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Cancer genetic counseling in China and Denmark; a comparative anthropological perspective

PhD Dissertation

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List of abbreviations

BC	Breast Center, Beijing Cancer Hospital, Peking University Cancer Hospital
BRCA	Breast Cancer (Genes)
DCG	Aarhus University Hospital's Department of Clinical Genetics
MOH	Chinese Ministry of Health
OOP	Out-of-pocket payment
PUTH	Peking University Tumor Hospital

Chapter 1

Introduction

Purpose

The purpose of this PhD dissertation is to compare how the increasingly used phenomenon of genetic counseling unfolds in Denmark and China using a comparative anthropological perspective. In the literature genetic counseling is described as particular forms of clinical social practices. The practices where the shared substance of genes and the potential risk of disease give rise to novel forms of genetic responsibility. These practices require investments by patients and families, both in the care for the self and for the kin potentially affected by a genetic cancer disease.

The comparison between China and Denmark in this dissertation studies the role of local situatedness in articulating very different forms of genetic counseling practices.

Based on two subsequent periods of fieldwork in clinical environments in both China and Denmark, this dissertation aims to empirically illustrate how cancer genetic counseling rests on different terms of professional, patient, and family collaboration in these two countries. This is despite the fact that these two countries share a common point of departure in genetic science and have a long tradition for collaboration in both genetic research and in clinical practice.

This dissertation focuses on the impact of local organizational conditions on health care services concerning the practices of genetic counseling in China and Denmark, respectively.

It aims to show how using a Science and Technology Studies approach to analyze organizational conditions inspired by the anthropologist Annemarie Mol's framework of *Body Multiple* and the method of *praxiography* may provide a different perspective to existing anthropological studies of genetic counseling practices. The dissertation aims to illustrate how different local organizational conditions may give rise to very different webs of related human and non-human actors in China and Denmark, respectively. These result in different practices, different demands for collaboration between professionals, patients and families, resulting in very different social relations between patients and their families.

By comparing China and Denmark, the research aims to illustrate how a comparative praxiographic approach to genetic counseling may help explore and challenge existing ideas in comparative genetic counseling studies. Ideas that point out differences in western and non-western genetic counseling as a result of different cultural- and societal views on family and individuals. This

dissertation aims to demonstrate that current clinical genetic practices among professionals are also the products of local organizational conditions. By studying Chinese and Danish genetic counseling practices, this research shows how a comparison may contribute with new perspectives to the existing challenges in the field of genetic counseling.

Research questions

The research questions addressed in this dissertation are:

1. How do China and Denmark, respectively practice genetic counseling related to risk of hereditary breast and ovarian cancer?
2. How may we comparatively study and understand genetic counseling and the different practices in China and Denmark, respectively?
3. What do differences anthropologically mean for the unfolding of genetic counseling practices in China and Denmark, respectively?
4. How may a comparison of genetic counseling practices in China and Denmark contribute to anthropology and the field of clinical genetic practice?

Background

In the following, stories are unfolded about families tragically struck by multiple onsets of cancer making them approach new forms of genetic health care services. The stories unfold how such patients are met and cared for in everyday clinical practice by professionals in China and Denmark, geographically separated by more than 10,000 km.

In the last twenty years, there has been a rapid development in genetic research. This development has generated new knowledge about each individual's genetic composition. It has also provided knowledge about possible predispositions for developing diseases (Lock, Lloyd, Sharples, & Freeman, 2006; Lock & Nguyen, 2010) . This development has a great impact on health systems around the world, where access to genetic information makes it possible to offer genetic elucidation and genetic counselling to people with a strengthened and sometimes imagined suspicion of possible hereditary gene-dependent predispositions to certain diseases (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Keating & Cambrosio, 2006; Sleeboom-Faulkner, 2014) . This development has led to an increased global focus on and interest in genetic counselling practices in a multitude of different genetic diseases such as the genetic risk of cancer.

Genes and genetics deal with relationships and human connections. Genes are the substance of life passed on through generations from parents to children. As humans, we share fundamental life-giving traits with what can be seen as our genetic kinsmen. Sometimes genes may carry risks of disease. Due to gene mutations disorders may become socially shared through the substance of family DNA (Svendsen, 2004).
Shared mutated genes may give rise to a family history of disease such as cancer, which can be traced through generations. This leaves individuals within such families with a sense of relatedness and it raises existential and practical questions such as: Why us? When, and who will it strike next? How may we prevent further onsets of disease? (Sachs, 2014).

For patients and families with a family history of cancer, finding ways of knowing and responding to the existential social threats of a family history of cancer becomes pertinent. Genetic counselling offers possibilities to such families. Genetic counselling constitutes an enterprise potentially capable of managing uncertain and dangerous futures (Svendsen, 2005). It does so by offering knowledge and practical pathways capable of countering what is perceived as an inevitable line of disease onsets only waiting to strike again.
Genetic counselling rests upon practices of tracing possible hereditary links within a family´s history of disease (Richards, 1996). It studies family histories of disease, and together with genetic tests of blood samples from patients and their families, calculates and estimates genetic risk of disease. It is a practice performed by experts, transforming heart-breaking patient narratives into numbers and patterns capable of classification. However, expert practices rely on the collaboration of those who seek out genetic counseling services. In return, genetic risk estimation provides knowledge, enabling adequate clinical prevention trajectories (Himes et al., 2016; Riley et al., 2012).

The promises of knowledge and preventive measures offered by such novel genetic counselling practices come at the price of new forms of responsibility (Hallowell, 1999): Genetic responsibility. Genetic counselling practices make individuals not only responsible for their own health but also for the health of others (Konrad, 2005; Lupton, 1995). Only through the unselfish collaborative responsibility of patients receiving genetic counselling, may knowledge of risks capable of saving the life of patients and genetically related kins become a reality (Hallowell, 1999; Keenen, 1994).

Having to manoeuvre between individual rights to bodily knowledge and moral obligations towards a genetic family becomes a salient condition, demanding practical social responsibility investments to be made (Cox & McKellin, 1999; K. Featherstone, Atkinson, Bharadway, & Clarke, 2006; Finkler, 2001; Hallowell, 1999; Sachs, 2014; Svendsen, 2006).

Such investments may include the sharing of genetic information among family members (Sachs, 2014; Svendsen, 2005). It may include undergoing tests and harsh surgical preventive measures. Common to all such responsibility investments is that they must be made not only for the sake of the self, but for the protection of significant others to which one is genetically related(Hallowell, 1999). If patients and their families are to succeed in managing risks posed by shared genes, family-social sacrifices need to be made. Thus, genetic counselling practices are social responsibility practices (Gibbon, 2011).

The inherent sociality of genes, its knowledge and the kinds of questions they raise are well known in clinical practice. For the professionals providing genetic counselling, the nature of genetic material and the science of heredity upon which genetic counselling is built, challenge established ways of working in clinical practice. Well-established clinical dogmas such as the protection of autonomous and judicial rights to knowledge are challenged by practices resting on something as inherently social as risks tied to shared DNA. Who is the patient when risky genes are shared? Who is to know what? What kind of social responsibility investments can one reasonably expect from individual patients in services where genes and thus risks are shared with other family members (Himes et al., 2016; Offit, Groeger, Turner, Wadsworth, & Weiser, 2004; Ormond, 2008; Surbone, 2011; Vos et al., 2011) ? What kind of impact do genetic counselling practices have on patients and their families when they leave the clinics? (Himes et al., 2016; Kenen, Ardern-Jones, & Eeles, 2003; Riley et al., 2012). During the last decade, it has been a growing topic how to best understand and handle the issues posed by professional genetic practices and placed upon patients and their families. These questions also sparked the empirical part of this research, comparing genetic counselling in China and Denmark for breast and/or ovarian cancer related primarily to the *BRCA* genes.

Hereditary breast & ovarian cancer – the *BRCA* genes

The topic of this dissertation is genetic counseling for hereditary predisposition to breast and/or ovarian cancer related to the *BRCA* genes. Identified in the early 1990s, the *BRCA genes* or *Breast Cancer Genes* have gained prominence and sparked an increasing public awareness, even giving rise to public organizations aimed at carriers of this mutation (see. (Gibbon, 2008)). In the social sciences these genes have gained prominence through a plethora of academic studies (see. (Gibbon, 2007; Hallowell, 1999; Sachs, 2014; Svendsen, 2004). Individual bodies become highly social as the rules of inheritance, specified by the Austrian monk Gregor Mendel, mean that the presence of a pathogenic mutation within the *BRCA* genes is believed to give the carrier a risk of up until 80% of developing breast cancer and as high as 50% of developing ovarian cancer. As studies show this leaves not only the individual body with a genetic risk of cancer, but it also leaves a genetic family of bodies with a 50% risk of carrying that very same predisposition to disease.

Genetic cancer counseling practices through a Danish and Chinese comparative lens

Choosing to compare Danish and Chinese genetic counseling practices and how issues of genetic responsibility are handled in daily clinical practice is in no way a co-incidence and it did not simply evolve from questions raised in the literature. The decision to compare these two countries came from equal amounts of anthropological and Danish genetic professional curiosity.

Danish professionals are increasingly left with a strong sense of concern about the potential impact of genetic counseling on patients and their families. How do we and other genetic professionals like us resolve this task of having to work with both patients and families in the best possible way if a genetic risk estimate is to become a reality? How do current ways of practicing genetic counseling affect patients and their families? These were among the key questions raised by Danish professionals when I first met them in their clinics during a pre-study in 2012. These questions strongly echoed the questions raised in the clinical literature. These questions also sparked a common interest in conducting a comparative research project, as such questions are seen as particularly pertinent among Danish professionals in the light of increasingly having to collaborate with other countries – among these with China.

Developments in genetic research and clinical practice increasingly unfold on a broader international arena and through international collaborations (Döring, 2009; Sleeboom-Faulkner, 2014). These tendencies are also true for the situation in Denmark and China, respectively.

Despite having very different health care systems, Denmark and China have a long history of close collaborations in research and development within the field of clinical human genetics.
Chinese genetic researchers are increasingly enrolled as students at Danish universities and vice-versa. Moreover, Danish and Chinese universities have established a common University Partnership (SDC), physically located in both China and Denmark, exchanging knowledge on genetics. In 2012, BGI (*Beijing Genomics institute*) opened their first European genomic research facility in Copenhagen, further strengthening this collaboration (Bak, 2012). New research collaborations between Denmark and China within the field of genetics are continuously unfolding, such as The Danish Reference Genome, a project aimed at constructing a common reference genome for the Danish population in a collaboration between Chinese and Danish researchers (Danske Regioner, 2015).

Such collaborations provide grounds for raising comparative questions. Sharing a strong common ground in genetic science, these collaborations have made Danish professionals increasingly question how Chinese professionals working in a different health care system address the complex genetic responsibilities emerging as the result of genetic counseling services: How do Chinese professionals resolve the task of having to work with both patients and families in the best possible manner if a genetic risk estimate is to be produced? How does the Chinese way of performing genetic counseling affect patients and families in comparison with the Danish approach? What has ultimately triggered the initiation of this comparative anthropological research between China and Denmark is thus an interest in answering empirically grounded questions comparing how professionals handle patients, their families, and the genetic responsibility that emerges as a result of genetic counseling practices.

Comparing practices and genetic responsibility through an anthropological lens

Although international clinical collaborations and a strong clinical literature may spark interesting comparative questions such as those mentioned above, comparative anthropological fieldwork may come to reframe them. Departing in a comparative fieldwork in China and Denmark it was revealed how genetic counseling practices, despite being anticipated as very similar, in reality were very different upon closer ethnographical examination. Examples are shown on how genetic counseling practices in China and Denmark produce knowledge through very different practices, although sharing common theoretical departures in the science of heredity, common goals of providing

genetic risk knowledge, and adequate prevention trajectories; practices involving very different arrangements of non-human entities, patients, and families.

In the initial stages of the study, little participation or involvement of families in genetic counseling in China was found. When compared to Denmark and the clinical literature, where participation and involvement of families are an inherent integrated part of genetic counseling, this was a surprise. It led to an important new set of reframed comparative questions exploring the intimate relationships between genetic practices, locality, patients and families, social genetic responsibility, and the types of comparative inquiry that needed to be applied to facilitate such an understanding.

Initially aiming at comparing how professionals in China and Denmark, respectively manage the well-described problems of how to handle patients, their families, issues of genetic responsibility, and demanded forms of investments, this dissertation is founded on the anthropological literature seeing genetic counselling practices as specific forms of knowledge production and unfolding as the products of social performances(Hallowell, 1999; Konrad, 2005; Rapp, 1999; Sachs, 2004; Svendsen, 2004). It argues that genetic knowledge and the issues of genetic responsibility must be seen as the products of heterogenic sets of practices, protocols, technologies, and multiple actors shaped by the dynamics of the local contexts in which counselling takes place (Bharadway, 2003; Franklin, 2006; Gibbon, Kampriani, & Nieden, 2010; Rapp, 1999; Rapp, 2014) .
The dissertation builds upon the premise that different worlds give rise to very different genetic practices, meaning that different actors come to participate, different stakes become raised, and very different genetic responsibility investments are demanded by those who become involved as a result (Gibbon et al., 2010; Gordon, 2014).
Taking a comparative approach to genetic counseling in China and Denmark, this comparison explores how different genetic counseling practices in China and Denmark, respectively lead to very different modes of genetic responsibility and demands for investments to those who become involved in such practices.

This research approaches these questions and is inspired by the work of anthropologists stressing links between genetic counseling, its practice, products, derived dilemmas and the conditions of the health care organization in which such services are unfolded (Gammeltoft & Nguyen, 2007; Sui, 2010) .

As a way of understanding the practical and material roles of different organizational conditions in genetic counseling, a turn towards Science and Technology Studies (STS) was made. Taking the starting point in a theoretical and methodological approach inspired by the framework of anthropologist Annemarie Mol(2002), this dissertation comparatively approaches genetic counseling as arrangements of practices and webs of related human and non-human actors, opened up by specific organizational conditions.
Pursuing these research questions by means of a comparative praxiographic approach to organizational conditions surrounding genetic counseling in China and Denmark, this study attempts to explore its influence upon well-known notions such as the social production of genetic risk, social agency, social genetic responsibility and demands for genetic responsibility investments.

Outline of the dissertation

Chapter one is an introduction to the dissertation. It delineates the current genetic developments and illustrates the questions raised in anthropological and clinical environments. It then uses these to present the rationale and the purpose of the study.

In **Chapter two,** the background for the dissertation is provided. Following the description of the preparations for the comparative fieldwork, this chapter demonstrates how encountering a breakdown in my Chinese fieldwork, led to new research questions. This dissertation asks: What makes patients and their families a salient and necessary ingredient in Danish genetic counseling, while Chinese counterparts happily rely on patients alone? Finding ways of theoretically and methodologically approaching this comparative question is the topic of chapter three.

C**hapter three** is the main theoretical chapter of this dissertation. Here the dissertation shows how profound differences in the material ways that cancer genetic counseling unfolds in China and Denmark results in more traditional anthropological frameworks focusing on cultural dicursivity and human agency being less applicable. Instead this study turns to organizational conditions albeit using the anthropological STS framework of *Body Multiple* and the method *praxiography* developed by Annemarie Mol.

Chapter four unfolds the methodology and methods used in the study. It provides a description of the material for the comparative analysis as well as reflections on the possible challenges following the adaptation of such a comparative approach.

Chapter five presents an empirical description of the entrance into the two fields of the comparison. Comparing the sites and organizational conditions for genetic cancer counseling in China and Denmark, respectively it shows how current practices unfold within different guidelines, different forms of economical governance of health care services, and within very different arrangements of available health care data. These organizational conditions are the central departure for the comparative praxiographic analysis of genetic counseling in China and Denmark, respectively

Chapter six delineates genetic counseling practices in China. Praxiographically following the practices, and the actors introduced by the current organizational conditions described in chapter 5, this chapter illustrates how these conditions in China means that genetic risk estimation unfolds within specific webs of both human and non-human actors. This results in practices and their products becoming understood as strictly *Geren* or individual.

Chapter seven delineates genetic counseling practices in Denmark. Praxiographically following the practices and the actors introduced by the current organizational conditions described in chapter 5, this chapter illustrates how these conditions in Denmark means that genetic risk estimation unfolds within specific webs of human and non-human actors. This results in practices becoming understood as suspended in a tension between *family and individual orientation*. Despite this tension the chapter shows how the practices and products ultimately become *family orientated,* as genetic risk estimates are produced and modes of prevention are offered.

Chapter eight comparatively analyzes and discusses the roles of different organizational conditions not only separating Chinese and Danish genetic counseling practices, but also the salient modes of genetic responsibility and demands for genetic responsibility investments that follow. The chapter then uses its comparative analysis to discuss the empirical findings obtained through means of praxiographic modes of comparison within existing anthropological studies of genetic counseling.

Chapter nine is the conclusive chapter of this dissertation. Here the findings of this research will be summarized, and reflections will be made on its contributions. The chapter ends with a short look to future trends.

Chapter 2

A comparative Danish-Chinese project on cancer genetic counseling

The best we can do is to draw a pedigree here. You have to remember, you come here as a person, but importantly you also come here as a part of a family. (P5)

I am in the outpatient clinic at Aarhus University Hospital's Department of Clinical Genetics (Abbr. DCG) where I hear these words. We have just begun a new genetic counseling session scheduled to last two hours. We are seated in a fairly large room, and there is a sense of silence. The presence of a few other patients seated in the waiting area outside this room is hardly noticeable.

The healthcare professional who has just uttered these words sits next to me. At the opposite side of a large table is a woman in her 50s. She is called Ulla. On the table in front of us is a small piece of paper. On this piece of paper circles and squares have been drawn and they are connected with lines. Ulla´s name is written next to a circle. This paper shows Ulla´s pedigree or family history. Soon more names of family members and their association with Ulla will be written on this piece of paper. But this is not just a family history. Some family names already written on the paper have small black marks. These black marks indicate cancer. The paper shows cancer incidents in Ulla's family, and that is the reason for Ulla's appointment at DCG. She has been diagnosed with a pre-stage of cancer and now she tells us about her anxiety. Ulla continues to tell how this pre-stage cancer condition came as a shock to her. She has always been eating organic products but nevertheless this had happened. Her half-sister has already been struck by cancer, and it has taken great tolls on her life. The story of her half-sister makes tears appear in Ulla's eyes and her voice changes slightly.

Seeing her half-sister fight cancer has led to fear for Ulla. This has only gotten worse after she found out that she herself also has early signs of cancer. She continues to tell, how she suddenly feels that she is a part of a "cancer family". Having heard about genetic mutations from her doctor, Ulla wishes to know more because she has a responsibility, she says. Her children also want knowledge, she continues! Do we have a genetic risk of cancer? If so, will it be possible to prevent future cancer*?* When the professional utters the sentence from the beginning of this chapter, there is no sign of surprise on Ulla's face. Her anxiety is accompanied by a sense of determination. She just needs to know, she tells us again.

After hearing these words from Ulla, the professional quickly begins to explain to her about genes and genetic risks related to the most prevalent and known genes - the *BRCA* genes. Listening with interest, Ulla responds by asking about blood and blood testing. These are her reasons for coming. The professional responds that this is only done if the pedigree reveals certain "*leads*". Ulla reacts casually to this news and continues to examine the family history on the paper in front of her. The professional continues:

P5: We always screen a person who has been sick, and then we could test others in the family. If others haven´t inherited it, then that´s it. It doesn´t skip (a generation).

Upon hearing this news Ulla makes a surprised expression:

U: Ok that's what I ... Uhh !I thought, I was going to have a blood test?

To the professional, Ulla's sudden expression comes as less of a surprise. This is a line of questioning she has heard many times before. She answers:

P5: I´m afraid it is not that simple. It depends on the leads in the pedigree. She informs Ulla about genetic inheritance before again turning to the pedigree in front of us. The professional begins to fill out the pedigree asking Ulla about information. Ulla tells that her half-sister on her mother`s side has been diagnosed with cancer, and so has two of her cousins on her mother`s side.

U: She had breast cancer when she was in her 40s, but she doesn´t want to cooperate. They don´t talk to each other you know (making a gesture at the pedigree at the two sisters) It´s a bit complicated.

P5: What we need to know, is the situation of your mother`s sister (the mother of the two cousins), because here we have two sisters with breast cancer. I think we have to continue over here (points to Ulla`s mother`s sister). It is important that we find the right person, if we are to get any wiser. So I would like you to find out more information over here (pointing again to the pedigree). If she (the cousin) says that there are more women with breast cancer over here, then I think she should be referred for genetic counseling herself. I think we need to get this information first, and then wait with the blood samples.

When Ulla learns she has to contact these family members with whom she has only very sporadic contact and furthermore may have to wait for those persons to have a blood sample taken, Ulla begins to look very skeptical.

U: I thought, <u>I</u> just had to have a blood sample taken to look at the genes, so I could inform my daughter.

P5: But it doesn´t quite work like that. And you have to remember, this (service) is not only something that may affect you but others as well. It is important that you inform them well during the process. Some people want to know, but some might not want to know. Also you often have to contact some of these family members during the process.

Ulla looks confused and tries to hide her obvious disappointment at this stage. The professional hands Ulla a pile of informed consent forms that Ulla will have to give to her cousin to sign, so that the professional can legally access the relevant health records to obtain information. The session ends, as the professional hands Ulla a card, where she writes a number stating that not only Ulla but also her family can use this number, for it is a family-number.

To Ulla, as to so many of the women arriving at DCG, the need for involving family members had come as a surprise. Many arrived fearing onsets of cancer not just for themselves but for their children as well. These women were more than ready to go through genetic counseling. Yet, just as in Ulla's case, often anticipating genetic counseling to involve a quick blood test to be taken and a risk estimate to follow, their missions would usually be temporarily thwarted by the professionals. More information was needed, they learnt, and as seen in this case, it had to come from other people than the one showing up for the appointment for genetic counseling. To make it all the more complex, the people these women now have to depend on, are not only closely related family members with whom they share a life, they also sometimes have to rely on other people in their family they know very little about and who may not have any interest in participating.

The result for many women like Ulla when leaving these sessions was that they had to face the difficult task of gathering information and consent, which caused quite a bit of frustration. But as these women, just like Ulla, would conclude that this was something they would have to overcome. Not just for the sake of themselves, but also for the sake of others to whom they felt a sense of responsibility.

Cancer genetic counseling from a Danish clinical perspective

Ulla's anxiety and frustration being presented with such a task was not new to the healthcare professional working at this department. For them this was genetic counseling in a nutshell. The professionals fully acknowledged women like Ulla's wishes for getting a risk estimate. Although these professionals were determined to estimate Ulla's family's genetic risk of cancer, a blood test was not the next step; obtaining more information was. That women like Ulla left the department

disappointed was nothing new. But that was the name of the game when making a risk estimate, I was told.

In order for the professionals to make a proper risk estimate and initiate an adequate prevention strategy, information had to be as precise as possible. This required a different kind of information than the women were prepared for when arriving for the genetic consultation. What was needed according to the professionals was proper clinical information, and this could only be found in patient records. But these records, I learnt, were outside reach of the professionals. In order to access these records each individual family member would have to give consent. And as these professionals were not allowed to contact people who were not registered as patients, the task of obtaining consent relied on women like Ulla. Getting the desired result would now depend on an entire family working together.

Though such collaborative practices were seen as vital parts of genetic counseling, this did not relieve professionals from feeling concerned about their implications. How would the rest of the family members respond when being confronted by women like Ulla asking for their collaboration? Would they simply cooperate and be happy that Ulla had taken the time to seek genetic counseling on behalf of the family? Would they become anxious and surprised when learning that someone in their family suspected a genetic risk to be present, and that they would have to participate in order to find out? Would they become so anxious that they would refrain from participating, and thereby leave Ulla incapable of obtaining the risk estimate she called for? What would happen when women like Ulla left these sessions? What kind of havoc could be the result of the standard clinical way of conducting genetic counseling for families like Ulla's? These were worries that professionals at DCG would voice to me on a daily basis.

Cancer genetic counseling in a Danish – Chinese context

Getting insights into the life-world of patients and their families, and how genetic practices were dealt with was, however, not the sole reason why these professionals had invited me as an anthropologist into their field of work. No doubt, they were very interested in gaining an understanding of how these risk estimation practices in a Danish genetic counseling setting influenced families being forced to work together. But this was not their only incentive for inviting me. Their reasons for inviting an anthropologist were also rooted in an interest in studying what could potentially be the future of these intricate practices and thus the future for these families? The

reasons for inviting an anthropologist was spurred by their increasing collaborations with researchers from China. The Danish healthcare professionals were increasingly working together with researchers on international projects and they also more often send material to China for genetic sequencing as a part of their work with estimating risks.

For the professionals at DCG and the rest of the clinical world, China is the favored partner in the field of genetics. Often the Danish professionals would visit China and vice versa. For the professionals at DCG, the benefits of working with China are clear. Working with China on genetic research provides new genetic knowledge, which can be obtained at a much quicker pace, as the research capacity is much bigger in China than in Denmark. But collaborating with China not only allows quicker gains in research, it has also opened up a completely different world to the Danish professionals. What they meet through their collaboration with China is a very different attitude towards genetics. An attitude where less attention seem to be given to the practical ethical problems of caring for patients and their families in connection with genetic risk estimation compared to Denmark. The Chinese are much more interested in discussing testing and in techniques, I was told. What the Danish professionals had learnt was that genetics seemed to be handled completely different in China and testing seemed to be much more accessible than in Denmark. These experiences left the Danish professionals with a sense of both anxiety and curiosity.
In China, tests are readily available: "*Gene-tests are exploding in China"*, one professional told me! "*You can get everything in China when it comes to genes if you want to pay"* another had remarked during our opening meetings. The literature to some extent echoed what the professionals experienced in China being a country with a growing capacity and selection of accessible genetic services, more often offered on market-consumerist conditions. (Greenhalgh & Winckler, 2005) . These examples of Chinese health care consumerism left them with a sense of anxiety. "*If a Chinese approach to genetics arrives in Denmark, where you just pay for having a test done, what will this do to the patients, their families and to us"* (professional 2), a professional told me. She quickly continued to explain the anxieties she and her colleagues debated on a daily basis. "*If everybody can just arrive and ask for their risk estimates, we will ultimately have to make them contact their families. Imagine the amount of people these tests will have to deal with*?" She continued: "*If these tests become fast and cheap enough we will potentially end up having half the Danish population here (at DCG). What we are doing together with patients and families is already*

problematic as it is, imagine if we magnify it 10 times? What kinds of pressure will that put upon patients and their families, and upon us?"

Thinking of the women I had encountered (like Ulla), the idea of having patients arriving by the thousands to have their risks estimated could be seen as a potential challenge to the current practice of risk estimation. After all they would all need to contact their families, and I could readily imagine the entire Danish population becoming part of risk estimation sooner or later. Not knowing what current practices were doing to patients and families, as they had to cooperate to produce a risk estimate I could understand their worries.

What these professionals encountered when working with their Chinese counterparts was a weird sense of immense differences and also a profound sense of familiarity. The fundamental premise that genetics is a matter of family was an unquestionable fact shared and so were the techniques. "*We are both looking at the same material and we use the same techniques",* one of the professionals told me. *"They talked of the BRCA genes and she showed me an Illumina (a machine to sequence genes)"*, she continued. But something was also very different between Denmark and China I could understand, and it apparently had to do with health care consumerism. When looking closer at the Chinese and Danish health care systems, there are definitive differences in the provision of genetic services.

Chinese and Danish genetic cancer services at a comparative glance

Looking to China, little is currently published internationally on the state, provision and organization of genetic cancer services in China. Scholars such as (W. Cao, Wang, & Li, 2013) have argued that research on hereditary breast cancer in China is still only an emerging field. This means that clinical and organizational studies published internationally in this field are still scarce, and those actually published are mainly reported in Chinese national journals. Studies show how officially the field of genetic cancer testing is marred by a lack of overview from a medical organizational perspective (Zhao, Wang, Tao, & Zhong, 2013) . This has been argued as being exacerbated by the lack of acknowledgement given by Ministry of Health (MOH) to the field of genetics. Currently, the MOH in China does not acknowledge genetics as a medical specialty(Sui, 2009).

The lack of overview means that the actual numbers of genetic cancer tests in the Chinese healthcare system are hard to obtain. Nevertheless, genetic testing is believed to be increasing nationally, and calls for establishing a dedicated Chinese medical education in genetics has been

made (Wen, You, Qing, & Dan, 2006) . Despite the lack of overview, genetic testing for cancer is still offered as a public health care service in many parts of China as parts of research programs at major universities and at private companies. As a public health care service, patients are recruited through local hospital branches of universities but the actual testing of DNA is formally done as part of research programs in the university research laboratories (Zhao et al., 2013)[1]. These services are legally very low-regulated and subject to little national standardization.

In Denmark, genetic counseling became an official hospital service when the general field of genetics became a medical specialty in 1996(Hodgeson et al., 1999). Today clinical genetic services are offered at six major Danish hospitals.
Danish clinical genetic services are offered in clinics at specialized genetic departments. Most Danish clinical genetic departments have access to own laboratory and research facilities and they have their own specialized outpatient clinic. This means that the content of meetings in these clinics between professionals, patients and their families are specifically aimed towards genetic counseling services. Preventive treatments are however not offered at the local genetic clinics but are done at other departments within the health care system.

The organization and regulation of genetic elucidation and counseling is strongly connected to Denmark being a well-fare state. In a well-fare state, most public health care services, such as elucidation and counseling for cancer, are tax financed (Vallgårda, 2003). This also means that access and use of public health services is tightly regulated by the state, which is responsible for allocating funds to the health care sector. Five local Danish administrative regions are responsible for the organization and local distribution of health care funds to hospitals. Health care budgets for hospitals are negotiated each year between the regions and the government. The regions are also, among other things, responsible for meeting national goals for public health.
In practice this means that, although there is free and equal access to healthcare for all Danish citizens, access to specialized health care services are regulated through a referral system. Only emergency care is offered without prior referral. In the Danish healthcare system, general practitioners act as gatekeepers, and patients need to consult the general practitioner, who decides whether a referral to hospital or specialist is required (Olejaz et al., 2012). The aim of this referral

[1]The place, where I did my fieldwork for this dissertation, was just such an arrangement. The genetic testing was done at Breast Center, Beijing Cancer Hospital, Peking University Cancer Hospital (abbr. BC), and the patients were recruited as well as offered further treatment at the Peking University Tumor Hospital (abbr. PUTH)

system is to limit health care services to those in need. But it serves an additional function. By regulating access, the referral system acts as a guarantee for national health care budgets not to run wild.

Despite tight regulations of healthcare in Denmark, there has been a dramatic increase in referrals for genetic elucidation and counseling. Recent national numbers[2] indicate an increase from 4000 seeking genetic counseling in 2005 (Danish Board of Health, 2007)to more than 10,000 in 2013 (Holhmann, 2014). At DCG where this research was conducted, the number of referrals had almost doubled from 2005 to 2013.

Although the Chinese health care system is partially funded by the Chinese government, most health care providers currently rely on heavy degrees of external funding (Hougaard, Østerdal, & Yu, 2011). Receiving public healthcare services usually involves either own payment or payment through insurance programs (Blomqvist & Qian, 2008) . The extent and depth of these programs differ among income and geographical groups in China. Rural populations have traditionally had a worse position than the urban population (Yip et al., 2012). Since 2009, the Chinese government has worked on a health care reform to ensure better coverage for the entire population

In China, 90% of the population is now said to be covered by a basic health care insurance (Yip et al., 2012). But despite raised governmental subsidies to public hospitals and care providers, as well as the introduction of better health insurance, receiving health care for many Chinese citizens is still a strain on the budget[3]. Coverage and subsidies only account for a certain portion of the expenses of health care and do not cover all services. Some services, such as genetic counseling services, are not included (Zhao et al., 2013). Others are only to some extent reimbursed (ibid). For Chinese citizens with adequate income, private companies offer additional health insurance that may include genetic services. This means that a test costing a little less than 2000 RMB can be reimbursed, resulting in some patients paying only 300 RMB for genetic services (ibid). Although the service of genetic testing may seem cheap, going through the preventive surgical procedures that follow is a different ordeal. Going through cancer treatment may cost between 100,000-200,000 RMB, which to some citizens is the equivalent of 10 years of salary[4]. The special position of genetic cancer services in

[2]Numbers are based on referrals for genetic counseling. Although a high proportion of these are referrals for cancer genetic counseling, the total numbers also contain counseling for other genetic dispositions (Holhmann, 2014).

[3] A literature review conducted in 2008, found that as much as 60% of all payment for health care services is done directly by consumers, 20% is done by insurance companies, and the remaining 20% is covered through government subsidies (Eggleston, Ling, Qingyue, Lindelow, & Wagstaff, 2008)

[4]The system is, however in the middle of reform, and the government promises improved economical possibilities for especially the rural as well as poor urban residents to access health care services (Yip et al., 2012).

the public health care system[5] and the lack of public re-imbursement means that public access to these services is regulated by the local hospital and laboratory. Genetic cancer services are also offered by private companies in China (Sui & Sleeboom-Faulkner, 2007; Sui, 2010) . In the private sector, a rapid increase in genetic services has been seen, and many private companies have focused on delivering tests focusing on lifestyle issues (such as weight loss). Yet, companies are increasingly also providing tests for hereditary predispositions such as cancer. Here access to testing and knowledge is ultimately decided by financial means (ibid). Broadly speaking, access to genetic services and knowledge in China is a rapidly developing market (Sui & Sleeboom-Faulkner, 2015) driven to a large extent by economical sentiments with little government regulation.

Looking at these different systems, the anxieties expressed in the opening of my project could seem justifiable. Even I started wondering how very different Chinese genetic risk estimation practices could influence the Danish approach. Looking into research, my thoughts were only strengthened. Researchers have since the late eighties been aware of the speed with which knowledge travels across the globe eroding national boundaries on its way (M. Featherstone, 1991; Franklin, 2006; Lash & Urry, 2002; Ong & Collier, 2005; Sleeboom-Faulkner, 2014) . This means that countries are woven together in a tapestry of knowledge and experiences. Developments in one country potentially have a fundamental significance for the construction of daily life in another country. The Danish professionals voiced their concern on whether these genetic practices spurred on by economic sentiments in China could also gain footing in Denmark.
What would happen if Chinese approaches to genetics became the reality in Denmark?
How would this influence the questions about genetic practices already raised here in Denmark?

