11. Can Not Wanting to Know Be Responsible?[1]

Conceptual Analysis and Meanings of Not-Knowing in Israeli and German Prenatal Genetic Practices

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> Granted, we will truth: why not untruth instead? And uncertainty? Even ignorance?
> Friedrich Nietzsche, *Beyond Good and Evil*, I/1.

What we know about who is about to be born, what we do not know, and what we should know, has become an essential part of the parental relationship and parental care. Currently, prenatal screening and prenatal tests imply that parental care is organised according to a binary code of knowing / not knowing, and is accompanied by information, counselling, public debates, moral and ethical discourse, professional guidelines and laws. These different facets and levels constitute the practice of prenatal testing. It involves personal decision-making in families, for which the pregnant woman is assumed to take the ultimate responsibility, in the name of what is often termed "reproductive autonomy" (Johnston/Zacharias 2017). Not wanting to know what one could possibly know about the future baby can have morally charged meanings, and can even be considered as wrong or irresponsible.

In this context, not-knowing appears in the horizon of knowing that one *could* know something, while not yet knowing it, having no access to the testing tools, or having decided not to use them. The decisions about the options

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[1] We like to extend our gratitude to Tamar Nov Klaiman who conducted the interviews in Israel, selected for us an appropriate sample of interviews, and supported this text with her interpretations and helpful comments.

of genetic testing are complex: they imply the possibility of a termination and therefore involve difficult existential, social and ethical questions about what we want for ourselves and for our family, or about what we owe to our future children. Laura Völkle and Nico Wettmann have identified seemingly paradoxical temporal references in this practice of knowledge: "Prenatal diagnostics seem to be mainly prognosis of the postnatal, whereas (non-)parental projections of biographies and life plans primarily determine what the current prenatal entity is" (2021: 2).

Prenatal genetic testing provides a distinct set of information that not everybody wants to have. It is a form of information some people find desirable, but others do not. This form of information is defined and limited by the arrangement of available biomedical tools: information about selected health-related traits of the future child. Information provided by a prenatal genetic test therefore suggests knowledge about the future, which can be reassuring for some people but not for others.[2] Such kinds of information often bring new uncertainties. Much of the information is about probabilities, rather than definitive knowledge about life with the future child. Sometimes it is even difficult for future parents to know *what* they want to know. Both the availability of testing and the (presumed) future knowledge that the test is assumed to bring have implications for the present. Some people feel good when they find out something about their unborn child that is reassuring, while instead others feel more insecure in the light of such possible knowledge. The possibility of knowledge itself might be a burden. The theme of not-knowing is especially interesting in the case of non-invasive prenatal tests (NIPT), because unlike with amniocentesis, arguments against testing are not based on concerns about iatrogenic pregnancy loss.

Prenatal diagnosis is always predictive. As such it is written into an "expectation arc" (Völkle/Wettmann 2021: 2) that constitutes the situation of a (wanted) pregnancy. Prenatal diagnosis can serve interests that may be contradictory: life and health interests of the foetus, the future child, the pregnant woman, her family, or society. The practice of testing, with its peculiar timing, rhythm and necessary waiting intervals, as well as the knowledge offered

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[2] The terms "information" and "knowledge" are not the same; there are subtle differences between them. For our context, "information" refers to the analysed medical data, while "knowledge" is taken to be the result of relevant information gained through learning, experiences or reflective processes of understanding. Knowledge is grounded on information, but information does not necessarily lead to knowledge.

by the results, provides new possibilities of responsible choice, but can also unsettle, frighten and even burden the woman or the couple. Prenatal testing followed by "abnormal" findings can imply the discontinuation of foetal development, since such pregnancies are often terminated. However, the ethics of abortion after a diagnosis, or the complicated questions of the moral status of foetal life in different discourses[3] in Israeli and German society, are not the subjects of this chapter.

In bioethical discourse and in lay people's discussions, particularly in Israel, it is often held that the (future) mother or parents have the responsibility to acquire genetic information relating to the future child. It may be considered irresponsible *not* to test and *not* to gain such knowledge. But the correspondence between the possibility of genetic testing, the care for the child and the responsibility to obtain genetic knowledge is not always taken for granted. In the chapter 2 of this book on genetic responsibility, Christina Schües explored different questions that emerge around the concept of "genetic responsibility". One of them is straightforward: Does *not testing* mean being irresponsible?

This chapter discusses how to understand *not knowing* and *not wanting to know* the genetic dispositions of the foetus. After introducing the "right not to know", we first discuss this issue by looking at the philosophical meanings of not-knowing, non-knowledge, and ignorance. How can we draw conceptual lines between them? How can we evaluate *not*-knowing with regard to certainty, relevance or responsibility? In addition to conceptual considerations, we discuss empirical material that we have collected in our comparative qualitative study. We asked women in Israel and Germany who had been pregnant about their reasoning for not wanting to know, or for regretting the decision to test for a trisomy. In the interviews, women retrospectively reconsidered the decisions they made during their pregnancy. Most of the interviews included in this analysis were with women who either decided against NIPT and did not regret it, or who had opted for more comprehensive testing, such as amniocentesis, possibly with chromosomal microarray analysis (CMA). Among our interviewees were two Israeli women whose NIPT gave them false negative results, so the regret they experienced was for not having had amniocentesis. We did not encounter any women who had NIPT with true negative results who regretted having them.

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[3] See chapter 7 of this book.

We start the conceptual discussions with some reflections about the right not to know, as is often addressed in bioethical discussions about genetic tests.[4]

1. The right not to know

Claiming a *right not to know* implies an obligation to respect the freedom of not wanting to know something. With regard to genetic information, we can argue that (i) genetic information is personal, and (ii) there can be no obligation to test or to know results of a test if the person at risk prefers not to know. In some situations, knowledge might be unhelpful, even burdensome. In such situations, therefore, everybody should be entitled to reject this knowledge. This reflects common sense, as in poet Thomas Grey's famous line: "where ignorance is bliss, 'tis folly to be wise" (Grey 1742).

The right not to know one's own genetic status has been internationally recognised in emerging biomedical law (Andorno 2004). It is a special right in the context of medical practice, which is based on the view that, in a relationship of genetic counselling, voluntariness is one of the overarching ethical principles (Soniewicka 2016). Thus, the disclosure of health risk information to the person affected needs justification (as well as non-disclosure), and this again requires the recognition of the free will of the counselee (Chadwick 2009). There are exceptions, as in the case of a foetus or a child who cannot (yet) make a decision, which will be discussed below. There are, however, diverging views about how far into the field of genetic diagnostics this right should reach (Duttge/Lenk 2019). For instance, there is currently an international controversy about whether and how to return incidental and secondary findings of genetic tests to patients and research participants (Flatau et al. 2018).

In Germany, the right not to know one's genetic status is provided explicitly (Genetic Diagnostics Act of 2010: §9,5). In Israel it is not explicitly stated, but is implicit in the requirement to obtain informed consent, based on a pre-test explanation (Genetic Information Law of 2000; cf. chapter 3). This right not to know is directed at a field of not-knowing that is reasonably well defined. The German Ethics Council (Deutscher Ethikrat 2013) has extensively dealt with genetic diagnostics. The Council endorsed the view that detailed consultation is mandatory and the "right not to know" should be granted as an individual

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[4] Legal aspects are considered in the section II of this book.

right. The Council stressed that not every form of knowledge promotes agency and self-determination. Genetic predictive or prenatal tests are not a duty, and neither is it obligatory to find out the results of any tests one has had.

Generally, the governance of predictive genetic testing to foresee a person's future illness or physical or mental limitations is based on the following four principles: (i) voluntary consent to testing is required; (ii) the person concerned has a right not to know, (iii) there is a right to self-determination over whether to collect genetic or other data, and which data to collect if so; (iv) the particular psychological or social situation of a person at risk of illness, either for herself or another person, needs to be carefully considered in a genetic counselling session. Genetic testing of a foetus follows basically the same four principles. However, the foetus is placed into the charge of the pregnant woman, since its consent cannot be sought. There is no discussion in either country as to whether the former foetuses should be asked later, as adults, whether they want to know genetic information that had been obtained from a prenatal test.

For many people in both Germany and Israel, prenatal genetic tests are conducted with the intention of deciding about terminating the pregnancy should the result be positive. Women who have the test are usually shocked and sad if they receive results indicative of a trisomy. Unless they had already previously decided to keep the child regardless of the result, they are then confronted with difficult choices about ending the pregnancy. The imagined link, and often practised connection, between NIPT and abortion leads some women to decide against having the test in the first place. These women do not want to know because they do not want to be faced with such a decision, or because they do not want to abort regardless of the result. They seem few in number, but sure about their feelings and reasoning; for them, a test result would not be desirable because it gives them *useless knowledge*. We found examples of this reasoning among our interviewees in both countries.

Nora, a 36-year-old German mother of a healthy child, who works as a political disability advocate, was in her second pregnancy at the time of the interview. She criticised the wording of the information leaflets about NIPT as being one-sided and overwhelmingly pro-testing. In her view, the materials given to the women did not provide impartial information and therefore tended to restrict their freedom to decide. She was highly critical of this, referring to the "right not to know" as a protective shield and the disadvantages of knowing certain things:

> But I think it's just as legitimate to write more about the right not to know and what the disadvantages are of getting a result, so to speak, and what the advantages of not testing are. And how do people with Down syndrome live, so to speak, because the thing that really jumped out at you was: "you should avoid it." (GE 2018, Nora)

There could also be other reasons why not-knowing about the foetus' genetic characteristics can seem preferable to some women. For instance, a parent may prefer not to know information about susceptibility for late-onset diseases, something the foetal DNA can be searched for in principle (although it is illegal in Germany); even if it is not considered relevant for termination, parents may prefer not to burden the child's youth with the prospect of a disease later in life.

