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Difficult Questions and Ambivalent Answers on Genetic Testing

By Andréa Wiszmeg, Susanne Lundin, Eva Torkelson, Niclas Hagen & Cecilia Lundberg

Abstract

A qualitative pilot study on the attitudes of some citizens in southern Sweden toward predictive genetic testing – and a quantitative nation wide opinion poll targeting the same issues, was initiated by the Cultural Scientific Research Team of BAGADILICO. The latter is an international biomedical research environment on neurological disease at Lund University. The data of the two studies crystallized through analysis into themes around which the informants' personal negotiations of opinions and emotions in relation to the topic centred: *Concept of Risk*,'*Relations and Moral Multi-layers, Worry*, *Agency and Autonomy*, *Authority*, and *Rationality versus Emotion.* The studies indicate that even groups of people that beforehand are non-engaged in the issue, harbour complex and ambivalent emotions and opinions toward questions like this. A certain kind of situation bound pragmatism that with difficulty could be shown by quantitative methods alone emerges. This confirms our belief that methodological consideration of combining quantitative and qualitative methods is crucial for gaining a more complex representation of attitudes, as well as for problematizing the idea of a unified public open to inquiry.

Keywords: Genetic testing, risk, public attitude, responsibility, complexity, ambivalence

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Introduction

Ulrich Beck (1992) declares that the proliferation of risks is the hallmark of our current situation. Whereas dangers in the pre-industrial society 'assaulted the nose or the eyes and were thus perceptible to the senses, the risks of civilization today typically escape perception' (Beck 1992: 21). The expansion of these unseen and abstract hazards constitutes a shift wherein a new cultural and social formation can be seen: the risk society (Beck 1992; Mythen 2007). In relation to the proliferation of risks, this late modern configuration has partly removed the collectivist risk management of the traditional welfare state, favouring a form of prudentialism where the individual is responsible for managing risks (O'Malley 1996: 197).

In today's biosociety, the responsible individual is seen as someone who takes rational steps to avoid and insure against risk. This is done in order to become independent, and to avoid becoming a burden for others. Hence, a rational self-interest and risk management is articulated as an everyday practice of the self (O'Malley 1996: 200). In addition, in today's biosociety, and parallel to the cultural, social and political development; scientific development within genetics and genomics has produced an increased knowledge about human genetics. This scientific development has created new possibilities for diagnostic prediction by means of using genetic tests. Subsequently, genetics and genomics is placed within a general discourse of disease prevention, illustrated by the advent of such sub-disciplines as public health genomics and community genetics (cf. Khoury et al. 2000).

Previous research have shown that methods such as the use of genome analysis and genetic testing will alter the individuals' self-understanding as much as it changes the health system and how society treats disability and illness (cf. Novas & Rose 2000; Lemke 2004). As preventive medicine intersects with genetic research and technology (Arnoldi 2009: 100), it makes the responsibility for one's genes and the risks they might encompass a personal and individual obligation. Genetics and genomics seem to give rise to reactions that contradict the rational and prudent responses about responsibility that are proclaimed within today's biosociety. Our point of departure in this article is that scientific understanding and evaluations of risk seem to be incompatible with those representations that are invoked by lay-men in their everyday life. Genetics is deeply connected to human emotions and moral beliefs.We draw on our own previous research as well as on broad multidisciplinary discussions (Wexler 1996; Lundin & Åkesson 2002; Ferreira & Boholm 2005; Franklin 2006; Liljefors, Lundin & Wiszmeg in press). We are interested in what happens when genetic risk assessment enters the realm of everyday life and matters of the body. How do people perceive risk, and which strategies will the individual be in need of? We use the concept of risk perception

in Beck's sense, that is to describe why people define and sense risk and threats in different ways (Beck 1992).

The article aims to explore how people relate to and talk about situations that arise in relation to genetics and genomics. This is done on the basis of two studies conducted by the authors: the qualitative survey *Knowledge of Disease* (2010), and the nationwide opinion poll *Public Research – Genetic Diseases* (2011). The authors belong to the cultural, social, and natural sciences, which means that we also lean on previous qualitative and quantitative studies (Lundin 2002; Lundin & Idvall 2003; Torkelson 2007 et al.; Lundberg et al. 2008; Hagen 2011).

