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# DIPLOMARBEIT

Titel der Diplomarbeit

**The One is the Many:  
Co-producing Individuals and Collectives in Genetic Testing for  
Hereditary Breast and Ovarian Cancer**

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## 0. Preface

To me, this thesis is a journey. It is an expression of where I started and of where I want to go. It is an expression of interests I have held for a long time, of perspectives I gained and of skills I could develop. It links different parts of my life and allows me to combine them in a way of working that is stunning, exciting and that I appreciate a lot.

I could never have made this journey without being on board the VIRUSSS vessel. Hence, I want to first of all thank Ulrike Felt for bringing me on board this ship, for making me part of the “Challenges of Biomedicine” project and conducting this study with me. I would like to thank her for supporting me intellectually and practically, for sharing her skills and experiences with me and for giving me the time and place to learn and develop. Moreover, I would like to thank my dear colleague Maximilian Fochler, who still says that none of my thousand questions ever bugged him, for helping me through stormy parts of the journey and for the ongoing intellectual exchange. I would like to thank Peter Winkler for his kind support, as well as Annina Müller, Lisa Sigl, Astrid Mager, Bernhard Höcher and Alexandra Supper, who all offered invaluable emotional and intellectual support at different points in time. I would also like to thank all of my colleagues at VIRUSSS for their feedback to presentations of my work in its various stages, as well as the other participants in summer schools and seminars. I would also like to thank Dr. Teresa Wagner for cooperating with us in this study, as well as her collaborators for their kind support, especially Dr. Verena Winkler.

Furthermore, I would like to thank my parents. I would like to thank them for their interest in what I am doing in life and for their support in my change of course, out of the labs and towards the social sciences. I know that I can rely on them at any time as I can also rely on my dear friends Claudia, Lisa and Yvonne, who were there for me when I needed them. Last but not least I would like to thank Ronald, who is not with me at the moment, but who walked by my side for years and whom I will always hold dear.

As much as I hope that this thesis will be enjoyable and interesting to read, I do apologize for all errors and mistakes it may include.



## 1. Introduction

Breast cancer is the world's most frequent cancer in women. While this disease is perceived to affect femininity more than any other cancer and hence was tabooed for a long time, global patient movements have engaged in removing this stigma during the last decades<sup>1</sup> quite successfully. In the Austrian context, breast cancer has become a topic of public awareness rather late, mainly during the last years. Medical professionals organized several events to draw attention to the rising numbers of breast cancer as well as to the decreasing age of the affected female population and they tried to encourage women to attend mammary checks regularly. Their "Foundation for Breast Health" provides information on breast cancer on their webpage and has started to cooperate with companies to raise public awareness and money for research projects. The "pink ribbon", the symbol of solidarity with women affected by breast cancer, now decorates bathrobes, bottles of mineral water as well as a specific sort of bread called "Eve's Bread". It is advertised as especially healthy for women as it contains soy, which is supposed to lower the risk of breast cancer.

"Regular preventive check-ups and a well-balanced lifestyle are important factors to be able to actively prevent cancer," the leaflet attached to the bread says. This exemplifies that in the public debate, breast cancer is mainly framed as an illness related to lifestyle choices. That breast cancer can also develop due to genetic reasons is at the margins of the increasing public awareness. Only when the Ministry of Health announced that it would finally finance genetic testing for this special form of breast cancer, which was until then only sustained by research funds, this topic was widely present in the media. Just for one day though, but that was enough to cause a run towards counselling centres. Hundreds of concerned women called to find out whether their family history could hint at a genetic predisposition in their family.

In fact, five to ten percent of all breast cancer cases are caused by mutations in two distinct genes. The associated form of cancer is called Hereditary Breast and Ovarian Cancer (HBOC), as these mutations are also responsible for an elevated risk of ovarian cancer. They account for strong family histories of one or both of these forms of cancer. Since 1994 a genetic test exists that allows identifying these mutations. This test opened up

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<sup>1</sup> Klawiter 2000

entirely new ways of dealing with familial forms of breast cancer. Genetic testing offers to find out if breast and ovarian cancer is really “running in a family”, if the high incidence of cancer was caused randomly or if there is a detectable genetic risk some family members share. It makes it possible to identify these individuals that carry the mutation, and grants them access to intensified early diagnostics or preventive surgery. Hence, whereas genetic causes of breast cancer are only scarcely debated in the Austrian public, individuals already make use of this technology. The run on the counselling centres in connection with the briefly increased media presence of this topic suggests that the number of people undergoing genetic testing could rise during the next years.

Genetic testing, but also technology in general, is part of the social, participating in social interactions and transforming relations. Thus, emerging technologies do affect and rearrange the social structures they emerged from and are embedded in. Far from being just a medical tool, genetic testing is reorganizing its social contexts. Moreover, distinct imaginations about these contexts are already embedded into the technology itself. There are imaginations about the frameworks of its application, its users and the way they should handle the knowledge it produces.

This knowledge is of a special, yet uncommon kind. It provides information about the genetic status of an individual, about an “abnormality” he or she carries that is hereditary and that is related to high risk of cancer. How does obtaining this knowledge affect an individual, which kind of affectedness does it create? And thus, in what way are social contexts transformed, how are they rearranged around individuals that have engaged with this technology?

These will be the issues at the core of my thesis. I will argue that undergoing genetic testing and consequently obtaining risk information affects the individual in a very complex way, that is far from creating simple binary categories of affectedness like “at risk” or “not at-risk”. It rearranges social contexts in relation to the complex character of the knowledge produced, as it is not only knowledge about *one* individual but always also knowledge about other individuals, about more collective forms of affectedness.

My work will focus on these collective dimensions of affectedness that are created through genetic testing and on how they are articulated within the narratives of individuals who underwent genetic testing. Hence, drawing on accounts of affected women and men as well



as other contextual data, I will identify, describe and analyse three dominant forms of collectivization that are evoked by genetic testing.

To do so, I will start by providing the biomedical backgrounds of genetic testing, as well as its specific legal regulations in Austria. Moreover, this first chapter will describe the clinical procedures of genetic testing in the counselling centre the data of this study was obtained in.

The next chapter presents the conceptual and theoretical framings of this work. It is organized along three main perspectives. The first one frames genetic testing as part of broader societal transformations in the contexts of biomedical technologies referred to as the “biomedicalization of society”. It explores the multiple ways in which biomedical technologies are affecting societal structures as well as individual and collective identities. The second addresses the relation of biomedical knowledge and agency, the way individuals frame the genetic knowledge they obtain and how they connect it to distinct forms of agency. Finally, the third part reflects the discussion about the relation of individual and collective biomedical identities and introduces central perspectives this work draws on.

This is followed by a chapter on the way this thesis was done, outlining the research questions addressed in the empirical work and describing the methodological approach that was deployed to do so. Further I will reflect on the setting of the data collection as well as on our sample of interview partners.

The core chapter of this thesis will then present the empirical findings: It describes and analyses the different levels of collectivization through genetic testing and thus is structured along the three emerging forms of collectives identified. The first part explores the reconfiguration of familial structures through genetic testing. The second focuses on a collective that is formed by the specific interactions of professionals from diverse backgrounds and affected people in the clinical contexts of genetic testing. The third and last part of this chapter investigates imaginations about collectives that share specific ways of thinking and acting in relation to genetic risk.

Then, the final conclusions will focus on how genetic testing affects individuals in relation to the formation and transformation of collectives.

As the data this work is based on was produced in German language, this thesis includes an annex containing the original quotations.

## 2. Genetic Testing for Hereditary Breast and Ovarian Cancer (HBOC): Biomedical Backgrounds, Legal Regulations and Clinical Procedures

This chapter gives an overview of the biomedical backgrounds of genetic testing for HBOC and of the way it is legally framed in Austria. Furthermore, it describes the clinical practices of its application in the local setting of the counselling centre where our interview partner underwent genetic testing.

### 2. 1. Biomedical Backgrounds<sup>2</sup>

In the mid-nineties, mutations in the so-called “Breast Cancer Genes” BRCA1 and BRCA2 were found to cause a hereditary form of breast and ovarian cancer called Hereditary Breast and Ovarian Cancer (HBOC). Both mutations raise the lifetime risk of breast cancer to about 85%. Still they are slightly different in character.

BRCA1 mutations are likely to cause cancer at a very young age – more than 50% of all carrier women fall ill before the age of 50 (Fig. 1). The lifetime risk of ovarian cancer is about 65%. In addition, there is an enhanced risk of developing cancer in the second breast after one has already been affected once. Moreover, BRCA1 mutations increase the risk of colon cancer four times, and the risk of prostate cancer in men three times.

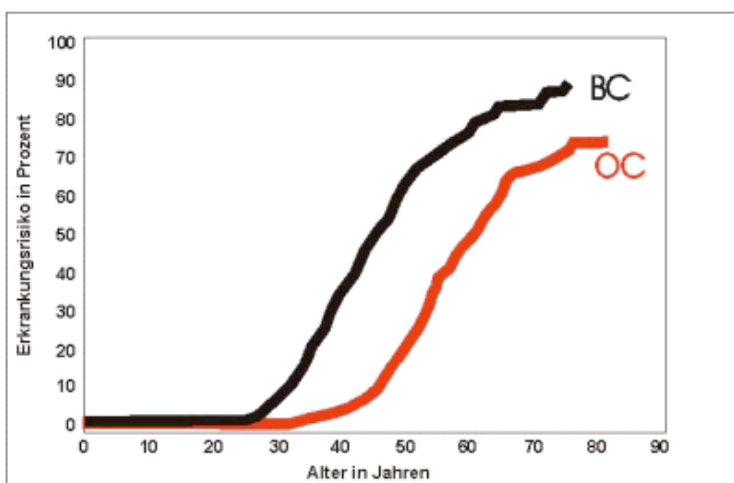


Fig. 1: Statistical risks of breast cancer (BC) and ovarian cancer (OC) due to BRCA1 mutations in women (y-axis/percent) in relation to age (x-axis/years) in Austria.<sup>3</sup>

<sup>2</sup> Wagner/Kubista 2003, Kubista/Wagner/Breiteneder 2004

<sup>3</sup> Wagner/Kubista 2003

BRCA2 mutations are slightly different. They do convey about the same risk of breast cancer (~85%), but the patients tend to be slightly older. The risk of ovarian cancer is about 27%. Furthermore, BRCA2 mutations can also cause male breast cancer, which is normally extremely rare (0,1% risk in the normal population). In male BRCA2 mutation carriers, this risk rises to 6%.

The expected frequencies of the mutations throughout the population are 1 in 500 for BRCA1 and 1 in 700 for BRCA2. This means that in Austria there would be about 27.000 individuals carrying either a BRCA1 or a BRCA2 mutation.

The young age of onset of breast cancer poses a specific danger to the carrier women among them, as statistically, breast checkups are mostly only performed at periodic intervals above the age of 50. Ovarian cancer has a later onset: there are no known cases due to genetic causes before the age of 40.

BRCA1 and BRCA2 mutations are passed on by autosomal dominant inheritance. Each offspring of a carrier individual has a fifty percent chance of inheriting two healthy genes, which would mean that he or she is at “normal risk”.<sup>4</sup> If one inherits a mutated gene, the risks rise to the numbers listed above.

## 2. 2. Legal Regulations<sup>5</sup>

Genetic testing for HBOC is not regulated specifically. Genetic testing for medical purposes in general is regulated by the “Gentechnikgesetz” (Austrian Gene Technology Law, GTG). This law does not only deal with pre-natal and post-natal human gene analysis and therapy, but also with the regulation of genetically modified organisms.<sup>6</sup>

Pre-natal and post-natal genetic tests are not distinguished legally, only pre-implantation-diagnostics is prohibited by the law regulating reproductive medicine.

Genetic Testing of humans for *medical purposes* is permitted by law only

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<sup>4</sup> For women, that means still a 10% risk of breast cancer during their life span, and numbers are still rising.

<sup>5</sup> This section is largely based on the State of the Art Report of the CoB-project (Felt et al. 2004).

<sup>6</sup> In Austria, green gene technology is not favoured by the public in general, so a lot of the legal regulations and institutional efforts centre around that issue rather than on medical purposes.

(1) on the instigation of a physician trained in human genetics or a medical specialist concerned with the respective area of indication to determine a person's *predisposition* for a disease or to identify a person's *carrier status* of an inherited disease, or,

(2) on the instigation of any physician to diagnose a *manifest disorder* or to prepare and *evaluate medical therapies* (§ 65, 1-2 GTG).

This means that so far, only human geneticists and medical specialists are allowed to carry out predictive genetic testing, while any other physician is allowed to carry out tests for manifest (genetic) diseases. Predictive genetic testing, i.e. testing to determine a genetic predisposition and/or carrier status, must be carried out by a licensed institution only. This license is granted by the Federal Ministry for Health, Family and Youth (Bundesministerium für Gesundheit, Familie und Jugend, BMGFJ), which is the regulatory institutional body in charge.

The dissemination of information about genetic risk is strictly regulated: No one must be informed about carrying a genetic risk, and neither insurance companies nor employers are allowed to obtain or to use genetic data of any kind (§ 67 GTG).

Obtaining informed consent before carrying out any genetic testing is obligatory, as well as “extensive counselling” before and after the test. Counselling has to provide a “factual, broad discussion of all testing outcomes and medical facts as well as the social and mental consequences thereof”. Genetic counselling has to be a “non-directive” process by law (§ 69 GTG).

As genetic counselling is regulated by law only very broadly, it is up to the institutions themselves to develop directives for the counselling practise. There have been some attempts to draft genetic counselling guidelines, but none of them resulted in general and binding guidelines.

In the case of genetic testing and counselling for HBOC in Austria, a Department for Gynaecology at a Vienna Hospital is the leading force in establishing genetic testing throughout Austria. They started testing in 1994, only shortly after the mutations were first found. One of their chief physicians is a main figure in raising public awareness for breast cancer in general and for HBOC in particular. Genetic counselling and testing is performed according to international guidelines, for example concerning the criteria that must be

fulfilled to be admitted to testing or the molecular-genetic methods in use. At the time the data underlying this thesis was collected, genetic testing was financed by research funds and not covered by public or private insurance or any other source of public money.

### **2. 3. Clinical Procedures**

In 26% of all families that show several cases of breast and/or ovarian cancer, these cases are due to BRCA mutations.<sup>7</sup> There are certain criteria to distinguish random incidence from a possible hereditary cause. Thus, in order to hint at a genetic predisposition, one of the following constellations must be found within either the maternal or the paternal branch of the family:

- 2 cases of breast cancer before the age of 50
- 3 cases of breast cancer before the age of 60
- 1 case of breast cancer before the age of 35
- 1 case of breast cancer before the age of 50 plus one case of ovarian cancer at any age
- 2 cases of ovarian cancer at any age
- Male and female breast cancer within the same branch of family

In Austria, genetic testing is only available to individuals who have a family history that fits one of these criteria.<sup>8</sup> Thus, before the first counselling session, individuals wanting to undergo genetic testing are asked to gather as much information as possible about their family structure and medical family history concerning cancer.

The first counselling session focuses first on providing biomedical information about HBOC and the procedures of genetic testing, and then, if the individual wants to proceed, on transforming this family data into a medical pedigree.

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<sup>7</sup> Wagner/Kubista 2003, Kubista/Wagner/Breiteneder 2004

<sup>8</sup> This is rather different to e.g. the US-American situation, where genetic testing for HBOC is provided on a commercial basis by Myriad Genetics to everyone who pays for it. See Parthasarathy 2005 and 2007 for details.

On the basis of this pedigree, epidemiological-genetic calculations conclude if there is an elevated risk of breast and/or ovarian cancer within this family and further if autosomal dominant inheritance is likely. If this is the case and the person decides in favour of the test, the bodily experience of undergoing testing is limited to giving a sample of blood. This can be done directly after the counselling session, but also at another time.

Then a molecular genetic analysis of the genetic sequence of the BRCA genes is performed in order to identify a possible mutation. Though there are several preliminary tests e.g. protein truncation analysis, the final result is always obtained by genetic sequencing.

Sequencing takes quite a while, at least in the Austrian case, where there is lack of lab technicians, machinery and first of all public funds. It takes either up to one year per gene, if a mutation has to be identified *de novo* and thus both BRCA genes have to be sequenced full-length, or up to six months, if the mutation has already been identified in another family member and thus sequencing can be limited to a distinct part of one gene.

In case of a *de novo* analysis, sequencing starts with the BRCA1 gene. After this first result is ready, individuals receive a letter to make an appointment at the centre. Both a positive and a negative test result are only communicated personally. In case the result was negative, analysis of the BRCA2 gene starts and after yet again up to another year, a definite test result is available.

If a mutation is found, which is referred to as a positive result, the analysis is done a second time to avoid false positives. In order to link a distinct mutation causally to an elevated risk of breast and/or ovarian cancer, it must either be already approved to cause HBOC by the international research community,<sup>9</sup> or it must also be found within the genome of at least one family member that is or was affected by breast or ovarian cancer.

A negative test result is only readable in connection to the genetic status of the family: If no mutation has been identified in any affected member of the family, this means that the uncommonly high incidence of breast and/or ovarian cancer is apparently *not* due to a BRCA mutation. Mostly, these women are also invited to undergo early diagnostic screenings, as it can't be ruled out that they are at high risk, due to other, yet unknown hereditary factors. Thus, a negative test result only rules out an elevated genetic risk if at

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<sup>9</sup> There are some mutations that are internationally known, as for example the Ashkenazi mutation that is found within Jewish populations (Kubista/Wagner/Breiteneder 2004).

least one other family member, who is or was affected by breast or ovarian cancer, is confirmed to carry a BRCA mutation.

To women who are found to carry a mutation that can be linked to HBOC, advanced early diagnostic screening is offered. This consists of a combination of several methods including:

- Palpation and ultra sound scanning of the breast twice a year starting at the age of 18
- Nuclear Magnetic Resonance (NMR) scans and mammography once a year starting at the age of 25
- Vaginal ultra sound and CA125 tumour marker blood count twice a year to scan for ovarian cancer starting at the age of 35
- Hemocult once a year to scan for colon cancer starting at the age of 35

The sensitivity of detecting an abnormality of the breast tissue is about 95% using this combination of methods. The certainty to which vaginal ultra sound and CA125 levels help to detect ovarian cancer early on is still unclear, but there are no better methods available yet.

Furthermore, there is the option of prophylactic surgical removal of ovaries (ovariectomy) and breasts (mastectomy). Ovariectomy is rather undisputed among high-risk women and medical professionals. It reduces the risk of ovarian cancer to nearly zero, and additionally reduces the risk of breast cancer by 50% due to the decrease in hormones. As there are no known cases of ovarian cancer before the age of 40, most women that undergo ovariectomy do so after they have completed their family plannings. However, ovariectomy causes rapid decrease of female hormones in pre-menopausal women. This halves the risk of breast cancer, but may be a very unpleasant experience, both physically and psychologically. For women who had not been ill with breast cancer before, this decrease may be counteracted by a special hormone treatment without further elevating the risk of breast cancer.

Mastectomy is not that undisputed. After long standing debates in the medical field, its efficiency in reducing the risk of breast cancer by 90% is largely accepted, but the debates about its psychological effects are still ongoing. Despite the possibility of plastic

reconstruction, it is frequently perceived as a quite radical procedure, drastically affecting femininity. However, an increasing number of physicians tend to consider mastectomy a relevant option for high-risk women.

