which the information is

1 UZ Leuven for instance works with NIPT-PLUZ, but AZ Delta works with VeriSeq™. NIFTY®, was the first available test (for more examples of commercialized NIPT see Allyse et al. 2015: 155).

2 As was also pointed out in Opinion 66 by the Belgian Advisory Committee on Bioethics (2016), the goal of NIPT will be interpreted on the basis of the ethical point of view one subscribes to. Some people argue that the purpose of NIPT is to avoid people with a disability like Down syndrome from being born (see e.g. the principle of procreative beneficence (Savulescu 2004)). Others argue that the purpose of NIPT is gathering knowledge in order to prepare for whatever the test finds, and in order to make autonomous reproductive decisions (see e.g. Beulen et al. 2016).

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provided (Kupperman et al. 2009, Björklund et al. 2012); and the way women bring together personal values and scientific knowledge (Potter et al. 2008).

Moreover, based on stakeholder interviews with representatives of *Downsyndroom Vlaanderen* (a contact group for parents with a child with Down syndrome) and *Cozapo* (a contact group for parents who decide to terminate a pregnancy following prenatal screening), Costan et al. (2018) note that in Belgium, in the event of a positive NIPT result, expectant parents feel ill-prepared for the decision they are confronted with (2018: 41). Additionally, health professionals are reported by both contact groups to tend to steer expectant parents toward termination (Ibid: 41–42). Costan et al. (2018) traced this to the often purely medical perspective health professionals have of Down syndrome (Ibid: 42). Similar trends were communicated to us during our interactions with various stakeholders in Belgium, who further point to a lack of unified strategies for providing information and stimulating reflection in both expectant parents and health professionals. Additional factors the stakeholders report to impact prenatal counseling practices in Belgium are: the routinization of NIPT (see also Belgian Advisory Committee on Bioethics opinion 66; Cernat et al. 2019), a lack of reflection from expectant parents, the lack of resources for good quality counseling (both time and funding), the fragmentation of healthcare in Belgium, confusion about who should do the counseling, and the content and format of information given to expectant parents about NIPT.

Given these issues, the aim of our inquiry is to gain insight into what local stakeholders believe to be promising strategies to stimulate informed decisions about NIPT that are, up to this point, underexplored or underutilized in Belgium.

2. Method: A Three-Tiered Approach

The aim of this article is to gain insight into stakeholder perspectives in Belgium about ways to stimulate informed decisions about NIPT. A transdisciplinary research perspective (Dehens et al. 2017) was adopted to tackle this aim. The choice for the transdisciplinary framework is motivated by two reasons. First, it gives a central place to stakeholder perspectives: stakeholder perspectives are considered a crucial source of information for our inquiry. Second, we need an approach that can deal with the complexity of the issue at hand. Transdisciplinary research involves interaction between academic disciplines, as well as stakeholders. This creates a unique exchange of knowledge.

Essentially, transdisciplinary research aims to co-create knowledge among different stakeholders, who each bring their particular first-hand experience to the table. Characteristic elements of transdisciplinary research (Dehens et al. 2017, and footnote 3) that we incorporated were an interdisciplinary literature study, an actor-constellation game (building on Costan et al. 2018: 64), consulting experts and including various stakeholders in the project. We identified and followed three steps to gain insight about what stakeholders in Belgium believe are promising strategies to stimulate informed decisions about NIPT: (a) identify stakeholders; (b) identify good practices and guidelines as strategies; (c) combine (a) and (b) and find out the identified stakeholder's opinions about the selected strategies.

Step (a): Identify stakeholders

For the identification of stakeholders this paper builds on the publication "Down to Counsel: Towards a Transdisciplinary Toolbox for Non-directive Counseling in Prenatal Screening for Down Syndrome" (Costan et al. 2018). This publication was the result of a project by a team of students from various academic disciplines in 2017–2018 within the framework of the KU Leuven Transdisciplinary Insights Honours Programme. In this program teams of students from various academic backgrounds work on transdisciplinary issues that are called 'societal challenges'. The main aim of the team in 2017–2018, which was the first to address the NIPT challenge, was to map out the stakeholders and issues involved with NIPT. They did this according to an actor-constellation game, a method from the Transdisciplinary Toolbox (Costan et al.: 64). This is "a role-play, in which all scientific and societal actors involved in a project are represented and positioned around the central research question. The distance from an actor to the research question, and to other actors, expresses how relevant (s)he is in the project."[3] In 2018–2019, a new team of four students, supported by two students from the previous year as co-coaches, started off from this map of stakeholders. Following this map, we selected stakeholders for interviews (see Table 1), and stakeholders to participate in the round table discussion (see Supplement 2).

3 https://naturalsciences.ch/topics/co-producing_knowledge/methods/td-net_toolbox/actor_constellation_final_

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Stakeholder	Location	Number	Further specification
Members from centres of human genetics	Gent	1	Paediatrician & clinical geneticist
	Leuven	3	Clinical geneticist, midwife, genetic counsellor
	Antwerp		Gynecologist & clinical geneticist Paediatrician & clinical geneticist
	Brussels	2	Gynecologist, genetic counselor
Bioethicist	Leuven	1	
Communication expert	Leuven	1	
Gynecologist	Leuven	1	
Psychologist	Leuven	1	From the Fara vzw organization
Mother who lost her child with Down syndrome	Antwerp	1	
Member of a disability rights organization	Brussels/ Leuven	1	
Midwife	Gent	1	Mother of a child with Down syndrome

Table 1. List of interviewed stakeholders 2018-2019.

Step (b): Identify good practices and guidelines

In order to obtain an overview of initiatives that can help expectant parents make prenatal decisions we consulted four types of sources. First, following the transdisciplinary approach, we reviewed literature from various academic disciplines. The main emphasis of our literature study was on pregnant women's attitudes toward prenatal screening, the use of decision aids in the prenatal context, and ways in which information is best provided. We further explored literature from disability studies. Secondly, we consulted and inventoried currently available prenatal screening guidelines and good practices. We also evaluated hospital booklets and brochures about NIPT (see Table 4). We further compared Belgian prenatal screening guidelines and good practices with an example of a protocol in the Netherlands.[4] Lastly, we arranged interviews with various stakeholders. We conducted 11 interviews with a total of 13 participants (see Table 1). Because we wanted to gather a variety of perspectives, the stakeholders we interviewed have different relations with the prenatal screening process. We generally worked with a basic skeleton of questions for each interview that we loosely adhered to. These questions pertained mainly to information provision. For instance, what information should expectant parents be provided with? At what point during a pregnancy? In what way? By whom? However, depending on the kind of stakeholder, we would ask questions tailored to what we would like to know from them specifically. Because the interview usually took on the form of a conversation, many questions were formulated during the interview itself, responding to input from stakeholders.

The literature study, guidelines, good practices, booklets, and interviews with stakeholders allowed us to identify four areas of intervention, and to identify various current practices and initiatives (Tables 2 and 3).[5]

Step (c): Bringing steps (a) and (b) together: What do stakeholders think?

The final step in reaching our aim is to see what stakeholders themselves think about initiatives: the stakeholders identified in step (a), the need to evaluate current practices and other initiatives identified and selected in step (b). In order to gain insight into the perspectives of the stakeholders, we opted for a qualitative method of gaining data in the form of a focus group—specifically a round table discussion. We acknowledge that quantitative data collection in the form of a survey would have given data on a larger sample of respondents. However, the focus group

4 The most recent version can be consulted here: https://www.rivm.nl/documenten/draaiboek-prenatale-screening-down-edwards-en-patausyndroom-en-structureel-echoscopisch

5 We acknowledge that this list may not be exhaustive.

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	Targeting Expectant Parents	Targeting Health Professionals
Stimulating Reflection	(Genetic) Counseling	CME, Info-Sessions, other Forms of Professional Support
Providing Information	Brochures, Online Information, 'Contact Parents',...	Guidelines, Good Practices,...

Table 2. Outlining four areas of intervention: Identifying current practices or initiatives.

allowed for discussion between different parties, which gives us additional perspectives on the way different stakeholders evaluate the practices and initiatives discussed. Moreover, this is in line with one of the cornerstones of transdisciplinary research, namely the co-creation of knowledge.

3. Findings: Stakeholder Meeting (May 8, 2019)

On May 8, 2019, a round table discussion was organized with 30 stakeholders (see below, and see Supplements 2–7b). Broadly speaking, the stakeholder meeting aimed to create an opportunity to discuss emanating issues about prenatal screening. To our knowledge, this meeting was one of the first of its kind in Belgium where a broad range of stakeholders was represented to discuss several initiatives.

3.1 Step (a): Identified stakeholders

We gathered a panel of 30 stakeholders for the round table among whom were gynecologists, midwives, bioethicists, parents, (genetic) counselors, politicians, psychologists, parents of persons with Down syndrome, disability organizations and ((bio)medical) students (see Supplement 2).

3.2 Step (b): Identified good practices, guideline, and other initiatives

This panel neatly represents the actors from the constellation game by Costan et al. (2018). Prior to the round table we conducted interviews (see 3.2 step (b)). The kind of stakeholders we interviewed are listed in Table 1.

On the basis of our literature study and interviews with stakeholders we were able to juxtapose four areas of intervention (Tables 2 and 3) and to identify various practices and initiatives which each correspond to one of the four areas. In Table 3, we present three initiatives that can stimulate informed choices: (1) a decision aid, (2) standardized counseling for prenatal screening (including NIPT) shaped by a protocol, (3) and a multimedia platform with testimonials (see Supplement 5). We selected these initiatives as they are not, or only marginally, in practice in Belgium, to as such explore more thoroughly what their possibilities in Belgium are.

	Targeting Expectant Parents	Targeting Health Professionals
Stimulating Reflection	(1) Decision Aid	(4) ?
Providing Information	(3) Testimonials	(2) Protocol

Table 3. Outlining four areas of intervention: Initiatives that could be incorporated in Belgium.

In what follows, we briefly outline each of the initiatives as presented during the meeting (for the presentation, see Supplements 3, 5 and 6).[6] As mentioned above, the initiatives (1), (2), and (3) correspond to previously identified areas of intervention. For the fourth area of intervention no immediate initiatives were found, hence we formulated this as (4) a question mark, as an incentive to stimulate debate during the stakeholder meeting.

3.2.1 A decision aid for the prenatal screening context in Belgium

A decision aid is a tool that assists patients to make decisions about treatment. The International Patient Decision Aids Standards Collaboration (IPDAS) defines

6 A shortened version of the presentation can be found in English in Supplement 8.

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decision aids as "tools designed to help people participate in decision making about health care options. They provide information about the options and help patients clarify and communicate the personal value they associate with different features of the options."[7] (see also Supplement 6) In essence, we can state that the desired effect of decision aids is an increase in the number of informed health-related decisions. As medical culture slowly shifts from paternalism to patient-centered care in medical decision making, decision aids are increasingly developed in various health contexts.

Since the introduction of NIPT in 2011 in Hong Kong, and over 60 countries since then (Allyse et al. 2015), studies about the utility of decision aids in the prenatal context have globally increased.[8] Most studies about decision aids for prenatal screening (before and after the introduction of NIPT) show that women who use an interactive (web-based) decision aid are better informed about prenatal screening, and subsequently make autonomous informed decisions more often (Kuppermann et al. 2009; Vlemmix et al. 2012; Beulen et al. 2016; Åhman et al., 2016; Smith et al. 2018). Women who use a decision aid are better able to formulate their own perspectives on screening and its possible consequences (Åhman et al., 2016). One reason for this can be that they employ more emotional and cognitive strategies in the decision-making process compared to women who are not decision-aided (Bekker, Hewison & Thronton, 2002).

Having to make difficult choices induces stress that in this context has been referred to as "decisional conflict". Bekker et al. (2002) found that decisional conflict leads to better decisional outcomes. However, this need not be the case. A more recent study found that decisional conflict was reduced when pregnant women were decision-aided by means of a combination of a decision aid and genetic counseling (Carlson et al. 2019). Contrary to Bekker et al. (2002), Carlson et al. (2019) did not find a difference in knowledge about prenatal testing and decisional conflict between the groups that either only used a decision aid, or only saw a genetic counselor. In any case, these findings suggest that if expectant parents are thoroughly informed about their choices and are encouraged to reflect on the extent to which those choices match their values, they are better prepared to make informed decisions.

Either way, decision aids should be accessible to all women. Hence, Smith et al. (2018) developed a decision aid that accommodates various levels of (health) literacy. This relates to the important challenge when developing a decision aid that "Special attention should be given to pregnant women with lower health literacy levels to increase their intention to use a [decision aid] and ensure that every pregnant woman can give informed and value-based consent to prenatal screening." (Delanoë et al. 2016: 5).

However, not all decision aids that are developed have the desired effect of increasing informed decisions (see for instance in Denmark Skjøth et al. 2015a and Skjøth et al. 2015b). Perhaps this is due to the limited amount of information that is provided through the aid, and the absence of questions that help stimulate expectant parents to include their values and beliefs in the decision-making process. Alternatively, the limited effect could be due to the high degree of health literacy of the women included in the study. In Denmark the 'Down screening programme' has existed since 2006. A 2012 Danish study shows that there is a ca. 80% informed choice to begin with; it is difficult to increase this even further (Skjøth et al. 2015b: 1333).

A shortcoming we see in the decision aids we had access to and evaluated is that they show a very narrow picture of Down syndrome and other aneuploidies.[9] This shortcoming extends to other tools, like clinical guidelines, used in the prenatal context. This brings us to a broader point: even if consensus exists that expectant parents should receive all the relevant information prior to NIPT, it is not clear what is included 'all the relevant information'. If the implementation of a decision aid is taken seriously as a way to stimulate informed decisions of expectant parents for prenatal screening in Belgium, more research is needed to delineate its format and content.[10,11] For

7 http://ipdas.ohri.ca/what.html

8 Studies about decision aids for prenatal screening before NIPT are still relevant. However, given the differences NIPT offers compared to invasive prenatal diagnostic tests, these studies need to be updated with NIPT in mind.

9 See e.g. the web-based decision aid developed in Denmark by Skjøth et al. 2015: http://graviditetsportalen.dk/; and the Patient+ Foundation initiative in the Netherlands: https://www.keuzehulp.info/pp/pnt/intro/2 (used in the Beulen et al. 2016 study).

10 In relation to the content of a decision aid, see for instance a study in the Netherlands that evaluates what knowledge is relevant for informed decisions in screening for Down syndrome: Schoonen et al. 2011.

11 The challenges of implementing decision aids are also addressed in the literature (see e.g. Portocarrero et al. 2017; Agbadjé et al. 2018). More research on how to implement a decision aid in Belgium is needed.

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instance: What do Belgian expectant parents deem important to know to make an informed decision?

In conclusion, the literature shows promising effects of decision aids on informed decision making in prenatal screening, especially for the Belgian context where additional resources for counseling are not yet available. If implemented effectively, a decision aid could reach a lot of pregnant women and would cost less to develop compared to resources for counseling.

3.2.2 Standardizing prenatal counseling: a nation-wide protocol

Another strategy to increase informed decisions is to develop a nation-wide protocol for prenatal screening. In contrast to the decision aid, which targets expectant parents, this initiative targets health professionals. A prenatal screening protocol would outline what information should be provided at what point during a pregnancy, in what way, and by whom. NIPT was implemented in Belgium at a rapid pace. This is considered a good thing: experts in Belgium agree that it is good that women with public health insurance in Belgium have equal access to NIPT, regardless of their financial situation. However, they also agree that the importance of (genetic) counseling was insufficiently addressed by the government. Since prenatal screening is an ethically sensitive issue, it is paramount that women have the choice to opt for screening, and that they genuinely consent to the tests. In this regard, counseling before and after the test(s) is essential. Such systematic genetic counseling seems contingent on a protocol for prenatal screening with the explicit provision for counseling.

The Belgian government currently does not offer a nation-wide protocol, and the more general guidelines on prenatal screening and NIPT currently seem to leave too much room for interpretation. We understand that a certain degree of indeterminacy in guidelines is justifiable, given that each hospital has its own culture and structure in which those guidelines need to be implemented. This also holds true for the Belgian guidelines we had access to, which state that physicians should communicate to patients about: what screening implies, what the consequences are, what will follow after a positive or negative result, the meaning of a positive test, explanation about possible detectable syndromes, and different screening options and their possible limitations.[12,13,14] One way of estimating the way in which hospitals interpret these guidelines is to analyze the educational booklets, brochures, and webpages about prenatal screening and NIPT hospitals provide expectant parents with. The booklets and brochures can be consulted via the websites of the hospitals. We analyzed six of these about NIPT (see Table 4) and four webpages with a similar informing function (see Table 4).

6 booklets, 4 websites (in Flanders, Brussels)	**Brochure**	**Website**
University Hospital Antwerp	X	x
University Hospital Leuven	X	x
University Hospital Brussels	X	x
University Hospital Gent	X	x
East-Limburg Hospital (ZOL) (regional)	X	
St. Lucas general Hospital (Brugge)	X	
Delta general Hospital (Roeselare)	X	

Table 4. Inventory of educational booklets and brochures about prenatal screening and NIPT.

In Table 5 we listed recurring and noticeable topics addressed in our sample of sources. We found that more essential topics such as ‘what is NIPT?’ are well addressed in every source. The medical terms and the variety of tests were also mostly explained well. These most frequently addressed topics are also listed in the Belgian guidelines. The lower frequency of certain topics, like specific information about Down syndrome, also reflects the content of the guideline. Only one brochure mentioned the fact that there are

12 Accessed via Domus Medica https://domusmedica.be/richtlijnen/zwangerschapsbegeleiding (Nicole Dekker et al.2015)

13 http://www.beshg.be/download/guidelines/20170126_NIPT_good_clinical_practice_guidelines.pdf; http://www.beshg.be/download/guidelines/BELGIAN_GUIDELINES_FOR_MANAGING_INCIDENTAL_FINDINGS_DETECTED_%20BY_NIPT_20171221.pdf

14 The Belgian Advisory Committee on Bioethics asserts that “The information will in fact have to be provided with the patient’s need for information in mind, with due regard for the patient’s moral considerations and in a non-directive way. This should create the right conditions to allow a pregnant woman to make an informed choice without pressure from outside. The focus on the availability of qualitative information in a patient friendly way should not only translate into support while the patient is undergoing NIPT but also when the result of the test is given and during any of the subsequent steps the patient may choose to take.” (2016: 14)

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6 booklets, 4 websites (in Flanders, Brussels) = 10 sources	Website + Booklet/ Brochure (10)	Website (4)[15]	Brochures/ Booklets (6)
How NIPT works	10	4	6
Potentially inconclusive results	10	4	6
Follow-up tests (invasive)	10	4	6
What NIPT tests for	10	4	6
When NIPT is not recommended	10	4	6
Medium through which results will be announced	8	4	4
How much NIPT costs	9	4	5
Fetal sex information	8	3	5
Other findings/ Incidental findings	10	4	6
What NIPT does not test	8	4	4
Specific information about Trisomy 21[16]	4	0	4
Specific information about Trisomy 13 and 18	2	0	2
Privacy	1	0	1
Importance of an echo prior to NIPT	5	1	4
Emphasis on freedom of choice	3	0	3

Table 5. Review of educational booklets and brochures about prenatal screening and NIPT.

different types of NIPT available, and what the differences are. When it comes to specific information about for instance Down syndrome, state that hospitals often refer women who are interested to Down syndroom Vlaanderen, or to a genetic counselor. The main problem we see, though, is that not all booklets provide the same information to the same degree. This may create differences in the way expectant parents are informed. Some may be better informed than others. For instance, in some brochures we noticed that more space was given to explaining the genome concept and NIPT, for instance with the help of metaphors. One brochure even had a glossary. Some brochures emphasized the freedom of choice in a separate paragraph. In others it was only marginally mentioned. The issue of privacy was mentioned in only one booklet. This is significant because NIPT works with biological data and record information.