It is our ambition to present how the presumed individualized responsibility of avoiding and preventing perceived risks is expressed on an individual level. We look at how this gradual shift in the discourse creates multiple layers of attitude and opinion in the individual (Bauman 1993; Frank 1995). Our studies point to instances of ambivalence in people's accounts regarding experimental biomedical research and predictive genetic testing, when discussed on a general level. We want to emphasize the methodological and political importance of paying attention to such ambivalence. This also means that we call for a more thorough consideration of the methods used for gathering data for ethical discussion and drawing up guidelines in modern biomedical research. Hence, in our discussion we wish to problematize the idea of a general public (cf. Ideland & Lundin 1997; Gottweis 2008; Hansson et al., 2011; Plows 2011). The idea of a one-dimensional public united by opinion is highly problematic. The ignorance of the existence of ambivalence may, in fact, help legitimize this false and simplified picture.

We will begin with a section that accounts for the methods that were employed in order to obtain our empirical material. The subsequent five sections will present and elaborate on this empirical material. In the last section, we address the question of a unified public in conjunction with genetics and genomics within the late-modern risk society.

Methods

Our discussion relies partly on a qualitative empirical study of the attitudes of a number of citizens in southern Sweden with regard to risk- and predictive genetic testing. This survey, *LUF 232 – Knowledge of Disease* (2010), was conducted by means of an open-ended questionnaire, distributed among 122 previously volunteering respondents of the Folklife Archive at Lund University, who receive questionnaires on different themes 3-4 times a year.[1] Our article also relies on the subsequent quantitative nationwide opinion poll *Public Research – Genetic Diseases* (2011) that explores the same theme as the survey, and aims at capturing ethical and moral dilemmas on these issues to a greater extent than quantitative surveys traditionally do. (For methodological details, See appendix, p.16) We chose this methodological design in order to make the opinion poll as nuanced as

possible. Both studies were initiated by the Cultural Scientific Research Team, which is part of the interdisciplinary research project BAGADILICO,[2] researching possible therapies for Huntington's and Parkinson's disease.

We discuss the results and the material of the open-ended questionnaire and the opinion poll, both from a qualitative perspective and in relation to the data generated by the quantitative methods applied in both studies (Calculations of frequencies of themes in answers to the open-ended questionnaire *LUF 232 – Knowledge of Disease* were also made, as well as a measurement of the level of agreement on a scale of 1 to 5 with regard to two different statements). We point to instances of ambivalence in people's accounts regarding experimental biomedical research and predictive genetic testing. Reasons for these ambivalences and the empirical, methodological, and political importance of paying attention to ambivalence, and the possible consequences if we do not, are also addressed. We will present a selection of statements produced by the open-ended questionnaire that hint at ambivalence on issues that arise from the interaction of concrete context and abstract reflection, when the individual tries to make sense of the posed questions in the inquiry. We have found five themes around which the respondents' negotiations centre: *the Concept of Risk, Relations and Moral Multi-layers, Worry, Agency and Autonomy, Authority* and *Rationality versus Emotion.*

The Concept of Risk

In the nationwide opinion poll, *Public Research – Genetic Diseases* (2011), we posed the question whether one would like to find out what diseases one runs the risk of being afflicted by, such as Alzheimier's disease or cancer. A majority of 60 percent answered that they would not. There were no significant differences between women and men. If the disease in question would be uncurable, as many as 70 percent would not like to find out, although more men than women were positive to finding out. When searching answers to these questions in qualitative data, as in the survey *Knowledge of Disease* (2010), another picture comes forth, showing how genetic tests raise questions about the *meaning* of being at risk. A young man put it like this:

> If you have, let's say, a 20 percent elevated risk of getting prostate cancer, what would you do with that information? And can you trust it? […] On the other hand: if there are tests that offer precise results, and if it is possible to discover elevated risks of treatable disease, and if they are discovered in an early stage, there might be a point in having a test and then acting on the basis of that. It's just not possible to give an unequivocal answer to a question like this.

The term *genetic susceptibility* denotes an elevated risk of certain diseases due to various genetic variations. In many cases the genetic tests that detect these genetic variations are applicable in testing for diseases where we have a complex interaction between several genes, and between these genes and the environment.