Most women in Austria choose early diagnostics, 34% choose ovariectomy, mostly after they have completed their family planning and 11% choose mastectomy,<sup>10</sup> mostly followed by plastic reconstruction.

Although BRCA2 mutations increase the risk of male breast cancer to 6%, any kind of early detection or preventive action is normally only advised to women. However, if there are cases of male breast cancer within a family, ultra sound screens of the breast are offered to men as well.<sup>11</sup>

To cope with the implications of genetic testing, the counselling centre offers psychological support to affected women and men during the counselling process, but also at any later point in time. Furthermore, the counselling centre organizes periodical information evenings for all members of families at genetic risk. These events provide information on specific difficulties, e.g. on how to talk to children about genetic risk and serve as an opportunity to pose questions to the medical professionals and psychologists. Moreover, the professionals use these events to get a closer look at the problems that arise in relation to genetic testing in the contexts of everyday life.

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<sup>10</sup> Compared to e.g. 50% in the Netherlands (Wagner/Kubista 2003).

<sup>11</sup> As it was the case for the two male interview partners in our sample



### **3. Conceptual and Theoretical Framings**

This chapter provides a conceptual and theoretical framework to the practice of genetic testing for HBOC, as well as to my empirical work. It moves from relating genetic testing to broader biomedicine-based transformations of society, over discussing the relation of biomedical knowledge and agency, to providing perspectives on the formation of collectives by this practice. Thus, this chapter situates my work within a network of perspectives and theoretical claims and thereby, it also provides a clue to the ideas that informed me while writing this thesis.

It is divided into three parts: The first part (3.1.) places genetic testing within a broader context of biomedical transformations referred to as biomedicalization. It explores the changing structures of biomedicine as well as its implications for the formation of individual and collective identities. Thus, it introduces the idea that in the context of biomedical technologies, identities are transformed on an individual but also on a collective level.

As these individual and collective identities are formed in relation to new forms of biomedical knowledge and agency, the second part of this chapter (3.2.) focuses on research that offers a framework to the way individuals relate to biomedical knowledge and to the role attributed to knowledge-based forms of agency within this process.

Finally, the third part (3.3.) introduces a number of theoretical perspectives on the processes and characteristics of the formation of biomedicine-based collectives as well as on the relation of individuals and collectives, perspectives which I will further explicitly use to frame my empirical findings.

### 3. 1. Biomedicalization and the Formation of Identities

Genetic testing for HBOC is part of broader changes that currently take place in medical practices. These changes are caused by the emergence of new technologies that find their application in medical settings and that affect individuals in society on multiple levels. The concept of **biomedicalization** tries to grasp those recent transformations in society associated with the innovation of biomedical technologies and their application. Within the frameworks of biomedicalization, the question how new biomedical technologies like genetic testing relate to the formation of individual and collective identities is a main focus of attention.

Biomedicalization grounds on societal transformations that have been referred to as the **medicalization** of society. Over the last centuries, (allopathic) medicine has become of growing importance to western and westernized societies. Since the 1970s, this phenomenon has been researched under the term medicalization in the literature of social sciences.<sup>12</sup> Medicalization means that throughout society, a variety of phenomena that have formerly not been described in medical terms, are increasingly defined and treated as medical problems. Medicine hereby gains jurisdiction and supervision over more and more aspects of everyday life. This process of expansion is accompanied – historically as well as in the present – by a growing professionalization and specialization of medicine, and furthermore by the creation of appending social forms and institutions like hospitals, clinics and specialized medical practices and professions.

The socio-cultural processes of medicalization may further lead to the establishment of medical social control, mostly characterized through surveillance of parts of the population as well as the population as a whole. This does not only include individuals designated as ill, but with the emergence of **surveillance medicine**,<sup>13</sup> even individuals who could be perceived as healthy have become defined as potentially ill. Since everyone is conceptualized as carrying distinct risks and risk factors within the body that have to be surveyed in order to prevent illness, everyone is target of surveillance medicine. Hence, the borders between illness and health get blurred.

One area that exemplifies these basic ideas of surveillance medicine very well is genetic testing. Research aiming at identifying genetic mutations that are thought to cause certain

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<sup>12</sup> E.g. Zola 1972, Conrad 1976; See Conrad 1992 for a review of medicalization literature

<sup>13</sup> Armstrong 2002

diseases has been heavily fostered through the last decades, and an increasing amount of genetic tests similar to those available for HBOC is already part of the clinical practice. This growing importance of genetic concepts and explanations in medicine is suspected to lead to a special kind of medicalization, namely the **geneticization**<sup>14</sup> of society. This term has been used more often within contexts of perspectives critical towards geneticization than it has been used to merely describe that something has become a matter of genetic medicine. A number of fears and worries are connected to the vision of a geneticized society and a rather unsettling picture of present and future developments is drawn: Through the emergence of genetic medicine, health and illness are increasingly perceived as being pre-encoded within an individual's DNA. Thus, genes become the main focus of medical reasoning and intervention. Other ways of framing and treating medical conditions are less emphasized and researched, e.g. the complexity of interactions between genes, environment and psychosocial conditions. Genetic technologies that aim at repairing "defective" genes are thus even more fostered. Such a circular reasoning is perceived as dangerous, not only because it is thought to subject individuals to genetic definitions and interventions, but because it is thought to lead to genetic discrimination of those who carry "defective" genes and thus to an increasing pressure to use genetic technologies to "repair" one's genetic "defects".

Though this is only a sketch, and the theoretical framework of geneticization is indeed more complex, it focuses on a rather simplified version of the individual that encounters genetic medicine. There is little space given to individual contexts and individual forms of agency, contesting and negotiating the implications of genetic medicine. Furthermore, less attention is given to the relation of the individual and the collectives he or she is part of. On the contrary, the individual is believed to become even more individualized through genetic medicine, which is indeed promoted as a very personalized form of medical care. Thus, the formation and transformation of collectives through genetic medicine and the multiple impacts this might have are given less attention.

The concept of **biomedicalization** in contrast tries to engage with the complex and contextual character of the transformations that take place in the contexts of the application of novel biomedical techniques like genetic medicine on individual and collective levels.

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<sup>14</sup> Lippman 1991/1992/1994

Biomedicalization is thus to be understood as both an **expansion and a transformation of medicalization**. “Biomedical” hints at the increasing infusion of medical clinical practice with bioscientific knowledge, approaches and techniques that originate from fields like molecular biology, genetics or proteomics. If medicalization was primarily the expansion of medical authority over “*aspects of life previously outside the jurisdiction of medicine*”<sup>15</sup> but being regulated otherwise, biomedicalization expands the authority of biomedicine even to realms of life that were not prone to any regulation before. For example, if alcoholism was deemed a merely social problem before, medicalization transformed alcoholism into an issue involving medical jurisdiction. Alcoholism became not only a matter of social misbehaviour, but also an illness that people suffered from, could be prone to and that could be treated medically. It came to be defined as an illness, which in turn has far reaching social impacts, e.g. in employee protection laws, which protect people who are ill from being dismissed. On the other hand, ill people can also be pressured to undergo treatment.

Alcoholism and similar social phenomena thus became subjected to medical social control. Though within biomedicalization control is still on the agenda, the crucial feature of biomedicalization is that certain **phenomena** do not only fall under the control of biomedicine but **are constructed and transformed** by it. Hence certain phenomena, like being at genetic risk, become not only subject to biomedical surveillance but are brought into being by means of biomedical techniques and technologies.

Consequently, appending social groups, like the individuals at genetic risk, emerge only through the fact that biomedical technologies nowadays allow to construct and subsequently identify them as such. As Clarke et al. phrase it:

*Biomedicalization is our term for increasingly complex, multisited, multidirectional processes of medicalization that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine.*<sup>16</sup>

Thus, a central feature of biomedicalization is its ability to both transform and create **new groups of individual and collective identities**. These identities are clearly linked to the

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<sup>15</sup> Clarke et al. 2003 p161

<sup>16</sup> Clarke et al. 2003 p162

respective biomedical techniques that (re)produce them. Their social contexts are shaped by the biotechnical and biomedical environments of their generation and they are negotiated between the multiple actors involved in their creation and distribution.

Emerging identities themselves in turn trigger the development of new biomedical practices. Hence, it is a *“fundamental premise of biomedicalization that increasingly important sciences and technologies and new social forms are co-produced within biomedicine and its related domains”*.<sup>17</sup> Identities form in close relation to new forms of technologies and knowledge and vice versa, co-producing one another.

Basically, biomedicalization is characterized by a **transformation of organisational structures** of biomedicine itself. Information technologies and new forms of interdisciplinary teamwork reformulate what constitutes biomedicine as both a knowledge producing domain and an area of clinical practice. These technologies are not determining but rather *“facilitating existing processes of transformation”*.<sup>18</sup> These transformations are referred to as the technoscientization of biomedicine and include *“major shifts in the social organization of biomedicine itself, the objects of biomedical knowledge production, the ways in which biomedicine intervenes and the objectives with which it does so”*.<sup>19</sup>

This technoscientization is characterized by increased computerization and data banking, molecularization and geneticization as well as technological hybridizations in medicine. It is producing hybrid innovations that are *“generated simultaneously through science and technologies and new social forms”*.<sup>20</sup> Thus, new forms of technologies, biotechnical services and practices are generated as a result of the fusion and interaction of different technologies and multiple disciplinary approaches. Genetic testing itself is representative for such new biomedical practices. It is not only based on the most recent technoscientific findings and innovations, but moreover it demands a complex interplay of advancing technologies from different scientific fields as well as interdisciplinary teams that consist of medical technicians, doctors, psychologists and many more. The sociotechnical practices of its application are indeed only possible as a result of the interaction of a multitude of disciplinary approaches and different technologies.

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<sup>17</sup> Clarke et al. 2003 p163

<sup>18</sup> Nettleton 2004 p676

<sup>19</sup> Clarke et al. 2003 p173

<sup>20</sup> Clarke et al. 2003 p173

But biomedicalization is not only affecting the organisational structures of the medical field. Rather it can be referred to as what Jewson termed a **medical cosmology** and as such, it must be considered as a sociotechnical network of “*conceptual structures, which constitute the frame of reference within which all questions are posed and all answers are offered*”.<sup>21</sup> Different areas of biomedicalization overlap to produce a phenomenon outspread through society, stabilizing itself and destabilizing other medical cosmologies as well as co-opting some of them.<sup>22</sup> It may be viewed as taking place at least throughout the westernized world, impacting also on those that are not exactly able to benefit from it.<sup>23</sup>

But biomedical transformations are also negotiated, contested and enforced in the respective national, local and individual contexts. Thus, biomedicalization is both, **local and global, individual and collective**. Major politico-economic shifts, such as the commodification and corporatization of health, and the centralization, rationalization and devolution of services, occur on a global level within the governing bodies of multinational pharmaceutical companies as well as on a very local level in the bodies of individuals enrolled within changing medical settings. Political systems and cultures are major actors within these transformations, framing the local interpretations of biomedical developments. Biomedicalization is mostly described from a US-American point of view, taking into account the specific economic landscape, the insurance sector being one part of it, and its legal regulations and non-regulations. Hence, some aspects of biomedicalization are more elaborated than others in literature and must be revised in its weight for other national contexts. Legal contexts and medico-economic linkages and the transformations occurring in this area of biomedicalization are major actors in influencing the specifics of other transformations.<sup>24</sup>

Biomedicalization is also producing **new forms of stratification** in society and reorganizing existing ones. Its organisational structures and practices are stratified, being both more inclusive and more exclusive simultaneously. Thus, access to biomedical health care is unevenly dispensed throughout society. While some are under pressure to participate in new biomedical communities, others may have to fight their way in. We may thus witness discriminatory practices that already existed in medical health care enforced,

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<sup>21</sup> Jewson 1976 p225

<sup>22</sup> As it is the case for some forms of alternative medicine

<sup>23</sup> Both within westernized countries as well as in other parts of the world

<sup>24</sup> See for example Parthasarathy 2007 for a comparison of the US and UK BRCA testing systems

but also contested or overcome. Race, class and gender are still crucial categories of stratification, but their status within biomedical structures is negotiated as well as cross-linked with novel categories of biomedical and technoscientific thinking. The sheer meaning of these categories, the idea of their essential nature is reformulated. Is the Afro-American citizen, who is defined as having some innate genetic risk due to her or his race, still the same one that was defined through her or his social and cultural background? What about insurance companies that deliver their pre-designed packages to these new born user groups that, independently of their social and economic status, share some common biomedical grounds? And what about women throughout the westernized world who are instructed to watch their risky breasts closely, learning that certain risks and their proper management have become central features of responsible womanhood? New modes of health care and developments in health related economic sectors interlink with existing and emerging subjectivities, restructuring inclusions and exclusions, thus reformulating the stratifications of medicalization in terms of biomedicalized meanings.

Within biomedicalization, the emphasis on **health and surveillance** that could be already witnessed within medicalization is refocused. As health has become another commodity, it has become something that has to be achieved. Still, health is only temporary in character, it is constantly under threat and needs a lot of effort to be maintained. Hence, health and illness are no longer matters of fate but of personal as well as public efforts and investments. Health becomes “*an individual goal, a social and moral responsibility and a site for routine biomedical intervention*”.<sup>25</sup> On the one hand, responsibility is outsourced to the individual e. g. through an increasing focus on self-surveillance, but the biomedical self is on the other hand highly regulated through a dense network of moral obligations constructed by the increasing emphasis on surveillance in society. Individual bodies become matters of collective health, commonly interlinked through medico-economic lines of argumentation, such as limited financial resources for health care. Improving one’s health does not remain optional but becomes a moral responsibility of the biomedicalized individual. Thus, ignoring surveillance as a prime parameter of health care as an individual is considered irresponsible towards society.

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<sup>25</sup> Clarke et al. 2003 p171

Discourses on surveillance are closely linked to risk considerations. **Risk and surveillance** mutually enrol and refine each other. Assessing risk is the basis of surveillance that itself produces refined data on risk. Together they “*shape both the technologies and discourses of biomedicalization as well as the spaces within which biomedicalization processes occur*”.<sup>26</sup> They structure medical check ups and laboratory routines, as well as health sections in newspapers and the way people look at their skin during morning showers to make sure there is nothing wrong with their moles.

In order to make sure to identify the abnormal, methods of **standardization** provide practices interlinking risk and surveillance. Standardization has become a driving force in medicine<sup>27</sup> and obtains a specific role within risk and surveillance interactions. Risk and surveillance define and refine one another and thereby give rise to standardized parameters of risk, standardized practices of surveillance and standardized groups of people entitled to make use of these parameters and practices. Defining a category of “high risk women”<sup>28</sup> concerning breast cancer is a controversial and ongoing process, establishing short-term reliability within a changing landscape of clinical trials and research agendas. Though standardization implies being able to define both fixed and general parameters of assessment, it has become a short-term endeavour within biomedicalization to be read as the state of the art agreement on risk assessment within a heterogeneous community of actors involved.

Standardization allows a seemingly robust distinguishing of the “normal” from the “abnormal”, and thus to survey and to control individuals and their bodies. But bodies are no longer objects of mere control, they are also perceived as being transformable in order to gain desired properties or to lose unwanted ones. This concept of the **transformability of bodies** is at the core of biomedicalization, this idea that bodies can be altered to be healthier or to cater other individual needs, wishes and expectations.

But biomedicalization does not only change concepts of desirable bodies, it also transforms the ubiquitous artefacts and practices of everyday life. It changes the parameters of what it means to eat, to work, to sleep and not to work out. It changes what it means to be healthy, to be sick, to grow old and to procreate. It changes what it means to be a member of a

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<sup>26</sup> Clarke et al. 2003 p172

<sup>27</sup> Timmermans/Berg 2003

<sup>28</sup> Fosket 2004



certain family and not of another. Pervasively webbed throughout politico-economic networks as well as throughout mass culture, biomedicalization presents itself as a “**culture per se**”, embodied in the perfect corporealities of the few (as seen on TV!). Thus, through transformations that take place on multiple levels of society, daily practices and relationships are incorporated into a dense network of biomedicalized meanings.

The type of **governance** that is hereby created could be described as one that works **from the inside out**. It suggests that individuals should complement lifestyle and behavioural changes with biomedical interventions in order to deal with their bodily imperfections. Furthermore, it encourages them to inscribe into new biomedical identities in order to participate properly in a biomedicalized society. Thus, biomedicalization is not bound to certain places or technologies, it implies transformation of self-hood, of individual identity as well as of the collectives we are – implicitly or explicitly – part of. Different values, expectations and strategies are attached to these identities, and not all of them are equally powerful and accepted.

Biomedicalization clearly defines specific **identities as particularly favourable** because they comply better with new biomedical structures and practices. Such favoured identities are technoscience-based, meaning that they are constructed through categories and means of technoscience, through its conceptual and material application onto individual and collective bodies. They can become of high value to the individual, as they may represent entry tickets to specific biomedical practices. Being e.g. a carrier of a BRCA mutation may be a more desirable identity than being branded by some unspecific family history of high incidence of breast cancer, because it grants legitimate access to advanced prevention.

Thus, at the core of such biomedical identities lies a specific problem/solution package. By offering such “**standardized packages**”<sup>29</sup> of theory and methods, biomedicalization defines on the one hand a clear set of “doable problems”, such as being at genetic risk for HBOC, which is met by a standardized set of technologies that allow to define and to treat – at least so some extent – these problems. As theory and methods co-define and co-restrict each other, they also “*narrow the range of possible actions and practices*”<sup>30</sup> of individuals. By constructing specific biomedical identities around such standardized problem/solution packages, the range of legitimate agency of individuals, who are ascribed

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<sup>29</sup> Fujimura 1992

<sup>30</sup> Fujimura 1992 p176

such an identity, is focussed on those predefined within the standardized packages. Thus, large-scale technoscientific thinking is incorporated both into the definition of biomedicalized identities and into appending forms of agency.

However, taking over such identities and agreeing on appending forms of agency does not have to imply a pervasive transformation of identity, it may also be **strategic in character**. Identities may be taken on in areas where they allow the individual to gain access to desired features of biomedicalization, but the same identity may be refused or reinterpreted in others realms of life.

Thus, biomedical identities are co-produced by new biotechnological practices and the emerging individuals themselves. Individuals are not just passively affected by biomedicalization but they are agents within it, who negotiate, contest or enforce the meanings of biomedicalization. Hence, how individuals relate to the structures and practices of technoscience and biomedicine frames the way they co-produce these identities. They do so within their own specific contexts and out of the collectives they are part of. In turn, it is not only the isolated individual that is affected by biomedical practices like genetic testing, but also its appending collectives. To analyse the relations of individuals in their collective contexts to technoscience and biomedicine is crucial to an understanding of the reconfiguration of individual and collective identities.

### 3. 2. Biomedical Knowledge: A Capacity to Act?

Biomedical technologies like genetic testing produce new forms of knowledge, in our case knowledge about a distinct genetic risk within a family. Thus it seems relevant to reflect on how individuals relate to that sort of knowledge, how they frame it and how they make sense of it in the contexts of their lives.

On a broader societal level, knowledge in general is framed as becoming increasingly important. In 2000, the European Union has declared that its future is envisioned in becoming a knowledge-based or in short, a **knowledge society**. As knowledge is perceived to constitute a productive force equivalent to work or capital,<sup>31</sup> an emphasis on the production and integration of knowledge within multiple areas of society is supposed to boost the economy as well as secure social welfare and cultural striving.

