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# **Traveling questions: uncertainty and nonknowledge as vehicles of translation in genetic research participation**

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*Abstract: In this paper, I argue that uncertainty and nonknowledge, and not just research results, can be important vehicles of translation through which genetic research participation come to affect the lives of research participants. Based on interviews with participants in a genetic research project, I outline epistemic, emotional, relational and moral implications of research participation. Many of them resemble what the literature has described as the social implications of genetic counseling, but here they stem from interaction with knowledge-in-the-making or what I simply call nonknowledge. While policies aimed at stimulating translation from bench to bedside tend to build on the assumption that research only works when knowledge translates into technological ability and creates utility, I suggest acknowledging that research has implications long before any clinical applications are at hand. Research questions, and not just results, may serve as a generative form of knowledge that can travel as fast as any answer.*

**Keywords:** genetics, knowledge, nonknowledge, translation

## **INTRODUCTION**

Genetic research is enmeshed in politically articulated hopes and expectations of fast translation (Brown 2003). Even basic research faces demands for immediate translation into clinical utility and economic growth (Hood, Lovejoy and Price 2015), and accordingly research is continuously criticized for delivering insufficient or delayed societal impact (Arribas-Ayllon 2010; Levin 2014).

The Human Genome Project has been followed by numerous projects aimed at translating genetic research into clinical application, and currently a wave of projects on whole genome sequencing (WSG) have received significant political and financial support based on the promise of offering personalized medicine and altering healthcare as we know it (Hedgecoe 2004; Tutton 2014).<sup>1</sup> Research aimed at understanding basic biological mechanisms thus develops in a political landscape focused on shortening the distance from “bench to bedside”. The tacit premise seems to be that research must generate results (knowledge) that can be translated into technology (ability) and thereby create real changes in people’s lives (utility). In the following, however, I illustrate how basic research in and of itself can involve changes for those enrolled as research participants in ways that differ significantly from the linear political logic of knowledge-ability-utility. In genetic research participation, research *questions* (nonknowledge) can travel and interact with the doubts and concerns of the research participants (their feelings of *in-ability*) and nevertheless result in very real effects (social implications). Indeed, nonknowledge may serve as an important vehicle of translation.

The paper takes point of departure in a basic genetic research project seeking to explore the biology of balanced chromosomal rearrangements. To understand how genetic research participation influences the research participants, I suggest that we need to understand better the social dynamics of research participation. Knowing these dynamics is important in order to design research projects in responsible ways, but it can also be a precondition for evaluating the type of data that research participants deliver. Furthermore, some of the dynamics involved in genetic research participation can be surprisingly similar to participation in social science research. In both forms of research, nonknowledge – research *questions* – can perform work similar to the one usually ascribed to certified answers and research results. I first provide a short introduction to discussions about genetic knowledge, nonknowledge and translation of research. Following a

description of my methods and the setting in Denmark in which the study was carried out, I then provide examples of social implications encountered in the specific genetic research project I explored.

## **GENETIC KNOWLEDGE AND TRANSLATIONAL RESEARCH**

The type of genetic research described in the following involves a search for new aspects of genetic influences on health and disease and it depends on both phenotypic and genotypic data. It was once a truism that genes (genotype) were unaffected by sociality (Keller 2000), but with the rise of epigenetics the social embeddedness of human biology is becoming more and more widely acknowledged and the causal links between phenotype and genotype seen as potentially multidirectional (Lock 2005). Lappé and Landecker furthermore argue that we should begin to understand not only the “decoding” of genes as socially embedded, but also the very structure of the folding of DNA as carrying a socially engrained history (Lappé and Landecker 2015). As we are rewriting the relationship between genotype and phenotype, the twin pair of what is believed to be 'known' and what is 'not known yet but worth knowing' about the causes of health and disease continuously change. It continues to be contested what counts as valid genetic knowledge depending on the subfield of the geneticists (Levin 2014; Timmermans 2015). Genetics as a form of knowing is multiple (Mol 2002), and historically (Keller 2000) as well as geographically contingent (Taussig 2009).

Nevertheless, the public narrative of genetics is often one of universal truth. In Lindee's (2015) historical treatment of the rise of genetics as an explanatory device for human health and illness, we learn how genetic information has moved from the margins of medicine to the very center. Genetics has come to convey authority and become essential to attract funding despite its often limited explanatory power in relation to, for example, complex diseases (Ackerman et al.

2016; Timmermans 2016). Today, Lindee (2015) suggests, revelation of genetic information constitutes “moments of truth” overruling other understandings and explanations. This is certainly the case in much of the material presented below, but what actually counts as “genetic knowledge” is in many cases not authorized genetic claims, but research questions conveying information about what geneticists do *not* know. It is nonknowledge.