In Table 5 we can further observe some differences between hospital booklets and websites. Also, across the board, general hospitals that offer NIPT seem more thorough in their information provision. This difference suggests that the guidelines are not followed in the same way, and illustrates that there is room for interpretation. For instance, hospitals realize that too much information can be overwhelming. They could have different opinions about what extra information they want to provide and how much responsibility expectant parents have to seek additional information.

A more comprehensive prenatal screening protocol, with special attention to counseling, that standardizes information provision and care seems warranted. Aside from medical information about the tests, and the conditions they screen for, the protocol could include more information about the conditions screened for, and outline the appropriate social skills and attitudes when talking to expectant parents about screening.

3.2.3 A multi-media platform featuring a balanced representation of testimonials about prenatal decision making and decisional conflict, and various experiences with the conditions screened for

Our review of educational booklets, brochures, and websites found that medical information on NIPT is generally well-addressed. It is clearly stated what NIPT is, and what it tests for. However, little to no attention is paid to the attitudes, values, and beliefs of pregnant women, and how they can match these with the medical options.

As a study in Belgium shows, 30–40% of pregnant women do not have sufficient knowledge about prenatal screening and the conditions screened for, most notably Down syndrome (Buyle 2018). Also, the previous section reveals how most Belgian hospitals that offer NIPT inform pregnant women through educational booklets, information brochures, and/or webpages. Findings from, among others, Kupperman et al. (2009) and Björklund et al. (2012) stipulate that in the context of prenatal screening these formats are not

15 We exclusively examined the webpages that included information on NIPT. It is possible that additional or more general information about prenatal screening is available in different sections of the websites.

16 We made a distinction between trisomy 21 and the other trisomies here because the latter are remarkably less explained.

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the most efficient or effective way to convey information. Much health communication to patients is done through this format, and often presents factual information (reports, professional opinions, and statistical information) (Braverman 2008). However, Braverman shows that testimonials can be more effective because "testimonial or storytelling is more effective than expository or informational messages for those individuals who are not motivated to scrutinize the message" (Braverman, 2008: 688; see also Green, 2006). Testimonials in this context "may include a personal story, a description of an individual experience, or a personal opinion." (Braverman 2008: 666).

The subjective nature of testimonials tends to prompt rightful concern about directive communication (see section 4). This is why the content of the testimonials should be balanced,[17] even though, as Hippman, Inglis & Austin (2012) point out, it is less clear what 'balanced' means. Preliminarily speaking, this likely entails that the online platform should include testimonials from a variety of perspectives, viz. people with Down syndrome, their family members, health professionals, people who have decided to terminate a pregnancy, and bioethicists.[18] The testimonials should provide snippets of the good and difficult experiences of, for instance, life with Down syndrome, as well as life after the decision to terminate a pregnancy.

Above, we mentioned the dilemma of what 'relevant information' entails for informed decision-making. In the context of this initiative, relevant information means that should expectant parents wish to learn more, they can consult audio-visual and written testimonials of different experiences during and following the choices that were made (1) about prenatal screening, and (2) on the basis of the results of the tests.

In sum, the medium and format of health communication has an impact on the way people absorb knowledge. Following the above-mentioned findings, we identify an opportunity to optimize communication about prenatal screening, NIPT, and the conditions it screens for in order to increase knowledge. This knowledge is deemed relevant for informed decision-making. The optimization can be done by creating a multimedia online platform featuring balanced testimonial content, that can be offered to expectant parents in addition to the booklets.

17 This is also one of the recommendations to support women in their decision-making formulated by Skirton & Barr (2009: 601)

18 This list is not meant to be exhaustive.

3.3 Step (c): Steps (a) and (b) brought together: What do stakeholders think?

In order to gather feedback about and create support for these initiatives we organized a round table discussion with 30 stakeholders. A summary of reactions and other input from the stakeholders is added in Supplement 7a (Dutch) (translation in Supplement 7b). The discussions between stakeholders following the presentations of the initiatives confirmed that there is a common need for a broadly carried uniform protocol. The creation of such a protocol, stakeholders urge, is the responsibility of the government. In addition, further research is needed about the observation some stakeholders make about people's tendency in Belgium to equate 'disability' with 'unhealthy' and 'unhappy'. More research is necessary to investigate how this outlook on disability affects the reproductive choices expectant parents make.

A concluding poll at the stakeholder meeting (see Table 6 and Supplements 7a, 7b) showed a strong consensus concerning the need to develop a prenatal screening protocol and a decision aid in order to help health professionals, as well as expectant parents, navigate through prenatal screening programs in Belgium. Anticipating the widening scope of genetic tests, a general plan of action is necessary to ensure counseling possibilities and thus informed decisions. Counseling requires additional resources. Without governmental support, this challenge will become increasingly problematic.

Initiative	Number of preferences
Decision aid	15
Testimonials	1
Protocol	21
Miscellaneous/Question mark	2

Table 6. A poll of the preferences for each initiative per initiative presented at the stakeholder meeting.

The results of this poll of 30 stakeholders showed that the protocol initiative represents 54% preference votes, the decision aid gained 38% support. Table 6 shows the votes per initiative in absolute figures. Nine stakeholders chose more than one initiative, 44% of whom had a slight preference for the protocol. (see Supplements 7a and 7b). Below, we briefly describe some key findings for each of the initiatives.

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The ***'Decision aid'*** gained 38% of the votes. A shared opinion was that there is a greater need for pre- and post-counseling. Stakeholders present stressed that such a decision aid could guide expectant parents through the first important decision of whether they want to screen for fetal anomalies. According to a politician,

> *beside the right to know, the right to not know is only barely discussed with patients, which results in a lot of prenatal tests that have been carried out without a genuine approval.*

Most stakeholders were convinced that it is the government's responsibility to provide a protocol for healthcare with clear instructions for doctor-patient communication about NIPT to ensure that parents' rights in this respect are safeguarded. Furthermore, a gynecologist added:

> *We have to keep in mind that the counseling practice should not be oversimplified either. It should be adapted to religion and various cultural backgrounds.*

Turning to the ***'Protocol'***, 54% of the votes marked this as the initiative they wanted to see developed in the future. Setting up a protocol ensures that all future parents will receive the best support. This protocol could, for instance, ensure better agreements between first and second lines of care. Right now, according to a self-employed midwife

> *The first line of healthcare [general physicians and, in some cases, midwives] is too frequently forgotten, although they have more time for more extensive prenatal consultations.*

However, a paediatrician warns that

> *The willingness of doctors to follow a protocol is probably insufficient at the moment.*

The ***'Testimonials'*** were clearly the least preferred initiative with only one vote out of 30. During the discussions, concerns were raised about the subjective or directive nature of testimonials. In addition, the people providing the testimonials might experience a great sense of responsibility that should not go unacknowledged and would need support. A philosopher argued however that

> *neutral information is an illusion, but neutrality could be preserved in a way by putting different points of view side by side.*

An organization for people with disabilities argued for the importance of including people with the disabilities screened for (primarily people with Down syndrome) in this kind of initiative.

Finally, the ***'question mark'*** allowed us to collect additional thoughts or suggestions from stakeholders. A medical student suggested improving communication between doctors and patients through a patient-feedback system. Concerning the issue of stimulating physicians to seek additional professional support for communication about the conditions screened for, a parent of a child with Down syndrome raised the concern:

> *In any case, seminars for healthcare providers are important, but those who already know a lot will come, while those who need it will remain absent.*

Another participant proposed philosophical discussions for professionals in order to stimulate reflection and listening skills.

4. Discussion

In this section, we integrate relevant points from our literature study, inventory of guidelines and booklets, and input from stakeholders during interviews and the stakeholder meeting.

The decision to opt for prenatal screening, including NIPT, should be informed and well-considered. Some people state that expectant parents should screen for fetal abnormalities only if they know what they would do if the NIPT result were positive. Due to the ethically sensitive nature of these difficult decisions, it is paramount that each pregnant woman (and her partner) has access to good-quality pre-test and post-test counseling.

Given the low cost of NIPT in Belgium, it has become a more or less routinized practice. Accordingly, the percentage of women that opt for NIPT is very high. The routinization of NIPT may form a risk for informed decision making because it is more easily portrayed as 'just another test' by both physicians and expectant parents. As such the moral weight of the decision may be trivialized. The routinization of NIPT was already warned against in 2016 by the Belgian Advisory Committee on Bioethics, and more recently by Cernat et al. (2019).

Studies show that indeed pregnant women too rarely make informed decisions about prenatal testing (Beulen et al. 2016; Buyle 2018). Our interviews with stakeholders in Belgium show a similar tendency. These findings suggest that the information provided seems inadequate or does not seep through. Explanations for this can be found in the content and/or format of this

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information. In Belgium, we observe that most information is offered to expectant parents in the form of an educational booklet or a brochure. However, studies indicate that this is not the most effective medium for transferring complex medical knowledge about, in this case, prenatal tests (see e.g. Kupperman et al. 2009; Björklund et al. 2012; Beulen et al. 2016; Carslon et al. 2019). Interactive, audio-visual, web-based formats and testimonials (Braverman 2008) are proven to be more effective. Additionally, the content of the booklets is mainly medical. Information on living with (someone with) the condition screened for in all its complexity is lacking.

Offering expectant parents a decision aid shows much potential for remedying the shortcomings seen in prenatal screening guidance in Belgium today. Moreover, given the high (societal) cost of reimbursing genetic counseling, a decision aid could be a low-cost compromise. However, the decision aid should not replace counseling. While there is no difference in knowledge between pregnant women who use a web-based decision aid and those who see a genetic counselor (Carlson et al. 2019), decisional conflict is significantly lower when women have had the opportunity to combine the two options (Carlson et al. 2019).

A decision aid should be accessible to all pregnant women. Hence, it needs to be sufficiently flexible to accommodate on the one hand various degrees of (health) literacy and on the other hand different cultural backgrounds, languages, belief systems, values, religious backgrounds, etc. Most stakeholders agree that the choice to use a decision aid should be free. Notwithstanding, one person argued that the reimbursement of NIPT should be connected to having completed a decision aid or genetic counseling.

Our stakeholder panel agrees that it is a good thing that there is no financial barrier to NIPT. However, due to the fast pace with which the reimbursement of NIPT was implemented, laws and guidelines could not anticipate the needs (e.g. for counseling) that would follow. Furthermore, in the absence of a detailed formal standard including appropriate attitudes and ways of conveying information, health professionals struggle to adequately communicate about NIPT to patients. Directivity will inevitably find expression in body language, in which information is given or skipped, and in the emphases that are made. Moreover, as was alluded to by a stakeholder (see section 3.1), health professionals who do not recognize anything problematic in the way they communicate with expectant parents about NIPT and disability may feel less inclined to improve. From interviews the student teams conducted in 2017–2018 and 2018–2019—though not representative of the entire population—we noted several negative experiences about the way NIPT was presented to some women. Some stated that they did not feel comfortable refusing, or the option to refuse was not presented to them, they were not informed very well, or the patient-doctor communication was not positively evaluated if a decision was made to continue a pregnancy where a chromosomal abnormality was indicated by NIPT. However, it must be said, that there were also positive experiences communicated to us about each of these points.

There are voices that advocate the illegalization of commercial NIPTs. The difference between commercial and non-commercial tests is confusing for expectant parents. Commercial tests put too much power in the hands of laboratories and clinical biologists.[19] Depending on the laboratory (hospital or commercial) physicians are connected to, pregnant women are offered different NIPTs. To our knowledge, there is no control mechanism in place. Standardization of NIPT, curbing variability, is complicated by commercial interests. Moreover, this variability in NIPT jeopardizes informed decision making because not all women are presented with the same test, leading to confusion about what can and cannot be detected by NIPT. Furthermore, the more NIPT can detect, the more choices expectant parents are presented with, which may cause stress associated with decisional conflict. This also means that they have to be informed about additional conditions, which demands more time and resources.[20]

A nation-wide prenatal screening (including NIPT) protocol standardizes prenatal care. The challenge for health professionals lies in the fragmentation of care, as we know it today in Belgium. This fragmentation creates inequality in care-receiving because, among other reasons, it is not clearly stipulated who should counsel expectant parents. A protocol creates a guiding thread for health professionals ranging from best

19 Via commercial tests there is not always access to genetic counseling or network of care. And if there is, it is organized by the private companies offering NIPT. In this scenario, there are questions about possible conflicts of interest genetic counselors have (Pollack, 2012 in Allyse et al. 2015).

20 This would be especially problematic if private companies offered direct-to-consumer NIPT. To this day, this is not yet possible in Belgium.

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communicative practices to role divisions.[21] This, in turn, may positively affect informed decisions of expectant parents. Most stakeholders agreed that the standardization of care is the responsibility of the government. However, at this point, some stakeholders remark that it does not seem like the government is much concerned with the accessibility and quality of counseling.

A protocol should clearly stipulate what information should be given at what point during a pregnancy and in what way. The example of the Dutch protocol for prenatal screening can be helpful.[22] Aside from medical information about trisomy 21, 18, and 13, and the role division of genetic counseling among health professionals (gynecologists, genetic counselors, midwives and social workers), this protocol also stipulates communication strategies, social skills, and attitudes the professionals can employ in their counseling practice. Input from our stakeholder panel highlighted the importance of including counseling before and after NIPT. The importance of counseling is also particularly stressed in a recommendation of the Belgian Advisory Committee on Bioethics (opinion 66, 2016). However, at this point, it is not clear in what shape or form this should be implemented.

Lastly, this discussion should be contextualized in a broader debate about (intellectual and developmental) disabilities in society. Some stakeholders indicated that the image people have of Down syndrome in Flanders has hardly evolved in the past two decades. To deflate the medical model with which the medical world still frequently approaches disability, people who are expert by experience need to be included more in the debate (i.e. people with the conditions screened for, their family, carers, and teachers).[23] Including first-hand experiences with the conditions screened for through testimonials offers expectant parents—who are afraid of the unknown—a different perspective. Contrary to the already existing 'contact parents' initiative (Dutch: *contact ouders*), which consists of a (postnatal) meeting between parents with children with Down syndrome and (expectant) parents, audio-visual and written testimonials create a kind of distance. Even though non-directivity is illusory when it comes to testimonials, this distance is good. Directive communication is one of the major hurdles when it comes to information provision in prenatal screening. However, this does not need to be problematic if the subjective nature of the testimonials is openly communicated about, and they represent a wide array of experiences (including expectant parents who chose to terminate the pregnancy). There is also a role for medical education to play here.

Stakeholders at the round table had the opportunity to propose additional initiatives to improve guidance during prenatal screening. Someone proposed systematized patient feedback for physicians. Patient feedback can improve patient-doctor communication in prenatal screening and create awareness among those health professionals who are unaware of problems with the way they communicate about, for instance, NIPT.

In conclusion, all three initiatives are complementary. They address different needs and target different groups. Ideally, the three initiatives can be integrated. The decision aid could be part of the protocol—as something that needs to be offered to expectant parents—and testimonials could be incorporated in the decision aid. We hope that by addressing different needs and targetting different groups more awareness can be created across the board.

5. Facing the Future: Some Reflections

Physicians and patients need a solid base of information and reflexivity to guide them through prenatal screening. Medicine increasingly moves towards patient-centered care and shared decision making; initiatives of the kind we propose can be beneficial to further promote this and to strengthen the patient-doctor relationship. Health professionals are expected to correctly use knowledge and science, hence the correct implementation of new developments in biomedical technology should be central to good care.

We think that a precondition of an informed decision in the context of NIPT, aside from having knowledge of NIPT and diagnostic tests, is to have knowledge of the conditions screened for. By knowledge we do not mean only medical knowledge of for instance Down syndrome as a chromosomal abnormality, but also of Down syndrome as a meaningful life. We proposed three initiatives that can help stimulate informed choice in

21 Steps like this have already been taken in Belgium for neonatal screening and for breast and colon cancer screening programs.

22 https://www.rivm.nl/sites/default/files/2018-11/111488_010415_Down%20SEO_8_TG.pdf.

23 By the medical model of disability we refer to the view that reduces the disabled person to their impairment, and reduces their impairment to something medical, a medical object that needs to be fixed, cured. For an overview see for instance *The Minority Body: A Theory of Disability* by Elizabeth Barnes (2016).

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prenatal screening in Belgium. In all, we hope that our findings, which we presented at the KU Leuven Facing the Future Symposium (Supplement 9), create concrete steps for further research.

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Supplementary Material

(1) Original challenge
(2) List of Participants in the stakeholder meeting
(3) Program of the stakeholder meeting
(4) Invitation to the stakeholder meeting
(5) Presentation held during stakeholder meeting (Dutch) (May 8, 2019)
(6) List of decision aids
(7a+7b) Summary of stakeholder meeting (Dutch and English)
(8) Presentation held at Transdisciplinary Insights Symposium (English) (May 8, 2019)
(9) Recording presentation—Counseling in prenatal screening for Down syndrome—Transdisciplinary Insights Honours Programme Symposium, May 8, 2019.