Thus, on an individual level, the demand to deal with an increasing amount of information is rising. As obtaining scientific knowledge is framed to convey a **capacity to act**<sup>32</sup> in private as well as public concerns, access to scientific information is increasingly supposed to serve as basis for rational decision-making and appending forms of agency in multiplying areas of society, such as medicine.

The concept of the **informed patient** exemplifies this idea of information-based decision making.<sup>33</sup> It is based on the assumption that providing neutral and comprehensive information constitutes the adequate basis for rational decision-making. The patient is imagined to decide mainly on the basis of this provided information if he or she wants to consent to a medical procedure, other contexts and knowledge forms being framed as marginal. Thus, informed consent is assumed to secure patient autonomy by granting access to scientific information.

Criticism of this procedure mainly focuses on the question whether the patient is able to sufficiently understand the provided information to base a decision upon. However, less attention is given to the question of how individuals relate to and make sense of the scientific information they encounter.

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<sup>31</sup> Stehr 1994

<sup>32</sup> Stehr 2005

<sup>33</sup> Berg et al. 2001

This focus on whether or not lay people understand science sufficiently well implies a conceptualization of science-society relations that is referred to as the “deficit model”.<sup>34</sup> Within this model, lay people are assumed to relate to science largely only along the gap of understanding or not understanding science. Thus, the quality of science-society relations is mainly framed as depending on whether the public is capable of grasping scientific knowledge or not. “Understanding science” is implicitly assumed to result in supporting science, whereas not or “misunderstanding science” is thought to cause mistrust and rejection.

This model is heavily opposed by the **critical “public understanding of science”**. A multitude of studies have shown that individuals relate to scientific knowledge in a much more complex way than a mere factual understanding or not understanding. Indeed, a higher level of knowledge among patients was observed to lead to less rather than more trust in the scientific information. Patients that acquired a significant amount of scientific knowledge about their disease were found to show an increased awareness that this information is not at all uncontroversial, as it becomes visible that it is not universal but often temporary and contested.<sup>35</sup>

Hence, in situations where individuals feel that they are dependent on a specific kind of knowledge or on the expertise of those that hold this knowledge, not trying to understand science can also be understood as a way to maintain trust in this particular scientific information, actor or institution.<sup>36</sup> Thus, **“ignoring science”** can’t be interpreted as a mere lack of intellectual capacities, but it can also be the result of an intuitive understanding of the social hierarchies and dependences one is embedded in.

Moreover, ignoring scientific knowledge may as well hint at the role an individual attributes to science within the contexts of his or her life, e.g. that scientific knowledge is simply not perceived to be of central relevance for one’s life and thus, individuals do not want to familiarize themselves with this knowledge.<sup>37</sup>

Still, even lay people that are familiar with a specific area of science that touches their lives are often found to refer to themselves as ignorant to “science-in-general”. Drawing on a number of in-depth interviews, Michael showed that people differentiate quite clearly

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<sup>34</sup> E.g. Irwin/Wynne 1996, Wynne 1995

<sup>35</sup> Lambert/Rose 1996

<sup>36</sup> Michael 1996

<sup>37</sup> Michael 1996

between “science in particular”, a scientific domain they know quite well, and what they believe to be “science in general”.<sup>38</sup> Thus, people hold distinct imaginations about what science is. They are often framed by what it is not, for example that science is not any knowledge lay people can hold.<sup>39</sup> Thereby they perceive science as self-defining and exclusive and hence as excluding the lay.<sup>40</sup> This shows that lay people do not only relate to factual contents but also to how they experience the **institutional and interpersonal settings** this knowledge is embedded in. This implies that, in addition to broader perceptions and imaginations about the character of science, also prior experiences with scientists or scientific authorities influence the way lay people frame scientific knowledge, e.g. whether they perceive scientific actors and hence the knowledge they provide as trustworthy or not.

Particularly, the way scientists react to a **specific expertise lay people hold** affects their relation to science, as Brian Wynne showed in an in-depth study of the relation of scientists and sheep farmers in the Cumbrian Hills.<sup>41</sup> After the Chernobyl accident, this area of Northern England had been heavily affected by fall-out. As the sheep had been contaminated as well, the farmers could neither sell nor move them. Against first scientific estimates, this contamination did not decrease after six weeks. Thus, scientists started experimenting on the sheep to find out why the levels of radioactivity within their bodies didn’t drop. The hill farmers, a very traditional community that has been living on sheep for generations, have developed very distinct knowledge about their sheep and the country they farm. But when the scientists started to conduct their experiments, they ignored this local expertise. They fenced the sheep although the farmers told them they would panic because they were not used to being confined. Indeed, the sheep did panic and the elevated metabolic rates rendered the test results useless. This was not a singular case where experiments failed because scientists had not listened to the hill farmers. Although the hill farmers held valuable, experienced-based knowledge that was well appreciated within their own community and that would have aided the scientists to reach their common goal of decontaminating the sheep, the scientists did not acknowledge but ignore their expertise. This resulted in an increasing mistrust towards the scientists and thus in a rather

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<sup>38</sup> Michael 1992

<sup>39</sup> Lambert/Rose 1996

<sup>40</sup> Michael 1992

<sup>41</sup> Wynne 1992

ambivalent relation towards them: On the one hand, the farmers depended on their expertise on radiation, on the other hand they perceived them as “educated idiots” that could not handle any practical problems the sheep and the country posed.

The scientists’ ignorance (as well as arrogance) contributed to an experience-based mistrust towards science, scientists and scientific institutions, which had already started to develop earlier in connection to a number of incidents in the local nuclear power plant. The farmers thought that the real extent of the radioactive contamination due to these incidents had been covered up, including the (in)famous Sellafield-Windscale fire in 1957. They doubted that the contamination of their sheep was solely caused by the Chernobyl accident, rather they believed that it had long been present due to the incidents in the power plant. However, the hill farmers did not voice these concerns openly, as many of their kinship and friends depended on the work the power plant provided. Hence, they also integrated the **collective interests** of the communities they are part of into their relation to scientific actors.

Hence, multiple factors influenced the relation of hill farmers and scientists: the way the scientists personally behaved, how they ignored the farmers’ collective knowledge; the prior experiences these farmers had made with science and scientific actors; the interests of the broader communities they were part of. This illustrates in what complex ways lay people relate to science. They do not simply understand or not understand science but they actively relate to knowledge out of the individual and collective contexts of their everyday lives. Thus, critical public understanding of science argues for a much more contextual approach towards the way lay people give meaning to science within their own worlds of relevance and in relation to their own forms of knowledge.

Hence, despite its scientific character, knowledge that does not reflect and match these forms of knowledge may as well be contested. Busby, Williams and Rogers<sup>42</sup> found that patients suffering from rheumatic conditions did not accept the scientific explanation of “wear and tear” that implied that the aberrations of their joints were simply caused by normal aging. They clearly related the intensity of the pain they felt to distinct bodily experiences at that point in time, such as especially hard manual work. They found the explanation given to them by the doctors very unsatisfying, as it did not reflect their own

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<sup>42</sup> Busby/Williams/Rogers 1997

experiential knowledge of their disease. Hence, as with the sheep farmers, if the doctors ignored this lay expertise on their bodily conditions, this clearly burdened their relation. Yet, genetic risk is a distinct kind of knowledge conveyed in medical settings. As it can't be related to any bodily sensations unless the disease becomes manifest, knowing about one's genetic risk is a disembodied form of knowledge. Lambert and Rose<sup>43</sup> engaged in an in-depth analysis of how people relate to such **“disembodied knowledge”**. Familial Hyperlipidaemia is a severe but asymptomatic condition characterized by high blood fats that have to be monitored in order to avoid increased risk of heart attack. The treatment consists of regular blood checks as well as dietary prescriptions and medications. Although the individuals perceive themselves as being dependent on the medical professionals to translate the results of the blood checks for them, they do not passively relate to their condition in general. They create informal networks of exchange, e.g. among affected family members, and decide actively which knowledge they want to obtain and accept.

*We found that most people actively apply their own general knowledge, clinical observations, and knowledge of personal and familial medical histories to make sense of new medical information, and try to utilise it effectively and appropriately in the risk reduction strategies that constitute management of this “disembodied” disorder.<sup>44</sup>*

Hence, Lambert and Rose found that **individuals actively select what constitutes significant knowledge for them**. Knowledge they perceived as relevant and thus as worth acquiring is such that allows them to reach their main aim of reducing their health risk in the contexts of their everyday lives. Furthermore, in selecting the knowledge they would obtain, they balanced their wish to engage in risk reduction, e.g. by dietary restrictions, with their wish to lead a “normal” and enjoyable life.

**Thus, individuals in biomedical contexts make sense of knowledge they encounter by assessing whether it improves their capacity to act.** This is not related to a mere process of understanding or not understanding science, but it is an active way of selecting and deciding which knowledge offers them the possibility to improve their situation within the contexts of their everyday lives.

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<sup>43</sup> Lambert/Rose 1996

<sup>44</sup> Lambert/Rose 1996 p69

### 3. 3. Biomedical Identities: From Individual to Collective

*Critics also tend to suggest that the new medical genetics leads to a focus upon the individual as an isolate. We disagree. Within such practices, individuals are subjectified through their location in a matrix of networks.*<sup>45</sup>

This quotation of Novas and Rose nicely illustrates what this chapter is about: Genetic medicine produces a new form of identity, the individual at genetic risk.<sup>46</sup> This individual is subjectified through its location in collectives that are as well created in the process of genetic testing. Thus, new identities and distinct collectives are co-produced in the process of genetic testing.

These collectives form mainly on three levels: family relations (I), biomedical contexts (II) and on a broader societal level (III). They are the focus of the empirical chapter and thus, in the following I will introduce contextual and theoretical framings important to my analysis.

#### (I) Family Relations

Genetic information on *one* individual is always simultaneously information about her or his genetic kinship. Thus, Pascale Bourret argues that in genetic testing there is no individual patient anymore, but an *extended* or *family patient*. This family patient is defined

*by the articulation of clinical data (the disease), biological data (the gene and the mutation) and social data (family links and degrees of relationship).*<sup>47</sup>

Thus, the patient in genetic testing is defined in relation to other human and non-human actors. He or she is perceived to be a representative of a family that is defined by genetic

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<sup>45</sup> Novas/Rose 2000 p490

<sup>46</sup> Novas/Rose 2000

<sup>47</sup> Bourret 2005 p48



kinship and a common genetic mutation. This mutation is linked up “*to an actual network of family bodies*”<sup>48</sup> and a new risk-based, genetic version of family is created.

Constructing a medical pedigree is a central practice in establishing that new version of family. It combines different sorts of data, like oral family history, medical records or test results and translates them into a formalized representation of a family that is connected through genetic risk.

It translates the individuals that are part of this family literally into the icons it is made of. In other words, it turns them into “*elements of a collective, familial, and thus biosocial body*”<sup>49</sup> and thus into “*objects of medical intervention*”.<sup>50</sup>

Data not deemed relevant is lost during this step of translation, it does not appear in the pedigree. In addition, information that is not accessible or known to the patient is also not present in the pedigree, incorporating yet another social dimension into what is presented as a mere depiction of a biological family.

A pedigree does not simply represent only selected aspects of reality but it also constructs a reality of its own – a family that is at genetic risk. Familial connections between past, present and future family members are defined by kinship and a common genetic risk. Thus, in the process of drawing a pedigree, family bonds are reworked and family history is rewritten, hence *revealing* a family at genetic risk.<sup>51</sup>

Individuals that are part of such a family appear to construct themselves not “*as individuals per se, but as selves-in-relation, as interconnected to past, present and future generations*”.<sup>52</sup> Out of these relations, new forms of responsibilities are created within such families.

Novas and Rose argue that these responsibilities are the “*burden of mutual obligations and caring commitments*”<sup>53</sup> individuals at genetic risk have to carry, as they have to make decisions and take actions that do not only affect themselves but also their present and future kin.

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<sup>48</sup> Bourret 2005 p53

<sup>49</sup> Nukaga/Cambrosio 1997 p29

<sup>50</sup> Nukaga/Cambrosio 1997 p33

<sup>51</sup> Armstrong/Michie/Marteau 1998

<sup>52</sup> Hallowell 1999 p616

<sup>53</sup> Novas/Rose 2000 p490

These responsibilities concern mainly obtaining and disseminating knowledge about one's genetic status, engaging in risk-management and persuading others to do so as well.<sup>54</sup> How individuals deal with these responsibilities is highly gendered.<sup>55</sup> Women's own risk management choices concerning HBOC were found to be highly limited by gendered concepts of taking responsibility and caring for others within their families. Though it is unclear in how far the genetic character of the risk information triggers this, Hallowell<sup>56</sup> suggests that it is mainly the women's perception of their social connections and subsequent social obligations that made them engage in managing their own and their relatives' genetic risks.

As many of these women have traumatic experiences with relatives (mostly mothers) dying of breast cancer, these responsibilities also include that they themselves have to spare others, especially their children, the emotional trauma of witnessing their illness or even death.

Furthermore, women are found to feel a greater need to disclose their own and their relatives' test results to other family members. Still, most men and women do not feel the need to disclose genetic information to family members they don't know, arguing for the central role of social connections for the conceptualizations of genetic responsibility.<sup>57</sup>

## **(II) Biomedical Contexts**

Still, rewritten family networks are not the only types of collectives within which genetic identities emerge. The individual at genetic risk also "*becomes either willingly or unwillingly implicated in a web of professional and lay support networks as part of being identified at genetic risk*".<sup>58</sup>

Rabinow<sup>59</sup> points out that the application of genetic testing leads to the formation of biomedical collectives that assemble around common genetic risks. These *biosocialities* share exclusive medical practices and specific forms of agency, which rather centre on

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<sup>54</sup> Hallowell 1999

<sup>55</sup> For the gendered character of genetic responsibility see e.g. Hallowell 1999, Hallowell et al. 2005 and 2006, and d'Agincourt-Canning 2001.

<sup>56</sup> Hallowell 1999

<sup>57</sup> d'Agincourt-Canning 2001

<sup>58</sup> Novas/Rose 2000 p494

<sup>59</sup> Rabinow 2004

prevention than on therapy. Such emerging biosocialities are then accompanied by “pastoral caretakers”, such as scientists or medical professionals, who help them understand and manage these newfound genetic identities.

However, individuals that are part of a distinct biosociality are also found to join forces with their pastoral caretakers and form a collective to reach a common aim. The AFM (Association Française contre les Myopathies) is an example for such an association of affected people and professionals, in this case geneticists, who have decided to follow a common aim: finding a genetic cure to muscular dystrophy. To do so, they agreed on a collective agenda: the research should start at the patients needs and eventually return to them in form of a therapy.

Rabeharisoa and Callon<sup>60</sup> use the term *hybrid collective* to describe this association of lay people and scientists that together engage in the common endeavour to fund and thus conduct research on this very rare disease. Both parties contribute different resources to this endeavour: They bring in different forms of knowledge, such as experiential or scientific knowledge, as well as different material resources, such as bodily materials, laboratories or the money raised by organizing charity events on TV.

Scientists and affected people in the AFM engage in a permanent dialogue about their aims and about what they have already reached. They discuss difficulties and decide collectively on how to proceed. To do so, they have established an intermediary discourse that allows them to talk about the process of research without in-depth knowledge about its technical details.

Thus, a hybrid collective describes a collective of lay people and experts that share a common aim and engage into a collective endeavour together. In the empirical chapter, I will show that in the specific contexts of genetic testing for HBOC we researched, the individuals at genetic risk and the professionals, who take care of them, engage in such a common endeavour and thus form a hybrid collective.

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<sup>60</sup> Rabeharisoa/Callon 1998

### (III) A broader societal level

To be able to engage in a collective endeavour implies to agree on a distinct way to relate to being at genetic risk. For example, it implies to agree on prevention as an acceptable strategy to deal with genetic risk.

Fleck<sup>61</sup> argues that each individual is part of distinct thought collectives, communities of people that share a common thought style. This thought style defines what a collective of people perceives as acceptable ways to think about something, e.g. how to frame a distinct problem like genetic risk.

Novas and Rose argue that the creation of the individual at genetic risk links up with prevailing forms of enterprising responsible personhood that intersect with „*contemporary norms of selfhood that stress autonomy, self-actualization, prudence, responsibility and choice*“.<sup>62</sup> Thus, the creation of the individual at genetic risk is accompanied by the formation of distinct thought styles that are considered to be shared by the individuals at genetic risk.

These thought collectives may be real, in that sense that they consist of people that actually meet, but they may also be imagined. They may represent how individuals perceive that one *should* think about issues related to genetic testing.

Imaginations about collectives are quite commonly created in connection to the application of new technologies like genetic testing. Simpson<sup>63</sup> e.g. quite critically argues that genetic analysis also serves as a basis for imagined ethnic communities, and hence both changes and reinforces already existing ethnic identities, thereby producing new inclusions and exclusions.

He therein refers to the concept of imagined communities by Benedict Anderson,<sup>64</sup> who argued that in colonial times, certain communities were shaped into being by the imperial technologies of the census, the map and the museum. By defining certain ethnic communities on the forms of the census and making people use them, certain ethnic communities that did not exist in that way before were brought into being, first only virtually but later on also on a level of social interactions. People started to define

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<sup>61</sup> Fleck 1980 [1935]

<sup>62</sup> Novas/Rose 2000 p502

<sup>63</sup> Simpson 2000

<sup>64</sup> Anderson 1983

themselves in relation to the ethnic communities the technology of the census assigned to them.

Simpson and others argue that similar processes are at the moment transforming the imaginations about ethnic communities on the basis of genetic relatedness. For example, genetic analysis allows Afro-Americans to retrace which ethnic communities their ancestors belonged to, when they were adducted from the African Continent, thereby destabilizing the Afro-American community as a whole by introducing ethnic divides and genetic sub-communities.<sup>65</sup>

Thus, distinct imaginations about collectives are connected to the socio-technical practices of genetic testing that create the individual at genetic risk. Some of them are imaginations about distinct thought collectives one should be part of, as they are perceived to share a thought style that is preferable.

However, Fleck argues that each individual is part of more than one thought collective. These thought collectives can hold thought styles that frame a distinct problem quite differently. Thus, the imagination of being part of specific thought collectives, for example of being part of a collective of people that agree on prevention as *the* preferable way to relate to genetic risk, can cause conflict with other thought collectives one is part of.

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<sup>65</sup> Brodwin 2002

## 4. Research Questions and Methodological Approach

### 4. 1. Research Questions

The last chapter outlined the concepts and theories framing the empirical focus of this thesis. It depicted transformations induced by biomedicalization, described ways individuals relate to biomedical knowledge, and offered perspectives on the collective dimensions of biomedical technologies.

Hence, in relation to these conceptual and theoretical frameworks, the empirical focus of this thesis rests on the formation of collectives through genetic testing for HBOC. Furthermore, it explores the positioning work of individuals within and towards these collectives. Thus, the main research questions addressed in my empirical work are:

- Which kinds of collectives are formed in the process of genetic testing for HBOC in the specific local contexts of this counselling centre?
- How and why do individuals become part of these collectives?
- What does becoming part of these collectives mean for the individuals?
- What understanding of knowledge and its relation to agency is deployed?
- And hence, what can be said about the relation of the formation of biomedicine-based collectives and the creation of individual biomedical identities?