Most of our common diseases, such as diabetes and cardio-vascular diseases have this complex interaction. Due to this complexity the actual prediction on the basis of a genetic test is difficult to make. This situation can be compared to so-called monogenetic diseases (where the disease is caused by a single mutated gene), like Huntington's disease, where the genetic status decides whether you will fall ill or not. The genetic test for Huntington's disease only gives you information on *absolute* risk, in comparison to most of the genetic susceptibility tests that in many cases only provide information on relative risks.

It is often extremely hard for individuals to make sense of statistical risk on a personal level (Sachs 1998) and test results showing a genetic predisposition that indicates a heightened risk of a disease (Lock & Nguyen 2010). This means that the individual risk-ratio given by the susceptibility test has to be related to the general risk within the population and the incidence of disease in the individual´s family. The existence of these different kinds of tests raises a great many questions about what a risk really is, and what significance and meaning this worrying concept is (or should be) given in your life.

The problem with the concept of risk in relation to test results and in relation to something as culturally elusive as genes (cf. Åkesson 1999) is that, as with the case of knowledge, it is irreversible. It is indeed impossible to go back to not knowing of your estimated risk once it has been stated. So in some sense, it is the knowledge of the risk that brings the risk into existence for the individual. The risk originates from the knowledge. But what is a risk, and what does knowing about it really mean? How can you assess how or whether a percentage point of elevated risk is going to affect your life? Previous studies show that undefined knowledge, such as that of risk, possesses great power to affect and influence people's emotions (Lundin 2002).

As mentioned in the introduction, the prolifieration of invisible hazards and dangers are an important feature within the late-modern society. The elusive and invisible character of our genes makes it difficult for individuals to understand the meaning of the risk estimates (Hagen 2011). As the quotation above exemplifies, by indicating that risk has been confused with discoveries of actual disease, it can also be problematic for a layperson to discern the difference between an 'elevated risk' and an early stage of a disease. The increased use of these kinds of tests also raises the question of where to draw the line between an observed deviation, that is, a *diagnosis*, and a prediction of progression, a *prognosis* (cf. Konrad 2005).

As Beck argues (1992), the notions of modern risks are often detached from the sensations of human experience, making them all the more difficult to fathom and even calculate. Estimating the impact of the risk, even if not knowing the actual numbers, of something quite tangible such as being hit by a car when crossing a busy road gives you agency to choose not to cross the road, because you can physically and emotionally relate to what could happen if you do. Test results stating elevated risks of certain diseases do not provide that kind of agency

based on direct lived experience. In order to make sense of such risks in this same concrete manner, there is need for previous reference. This could, for example, be to have had a close relative suffering from a genetically hereditary disease. However, not even this experience grants clear alternatives of action.

Relations and Moral Multi-layers

Our opinion poll showed that a slight majority was negative towards finding out about what diseases they were at risk of passing down to future generations. Between men and women no difference was detectable, but the youngest respondents (age 15-29) were the most positive. When asked to state how much they would *worry* about being afflicted with or passing down a genetic disease, the majority stated a mean value of 3.5 on a scale from 1 to 5, where 1 symbolized the least worry and 5 the most. Here, a significant difference between men and women were detectable in that women would experience the highest level of worry to a greater extent than men.

Relational and societal contexts can help us better understand this seemingly general negative attitude. As discussed by other scholars (cf. Sachs 1998; Åkesson 1999; Lock & Nguyen 2010, etc.), effects on kith and kin can deeply affect how we reason regarding what actions are preferred and what precautions should or should not be taken to prevent disease or passing on affected genes. An elderly woman reflecting on and discussing these issues with herself illustrates this:

> I don't know if I, when I was young, would have wanted to know whether I would be afflicted with a genetic disease. I guess I wouldn't have had children in that case. My grandchildren's grandmother on their mother's side was afflicted with a serious genetic disease, but no one knew, and she died after my grandchildren were born. They can't donate blood, but in other respects I don't believe they think about falling ill. It would have been very sad for me if these children did not exist. They grew up so close to me.