In prenatal situations however, knowing or not-knowing and their connections to the future life of the child and the family, to feelings of certainty and responsibility, are often less obvious.[5] We shall now discuss different ways in which not-knowing something can *manifest*, referring to selected literature from philosophy and bioethics, and using the empirical interview material that we collected in Germany and Israel as examples.

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[5] A right not to know may be insensitive to considerations of responsibility connected to that knowledge. If there is a right not to know, the person may exercise this right even in a situation where it would be important for that person or others to seek and accept this knowledge. If another person has an interest in knowing about the genes of the first person, perhaps because medical treatment depends on it, her or his right to know would need to be considered to take precedence over the first person's right not to know. Anneke Lucassen has described a complicated ethical dilemma within a family, where Jane's preventive mastectomy could only be avoided by having information about the precise mutation that caused her aunt Phyllis' cancer. However, Aunt Phyllis, whose feelings toward her family are hurt for other reasons, does not want anybody in the family to know about her cancer and cannot therefore be asked to take a genetic test (Lucassen 2005). A right not to know presumes a possible wish of the person to avoid certain knowledge and provides that this person is entitled to be protected from that knowledge. A right not to know does not, however, presume that the right is always exercised for ethically sound reasons. Thus, in certain special situations it can be ethically irresponsible to exercise a right not to know despite being legally entitled to do so. But in most cases we see it as an act of responsibility to respect a person's right not to know. This is relatively easy to see, if we assume that knowledge is simply either present or absent.

2. Concepts of not-knowing

Contrary to the assumption that not-knowing is only a notion of deficiency, i.e. a negative phenomenon, we now want to explore its complex and meaningful presence. Not-knowing therefore has its own epistemic qualities within the realm of experience. In trying to explain this epistemic constellation we need to look closely at the lived experience of not-knowing, and how not-knowing *manifests* itself in people's experiences and in social contexts.

2.1 Traditional thinking: Not-knowing as deficiency

In the context of the modern belief in the continuous progress of knowledge, which is leading humanity to ever-better living conditions, not-knowing is primarily negative and has always had a precarious status. Knowing always seems to be better than ignorance or not-knowing. As Michael Smithson (1989: 1) puts it: "Western intellectual culture has been preoccupied with the pursuit of absolutely certain knowledge, or, barring that, the nearest possible approximation to it." The knowledgeable person is the better one, not the person who refuses to know, or who is unable to understand. In this explanatory context, not-knowing something is at best provisional: we do not know it *yet*.

Not-knowing in this sense denotes a specific field of lacking knowledge: a kind of not-knowing where a person does not yet know something but has the urge to know or the feeling that she *should* know, or thinks she may benefit from the knowledge. In this case not-knowing comes as a deficit that demands compensation, i.e. striving for knowledge. In other instances, absence of knowledge may mean a field of knowledge that a person now believes they know, but at some later point in time, will retrospectively acknowledge not to have known in full. Or, to imagine a third constellation, absence of knowledge may mean knowledge that one believes one has, but this later on proves to be wrong. In such cases the lack of knowledge is a not-known or non-knowledge.

Throughout Western history, people have flirted a little with not-knowing and ignorance. Standing on the market square of Athens, Plato's Socrates confidently and eagerly showed his dialogue partners that they actually did not know what they thought they knew. During the trial in which he had to defend himself for blasphemy and corrupting youth, he reflected that he actually knew that he was – adjectivally speaking – not-knowing. As translator Grube renders it: "I am wiser than this man; it is likely that neither of us knows anything worthwhile, but he thinks he knows something when he does not, whereas when I do not know, neither do I think I know; so I am likely to be wiser than he to this small extent, that I do not think I know what I do not know." (Plato, Apology: 21d) This reference indicates an ambiguity between being a not-knower and the verb (not-)knowing, which lies at the root of the history of not-knowing. This ambiguity paves the way for the modern ontological and epistemological differentiation of *knowing what* and *knowing how*: What we think we know, we always know in the horizon of not-knowing. This is how we know what we think we know. In Socratic dialogues, this thesis about not-knowing is regarded as a key motive for philosophising. Insight into and consciousness of one's own not-knowing is the first step on the path to knowledge. And the last steps on this path invite us to submit the (supposedly) gained knowledge to the *logos* that provides a strict argumentative test, which can fail and may expose the "knowledge" to be a "mere wind-egg" (Plato, Theaetetus: 151e). Central to the Platonic approach to knowledge is the idea that the knowledgeable person – and even more so, the wisest person – is the most ethical one.

Partially following the pattern of using not-knowing as an epistemic motive and as a new justification for the legitimisation of knowledge, Descartes presented a methodological form of scepticism as a path for establishing the foundations of knowledge. Everything I see around me and feel within me can be illusionary – I can know nothing for sure – except that I am thinking, even when I am doubting the truth of my perceptions. As the only form of reliable knowledge, he proposed the evident insight of the *cogito*. What is not proven, we do not know, but only believe. However, Descartes also saw not-knowing as a deficiency and as undesirable. It could therefore function as a motive to strive for knowledge. It seems that the search for epistemic certainty and security, as (rhetorically) proclaimed by most providers of prenatal genetic testing, is deeply rooted in the history of Western thought. Knowledge and the sciences that provide it are rated more highly and considered to be more valuable than the lack of knowledge, ignorance, and mindsets that reject knowledge. Against the background of this way of thinking, which is typical and constitutive of modernity, the justification of wanting to remain ignorant must always be stronger than justifying the pursuit of knowledge. The burden of proof is on the ignorant, not on the person who seeks to know.

For scientists, not-knowing has a positive function in the research process: it is a research opportunity, a defined lacuna, inviting us to fill it. In scientific publications, a state of knowledge is very often described and the research question is shaped (and justified) by the aim to provide insight that we do not yet have. Conversely, in technology assessment, not-knowing seems problematic if technology entails risks, such as risks to human health or the environment. It seems we should know about them. Decision-making under such conditions of uncertainty is considered a challenge (Böschen et al. 2006). However, in other life contexts, not-knowing can also be valued positively: it may protect privacy and confidentiality; or provide security for society, e.g. in the case of bomb-making instructions, genome sequences of deadly synthetic viruses, security gaps in computer software, or methods of suicide. But ignorance can also be at the root of epistemic injustice, for example, when a witness is not believed because of her gender or skin colour, or when simply the vocabulary for describing a fact is not understood because of prejudice (cf. Fricker 2007; Schües 2018).

Thus, ignorance is not only a political problem, as in the case of disinformation campaigns, but may be also an issue in medical discourse with regard to the lifeworld of women, families, or people with disabilities. We think it is important to keep this in mind in transcultural studies, because white ignorance or Eurocentric ignorance, or related forms that are influenced by prejudice, may become a hidden driver of interpretation. In the general practice of daily life, ignorance can be used as an excuse for not being able to decide, or for not having acted as one should have, but it may also protect against excessive moral demands and so against being paralysed when having to decide or to act. In this essay we mostly use the notion of not-knowing, and the term "ignorance" only in specific contexts.

Following the Thomistic distinction between *scientia* and *opinio*, it is not enough merely to have an opinion about something. To count as knowledge, a claim must be based on some version of the "scientific method", i.e. on reliable evidence and sound argument. An opinion that happens accidentally to be true can therefore not be counted as knowledge in this sense. Not-knowing – traditionally defined as a lack of knowledge – may either mean general ignorance about unspecific and undefined areas in the world or ignorance about a more defined field of (possible) knowledge. However, there are good reasons to believe that not-knowing has, at least for some people or in some situations, a value of its own as well, and therefore its own meaning and sense-constituting power. Not wanting to know cannot be reduced to mere deficiency; it reflects a subjective process of deliberation, weighing up the pros and cons.

In the case of prenatal genetic testing, for instance, the right not to know refers to a field of information that is not necessarily well defined, but limited, namely information about the genetic make-up of the foetus. To decide not to know in the context of prenatal testing, whether by invasive methods (e.g. amniocentesis) or non-invasive methods (NIPT, ultrasound), refers to a defined field of not-knowing when an expert (human geneticist, genetic counsellor) or a physician, i.e. obstetrician or gynaecologist (ob/gyn) offers to find something out that the pregnant woman might not want to know while she is pregnant.

2.2 Manifestations of not-knowing

Phenomenologically we can distinguish between different manifestations of not-knowing by bringing out the differences between knowledge and not-knowing on the one hand, and between known and unknown on the other. There is *known* knowledge and *known* not-knowing, while there is also *unknown* knowledge and *unknown* not-knowing. The table in four quadrants reveals both an asymmetry and an intertwining between knowledge and not-knowing. Focusing on the manifestations of not-knowing with regard to knowing or not-knowing that one is ignorant, we need to consider the epistemic, social and ethical contexts, that both not-knowing and knowing always have.

category / character	**knowing**	**not-knowing**
known	known knowledge	known not-knowing
	(1) knowledge that is known, but not apparent	(2) knowledge that we know we do not know
unknown	unknown knowledge	unknown not-knowing
	(3) knowledge that we do not know that we have	(4) knowledge that we not (yet) know that we do not know

Table 1 Manifestations of not-knowing.
Adapted from Wilkesmann 2019: 213–216.