Research aims at undoing previous “knowledge”, and therefore, the line between knowledge and nonknowledge is always under construction. As Gross (2012) remarks, it has long been recognized as a feature of science to produce new doubts and new questions: "any growth in knowledge can bring about a concomitant growth in what is not known" (2012:425). Drawing on Simmel's concept of '*Nichtwissen*', Gross suggests seeing nonknowledge as "both inevitable and productive" (2012:424) and always part of any knowledge project. Knowledge and nonknowledge are each other's reverse sides. There are many other forms of ignorance (Callon and Rabeharisoa 2004; Fainzang 2015; Geissler 2013; McGoey 2012; Proctor 2008), but with nonknowledge I mean the type of unknown, that researchers seek to convert to known. Nonknowledge presents itself as a gap in knowledge, and this gap facilitates action. The space of nonknowledge can be politically contested (Böschen et al. 2010), and it is sometimes used strategically to marginalize those that are deemed 'ignorant' (Rayner 2012, Vitebsky 1993). In Decoteau and Underman's (2015) studies of the trials determining whether vaccines could cause autism, the defendants argued that nonknowledge was limited to the genetics of autism, while the parents raising the case wanted researchers to acknowledge that also the environmental causes, including vaccines, were unknown and in need of investigation. To define nonknowledge was central to the politics of the case.

Claims to knowledge are dependent on various forms of tacit knowledge that selects, orders, and uses information in light of the interests of the knower (Polanyi 1966). Knowledge does not 'know' itself. Furthermore, knowledge claim often carry a moral weight: like accusations of

ignorance, they are never neutral but serve as devices for social ordering (Last 1981, Mair, Kelly and High 2012, Vitebsky 1993). If nonknowledge is defined as the reverse side of knowledge, there is always a more encompassing form of uncertainty surrounding this struggle of known and unknown. Uncertainty as a basic human condition cannot be eradicated (Perron and Rudge 2016:29ff; Whyte 1997), and the dialectic between knowledge and nonknowledge is just one particular approach to dealing with the boundless sea of the unknown.

From the perspective of the carrier of a genetic disposition the distinction between knowledge and nonknowledge can be even more blurred than for the geneticists, but even more importantly, the carrier faces uncertainty along multiple dimensions. Ever since Evans-Pritchard's (1976) classic study of Azande witchcraft from 1937, medical anthropologists have stayed attuned to the way in which people fill the space of uncertainty with faith and socially engrained convictions. As noted by Whyte, it can be a matter of pursuing meaning rather than explanation (Whyte 1997). Not only is it impossible to fully eradicate uncertainty; it can be more meaningful for the individual to opt for the “potentiality” it involves and use the leverage it creates (Taussig, Hoeyer and Helmreich 2013).

If policymakers tend to focus on knowledge-making as a process of acquiring knowledge to generate utility, we still need a better understanding of the actual modes of translating research into social change beyond the knowledge-ability-utility nexus. Genetic research has been shown to affect many important areas of public life including negotiations of legal entitlements (Kowal, Radin and Reardon 2013), the formation of social groupings and international relations (Reardon 2005), national identities (Tupasela, Snell and Cañada 2015), and social groupings based on genetic traits (Gibbon and Novas 2007). Furthermore, genetic research can influence understandings of disease and have looping effects on identity without necessarily offering actual treatment opportunities (Eyal et al. 2014). Many such changes relate to macro-level

reconfigurations of relations, conceptions and categorizations. In the following, I focus on the micro-level changes playing out among the research participants as a consequence of their participation in genetic biobank research. Interestingly we find that many of these changes resemble what have been found in relation to genetic counselling (Arribas-Ayllon, Featherstone and Atkinson 2011; Arribas-Ayllon, Sarangi and Clarke 2008; Hallowell 1999; Huniche 2002; Mozersky 2012; Svendsen 2006), though here unfolding on the basis of research questions, i.e. genetic nonknowledge, rather than authorized genetic knowledge.

Genetic research participation is an activity full of uncertainties and knowledge gaps (Skolbekken et al. 2005) as well as moral ambivalence (Kerr, Cunningham-Burley and Tutton 2007). If, indeed, these gaps and ambivalences provide room for agency, how do participants use these opportunities? If we view research participants as active *participants*, and not as passive donors, as Tutton (2007) among others suggest, what is it that people actually do in the space of uncertainty created as they encounter the nonknowledge of a research project, and what are the social implications?

## **METHODS AND SETTING**

In a prominent genetic research lab in Denmark, a group of researchers is investigating the biological function of genes. The lab used to be part of a diagnostic unit also providing genetic counseling, but today it serves as a research laboratory. For this paper I followed a project in which the lab explores the implications of *balanced* chromosomal rearrangements (where all elements of the chromosome are intact but appear in an unusual order, see also Hoeyer, Tupasela and Rasmussen, forthcoming). Such rearrangements are supposed to cause no problems for the carrier, but they do imply an increased risk of new (unbalanced) rearrangements in potential offspring, which tend to cause disabilities. This implies that several of the carriers of balanced rearrangements

have learned about their condition in conjunction with parenting a disabled child. The research staff continuously stresses how research cannot be separated from genetic counseling, diagnostics and care (see also Lappé 2014). It all revolves around the making of new knowledge. In practice, as we shall see, they also provide elements of counseling to research participants who pose questions in the course of their research participation.