References

Agbadjé, T.T., Menearl, M., Dugas, M., Gagnon, M.P., Abbasgholizadeh Rahimi, S., Robitaille, H., Giguère, A.M.C., Rousseau, F., Wilson, B.J.W. & Légaré, F. (2018) Pregnant women's views on how to promote the use of a decision aid for Down syndrome prenatal screening: a theory-informed qualitative study *BMC Health Services Research 18*, 434. https://doi.org/10.1186/s12913-018-3244-1

Åhman, A., Sarkadi, A., Lindgren, P. & Rubertsson, C. (2016) 'It Made You Think Twice' - an Interview Study of Women›s Perception of a Web-based Decision Aid concerning Screening and Diagnostic Testing for Fetal Anomalies. *BMC Pregnancy and Childbirth 16*(1), 267 https://doi.org/10.1186/s12884-016-1057-y

Allyse, M., Minear, M.A., Berson, E., Sridhar, S., Rote, M., Hung, A. & Chandrasekharan, S. (2015) Non-invasive prenatal testing: a review of international implementation and challenges *International Journal of Women's Health 7,* 113–126. http://dx.doi.org/10.2147/IJWH.S67124

AZ Sint-Lucas. (2018). NIPT: De niet-invasieve prenatale test voor trisomie. Retrieved from https://is.gd/XsIZJK

Bekker, H.L., Hewison, J., & Thronton, J.G. (2002) Understanding why decision aids work: linking process with outcome. *Patient Education and Counseling 50*, 323–329. http://doi:10.1016/S0738-3991(03)00056-9

Belgian Advisory Committee on Bioethics (9 May 2016) *Opinion no. 66 - non-invasive prenatal testing (NIPT)* Retrieved from https://www.health.belgium.be/en/opinion-no-66-non-invasive-prenatal-testing-nipt

BeSHG Prenatal Committee. (2017). NIPT good clinical practice guidelines. Retrieved from https://is.gd/YmqbpC

BeSHG Prenatal Committee (2017) Belgian Guidelines for Managing incidental Findings Detected by NIPT. Retrieved from http://www.beshg.be/download/guidelines/BELGIAN_GUIDELINES_FOR_MANAGING_INCIDENTAL_FINDINGS_DETECTED_%20BY_NIPT_20171221.pdf

Beulen, L., Van Den Berg, M., Faas, B.H.W., Feenstra, I., Hageman, M., Vugt, J.M.G. Van, & Bekker, M.N. (2016) The Effect of a Decision Aid on Informed Decision-making in the Era of Non-invasive Prenatal Testing: A Randomised Controlled Trial. *European Journal of Human Genetics 24*, 1409–416. https://doi.org/10.1038/ejhg.2016.39

Björklund, U., Marsk, A., Levin, C. & Öhman Georgsson, S. (2011) Audiovisual information affects informed choice and experience of information. *Patient Education and Counseling 86*, 390–395. https://doi.org/10.1016/j.pec.2011.07.004

Braverman, J. (2008) Testimonials versus informational persuasive messages: The moderating effect of delivery mode and personal involvement. *Communication Research 35*(5), 666–694. doi: 10.1177/0093650208321785

Buyle, M., Goemaes, R., & Roelens, K. (2018). Prenatale testen voor downsyndroom: Een onderzoek naar kennis, attitude en praktijkervaringen bij zwangere vrouwen

Carlson, L.M., Harris, S., Hardisty, E., Hocutt, G., Vargo, D., Campbell, E., Davis, E., Gilmore, K. & Vora, N.L. (2019) Use of a novel computerized decision aid for aneuploidy screening: A randomized controlled trial. *Genet Med. 24*(1), 923–929. doi:10.1038/s41436-018-0283-2

Centrum Medische Genetica UZ Antwerpen. (2018). Niet-Invasieve Prenatale Test (NIPT). Retrieved from https://is.gd/F8JHTc

Centrum Medische Genetica UZ Brussel. (2018). Wat doet de niet-invasieve prenatale test (NIPT). Retrieved from http://www.brusselsgenetics.be/nipt?doscroll=true#NavL3

Centrum Menselijke Erfelijkheid UZ Leuven. (2017b). NIET-INVASIEVE PRENATALE TEST:RICHTLIJNEN VOOR BLOEDAFNAME. Retrieved from https://is.gd/bALA0W

Cernat, A., De Freitas, C., Majid, U., Trivedi, F., Higgins, C. & Vanstone, M. (2019) Facilitating informed choice about non-invasive prenatal testing (NIPT): a systematic review and qualitative meta-synthesis of women's experiences. *BMC Pregnancy and Childbirth 19*, 27. https://doi.org/10.1186/s12884-018-2168-4

Costan, L., Devine, M.J., van Dinter, M., Hendrickx, L., Meijer, J., van Uffelen N., Zenner, E. (2018) Down to Counsel: Towards A Transdisciplinary Toolbox for Non-directive Counseling in Prenatal Screening for Down Syndrome. *Transdisciplinary Insights 2*(1), 38–77. doi: https://doi.org/10.11116/TDI2018.2.2

Dehens, J., de Hemptinne, M., Galouchka, M., Sajud, A., van Otzel, R.P., Vanhoorebeeck, C., Wyszkowska, M., Kiekens, A., Blanco, J.R.N., Vandamme, A. (2017) Transdisciplinary experience in a pilot year of a new Honors Program at the KU Leuven – University of Leuven: building a team, developing and improving a transdisciplinary project through addressing a challenge on HIV drug resistance in Africa. *Transdisciplinary Insights1*(1), 33–39. doi: https://doi.org/10.11116/TDI2017.1.3

Delanoë, A.E., Lépine, J.J., Portocarrero, M.E.L., Robitaille, H., Turcotte, S., Légaré, F., Lévesque, I., Wilson, B.J., & Giguère, A.M.C. (2016) Health Literacy in Pregnant Women Facing Prenatal Screening May Explain Their Intention to Use a Patient Decision Aid: A Short Report. *BMC Research Note 9*(1), 339. https://doi.org/10.1186/s13104-016-2141-0

Dekker, N., Goemaes, R., Neirinckx, J., Seuntjens, L., & Smets, K. (2016). Zwangerschapsbegeleiding: Wat zegt de richtlijn? Retrieved from https://is.gd/b2m7vQ

Dekker, N., Goemaes, R., Neirinckx, J., Seuntjens, L., & Smets, K. Z. (2015). Richtlijn voor goede medische praktijkvoering. *Domus Medica*.

Dugas, M., Shorten, A., Dubé, E., Wassef, M., Bujold, E. & Chaillet, N. (2012) Decision aid tools to support women's decision making in pregnancy and birth: A systematic review and meta-analysis. *Social Science & Medicine 74*, 1968–1978. http://doi:10.1016/j.socscimed.2012.01.041

Gil M.M., Accurti V., Santacruz B., Plana M.N., Nicolaides K.H. (2017) Analysis of cell-free DNA in maternal blood in screening for aneuploidies: updated meta-analysis. *Ultrasound Obstet Gynecol 50*, 302 – 314. doi:10.1002/uog.17484

Green, M.C. (2006) Narratives and Cancer Communication. *Journal of Communication 56*, 163–183. doi:10.1111/j.1460-2466.2006.00288.x

Fonda Allen, J., Stoll, K., & Bernhardt, B. A. (2016). Pre- and post-test genetic counseling for chromosomal and Mendelian disorders. *Seminars in perinatology, 40(1)*, 44–55. doi:10.1053/j.semperi.2015.11.007

Hippman, C., Inglis A, Austin J. (2012) What Is a 'Balanced' Description? Insight from Parents of Individuals with Down Syndrome. *Journal of Genetic Counseling 21*(1): 35–44. https://doi.org/10.1007/s10897-011-9417-2

Hulstaert, F., Neyt, M., & Gyselaers, W. (2014). The non-invasive prenatal test (NIPT) for trisomy 21—health economic aspects. *Health Technology Assessment (HTA). Brussels: Belgian Health Care Knowledge Centre (KCE), 22*(05), 2014.

Kupperman, M., Norton, M.E., Gates, E., Gregorich, S.E., Learman, L.A., Nakagawa, S., Feldstein, V.A., Lewis, J., Washington, A.E. & Nease, R.F. (2009) Computerized Prenatal Genetic Testing Computerized prenatal genetic testing decision-assisting tool: a randomized controlled trial. *Obstetrics and Gynecology, 113(1)*, 2009.

Pollack A. (2012, July 13) Conflict potential seen in genetic counselors. Retrieved from https://is.gd/37Q8Vz

Portocarrero, M.E.L., Giguère, A., Lépine, J., Garvelink, M., Robitaille, H., Delanoë, A., Lévesque, I., Wilson, B.J., Rousseau, F. & Légaré, F. (2017) Use of a Patient Decision Aid for Prenatal Screening for Down Syndrome: What Do Pregnant Women Say? *BMC*

Pregnancy and Childbirth 17(1), 90. https://doi.org/10.1186/s12884-017-1273-0

Potter, B. K., O'Reilly, N., Etchegary, H., Howley, H., Graham, I. D., Walker, M., Boland, I. (2008). Exploring informed choice in the context of prenatal testing: findings from a qualitative study. *Health Expectations, 11*(4), 355–365. https://doi.org/10.1111/j.1369-7625.2008.00493.x

Reid, B., Sinclair, M., Barr, O., Dobbs, F. & Crealey, G. (2009) A Meta-Synthesis of Pregnant Women's Decision-Making Processes with Regard to Antenatal Screening for Down Syndrome. *Social Science & Medicine 69*(11), 1561–73. https://doi.org/10.1016/j.socscimed.2009.09.006

Schoonen, H.M.H.J.D., Van Agt, H.M.E., Essink-Bot, M.L, Wildschut, H.I., Steegers, E.A.P., & De Koning, H.J. (2011) Informed Decision-making in Prenatal Screening for Down's Syndrome: What Knowledge Is Relevant? *Patient Education and Counseling 84*(2), 265–70. https://doi.org/10.1016/j.pec.2010.07.037

Skirton, H., & Barr, O. (2010). Antenatal screening and informed choice: a cross-sectional survey of parents and professionals. *Midwifery, 26*(6), 596–602.

Skjøth, M.M., Hansen, H.P., Draborg, E., Pedersen, C.D., Lamont, R.F. & Jørgensen, J.S. (2015a) Informed Choice for Participation in Down Syndrome Screening: Development and Content of a Web-Based Decision Aid. *JMIR Research Protocols 4*(3), 113. https://doi.org/10.2196/resprot.4291

Skjøth, M.M., Draborg, E., Lamont, R.F., Pedersen, C.D., Hansen, H.P., Ekstrøm, C.T., & Jørgensen, J.S. (2015b) Informed choice about Down syndrome screening – effect of an eHealth tool: a randomized controlled trial. *Acta Obstetricia et Gynecologica Scandinavica 94*, 1327–1336. https://doi.org/10.1111/aogs.12758

Smith, S.K., Cai, A., Wong, M., Sousa, M.S., Peate, M., Welsh, A., Meiser, B., Kaur, R., Halliday, J., Lewis, S., Trevena, L., Yanes, T., Barlow-Stewart, K. &Barclay, M. (2018) Improving Women's Knowledge about Prenatal Screening in the Era of Non-invasive Prenatal Testing for Down Syndrome - Development and Acceptability of a Low Literacy Decision Aid. *BMC Pregnancy and Childbirth 18*(1), 499. https://doi.org/10.1186/s12884-018-2135-0

Van Schendel, R.V., Kleinveld, J.H., Dondorp, W.J., Pajkrt, E., Timmermans, D.R.M., Holtkamp, K.C.A., Karsten, M., Vlietstra1, A.L., Lachmeijer, A.M.A. & Henneman, L. (2014) Attitudes of pregnant women and male partners towards non-invasive prenatal testing and widening the scope of prenatal screening. *European Journal of Human Genetics* 22, 1345–1350; https://doi.org/10.1038/ejhg.2014.32

Vlemmix, F., Warendorf, J. K., Rosman, A. N., Kok, M., Mol, B. W. J., Morris, J. M., & Nassar, N. (2013). Decision aids to improve informed decision-making in pregnancy care: A systematic review. *BJOG: An International Journal of Obstetrics and Gynaecology*, Vol. 120, pp. 257–266. https://doi.org/10.1111/1471-0528.12060

Universitair Ziekenhuis Gent. (2018). ZWANGERSCHAP: PRENATALE RAADPLEGING. Retrieved from https://is.gd/yZj6LL

UZ Leuven. (2019). Niet-invasieve prenatale test (NIPT). Retrieved from https://www.uzleuven.be/nl/nipt

UZ Antwerpen. (2019). Niet-invasieve Prenatale Test (NIPT). Retrieved from https://is.gd/Nadtcp

Ziekenhuis Oost-Limburg. (2019). Zwangerschap - Niet Invasieve Prenatale Test (NIPT). Retrieved from https://is.gd/xQQz3z

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Supplement 1: Original Challenge

ABOUT YOUR CHALLENGE

NAME OF THE CHALLENGE

Would the world be a better place without them?
Strategies for non-directive counseling in prenatal screening for Down syndrome: From concept to application.
(Written by Eline Zenner on behalf of Downsyndroom Vlaanderen September 2017)

Could you please state a specific challenge, problem or question? If you have more than one challenge, please submit each challenge separately. Please be aware that if the same or a very similar challenge is submitted by multiple actors, we will pool this into a single challenge, and as a result, the challenge might diverge slightly from what you submitted.

When we look at our children, we see people. We see people with hopes and dreams, fears and desires, hands, fingers, toes, favorite food, bath time rituals, bubbles and images of the life we share. What we see as parents of a child with Down syndrome stands in sharp and bleak contrast with what society sees. Society sees a medical risk, increased odds for early-onset dementia, heart condition, visual impairment and autism spectrum disorder. Society sees a financial burden, and waiting lists for care facilities for the intellectually impaired. Society sees a syndrome that no longer needs to be. A syndrome that we can screen for.

From 2013 onwards, a new and non-invasive way of prenatally screening for Down syndrome gained ground in Belgium and abroad. The NIPT (Non-Invasive Prenatal Test) is more accurate than the traditionally used double test, it holds less risks for the fetus than an amnio (where a needle is guided through the abdominal wall and into the fluid sac), and can be conducted at a much earlier point in pregnancy. Without going into medical detail, the test isolates the fetus's DNA from a blood sample taken from the mother and offers a near-conclusive diagnosis (with more than 98% accuracy) for trisomy 13, trisomy 18, and trisomy 21.

On Monday 29 May 2017 Belgian Minister of Social Affairs and Health Maggie De Block announced that 15 million euro will be made available to refund the NIPT to every Belgian pregnant women. Belgium is currently as such the first European country to refund the test to every future parent instead of targeting parents in high-risk groups (e.g. using maternal age as decisive factor). At Downsyndroom Vlaanderen (an organization of and for parents with a child with Down syndrome) we absolutely support this initiative, as it prevents an opposition between "medicine for the rich" (those who can afford the expensive test) and "medicine for the poor" (those who cannot afford the test). What we however object to is that the available funding solely covers the costs of the lab test itself. Money for non-directive multidisciplinary counseling is not foreseen. That is what this proposal is about, with a specific focus on trisomy 21, the chromosomal variant more commonly known as Down syndrome.[1]

The reason to focus on Down syndrome is three-fold. First, the NIPT is publicly often referred to as "the Down test", as this condition has the highest prevalence and hence the highest visibility of the three trisomies. Additionally, where babies with trisomy 13 and trisomy 18 usually die in the womb or in their first year of life, most people with trisomy 21 can lead a long and relatively care-free life (with a current mean life expectancy of about sixty years). Finally, because of the higher visibility of Down syndrome, there is a more outspoken and more public debate on the NIPT and its consequences for people with this syndrome than for any other condition that can be detected prenatally. Are we heading towards a world without Down syndrome?

1 See http://www.downsyndroom.eu/nieuws/over-de-nipt-en-informatie for the vision of Downsyndroom Vlaanderen and an overview of media coverage in the immediate aftermath of the prime minister's decision.

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The answer to this question is not what we as parents of a child with Down syndrome want to focus on. If future parents make a well-informed and well-considered decision following a prenatal diagnosis of Down syndrome to terminate their pregnancy, then it is by no means our desire to stop them. No matter how dearly we love our children, we support a pro-choice vision on prenatal screening: every parent has the right to choose whether to terminate or to continue a pregnancy.

This one key sentence forms the cornerstone of our challenge: every parent has the right to choose.

Historically, this pro-choice vision largely served to provide a contrast with the traditional pro-life stance: abortion was illegal in most countries under all circumstances, in Belgium even until 1990. Women around the world defended (and still need to defend) their right to have a choice in whether or not to continue a pregnancy, in essence defending their right to terminate. Because of this sociopolitical context, the decision to terminate a pregnancy is subsumed under the flag of a “pro-choice” vision. It is however incorrect to equate a pro-choice vision with a pro-termination stance: we should be careful not to evolve to a point where, under certain conditions, allowing a woman to choose entails that we expect a woman to terminate. Under a true pro-choice approach, the choice for life and the choice for termination should at all times be measured with equal scales.

In the specific context of the NIPT, a pro-choice vision entails that future parents first and foremost make a conscious decision whether or not they want to screen for disabilities and abnormalities during pregnancy. Once they decide to screen, a second choice then is what to do with the outcome of such screenings. In this respect, society seems to be evolving to a point where screening is a given rather than a choice, and termination is the standard outcome of a positive diagnosis in prenatal screening. The parents in our network who have consciously decided to keep a child with a disability after positive results in prenatal screening find themselves faced with hostile comments and repeatedly have to defend their choice to others, including medical staff. Why bring a child into the world with a syndrome that no longer needs to be? The recent decision to refund the NIPT on a national level without mirroring this financial initiative with efforts concerning counseling further illustrates this termination- oriented climate.

As parents of a child with Down syndrome, who have joined forces in the voluntary association Downsyndroom Vlaanderen, we believe that this evolution presents an opportunity and a challenge to society. How can we provide future parents, and society at large, with the tools required to make a conscious and well-informed decision on the outcome of prenatal diagnosis without passing judgement or steering parents in specific directions? We ask this question specifically for trisomy 21, but insist on the much broader impact of the answer. Down syndrome is one of the most traceable conditions, and hence the first to be subject to this type of large-scale prenatal screening, but it is on average definitely not the most life-shattering condition one can be faced with in terms of quality of life.

Put differently, screening for Down syndrome is merely the beginning of a general societal tendency to screen for conditions, deviations and abnormalities during or prior to pregnancy, and as such presents us some questions we need to address today rather than tomorrow.

Would you like to add some objectives to that challenge? For example, can you imagine how you want the future to be with regard to this specific challenge. Is there any specific result that you want the research group to reach?