As mentioned earlier in this chapter, Danish professionals working with China were not only anxious about the Chinese approach, they were also curious.
These Chinese professionals were not aliens from another planet, they were close medical colleagues, and they were engaged in the same line of work of risk estimation as the professionals in Denmark. The curiosity among Danish professionals concerned how Chinese professionals handled the tough situation of having to produce a risk estimate of a family under such circumstances. How did professionals in China handle the tough questions raised in sessions such as Ulla's described above? What did the Chinese professionals tell their patients and their families?

[5]Clinics and research institutions

How did professionals, patients and patients' families cooperate when estimating risks and how did Chinese patients and their families respond to these genetic practices? At the heart of their curiosity was a wish to understand and learn from others working within environments that could one day be the reality in Denmark.
Based on this, the outlines for a comparative project were drawn.

Outline of a comparative project

The topic of my research was to compare genetic counseling for patients and their families concerning their genetic risk of cancer in China and in Denmark. This was later specified as a comparison of practices of estimating risk of hereditary breast and ovarian cancer related to the most common genes - the *BRCA* genes.[6]

Many oncologists had suspected a possible association between family history and cancer before the technological developments in genetics. This suspicion was however finally confirmed with the identification of the *BRCA* genes[7] ("Breast Cancer" genes, *BRCA1&BRCA2*) in the early nineties (see *BRCA1* (Hall et al., 1990)) (*BRCA2* (Wooster et al., 1994)). Although hereditary cancer is currently perceived to be responsible for only 5-10% of cancer cases (Lee, Oestereich, & Davidson N.E., 2014) , the field of oncogenetics is constantly developing, and pathogenic mutations in more genes leading to risk of disease are being identified. Looking closer at hereditary risk of breast and ovarian cancer, the *BRCA* genes have become central. Although mutations in other genes may also increase the risk of developing breast cancer, it is generally agreed that *BRCA1* and *BRCA2* remain the most important genes regarding breast and ovarian cancer (Hodgson, Foulkes, Eng, & Maher, 2014) . Mutations in the *BRCA1* gene positioned on the q arm of chromosome 17, is believed to account for the majority of breast and ovarian cancer incidents occurring within a family with a history of breast and ovarian cancer. Approximately 40% of breast cancer incidents among women younger than 45 years of age are linked to the *BRACA1* genes (Hodgson et al., 2014). Mutations in the *BRCA2* gene positioned on the q arm of chromosome 13, also accounts for breast cancer incidents in families with a history of breast cancer, but this gene carries a smaller risk of developing ovarian cancer(Lee et al., 2014). Both genes are classified as tumor-suppressor genes, and they play a vital role in the repair of double-strand DNA breaks (Ibid). Studies have shown that sporadic incidents of simultaneous breast and ovarian cancer in rare cases may be attributed to a de

[6] These are not the only, disposing to cancer, but are the most prevalent.
[7] Along with other cancer disposing genes also found in this period.

novo germ-line mutation. However, most cases of breast and ovarian cancer attributed to mutations in *BRCA1/BRCA2* are perceived to be germ-line mutations inherited in an autosomal dominant manner. This is often referred to as following the laws of Mendelian inheritance named after the Austrian monk Gregor Mendel, whose work on pea-plants in the 19thcentury was rediscovered and became the backbone of genetics in the 20thcentury (Dupré, 2008; Keller, 2000). Following the notion of Mendelian inheritance:

During the process of human reproduction, gametes from both parents carrying 23 chromosomes merge and form a zygote containing 23 chromosome pairs, half are inherited from the mother and half from the father, respectively. Pairs 1-22 are known as *autosomes* and the 23rd pair determines the sex. The genes are located on the chromosomes and every zygote thus inherits two copies of all genes on the autosomes - one from the father and one from the mother. Only one parent needs to carry a mutated copy of a gene located on one of the autosomal chromosomes (for hereditary breast and ovarian cancer, it concerns the *BRCA* genes positioned on chromosomes 17 and 13) for each zygote to be left with a risk of 50% of receiving the abnormal copy of the gene and, if inherited, thus an increased lifetime risk of breast and ovarian cancer.

This means that carriers of a cancer predisposing genetic mutation on one of the *BRCA* genes have a 50% risk of passing on the mutation to their offspring. Although a pathogenic mutation was initially believed to increase the lifetime risk of developing cancer by approximately 80%, these numbers are under constant scrutiny meaning that estimates of lifetime risk now vary accordingly[8].

It was decided that I was to focus on how Chinese professionals handled patients and their families in the estimation of risk of cancer and compare to practices in Denmark. Here I was to focus on how professionals, patients and their families made sense of genetic risk counseling when participating in genetic risk estimation in Denmark and China, respectively. I was supposed to try to study the consequences of these practices for the people involved. What did the societal differences mean for the well-known challenges of working with both individuals and families when estimating genetic risks? How did the Chinese handle these challenges? This seemed as an obvious and very fruitful undertaking for the professionals and myself.

[8] Depending on gene *(BRCA1 & BRCA2)*, the risk percentages for both breast- and ovarian cancer are still debated, and they vary accordingly (Easton, Ford, & Bishop, 1995, Easton, Narod, Ford, & Steel, 1994, Fodor et al., 1998, Skolnick, Frank, Shattuck-Eidens, & Tavtigian, 1997, Struewing, Tarone, Brody, Li, & Boice, 1996) .

When considering the outline of the initial research project, a clear observation should be made. In designing this project the comparative object of study was framed as cancer genetic counseling services for patients and their families in China and Denmark.

In retrospect, what emerged was a very specific approach to genetics. One that is also seen shared by a broad part of the clinical literature on genetic counseling, by many clinical professionals, and now me. The project was therefore initially based on the established assumption that, although we think there may be variations in our approach to genetics, there is a universal approach to genetic science and clinical practicing. Although practicing in different countries, the discussion is therefore not whether it is about DNA or about families (Konrad, 2005).

In the broad clinical literature concerning the practices as well as the challenges of genetic counseling, there is a striking universal agreement between authors. When it comes to clinical genetic practices, there are certain common traits internationally in practices related to clinical genetics in cancer, genetic counseling and risk estimation. What is commonly agreed to be central aims of genetic counseling are to provide patients and families with an estimate showing risks of hereditary disease predisposition, information about the consequences, about the probability of passing the condition on to genetic kinsmen as well as ways how predispositions may be prevented(Harper, 2004). It is commonly agreed that a genetic risk estimate is established using methods such as recording family history of diseases. This is done by noting down incidents of cancer or other diseases to detect signs of hereditability (Richards, 1996). Blood sampling is also used as a part of the genetic risk estimation to detect the presence of pathogenic mutations through use of genetic sequencing technologies. The results of these estimation practices are then used to decide upon possible preventive health trajectories such as screening programs and/or preventive surgery that may be offered to patients and family members (Bougie & Weberpals, 2011; Burke et al., 1997; Richards, 1996) **.** Genetic counseling is an attempt to help patients and/or families to understand the medical information (the disorder, the probable course of the disorder), and to help them understand alternative ways of dealing with their risk. This includes helping them to understand available preventive trajectories and, in accordance with their personal wishes, to support them in choosing relevant management strategies(Harper, 2004; Tibben et al., 1994).

Taking (as I also did at the introduction to this dissertation) a quick glance at the general clinical literature on cancer genetic counseling and the challenges involved, a clear pattern also emerged here. This pattern echoes the concerns I heard in the beginning of my fieldwork at the Danish genetics clinic, illustrated by the case of Ulla. The proliferation of genetic knowledge and genetic

counseling services carries potentially ethical and psycho-social challenges to individual patients and their families (see (Himes et al., 2016; Offit et al., 2004; Riley et al., 2012; Surbone, 2011; Vos et al., 2011).

What was interesting in the initial stages of the research was to compare how challenges of working with both patients and families (such as Ulla and her family) were handled when estimating genetic risks. This was to be studied within a frame of genetic counseling (a day-to-day concept used in Denmark to describe everything that has to do with genetic elucidation and the risk estimation process) for cancer in patients and their families. By framing it in this way we all acknowledged a sense of similarity between China and Denmark. China probably had, if not completely identical genetic practices, then certainly common practices compared with Denmark. Practices formed around an essential and universal idea of genetics as dealing with the production of a risk estimate through genetic linkage of individual patients and their families, the use of family histories and technological equipment for testing of blood. Surely, both the professionals and I were aware that China was different. But at this stage, concerns were mainly focused on differences in societal speed and in cultural differences, not on the linkage between individuals and families in genetic practices. Looking again to the clinical literature (seen in the above), we cannot completely be blamed for these assumptions. As reflected in the clinical literature on genetic counseling, working with both individual patients and their families is echoed as something universally intrinsic to the field of clinical genetics (see also Konrad's discussion on this(Konrad, 2005).
Yet, my project was rapidly about to change, as I embarked on my first trip to China.

"This is an individual service": Comparative genetics and the field kicking back

As I began preparing for my studies on China in late 2013, the idea of studying cancer genetic counseling for patients and their families still seemed straightforward. A collaborative hospital had been found in central China, and its management was very eager to participate, as they found our theme important.
Yet, as time passed by, a certain amount of anxiety started to arise on my behalf. The board of management at the Chinese hospital seemed quite eager to begin the research project. However, the answers received in my correspondence with the actual department responsible for the task of providing genetic counseling or "yichuan zixun**"** (genetic counseling in Chinese) seemed to be, if not reluctant, then somewhat puzzled by the intention of my research project. Although authors (see

for example (Sui & Sleeboom-Faulkner, 2007) working on China had pointed out that genetic services had previously been extensively provided without "counseling", Chinese scholars had increasingly been highlighting the need of counseling. This had been followed by suggestions of implementing educational programs on genetic counseling in China (Zhao et al., 2013). It had even been stipulated as a field in need of more development by the government, but services were reported to be surfacing around the country (Sui, 2009; Sui, 2010). I was continuously assured that I should just come to China and participate to see how they conducted genetic counseling. As time passed, I was, however, struggling to get basic information on the flow of patients participating in genetic counseling (yichuan zixun*)* for hereditary cancer. Often I would be left with answers like:*"Well, we don't have that many"(Chinese professional 2),* and when pressed harder the response would be:*"We don´t have any right now"(Chinese? professional 2).* In the autumn of 2013, I had the opportunity to go on a visit to the hospital as a part of a collaborative hospital conference between my Danish partner and its Chinese counterpart. I was invited to give a speech explaining my thoughts on Sino-Danish genetics. Before giving my speech, I was invited on a tour around the hospital area. Here I saw both the department of molecular biology and genetics and rooms for genetic consultations. And later I saw the facilities for genetic counseling.

Photo 1: Genetic counseling room at Chinese partner hospital

Photo 2: Genetic counseling room at Chinese partner hospital

I held my speech and it was warmly received both by the clinical staff and the hospital management. After the formal arrangement, local professionals approached me and we talked about the interesting perspectives of comparative genetics in the future. Yet, as I was standing in the limelight, a young professional approached me looking rather skeptical. He introduced himself as Wang. He had studied abroad within the field of genetics and had also worked on cancer genetics, he assured me.

W: It sounds very interesting, but why do you want to do cancer (aizheng) and genetic counseling (yichuan zixun)? I mean why ...? (pausing)
M: I think, it could be interesting to see how we (our two countries) approach the idea of counseling on the genetics of cancer for patients and their families, I said, cutting off Wang, trying to seem confident at my initial idea for the PhD project. But Wang did not give up that easily. Still looking very skeptical he continued:
W: But cancer (aizheng) and genetic counseling (yixhuan zixun)?

Still not really sure about his objections, I continued.
M: Yeah, but you see in the future, genetic counseling for cancer is…. I paused.
Wang, sensing that I did not understand him, tried to explain:
W: What I mean is why cancer? I mean, why not pregnancy? Prenatal conditions? Why cancer (aizheng) and genetic counseling (yichuan zixun) for patients and their families?
Failing fully to understand what the apparent problem was, we continued our formal talk about the possibilities of transnational genetics.

Not knowing why, Wang somehow did not understand the purpose of my research. Why did I want to study how patients and their families made sense of genetic knowledge during genetic counseling provided by medical professionals? Something within my initial frame of studying patients and their families within genetic counseling somehow did not seem to make sense to him. His objections to my comparative research frame had made me wonder. What was keeping us apart? Why did it not make sense to make a comparative project with our particular scope in mind?
The response Wang had given me showed a strong sense of ambiguity.
Wang's response, as well as my tour around the hospital had clearly revealed to me that genetic counseling was in fact a meaningful medical practice in both China and Denmark. His response underlined what the Danish professionals had told me about China. These were not aliens from another planet, but close medical colleagues sharing a fundamental understanding of clinical genetics. His response also affirmed the tendencies I already knew from literature of constantly increasing emergence of genetic practices in the Chinese health care sector (see (Sui & Sleeboom-Faulkner, 2007; Zhao et al., 2013) . Until this point, his answers proved that some elements of the outline of my comparative project were still intact. Yet, despite the fact that we clearly shared some understandings of genetic practices, his obstinate response had also clearly illustrated that we somehow shared very little. The fact that genetic counseling was actually practiced in China, seemed to mark the boundaries of the common understandings I shared with Wang. For Wang, comparing genetic cancer counseling for patients and families seemed like an incomprehensible object of comparison.
As I returned from my visit to China and revisited my dialogue with Wang, questions were piling up. Based on my experiences from the Danish setting, where I would constantly be corrected for using the wrong terminology my attention was drawn to issues of language. Could Wang's objection stem from my choice of Chinese wording? Did linguistics separate us? In my dialogue

with Wang I had used the common Chinese word Yichuan Zixun (counseling for something passed on to next generations) about genetic counseling. Was this the right word, I pondered? Using Yichuan zixun did not seem to pose a problem for Wang as long as it was connected to issues of pregnancy and studies linked to the clinical prenatal area; linking it to cancer somehow did. Did Chinese professionals in fact use a completely different wording for genetic counseling for cancer? Could this be the reason why our comparison made less sense to him? Could other language mistakes have caused Wang to object?

Talking to Wang I discovered that I had used the Chinese word aizheng (cancer) about cancer, rather than the specific forms of cancer ruxian ai and luanchao ai (breast & ovarian cancer) - the types of cancer I was interested in comparing. Would my comparative project have made sense to Wang if cancer genetic counseling for patients and their families had been presented as a project focusing on ruxian ai and luanchao ai, rather than simply aizheng (meaning cancer), I wondered? At this stage, my trip to China and my dialogue with Wang left me puzzled to say the least. Though my dialogue with Wang had shown me that we shared something related to genetics, something was also clearly making him object to my initial comparative frame, and even worse, he had not made me any wiser about the possible reasons for his objections.

Before I had the opportunity to pursue the linguistic questions my initial partner withdrew from the project, and I never had the chance to meet Wang again. I spent much time trying to find a new partner hospital, where genetic counseling for cancer was being offered to patients and families. This proved to be rather difficult. No matter how much time I spent, I could not find a hospital in China where they conducted genetic cancer counseling for patients and their families. For long I feared that my questions would never be answered, and this left me on the edge concerning the state of my project. Was I to leave the idea of comparing China and Denmark altogether?

Still puzzling where to go, I decided to leave China in the back of my head and continue my Danish fieldwork, which was just about to begin. The frustration of initiating a comparative fieldwork where only half of the equation was available was a nerve wrecking task! I was seriously considering abandoning the idea of making a comparison with China at this stage. I wrote to several hospitals, but still to no response. Months passed and the feeling of failure was growing day by day.

Yet, my luck was about to change. In 2014, I was invited to participate in a matchmaking seminar at Aarhus University, where a delegation from Beijing University had been invited. At this point I was

seriously considering simply passing on the invitation and continue my research as an all-Danish study. Sheer curiosity, however, convinced me to go, as I could see from the invitation list that this particular Chinese delegation had participants coming from hospital departments in Beijing with research in cancer and molecular medicine.

The delegation with researchers from Peking University Cancer Hospital soon presented new data on the prevalence of *BRCA* mutations identified in China within the last eight years. As the speech ended, and there was still no mentioning of counseling, I saw an opportunity to join the group for lunch. I presented my research project, and found a great interest and curiosity as to what the actual point of my PhD was going to be.
At this point I was still trying to grasp my dialogue with Wang and his apparent objection to my comparative project. I now worked under the assumption that misunderstanding in wording had been keeping Wang and me apart and this made me approach these professionals differently. Acknowledging that genetic counseling (*yichuan zixun*) for patients and families had not been mentioned during their presentation, I completely avoided the term genetic counseling. Instead I asked whether they "talked with patients of risk" (*gen bingren taolun fengxian*).
The Chinese professional sitting in front of me looked at me and smiled:

”*But of course we do, and that is what I think is difficult in my work you know (pausing). I mean, what do the patients actually get out of my information? What kind of stress (yali) does the result of our gene test cause (jiyin jiance)?*

His answer made me jolt with excitement. Finally, a recognition not only of the actual presence of genetic cancer services in China (something I already knew, but only from the literature) but also a very clear confirmation that producing and providing risk estimates for patients was the object of practice in China, too.
As he continued to talk about his meetings with patients, and how he delivered his risk information, I also became aware that he never mentioned genetic counseling (yichuan zixun), but instead preferred to use the word gene test (jiyin jiance*)*. This could explain why I had not been able to find genetic counseling for cancer mentioned in Chinese hospitals, I thought to myself. I later encountered *gene test (jiyin jiance)* on many occasions during my fieldwork in China. Not only in

hospital environments, but also in TV adds promoting genetic services and in health TV programs (BTV, 2015, April 21st. , 18.30-18.45).

Again thinking back on my encounter with Wang and his objection to our comparative project, I wondered if this was the final proof that a wrong use of Chinese clinical words had been the reason for his objections? Trying to obtain the possibility to observe the process of genetic counseling for risk of genetic cancer for individuals and families could we actually have been kept apart because a project simply linguistically defined in too narrow terms? Was the reason for my troubles something as trivial as a collision of how to term concepts where I had missed emic practice categories? An error resulting in a comparative clash between "genetic counseling for patients and their families" as it was naturally referred to in Denmark and its Chinese counterpart termed as a "gene test" (jiyin jiance)? Or had something more been at stake?

Although I to some extent felt content that my troubles were probably rooted in faulty translations, certain observations later during that particular lunch led me to believe that something else could be at stake. During our lunch I noticed that the professional in front of me, when discussing his genetic services mentioned both family history, which I knew from fieldwork in Denmark, as well as the techniques related to testing of blood. However, he only mentioned patients and never the patients` families as taking part in these discussions? Where were the patients' families during these practices, I thought to myself thinking back on the many sessions like Ulla's that I had participated in in Denmark?

As our lunch ended, the questions about the absence of families during genetic counseling piled up, but were, needless to say, unapproachable solely based on the two very short meetings presented above. Luckily the kind Chinese professional invited me to come and visit him and participate in his work. I would be following the meetings between patients and professionals regarding genetic testing aimed at estimating the risk of hereditary breast and ovarian cancer during a three-month stay in China in 2015. What I met here was far more than differences in linguistic interpretation. What I met coming from Denmark with my experience of sessions like Ulla's was a different world of genetics altogether!

Entering genetic counseling in China

At my partner hospital I quickly learnt that genetic services followed the descriptions I had met studying literature on Chinese health care. Genetic cancer services were not offered at specialized clinics as in Denmark. Patients, would first have to go to a university hospital (in this case a hospital specializing in cancer tumors) to meet a senior professional. Here they would have to draw a number and wait among "normal patients"(*putongde bingren*) coming for treatment or further examination of their cancer disease at different stages.

In China I learnt that the family history was just as essential as I had seen it in Denmark. The family history needed to show certain indications, before patients were referred for genetic testing at the laboratory. As a professional told me: ”*We don´t test anyone without an indication, that is a waste of resources. If they don´t have a family history we don´t test”(senior professional).* But all of that would make much more sense to me, when I visited the clinic, I was told. Thinking about Denmark and the opening case with Ulla, it sounded remarkably like what I had encountered here. The first place where I could meet the patients I wished to observe would be at a local tumor hospital, the Peking University Tumor Hospital (abbr. PUTH).

A day in a Chinese clinic

I arrived at the hospital on a Thursday. I entered the hospital and a friendly guard, who looked rather perplexed, first greeted me. As I explained my intentions and my contact´s name, he relaxed and told me to go to the second floor. In the lobby of the hospital people were already forming long queues. I asked a woman in the queue why they were queuing: ”*To take a number”(gua hao)* she said and smiled at me (I was unaware at that time "To draw a number" would later reveal itself to be a vital practice, which is presented in Chapter 4). As I began to walk towards the lift taking me to the second floor, I could hear quite clearly that she was talking to the people standing next to her about the “*laowai”(foreigner)*, and I could see that the guard who had just given me directions was also talking and pointing in my direction. “*So much for sneaking in and being a fly on the wall*“, I thought to myself. As I arrived on the second floor, a nurse greeted me and asked me to go to the examination room.

This room was just big enough for two tables with computers facing each other and a bed for examination. At each workstation a small chair was placed for patients. Next to the door a small curtain made it possible to separate the room in two. We are currently two people in the room. I am

sitting on a small chair positioned next to the examination bed, and a junior professional is sitting at one of the workstations.

Someone knocks at the door and a friendly guard in a uniform hands us a couple of bottles of water, and puts one on the table by the still empty workstation. I recall seeing him when I entered the examination room. He was standing at a small desk, and patients would frequently approach him with questions, about directions. I remember he gave a distinct impression of stoic calmness. He did not seem irritated by the many questions from patients already waiting in large numbers just outside our room, but he did not smile. Upon entering the room my eye caught sight of a long pole right next to him. It had been designed to ward off people trying to enter the rooms, and I remember Chinese officials telling me that assaults on doctors are not uncommon in China[9] (I will return to this later in this dissertation). We wait for five minutes in silence in the examination room, until a senior professional opens the door. He greets me with a smile and engages in a bit of small talk with the junior professional. He sits down, opens his computer, and glances causally at his cell-phone. He takes a sip of water before saying: ”*What number?”*- “3”, the junior professional replies and presses a button and outside our room a loudspeaker announces: ”*Number 3”*.

A woman in her 50s or 60s enters accompanied by a man. She jolts, as she sees me saying: ”*Ai you - a foreigner”*. “*He is a student from Denmark studying in China”,* the junior professional explains. “*A young Western student”,* she replies nodding at the senior professional. She sits down and hands her record to the senior professional. ”*How do you feel when taking this medication?”* the senior professional asks. The woman explains that she feels some pain in her left side. The senior professional shakes his head and raises his hand in a quick motion. A small gesture that I soon learn is an indication that the patient is to do her "stretching exercises" after having completed surgery to prevent stiffness in the surrounding tissue. “*No problem, continue to take the medicine”,* the senior professional says before pointing to the chair in front of the junior doctor. The woman continues:*“But”,* she is interrupted by the senior professional shaking his head still pointing to the chair ”*Sit there. Next”,* he says. A loud speaker calls out another number, and within minutes the door is opened and another patient enters the room.

[9]This is also identified in literature (Hesketh, Wu, Mao, & Ma, 2012, Liebman, 2013, Pan et al., 2015) .

The next patient is a woman in her early 50s together with her husband.

"Give me your record", the senior professional says. He looks at me. *"Young man",* he says while nodding towards the corner indicating that I am going to stand in the corner and close the curtains behind me while he performs a breast examination. As I close the curtains behind me, the relative of the first patient joins me in the corner. She is, however, still seated together with the woman being examined, sitting next to her while she is talking to the junior professional about medicine. There I stand nodding somewhat nervously to the relative of patient number 1, he simply smiles back at me before he starts fiddling with a cell phone as if this situation is nothing out of the ordinary. I can hear the senior doctor from behind the curtain:*"Ok ok not bad right?"*, he says addressing the results of the surgery performed on the second patient. During my period of fieldwork, I often thought about the word "*privacy"*. But it seems I am the only one who is troubled by this question, as I can hear the first patient continues to discuss her medication seemingly not noticing the patient next to her. Suddenly the curtain is drawn away, and I go back to my seat again. A nurse enters the room to talk to the senior professional about changes to his daily schedule.

At that moment, we are eight people in the examination room: Two patients, two relatives, two doctors, one nurse and me, the anthropologist. I get an urgent feeling of claustrophobia, but it does not seem to bother neither the patients nor the professionals, or there is no indication of taking notice. Other than occasional glimpses of the patient sitting right next them, none of the patients or their relatives seem to acknowledge the presence of the other patients and their relatives in the room.

It continues like this and as the first patient leaves the room along with her relative, patient 2 is asked to move from the chair in front of the senior doctor to the chair in front of the junior doctor, and a new patient is called into the room. I check my watch and although much has happened, only around five minutes have gone by.

As the hours go by, more than 50 patients move between chairs within the small examination room, never spending much more than a couple of minutes in each chair. Only on a few occasions during this morning session the number of people in the room constitute a problem and relatives are told to wait outside. And so the day continues, patients come and go, at what I feel is a hectic tempo compared to what I am used to from Denmark.

Initiating a trajectory of genetic counseling

It is this hectic atmosphere at the outpatient clinic at PUTH that patients participating in genetic testing first meet. Either they come by themselves specifically seeking a test or they are recruited by the senior professional among the patients already at the clinic, undergoing either diagnostics or treatment for cancer. Most, however, arrive with the purpose of seeking out genetic services.

I sit in the consultation room as we go through the "ordinary oncological patients". A woman, Yu ting, in her 40s enters the room and sits down in front of the professional. Yet again the professional looks at his screen at the record before addressing her:

SP: *What is your situation?*
YT :I have come because we have breast cancer in our family, so I want to do a genetic test.
SP: Ok, so you have a family history?
YT: My grandmother had cancer in both breasts when she was around 55 years old, my mother had breast cancer, when she was 70, and I had it myself. That's why.
SP: So you want to have your genes tested. Your mother`s onset was a bit late in life. Do you have children?
YT: A son.
SP: Does his family have any cases of breast cancer (ta de jia – not the same family)?
YT: No. I just have to take a blood test right?
SP: Yes, you have to take a blood test, but if you have a mutation, your risk (of disease) may be higher, up to 80%. You have to consider that this (receiving the test result) could be stressful for you.
YT: But If I have to do it; I want to do it right.
SP: Ok, you can go and have your blood test taken at 13.30pm (Looks at the junior doctor). Make a referral.

Yu ting is pointed towards the chair in front of the junior professional, who quickly prints out a referral, before giving her directions to the nearby laboratory where the test will be taken. While this is going on, yet another patient has entered the room, and the senior professional is soon again concentrated on measuring a tumor based on an x-ray image.

In a session lasting no more than five minutes altogether, the first opening meeting had transpired, a family history showing indications had been established, Yu Ting had moved to the next chair, and a referral has been made and printed out for her. She soon left the examination room, and I was told that she was on her way to the have a blood sample taken. This encounter, which was one on the many encounters I observed, illustrated how genetic testing took place at PUTH in China.

Comparative reflections

Looking back to my encounters with patients like Ulla, the encounters in China had left me baffled. Comparing to my Danish encounters, the women I met in China seemed to share much of Ulla's motivation and cancerous experiences. When talking to Chinese women like Yu Ting later in the process, many of them would tell stories similar to the stories of the Danish women I had met relating to cancer incidents in the family and painful memories of disease and death. Just as in Denmark, most of the Chinese women had experienced cancer or cancer-like symptoms themselves making them ask the similar questions as Ulla had asked. Am I next in line? Do I have a genetic risk? How can I best counter these potential risks? As we discussed these issues, tears were a natural companion. This was real to these women here in China, just as it had been to the women such as Ulla in Denmark! Just as in Denmark, patients here in China had strong feelings of a special genetic responsibility to both themselves and to other close family members. Very often children (similar to the case of Ulla) had prompted them to seek out these services.

These similarities among the patients in China and in Denmark made the differences I encountered in the clinics seem all the more surreal to me. Despite sharing a very similar wish of responding to feelings of social genetic responsibility, the investments they would have to make in clinical genetic counseling practices allowing such a response were very different. Ulla was given a huge assignment taking contact to other family members, depending on their cooperation; moreover, some of these family members were not very close relatives. Yu Ting getting from the opening stage of the genetic counseling session to having an actual test had taken five minutes. And as with the other women I followed in China, she continued to the next step without involving anyone else but herself and the professional.

I became increasingly aware of the differences between clinics and clinical practices in China and Denmark during my time in China. To some extent this was very puzzling. For the practices also

seemed to have many similarities. Both in Denmark and China the practices I followed explicitly concerned counseling related to the *BRCA* genes. Both clinical settings had a common aim for their genetic services - to estimate genetic risk of cancer or to produce a risk estimate. Both places used family histories (in ch.jiazushi/jiatipu; in da. familiehistorie/stamtræ) as the tool for tracing hereditary patterns. Both places based pathogenic mutational findings on use of similar technical equipment when sequencing blood (Illumina sequencers).
Despite these obvious similarities found both among patients and in practices in Denmark and China, patients were still met in widely differently ways. In Denmark, they were met with remarks like: "*You come here as part of a family, and you leave here with knowledge that affects others."(Professional 2)* and "*As opposed to other places within the healthcare sector we deal with entire families here"*(*professional 2 discussing with professional 1*) whereas patients in China were met with remarks like *"We deal with patients not families"(Senior professional) or "This (genetic testing) is an individual service (geren fuwu)"(Junior professional).*

Thinking back on my encounter with Wang, it now seemed potentially clearer what could have made him misunderstand the way I initially outlined my comparative project. This was probably more than a misconstrual of words: I said genetic counseling (yichuan zixun) when I should have said genetic testing (jiyin jiance) (although this probably did not add much to clear up our common confusion). What was fundamentally different was that I mentioned a service for patients and families as the basis for our comparison, which empirically I could now see was non-existent in China. To my amazement, there were no families participating in these risk estimation practices! This came as a double surprise for me. It did so because I had been so used to talking and thinking of patients and families as naturally connected within the practice of genetic risk estimation. Not only from my Danish experiences but also from the discussions of genetic health care services in the broad clinical literature. Comparisons are, however, not static, they are contingent processes (Niewöhner & Scheffer, 2010) . However, never once during my preparations for going to China, had I/we seen them so. Doing our preparations we had not questioned the *tertium comparationis* of the project outlined as a comparison of the intricacies that physical interconnections of patients and families in genetic counseling practices bring forward. Never once, in my period of preparations had I speculated that genetic counseling could be conducted without the involvement of families. Having studied Chinese culture for many years, the position of the Chinese family as the natural

nexus for Chinese life, seemed almost self-evident to me[10]. Finding families so explicitly excluded from genetic counseling pertaining to hereditary dispositions therefore seemed perplexing.

I had now also learnt a different valuable lesson. Despite sharing practices in Denmark and China (establishing a family history, estimating risks), what was primarily shared was the labeling of these. The ways these practices unfolded, their content, the people involved, the objects used, and the rooms where they took place were now shown to be very different.

What was slowly becoming clear to me at this stage was the interesting perspectives that potentially could be found in the sums of the differences I had encountered in the two countries. What these differences prompted was a very different series of comparative questions than the ones I had initially set out to study, which showed a salient gain made achievable through an ethnographic comparison. Thinking again back on my dialogue with Wang, albeit now reflected in the light of my experiences, his obstinate initial response now showed me how he had made me ponder. His response had first made me seek an explanation in linguistics, eventually leading me towards issues of involving families or lack of involving these in Chinese genetic counseling. What Wang's objection as well as the works of Chinese professionals had made clear to me was how comparisons not only help us to pursue answer to certain questions, but more fundamentally may help us ask questions to begin with. And so I gradually left behind my initial comparison of how patients and families were handled during genetic counseling in Denmark and in China. What my fieldwork experiences had made me realize was that "differences" were still the object of study, but of more interest was to try to understand how Denmark and China with an apparently common clinical and scientific approach to the *BRCA* genes could lead to such different practices.

What makes estimating genetic risks an individual and a family practice in Denmark but a strictly individual practice in China?

How do family members and their physical participation become a natural inherent necessity in Danish genetic cancer risk estimation practices and not in China?

How could I approach, study, and understand the reasons for such differences in Chinese and Danish genetic counseling?

And what do these differences ultimately mean for the people participating in these practices?

[10] The position of the family as a vital nexus of Chinese society and life has been traditionally emphasized by many social scientific researchers specializing in Chinese history and culture (Davis & Harell, 1995, Freedman, 1979, Stockman, 2000) . This is increasingly however being scrutinized and this dissertation is going to take up this in chapter 8

These are the empirical questions that my fieldwork experiences spurred.

The answering to these questions will guide the following chapters. First, I turn to theory and contemporary current anthropological research, where I show how current anthropological and sociological works on genetic counseling, science and technology practices may help us approach the empirical questions in this dissertation.

Chapter 3

Approaching differences in Danish and Chinese genetic counseling practices – in theory

In this chapter the theoretical framework and methodology of this dissertation will be outlined. The purpose of this chapter is twofold: First of all the chapter intends to situate this research within an already considerable amount of anthropological and sociological literature on genetic counseling practices and discussions of genetic responsibility. Similar to this study, an increasing number of studies compare sites performing genetic services around the world. The second purpose is to show how my empirical experiences from conducting comparative fieldwork have led me to explore different theoretical and methodological approaches as a way to study and understand the differences in Chinese and Danish genetic counseling practices as described in Chapter 2.

Genetic counseling practices as social and cultural responsibility practices

This research is far from being the first anthropological study of genetics, its practices, and its links to the emergence of novel forms of genetic responsibility. As mentioned at the opening of this dissertation, this research partially takes its departure in questions framed by a world of anthropological studies of genetic counseling. Many anthropologists have particularly focused on the kind of questions novel forms of genetic knowledge practices may have upon the social human constituency. Genetics and its practices, relying on models of inheritance (the laws of Gregor Mendel (Pálsson, 2007), have raised central questions about belonging, kinship and individualism (Edwards, Franklin, Hirsch, Price, & Strathern, 1998; Finkler, 2001; Franklin, 2001; Rabinow, 2005; Strathern, 1992) . Studies of genetic practices have been shown to have a powerful capability of enacting categorizations of kinship-relations based on molecular data. These may increasingly make people see themselves *as selves in a genetic relationship to others* (Keenen, 1994).
These debates have also been seen to be of particular salience among scholars studying the field of genetic counseling.