To identify research participants for the project on balanced chromosomal rearrangements, the lab uses a public register in which the results of genetic tests carried out anywhere in Denmark are recorded. Danish registers employ a system with a personal identity number for each individual, where the name and address are recorded and updated in a base register, and all other registers use the same number (Hoeyer 2016). In this way, it is possible to acquire contact details for people who have had tests done more than 20 years ago. It is possible to track all who have undergone testing because Denmark has a publically funded healthcare system with universal access. The genetic register in question was established partly to avoid repeating the same tests several times, but it was quickly seen that it could facilitate also research (Videbech and Nielsen 1979). Before inviting carriers to participate in research, the researchers contact the local clinics where the tests were done to make sure that the persons in question were informed about the results. The researchers are very careful never to introduce information about genetic heritage that people do not already possess and might not wish to acquire. In some instances, the local clinics prefer to contact the individuals, in other cases the lab contacts the potential research participants directly. If the participants agree, they are invited to fill in an extensive questionnaire on everything from musical aptitude to hearing impairment and psychiatric symptoms. At some level, the questions reflect ideas circulating among researchers about potential implications of a balanced chromosomal rearrangement. These ideas are tested with the questionnaire exactly because they



have not been proven. In some cases, but not all, the respondents are invited to donate a blood sample.

In the questionnaire used by the lab in its 2013 round of recruitment, respondents could also indicate whether they were willing to participate also in my project aimed at exploring their experience of being involved with genetic research participation. The majority agreed. For data protection reasons, I could not access the data files, and I therefore asked the genetic researchers to select respondents for me with broad variation according to age, gender, and other characteristics that they as researchers had found important, including ethnicity, educational and socio-economic level as well as the reactions they had had from the participants. Some participants had been positive, some concerned, some found it exciting, some dull.<sup>2</sup> During the autumn of 2014, I continued recruiting participants until I reached a point of saturation. The respondents are listed under pseudonyms in Table 1 organized according to gender and age.

My questions were aimed at exploring their experiences with research participation and the hopes and concerns they attached to the genetic research endeavor and the extent to which the governance of research addresses them. I asked questions such as: “How did you get involved with this research project?”, “Have you subsequently thought about your samples and what they have been used for?” “Was there anything you needed to know before agreeing to participate?”, “Was there anything special you hoped to gain from your participation?”, “Can you think of anything that you would not accept they did with your health data and materials?” These questions stimulated a wide range of thoughts and reactions among the participants that they had not previously engaged – and many respondents commented on this. Gradually, I realized that not only my own questions, but also the questions posed by the genetic researchers in the questionnaire had social effects.

The interviews were originally conducted to understand the hopes and concerns of the research participants and to explore how regulatory landscapes cater for them. I was struck, however, by the stories people told about how research participation had impacted their lives. I therefore marked anything that came across as a ‘change’ or social implication resulting from research participation in a thematic coding of the material (Madden 2010). I then categorized the changes into types distinguishing between “epistemic” implications (things that people were thinking differently about), “emotional” implications (reactions articulated in a language of emotions), “relational” implications (when research participation seemed to change how they relate to other people or institutions), and finally “moral” implications (when research participation installed moral dilemmas or new forms of valuations). Of course, the categories are just analytical distinctions: in practice epistemic implications can induce emotional as well as relational and moral reactions. Accordingly, some of the narratives below fell into several categories but are only reported once. In the course of analyzing the implications, it became more and more obvious that they often reflected action taken on the basis of nonknowledge – the *questions* posed by researchers – rather than authorized genetic knowledge. In a process of what Timmermans and Tavory (2012) call “abduction” I thus came to focus on the role of knowledge and nonknowledge in processes of translation of research and how this translation relate to people’s pursuit of meaning.<sup>3</sup> I present the findings in line with the coding of the material according to types of implication to maintain optimal transparency and to illustrate the range of social implications that research sets in motion.

## **EPISTEMIC AND EMOTIONAL IMPLICATIONS**

As noted above, there are somewhat floating boundaries between research, diagnostics and care in relation to rare genetic conditions. The implications of research participation are therefore also difficult to disentangle and often the participants make little or no distinction between their role as

patients and participants. Researchers serve as important sources of information and counseling for the respondents when various queries arise. For example, when Anne received the invitation to participate in research, she got worried that her chromosomal rearrangement was the direct cause of autism in her grandchild, but as she contacted the lab, she was quickly consoled. She gained new genetic knowledge as a consequence of her research participation and came to subscribe to the same *type* of knowledge as the genetic researchers. Instead of focusing on these cases of aligned understandings of knowledge, however, I focus in the following on *unaligned* knowledge and the *unanticipated* implications of genetic research participation that emerge in the gaps of uncertainty and nonknowledge. Several forms of social implications emerge from personal interpretations of pieces of information picked up in the course of the research participation.