Table 1 illustrates the four different ways that not-knowing can manifest itself, either in somebody's mind or in a discursive situation (cf. Wilkesmann 2019: 213–216; Bammer et al. 2008). It is a map of four different kinds of knowing and not-knowing, construed in a phenomenological perspective. Not-knowing never appears alone but always in relation to some knowing. Knowing and not-knowing are asymmetric, but also "symbiotic" (Kerwin 1993:

172). Table 1 is not based on a scientist's presumption that not-knowing is mainly relevant for gaining knowledge. It does not represent the (possible) transformation of not-knowing into knowing. Our explanation focuses on how not-knowing may manifest itself in terms of both knowledge and the lack of knowledge.

Since the manifestation of not-knowing can be specific in different scientific, medical or social fields, we will first give some general ideas to clarify what is meant in this category, and then provide examples from the practice of prenatal diagnosis.

1. Known knowledge. It might at first sound counter-intuitive to look under this heading for a manifestation of *not*-knowing. If, for example, Jack knows that Jill is pregnant, in Jack's mind not-knowing about Jill's pregnancy is not intermingled with this knowledge. He just knows it and is conscious of his knowledge. Whether *Jill* knows or believes that Jack knows that she is pregnant is another story.[6] Here is why we think that even from Jack's point of view not-knowing can still be involved in "known knowledge": Known knowledge is not just knowledge that one knows one has. We can know something but not really "have" it in the sense of being aware of it. This manifestation of not-knowing applies to knowledge that has the characteristic of being known, but is not apparent as such. We know that we know something but we cannot grasp it. Jack, for instance, in a situation where Jill's pregnancy is not evident, may know that Jill is pregnant, and can even be sure about it in the depths of his heart, but still answer honestly, in all good conscience: "I don't know, I am not sure." We see two kinds of situations where this might happen, one about knowing how, the other about knowing what:

a. NIPT are tests that most patients know are available. NIPT is today an established method in the practice of prenatal care, a tool that can be used to identify chromosomal variations in the child to be born. But sometimes the test is not used, whether for ethical, social or simply practical reasons. Thus, even though the know-how is present, i.e. the person knows how to

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[6] A similar example from ordinary language can be found in Smithson (1989: 2), who refers to Peter Unger's book *Ignorance: A Case of Scepticism* (1975: 93) in which he claims that "no one ever knows anything to be so". This thesis and its further debates are far from our concerns about prenatal genetic practice, yet the example might illuminate the concept of known knowledge.

acquire information about a genetic disposition, for some reason this is not made apparent. Hence, a couple might ignore their knowledge about NIPT, or refuse its application. Refusing a test falls under the right not to know. Formally, an individual can only rely on the right not to know with regard to a knowledge that is generally known or can be retrieved in principle.

b. The second category might include the problem of really knowing what a piece of bioinformation will actually mean. There is a difference between data and knowledge; knowledge can also have degrees of concreteness. Obtaining knowledge of the test results (data) might still not mean knowing what one wants to know about the future child (concrete knowledge). Women see genetic test results as information, although this does not tell them how life will be for a child with Down syndrome, for example. One German woman, herself a physician, who has a younger sister with Down syndrome and who did not want to have the test during her own pregnancy, commented on the lack of information given to women being confronted with decisions about testing or not testing:

> I think it's ABSURD that this explanation is given without even explaining to the people which symptoms it actually refers to, and what it actually means, okay? That Down Syndrome is NOT AT ALL just Down syndrome, right, that there are HUNDREDS of different degrees of how severely people are affected. (GE 2018, physician)

This woman distinguishes between information about the chromosomes and the knowledge that relates to a person's life. Thus, as explained above, we have here a further example showing that knowledge and information are not the same.

2. Known not-knowing, or known unknowns is a common epistemic category in science studies: knowledge that we know that we do not know. This is an obvious and explicitly circumscribed instance of not knowing something. Researchers specialise in different specific fields of study and leave to one side others about which they know little. Or scientists know that there is a specific lacuna of knowledge that they decide to address.

In prenatal genetic diagnosis this might refer to the possible expansion to further fields that could be included in NIPT. In consequence, women will not be confronted with the possibility of knowing every genetic detail about their foetus via NIPT. The information leaflets should be clear about the fact that this test delivers particular information, and not everything (perhaps) possible. For a pregnant woman who considers but refuses testing, the known not-knowing also represents the constellation of knowing that there is a test that could possibly show a specific genetic disposition. While she knows about the how, i.e. about testing, she might decide that she does not want to receive that particular piece of knowledge about the foetus. Not wanting to test (or, after testing, not wanting to learn the test results) means not wishing to know a specific kind of knowledge that could in principle be known. It is therefore a known unknown.

3. Unknown knowledge is a type of not-knowing when somebody, despite knowing something, actually does not know that she knows it. This would be the case when someone cannot reflect upon or formulate what she knows. This form of knowledge has been called tacit knowledge (Polanyi 1958). Such a constellation of not knowing that one knows something is realised, for instance in intuitions ("I *knew* it but did not know why I knew it"), or in care-giving situations, when a caregiver *simply knows* what to do without being able to explain it.

In the realm of pregnancy and motherhood this type of not-knowing represented by unknown knowledge occurs rather often, for instance when mothers intuitively act appropriately with regard to their child. Or while giving birth, when a woman feels that her body "knows" what to do and what comes next. Intuitive knowledge about what will be good for the family (and for herself) is also important in decision-making about prenatal genetic testing, when the previously established "risk" is only one factor that motivates her to decide about testing. For example, in Ohad Milstein's documentary film *Week 23*, the protagonist Rahel, who is diagnosed with a high-risk pregnancy, *knows* at some point that everything is "ok" with the baby and she stops worrying.[7] This believed "knowledge" that everything is ok with the baby does not, however, always prove true.

4. Unknown not-knowing is applied to a kind of knowledge that we do not know that we do not have. Unknown not-knowing can only be discovered retrospectively, i.e. after we realise that, at a previous point, we did not yet realise that we did not know what we happen to know today.

With regard to pregnancy and birth, this category can refer to the detection of a trisomy that was there without being recognised, and the possibility of its presence (and the corresponding non-knowledge) was not something parents

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[7] See chapter 9.

thought or worried about. Or this kind of unknown not-knowing might also occur in the situation of false-negative or false-positive results, when parents see that their child actually does (or does not) have a disposition they believed to be otherwise.

We interviewed Anna-Lena when her son with Down syndrome was 10 months old. She told us that she had a carefree pregnancy after receiving a falsely negative result from NIPT. After the birth they could not believe what they started to realise:

> […] the boy had, *mhm*, he opened his eyes and I was puzzled, because you could see it in his eyes a bit. We weren't sure, because we thought, well, I saw it, my husband saw it too, um, we thought "OK, now we're seeing something that isn't there!" (GE 2017, Anna-Lena)

In light of these distinctions between different manifestations or kinds of not-knowing, it does not seem at all convincing to consider not-knowing things about the genetic constitution of the foetus as a simple opposite of knowing. Not-knowing does not mean simply the deficit or the lack of knowledge; rather, knowing and not-knowing are two non-exchangeable poles that lie on different levels, and are therefore in *asymmetric* opposition towards one another. The implication of this finding is: not-knowing has a particular and constitutive role on its own. The observation that both knowing and not-knowing have their own constitutive status is shown in the observation of uncertainty about the test results and the corresponding ideas about their certainty and security.

In the next section we will examine questions of certainty and security in the light of interview data that we gathered from women who had made a decision about using or not using NIPT. This will show that the decision not to learn about the genetic make-up of their offspring can be supported by a range of different reasons and feelings.

3. Uncertainty and insecurity

The interpretation of these interviews and the following conceptual thoughts were guided by the overall question about the relation between not-knowing and responsibility. The above chapter about "genetic responsibility" has tried to explain the meaning of responsibility and irresponsibility in prenatal genetics and for care for a future child in a societal context. However, the interviews show that responsibility is not the only issue involved. Furthermore, the relevance of the genetic test, the way the procedure and consultations take place, and issues of empowerment, uncertainty or insecurity very much influence the experience of pregnancy. Therefore, before we explicitly refer to aspects of responsibility and irresponsibility, we need to focus on different meanings of not-knowing for the people concerned. These different meanings are accompanied by impressions of the standard procedure of NIPT and its informational context, and feelings of empowerment, uncertainty or insecurity that may accompany knowing or not-knowing.

3.1 Standard procedures and future retrospective view

When testing becomes standard or is routinely offered to particular groups of pregnant women, it may be harder for them to decline and justify their wish to avoid the associated knowledge. This concern has been voiced by a great many critical observers of prenatal genetic practices (Suter 2002; Nuffield 2017; Rubeis et al. 2020). As we argue elsewhere (Rehmann-Sutter, Timmermans, Raz, submitted ms.) routines can differ considerably in how much emphasis they place on fair and comprehensive information and free decision-making. Although well-intentioned, some contexts or constellations where the testing itself becomes routine practice without thinking, may fail to provide space for women to deliberate, or even to feel the desire to do so.

The following examples from women's reports show how the "standard procedures" of explanations, information about women's right not to know, and free and informed decision-making about testing may be neither useful nor appropriate for all people concerned. This aspect is important for those who retrospectively consider that they did not really want the test.