The close relationship to her grandchildren is the main reason this woman finds it hard to believe that she herself would have made the decision to take a predictive genetic test, had she had the chance when she was younger. She expresses worry that her standards of that time may then have influenced her to make the seemingly emotionally difficult decision not to have children, which would have resulted in not having these dearly loved grandchildren. This exemplifies how layers of time perspectives, experiences and different relations present in the moral negotiations within a person can create a kind of pragmatic moral that is mouldable to the situation at hand. What affects your personal and intimate sphere of relations and yourself might not always, or maybe even not very often, coincide with your moral and ethical standards formed in, for and adapted to a contemporary general level. As one of our recent studies point out, people's reflections are based on a personal and situation bound morality, which does not necessarily coincide with what they generally consider to be ethically justifiable (Lundin & Idvall 2003).

In addition, the woman above indirectly reasons about how age and its cultural implications in relation to starting a family is highly relevant when debating with herself about wanting or not wanting to know of coming diseases. If her awareness of a genetic disease had hindered her from having children when younger, she would not have wanted to know. The love for her existing children and grandchildren can make the thought of not having them unpleasant and even unimaginable. The woman's response illustrates the contradictory thoughts that genetics raises, in this case paradoxical attitudes towards parenthood.

The correlation[3] we found between age and a high assent in will among our respondents to *LUF 2323 – Knowledge of Disease*, to know what diseases they are at risk of being affected by, irrespective of whether they are curable or not (one of the statements to which the respondents graded their concurrence), adds more complexity to this issue. The correlation indicates that within the context of our open-ended questionnaire; the older you are the more willing you are to obtain knowledge about possible diseases, regardless of whether they are curable or not.[4] This is interesting to consider in relation to the quotation above. The account given from this one single woman gives us an insight into the complexities of trying to consider possible outcomes in hindsight, and the different layers of reason undoubtedly added by time and experience. This is a piece of information that, with difficulty, could be gained from quantitative data only.

Another interesting finding is a correlation[5] in the will to know what future diseases you (our respondents) are at risk of being affected by, irrespective of whether they are curable or not, and on how important our respondents rated receiving information on new medical research findings in general, implying that the will to know about your own health coincided with a will to know about medical findings in general. The correlation between the two statements in our survey is worth noting in relation to their possible correlation with the European Union report *Europeans and Biotechnology in 2010: Winds of Change?* (Gaskell et al. 2010). This report states that the more information available, the greater the will to know and the thirst for more information. A question worth asking in relation to this, as previously addressed in The Concept of Risk, is to what extent this thirst for information arises from the irreversibility of knowledge that people have gained? Could this situation rather be an unavoidable effect of the increased knowledge proliferation in this field, than an attitude by choice?

Worry, Agency and Autonomy

Two thirds of our respondents of *LUF 232 – Knowledge of Disease* shared the view that the most important factor was the possibility of taking measures in relation to the information received. One third of them also stated that they would like to obtain information about diseases they might be at risk of, even if no cure or palliation is available at the moment. Two thirds did not. The opinion poll

Public Research – Genetic Diseases also showed that, nationwide, more than two thirds of the respondents do not want to know about incurable disease.

Two middle-aged men in the survey *Knowledge of Disease* (2010) illustrate the importance of being able to act upon the information given to you:

> This [genetic research] opens for possibilities of circumventing some built-in threats to our health, or lessening their effects. This is of course positive in many cases, but can also mean groundless worry and anxiety about being afflicted with inherited diseases and premature death, in many people. Thus, the knowledge in itself can form a larger threat than the possible disease itself.
>
> If there is something that can be cured or at least be relieved, then that's a different story. However, if I just know that it might break out but not when, and I can't take any measures to prevent it, then I think it's a bit useless.

From their accounts you can also understand how they perceive it as meaningless to get information that does not give you any options or alternatives of action. This attitude is interesting in relation to that, nationwide (*Public Research – Genetic Diseases* 2011), men in larger proportion than women would like to find out about uncurable disease. The opinions expressed in the accounts provided by the men above can be described as a strategy of handling the fact that they themselves are objects *and* subjects of science. Although, choosing to live with uncertainty as to whether one is going to be affected by a disease without a cure, is not an apparent choice for all. Certainty in the form of a test result can, despite the high degree of complexity involved, provide meaning for individual subjective experiences, even if the test result proves to be positive (Konrad 2005; Hagen 2011).