Anthropological literature on genetic counseling has demonstrated, how the re-classification of certain diseases as genetic in origin has lead to the possibility of calculating and estimating risks of disease through genetic counseling practices. The literature shows how genetic counseling is

capable of labeling individuals at risk. Genetic counseling not only presents risks as manageable, but also implicitly places an obligation on individuals to act on these risks, when considering their own future health (Gibbon, 2007; Konrad, 2005; Lupton, 1995; Sachs, 1999; Svendsen, 2005).

Just as genetic technologies open up re-constituted kinship-categories that increasingly influence people to see themselves *as selves in a genetic relationship to others*, the use of genetic technologies in health care has been shown to add an extra dimension to such categorizations. Building upon the science of genetic pathology and the possibilities for obtaining knowledge of their risk of disease through genetic counseling, people also learn to see themselves as *selves in a pathological relation to others* (Hallowell, 1999). Such powers of categorization have consequences. Relying on the substance of shared DNA, genetic counseling practices not only provides individuals with new possibilities for managing their own health but also the health of those with whom they share such DNA.

This has given rise to new ideas of individuals who have a special kind of *genetic responsibility* to those with whom they are genetically related. With the idea of genetic responsibility, inherent demands have followed to live up to one's genetic responsibility by participating and investing in genetic counseling practices for the sake of one self and genetically related others (Hallowell, 1999; Konrad, 2005).

Genetic responsibilities are not abstract philosophical conditions but, as studies by Nina Hallowell(1999), Lisbeth Sachs(2014), Sahra Gibbon(2007), Monica Konrad(2005), and Mette Nordahl Svendsen(2004) have empirically shown, they emerge and manifest themselves through the everyday practices of genetic counseling that patients and families invest in. In other words, genetic responsibility and demands for investments are invoked through the very practices of genetic counseling.

Nina Hallowell's(1999) study among women seeking out genetic counseling for cancer in the UK shows how genetic counseling practices make patients experience strong feelings of genetic relatedness and responsibility. Such feelings make them accept a complex role of being responsible for disclosing and sharing information within their families, but they do so at the expense of personal rights to knowledge and individual feelings of intimacy. This more than often results in feelings of personal conflict (a point she shares with the study by Gibbon(2007)). Svendsen's(2005) research among Danish patients, and Sachs's(2014) research among Swedish patients seeking out genetic counseling for cancer both illustrate similar points. In responding to feelings of genetic

responsibility, many patients accept a role of having to supply both blood and body to specific testing procedures with the purpose of producing a risk estimate, which will be beneficial to the health of others. Afterwards many also agree to undergo elaborate and often severe preventive surgical interventions, such as the removal of organs and body parts and even sometimes preventive trajectories for generations yet to come. These include PGD[11], involving strong hormonal treatment regimes. Yet, similar to Hallowell's study, many patients undergoing genetic counseling and preventive interventions also find that in the attempt to live up to their perceived genetic responsibilities, their possibilities for asserting and upholding personal autonomy become highly constrained.

In these anthropological studies emphasizing that genetic counseling gives rise to novel forms of genetic responsibility and demands for genetic responsibility investments, genetic counseling and its effects have been approached and treated as the products of social co-produced negotiations. At the center of this argument is the acknowledgement that any biomedical practice consists of a complex set of local doings and ways of thinking rather than stable universal forms of clinical science (Gibbon, 2011; Lock & Nguyen, 2010) . Genetic counseling and genetic risk estimates constitute particular kinds of social cultural constructions, and they emerge through negotiations between actors within specialized clinical institutions and also through the everyday lives of people outside the clinics[12] (see. (Cox & McKellin, 1999; K. Featherstone et al., 2006; Svendsen, 2006))
Approaching the practices of genetic counseling in clinics as specific kinds of cultural constructions giving rise to feelings of genetic responsibility, anthropologist Rayna Rapp's (Rapp, 1999; Rapp, 1994) studies of prenatal diagnostic and counseling practices for pregnant women provide an important example. Her research shows how the negotiations of knowledge within such technological practices, the choices, and the kinds of responsibilities they open up to, are never neutral as such. They unfold within complex and often conflicting intersecting local cultural and historical discursive categories such as that of gender, religion, race, class and ethnicity (a point shared by others see. e.g. (dAgincourt-Canning, 2001; Franklin, 2006; Gibbon, 2007).
Many earlier studies of genetic counseling, such as those presented in the section above, are conducted in mainly Western cultural settings. Yet an increasing number of studies are conducted

[11] Pre-implantation genetic diagnosis, meaning the genetic profiling of embryos, aimed at selecting embryos without pathological genetic mutations for further artificial insemination trajectories.
[12] Though I mention and acknowledge the specific roles that the daily lives outside clinics play in the ways that genetic risk estimates become socially negotiated within families, the focus of this dissertation is specifically on clinics.

outside this Western framework. The findings of these studies echo Rayna Rapp's(2014) observation, that although the protocols and technologies of breast cancer spread internationally, this spread is heterogeneous (and often uneven) both concerning material extent and application. Genetic counseling studies show how such practices around the world, though sharing certain characteristics, are always provincialized. Different locations offer different spaces of knowledge production as well as different cultural and historical discourses. This means that these differences construe the modes of genetic knowledge production becoming possible, as reported by the medical anthropologist Deborah Gordon(2014). When form, extent and meanings of genetic counseling practices change due to shifting locations, so do the complex questions about individual and social responsibility and the demands for social investments that need to be made. Genetic counseling always needs to be understood and studied as situated within inherent local cultural social worlds (Beck & Niewöhner, 2013; Bharadway, 2008; Franklin, 2006; Gibbon, 2013; Gibbon et al., 2010; Nahman, 2008; Roberts, 2008; Strathern, 1992; Waldby, 2009)

Taking a departure in genetic counseling, discourse and its role in the emergence of genetic responsibility, many scholars have approached this linkage as a particular kind of construct. They see this construct as the product of particular ideas of statehood unfolding through the practices of strong local societal and state institutions. (Gibbon et al., 2010; Greenhalgh & Winckler, 2005; Novas & Rose, 2002; Rose, 2011; Sleeboom-Faulkner, 2010; Zhu, 2013)
Studies emphasizing this argument depart in Foucauldian perspectives, stressing that genetic services exemplify specific institutional practices aimed at enforcing what Foucault has termed bio-power(Foucault, 1994). Foucault argues that in a modern society, power is not direct and explicit, but works from within. This often happens through hidden forms of regulative knowledge practices and social technologies internalizing specific forms of bodily subjectivity. Genetic practices are here argued as exemplifying exactly such a particular state regulatory practice, aimed at evoking both specific normative ideas about proper personhood and what may count as "normal" or "deviant". In offering these public technologies, countries produce specific ways of both being normal and achieving normality. Genetic practices are thus to be seen as local social subjectivitazion practices where people as individuals learn to act upon themselves and conduct themselves in certain genetically responsible as well as normative and self-regulating ways (Dean, 1999; Lupton, 1995; Novas & Rose, 2002) .

Svendsen's fieldwork in Denmark also exhibits such theoretical conclusions. Her work on genetic cancer counseling practices demonstrates how genetic practices constitute a specific form of social technology. In this technology, certain genetic trajectories are inherently constituted as morally more correct than others producing specific kinds of subjectivities. Drawing upon fieldwork in Danish clinics and analysis of policy documents and Danish historical records, Svendsen and her colleague Koch analyzed Danish genetic counseling practices. This study demonstrates how individual and social responsibilities are internalized as a stable part of genetic counseling practices in Denmark (Koch & Svendsen, 2005) . Genetic practices are specific kinds of institutionalized practices, and in Denmark as in other Western countries these draw upon specific eugenic histories and Western liberal ideals of "a responsible individual freedom" to produce specific forms of responsible subjectivity (see also (Vallgårda, 2003)). In practice, Svendsen's studies of genetic counseling show how a Western approach to genetics put pressure on patients in Danish genetic practices. These genetic counseling practices implicitly pressure patients to seek out as much knowledge as they can and to actively seek out preventive measures both for the patients' own sake and for their biologically related families. This as a way to live up to Western state ideals of an individual personhood in which such individuals are assumed to be morally responsible for achieving health (Koch & Svendsen, 2005; Svendsen, 2005; Svendsen, 2004)

As genetics deal with hereditability and biology, genetic counseling practices and their production of individual moral subjectivity therefore also come to encompass the subjective production of kinship subjectivities.

The findings by Svendsen and Koch from Denmark, echo a broader tendency found in similar studies conducted in Western countries showing that genetic technologies unfold within what Rose and Novas(2005) call a "stringent discursive regime of the self". New genetic technologies in Western countries and the responsibilities these open up to, are to be understood as responsibilities drawing on a discursive world of self-regulating prudent, yet enterprising individuals, actively shaping their life course through acts of choice (See also (Lupton, 1995).

Where studies in Western countries have shown to frame genetic counseling practices and the emergence of genetic responsibilities within discourses of liberal self-regulating individuals, an increasing number of studies conducted from outside Europe and the US have shown how other state-discourses are in play.

The anthropologist Jianfeng Zhu(2013) demonstrated how strong state initiatives in public health education for pregnant women in China powerfully regulate the production of specific genetic subjects. Following these women through this education, Zhu shows how the women learn to see their fetus and their pregnancy within state-economic genetic discourses of "loss and gain" and learn to choose medical trajectories accordingly. Zhu shows how this way of providing education means that women learn to see it as their personal genetic responsibility to produce healthy offspring by seeking out all available pre-natal test measures to accommodate what the state has framed as a *good healthy life*. Zhu argues that these women become subjects in specific governmental practices aimed at producing a collective population of bodies. A specific kind of bodies whose quality (*suzhi*[13]) may accommodate the economical aspirations of the Chinese government. The choices of these women themselves to seek out test measures reflect just that. A conclusion Zhu shares with others studying Chinese genetic practices (Greenhalgh & Winckler, 2005; Greenhalgh, 2009; Sleeboom-Faulkner, 2010) . What emerges from studies such as Zhu's conducted outside Western settings is that genetic counseling practices and genetic responsibilities are framed within state-discursive ideas of collectivism rather than liberal individualism (see also (Gibbon et al., 2010)).

Genetic practices constitute sites of production and even though state discursive ideals of citizenship have been shown to play a very prominent role in the production of novel forms of genetic responsibility, they do not play a solitaire role. This was also emphasized by Svendsen, stating that genetic practices are always situated in local cultural worlds (Svendsen, 2005).
The increasing comparative studies between Western and Non-Western countries have also helped to show how shifting sites influence more than the Western individualist or the non-Western (Chinese) more collectivist[14] state-discourses, acknowledged as giving rise to specific forms of genetic responsibility. Comparative studies of genetics and its related practices in Cuba, Greece, and Germany by Gibbon and colleagues (Gibbon et al., 2010) demonstrated how more than local regulatory state discourses are in play. Through comparison, their research has helped to show how institutionalized genetic practices are also unfolded within sometimes conflicting and very different local cultural ideas about moral personhood, kinship and religion. These cultural ideas, as studies of genetic practices in non-Western countries have helped demonstrate, often differ from their specific

[13] A great deal has been written about the Chinese state-idea of improving the quality of population (Tigao Renmin de Suzhi) for more information see fx (Anagnost, 2004)
[14] For more studies of non-western collectivist state discourses see also Sahra Gibbons work in Cuba (Gibbon, 2011).

western counterparts in that the strong western ideals of individualism are given much less emphasis, if any.

Acting as a comparative counterweight, studies by e.g. Roberts (2007), Gibbon(2011), and Sui & Sleeboom-Faulkner(2010a) have helped show how genetic practices and its responsibilities have unfolded in countries outside the West within inherently sociocentric conceptions of moral personhood in which the boundaries between individual and family are often more transcendent. Such modes of sociocentrism have been shown to originate in local cultures and in the social cultural lives that patients live outside the clinical setting. Yet, they intersect genetic counseling practices[15]. They influence the ways that genetic products and their responsibilities are articulated in non-western societies giving rise to local concerns and local stakes very different from those seen in Western societies[16].

Comparisons between countries around the world have helped to show that genetic practices need be approached as both local politics and at the same time very local social cultural productions of individual or sociocentric subjectivities (Gibbon et al., 2010).

But more layers may be added. With the increasing amount of scholars who have studied genetic practices outside Western contexts, different points have been raised. These scholars have not disavowed the positions of neither political nor cultural discursivity within health care. However, what these scholars have comparatively called for is the need to include the very different material roles that specific local socio-economic conditions have for the ways that health care and its meanings may become enacted. These material conditions have a natural but salient impact on the bodily products of these genetic practices. Gammeltoft & Ngyuen (2007) showed how strong economic disparities in Vietnam means that professionals working with ultrasound and counseling for pregnant women pay specific attention to economy when providing counseling. When counseling women on abortion, professionals' focus on the economic impact on giving birth to an abnormal child may have upon families already under financial pressure. This means that women are openly advised by professionals to choose an abortion as a family-protective measure by the professionals. They do so because they see these abortions as proper moral choices that help counter

[15] Anthropologist Elizabeth Roberts comparative study of IVF practices in Ecuador provides a very telling tale. Her study shows how religious ideas of Ecuadorian kinship intersect with genetic counseling in here meaning that termination of embryos in IVF emerge as specific practice of kinship protection(Roberts, 2007).

[16] Exploring this dichotomy of non-western sociocentrism set against western individualism was also what lay the grounds for initiating this comparison at hand. It has also been what made me surprised when finding plenty of family in "individualist Denmark", and none in what I thought was "sociocentric China"

future economical disparities for the affected families. Comparing genetic counseling in China and the UK, the anthropologist Sui Suli(2009) showed a similar trend. Sui's work shows, similar to the work of Zhu, how strong governmental ways of thinking about proper subjectivity impact on the ways that genetic counseling unfolds. Yet, compared to the UK, Sui stresses that very concrete local material conditions play an equally important great role here as it does in many other developing countries. Following pre-natal genetic counseling for Thalassemia in China, Sui showed how economic pressure and social disparities in China influence how both counselees and counselors negotiate possible clinical trajectories following genetic tests. Following genetic sessions, Sui demonstrated how strong economical pressure on Chinese families and a lack of social supportive systems for handicapped children weigh heavily in clinical counseling practices. This means that genetic results are negotiated by professionals and patients with an eye to the future economy of the affected family. In her collaboration with Margareth Sleeboom-Faulkner, Sui showed how economic disparities in China and the lack of proper health care support influence choosing an abortion when a genetic disorder is found and how this becomes the natural choice to make in genetic clinics (Sui & Sleeboom-Faulkner, 2010b) .

Within these outlined approaches in current studies on genetic counseling, a certain sense of privilege has been given to some actors within these meetings at the expense of others. Where human agency has been studied as the catalyst of these productions the different mundane objects/things involved in genetic practices are left passive. This may result in certain insights to be overlooked within such comparisons.

Turning to science and technology studies (STS), where special attention has been given to the workings of technologies and objects, a wide arrange of scholars have argued for paying equal attention to the agencies of both human and non-human actors when studying scientific and biomedical practices (Cetina, 2001; Latour, 2000; Law, 2008; Mol, 2002; Woolgar & Lezaun, 2013) . Mundane things, such authors claim, are never just blunt objects, but are actors too, whose agency plan an important role within scientific and biomedical productions and thus should be studied on equal footing with their human counterparts (Latour, 2007).

In the following sections, I intend to show how departing in discussions and studies of reality as a multiple product of performance and of agency as something to be understood relationally may provide a different perspective on transnational comparisons of genetic counseling practices. In the following section I will provide a broader description of certain common assumptions within these

STS frameworks. Then I more specifically turn to the works of the Dutch anthropologist Annemarie Mol (2002) and her Actor-Network-Theory (ANT) inspired local comparative framework of the *Body Multiple* and her method of *praxiography.*

Actors, relations, and genetic practices: Body Multiple and praxiography

The comparative analysis in this dissertation is inspired by the equally comparative insights provided by the works of STS scholar Annemarie Mol. As mentioned above, this framework is situated within a much wider frame of STS scholars approaching science and technology within a *performative* idiom of *practice*. I do not intend to dwell in the many different aspects of these individual scholars, but rather elicit some of their common understandings about departing in practice. Common for scholars such as Annemarie Mol is that they address issues of ontology rather than epistemology. Reality is claimed as being the product of practices (or performances).

Neither performance nor *practice* can be considered new notions within anthropology, as they have been extensively used in the works of Pierre Bourdieu(1977), Sherry Ortner(1984) and Catherine M. Bell(1992). However, the notion of practice has in recent years gained prominence in the light of the ontological turn. The catalyst within this "turn" has been a rejection of the world to be understood as "one" to be represented and interpreted through epistemic intermediaries, cultural, or social systems. What has been at the core of this turn, especially within anthropology, has been the acceptance of the existence of not only one world but of the existence of multiple worlds. Behind the ontological turn is a renewed sensitivity towards understanding how worlds come to be multiple, and it thus moves away from prior emphasis upon how the differences in worlds we encounter may be understood in terms of translation (A. Pickering ed. & Guzik, 2008; Woolgar & Lezaun, 2013) .

Such thoughts have found particular merit within studies of science practices. For STS scholars working broadly within the idiom of performance or practice, transcending the grip of "representationalism" has been emphasized arguing instead that "what can be" in science (and anywhere else for that matter) results from and transpires through practices and their aggregations(Cetina, 2001; Mol, 2002; A. Pickering, 1995; Rouse, 1996). Reality in science does not "live outside"; rather it transpires through the real time accomplishments of ordinary activities

being performed [17] (Mol, 2002). What has thus been proposed within the inter-linkage of performance and reality is effectively a reworking of the study of knowledge production from a world of "how we can know" to "what can be" as a result of the worlds becoming a product of practice. What is at stake within the realm of scientific knowledge practices is fundamentally a re-positioning of reality seen as a product of performance. Shared among those STS scholars working within the performative idiom of practice is, that reality is relational. To scholars like Annemarie Mol working within the Actor-Network-Theory (ANT) tradition, this implies that in order to understand the reality of a specific phenomenon one must adopt a specific semiotic materialist approach to research (Mol, 2010).

To Mol, as to others working within the ANT tradition, the world and its phenomena are the products of relations. Where semiotics has shown how meaning emerges as the product of relations between words, semiotic materialism holds that the ontological beingness of any phenomenon (understood as an actor capable of acting) is determined by the enactments of the webs of relations to which it is a part (Law & Mol, 2008) . Actors are not only to be seen as something or someone capable of doing something in the world through their relations to others. Actors themselves also constitute a kind of semiotic material relationship or network (hence the term actor-network). Of this double sidedness ANT scholar Michel Callon states "reducible neither to an actor alone nor to a network…An actor-network is simultaneously an actor whose activity is networking heterogeneous elements and a network that is able to redefine and transform what it is made of"(Callon, 1987:93).

Commonly in this tradition is thus that the reality of any phenomenon/actor is the product of enactments of specific actors within webs of relations. To Mol and others within the ANT tradition, a special position is therefore taken towards the nature of agency and actors. Considering what I have just written, it follows naturally that actors in this tradition cannot be reduced to humans, but rather includes both humans and non-humans. The boundaries of actors are not stable. What an actors is and what kind of agency the actor has, is rooted in the web of relations to which it is a part (Law & Mol, 2008; Mol, 2010; Mol, 2002) . Some phenomena or actors emerge rather stable because their emergence happens through webs of relations taking the shape of stable networks of actors. In the event that an actor leaves the network, such phenomena fall apart. In the early days of

[17] Different scholars have here used different vocabularies, British Sociologist Andrew Pickering(A. Pickering, 1995) favoring *performativity*, Annemarie Mol and British sociologist John Law (Law, 2008, Law & Mol, 2004, Mol, 2002) favoring *enactment*, and Austrian sociologist Karin Knorr-Cetina(Cetina, 2001) favoring *relations (to name but a few).* Common however to these are however that they share the fact that reality is seen as unfolding through the works of concrete *doings*

ANT, much attention was given to show how the reality of a phenomenon was linked to the stability of its network. It was here shown how the instability of a network would make a phenomenon falter. Later, however, Mol and colleagues have shown how some phenomena emerge through multiple webs of relations, and as such become more fluid in nature. I will return to this exact distinction later, first regarding Mol's specific framework and later in my discussion. The distinction between kinds of webs of relations will prove to be central in distinguishing between Danish and Chinese genetic counseling practices.

My interest in the works of Mol for the topic of this dissertation comes from her application of these insights within the study of clinical practices exemplified in her comparative framework of *Body Multiple*. To Mol diseases or medical conditions constitute actors, and thus need to be understood as the product of specific forms of enactments, doings, or practices of actors situated within webs of relations. It could be argued that this does not sound completely different from those frameworks approaching medical conditions, such as genetic risk as a product of social negotiations among human actors. Yet, substantial differences are to be found when examined closer. To Mol medical conditions are exactly not social human constructions in hospitals on top of a biological reality. What is produced in practice at hospitals is the reality of these medical conditions. Mol´s local comparative research in a Dutch hospital showed how an atherosclerotic body emerges altogether different within different hospital departments. These different bodies are not different versions of a real body, but are "ontologically multiple" she claims, and they co-exist within a single hospital (Mol, 2002) .

Following the day-to-day work of clinical professionals at different departments, Mol showed that what emerges, as an atherosclerotic body is different in these settings because they are enacted differently. Different bodies emerge because different techniques and different webs of relations enact these bodies in very different sites. According to Mol, each arrangement of practices and actors generates its own unique material reality of the body, hence her term *Body Multiple.* As mentioned previously in this chapter, Mol pursues the point that not all actors take the form of stable networks. Sometimes an atherosclerotic body as an actor takes the form of a network of actors with a clear and stable form. Mol here shows how this is the case of the atherosclerosis body emerging in laboratories. Laboratories, she confides, work through stable relations, leaving bodies to emerge within a very strictly determined syntax (Mol, 2010; Mol, 2002). Other times, however, atherosclerotic bodies emerge more fluid because the webs of related actors are fluid. Mol demonstrates how this is the case of the atherosclerotic body emerging through the clinical practices

in clinics where doctors examine and counsel patients. What an atherosclerotic body is here does not follow one strict syntax, but requires tinkering among many[18] different syntaxes (Mol, 2002).

In order to understand the emergence of a medical condition as an actor, sometimes taking multiple forms (either stable or fluid), Mol argues that we need to approach these and study how these emerge through means of practice. In order to open up such understandings, she holds, one must make a detailed account of how medical conditions unfold at hospitals, focusing on what is done, who does the doings and through what kind of webs of relations (networks or fluids) these work. In doing so, Mol stresses one should not neglect to acknowledge that even the smallest un-bracketed entity may have a fundamental impact on the final product. Even the smallest thing within a practice may be an important actor. As Mol explicates: "The desk, the chairs, the general practitioner, the letter: They all participate in the events that together "do"" (Mol, 2002 p.23).
This way of studying the emergence of medical conditions by staying close to practice and to the concrete actors doing the doings in practice through means of their often manifold relations, has been coined by Mol as a study of praxiography. The 'graphy' in Mol's praxiographic approach signifies that mapping is central to praxiography. "Graphy" or mapping, according to Mol, consists of the practical ethnographic task of describing, recording and writing down. 'Praxis' (in praxiography) denotes that such mapping actions are aimed at practices as they unfold. Central to Mol's praxiographic method is that it provides a platform for understanding how diseases emerge by following the practices, describing, recording and writing down in an ethnographic sense what kind of techniques/doings and webs of related agencies are involved in making this particular kind of condition visible, audible, tangible, and knowable (Mol, 2002).

Mol's local comparative study of atherosclerotic bodies holds a second point. Other than revealing the multiplicity of bodies in hospitals made acknowledgeable through means of praxiographic studies, her fieldwork also reveals how fragmentation is avoided through daily practices of inclusion, distribution and coordination. These allow for a co-existence of bodies to endure seemingly without greater tensions. Due to limitations and the framework for this dissertation, this

[18] This then also implies that a single actor does not determine whether a fluid phenomenon falls or not (De Laet & Mol, 2000, Mol, 2010)

point and emphasis on practices of co-existence are, however, not pursued further in this dissertation.

So what are the contributions of Mol's *Bodily Multiple* (a *multiplicity* owing itself view of medical conditions as the practical enactments of webs of related actors in either fluids or networks) and her method of *praxiography* to a transnational comparative study of genetic counseling practices, such as the one undertaken in this dissertation? How may such insights contribute to existing frameworks currently favored in transnational comparisons of genetic counseling and the ways these influence the emergence of genetic responsibilities?

Using *Body Multiple* & *praxiography* as a framework for comparing genetic counseling

Looking as I did earlier in this chapter to the existing studies of genetic counseling few, if any, have departed in the frameworks such as the one proposed by Mol. Even fewer have used her local comparative framework as a basis for transnationally comparing and understanding the link between genetic counseling and local modes of genetic responsibility. However, taking a departure from Mol's *Body Multiple* and her method of *praxiography* may provide certain contributions. What it provides is a different perspective to these discussions and a different way of approaching the kind of questions raised by a comparison of genetic counseling practices and their links to specific modes of genetic responsibilities.

Looking first to the favored approach to comparative studies of genetic counseling and genetic responsibility departing in frameworks of societal discursivity. As mentioned earlier in this chapter, those doing comparative studies with discursive political approaches to genetic counseling practices usually find genetic responsibilities to be the products of a specific societal discursive order emerging from governmental or cultural societal institutionalizations. These are then understood as working their way down into everyday genetic counseling practices of humans interacting in clinics. Taking a departure in Mol's framework should not be seen as debunking of discourse or order as is involved in genetic risk estimation and its production of genetic responsibility, but rather as a way of opening up a different perspective on the emergence of order. What Mol's framework provides is a perspective that combines meaning with modes of local beingness. What this gives is a perspective that sees order as decentralized and plural making them a product of every day down-to-earth performances happening in genetic counseling rooms, rather than products of centralized

norms and ideas working abstractly from a sense of the above (Law & Mol, 2008; Mol, 2002) . What Mol's framework and method thus allow is to capture, in a more general term, a perspective that allows us to understand how such genetic responsibilities originate as the products of specific locally combined modes of meaning and beingness. It does not remove well-known discursive categories of gender, race, ethnicity, or citizenship from such discussions but position them locally, as emerging from sites of very concrete everyday genetic counseling practices. Practices unfolding not only among humans but also among related agencies of human and non-human actors.

This broadening of agency to include the non-human actors is also a way in which Mol's approach may provide a different kind of perspective to the approaches by those authors arguing for focus to be put on the ways that health care is organized and distributed when understanding the genetic responsibilities that emerge from genetic counseling practices in comparative studies. What Mol's closeness to the everydayness of mundane clinical practices and her method of "studying down" provides to such studies of genetic counseling practices and of genetic responsibility is a perspective that puts everyday face and everyday materiality to material conditions. Rather than taking distribution and financial organization of health care as material mental notions providing a frame for human negotiations within genetic counseling, Mol's ANT perspective provides a sensitivity towards comparatively understanding the kind of everyday local mundane, non-human actors that such abstract notions operate through, and the role they have in making specific modes of genetic responsibilities emerge in genetic counseling practices.

When looking broadly to existing approaches comparing genetic counseling practices, This kind of comparative approach to genetic counseling practices would open up for a twofold perspective: It may help reveal a vital knowledge about how the otherwise easily silenced, often mundane actors actively participate in webs of relations making genetic risk estimates emerge the way they do. But when focusing on the web of relations as an approach to comparing genetic counseling and its practices, we are automatically also offered a perspective on the genetic responsibility in such practices. It does so by seeing genetic responsibility emerge as the product of the kinds of modes of agency being offered or even demanded through the participation within such webs of relations.

The point is, in Mol's words, to enrich comparative accounts by adding different layers and possibilities to our descriptions(Mol, 2010). What Mol's local comparative approach then may offer

is a very practical perspective to transnational comparative studies. A perspective that allows genetic responsibility to be comparatively studied and understood as the result of specific modes of meaning and beingness in practice. A perspective that furthers such responsibilities to be made understandable through studies of the spaces of possible and demanded agency that human participation may take up within local webs of human and non-human relations in genetic counseling practices.

However, taking an approach to genetic counseling explicitly focusing on materiality and everyday practices means that the explicit role of societal discourses is not being given privilege in this research. Concerning this dissertation it should be noted that this does not mean that I do not acknowledge their existence or their role.
Choosing to follow the day-to-day practices of genetic counseling with a special eye to human and non-human agency rather than societal discursivity, this dissertation admittedly does not offer any explanations to the role societal discourses may have played in bringing these material non-human entities into life in China and Denmark, respectively. Moreover, explanations are not provided to the kind of modes of societal or cultural discursive routinization that have historically made these non-human material entities an established part of genetic practices. This I fully acknowledge as a limitation.
During the work with this dissertation, I have tentatively tried to overcome this separation of discourse and materiality by trying to adopt the framework of quantum physicist and feminist scholar Karen Barad(2007) to study genetic counseling as entanglements of discursivity and materiality. However, I had to give up this approach, as my material did not provide a suitable case for such a study.

Applying the framework of *Body Multiple* and more specifically its method of *praxiography* in a comparative field study distanced by 10,000 km has, however, not been easy. In the following section, I will describe how studying of often dispersed practices, actors, and agencies has certain methodological constraints and consequences possibly influencing the conclusions.

Chapter 4

Approaching differences in Danish and Chinese genetic counseling practices – in practice

This dissertation uses a comparative praxiographic approach inspired by the framework of Mol to perform the comparative study of Chinese and Danish genetic counseling practices.
With inspiration from Mol, I have approached my comparative fields asking: How do genetic risk estimates appear in China and Denmark? What kinds of practices make them appear? Which kind of webs of human and non-human relations make the enactments of different genetic risk estimates in China and Denmark possible? As a way to pursue these questions, this dissertation draws upon a salient arrangement of anthropological methodology and methods as also specified by Mol. In my efforts to provide a comparative praxiographic account, I have relied on what could best be described as a multi-modal ethnographic toolbox, including both mapping practices but also human-to-human interviews and informal conversations. As also suggested by Mol (2002)
, it is central to all the methods applied within this praxiography that they rest on the salient tradition of ethnographical fieldwork (in this dissertation comparative ethnographical fieldwork), unfolding through hours of stringent participant observation.

The ethnographic material used in this comparative praxiographic study
The empirical material providing the backbone of such a praxiographic analysis has been collected through specific comparative ethnographical fieldwork.
The research presented in this dissertation rests on two periods of fieldwork. My first period of fieldwork lasted nine months and was conducted at DCG. My Chinese material was collected through three months of fieldwork at the research lab at BC as well as at the outpatient clinic at PUTH.

In this comparative praxiographic study of genetic risk estimates achieved through genetic counseling I soon realized a natural issue related to dispersion of sites. Not only is this study of Chinese and Danish genetic practices situated geographically apart by approximately 10,000 km, but my fieldwork of the unfolding of these practices in these two countries has naturally come to include studies of practices in multiple local sites. Approaching a comparative praxiographic study

of genetics in my case involves moving with the practices and actors across sites rather than simply staying in one place. It thus became a multi-sited form of ethnography, echoing the works anthropologist George Marcus(1995). Conducting a praxiographic comparison of genetic counseling as a multi-site study leads to certain challenges influencing the knowledge that such a study is capable of producing. I return to these challenges later in this chapter. Now I specifically turn to the praxiographic practical methods that were used to collect and later analyze the material in this dissertation.

Praxiography: Mapping in practice

In this dissertation I have followed Mol's(Mol, 2002) call for foregrounding, following and mapping the *practicalities, the materialities* and the *events* related to genetic risk estimate practices in China and Denmark, respectively. "Mapping" has thus been a consequent ethnographic practical and analytical method that I have used during two ethnographical fieldworks in China and Denmark, and as the backbone of my comparative analysis.

In practice, I have chosen to follow professionals through entire trajectories of genetic counseling from the very beginning when patients arrive in clinics in China and Denmark for a first meeting, through various stages of risk estimation practices conducted by professionals, until patients are presented with results at what can be described as the end of a trajectory.

In accordance with Mol(ibid), I started my mapping of practices by literally drawing them on paper. I first drew the independent genetic counseling trajectories in China and Denmark, respectively on two independent maps.

I then focused on drawing each individual practice within these independent trajectories on separate pieces of paper while paying careful attention to specifying which actors were involved in these individual practices, what kind of actions they performed, and what kind of related actors these actions made possible.

Secondly, I examined what kind of meanings, questions, demands for action, and challenges that each individual practice and its webs of related of actors would lead to. This was noted on the relevant individually mapped practices. I then took these individually mapped practices and proceeded to once again place them on the common independent maps, which showed the whole trajectories. Here I visually tried to study the role of each individual practice in each trajectory by

studying what kind of products and meanings each practice would contribute with, and how these would be connected to the other practices and actors within the trajectory as a whole.
I would then compare each individual trajectory to examine and establish common patterns of webs of related actors, doings and meanings emerging across the trajectories.
I then used these now aggregated maps from China and Denmark to compare and explore differences in practices, actors, webs of relations, products, and meanings within genetic counseling practices, in China and Denmark, respectively.
In this presentation of how my praxiography was conducted in practice, it may sound like a linear process. However, the truth is that this very concrete ethnographic method of drawing individual maps and using them as objects of comparison has been an ongoing process.
Many drawings have had to be redrawn during the process. Several webs of related actors, actions, and meanings have been explored only to become reframed along the way, and several comparative differences and similarities have been explored and reframed.
Such processes are not exclusive to praxiography, but it has reminded me how any piece of anthropological empirical research (comparative or not) emerges through means of what Wadel (1991) has called a constant "round dance" between the theoretical and empirical field.

However, this process of drawing and redrawing of maps has helped provide me with a very visual way of comparing genetic counseling practices. By drawing the practices, actors and their products, their salient complex relationships helped give rise to new field questions as well as the analytical categories that provide the basis for this study.
The type of material and how it was collected making this praxiographic analysis possible is presented in the followings sections.