The questionnaire that they fill in is a key actor in this process. Many respondents mentioned “information” that they had acquired from the questionnaire. But does a questionnaire contain “information”? On the one hand, it could be said it contains no “information” and conveys no knowledge, but just questions reflecting what we do not know yet. If researchers knew, they would not need to include the questions in the questionnaire. On the other hand, questions do reflect research hypotheses. As such the questionnaire comes to convey information about what researchers suspect might be relevant. The questionnaire is in this sense a form of “blank figure” (Hetherington and Lee 2000). It acts on people by way of its ability to contain and connect multiple interpretations. Several people use items from the questionnaire to make sense of the conditions they identify in relatives, for example by identifying potential genetic causes of their perceived illnesses. Morten did so in relation to his daughter, Olga in relation to her niece, and Jens Ole in relation to his mother. Others focused on questions unrelated to disease such as those relating to musicality and wondered whether they or their relatives could be particularly gifted as a consequence of the chromosomal rearrangement. Nina wondered if a chromosomal rearrangement

could imply “that you are, like, *super* something [laughs], or a super-human who will live to 130”, just as Anne-Sophie thought that “it might be that you’re lucky and you have some form of, what should I call it, you’re a genius, because of [the chromosomal rearrangement]”. When using questionnaire questions to interpret themselves and their surroundings, they in effect transform what the researchers *do not* know, but wish to investigate, to sources of understanding and explanation.

Some of these epistemic implications involve also emotional reactions. See, for example, how Mette describes her use of the questionnaire to interpret her brother and mother:

“When I read all those questions (...) I was left wondering... It was weird with all those questions because I could recognize some of that from my brother and mother. I did get, somehow, a little worried, because I thought it was weird. Why these questions, and why so concentrated? And then this thing that I could see that my brother and mother could suffer from some of those things”.

Mette’s sense of insight involves also an emotional reaction (“a little worried”). Mette was particularly struck by questions indicating what she perceived as “psychiatric disorders” and she contacted her mother to learn how she (also a carrier who had been invited to fill in the same questionnaire) had responded to those questions:

“...and I learned that there were some questions she had not answered to the full because she felt it got a little too intimate (...). And I remember that I thought, ‘Can it really be connected?’ And then it’s not at all what they said when I was a kid [that the balanced chromosomal rearrangement was insignificant]”.

We learn here that the mother did not deliver the data the researchers needed if they were to investigate a potential link between her carrier status and a particular psychiatric symptom, because she already felt the question touched something too intimate. The interpretation of the questions thus precluded getting the answer needed to determine whether the link exists. The researchers have

noted that questions about psychiatric symptoms (and about body weight) are left unanswered more often than other questions.<sup>4</sup> If it is not just a matter of stigma and privacy, but of research participants seeking to use available resources to make sense of family relations, it shows how we as researchers need to understand the social dynamics of the creation of research data to assess the validity of the data. We cannot see the social processes of data generation as external to scientific substance because data are socially constructed all the way through (Gitelman and Jackson 2013).

In some cases, emotional reactions unfold in the course of talking to researchers and then researchers stand a chance of learning about participant concerns. Kirsten explained how she had phoned the lead researcher and in the course of the conversation got the impression that she might be at risk of leukemia:

“Then I thought, oh no, my heart stopped beating, I’ve only got a couple of years left, and then what? But as I spoke to her she actually de-mystified it pretty well”.

For Kirsten the conversation was in this sense an emotional roller-coaster, and it illustrates the skills that researchers must possess to carry out this type of recruitment (Lappé 2014). Christian was worried after filling in the questionnaire and also called the lab. In the course of the conversation he got the impression that by looking at the potential risks associated with a balanced chromosomal rearrangement (not otherwise thought to cause any disease) researchers in effect consider the rearrangement a cause of disease:

“I’m beginning to understand that something has happened to our understanding of disease. Perhaps I *am* diseased (...) Now, I’m diseased because of the chromosomal rearrangement”.

He is right, of course, in the sense that the researchers are testing a hypothesis that balanced chromosomal rearrangements might have implications, only they do not yet have any proof. For Christian the hypotheses conveyed in the form of questionnaire data are interpreted in light of what

he articulates as eugenics and a special family history. Before serving in the German military during World War Two, some members of his family received papers stating they were of pure-bred Aryan race, but now Christian joked that “if Adolf [Hitler] knew about the chromosomal rearrangement” Christian would probably find himself –

“– stuffed into the gas chamber. Now I’m not so ‘purebred’ anymore. I guess you understand that I’m always very concerned when people push the genetic heritage button”.