The prudentialism of the neoliberal citizenship expects the men from our study quoted above to act as subjects upon information, considering their health and bodies as objects (O'Malley 1996; Rose 1996). Furthermore, as the first man puts it, there is reason to worry that the knowledge these new techniques facilitate might cause anxiety. To understand the concern this man expresses, Beck's concept of *the latent becoming manifest* when risk is highlighted (1992) might be of help when trying to understand the possible implications of the subject/object positions of the individual. The threat has become manifest and calls for action, but if no measures (either in form of choices or actions) can be taken in relation to this newfound risk, the manifestation does not automatically provide the individual with agency.

Some people risk feeling left with a sense of helplessness and not being able to fulfil one's responsibility (cf. Rose 2007). Others yet feel empowered by having gained information to help guide their decisions for life adjustments – even if those do not encompass a cure. This is obviously highly dependent on one's general life situation and former individual and collective experiences, such as social position, gender, and age.

Authority

Not all respondents seemed to agree that their own autonomous agency in itself was the most valuable factor in these issues, nor that the presence of choice in itself safeguarded positive outcome of personal agency.

The opinion poll confirmed this latter view by informing us that the majority of the Swedish population, on a scale from 1 – not adjusting at all – to 5 – fully adjust – would *totally* (5) adjust their lifestyle to doctor's orders if it would have impact on their risk of developing some genetic diseases.

There might be several reasons for this, and the examples of certain statements seem to ascribe value to something other than personal agency and control. To some, the authority of a clinician or trust in research findings seemed to be more of a guarantee that what would happen to them was the best possible, which was also indicated by the recurring theme *'adjusting my lifestyle'* in response to the question of what to do with presumed information about genetic disease. Two women in our qualitative survey express this trust in doctors and medical findings. One of them focuses on the prescription and order itself, saying that 'I'd adjust my life to what was prescribed as the best for me'. The other woman to a higher extent assumes the desired individual responsibility of today for her health, although she makes it clear at the same time that she would also trust the information she finds to be able to help her:

> Then I'd try to gain all possible knowledge, to be able to prevent and ease the symptoms of the disease.

This trust in authority and in doctors' direct orders or information from elsewhere, could indicate a desire to be free from a responsibility that threatens to be overpowering. This trust can open up for, and originate from, an urge to be morally freed from potential consequences that might be impossible for the individual to grasp. As for the quotation from the first woman, her reaction could be interpreted as an act of resistance to the increasing demands on the individual to assume this responsibility and to prevent potential risks. But it is worth noting that trust in authorities in the field does not necessarily mean letting go of your agency. Choices in accordance with advice from authorities are just another way of facilitating your personal agency and taking advantage of the knowledge already gained by others.

Rationality versus Emotion

As discussed above, many respondents find it difficult to answer whether they would have had children if they had known that they could pass on genetic disease. In a similar way, it is difficult to answer whether they would want to know what diseases they might be afflicted with while they are healthy.

There are no guarantees that, with a positive test result in your hand, you would still be happy that you took the test, when rationally arguing the pros and

cons with yourself. An elderly woman in our qualitative survey reflects on how there is no going back from knowing:

> Yes, I would like to know what diseases I risk being afflicted with or passing on. […] Even if there is no cure now, there might be one in the future. I would always like to know. (Why, this is written while I'm healthy. How I would react when sick, no one knows.)

On the other hand, one might need to view the human as a versatile creature, with resources to try out new ways of constructing meaning about what life brings. The knowledge attained, and the reasons for attaining it, are mouldable entities. Ways will be found to fit knowledge into our personal world of social, cultural and emotional landscapes. Explanations as to why a test was or was not taken or what the result of a test meant for us can be constructed and re-constructed over and over, and narration in itself changes the story and the feeling of initial experience (see e.g. Butler, 2001 on narration *per se*; Frank, 1995; Sachs, 1998).

The following statement of a woman in the qualitative study shows a very sober way of reflecting over the complexities of reason contra emotional response:

> Having thought about it some more, I feel that it might be good to know, and to get used to the thought of future diseases. I think I'd like to know. […] My reason tells me all this, but I'm more uncertain of my emotions. It takes a lot of courage to receive knowledge about a possible future severe disease, and it takes great strength to be able to handle that knowledge.