Babies with Down syndrome are sometimes said to be the canaries in the genetics coalmine. This vibrant metaphor is not per se nuanced, but does underline the urgency of our challenge. Non-invasive screening for Down syndrome is merely the tip of an iceberg that will in any case be revealed over the following decades. The breathtaking speed of knowledge acquisition in genetics has left our moral compass in the need of recalibration. How have we, as a society of human beings, embarked on the endeavor of extensive genetic screening without equally explicitly and, more importantly, publicly, addressing the question of the value of a human life and of the scales that are used in weighting this value: who decides what a meaningful life is? We need to address this issues from a transdisciplinary scientific framework, but we also and more importantly need to come up with a strategy to disseminate insights on the matter to a wide audience.

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On the broader level of genetic screening, the question is how we can (re?)introduce fair play in the public debate on prenatal decisions, how we can contribute to a correct perception of life with (a child with) a disability?

On the more specific level of screening for Down syndrome, which this challenge focuses on, the question is two-tiered. First, we need to find out how we can provide non-directive information on Down syndrome to all future parents. How can we make sure that up to date information on the possible impact of Down syndrome on a child's and a family's living conditions finds its way to future parents, ideally even before they decide to undergo prenatal screening? As we see that centers for human genetics typically already undertake efforts in this respect, we secondly want to question the position of GP's and gynecologists in providing this information. Which tools, data, approaches etc. can we offer medical teams to inform parents of life with a child with Down syndrome in all its respects, surpassing the traditional clinical perspective of "medical risks attached to trisomy 21" (e.g. higher incidence of heart conditions, leukemia, autism spectrum disorders and visual & auditory impairments). At this point, the type and manner of communication is (too?) idiosyncratically tied to individual profiles. Where some doctors take efforts to provide a nuanced and well-informed position, others can't help but take stance in one direction or another. How can we broaden the perspective and make clear that our children are people, not risks? The group of students who took up this challenge in the academic year 2017–2018 focused on this particular challenge, and in interaction with different stakeholders came up with the idea to make a website with FAQ concerning down syndrome, that can be used to broaden the often all too medical perspective of gynecologists and GP's. The challenge for the academic year 2018–2019 is to decide on what information needs to be provided and in which format: the team is asked to explore the desired information and to disseminate it in an attractive and insightful manner via an online platform. The main idea is to provide insights and information on the implications of living with (a child with) down syndrome, including its charms and problems.

In creating this website, students may wish to account for the role of the media in the debate. Currently, the media frequently offer broad platforms to individuals who have strong opinions on prenatal screening, but do not necessarily have any notable actual experience with people with Down syndrome. Several individuals for instance make public assessments on the "unbearable suffering" that is tied to trisomy 21, often relying on old and colored terminology (calling people with downsyndrome *mongooltjes* - a term that was abandoned by WHO in the 1960s). Although this assessment may hold for a number of people with Down syndrome, it most surely does not apply to all. At the same time, programs foregrounding successful individuals with Down syndrome (such as the popular Een show "Down the road") may raise unrealistic expectations concerning the possibilities for people with Down. It is important to take these factors into account, as the public opinion on the genetic condition is greatly colored by the media. Schooling and care for people with Down syndrome still (especially in the later years of life) typically adopts the form of segregation rather than of participation or inclusion, day-to-day contact with people with Down syndrome is so limited for most would be parents that they have to make decisions on screening without ever having met a person with Down syndrome: the information shared in the media (both in terms of form and content) hence is of crucial importance for future parents' perception of Down syndrome.

Finally, more ethical questions can also be addressed on the website, as a means to open up the perspective of GP's and gynecologists. How much is society paying for prenatal screening for Down syndrome and comparable syndromes; conversely, what is the cost of supporting families with a child with Down syndrome; and what is the relation between both? What is the social meaning of increasing expenditure for scientific research on prenatal screening whilst decreasing the budget for supporting families with a child with Down syndrome? Using a raw economy-driven formulation, what is more expensive: providing the correct type of life-long support for people with down syndrome, or refunding the NIPT to all future parents in the presupposition that the default choice following a positive diagnosis is termination (and hence not having to foot the bill as society)? What are the risks of valuing lives with such purely economic scales, also for people who do not have an extra copy of their 21st chromosome?

It may also be worthwhile to elaborate on potential changes in the society, including in the medical field, that may affect the future of children with Down syndrome.

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The team of last year suggested to create an online tool for GP's and gynecologists in a succinct Q&A format. The goal of such a website would be to provide up-to-date, easily accessible and balanced information for general practitioners and gynecologists on multiple aspects of Down syndrome. This way, in anticipation of and directing explicitly towards further counseling by a multidisciplinary team, physicians can provide expecting parents with a more balanced, transdisciplinary view of Down syndrome, thereby enhancing their capability to make informed, autonomous and hence sustainable decisions about their pregnancies.

In the next section of this proposal, we sketch precisely how this challenge could be addressed by a properly transdisciplinary team.

Could you please let us know the context of the challenge and why you think this challenge is relevant to a transdisciplinary research team? Please be aware that our transdisciplinary research teams accept only challenges that have to be dealt with from different points of view.

Below, we present some specific perspectives and questions related to the challenge. We do this for each of the KU Leuven faculties that, in our opinion, can add interesting insights or expertise for the website. Of course, not all of these perspectives need to be addressed. Likewise, other initiatives and points of view are more than welcome.

Philosophy:

- the ethics of genetic screening;
- a cultural-historical analysis of "normality";
- the position of uncertainty opposed to the desire for control and perfection;
- the consequences of agency in ethics ("you chose this child, so you deal with it").

Medicine:

- critical analyses of medical training: is it more advisable to opt for in-depth experience with people who live with the disabilities that you screen for;
- how will care for people with disabilities improve in the future, and how could that influence the decision making?

Arts & Social Sciences:

- communication in prenatal context: how to convey information on people with a disability at a point in time (early pregnancy) when potential future parents are not particularly open to this type of information;
- website usability and design, copywriting;
- audiovisual & multimedia approach to information sharing on the website;
- storytelling & interview techniques

Economic Sciences:

- economic factors in prenatal screening and prenatal counseling;
- the "value" of life;
- "something's gotta give": what are we losing by spending 15 million euro on refunding the NIPT? What are we gaining?

LUCA (Associatie KU Leuven):

- people with down syndrome often have great artistic abilities: what is the value of this for society?;
- website usability and design, copywriting;
- audiovisual & multimedia approach to information sharing on the website

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Thomas More (Associatie KU Leuven):

- website usability and design
- audiovisual & multimedia approach to information sharing on the website
- storytelling & interview techniques
- communication

Psychology & Pedagogy:

- psychological factors involved in the process of making life-changing choices;
- living with a family member with Down syndrome;
- skills and insights in teaching about disabilities;
- the evolution in models of thinking about disabilities (from medical to social model);
- what does the future have in store in terms of teaching (M-decreet?) and training (see stakeholder Konekt's efforts) people with down syndrome, where are we in the scale from exclusion over segregation via participation to proper inclusion?

Science:

- make predictions on the future of science and the impact on the quality of life for people with down syndrome
- make predictions on how expected innovations in technology can help people with disabilities gain independence, social networks, etc. (see e.g. Spotter, a GPS tracker for tracking children)
- website usability and design

After reading this proposal, it should be clear that the societal impact of addressing our challenge is significant. Current advances in prenatal screening have put society at a turning point. This challenge is all about the question which way to tip, and how we can provide a nudge in the preferred direction, ensuring that parents can truly hold on to their right to choose. As such, in addressing the issue of counselling for prenatal screening for Down syndrome, we hope to pave the way for similar strategies for other prenatal tests, now and in the future. It is crucial to appreciate that this proposal sees the issue of counseling in prenatal screening for Down syndrome as a first case study for a broader societal challenge. Society is evolving to a point where parents are advised to test as much as possible in advance. How can we offer parents the correct tools to deal with these tests and the information they provide?

Possible partners, experts and/or other stakeholders to involve in this challenge If you want your challenge to be dealt with not only by a transdisciplinary research group but also by stakeholders, could you please suggest stakeholders' name(s) to get involved in this research and if you have them, some contact details of each one?

In this section, we present a list of ten potential stakeholders, nine of whom have already agreed to function as stakeholder in the project. Some more information is provided on the organizations and on their position with respect to this proposal. Although we believe that this list will go a long way, other national and international stakeholders can of course be thought of.

Downsyndroom Vlaanderen vzw. Needless to say, our own organization is a stakeholder for this project. We deeply care for the topic, as we are afraid to see society evolve to a point where only traditional interpretations of perfection are welcome. More information on the position of Downsyndroom Vlaanderen in this debate can be found via this link, which also contains an overview of the national media's attention for the topic in light of the decision of Minister Maggie De Block to refund the test. Downsyndroom Vlaanderen can be found on www.downsyndroom.eu. Our organization can be contacted by e-mailing eline.zenner@gmail.com and jurgen@downsyndroom.eu.

CME's: The centres for human genetics (Centra voor Menselijke Erfelijkheid, CME) of the university hospitals in Flanders and Brussels are natural stakeholders in this project: they are the prime location for innovations in genetic

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research and at the same time have always strongly adhered to neutral counseling. The CME's are on board as stakeholders, though they wish to underline their own neutrality in the matter. Professor Bert Callewaert from UGent phrases the position of CME UZ Gent as follow: "non-directive counseling has always been one of the basic guiding principles of the CME's. We however need to acknowledge that once a screening test becomes 'standard and refundable', it soon finds its way to peripheral hospitals. The current criteria for refunding the NIPT are not connected to any requirements concerning counseling. This means that there is a significant risk that this crucial component of prenatal screening runs the risk of being backbenched in daily organization." The different CME's can be contacted as follows: bert.callewaert@ugent.be (UZ Gent), griet.vanbuggenhout@uzleuven.be (UZ Leuven), maryse.bonduelle@uzbrussel.be (UZ Brussel), geert.mortier@uza.be (UZ Antwerpen). Please note that the Pediatrics Department of UZ Antwerpen (contact stijn.verhulst@uza.be) is also interested to be involved in this project. Also marek.wojciechowski@telenet.be from UZA can be contacted as specialist in down syndrome.

VVOG: We have also contacted the Flemish organization of gynecologists and obstetricians (Vlaamse Vereniging voor Gynaecologie en Obstetrie, VVOG). Although a number of gynecologists are very aware of their role as counselors in the process of prenatal counseling, others take a rather clinical perspective on the matter. This way, the possibility of providing true non-directive counseling has sometimes already been closed off by the time parents arrive at CME's for advanced testing. Hence, it is crucial to include VVOG as stakeholder in this project. The organization agrees to operate as stake holder for the project. Professor Luc De Catte is our contact at VVOG (luc.decatte@kuleuven.be).

Kind & Gezin: Kind en Gezin, together with its partners, aims to create as many opportunities as possible for every child, regardless of where he or she was born or where and how he or she is growing up. Kind en Gezin (Child and Family) is an agency that works actively in the 'Public Health, Welfare and Family' policy area. This Flemish agency focuses on preventive treatment and guidance of young children geared to good outcomes in the future. Kind en Gezin describes its role as follows: "We work hard to enable children to achieve their full developmental potential, physically, mentally, emotionally and socially, with respect for diversity and children's rights. This principle holds for all the different areas that we work in. Kind en Gezin is responsible for registration of high quality child care, optimal support for parents-to-be and parents with young children and the criteria that adoption agencies have to meet. We closely monitor all changes in society as a matter of course. Day in day out we come into contact with thousands of families and work with partners and other actors in the field. This gives us a wealth of information, allowing us to respond proactively and at the most appropriate time. We develop scientific methods, in both educational and medical fields, to assist us in our work. We constantly adapt our services, so that we can offer every parent and every child the best help possible. We also participate in national and international campaigns and projects: with boundless respect for every child and for the rights of the child. Child and Family wants to support parents by objective and nuanced information on prenatal screening on behalf of making an informed choice. Hereby we refer parents to several organizations with expertise in pregnancy choices, prenatal screening and diagnostics. After birth, Child and Family offers family-based support. Our services can therefore be different for each family. If there are any questions or difficulties we can't support, we provide the necessary information about who can and refer to another service or organization. If wanted, the family can further count on us. More information on Child and Family can be found on www.kindengezin.be. Kind en Gezin can be contacted by e-mailing evelyne.deguffroy@kindengezin.be".

Fara vzw: Fara is an organization that informs and counsels about pregnancy-related choices. Fara has described its own position as a stakeholder in this project as follows: "Fara regularly comes into contact with issues regarding prenatal testing/diagnosis. In our work, we have always put forward the model of non-judgment counselling and shared decision-making, both internally (in the work we do with clients) and externally (in our training of professionals). We emphasize the responsibility of the care providers to support parents as best as possible in making a conscious, well-considered choice they can (continue to) live with. It is our experience that parents are often not concerned with the social impact of their individual choice. The question of whether the world would be a better place without people with a disability doesn't factor into their decision, and we should not be tempted to blame them for this. Conversely, in their individual choices, they seem to feel the influence of a social tendency to equate responsible

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parenthood with participation in screening and opting for termination after a prenatal diagnosis. Social imaging about disabilities can certainly lead to social pressure that limits the freedom of choice of parents. Individual professionals often make a lot of effort to provide accurate and objective information in their counselling and assist parents in their choices. Of course, improvement is always possible and it is a goal we need to strive for. With regard to this project, Fara is especially interested in how to create a social context in which genuine freedom of choice remains safeguarded." More information on Fara can be found on www.faranet.be. Fara can be contacted by e-mailing silke.brandts@faranet.be as of October 2018. Prior to that date sindy.helsen@faranet.be can be contacted, as Silke is on maternity leave.

Cozapo: Cozapo is a contact group concerning termination of pregnancy following prenatal screening and was founded in 2009 by two experience experts. We are a Flemish contact group aimed specifically at parents who let a wanted child die because prenatal screening revealed serious anomalies in their children. Cozapo is there to support parents. Feelings of doubt, guilt, sadness and so much more can sometimes be shared more easily with peers, if only because they acknowledge and recognize these feelings. At the same time, Cozapo offers the parents some perspective, to carry on with their lives after this decision, thanks to this contact with people who are at different stages of the grieving process. Taking the decision to let your unborn child die, is one that you will carry with you for the rest of your life. Often parents experience a very dual feeling, on the one hand, you will cherish this unborn child, on the other hand, you take the decision to just let your child die. The vast majority of parents go through a very intense grieving process that in most cases remains hidden from the people surrounding them. Whatever choice is made (Cozapo respects any choice!), it is important that parents support this choice as well as possible. Sufficient and clear information is essential to guarantee this. Cozapo understands very well this is not an easy task, in prenatal screening, the anomalies are often not entirely predictable. To Cozapo, it's crucial to explain the type of anomalies from all possible angles. Not only considering the medical consequences for the child, but also reveal what it means to the whole family on a social, financial, emotional, relational, ... level. Within the support group of Cozapo there are several couples who have terminated pregnancy because of trisomy 21. Have they been influenced by media aspects, their financial situation, their environment ...? Did parents actually freely make their choice? These are important questions, because we see that if parents are only partially supporting or not supporting their choice, this has a huge effects on their grieving process. Cozapo therefore looks forward with great interest to the results of this project. You can get in touch with Cozapo via mail on info@cozapo.org. More information about Cozapo can be found on the website www.cozapo.org.

Grip vzw: GRIP (Equal Rights for Each Person with a Disability) is a Flemish civil rights organization for people with disabilities. Patrick Vandelanotte has phrased Grip's position with respect to our proposal as follows: "Grip's goal is to achieve equal rights and opportunities for people with a disability. GRIP wishes to influence and stimulate policy and to correctly inform society at large. GRIP supports this challenge to provide future parents, and society at large, with the tools required to make a conscious and well-informed decision on the outcome of prenatal diagnosis without passing judgement. Raising awareness is one of our major objectives. In 2016 GRIP released a reflection about the influence of disability vision on the treatment of ethical questions. One of the proposals of GRIP was to create a framework for hospitals, genetic centers and services about the guidance and support for parents." More information on Grip can be found on www.gripvzw.be. Grip can be contacted by e-mailing patrick.vandelanotte@gripvzw.be.

Konekt vzw: Konekt is an organization that aims to strengthen people with a disability and their network. Konekt has formulated their position with respect to this project as follows: "We are curious about and fear for the effects of a society where striving for normality will become stronger and where more and more people will fail to meet the requirements of normality that we impose on others and ourselves. Providing 'neutral' information in the context of prenatal screening to us seems as impossible as it is necessary. We have a natural interest for the impossible, so do keep us posted!" More information on Konekt can be found on www.konekt.be. Konekt can be contacted by e-mailing koen.deweer@konekt.be.

Inclusie Vlaanderen: Inclusie Vlaanderen is focused on providing support to people with an intellectual disability. They emphasize the long way that society has come in the way that people with a disability are treated (from

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exclusion over segregation to participation), but indicate where there is room for improvement. They take it at hart to show the value of people with an intellectual disability, and underline their right to an equal treatment in society. More information on Inclusie Vlaanderen can be found on www.inclusievlaanderen.be. Inclusie Vlaanderen can be contacted by e-mailing bernadette.rutjes@inclusievlaandren.be.

Gezin en Handicap: The baseline position of Gezin en Handicap vzw, a member of the KVG-group (Katholieke Vereniging Gehandicapten) is that parents who can share their own experiences with others will feel stronger and empowered. They organize meetings where information is provided and experiences are shared, they have a documentation center containing more than 4000 books, papers, journals and DVD's on handicaps in general, they provide advice to organizations and generally defend the interest of people with disabilities in a number of advisory boards. When asked to describe their own position as stakeholder to this project, they list the following: "We could help organize information sessions. In 2015 we have already organized an information session on prenatal counseling for future parents. We mainly focused on ways to ensure a valuable process for parents facing a tough decision. Most participants, however, where future midwifes, future nurses and future social workers. It proved quite hard to reach the parents themselves. We can additionally also help by publishing an article in Handiscoop, our journal." More information on Gezin en Handicap can be found on www.gezinenhandicap.be. Gezin en Handicap can be contacted by e-mailing lief.vanbael@kvg.be.

RIZIV: The Belgian Government for Health Insurance (Rijksinstituut Voor Ziekte- en Invaliditeitsverzekering, RIZIV) is the organization that is responsible for advice on the (conditions for) refunding medical tests and treatments, including prenatal screening. We have contacted Dr. Ri De Ridder (ri.deridder@riziv.fgov.be) on the matter. Although RIZIV is intrinsically interested in the matter, the organization would currently rather not be involved as stakeholder for the project, as this proposal was drafted in a delicate period concerning the decision-making process of refunding the NIPT (see above).