## 4. 2. Methodological Approach

### Choosing a Basic Methodological Approach

The data this thesis is based on was collected in the wider context of the EU funded project “Challenges of Biomedicine – Socio-cultural contexts, European Governance and Bioethics” (CoB) a research team at the Vienna Interdisciplinary Research Unit for the Study of (Techno)Science and Society (VIRUSSS) worked on.<sup>66</sup> The focus of the project was to frame lay people’s perspectives on biomedical technologies, respectively organ transplantation and post-natal genetic testing. The core data of this project consisted of separate focus groups with people that perceived themselves to be affected by these technologies, and with people who felt that they were not.

In the focus group with the affected people on genetic testing, only two of them had indeed undergone genetic testing themselves. This broad definition of affectedness, e.g. also including people that felt affected by genetic testing as family members or medical professionals, was very fruitful for the project, but it granted less dense insight into how people that have personally experienced genetic testing frame this technology. Hence, the data of this thesis was designed to supplement the CoB core data and shed light on the way people that underwent genetic testing perceive and experience this biomedical technology. We decided to conduct a qualitative study<sup>67</sup> based on open narrative interviews. Open narrative interviews were chosen because they allow individuals to develop their narrations on their perceptions of genetic testing as freely as possible, in their own way of telling a story.<sup>68</sup>

To analyse this data, grounded theory<sup>69</sup> was the method of choice, which means to develop a theory out of the collected data by an open coding procedure and not to apply a preconceived theoretical concept onto the data.

### Choosing and Approaching the Field

The decision to focus on genetic testing for HBOC was mainly due to two reasons and a lucky constellation of projects, aims and personal interests. On the one hand, I approached

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<sup>66</sup> <http://www.univie.ac.at/virusss/cob/>

<sup>67</sup> Silverman 2000, Diekmann 1998

<sup>68</sup> Lamnek 2005

<sup>69</sup> Strauss/Corbin 1998

my supervisor Ulrike Felt explicitly with the idea to write my interdisciplinary master thesis on breast cancer. I had developed an interest in the perception and construction of this disease while I was working in a research group on breast cancer for years besides my studies of molecular biology.

On the other hand, people that had personal experiences with genetic testing and were willing to share them appeared to be rather hard to find, unless they were approached by a gatekeeper in the field. Hence, conducting a qualitative study in the area of genetic testing in Austria would require support of a gate keeping person. Fortunately, my supervisor and leader of the CoB project Ulrike Felt had already established contact with the head of a counselling centre for HBOC while recruiting participants for the CoB focus groups.

Thus, choosing genetic testing for HBOC as our field of research allowed to combine the production of supplementary data to the CoB project, personal interests and established contacts to a major gatekeeper in the field of genetic testing.

When we approached the counselling centre with the idea of an in-depth study in November 2005, they were interested in the insights the project could yield, but also concerned that the interviews could do some harm to the interview partners since genetic testing is a very sensitive topic.

Thus, we agreed on three preconditions for the interviews to ensure the well being of our interview partners: First, all interviews would be conducted exclusively by Ulrike Felt due to her interview experience in medical contexts. Second, they would take place in the rooms of the counselling centre to provide a setting as non-disruptive as possible. Finally, a psychologist of the counselling centre would be present during the whole interview.

We submitted a research proposal to the hospital's ethics commission. They approved our proposal in February 2006 under one condition: We should avoid the term affected in our information leaflets and during the interviews as this could confuse our interview partners about either their genetic status or their state of health.

To further prepare ourselves for the interviews we had several meetings with the head of the counselling centre and with the counselling centre's psychologist. We discussed the clinical procedure of genetic testing for HBOC, problems the medical professionals and psychologists perceived to be common, particularly sensitive issues as well as possible



criteria to sample or interview partners along the variety of cases the counselling centre is confronted with. We agreed on a sample that would include individuals that differed in carrier or non-carrier status, gender, familial background, age, state of health as well as familial affectedness by breast or ovarian cancer.

Furthermore, the counselling centre's head advised us to avoid referring to genetic testing as "technology" in our information leaflets as well as during the interviews as it was uncommon in the clinical contexts of genetic testing to refer to it as a piece of technology and interviewees might be puzzled by this labelling. Rather it would be perceived as a medical practice, as a more sophisticated blood scan. We followed this advice.

Finally, the psychologist of the counselling centre started to contact potential interview partners by phone. All but one consented to give an interview about their perceptions of genetic testing.

### **Data Collection**

The core data of this study consists of eleven interviews that were conducted between April and September 2006. The final sample of interview partners varied in gender, carrier and non-carrier status, affectedness by breast or ovarian cancer and age.

- It included nine women and two men. Both men were carriers, as well as six of the women.
- Three women were non-carriers. Two came from families that were confirmed to have a history of HBOC due to a mutation in a BRCA gene. One woman had a strong family history of HBOC that couldn't be related to a BRCA mutation.
- Four of our interview partners had been ill with breast or ovarian cancer before undergoing genetic testing, among them one man.
- Two of our interview partners had a family history of only ovarian cancer with no recorded breast cancer cases.
- The age of our interview partners ranged from the early twenties up to seventy plus.

Before the interview, we explained the project to our interview partners in some detail and handed out written project information. We emphasized that they could quit the interview at any time and already collected data would be destroyed. Finally, informed consent was obtained.

We started each interview by asking our interview partner how they had heard about genetic testing, how it came that they decided to undergo the test and what had happened then. After the interview we discussed our perceptions of the interview with the attending psychologist. Each interview was about 35 minutes in length. All were taped and transcribed for later analysis.

In addition to this data, participant observation of one information evening in the counselling centre in April 2006 was used to contextualize the interviews. Field notes were taken, however, they were exclusively handled as contextual and supplementary information to the interviews.

### **Data Analysis and Reflection**

The interview data was analysed using a grounded theory approach. Grounded theory and thus open or “bottom up” coding allows building micro theories on the basis of inductively coding the data material.<sup>70</sup> This means that first codes were assigned to sentences or passages of the interviews. Then the relations between the different codes were analysed, and, as first theoretical assumptions emerged out of the open coding process, this set of codes was further refined.

The distinct focus on the formation of collectives emerged after the first round of open coding. Thus, codes were refined in relation to this focus and finally assigned to answer the specific research questions listed before.

Grounded theory was considered particularly suitable for Science and Technology Studies (STS) research, mainly for two reasons. First, in order to find coding categories that emerge out of the data and are not simply applied onto it, grounded theory vouches for an in depth engagement with the data, for asking questions to the material and for making comparisons, to grasp the specifics of the data and thus the specific and local contexts of the particular case one does research on.

Second, grounded theory does not claim that there is one “right” way to do open coding. It acknowledges that also scientific analysis is a subjective as well as creative process and that thus there is more than one way to analyse a set of data “correctly”. Thereby it acknowledges that knowledge production itself is a social process, a stance that is central to STS research.

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<sup>70</sup> Strauss/Corbin 1998

As grounded theory also favours a contextual approach towards one's data, I want to make two reflexive remarks on the setting this data was generated in. First, I want to stress that all of our interview partners had decided *in favour* of undergoing genetic testing. We did not talk to anyone who decided against genetic testing. Thus, we did not catch the perspectives of people who disapproved the basic idea of genetic testing.

Second, the interviews took place in the counselling centre, in presence of a psychologist who works there. Some interview partners appeared to know her well, others seemed to be not that familiar with her. This whole setting may have had some influence on how our interview partners enacted their relation to the medical contexts of genetic testing. I can only guess how a different setting might have influenced the data. However, this setting was designed to be as non-disruptive as possible for our interview partners and hence it ensured the well being of those people, who made this thesis possible in the first place. I want to thank all of them for the time, thoughts and experiences they shared with us and thus for the interesting insights they granted us.

## 5. Co-producing Individuals and Collectives

In the following chapter the empirical findings will be presented and I will argue that genetic testing is a technology tending to evoke the emergence of multiple collectives. I will show that in the specific contexts of genetic testing for HBOC in the counselling centre we conducted this study in, collectivization occurs in three different ways: by forming and transforming familial relations, by the specific ways of interaction of professionals and affected<sup>71</sup> people in the counselling centre and by referring to broader imaginations about collective ways of thinking and acting in relation to genetic risk.

Familial relations are transformed by the creation of the **family at genetic risk**, a version of family defined by kinship and genetic risk, visualized by the medical pedigree and characterized by new forms of responsibilities among its members.

The specific ways affected people and professionals of diverse backgrounds relate to each other result in the formation of a second form of collective, which I will refer to as a **hybrid collective**. It is characterized by sharing multiple forms of knowledge, committing to distinct ways of how to relate to genetic risk and thus to particular practices of common agency.

On a broader societal level, individuals frame the challenges they face, the decisions they make and the actions they take by referring to imaginations about communities of people that share or do not share these forms of thinking and acting in relation to genetic risk. Thus, they refer to **imagined collectives of thought and agency** in order to frame how they could and should deal with the contexts and implications of genetic testing, a normative stance that is sometimes hard to reconcile with other collectives one is part of.

Hence, this chapter explores the distinct capacity of a biomedical technology like genetic testing to co-produce individuals *and* collectives in specific local settings. It tries to grasp how these collectives are formed and why individuals become part, in order to understand how they relate to these collectives. Further, it traces the relation of knowledge and agency within these collectives and within the process of their formation. Finally, this should offer

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<sup>71</sup> In this chapter, I will use the term “affected” to describe all people that come from at risk families and that feel they are affected by HBOC, whether they are carriers or non-carriers or life partners of family members.

some perspectives on the specific nature of the relation of individuals and collectives co-produced by biomedical technologies.

### 5. 1. Becoming Part of a Family at Genetic Risk

*A young woman is sitting on a table in a counselling centre, in front of a doctor, nervous and maybe a bit confused. Some weeks ago, her sister was diagnosed with breast cancer at the age of only 38, just like her mother, who had died when both had still been teenagers. She had always thought that their loss was just bad, bad fortune, but now? “They said it could be genetic. There is some sort of test.” her sister said, and told her to call the centre. The last weeks, after she had finally made the phone call, she spent researching her family, called an aunt she had never met before, heard different stories about the lives and deaths of former generations, of people she never thought of. Suddenly, a family started to emerge that didn’t exist before, that she had never felt part of. One that is connected not through social bonds and collective memories, but through genetic kinship. Now, at this table, while the doctor is drawing a pedigree made of all the information she could gather, she sees that cancer is running through this family, or better to say, through a part of this family, like a red thread. “Well, it looks like your family could be at genetic risk.” the doctor finally says.*

This is a merely fictional account, a story I made up using different bits and pieces of the narratives encountered in the interviews. It tries to illustrate one major transformation of collectives in genetic testing: family structures are rewritten, generating a new and unfamiliar vision of one’s family that is closely connected to genetic risk.

Hence, in the process of genetic testing, individuals appear to acquire a distinct imagination about their family that can be labelled as being part of a *family at genetic risk*. It is the imagination that, whether there are social bonds or not, one is part of a distinct collective of individuals that are connected through a specific genetic mutation linked to an increased risk of breast and ovarian cancer.

Thus, how is such an imagination created? How does it relate to other imaginations of family that are not based on sharing a distinct genetic risk? And what does becoming part of a family at genetic risk mean for one’s social relations within one’s family and towards specific members?

### Creating a Family at Genetic Risk: Practices

*In our family, it is genetic. In fact my mum had a mamma carcinoma when she was, I think, 37 or 38, and my aunt one or two years later, well, my mother's sister. And well, the gene is in the family from my mother's father's side. (Q1)*

The quote above illustrates a typical reference to the imagination of being part of a family that is at genetic risk as they are found throughout the interviews. The family is perceived to share a collective genetic risk that is further allocated to specific individuals and specific sides of the family.

Creating and becoming part of such a family at genetic risk is a **precondition to get access to genetic testing in Austria**. Only individuals that come from families that show a distinct pattern of cancer within their family history matching the criteria of “being at risk” for HBOC are allowed to undergo genetic testing. Hence, becoming part of a family at genetic risk is a process at the very basis of genetic testing and thereby represents a gate keeping mechanism towards this technology.

To assess whether a family history of breast and/or ovarian cancer complies with this distinct pattern, information about family structure and medical family history is transformed into a medical pedigree. Drawing the pedigree translates data on family configuration and cases of illness into a schematic that visualizes genetic connectedness and the distribution and frequency of breast and ovarian cancer within this family.

Thus, **this medical pedigree is a visualization of the family at genetic risk**. It represents a version of family that is defined through genetic kinship, and it visualizes the distribution and allocation of genetic risk to distinct individuals within this family.

Its construction is a complex socio-technical process that involves heterogeneous actors, such as individuals that want to undergo genetic testing, relatives that hold information, counsellors that filter and transform this information, as well as the information itself, medical records, death certificates, the pedigree and the icons it is made of.

The secretaries of the counselling centre instruct individuals that want to undergo genetic testing to bring as much information about family structure, family history and cancer in the family as possible to the first counselling session. Thus, before even entering the

counselling procedure, individuals have to gather a distinct form of information about their family.

Obtaining this information is not always easy. In most cases, it involves contacting other family members, which means that then at the latest, other family members know that someone wants to undergo genetic testing.

Moreover, the medical history of past generations, of our interview partners' grandmothers and great-grandmothers, is sometimes hard to reconstruct. Cancer, especially cancer linked to the female reproductive organs and breasts, was often treated as a taboo in these times, so it is common that there is no precise information within the family whether they suffered from breast or ovarian cancer or not.

In addition, medical records from that era are hard to obtain and often imprecise. Many records e.g. only refer to cancer of the abdomen, which could mean colon cancer, uterine cancer or ovarian cancer. Thus, in some cases the exact medical history of some family members remains unclear.

All available family data is translated into the pedigree.<sup>72</sup> Family narratives and medical records are then transformed into the icons the pedigree is made of. **The individual is set in relation to the other individuals in the pedigree.** They become "*elements of a collective, familial, and thus biosocial body*".<sup>73</sup>

The pedigree visualizes the distinct allocation of cancer within the family, and thus it visualizes who could carry the mutation and who not. Thereby, it creates a distinct network of risk and risk distribution.

Before there are any actual test results, individuals are defined as being potentially carrying the "defective" gene to varying degrees. The children e.g. of a woman who was ill with breast cancer are defined to carry it more probably than the children of her sister who has not been ill. Thus, the individuals within a family at genetic risk are ascribed different probabilities of having inherited the genetic defect. As test results are added to the pedigree, some individuals are finally "identified" to be carrying the family mutation, others not to. To establish the genetic status of one individual may also change the potential status of others, e.g. when a mother is proven not to have the mutation, her children are also defined as not at risk of having inherited a defective gene.

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<sup>72</sup> See Nukaga/Cambrosio 1997 for a detailed analysis of this process

<sup>73</sup> Nukaga/Cambrosio 1997 p29



Thus, adding test results to the pedigree may mean that only parts of a family are constructed as sharing a genetic defect, whereas others are constructed not to. The example below shows how one branch of a family is referred to as carrying the mutation and another as not carrying it.

*Well, in my family there are several cases of abdominal and breast cancer, well, in fact quite a lot. And then I did some research and found out that there were three sisters, one of them my great-grandmother. And two of these sisters had cancer. And that continued. And my second cousin did the test after her mother died of cancer and found out that she has that cancer gene. [...] Well, and I thought several times that it would be quite interesting to find out whether I also have that or not. Because, in fact, none of the offspring of this one sister [her great-grandmother, comm. RM] fell ill. But, of course, we didn't know really what was there or what not. (Q2)*

As this woman is confirmed not to carry the mutation, her branch of the family is further defined as (most) probably not carrying the genetic mutation. Although not all members of this branch are tested, the combination of family history and test results makes it most unlikely that any member of this branch is carrying the mutation. Thus, in the process of constructing the pedigree, different branches of her family are assigned different states of risk.

The sister that her branch descends from is reconstructed as the one sister not carrying the mutation, the other two as carriers of the mutation. Whereas they were formerly described as having been ill or not, they are now described by their genetic status. Hence, the construction of the pedigree also involves the reconstruction of the genetic status of past family members on the basis of the genetic status of their offspring.

Furthermore, as the connective element between the members of the family at genetic risk is not a shared illness but a shared genetic status, men are also integrated into this collective. Whereas most familial narration about breast and ovarian cancer in the family only focussed on the women, translating these family histories into a medical pedigree incorporates men as carriers of genetic risk into this version of family.

Thus, in the process of genetic testing one becomes part of a distinct imagination of family, the family at genetic risk. However, as we shall see, this imagination does relate quite

differently to perceptions of health, illness and risk within their families individuals had before they entered genetic testing.

### **Contrast or Coherence: How does the Imagination of Being Part of a Family at Genetic Risk Relate to Prior Imaginations of Health and Family?**

The perception that one is part of a family at genetic risk is shared among all interview partners. All of them have acknowledged this version of family that is central to the socio-technical practices of genetic testing. In fact, without inscribing into that version of family, they would not have been able to undergo genetic testing.

However, how this imagination relates to prior perceptions of family, of who are its members and how it is connected to breast and ovarian cancer, shows a whole spectrum of possible variations. On the one side of the spectrum, there are narrations about having had **no perception of any familial predisposition** at all before undergoing genetic testing.

*My mother fell ill with breast cancer in 94 [...] and in 99 she died of it. And then it was more or less in the [name of hospital], when we announced that the mother had died, that we were offered, my sister and I, that by genetic testing, we could find out whether we were having that carrier or not. [...]*

*I: Besides your mother, were there other family members... ?*

*There was my mother's sister, but I don't know for sure whether it was ovarian cancer. Anyway, she had a tumour of eight kilogram in her uterus, but that was her own carelessness, I say. And what I know is the grandmother of my mother had it, too, from the genealogical research that came then, there has somehow been found out, that the grandmother of my mother had just this gene, too. (Q3)*

Before she was offered to undergo genetic testing, this woman had no idea that there was any hereditary predisposition in her family. She knew that her mother had had breast cancer, she knew somehow that her aunt had had some tumour in her abdomen, but that

didn't lead her to the conclusion that this could pose any genetic risk to her. It was only through researching her family history, constructing the pedigree and thus reconstructing her family history that she started to perceive herself as part of a family at genetic risk.

Whereas this was quite an extreme example of how being part of a family at genetic risk does not match any prior perception, most interview partners rather told stories of a translation of a **perception of a high incidence of breast and/or ovarian cancer** into a distinct imagination of being part of a family at genetic risk.

*Well, we talked about it, with the cousin. She said, oh, your mother and we [her mother and herself, comm. RM], and now you got it, too. But that one could be having genes, no, it's just coincidence, that I got it, too, but that it was caused by the genes, we didn't know that or didn't think about that. (Q4)*

This woman's family was affected by breast cancer for generations. Within her family, there was awareness of an uncommonly high number of cases of breast cancer. However, the idea that this could be due to genetic reasons was new to her before she fell ill herself and a doctor at a hospital approached her with that idea.

Thus, in her case, becoming part of a family at genetic risk translated a vague perception that there are somehow a lot of breast cancer cases within her family into the distinct imagination of being at genetic risk. Hence it changed the collective of family members whom breast cancer concerns: Whereas before it was something that was limited to the affected women, it now includes all members of the family that are genetically connected, to a varying degree. It includes young women who have never been ill with breast cancer, but are at risk and thus "potentially ill", it includes men, who are unlikely to fall ill themselves but can hand down the risk. It also includes those that are not at risk individually, as they still live in a family that is collectively at risk.

