

# The Influence of Experiential Knowledge and Societal Perceptions on Decision-Making Regarding Non-Invasive Prenatal Testing (NIPT)

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## Research article

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RESEARCH

# The Influence of Experiential Knowledge and Societal Perceptions on Decision-Making Regarding Non-Invasive Prenatal Testing (NIPT)

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## Abstract

**Background:** Non-invasive prenatal testing (NIPT) allows women to access genetic information about their fetuses without the physical risk inherent to prior testing methods. The advent of NIPT technology has yielded concerns among bioethicists regarding the quality and process of informed consent, as the routinization of this technology could degrade the intentionality of women choosing whether to undergo testing. Prior studies evaluating the NIPT decision-making process have focused on the clinical encounter as the primary environment for acquisition of biomedical information and decision formation. While important, this conceptualization fails to consider how additional sources of knowledge, including both embodied and empathetic experiential knowledge, shape perceptions of risk and the societal use of NIPT.

**Methods:** In order to address this issue, qualitative, semi-structured interviews with 25 women who had been offered NIPT were performed. Women were categorized by NIPT use/non-use, as well as whether their described decision-making process was routinized. Qualitative analysis of the data using a phenomenological approach was used to explore themes in the data, develop a framework of NIPT decision-making, and compare the perceptions of women with differential decision-making processes and outcomes.

**Results:** A framework for decision-making regarding NIPT was developed based on three emergent factors: perceptions of the societal use of NIPT, expected emotional impact of genetic information, and perceived utility of genetic information. Qualitative analysis revealed that perceptions of widespread use of NIPT, pervasive societal narratives of NIPT use as progressive and “forward-thinking,” and a perception of more information as anxiety-relieving contributed to routinized uptake of NIPT. In contrast, women who displayed a lack of routinization expressed fewer stereotypes regarding the audience for NIPT and relied on communication with their social networks in-person and online to consider how they might use the information provided by NIPT.

**Conclusions:** The findings of this study reveal the societal narratives and perceptions that shape differential decision-making regarding NIPT. Understanding and addressing these perceptions that influence NIPT decision-making, especially routinized uptake of NIPT, is important as the use and scope of this technology increases.

**Keywords:** non-invasive prenatal testing; decision-making; routinization; experiential knowledge; informed consent; prenatal genetic testing

## Background

### Non-Invasive Prenatal Testing Technology

Non-invasive prenatal testing (NIPT) has significantly reshaped the options available to pregnant women to access genetic information about their fetuses. NIPT technology analyzes cell-free fetal DNA (cffDNA) in maternal circulation to determine the risk of chromosomal abnormalities in the fetus [1]. Other established genetic testing methods, such as amniocentesis and Chorionic Villi Sampling (CVS), are invasive and therefore pose risks to the fetus and mother [2]. NIPT can be performed earlier than amniocentesis and CVS, as early as 9 to 10 weeks, and poses no physical risk beyond that of an already routine blood draw [3, 1]. Since its introduction into the U.S. market in 2011, NIPT has been transforming the prenatal testing paradigm [3, 1]. NIPT is most often used for detection of aneuploidies in chromosomes 13, 18, and 21; however, coverage varies by testing company and an increasing amount of chromosomal abnormalities are being validated for testing [4]. Sensitivity rates of NIPT vary by aneuploidy, ranging from greater than 99% for trisomy 21, 96% for trisomy 18, and 69% for trisomy 13 [4, 5]. Although NIPT is a screening tool, rather than a diagnostic test, its relatively high sensitivity and specificity for trisomy 21 in particular “blurs the one-bright line between screening and diagnosis” [6], with evidence suggesting that women may misinterpret these screening results as diagnostic [7, 8].

### Routinization and Concerns about Informed Decision-Making

As technological advancements have facilitated a safer, less invasive form of prenatal genetic testing, the removal of physical risk allows for the perception of NIPT as a simple blood test. As a result, women may interpret NIPT usage as routine [9, 10]. Routinization changes how women imagine and weigh their options, such that some women may view NIPT as part of standard care and perceive the uptake of NIPT as less of a “deliberated action” than the decision to not undergo testing [11]. Thus, the technological ease of NIPT may obscure the significance of the decision to utilize it [12] and paradoxically undermine the ability for women to make autonomous, informed reproductive choices. Concerns regarding routinization and its implications for informed decision-making have arisen among bioethicists [11, 9, 13, 10], with studies finding that both women and practitioners view the consent process for NIPT differently than invasive prenatal testing, and women are likely to make uninformed choices regarding NIPT [8, 14].

Addressing concerns about routinization is increasingly important as the scope of NIPT sequencing expands [15] and the degradation of informed decision-making leaves women emotionally unprepared for the results they may receive [13, 6]. For example, as testing expands to non-chromosomal genetic disorders that are less accurately detected through NIPT technology, women may be less likely to understand the results they are receiving, and the necessity for robust informed decision-making will increase. Therefore, it is important to develop a comprehensive understanding of how women approach decisions about non-invasive prenatal testing in order to evaluate how such routinization occurs and better support women in their decision-making processes.

### **Influence of Experiential Knowledge and Societal Perceptions on Decision-Making**

Prior studies investigating NIPT-related decision-making have primarily focused on the clinical interaction as the environment for acquisition and application of biomedical knowledge to make informed decisions [16, 17, 18]; for exceptions see [19, 20, 21]. However, analysis of decision-making must consider “discourses beyond the biomedical domain” [20] since a significant portion of the decision-making process occurs outside of the clinical encounter [22] and may rely upon perceived societal values and experiential knowledge regarding NIPT. In terms of the potential influence of perceived societal values on NIPT decision-making, prior investigations have noted how technological advancements in prenatal technology are accompanied by a societal expectation to uptake such technologies in order to avoid what are increasingly seen as avoidable consequences [23, 24, 25]. Maternal responsibility thus shifts from caretaker to “quality control” [25]. Such societal perceptions regarding the use and implications of NIPT may shape how women approach the decision of whether or not to use it.