Maja, a 28-year-old mother and primary school teacher from southern Germany, had two pregnancies: she had the test in the first but not in the second. She said that in her first pregnancy she had not given much thought to NIPT but agreed to have it because it was suggested by the ob/gyn. Although, as she firmly states, "money wasn't the main reason for us to take the test", she suspects her ob/gyn proposed she have the (then) new NIPT, namely the HarmonyTest, because of her insurance status: since she was on private health insurance, her insurance company would be likely to cover the costs, she was told. She and her long-term partner "didn't think long about having the test", but just followed the physician's suggestion.

> *I:* Was there a counselling process? I mean somehow when you got the leaflet.
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> *M:* Well, not from her, actually, no. I mean, as I said, she did explain briefly, in about five minutes, and really no more than was on the leaflet. Basically, that there was no danger for me, or my child either, because it's just a matter of taking blood. […]
> And otherwise, it's actually quite a while ago, but what I've got in my head is that there wasn't much information given.
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> *I:* And the information you were given, would you describe that as neutral?
>
> *M:* In retrospect, I'm finding it quite difficult, I mean, at that time I definitely thought it was neutral, and I think it's good, or I think so at any rate. I mean, knowing that it's there and not somehow […] coming across it myself, let's say, doing something like this.
> But despite that, I mean especially with hindsight, I also view this critically.
> […] Because – and now we're getting to the point – where do you distinguish it?
> I mean, what do I get out of the result, or what do I do with it afterwards, and I think […]
> So, retrospectively, I gave much more thought to it than beforehand, to be perfectly honest. (GE 2018, Maja)

Maja also now believed that she and her husband were a bit naïve to think everything would be "ok" anyhow. In their discussion following the test while awaiting the results, the couple decided they would not consider an abortion if a trisomy were detected. So, during the second pregnancy, at the time of the interview, the couple decided not to have NIPT.

> What would be the consequence of it for us? […] after all we said: well, if we do have it, it wouldn't actually change anything. […] I don't feel: oh, I could know that […] What's the *use*, well, the *added value* is simply not there, and it's not that I'm afraid of it, either." (GE, 2018, Maja)

After deciding not to have NIPT, she felt much more relaxed and able to "enjoy" an "unburdened" second pregnancy. It was not only her own actions that Maja questioned and evaluated. She was also critical about the way she was put into a situation where she was tested without having thought twice about the consequences of obtaining the information.

This perception is rather different from what women in Israel said. One Israeli woman, Nira, who had NIPT in two pregnancies, said that she was given a checklist of tests at the beginning of each. This was a schedule she perceived she needed to follow:

> That pregnancy – I really did it by the book. Like – how should I describe it – like when a baby is born you receive a detailed vaccination plan that needs to be given each week: in the hospital – this one and that one; a week or a month after – another one; and then three and six months later and so on – this is exactly how I was during pregnancy. I was completely on top of it. It was by the book. My doctor told me: "These are the tests" – I had a plan. I did everything without exception. […]
>
> I: Did you ever stop and ask yourself or him why you even need all these tests?
>
> No, I just went for it. I didn't ask why at all. It is clear to me that he's the authority here. Just as I don't ask about the vaccines. Some people ask why to vaccinate or why have this combination of vaccines together and some split them. I don't. This is what I was instructed – so this is what I do. That's what I did. (IL 2017, Nira)

Nira told us proudly that she did everything "by the book", and that that was fine with her, while other women had second thoughts, and did not want parts of a testing plan – as Maja explained. Maja's evaluation in her second pregnancy, being more alert to what follows, was that she simply did not want to know: "What's the use?" Nira's reasoning, however, was that she wanted to have done everything correctly so that in retrospect she would not blame herself for things she had left undone. Like a vaccination plan, the physician's plan was – in her judgment – the most trustworthy guidance on that course of action.

3.2 Empowerment and insecurity

Genetic tests generally yield a special kind of bio-information, the collection and status of which are controversial because of the far-reaching prognostic implications of genetic data for the life of a person (Rehmann-Sutter/Müller

2009). Knowledge about the genome can, under certain circumstances, contribute to a feeling of security, but it can also create new insecurities. Knowledge can empower people, and can also make them powerless. What they may wish for in a prenatal test may be security, but genetic knowledge is just a means of obtaining this security. The lack of information would then be judged not so much from a cognitive point of view (as ignorance, not-knowing something) but from the point of view of security, which having had a test may bring.

Some future parents find the information that comes from prenatal test reassuring and beneficial. The reason can be that the information is empowering. Tehila, for instance, an Israeli mother of four children, 31 years old, a modern religious woman who works at a bank, has had different tests in each of her pregnancies. At one point in the interview she talked about her decision to have amniocentesis plus chromosomal microarray analysis instead of NIPT:

> *I:* Please tell me about this move that led you to have a test, which is an invasive test and entails a risk, when you were actually not given a recommendation to do so. What were your considerations pro and con the test? What determined the decision?
>
> *T:* Peace of mind. Knowing that everything is ok in that respect. […] There is great uncertainty around the entire pregnancy. No matter how many tests you had, you are still afraid. If it isn't about the foetus, it could be during the delivery. A thousand issues. So at least if there is one thing I can get a stamp on [i.e. a guarantee] – then I take it. (IL 2018, Tehila)

Tehila is concerned about a thousand things, and wants to lower the number of open questions. The field of not-knowing is too large and too uncertain for her. "Peace of mind", what she is striving for, is achieved in reducing the field of the unknown, and she finds even a small fraction beneficial. For Tehila, the medical information is like putting a reassuring "stamp" on an unclear and confusing situation. Since this stamp is something she gets from experts, she does not need to decide for herself that "everything in this respect is ok". It is somebody else's judgment, that of an expert.

For another set of women, in addition to being reassuring the genetic information was also empowering. Sarah, a 41-year-old Israeli woman who did not have NIPT, explained:

> As far as I understand, the genetic chip [i.e. the CMA] is far broader than all other tests. So I thought that if I am having a test – and I was going

> to have amniocentesis because it is funded – then I might as well have the reliable, most precise and broadest test. (IL 2018, Sarah)

She saw the information yielded by genetic tests as empowering:

> I: So, what are your feelings when you receive medical information?
>
> S: First, it lowers my anxiety. Second, it empowers me. It gives me the power to choose. Power in general. In my view, knowledge is power. (IL 2018, Sarah)

Sarah is a modern religious Israeli woman in her third pregnancy after two miscarriages, who had all the routine tests as well as amniocentesis and CMA. She agreed with her husband that they would terminate a pregnancy diagnosed with genetic disorders. The reason for this is her daily acquaintance with the suffering caused by disability due to her job as a physiotherapist, where she treats disabled people. Power for her means being able to choose – so she is a good illustration of the citizen who takes autonomous decisions.

But there is also the other side. The meaning and the value of testing is not always clear for everyone. How much can a person's choices rely on such tests? Genetic information seems to provide prognostic information, i.e. insight into the future, but is such prognostic information already "really" knowledge? Here, the differences between information and knowledge might loom large. And in the context of genetic knowledge as well, there is the challenge of information overload. It might be that lack of clarity about the meaning of information provides a reason for preferring not to know. We found an example of this type of reasoning in the interview with Maja in Germany, quoted above.

Some people also fear the misuse of bioinformation. Although the disclosure of genetic data to third parties in is prohibited most countries, there is still concern that insurance companies or employers could have an interest in genetic data. Thus, the voluntary transfer of data would not eliminate the possibility of "genetic discrimination" (Lemke 2013; Rehmann-Sutter 2003) against risk carriers by employers or insurers.[8]

Furthermore, there is the difficulty that originates in the ambivalence of bioinformation itself. On the one hand, more security and self-determined life planning could be enabled if a disease/disability risk can be clearly determined,

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[8] There is a concern that certain persons with a positive test result would be charged a higher insurance premium. (Mieth 2001: 105–108; Breyer / Bürger 2005).

especially if possible therapy exists for the health problems that sometimes accompany disability. On the other hand, there is the threat of *more uncertainty*, or "enlightened powerlessness" (Lemke 2004: 72: "*aufgeklärte Ohnmacht*"), because the conditions associated with many genetic findings cannot be altered. A positive result can only be interpreted in the context of personal imagining about the future as a mother/parent and the family, as well as one's own means of caring for a child, not knowing how much support it will need. Those who decide in favour of a test then have perhaps more information, but at the same time more uncertainty and not-knowledge. But this can also be said about those who do not have the test despite being aware that the pregnancy might be abnormal.

Knowing and not-knowing are temporally contextualised, and they are not value-free. Imagining is prospectively informed about the future child, and considering such knowledge retrospectively can show the participants that (a) any information is transformed when it is seen within the personal and social context; hence (b) good information gives security and bad information gives insecurity, even though there might be the wish that it would have been better not to know; (c) knowing something or not-knowing something is re-evaluated when reflecting retrospectively how life has turned out.

3.3 What non-knowledge and not-knowing mean

A sociological perspective observes different ways in which non-knowledge is recognised, defined and dealt with in various "cultures of non-knowledge" (Böschen et al. 2006; cf. Wehling 2001; 2006). The recognition of non-knowledge is often tacit, its definitions are often indirect, and how people deal with it is often implicit (Böschen et al. 2006: 296). When we speak of *not-knowing* we always think of people who do not know certain things, whereas when we speak of *non-knowledge* we have in mind the absence of knowledge in certain circumstances. Smithson, followed by Böschen et al., defines ignorance in a more specific way referring to knowledge that could theoretically be present but is actually absent. In Smithson's words: "A working definition of ignorance, then, is: "A is *ignorant* from B's viewpoint if A fails to agree with or show awareness of ideas which B defines as actually or potentially valid" (Smithson 1989: 6). Ignorance thus implies the possibility of knowing. It is a form of not-knowing that is theoretically regarded as unnecessary, and therefore potentially reversible. We can however also fail to know, and even know that we do not have this kind of knowledge, without implying that it would be possible to know it.