Fieldwork and participant observation as a praxiographic way of studying

The material used in this praxiographic comparison has been collected by ethnographic fieldwork for nine months in Denmark and three months in China. During my two periods of fieldwork, much of the material for my praxiographic analysis has been gathered through participant observation, which is seen as the standard tool of anthropological fieldwork (Spradley, 1980). Fieldwork is often described as the subtle method of inquiring, through participation, the often hard to talk about inherent cultural meanings within a field, stipulating what can count as meaningful doings and sayings among the actors within the practice which is the subject of research. This has been hailed

in anthropology as only realizable through “being there”, participating and learning the practical ropes (Wolcott, 2005). I as an anthropologist eager to praxiographically learn how genetic risk estimates are produced, have entered both my respective fields trying to assume the role of "the student", building up an understanding of the field and, most importantly, a sense of rapport with the professionals and patients involved to understand the extent, form, and meaning of genetic counseling practices.

At the beginning of my fieldwork in both Denmark and China, I deliberately tried to allow my participants in the field to assume the role of "experts" and thereby let the practical logics of the field and the extent and form of its practices reveal themselves through its human participants. What emerges by employing this strategy is, according to Spradley (1980), that we obtain an "explicit awareness". By using participant observation assuming the role of a student, the patterns of genetic counseling, otherwise embedded and natural to the patients and health professionals in question, become visible to the researcher (see also (Hammersley & Atkinson, 1995; Hastrup, 2003; Wadel, 1991) . Yet, adopting such strategies in two very diverse fields as those of clinical environments in China and Denmark have not been easy, because they rely upon several factors such as specific social agreements linked to the roles one may have in the field.

Participant observation & roles during fieldwork

During my presence in the fields, I learnt that my possibilities for conducting participant observation as a way to collect data for my praxiographic analysis became linked to my role. As Hammersley and Atkinson(1995) states: Just as an anthropologist will try to position informants within specific roles, so too is the situation in reverse, making role-consideration an intrinsic part of fieldwork if we are to gain the kind of access to practices and understanding that makes ethnographic analysis possible (a similar point is found by (Bernard, 1994; Hylland Eriksen, 1998). Although I at the beginning of my fieldwork had readily talked metaphorically of being a “student” and the locals being the “experts”, challenges arose as I entered the fields. I leant, that the role of the participant-observing anthropologist in this regard is not a trivial one, and cannot be decided upon from outside the field. Though I would often explicitly call myself a student, it quickly became obvious that such a role made less sense to the participants I was following. “What kind of student are you?”(Eliza), a patient once very explicitly asked me after a session in Denmark. This made it obvious that I had to frame roles in different terms. I was clearly not educated as a genetic

professional as I was lacking both knowledge of and adequate responsibility for clinical services. Yet, I could assume the role of a patient not having any genetic worries myself, and my focus was tipping towards the professionals in the clinic. What emerged was an “in-between role” (both in China and in Denmark). A role where I was allowed to be exactly in-between, neither identifiable as a professional nor as a patient, but as a person on the border between participants. Someone seemingly interested in learning the ropes, while asking many weird questions to both the professionals and the patients. Particularly working among the professionals this “in-between role” meant that I was given a chance to inquire about everything, even the most obvious things happening in the clinical room, without being met with anything else than a bit of curiosity. Along the way my role changed and I became "an educated anthropologist". This meant that professionals would seek me out as a person to play ball against in times when they found their work hard and they felt that the motivations of the patients seemed to be hard to grasp (this happened mostly in Denmark, though).

This gave me many opportunities to gain insights, but there were also moments when my roles as an anthropologist researcher and in-between participant observer were challenging. Especially during my fieldwork in China, the role of anthropological researcher - “the in-between role” and the scope of my research seemed hard to grasp for some of the professionals involved. As opposed to in Denmark, this gave rise to suspicion. “Was I there to evaluate their practices”, a junior professional once asked me.

These experiences meant that I here instead deliberately chose to take on the role of the PhD student studying Chinese culture, eager to learn about genetic practices in China. This role was explicitly voiced as easier to understand among the professionals in China. Assuming this role of participant observer reformulated as a PhD student, I also learnt that I in this way stepped into the hierarchy of the Chinese education system. Often senior professionals would address me in similar tone as local PhD students, which at times seemed rather harsh to me. I learnt to accept this as a part of the fieldwork and I believe that these strategies helped provide a sense of intelligibility as to who I was, and what I was after. To some extent this allowed me to conduct fieldwork in a Chinese hospital, something rarely allowed for foreigners.

Participant observation, notes & dialogue material

A substantial part of the praxiographic material presented in this dissertation comes from clinical sessions in both China and Denmark. Neither professionals in Denmark nor in China allowed me to use a digital recorder to record their dialogues. As a result, the material from genetic counseling interactions used in my mapping approach is based upon fieldwork notes. In China, my material was collected at two main sites, at PUTH and at BC. At PUTH, I followed professionals as they conducted examinations and assessments with patients with cancer as well as patients involved in genetic testing. During my time at the outpatient clinic, I participated in more than 400 oncological consultations. These consultations lasted between 2-3 minutes and 10-15 minutes. I participated in all together 15 meetings between professionals and patients regarding genetic testing. During my time at the outpatient clinic, I would talk very briefly with the doctors but I mainly focused on observing what was going on in the room. This was my only option as the timeframe would often be very limited leaving little time to talk.

At the laboratory I followed the professionals in their daily work of doing research and writing scientific articles. But I also followed the professionals at the laboratory when patients came to be tested. Afterwards I followed professionals when genetic estimates were made. Here their time schedule was less constrained. This gave me a chance to discuss my material and ask questions related to the practices at both PUTH and BC respectively.

During my time at DCG in Denmark, my position was that of a research assistant. My fieldwork consisted of following the professionals in their daily work at DCG. This in practice meant following professionals during genetic counseling sessions with patients, participating in medical record work, laboratory practices, drawing genetic pedigrees, following phone shifts, participating in oncogenetic conferences, ordinary genetic conferences, fetal-medical conferences, morning conferences and meetings with other professionals in the Danish Society for Medical Genetics. I also followed professionals during informal activities such as daily breaks and lunches. During my fieldwork, I attended 105 counseling sessions and more than 40 of these were related to hereditary breast and/or ovarian cancer.

In the counseling sessions on these types of cancer, there was a similar approach to the clinical meeting between professionals and patients. During patient and professional interactions, I would write down the dialogue as quickly as I could. I would also take notes on the kind of non-human actors present in the room during the session. More than often I would engage in a dialogue with the

professionals afterwards to discuss what I had heard and seen during the session. Here I had the opportunity to ask clarifying questions. Svendsen has also used this approach during her fieldwork in the field of Danish genetics (Svendsen, 2004). At the end of each day, I would assess my notes, and use them to map practices, establish categories and develop further questions.

Writing down dialogue, naturally, has some limitations, as my writing could only be done as fast as I could. This should be taken into consideration when reading this dissertation. This was especially salient during sessions with both patients and professionals. Words and doings of humans as well as doings of non-human actors may have slipped in the process. When certain dialogues and practical doings have seemingly had a specific importance during the clinical interactions between patients and professionals, these have been discussed afterwards with the relevant professionals.

Entering the field of genetic counseling practices in Denmark and China, everything was new to me as it is to most anthropologists entering a new field, especially a field so heavily loaded with technological language and equipment. The early stages of participant observation along with the field notes I produced in this period were plentiful but also but less focused. Participating in and observing clinical sessions in both China and Denmark as well as the day-to-day work of the professionals at both locations meant that a whole new world was opening up to me. I drew pedigrees, I participated in estimating risks, filled out necessary paperwork, and worked with computer workstations, but I also participated in social lunches and informal chitchats that often occurred during work situations.

As time went by, my observations began to be focused, as my initial concepts arising from my approach in the field were becoming clearer and I could thus test them more directly underway. Gradually, I began to listen to and observe more specific forms of communication as well as specific forms of practices and thus non-human actors.

Yet, not all rooms were open to equal amounts of participation and some were not open at all, I soon learnt.

Where some rooms allowed a great deal of focused participation such as the sharing of a lunch with a professional, other places were less inviting. This raised a question for me during my study: How does one really do participant observation, when professionals sit silently at their workstations estimating risks or simply writing something? (A question equally raised by others (see for example (Hannerz, 2003)).

Genetic practices in both China and Denmark rely on work involving a computer. This work is often solitary and to many professionals a silent practice. Because professionals spend long periods of time in front of a computer looking or writing, it has meant that I have had to force myself to actively and explicitly engage in asking constant questions to the professionals during these periods. In what may undoubtedly have caused some irritation at times, it has been vital for me to find ways to open up these silent practices in light of the value these practices could have within the phenomena unfolding.

In China, some rooms where off-limits to me. Meetings in China would occasionally be conducted without my participation, as they were focused on the clinic's research agenda and not related to my research field, according to the professionals. I did however, during my time in China, find that some transgression between research and clinical practices did take place at these meetings, meaning interesting practices may also have unfolded during these meetings but were outside my reach.

The clinical session rooms proved to be sites where certain rules had to be followed. Upon request from professionals in both China and Denmark, I was to introduce my project and obtain informed consent from patients, both in relation to allowing me to participate in their session and to use of the material collected in an anonymized form. This was to be done before each specific genetic session. I found that this always sparked questions of interest about who I was and what I was doing; maybe as a result of this, not one patient declined my participation.

Both in Denmark and in China I would deliberately sit between the professional and the patient to try to show my position as an "in-between", though keeping silent during the remaining session. Despite these efforts, my role was at times less clear to professionals, patients, and relatives. But other than raising questions at the beginning of the sessions, I was seldom referred to after sessions had begun, and I did not take the initiative to disturb.

Interviews and informal conversations

The praxiographic data in this dissertation have furthermore been collected through interviews and notes on informal conversations. Described in a wide plethora of literature, interviews as well as informal conversations are used to explicate the local taxonomies of practices in both individuals and groups (Bernard, 1994; Spradley, 1979). Moving from informal conversations where agents frame the agenda to interviews where a frame, although open, is provided by the researcher, means

that certain topics, individual reflections, and social concepts can be brought out into the open and made objects of inquiry (Spradley, 1979).

Much of the empirical data presented in this dissertation rest on either informal conversations or utterances which have been observed and written down during my fieldwork at the clinics. I have continuously used informal conversations as a way of discussing my findings with professionals as they were unfolding in real-time. But I have also used them as a way to enter the very complex world of medical genetics. During my fieldwork, I have used informal conversations to gradually learn the local clinical language both in Denmark and in China. As a native Danish speaker and only an educated Chinese speaker, I have naturally found it easier time to understand the language at the Danish clinic. In China the native language, the use of a medical vocabulary, and a very strict hierarchy have made research challenging at times. In both clinical settings the inclusion of informal conversations has been valuable as a way to approach this complex local language and the clinical categories emerging. In both Denmark and China I have used, lunch breaks or at quiet moments in the laboratory, as an opportunity to ask inquisitive questions related to my observations. Informal conversations have thus allowed me gradually to pursue an understanding of the meanings that professionals attach to the practices of risk estimation in genetic counseling.

The use of informal conversations has furthermore been a valuable approach to establish both a personal and a research-oriented rapport between me and my informants, allowing us to discuss issues and subjects. Some of these discussions would have been difficult if a recorder had been present in the room.

My aim with the semi-structured interviews in both Denmark and China was to discuss more directly the doings and sayings, as well as the potential meanings that I had encountered during the practices of genetic counseling in my fieldwork. The interviews gave me an opportunity to test my ever-unfolding observational findings, and to gradually narrow and focus my analytical categories and piece together the empirical data to establish an overall comparative praxiographic puzzle.

As the speed in clinics (still to be unfolded in the chapters to come) was high and mostly focused on practical and formal matters, interviewing gave me an opportunity to get to know my informants outside the strict clinical contexts. My aim was to get a closer understanding of the more personal and intimate perspectives of my informants on the otherwise formalized practices unfolding every day at the clinic.

In both Denmark and China, a semi-structured interview guide was developed with specific questions related to knowledge practices as well as questions trying to address my informants' approaches to these practices. I conducted nine interviews with professionals in Denmark and three interviews with professionals in China.

All interviews in Denmark were conducted in the clinic, in Danish, recorded and transcribed verbatim. In China, interviews were conducted in Chinese in the clinic and in writing due to an implicit rejection of recording the interviews. It was hard to establish insights into the personal motivations and understandings of genetics among the professionals in China. Often, I would be met with the phrase "speak clear" during both interviews and informal conversations, implying as I learnt to keep my questions direct and short. Although this caused some irritation at the beginning of my fieldwork in China, I soon learnt that speaking clearly was in fact a very profound way of speaking in clinics in China.

Material anonymity

As any anthropological study based on empirical data collected among people, issues of anonymity need to be raised. This is certainly important in a field study among people whose medical conditions are only found among a small percentage of the population and when studying among professionals in areas employing only very few people. In working with the material collected among patients and professionals, I have left out details that would make patients or professionals identifiable. This naturally means that I have had to remove certain fragments of dialogues between patients and professionals to ensure anonymity. This has been a careful process, constantly balancing my responsibility towards my informants and the points to be made in this dissertation.

Professionals in Denmark have been described by numbers; in China, the nomenclature of senior and junior professional has been used to adapt to the work environment in China. The clinical environment I followed in Denmark had many employees making anonymity easier, whereas the clinical environment in China was much smaller, prompting the need to use different categories.

Spoken languages – from Danish and Chinese to English

This dissertation is written in English, but the study has been conducted at two fieldwork sites using different native languages in the day-to-day lives of informants at the clinic. In Denmark, fieldwork observations from the clinic and interviews were conducted in Danish, and in China in Chinese. I have been very careful in the translation of my analysis of the phenomena presented. Regarding the

Danish fieldwork, I have discussed the translation of my material with fellow anthropologists at my PhD school (some were native Danish and others native English speakers) as well as with my supervisors.

Regarding my fieldwork in China. I hold a degree in Chinese language and have both studied in Denmark and at Beijing Language and Culture University in China. I have however been greatly helped in the translation proces. During the writing of this dissertation I have debated my translations and understandings of central notions of the analysis with the clinical staff in China. I have also been fortunate enough to be able to discuss translations with my wife who is a Chinese citizen and naturally a native Chinese speaker. The clinical staff in China and especially my wife have both been a great help in the translation proces by providing a detailed examination (and critique) of my translations. Their help has ensured that I captured the subtle nuances of the local (Chinese) language, which is central to any type of local empirical anthropological material.

In writing this dissertation, I have thus tried to consider these linguistic nuances and the possibilities of them being *lost in translation*. I admit that, although my analytical points stand, some of the colorfulness of practical engagements unfolding within local languages may have been lost in the translation process.

Clinical genetic language - writing within a specialized field

Danish, Chinese and English are not the only languages unfolding on these pages. As it will appear from the next empirical chapters, the language of genetics proves to be yet another issue of quasi-linguistics. Learning to speak of and understand dialogues and practices related to genes and Mendelian inheritance has proved to be a challenge in Danish but certainly even more so in Chinese. I have participated in specific courses on genetics during my period of fieldwork but could not have arrived at the conclusions I have, if it had not been for the help of the clinical staff involved in my study in both Denmark and China. Often I would send written passages to the professionals, and they would help to rectify any clinical genetic misunderstandings. This has not only strengthened my material, but it has also made me aware of the differences between doing anthropology and doing genetics of cancer. In some situations during the PhD process, this even made me afraid of writing anything out of fear of misunderstanding the field.

Yet, in working closely with professionals I have become more aware of my role within the scientific world. Obviously, still aiming at providing the most precise account of the field what is presented here is anthropology and despite writing, to paraphrase the anthropologist Arthur

Kleinman(1997) “At the Margins” between bio-genetics and anthropology, my contribution is strictly to be considered an anthropological contribution and not a genetic one.

Challenges of adopting a comparative praxiographic approach

In her work on the *Body multiple* Annemarie Mol states that any praxiographic account rests on *an endless list of heterogenic elements some highlighted and others kept silent* (Mol, 2002 p.26). I have until now primarily concentrated on accounting for how the elements included in this comparative praxiographic study of genetic counseling have been collected, and paid less attention to the elements mentioned in the second part of Mol’s statement: Those, that are *kept silent.* I take up this issue because they influence the argument I have been able to produce. Just as any form of phenomenon is the product of specific performances, so is an ethnographic account describing a performance. No researcher stands outside his or her research. Quantum-physicist and feminist scholar Karen Barad writes:

"We are responsible for the world of which we are a part, not because it is an arbitrary construction of our own choosing but because reality is sedimented out of particular practices that we have a role in shaping" (Barad, 2007 p.390).

As a researcher doing a study on comparative genetic counseling, I have participated in bringing to life certain kinds of genetic practices and products through the *cuts* that I have made as a researcher (Candea, 2009). Thus, I also acknowledge that other phenomena might have emerged if other paths, practices, people, and questions had been asked. What is presented accordingly is a process as well as a product in many regards, where *cuts* have been made bringing forth the phenomena presented in this dissertation. Understood not only as *cuts* instigated at the beginning of the research process, but also understood as an ever-evolving series of *cuts* conducted as my fieldwork and analysis progressed, giving rise to constant reflective questions as the study has unfolded.

In choosing the approach of praxiography entailing constant mapping of practices, questions as to how one determines what practices are to be included within a trajectory of genetic counseling, have followed me consequently in my fieldworks in both Denmark and China. These questions have been accompanied by questions on how to decide when one is to stop mapping practices? How does one decide who "speaks" within a practice? How does one as a researcher influence the equations that one seeks to explicate? What kind of knowledge may such a study come to produce?

Such questions cling to this study and have followed me throughout my research[19]. There is no easy answer to these questions [20].

They rest on what Nikolini & Moyer(2017)have called a salient kind of a mutual relationship between the actors in the field and the researcher. A salient symbiotic relationship between the researcher and the field making some heterogenic elements speak at the expense of others, allowing specific products of research to emerge. The results and trajectories in this dissertation build upon such a symbiotic relationship in which matters of research interests, research pragmatics, field constraints, and considerations as to how to best take personal care of the informants, who made this study possible in the first place, have been salient. What is provided in this dissertation is the result of a series of *cuts*. Some have quite openly and explicitly been conducted by me, others have been conducted for me.

In order to account for the paths and *cuts*, I have chosen to pursue, I try to put forth my empirical data as broadly as possible. Furthermore, I need to emphasize that during the entire research process, I have been constantly re-assessing my material focusing on the inclusions and exclusions during the process.

Cuts realized by field constraints have, however, also been a salient condition in this study, and these have not necessarily been evenly distributed among my respective fields. China and Denmark presented me with widely different amounts of accessible spaces allowing me to follow actors and practices (as seen in the case of closed meetings in China earlier in this chapter). They have also differed in the scope of time and material available. This dissertation presents empirical descriptions and an analysis based on nine months of fieldwork in Denmark and three months in China. In Denmark, I had access to and participated in more than 100 genetic counseling sessions; in China, I participated in far less.

Such differences in access and material may influence the kind of study possible and the kind of conclusion one is capable of making when setting out to comparatively study the differences in genetic counseling through a praxiographic perspective.

Field constraints are, however, an intrinsic part of anthropological field studies (Hannerz, 2003).

[19] They have been explained as a salient condition of working within the ANT framework, and as Latour has suggested one naturally stops mapping, when one runs out of money (Latour, 2007).

[20] Such issues have been heavily debated within both multisited anthropology (eg. (Candea, 2009, Falzon, 2009, Hannerz, 2003)as well within the field of ANT (eg. (Miettinen, 1999))

Thus, setting up a 1 to 1 comparison is a difficult (if not impossible) task (Niewöhner & Scheffer, 2010) .

However uneven, field constraints do not undercut the gains of pursuing a comparison, but the constraints need to be taken into consideration in a comparison such as this. The reader should therefore be reminded of and consider the uneven comparative distribution of access, material, and time, the Chinese and Danish practices described in this dissertation.

Chapter 5

Genetic counseling in China and Denmark

This chapter concerns genetic practices in China and Denmark and has a twofold purpose. The chapter aims to ethnographically illustrate my entrance into two very diverse fields of clinical genetics. More importantly, however, it illustrates some of the salient differences and similarities found when comparing genetic counseling for cancer practices in China and Denmark, respectively. The differences and similarities presented in this chapter are further pursued in the two analysis chapters 6 and 7.

Entering the field in China

I had only just arrived in Beijing, when I contacted the Breast Center. I was told to come directly to the Center located at a hospital near the Ding Hui Qiao, close to the 4th ring road in Beijing. After having experienced a few problems finding a taxi driver who knew this hospital (partially because the name of the hospital was closely related to several other hospitals in Beijing), I was dropped off in front of a line of tall grey buildings. The Chinese letters said that I had arrived at the correct place.

All sorts of people were gathering in front of the hospital. Some were sitting on the sidewalk with small signs telling about the financial hardships either of their own or their family members brought on by cancer. Little cardboard signs stated how they wishfully hoped to get money from people passing by. Others were being dropped off in huge fuel guzzling Range Rovers. The frantic honking of horns (a trademark of most Chinese modern cities) blended with a scent of roasted sweet potatoes. As I entered the main building where I was to meet the professional I had initially corresponded with, I couldn't help thinking of the colloquial expression so often used by Chinese of "too many people" (*ren tai duo*[21]).

In the main lobby, I was immediately met by looks from the hundred or so patients waiting. What looked like small booths were encircling the bench rows in the middle of the lobby. Letters on the windows of the booths` stated the kind of services offered by the hospital. Nurses and doctors quickly moved around the room, some stopping briefly, when addressed by patients or relatives. I

[21]This expression has lately been described in greater detail by anthropologist Anders Hansen (Hansen, 2015)

tried to find my way around but unsuccessfully. Asking a nurse passing by did not make me any wiser. Even after countless attempts at explaining my purpose for coming, namely to do research, I realized that I had not come any closer to finding the research center.

Remembering what my contact doctor had told me, I proceeded to a building at the back of the hospital. Here an entrance sign said "Beijing Cancer Hospital". I quickly went inside and took the lift to the 6thfloor, which was to become not only my place of research in the following months, but also what I later learnt, one of the important sites for the unfolding practice of genetic risk estimates in China.

Picture 3: Breast Center, Beijing Cancer Hospital, Peking University Cancer Hospital(BC)

Trajectories of genetic counseling in China: laboratories and hospitals

I quickly learnt that my fieldwork would have to be adapted to the general situation currently facing genetic testing in China. This means that my fieldwork would take place at two sites (as also mentioned in Chapter 2): at a public hospital, and at the research laboratory. Currently, there are no official guidelines on genetic testing for cancer in China (Zhao et al., 2013)and procedures are therefore generally decided by the individual laboratory and hospital. A general rule, I was told, required that genetic counseling entailed assessment of the family history, undergoing a genetic test and calculation of a risk estimate.

A trajectory of genetic counseling in China

In a trajectory of genetic counseling in China, patients are first met in a hospital; in this study at the Peking University Tumor Hospital (PUTH). Currently, there is no triage system, I was told, and

patients could thus enter directly from the street. At PUTH, the first thing would be to assess the patient's family history to establish whether a possible onset of cancer either in the individual patient or in the immediate family could be genetically related. This family connection had to be determined before patients could be referred to testing and risk estimation at the laboratory. As a professional told me during interview: "*We don´t test anyone without an indication, that is a waste of resources. If they don´t have a family history we don´t test"(senior professional).*

Certain conditions could reveal possible hereditary patterns, I was told. Young age when developing cancer in China is seen as a very strong indicator of a genetics playing a role.

When professionals encountered patients with bilateral cancer or triple-negative cancer, they paid special attention. "*You know, studies show that genetics may be involved, when patients develop these forms of cancer." (Junior professional).*[22] Spotting possible links between cancer and genes was thus the core of genetic services and here the family history was essential

I was told that establishing a family history showing a genetic indication in China was done through dialogue with patients, and by use of information from medical records. In China, medical records are stored locally at the hospital where a patient has been treated. When undergoing treatment, patients also have a print out of their medical record. Chinese hospitals do not yet have a system allowing them to share medical records, I was told. Thus, professionals could only access information in local medical records from PUTH and not from another hospital unless the printed medical record was brought along by the patient.

Another reason for starting a trajectory at a hospital like PUTH, professionals confided, was that research laboratories performing the testing and risk estimation needed patients to be registered and pay a fee for the laboratory services. None of these tasks could be currently be performed at the research laboratories such as at the one I visited. As most services in China require a form pre-payment, patients need to initiate the trajectory at a hospital, capable of handling such transactions, I was told.

If indications are established, a referral is made and a fee is paid. After this patients would be allowed to proceed to a laboratory such the one at the Breast Center, Beijing Cancer Hospital, University Cancer Hospital (Abbr. BC).

[22]These signs of possible hereditary predispositions, echoed those mentioned in international literature on cancer genetics (see chapter 2)

At the research laboratory, blood samples are taken to perform the testing and risk estimation. Currently, the majority of testing is for research purposes. Although the field of genetic testing has expanded, the professionals at BC were still in the process of expanding their capacity. This not only concerned the technical equipment used for sequencing, (they were preparing a shift from Sanger to NGS[23]), but also in their capacity to perform local registry research.

Patients arriving at the laboratory at BC first go through a registration process (*Dengji*) where informed consent is obtained from the patients, and a pedigree containing information is drawn. This, I was told, is currently only for research purposes, but the aim was to build up their own Chinese registry[24]. After registration, patients have a blood sample taken (*chou xue)* to be used for further for testing. Testing, the professionals told me, is conducted at the laboratory's own research personnel. Using Sanger Sequencing tests were now made in order to detect any possible pathogenic mutations within the *BRCA* genes[25]. Actual testing not done by the professionals, I was to follow, but by a medical laboratory specialist. If a mutation was found, its potential pathology would be determined by consulting a genetic database, the professionals told me.
This is not a local Chinese database, as they have yet to be developed. Currently, professionals draw upon data from an American cancer genetic database (BIC), which is accessed via the webpage "http://research.nhgri.nih.gov/bic/", and here the possible pathogenic mutation is looked up. A junior professional later explained to me that there are no official national guidelines that determine the kind of risk categories that may emerge from testing. Some sense of agreement was, however, found among hospitals, I was told, and following these the professionals I followed currently work with three kinds of test answers: Positive known pathogenic mutation found, Negative, and unknown variant found (variant of unknown significance).

Results of these tests are filled into a rapport (*Baogao*) containing the information to be given to patients. Delivering the test results would again usually[26] take place at PUTH. There are no current national guidelines stipulating what kind of preventive measures patients are offered according to the risk categories. I was told, that most hospitals follow international recommendations, offering

[23]This meant that they would become capable of screening many genes at the same time (panels), instead of just concentrating on the most known genes, the *BRCA* genes.
[24] As the professional told me, actual Chinese indigenous genetic registries allowing research were still being established, but at BC they had been collecting pedigrees and test answers for almost 10 years. Now they had more than a thousand Chinese families in their local database.
[25] During my stay, they were preparing expanding to gene panels, thereby analyzing more genes at the same time.
[26] On rare occasions patients went to the lab to have their results and some had their results communicated by telephone.

preventive screenings and possible surgical interventions in accordance with the risk estimates. Like other health care services, these would have to be paid for by the individual patient.

The work schedule of the professionals I followed, was divided between PUTH and BC. Their job at PUTH was not solely focused on genetics. Any form of genetic testing or assessment was also offered to so-called regular patients at PUTH with either suspected or diagnosed cancer Staying at PUTH, could be a hectic experience, I was warned. *We often have more than 50 patients each on one day, and they all want a good service, because they have paid for it* (senior professional). The professionals assured me that this was not a special situation for them, but was common for their colleagues at other Chinese hospitals.

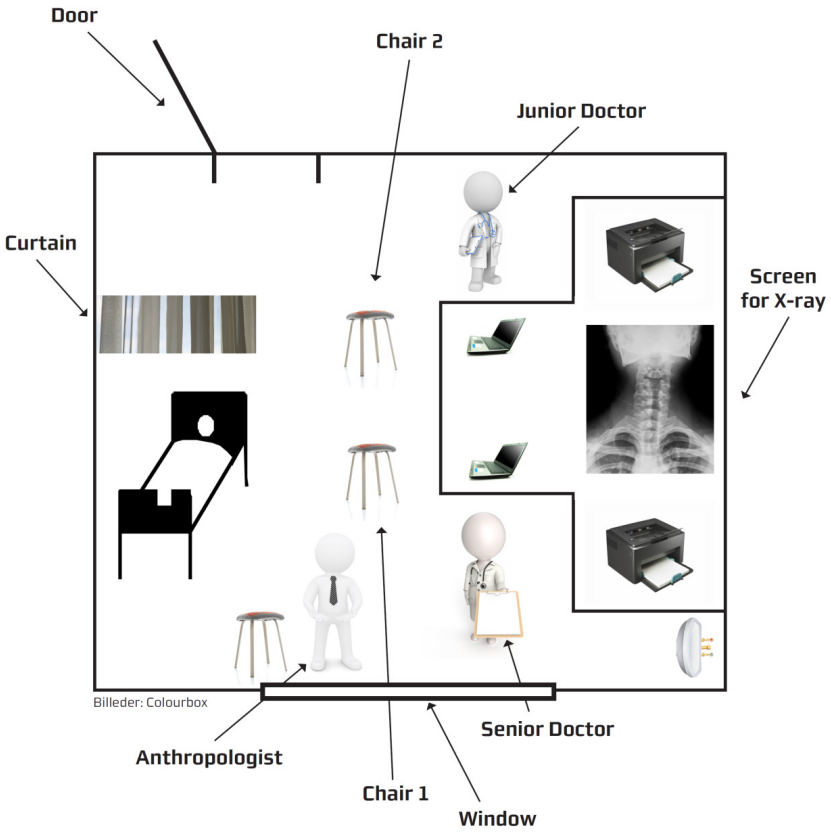
Pictures 4-5: Laboratory at BC(left) Hospital(PUTH)(right)

Sites of genetic counseling in China

When entering PUTH, patients meet a series of small booths. Here patients are first expected to draw a number (*gua hao*) and be registered for examination. To be registered and have a number, each patient will have to pay up front (*fu guao hao fei*) at the booth marked with the sign "cashier". Each trajectory thus begins with payment and the drawing of a number. At the second floor of the hospital, professionals do the examinations. Meeting patients as they exit the elevator is a waiting area with, benches facing four doors leading to the examination rooms (*jiancha shi*). When patients

enter these rooms, they first have to pass a guard counter. The four examination rooms each contain a desk where two professionals sit facing each other.

During consultations with patients, one professional (usually a senior) engages in diagnostics and examination, while the other (usually a junior) manages patient files, write prescriptions and fill out referrals. A chair is placed in front of each professional. The examination rooms also contain an examination bed and a small curtain (see picture 8). This is the site first patients meet when arriving for genetic counseling at PUTH in China, and it would also be the setting in which test results of the risk estimation process are primarily given.
If patients were offered further testing procedures, this would take place at BC. At BC, patients are met in a laboratory environment (picture 7), and the room where patients are met is roughly divided in two. First, patients need to pass several tables with laboratory equipment such as bottles with fluids and a different types of machines, before arriving at the far end of the laboratory where they would be further guided by professionals, each sitting in one of several small workstation cubicles.



Picture 6: Consultation room at PUTH

Entering the field in Denmark

Aarhus University Hospital's Department of Clinical Genetics (DCG) in Denmark also offers genetic services at two locations outside the main facility, in Herning and in Viborg. These two offices are not situated at a specific clinical genetics department, but are physically located at other departments. During my fieldwork, I participated in genetic counseling both in Herning and in Viborg, although the major part of my fieldwork was concentrated at the main facility in Aarhus.

Pictures 7-8: Aarhus University Hospital's Department of Clinical Genetics *(DCG), Denmark*

On my first day at DCG, I was told to go directly to the main building[27]. This building was already familiar to me. The building is situated just outside the main hospital area, in a concrete building where a sign indicating the names of other departments. When arriving I was quickly greeted by my contact professional, who told me that they had arranged an official meeting where I would be introduced and my project would be discussed.

Entering the main office, we walked past many small offices. Many of the monitors showed what I would later learn to be family histories or pedigrees. The professional informed me that professionals here at DCG had many small tasks during the week. A week`s work for most professionals, I was told, involved participating in conferences, seeing patients at the out-patient clinic, and doing risk estimation work at their workstations. Finally, junior professionals took turns answering the telephone with calls from other departments. Senior professionals had a similar work schedule, although senior staff was only on call in connections with telephone inquiries.
During the official meeting, the professionals informed me of the procedures involved in a trajectory of genetic counseling at DCG.

[27]This was were I did my pre-study in 2012

A trajectory of genetic counseling in Denmark

Genetic counseling trajectories at DCG (and in Denmark in general), follow national guidelines on the performance of genetic counseling, I was told. In Denmark, a genetic counseling trajectory normally includes 2-3 counseling sessions (may vary according to families and conditions). A trajectory of genetic counseling as a general rule involves:

1. Elucidation of the family through the drawing of a pedigree
2. An estimation of family risk
3. If needed, further genetic diagnostics[28]

(See (DBCG, 2014; DSMG, 2009).

Each trajectory would result in a risk estimate for patients and their families. Based on these risk estimates I was told that patients and their families would be placed within certain risk categories (no increased risk, moderate risk, high risk, and mutation positive (+mutation) See Appendix 1). These nationally agreed standard categories would then lead to different preventive measures for patients, but also to selected family members.

In order to enter a trajectory of genetic counseling, patients first need a referral from their GP or from another hospital department. Here patients are first screened to discover if something resembles a family history of cancer[29]. If referred, patients would first be met by a professional from DCG at their outpatient facilities. Here the first task was to establish whether a family history of disease incidence could show indications of possible genetic disease predispositions. According to professionals, this was to be done through establishing a broad family anamnesis or pedigree. Drawing a pedigree, I was told, was thus considered the vital part of genetic counseling at DCG. Later I learnt that certain findings within a family history could lead the professionals in certain directions. Many incidents of either breast or ovarian cancer, incidents of bilateral breast cancer, incidents of triple negative cancer as well as cancer incidents at young ages in a family could raise suspicions of possible pathogenic mutations. In many ways this echoed what was seen in China.