In addition, NIPT decision-making may be influenced by experiential knowledge. Experiential knowledge takes two forms, embodied and empathetic. Embodied knowledge is defined as knowledge obtained through personal, bodily experience (e.g. prior pregnancy), whereas empathetic knowledge is gained through exposure to the experiences of family and friends [26]. Etchegary et al. [26] and Browner and Press [27] have explored how experiential knowledge influences prenatal decision-making; however, this theoretical lens has not been directly explored among women considering NIPT.

Personal characteristics, such as age, health history, and health status contribute to embodied knowledge [28, 26] which may inform NIPT decision-making. Positive health status has been identified by women “as a factor that would decrease risk”, whereas a personal history of miscarriage or infertility leads women to lose “a sense of control over their bodies” and perceive greater risk [28]. Thus, embodied forms of knowledge inform subjective risk perception, which is not necessarily associated with actual risk [29], but may significantly shape NIPT decision-making. In addition to personal characteristics and experiences, vicarious knowledge about the experiences of friends, colleagues, and family contributes to empathetic knowledge that shapes perceptions of NIPT and may inform subsequent decision-making [26].

While theoretical foundations regarding experiential knowledge and perceived societal values have highlighted important influences on prenatal testing decisions [27, 26, 6], many of these theoretical foundations have not been directly explored among women offered NIPT. Additionally, prior studies investigating perceptions of, and knowledge about, NIPT among women considering its use have not evaluated differences in the frameworks used by women who do or do not uptake NIPT or who display routinized as opposed to significant decision-making [21]. Understanding decision-making frameworks among women from these different categories will help inform strategies for avoiding routinized decision-making regarding NIPT.

## **Aims**

This study sought to elucidate the decision-making frameworks used by women contemplating uptake of NIPT as well as how these frameworks are shaped by background knowledge about NIPT, perceived societal values, and experiential knowledge, both embodied and empathetic. This study also aimed to compare decision-making between women with different decisional processes (routinized vs. significant consideration) and outcomes (use vs. non-use of NIPT).

## **Methods**

In order to assess the decision-making processes regarding NIPT, qualitative interviews were conducted with women who had been offered NIPT. Potential participants were recruited with flyers and Facebook postings in community groups. Women who contacted the researcher were screened for eligibility. Eligibility was determined by residency in the rural area surrounding a major academic research hospital in the Northeastern United States and by having a current or recent pregnancy (with a child 2 years or younger). This cut point in child age was used to ensure that mothers involved in the study were pregnant recently enough to have been offered NIPT and to be able to recall their decision-making process.

The interviewer, study author SM, arranged qualitative, semi-structured interviews with participants via email. The interviewer had no relationship with the participants outside of the study. Interviews were conducted one-on-one in private or public locations chosen by participants from September 2018 - February 2019. An interview guide [Additional File 1] was used to guide discussion with questions regarding decision-making, including background knowledge about NIPT, the perception of the significance of the decision, the reasons for the ultimate choice of whether or not to undergo NIPT, perceptions of the test and its societal use, as well as influence of others on decision-making, including providers, friends, family, and social media. Interviews lasted twenty minutes to one hour and were recorded with participant consent for subsequent transcription by study author SM. Brief field notes were written by the interviewer after each interview. Interviews were transcribed, with transcripts uploaded to NVivo for coding. A phenomenological approach was used for the qualitative analysis, resulting in themes in the data that allowed for the development of a framework used by women considering the uptake of non-invasive prenatal testing. Women were categorized based on whether they used non-invasive prenatal testing as well as whether they considered the decision-making process to be significant (routinized vs. significant). This allowed for comparison of the perceptions and factors that shape decision-making among women who differed in routinization and use of NIPT.

## **Results**

### **Participants Characteristics and Uptake of Non-Invasive Prenatal Testing**

This study consisted of 25 women who were between the ages of 27 and 39 during their current or most recent pregnancy, and who had been offered non-invasive prenatal testing during that pregnancy. Seventy-two percent of women in this sample used NIPT technology during their current or most recent pregnancy. Approximately half of the women in this sample (72% of those who used NIPT) displayed

routinized uptake. Approximately two thirds (n=17) of women were younger than 35 during their current or most recent pregnancy, meaning that fewer than one third (n=8) of women were 35 or older and therefore clinically defined as advanced maternal age (AMA). At the time of the study interview, ninety-two percent of participants were married, and eighty-four percent had earned a bachelor's degree or higher. The women in this sample were predominantly white (96%) and of high socioeconomic status (84% with household income above \$90,000). Additionally, twelve percent of participants self-reported family history of genetic disorders, forty percent reported a history of miscarriage, and one participant had been previously told she was infertile.

### **Background Knowledge about NIPT**

Almost all of the women described a vague understanding of prenatal genetic testing before they encountered the decision of whether to use NIPT. Due to the novelty of NIPT technology, most of the prior knowledge women had acquired about prenatal genetic testing through their social networks was about amniocentesis:

“That’s the only thing I’d ever heard was like a needle will go through your belly. That’s pretty much all that I ever knew about genetic testing prior to being pregnant.” (Participant 17; non-AMA, personal history of miscarriage; family history of genetic disorders)

“I had this vision in my head of like, you know, that needle going into her stomach, like it was not really something I wanted to do or to go there” (Participant 13; AMA; used NIPT)

“I have heard the term amniocentesis, so I was more familiar with that, but my main knowledge of it is it’s a big needle and I was not interested in that.” (Participant 5; AMA; used NIPT)

Thus, stories from mothers, aunts, and friends informed empathetic experiential knowledge regarding amniocentesis, and these perceptions of amniocentesis were largely negative and often accompanied by a vivid image of a “big needle through the uterus”. Based on this background, NIPT was evaluated in comparison to amniocentesis, rather than exclusively on its own terms:

“Yeah, I think when I thought genetic testing, that was kind of the thing that I represented in my mind. And I guess I was happy to know that there were noninvasive methods to use.” (Participant 12; non-AMA; used NIPT)

“Yeah. I think if the like entry-level tests had been amniocentesis, I would have thought about it a lot more because of the risk and the just more invasiveness and the bigger needle. It all seems just like more intense. But they were like, they were taking my blood for a bunch of stuff anyway.” (Participant 11; non-AMA; used NIPT)

“I thought that it was good that there was a less invasive option that didn’t put the baby or the mom or anybody in harm, so I appreciated that.” (Participant 19; non-AMA; used NIPT)

This basis for contemplation of NIPT emphasizes its non-invasive nature compared to amniocentesis and thus frames the technology as especially appealing as a high benefit procedure without the risk of miscarriage present in earlier genetic testing technologies.