As we have stressed earlier, the concept of not-knowing is rather dispersed and heterogeneous. Depending on whether knowledge or not-knowing is considered with regard to the natural sciences, medicine or social science, it is construed and also understood differently. As laboratory sociologist Karin Knorr-Cetina has pointed out, the epistemic cultures of non-knowledge differ between scientific disciplines. She studied high-energy physics and molecular biology. While high-energy physicists actively deal with the edges and limits of knowledge and are attentive to disturbances, distortions, errors or unexpected events, and treat them as interesting phenomena in their own right, she found molecular biologists to be less interested in the limits of their knowledge. Instead, they tend to vary the conditions of an experiment, for instance in genetic engineering, in order to produce the kind of outcome they are interested in (Knorr-Cetina 1999; cf. Böschen et al. 2006: 296). In more practical contexts as well, for instance in medicine, the dimensions and types of not-knowing have different meanings and impacts.

In order to understand what people say when they speak about not-knowing, we therefore need a more precisely specified conceptual basis. Böschen et al. (2006: 296) have convincingly suggested distinguishing between three dimensions that characterise specific cultures of non-knowledge: awareness, intentionality, and temporal stability of non-knowledge. The authors understand these terms thus: (1) Awareness means knowledge about non-knowledge. It "spreads between full awareness of nonknowledge (we know what we don't know) and complete unawareness ('unknown unknowns')"; (2) the intentionality of not-knowing "contrasts unintended non-knowledge with the conscious refusal of certain cognitions"; (3) temporal stability of non-knowledge means the extent of its reducibility. It "extends from what is not yet known, but (presumably) does not present any substantial difficulties to cognition, to the entirely 'unknowable' and therefore uncontrollable." We can also use this to specify the general field and meaning of not-knowing in prenatal genetic testing, and in particular NIPT. Each of the dimensions suggested by Böschen et al. has degrees of intensity. Awareness can be fully recognised or be not recognised at all; not-knowing can be unintended or knowledge can be consciously refused; temporal stability can refer to reducible ignorance, when something is not yet known, or it can refer to something that is entirely unknowable. We therefore propose to place each of the dimensions in a table into three degrees of intensity: strong, partial and low.

dimensions degrees	(1) awareness or knowledge of not-knowing *field*	(2) intentionality of not-knowing *Agent*	(3) temporal stability of not-knowing *time*
strong	specified ignorance, clear non-knowledge	actor decides not to know, rational ignorance	something is impossible to know, ignorance is irreducible
partial	intuition, anticipation	actor is ambivalent, insecure	ignorance is disputable, unclear, uncertain
low	unknown unknowns, total ignorance	actor is unaware of the possibility of knowing	something is not yet known, ignorance is reducible

Table 2 Dimensions and degrees of not-knowing or non-knowledge.
Cf. Wehling 2006; Böschen et al. 2006; Heidbrink 2013.

The distinction between different dimensions and grades of not-knowing provides an ordering that can, on the one hand, be useful for comparing the not-knowing of a test such as NIPT for trisomy, with a genetic test that can do a lot more. On the other hand, specifying the particular dimensionality and degrees of not-knowing helps to identify different meanings of not-knowing for non-users of NIPT, as well as for users of NIPT who wished retrospectively that they had not used it, for example where the test has failed to detect "an issue" and created false reassurance. It will thus become apparent that knowing and not-knowing are not value-free. They are linked to particular feelings and attitudes, which may change according to the temporal perspective, i.e. between a prospective and a retrospective view.

The difference between knowing-what and knowing-how is important in practical contexts for a differentiated understanding of the use and not-use of a test in its function as access to knowledge. *What* is known refers to a field, a subject, or a theme of knowledge: that something is, or is not, the case. Knowing *how* refers to using a test as epistemological access to gaining knowledge or information about something.

In the following, we ask how these dimensions apply (i) to the field in which not-knowing occurs, (ii) to the agential perspectives involved, and (iii) to temporality in the lives of parents and families.

i. The relevant *field* of knowledge and non-knowledge is primarily medicine but, no less importantly, social understandings of this technology. Medically speaking, NIPT is known as a technique; thus, the knowing-how is quite clear, and medical professionals know well what type of knowledge can be given by particular forms of NIPT (today, chromosomal aneuploidies plus a few other common conditions). NIPT has been more or less well introduced into a number of societies, and many people have at least a rough idea about what it means, and what the issues are. Particularly in Germany there have been numerous discussions in wider society, e.g. the question of whether testing should be financed by health insurance was hotly debated in newspapers, on radio, TV and on the internet. In Israel, however, there was rather little debate on these themes. Public opinion, place and time influence a decision to test or not to test. The field of knowledge is certainly intertwined with the agent who is knowing or not-knowing.
ii. The degrees of intentionality of not-knowing refer to one or more *agents* or agential perspectives who engage more or less intensively in forms of knowing or not-knowing. Intentionality encompasses several volitional possibilities, including the will not to know (protected by the right not to know), the suppression or the suspension of deciding to know or not to know, or even a general ignorance. The special focus of this chapter is about intended ignorance, deliberate not-knowing, which is often related to the question of accountability and responsibility because it is commonly believed that deciding and acting responsibly requires and therefore presupposes appropriate knowledge. But interviews show that this is not so clear.
iii. Not-knowing has a *temporal* dimension in the lives of those involved, insofar as some not-knowing is actually not-yet-knowledge that will be transformed into a known within a particular timeframe at a later stage of pregnancy. It might be relevant to mention here that NIPT has an inherent ambivalence or partiality of knowing since it is not diagnostic, and a positive test result needs to be confirmed by amniocentesis. The other pole of not-knowing as not-yet-known would be the never-known, which is a form of non-knowledge that agents do not know about, and hence cannot care

> about. Epistemology and philosophy of science are primarily concerned with not-knowing as not-yet-known. The transitions from one stage to another cannot be explained by objective scientific criteria. On the one hand, they "remain disputable and dependent on epistemic possibilities and resources" (Wehling 2006: 146). Yet on the other, the agents' wish or will to know (or not to know) are influenced by scientific developments and driving forces from their families or wider society.

The question of what sorts of not-knowing relate to NIPT can, we hope, be better understood by using table 1 of different manifestations, together with the dimensional table 2. We can differentiate the interviews with women who said "No" to NIPT into roughly four groups. Two groups were following routines. The first followed religious routines, i.e. they said "No" to NIPT because their religion prohibits abortion; a second group followed medical routines, i.e. they said "No" to NIPT because the medical routine does not require it. Both had what table 2 calls a "specified ignorance". Ignorance was decisive and more or less irreversible. Two other groups also said "No" to NIPT, but not because they followed routines. They reasoned out of their personal position: the first were non-users of NIPT in Germany, and Ultraorthodox women in Israel, who declined NIPT to avoid "knowing something that would burden their pregnancy." This can be seen as an instance of "rational ignorance". In contrast, a significant group of Israeli non-users of NIPT were secular women who sought more knowledge about their pregnancy, and therefore preferred the more comprehensive and reliable invasive diagnostic tests (amniocentesis + CMA). This amounts to "reducible ignorance".

Some people feel that more knowledge may not just be reassuring, but also lead to uncertainty. There is, we believe, a qualitative difference between not-knowing und uncertainty. This difference cannot be reduced to a graduation between uncertain and unknown knowledge. Uncertainty can be the consequence of knowing; knowledge can itself create uncertainty. It is a characteristic of uncertainty that it is often attached to knowledge that concerns the future by way of statistical probabilities and/or information about a risk that cannot easily be translated into daily life. Uncertainty includes a "probabilistic evaluation" (Heidbrink 2013: 122) of a risk process or, in our case, the manifestation or the realisation of a genetic disposition. Thus, uncertainty might emerge not just because of the absence or lack of knowledge, but can also be brought about by knowledge itself. Knowing about a genetic disposition means being uncertain about its concrete implications for the life of the person affected. Without knowing the genetic disposition, the questions about uncertainty of the future manifestation of a disease might never come up. This connection lies within the horizon of expectations or attention because it is bound to the limited frame of observation and information, and also because it has no further socio-cultural system of reference. What a diagnosis for trisomy 21 really means for the life of the person and the family is not predetermined and certain. If a pregnant woman and her partner do not know that DS can also mean a fulfilled life for the individual and her family, the decision to have an abortion is unsurprising. Yet some women or couples also choose NIPT in order to prepare for a life with a disabled child. Evidently, once such information is known, an agent cannot successfully pretend not to know. Thus, in distinction to not-knowing, the choice to know cannot be reversed.

However, a lack of knowledge may also lead to feelings of insecurity, as Ateret told us in her interview. She is a mother of two, 31 years old, religious, works in an organisation that teaches Jewish tradition in primary schools, and lives in an Israeli city. Ateret had all the routine tests. In her second pregnancy, she was recommended to have amniocentesis following the result of her second-trimester screening test. After a great deal of contemplation she decided not to have amniocentesis or NIPT, and to put her trust in God.

> The birth was overcast by some fear. We wanted to be done with it already and know that everything is ok. I went to the delivery room with mixed emotions. […] If I had the test [NIPT] and it came back normal, perhaps I would have come to give birth feeling more peaceful and calmer and not as fearful. (IL 2018, Ateret)

Insecurity can be caused by a lack of knowledge, like a blind spot or an abyss, and it may or may not result in a search for knowledge. The compensation for insecurity would be measures of protection against the dangers or the particular risks identified, but also interpersonal phenomena such as trust and promise (or hope).