[28]This tri-part division of services mentioned in the national guidelines is equal in wording to the letter patients first receive when they are referred to genetic counseling at DCG where I conducted my fieldwork (see Appendix 2).
[29] These screening procedures were outside the scopes of my study

The information about cancer incidence in the family was obtained through a dialogue with patients at the first meeting. Before this meeting, patients would be expected to fill out a small booklet called "the book of kinship". Here information about incidents of diseases would be recorded. As an added practice, patients would be expected to fill in information regarding themselves, their spouse, children, siblings, half siblings (having either the same biological father or mother), parents, parents` siblings, and cousins on either side of the family and grandparents of both parents.
The information collected should include names, dates of birth or Danish civil registration number (CPR number), date of death (if deceased), incidence of cancer, admission to hospitals including year and name of the hospital. The information would be used to draw a preliminary pedigree at the opening meeting.
Asking about the need to fill in civil registration numbers of family members, I was told that having access to these was vital for the further risk estimation process. Denmark has a series of central archives in which all medical records are stored and these records are accessible by the civil registration number.
Knowing the civil registration number, I was told, made it possible to check the information the patient had given about the disease history of their family members. Often, I was told, patients would not remember the type of cancer of their family members, and the civil registration number could be used by professionals to verify information during the risk estimation proces.

The process of risk estimation usually contained several steps, I was told. First, information was verified if possible, and then an actual initial risk estimate would be calculated usually using a risk-estimation program called *Boadicea.* Sometimes if indications were strong enough, this led to selected family members[30] being invited to come and have a blood test taken to be used for actual genetic screening. In other situations, the initial risk estimate would be discussed at a department conference, where the professionals would collaborate on assessing each trajectory. In some patient cases, more information would be needed, others should be offered further genetic screening, and finally for some trajectories, the initial risk estimate would be accepted as the final result

Depending on findings in the pedigree, each trajectory would be placed in to pre-determined categories as described earlier (appendix 1). Each category would open up different trajectories for preventive measures for patients and their families.

[30] Sometimes this could be the patient in question, but many times this could also be the patient's relatives

As risks increased, however, these nationally agreed risk categories would increase in severity and so too would the corresponding preventive interventions to be offered. Moving from one category to another could mean moving from offering preventive screening to offering preventive surgery. These changes in categories would also encompass an even broader selection of family members (Appendix 1).

A final risk estimate along with offers for preventive measures would be delivered at a meeting with the patient at the outpatient clinic at DCG. The patient would do a lot of work during this process, the professionals told me. Currently, Danish health laws, they told me, prohibited professionals from contacting and using information about citizens not engaged in a treatment pathway at the department. This means that obtaining permission from family members to access medical records for verification depends on the patient, who has to make contact to these family members. It also meant that any family member to be offered preventive interventions would have to be contacted and informed by the patient, and not the professional.
No direct payment is expected by patients seeking out such services. All services such as risk estimation, genetic screening, and prevention methods are a part of the tax-financed Danish welfare system.

Sites of cancer counseling in Denmark

The actual task of conducting risk estimation as a part of a trajectory of genetic counseling is done at the office building, where I was first welcomed. At DCG, screenings and tests of blood are not done at their facilities in Aarhus. Depending on possible genetic conditions, blood samples are taken at the laboratories of the main hospital and then sent to other laboratory facilities around the country. Most of these are public and situated at other hospitals. In rare cases, blood samples are sent to private laboratories, some of these located in China.
Meetings with patients and patients' families do not take place in the office building, but at the adjacent outpatient clinic.
At the clinic, four separate rooms made up the counseling facilities. Each session is strictly confidential, and only one patient or family would be present during these at a time. Arriving for the first time in 2012, I remember thinking to myself that this clinic resembled a private office environment rather than a clinic. I remember feeling that the nice wooden floors and easy lighting

made it a nice but also a very un-clinical environment. Patients arrive and are seated in a small waiting area.

In the waiting area, there are two small desks and toys for children. A few chairs are placed in the room to accommodate those waiting. I seldom experienced this room to be crowded, and the outpatient clinic was always a quiet place.

Pictures 9-10. Danish outpatient clinic, waiting room and examination room

The organizational setup of Chinese and Danish genetic counseling

Looking at the two comparative sites showed similarities but also very salient differences when comparing genetic counseling practices for cancer unfolding in China and Denmark, respectively.

Professionals in both China and Denmark use the establishment of a family history showing certain indications as the primary opening practice in genetic counseling for cancer. Both countries conduct risk estimation practices utilizing sequencing equipment as a means to detect specific pathogenic mutations. These are, however, not always used in Denmark as opposed in China where they are a regular part of the risk estimation process. Both countries offer preventive screening interventions and, if necessary, preventive surgery.

The description in this chapter, however, also illustrates differences between genetic counseling for cancer in these two countries, in which different the organizational framework for health care emerged as salient.

In my comparative analysis, I have chosen to focus on the following differences described empirically between the genetic counseling practices in Denmark and China:

Denmark	**China**
Guidelines for genetic counseling for Cancer	
National guidelines: • Developed at a national level by professionals. Stipulating legal rights of genetic counseling trajectories, risk estimation categories to be used during such counseling trajectories, and adequate prevention trajectories to be offered in accordance with these categories	Currently no official guidelines: • Content of trajectories of genetic counseling for cancer, of risk categories, and for trajectories of prevention are decided at local hospitals
The financial governance of health care	
Genetic counseling as a part of welfare health care service: • Genetic counseling, just like most other forms of health care services, is tax-financed and part of the national welfare health program • Dependent on a referral from GP or another department in the healthcare system before being allowed to enter genetic clinics • One patient/family is allowed at a time in the counseling rooms. Time reserved for such sessions may be as long as two hours.	Genetic counseling as a patient Out-of-pocket paid for service: • Individual payment for both examinations at the outpatient clinics and the further laboratory testing • Patients may enter directly from the street • Currently conducted in rooms where multiple patients are to be found at the same time, and within a timeframe usually spanning from 5 to10 minutes.
Availability of health care data	
• Data from dialogue with patients • Data from medical records obtained from legally regulated National achieves	• Data from dialogues with patients • Data from medical records obtainable from individual hospital archives or individual patients

Organizational differences from a praxiographic perspective

Emphasis on differences in the organization of the health care systems in China and Denmark echo Gammeltoft & Nguyen's (2007), and Sui's (2009) work as seen in Chapter 3. The social organization of health care systems is easily overlooked in studies of genetic counseling. However, they play an instrumental role in defining the type of local genetic counseling practices, which are considered both possible and necessary.

The different organization of health care systems I encountered in China and Denmark, is to a great extent reflected in the current literature on health care organization in these two countries.

Studies by Zhao and colleagues (2013), Cao and Colleagues (2017), and Sui (2010)have shown that while explicit national guidelines are currently in place for pre-natal genetic counseling services, no official clinical programs or guidelines have been developed in the field of genetic cancer in China, and that professionals instead rely on locally developed guidelines. Koch & Svendsen(2005) have shown how national guidelines for genetic counseling for cancer have been steadily developing in Denmark. Reports by Danish national clinical organizations (See (DBCG, 2014; DSMG, 2009) reveal how Danish genetic counseling now base its practices on explicit national guidelines stipulating the content of a standard counseling trajectory, nationally risk estimation categories, and specific programs for preventive interventions.

Clinical guidelines determine the form of clinical practices. They offer a mode of objective standardization of clinical practices allowing patients to become divided into homogenous categories ensuring that services are provided on an equal basis (Berg, Horstman, Plass, & Heusden, 2000) . Guidelines are products of clinical professionals (Feidson, 1989). Their form and objectivity emerge through the possibilities offered by the health care organizational conditions within which clinical professionals work (Berg et al., 2000). The financial governance of health care systems, and the extent and availability of health care data, I argue, are two other important organizational conditions determining the production of clinical guidelines for genetic counseling.

Studies by Eggleston and colleagues (2008), Zhang & Liu (2014), and Hsiao & Blumenthal (2005) have shown, how moving from communist organization towards an increased market orientation means, that the financial governance of hospitals has been fundamentally changed. Public hospitals providing health care services are currently experiencing decreasing government subsidies, meaning that their budgets increasingly come to rely upon direct out-of-pocket payments from patients.

Faced by an increasing number of patients seeking out health services, government hospitals in Chinese urban areas are increasingly pressured to think in terms of optimization to accommodate an increasing number of patients and still make money in doing so.
In Denmark, studies by Olejaz and colleagues (2012) and Vallgårda(Vallgårda, 1999; 2003) have demonstrated how Denmark's position as a welfare state means that the financial organization of Danish health care relies on a system where access to genetic health care is obtained through a system of referral, and where payment for such health care services is tax-financed and part of the public welfare health program.

Finding that genetic counseling relies only upon local sources of information in China, echoes the findings of Sui(2010), Zhao and colleagues(2013) and Zhang and colleagues (2014), whose work demonstrate how China is currently marred by a lack of national public health databases and registries. Correspondingly, Koch(2010), Nielsen(1991), and Rudiger(2003) found that the organization of Denmark as a welfare state has resulted in the establishment of broad historical national data archives usable as databases for health care services.

Though my empirical findings may be seen as given academic merit by such studies, approaching these different organizational conditions from a comparative praxiographic perspective, they offer more than a re-affirmation of what these studies have already demonstrated.
What these studies may offer to my study is important background knowledge. They show important perspectives on the ways China and Denmark have currently organized their health systems. What my ethnographical analysis in Chapters 6 and 7 may add to such studies in return, is a comparative perspective on the everyday genetic counseling practices. A perspective showing how such differences in health care organization influence the day-to-day routines of genetic counseling practices for clinical professionals.
A perspective which shows the different kinds of local everyday practices, actors (human and non-human) and local modes of clinical genetic reasoning illustrated by two different ways of organizing health care systems and organizing the provision of genetic counseling services.

In the next two analytical chapters, these two health care systems and their differences concerning guidelines for genetic counseling, financial governance of health care, and the organization and availability of health care data will be unfolded.

Though comparatively described in this chapter, it follows that each organization does not necessarily take up equal importance in each country.

It should furthermore be stressed that, although specific conditions of health care organization are mentioned here as individual themes, the analysis in Chapters 6 and 7 will reveal how such themes relate in salient but also very different ways of performing genetic counseling practices in China and in Denmark. In Chapter 8, a final comparison will be made based on the analytical chapters.

Chapter 6

Genetic counseling for cancer in China

This chapter presents an analysis of genetic counseling for cancer in China. The chapter will demonstrate how specific conditions in the current Chinese health care system determine how the day-to-day practices of genetic counseling for cancer may unfold and how specific modes of clinical genetic reasoning will follow.

In continuation of Chapter 5, this chapter will focus on analyzing conditions related to:

- Guidelines for genetic cancer counseling in China
- The financial governance of health care at Chinese hospitals
- Available health care data in the Chinese health care system

The chapter ends with a summary of the major finding in the analysis.

Guidelines for genetics in China

China has seen a blossoming development in the provision of genetic counseling services. The eugenic campaigns of the 1970s (*yousheng youyu*) and the implementation of a now defunct one-child policy[31] has meant that provision of genetic health care services have been focused on pro-creation and the establishing of a higher collective quality[32] for the population (Greenhalgh & Winckler, 2005; Sui, 2010) . In 2003 and again in 2011, the Chinese Ministry of Health (MOH) promulgated *National guidelines for genetic counseling,* to regulate the provision of genetic services (Sui, 2010; Zhao et al., 2013). These guidelines currently state that genetic counseling should be offered only by clinicians with a background in genetics. Genetic counseling sessions should include collection of information, drawing of a pedigree, provision of information about genetic diagnosis, provision of information about genetic disease disorders and inheritance modes, and advice on relevant management strategies (Sui, 2010). Guidelines state that genetic counselors should offer advice about marriage, reproduction and family planning during such sessions to prevent continuing transfer of genetic disorders (Ibid).

However, at the time of my fieldwork in China, these guidelines by the MOH did not include genetic counseling services for cancer (Zhao et al., 2013), and clinical genetic researchers have called for nationally coordinated guidelines for provision of genetic counseling for cancer (Wen et

[31] See Stockman(Stockman, 2000)

[32] *Tigao renmen de suzhi* (highten the quality of the population) (see (Anagnost, 2004)

al., 2006; a. Yu, Hongyan, Li, Bailin, & Daru, 2013; Zhao et al., 2013) . Currently, genetic counseling for cancer (genetic testing) is only offered in collaboration between research laboratories and specialized cancer hospitals. The status as a collaborative research clinic field means that formal guidelines about content and extent of such services are only in the process of being developed. This means that professionals currently engaged in genetic counseling for cancer can only to a limited extent rely on the current guidelines provided by the state, when offering genetic counseling for cancer and preventive management strategies to patients.

Local guidelines for genetic counseling for cancer at BC and PUTH

For the professionals at the collaborating hospital (PUTH) and laboratory (BC), the lack of formal national guidelines means that they largely have to rely on their own set of locally developed guidelines. Although these guidelines do not have the formal form of a written paper, my analysis showed the presence of agreements between professionals on the practices included in a trajectory of genetic counseling, the type of genetic risk estimates they may make and finally what kind of possible modes of clinical preventive management these estimates may lead to.

As already mentioned in Chapter 5, each trajectory of genetic counseling has been seen to consist of three stages.

The first stage takes the form of an opening meeting in which a family history of cancer incidents is established. This takes place at the outpatient clinic at PUTH.

The second stage is the actual risk estimation process. Patients have a blood sample taken at BC. The blood is then sequenced and any mutational findings are then correlated with an American genetic cancer database (BIC).

At the third stage, patients are again usually instructed to go to PUTH to receive the result of their tests, as well as recommendations for adequate preventive interventions. Preventive interventions are offered at the local hospital.

In the development of local guidelines, professionals emphasize reliance upon general international research results and practices. This means that the stipulated way of doing proper cancer genetic counseling is supported by international literature.

Professionals at BC and PUTH would remark that this is the general approach among their colleagues offering cancer genetic counseling services in China. Thus, clinical practices and modes of reasoning are identifiable within the trajectories of cancer genetic counseling in China. As mentioned in Chapter 5, risk estimates require assessment of the patient's family history. Only if

indications of possible mutations are present, further steps in the trajectory may be taken, the professionals informed me: ”*We don´t test anyone without an indication, that is a waste of resources. If they don´t have a family history we don´t test”(senior professional).* Professionals in China openly state that young age at onset of cancer, multiple onsets of cancer within a family, intergenerational cancer onsets, onsets of triple-negative and bilateral cancer incidents are all taken as indicative of genetic predisposition. Recognizing these as signs of possible indications of genetic predisposition are generally reflected in international literature (Bougie & Weberpals, 2011; Peshkin, Alabek, & Isaacs, 2010; Rogoziska-Szczepka et al., 2004)

When testing patients for mutations, results fall in three main categories: 1. Pathogenic mutation found, 2.Variant of unknown significance found and 3.No mutation found. Just as when establishing indications, the local clinical categories are reflected in international research findings, professionals emphasize.

Offers for prevention based on risk estimates follow a similar mode of reasoning. Offers for preventive surgery (mastectomy and oophorectomy) and screening (mammography and ultrasonography) are offered as prevention (*Yufang*) to patients with test results showing pathogenic mutations, while the remaining two categories of patients are only offered possible examinations (*fuca)* (mammography and ultrasonography). To a large extent, the association between risk categories and possible modes of prevention is reflected in international literature on genetic counseling for cancer (see chapter 2).

Guidelines and international literature

Although professionals emphasizing the strict adherence to international research on genetic counseling for cancer, there are discrepancies between international research tendencies and the day-to-day practices in China also found within these local guidelines. Though often emphasized as vital factors to the provision of genetic counseling related to cancer in international literature (see (Harper, 2004; Riley et al., 2012)), current local guidelines in China reveal a salient absence of attention to family risk information disclosure and to providing possible preventive programs to entire families.

In interviews with professionals, this salient absence is further underlined. There is little or no mentioning of families when discussing the form and content of the clinical practice of genetic counseling trajectories. However, when asked more directly about this discrepancy, interviews with professionals reveal that although families are thought of as central to the science of hereditary

cancer, there are still strong barriers between such scientific ideas and the realities of the day-to-day clinical practices based on local guidelines.

JP: When we find a mutation, we know from studies that there is a certain risk that it has travelled from mother or the father to a child.

M: So when you test someone and they are positive, how do you deal with the other family members? What about the family and how do you decide who could be offered what?

JP: We work with the patient.

Although acknowledging hereditary bonds as central in genetics, current local guidelines regulating day-to-day practices leave no explicit room for family issues; they are explicitly directed towards individual patients only.

To professionals, working with the patient or the index person rather than families, is recognized as central to all aspects of their current clinical practice. This ranges from testing procedures being strictly individual, risk estimation, and provision of a final risk estimate and offers for risk management strategies. These are all seen as strictly individual. As one professional commented:

SP: In China, we work with the index person not with the family as such. It is the patient we work with. If there is a mutation within the family, then we also offer a test to others in the family, or if the family history has something, then they can come by themselves for a test. (…) People have to decide themselves in the families, whether they want to be tested. I deal with the patient, the index person. Family affairs are not my job.

The discrepancy between international genetic research literature emphasizing risk as something pertaining to families, and the strict individual focus of Chinese professionals in genetic practices is openly attributed to specific conditions found in the organization of the Chinese health care system. A professional remarked:

JP: We have to take care of the patient who comes to us, that is how it is in Chinese hospitals. We think more individually here. But of course we know that they need to discuss it in their family. But the patients have to do that by themselves. They have talked about it in the family first. But if they want more, they will have to come by themselves and get a referral for testing. That is how it works here (in China).

The interviews with professionals about the local practices of genetic counseling contribute to the drawing of very fine-grained lines within their local guidelines between who may count as a possible clinical recipient of services and the current referral system. Here the second theme concerning the financial aspect comes to play a vital part. Specific modes of practical payment for health care services are tied to the current referral system as a result of the current financial governance and organization of the Chinese health care system. My talks with professional revealed that this is decisive for carving out dividing lines between families and individuals in the current genetic counseling practices.

The financial governance of Chinese hospitals

The Chinese health care sector has undergone a tremendous development in the last 20 years. From being of a completely state-driven enterprise in the 70s, hospital funding (THE) now comes from three main sources: Government subsidies (GHE) (covering buildings and equipment), patient out-of-pocket payments (OOP), and payment obtained via social insurance providers (SHE) (Hougaard et al., 2011). Before the Chinese economic reform in the late 1970s, the GHE as a share of THE accounted for over 32%, the SHE accounted for 48% of THE, and OOP for 20% (Ibid). However, the distribution of health care expenses has dramatically changed during the past decades. In 1998, OOP had increased to 55% and though falling to 40% in 2008, OOP still make up a substantial part of the payment for health services for patients (Zhang & Liu, 2014) . Seen from a hospital perspective, though categorized as government-run, these are increasingly run according to what can best be described as market conditions, receiving more than 60% of their bulk funding from OOP (Eggleston et al., 2008). Scholars have argued that such conditions have led to performance incentives in clinical practice, meaning that increasing focus has been put on delivering services with a broad profit margin (Ibid). In 2009, the initial steps were taken to implement a new health care reform, aimed at providing a much broader coverage of health care financed by the state. Although this has been believed to gradually quell the ever-increasing dependence upon OOP in the health care sector, the final evidence of this was not yet seen as I conducted my fieldwork in China. Even though gradual implementation of a new health care reform is expected to limit the need for OOP by providing a broader public coverage, a number of services are still not covered by such initiatives. Genetic services are currently not covered (Zhao et al., 2013). In order for a trajectory of genetic counseling to be initiated requires OOP from patients. Paying for these services is done by the patient. Some patients may have their expenses reimbursed through private health insurance

companies, while others, usually low-income families, depend on often scarce, personal savings. Specialized urban hospitals like PUTH offering genetic counseling for cancer are increasingly experiencing a surge in patients seeking out health care services. Although there are rural health care facilities some services, such as genetic counseling for cancer, are still only offered at urban hospitals (Ibid). As many patients consider urban health care facilities as superior to rural health care services, patients increasingly travel from the Chinese countryside to urban centers like Beijing to receive health care services, thus increasing the pressure on urban health care facilities (Eggleston et al., 2008). Studies have, however, also emphasized that the reasons for increasingly crowded urban specialized hospitals in China (such as PUTH) are attributed to a range of other organizational factors. Lacking a system of general practitioners (GPs) in China means that clinical triage practices are practically absent in the Chinese health care sector (Zhang & Liu, 2014) . As a result, patients with minor medical issues are now placed alongside patients with more critical medical needs. As a way to deal with the pressure of an increasing number of patients, outpatient services are usually offered in rooms with more than one patient at a time, which was also emphasized by the professionals I followed. Studies have suggested that financial incentives play a central role in the emergence of such health care conditions. Depending upon funding from out-of-pocket payments from patients, and funding from the central government according to patients serviced, have been suggested as reasons for hospitals trying to service as many patients as possible, rather than providing a limit for patients to be serviced a day (Eggleston et al., 2008; Hou & Xiao, 2012) . Studies show that professionals are often quite explicitly expected to meet a certain quota of patients every day to meet hospital budgets (Blumenthal & Hsiao, 2005; Eggleston et al., 2008; Sui, 2010)

Health care service and practices of payment

In practice, all health care trajectories (including genetic counseling for cancer) begin at the payment booths at hospitals like PUTH. For patients at PUTH and patients at any other hospital I have visited in China to be allowed to enter the examination room and receive a health care service, the patient will first have to draw a number[33] (*gua hao*). To obtain such a number, you queue up in front of the payment booths. When drawing a number at PUTH, personal details are registered for use at the examination and a referral note is issued. Central to in this enactment is that the examination is also paid for (OOP) at the same time (*fu gua hao fei*). When entering the examination room, patients are expected to be able to present their number, referrals and receipts to

[33] Some actually did bypass the system without a number, but all patients had to present a receipt.

the professionals. In this way, patients not only transfer potential vital clinical information to the professionals, they also demonstrate to the professionals that they have participated in the practice of payment *(fu gua hao fei)* on the first floor. To the professionals working at PUTH, this practical enactment of payment was represented physically by numbers, referrals and receipts, as well as the presence of multiple patients in each consultation. This gives rise to specific considerations regarding the clinical work of professionals.

Numbers, referrals and receipts as well as multiple patients as temporal actors

Each clinical session at PUTH is started in the same way. First, a professional inspects the number and the receipt of allowing the patient entering the room and the session to start. As each professional is required to meet a certain quota of patients every day (approx. 50 patients according to professionals at PUTH), these notes serve as a physical reminder to the professionals of the number of patients they are expected to service and their current progress in meeting the quota of the day. Failing to meet the quota over a specific period of time could mean losing your job, a younger professional later told me: "*We have to service many patients, and we are evaluated. We have to work fast"(junior professional).* Although pressured by large numbers of patients, professionals are still expected to meet rigorous clinical standards. Each patient is expected to receive an equal and proper clinical service, and each number and patient also symbolizes a paying customer (JP: *Bixy dou gei tamen yiyangde hao fuwu).*

To balance between such considerations, certain implicit practical time-regulating strategies are applied by professionals. An explicit timeframe is never given to patients, but professionals at PUTH nevertheless apply a specific regulative strategy to control the time consumption, limiting the clinical dialogue with each patient to ensure that each examination never exceeds 5-10 minutes. In this way professionals are capable of both giving an equal service to patients and limiting the time spent on each patient. From my case material, this strategy is identified as delivering clinical services by: *Working fast and saying enough.*

Regulating clinical time - practices of working fast and saying enough at PUTH

The colloquial expression, *working fast and saying enough,* in practice covers a specific form of time regulation, enforced through means of interrupting dialogue with patients once 5-10 minutes were spent providing clinical services to a particular patient.

Case 1/2 working fast and saying enough
We are sitting in the examination room at PUTH (Pic 8). A senior professional is engaged in examining what could be a tumor found in a female patient, seated in chair 1. The senior professional quickly concludes his examination asking her to prepare to be referred for an ultrasound/mammography examination. This patient is instructed to move to chair 2. This is, however, not possible as his previous patient is still seated here. This patient and the junior professional are engaged in a discussion about the patient's future use of medicine. The senior professional begins to tap his fingers on the table impatiently, before finally telling the junior professional
SP: *Young lady (Xiao Guniang)! You need to speed up (angrily). Work fast!*
This is not a laboratory experiment!
JP: *But but ...*
SP: We have many patients, we are only at number (I didn't hear the number).
JP: But I was ...
SP: Say enough and don´t waste time! Next number.
The junior professional nods and finishes writing a referral for her patient, and the patient seated in chair 1 is allowed to move to chair 2.

Case 2/2 working fast and saying enough
We are again sitting in the examination room at PUTH. Patients are currently seated in both chair 1 and chair 2. The senior professional is listening to a patient seated in chair 1, telling about reactions to her current medical treatment. This patient is worried and begins asking about alternatives to her current treatment. The senior professional responds dismissively waving his hand. She is then told to in a strict voice to move to chair 2. This chair is, however, not empty. A patient is still sitting here talking to the junior professional about her treatment and where this is to be conducted. As this discussion after a minute shows no signs of coming to an end, the senior professional interrupts.
SP: That's enough (keyi ba)! Faster, faster (Kuai yidian, Kuai Yidian)! You have to work faster (Ni bixu kuai yidian)!
Just say enough, and then punch in the next number. We have many to go. Other patients also need time. If you spend so much time on each patient, others won't have time.
The junior professional quickly ends her session. And the senior professional hereafter focuses his attention to the patient seated in chair 1 asking her to move, before calling in a new patient.

To professionals, time-regulating strategies on *working fast and saying enough* by interrupting dialogues (either vocally as in both cases 1 and 2, or simply through the gesture of a hand as in case 2) are understood as vital to the clinical practice at the outpatient clinic at PUTH.

Professionals who fail to *work fast,* it could mean that extra time is spent on one patient, and professionals thus risk getting behind schedule and making it hard to reach the quota of the day. The only way professionals can catch up will then be to take time from other patients. Effectively, this leaves other patients with less time for clinical service. This situation is considered to be irresponsible by the professionals. A senior professional tells about this:

SP: We have to be fast (zuo kuai), to speak clearly and only say enough (shuo goule) when we do our work. (…) We have to speak clearly, so the patients will understand us, but we also have to think about other patients. If we say too much it will make patients confused and it will take time from other patients. (…)We have 50 patients (that all have numbers) and we need to see them all, we can´t waste all our time on a single patient.

A junior professional later confirms the explicit existence of these strategies. She also tells that these are strategies must be learned as a part of the ongoing clinical education towards becoming a proper professional.

JP: It's tough, but we are used to it. It's nothing personal, we need to learn it. That is also part of becoming a professional.

These cases show how professionals with success regulate time during clinical sessions, but their strategies are not always successful.

Patient interruptions – challenges to professional time control at PUTH

Despite exerting a strict degree of power in their clinical work at PUTH, professionals cannot expect their patients to naturally comply. Although Chinese health professionals have traditionally been seen as "angels in white", understood in terms of benevolent paternalism, professionals are increasingly met with suspicion and distrust by their patients (He & Qian, 2016; Hesketh, Wu, Mao, & Ma, 2012). Increased financial pressure on patients and their families has been argued as one of the reasons for a surge in patients challenging the medical authority of professionals, sometimes even violently (Jiongtu, 2014; L. Zhang, Stone, & Zhang, 2017). I did not witness any kind of violent behavior during my time at PUTH. What I did encounter as a frequent practice of patients during counseling was the use of interruptions. During sessions it is not uncommon for patients to try to disrupt the time control exercised by professionals by simply interrupting other patients, asking questions to a senior doctor after having moved to chair number 2. As a general rule, professionals try to spurn these attempts. Sometimes arguments break out, but more than often these small interruptions and arguments result in a brief amount of extra time being assigned to the

obtrusive patient. Claiming more time through means of interruptions was voiced as a recognized strategy among patients I talked to at PUTH. A younger woman told me:
Sometimes it's really unfair. I mean I have a big problem. It's cancer! I have so many questions, but only so little time. That's why we keep asking questions. We know it as patients. That's the only way to get what you want. If I don't ask, I have to start all over again and wait in line an entire day.

Though often adhering to the general principles of interrupting patients, the occasional acceptance by professionals of such challenges to their time controlling practices come at a price. In order to compensate for time lost due to the interruptions of one patient, time needs to be gained from another. This, however, is easier said than done. For the patients that now face allocation of less clinical time with the professional due to such interruptions, measures are usually taken towards gaining what was lost. This usually means that these patients also interrupt as a way to make up for the less amount of time. Thus, a circle of patient interruptions often endures throughout the entire day, causing tension in the room as professionals try to manage without getting behind schedule and not meeting the quota of patients.

Genetic counseling as an individually paid-for service
As most public genetic cancer counseling services unfold as collaborations between hospitals and research laboratories in China, patients usually initiate and end their trajectories (described in Chapter 5) at normal cancer hospitals among patients receiving traditional oncological health care services. Just as regular cancer patients, those seeking out genetic services are expected to register, pay for services and draw a number that places them in the same position as other patients seeking out clinical services. This means that genetic counseling practices effectively become subject to the same constrained conditions as regular oncological practices.

You Jiazushi Ma[34]*? Establishing family histories in a frame of constrained time*
As already mentioned, any establishment of a trajectory of genetic counseling for cancer is determined by first confirming that a patient's family history of cancer incidents shows indications of genetic predisposition to disease. Indications of familial genetic predispositions may be revealed through onsets of particular kinds of cancers (bilateral, triple-negative breast cancer), multiple incidents of cancer and onset at a young age. This information is partially obtained by means of

[34]Do you have a family history (in English)

reviewing medical records, but primarily through a dialogue between patients and professionals. As genetic sessions are considered as any other clinical service, professionals have to establish any indication of a family history through dialogue with patients in a constrained timeframe of 5-10 minutes per patient in the outpatient clinic. This means that specific clinical modes of inquiry are pursued within this practice.

For patients seeking out genetic services, however, family histories are usually seen in a particular light. To patients, family histories often contain many incidents of cancer, many times on both the maternal and paternal side of the family. To the patients I talked to, a high number of cancers not only proved that something special and possibly genetic may be at stake; it also meant that they developed a keen interest to explore the origin of the possible predisposition to find out who would be affected by the familial predisposition. When providing the professional with information about cancer incidents, patients would therefore be careful to describe the entirety of the cancer incidents. To professionals, however, relating to elaborated family histories constituted a challenge due to the 5-10 minute timeframe currently allocated to each session. As a way to control the practice of establishing a family history, professionals had to exert an explicit time control. Only very specific types of information to establish a possible indication to emerge are allowed to be pursued during such a session.

Case 1/2 Xiao Yang

A woman Xiao Yang, aged 32 is sitting in chair 1. She tells how she has experienced something cancer-like. The professional enquires about the family history: *SP: Do you have a family history (Ni you jiazushi ma)?*

Xiao Yang tells. Her mother, it seems, has also had something with her uterus. While she speaks, the previous patient now seated on chair number 2, interrupts her by asking the senior professional about how she is to take her medicine. At first, the professional pays no attention to her, but as she continues he turns towards her. First he scolds her, but afterwards he attends to her medicinal questions. The interruption lasts only 1 minute or so, and soon the senior professional asks Xiao Yang to continue. In addition to the cancer incidents on her mother's side, she continues to tell of other incidents of cancer on the paternal side of her family. Her grandfather and his brother apparently have also been struck with cancer. As she begins to provide this information, Xiao Yang is interrupted by the professional: *SP: ok ok, that's enough (Hao le hao le, keyi keyi)!* He tells her how she will proceed for further tests. Lasting only a couple of more minutes the session ends, as Xiao Yang moves to chair number 2, where the junior professional prints a new referral slip, and instructs her to go back to the first floor to pay for this new service. Then she is instructed to go to the laboratory for the testing to be performed.

Interrupting a patient in the middle of story is not uncommon during the establishment of a family history. A similar example is seen in the case of a patient called Liu.

Case 2/2 Liu
Liu, a woman in her early forties, is sitting in chair number 1. She, and other family members have experienced onsets of cancer and now she wants to have a genetic test taken. The professional routinely checks her record, number and referral note.
The professional looks at her: *SP: Do you have a family history (Ni you jiazushi ma)?* He asks. Liu informs the professional that her mother also had cancer and so has members of both her and Liu's father's family. First she tells, how her mother had cancer in her fifties, and how she has told Liu, that several of her maternal grandmother's sisters apparently also had something resembling cancer. The professional listens with interest. She continues to tell about other members of her mother's more distant family having had cancer as well as members of her father's family. The professional interrupts her. *SP: That's ok.* Liu still not sure whether she is expected to provide more information, continues to tell of cancer incidents in her father's family, but is again interrupted by the professional, now in a harsher tone. SP: *Ok ok, enough enough. You don't have to continue (hao hao, goule goule. Bu xuyao hai shuo). You should go and have a test taken.* He instructs Liu that a test will take four months. She is then told to move to chair 2, to have a referral issued and to go and pay before she proceeds to the laboratory at BC.

Patients being interrupted as described in these cases were a common experience during such openings sessions at PUTH. They usually occurred when patients would talk about both sides of their families during the establishment of a family history or when patients had mentioned cancer onsets of more than three members of their family.

These cases reveal how interruptions served as instruments of control during genetic counseling for the professionals, similar to cases of traditional oncological services. Verbal interruptions or interruptive gestures during the establishment of a family history serve as a vital time controlling tool, allowing professionals to control the dialogue with patients. Such measures ensure that professionals only get what they perceive as important information to enable them to establish a family history of cancer within the allocated timeframe, while preventing unimportant information to take up vital time during genetic counseling practices.
When interviewing a professional, the use of interruptions was explicitly emphasized as a necessary strategy during genetic counseling to prevent wasting time:

SP: We need to be very precise when we talk to our patients. Many times they want to tell us a lot because they are scared. But they are not the only ones here. If they talk too much it's a problem because we have to work fast. We have to be very careful that we don't waste time. We need to stop them, when we have what we need.

Though information about the onset of cancer in many family members on both the paternal and maternal side of a patient's family may seem vital to patients to trace the origin and get as broad a picture of a possible genetic predisposition as possible, such information is viewed as less important and time-wasting to the professionals. A professional tells me during an informal conversation
SP: We have to work fast!
M: But isn't it hard to get a broad picture of the family history then?
SP: Listen, I have more than 50 patients a day. They all have a number. I need to be fast, and see if there is something I need to react on. We don't have time to talk about a broad family history. I only need to follow what the patient tells me and what I can read in the records. Then I see if there is something we need to explore further.