**Frameworks for NIPT Decision-Making**

Thematic analysis of interview transcripts was conducted to develop a framework by which women approach decision-making regarding the uptake of NIPT. Women’s evaluations and perceptions of three factors were identified as instrumental in decision-making:

1. **Perceived societal use of non-invasive prenatal testing.** Women’s perceptions of how often NIPT is used, who uses it and why, as well as how they categorize themselves in relation to these classifications informs decision-making.
2. **Expected emotional impact of genetic information.** Women’s forecasting of how the information provided by NIPT will affect them emotionally also factors into decision-making. Women may perceive information as emotionally neutral, anxiety-inducing, or anxiety-relieving.
3. **Perceived utility of genetic information.** Women’s evaluation of how the information provided by NIPT may be of use to them shapes decision-making. Information may be seen as valuable due to its ability to allow parents to prepare for having a child with chromosomal abnormalities. Conversely, information may be seen as valuable in terms of how it may inform termination decisions.

Women were categorized based on whether they used non-invasive prenatal testing as well as whether they considered the decision-making process to be significant (routinized vs. significant). Characteristics of women in each of these categories were considered as well as how women in each of these categories differ along the three factors outlined above. Women who displayed non-routinized decision-making, regardless of NIPT use, were analyzed together (Group 3) and compared to women displaying routinized use (Group 1) and routinized non-use (Group 2) of NIPT. Results of this analysis are presented below, with a summary presented in Table 1.

**Table 1 Frameworks for Differential Decision-Making. The table below summarizes the perceptions of women in each category of decision-making of the three factors in the framework outlined above.**

	<b>Routinized</b>	<b>Non-Routinized</b>
<b>Uptake</b>	<b>Group 1: Routinized Uptake of NIPT (n=13)</b> 1 Common usage for science-friendly people 2 Information as anxiety-relieving or emotionally neutral 3 Perceived utility is preparing for a child with a disability	<b>Group 3: Significant Consideration of NIPT Resulting in Uptake or Non-Use (n=8)</b> 1 Mixed usage; individual choice based on circumstances 2 Information as anxiety-relieving or emotionally neutral 3 Perceived utility is informing termination decisions
<b>Non-use</b>	<b>Group 2: Automatic Dismissal of NIPT (n=4)</b> 1 Only use if specific risk 2 Information as anxiety-inducing 3 Perceived utility is informing termination decisions (not willing to terminate)	

**Group 1: Routinized Uptake of NIPT**

Classification of participants as having ‘routinized’ decision-making during pregnancy was based on descriptions of routinization in prior research as the normalized

uptake of NIPT with minimal consideration [9, 10, 11]. Women with routinized uptake did not perceive the decision of whether to undergo prenatal genetic testing as significant, and many did not consider it to be a decision at all. As two participants stated:

“I think I just assumed we would [do the test] because it’s not like super invasive.” (Participant 11; non-AMA)

“I felt like yeah, since it seems like it was not invasive, you know, why not get this information” (Participant 23; non-AMA)

Approximately half of the women in the study sample demonstrated routinized uptake of NIPT (n=13). Most of the women in the routinized uptake category were below age 35 (71%) and did not self-report a family history of genetic disorders. Women in this group characterized the factors in the aforementioned decision-making framework in the following ways:

### ***1. Perceived societal use of non-invasive prenatal testing***

Women with routinized uptake of NIPT perceived common usage of NIPT technology. This perception was bolstered by stories from friends and family who used the test. Although women with pregnancies in this category did not discuss NIPT much with their network as they were considering whether or not to use the test, with many only speaking to their partner and provider about the decision, their perceptions of NIPT were shaped by discussions about prenatal genetic testing before their pregnancy. For example, women who perceived that others in their social network were using the test often expressed that this increased their comfort with NIPT:

“Well, my sister had done the testing, the blood test... I felt okay to do the blood tests, that type of testing because she did it, so I assumed it was safe.” (Participant 10; non-AMA; family history of genetic disorders)

“I think given the societal comfort with that kind of screening, it probably made me feel more comfortable even on an unconscious level about having the testing done.” (Participant 2; non-AMA)

This perception of common usage normalized uptake of NIPT and increased comfort with the technology. Thus, conversations with other women undergoing testing served as a form of empathetic experiential knowledge informing women’s perceptions of the test and its societal use.

In addition to ideas about how often NIPT is used, women displaying routinized uptake also expressed common perceptions regarding who uses NIPT technology. In describing their own usage of the technology, women in this routinized category characterized themselves as science-friendly and “pro-information” while emphasizing this orientation as a reason for their uptake of the test and implying that denying use of NIPT would be motivated by an anti-science or religiously-oriented approach:

“I try to surround myself with like science people and with information about new breakthroughs in science and my niece has Type 1 Diabetes and so my family does a lot of

lobbying with Type 1 Diabetes for stem cell research and stuff like that. And so, like if we're counting all of those groups, kind of society at large for me, um, I think that would all be very pro information and like have as much information as we can." (Participant 7; non-AMA; personal history of miscarriage)

"I work in a culture that is science-friendly. And so tends to be, you know, it's data-driven and I know the differences between screening and a definitive test, you know. And so I think in my most immediate cultural circles I felt encouraged." (Participant 6; AMA)

One participant, while not part of the routinized uptake group, articulated this association of NIPT use with pro-science tendencies as follows:

"I felt like in society the general measure of things was kind of, it was treated as like, if you were scientific and forward-thinking you were in support of these things and if you are maybe from a religious community or didn't understand science, then you were against them and there was a sort of polarization that I felt like happened along those lines." (Participant 3; AMA)

Perceptions about who uses NIPT technology were also influenced by the clinical definition of AMA as 35 or older. The AMA women in the routinized group cited their AMA status as a reason to undergo testing, with the assumption that all women of advanced age should be undergoing testing:

"So, I kind of also figured after turning 35 that whenever I got pregnant, I just had this perception that doctors would be like you're high risk, we must do everything." (Participant 6; AMA)

## ***2. Expected emotional impact of genetic information***

Women in the routinized use category tended to anticipate that the information provided by genetic testing would be anxiety-relieving or emotionally neutral. Anxiety-relief was cited as a major reason for pursuing testing by many:

"I wanted to know that the baby was healthy. Um, you know, to the extent that we could know that. So seeking to manage my anxiety that way." (Participant 23; non-AMA; prior screening result indicating possible fetal abnormality)

"The physician, so in that one appointment she brought it up and we already knew that we wanted to do it. Not that we have any risks, you know, I mean but just for peace of mind." (Participant 19; non-AMA)

Some of the women who had experienced miscarriages prior to their current pregnancy expressed a greater desire for reassurance due to this experience:

"It was fairly recently after my miscarriage when I had the second pregnancy. So I just wanted that extra assurance." (Participant 25; non-AMA; personal history of miscarriage)

"Because I had lost a pregnancy previously, it was sort of part of the sensitive topics of, you know, trying to make me just at ease with just things are going okay." (Participant 15; AMA; personal history of miscarriage)

Thus, prior experience of miscarriage served as a form of embodied experiential knowledge that affected risk perception and the desire for reassurance.

For those who saw genetic information as emotionally neutral, the decision to obtain information was seen as a precursor to the actual decision of what to do with it. These women cited an emphasis on informed decision-making and a desire to always have more information rather than less:

“I just was like, of course we’re going to do it because, because um, when we have information, we have data, so we pretty much decided and just went with it” (Participant 21; non-AMA; personal history of miscarriage)

“I like being informed. I like making informed choices. I didn’t know exactly what we would necessarily do with the information, but I knew that we wanted it” (Participant 6; AMA)

This emphasis on having as much information as possible aligned with the science-friendly, forward-thinking self-perception of women displaying routinized uptake.

### ***3. Perceived utility of genetic information***

Women in this category predominantly characterized the perceived utility of genetic information as its ability to allow parents to prepare for having a child with a chromosomal abnormality. Many women expressed positive views of disability and an intention to continue their pregnancy regardless of NIPT results. Given this intention, NIPT offered a way to be prepared:

“Like if it’s trisomy whatever and baby’s not going to survive past the first week, then you know, just mentally preparing for that. And then of course for Downs. We would just again prepare for that. So at the time of the birth you can really celebrate, even though it’s going to be difficult, you can celebrate the birth and not be focused on like this new, very devastating diagnosis. You can kind of deal with it in advance, prepare for it mentally. So when the baby comes you can really just still celebrate. Yeah, so I think it was just preparing.” (Participant 16; AMA)

“I was still committed to the pregnancy, but I felt like I wanted to know if the child is going to have some illness or disability that was going to make the delivery more difficult or so that I can prepare for being a parent of a child with a disability.” (Participant 23; non-AMA; prior screening result indicating possible fetal abnormality)

Overall, the decision-making process regarding NIPT use for nearly half of the women in this study sample was routinized. For these women, the decision of whether to undergo NIPT was seen as a “no-brainer” due to perceived common usage of NIPT among science-friendly people, an expectation of receiving information that is anxiety-relieving or emotionally neutral, and the ability of this information to help families prepare for a child with chromosomal abnormalities.

### **Group 2: Automatic Dismissal of NIPT**

Women who did not use NIPT technology and who did not significantly consider its use were classified as part of Group 2. The decision-making process of these women was therefore considered routinized in a different sense. Similar to women who displayed routinized uptake of NIPT, the women in Group 2 did not perceive the decision of whether to undergo prenatal genetic testing as significant. Additionally,

similar to the women displaying routinized uptake, women who dismissed the use of NIPT during their pregnancy made the decision quickly and usually discussed it only briefly with their partner and provider.

There were four women in the sample that could be categorized as part of this group. These women were all below 35 and therefore not considered AMA. Only one woman in this group had a history of miscarriage, and none of the women in this group had a self-reported family history of genetic disorders. Women in this group characterized the factors in the NIPT decision-making framework in the following ways:

### ***1. Perceived societal use of non-invasive prenatal testing***

Similar to the women displaying routinized uptake, women who immediately dismissed the use of NIPT during their pregnancy perceived widespread use of NIPT. However, unlike women with routinized uptake, the women in Group 2 thought that the use of NIPT was specifically meant for women considered “high risk” due to factors like advanced maternal age or family history of genetic disorders. In addition, experience of a prior healthy pregnancy led women to also perceive their current or most recent pregnancy as “low-risk.” Therefore, women who automatically dismissed NIPT did not consider NIPT use largely because they perceived that the test was meant only for a “high risk” category which they did not see themselves as part of:

“I always viewed it as like genetic testing is something that you get if you know it runs in the family. . . or if you are older than 35 or in your forties and you’re pregnant, the doctor is more likely to be concerned.” (Participant 1; non-AMA)

“We didn’t do any genetic testing just because again, we didn’t feel that I had any familial history of risk factors to want to know.” (Participant 14; non-AMA)

“I felt, having done it before, having had a healthy child before, I didn’t need that degree of reassurance maybe the second time. . . I seem to be able to carry them to full term no problem.” (Participant 23; non-AMA)

In sum, women’s perceptions of their individual risk, which is likely shaped by experiential knowledge as well as the clinical encounter, led them to perceive their pregnancies as “low risk” and therefore to believe that they were not part of the target NIPT audience.