4. The reasoning behind deciding not to know: The issue of responsibility

With regard to German and Israeli prenatal genetic practices and discourses, the options of knowing and not-knowing become an issue of varying intensity and complexity. Certainly, the questions about how we test and what we should know about the foetus expand the medical realm and are intertwined with the *social realm*. The ob/gyn and the pregnant woman (and her partner, her family, a rabbi, church leader, friends or other persons) may consult about medical tests. They may have opinions about life in general and the concrete life with a child affected by trisomy. The deliberation circles around questions of what can be known, what should be known, and what must be known. It also includes questions of responsibility. Generally, most interviews show the conviction that testing is reasonable and, hence, a responsible thing to do. This is illustrated by Israeli woman Inbar, age 43, who did have the test and believes that not testing was not an option:

> In my case, it would have been irresponsible. Even if I weren't a single mum […] I don't know how you could [raise a disabled child]. It is irresponsible to give birth and then reject the child. But if you are capable of raising the child and you have the means and the energy – then very good. (IL 2018, Inbar)

In Inbar's first pregnancy, DS was diagnosed and she terminated. In her second pregnancy, she had NIPT alone and, as she puts it, gave birth to a "healthy" child. In her third pregnancy, she had amniocentesis and CMA, and another healthy child was born. For her it was very clear: "all these tests exist in order to prevent." She reasons as follows for the need to know:

> I see no reason to bring a child into this world when you know beforehand that there is something wrong. It isn't a missing finger or something like that, which you can live with. It isn't a congenital problem that can be fixed. It is something that will never change. It would mean condemning her to a life that is not […]. It isn't an option in my view. (IL 2018, Inbar)

Although the word "responsibility" is not explicitly said, Inbar does opt for genetic knowledge and acts in what she considers to be the only responsible way.

However, it seems too simple to *necessarily* bind responsibility to knowledge and irresponsibility to not-knowing when discussing genetic testing. In our interviews we found very different feelings, concerns, and attitudes of responsibility relating to the scope of genetic knowledge towards the foetus, the family, society, culture's values, the time to come, and where one lives. The refusal to test may still involve a form of non-responsibility that is not equivalent to irresponsibility. While irresponsibility denies responsibility for no reason or for bad reasons, non-responsibility would be, as Schües argues in chapter 2 on genetic responsibility, a decision that involves declaring oneself not responsible for the realm of *genetic* decision-making, but nevertheless assuming responsibility for devoted care and nurturing of a child with whatever genetic disposition. This form of reasoning for a non-responsibility in such cases denies the transformation of a general moral responsibility to care into a genetic responsibility for a biological genetic disposition. However, even though the decision not to test may not be seen as irresponsible, that does not mean that it should be interpreted as a right or good decision.

In order to be attentive to different dimensions of responsibility that are inherent in women's (and couples') attitudes to prenatal screening, we first look at an *existential or personal dimension*, and then at her (or their) understanding of the *inter-generational relations*, i.e. of the relationship to her future child; and we also look at the relationships within the family as part of *society*. Since our interviews were conducted after testing (or declining to test) they are set in a retrospective context. This allows us to address temporal aspects such as feelings in the past, during the pregnancy, and also later on. First, we briefly introduce the three interpretative dimensions:

1. The *existential dimension* encompasses the personal life, feelings and attitudes of the person (and her partner) confronted with the test. In the interviewees' answers they may refer to themselves, to the family, to society in general, or to particular others. The existential dimension concerns the woman herself with regard to her past and present, and her possible future feelings and thoughts. How does she see her feelings and reasons about genetic testing with regard to her own life?
2. The *intergenerational dimension* refers to the vertical structure within the family and society with regard to the relationships between generations. The next generation is brought into the world having been tested (or not). How do pregnant women relate to their foetus or their future child? What sort of "generative" bond is created? How is the responsibility between the generations considered?
3. The *social dimension* denotes the horizontal structure within the family and society. People who are with us in the world, those with whom we live and those we have to deal with, those with whom we share particular norms and at least parts of a value system, and those who are family members, friends, acquaintances, simply our fellow humans. What is the social situation from the point of view of the interviewee? How do they feel about being responsible or being irresponsible towards their family members or further contemporaries?

When we looked at the reasons women gave to explain their decision not to have NIPT, we essentially found four types of most common reasons:

a. Not wanting to know
b. Not wanting the immediate consequences of tests
c. Feeling ambivalent
d. Considering the test to be useless.

Only the first type however addresses the theme of not wanting to know directly. We will first list the four types of reasons for not testing in a rather idealised manner, and then elaborate on them according to the existential, intergenerational and social dimensions. In order to give a richer account of not-knowing we have also included women who had a test but later wished they had not.

a. *No testing because of not wanting to know.* Some women reasoned that knowing the genetic information has unwanted consequences, i.e. becoming responsible for aborting a child with a disability. For the German woman Maja, Down syndrome is no problem. Sabine would not want an abortion. And Lisa said that, if the child had a trisomy, s/he would "be there anyway". These women did not want to bear this responsibility for a decision. Not having the test because they did not want to know also includes religious non-users who were unable to reconcile testing (and abortion) with their conscience and religious beliefs.
b. *No testing because of unwanted immediate consequences of tests.* Some women did not want to have the test because they felt that the "pregnancy would be less burdened" (GE 2018, Maja) if they did not have to wait for results. Other women, like Sabine, did not want to test because they were afraid of making a wrong decision should the test result be a false positive, and aborting a healthy child.
c. *No testing because of feelings of ambivalence.* Other women, like Sabine, felt ambivalent about testing. They would have taken the test (perhaps) if it were covered by insurance, i.e. if it were a standard medical procedure. An illustration can be found in the interview with an Israeli woman, Libi (IL 2018): "If it [NIPT] were free – yes. I would have done it. I think the financial aspect is the main thing that prevented me."
d. *No testing because the test is considered useless.* Some women said "No" to the test because they did not see a reason for it. Hence, they saw no use in it.

> Sabine was relieved after nuchal translucency measurement in ultrasound and considered NIPT useless since she would not have amniocentesis anyway, and would not abort the child she had seen in the ultrasound ("five fingers, a little leg, a nose"; GE 2018, Sabine). Another non-user of NIPT, the anaesthetist Anina, felt great confidence in her partner, which left no room for doubts, and hence saw "no point" in it and considered NIPT unnecessary (GE 2018, Anina).

We now relate these types of reasons for saying "No" to NIPT to the three dimensions of responsibility that we have described before. We intend to detect meanings of not-knowing that contribute to how women and couples can make sense of their situation. If we can find such contributions, we have reason to claim that there is a particular sense-constituting role of not-knowing and of some of the reasons and feelings behind it.

4.1 Existential dimension

When a person refers to reasons of type (b) – not wanting to test because of unwanted immediate consequences of testing – a defined area of potential knowledge is excluded from the knowledge a person wants to acquire, because they fear existential burden or harm. Heidi, a 37-year-old mother of a healthy child who worked as an assistant in a property management company in a small town in eastern Germany, told us that for her, not-knowing was a form of protection from knowledge that would be harmful for her. After losing two pregnancies, she decided to have the best possible examination in her third pregnancy, which eventually led to the birth of her child in 2017. She took several prenatal tests, such as ultrasound, but not NIPT (or other genetic tests). Although her partner wanted to have the security of NIPT, she did not so they decided against it. Her reasoning was that she did not want to be confronted with the need to make a decision about continuing the pregnancy should the result of the NIPT be positive. The regular special check-ups made her feel safe, and she was glad that the nuchal translucency was "relatively fine", meaning they reduced the likelihood of Down syndrome. So she felt no other tests were necessary. This is also because she would not have known how to react. Heidi has explained it as follows:

> This is, you can't just make a blanket recommendation or not. I think every woman should know that this [NIPT] is really an examination,

> whether the child is healthy or not, that it isn't just a film show ("Baby-Kino"). Full stop. And it's just, that it's an examination whether the child is healthy or not, and that maybe you'll face this question at some point, even in the middle of your pregnancy: are you going to keep the baby, or do you get rid of it? (GE 2018, Heidi)

For her, knowing a positive test result could lead to uncertainties, worries and anxieties because of the knowledge; we have already discussed some of the aspects involved in the section above. Part of these are the concerns whether or how much the baby's health is/will actually be affected. Out of this uncertainty within the knowledge, the wish may later emerge. And at this point knowledge can no longer be undone; it is transformed into an existential weight.

This observation of being existentially affected is in line with a common attitude that emerged from many interviews with Ultraorthodox women in Israel. For some of them, receiving abnormal results would mean burdening the pregnancy (reason type b), while they can do nothing about it, since termination is mostly not morally acceptable even though some rabbis give permission for it (Ivry/Telman 2019; chapter 7). Some women claimed such knowledge would result in harming their attachment to the baby, and they did not want to burden the pregnancy with testing. Thus, not wanting to test might not necessarily mean not wanting to know. Testing means that the pregnant woman or couple has to wait for the result, and the result may consist in another likelihood that may cause new uncertainties and anxieties. For some people this waiting for information is felt as a burden and as holding off on a relationship with the foetus.