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Supplement 2: List of Participants in the Stakeholder Meeting

Total of attendees of the stakeholder meeting (organizers included): 37

*Specific organizations that were represented:

> Downsyndroom Vlaanderen vzw; GRIP vzw; Konekt vzw; Kind en Gezin; Wit-Gele Kruis; University Hospitals from Leuven, Antwerp, Gent & Brussels, Regional Hospitals from Groeninge, Bonheiden & Leuven; KU Leuven (University of Leuven): Faculty of Medicine, Faculty of Economics and Business, Faculty of Arts, Faculty of Social Science, Institute of Philosophy, Centre for Biomedical Ethics and Law; UGent (University of Gent); ULB (University of Brussels); National public health institute Sciensano; VVOG(Flemish Association of Obstetrics and Gynecology), De Bakermat vzw (expert in maternity care), Geboorte Informatie Centrum vzw ('birth information centre').

**Some persons can be considered to belong to two or more of the categories listed. We considered the most relevant capacity in which they attended first.

Function	#	**More information**
Members of disability (rights) organizations	5	Downsyndroom Vlaanderen vzw, GRIP vzw, Konekt vzw
Parents of persons with Down syndrome	3	
Politician	1	Member of the Federal Belgian Parliament (at the time [the round table discussion took place])
Bioethicist	1	
Gynaecologist	5	From regional hospitals, from university hospitals, ...
Midwife	5	Self-employed, Wit-Gele Kruis, university hospital, ...
Genetic counselor	3	University hospital
Neonatologist	1	University hospital
Pediatrician	1	University hospital
(Bio)medical student	4	
Other students	4	Faculties: economics and business, philosophy, social sciences
Professor	1	Philosophy
Scientific assistant/researcher	3	National public health institute Sciensano, Universities, University Hospitals

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Supplement 3: Program of the Stakeholder Meeting

Stakeholderoverleg

Initiatieven om duurzame keuzes stimuleren bijprenatale screening

woensdag 8 mei (13:00—15:00)
Kardinaal Mercierzaal (HIW)
Kardinaal Mercierplein 2, 3000 Leuven

Programma

Op dit stakeholderoverleg verzamelen we graag uw visie op enkele initiatieven rond NIPT bij Downsyndroom. De initiatieven zijn: een reflectietool om de ouders bij te staan in hun beslissingsproces, een draaiboek voor de zorgverleners, en testimonials om de ouders te voorzien van bijkomende en genuanceerde informatie.

12.30	*Onthaal*
13.0	Inleiding **Waarom er nood is aan een transdisciplinaire discussie over counseling bij prenatale screening in Belgie**
13.10	Reflectietool **Om bewustheid te creeren bij zwangere vrouwen en hun partners over de keuzes dat prenatale screening met zich meebrengt**
13.20	Debat
13.35	Testimonials **Online platform met representatieve en gebalanceerde inhoud over leven met het syndroom van Down**
13.45	Debat
14.0	*Pauze*
14.10	Draaiboek **Argumenten voor een draaiboek voor prenatale screening om op een uniforme manier tegemoet te komen aan informatie noden bij prenatale screening**
14.20	Debat
14.35	Overige ideeen
14.40	Debat
15.00	*Einde*

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Supplement 4: Invitation to the Stakeholder Meeting

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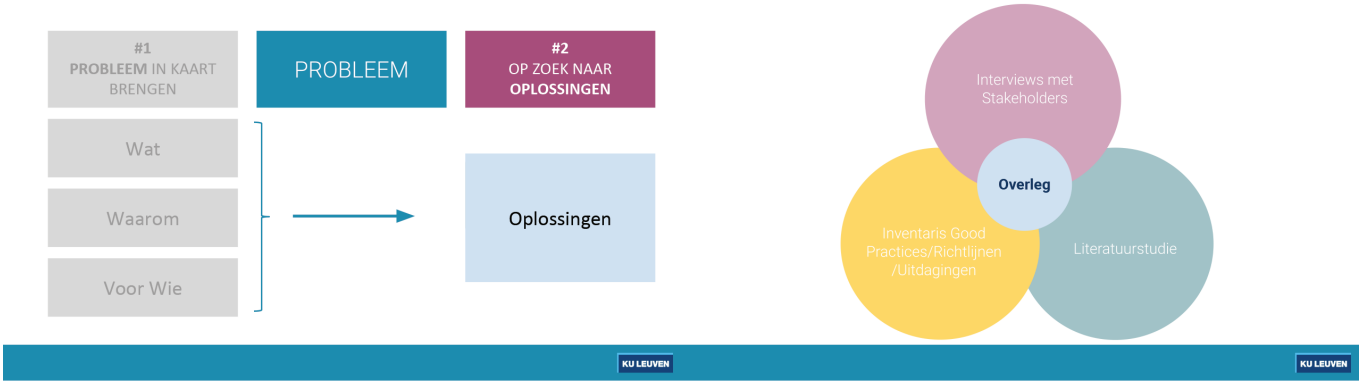
Supplement 5: Presentation Held During Stakeholder Meeting (Dutch) (May 8, 2019)



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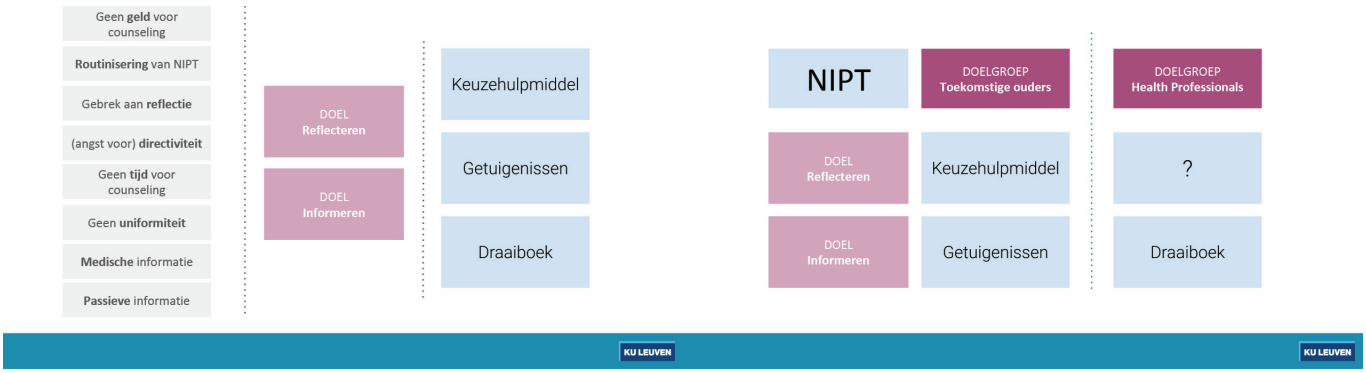

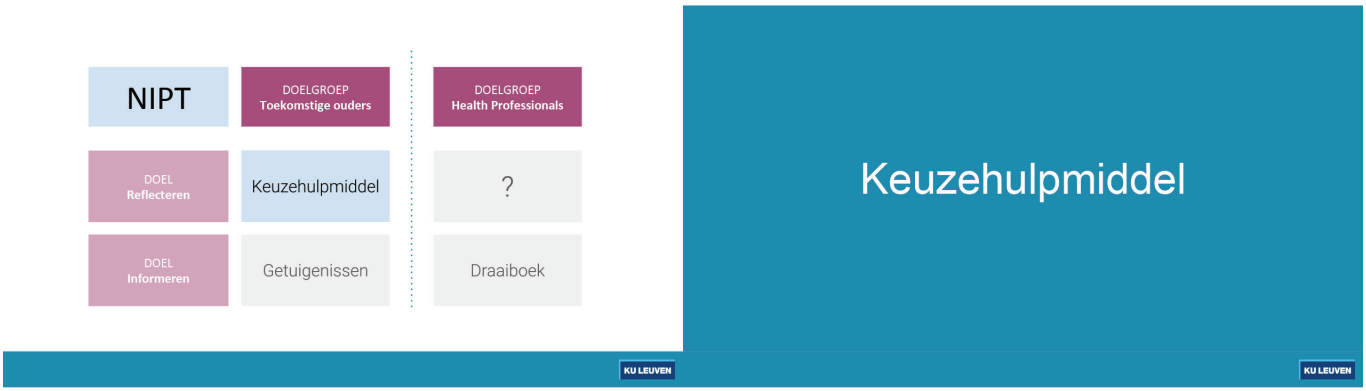

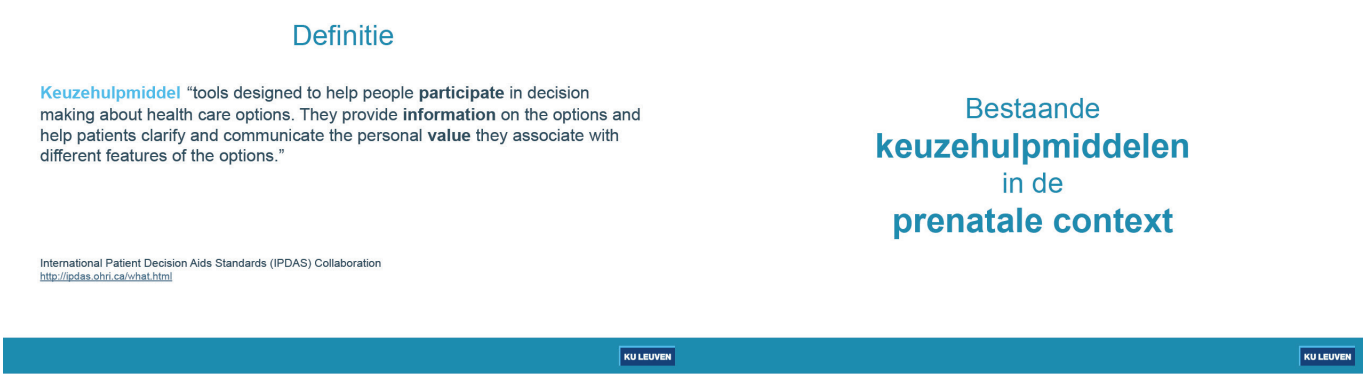

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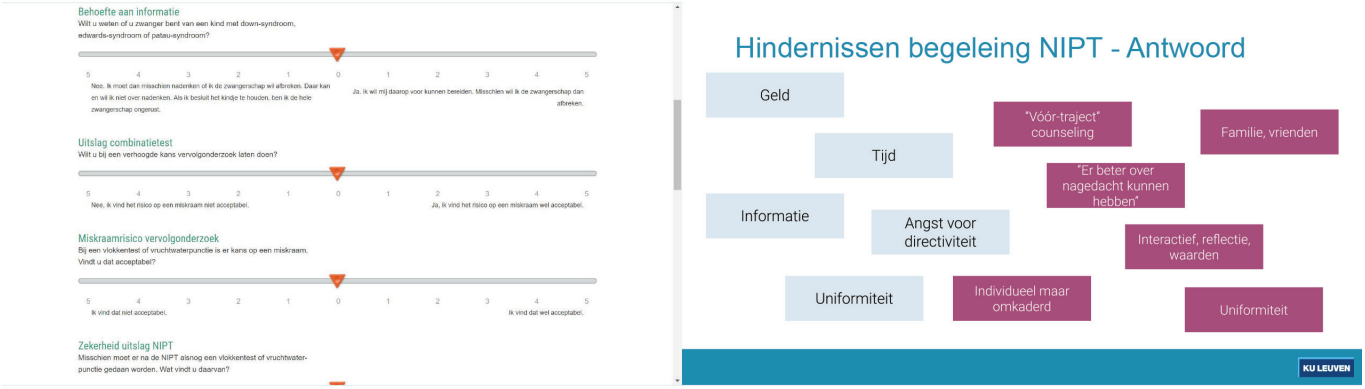

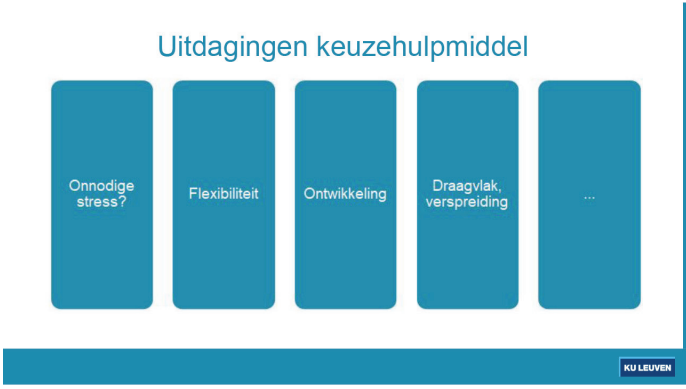

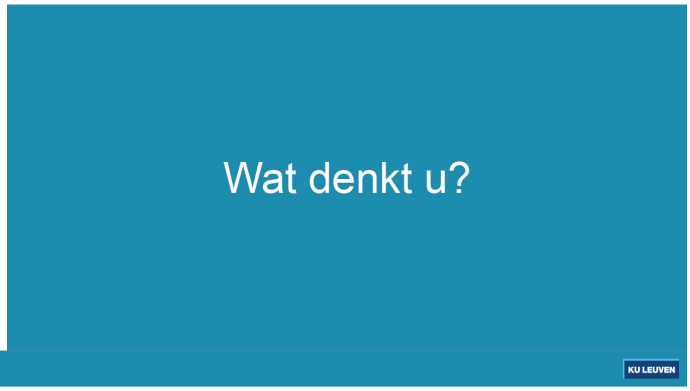

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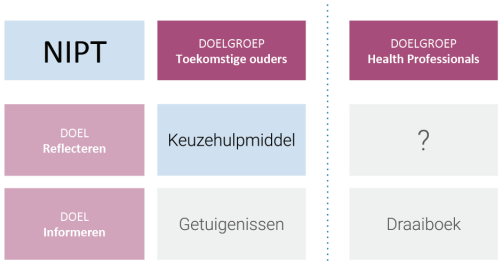

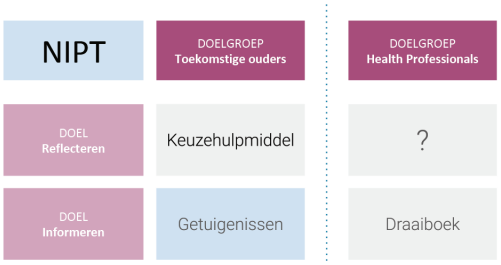

KU LEUVEN KU LEUVEN

Getuigenissen

Analyse infobrochures/sites over NIPT voor de patiënt

UZ Antwerpen	UZ Brussel	UZ Leuven	UZ Gent	ZOL	AZ St.-Lucas	AZ Delta
Brochure	Brochure	Brochure	Brochure	Brochure	Brochure	Brochure
Website	Website	Website	Website			

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Analyse infobrochures/sites voor de patiënt

Elementen die meestal wel aanwezig zijn

- Interpretatie van het resultaat
- Terugbetalingsregel
- Wanneer NIPT niet geschikt/aangewezen is
- Wat te doen bij afwijkend resultaat?
  opmerking: hoe er contact opgenomen wordt is niet altijd even duidelijk
- Wanneer resultaat beschikbaar is en hoe
- Wat NIPT juist wel/niet opspoort (maar niet altijd even specifiek)

Elementen die soms ontbreken

- Wat de aandoeningen juist inhouden (+ hoe de ouder het beleeft)
- Nadruk op vrijheid van keuze (screening is niet verplicht)
  korte reflectievragen
- Waar de NIPT geanalyseerd wordt (+ naam van product)
- Patiënt informeren over informatie verklaring

Definitie

Getuigenissen *"kunnen een **persoonlijk** verhaal, beschrijving van een individuele ervaring of een persoonlijke mening bevatten. In een typische getuigenis **vertelt** een individu zijn of haar persoonlijke ervaring."*

Definitie naar Braverman, J. (2008). Testimonials Versus Informational Persuasive Messages: The Moderating Effect of Delivery Mode and Personal Involvement. Communication Research, 35(5), 666.

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Voorbeelden

"Het heeft mij veel geholpen te spreken met een vriendin die ook een kindje met Down had, maar daar achteraf dankbaar voor was. Zij had eerst het idee het niet te laten gebeuren, maar toen gebeurde het toch. En dan zie je dat mensen hun leven niet stopt, maar dat het toch wordt verrijkt. Het is belangrijk dat te zien en te voelen, en dan kan je altijd nog keuzes maken. (...)

- Anonieme getuigenis

Voorbeelden

(...) Maar als je enkel de medische kant bekijkt en enkel de dokters hoort praten heb je objectief geen reden om de zwangerschap voort te zetten, want het lijk allemaal problematisch. En als je dan kijkt naar de familie en het gezinsleven blijkt dat allemaal wel mee te vallen. Die beiden zaken gecombineerd zorgen voor een meer genuanceerd beeld van wat het effectief is. En ik miste dat. "

- Anonieme getuigenis

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Voorbeelden

Voorbeelden

"Het is belangrijk om goed geïnformeerd te zijn over alle mogelijkheden gedurende het volledige proces. Dit gebeurt het best meteen wanneer je het nieuws van een positieve NIPT te horen krijgt. De informatie zorgt ervoor dat je, ongeacht de uitkomst, een beslissing kan maken waar je als persoon achteraf beter mee kan omgaan."

- Anonieme getuigenis

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Ouders zijn bang voor het onbekende

Goed geïnformeerd?

Counseling?

Concept "getuigenissen"

Focus op andere aspecten

Realistische weergave

Concreter

Verschillende situaties

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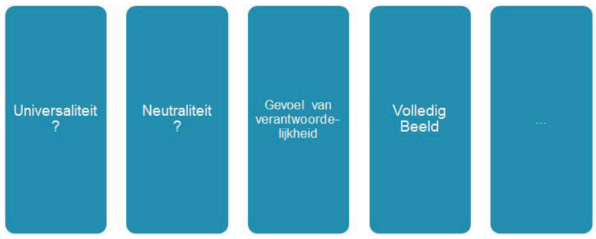
Uitdagingen "getuigenissen"



KU LEUVEN

Wat denkt u?