Some interview partners clearly framed the high incidence of breast and/or ovarian cancer as being hereditary, sometimes even genetically caused before the test. Thus, in the process of genetic testing, this **perception of a hereditary predisposition** in one's family is translated into the distinct concept of being part of a family at genetic risk. This is often

experienced as a verification of one's perception of family and furthermore as a basis of action.

*Because, I in fact already thought that there must be something, well, like a genetic defect and that it is probably there within my family. That was in fact already clear to me. And I wanted assurance to be able to make further steps, like for example a mastectomy. (Q5)*

Thus, although the family at genetic risk matches this woman's prior perception of her family, it is also fundamentally different to her as she perceives this version of family to offer her a basis for a distinct kind of agency.

Whereas the last two examples illustrate the broad middle field of narrations within the interviews, on the other end of the spectrum there are individuals who grow up in families that are already established as being at genetic risk collectively. A young woman in her mid twenties tells us that her mother was tested when she was a teenager and that she grew up knowing that her mother had had cancer because she carried a genetic mutation. It was clear to her that she would also undergo genetic testing when she turned eighteen, however, it was an unexpectedly difficult decision then, she told us.

*I did not do it until I turned 19, or near my 19th birthday. Well, I let one year pass, because it was possible at 18, and I thought, do I really want to know that? (Q6)*

To her, undergoing genetic testing didn't create a new version of family, that family was already established. She grew up as a part of a family at genetic risk. She considered taking the test as the logical consequence of being part of such a family in order to clarify her own position within that family whereas not taking the test would have been an aberration from the "normal" course of action. Thus, there are distinct imaginations emerging about how members of a family at genetic risk should act in relation to the familial risk, imaginations that are as well resulting in specific forms of responsibilities that are perceived to be linked to becoming part of this version of family.

## Creating Responsibilities

Becoming part of a family at genetic risk, so our data indicates, affects how individuals within these families relate to each other mainly by producing new forms of responsibilities. These responsibilities are perceived as linked to the knowledge that is contained within this new version of family and furthermore, to distinct forms of agency.

By undergoing genetic testing and thus constructing a family at genetic risk, an individual does not only obtain knowledge about her or his own genetic status, but also knowledge about who else could be at risk in the family. Most individuals feel **responsible to inform these others about the risk they possibly carry**. This young woman tells us that she feels that she really should inform a niece of hers that she could be at genetic risk, too.

*I don't doubt that I will tell her, because I think, that is important that one tells that. Because I don't have a problem that she knows that.*

*I: Well, but there is also the question that somehow you also decide for someone else what she does know or does not know. [...]*

*Yes, but on the other hand, if there was really something, I would feel guilty forever. And I don't want that. (Q7)*

If she would not inform her niece, she would feel guilty if her niece fell ill. Thus, informing others about the genetic risk that is found to be running in the family is a responsibility that is created by being part of a family at genetic risk.

This “feeling responsible” seems to largely outweigh concerns about deciding for others what they want to know and what not. In fact, within the interviews there are rarely remarks about such concerns. Knowing seems to be strongly constructed as positive and thus sharing this knowledge with others is framed as quite unproblematic in our sample.

Whereas some feel that they are only responsible for disseminating the information to their relatives, others also feel **responsible to encourage them to undergo genetic testing**

themselves. They try to convince other family members to get tested, sometimes quite persistently.

*Well, I convinced my sister to this test as well. But, I say, she did it primarily because she has got two daughters and she probably wanted to know if there was the possibility that she would hand it down to them. (Q8)*

Trying to convince others to undergo genetic testing is a common narration within the interviews. Mostly these others are close family members. Although other relatives are also informed about the genetic risk in the family, how they deal with it is mainly only an issue if they are close.

*I mean I don't know, if my cousin did undergo, of my aunt who died, if they really did undergo, well I don't know that. I don't have any contact with them anymore. (Q9)*

Although this woman told us that she would have “forced” her brother to undergo testing if he would have objected, she is not interested in whether her female cousin, to whom she does not have any contact, undergoes testing or not. Hence, it seems that, similar to what d'Agincourt-Canning<sup>74</sup> describes, social connectedness does crucially influence towards whom one feels genetically responsible. It thus can also be perceived as a way to take care of those one holds dear.

Consequently, distinct forms of responsibilities are created towards one's children, first of all the responsibility to **obtain knowledge about one's genetic status**. Generally speaking, within our sample, parents are considered to have the responsibility to undergo genetic testing in order to find out if they carry a risk they could pass on to their children, especially to their daughters. One father that was affected by breast cancer himself tells us that although he is happy to know why he suffered from breast cancer, he mainly perceives that undergoing genetic testing was important for his sons. As they know he is carrying the mutation, they can decide if they want to find out if they also carry it and hence act in advance.

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<sup>74</sup> d'Agincourt-Canning 2001

However, men who are not affected by breast cancer themselves and thus form the majority of men within families at genetic risk, are largely described to be reluctant to undergo genetic testing in order to clarify if they carry a risk they could pass on to their children. Thus, they are perceived to refuse the responsibilities that being part of a family at genetic risk would entail.

*My [male, comm. RM] cousins, well, they don't want to, I think they are afraid. [...] They said, well, when they want children, then they undergo testing. [...] But if they will really do that then? (Q10)*

Hence, within our sample of interview partners, undergoing genetic testing is thought to be the responsible course of action towards one's children, future or present, as it is generating knowledge that is not only relevant for oneself but also for the children. Although men that are part of the family at genetic risk are perceived to bear this responsibility as much as women do, they are often perceived as not living up to these expectations. This is often interpreted as "typically male" and somehow tolerated.

To women, yet another responsibility towards their children is added: **remaining healthy**. Thus, undergoing genetic testing and, in case risk is proven, taking preventive action is perceived to be a responsibility not only towards one's own health but also towards one's children.

*I witnessed it, and it was clear to me that I don't want to experience that again and that I want to spare my children from that as well. [...] That's something that does not only influence my life, but also the children's. (Q11)*

Many of our interview partners have witnessed their mothers' deaths. Thus they express that it is their responsibility to spare their children the same experience. They perceive that undergoing genetic testing and adhering to prevention is a way to fulfil that responsibility towards their children as properly as possible.

Summarizing, the family at genetic risk is a version of family created in the process of genetic testing and visualized by the medical pedigree. Its members are connected by kinship and a distinct genetic mutation that conveys elevated risk for breast and ovarian cancer. This imagination of family may be or may not be similar to those individuals had before. However, it often encloses individuals that have not been considered to be affected by cancer running through the family before, such as healthy women that become defined as being at risk and thus “potentially ill”, and men as carriers and transmitters of risk. Moreover, within our sample, ascribing genetic risk to a family is experienced to create new responsibilities among family members in connection to the collective character of the genetic knowledge produced, and moreover, in relation to what is perceived to be an adequate way to (re)act in the face of this knowledge.



## 5. 2. Creating a Hybrid Collective

*Although we are in time, my supervisor and I are some of the last to arrive at the information evening at the counselling centre. The room is already filled with women, some in white coats, some not. Normally, this room is used for staff meetings and student lectures, it doesn't have windows, because it is in the very heart of the huge cubic hospital. The table with orange juice and pretzel sticks looks a bit improvised and is largely ignored. There are about twenty-five women in the room, nearly half of them work at the counselling centre, as lab technicians, psychologists, secretaries and physicians. The psychologists and secretaries walk around and welcome the attendants personally, they know most of them by name. The chief physician is there as well. She is standing among a group of women, shaking hands, chatting.*

*"Look, this must be the guy we were told about in the interview." I say, referring to the one and only man sitting among all the women. We know his wife brought him along because she hopes that coming to the centre could convince him that mastectomy is not such a bad thing at all.*

*"Last time, someone asked if going for an x-ray was dangerous and I didn't know it for sure, but I have done some research on that." the chief physician opens the meeting. She has prepared a Power Point Presentation and explains exactly how much radiation is contained in the different kinds of x-rays – some women are relieved: dentists' x-rays are harmless, even for women that are at high risk of HBOC. "Don't worry." the chief physician says.*

*Then there's a presentation by one of the psychologists on the main topic: How are children affected if cancer is running in the family? The women listen silently. After she has finished, most questions centre on how to deal with risk information: How do I tell my child, my daughter that she might carry the mutation? Is she old enough? How long can I wait? What will this knowledge do to her?*

*The women ask questions, the physicians and psychologists answer or they ask back first, to get to know the exact situation in greater detail. If the physicians can't answer a question, they refer to the psychologists and vice versa. Only rarely, one of the women answers or refers to another woman's statement. The conversation is friendly and casual. Although the upcoming issues are obviously concerning and frightening to the women, the*

*atmosphere appears to remain light. “Don’t worry.” the chief physician says again, “Much more important than what you say is the example you give.”*

This prefix is based on field notes taken during an information evening at the counselling centre. It is there to sketch the distinct ways professionals and affected people relate to each other and thus form a kind of collective, which I refer to as a **hybrid collective**. It is emerging as an outcome of the multiple ways of interaction between physicians, psychologists, other members of the counselling centre’s team and the people who undergo testing.

Hence, these are the main questions addressed in this chapter: What is exactly meant by hybrid collective in these contexts? Why do people become part of this collective? And which kind of relation between affected people and professionals is generated through being part of a hybrid collective?

The term *hybrid* has two meanings. First it implies that something is made out of heterogeneous materials, such as human and non-human actors. As this collective assembles around a specific genetic marker and therefore also around specific practices, artefacts and technologies, it is indeed a hybrid one in that sense.

Furthermore, a second meaning of *hybrid* is found in the work of Rabearisoa and Callon<sup>75</sup> on the French patient organisation AFM (Association Française contre les Myopathies). There they use the term *hybrid collective* to describe an association of lay people and scientists that together engage in the common endeavour to fund and conduct research on a very rare disease. Both parties contribute different resources to this endeavour: They bring in different forms of knowledge, such as experiential or scientific knowledge, as well as different material resources, such as bodily materials, money or laboratories. During their common efforts, they exchange some of these resources, acquire some of the knowledge that was formerly restricted to one of the groups. To do so, they established an intermediary discourse to facilitate this kind of collective work.

Drawing on accounts in the interviews, but also on participation observation of the information evening described above, a similar kind of hybridity seems to develop in the specific local contexts of this Austrian counselling centre: By sharing multiple forms of

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<sup>75</sup> Rabearisoa/Callon 1998

knowledge as well as distinct aims and practices physicians, psychologists, other staff members and affected people are creating a hybrid collective.

These actors contribute **different types of knowledge** to the hybrid collective. There are different forms of biomedical and psychological knowledge, thus forms of knowledge that can more generally be referred to as scientific knowledge. There is experience-based knowledge contributed by affected people, such as knowledge about distinct family histories. Furthermore, there are also experience-based forms of knowledge that are created in the interaction of professionals and affected people, e.g. on how people deal with risk information in their everyday practice or on other sensitive issues related to genetic testing. Finally, there is the knowledge that is contained in the bodily materials of people coming from families that are affected by HBOC as well as the knowledge that takes the material forms of DNA sequencers and other laboratory equipments.

As both, affected people and professionals, acquire different types of knowledge through their process of interaction, these different forms of knowledge are exchanged to a certain extent and thus overlap in the individuals that are part of the hybrid collective. Therefore each individual in the hybrid collective holds these multiple forms of knowledge to differing degrees.

Hence, in the hybrid collective multiple forms of knowledge are combined and thereby create a common basis for collective forms of agency. They constitute a resource for addressing what appears to be the **common endeavour** of the hybrid collective: to prevent carrier individuals from falling ill. This is perceived to be the shared aim of professionals and affected people, the goal of their collective efforts.

In relation to this more general endeavour, all members agree on a number of specific commitments and subsequent practices. First, this concerns the decision to undergo genetic testing, which all members of the hybrid collective appear to approve and support. Second, the knowledge created through genetic testing is collectively framed as exclusively beneficial, as something that improves one's situation because it is perceived to constitute a basis for preventive action. Thus third, engaging in preventive action is the common practice of dealing with risk. How these preventive actions exactly look – whether it means attending early diagnostic check ups or undergoing preventive surgery – varies, but the basic commitment to transform genetic knowledge into preventive biomedical action is

shared. Finally, there are also distinct agreements on how to handle genetic knowledge, e.g. that it should be passed on to others in the family who could be at risk.

Thus, from our interview partners' perspective, the hybrid collective forms around the common effort to prevent breast and ovarian cancer in high-risk individuals and further around the collective commitment to "know" and to "act". Thus, obtaining biomedical knowledge and subjecting to biomedical risk management strategies are practices that are shared among the individuals in the hybrid collective.

### **Why Become Part of the Hybrid Collective?**

Why people become part of this emerging collective appears to have multiple reasons. Moreover, there are also different degrees to which the individuals become member in this hybrid collective. Within the interviews, some individuals explicitly emphasized that they felt to be part of something, whereas others only referred to specific aspects of the collective they accessed and made use of at specific points in time. Thus, there are different accounts on the nature of the benefits of being part of the hybrid collective. These narrations are not exclusive, thus several of them can coexist within one interview.

One major narration is that inscribing into the hybrid collective means escaping from becoming just a number elsewhere in the medical system. One is **acknowledged and taken care of as an individual human being**. As the quote below illustrates, individuals frame "being part of the hybrid collective" as granting them access to a medical setting where they are recognized as a person and not, as it is perceived to be the case in most other parts of the medical system, just as another anonymous case. Thus, this narrative distinguishes the hybrid collective from what is seen as the normal situation within the medical system. Being part of the hybrid collective is hence considered a privileged position as compared to being an anonymous patient.

*And that's how we came here and one led to the other. And today we could not imagine that we were not part of it, because we are accommodated so friendly and all. I have, I was here several times, I had a lump several times, I have never had fear, because I knew, there is someone one can turn to, whom we know. (Q12)*

This quote illustrates that the hybrid collective is seen as a rather stable entity of people one is familiar with and who are familiar with one's specific situation as well. Thus "*being part of*" this social structure is perceived as assuring that there is someone one "*can turn to*", someone one knows and can rely on. Hence, this narrative is also a narrative about professionals who are involved in the individual's fate more than they would have to and than it is common in the medical system as well. They are thus perceived to be *personally* engaged in the common endeavour of preventing illness.

The technological means that the professionals use to prevent this illness are rather marginal within these narrations. They are not in the focus of what is perceived to be gained by becoming part of the hybrid collective and thus seem to be rather blackboxed. Their existence appears to be presupposed, but the personal engagement of the doctors is not. Thus, it is the latter, this personalized care that is perceived to be the major benefit. Other narrations on the contrary emphasize exactly **access to these advanced technologies** as the major gain of being part of the hybrid collective.

*I mean, it is somehow the only chance that one has the diagnostic provisions. Because otherwise one is not taken seriously anyway and the option that one has that checked out if that is okay, doesn't work. (Q13)*

In this quote, becoming part of the hybrid collective presents a gateway to gaining access to specific technologies that are perceived as important in order to remain healthy. Again, this narrative also contains a process of border-drawing towards the medical system in general, which is experienced as being rather uninformed and underequipped concerning HBOC, and thus as not offering enough expertise and technological options to the individuals that are or could be affected.

Thus, the expertise and technological options the hybrid collective is perceived to hold are a reason to join the collective. These options are often contrasted to prior experiences in the medical system, where especially young women have felt that they haven't been taken seriously with their concerns and thus couldn't gain access to advanced technologies of prevention.

*I always had the feeling that it could be hereditary [...], that there will be something, and therefore I went to my gynaecologist. And he somehow didn't take that seriously, and hence I saw several gynaecologists, till someone sent me to [name of hospital], where there was the possibility to make this genetic tests, what I saw as a chance that one can diagnose it early on and [...] not when its to late. (Q14)*

Hence, framing the access to specific technologies as a central benefit of becoming part of the hybrid collective is often connected to narrations about finally finding someone in the medical system who acknowledges the multiple forms of experience-based knowledge associated with a family history of breast and/or ovarian cancer. Thus, being member of a community that **regards this experience-based knowledge as valuable** constitutes what is perceived to be another advantage of being part of the hybrid collective.

Indeed, in the hybrid collective parts of this experiential knowledge are formalized and translated into a medico-scientific form, e.g. the knowledge about a specific family history of HBOC that is transformed into a medical pedigree. Drawing a pedigree is, as described in the last chapter, a complex socio-technical practice that is creating or verifying distinct perceptions of affectedness in biomedical terms. Thus, it transforms experience-based knowledge that is perceived to be ignored and dismissed in most parts of the medical system into medico-scientific knowledge that is framed as being more broadly acknowledged.

Other parts of that knowledge are not formalized but still contribute to the experience-based forms of knowledge that are generated within the hybrid collective. This concerns particularly knowledge about the specific characteristics of HBOC within one family that are yet not elucidated by clinical studies. Though such knowledge e.g. about the very early onset of breast cancer within one's family, can't be translated into standardized forms of medico-scientific knowledge, it becomes part of the experience-based knowledge that is generated and shared within the hybrid collective. Thus it can be incorporated into knowledge-based forms of agency. As one woman tells us, her family is carrying "*a very aggressive gene (Q15)*" and she explains that consequently the women in her family have to be particularly vigilant already at a very young age and respectively should think about mastectomy earlier than others. What has happened here is that, within the hybrid collective, the knowledge about the very early age of onset of breast cancer in her family is

transformed into the concept of a more aggressive gene and as such considered relevant for the common endeavour of the collective to prevent her family from falling ill.

Thus, individuals express that within the hybrid collective their own forms of knowledge are appreciated and acknowledged, either as they are transformed into medico-scientific forms of knowledge or as they are perceived to be incorporated into the collective pool of experience-based knowledge that is related to the specifics of subsequent forms of agency.

Furthermore, the hybrid collective is framed as a place where **the implications of undergoing genetic testing are given room and consideration**. It is perceived to create a community of people where problems that arise in the context of genetic testing can be addressed and discussed. This can happen in private, between the medical professionals or the psychologists and the affected people, but also in collective events like the information evening described above. This evening was dedicated to the question of how to talk to children about genetic risk in the family. It was designed to give some expert input on this topic by means of a Power Point Presentation by one of the psychologists, but also to give room to a discussion of these difficult issues among affected people and professionals. Affected people appeared to make use of this possibility to openly address anxieties that are connected to talking to their children about genetic risk, as well as problems they experienced when they tried to do so. The medical professionals and the psychologists asked questions to get to know their distinct situation better, as they explained during the event, and provided them with suggestions on how to deal with these problems. Thus, such events can be used as a forum to voice and discuss the multiple implications of genetic testing and to hear other experiences and perspectives. One interview partner told us explicitly that she went there to see *“how others deal with it” (Q16)*, because she had a niece she wanted to talk to about the possibility that she could also carry a BRCA mutation. Hence, she expressed that she felt that going to the information event could support her in dealing with what she perceived to be a responsibility of hers.

However, the hybrid collective is not only perceived as providing support in dealing within emerging responsibilities, it is furthermore framed **to create perspectives that resolve distinct responsibilities**. As portrayed in the last chapter on the family at genetic risk, undergoing genetic testing creates distinct imaginations about responsibilities that are

attached to gaining knowledge about genetic risk. These are responsibilities towards other family members, and first of all, towards one's born or unborn children, who could be directly affected by the outcomes of genetic testing and thus by genetic risk.