### ***2. Expected emotional impact of genetic information***

The genetic information made available via NIPT was characterized by women in Group 2 as anxiety-inducing. The potential anxiety of receiving the information was cited as a deterrent to pursuing testing:

“But it’s scary because if you know that there’s nothing you can do, at least with my personality, I’m just more likely to just worry and stew be like, oh, was there something that I could do? Um, whereas if I didn’t know, like I would just deliver the baby and yes, I would get the news that the baby had, you know, x or y condition. Um, and then I would start dealing with it right then and there instead of having the worry of baby can be healthy, the baby might not be healthy and so it’s just kind of the worry” (Participant 1; non-AMA)

“I’m a big worrier in general, so I felt like I would be worrying plenty without adding that piece.” (Participant 14; non-AMA)

This characterization of biomedical information as anxiety-inducing contrasts with women in Group 1, who primarily viewed this information as anxiety-relieving or neutral. This is particularly interesting given women in Group 2’s self-perception as “low risk,” and indicating that the characterization of biomedical information as anxiety-inducing is not due to any heightened personal risk but rather a general response to biomedical testing that these women perceive as personally unnecessary.

### ***3. Perceived utility of genetic information***

Women in Group 2 saw the utility of genetic information in its ability to inform termination decisions. Therefore, according to this view, testing is done by parents interested in pursuing termination in response to test results indicating chromosomal abnormalities. Based on this perception, their own intention to carry the pregnancy to term regardless of NIPT results contributed to their lack of interest in NIPT:

“We felt that no matter what we were going to carry the pregnancy full term. So it sort of didn’t matter if you will.” (Participant 14; non-AMA)

“We just decided that even if we found out anything we probably wouldn’t have done, like we wouldn’t have aborted or anything like that if there was a problem.” (Participant 8; non-AMA; personal history of miscarriage)

This view directly contrasts with that of women displaying routinized uptake of NIPT (Group 1), for whom genetic information is not for informing termination decisions, but rather has utility in preparing parents for having a child with special needs.

Overall, the women who displayed automatic dismissal of NIPT characterized the information provided by NIPT as anxiety-inducing and understood its utility to be for those with specific risk who would potentially terminate a pregnancy. Based on these perceptions, the women in this category did not consider using NIPT and little consideration was necessary to decide to decline testing.

### **Group 3: Significant Consideration of NIPT Resulting in Uptake or Non-Use**

About a third of women (n=8) in the study significantly considered the uptake of NIPT. In five instances, the women ultimately decided to use NIPT, while in three they did not. The women in these two categories are considered together in this analysis due to similar characteristics of their decision-making processes and perceptions. Almost all of these women (n=7) were 35 or older, had a prior screening result indicating possible fetal abnormalities, or had a self-reported family history of genetic disorders. Women in this category approached the decision-making process using the framework described above with distinct perceptions of each of the three factors:

#### ***1. Perceived societal use of non-invasive prenatal testing***

Women who significantly considered the use of NIPT acknowledged widespread societal use of the test. However, unlike women in Group 1, they did not associate NIPT use with a forward-thinking mindset or assume that most women use testing.

Additionally, unlike women who dismissed NIPT, women in this group did not assume that NIPT is only for use by women with specific high risk. Instead, these women described mixed use of NIPT societally and pointed towards the potential positives of testing for some women, while also noting the importance of individual choice based on personal preferences:

“So I think it certainly is something that I think some certain people really go to and others shy away from it. I think we fell right in that middle ground seeing where it’s useful, but also not doing it just because. So I’m certainly glad it exists even though we didn’t partake in it.” (Participant 17; non-AMA; personal history of miscarriage; family history of genetic disorders; did not use NIPT)

“Ultimately I very much feel it’s the individual’s right to choose whether prenatal testing is right for them. But I do think it’s something that should be accessible to people as an option.” (Participant 13; AMA; used NIPT)

“I feel like that needs to be an opportunity given to everybody– a choice that everybody should be given.” (Participant 22; previously told infertile; prior screening result indicating possible fetal abnormality; used NIPT)

When asked to consider how their peer networks or broader societal influences may have shaped their perceptions of NIPT and decision-making, many of the women in this group asserted that they did not feel pressured to decide one way or another and that the decision was ultimately a personal one:

“But personally, I felt really secure with my choice and with friends and other people. . . I think they were really all very like, yeah, whatever you feel more comfortable with is fine. . . I feel like people were like, oh, what are you going to do? And that was it. So I never really had any feel about what other people’s perceptions of the tests or if we should or shouldn’t do them.” (Participant 17; non-AMA; personal history of miscarriage; family history of genetic disorders; did not use NIPT)

“I think some of those tools are very powerful and I also think that each use of them should be evaluated personally. Um sort of along the lines of, okay, what’s useful about this? Is it me that’s going to benefit from this, um, who else benefits or doesn’t benefit? And then what are the next steps that I would take, um, given the information, rather than just sort of like more is always better, if that makes sense.” (Participant 3; AMA; first pregnancy; did not use NIPT)

“I must not really care that much about what society thinks. Maybe it’s just more, okay, well how does this affect me?” (Participant 24; AMA; used NIPT)

Women in this group thus conceptualized NIPT as a powerful tool which may be useful in some situations, but which each family must consider within the context of a pregnancy to determine if it is right for them. This perception of NIPT use formed the foundation for a significant decision-making process as women considered their own use.