Like the other research participants, Christian interprets research into chromosomal rearrangements from a personal perspective, and it comes to influence his perception of himself as well as his understanding of disease. In this way, research participation has unintended epistemic and emotional implications. The epistemic and emotional implications can also spill over into relational implications understood as instances where the research participants come to rethink how they relate to other persons as a consequence of dealing with their chromosomal rearrangement.

## **RELATIONAL IMPLICATIONS**

Genetic research can interact with people’s sense of family in much the same way as genetic diagnostics and counseling: people contemplate relations and they sometimes have to make choices concerning who to contact. In such cases it becomes obvious that genetic closeness is not the same as social kinship (Arribas-Ayllon et al. 2011; Svendsen 2006). For example, Christian felt he had to contact a sister he otherwise avoided, while he had decided *not* to tell his own daughter that she was carrier. The daughter, he explained, should continue to feel healthy and, if an insurance company asked, she should be able to say in all honesty “I’m well”. As a purveyor of sensitive information, the research project thus affects the relations between the research participants and their relatives.

Often it was in the course of the initial diagnostic phase (when entering the register from which they were later recruited) that people had had to think about their “family tree”. Lisbeth mentioned that it is annoying how she as a consequence of the genetic register remains “affiliated” with a half-brother that she never met. Others, such as Hilma, matter-of-factly contacted genetic relatives that they never previously considered contacting. Yet others, like Olga, were sad that, during the diagnostic phase, they had to convey information about the chromosomal rearrangement and in this way bring something unfortunate to the relationship (which is interesting when it is considered that the rearrangement is not supposed to be a cause of disease).

For some, the consequences are relatively dramatic. Nicklas, for instance, who has a psychiatric diagnosis, learned as a consequence of his research participation that his father had enrolled both him and his sister in another research project when they were kids. He was furious that he had never been told and had now confronted his father. They had had very limited contact following the fight, but probably for other reasons too. Else also encountered dramatic changes in her family life. When Else had a son with a rare chromosomal disorder, she learned that she had a balanced chromosomal rearrangement, and she told her family that everyone was invited to undergo genetic testing to determine their own carrier status. Looking back at the ensuing events, Else explains:

“My mother and father live just down the road. One day, my father pops by and tells me that he has spoken to this doctor and then adds that...I’m adopted. That was somewhat dramatic [voldsomt]. Afterwards I’ve been happy that he told me, but right there it was a traumatic experience. Especially because my mother wouldn’t talk about it. My father wanted to talk. My mother wouldn’t talk about it at all!”

I asked Else why her father decided to tell her about the adoption:

“It was because the doctor wanted a blood sample, and then I think...well, they could have decided not to tell, or just tell the doctor, but, but, but I could feel how my father wanted me to know (...) And I really appreciate it. In the end, I came to appreciate it.”

Note how the search for genetic explanations (primarily for research reasons as the grandparents were not in need of reproductive counseling) come to serve as reason for telling about an adoption that had otherwise been kept secret. It had significant relational implications. It delivered what Strathern calls “constitutive knowledge” about kinship – knowledge that is formative for relations (Strathern 1999, 68). In fact, Else had long suspected something:

“I was no more than 10-11 years old and I sat playing by the piano when I overheard my mother talking with her sister on the phone, and there was some kind of problem with my aunt’s son, and my mother apparently says something to my aunt and she replies, ‘How would you know when you haven’t given birth to a child’. My mother repeats that sentence to my father, while I’m sitting there playing next door.”

Else had confronted her mother with what she heard several times, also as a teenager, but the mother always denied any talk about adoption. In contrast, Else says of her father:

“For him it was important to tell, so that it wouldn’t come from the doctor. I shouldn’t be told by a doctor. It should come from him.”

Else thus simultaneously interprets it as a desire to tell and a fear of it being revealed by somebody else. Of course, the doctors would never reveal an adoption. The revelation of the adoption happens through a route of personal interpretations and desires *using the gaps of uncertainty* to create room for agency. For Else, the chromosomal rearrangement furthermore becomes as a reason to contact her biological family:

“I was very interested in finding out – it was primarily *this* I wanted to know: Does anybody in that family have the same gene error?”



Through the biological mother Else learned she had a sister. And so she asked her mother about the chromosomal rearrangement:

“I asked her. It was one of the most important things for me, though I also wanted to meet her, just as I’d like to meet my sister. But I didn’t do it to become part of the family, that family, ‘cause it’d be really strange for me. I really don’t need that.”