This example of a young carrier woman exemplifies the way distinct responsibilities are perceived to be resolved. When she got to know that she was carrying a BRCA mutation, she decided that she would rather “*eradicate the gene*” (Q17) than hand it down to a child. But then, she tells us, one of the staff members said that she should not worry about her children because when they will be grown up, there will probably be methods to cure BRCA mutations.

*“And then they told me, well, that should not be the handicap now, that I abandon my family planning just because of that, because in twenty years the medicine is that far that they can already do something about that, well, that they can take that away at the outset. That was actually the crucial factor, that I then said, okay, fine.” (Q18)*

Hence she decides to have children. Although she at first felt that it was irresponsible to risk handing down the mutation to a child, she tells us that she then decided to confide in the scenario of the future created within the hybrid collective. During the information event, we could observe that concerns that centred on passing on genetic risk were indeed dismissed by the professionals on behalf of that vision of a possible future cure. Moreover, they insisted that no one could be denied to have children.

Thus, creating visions that there will be better solutions to the distinct problem of genetic risk for one's children is a way to loosen the responsibility of possibly handing down a mutation. However, this grounds on the assumption that these future children will be equally willing to obtain genetic knowledge and adhere to biomedical solutions if they carry the mutations.

Summarizing, becoming part of the hybrid collective is perceived as beneficial because one is taken care of as an individual human being and gains access to advanced technologies. Furthermore, experience-based forms of knowledge are acknowledged and the wider implications of genetic testing are given room and consideration within the



collective. Finally, perspectives created in the hybrid collective are perceived to loosen distinct forms of responsibilities related to genetic risk.

Hence, what does this mean for the relation of affected people and professionals within the hybrid collective?

### **What is the Relation of Affected People and Professionals within this Hybrid Collective?**

Although I frame the collective emerging in the context of the counselling centre as a hybrid collective, because of the distinct ways affected people and professionals engage in a common endeavour and share multiple forms of knowledge, I want to emphasize that the evolving relations between them are significantly different to the AFM.

The French AFM is a patient organisation of affected people and parents of affected children. The association decided to improve their situation by two means: On the one hand, they would offer help to affected people in a mutual self-help spirit, on the other hand they would engage with scientists and support research that contributes to the aim of finding a cure for Muscular Dystrophy. Thus, it is a patient-led organisation that acquired a hybrid character through the specific way of their interaction with scientists.<sup>76</sup> The AFM is characterized through self-help bonds between the affected people and an exchange relationship between scientists and affected people. Affected people contribute experience-based forms of knowledge, bodily materials and high amounts of money, whereas the scientists engage in research on the genetics behind Muscular Dystrophy. Thus, this relationship is one of mutual dependency, where each party is perceived to contribute indispensable resources.

The hybrid collective emerging in the context of the counselling centre for HBOC is structured quite differently as it has very different backgrounds. It did neither start as a patient organisation, nor is there an agenda of mutual self-help between the affected people. At the information evening we attended, hardly ever any affected person answered or at least referred to what another affected person had said before. Rather, all statements were addressed to the professionals, who appeared to be the lynchpins of the discussion.

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<sup>76</sup> Rabeharisoa 2003

Asking interview partners if they knew other affected people they said that they did not. Thus, affected people do not appear to connect to each other directly, rather they are connected via the professionals and their engagement.

Affected people do not seem to engage in mutual self-help. Actually, the main support structures are perceived to be provided by the professionals by offering a specific setting within the clinical contexts of a hospital where affected people have access to a distinct form of support. Thus, the hybrid collective is largely not about supporting each other, but about being supported by the professionals. Thus, the relation between professionals and affected people is different to that within the AFM. Affected people do not engage in self-help but are provided with help by the professionals.

Hence, how do the affected people relate to the professionals, given that the professionals provide all main support structures? How do they perceive what affected people contribute to the collective?

The data indicates that they frame their relation to professionals as an **exchange relationship**, but they frame their own contributions mainly as supporting the professionals, as giving back something for their efforts and thus as rather marginal to improving their own situation. Neither in the interviews, nor in participant observations we found accounts that affected individuals are perceived to *support each other*. Thus, their main contribution is to *support the professionals* who provide the support structures for the affected people.

Three main levels of what is considered as a contribution could be identified: First, participating in collective events, second, disseminating information about genetic testing and subsequent prevention and finally, providing bodily materials for clinical studies.

First, **participating in collective events** at the counselling centre, e.g. attending an information evening is not only conceptualized as doing something for oneself, but is also perceived as acknowledging the work the medical professionals do. During one interview we conducted before the information evening, our interview partner excused her niece who couldn't come to the event that day.

*And the niece, who can't come today, gives her best regards to the doctor, and she is so sorry, but she has to work today and couldn't take off, she would have liked to come so much. (Q19)*

Thus, attending collective events seems to be framed as a way to honour the personal engagement of the medical professionals and as a way to support them and thereby as a contribution to the common endeavour affected people and professionals share.

To reach this common endeavour, affected people and professionals have agreed on obtaining biomedical knowledge and engaging in subsequent forms of prevention. This commitment includes a normative stance that this is the best way to deal with genetic risk, and thus it implies that people in general should deal with genetic risk like that. Indeed, the medical professionals in the hybrid collective try to raise awareness about the hereditary forms of breast and ovarian cancer and the possibility of genetic testing. Hence, **disseminating information** about genetic risk, genetic testing and subsequent forms of prevention to a wider public is perceived as a way affected people can support the medical professionals in their efforts and thus contribute to the hybrid collective.

*Well, I work in a rather big company. And wherever I have the opportunity – we have several projects on health – there I already posted our [laughs], the brochures from [name of hospital]. Well, I think that should be done. [...] Well, I think it needs to be propagated, at least by word-of-mouth advertising, because otherwise I think, one notices it too little. (Q20)*

By posting “our” brochures, she contributes to the common endeavour of preventing illness, on a broader societal level. She perceives herself to propagate the ideas of the hybrid collective to a wider public, something she feels “needs” to be done. Thus, apart from their own well being, affected people appear to adopt the role that it is their obligation to spread information about genetic risk and thus support the professionals in raising awareness.

Finally, **providing bodily materials** for clinical studies is regarded as a contribution to the collective endeavour of preventing illness. As outlined in chapter 2, by the time the data of this study was collected, genetic testing in Austria was still financed by research funds. Hence, in addition to the clinical care they offer, the counselling centre must have a scientific output linked to genetic testing. Thus, from time to time tested individuals are asked to consent to research done on their blood or to give another sample of blood. Providing such bodily materials is framed as a third way of contributing to the hybrid

collective. It is considered as support to the familiar professionals who engage in research, but also as a way of contributing to research in general in order to improve the situation of present and future affected people. However, contributing bodily materials is not perceived as a rare resource affected people provide, but consent is framed as self-evident given the personal affectedness. Thus, this is an example where informed consent is not based on the information provided before giving the blood sample, but on the contexts this procedure is embedded in.

*Then she said, if I was so nice and would provide once again some vials of blood. And those I have provided, I have signed that they can do with them what they want. Well, I think, if someone is that afflicted, and he can help somehow, for others, if there is something, why not, some vials of blood. (Q21)*

Thus, drawing on accounts in the interviews as well as on participant observation, the relation between affected people and professionals can be framed as an exchange relationship. The main structures of support are perceived to be provided by the professionals, hence individuals do hardly frame themselves as supporting each other. Their own contribution is mainly limited to supporting the professionals by acknowledging their efforts through participation in collective events, aiding them in disseminating information about HBOC and genetic testing as well as providing bodily materials for clinical studies.

### 5. 3. Referring to Collectives of Thought and Agency

*Well, within my circle of friends there are quite a lot who don't want to know it. Well, I say, then it's your own misfortune, but don't cry, when you get something later on. If they offer you the chance, I say, and you are so stupid and don't take it, then it's your own fault. That's simply my opinion and I stand by that point of view as well. It's everyone's own fault, because of one's carelessness, that one gets something later on. One is offered enough, and if one doesn't take that, yes, then it's one's own fault. And I think often that, the contributions to the health insurance, I'm well aware, that they are exhausted somewhen, but then they should make the patients themselves pay. Because then one perhaps gets the idea sometime that one says okay, that was my own foolishness, or, I should perhaps really care for my health more, because everyone still saves costs for health. For everything else they spend money. I address for example the smokers, because I myself was one, and I stopped from one day to the next. And when I think about all the money I splashed on that, that I could actually have invested in my health. (Q22)*

While I have shown that the family at genetic risk and the hybrid collective are constructed and materialized in the very process of engaging with genetic testing of HBOC, there are yet other, more imagined forms of collectives that play an important role. These I want to label **collectives of thought and agency** and they will be the focus of this chapter.

What is exactly meant by collectives of thought and agency in the specific contexts of genetic testing for HBOC? What is their function and role? And what is the relation of the individual to these collectives?

As already outlined earlier, (new) technologies affect the social contexts they are employed in. Particularly, some specific technologies have the capacity to create new collective identities, such as Anderson<sup>77</sup> describes the creation of distinct ethnic communities in colonial times by the imperial technologies of the census, the map and the museum. These technologies assigned common identities to people that had not felt that they belonged together in this specific ways before. Some of these new collective identities were based on what was assumed to be “common ancestry”, but still others were assembled around what were believed to be shared religious beliefs and practices. Although these communities had

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<sup>77</sup> Anderson 1983; For related case studies on genetic analysis and ethnic communities see e.g. Simpson 2000 or Brodwin 2002

at first only been imaginations inscribed into the technologies, e.g. categories on the forms of the census, they started to become real as people slowly took over the imposed identities. In a similar manner, the socio-technical practices of genetic testing for HBOC contain and evoke distinct imaginations of collectives. But they do not only create new visions of families that are connected through a common genetic risk as I have described before, but moreover, the practices of genetic testing generate imaginations about communities of people that assemble around shared beliefs and practices of relating to genetic testing, the knowledge it produces and the forms of agency it entails.

Such imaginations appear to constitute important points of reference for individuals, as their social contexts become gradually reorganized by the technology and individuals thus have to find a way to get hold of what actually is or could be their own position towards and within these transformations. Thus, within this chapter, I want to focus particularly on imaginations about new collective value systems and collective forms of agency that are emerging more or less closely linked to this new technology of genetic testing. I want to investigate what it means that people relate their own (re)actions in face of genetic testing to what they perceive are accepted or acceptable ways of acting that are shared by wider communities of people in society.

For my analysis it seems promising to introduce Fleck's<sup>78</sup> concept of a thought collective. By that he means a community of people who share a common thought style that defines the spectrum of possible ways of thinking for those who are part of this collective. Referring to imagined collectives of thought and agency, rather than to collectives of thought only, emphasizes that in the context of genetic testing, imaginations about collective forms of thought are perceived as inseparably linked to imaginations about subsequent collective forms of agency.

Thus, the imagined collectives of thought and agency represent imagined communities of people who share a common style of thinking and acting in relation to genetic testing in particular, and in relation to health issues in general. These collectives are multiple, among them some being perceived to represent what is a normal and/or favourable way of thinking and acting, whereas others in contrast represent what is perceived as abnormal and/or unfavourable.

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<sup>78</sup> Fleck 1980 [1935]

By referring to these collectives, by inscribing into some and taking distance to others, our interviewees **create and balance their own ways** of thinking and acting. They negotiate what to them could be a possible framework to think about undergoing genetic testing as well as consequently an acceptable course of actions.

In this process they also **generate imaginations about collectively preferred and preferable forms of thought and agency** on a broader societal level. For most areas of our life we experience step by step what is the range of accepted positions one can take, which behaviour is considered normal and which is not. Thus we learn to relate our own ways of thinking and acting to these normative positions in some way. For genetic risk, such normative frameworks do not exist yet, at least not on a broader societal level, as it is neither a frequent topic of public discussion nor of media debates. Thus, a priori there appear to be no clear ideas about what are acceptable or preferable ways of thinking and acting in relation to genetic risk. Creating imaginations about a collective of people who share and represent such a preferable way of thinking and acting is a way to give some broader framings to an otherwise largely frameless position and thus allows constructing a framework of reference that exceeds individual opinions and decisions.

Thus, the references to collectives of thought and agency also represent **strong normative claims** about what is a right and what is a wrong way of thinking and acting in medical concerns. Making these claims by referring to *imagined* collectives allows formulating such normative statements even more easily, because they don't have to be related to any specific individual, and thus his or her particular contexts do not have to be considered. This permits constructing an "ideal type" of handling genetic risk that does not have to be set into relation to the difficulties and specifics of individual contexts.

Although there are some collectives that are quite dominant, generally there is **more than one collective of thought and agency** each individual is relating his or her position to. Every individual is part of a number of different collectives that hold partly distinct thought styles that may support, but also contradict each other. Some collectives are strongly influenced by biomedical ways of thinking, whereas others are rooted in social communities, may they be familial, local or national. Some of them may also carry highly gendered connotations, ascribing very different roles and capacities to men and women. Thus, generating one's own position is also a process of balancing these different collectives of thought and agency one is part of.

In a context that includes fear, sorrow and hard decisions, being part of some collectives of thought and agency is perceived as more supportive, whereas others are perceived as more burdening. Thus, inscribing into specific collectives at specific points in time represents a **resource to deal with upcoming challenges**. In turn, dismissing diverging forms of thinking and acting as inappropriate or unwise is used to strengthen these inscriptions and hence appending decisions and forms of agency.

However, these processes of balancing and negotiating one's position is one that is **temporary and multilayered in character**, as the contexts and challenges one is facing may change over time. As time passes by, one may become part of new collectives of thought and agency or the importance of certain collectives may shift. Thus, defining one's own position is never finished: it needs a constant rebalancing of the different collectives one is part of and of the different values, attitudes and worlds they represent.

**Contradictions and divergences** between some of these collectives can't always be resolved. Thus, some positions integrate seemingly conflicting stances, which allows the individual to remain part of diverging collectives of thought and agency by emphasizing different aspects of this position in different contexts.

After these introductory remarks have highlighted the basic characteristics of imagined collectives of thought and agency, I will in the following describe three major aspects of their formation. First, I will outline how the formation of imaginations about such collectives is linked to particular challenges individuals encounter in the process of genetic testing. Second, I will show how the specific character of the way people relate to these challenges leads to the formation of one major collective that I will label the imagined collective of preventive selves, and further how people argue why it is important for them to inscribe into that particular collective. Finally, I will show how this inscription interacts with other collectives our interviewees consider themselves part of.

### **Encountering Major Challenges – Referring to Imagined Collectives**

Mainly, references to specific imaginations of collectives of thought and agency appear in connection to aspects of genetic testing that are particularly challenging to the individual.



These main challenges are to find a way how to frame what it means to be genetically different from the norm (I), the knowledge that is produced in genetic testing (II) and the responsibilities that are co-produced (III).

(I) How to frame what it means to be “genetically different” from the norm?

*“Now we have that, and now we just say, others have the gene with the heart attack and we just have that breast cancer gene. And if, one can do something against that. And in good hands, we say, we are as well.” (Q23)*

Within this statement there are multiple layers of references to imaginations about collectives that lend a frame to what it means to be genetically different. Being genetically different means *having* “that breast cancer gene” and *sharing* that gene with other members of the family. Furthermore this is connected to practices of *doing* “something against that” as well as to people *caring* for those who have that gene. This having, sharing, doing and taking care are the main attributes of the collective that this woman describes as well as inscribes herself into. This collective resembles what Paul Rabinow has called a biosociality.<sup>79</sup> Rabinow points out that the application of genetic testing leads to the formation of collectives that assemble around shared genetic markers. These collectives also share exclusive medical practices and specific forms of agency. Furthermore, they are supervised by “pastoral caretakers”, medical professionals that are specialized in taking care of them by biomedical means.

Within her statement this woman imagines that she is part of such a biosociality. That could be something special, something odd. But it is not, because she furthermore imagines that there are similar forms of such biosocialities based on other genetic differences present throughout society, for example biosocialities that assemble around a genetic risk for heart attack.

Thus, coming back to the question how people frame what it means to be genetically different, they frame it by normalizing that difference on two levels: On the one hand, they normalize the genetic difference itself by referring to this specific genetic difference as one

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<sup>79</sup> Rabinow 2004

out of many genetic differences. On the other hand, they also do so by normalizing the biosociality they inscribe themselves in by assuming that being part of such a social form is widespread and common throughout society. Consequently, by referring to these imaginations, the genetic difference as well as the appending social forms are largely rendered something “normal”.

(II) How to frame the knowledge that is produced in genetic testing?

*“Because most say, in fact they don’t want to know that. I say, well, then you are foolish. I say then you are stupid in my view.” (Q24)*

Within all imaginations about collectives of thought and agency found within the interviews, the role attributed to knowledge is of special importance. The biosocialities described above are based on a commitment to acquire biomedical knowledge and to accept its ascribed capacities as directive and thus to transform it into biomedical forms of agency.

This approach includes a conceptualization of knowledge as being exclusively of benefit, and thus, possessing this sort of knowledge is conceptualized as being intrinsically good as it is perceived as the foundation of forms of agency that are evaluated as being the most adequate – or the only adequate – form of agency.

As indicated in the statement above, it is common to draw quite harsh borders towards those who do not evaluate this knowledge in a similar manner. Attributing negative effects to acquiring genetic knowledge is refused, as the vast majority of our interview partners do not consider “not wanting to know” to be a legitimate attitude. Thus, the way one relates to knowledge is a fundamental category of in- and exclusion into imaginations of collectives of thought and agency. Within our interviews, people inscribed themselves into an imagined collective of those who want to know and want to act upon the basis of this knowledge. At the same time, they distanced themselves from those who refuse to relate to knowledge in such a manner. However, it is important to keep in mind that all interview partners belong to a group of people who actually decided in favour of undergoing genetic

testing and subsequent prevention, thus in favour of acquiring knowledge and adhering to knowledge-based forms of agency.

This emphasis on acquiring knowledge is firstly related to the degree of risk that is ascribed to an individual. Thus, our interviewees seem to accept if men, to whom carrying a mutation would mean only a very small risk as compared to women, do not want to know. But secondly, acquiring or refusing knowledge is also assessed in relation to the responsibilities that are ascribed to individuals: If men want to become fathers or are already fathers, refusing to know is no longer accepted as a legitimate decision, as they are perceived to put potential or actual daughters at high risk.

Thus, there are imaginations about distinct moments where individuals should obtain knowledge in particular: First, if there is imminent risk to one's own health and/or second if someone else could be put at risk. In both cases it is perceived as the very basis for any capacity to act.

### (III) How to frame the responsibilities that are co-produced?

*I: Did you ever think about just saying, I just forget that it is in our family, I really don't want to think about it, I don't want to know that?*

*I think there have been brief moments, really very, very brief moments. I mean, I was aware that it is there and I witnessed it, and it was clear to me that I don't want to experience that again and that I want to spare my children from that as well. [...] That's something that does not only influence my life, but also the children's. (Q25)*

There are specific forms of responsibilities that are created in relation to the knowledge one gains in genetic testing. Knowledge is conceptualized as such that shall result in agency with the aim to avoid falling ill. Not to fall ill is perceived as a responsibility towards oneself, but also towards others, as the quote above illustrates. These others range from one's close relatives and first of all one's children, who must not witness one's suffering, to the medical system and the society in general, who must not be burdened by the costs this suffering would bring along. Thus, defining limits to what constitutes

responsible behaviour towards these different others, to inscribe oneself into a broader collective of people who think and act responsibly, is a major strategy to deal with issues of guilt that can and do emerge in the contexts of expectations about responsible behaviour.