The colloquial expressions in the interview of *working fast* and *only saying enough,* carry a special meaning for professionals during genetic counseling practices. *Working fast* and s*aying enough* cover a set of meticulous interruption practices (interrupting patients when they say too much), that allow professionals to ensure that time for services is equally balanced between patients and that it complies with the current time constraints. Yet, to professionals they also serve as meaningful tools to allow them to regulate the line of clinical genetic inquiries in these sessions. Though questions of the possible origin of a mutation may serve as valuable information for patients, such information exceeds what is perceived as something, *which needs to be reacted on* for professionals.
For professionals, the justification and merit for enforcing such interruptions as explicit modes of time-control emerge from a second organizational condition tied to the practice of payment at Chinese hospitals. For professionals, each individual payment also signals a direction and ownership to the time allocated for the care service. The service is orientated strictly towards the individual patient or consumer who has paid for it.
In deciphering what kind of information that may count as *something they need to react on*, and what kind of information is considered a waste of social time, individual OOP practices for patients

play a vital role in carving out such a distinction by providing a specific direction for one's professional service.

Geren payment, geren practices

For professionals, what may count as *something they need to react on* is made meaningful as a balance between staying within a specific allocated time and keeping a watchful eye on the direction of the service they provide. For professionals at PUTH, an explicit strict focus in genetic counseling service is only to the individual who has paid for the service. This was voiced in interviews and in daily dialogues using the colloquial expression for genetic counseling "*Geren Fuwu"* - to an "index-person". In Chinese, *Geren Fuwu* means *individual service.*

Seeing genetic counseling as a *Geren Fuwu* means that professionals need only to pursue specific trajectories of information that may help the individual when establishing a family history showing a possible indication of a genetic predisposition. This means that elaborate information about the possible origin of a mutation within a family is considered as unnecessary extra information when answering the central clinical genetic question: Does this patient (as an individual) have a genetic predisposition to cancer?

When interviewing a professional about what may be perceived as *something they need to react on,* emphasis on the focus on the individual was underlined:

M: But how do you decide when you have enough to go on? Sometimes you have cancer incidents on both paternal and maternal side, but often I have observed you only follow one side.

SP: But if I can see an indication from one side alone, why should I ask about more information? We only need to say enough that's it. My aim is to an establish indication about mutations for cancer for this patient, not to know everything about a family. This here is an individual service (Geren Fuwu). Remember outside other patients are waiting to be seen as well. We can't risk falling behind.

It is not that elaborate descriptions of many onsets of cancer do not raise the interest of the professionals. Talking to professionals reveals that they are well aware of the links between cancers in a family and genetic predisposition. However, to them, obtaining information other than that related directly to the possible risk status of the individual having paid for the service is seen as outside the framed direction of their services, and thus as a waste of time spent taking time from other patients.

A professional told me during a conversation, when asked about such elaborate family narratives:
P: It's interesting of course, and it would be nice for us to know more about it. But that's not really my job here. I have to focus strictly on the patient (individual patient) coming. If they want to know more about their families, then they have to come here as well.

For professionals, the practices of individual payment in the Chinese health care system lead to a salient direction towards clinical individuality when initiating trajectories of genetic counseling for cancer. This direction towards individually paying patients, emphasized in the notion of *Geren Fuwu*, manifests itself through the entire practices of genetics at PUTH, but also to practices carried out at the laboratory at BC.

Estimating risks at BC

If indications are established at the outpatient clinic, each opening meeting ends with patients being told to move from chair 1 to chair 2 (picture 8) where a referral is issued. The patient is then told to go to the payment booths, to pay for the further testing and risk estimation procedures, before leaving for the research laboratory (BC).

A referral and receipt need to be presented by the patient upon arrival at BC proving that payment for their service has been made, and that an indication has been established.

For professionals at BC, current clinical risk estimation practices involve a short introduction dialogue with patients explaining the scope of the services and the signing of a consent form. After this a blood sample is taken for further testing. The blood sample is then sent to the laboratory for testing and the results are then looked up in an American Genetic cancer database (BIC), which is accessed via the webpage http://research.nhgri.nih.gov/bic/. Here the database may reveal the mutation to be a known pathogenic mutation predisposing to cancer, or a variant of uncertain significance (VUS). The results of these practices are then printed in a report (*Baogao*), and made ready for the patient as their final risk estimate.

Testing and risk estimation as a Geren Fuwu

To professionals the inspection of referral and receipt note at the opening of each patient meeting echoes the situation at the outpatient clinic described earlier in this chapter. At the outpatient clinic, these notes symbolizing payment both act as fundamental "door openers" or "door stoppers" to going further in the genetic risk estimation process. If they fail to present a receipt, no further

practices will be carried out. But, they also here carve out a specific individual direction for the professional practices of risk estimation.

For professionals at BC, just as any other medical professional in China, their main objective is to help patients. The professionals at BC and PUTH understand such help as producing and providing genetic knowledge that will allow patients choose suitable risk management strategies. Interviewing a professional:

M:I often hear you talk about helping patients. What do you mean by helping patients? What does it mean to help?

SP: That a patient can come here and have a test taken and get a result.

M: Ok, but.

SP: My job is to help the patient that comes to us. If I can find a mutation then there are certain kinds of medicine that will work better. And the patient can also be offered preventive interventions (yufang) such as a mastectomy (chuanqie).

Just as at the outpatient clinic, such understandings of knowledge and help among professionals have a strict focus upon the individual patient (*the patient that comes to us (bing ren lai women zheir)).*

For professionals at BC, payment practices physically represented by receipt and referral notes, direct the meaningful provision of risk estimates. When interviewed about the role of genetic risk estimates produced at BC to the social lives of families in which individuals must to choose adequate risk management strategies, this strict focus upon individuality was further underlined as central to their clinical practice.

M: What about the family and stress?

SP: In China we work with the index person not with the family as such. It is the patient we work with. If there is a mutation within the family then we also offer a test to others in the family, or if the family history has something, then they can come by themselves for a test. (…) People have to decide themselves in the families, whether they want to be tested. I deal with the patient, the index person.

In an interview with another professional, the emphasis on individuality was further underlined:

M: What do you mean, "we work with the patient"?

JP: *It´s up to them. You can say we are probably more an individual service (geren fuwu).*
M: What do you mean by individual service (geren fuwu)?
JP: We have to take care of the patient, that comes to us, that is how it is in Chinese hospitals. We think more individual (geren) here.
Payment for clinical services is individual, and so are the genetic risk estimation practices that such payments may open up, according to professionals. It is not that the importance of potentially risky genetic material among family members was not mentioned by the professionals in interviews. However, as a clinical intervention and service, the current economic arrangement with explicit individual payment means that genetic risk estimation carried out by professionals in the laboratory is seen as only directed at information valuable to the individual patient having paid. When blood samples are taken, sequenced, and the adequate databases have been consulted, the result is considered the property of the individual paying patient. For professionals, family members are not necessarily excluded a priori from obtaining a risk estimate, but to get a risk estimate, these family members will also have to follow the procedures and individually pay for services. By being placed within the clinical realm, any final results produced at BC, regardless of whether a mutation has been found or not, are considered strictly *Geren* by professionals.

Delivering a final risk estimate as a paid for practice
The opening of a genetic trajectory usually unfolds at outpatient clinics, and so does the delivery of a final result. For professionals, this means that the result is also unfolded within the salient constrained economic frames of outpatient clinics in China. The provision of a risk estimate to patients once again depends on the patient drawing a number, and once again this service unfolds among patients receiving traditional oncological services.

For patients arriving to receive their final risk estimate, these are seldom seen as strictly individual. For most patients who arrive at PUTH, deep explicit considerations are given to the possible impacts of a risk estimate for themselves but also for their families. Often: ”what does this mean for my …” is heard during these final meetings with professionals, and often professionals are openly asked about how risk estimates should be managed within the family in question.
To professionals, however, the return to the outpatient environment means that interests in family issues transgress the possible modes of clinical reasoning and the practices of individual payment. The means that inquiries about families are generally treated dismissively, by referring to genetics as an individual service.

Case Zhang 1/2
A young woman, Zhang, enters the examination room. The professional quickly looks at her local record and notes. Acknowledging that she has taken a genetic test, he quickly discloses to her that no mutation was found in her test. He quickly continues:
SP: Do you have a family history (jiazushi)?
ZH: Yes
SP: There still can be other genes. If you want, you can have an examination (fuca).
The professional explains how a breast screening may be a viable option for her, and should she choose to do so, he will open a referral. Zhang nods, but continues to ask about her family.
ZH: What about my sister? She is also afraid?
The professional quickly continues to tell Zhang:
SP: If she wants to know, she can also come here and have a test taken.
Zhang nods, and after agreeing to go on to further examinations, she moves to chair 2.

To professionals, it is not that families cannot receive knowledge of genetic risks, but they cannot do so collectively based on a single act of payment. It is important for professionals to emphasize to their patients that family risks (such as Zhang's) need be pursued individually. A professional states:
SP: Of course they (patients) are worried about their families, but we deal with those who come to us. If their families want more, then they need to come here as well. I only deal with the index person.

Although professionals openly offer to meet the patients' need for knowledge by offering genetic services for their individual family members, patients do not always accept such individual service offers. Professionals often meet patients who try to circumvent the strict individual focus on servicing paying individuals only, seeking to gain more information about family risks as parts of their own trajectory. Such attempts, however, are seldom successful for the patients as professionals openly exert control of both content of and time on counseling through verbal interruptions whenever patients challenge the mode of individually focused clinical genetic reasoning.

Case 2/2 Xiao Li
Xiao Li, a younger woman, enters the examination room. First, the professional checks her "brought along paper", then he quickly announces that her genetic test has come back negative, meaning no mutation has been found. He then inquires whether she has a family history, to which she nods. She tells how cancer onsets have struck two more person in her immediate family. The professional quickly reacts stating:
SP: If they want to, they can come and take a test or they can come in for examinations (smiles). Xiao Li, however, wants to know what she should tell them regarding family risks:
The professional now seemingly irritated:
SP: Tell them that you don´t have a mutation.
Xiao Li still persistent: *Xl: Ok, but what if they don´t …*
*SP: Listen, I deal with the patient here, family issues are not my thing. (*The professional waves his hand dismissively)
Xiao Li looks down uttering, *Never mind.*
She moves to chair 2, and a new patient enters the room.

Discussing risk estimates within a family context, challenge the current economic frame of the clinical room, and as such discussions are readily met by dismissive strategies by professionals for them to make ends meet. A professional tells during an interview:
M: Often patients want to talk about families and risks?
SP: Yes, but remember I deal with the person coming to us. I have to give an individual service (geren fuwu). I could of course discuss issues of family, but then again, I have many other patients as well. No (bu keyi zheiyang). If everybody wants to know something like that, then we won't have time to do our job.
The two cases above show trajectories where no mutation was found. However, small differences in direction and time allocation was seen when I followed the trajectories where a mutation was found. Though a larger proportion of the allocated 5-10 minutes was spent informing about the specific mutation, the risks and the possible preventive measures, a similar frame of individuality was in play. Just as in Zhang's and Xiao Li's case, patients were also here informed that their families too could come for testing.
After patients receive their risk estimates, they are offered preventive measures (yufang) in the form of screening or preventive surgery if a mutation is found; in those where a mutation has not been found are offered to be examined (fuca).

Regardless of the further trajectory, these clinical interventions are offered as services at the local hospital. Just as the opening trajectory, the individual patient must pay for these services.
The current economic organization of the Chinese health care system means that payment practices play a vital role in making genetic counseling practices and their products strictly individual. This tendency is only further exacerbated by the current organization of health care data used during genetic counseling practices in China.

Availability and use of health care data in the Chinese health care system

With the transition towards a greater market orientation in the Chinese health system, Chinese hospitals in many ways function as independent units (Eggleston et al., 2008). This not only means that each hospital is made individually responsible for its own referral and payments to ensure its economic survival, it also means that there is little, if any, collaboration between hospitals (Sui, 2010). When considering the availability of health care data to be used in genetic counseling, there is no current official central health data registry in China (Y. Zhang et al., 2014). Usable data such as medical records containing information about patients' disease trajectories are kept strictly local at the hospital where the patient has been treated. As hospitals act as independent units, it means that each hospital opens a new medical record for the patient upon arrival, and there is no exchange of data between hospitals (Sui, 2010). Even though hospitals are increasingly starting to use electronic medical records (EMR), these are currently also kept strictly at the local hospital, and are not -accessible by other hospitals (Gao, Xu, Sorwar, & Croll, 2013) . Most hospitals give their patients a print out of their medical record to bring to another hospital if the patient chooses to seek out services at another hospital. Though patients may choose to bring medical records from one hospital to another, clinical professionals are generally reluctant to use information from another hospital (Sui, 2010).

Individual data – individual genetic counseling

When providing genetic counseling, professionals may rely on a very distinct arrangement of strictly local information sources as instruments in their clinical practices. During the opening of a trajectory of genetic counseling to establish whether a family history shows indications of genetic predispositions to cancer, professionals come rely on two main sources of information for this practice: 1. The patient having arrived and 2. The local medical record.

Dialogical information as a source of data:

When establishing a family history, the primary part of the information for professionals is achieved through dialogue with the patient. Fundamental characteristics within a family history may reveal whether mutations are likely to be found. Indications may be shown through characteristic cancer onsets (onset of cancer at an early age, special types of cancer, and intergenerational cancer onsets). Information about some of these traits is directly obtainable through dialogue. Among professionals, patients are generally considered valid sources of information when pertaining to specific forms of information. Information about cancer related to the patient in question is to a great extent seen as valid. The same applies to information delivered by patients about cancer and age of onset in their immediate family (siblings, mother ect.). Such information is naturally assumed to be shared within Chinese families. As a professional states:

SP: When it comes to the family, their mother and their sister, they know it. In China, families talk about it (cancer). That is normal!

Although information about cancer provided by the patients themselves and about cancer in their immediate family is acknowledged by professionals, professionals may consider information about the actual onsets of cancer and the age of these onsets within immediate family as well as about specific biological indicators to be less certain. Professionals state that they can usually rely on information on onsets of bilateral breast cancer cases within the immediate family, as these take a very physical form. However, when inquiring about such conditions as the existence of triple-negative cancer tumors in the family, information obtained through dialogue with patients may prove inadequate. As a professional states:

P: Bilateral breast cancer is easy to see and remember, but other forms of cancer that need to be tested are not as easy. Patients seldom know about this information.

When establishing a family history of cancer, such information is only accessible to professionals through medical records.

Medical record information as a source of data

The hospital medical record plays an active role in strengthening the indications within the family history. For the professionals at PUTH, hospital medical records can inform about aspects that cannot be obtained from patients (such as triple-negative cancers). Yet, when taking a closer look at these medical records, the current fragmented organization of such medical records in China means

that professionals may have to depend on specific conditions if they are to use medical records as instruments of genetic counseling.

When establishing a family history showing indications, professionals can only access hospital medical records from PUTH, if the patient arriving has been examined or treated previously at PUTH. If the patient, on the other hand, has been examined or treated at other hospitals, the professionals come to rely totally on the patient arriving, carrying her medical record from another. Only a few of the patients I followed who had purposely sought out genetic counseling at PUTH, had had prior engagements at that hospital. In the majority of the cases I followed, this means that professionals rely on patients bringing medical records. Sometimes these records are used, sometimes they are openly rejected as this case of a young woman *Hao.*

Case 1 Hao
Hao, a younger woman, sits in chair 1. She is here to have her family history assessed. The professional is in the process of looking through the records she has brought along:
H: The doctor gave me these (points to the record information)
SP: These are no good! I can't use these. Look (takes out X-rays)! I can't see anything on these! No you have to first have an examination here, this is no good.
Hao is instructed to first have new X-rays taken before they are to continue.

Medical records from hospitals, many times fall under the category of being sub-standard. A professional openly addresses the problem in using medical record information from other hospitals:

P: We have to be careful. Sometimes the information we can get is good. But not always! Sometimes these patients come from small hospitals in the countryside, and this means that the information we get is bad.

Rejecting medical record information from other hospitals as sub-standard means that emphasis is solely put on dialogue with patients.

When information about family members was pursued, limitations in access to medical records are even more problematic. During my period of fieldwork, few patients were capable of bringing medical information about family members. Distances in China are huge, and among the patients I followed, many had family living thousands of kilometers away. When pertaining to older family members, many had been deceased for several years, meaning that their records had long been lost.

For professionals this means that information about other family members is exclusively retrievable through dialogue with patients. In practice, this means that in the establishment of an indication leading to the initiation of a genetic counseling trajectory, they become highly dependent on individual patients and the information these may disclose.

The current organization of health care data in China, and its constrained accessibility in clinical practices, not only means that reliance is put upon the individual when establishing indications of genetic mutations, but also in the actual practices of risk estimation at Chinese laboratories such as at BC.

Individual data and individual risk estimations

When conducting risk estimations at BC, the professionals also deal with individual results. Currently, no national formal genetic cancer registries are in place (Y. Zhang et al., 2014), and Chinese professionals have neither access to information that may reveal patterns of cancer onsets within whole families, nor to important information about pathogenic mutations identified among the patients who seek out such services.

Thus, practices of risk estimation in China currently rest on identification of individual mutations solely based on international genetic registries such as BIC. These registries only include specific information about the pathogenic status of individual mutations. This information is then correlated with the tests conducted in the individual patient arriving for genetic counseling.

Lacking national registries with information on mutations means that professionals currently have no possibility for cross-referencing results between individuals from the same family seeking out such services. Each individual arriving for testing is treated as an individual, (and currently this also means that no programs for prevention for families have been be developed).

In my interviews professionals were well aware of the potential deficiencies caused by the lack of such registry information may have for their services, and reveal that research initiatives have granted them the possibility to record family rather than only individual information as part of their research program. A professional states:

SP: It would be good to have them (registries), but we don't have them here in China, yet. That's why we are making our own here at the lab. We now have more than 1000 families/persons in our own database. This will allow us to do research and make better programs for them.

Building up local registries through research programs, professionals emphasize, will allow them to draw lines between individuals within families in the future. To patients such a possibility would

mean that they, in the future, would not need to arrive and start from scratch. Each patient becoming a part of these research programs is currently assigned a unique family number, allowing them to be connected to other members of their families having been serviced. A professional underlines:
P: We now give our patients a number when they come here, that is their family-number and that is recorded as well as their social security number (shenfenzheng). If other family members want to have a test, they can use the same number. In that way we get family information.

To professionals, such local research initiatives are considered the first step towards establishing what they see as much-needed registries with data on families and their potential risks. Whether such information is to continue to rest upon local initiatives, was unclear at the time of my fieldwork. Current tendencies, however, suggest that initiatives towards establishing more formal national registries containing both genetic information as well as broad health care information may be on the way. In 2017, the Chinese government took the first steps towards establishing a national DNA register. Whether this will effectively replace or only supplement local registries, only time can tell (Xinhua, Xinhua | Updated: 2017-10-31 10:54).
Among the professionals I interviewed, it was stressed that although the future might allow them to obtain such family information, this would not mean that whole families would be allowed to be serviced based on payment for a single trajectory. Though patients and their families may come to socially benefit from this information, each member of the family would still need to seek out services and pay for them individually.

Chapter conclusion

The analysis of this chapter illustrates how the organization of guidelines for genetic counseling, the financial governance of health care services, and data from medical records, influence the day-to-day practices of genetic professionals in salient ways in the Chinese health care system. The chapter reveals how the lack of formal national guidelines for genetic cancer counseling means that professionals develop and depend on their own locally developed guidelines for genetic services, based on broad international literature on genetic cancer counseling. The current specific health-economic conditions of the Chinese health care system concerning genetic cancer counseling services also play a role. Chinese hospitals currently rely on patient OOP, in which each individual patient arrives, pays for a service and receives a number. Coupled with an increased economic pressure on hospitals in which professionals are expected to deliver faster services, this means that

more patients are present in examination rooms at the outpatient clinics, and that professionals are expected to explicitly focus on meeting the specified quotas of patients to be seen per day.
When approached from a practical perspective, this chapter illustrates how such economic conditions cause payment practices to become part of a trajectory of genetic counseling operating through several human and non-human actors in practice. These conditions introduce a strict allocated time frame for each patient and a strict individual focus in clinical practices. The economic conditions also call upon professionals to develop strict time- and direction-controlling strategies to ensure that individual timeframes and modes of focus are kept to equally benefit all patients and hospital budgets. For the practices of genetic counseling, the analysis demonstrates, how payment measures mean that only information strictly relevant to the genetic risk estimate of the individual is pursued by professionals when providing genetic services at the outpatient clinic. This is also the case when making estimations at the research laboratory. By basing services on the individual patient OOP system, not only are risk estimates strictly focused on the individual patient having paid, but so are the options for offered clinical preventive interventions at the end of the clinical trajectory in the outpatient clinic.

The chapter also demonstrates how professionals in China to a great extent rely on the information provided by the individual patients alone, due to the lack of accessible national registries and exchange of medical record information between hospitals. Patients become the primary source of information when genetic counseling practices are conducted in outpatient clinics. The current data condition in China also means that genetic risk estimates are produced in laboratories and compared only with data in international cancer genetic databases. Here professionals only obtain information about the pathogenic status of individual mutations. Being unable to trace mutations within families through means of cross-references, day-to-day practices of risk estimation at laboratories make professionals focus strictly upon the individual patients arriving for testing. However, changes are on the way. The Chinese state, is currently taking initiatives towards building up broader genetic registries, which can potentially change current practices.

Chapter 7

Genetic counseling for cancer in Denmark

This chapter presents an analysis of practices for genetic counseling for cancer in Denmark. Just as the preceding chapter, this chapter will demonstrate how specific organizational conditions currently found in the Danish health care system determine how the day-to-day practices of genetic counseling for cancer may unfold. It also shows how specific modes of clinical genetic reasoning emerge as a result of this.

This chapter will, as Chapter 5, focus on analyzing conditions related to:

- Guidelines for cancer genetic counseling in Denmark
- Availability and use of health care data in the Danish health care system
- Financial governance of health care at Danish hospitals

The chapter ends with a conclusion, summarizing the major findings of the analysis.

Guidelines for genetic cancer counseling in Denmark

Denmark has a long history of working with programs related to genetic material, though mainly in relation to issues of fertility. Just as in other European countries in the early 20th century, Danish research and clinical services concerning issues of heredity and genetic material had a salient eugenic focus (See e.g. Danish sociologist Theodor Geiger's works (1935)). Danish genetic researchers put great emphasis on developing programs ensuring a high quality of the population, as a way to protect a fairly new but already blossoming welfare state(Koch, 2000; Koch, 2010). This led to government-funded programs for forced sterilization to protect the state from the perils of faulty genetic material being passed on. These clinical genetic programs were not officially banned until 1967. Following the focus on autonomous rights of individuals meant that clinical professionals within this field gradually developed guidelines for clinical services such as prenatal genetic diagnostics. The tradition where guidelines are developed by clinical professionals is considered pertinent in Denmark (Koch, 2000; Lou et al., 2017). The field of clinical genetics concerning prenatal genetic diagnostics has been given long and salient attention by the Danish state, which means that practical state-approved guidelines now exist (Lou et al., 2017). The field of genetic counseling related to hereditary cancer, however, has had a much shorter and inconspicuous life. Only gradually genetic counseling was taken up as a service by professionals during the 1990s and in the first many years, genetic counseling for cancer was seen as an academic sub-discipline

and not a clinical field. With an increase in people seeking out knowledge about genetics and cancer due to new technological measures developed in the 1990s, and the acceptance of clinical genetics as an official clinical profession in 1996 (Hodgeson et al., 1999), this situation was gradually changed. Since then professional guidelines containing recommendations related to genetic counseling pertaining to cancer have been undergoing a gradual development (see. e.g. (Koch & Svendsen, 2005)). Currently, guidelines containing recommendations for genetic counseling, and more specifically services related to hereditary cancer in Denmark, have been gradually developed. First clinical genetic professionals and oncologists collaborating in small cross-national groups developed recommendations, and later guidelines were further developed by professionals working together with specific clinical medical societies. General practical guidelines for genetic counseling in Denmark have e.g. been developed within the Danish Society for Clinical Genetics by clinical genetic professionals from the departments around Denmark (DSMG, 2009). Recommended guidelines for providing genetic counseling to patients who are suspected to have a predisposition to genetic risk of breast and/or ovarian cancer as well as recommendations for preventive measures have been developed by genetic professionals (some of which represent DCG) in collaboration with other medical specialties in The Danish Breast Cancer Cooperative (DBCG, 2014)[35]).

Current guidelines on and recommendations for genetic counseling in general and genetic counseling related to breast and ovarian cancer in particular, should not be seen as the development of a tight set of rules. Rather, according to professionals, current guidelines and recommendations should be seen as attempts to establish a kind of consensus among those working with patients with a suspected genetic predisposition to disease. This consensus ensures that patients are offered similar services across Denmark. Despite such goals, local interpretations and slight local variations are still found among those providing genetic services.

Practical guidelines and recommendations

Current practical guidelines developed by genetic professionals in the DSMG state that clinical genetics differ from other medical specialties in that:

- The patient is often a healthy person, and can have any age
- Genetic diseases are considered to be a family issue and not an individual one.

Genetic counseling in Denmark is considered a process in which a patient is helped to understand and adapt to medical, physiological, and family-related implications of genetic predispositions to disease (DSMG, 2009).

[35] A later version of this guideline has been released, but that was prior to the period where I did my fieldwork

Referrals for genetic counseling may be obtained from either the GP or another medical department. Genetic counseling involves collecting information and verifying diagnosis concerning the individual and, if needed, family members. It involves drawing a pedigree and clinical and para-clinical tests including genetic screening. These activities are then used to estimate genetic risks. Conclusions are delivered during a final session, and here options for further risk management strategies are discussed. This marks the immediate end of a trajectory. From here follow-up is made by professionals to ensure that patients and their families are referred to other departments where preventive services are offered and carried out (DMSG 2009).

To professionals, a trajectory of genetic counseling thus specifically involves risk estimation practices and communication with patients and their families.

Estimation of risks pertaining to hereditary cancer is based on information found within the family history or pedigree. Among professionals in Denmark, it is generally agreed in guidelines that the information provided by patients about family members is verified. Professionals agree that this verification may be achieved by collecting information about disease onsets within families from patients and family members. Information may be collected from medical records, death certificates, and other forms of data in national clinical databases and archives. A risk estimate is established using the pedigree. Risks may be estimated either by using specified computer programs or designated risk estimation systems. Initial risk estimates are then used to guide further interventions. Such interventions may involve referral to preventive follow-up programs, or molecular genetic tests depending on indications.

In guidelines, genetic counseling involves communication about the pedigree, information about risks and relevant genes predisposing to risks, inheritance patterns, risk of recurrence, molecular genetic diagnostics, clinical control measures and preventive risk-reducing surgery. Furthermore, it involves communication about participation in genetic registries, social, judicial and insurance issues, and information about relevant patient organizations. Genetic professionals in Denmark agree that such information is to be delivered to patients and their families, as genetic counseling is considered to be a concern for families and not only individuals (DBCG, 2014). This is considered central to the field of clinical genetics. However, professionals may openly state that genetic practices and recommendations concerning prevention may occasionally become subject to local interpretation. This gives rise to variation around genetic clinics in Denmark. Yet, seeing genetics as something pertaining to families is considered indisputable among professionals at the DCG and

their colleagues at other clinics[36] in relation to genetic counseling services.

Family risks and family preventive categories

To genetic professionals at DCG, genetic conditions are considered family conditions. When estimating genetic risks, the aim is to identify the risk among members of a family. Based on risk estimations using a pedigree, and sometimes mutational screenings, families are placed within nationally agreed risk categories (see (DBCG, 2014). Specific recommendations for preventive interventions are correlated with these categories. In Denmark it is agreed that risk estimates, risk categories, and preventive interventions are aimed towards families and not only individuals (Appendix 1). During my period of fieldwork, the following primary risk categories and recommendations for prevention were used:

No increased risk means that family risks are estimated to correlate with the general population and therefore no special recommended prevention be offered.

Moderate risk of breast cancer means that the lifetime risk of developing cancer has been estimated to be between 20-30%. For the primary woman below the age of 50 years and having sought out genetic counseling this means that it is recommended that she be offered yearly clinical mammography screening from the age of 40. This should also apply to women in the family who are affected and for women in the family who are unaffected and first-degree relatives of the affected person.

High risk of breast cancer and *high risk of breast and ovarian cancer* means that the lifetime risk of breast cancer has been estimated to be >30% and for the latter category it means an additional lifetime risk of ovarian cancer >10%. For families in these categories, yearly mammography screening should is recommended from the age of 30. For women suspected to carry a dominant hereditary predisposition to ovarian cancer, annual vaginal ultrasound screening from the age of 30 should be offered. Women with a dominant hereditary predisposition to ovarian cancer may be recommended to undergo an oophorectomy. Though generally not recommended, prophylactic mastectomy may be performed in women with a >30% lifetime risk of breast cancer.

Such recommendations apply to women in the family who are affected, unaffected first-degree relatives of an affected person, or unaffected second-degree relatives of an affected person via a man.

Families are placed in the category *HBOC, +mutation* if a mutation is found. For families placed in this category, yearly mammography is recommended to women from the age of 30. Women with a

[36] This I found explicitly debated during meetings in DSMG that I participated in during my period of fieldwork.

dominant hereditary predisposition to ovarian cancer may chose annual vaginal ultrasound screening from the age of 30. They are also recommended to be given the choice of undergoing oophorectomy and mastectomy. These recommendations apply to women in families, which are affected, women that carry the pathogenic mutation, women who are unaffected first-degree relatives of an affected or to a carrier of the pathogenic mutation, and women that are unaffected second-degree relatives of an affected or of a carrier of the pathogenic mutation via a man (DBCG, 2014).

Family risks, individual rights

Though genetic counseling services aimed at estimating possible genetic predispositions in Denmark are broadly acknowledged as a family condition, these practices are considered differently legally speaking. Having to abide by national health laws when working in the Danish health care system, professionals need to pay close attention to the rights of individuals within such families. When providing genetic counseling, professionals need to follow national health laws stating that all participation in health services depends on the wishes of patients, who are considered autonomous, free individuals(Danish Health Law Chapter 5 §15, 2014). As specified in the Danish Health Law (Danish Health Law Chapter 5 §16, stk 2, 2014), professionals are not allowed to force information upon someone who has not explicitly requested it. They should both respect patients` wishes for *non-knowledge* as well as for *knowledge.* When working with patients, health professionals in Denmark are only by law allowed to obtain information from medical records in databases and archives concerning the individual patient they are treating and only if it is necessary in connection with their further treatment ((Danish Health Law Chapter 9 §42a, 2014)see also (DBCG, 2014) and (DSMG, 2009)). When obtaining health information from sources such as centralized medical record databases and archives, professionals need to obtain consent from the patient in question (see also (Danish Health Law Chapter 5 §15, 2014). Informed consent may be given either orally or in writing as specified in the Danish Health Law (Danish Health Law Chapter 5 §16, stk 2, 2014). These laws apply both when accumulating data for making a pedigree, which is used in the risk estimation process and when subsequently providing knowledge about risks of cancer and offers for prevention (see (Koch & Svendsen, 2005)).

Though explicitly understood as a clinical practice working with families, current Danish laws therefore prescribe that genetic professionals also are to conducts this work as practices orientated towards the protection of individuals. Having broadly agreed in Denmark that genetic counseling

practices entails using pedigrees as investigative tools and occasional genetic testing to estimate genetic risks of cancer, treating genetic risks and modes of prevention pertaining to families, such agreements open up to specific kinds of human and non-human actors determining clinical practices, modes of clinical reasoning, and also salient dilemmas. This happens when such agreed upon practices of genetic counseling become related to the very specific existence of accessible health care data, the legally regulated organization of health care data and the financial governance of the Danish health care system.

Availability and use of health care data in the Danish health care system

Denmark has a tradition of collecting and storing population data. During the period of absolute monarchy, the church was responsible for registering information about birth, death, marriage, and baptism for the inhabitants of their parish (Rudiger, 2003). During the 1920s, however, an increasing dependency on public taxation meant that the Danish state established the new municipal registries. These not only contained the standard information already found in the parish system, but importantly also information about tax payments and employment status. This made it possible for the central government to closely monitor its tax budget (Ibid). From the 1930s and onwards, Denmark's gradual transition into a welfare state with access to health care, insurance and pension for the majority of Danes, caused a greater dependency on public taxation and thus more emphasis was put on ensuring registrations in municipal registries. This development also precipitated an expansion in the type of information collected. Following the establishment of the welfare state, the need rose for the state to constantly monitor the health and social status of its population (Koch, 2010). Municipalities increasingly collected health information as well as information regarding social status (Nielsen, 1991). As municipalities were increasingly obligated to offers an ever-expanding array of public services, the placement of Danish registries at the local municipal level became a problem, and steps were taken to establish a central register accessible by using the unique civil registration number assigned to all Danish citizens (Ibid); the civil registration number was implemented in Denmark in 1968 (Rudiger, 2003). The civil registration number is used as a broad identification number to access to a wide range of welfare information stored in public as well as private databases/archives and registries. This data includes insurance, income, tax, social affairs, and health issues just to name a few. The civil registration number is a 10-digit number. The first six digits refer to date and year of birth, and the last four are unique digits assigned to each

Danish citizen. The last two digits indicate gender; even numbers for women and odd numbers for men (Nielsen, 1991).

With the implementation of the civil registration system, access to specific forms of social and health care information was established and it made it easier to retrieve data for public authorities and professionals. The development of the civil registration number resulting from pressure on municipal registries, also had implications for other registries in Denmark. Denmark has a long tradition of storing not only patient health information and death certificates, but also tissue samples[37] within databases and archives. Just as with the implementation of the civil registration number, this tradition has been closely linked to the transition of the Danish state into a welfare state and its need to monitor the health of its population (Koch, 2010). Though some health information is registered at the municipal level, most health care and medical records are kept locally at Danish hospitals and at GPs. It was decided that more information should be identifiable by use of the civil registration number, such as information in medical records, death certificates, and information about stored tissue samples (Nielsen, 1991).