In terms of how women developed perceptions of societal usage, women in Group 3 relied to a greater extent on vicarious experiences of others in their network as a form of knowledge to inform decision-making. In talking to friends, family, and

colleagues, or reading blogs online, women collected stories of others' experiences as scenarios to think through:

"I also read like chats on forums. So there are a lot of conversations out there where moms would try and make this decision. Um, and I read those conversations to get a better feel for this, like the cascade of events that happens after, because that's the main question that I had. . . . I just like read people's sort of thought processes and um, read about people's experiences either getting a clean test or getting a test results back that indicated there was a problem." (Participant 3; AMA; did not use NIPT)

"The one that I remember the most is my sister-in-law and just saying that she thought it was helpful to get genetic testing . . . first of all kind of like for peace of mind and to not be wondering and worrying like that was good for her . . . So, um, I think that did influence me because I was on the fence about this and I think hearing that from her I was like, I think that makes sense. Like I'm the type of person who probably wants to not continue to, like not be wondering." (Participant 18; non-AMA; used NIPT)

## ***2. Expected emotional impact of genetic information***

Among women who significantly considered the use of NIPT, women who ultimately decided to use NIPT differed from women who did not in terms of their characterizations of information as anxiety-inducing or anxiety-relieving. As one woman who decided to use NIPT after significant consideration stated:

"It was reassurance, just knowing that, okay, he's got less than one in 10,000 chance of being Down syndrome. So, um, it's still because it's, there's still a chance, there's still a little bit of a nagging thing in the back of your head, but it's a little tiny chance. So you can kind of feel better about it. You're not going [in] blind." (Participant 22; previously told infertile; prior screening result indicating possible fetal abnormality; used NIPT)

In contrast, a participant who decided to not use NIPT after significant consideration explained the potential stress of receiving genetic information indicating an abnormality:

"If my baby's born with this, do I really want to panic my whole pregnancy and not enjoy it knowing that my baby is going to come out, you know, needing extra help or do I just grin and bear it and when he's born, if he needs that help then we'll get into that help? Like that's where I was like really stuck out." (Participant 4; non-AMA; personal history of miscarriage; family history of genetic disorders; did not use NIPT)

Similar to women in Group 2, women who ultimately decided not to use NIPT after a significant decision-making process viewed the information provided by NIPT as anxiety-inducing and expressed a preference for other forms of bodily knowledge about their pregnancy. One participant described how her body served as a source of embodied experiential knowledge:

"It was a source of anxiety while I was trying to do all the research about it and by the end of trying to do all this research about it, the fact that it was such a source of anxiety actually started to factor into my decision-making because as soon as I made the decision not to do it, it was just sort of like this huge weight was lifted and I was like, okay, good, now I can get back to just like being present for this pregnancy, which is what

I went into it wanting in the first place, you know? And trusting my baby and trusting my body's communication with my baby and sort of trusting, um, trusting my intuition." (Participant 3; AMA; did not use NIPT)

### *3. Perceived utility of genetic information*

Similar to women in Group 2, women in Group 3 perceived the utility of NIPT technology as its ability to inform termination decisions. The decision about whether to use the test therefore became a decision about whether one would be willing to have a child with a disability. Based on this understanding of the utility of NIPT, women in this group who ultimately decided to uptake NIPT did so citing a willingness to potentially terminate a fetus, while women who did not use NIPT did so due to their stated decision to carry to term regardless of NIPT results:

"You know, for me I felt like, I guess I wasn't sure if I wanted to have a child with a disability and if there was an option to test for that and to terminate the pregnancy that, that would be my preference." (Participant 13; AMA; used NIPT)

"How many cases does it really make a drastic change to parents' choices in their treatment along the way rather than just like adding to the information overload that may make companies a lot of money and it may, um, sort of like detach parents from being in the physical process of pregnancy? It wasn't clear to me that there were a lot of families and babies who had a different outcome in the end." (Participant 3; AMA; did not use NIPT)

"Then my doctor told me it was past the date for an abortion. So if you did have the baby and it did have a genetic disability, I'm already past the date, so that's when I was like, I'm not going to do it because I'm not going to worry." (Participant 4; non-AMA; personal history of miscarriage; family history of genetic disorders; did not use NIPT)

One of the participants in the study described how her use of NIPT changed across two pregnancies. She significantly considered NIPT for both pregnancies, but came to different decisions for each, declining use of NIPT for her first pregnancy but deciding to use it for her second. When describing her change in decision, she explained that her willingness to terminate was altered due to life circumstances, and this ultimately led her to use NIPT for the second pregnancy:

"My first pregnancy, we declined most testing with that pregnancy. I think our thoughts were for all we know this might be our only opportunity to have a child and there are certain disabilities that we're okay with being parents to this child, like we're up for that challenge. . . . If we were to have a child with disabilities now, we're not sure that we would be able to cope with that. Like it would really be a huge transformation of our lives and in a way it would be taking away a lot of time and resources to our older daughter. Um, so that was why we were sure that we wanted to do testing this time around" (Participant 13; AMA; used NIPT)

Another participant similarly described how consideration of other children affected the potential utility of NIPT and thus shaped decision-making based on the specific circumstances of the pregnancy:

"I think that the consequences of potentially having a baby that did have a lot of additional needs would also affect our daughter, you know, whereas with a first child it wasn't going

to affect another baby, so that would factor into my decision. . . I would maybe be willing to not have that child in order to not, um, sort of jeopardize our ability to maximize what we can give to our one child.” (Participant 3; AMA; did not use NIPT)

Overall, women in this group who did use testing varied in terms of what conditions they deemed significant enough to warrant termination; however, the underlying assessment of NIPT as a means of informing termination decisions remained consistent, and women may make different decisions across their reproductive careers due to altering circumstances which affect their willingness to terminate a pregnancy.

## **Discussion**

The widespread availability, early period of testing, and low physical risk associated with NIPT is rapidly transforming accessibility and uptake of prenatal genetic testing. There are concerns, however, that these factors may contribute to routinization of decision making around this procedure, thus undermining informed consent. We interviewed a group of 25 women who differed in use and non-use, as well as routinization of decision making, around NIPT for their current or most recent pregnancy. We found similarities among women exhibiting non-routinization of NIPT, regardless of NIPT use or non-use decision, and differences between women exhibiting routinization depending on use or non use.