This woman is obviously worried about how she might react if she took a predictive gene test and the result was positive. Even if it is not mentioned in this case, it seems to be connected with an irreversibility of knowledge. As previously discussed, the information you gain will unavoidably influence and be integrated with your actions, and it will create and make visible what we call 'ambivalence' in qualitative accounts on genetic research. In our experience drawn from the work with the opinion poll *Public Research – Genetic Diseases*, the process of negotiations between the self and society resulting in ambivalences toward genetic testing, cannot be visualized solely with quantitative methods.

To Make Solid What's Liquid: The Question of a Unified Public

The background of our investigation is the cultural and political formation of the risk society, wherein the individual citizen is positioned as an active and prudent subject (Beck 1992; O' Malley 1996). Due to the development within genetics and genomics, bodily risks can be detected on the level of the DNA-molecule. The individual is supposed to manage these risks through actions that are both rational and preventive. As noted by Åkesson (1999), the expansion of genetics and genomics relocates threats and dangers to the inside of our bodies. Moreover, these threats and dangers diverge from traditional forms of cultural

representations as these genetic threats and dangers are represented through abstract forms of statistical calculations (Åkesson 1999: 121). The notion of genetic risk is difficult to understand, and cannot easily form the basis for rational and responsible action on behalf of those who go through genetic testing. The genetic risks can thus be said to create experiences of abstract uncertainty.

One aim of this article has been to capture and discuss people's attitudes to biomedicine, genetic diseases and genetic research. The empirical material shows that the responses of many participants within our studies can be characterized in terms of ambivalence towards the issues that arise in relation to genetics and genomics. The ambivalence visible in our studies can be interpreted as an example of the form of abstract uncertainty described above.

Moreover, the answers given by the participants in the studies are also complex in relation to different layers of time perspectives, experiences and different social relations upon which the answers are situated within. The attitudes that come forward in our investigations are of a pragmatic kind, very much dependent upon the actual situation within which the genetic test is taken – a circumstance that quantitative research on its own with greater difficulty can capture. Previous research, conducted on Huntington´s Disease, has shown that the results of predictive genetic testing for the disease is often correlated with so called transition points (Tibben 2007). These transitions points can be events such as entering a long-term relationship or deciding to have children, and it is at these points that individuals become fully aware of the result of the genetic test (Tibben 2007: 166).

The views and attitudes of individuals – the so called public – can thus be understood as both complex, heterogenic and dynamic towards genetics, genomics, and biomedicine. Previous studies suggest that there is no unified public whose attitudes and opinions can be captured (e.g. Plows 2011). It is particularly difficult, as discussed, to get a picture of how people view biomedical and genetic research (Åkesson 1999; Gottweis 2008; Ideland & Holmberg 2010; Hagen 2011). However, with the need for legitimization of research follows a wish to gain these citizens' participation and approval. There is reason to believe that these endeavours are at risk of failing, if they are based upon a notion that such thing as a unified public exists. If anything, the idea of a unified public excludes the diversity of the many, often contradictory approaches that appear when people reflect upon issues such as biomedicine and genetic research. Furthermore, the idea of the unified public excludes the voices of specific stakeholders and 'opinionated' persons.

Along the lines of Gottweis (2008) and Plows (2011), and with our empirical material as support, we would argue that there is no unified public and therefore no cohesive public opinion that can be addressed on the issue of genetic preventions. Attempts to create formal participatory arrangements where the public is viewed as united could lead to disarming self-appointed interest groups

who view themselves as stakeholders, by replacing their voices in the debate with those of a non-engaged and disinterested public (Hansson et al. 2011). Furthermore, as our two studies indicate, we would argue that even the most seemingly non-engaged individual or group of people harbour complex feelings and opinions on this topic. Our material shows how allowing complexities from people's individual experiences and relational negotiations to be visible can 'liquefy' the seeming solidity of quantitative accounts.