Though being locally stored, medical records and death certificates ect. are organized as parts of the state-centralized health care sector. This means that each hospital has the possibility to order a health record to be delivered from a different hospital. In recent years, new IT solutions have been implemented and medical records are becoming digitalized. This means that an increasing amount of patient information is being placed within systems such as EPR (electronic patient record). EPR acts as a central archive in which patient records from hospitals and GPs may be accessed online by professionals. These systems, albeit still in a phase of implementation (currently different systems are used across Denmark), have precipitated an increase in the speed at which information about patient referrals, diagnostics, and test results are made accessible to professionals within the healthcare system (Groth, 2015).

To access information in medical records, the civil registration number currently function as one vital key, albeit among a series of others. Civil registration numbers are normally used either when professionals sit at their computers looking up information within medical records or as an identification number when ordering medical records physically from other local hospitals by phone. Lacking a civil registration number makes acquisition of information, if not impossible, then substantially harder. However, health information may be assessed through other means. Having

[37] (e.g. tissue having been removed from tumors following surgery)

access to the name of the patient, the name of a hospital and the date of the hospital admission, medical records may also be obtained from these databases and physical archives.

Data in genetic counseling: Verified or Unverified

When providing genetic counseling in Denmark, the existence of and the possibility to access health care data in medical records means that professionals come to rely on these data rather than simply the words of patients.

As seen already in Chapter 2 in the case of Ulla, and as officially stipulated in the general guidelines on genetic counseling in Denmark, the goal is to establish whether there is a possible indication of a genetic predisposition. This indication is established by assessing the family history and drawing a pedigree. During the opening of a genetic counseling trajectory, where a family history showing possible indications of a genetic predisposition are pursued initially, professionals rely on several sources of information: 1. The patient(s) having arrived, 2. Data in medical records.

The possibility of obtaining additional information in Danish health record databases and archives means that the information provided by the patient and the data sources, respectively are not weighted equally by professionals at the opening meeting.

Dialogue information and medical record information as sources of data

When assessing a family history and drawing a pedigree during the opening meeting, the primary information for professionals is achieved through dialogue with the patient. Certain characteristics in a family history may reveal whether any kinds of genetic mutations are likely to be present. Indications of a genetic predisposition to cancer may be shown through characteristic cancer onsets (such as multiple early age onsets of cancer or special types of cancer, as well as intergenerational cancer onsets).

Although information about cancer onsets within families delivered by patients during the opening meeting may help professionals to establish possible links, such information is not taken at face value by professionals in practice; this was already seen in the opening case of Ulla in Chapter 2. Patients may know of cancer onsets within their families, but to professionals this information may have become misconstrued: A professional states:

P5: Many times people have heard about things in the family. However, often they may have heard it wrong. I mean many times it (the cancer onset) happened ages ago.

Another professional adds that such misconstrual of information is a natural part of the work in genetic counseling:

P3: Things (misconstrued family information) like these happen, people have heard something in the family.

Professionals meet information from dialogues with the patient during the opening meeting with a sense of caution. Though the information may reveal hints about possible indications to a genetic predisposition, this information cannot stand alone. The existence of medical record data and other data in national databases and archives accessible by use of civil registration numbers supplement the information provided by patients.

To genetic professionals in Denmark, the availability of accessible health information means that data about the family history in the drawn pedigree can be divided into two specific categories: *unverified and verified* information. Unverified information is marked with an "F" in the pedigree next to the recorded information. Information in a pedigree may be moved from one category to another through the practice of verification.

To professionals verification involves verifying information about disease onsets provided by patients about themselves and their family members in medical records. In this way a *verified pedigree is produced.*

The fact that it is possible for professionals to distinguish between unverified and verified information (and thus the production of a verified pedigree), accessible medical record information exerts a salient influence on risk estimation practices in Denmark. According to my analysis, this dichotomy makes it possible to produce a pedigree that can show a *proper* rather than a *thin indication*, which is meaningful to professionals.

Verification as clinical practices of doing good, harm, and properly

Verification of a pedigree among professionals at DCG is not considered as a luxurious extra during genetic risk estimation. To professionals, verification carves out boundaries between possible indications of genetic predisposition to disease to be understood as "proper" or "thin".

In interviews with professionals, the pursuit of "properness*"* when establishing indications and the avoidance of "thinness" are considered to be fundamentals of moral imperatives in the professional genetic trade. This is identified among professionals as aiming to *do good* and subsequently prevent that one *does harm. Doing harm (*or *doing bad things)* and *doing good* are modes of speech frequently heard at DCG. As a professional said to me during an interview:

P2: We are probably very Florence Nightingale here. We want to help these people. Fundamentally we want to do good. I don't think we are any different than other doctors. Genetics is a complex science, but what we do is to apply it in a practical world where there are people. People whom can have their lives changed by our use of genetics.

This idea of wanting to do good while acknowledging the impact that genetics may have upon patients' lives is shared broadly among professionals at DCG. As a professional states:
P14: *I mean it's fantastic -we can help these people, that's what's in it I think. To help them, to do good.*

My analysis showed that for professionals at DCG, the idea of *doing good* is closely tied to ideas of providing a *proper* knowledge of risks. *Doing good* is broadly seen as providing patients and families with information they can use to make decision about how to live their lives. As a professional states:
P14: I don´t want to choose for them. In fact I think it is important that I don't choose for them. I hope I can lift them, so they can make their choices on a qualified background (…) A qualified choice is an informed choice. What I can do is to inform them properly to the best of my ability. Then it is up to them to decide what is good for them.

When discussing how to *do good* for patients, reflections on the opposite - *doing harm* to patients *automatically* follow. While *doing good* is tied to the provision of "proper knowledge", allowing qualified choices to be made, *doing bad* reflects the opposite.
Prof 1: Doing harm, I mean when it's not ok, when you haven´t done it properly. Either because you have made bad interpretations or have interpreted something unnecessarily, meaning that this is something people use to change their lives.
Such potential harmful doings are, however, seen as preventable through means of proper work by seeking out data and verifying it:
P5: When you make an elucidation, you try to do it as properly and thoroughly as possible. You try to find as much data you can because that is what changes these risks. In that way you don't do harm!
Doing harm can be many things; they are however all closely tied to the physical day-to-day practices of risk estimation at clinics such as DCG in Denmark.

Doing good or harm during practices of risk estimation

Across Denmark, patients seeking out genetic counseling services are provided with a risk estimate. At DCG, as at other departments, risk estimates are produced through a series of practices involving specially designed genetic cancer risk calculation programs[38] (Boadicea) or specialized risk tables. Professionals use these tools to produce what is seen as an initial risk estimate. These risk estimates are then part of a special oncogenetic conference where they are assessed together with other professionals.

Boadicea is a program used at Danish departments of clinical genetics. It is a computer program used to calculate the lifetime risks of breast cancer for women based on their family history. It is also used to calculate the probability of being a carrier of cancer-associated mutations in the BRCA1 or BRCA2 genes by entering information about cancer incidents in families (type and age of onset) into the program. To avoid "underestimating risk", Boadicea officially recommends entering as precise information as possible. Entering data into the program provides the professional with a lifetime risk estimate that will help to define the risk categorization for the entire family. This number will then help to divide families into the clinically agreed risk categories, by correlating the statistical output of Boadicea with the stipulated risk categories in guidelines. Families found to have a 20-30% lifetime risk of developing breast cancer are placed in the *Moderate risk of breast cancer category*, and families found to have >30% risk of developing breast cancer are placed in the *High risk of breast cancer*[39] *category*.

Entering precise information is acknowledged as vital among professionals working with Boadicea:

P5: These estimates are never better than the information, we put into them. When we start to have unclear information from the families, we might get a number, but what does that really tell us? That´s why we have to be very diligent (and get information verified) when we make the family anamnesis, (…) It´s not only about the one who has been sick, it´s about the healthy ones as well. Family members who haven´t been sick, can pull the risk estimate in a different direction.

Another professional underlined:

P7: *If we enter unclear data, Boadicea gives us unclear numbers back.*

[38] This is generally the case. A few professionals, however, relied on other systems estimating probability of disease onsets.

[39] Boadicea does not assess risks of ovarian cancer. This is done through use of the pedigree

To professionals the distinction between verified and unverified information based on their current access to data means that the risk estimation results produced by Boadicea may follow a similar line: Using verified information means a more precise risk estimate as opposed to the imprecision offered by using unverified information.

To professionals, the practical different consequences of working with imprecise information placed on either side of this distinction takes a very physical form and practically draws a line between potentially *doing good* or potentially *doing harm*.

When producing a partial risk estimate, which will be further assessed at conferences, Boadicea helps to provide professionals with a number allowing them to tentatively place families in the risk categories. This leads to very different offers for prevention for a very different arrangement of actors.

Imprecise information such as entering the wrong age of a person or wrongly enter data on a cancerous person who in fact is healthy may misconstrue the risk estimate. Misconceptions may mean that families are placed in the wrong categories. Such situations are openly discussed during assessments at conferences, when risk estimates may be drawn in different categorical directions.

Case Marian

A professional places a pedigree in front of us and explains that she has talked to a middle-aged woman. She continues to explain that this woman`s family has already received genetic counseling at two other hospitals albeit separated by a period of time. She continues to explain as she points to the pedigree:

P7: Here is the thing. I have entered the information we have and…, but depending on what we include, Boadicea says between 27 and 34.

P8: That's just on either side of a moderate risk and high risk.

The professional presenting the case shows the extent of the information collected up until this moment. Some information has been verified and some still hasn't. The debate continues as the placement between these two categories results in different options on who should be offered control programs as well as the extent of the control program.

P8: I think, more information would make a big difference here. Have you tried over here (pointing at some circles on the pedigree which still say "F", and an area where nothing seems to be recorded at all)?

P2: This is why it`s so important that we do this properly. We have to help Marian (the patient who has been at the clinic). But it´s not just about one person, but her relatives as well. (The professional looks around and the other professionals nod in her direction).

The professional agrees that more work should be made turning unverified into verified information. She puts the papers back in the folder.

When Danish professionals, as in Marian's case, estimate risks and subsequently place patients in risk categories resulting in recommendations for modes of prevention, the boundary between using verified and unverified information marks a definitive line. Distinguishing between categories of *moderate-* and *high risk,* Marian and other members of her family effectively hover between being recommended screening controls from the age of 30 or from the age of 40 years. If placed in *high risk,* mastectomy and particularly oophorectomy also become options to be considered. Moving from moderate to high risk also means that more members of the family are to be offered such prevention trajectories (Appendix 1).

The possibility of verifying information during risk estimation infers a sense of personal responsibility among professionals to do so in the light of the dramatic and irreversible consequences that the alternatives may produce when estimating risks. A professional states:
P2: You can't really put someone's ovaries back up, once they have been removed. When they are out, that's it. Done is done, but then what if you want to have children? This is serious business.
Another professional underlines:
P1: You don't want to act on a thin indication, because it can really have some bad consequences. Cutting of parts is no task to be taken lightly.
Making mistakes based on *unverified information* that leads to a *thin indication* is thus recognized as a very real threat by professionals[40].
In some trajectories, risk estimates are not established using statistical programs alone but also through screening of genes. The current Danish practice of genetic screening of genes further underlines the need for rigorous pursuit of verified information.

Verified information and genetic screenings – family mutations
At DCG (as seen current in guidelines as well), screening of genes should preferably be done in patients who had been affected by disease. Screening of a healthy patient would yield a genetic result, though. Yet, my analysis finds that to professionals in Denmark, simply screening a healthy index person poses two salient problems. First, since genetic screenings are not viewed as completely accurate, actually finding a mutation is seen to be a task marred by technical problems.

[40] One professional recalled: She told me how she had originally screened a women in her 40s and found a *BRCA* mutation. This woman chose to have her ovaries and breasts removed but later a new test revealed that the mutation wasn't there.

Here verified information is considered to provide guidance when choosing where to conduct a genetic screening. A professional states:
P7: If we screen we want to do it, where the chance of finding something is the highest, rather than just doing it arbitrarily. That is a waste. We need to go by indications in the pedigree.

Secondly, however, more than issues of accuracy are at play. To professionals, simply screening whoever walks through the door also misses what is perceived as the objective of their practice: to answer the question: Does this family have a genetic risk?
A professional elaborates:
P9: Let´s say, I screen you, and you haven´t been sick, and I don´t find anything.
M: Well then I´m off (smiling)
P9: Hmm no, because, I have only looked for one thing, it could be something else, and if I don´t find it- something could still be in your family (…) That's why we screen a sick person, because that means, that if we find a mutation, it is probably that mutation causing the disease, and then we can use that result to see if the other patient has inherited that mutation. If I just screen you as a healthy person, I wouldn´t know if that mutation was the one causing the problems in your family. That´s why, we use the pedigree to help us decide, where to screen.

To professionals at DCG, using verified information is a vital component in screening practices similar to using pedigrees to estimate risks. However, regardless of using programs and conferences, or genetic screening to estimating risk, the current Danish legal regulation of public database information infers specific demands to the perceived necessary verification practices of professionals.

Risk estimates and preventive trajectories as social products
Though medical record information, and civil registration numbers may provide the basis for verification practices, the accessibility and use is subject to tight legal regulations stipulating:

- Patient autonomy (Danish Health Law Chapter 5 §15, 2014)
- Access and use of data from patients, including demands for oral or written consent ((Danish Health Law Chapter 5 §15, 2014; Danish Health Law Chapter 9 §42a, 2014).
- Respect for individual wishes for *knowledge* as well as *non-knowledge* (Danish Health Law Chapter 5 §16, stk 2, 2014)

Producing genetic risk estimates as an encouraged social practice

To professionals, such legal regulation of health services and use of health record information mean that the practices of verification come to rest on a set of interdependent responsibilities. According to Danish law, retrieval of information is only allowed concerning patients currently undergoing treatment or who are part of a diagnostic process. Professionals are well aware of the legal boundaries surrounding their current genetic counseling practices and more specifically those pertaining to verification. A professional states:

P2: Legally, these family members are not my patients, because we are looking at risks here.

To counter a violation of Danish law and the rights of individuals, Danish professionals here instigate a specific practical strategy allowing them to work around such legal constraints. This involves obtaining informed consent from such family members. Yet, when obtaining informed consent from the patient's family members to legally access their medical records, professionals in Denmark are faced with another legal constraint. According to Danish law, professionals are to respect an individual's rights to "non-knowledge". To professionals this means that they are prohibited from simply contacting these family members to obtain the needed consent. Such legal issues are well recognized as a part of the practices of Danish professionals and it does require them to apply circumventing strategies in practice. As one of the senior professionals made it clear to me:

P1: *We have to respect the individual`s right to non-knowledge. I mean we don´t know, if they all want to know (…) your sister´s and your mother`s disease can be essential for you, as opposed to the information you can bring by yourself (…) that's why we need the patients to go out and talk to them.*

In order for them both to respect individual wishes for non-knowledge and still keep the possibility for further verification measures open, professionals actively apply an adaptive strategy. This strategy entails explicitly encouraging patients to seek out relatives to obtain the needed informed consent, making verification of information comply with legal practice. This also applies when genetic screenings of family relatives are to be conducted.

Although putting pressure on patients to collaborate is generally frowned upon as a violation of individual rights, discussions with professionals nevertheless reveal that patients are expected to exhibit moral willingness to collaborate as parts of a genetic counseling trajectory.

If not for concern of themselves then out of concern to their family. A professional states:

P3: I acknowledge that it is tough (contacting families), and that sometimes you can't get what you want. But, they also need to try. We do it for them. The least they can do is to try their best as well. It's not only about them (the patients) you know.

Another professional underlines:
P14: It requires something and not from just us. They need to put an effort into it. They are not doing it for us you know.

To professionals, laws concerning available data, risk categories and agreed upon recommended offers for prevention in Denmark have certain consequences. It means that practices of verification and risk estimation aimed at *doing good* preventing *harm* to a great extent rest on the salient successful collaboration of patients and their relatives throughout the entire proces of genetic counseling.

Offering a risk estimate and prevention as an encouraged social practice
As openly agreed upon in Denmark, risk categories pertain to families. They do not only decide what kind of preventive efforts should be offered, but also to whom (see appendix 1). As risks increase, the number of family members to be offered preventive control programs increases. To professionals, offering preventive measures to an increasing number of family members has certain implications. As these family members are not legally considered primary patients, professionals depend on consent if they are to offer them recommended preventive interventions. My analysis reveals that in some situations this may be more challenging. Some family members may have participated in the practices of verification or screening already, which means that lines of communication already exist between them and the primary patient.
However, professionals often encounter family members who have not been part of the risk estimation process, and now need to be informed about final risk estimates and preventive measures. When delivering the final risk estimate at the outpatient clinic at DCG, such situations are legally challenging to professionals who come to rely on patients taking on a specific responsibility. To ensure that unknowing family members are also informed, professionals come to rely on patients to ensure that information is disclosed. Sometimes asking patients to solicit news about risk estimates and preventive measures to yet unknowing family members is effortless and sometimes challenges arise:

Case Audrey
I find myself sitting together with a professional in counseling room 2 at the outpatient clinic at DCG. In front of us is Audrey, who is 46. The professional looks at Audrey and pulls out her file. The professional proceeds to tell Audrey that based on the information within her pedigree, she and her family is placed within the category of moderate risk, and that she and members of her family (her sister and niece) are to be offered preventive screening (mammography), and that Audrey will have to let them know. Yet, this raises certain dilemmas. Though her sister has been part of the process and is eager to know more, Audrey's niece has been kept blissfully unaware about the whole genetic trajectory, as the relationship between Audrey and her niece according to Audrey, is less sympathetic.
A: You see, I don´t really talk that much to my niece, we are hmm. I have less sympathy for her.
P7: The thing is, we need a referral, if we are to offer her a control. She needs to come here so we can talk to her and explain this to her. She needs to decide this for herself.
Audrey continues stating that she is very hesitant to contact her niece, as she really does not care much for her. The professional continues to tell her that she will need to talk to her, if she is to get controls as they as professionals are not allowed to contact her. The professional suggests that Audrey could consider going through her sister and Audrey agrees to this solution.

As family risks increase, the correlated risk categories effectively expand the number of people who are to be offered preventive interventions, thus exacerbating the potentially challenging issue facing professionals of how to provide this expanded group with information.

Case Hanna
Hanna is 31 years of age. After having been through the process of risk estimation, entailing mutational screening of her mother, Hanna has ended in the category of high risk of cancer. This means that attention by the professional is now turned towards the pedigree. The professional explains that when comparing the information about cancer in her family, and their knowledge of hereditary disease, it still looks like a mutation is present, but that they simply cannot identify it. This now means that Hannah and her family are to consider prevention for risks posed by what could be an unidentified mutation. Hannah is offered screenings but also prophylactic treatment, meaning the removal of ovaries. The professional explains that although taking such steps may seem harsh, she is to consider surgical measures as especially screening of ovaries has a lower success rate. Attention then shifts to Hanna's family. The preventive offers are now also offered to other members of her family, and this gives rise to concern for Hanna:

H: What about my mother´s brother´s daughters, should I contact them regarding control?
P12: I think that could be relevant.
H: Ok, I haven´t really talked to them about this.
P12: It can be difficult, because we are all different about this. It can be a bit tricky, if they don´t know about this, or if they don´t want to know about this.
The professional asks if someone else in the family can help her disclose the information, and to this Hannah somewhat reluctantly says that she will have to contact her mother.

To professionals at DCG, working within the field of genetic counseling entailing risk estimation and subsequent offers for prevention, is to work within a field of discrepancy where genetic science pulls them in one direction and Danish laws in another. To professionals such different demands are acknowledged as being fundamental to practicing genetic counseling in Denmark: A professional states:
P1: That's, what´s tough, because none of our systems or the law are focused on others but on individuals. So that gives us so many challenges as we see the patient also as a family.

Just as being a professional is acknowledged, as being trapped within clinical practice and law, so are the strategies that professionals turn to concerning the information of risk estimates and recommended preventive. Another professional states
P12: You see, we are caught between laws and genetics. That's why we have to go through the family, that's the only way we can go currently.

Though acknowledged as a challenging situation, to professionals the current situation means that they have no other option than to rely on a successful patient-to-family collaboration if risk estimates and recommended preventive efforts are to be disclosed.

When actual mutations are found, which accounts for a very small percentage of the trajectories I followed, situations change. To professionals, finding actual mutations effectively changes the role of the pedigree. Finding a mutation means that their verification work has been conducted proficiently and that their established indication now has become validated. It means that a final risk estimate now no longer rests on the individual and collective choices made by professionals during the practices of risk estimation, but that responsibility for the final risk estimate has been effectively deferred to the mutation found. A professional states*:*

It's a strange relief to find mutation. Don't get me wrong it would be better that we didn't find it at all, but it also shows that what we were doing was correct. What we saw in the pedigree was correct (P7).

Such feelings are echoed broadly among professionals. Another professional underlines:
"*It is just so much easier to debate an actual mutation rather than high risk. Don´t get me wrong, it would be better if they didn´t have any mutation, but in this situation finding a mutation, just makes it so much more concrete"* (*P10*).

Although finding a mutation may be a heartbreaking situation to the professionals, it means that the capabilities of the pedigree are changed. The pedigree is still seen as responsible for pointing out who should be asked to have a predictive test for that particular mutation. Finding a mutation may mean that new family members not yet having been made part of the elucidation process now also become included. But to professionals, their inclusion into the process is followed by the possibility that they may leave with the result of not having an increased risk. As, opposed to the categories of moderate and high risk, finding a mutation means that risks emerge as a physical entity. When a mutation is found it not only means that further prevention may be offered on more secure grounds, but also that when not finding it may result in a complete acquittal of risk. Professionals value such possibilities:
That means that we can also start acquitting other people at risks, rather than keeping them in risk categories"(Professional 5).

Until this point, the rigorous pursuit, utilization and dependence upon accessible health care data in Denmark demanding that patients and their families work together have been linked to professional practices aimed at doing good and preventing harm for the family. However, the current health financial governance of the Danish health care system, including the provision of genetic counseling, plays an equally important role in demanding professionals' collaboratively obtained data for genetic counseling trajectories.

Financial governance of the Danish health care system

Denmark has a long history of providing public welfare services including health services. Owing itself to the welfare politics of the 1930s, public health services have been offered free of charge to

Danish citizens (Olejaz et al., 2012). Payment for public services has been through means of public taxation. Since the 1940s, general political consensus in Denmark has deemed that equal access to health care services should be offered to the public regardless of demography and income (Vallgårda, 1999). Consensus among political parties has been changing since the 1980s, allowing oppositional viewpoints and critique to emerge of the welfare organization. Denmark still has a broad political consensus towards maintain that the state is responsible for delivering broad welfare services for all (Olejaz et al., 2012; Vallgårda, 2003). Healthcare services, including genetic counseling, as well as the prevention programs being offered, are free to all Danish citizens with a civil registration number. Funding of the health care system still relies upon general public taxation. Each year a certain amount of money from taxation is channeled into the healthcare system and at hospital level, money has to be divided among the different departments according to the services they provide (Olejaz et al., 2012).

Political awareness of the public health expenditure began to rise as early as the 1970s (Vallgårda, 1992), but throughout the 2000s, discussions as to how to make health care more efficient and cutting welfare funds to be better utilized have been a growing political and public discussion (Olejaz et al., 2012). Currently, the economy of the Danish health care sector is carefully monitored and programs towards achieving better cost-efficiency and quality are implemented (ibid).

Funding of the Danish healthcare system is regulated by the state, but administered by five Danish regions, which, among other areas, have the responsibility for hospital and specialist medical care. These regions are responsible for managing the healthcare sector in practice and they negotiate their budget on a yearly basis. Budgets have to be kept and any deficits will have to be solved at a local regional level through increased health care service production or through financial cuts, often resulting in lay-offs (Olejaz et al., 2012).

At DCG, risk estimation and actual testing are therefore paid for through the public welfare health system. From 2014 when I did my fieldwork at DCG, the normal practice of payment was two-fold. Entering a trajectory of genetic counseling, patients could either be referred from a GP or referred from another hospital department. If referred from a GP, any services offered to the patient would have to be paid for by the local budget at DCG. If a patient was referred from other hospital departments (e.g. a department of oncology), that particular department would have to pay for the services delivered at DCG. As most of the patients were referred from their GP, most, counseling and testing was covered by DCG's own budget. A genetic test or screening could be ordered as

needed, but the screening of either an individual gene or an entire panel of genes would amount to a price of approximately DKK 10,000[41].
Preventive measures offered at the end of a trajectory of genetic counseling are also paid for by the welfare state. When professionals from clinics refer patients or family members to a department to be screened, the delivery of that service will have to be covered by the budgets at the department, the patient is referred to.

Verifying information. Practices of preventing waste of Common money
To professionals at genetic clinics such as DCG, the economic governance of health care services gives rise to specific considerations regarding the day-to-day genetic counseling practices. In clinical meetings with patients, discussions of economy and payment for services are missing. This is in great contrast to practices conducted by professionals when patients are not around. Here discussions of money and payment are often very explicit by professionals.

When providing genetic counseling along the lines of agreed upon practices of risk estimation, risk categories and offers for recommended prevention, the current financial governance of the Danish health care system shows specific modes of welfare-economic reasoning. Here verification practices not only emerge as saliently necessary to be pursued by professionals to do clinically good and prevent harm; such tasks also become necessary as a strategy aimed at preventing *"waste of public money"* or *"waste of common money"*.
To professionals each trajectory of genetic counseling involves payment practices. At DCG, payment for services (such as testing and counseling) is registered physically using specific codes determining who is to pay from the common welfare budget of the health care system. My analysis finds that having a tax-financed welfare system including the health care system means that payment practices at DCG prompts a three-fold attention: 1. It calls for professionals to explicitly deliberate who is to pay for the services, 2. When doing so, it prompts professionals to consider how much of the local budget at DCG that each new individual patient trajectory may spend, and finally 3. It further prompts professionals to consider how much each individual trajectory may come to draw upon the budgets of other departments and the health care system as such.

To professionals such three-fold considerations lead to frequent day-to-day discussions on how to spend money in the best way in genetic risk counseling. The possibility for verifying information

[41]These were rough numbers I received from the professionals

using the current system of accessible medical records databases in Denmark offers a concrete instrument to regulate the cost-efficiency of the services. To professionals verifying information in pedigrees may help to ensure that common budgets are put under less strain. They allow professionals to decide if screening is to become a viable intervention option at all. They also help to open up a possibility to distinguish between who is or is not a potential screening subject and what kind of genes should be made objects of investigation.

Case Inga
A professional is in the middle of assessing a family pedigree o provide a risk estimate. Inga, as the patient in question is called, has experienced incidents of breast cancer in her family. While assessing her pedigree, it has, however, revealed that her family has also had several onsets of colon cancer. The professional now stands with a pedigree showing signs of both a possible *BRCA* mutation, but also what could be signs of *HNPCC (Hereditary Nonpolyposis Colorectal Cancer).* She seeks out advice from a senior professional:
P4: Hmmm this over here might look like HNPCC, but over here (pointing at the pedigree) it looks like BRCA. But we can´t really put them into two high-risk programs. If you ask one of the other professionals, she will probably say run all 6 genes.
P3: But that costs a lot of money, on the other hand it is also expensive to put her through many years of controls. Hmmm.
P4: It is your decision, where to go from here, but I find it hard to estimate with all these F´s in here (points at the pedigree). I would wait just a little longer, and see if new and better information comes in.
The professional puts the pedigree back into the file, and writes a note reminding her to contact the patient to make her obtain more information from her relatives.

Running a series of six genes targeting both genes related to *HNPCC* and *BRCA,* can be done in practice. Yet, to professionals, verification of information symbolically represented in the pedigree by the letter "F" (unverified information) opens up possible and potentially cost-efficient alternatives. Using verification makes it possible to exercise economic prudence. Verification allows professionals to manage and hold back costly screenings if not necessary. Such possibilities fuels feelings of responsibility. A professional says during an interview:
P1: We are in a situation where we are poor. The money we have, we shouldn't waste them. We should spend them on the right things at the right time.

Another professional underlines:
P14: I think about money, not as a completely decisive matter. But it is always hard (…) Should we really blow all this money on a panel? (…) We have many patients here, you know.

To professionals, verifying information is more than achieving cost efficiency in their local genetic risk estimation practices while protecting the budgets at DCG. Verifying information also opens up for the protection of the greater social *good* of the health care system. A system that most professionals interviewed stressed that they felt as a part of and responsible towards. In the current financial organization of Danish health care there is a social relationship in which the economic impact of genetic practices by far supersedes the budgets of local departments.

When patients leave with a risk estimate, current guidelines recommend a selection of possible preventive measures. As already established, some preventive measures include participating in years of screening of breasts and ovaries (and in more severe cases the removal of both). Such preventive measures are all paid for as a part of the Danish welfare system. This means that the economic impact of placing a family such as Inga's within a risk category is substantial. Each risk category opens up for specific preventive interventions. If her family were placed in the wrong category, these interventions would be unnecessary and could potentially drain the funds at the other department.
Such drainage of funds at other departments is not taken lightly among professionals at DCG. Verifying information through medical record information is seen by professionals as a help to manage and protect the resources of other departments to which they feel a social obligation. A professional states:
P1: We could just do what we want, but then again that wouldn't be fair now. If we just put a lot of people into prevention programs for example, we are not only subjecting them to potential harmful radiation, we also put a financial pressure on the system of our colleagues, who need to deal with this.

In the analysis, verifying information to prevent waste of resources not only emerges as a mandatory task due to the immediate impact it may have upon the local hospital. To professionals preventing waste of common money also speaks to feelings of having to live up to one's responsibility as a professional working within a larger frame of a social welfare system. Doing

work properly not only prevents budget deficits of the local hospital, but it also helps prevent a negative impact on the health care system and the system as a whole. As uttered in a discussion among professionals during a meeting:
"*The money we use here comes from our common piggy bank*[42]*. I think we owe it to society to look after our common money'(prof 2 during meeting with prof 1 and prof 9)*

Another professional underlines:
P1: We can't really sit here and play with money, because it's our common money. When we do stuff here, it draws money from other places in society. We have a responsibility as professionals towards our patients and our common society.

In the light of such feelings of responsibility towards the funding of departments, hospitals and society as a whole, professionals show great willingness to pursue verification of information to ensure that their genetic practices are carried out in the most cost-efficient way.

Collaborative interdependence to prevent waste of social welfare funds
Faced by what professionals see as strong incentives towards protecting the monetary status of all (local department, the hospital, the health care system and state as a whole), verifying information as a part of the risk estimation process is considered vital. Faced by the Danish laws prohibiting professionals contacting relatives by themselves means, however, that in order to exercise economic prudence, professionals also here come to rely on the successful collaboration with patients, and the successful collaboration between patients and their families.
To professionals, this means that such collaborations are filled with ideas about how one is to act in a moral and economically responsible way.
Though no patient or family is totally denied services based on their willingness to collaborate, professionals still see active collaboration efforts from patients and their families as something to be rewarded. Lack of efforts to collaborate are seen as signs of neglect to the common whole, and thereby as something to be disciplined.

[42]"Fælleskassen"

Case Mette
We are seated around the table at the oncogenetic conference. The professionals turn to a case where a young woman has been referred. She herself has had cancer, but information from the family, particularly from her sister, is still missing.
P1 :I mean it doesn´t make sense to start screening for something here, after all it costs 10,000. She could call her sister, that doesn't cost much (looks around, everybody nods). I mean we are in doubt here, about what her sister has.
P12: They also have to show something (make an effort) themselves.
P13:If she doesn´t show something then there is no control for her.
They agree that Mette must be contacted again and made aware that they rely on more information.

To professionals at DCG, being part of a social welfare financial governance means that each trajectory in the day-to-day practice is seen a part of a whole. To professionals the salient relationship of: 1. Agreed upon guidelines containing risk categories and correlated modes of prevention, 2. The welfare system and 3. The possibility for retrieving medical record information through accessible public databases means that patients are given part of the responsibility for the success of genetic counseling, and for the success of society as a whole. A professional states:
P12: *"You know Morten, I often get irritated, when patients say this is free! No it is not. Our common money pays for this service and that has to come from somewhere. We only have this much, and why waste it! I mean, we could take it from some other patient who may need it more (…) The common money would be better spent wiping old people's arses rather than just screening".*

Another professional states:
P5: You know, I don't think we are being unreasonable here. We have the opportunity to check this information and save a lot of money. All we need is for them to play along the best they can.

Among the professionals I interviewed, it was stressed that by being faced with the constraints of a welfare financially governed health care system, moral stakes are raised for professionals, patients and their families. Being offered the opportunity to use data from databases/archives for verification purposes to save money not only means that such possibilities could be sought out, but rather that they should be sought out. Professionals do not expect any patient or family to be able to provide information beyond their capability. Yet, patients and families are expected to show a moral

willingness to collaborate to the best of their ability. Not only for themselves, but also for the sake of the Danish health care system and society as a whole.

Chapter conclusion

The analysis of this chapter demonstrates how guidelines for genetic counseling, the economic governance of the health care services, and of medical record data in the Danish health care system, influence the everyday practices of professionals in genetic counseling. The analysis illustrates how Denmark has a tradition in which professionals from all over the country meet and together develop common clinical guidelines and recommendations for both the provision of genetic counseling and for modes of prevention. In Denmark, this means that genetic counseling and its practices are agreed upon as pertaining to families. This is echoed in both practices of risk estimation where pedigrees are used, in risk categories and in the recommended offers for prevention. But where genetic counseling may be seen as pertaining to families, Danish health laws see such services differently, emphasizing that these are to be delivered with a straight focus upon protection of individual rights.

It is demonstrated in this chapter that genetic counseling unfolds within a specific health care system, where broad sets of health care data are accessible to professionals, and where services are paid for by the Danish welfare system. This means that different webs of actors become available and with them specific genetic practices as well as modes of clinical and economical reasoning.

Approaching such conditions from a practical perspective reveals how the long tradition for storing health care data and linking them using the unique individual civil registration number, make it possible for professionals to verify information that patients may provide about cancer onsets in their families. For the daily practices of professionals, the possibilities for verification fosters a specific demand to do so because of the important role that information plays in estimating risks using statistical programs and in deciding who to screen. This chapter shows how being capable of verifying information marks the difference between producing a *proper* or a *thin* indication, when working with family risk categories and correlated preventive interventions. The difference between working with a thin or proper indication is a potential difference between *doing good* or *harm*. While doing good is seen as providing information allowing families and patients a platform for seeking out relevant risk management interventions, so may *doing harm* come to mean unnecessary and irreversible forms of screening and surgical preventive measures. Verification as a result emerges as the essential practice to be pursued in Danish genetic counseling.