### **Perceptions of Societal Use and Values**

Women’s perceptions of the frequency of NIPT use as well as who uses this technology shaped whether they viewed themselves as part of the intended audience for NIPT. For example, women who displayed automatic dismissal of NIPT did so due to their perception that NIPT is exclusively for those who have specific risk, such as family history of genetic disorders or advanced maternal age. Their own self-perception as low-risk and therefore perception that they were not part of the intended audience of NIPT led to an automatic dismissal of its use. In contrast, women who displayed routinized uptake of NIPT perceived its usage to be common among all women and thus their use of NIPT required minimal consideration. Women for whom the decision of whether to use NIPT was significant (non-routinized) did not describe a specifically prescribed audience for the test. Instead, they acknowledged widespread use of the technology while emphasizing the personal nature of the decision based on individual preferences.

In terms of the impact of perceived societal values on decision-making, women who displayed routinized uptake of NIPT expressed the perception that use of the technology is associated with being science-friendly and forward-thinking. This expectation of NIPT uptake and evaluation of non-use as resistant to progress aligns with analyses by Rapp and McCoyd, who emphasize that increasing uptake of NIPT is accompanied with an expectation to use the technology [25, 23].

These findings of the perceptions that shape routinized decision-making suggest that societal discussion and clinician framing of NIPT should aim to emphasize that although it is a powerful technology, NIPT uptake requires individual consideration, as women who perceived the decision as significant described. Lessening routinized uptake also requires countering societal perceptions of technology as always progressive and the non-use of NIPT technology as regressive.

### **Expected Emotional Impact and Perceived Utility of Genetic Information**

Women who used NIPT, whether via routinized uptake or after significant consideration, described the emotional impact of information as reassuring. In contrast, women who did not use NIPT, whether via automatic dismissal or after significant consideration, conceptualized the genetic information as anxiety-inducing. These differential characterizations did not necessarily align with differences in an individual's risk of receiving results indicating a chromosomal abnormality. For example, women in the automatic dismissal group, who described the potential anxiety accompanied by genetic information, were all low risk with respect to age and family history of genetic disorders and thus were not more likely than women describing genetic data from NIPT as anxiety-relieving to receive results indicating a chromosomal abnormality. Therefore, perceptions of information as anxiety-inducing exist independently of perceptions of one's own risk of receiving results indicating a chromosomal abnormality.

Women displaying routinized uptake were also likely to describe the information as emotionally neutral and emphasized their desire to make "informed decisions", regardless of whether they have an idea of how they may use the information. These same women displaying routinized uptake emphasized the utility of genetic information as allowing them to prepare for having a child with a disability. Thus, their use of NIPT centered around gaining knowledge. This perception stood in contrast to that of women displaying automatic dismissal or significant decision-making, who saw the utility of the information as informing termination decisions. In this case, the decision of whether to uptake NIPT becomes entangled with the decision of what to do with the information and whether one is willing to terminate.

Since women displaying routinized uptake did not consider this test within the context of termination, it could result in women being unprepared to receive results indicating a chromosomal abnormality. Mozersky describes this detachment of the decision to use NIPT and the decision of how to use that information as deferred ethical thinking and argues that women's desire for reassurance may come at the cost of women being unprepared for the results they receive [13]. Our results suggest that the women who saw themselves as the most forward-thinking actually displayed the most routinized uptake, aligning with concerns expressed by the medical community and rendering them vulnerable to the shock and distress that Mozersky describes.

### **Embodied and Empathetic Forms of Knowledge**

Embodied experiential knowledge influences risk perception, which subsequently shapes decision-making by influencing the level of desire women express for reassurance. One of the most relevant bodily experiences informing prenatal testing decisions is prior pregnancy. Personal history of miscarriage or infertility may lead women to lose "a sense of control over their bodies" and perceive greater risk of receiving non-favorable results [28]. Women with a personal history of miscarriage often cited this experience as a reason for pursuing testing due to an increased desire for reassurance. In contrast, some women mentioned that prior healthy pregnancies increased their trust in their bodies, leading them to feel a decreased desire for reassurance, and therefore they did not pursue testing.

In addition to these past pregnancy experiences, women often use the clinical cutoff for AMA (35 years old) as a heuristic for assessing their own risk. This dichotomized conceptualization of age-associated risk as existing in two categories (below 35 or above 35) does not align with the actual continuous increase of risk with age [30] and is predicated on the clinical definition of “advanced maternal age”. Thus, while there are clear increases in risk of chromosomal abnormalities with older maternal age, an over-emphasis on a strict clinical cut-point could artificially increase or decrease a woman’s perceived risk.

In terms of empathetic experiential knowledge and its impact on decision-making, many women reported hearing stories of their mothers and aunts using amniocentesis, and these stories informed experiential knowledge about this method as invasive and unpleasant. This background knowledge shaped views of NIPT as relatively non-invasive. Additionally, although many women displaying routinized uptake or automatic dismissal of NIPT did not perceive the decision to be significant and therefore did not consult their social networks beyond their partner and provider while deciding, conversations and stories prior to pregnancy contributed to their perceptions of NIPT. For example, women displaying routinized uptake of NIPT perceived common usage of NIPT due to their prior conversations with people in their social networks, which contributed to their routinized uptake of this technology. In contrast, women who saw the decision of whether to uptake NIPT as significant consulted their social networks and searched online to a greater degree while making their decision and used the scenarios they learned about to think through how they may use the information provided by NIPT.

An emphasis on the impact of embodied and empathetic experiential knowledge reveals how decision-making frameworks change as these forms of knowledge change. Many women expressed that the embodied knowledge gained from prior pregnancy experiences (whether ending in miscarriage or a healthy child) affected risk perception and decision-making in subsequent pregnancies. Thus, women do not approach decisions with a fixed set of “values” and “beliefs” as prior studies posit [31, 16]; instead, decision-making is a dynamic process that may change between pregnancies based on changing experiential knowledge and circumstances. The specific context of one’s life at the time of pregnancy shapes the approach taken to decision-making, and women who had multiple pregnancies often described differing decision-making processes and outcomes between pregnancies.