For Tanja, a 42-year-old German lawyer, the decision-making process for the Harmony Test and the ensuing amniocentesis was accompanied by an intensive search for information. The wait for the results of the first Harmony Test took one week, and they then came as "invalid" ("gar nicht auswertbar"; GE 2018, Tanja). The second attempt turned out to be a 98 per cent probability for Down syndrome. The result was communicated by telephone: "The earth opened up beneath me." The ensuing amniocentesis confirmed the result. All in all, the diagnostic process was a time filled with a lot of waiting, a lot of worrying, but in the end, time had "absolutely played on the child's side":

> There is an incredible lack of time, you know. Well, it all comes down to that, even if we now say that the prenatal testing or Harmony Test or whatever is brought forward to the 12th week of pregnancy, and for everyone, hmm […] then no-one will take their time to give the women

> good advice on how to deal with a diagnosis like that. Because they simply won't have the time any more. Then in a case of doubt it's a race against the clock, checking that they don't miss this 12th week, until when, er, the indication solution is possible, you see. (GE 2018, Tanja)

Her "connection to the child was cut from the moment of the ultrasound", i.e. independently of the NIPT, and she describes her pregnancy then as one of the "hidden pregnancies" (English in the original). Later on, after she had cancelled the abortion, her belly bulged out, and she felt the child's movements and heard its heartbeat. Thus, we see here that the temporality of the testing practices, the decisions and worries, existentially influence the bodily being of the pregnant woman.

An interview with Adva (age 34), an Ultraorthodox mother of four children, the third with Down syndrome, gives a reasoning that refers to the untoward effects of testing:

> I am happy I didn't know during pregnancy. Very happy. Because I think it would have made it a difficult pregnancy. You don't know what's going to happen, what's going to come out. […] It seems to me like a very unpleasant experience. Both for you and the foetus, and the foetus feels it. It feels if it is wanted or not. I think the fact that my child felt all through the pregnancy that it was wanted, it's meaningful for the rest of his life. (IL 2019, Adva)[9]

Testing would have made her pregnancy "difficult", an "unpleasant experience".

An example of reason type (d), mixed with (b), i.e. not wanting to know since knowledge is considered useless, is the interview with Hodaya, a 24-year-old Ultraorthodox mother of two children, the older one with Down syndrome:

> I think it [testing] is unnecessary for our community, since we don't have abortions anyhow, and it just provokes stress and worries during the entire pregnancy [when abnormality is detected]. You carry fear and depression much more. (IL 2018, Hodaya)

A similar reason was given by Anna, a 30-year-old German archaeologist who considered herself an atheist, with two children, both born during her studies at the university, the second child with Down syndrome. She also explained her

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[9] This quote has been also discussed in Nov-Klaiman et al. (2019).

decision not to have the test in terms of the irrelevance of such information at this stage in the pregnancy:

> And we didn't have the tests because, firstly, you can see that after it's born, you would still see it, and secondly, they wouldn't have had any consequences for me anyway, I wouldn't have aborted the child, regardless of whether it had a trisomy or not. (GE 2018, Anna)

Genetic information was not needed for this group of women because it would not be used to prompt the decision to have an abortion. For some of them, like Anna, it would also be useless as preparation. The impression that they were receiving useless information is not connected to religious conviction. The reasons may be manifold, but this group of women claimed that they would not abort, regardless of the test result. Furthermore, it seems that in an existential dimension, as understood in light of these interviews, the issue of responsibility seems less prominent.

4.2 Intergenerational dimension and the relationship with the child

Not knowing in relation to the intergenerational dimension touches several difficult aspects, such as insecurity, which thus endangers the relationship to the child. In the following example, Sophie-Louise was called upon by her ob/gyn to accept her responsibility and seek information, which she refused. For her, the abstract genetic information is different from lived knowledge that would include the prospect of what it is like to live with a disabled child. She felt that genetic knowledge would endanger her relationship with the child. Instead of medical reassurance, she was looking for a more beneficial kind of security in being accompanied and supported. Sophie-Louise is a 29-year-old mother of two, one with Turner syndrome (6 y), the younger child normal (3 y). She worked as an educator (*Erzieherin*) and lived in a major city in eastern Germany. She was also an activist who blogged about Turner syndrome, and had written a book on the subject. For her, what she called "the diagnostic voyage" began with an enlarged nuchal skin fold that was detected in the first routine ultrasound in week 10 of her pregnancy. Because of the suspected Down syndrome, the ob/gyn arranged a clinic appointment for her with a prenatal diagnostician, ending the consultation, as she recalled, with the words "You do know what Down syndrome means" (GE 2018, Sophie-Louise)

We may say that the ob/gyn assumed that Sophie-Louise wanted to know. Under this assumption she was acting on behalf of her patient, in her best interests. However, the physician also called upon her to take responsibility for knowing about the possible diagnosis. Here, the physician was in line with Sophie-Louise's husband, who had multiple sclerosis with associated visual impairments. His own disability led him not to want a child with a disability, and he was afraid that he would become a wheelchair user and unable to care for a disabled child. The husband here did not see himself as able to take the responsibility for a child, because he feared losing control of his own life. Sophie-Louise told us in the interview how she remembered her decision. She rephrased how she told it to her husband: "No, we're doing that now! It's *here* and I was *so* happy, and it *will be ok!*" (GE 2018, Sophie-Louise).

Even though she did not once use the term "responsibility" during the interview, we think that is what she actually described: against her physician's and her partner's calls to be responsible in the sense of having the test, she took responsibility in another sense – responsibility for the child that comes, no matter how it comes.

The decision that was expected or even imposed upon her by her partner has "left traces that never went away," although ultimately he "supported the decision" (GE 2018, Sophie-Louise). The couple eventually split up. Despite her initial resolution to go along with what comes, after the prenatal diagnostician told them it might be something other than Down syndrome, something rarer, and advised her to have amniocentesis, Sophie-Louise wanted to know everything at this point, as she explained:

> I have to admit, on the one hand I wanted to know everything, but on the other I was very, very naïve and somehow, I was very sad and […] somehow, I didn't feel like that, that I could have just gone home and let things go on as they were. Because then, because there was such a – well – a bad feeling there. (GE 2018, Sophie-Louise)

With regard to our list of possible reasons not to know, we see in Sophie-Louise's statement reason type (c) – ambivalence – even though in the end she decided to know. The confirmatory amniocentesis then indicated Turner syndrome. It was in week 20 and she personally was happy that she heard the confirmation after the end of the first trimester, because she did not want to face a conflictual decision about an abortion (GE 2018, Sophie-Louise: "because I didn't want to enter into this conflict at all") – reasoning that may be understandable morally, but is not juridically valid since in Germany, abortion for medical reasons after amniocentesis is permitted with no time limit.

The information that she received about Turner syndrome was "not very humane", as she put it, since it was essentially saying that "life expectancy is reduced by five per cent" (GE 2018, Sophie-Louise). In our typology of reasons for not-knowing, in her retrospective evaluation this would come under (d) – useless knowledge. Being opposed to "prenatal selection" she said that in her view: "I don't think [these statistics] create knowledge in a form you would want. They open the door to so many uncertainties" (GE 2018, Sophie-Louise). Sophie-Louise considers prenatal diagnosis in general "superfluous" and "endangering the relationship with the child" (GE 2018, Sophie-Louise). The information from prenatal diagnosis was superfluous for preparing to live with her child, because the child was not as the literature had predicted, and diagnosis after birth would have sufficed (GE 2018, Sophie-Louise).

However, she learned this only with time. Here we see a second facet of the temporal dimension: knowledge that emerged later in life and that led to a different way of taking responsibility in a subsequent pregnancy. This is what she did. During her second pregnancy, Sophie-Louise chose to have only minimal diagnostics, underlining her "right not to know", and wishing for a different kind of security, through the midwife's emotional support. Sophie-Louise thought NIPT has a negative side-effect because it creates an expectation of false security that everything will be fine. Furthermore, she criticises how the test is used and how people make sense of results, in that they contain an ableist attitude:

> […] and the test said there's nothing there, *thank God*. Because I see this hostility towards the disabled in that, because it doesn't have to be "thank God". (GE 2018, Sophie-Louise)

Another reason that has been raised against testing was the message such an act (testing) would send to a sibling with the condition tested for. As Ilanit, an Israeli mother of a child with Down syndrome, put it:

> Having this test (NIPT) put me in a situation of an inner conflict. Having this test – what does it mean? What does it say about my child who is alive? […] What am I saying as a mother who has a child with Down syndrome and who is thankful for that? What am I saying? That actually I am not thankful [to have this child]? My arguments were complex. On the one hand, it is very important to know and to prepare and to know

> what it really means. On the other hand, it puts me in a place of "what am I really saying about my child who is already alive?" (IL 2018, Ilanit)

Ilanit was a mother of three, the first child with Down syndrome. She was 35 years old, religious, a PhD student. In her third pregnancy she had NIPT and said that in the current situation, when they already had one child with DS, termination was not out of the question if abnormality were detected.