The biological mother did not think they had the rearrangement, and it turned out that she wanted to limit the contact and avoid introducing Else to her sister. Considering the fact that the chromosomal rearrangement is not related to any known disease – linkage is only a research hypothesis – it is remarkable that the search for “genetic truth” (Lindee 2015) can overrule first the adoptee mother’s wish to conceal the adoption and then serve as explanation when justifying the interest in contacting the genetic relatives. Genetic *nonknowledge* can do much the same work as established genetic knowledge.<sup>5</sup>

## **MORAL IMPLICATIONS**

When research participation interacts with relations between people it easily spills over into moral anxieties relating to responsibility and questions about what is right and wrong, good and bad. Previous studies have shown how genetics can involve “a moral imperative attributed to clients or patients – a responsibility to disclose information to other family members who may be genetically at risk” (Arribas-Ayllon, Featherstone, and Atkinson 2011, 6). Often the sense of genetic responsibility is gendered so that women in particular are expected to care for other relatives (Hallowell 1999). Research participation stimulates some of the same social dynamics because it makes the participants contemplate relations, as we saw above, and thereby also what they owe to whom. We already saw above how Christian, Hilma, Lisbeth and Olga contemplated their

responsibilities. Olga furthermore explains that following the invitation to participate in research, she informed her children about their carrier status:

“I did not dare not telling them. I didn’t want to be the reason [skyld] they would get a child with Down’s Syndrome.”

Again it is Olga that makes this interpretation – that she could be the “reason” and that the chromosomal rearrangement would cause Down’s Syndrome. Personal interpretations of genetics form the basis of decisions and are used to direct blame irrespective of what researchers would see as genetically relevant (Arribas-Ayllon et al. 2008; Mozersky 2012). It is worth noting also that the Danish word that Olga uses, which I translated as “reason” [skyld], is also the word used for “guilt” and “blame”. Hence, she is also saying she does not want to be guilty. Similarly, Sonja writes in an email correspondence that she wants to know more about the risks her daughters will face because:

“I want to be able to help/inform them so that they won’t have children with a genetic handicap. Would feel guilty [skyld] if I didn’t tell them about things that could have been avoided.”

For some, research participation involves blaming or belittling themselves. Several of the people I interviewed had forgotten about the balanced chromosomal rearrangement until they received the invitation to participate in research, but now they referred to it as a flaw or error characterizing them. Half of the respondents use terms like “gene error”, “DNA disorder”, “chromosome error” and so on, though a balanced chromosomal rearrangement is not a disease. Hilma, for example, who has had no indication of any problems and who had forgotten about the old tests, now referred to it as “the damned chromosome defect”. Here again it is as if “genetic truth” overrules phenomenological experience (Lindee 2015), but it remains personal versions of “genetic truth”. In one case, however, Patrick specifically states that he still “feels normal” and therefore does not fear the results of the research.

Anette is more ambivalent. The invitation to participate in research has made her contemplate a disablement that she has had throughout her life (which, she has otherwise been told, is unrelated to the balanced rearrangement). She states that she feels “guilty”, and when I ask why, she explains: “I just know that it is not always as healthy as it ought to be... my diet. I probably ought to eat more organic food, if that is wholesome...” We might characterize her remark as a “misunderstanding” (see discussion in Arribas-Ayllon et al. 2008), but perhaps we should focus instead on how Anette makes sense of her situation using nonknowledge to maneuver uncertainty. Like the Azande she is looking for meaning, an orientation in the world when faced with misfortune (Whyte 1997). She hopes that the researchers can figure out whether her genes have changed since the original samples were taken in 1971. Trying to understand why she has this curiosity, I ask whether she feels different, and she replies: “No I haven’t thought about that.” She is quiet for a while and then continues: “You can’t treat the chromosomes. You can’t. It’s just the way it is”. In this way, research participation makes her go through phases of both moral guilt and consolation and, importantly, it happens in the course of participating in both the genetic research project and the interview with me. Both types of research serve as occasions for negotiating blame and attributing meaning to her misery. The unknown cause of disease – the nonknowledge – creates a moral space of full of hope and concern, consolation and blame. In conclusion, Anette says that she *hopes* genetic research will prove she is not to blame for her impairment.

Some respondents held personal hypotheses that they hoped research would prove right. Nicklas (who was diagnosed as with a psychiatric disorder) wondered whether genetic difference could be an advantage rather than a risk, much in line with the optimism uttered by Nina and Anne-Sophie above. Nicklas hoped research would establish his disorder as an advanced evolutionary step where the brain has reached a higher level of consciousness. He felt quite certain that the voices he heard were real and his hypothesis was that when others could not hear them, it

was because of lower levels of brain activity in ordinary people. He hoped the genetic research he participated in could promote a better understanding of brain biology, but he also wanted to stay realistic and not expect too much of the researchers. Nicklas' personal theory has interesting resemblances to the current wave of interest in so-called neuro-diversity in the USA following the publication of Silberman's book about autism as a labor market resource (Silberman 2015). Silberman's point is that autism is a difference, not a pathology, and that we should embrace it for its strengths rather than seeking its cure. For Nicklas the aspirations can build on that which is *not known* yet, on nonknowledge.