There is a rather clear definition present of what constitutes this responsible behaviour. It is characterized by the willingness and the commitment to know and to act on the basis of this knowledge. By imagining that this definition of responsible behaviour is shared by a larger group of people, norms of responsibility can be established. Hence the individual does not stand alone in deciding which kinds of actions are responsible. Thus, imminent guilt of having acted irresponsible can be kept at distance by imagining oneself to be a part of a collective that is characterized by acting responsibly.

Framing the emerging forms of responsibilities is one challenging aspect of genetic testing that is highly gendered. Especially in family contexts, women are much more expected to look after their family members than men.<sup>80</sup> Thus, imaginations about what can be expected from a man and from a woman influence how much devotion towards these norms of responsibility is expected in order to be legitimately part of such an imagined collective of people who think and act responsibly.

### **Becoming a Preventive Self**

So far I have outlined that within our sample of interview partners, referring to imagined collectives of thought and agency appears to serve as a way to normalize genetic difference and to frame genetic knowledge and subsequent forms of agency as exclusively beneficial as well as responsible. Thus, any imagination of a broader collective our interview partners would inscribe into must be based on a conceptual framework that combines these ways of relating to the challenges of genetic testing. “Prevention” appears to be this concept. First, it constitutes a way of relating to risk that our interview partners perceive to be increasingly important throughout society and thus appears to be relevant and “normal” for more people than only for those at genetic risk for HBOC. Second, it is largely centred on creating and obtaining risk-information. Third, it implies to act in advance on behalf of this

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<sup>80</sup> For further studies on this issue see Hallowell 1999 or d'Agincourt-Canning 2001.

information, in order to prevent oneself and others from being harmed by illness. Thus, it is perceived to acknowledge both the commitment to knowledge and knowledge-based agency and the subsequently emerging responsibilities. Hence, it seems to be the case that our interview partners imagine themselves as being part of a collective that shares a commitment to biomedical forms of prevention. The biosocialities mentioned before are considered to be a sort of prototype to this idea of a collective that engages in responsible knowledge-based forms of agency that are based upon preventive thinking. Drawing on the concept of the “*preventive self*”,<sup>81</sup> that “*ideal individual that works on his or her health*”, this imagination could be described as an imagined collective of preventive selves. To be able to envision oneself as a part of these preventive selves appears to be a major strategy in arranging oneself in the difficult and ambiguous settings of genetic testing. Narratives of inscribing into this collective are found throughout the interviews, though to varying degrees.

Why become a preventive self? Although throughout the interviews inscribing into the collective of preventive selves is portrayed as preferable on a general level, there are different narrations on *why* one should become a preventive self. They range from referring to making use of a chance (I), to being a necessity without any alternative (II), to representing the result of a process of maturation or enlightenment (III). These narrations present a set of different concepts that may coexist in one person and in one interview. They can be adapted to the specific contexts of a person, for example though one can refer to one’s own process of inscription as a necessity, one can grant others the right to undergo a process of maturation until he or she finally arrives at the “right decision” to join the preventive selves. What all these narrations have in common is that they clearly argue for inscribing oneself into the imagined collective of preventive selves in a normative sense.

#### (I) Making use of a chance

*I just accepted the whole thing, well, that’s just the way it is, and I just have the chance – there are many women for sure, who don’t have that – and I now have the chance, that I do all that preventively here. (Q26)*

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<sup>81</sup> Beck 2007

At the first glance, framing becoming a preventive self as making use of a chance seems to be a rather simple concept. But when taking a closer look, it becomes visible that embedded into this idea of taking a chance is a complicated relation of free decisions and normative instructions.

On a first level, conceptualizing the inscription into the imagined collective of preventive selves as a chance turns *not* inscribing into letting go a chance. Thus, getting a chance does not equal having an option: it is a much more normative stance in the sense that it holds a clear preference for *taking* the chance. Hence it allocates the need for explanation of one's action unevenly between those who opt in and those who opt out.

On a second level, this normative stance creates a field of tension with the again normative stance about the importance of a free decision towards genetic testing. On many occasions, the interviewees refer to the idea that it is very important that each individual decides freely about undergoing genetic testing. Nevertheless, deciding for the test is portrayed as being normatively better, because *"if medicine is that advanced, one should make use of it"* (Q27).

This reflects a tension that is already integrated in the standardized package of theory and method<sup>82</sup> that constitutes the socio-technical practices of genetic testing. Genetic testing is meant to enable preventive action. It is meant to be applied by individuals that could carry a specific genetic marker to provide them with knowledge to act upon preventively. However, the medical contexts of its application have strongly incorporated the agenda to assure deliberate decision-making, which is realized through rules of non-directiveness of counselling processes as well as through informed consent procedures.

Both represent ideas about valuable forms of agency that cannot be reconciled. If taking preventive action is better than not taking preventive action, then a free decision to refuse genetic testing is a wrong decision. Then again, if freedom of decision-making is of indisputable value, every decision must be accepted equally. Both logics are present, as the interviewees inscribe themselves into both thought styles. Thus inscribing oneself into the imagined collective of preventive selves causes tension with perceiving oneself as a part of a collective of people that value personal autonomy in decision making.

On a third level, this tension is a tension between two different points of view, one that always integrates the collective dimensions of genetic testing, and one that is largely

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<sup>82</sup> Fujimura 1992

focussed on the individual. Letting go the chance to act in advance, to adhere to concepts of prevention and hence not to make use of the chance of genetic testing is not only criticized as unwise on a personal level, but also always as irresponsible on a collective level, for example as irresponsible towards one's children. Personal autonomy is a concept that basically does not stress any collective dimension. It is about individual choice and individual freedom. Although the concept of taking a chance seems to acknowledge both, freedom of decision-making and what is conceptualized as the benefits of genetic testing, it cannot reconcile these two fundamentally diverging agendas that are part of the standardized package of genetic testing.

(II) Being a necessity without any alternative

*The test, I know, it is not pleasurable, but I know I have to do it, for that I eventually have some chance to survive. (Q28)*

In her work on how people that underwent genetic testing for Chorea Huntington explain how they arrived at the decision to take the test, Sue Cox<sup>83</sup> shows that some do not refer to any decision-making process at all and simply state that they *had to know*. Similarly, inscribing into the imagined collective of preventive selves is sometimes conceptualized as a necessity without any alternative. The inner pressure to avoid illness and death is so immense, that every way other than clinging to preventive action is totally out of the question. There is no room for any understanding of those who do not want to know. Becoming a preventive self is not perceived as a choice, but as the only possible course of action.

However, such narrations that postulate a necessity to become a preventive self undisputedly and immediately can be faintly interrupted by hints at some vague imaginations about what could have been if one had never known anything about any possible genetic predisposition in the family.

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<sup>83</sup> Cox 2003

*Umm, well, from the moment that I then knew that there is basically the possibility that I'm genetically predisposed, it was pretty clear that I want to know if this is the case. And, well, as it happened all in one moment, there were no considerations in between if I want to get tested or not, that was obvious. (Q29)*

This suggests that narrations that refer to becoming a preventive self as something unavoidable ground on a great fear that is evoked by knowing that there is the possibility of a genetic predisposition. Only the state of not knowing anything about such a possibility could resolve the urge to cling to prevention. Hence, the inscription into the imagined collective of preventive selves is evaluated differently according to different moments of knowing and not knowing about any genetic risk. Knowing about a possible predisposition is equated with *having* to become a preventive self.

Typically, individuals that perceive that becoming a preventive self is an absolute necessity learn about a possible *genetic risk* within medical settings without having had any long held idea of a *familial predisposition* before. Thus, as the quote above illustrates, learning about a possible genetic risk is immediately connected to the availability of a genetic test and subsequent forms of prevention. In other words, the possibility of having a familial predisposition is instantly defined as the distinct doable problem, that of genetic risk, to which there exists a standardized package of solutions, namely to undergo genetic testing and thus to become a preventive self.

Consequently, without agreeing on the solution, the problem of genetic risk one suddenly faces is no longer defined as “doable”. Hence, agreeing on that solution of becoming a preventive self is perceived as a necessity, because otherwise, one would face a problem that is no longer a doable one.

In contrast, narrations that centre on chance are mostly created by individuals that have lived with the idea of a familial predisposition for quite a while. Hence, defining the familial predisposition as genetic risk and thus as a doable problem is an improvement to their situation, and thus equals a chance. To the individuals that conceptualize becoming a preventive self as a necessity, learning about genetic risk *is* the problem that suddenly arises. Thus, keeping this problem doable by unconditionally agreeing on the offered solution of becoming a preventive self appears to be a necessity for them.



## (III) Representing the result of a process of maturation or enlightenment

*Well, I think the decision is much to grave to make it that easily. Well, you need to engage yourself in it, no matter how. For me, it was conversations with close and loose friends, and doctors and simply the time and the things that happen to me in that passing time. (Q30)*

In contrast to the first two approaches, the approach of maturation or enlightenment has a different temporal dimension. Whereas the others focus on one specific moment, this approach allows for a longer period of time to pass. Within this time, the individual is imagined to gradually grow into the collective of preventive selves.

Cox<sup>84</sup> refers to similar narrations about decision making for genetic testing for Chorea Huntington as *evolving towards* the decision. Both terms, *evolving* and *maturing*, imply that the endpoint of these processes is more favourable than its starting point. Thus, becoming a preventive self is portrayed as normatively better than not becoming a preventive self. If one does *not* evolve into being a preventive self, something has gone wrong, the logic of maturation implies.

The process of maturation is conceptualized as one that requires work. One needs “*to engage*” with the possible decision, to talk about it and to confront and integrate what is happening. Thus, those who do not mature are conceptualized as people who either do not want to engage in this kind of personal work or who do not hold the emotional or intellectual capacities to do so. However, both explanations imagine that the individual has for some reason failed to become mature and thus to become a preventive self.

Often men are perceived as especially resistant to such a process of maturation. As one woman phrased it: “*The girls, they take it seriously now, but my sons don’t take that the right way.*” (Q31) However, men who remain in this position are more often excused than women, as they are not at high risk themselves, but also because refusing to become a preventive self is considered to be something typically masculine. Hence, men are perceived to remain immature not because they lack the capacity of maturation, but because becoming a preventive self would contradict what is conceptualized as their masculinity. Thus, the concept of being a preventive self is understood as a largely

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<sup>84</sup> Cox 2003

feminine concept as it links up with traditional imaginations of women caring more about their health and the health of their beloved than men do.

The imagination of becoming enlightened<sup>85</sup> is similar to the process of maturation, but is conceptualized as a less active process. It is a narration that is based on the idea that after one has encountered the basic ideas of being a preventive self, one at least after a while realizes that this is the best way to think and act. Thus, whereas the idea of maturation stresses the importance of personal and autonomous engagement in decision-making and acknowledges the difficulties it holds, the idea of becoming enlightened emphasizes more strongly the idea that someone finally realizes what has obviously been the “best” way of thinking and acting all along.

Within imaginations of becoming enlightened, medical professionals are more present and important than in other narratives. They possess the significant knowledge and by sharing that knowledge, they allow the individual to become enlightened. Thus, “becoming enlightened” is not only to acquire knowledge and to embrace the notion of action tied to this special kind of knowledge, but it is also a reference to a specific social status that is gained through a personal relation to these medical actors.

Both narratives about maturation and enlightenment represent imaginations of personal evolutionary processes towards becoming a preventive self. This idea of personal evolution is paralleled by the idea that also society as a whole is undergoing a similar process. Being a preventive self is imagined as something modern and urban, that is slowly but steadily spreading to other parts of society that are not yet modern. That “*it has spread to the Burgenland*” (Q32), which is a rather rural part of Austria, is perceived as a surprise, but as a positive one. Thus, inscribing into the collective of preventive selves is also perceived as something modern.

Summarizing, chance, necessity and maturation/enlightenment are different imaginations about how and why people become part of the imagined collective of preventive selves.

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<sup>85</sup> In German, the term „aufgeklärt“ has a more ambiguous meaning than the English term “enlightened”. In addition to the more historical connotation, it also has an everyday meaning that is similar to being informed, but also includes that one has understood something in the process of information and that one is now able to see things more clearly – more enlightened.

Nevertheless, all of them make the normative stance that it is preferable to inscribe oneself into this collective, and they devalue other decisions to at least some degree.

### **Living in Diverging Collectives**

Each individual is part of different collectives, some imagined, some real. Hence, becoming a preventive self and thus inscribing into a new collective of thought and agency has to be balanced with being part of other collectives as well.

Within our sample, being part of the collective of preventive selves is a rather dominant imagination about what is normatively the most preferable way of thinking and acting. However, it is not an imagination that is perceived to be shared throughout society. There are areas where it is more common to commit to prevention, such as the contexts of the counselling centre, and others where it is rather uncommon.

Thus, this part focuses on the way people transfer being a preventive self into these other collectives that are not primarily dominated by the idea of prevention. There is a broad spectrum of how people do that, but these different ways are located between two extremes that are linked to the question whether an individual perceives that his or her position within this other collective is improved by becoming a preventive self or not.

Living in a rural area, a woman coming from a family that is heavily affected by breast cancer draws on the idea of having been enlightened to explain why becoming preventive selves was the best thing that could have happened to her and her family. First, she feels that she has found a way to do something against “the illness”. But on a second level she feels that becoming a preventive self has also improved her position in the local community of the village. She refers to former incidences where she felt stigmatized because of her family’s illness, e.g. when she was openly addressed as the next in line to die by another woman in the local grocery store. Now, knowing the genetic causes of the family history and having become a preventive self, she feels that she is no longer subjected to bearing a stigma. On the contrary, she now perceives herself in an enlightened and privileged position that she feels is also recognized by the local community. Indeed, she has become the local expert concerning breast cancer in general and hereditary breast cancer in particular, that is consulted anytime there is a case of breast cancer in the village.

Thus, she has become a representative of the collective of thought and agency she has inscribed herself into and her position in her local community is hereby transformed and, as she perceives it, improved. She no longer feels stigmatized. Thus, transferring her position into this other collective is a process of expansion and hence of further stabilization of her position.

In the case explored above, becoming a preventive self is experienced as removing a stigma, whereas in other contexts it can also be framed as *creating a stigma*. One of our interview partners, a young, highly educated woman, emphasized explicitly how happy she was with her decision to undergo genetic testing and later on mastectomy as well. However, she expressed that she was very concerned that the majority of society would not understand why she has done so and thus she keeps her ideas and decisions to herself.

*That is just my fear, why I don't want to shout it out loud. Because I would have the feeling or the fear, that I'm perceived as malfunctioning or not fully operational anymore. Well, the concern that it lifted from me, and I just know, that it's not like that, indeed, I feel much more operational than ever or than during the last ten years, that's something I don't believe that society is capable of, honestly speaking. (Q33)*

Although this woman perceives that having become a preventive self is beneficial and empowering for her on a personal level, she is concerned that society in general would not understand that and instead regard her as ill or handicapped or would disapprove her actions taken. Thus, although she feels that becoming a preventive self has improved her position on an individual level as it has removed her fear of falling ill, it has put her in a difficult position on a societal level. Hence, her being a preventive self is experienced as *creating* a stigma in another collective she is part, in this case, society at large. Transferring her being a preventive self openly into this other collective she is part of is experienced as difficult and thus as rather destabilizing her position.

Keeping one's attitudes secret is a common way to deal with the tensions that appear to exist between different imagined collectives of thought and agency. But such tensions do not only arise towards others, they also occur within *one* individual.

Each individual is part of more than one imagined collective of thought and agency. Reconciling the imagination of being a preventive self with other identity claims and diverging collectives of thought and agency one is part of constitutes a process of ongoing negotiation. Sometimes these different imaginations can't be reconciled at all and the individual remains in zone of tension.

One moment that can cause such conflicting imaginations to surface appears to be the effort to frame one's own position towards the preventive removal of the breasts. Mastectomy represents the most drastic realisation of preventive thinking. It nearly eliminates any elevated risk of breast cancer. Thus, within our interviews, it is often explicitly and implicitly referred to as the most committed act of prevention possible. Having said this, it is obvious that removal of the breasts is a serious issue concerning imaginations of womanhood and sexual attractiveness. Thus, if undergoing mastectomy is on the one hand perceived as most desirable because it is the perfect realization of preventive thinking, but on the other hand unthinkable because it would so much shatter one's sense of femininity and attractiveness, it is hard to reconcile these two positions into a coherent one. The decision *not* to undergo preventive surgery is not a fully acceptable one within the frames of being a preventive self. So, in the course of the interview, this young woman comes back to the issue of preventive surgery several times. She is very committed to preventive action, but then again she can't imagine living with artificial breasts.

*Well, then I said, I want to know about everything and everything... I mean, the amputation, I do push away that very far for once, because I, I don't want to acknowledge it at all. [...] Removing the uterus, I would have no problem with that, but up here, no, I don't want that. [...] They have to remove the nipples, too, and I can't imagine that it will look like natural breasts again. Of course, there is this possibility, but not for me. (Q34)*

Through her reoccurring references, it becomes apparent that she cannot reconcile these different identity claims of being a committed preventive self and an all-natural woman at the same time. Thus, while inscribing into the imagined collective of preventive selves that is perceived to be normatively better than other approaches to health matters constitutes a way to deal with the challenges that are embedded in genetic testing, its normative

character can also become a challenge in itself. It can cause serious tensions in case the individual needs to reconcile this strong normative claim of fully committing to prevention with diverging ideas of selfhood present in other collectives of thought and agency he or she is part of.

## 6. Conclusions

In this thesis I have argued that genetic testing affects individuals through complex processes of collectivization. In a way this is a narration quite similar to Anderson's<sup>86</sup> accounts on the census, the map and the museum as technologies, which do not simply represent but reconfigure a population, a country in a specific way. It explores how a technology like genetic testing brings collectives into being by creating distinct imaginations about a common identity.

While the practices of drawing a pedigree only visualize a “family at genetic risk”, this version of family does not remain purely imaginary at all. It comes to live as relations between its members are reorganized around genetic risk. These processes of rearranging familial collectives are intertwined with yet other processes of collectivization, resulting in collectives of professionals and affected people and creating again other imaginations about communities of people who relate to this technology in a distinct manner. Thus, whereas for example the census facilitated a process of colonization of ethnic groups by ascribing them distinct identities related to religion or ancestry, genetic testing colonizes individuals and bodies in relation to an imagination of genetic risk that is framed as relational and collective.

Hence, I have shown that genetic testing appears to be a technology characterized by the tendency to induce processes of collectivization. It is thus far from creating simple binary categories of affectedness such as being or not being at risk. Rather individuals become situated in a complex network of relations to multiple others, to family members, to professionals of diverse backgrounds and to imagined communities of people they perceive to represent or not represent how one should deal with genetic risk.

I have described and analysed that these emerging collectives form in close relation to specific individual as well as local clinical contexts. As such contexts are shifting over time, individuals give different meanings to the collectives they are part of at different points in time. Thus, there is not one, but there are multiple, highly situated versions of these collectives, interacting with one another.

Individuals within these networks of collectives create their own positions by balancing and negotiating, arranging and rearranging multiple identity claims, responsibilities and

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<sup>86</sup> Anderson 1983

commitments. Thus, emerging biomedical identities always have to be understood as both, individual *and* collective.