### **Influence of Providers on Decision-Making**

Concerns have arisen regarding the potential influence of providers in encouraging routinization due to the patient-provider power imbalance and the possibility of women accepting clinician recommendations as “edicts to be followed” and feeling pressured to uptake NIPT [23, 28, 20]. When asked specifically about provider influence, women across all groups in this study emphasized the neutrality of their providers and felt that they would be supported in whatever decision they made. Hence, provider influence was not included in the framework described above since this was not a significant factor for women in this sample. While some clinical environments may result in women feeling pressured to uptake NIPT, the lack of

clinician pressure experienced by women in this study along with their routinized uptake of NIPT suggests that routinization can be shaped by forces outside of the clinical encounter. This observation suggests that addressing concerns for routinization requires reshaping societal conversations about NIPT and countering narratives of it as a “simple blood test” for those with a forward-thinking mindset.

When asked about clinician influence, many of the women in this study attributed their clinician’s neutrality to their use of a midwife for care during pregnancy. The majority of the women in this sample (72%) used midwives, and it is possible that the perceived provider neutrality is related to the midwifery approach. When describing why they chose to use a midwife, many women described themselves as desiring a more “holistic” approach to pregnancy [32] and were largely critical of what has been referred to as the biomedicalization of pregnancy and childbirth [33]. Women cited their desire for a more “natural” and less “invasive” pregnancy experience as the motivation for seeking midwifery care. At the same time, the majority of the women in this study used NIPT, with half fitting into the routinized uptake category. While prior studies have expressed concern for clinicians pressuring women to use NIPT in highly medicalized environments [28, 20], the findings of this study suggest that routinization also occurs among women who identify as adopting a more “holistic” mindset and who use midwife providers. The marketing of NIPT as a “non-invasive” test, especially in contrast to amniocentesis, may make it more palatable to these women. Thus, while many of these women adopt aspects of a holistic paradigm [32], routinized uptake of NIPT is still pervasive, perhaps reflecting the societal privileging of data and information.

This seemingly contradictory uptake of NIPT among women who identify as adopting a more “holistic” mindset may also reflect the specific demographics of the women in this sample. As a highly educated sample, these women may be more likely to feel the need to align themselves with a “pro-science” mindset. Thus, aspects of identity may shape the extent to which women feel that they should use NIPT, and further research should aim to explore this framework among demographically diverse groups to explore how these patterns may differ.

### **Limitations**

There are several limitations of this study that should be addressed in future work. Women described their decision-making experiences within the last two to three years, and these retrospective descriptions may be biased by the outcome of the pregnancy. Additionally, this study did not inquire about insurance coverage specifically, and while self-reported family history of genetic disorders or screening results indicating possible fetal abnormalities indicate a high-risk pregnancy and likely insurance coverage, evaluation of insurance-coverage and its influence on decision-making should be evaluated in more detail in future studies.

The sample in this study is largely composed of white, married women with high socioeconomic status and educational attainment, and therefore does not account for how variations in race, socioeconomic status, and education may shape experiential knowledge and factor into NIPT use decision-making. Future studies should aim to evaluate this framework of decision-making in a more diverse sample [34, 35, 19].

## Conclusion

The framework and findings of this study highlight the iterative nature of decision-making regarding NIPT, with relevant perceptions regarding prenatal genetic testing being formed before women consider the uptake of NIPT. Decision-making is thus a dynamic process that is not based on static “values” and “beliefs”, but evolving embodied and empathetic experiential knowledge. These forms of experiential knowledge shape perceptions of societal use of NIPT as well as one’s own risk. Such perceptions, along with the expected emotional impact and perceived utility of genetic information, guide decision-making in terms of what women decide (uptake vs. non-use) as well as how they make their decision (routinized vs. significant decision-making process).

Routinized decision-making was prevalent in this sample, confirming concerns in anthropological and medical literature [11, 9, 13, 10]. Evaluation of how women with different decision-making processes differ in their decision-making frameworks reveals the perceptions and factors that contribute to routinization, including the perception of common use of NIPT among women across all categories of risk, an identity as “science-minded”, expectations of emotionally neutral information, and a privileging of information for information’s sake. The observed routinization among women desiring “holistic” and non-medicalized births reveals the palatability of NIPT as a non-invasive test among these women and suggests that routinization occurs not only in highly medicalized environments but also elsewhere due to pervasive societal perceptions. The lack of clinician influence found in this study also highlights how the factors that shape routinization can occur outside of the clinical encounter, and thus efforts to combat routinization must occur through reshaping societal conversations about NIPT.

Exploring the factors that contributed to significant decision-making in this sample reveals perceptions that can be used to bolster informed decision-making around NIPT use. Women who significantly considered NIPT did not perceive a prescribed audience for the test, instead emphasizing the importance of individual choice. They also relied more heavily on conversations with others in their social networks, in-person and online, as they considered how they might use the information provided by NIPT. These findings suggest that clinicians aiming to support decision-making should encourage their patients to think through what they would do with the information NIPT provides and counter societal stereotypes about who should be using NIPT.

Understanding these factors that contribute to different forms of decision-making is important as anthropologists, bioethicists, and clinicians consider how to combat routinization and bolster informed decision-making. Without such support for informed consent, women may continue to adopt NIPT without significant consideration and may be shocked and unprepared by the results they receive [13]. This is especially important as the scope of NIPT expands to include genetic markers that are less accurately assessed with this technology [36].

### List of Abbreviations

NIPT: Non-invasive prenatal testing

**Competing interests**

The authors declare that they have no competing interests.

**Ethics Approval and Consent to Participate**

This study was part of a student independent study and was conducted in accordance with the Declaration of Helsinki. Exemption for Ethical approval was granted by the Dartmouth College Committee for the Protection of Human Subjects with registration number 00031256. All participants verbally provided informed consent.

**Consent for Publication**

Not applicable.

**Availability of Data and Materials**

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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**Author's contributions**

SM and ZT were responsible for the conception and design of the study. SM interviewed all participants and analyzed the interview transcripts with the guidance and input by ZT. SM wrote the first draft of the manuscript, and SM and ZT edited the draft together to its completion. SM and ZT both contributed to the publication process of the study. All authors read and approved the final version of the manuscript for publication.

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#### Additional Files

Additional file 1 — Interview Guide