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NIPT	DOELGROEP Toekomstige ouders	DOELGROEP Health Professionals
DOEL Reflecteren	Keuzehulpmiddel	?
DOEL Informeren	Getuigenissen	Draaiboek

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NIPT	DOELGROEP Toekomstige ouders	DOELGROEP Health Professionals
DOEL Reflecteren	Keuzehulpmiddel	?
DOEL Informeren	Getuigenissen	Draaiboek

KU LEUVEN

Draaiboek

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Definitie

Richtlijnen *voor klinische praktijk zijn uitspraken die* ***aanbevelingen*** *bevatten om de* ***patiëntenzorg te optimaliseren*** *en zijn ontworpen om beoefenaars te* ***helpen bij het assimileren, evalueren en implementeren*** *van de steeds toenemende hoeveelheid bewijsmateriaal en meningen over de beste huidige praktijk.*

NGC and NQMC Inclusion Criteria. 2018. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/gam/summaries/inclusion-criteria/index.html

Draaiboek *is eerder een* ***bindende richtlijn*** *dat als professionele standaard dient gebruikt te worden.*

Rijksinstituut voor volksgezondheid en milieu.2019
https://www.rivm.nl/documenten/draaiboek-prenatale-screening-down-edwards-en-patausyndroom-en-structureel-echos copisch

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Bestaande richtlijnen/draaiboeken

- Huisartsen: domus medica, richtlijnen
- Gynaecologen: VVOG, richtlijnen
- Counselors: eigen draaiboeken/richtlijnen
- College genetics: richtlijnen
- Federale overheidsdienst: ethisch advies
- RIVM (Nederland) draaiboek

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Bedenkingen uit interviews...

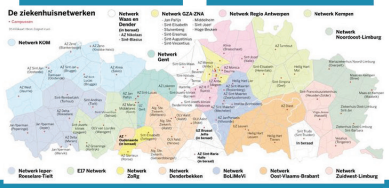
Iedereen recht op dezelfde zorg → uniforme aanpak?

Verwijzingen

Rolverdeling

"De ene NIPT is de andere niet"

Overdracht informatie



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Uitdagingen draaiboek

- Draagvlak
- Verschillende populatie-noden
- ...

KU LEUVEN

Wat denkt u?

KU LEUVEN

NIPT	DOELGROEP Toekomstige ouders	DOELGROEP Health Professionals
DOEL Reflecteren	Keuzehulpmiddel	?
DOEL Informeren	Getuigenissen	Draaiboek

NIPT	DOELGROEP Toekomstige ouders	DOELGROEP Health Professionals
DOEL Reflecteren	Keuzehulpmiddel	?
DOEL Informeren	Getuigenissen	Draaiboek

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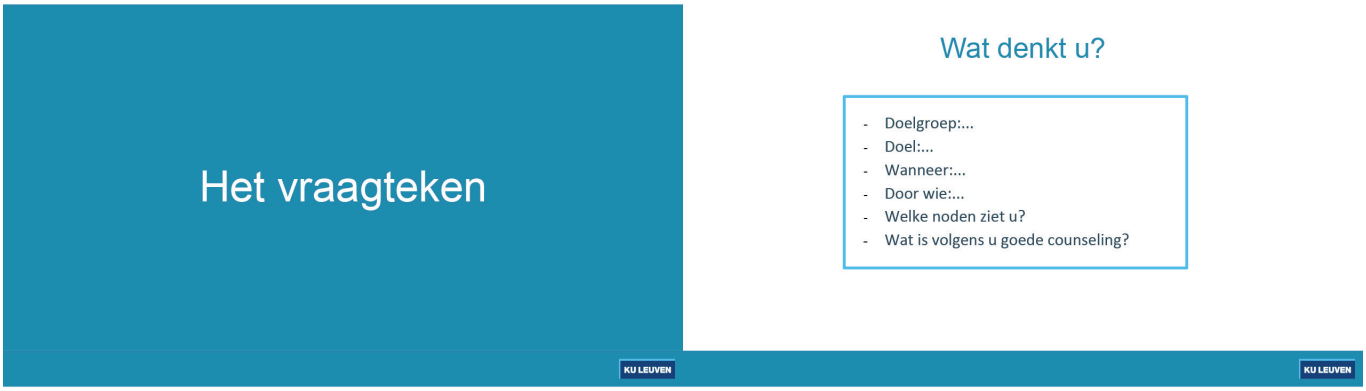

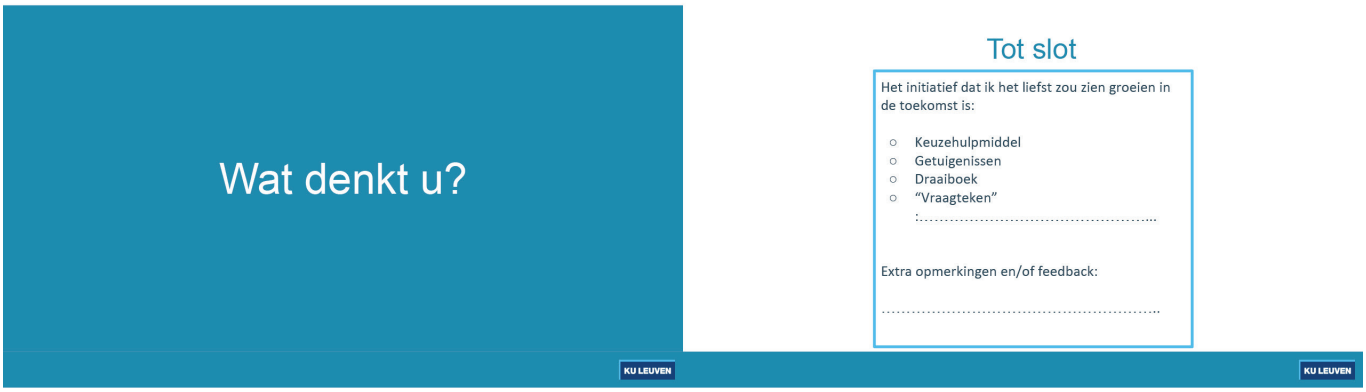

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Supplement 6: List of Decision Aids

- International Patient Decision Aid Standards (IPDAS): http://ipdas.ohri.ca/
- Examples of decision aids in the prenatal context:
  - Australia:
    - https://www.mcri.edu.au/sites/default/files/media/documents/prenataltestingdecisionai d.pdf
  - Denmark:
    - http://graviditetsportalen.dk/
  - Canada:
    - http://www.hss.gov.yk.ca/pdf/prenatalscreeningguide.pdf
    - https://decisionaid.ohri.ca/AZsearch.php?criteria=prenatal (developed by *Healthwise* U.S.)
    - http://www.hss.gov.yk.ca/pdf/prenatalscreeningguide.pdf
    - http://www.perinatalservicesbc.ca/Documents/Screening/Prenatal- Families/ScreeningDecision-Aid.pdf
    - https://www.boitedecision.ulaval.ca/fileadmin/documents/Boites PDF/Trisomie/prena tal.screening. EN.May 15.pdf
  - The Netherlands:
    - https://www.keuzehulp.info/pp/pnt/intro/2 (NL)

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Supplement 7a: Reconstruction of the Main Insights (Dutch)

Stakeholderoverleg 8 mei 2019
Initiatieven om duurzame keuzes stimuleren bij prenatale screening

Dit is een samenvattende reconstructie van de voomaamste inzichten en reflecties die tijdens het stakeholderoverleg van 8 mei 2019 werden gedeeld. Het verslag werd samengesteld op basis van de notulen van Laura Barilla, Zoe Claesen en Job Meijer, en op basis van een poll ingevuld door verschillende aanwezige stakeholders. De reconstructie volgt de structuur van het overleg, waarbij per voorgesteld initiatief (zie supplement 5) de opmerkingen van de stakeholders worden weergegeven. Om de anonimiteit van stakeholders te bewaren worden zij niet bij naam vermeld maar bij functie of organisatie die ze vertegenwoordigen.

INITIATIEF 1: KEUZEHULPMIDDEL
Toelichting: zie supplement 5, p.2

Bio-ethicus: Het is niet vanzelfsprekend, maar wel nodig, om ervoor te zorgen dat iedereen hetzelfde zorgaanbod en dezelfde begeleiding aangeboden krijgt bij prenatale screening. Hoe kunnen we ervoor zorgen dat toekomstige ouders de best mogelijke omkadering krijgen? Verdere standaardisering en protocollering van de zorg kan helpen, waarbij de overheid zijn verantwoordelijkheid moet opnemen: zij zou moeten inzetten op de ontwikkeling van draaiboeken en keuzehulpmiddelen, zoals dit ook het geval was bij screening voor borst- en darmkanker, en bij neonatale screening. In de context van prenatale screening is dit veel minder het geval: het werkveld moet het maar regelen. Momenteel ontbreken die, wat kan leiden tot onzorgvuldige en ondoordachte beslissingen. Je zou kunnen zeggen dat mensen in een soort van ‘screenings-val’ dreigen te trappen. Er is dus zeker marge om te groeien, om protocollen te ontwikkelen.

Politicus: Als we willen dat er iets verandert, moet counselen bij prenatale screening in het regeerakkoord komen. Artsen moeten ook vaker naar hun patienten communiceren dat ze naast het recht op ***weten*** ook het recht hebben op ***niet weten***. Het recht op ***niet weten*** wordt door zorgverleners nauwelijks met hun patienten besproken, waardoor prenatale testen vaak worden afgenomen zonder bewuste voorafgaande toestemming van de patient. Dat kan tot ondoordachte beslissingen leiden bij onverwachte resultaten. Zorgverstrekkers moeten hier meer rekening mee houden. Het aantal prenatale testen dat wordt afgenomen blijft stijgen, maar de patient beschikt over te weinig informatie om de test te accepteren of af te wijzen.

Gynaecoloog: Ik geef graag vier bedenkingen mee. (1) De problematiek omtrent de NIPT in Belgie is ontstaan omdat de test te snel is ingevoerd, zonder omkadering over de inhoud of vorm van counseling. (2) Bovendien zijn toekomstige ouders vaak ook niet voldoende gei’nformeerd over het verschil tussen commerciele en niet-commerciele testen. Dergelijke commerciele testen zouden bij wet verboden moeten zijn. (3) Het lijken ook vooral de klinisch biologen veeleer dan de gynaecologen die keuzes opdringen bij ouders. (4) Als we het hebben over counseling vandaag moet gezegd worden dat deze slechts oppervlakkig is voor de testen worden uitgevoerd. Na het afnemen van de test is counseling meestal onbestaande.

Mensenrechtenorganisatie voor mensen met een beperking: De maatschappelijke context waarbinnen een kind met het syndroom van Down wordt geboren, is de laatste 25 jaar nauwelijks veranderd. Een kind met down krijgen, wordt nog steeds gezien als een ongeluk of een drama. Mensen met het syndroom van Down worden niet behandeld als volwaardige mensen in onze maatschappij. Daarbij is er binnen de politiek duidelijk nog steeds geen bewustzijn over (de kwaliteit van) counseling bij NIPT.

Kinderarts: Graag maak ik drie bedenkingen. (1) De ontwikkeling van een keuzehulpmiddel wil ik ondersteunen. Het is immers moeilijk om op een niet-directieve manier te counselen als er geen leidraad beschikbaar is. De directiviteit

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zal dan onvermijdelijk naar boven komen in bijvoorbeeld je lichaamshouding, in de informatie je wel en niet aanbiedt, in de accenten die je al dan niet bewust legt. Zorgverstrekkers hebben nood aan ondersteuning bij counselen, net om deze reden. Als je een keuzehulpmiddel maakt, is het tegelijk belangrijk om er zowel een voor de zorgverleners als een voor de ouders te maken. (2) Studies in bijvoorbeeld Canada tonen aan dat ongeveer 30% van de zwangere vrouwen die de NIPT ondergaan, niet weten wat de test inhoudt. Een keuzehulpmiddel kan helpen om dat probleem aan te pakken, om ouders ook bewust te maken van het recht om ***niet*** te weten, om hen te helpen onbevooroordeeld tot een beslissing over weten of niet weten te komen op basis van hun eigen normen en waarden. (3) De terugbetaling van de NIPT is goed, dat wil ik ook benadrukken, hoewel de terugbetaling te snel is doorgekomen waardoor er onvoldoende aandacht kwam voor het stroomlijnen van de counseling. Iedereen, ongeacht financiele of sociale klasse, moet even eenvoudig toegang krijgen tot de NIPT.

Vroedvrouw: Uit ons onderzoek in Gent komen gelijkaardige cijfers: 30–40% van de zwangere vrouwen weet niet juist wat de prenatale testen inhouden. Een keuzehulpmiddel zou dus zeker een meerwaarde kunnen betekenen. Tegelijk is het belangrijk dat zo'n hulpmiddel vrijblijvend blijft, en ook belangrijk, dat het als aanvulling en niet ter vervanging van counseling aangeboden wordt.

Kind en Gezin: Het basisprincipe bij elke screening is dat je maar mag screenen als je weet wat je met het resultaat wil doen. Daarom moet screenen gekoppeld worden aan goede counseling. Voor Kind en Gezin is het tegelijk belangrijk dat iedereen, ongeacht sociale klasse, gelijke toegang heeft tot NIPT.

Gynaecoloog: Je mag de counselingpraktijk ook niet al te simplistisch voorstellen: counseling moet aangepast worden aan geloof en afkomst, en patienten moeten ook begrijpen wat hen wordt meegedeeld. Een keuzehulpmiddel zou voor de volledige bevolking moeten kunnen dienen. Een keuzehulpmiddel zou voldoende flexibel moeten zijn om hierop in te kunnen spelen.

Student geneeskunde: Het keuzehulpmiddel lijkt nu, zoals het in de presentatie werd voorgesteld, vooral te focussen op hoogopgeleiden. Het is misschien niet zo evident om er een keuzehulpmiddel te maken dat toegankelijk is voor alle lagen van de bevolking.

Psychiater: Bij de keuze die ouders bij prenatale screening moeten maken, gaat het ook om de vraag over bestaan of niet. Dat maakt het een existentiele keuze. Een dergelijke keuze kan je niet alleen maken. We mogen niet in de pragmatiek blijven steken. De bredere existentiele vragen, zoals 'wat is berouw?', 'hoe maken mensen keuzes?', moeten we ook stellen.

Mensenrechtenorganisatie voor mensen met een beperking: In de discussie over het al dan niet verplicht toepassen van een dergelijk keuzehulpmiddel mogen we toch ook vooral de rechten van het ongeboren kind niet vergeten. Het ongeboren kind heeft recht op een weloverwogen keuze.

Organisatie voor mensen met een beperking: Een cruciale vraag hier is: wat is de norm? De norm van hoe mensen zouden moeten zijn, bepaalt de obstakels waar mensen met een beperking tegenaanlopen. De maatschappij reduceert mensen met een beperking in hun normorientatie tot hun beperking. Ze worden niet als volwaardige leden, als mensen van de maatschappij beschouwd.

Ouder van een kind met Downsyndroom: Het zijn de ouders zelf die beslissen of het kind blijft, niet de test. Ook na de keuze is er counseling nodig: ofwel om de afbreking te verwerken, ofwel om ouders die kozen om hun kind te houden bij te staan bij allerlei praktische zaken. Onderwijs, bijvoorbeeld: het gaat erom of mijn kind welkom is/blijft in de maatschappij.

INITIATIEF 2: DRAAIBOEK
Toelichting: zie supplement 5, p.6

Vroedvrouw: De uitdaging van goede counseling ligt vooral bij de perifere gynaecologen. Een draaiboek kan zeker een meerwaarde zijn, mits dit op een juiste manier opgebouwd wordt.

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Kinderarts: De bereidheid onder de artsen om zo'n draaiboek op te volgen, schiet momenteel vermoedelijk tekort. Dit kan verholpen worden door het draaiboek aan de patient te geven in plaats van aan de arts, zoals we ook doen bij de ***Downpas.*** Dat is een gezondheidsboekje ontworpen voor kinderen en volwassenen met het syndroom van Down. Ouders brengen het mee op consultatie, en zo is de arts wel ongeveer verplicht om aandacht te besteden aan deze leidraad.

Vroedvrouw (zelfstandige): De eerste lijn in de gezondheidszorg wordt te snel vergeten, terwijl net daar wel de tijd gevonden kan worden voor uitgebreidere prenatale consultatie. Vroedvrouwen kunnen voor verstaanbare counseling op maat van de patient zorgen. Wanneer zwangere vrouwen in een ziekenhuis terechtkomen, komen ze vaak niet met vroedvrouwen in contact voor de twaalfde week van de zwangerschap. Dat zwangere vrouwen in Vlaanderen typisch niet doorverwezen worden naar de vroedvrouw, heeft vermoedelijk met concurrentie te maken, geloof ik. Vrouwen worden meteen doorverwezen naar de tweede lijn, omdat er weinig samenwerking is tussen zelfstandige vroedvrouwen en ziekenhuizen. Betere afspraken tussen eerste en tweede lijn zijn wenselijk.

Politicus: Het punt van een optimale rolverdeling is inderdaad erg belangrijk. Er zijn goede afspraken gemaakt in de postnatale context na het inkorten van de ligdagen, de eerste en tweede lijn zijn daar nu goed op elkaar afgestemd. In de prenatale context is er op dat vlak nog een lange weg te gaan. In Leuven zijn we hiermee aan het experimenteren. De rolverdeling moet goed en duidelijk zijn—ook om overconsumptie van de zorg tegen te gaan. Patienten moeten weten waar ze aan toe zijn en bij wie ze terecht kunnen.

Gynaecoloog: Toch mogen we niet vergeten dat er in de eerste lijn te weinig mensen zijn met de kennis die nodig is om te counselen bij prenatale testen. Hier moet aan gewerkt worden. Bovendien ontbreekt counseling niet in alle situaties. Een draaiboek moet inzetten op zowel pre-test counseling als post-test counseling, en ook het onderscheid tussen commerciele en niet-commerciele testen moet aan bod komen. Binnenkort kunnen we genoom-breed screenen, ook dit moet in rekening gebracht worden. Zo niet, dan wordt het eerder gemaakte draaiboek irrelevant.

Genetic counselor: Counseling is helemaal niet vanzelfsprekend. Het vereist een specifieke opleiding die peilt naar biomedische kennis, psychologische kennis, sociale kennis, ethische kennis, juridische kennis en nog zoveel meer. De complexiteit van post-counseling mag zeker niet onderschat worden.

Student geneeskunde: Vanuit het perspectief van een geneeskundestudent denk ik dat een draaiboek heel nuttig zou zijn voor toekomstige artsen. In de opleiding wordt er nu slechts heel beperkt ingegaan op het praktische luik van de test: het is niet altijd duidelijk hoe en welke informatie je het beste mededeelt aan patienten over NIPT of prenatale testen.