In retrospective interviews, as we conducted them, the timing of both the interview and the test results are important to bear in mind when we consider the evaluation women reported. Women who had a negative NIPT later mainly reported being reassured. However, although most women with a positive result reported being burdened by the result for the remainder of their pregnancy, we did encounter the opposite scenario. For example, one Israeli woman, who – following "abnormal" findings in the nuchal fold test – decided to have NIPT, in the hope of getting an early answer about the foetus' condition, without needing to wait for amniocentesis. The test detected trisomy 18. She recalled: "It helped me make the 'cut' and say: ok. An abnormal pregnancy. I must make an emotional cut and be done with it and only later [after the abortion] mourn it." She was strongly in favour of the test, even in this case which revealed an abnormality. (IL 2017, Ilanit)

This being said, for some women it is just important to know in order to be able to face the future, by reducing uncertainty about what is about to be born (Löwy 2017: 1). As has been shown in the literature, reducing not-knowing and creating "reassurance" is the most prevalent reason for women to use NIPT (Lewis, Hill & Chitty 2016). While for some women this would include the option of an abortion, others just want to know without necessarily wanting to abort in case of a positive result. Some couples would "welcome any child" (we found several examples); thus for them not-knowing may be preferred because knowing would not lead to an action and would be useless anyway (reason type d).

4.3 Social Dimension: Setting the discourse

The social dimension intersects with the intergenerational dimension. We observe a rich picture regarding genetic testing and responsibility. In Israel we observed that some women transfer their responsibility to the physician or to the rabbi, preferring to trust their judgement. Other women "took the lead" and had tests even though these were not recommended by their physician.

Yet other women did not have the test despite their physician's recommendation. Both scenarios can accord, in a way, with taking responsibility for the future child and the family. It seems that in Germany, responsibility tends to be placed on the pregnant woman who wants to decide, and is (socially) assumed to do so. She is supposed to take responsibility about what should be tested. In either context, following a physician's recommendation is not necessarily a manifestation of refusing responsibility in an unreflective way. Likewise, since there are very different ways of realising responsibility as well as irresponsibility, not following the recommendations can easily be regarded as either being responsible or as being not responsible or even as being irresponsible. This observation accords with the assessment that there is no consensus on whether genetic testing or not testing, knowing or not-knowing itself is considered to be either responsible or irresponsible. This ethical discussion therefore needs to take account of this.

In Israel, it is commonly perceived that responsible parents have a duty to prevent suffering for a future child and the entire family. Since disability is often considered a source of suffering, this responsibility begins in pregnancy, with prenatal testing. Testing during pregnancy seems a necessary tool for detecting disability and for allowing the termination of an affected pregnancy based on abnormal results (cf. see chapter 6 in this book).

To illustrate this, we quote from the interview with Efrat (age 38), a mother of two children, the younger with Down syndrome. She had a false negative result from NIPT:

> A friend of mine was pregnant around the same time I gave birth to my child and she decided not to do the tests, and I remember that in my view it was "How can you be a friend of mine, see what happened to us and decide not to perform the tests?" It was extremely irresponsible in my view. […] The message I receive both verbally and non-verbally is "how could you be so irresponsible and not do amniocentesis and how did it happen that you have a child with DS?" As if he has no right to exist in this world. (IL 2018, Efrat)[10]

The question of whether the mother expresses a view that is held generally in Israeli secular society is not the only issue here. We also want to indicate the reproach of irresponsibility is not trivial; it is strong and affects close, familial and social relationships.

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[10] This quote had also been discussed in Nov-Klaiman et al. (2019).

In Germany, disability was not found to be connected with suffering in the same way as in Israel. The triangle of "disability, responsibility and testing", as we have explained above in the chapter 6 on "disability", has different meanings in Israel and Germany. A common German rationale articulated by women who already had a child with Down syndrome was that testing enables disability to be detected, which is necessary for (prospective) responsible parents of a child with special needs to prepare – both emotionally and practically. However, this is not representative of German society in general: most women who receive a diagnosis of Down syndrome in amniocentesis decide to terminate the pregnancy.

A majority of both German and Israeli interviewees stressed that performing prenatal diagnosis was a decision for the individual or the couple. They explicitly refused to make any recommendations or judgments. In line with this was Laura, a German woman, who used prenatal diagnosis in two pregnancies, which led to abortions in both cases, and who told us that her own family and her partner's were supportive of any decision she and her husband took regarding prenatal tests and a potential abortion, or about raising a child. However, she told us that in the second pregnancy, her ob/gyn made her feel that if she "did not have the tests, [she] would be a bad mother" (GE 2018, Laura). She reported the ob/gyn's reasoning was "to be extra sure". For those women who experience such strong social expectations, the issue of becoming a responsible mother in the eyes of the professionals may be an important factor in their own decision-making.

5. Conclusion

In this chapter, we explore the question of the reasoning of women who did not want to know the genetic disposition of their foetus or who actually tested because they had a strong feeling about the issue of not-knowing. In order to form a better understanding of the phenomenon of not wanting to know, we analyse the philosophical underpinnings of not-knowing and narratives of people who have experienced a decision-making situation about genetic information. The philosophical tradition and lay understandings privilege knowledge and tend to link knowing with responsibility, and not-wanting to know primarily with irresponsibility. Not-knowing is therefore treated as inferior, and there needs to be a "good and convincing" reason not to know. Yet, briefly stated, we found in the empirical study of the women who did not want to test or who wished that they had not been informed about their foetus' genetics, that some perceived genetic test information as overwhelming and leading to anxiety and burdening of the pregnancy. Thus, not wanting to know does not necessarily lead to ignorance, in the same way that wanting to know does not always lead to certainty. The relationship between genetic information and responsibility is strongly influenced by different feelings, such as uncertainty and insecurity.

Since all interviews were conducted retrospectively, the theme of not wanting to know also needs to be interpreted temporally. Time makes a difference, and the relevance of information given may change over time and with new situations. A *phenomenology of pregnancy* (Bornemark/Smith 2016; Völkle/Wettmann 2021) shows the different phases and times of waiting. What may seem right before testing during pregnancy can appear different later on when a test result is known, a baby born, or just when time has passed. As explained above (Section 3.1), prospective and retrospective perspectives are very different and produce different questions. The retrospective question "what would I rather not have known?" cannot be posed earlier but may lead to some of the insights we found in the interviews and have presented in this chapter.

A conceptual analysis of not-knowing with regard to empowerment, uncertainty and responsibility, which we present in the theoretical sections of this chapter, is challenged by experiences and reflections of people who actually grappled with these questions. What can we learn from this? Here we summarise the insights that seem to us most important:

i. The philosophical conceptualisation of not-knowing has proved more complex than the empirical material. We have generated theoretical categories of different forms and intensities of manifestation of not-knowing and dimensions of how not-knowing is relevant. With regard to attitudes of responsibility and irresponsibility, as well as feelings of certainty and uncertainty, security and insecurity, the empirical material has nevertheless enriched the philosophical considerations. We suggest that particular rationales for not-knowing are more prevalent in one country than another and, hence, reflect different philosophical premises. In Germany, the rationale was by and large a construction of responsibility involving autonomy as individual self-determination. Prenatal diagnosis and NIPT are seen as a decision for the individual or the couple who explicitly refuse to give or be given any recommendations or judgments.

In Israel, the decision involved relational decision-making as informed by religion, following the recommendations of rabbis and family members. Here we found that the women either test and abort after a positive test result, or they simply do not have the test at all and leave it to fate. Contrastingly, our interviewees also included secular women (including some who rejected NIPT and amniocentesis), who explained that they are "settling" for the routine (and funded) tests. In other words, without abnormal findings from the routine tests and without a clear recommendation from their doctor, they saw no reason to risk the pregnancy with an invasive test or to spend a lot of money on a private test like NIPT.

Despite a common secular tendency to favour having as much information as possible, and thus testing, settling for the routine tests is not uncommon among secular Israelis. Rina, for instance, did not have NIPT or amniocentesis.

> To be honest, I'm not so sure if it was so clever or not [not to test]. I was simply optimistic. In our family we don't have many […]. There is one relative who has a genetic condition, but he isn't a close relative. It seemed to me like "nice to have", but not something that I really needed. […] We already had healthy kids at home, so we saw no reason why this time there would be a reason to test. (IL 2018, Rina)

ii. Not-knowing has a constitutive meaning of its own and has been explored on an existential, intergenerational and social dimension. It is not simply a negative derivative of knowing as a lack of knowledge; not-knowing can itself have a sense-constituting role. Not-knowing in terms of NIPT primarily concerns a *known unknown*, i.e. a particular field that someone does not want to know. Different feelings or reasons may accompany the refusal of genetic testing and its information, such as the fear of having to decide should the test result be positive. Still, some women wished retrospectively that they had not been informed because they felt overburdened, uncertain or insecure with the result. In certain circumstances – as was particularly found in the German interviews – not knowing can even mean something positive for the woman, for instance allowing a pregnancy to be experienced as unburdened and full of confidence.

iii. Some interviewees mentioned the judgment that not to test would be irresponsible. Yet the overall relation between genetic information and re-

> sponsibility is far more complex than assumed in an interview or in public discourses. Our interviews show that genetic information is not always accompanied by responsibility, security and certainty of judgment. The issue of the relationship between knowledge and responsibility, or of not-knowing and irresponsibility, is still philosophically and ethically debated. Thus, the question of when and why is it responsible to be ignorant about (genetic) information is still open.

Comparing Israel and Germany highlights the versatility of cultural and social ways of feeling, thinking and acting, and also emphasises not-knowing as a form of *responsible* decision-making that avoids information (rather than knowledge) for various reasons. While in Israel it is perfectly normal to do prenatal genetic testing, such self-certainty cannot be observed in Germany. The two countries seem not to differ greatly in terms of the decision to abort after a positive test result. When women decide against testing and do not want to know the genetic disposition of the foetus, there are some differences in the reasoning between Israel and Germany – yet in both countries, a woman who refuses to have the tests may be called a "bad mother". The focus on saying "no" to genetic information brings out different ways of reasoning according to their existential, cultural and social settings.

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