Henriette also had a personal hypothesis, but she was less optimistic. She suffered from Attention Deficit/Hyperactivity Disorder (ADHD) and regarded the fact that researchers wanted to research her genes as indication that it had a genetic cause. She intensely wanted that hypothesis to be confirmed so that the world would know that her disorder was "real": "I keep hoping that they, at some point, will prove that ADHD exists, that it is real". Lindee's notion of genetics as a particular purveyor of truth here again interacts with notions of confirmation, guilt and consolation. The researchers sometimes learn about some of these hopes and aspirations among the participants, and discussing them then becomes an important part of the recruitment process. It is, however, a task that remains unfunded. It is tacit work. And though private hopes and concerns potentially influence how people respond to the questionnaire, as we saw above, there is limited room for letting such narratives influence the scientific presentation and interpretation of the data.

Finally, it is worth noting that people through their participation, and in the course of the interview with me, evaluate the value of research as such from a moral perspective. Research is for almost all respondents associated with a sense of hope. In most cases, the hope remains abstract (and not as clearly defined as for Anette, Nicklas and Henriette), which probably reflects that the participants are healthy volunteers. However, there are also elements of doubt and moral

ambivalence (see also Kerr, Cunningham-Burley, and Tutton 2007). As Christian stated so clearly above, genetic research can stimulate reflections on “eugenics” (a term with many connotations and historically contingent meanings, Koch 2004; Koch 2006). Most respondents commented on eugenic effects when they noted how new genetic knowledge could stimulate more abortions. To understand the respondents’ thoughts about abortion, it is important to realize that Denmark is a highly secular country (Bondesen 2003; Zuckerman 2008) and that abortion is not a politically contested topic in the same sense as in the USA (Albæk, Green-Pedersen and Larsen 2014). There are no political parties in parliament opposing abortion, and access to abortion is one of the few guaranteed rights of treatment in health law (Hartlev 2005).

Two of my respondents who themselves had disabled children stated that the prospect of better prenatal screening was a major motivation for them to participate in research. They loved their children, but they would not like others to experience the trouble they had gone through, nor for anyone to have a child that demanded their care but which might outlive them. Kirsten, in contrast, had had several miscarriages before she adopted three children, and she was fiercely against abortion. For her the thought of contributing to new prenatal screening options was disconcerting. Mostly, however, new forms of prenatal screening that might facilitate abortion remained an unresolved moral puzzle. Maria wanted to get the tools to avoid a heavily impaired child, but continued:

“The only thing that restrains me from saying that I *only* want a healthy child is that I couldn’t bear having to kill a child, ’cause that’s what you do when you get an abortion, right? (...) I guess that at some point we won’t have anybody left with a disablement, they will have been deselected, and I don’t know whether that’s good or bad.”

Research participation in this way stimulates thoughts about the moral ambiguity of societal developments. It is important to remember that genetic research has both identified reasons for abortions and removed uncertainties that used to give rise to abortion. Hence, genetic knowledge can both increase and decrease abortion rates. Both Nina and Nicklas make a point of not opposing abortion but on the other hand not wanting research to remove everything “different” or “difficult”. Anne-Sophie wondered if too much was done to promote abortion:

“When I think about how little, how few [people] with Down’s you see anywhere in public spaces today. There aren’t many left. When I was a kid, they were part of everyday life.”

Research participation therefore interacts with hopes for a better future, but simultaneously makes the participants contemplate their doubts about what counts as “better”. Nonknowledge – that which we do not know yet – is central to accommodating the diverse interests and moral positions of the participants.

In short, research operates in a moral landscape of guilt, blame and consolation – not as a result of choices made by researchers, but because research participants bring their own agendas into the projects. The agendas develop in the space for agency that nonknowledge and uncertainty produce.

## CONCLUSIONS

Policies focusing on translation from bench to bedside tend to build on the assumption that research primarily stimulates change when *knowledge* translates into technological *ability* and creates *utility*. This vision essentially reduces science to engineering; knowing to doing (Nowotny and Testa 2010:5). Here, in contrast, I suggest that research may also translate through patterns of nonknowledge and feelings of in-ability, and still have very real effects. Research can have many

implications long before any clinical applications are at hand. These implications are, however, somewhat different from those articulated in the politically motivated bench-to-bedside literature. In this paper I have presented epistemic, emotional, relational as well as moral implications of research participation. They are all enacted before any scientific or technological innovation has materialized. Interestingly, many of the social implications resemble what has been found in relation to genetic counseling based on authorized genetic knowledge. What this study shows is that the social dynamics are very similar irrespective of the form of knowledge: people can use nonknowledge – research questions – in much the same way as they engage authorized genetic knowledge.