Although these plural identities are created through the technology of genetic testing, the technological artefact itself remains largely black-boxed. What this technology is or does becomes only graspable and relevant through the social networks it is embedded in, and in turn, through the social collectives it is creating. Hence, genetic testing is perceived mainly not as technology per se, but as a socio-technical practice generating collective modes of affectedness.

This collective character of affectedness is due to the very nature of the knowledge produced in genetic testing. “Genetic risk” is foremost framed as a relational kind of knowledge, one that is produced out of distinct interpersonal relations such as family structures, but also one that puts this individual in relation to others. Thus, to make sense of this relational character of genetic risk, its meaning is negotiated and interpreted in relation to other forms of knowledge, e.g. that are based on collective experiences. Hence, far from being a process of mere understanding or not understanding, making sense of genetic risk is a complex process of integrating this new form of knowledge into the contexts of one’s life. Thus, genetic knowledge gets interwoven into the social structures one is part of, into the “*cloth of everyday living*”<sup>87</sup> and this is where it is deploying its meaning.

Within the given sample of interview partners, this meaning is strongly connected to forms of agency that it is perceived to entail. Obtaining genetic knowledge is deemed relevant as it constitutes a capacity to act within biomedical settings. Agency based on this knowledge is framed as rational and responsible. Thus, the interviewees largely consider refusing to obtain this knowledge or not engaging in subsequent forms of agency irrational and irresponsible towards oneself, one’s relatives and society in general.

The data indicates that committing to biomedical practices of prevention, either by attending intensified early diagnostics or by undergoing preventive surgery, constitutes in an almost exclusive way what is accepted as a rational and responsible way of dealing with genetic risk. No alternatives to becoming a “preventive self” appear to be fully acknowledged. This exemplifies contemporary transformations due to the biomedicalization of society that tries to enforce self-responsible health-management.

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<sup>87</sup> Lambert/Rose 1996



However, in the Austrian society this thinking is not perceived to be commonplace. Thus, although there have been some accounts on a further expansion and stabilisation, most individuals that commit strongly to prevention appear to experience difficulties in transferring this novel biomedical identity claim to other communities they are part of and consequently, in reconciling diverging concepts of self-hood. This seems to particularly concern decisions on undergoing preventive removal of the breasts, as interviewees largely referred to this kind of preventive action as neither understood nor approved by the majority of society.

Despite these difficulties, our interview partners did not express any regrets about their decision to undergo genetic testing, nor about preventive actions they took. This may be due to the specific sample of people we talked to, or it could be due to the specific Austrian contexts, where legal regulations are largely considered to protect mutation carriers well, as e.g. employers and insurance companies are not allowed to obtain or use any genetic data. But this could also be a result of the specific local contexts of the counselling centre. The collectivization of professionals and affected people around their common endeavour to prevent breast and ovarian cancer in at risk individuals and the structures of support that are offered appear to contribute a lot to this positive assessment. Being part of this hybrid collective is perceived as granting affected people access to a privileged, familiar sphere within an anonymous medical system that is experienced as more or less ignoring the specific histories, situations and needs of individuals at genetic risk. The collective is framed as giving room to the multiple implications of genetic testing as well offering support in dealing with subsequent difficulties and responsibilities within a small, familiar community. Thus, the hybrid collective allows affected individuals to obtain and experience genetic knowledge in a social setting that makes it possible to interpret it in a rather positive way.

At the moment, genetic testing for HBOC is still rather unknown in Austria. It is neither a topic of media discussions nor of broader public awareness. However, it could become one during the next years. Public funding could provide both a basis to offer genetic diagnostics on a more routine level as well as to increase public awareness about its existence. Statistically speaking, there would be 27.000 individuals that carry a genetic mutation in Austria, thus thousands of families genetic testing for HBOC could concern. I have argued that the collective clinical structures genetic testing is presently embedded in

could be central for the overall positive resonance it evokes. Thus, it appears that it is the sum of socio-technical practices that are part of genetic testing that are perceived and received positively. Thus, what would it imply if the social setting of its application changed? What would it mean to individuals if they would encounter genetic testing in a much more anonymous context than they do now? What if the focus would shift much more to the mere technological practice of genetic testing, without being embedded into a familiar collective structure that offers support and care?

In order to understand what multiple challenges individuals then could face and what this in turn would mean in terms of challenges for the medical system, it is important to consider the collective forms of affectedness that are created through genetic testing, the complex networks of interpersonal relations individuals become part of.

## **Annex 1: Original Quotations**

Q1:

Bei uns ist es halt in der Familie genetisch. Und zwar meine Mama hat mit, ich glaube, 37 oder 38 ein Mammakarzinom gehabt und meine Tante ein oder zwei Jahre später, also, die Schwester von meiner Mutter. Und, ja, und es ist halt von meiner Mama ihrer Seite väterlicherseits ist das Gen in der Familie.

Q2:

Na, es ist so, dass in meiner Familie, gibt es einige Fälle an Unterleibs- und Brustkrebs, also, relativ viel eigentlich. Und ich hab dann irgendwie dann so ein bisschen mal nachgeforscht und herausgefunden, dass es da drei Schwestern gab, so meine Urgroßmutter. Und zwei von diesen Schwestern hatten Krebs. Und das hat sich dann fortgesetzt. Und eine Großkusine von mir, die auch eine sehr gute Freundin ist, die hat dieses, die hat sich eben auch testen lassen nachdem ihre Mutter an Krebs gestorben ist und hat dann festgestellt, dass sie dieses Krebsgen hat. [...] Ja, und da hab ich mir schon öfter überlegt, dass es ja eigentlich ganz interessant wäre zu schauen, ob ich das jetzt irgendwie auch hab oder nicht. Es ist nämlich so, dass eben von dieser einen Schwester alle Nachkommen ist zumindest noch niemand erkrankt. Also, so wirklich was ist oder nicht, haben wir natürlich nicht gewusst.

Q3:

Meine Mutter ist im Jahre 94 an Brustkrebs erkrankt, was halt dann weiter in Dünndarmmetastasen und Gehirntumor gegangen ist und ist im 99er daran verstorben. Und da war das mehr oder weniger dann im [Name des Spitals] dann, also, wie wir eben gemeldet haben, dass eben die Mutter verstorben ist, ist uns mehr oder weniger gleich der Vorschlag gemacht worden, meiner Schwester und mir, dass wir anhand einer Genuntersuchung feststellen können, ob wir diesen Träger haben oder nicht. [...]

I: Vielleicht ein kleines Detail sozusagen davor noch. Neben Ihrer Mutter gab's andere Familienangehörige...?

Es ist von meiner Mutter die Schwester gewesen, nur da weiß ich definitiv nicht, ob das jetzt Eierstockkrebs war. Sie hat auf alle Fälle einen acht Kilo schweren Tumor in der Gebärmutter gehabt, was halt Fahrlässigkeit von ihr war, sage ich jetzt einmal. Und was ich weiß, ist die die Großmutter von meiner Mutter hat das auch gehabt, also, von der Ahnenforschung dann her, die dann war, da ist irgendwie festgestellt worden, dass die Großmutter von meiner Mutter eben diesen Gen auch gehabt hat.

Q4:

Ja na, wir haben schon schon geredet, aber ned, nur mit der Kusine. Die die hat gesagt, ah, deine Mutter und mir, und jetzt hast es du auch und... Aber aber dass das dass man das, Gene haben, ned, es ist halt Zufall, dass ich's auch gekriegt habe, ned, aber dass das in den Genen liegt, das haben wir haben wir nicht gewusst oder nicht gedacht.

Q5:

Weil ich mir eigentlich eh schon gedacht habe, dass es, dass es so was geben muss, also, wie einen genetischen Defekt, ne, also, und dass der wahrscheinlich in meiner Familie da ist. Also, es war mir eigentlich eh schon klar. Und ich wollte eine Gewissheit, um weitere Schritte, wie z. B. eine Mastektomie machen zu können.

Q6:

Ich hab's dann erst machen lassen mit wie ich schon 19 war oder kurz vor meinem 19. Geburtstag. Also, ich hab mir dann noch ein Jahr Zeit lassen, weil ab 18 ist es dann gegangen, und hab mir gedacht, ob ich das wissen will?

Q7:

Nein, ich zweifle nicht dran, ob ich's ihr sage, weil ich denke mir, dass' wichtig ist, dass man das sagt. Weil ich habe kein Problem damit, wenn sie's weiß oder so, weil es ist...

I: Ja, gar nicht so sehr, aber auch die Frage, irgendwo entscheiden Sie ja auch für jemanden anderen, dass er das dann weiß oder nicht weiß. [...]

Ja, aber es ist, andererseits könnte ich mir, wenn dann wirklich was wäre, hätte ich dann ewig lang ein schlechtes Gewissen. Und das will ich wieder nicht haben.

Q8:

Also, ich hab dann zwar meine Schwester auch dazu überredet, diesen Test zu machen. Aber, ja, die hat das, ich sag einmal, sie hat's primär deswegen gemacht, weil sie zwei Töchter hat und wahrscheinlich wissen wollte, ob's da die Möglichkeit hat, an die das weiterzugeben.

Q9:

Ich meine, ich weiß nicht, ob meine Kusine jetzt gegangen ist, also, von meiner Tante, die auch verstorben ist, ob die jetzt wirklich gegangen sind, also, das weiß ich nicht. Ich habe mit denen auch keinen Kontakt mehr.

Q10:

Meine Cousins, ja, die wollen irgendwie nicht, die haben, glaube ich, Angst. [...] Und die haben gesagt, ja, wenn sie Kinder wollen, dann lassen sie sich halt testen. [...] Aber ob sie das dann wirklich machen?

Q11:

Ich hab's miterlebt, und ich, mir war klar, dass ich dasselbe nicht noch mal, mitmachen will, und dass man das eben seinen Kindern genauso ersparen will, ne. [...] Das ist was, was was nicht nur mein Leben beeinflusst, sondern das auch der Kinder.

Q12:

Und so sind wir nachher dazu gekommen, und so ist das nachher eins ins andere gegangen. Und heute könnte man sich das gar nicht vorstellen, wenn wir da nicht dabei wären, weil so freundlich aufgenommen und alles. Ich hab, ich war ein paar Mal herinnen, ich habe paar Mal einen Knoten gehabt, ich habe nie eine Angst mehr gehabt, weil ich gewusst habe, da ist wer, wo man sich hinwenden kann, die was wir kennen.

Q13:

Ich meine, es ist ja irgendwie die einzige Möglichkeit, dass man die diagnostischen Maßnahmen hat, ne. Weil sonst wird man eh sowieso nicht Ernst genommen und die Möglichkeit, dass man sich das anschaut lässt, ob das okay ist, funktioniert ja nicht.

Q14:

Also, nachdem ich irgendwie immer's Gefühl gehabt habe, dass irgendwas sein kann in die Richtung, dass das vererblich ist [...] dass da was sein wird, und bin deshalb zu meinem Frauenarzt gegangen. Und der hat das irgendwie nicht Ernst genommen, habe daraufhin mehrere Frauenärzte konsultiert, bis mich einer ins [Name des Spitals] geschickt hat, wo dann eben die Möglichkeit bestanden hat, diese Gentests durchzuführen, was ich dann eigentlich mehr als Möglichkeit gesehen habe, dass man frühzeitig was erkennen [...] und nicht erst, wenn's zu spät ist.

Q15:

Und wir haben so ein aggressives Gen, ned.

Q16

Also, mich hat's einfach, wie man damit umgeht oder so, einfach die Art der Kommunikation, welche wichtig ist und so, und was halt so... Weil's mich halt interessiert, was so Leute, oder wie's, wie's halt anderen geht damit oder so, ne.

Q17:

Weil das war damals eben auch irgendwie, ob ich jetzt eine Familienplanung überhaupt starten soll oder nicht, und wenn ich das Gen sowieso habe, na, dann breche ich das eigentlich gleich ab und rotte diesen mit mir gleich aus.

Q18:

Und dann haben sie zu mir damals gesagt, na ja, aber das soll jetzt nicht das Handicap sein, dass ich meine Familienplanung in Sand setze nur aufgrund dessen, weil in 20 Jahre ist die Medizin so weit, dass man da irgendwas schon machen kann, ne, dass man das vorweg

schon mal nimmt. Das war dann eigentlich das Hauptausschlaggebende, dass ich dann gesagt habe, okay gut.

Q19:

Und von der die Nichte, die kann heute nicht, die lässt eh die Frau Professor schön grüßen, und der tut das so leid, sie muss heute arbeiten, sie kann sich nicht freinehmen, und sie wäre auch gern hereingefahren, ned.

Q20:

Also, ich arbeite in einer ziemlich großen Firma. Und überall, wo ich die Möglichkeit habe – wir haben so verschiedene Projekte mit Gesundheit – und dort hängen schon unsere [lacht], vom [Name des Spitals] die Broschüren und so. Also, ich find das gehört schon, ja. Also, ich find, es gehört, es gehört weit verbreitet und durch Mundpropaganda zumindest, weil man so nicht, ich glaube, man nimmt's zu wenig wahr.

Q21:

Da hat's gesagt, ob ich so nett wäre und einmal ein paar Phiolen Blut wieder zur Verfügung stelle, ned. Und die hab ich zur Verfügung, hab ich auch unterschrieben, dass' damit machen können, was' wollen, also... Also, ich finde, wenn einer schon so befallen ist, und er kann irgendwie helfen, bei anderen, wenn was ist, warum nicht, ein paar Phiolen Blut.

Q22:

Also, in meinem Bekanntenkreis sind's relativ viel, die's nicht wissen wollen. Ja, sage ich, da ist' euer eigenes Pech, sage ich, nur weint's nicht, wenn's einmal was habt's. Sage ich, wenn euch die Möglichkeit geboten wird, sage ich, und ihr so dumm seid's, und das nicht annimmt's, sage ich, seid's selber schuld. Also, der Meinung bin ich ganz einfach, und den Standpunkt vertrete ich auch. Es ist jeder selber Schuld an, aufgrund seiner Fahrlässigkeit, dass er dann irgendwas hat. Es wird ihm genug angeboten, und wenn er das nicht annimmt, ja, ist er selber Schuld. Also, das ist irgendwie... Und da denke ich mir oft, und eben mit die Krankenkassenbeiträge, ja, mir ist schon klar, dass' irgendwann erschöpft sind, aber dann sollte irgendwie bei den Patienten selber auch in die Tasche gegriffen werden, denk

ich mir einmal. Das wäre irgendwie zum Raten, denk ich mir. Weil dann, vielleicht kommt er irgendwann einmal dann auf die Idee, dass er sagt, okay, das war jetzt Dummheit von mir, oder ich, ich sollte vielleicht wirklich mehr auf meine Gesundheit schauen, weil bei der Gesundheit spart ein jeder immer noch. Und sonst kann man für alles ein Geld ausgeben. Ich meine, da, da spreche ich z.B. die Raucher an, weil ich war selber eine, und ich habe von heute auf morgen aufgehört. Und wenn ich mir denke, was ich da an Geld verpulvert habe, was ich eigentlich in meine Gesundheit stecken hätte können.

Q23:

Jetzt haben wir halt das, und jetzt sagen wir halt, andere haben das Gen mit dem Herzinfarkt, und wir haben halt das Brustkrebsgen. Und wenn, kann man was machen dagegen, ned. Und in guten Händen, sagen wir, sind wir auch.

Q24:

Weil die meisten sagen, sie wollen das eigentlich nicht wissen. Sage ich, na, dann bist blöd. Sage ich, da bist in meinen Augen dumm.

Q25:

I: Haben Sie je, so einfach, haben Sie jemals überlegt, einfach zu sagen, ich vergesse das jetzt einfach, dass das bei uns in der Familie ist, ich möchte da eigentlich nicht drüber nachdenken, ich möchte das nicht wissen?

Ich glaube, dass' ein paar Mal kurz mal die Momenten gegeben hat oder so, aber die waren eigentlich nur wirklich sehr, sehr kurz. Aber nicht so von Dauer oder so. Ich meine, mir war's klar, dass' da ist und ich hab's miterlebt, und ich, mir war klar, dass ich dasselbe nicht noch mal, mitmachen will, und dass man das eben seinen Kindern genauso ersparen will, ne. [...] Das ist was, was nicht nur mein Leben beeinflusst, sondern das auch der Kinder.



Q26:

Ich hab das ganz einfach hingenommen, ned, das ist halt so, und ich hab halt die Möglichkeit – es gibt sicher viele Frauen, die das nicht haben – und ich habe jetzt die Möglichkeit, dass ich da das vorsorglich mache alles, ned.

Q27:

Und da hab ich mir dann gedacht, ja, also, es ist, die Medizin ist so weit fortgeschritten, man sollte es doch in Anspruch nehmen, wenn's schon angeboten wird und man einer der wenigen ist, die das nutzen darf.

Q28:

Die Untersuchung weiß ich jetzt, die ist zwar nicht angenehm, aber das weiß ich, das muss ich machen, dass ich eventuell irgendeine Chance habe zu überleben.

Q29

Ja, na ja, ab dem Zeitpunkt, wo ich dann wusste, dass es grundsätzlich eine Möglichkeit gibt, dass ich genetisch vorbelastet bin, war's sehr nahe liegend, dass ich dann auch wissen will, ob das der Fall ist. Also, nachdem das dann zu einem Zeitpunkt war, war dazwischen jetzt keine große Überlegung will ich getestet werden oder nicht, das war sofort klar.

Q30:

Also, ich glaube, dafür ist die Entscheidung auch zu gravierend, um sie einfach so zu fällen. Also, man muss sich da schon mit auseinandersetzen, egal wie. Also, bei mir war's, waren's Gespräche mit Freunden, Bekannten und Ärzten und die Zeit einfach, ne, und das, was mir passiert ist in dieser Zeit.

Q31:

Die Mädchen, die nehmen das jetzt schon ernst, das... Aber meine Söhne nehmen das nicht so richtig.

Q32:

Nur, ich weiß eben von der Arbeitskollegin eine Bekannte vom Burgenland, die hat das vor mir schon. Also, die muss ziemlich von, bei den ersten irgendwie dabei gewesen sein. Die hat das vor mir. Weil durch Zufall eben, wir sind auch eben nicht nur Arbeitskollegen, sondern auch privat befreundet. [...] Aber es geht bis ins Burgenland.

Q33:

Dass ist ja auch meine Angst, warum ich nicht will, dass es an die große Glocke gehängt wird. Weil ich das Gefühl hätte oder die Angst hätte, dass ich nicht mehr als funktionsfähig angesehen werde oder voll einsatzfähig. Also, die Sorge, die's mir genommen hat, und ich weiß ja auch, dass es nicht so ist, also, ich fühle mich jetzt ja viel einsatzfähiger als je zuvor oder als in den letzten 10 Jahren, die traue ich der Gesellschaft, jetzt ehrlich gesagt, nicht zu.

Q34:

Ich meine, die, die Amputation, die schiebe ich einmal ganz weit weg, weil ich, die will ich überhaupt nicht wahrnehmen. [...] Weil ich gesagt habe, sage ich, ich hätte kein Problem damit, wenn ich sage jetzt, okay, die Gebärmutter entfernen, hätte ich absolut kein Problem damit, sage ich, aber da heroben, sage ich, nein, da, nein. Sage ich, das mag ich nicht. [...] Weil es muss ja die Brustwarze genauso entfernt werden. Und ich kann mir das nicht vorstellen, wie das einer naturellen Brust wieder ähnlich schauen soll. Also, das ist, es gibt sicher die Möglichkeit, aber für mich nicht.

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