Gynaecoloog: We staan nog voor grote uitdagingen om de bijkomende bevindingen van NIPT in kaart te brengen. De wet wordt ingehaald door bijkomende bevindingen van NIPT—waardoor het niet altijd makkelijk of mogelijk is om gepaste counseling te geven. Een breder draaiboek kan daarbij helpen. Dat kunnen we echter pas maken als we weten wat we willen weten via de NIPT, en wat niet.

Mensenrechtenorganisatie voor mensen met een beperking: Voor euthanasie bijvoorbeeld is er wel een draaiboek. Hoe heeft dit een draagvlak gekregen? Net zoals euthanasie is de NIPT ook een ethisch vraagstuk, waarom kan hier geen inspiratie uit gehaald worden?

Kind en Gezin: Vanuit mijn ervaring is een protocol iets wat stap voor stap uitgewerkt wordt, en waar later ook nog aanpassingen in worden gemaakt. Zie bijvoorbeeld de protocollen bij het neonataal screenen voor gehoor en zicht.

Organisatie voor mensen met een beperking: Screenings hebben een impact, het is normaal dat ouders bij het maken van een keuze door een zwaar traject gaan. Beperkingen worden door de samenleving nu als zwaarder ervaren dan tien jaar geleden. De verklaring hiervoor is dat mensen meer en meer moeten voldoen aan de norm.

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INITIATIEF 3: GETUIGENISSEN

Toelichting: zie supplement 5, p.4

Organisatie voor mensen met een beperking: Een project van ons vertrekt vanuit het idee van de maakbare mens. Als deel van dat project stellen we mensen met een beperking systematisch de vraag: “zijn jullie gelukkig?”. Elke ouder wil een gezond en een gelukkig kind, maar de medische wereld gaat ervan uit dat een beperking gelijk is aan niet gezond zijn, als iets dat genezen moet worden en dat niet gelukkig maakt. Dit proberen we te weerleggen. Als mensen met een beperking niet gelukkig zijn, dan wordt dit niet veroorzaakt door hun beperking, maar wel door de structuur van de maatschappij, door de manier waarop de maatschappij omgaat met hun beperking. In deze context zou het goed zijn om mensen met het syndroom van Down zelf aan het woord te laten, ook al is dat niet makkelijk.

Student biomedische wetenschappen & brus van een jongen met het syndroom van Down: Ik wil de nadruk leggen op de nood aan een goede opleiding voor artsen en paramedici. Ik schrik soms van de verouderde en vaak gewoon incorrecte informatie die wij als student meekrijgen over het syndroom van Down.

Professor in de wijsbegeerte: Aan de getuigenissen kan schriftelijke informatie toegevoegd worden over onder andere ethische aspecten (waarden, existentiele aspecten). Je moet opletten met het contrast dat gecreeerd kan worden tussen het medische, wat als objectieve informatie wordt gezien, en de getuigenissen, die dan als subjectief worden gezien. Volledig neutraal informeren is een illusie, maar als je verschillende standpunten en perspectieven naast elkaar zou leggen kan je door de diversiteit aan beelden in zekere zin de neutraliteit toch bewaren.

Kinderarts: Deze getuigenissen mogen niet meteen na de diagnose getoond worden omdat ouders op dat moment een traumatische ervaring beleven. De arts moet echt wel als uitgangspunt genomen worden bij counseling. Zij kunnen concreet staven wat mensen met het syndroom van Down bijvoorbeeld gemiddeld kunnen op achttienjarige leeftijd. Zo gaat het in Nederland, en ik denk dat dit een goede manier is om de beperkingen en mogelijkheden van iemand met down bij ouders te introduceren. Toch moeten er ook niet enkel dokters aan het woord komen. Als ouders aan het woord komen, is een video wel een goed idee. Een video is afstandelijker, en dus beter. Ook het concept van contactouders dat Downsyndroom Vlaanderen hanteert, is het vermelden waard.

Ouder van kind met Downsyndroom & voormalig contactouder: Getuigenissen in de vorm van videofragmenten kunnen misschien toch een beter alternatief zijn dan wat we met de contactouders doen. Postnataal werkt het contactoudermodel prima, maar de verantwoordelijkheid die je als contactouder draagt bij een prenataal bezoek is erg zwaar, en directiviteit is onmogelijk te vermijden in zo’n context. De afstand die gecreeerd wordt met videofragmenten lijkt mij in die zin wel positief.

Mensenrechtenorganisatie voor mensen met een beperking: De contactpersonen krijgen inderdaad een grote verantwoordelijkheid. Daar moet voorzichtig mee worden omgesprongen. Als er een netwerk van getuigenissen komt, dan moet ervoor gezorgd worden dat dit kwalitatief is en erin wordt geinvesteerd. Ervaringsdeskundigen moeten wel degelijk meer worden betrokken.

Student geneeskunde: Praktisch gezien vraag ik mij af wie de selectie van getuigenissen zou doen? En hoe beslis je welke getuigenissen aan bod komen? Geen enkele getuigenis kan een volledig beeld schetsen, hoe zou je daarmee omgaan?

Organisatie voor mensen met een beperking: Het is moeilijk om een volledig beeld te geven. Stel dat ik al een volledig beeld zou kunnen geven van een kind, een gezond kind, dan zou niemand vermoedelijk nog kinderen willen, omdat dit ook het beeld inhoudt van alles wat kan mislopen, niet van de droombeelden.

Vroedvrouw (zelfstandige): Om terug te gaan naar het aspect van counseling denk ik dat continuiteit heel belangrijk is. Elke zorgverlener is betrokken, maar door versnippering van de zorg komen mensen telkens bij iemand anders terecht. Elke zorgverlener is zo slechts een stukje van het verhaal. Het is belangrijk dat ouders bij eenzelfde persoon een aanspreekpunt vinden doorheen hun traject. Het counselen zou door dezelfde persoon gedaan moeten worden.

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Organisatie voor mensen met een beperking: Ouders worden te weinig ondersteund en begeleid bij de keuzes die ze moeten maken, niet enkel in het geval van Down. De begeleiding moet doorgaan, ook wanneer ouders kiezen voor een kind met een beperking.

Bio-ethicus: Getuigenissen zijn per definitie subjectief. Het idee van niet-directieve counseling is een illusie. De basisvraag 'wil je een NIPT of niet' kan zelfs vanuit institutioneel perspectief al als directief worden gezien. Het is vermoedelijk weinig zinvol om te vertrekken vanuit het idee dat er geen directiviteit mag zijn. Als je eerlijk bent over het feit dat een getuigenis directief is, dan zie ik geen probleem met het gebruik ervan.

Vroedvrouw (thuiszorg): Ik wilde ook nog even benadrukken dat er ook mensen zijn die heel tevreden zijn over de counseling die ze krijgen. Er zijn ook heel mooie verhalen.

INITIATIEF 4: VRAAGTEKEN/VARIA
Toelichting: zie supplement 5, p.8

Mensenrechtenorganisatie voor mensen met een beperking: Er is weinig evolutie in de blik van de maatschappij op mensen met het syndroom van Down. In een ideale wereld zouden mensen in hun dagdagelijkse leven al zo vaak in contact komen met mensen met een beperking, met het syndroom van Down, dat je op het moment van screening niet meer zou moeten uitleggen wat het syndroom van Down is. Dan zou je niet meer moeten investeren in getuigenissen.

Student geneeskunde: Als zorgverleners niet altijd beseffen dat ze een steek laten vallen, hoe kan je de communicatie tussen arts en patient dan verbeteren? Ik denk dat het belangrijk is om feedbackmomenten in te lassen, dit is nog altijd de beste manier om dingen te verbeteren.

Wetenschappelijk medewerker: Hoe laat je health professionals reflecteren over de vraag of ze al dan niet op een effectieve manier counselen? Artsen moeten tegenwoordig alles kunnen, ik vraag mij af waar de beperkingen hier zitten. Wat kunnen we vragen van dokters?

Psychiater: Artsen moeten een persoon zijn, menselijk zijn. Studenten die voor arts kiezen moeten dit bewust doen. Als arts sta je op de frontlinie van leed. Een niet-discriminerende attitude van artsen is ontoereikend. Ouders zullen altijd een 'droomkind' in gedachten hebben. Wanneer dan blijkt dat hun kind hiervan zal afwijken, is dit ook een kind, namelijk hun 'droomkind', verliezen. Dit is ook een soort van rouw, want hun kind zal niet zijn zoals ze verwachtten en ze zullen dus ook moeten leren accepteren en apprecieren wat ze wel krijgen als ze besluiten het kind te houden.

Ouder van een kind met Downsyndroom: We hebben ooit geprobeerd een studiedag voor artsen te organiseren over het leven met het syndroom van Down. Dit was heel moeilijk. Er is een verdeling onder de artsen. Op zo'n studiedag zouden enkel artsen aanwezig zijn die je bijscholing niet meer nodig hebben. Hoe krijg je de ongeinteresseerden geinteresseerd? Studiedagen voor zorgverleners zijn in elk geval belangrijk, maar zij die al veel weten, zullen komen, terwijl zij die het nodig hebben afwezig zullen blijven.

AFSLUITENDE POLL

Uit discussies tijdens deze samenkomst blijkt dat er een gezamenlijke nood is aan een uniform beleid, ondersteund door de politiek. Bovendien wordt er verder onderzoek verwacht naar de norm en het existentiele aspect rond personen met een beperking in deze maatschappij.

Om het stakeholderoverleg af te sluiten, kregen alle aanwezigen de mogelijkheid een poll in te vullen. Deze poll gaat na welke initiatieven de stakeholders het liefst zo snel mogelijk uitgewerkt zien in de toekomst. Dat levert enkele kwantitatieve resultaten op over het initiatief dat het belangrijkste is volgens deze kleine groep van belanghebbenden. Hierbij kregen ze de mogelijkheid een ander dan de drie voorgestelde initiatieven, omschreven tijdens de presentatie als het vraagteken, voor te stellen en opmerkingen achter te laten als feedback. De stakeholders werden niet beperkt tot slechts een initiatief te verkiezen. Figuur 1 stelt deze poll voor.

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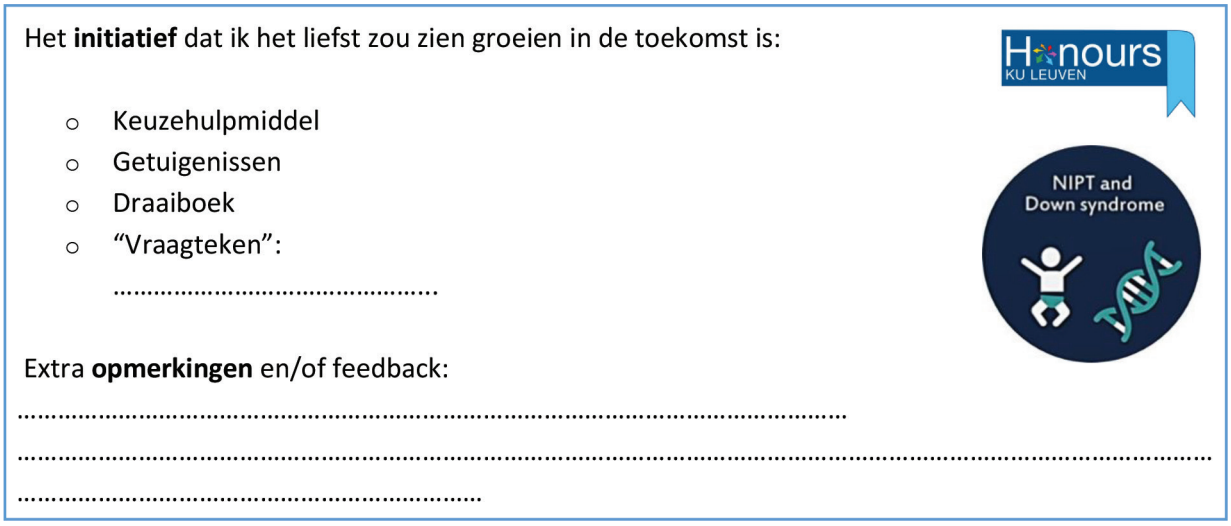

Figuur 1: Voorbeeld van de poll die de aanwezigheden kregen om in te vullen op het einde van het s takeholderoverleg.

Uit de resultaten van deze poll van 30 stakeholders bleek dat het draaiboek als initiatief 54% van de stemmen vertegenwoordigt en het keuzehulpmiddel een percentage van 38. Tabel 1 geeft de stemmen per initiatief weer in absolute cijfers. Negen stakeholders hebben meer dan een initiatief verkozen en hiervan heeft 44% een lichte voorkeur voor het draaiboek. Een stakeholder vulde het vraagteken in met een voorstel tot filosofische gesprekken voor professionals met als doel reflectie en luistervaardigheid te stimuleren.

Initiatief	Aanal voorkeuren
Keuzehulpmiddel	15
Getuigenissen	1
Draaiboek	21
Vraagteken	2

Tabel 1: A summary of the amount of preferences for each initiative per initiative presented at the stakeholder meeting.

Van de 30 ingevulde bevragingen hebben 24 stakeholders een opmerking neergeschreven. Hiervan hebben zeven aanwezigen hun emailadres opgegeven om verdere informatie te ontvangen en/of voor een toekomstige samenwerking. Herhaalde feedback duidt op de nood aan correct, duidelijk en eenvoudig taalgebruik in de verschillende tools, aangepast aan elk type stakeholder en rekening houdend met verschillende culturen. Er wordt verwacht ook meer dan enkel het syndroom van Down te onderzoeken en duidelijk te belichten 'wat in het geval van een positieve NIPT'. Zowel pre- als postcounseling moeten besproken worden. Het draaiboek moet zich bovendien niet enkel richten op directe zorgverleners, ook toekomstige artsen moeten betrokken worden. Als laatste benadrukten enkele aanwezige stakeholders dat het keuzehulpmiddel als aanvullend middel voor counseling moet worden gezien en niet als alternatief. Dat moet duidelijk toegelicht worden bij het gebruik van de tool.

In het algemeen kunnen we besluiten dat er een grote nood ondervonden is naar complementaire middelen als hulpverlening voor counseling. Velen zien dit echter als een enorme uitdaging die in de toekomst enkel groter zal worden zonder ondersteuning van de overheid.

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Supplement 7b: Reconstruction of the Main Insights (English)

Stakeholder Meeting May 8, 2019
Initiatives to stimulate sustainable choices in prenatal screening

This is a reconstruction of the main insights and reflections shared during the stakeholder meeting on the 8th of May 2019. The report was compiled based on the notes of Laura Barilla, Zoe Claesen and Job Meijer; and a poll completed by the stakeholders involved. The reconstruction follows the structure of the meeting and outlines the comments of the stakeholders per proposed initiative (see supplement 5). The stakeholders are anonymized and therefore not mentioned by name but by function or organization.

INITIATIVE 1: DECISION AID
Context see supplement 5, p.2

Bioethicist: It is not self-evident, but still necessary to ensure that everyone is offered the same care and guidance in prenatal screening. How can we ensure that future parents will receive the best support possible? Further standardization and protocolizing of healthcare can help. The government has to assume responsibility for this: they should focus on the development of plans and decision aids, as was the case with screening for breast and colon cancer, and neonatal screening. In the context of prenatal screening, this is much less the case: it was left to the professional field to make arrangements for NIPT. There is certainly room for growth in the developments of a protocol. Now clearly delineated instructions for doctor-patient communication about NIPT are lacking, which can lead to careless and ill-considered decisions. One could say that people are at risk of falling into a sort of 'screening trap'.

Politician: If we want anything to change, counseling in prenatal screening must be included in the coalition agreement. Doctors should also communicate more often to their patients that, in addition to the right to know, they also have the *right not to know*. This last right is only barely discussed with patients. As a result, prenatal tests are often taken without the patient's genuine approval. This can lead to ill-considered decisions in the event of unexpected results. Healthcare providers should take this more into account. The number of prenatal tests that are taken continues to increase, but the patient does not have enough information to accept or reject the test.

Gynecologist: I would like to raise four considerations. (1) The problem with NIPT in Belgium arose because the test was introduced too quickly, without any guidance for the content or form of counseling. (2) Future parents are often not sufficiently informed about the difference between commercial and noncommercial tests. Such commercial tests should be prohibited by law. (3) Clinical biologists rather than gynecologists seem to be the ones who force choices on parents. (4) When we talk about counseling today, it must be said that it occurs quite superficially before the tests are carried out. After taking the test, counseling is usually non-existent.

Human rights organization for people with disabilities: The social context in which a child with Down syndrome is born has hardly changed in the last 25 years. Having a child with Down syndrome is still seen as an accident or a tragedy. Moreover, people with Down syndrome are not treated as full-fledged members of our society. In addition, there is clearly still no political awareness of (the quality of) counseling in NIPT.

Pediatrician: I would like to make three considerations. (1) I would like to support the development of a decision aid. After all, it is difficult to counsel in a non-directive way without a clear guide at our disposal. The directivity will inevitably find expression, for example, in your posture, in the information you do or do not provide and on which information you lay emphasis, consciously or unconsciously. Healthcare providers need support in counseling, precisely for this reason. When you create a decision aid, it is also important to make one for the health care providers as well as one for the parents. (2) Studies in Canada, for example, show that about 30% of pregnant women who go through the NIPT do not know what the test entails. A decision aid can help address this problem, make parents aware of the right not to know, and help them make an unbiased decision about knowing or not knowing based on their own values and

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norms. (3) I would also like to stress that it's a good thing that the NIPT is reimbursed, although the reimbursement came through too quickly. This meant that there was insufficient attention for streamlining the counseling. Everyone, regardless of financial or social class, should have equally easy access to the NIPT.

Midwife: Our research in Ghent shows similar figures: 30–40% of pregnant women do not know exactly what the prenatal tests entail. A decision aid could therefore certainly be an added value. But it is important that such a tool should be offered without obligations, and more importantly, that it is offered supplementary to counseling and not as a replacement thereof.

Kind en Gezin ('Child and Family'; a Flemish agency that works actively in the 'Public Health, Welfare and Family' policy area): The basic principle of any screening is that you should screen only if you know what you want to do with the result. That is why screening must be linked to good counseling. For Kind en Gezin it is also important that everyone, regardless of social class, has equal access to NIPT.

Gynecologist: The counseling practice should not be oversimplified either: counseling should be adapted to religion and various cultural backgrounds. Patients should understand what is being communicated to them. Hence, a decision aid should be sufficiently flexible to serve the entire population and to respond to these differences.

Medical student: The way in which the decision aid is currently presented, gives the impression that it would focus mainly on the highly educated part of society. It might not be so easy to create a decisionmaking tool that is accessible to all layers of the population.