It remains contested and ambiguous what counts as “knowledge”. If knowledge claims are known to serve as “ordering devices”, we should note also how nonknowledge provides leverage for social ordering. Konrad (2003) has insightfully shown how genetic knowledge is used for social ordering as people employ secrecy and selective knowledge distribution to model kinship ties. Here, however, I have focused on nonknowledge, rather than family secrets, and shown how it opens gaps for action and facilitate social ordering through that which is not known by any of the involved family members. Nonknowledge provides a gap of uncertainty, which is infused with personal interpretations. In this gap, agency unfolds. Some might construe the participants as simply lacking knowledge, or misunderstanding the research they participate in. However, it is important to realize that the researchers running the project I studied do try very hard to communicate what they see as relevant and valid knowledge. They can in no way be seen as restrictive in their attempts to share their perception of genetic truth. Therefore, we cannot expect “misunderstandings” to go away irrespective of the number of educational campaigns.

Instead of focusing on “misunderstandings” as errors we could experiment more with how to engage and tackle people’s personal interpretations in ways that see them as productive for

both researchers and research participants. I do not suggest embracing some type of extreme knowledge relativism, because genetic researchers do know more about genetic causation than the research participants. However, the interpretations based on nonknowledge are bound to affect the research because they shape the information researchers can collect. If funding bodies would finance the infrastructures needed for a deeper social engagement between researchers and research participants, there could be more opportunities to enter a continuous conversation with the participants. One woman decided not to answer truthfully to questions relating to psychiatric diagnosis, others hoped to find proof of their own hypotheses, and others still were eager to support any study that would prove their chromosomal rearrangement related to some type of superiority. This implies that we should do more to engage the agendas and objectives that people bring from the bedside to the bench in order to understand both people's motivations and the nature of the data they deliver. This is, indeed, a question of approaching people as active research *participants* rather than donors or research subjects (Tutton 2007). It remains the case, however, that funding structures and journal requirements do little to accommodate the work this involves.

Finally, we need to appreciate the parallel between participation in genetic research and participation in the type of social science research that this paper represents. Throughout my study, I have had to realize that my questions – just like the questions in the questionnaire of the genetic study – interacted with the informants' hopes and concerns, and stimulated reactions. It might be minor effects, and yet it illustrates how translations take place in every interaction where research plans meet research participants. Perhaps we should think of the studies themselves, and the questions they raise, as agents of change in their own right. Perhaps our questions are as important as the results we seek to communicate. Questions represent a generative form of knowledge. They travel through the thoughts they stimulate. They are blank figures, forms of nonknowledge shaped by other knowledge projects, and in this form they work on people. We



could do more to acknowledge social science research questions as scientific outputs. Perhaps, social scientists should also experiment more with studying what questions – as carriers of nonknowledge – produce. Could greater acknowledgement of the work done by traveling questions perhaps provide new political spaces different from those of the bench-to-bedside paradigm where impact is supposed to be linear and value should relate to the plan of the funding agency rather than that of the research participant? When addressing such issues, policymakers and researchers alike will have to think more actively of research projects (and not research results) as important agents of translation. Questions can sometimes travel as fast as answers.

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### **Notes**

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<sup>1</sup> Consider, e.g., the national Institute of Health program on genetic screening in the USA, the 100K project on WGS in the UK, the similar plans in Iceland and on the Faroe Islands, or the plans by the authorities in Norway and Denmark to initiate such large-scale infrastructure projects. See also the

Bench to Bedside program initiated by the National Institutes of Health

(<http://clinicalcenter.nih.gov/ccc/btb/>).

<sup>2</sup> In 2014, I was provided with a list of respondents with contact details, age and gender, and no further information. I did not know who matched which of the additional selection criteria focusing on noted differences in reactions to participation. The selected respondents were invited by letter to participate in an interview and informed that it could be in a place of their own choice or, if they preferred, by phone or as a written response to a set of questions. Two persons did not wish to participate after all, and the rest agreed. Interviews were conducted from August 2014 and six months forward, and followed up with more work with the scientists to understand the project properly. The interviews typically lasted around one hour, but one was just 15 minutes and the longest almost three hours. Some interviews had follow-up interviews on the phone, or emails adding further reflections or comments. They were all conducted in Danish and transcribed verbatim. I have translated the quotes. In a few instances, where people were particularly worried about confidentiality, I have changed the gender or insignificant details relating to a disease to make the family narrative less recognizable.

<sup>3</sup> The emphasis in the following is on social change and human actors are the focus of the analysis both as agents and objects of change. Non-human agents and other types of implications could have been highlighted. For example, register and record-keeping formats exert forms of agency that this type of analysis does little to elucidate, and similarly the storage of samples and data involves a range of implications I do not seek to cover (see Kowal and Radin 2015).

<sup>4</sup> It is well-known also among questionnaire developers that people are selective in what they report in a questionnaire depending on what they assume relevant for the researchers: local interpretations precondition the data that can be acquired and patients and health professionals can use the same questionnaire with significant variation (Groenvold et al. 1997).

<sup>5</sup> Some readers might object that these are narratives about diagnostics rather than research participation. However, it is important to remember that research often leads to diagnostic information and vice versa. In the course of the diagnostic process, some relatives are contacted to provide a complete family history as much for research reasons as to undergo diagnostics or receive care and the genetic register is partly construed with research in mind.

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