We suggest that one important response to meet this heterogenic public is the development of methodological tools that better capture the complex attitudes among people (Lundin & Idvall 2003). This is especially important as genetics and genomics become entwined with visions of responsibility and prudence that presuppose both a rational and unified public in order to achieve a large-scale prevention of disease within society. By taking into account the complexity and ambivalence, the dialogue between researchers, patients, relatives and all the people viewed as the general unified public will be facilitated. Without dialogue and without accurate methods of research, the erroneous picture of a general unified public open to inquiry will remain, which in turn can result in negative consequences for research as well as for individuals. If room for ambivalence were allowed in the material used for drawing conclusions on how advanced technical genetic biomedicine is perceived and also accepted or unaccepted in people's everyday lives, there is a better chance of arriving at the core issues and main reasons for the manifest ambivalences that life sciences give rise to. We want to point out the importance of taking into account uncomfortable answers and deeply felt opinions, thereby starting the necessary process of dialogue.

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Notes

1 The majority of the respondents in *LUF 232 – Knowledge of Disease* are elderly people. The high age of the respondents affect the outcome of the study in the sense that the collective and individual experiences of gene technology, culturally and socially, are limited to the latter parts of their lives.

2 BAGADILICO (Basal Ganglia Disorders Linnaeus Consortium) is an international research environment at Lund University, working on developing and improving treatments for the neurologically caused Parkinson's and Huntington's diseases, and also for improving the quality of life for patients and their families. BAGADILICO consists of an estimated 120 researchers (March 2011) from the three disciplines Medicine, Engineering and Humanities, and is affiliated with the Department of Experimental Medical Science and the Faculty of

Medicine. The humanistic research within BAGADILICO is carried out by the Cultural Scientific Research Team (CSRT).

[3] r=.20, p<.05.

[4] No correlation was found between gender and the degree of "will to know" regarding the quantifiable statements of *X X – X X X*. We did find that the gender aspect considering motives of caring about passing on or not passing on genes might need further investigation, since we interpreted the qualitative material supplied by the women within the study as being more ambivalent regarding this.

[5] r=.54, p<.05.

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Appendix: The Survey

Method

Due to the space it would occupy in this article, we choose not to reproduce the exact phrasing of the questions in the qualitative open-ended questionnaire *LUF 232- Knowledge of Disease*, nor of the quantitative nationwide opinion poll *Public Research – Genetic Disease*. The full questionnaire is available through the Folklife Archive in Lund; search for *LUF232—Kunskap om sjukdom (Knowledge of Disease).* The main results of the nationwide opinion poll *Public Research – Genetic Disease* will be addressed later in the article under the thematic results in relation to the qualitative main findings of the open-ended questionnaire *LUF 232- Knowledge of Disease.*

The qualitative study was conducted first and the quantitative study second, in order to triangulate sources. We aimed at finding the most nuanced questions possible for the nationwide opinion poll, in order to contribute to methodological development in targeting the public.

The Qualitative Study: LUF 232- Knowledge of Disease received forty-three answers (at the time of the analysis), producing a response rate of 35 percent. In addition to being qualitatively evaluated, thirty-nine of these answers were also quantitatively analysed for the frequencies of themes mentioned in responses. This method does not make the results quantifiable or generalizable by quantitative research standards, but gives us an overview of the proliferation of opinions expressed within the group of respondents. We chose this combination of methods due to interest in methodology and because we wanted an explorative view on the data we produced. We are aware of the high variation in response rates among the different questions in the questionnaire, and we are interested in this methodological issue. Earlier questionnaires on biomedical and genetic research distributed via the Folklife Archive have shown the same tendency for low response rates. We can speculate that this internal tendency might derive from the complexity of the themes of these questionnaires in particular, causing the respondents to refrain from answering. Furthermore, the open-ended questionnaire format is a method with many special features; the surface impression is that of a survey, but the questions are usually embedded in some text intended to guide the respondent's thoughts to certain problems or themes. In addition, the respondents of open-ended questionnaires are free to compose their answers as it suits them, as they were in this case. This often generates a letter-writing style of text, enabling respondents to answer one question at length and to skip another. Answering an open-ended questionnaire in full length usually requires both time and effort (For more information on the open-ended questionnaire as a method, see e.g. Hagström 2009: Frågelistan som källa och metod. Lund: Studentlitteratur AB.).