Psychiatrist: The choice parents have to make in prenatal screening may also lead to choices about existence and the absence of existence, which makes it an existential choice. You cannot make such a choice alone. We should not get trapped into mere pragmatism. We must also ask the broader existential questions, such as 'what is regret?' and 'how do people make choices?'.

Human rights organization for people with disabilities: In the discussion about whether the use of such a decision-making tool is mandatory, we should not forget the rights of the unborn child. The unborn child has a right to a well-considered choice.

Organization for people with disabilities: A crucial question here is: what is the norm? The standard of what people should be like, determines the obstacles that people with disabilities face. Society reduces people with a disability to their impairment, that is, to what they cannot do, the point where they differ from the norm. And on the basis of that, they are not considered as full members, as people of society.

Parent of a child with Down syndrome: It is up to the parents themselves to decide whether the child stays or not, not the test. Counseling is also needed after the choice has been made either to process the termination of pregnancy, or to support parents who chose to keep their child in practical matters like education. It's about whether my child is/remains welcome in society.

INITIATIVE 2: PROTOCOL

Context see supplement 5, p.6

Midwife: The challenge of good counseling lies mainly with the peripheral gynecologists. A protocol can certainly be an added value, provided it is constructed in the right way.

Pediatrician: The willingness of the doctors to follow a protocol is probably insufficient at the moment. This can be remedied by giving a kind of scenario or outline to the patient instead of the doctor, as we do with the 'Downpas'. This is a health booklet designed for children and adults with Down syndrome. In this way, the doctor is obliged to pay attention to the content that the parents bring to the doctor's office.

Midwife (self-employed): The first line of healthcare is too frequently forgotten, although they have more time for more extensive prenatal consultation. Midwives can provide understandable counseling tailored to pregnant women.

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When pregnant women end up going to hospitals for their check-ups, they often do not encounter midwives before the twelfth week of pregnancy. The fact that pregnant women in Flanders are typically not referred to the midwife in early pregnancy, I believe, probably has to do with competition. Women are immediately referred to the second line, because there is little cooperation between independent midwives and hospitals. Better agreements between first and second line are desirable.

Politician: An optimal division of roles is indeed very important. Good agreements have been made in the post-natal context after shortening the period of stay in hospitals after giving birth. In this area, the first and second lines are now well coordinated. In the prenatal context on the contrary, there is still a long way to go. We are currently experimenting with this in Leuven. The division of roles must be good and clear—also to prevent overconsumption of care. Patients need to know where they stand and to whom they can turn throughout their pregnancy.

Gynecologist: However, we should not forget that in the first line there are not enough people with the qualified knowledge for genetic counseling. We need to work on this. Moreover, counseling is not lacking in all situations. A protocol should focus on both pre-test counseling and post-test counseling. The distinction between commercial and non-commercial testing should also be addressed. Soon we are moving towards genome-wide screening, this should also be taken into account. If not, the previously made protocol will become irrelevant.

Genetic counselor: Counseling is not self-evident at all. It requires specific training which assesses biomedical knowledge, psychological knowledge, social knowledge, ethical knowledge, legal knowledge and much more. The complexity of post-counseling should certainly not be underestimated.

Medical student: From the perspective of a medical student, I think that a protocol would be very useful for future doctors. The practical aspects of dealing with NIPT in relation to patients is not extensively discussed in class: it is not always clear how and what information is best communicated to patients about NIPT/prenatal tests.

Gynecologist: We still face major challenges in mapping out the additional findings of NIPT. The law is being surpassed by additional findings from NIPT, which makes it not always easy or possible to provide appropriate counseling. A broader protocol can help in this respect. However, we can only do this when we know what we want to know via NIPT, and what we don't want to know.

Human rights organization for people with disabilities: For euthanasia, for example, there is a protocol. How did it gain support? Just like euthanasia, NIPT is also an ethical issue, why can't we draw inspiration from the developments of other protocols?

Kind en Gezin: From my experience, a protocol is something that is worked out step by step, in which adjustments can be made later on. See for example the protocols for neonatal screening for hearing and sight.

Organization for people with a disability: Screening has an impact; it is normal for parents to go through a difficult process when making a choice. Disabilities are now perceived as more daunting by society than they were ten years ago. The explanation for this is that more and more people have to comply with the norm.

INITIATIVE 3: TESTIMONIALS

Context see supplement 5, p.4

Organization for people with disabilities: One of our projects is based on the idea of "the makeable human being". As part of that project, we systematically ask people with disabilities: "Are you happy?". Every parent wants a healthy and a happy child, but the medical world assumes that a disability is equal to not being healthy, as something that needs to be cured and does not make happy. This is what we are trying to refute. If people with a disability are not happy, this is not caused by their disability, but by the structure of society and by the way in which society deals with their disability. In this context, it would be good to let people with Down syndrome speak for themselves, even if that is not easy.

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Student biomedical sciences & sibling of a boy with Down syndrome: I want to emphasize the need for a good education for doctors and paramedics. I am sometimes shocked by the outdated and often simply incorrect information that we, as a student, receive about Down syndrome.

Professor of philosophy: Written information on, among other things, ethical aspects (values, existential aspects) can be added to the testimonials. You have to pay attention to the contrast that can be created between the medical, which is seen as objective information, and the testimonials, which are seen as purely subjective. Completely neutral information is an illusion, but if you could put different points of view and perspectives side by side you could in a way preserve neutrality through the diversity of images.

Pediatrician: These testimonials should not be shown immediately after the diagnosis because parents go through a traumatic experience at that moment. Doctors should really be the starting point for counseling. They can provide concrete evidence of what people with Down syndrome, for example, can do on average at the age of eighteen. This is the way things are done in the Netherlands, and I think this is a good way to introduce the limitations and possibilities of someone with Down to their parents. However, it should not be only left to doctors to talk about this, but also for instance parents of children with Down syndrome When parents share their experience, a video is a good idea because it creates a degree of distance. The concept of 'contact parents' that *Downsyndroom Vlaanderen* [a volunteer organization by and for parents of children with Down syndrome] uses is also worth mentioning.

Parent of a child with Down syndrome & former 'contact parent': Testimonials in video format may be a better alternative than the concept of contact parents. This works perfectly well postnatally, but the sense of responsibility you bear as a contact parent during a prenatal visit is very heavy, and directivity is impossible to avoid in such a context. In that sense, the distance that is created through the medium of video fragments seems positive to me.

Human rights organization for people with disabilities: The 'contact parents' will indeed have a great responsibility. This must be handled with care. If there will be a network of testimonies, the quality must be ensured and more funds need to flow to these kinds of initiatives. Experts by experience need to be more involved.

Medical student: In practical terms, I wonder who would do the selection of testimonials? And how do you decide which testimonials will be discussed? No testimonial can give a complete picture, how would you deal with it?

Organization for people with disabilities: It is difficult to give a complete picture. Imagine I already could give a complete picture of a healthy child, then no one would probably want children anymore. That's because it would be the picture of everything that can go wrong, not of the fantasies people have.

Midwife (self-employed): To go back to the aspect of counseling, I think that continuity is very important. Every care provider is involved, but because of the fragmentation of health care, people always end up with someone else. In this way, every care provider is just a piece of the story. It is important for parents to find a point of contact with the same person throughout their journey. Counseling should be done by the same person.

Organization for people with disabilities: Parents are insufficiently supported and guided in the choices they have to make, not only in the case of Down syndrome. Guidance and support must continue, also when parents choose to have a child with a disability.

Bioethicist: Testimonials are by definition subjective. The idea of non-directive counseling is an illusion. The basic question 'do you want a NIPT or not?' can even be seen as form of directivity from an institutional perspective. It probably makes little sense to start from the idea that there should be no directivity. If you are honest about the fact that a testimony is directive, then I see no problem with its use.

Midwife (homecare): I also wanted to emphasize that there are people who are very satisfied with the counseling they receive. There are also some very nice and positive stories.

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INITIATIVE X : QUESTION MARK/MISCELLANEOUS

Context see supplement 5, p.8

Human rights organization for people with disabilities: There is little positive development in society's view of people with Down syndrome. In an ideal world, people would encounter people with a disability, with Down syndrome, with sufficient regularity in their daily lives that, at the time of prenatal screening, you would no longer have to explain what Down syndrome is. Then you won't have to invest in testimonials anymore.

Medical student: If healthcare providers do not always realize that they inappropriately communicate about NIPT or disability, how could we improve the communication between doctor and patient? I think it's important to include feedback opportunities, this is still one of the best ways to improve things.

Scientific assistant: How do you get health professionals to reflect on whether or not they are counseling effectively? Nowadays, doctors have to be able to do everything, I wonder where the limitations are. What can we expect of doctors?

Psychiatrist: Doctors must be a person, a human. Students who choose to study medicine should do so consciously. As a doctor, you are on the front line of suffering. As a doctor, a non-discriminatory attitude is insufficient. Parents will always have a 'dream child' in mind. If it turns out that their child will deviate from this, this also means they are losing a child, namely their 'dream child'. With this a kind of mourning arises, because their child will not be as they expected, and they will have to learn to accept and appreciate what they get if they decide to keep the child.

Parent of a child with Down syndrome: We once tried to organize a seminar for doctors about living with Down syndrome. This was very difficult. There is a division among the doctors. Only doctors who no longer need your further training would be present at such a seminar. The question is: How do you get the uninterested interested? In any case, seminars for healthcare providers are important, but those who already know a lot will come, while those who need it will remain absent.

FINAL POLL IN CONCLUSION OF THE STAKEHOLDER MEETING

Discussions during this meeting show that there is a common need for a uniform policy, supported by politics. In addition, further research is expected into the norm and the existential aspect of persons with disabilities in this society.

To conclude the stakeholder meeting, all attendees were given the opportunity to fill in a poll. This poll examines which initiatives stakeholders prefer to see developed as soon as possible in the future. This provides some quantitative results about the initiative that is valued most important according to this group of stakeholders. They were given the opportunity to present a different initiative than the three proposed initiatives, described as 'the question mark' during the presentation, and to leave comments as feedback. Stakeholders were not limited to preferring just one initiative. Figure 1 presents this poll.

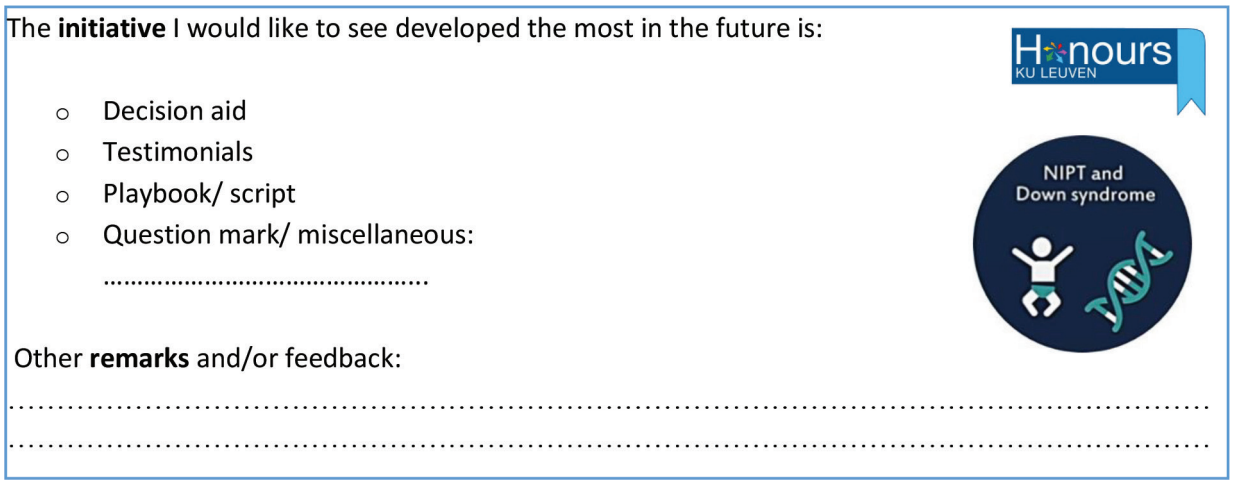

Figure 1. Example of the poll the stakeholders received to fill in at the end of the stakeholder meeting.

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The results of this poll of 30 stakeholders showed that the protocol initiative represents 54% preference votes and the decision aid gain a 38% support. Table 1 shows the votes per initiative in absolute figures. Nine stakeholders chose more than one initiative, 44% of which had a slight preference for the protocol. One stakeholder filled in the question mark with a proposal for philosophical discussions for professionals in order to stimulate reflection and listening skills.

Initiative	Number of preferences
Decision aid	15
Testimonials	1
Protocol	21
Question mark/miscellaneous	2

Of the 30 completed questionnaires, 24 stakeholders wrote a comment. Of those who commented, seven provided their email addresses in order to receive further information and/or for a future collaboration. Recurrent feedback indicates the need for correct, clear and simple language in the different tools, adapted to each type of target and taking into account different cultures. It is also expected to examine more than just Down syndrome and to highlight clearly where the choices lie and 'What to do in case of a positive NIPT?'. Both pre- and post-counseling need to be discussed. The protocol should not only focus on established healthcare providers, but also on future doctors. Finally, several stakeholders emphasized that the decision aid should be seen as an additional tool for counseling and not as an alternative.

In general, we can conclude that there is a great need for complementary resources to assist genetic counseling. Many stakeholders see this as an enormous challenge that will only increase without governmental support.

(Translation based on Deepl)

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Supplement 8: Presentation Held at Transdisciplinary Insights Symposium (English) (May 8, 2019)

KU LEUVEN

Honours KU LEUVEN

IF

Stimulating Informed Decisions in Prenatal Screening

Laura Barilla
Zoë Claesen
Charlot Diepvens
Eva Mensink

May 8, 2019

You're pregnant, Congratulations!

KU LEUVEN

NIPT

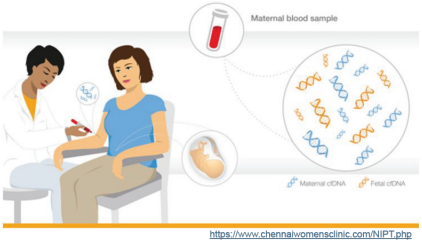
=

Non-Invasive Prenatal Testing

KU LEUVEN KU LEUVEN

NIPT

- Blood test
- 12 weeks (Belgium)
- Screens for chromosomal abnormalities
- No risk
- 98% accurate
- Probability
- Patient pays € 8,68 in Belgium



https://www.chennaiwomensclinic.com/NIPT.php

#1 EXPLORATION

What

Why

For whom

PROBLEM

#2 SEARCH FOR SOLUTIONS

Possible Solutions

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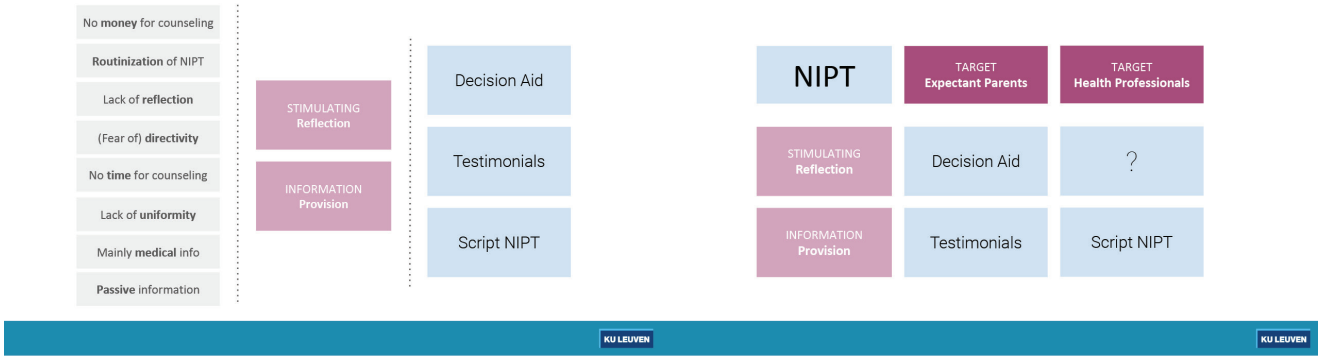

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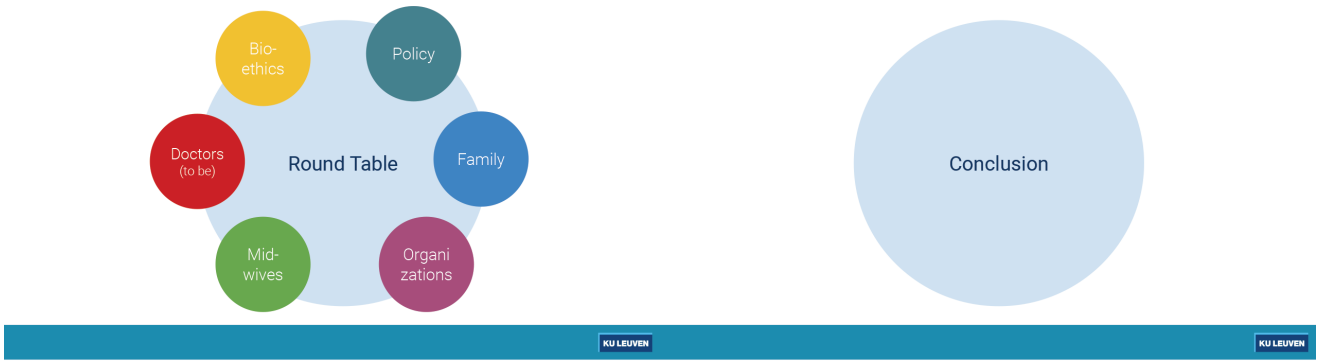

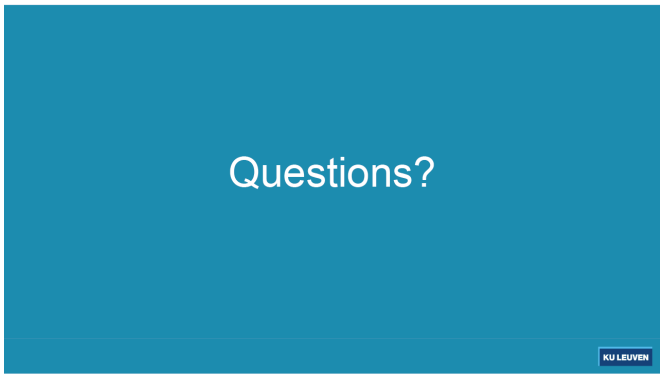

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Supplement 9: Recording Presentation

Counseling in prenatal screening for Down syndrome—Transdisciplinary Insights Honours Programme Symposium, May 8, 2019 – recording presentation here.