The qualitative evaluation of the accounts given in of *LUF 232 – Knowledge of Disease* examined the diverse ways of handling and negotiating the ethical dilemmas that occur between the consequences for the individual's life in relation to the idea of general guidelines for "the greater good", and the dilemmas manifested in the negotiations between what is identified by the subjects themselves as emotional reactions versus rational reasoning. We investigated how the respondents handled this by shifting between diverse and sometimes seemingly contradictory arguments. We looked into how these strategies in turn create multiple layers of opinions – ambivalences. Through this process, the material crystallized into themes, which are the ones presented and elaborated on in this article. The material was processed both by Wiszmeg and Lundin, and the themes developed through a dialectical process where the material at hand and Wiszmeg's and Lundin's preliminary understandings in the field were constitutive of the result.

In addition to the qualitative questions in *LUF 232 – Knowledge of Disease,* our respondents were to grade their assent to two different statements, with fixed alternatives. The statements were: *I would like to know what diseases I am at risk of being affected by, irrespective of whether they are curable or not*, and *It is important to me to receive information on new medical research findings in general.* The degrees of assent (the same alternatives applied to both statements) ranged from 1 *Do not agree at all* to 4 *Fully agree*. A fifth alternative outside the scale was also given: 5 *I do not care.*

The majority of the respondents of *LUF 232 – Knowledge of Disease* are elderly women, and the average age is just over 70 years. The sample of qualitative data from our study is chosen for

its relevance to the aim of discussing ambivalence in accounts, thus problematizing the idea of a unified public. The material has been translated from Swedish to English.

The Quantitiative Study: Public Research – Genetic Diseases is a nationally representative study. Its design was based upon our previous results from *LUF 232 – Knowledge of Disease*. *Public Research – Genetic Riseases* included 1000 Swedish respondents interviewed by telephone, and were conducted by Swedish branch SIFO of TNS, a market research company, in May 2011. The respondents were asked to answer 10 questions with on beforehand stated alternatives. The interviewers of SIFO were supplied with the minimum of background information they needed to able to conduct the interviews. The respondents had to answer the questions on the spot.

Results

The results of *LUF 232 – Knowledge of Disease* show that more than half of our respondents would like to know what diseases they are at risk of being affected by (11 out of 21 respondents would like to know what diseases they are at risk of being affected by, 10 out of 21 did not). A slightly larger majority, 70 percent of the responding respondents, would like to know what diseases they are at risk of passing on (7 out of 10 respondents would like to know what diseases they are at risk of passing on, 3 out od 10 would not). 33 percent of our respondents would like to know, even if there were no cure or effective palliation (4 out of 12 respondents would like to know even if there is no effective cure or palliation, 8 out of 12 would not). No responses were generated by the question whether they would like to know if there was a *risk* of being affected by disease, and only two responses were received on whether they would like to know if there was a *certainty* of being affected – and those two responses were positive. When respondents were asked what they would do with information about what diseases they are at risk of being affected by or passing on, statements that they would worry and that they would adjust their lifestyle according to the doctor's orders were the most common (Table 1).

Themes	**Number of times stated**
worry	8
adjust my lifestyle	7
do all the things I have wanted to	2
let it inhibit life	2
avoid passing it on	2
plan my life	2
"clean up" after myself	1
consider information to relatives	1
let it affect my career	1
trust in my faith	1

Table 1. Different themes concerning what the respondents would do with information about what diseases they are at risk of being affected by or risk passing on (more than one alternative per informant is possible).

In response to both quantifiable statements in *LUF 232 – Knowledge of Disease*, most of our respondents chose the highest degree of assent: *I fully agree.* We received a total of 31 responses to the first statement which were: *I would like to know what diseases I am at risk of being affected by, irrespective of whether they are curable or not.* Seven respondents chose the lowest degree of assent, four respondents chose the second lowest degree of assent, another four respondents chose the second highest degree of assent and twelve respondents chose the highest. Moreover, four respondents stated that they did not care. To the statement *It is important to me to receive information on new medical research findings in general*, we received 32 responses. Two chose

the lowest degree of assent, four chose second lowest degree of assent, seven chose the second highest degree of assent and eleven the highest. In addition, seven stated that they did not care.

As have been stated in note 1, the main results of the nation wide opinion poll *Public Research – Genetic Diseases*, is being addressed under the thematic results in the article in relation to the qualitative results of *LUF 232 – Knowledge on Disease.*