The chapter revealed that current Danish health laws state that when verifying information, professionals become dependent on patients and families working together if they are to avoid violating the health law. A similar situation faces professionals when risk estimates have been produced and preventive interventions are to be offered. To avoid violation of Danish law, professionals currently have no opportunity but to rely on patients seeking out and disclosing risk estimates to their families as well as the nationally agreed upon offers for prevention.

The chapter also reveals that verification practices are necessary for other reasons. Being part of a welfare health care system, in which services are tax-finance and increasingly subject to common demands for cost-efficiency, professionals also pursue verification as a means to prevent *waste of welfare funds.*

As demonstrated in this chapter, professionals see verification as offering them the possibility to more closely regulate both genetic screening measures and preventive offers. To professionals working in accordance with Danish law, the possibilities for exercising cost-efficiency mean that verification is seen as a moral practice that professionals, patients, and families need to willfully engage in to protect clinical departments, hospitals, and the welfare state as a whole.

Chapter 8

Comparing genetic counseling in China and Denmark

This research sets out to study how genetic counseling practices unfold in two widely different countries separated roughly by 10,000 km. First of all, the purpose has been to provide a comparative description of how China and Denmark approach something perceived among clinical professionals as universally scientific as genetic counseling for cancer. In this comparative process, differences have emerged.

The aim was to create an anthropological account to understand how the local organization of guidelines, financial governance of health care, and availability of data in China and Denmark, respectively impact on counseling practices and their results.

In this chapter, I systematically compare my analytical findings to illustrate how the differences found in this research has provided a different perspective to existing discussions of genetic counseling and the emergence of specific modes of genetic responsibility.

Comparing genetic counseling for cancer in China and Denmark

Chapters 6 and 7 empirically demonstrate that genetic counseling for cancer in China and Denmark exhibits an arrangement of salient differences but also of similarities. Both countries use the family history as a central tool when establishing indications of possible genetic predispositions. Danish and Chinese professionals use a very similar body of scientific knowledge related to types of cancer, intergenerational cancers, and age of cancer onsets when deciding on possible genetic indications. Professionals in China and Denmark both use genetic sequencing equipment to identify specific mutations (such as *BRCA1* and *2)*. In both countries, genetic risk estimation is considered a central practice to offering possible preventive interventions. Both countries use risk management trajectories that involve screening and surgical interventions.

Yet, underneath this fine layer of apparent practical and scientific similarities, differences also emerge. Chapters 6 and 7 reveal that the most distinctive difference between the two countries is that genetic counseling practices demand the strict collaboration of patients and families in Denmark, whereas in China practices only concern the individual patient.

Discovering differences when comparing the practices of genetic counseling in China and Denmark underlines the heterogeneous nature of scientific practices (Lock 2010). Scientific practices such as that of genetic counseling are never universal. Though protocols and technologies may spread internationally, the understanding and the way scientific content and methods are applied are always linked to the specific contexts in which such practices unfold (Rapp, 2014).
Genetic counseling and calculation of genetic risk estimates are first and foremost to be seen as a specific local practice leading to specific local risk estimate products (Lock & Nguyen, 2010) .

Inspired by previous anthropological studies of genetic counseling, I have in this dissertation suggested that comparative local differences in China and Denmark may be understood by approaching them as the products of specific modes of organizing health care systems in the two countries. Inspired by both academic and empirical experiences in China and in Denmark, I suggest pursuing the specific organizational conditions that surround 1. Chinese and Danish guidelines for genetic counseling for cancer, 2. Financial governance of health care in China and Denmark, and 3. Organization of medical record data in China and Denmark. The different organization of health care leads to different possible but also demanded practices of genetic counseling.
In my analysis I have started by studying current guidelines. The reason for doing so comes from the apparent influence these have upon clinical practices. Clinical guidelines provide practices with direction and exhibit a practical mode of organizing practices. As stated by Berg et.al (2000), guidelines offer modes of objective standardization. They explicate what to do, when, in what ways and by which means. Guidelines allow professionals to categorize patients into distinct homogenous categories ensuring uniform treatment of similar cases. They invoke transparency and modes of objectivity limiting unnecessary variation in medical practice.
Guidelines are the basis for practices ensuring the same aim in relation to specific goals and they establish understandings of necessity and properness in genetic practices (Sui, 2010).

Related guidelines, financial modes of governance and data availability

Both China and Denmark have guidelines on genetic counseling, but they differ in extent, form and distribution. However, they both stipulate what kind of clinical practical engagements, risk categories, and risk management strategies genetic counseling is supposed to encompass. Moreover, professionals in both countries consider guidelines to be central to practice.

Guidelines are not solitary organizational constructions determining clinical paths. Although being instruments of organization, guidelines are practical in origin. Clinical guidelines are not developed by bureaucrats but by professionals working within a field of clinical practice (Feidson, 1989). They build upon tacit understandings and practical engagements tied to the practical clinical fields where clinical professionals work.

This is the situation in both Denmark and in China. In both countries, professionals have developed guidelines. In Denmark, professionals working together nationally have developed them, while in China they have been developed locally at individual hospitals. Different social conditions means that different guidelines may follow(Sui, 2010).

The form and objectivity of guidelines are always influenced by the specific local clinical practice contexts facing those professionals who engage in the development of guidelines at any given time (Berg et al., 2000). While providing organizational rigueur and defining practice, guidelines are intrinsically linked to the social organizational contexts in which they have been developed.

Comparisons between China and Denmark show how different financial governance of health care and different organization of health care data influence the form, direction, and meaning of current clinical guidelines for genetic counseling.

In China, clinical guidelines are developed locally and have emerged and been subject to the current organization of financial governance and health care data availability facing most hospitals in China. Being a part of the Chinese health care sector relying on strict patient OOP for services and a system where data are stored strictly locally, have resulted in local guidelines stipulating that genetic counseling is to consist of practices of risk estimation, risk categories and offers for preventive interventions involving and aiming at providing services to patients understood as not only legal individuals according to Chinese laws but also as individual paying consumers. Practices in Denmark offer a contrast to this. Developing guidelines in Denmark reflects that clinical professionals work in a health care system paid for by a welfare system. Moreover, a system containing a broad arrangement of nationally organized and accessible medical record archives in which use of data and provision of health care services are subject to specific health laws protecting the rights of individuals.

What emerges accordingly are nationally developed guidelines for practices in which genetic counseling practices are naturally considered to draw upon medical record information about

families to estimate risk, establish risk categories pertaining to entire families, and to offer preventive efforts aimed at families rather than individuals.

Guidelines have a powerful formative influence on clinical practice, but they only play a partial role (Sui, 2010). Their influence on practices happens through their relation with other organizational conditions, in which financial governance and availability of health data have a salient position.

Comparing organizational conditions as webs of related actors

Different organizational conditions provide different ways of doing and thinking about genetic practices. They carve out boundaries determining the meaningfulness of genetic practices. They offer meaningful ways of thinking about one's work as a clinical professional and thereby cut out modes of direction for the provision of genetic counseling services (Gammeltoft & Nguyen, 2007) . This research finds that guidelines in China and Denmark reflect different terms of financial governance and different conditions concerning available health care data; this provides professionals with very different social contexts in which they may build a meaningfulness of practices.

The formative effects of organizational conditions upon practices and meanings of genetic counseling do not originate from a single point of departure. Guidelines, financial governance, and the organization of health care data, each provide central nodes that form practices (Sui, 2010). However, it is through their salient relations that the local distinctive practicalities and meanings of genetic counseling practices become molded to professionals.

This comparative analysis provides a particular perspective on how to understand the formative powers that organizational conditions of guidelines, financial governance of health care, health care data availability have on genetic counseling practices.

Organizational conditions provide spaces of meaning in which clinical questions and modes of reasoning are integrated in practice (Gammeltoft & Nguyen, 2007) . What is seen as good practice and responsible choices to offer to patients depend on the related social and organizational contexts of the health care system in question.

This research offers a comparative perspective showing how such related organizational and social contexts involve and depend upon both human but also non-human actors in practice.

Following Mol's(2002) framework of *Body Multiple* and method of *praxiography*, this comparative study sees the emergence of different genetic risk estimates in China and Denmark as different ontological practical phenomena. Opening and understanding of differences and their origin in practices have been the reason for turning to Mol, and not to make an emphasis on ontology as such. Departing in Mol's framework, this research points out that genetic risk estimates are the product of webs of related human and non-human actors that through practices make such phenomena come alive (Law & Mol, 2008; Mol, 2010) .

Guidelines, financial governance of health care, and the organization of available health care data, need to be seen as representing distinctive arrangements of webs of related human and non-human actors; when related, different genetic practices and meanings emerge in China and Denmark, respectively.

Related organizational conditions – related agencies

Different modes of organization promote different forms of practice-near webs of related actors. This results in different spaces for practice in which meanings and physical existences of genetic risk estimates may become looped (Cetina, 2001).

When systematically comparing the findings from the analysis of Chinese and Danish genetic counseling, this research underlines that the current financial governance of Chinese hospitals based on patient OOP (Eggleston et al., 2008; Zhang & Liu, 2014), local guidelines (Zhao et al., 2013), and the organization of clinical health data (Gao et al., 2013; Y. Zhang et al., 2014) makes Chinese genetic counseling practices unfold within very different webs of related agencies compared with its Danish counterpart, where practices are currently organized around tax-financed financial governance(Olejaz et al., 2012; Rudiger, 2003), national guidelines focusing on families (DBCG, 2014; DSMG, 2009; Koch & Svendsen, 2005; Vallgårda, 2003) , and broad national databases with health information (Koch, 2010; Nielsen, 1991).

Seen from the perspective of everyday practice in China, the comparative analysis illustrates how organizational conditions in practice operate through guidelines containing individual risk and preventive categories, multiple patients present in the out-patient examination rooms, numbers, referrals and receipts in both out-patient facilities and laboratories as well as medical records from other hospitals having to be brought along if to be used at another hospital. When related to what appears to be similar technologies used in China and Denmark (high tech such as sequencers and

computers, and low tech such as family histories), such webs of actors reconfigure the agency such technologies may come to assert.
Such relationships of actors provide professionals in China with specific practical grounds for genetic counseling practices while at the same time imposing them within specific meanings. These relationships demand specific practices and understandings of genetic services as something taking only an individual focus (Geren fuwu). To professionals they infer both implicit and explicit demands for accommodating the day-to-day clinical genetic practices. This leads professionals to constrain the time (zuo kuai), the form (shuo goule) and the explicit direction (Geren fuwu) of their genetic counseling services to patients.

This is in contrast to the Danish organizational conditions opening up a different web of related actors such as guidelines containing family risk categories and preventive categories, health laws, civil registration numbers, national medical records, consent forms, funding by the welfare system. A relationship of actors that in combination with well-known technologies (some high tech such as sequencers, and some low tech such as the drawing of a pedigree), provide professionals in Denmark with a very different specific practical basis for offering genetic counseling practices by imposing them with specific meanings. In Denmark, genetic counseling practices emerge in which *verifying information, and the possibility of producing a verified pedigree* becomes both a possibility and also a demanded clinical practice to prevent *harm by doing good*, and to *prevent waste of common money.* This relationship of actors gives rise to a specific dependency on and understanding of genetic risks as pertaining to families.

Genetic risk estimates constitute clinical phenomena. They unfold through the webs of related actors, who through their relations make genetic risk estimates knowable (Mol, 2002:33).
This comparison illustrates how different Chinese and Danish organizational conditions means that genetic counseling practices unfold within very different related webs of actors, giving rise to specific different clinical genetic practices, meanings, and genetic risk estimate products.

As emphasized in studies, organizational conditions play a key role in formulating the practices of genetic counseling. The organizational conditions of health care systems infuse genetic counseling with specific meanings in which the risk estimates are negotiated among human participants.

However, by approaching organizational conditions praxiographically, a different perspective to such argument is provided expanding the role and form of actors.
The current analysis and the comparative differences underline what Gammeltoft & Nguyen(2007) and Sui (2010) have stated influence of organizational conditions upon practices and modes of human agency.
However, this research takes this argument in a different direction adding that such agency needs to be understood as distributed among a broader set of webs of related human but also non-human actors. Non-human actors resulting from organizational conditions making genetic practices and products appear meaningful to the human actors that participate.

With this in mind, I turn this discussion towards the topic initially prompting this comparative study - the salient relationship between genetic responsibility, genetic counseling practices, patients and families.

Clinical practices, actors and genetic responsibility

This dissertation builds on existing anthropological studies identifying genetic services as a complex clinical and interpersonal field that gives rise to often very demanding questions about "self and others" (Gibbon, 2007; Hallowell, 1999; Konrad, 2005).
Thinking back on my encounters with patients in both China and Denmark participating in genetic counseling for the first time, there were many similarities. Most of the patients I have met during my field studies such as Xiao Yang and Ulla, though being separated by more than 10,000 km and clearly different contexts[43], they tell remarkably similar stories of their reasons for seeking genetic counseling. They arrive with ideas of what they expect to go through and what they aim to gain. They arrive due to the socialness of disease (Keenen, 1994). They arrive for counseling to *manage* what is perceived as an inevitable onslaught of family cancer, and they do so with very fixed ideas

[43] Now I say similarity acknowledging that this should be said with caution. Despite finding many similar traits in the stories told by my informants in both China and Denmark as they arrived for genetic services, China and Denmark differ after all. The reasons for feeling and pursing a sense of individual and social responsibility that I have encountered among patients in both China and Denmark, are bound to vary due to different social conditions in both countries. Though not having been the topic of this dissertation as such, studies by e.g. Faulkner and Sui among families seeking out genetic services in China have shown how the famous one child policy puts an immense pressure on families to secure the future for their one child. Seeking out genetic services is an act of affection but part of these acts of affection are also considerations about the future of the entire family in a country were older generations are generally still taken care of by their young relatives (Sui & Sleeboom-Faulkner, 2010a) . Naturally these individual and social reasons for seeking out genetic services in China may be seen to differ substantially when compared to Svendsen's study of patients seeking out genetic services in Denmark, where a social welfare system is in place taking care of the elderly (Svendsen, 2004).

about whom this knowledge may concern and ideas about how the genetic practices may impact on them (Svendsen, 2005).

Genetic counseling services open up spaces of action for patients within often heart-breaking family histories of disease and death. The knowledge that genetic counseling offers may help patients to not see cancer incidents in their families as inevitable, and instead seeing it as risks only. Risks that may be managed through knowledge acquisition and participation in preventive interventions (Ibid).

But they also open up questions of how to react when existentially threatened by risks of developing a disease such as cancer, being not only an individual issue but also a family issue (K. Featherstone et al., 2006; Finkler, 2001).

When there is a possibility for both individual and social management, participation in genetic counseling becomes an engagement within complex webs of genetic responsibilities and demands for social responsibility investments (Gibbon et al., 2010; Hallowell, 1999).

Such social responsibility investments involves practices of acquiring knowledge of cancer and modes of pursuing preventive trajectories such as surgery in collaborations of patients and families (K. Featherstone et al., 2006; Finkler, Skrzynia, & Evans, 2003; Gibbon, 2007; Hallowell, 1999; Sachs, 2014; Svendsen, 2005) .

Genetic responsibility and demands for investments are products of local practices. The anthropologist Deborah Gordon (2014)stated that different worlds mean different genetics. When cultural meanings of genetics and its counseling practices change due to shifting geographic locations, so do the complex cultural spaces of agency in which questions about individual and social responsibility and demands for social investments are unfolded. This point is widely shared by other scholars (Gibbon et al., 2010; Parthasarathy, 2007; Svendsen, 2004; Zhu, 2013).

As emphasized in other studies, genetic responsibility and terms of demanded responsibility investments may come from cultural and state defined discourses in genetic practices.

State and cultural ideas about how a society is to operate may give worldly form and content to genetic practices, modes of subjective responsibility and state infused demands for investments (Gibbon et al., 2010; Greenhalgh & Winckler, 2005; Svendsen, 2005; Zhu, 2013) . It may come from cultural ideas of moral personhood reflected in discourses of gender, kinship, and religion (Gibbon, 2007; Rapp, 1999; Roberts, 2011).

Compared to current studies of genetic counseling practices in western versus non-western countries, the findings in this dissertation comparing Denmark and China emphasize a different perspective. The local worlds open up specific modes of practice and with them spaces of agency in which genetic responsibility and demands for investments are formed (Gordon, 2014). But this research provides a different perspective on how to understand such spaces of agency by pointing to organizational conditions as webs of related human and non-human actors rather than culture and state discourse.

To professionals in Denmark, elaborated verification practices involving patients, selected family members, civil registration numbers, medical records, pedigrees, computer programs, and risk categories in accordance with national guidelines, provide the proper way of producing a proper genetic risk estimate. Yet, to professionals in China genetic counseling and risk estimates based on individual patient accounts, their own local medical records, a genetic sequencer, and an American database, are considered as an equally proper clinical practice.

The properness of a rigorous pursuit of verification in Denmark, made possible by some actors within the webs of relations in Denmark, emerges as an inescapable and stringent demand. It does so because it emerges as the only reasonable response to the stakes that other actors within the same web come to raise.
Running low on common welfare funding or *common money* and *doing harm* are not only analytical anthropological concepts, but also modes of reasoning covering very real threats for professionals in Denmark. They refer to job security, the ability to conduct day-to-day practices in a proficient way, and the services of the whole health care system. They refer to real threats posed by unnecessary wrongful screenings and surgery. Working in accordance with Danish health laws making individuals and families mutually dependent within these practices, naturally becomes an unavoidable part of Danish genetic counseling practices. Even though such interdependence causes considerable trouble, the alternative is considered so much worse.

To professionals in China the situation is similar. The properness of rigorous pursuit of genetic risk estimation practices as *Geren*, offered by the salient relationship of local medical records and a patient OOP system, are equally inescapable because they are related to other actors within that very same web. Having to service close to 50 patients a day means that any excessive time spent by

a professional with one patient is at the expense of another. Professionals are very aware that allocating too much time to one patient means that someone else may be receive less service, which may prove to be fatal dealing with patients and cancer. Stakes may be raised because of the patient OOP system but also by not servicing an adequate number of patients every day, which could cause a professional to lose his or her job.
Different webs of related actors carve out different boundaries for possible and demanded agency within medical practices (Mol, 2002).

The boundaries for clinical practice are somewhat *flexible* for clinical work and its practices are always contingent (Atkinson, 1995). To professionals working within practices defined by webs of related actors, each new patient trajectory in China and Denmark requires its own complex set of deliberations.
To some extent, clinical work always depends on modes of personal creativity (Berg et al., 2000). Nevertheless, this comparative study shows that to professionals, creative answers still need to be sought out in practice within the possible boundaries offered by the webs of related actors to which they become a part.

With different flexible boundaries opening up to professionals, different arrangements of local genetic responsibilities and demands for responsibility investments are opened up to patients (and their families). As a result, different spaces of agency for patients and their families will follow.
This research illustrates, how genetic responsibility and its demands for investments may be understood as the result of positions offered by possibilities and constraints of very local and specific webs of related actors. The point is not to suggest that cultural and state discourses about individuality and family do not play a role in genetic counseling practices, genetic responsibilities and demands for investments (as seen in studies by (Gibbon et al., 2010; Svendsen, 2005; Zhu, 2013). The praxiographic perspective taken in this research adds a different dimension to such an argument. It points to and underlines the role of social organization of health care, understood as webs of related non-human and human actors, in such cultural and discursive worlds. It promotes a salient attention to an otherwise easily overlooked role of mundane non-human actors, whose participation in genetic counseling reveals to profoundly influence genetic practices, their products and their meanings.

In the context of this comparative study, different flexible boundaries in the practices of professionals are followed by different responsibility investments demanding equally different types of responses from patients in China and Denmark, respectively if patients wish to succeed in managing the threats posed by their family history (Svendsen, 2005).

Different genetic responsibility investments - different genetic products

The praxiographic comparison between two very different arrangements of practices and two very different genetic end-products helps to illustrate, how two very different local webs of relations each carve out their own local arrangement of challenges facing patients and their families. Moreover, patients in China and Denmark had surprisingly similar motives for seeking out genetic services.

Each local web of relation produces its own unique possibilities and demands within clinical practice. This results in very different responsibility investments to be made by patients, which has consequences for the types of genetic products that emerge for patients in China and Denmark.
Where both Danish and Chinese patients may arrive to obtain knowledge of risk and access to adequate preventive interventions, their possibilities for succeeding, however, depend on very different practices and modes of collaboration. Even though patients in both countries arrive at the genetic counseling expecting to be the only participant, only the webs of related actors in in China allow Chinese patients to do so.

If Danish patients are to obtain a genetic risk estimate, their failure or success depends on a series of practices in which more than their own willingness to participate becomes necessary. Thus, social responsibility needs to be exercised in order to succeed. Only through interdependent practices drawing upon other family members, risk estimation and preventive measures can become a possibility. This very specific Danish social cycle of responsibility investments emerging from the Danish practices means that genetic risk estimates and options for preventive interventions for Danish patients and their families emerge as **family products**. Going through genetic counseling as an individual to achieve an individual genetic risk estimate and individual offers for prevention is simply outside the boundaries of the current organization of genetic counseling in Denmark.

In China, the possibility for obtaining a risk estimate and being offered preventive interventions ultimately depends on specific individual responsibility investments. Through an entire trajectory of genetic counseling, Chinese patients wishing to obtain a risk estimate are only allowed to rely on their own willingness and capabilities as individuals to invest in these practices; their family is allowed no role in these practices.
As a result, genetic risk estimates and any preventive interventions emerge as a strict **individual product**. This is because going through genetic counseling as an individual to achieve an individual genetic risk estimate and individual offers for prevention fall exactly inside the boundaries of the organizational conditions of actors who are part of genetic health care services in China. What this research therefore concludes is that in Danish practice which through its webs of related actors makes it impossible to obtain an individual genetic risk estimate; in Chinese practice, however, through its webs obtaining an individual genetic risk estimate is the only possible solution.

The perspectives of this study, illustrating that genetic counseling practices and the demands for genetic responsibility investments in China strictly servicing the individual and in Denmark servicing families, provides a somewhat different result when compared to other existing studies of genetic counseling.
As earlier stated, Danish genetic practices, just as the genetic practices of other western countries, have been intertwined with a mix of liberal, cultural and state discourses. This means that the emergence of genetic responsibility and needs for investment have been seen as unfolding within discourses of individuality, individual self-regulation and individual enterprise (Hallowell, 1999; Rose & Novas, 2005; Svendsen, 2005) .

Studies of Chinese genetic practices, just as the genetic practices of other non-western countries, are in contrast to this. As demonstrated in an increasing number of studies of genetic counseling practices in non-western countries showing how non-western cultural and state discourses result in practices opening up to genetic responsibilities of a much more explicit sociocentric form (Gibbon et al., 2010; Roberts, 2011; Zhu, 2013).

What this research finds illustrates how taking a different perspective to genetic practicing and its connections to the emergence of modes of genetic responsibility may result in different kinds of results and understandings. The individuality in China and the family focus in Denmark have

admittedly challenged my expectations, as described in Chapter 2. It does so because little had prepared me for the strong focus on the individual I encountered in China, especially when compared to the strong focus on the family in Denmark. I had anticipated finding a strong emphasis on families in China. Family plays a central role in the literature on genetic counseling in China e.g. in the work by Zhu Jianfang (2013), which I had read as a part of my preparations. Moreover, because Chinese families in the broad literature has been described as the salient point of departure when approaching ways of being in the world in China (see (Davis & Harell, 1995; Freedman, 1979; Stockman, 2000). The Chinese sinologist Daniel Bell (2008) echoes this tendency by placing the family, understood in a classical Chinese Confucian sense, as central to understanding the social organization in China. Family is by far the most important relationship to Chinese, he states, and all social practices ranging from the mundane everyday lives lived in Chinese homes to the contractual organization of Chinese workplaces, need to be understood as informed by and articulated through ways of thinking in which family is the smallest unit (Ibid).

Thus, finding the opposite with a scarce if any focus upon families in genetic counseling in China and a stringent focus upon families in Denmark, through a perspective of everyday practices of related human and non-human actors, illustrates how careful an anthropologist must be when comparing biomedical practices between and within countries. As Kleinman notes, established dichotomies still cling strongly to many social and cultural studies of biomedicine (Kleinman, 1997). Dichotomies where western countries, their practices of biomedicine and the results they produce, still often become approached as inherently intertwined with constitutive ideas of individualism when compared to non-western countries such as China, where practices and results are presented as unfolding within a paradigm of sociocentrism (see e.g. the work of Potter (1988)).

Using Non-western sociocentric countries as a comparative counterpart to Western individualized countries has had its definite merit in many studies of biomedicine. Such comparisons have helped to unfold and question the often taken for granted approach of universal individualism within biomedicine. But such dichotomies are also fragile and need to be approached with care and a critical explorative approach.

Studying the Chinese society for more than two decades, the anthropologist Yan Yunxiang (2009) notes that the position of family and kinship as a nexus for individual life is changing in China. Structural changes in the organization of Chinese society means that life for China's younger

population is increasingly being lived through emotions, desires and agencies that takes the starting point in the individual rather than the traditional extended family collective. Family has not disappeared, but it can no longer be used as an a priori defined concept to understand the practicalities of Chinese life, Yan states. Family, just as any other form of social relation, rather needs to be understood through a lens of practical individual needs and desires (ibid, (see also (Stafford, 2000)).

As Kleinman states, departing in established ideas of non-western sociocentrism as a contrast to western individualism when comparatively studying biomedical practices may therefore blur the complexity of such comparisons. Comparisons need to be critically approached (Kleinman, 1997).

This comparison of Chinese and Danish genetic counseling in many ways echoes the observations of both Kleinman and Yan. It demonstrates how inherent cultural ideas of individualism and sociocentrism need to be approached with care and critical reflexivity when doing a comparative study of genetic counseling.

Taking an open and reflexive praxiographic approach to comparison of genetic counseling has demonstrated exactly how everyday practices in China lack the inherent perception of the cultural Chinese family. Instead it depends on the strong ideas and strong practical engagement of individuals. The opposite was illustrated in Denmark, where families rather than the inherent perception of the cultural western liberal individual, provides the nexus for both everyday practices and genetic risk results. By demonstrating these surprising differences, this research theoretically and empirically adds to the call for critical comparative explorative studies.

It should be noted that the findings in the current study do not aim neither to debunk the cultural and state discursive position of families in China, nor the position of individual autonomy in Denmark within the field of genetics. Moreover, it should not be a general argument against studies illustrating the oppositions between western individualism and non-western sociocentrism, as that would be an unreasonable conclusion when considering the many powerful examples.

The point is rather to emphasize how the conclusions of such studies are explicitly tied to the relationship between local practices and the studying lens through which they are described. This research illustrates how approaching a study of genetic counseling in specific practices and webs of actors may bring forth a different perspective on such ideas ensuring that genetic responsibilities should be acknowledged as complex, contingent and also very strictly tied to the specific and individual practices at hand.

Patients in China like Xiao Yang, Xiao Li, and Yu Ting may very well be pushed into extreme individualism when participating in genetic counseling at PUTH and BC, but that does not mean that this applies to all practices of Chinese social life. Chinese patients may very well become part of sociocentric and culturally discursive conceptions of family when participating in social practices outside the clinical setting at PUTH and BC. Similarly, the Danish patients like Ulla, Audrey, and Hannah portrayed as sociocentric in this dissertation may become part of cultural ideas of western liberalism when living their lives outside the practices of DCG.

Comparative studies departing in everyday practices of webs of related actors, human and non-human such as in this dissertation, illustrate how an anthropologist could conduct a comparison, open and reflective, and thereby paying attention to effectively explore and challenge inherent dichotomies and even turn them up-side-down.

Initially, the intention of this research was to follow how professionals, patients and their families in China and Denmark, respectively produced genetic risks estimates in clinical practice, and how it impacted socially on parts of patients' lives outside these clinics. However, the study ended up focusing on the clinics. This does not mean that following what happens to these patients and families in China and Denmark as they leave the clinics is not an interesting aspect for making a comparative study; perhaps even more interesting in the light of the profound differences found in the current study.

Svendsen's (2006) long-term study of the effects of cancer counseling in Denmark for patients and families provides us with interesting insights into the everyday life of social genetic knowledge outside clinics in Denmark. However, little is known about this for the Chinese patients and their families having been a part of genetic cancer practices.

In conclusion, the very different consequences of producing genetic risk of cancer estimates for patients and their families in China are currently unexplored. Thus, it is suggested that others should further explore this field to contribute with knowledge of the impact of genetic risk of cancer estimates for patients and families in China.

The final section discusses the impact of such comparative findings in relation to genetic counseling practices for cancer among Chinese and Danish professionals.

Praxiographic comparisons and implications on clinical genetic work

Comparing genetic counseling in China and Denmark shows how professionals in both countries are faced with challenges. However, this comparison also very clearly demonstrates how Danish genetic counseling practices raise far more practical and ethical challenges for professionals, patients, and families than Chinese practices.

Finding such uneven challenges facing the participants of genetic counseling in China and Denmark provide a platform for discussing how such practices meet the goals and gains anticipated by those who seek out these services. Looking back at the patient stories, I was told upon arrival by patients in China and Denmark there was a striking similarity of their motives, the trajectories they anticipated to go through, and the results they expected to receive.

Yet, following these practices from the beginning until end also revealed that Chinese patients receive a service and a set of results much closer to their expectations and motives than the Danish patients.

The comparative study illustrates that patients in China are interrupted during counseling sessions when wishing to discuss the implications of genetic risks within their family. But ways of countering such challenges are open to them, either through salient modes of interruption or through means of contacting family members to make them approach genetic counseling in hospital and pay to this service themselves.

Such options have a serious impact on the financial status of patients and their families. As increasingly pointed out in the literature, clashes over health care provision and its pressure upon a family economy (known in Chinese as Yinao) increasingly lead to medical disputes with and assaults on doctors (He & Qian, 2016; Hesketh et al., 2012; P. Yu et al., 2015). Nevertheless, this study demonstrates that patients are left with the practical possibility of including families in genetic counseling by the current organizational conditions of the Chinese health care system. This possibility rests solely on the initiative of the patient. No explicit demands to involve others than the patient who has paid for the genetic service are made from professionals.

The collaboration facing professionals, patients, and their families in Denmark proved to be far less flexible and leaving far less room for personal decision-making. The existence of webs of non-human actors in Denmark makes it impossible to escape such challenging collaborative genetic responsibility investments.

But do Danish practices necessarily need to inherently rely on such challenging family collaborations when looking to the results found in China?
To Danish professionals this comparison with China can lead to new understandings when approached through a powerful lens of comparison. In anthropology, comparisons have been seen as providing a lens in which the exotic may become known to us, and the well known may become the subject of new reflections (Hastrup, 2003). Comparisons such as this helps the exotic Chinese genetic practices to become known to Danish professionals, and by doing so they may also help ask critical questions to the naturalness of current Danish genetic counseling practices. Thus, looking comparatively at the practices of genetic counseling in China provides a perspective that things could be different in Denmark and vice versa. Different ways of doing genetic counseling are possible, although they may come at a price.

Phenomena like genetic risk estimates are fluid. Though they rely on webs of related actors, a re-alteration of some ties within such webs does not necessarily mean that the phenomenon breaks down (De Laet & Mol, 2000) . Rather this may provide the possibility for other webs to be allowed to take form. Depending on the related organizational conditions such as guidelines, the economic governance of health care, and data availability, different modes of genetic counseling may become possible.

In a broader perspective, this comparison illustrates the contingency and situatedness of genetic counseling practices, the modes of genetic responsibility, and the social demands for responsibility investments in China and Denmark, respectively. Understanding genetic risk estimates as fluid products of practices underlines an important point. It proves that different genetic practices and provision of genetic risk products are possible if organizational conditions are altered; humans and non-humans are related according to Mol(2002).
This research illustrates that a difference in the organization of health care means that different webs of non-human actors carve out somewhat flexible boundaries for human agency. On the other hand, it also demonstrates that the possibility for non-human actors to act depends on the organizational conditions and it should be kept in mind that humans play a profound role in developing these.

The current situation in China and Denmark where risk estimates are either individual or family products cannot be taken as a static dichotomy. The future may bring changes, if health care systems are organized on different terms.

Chapter 9

Conclusion

This chapter is the conclusion of this dissertation. In my analysis comparing Chinese and Danish genetic cancer counseling practices, I now once again return to the four research questions in the opening of this dissertation to relate them to the findings.

The four research questions initially setting the scene for this comparative study were:

1. How do China and Denmark, respectively practice genetic counseling related to risk of hereditary breast and ovarian cancer?
2. How may we comparatively study and understand genetic counseling and the different practices in China and Denmark, respectively?
3. What do differences anthropologically mean for the unfolding of genetic counseling practices in China and Denmark, respectively?
4. How may a comparison of genetic counseling practices in China and Denmark contribute to anthropology and the field of clinical genetic practice?

The four research questions are addressed in the following sections.

The chapter finishes with a short look to future trends calling for future research to be conducted.

Chinese and Danish genetic counseling practices compared

How do China and Denmark, respectively practice genetic counseling related to risk of hereditary breast and ovarian cancer? This study was initiated due to the specific clinical interests and concerns among Danish professionals collaborating with Chinese professionals in the field of genetic research and clinical practice. The driving force of this research has been an interest in comparing the impact of genetic counseling on patients and families in two very different countries. Building upon the science of shared DNA, it is demonstrated how genetic counseling in China and Denmark leads to questions on how to act as a responsible individual and sometimes as a family when pursuing information about genetic risk and possible modes of risk management. Genetic risks are social (Keenen, 1994). Yet, as this study showed, genetic responsibility and demands for genetic responsibility investments are not unfolded equally in China and Denmark, as the genetic counseling practices through which they are articulated differ. Understanding how genetic counseling practices differ has been a central focus in this research, as reflected in the opening

research question. As shown in this study, although sharing a common understanding of genetic cancer disorders as hereditary, using almost similar technical equipment, and collaborating in research and exchanging knowledge about clinical practices, genetic cancer counseling practices in China and Denmark are unfolded on very different practical terms.
Thus, genetic counseling trajectories in China and Denmark differ in both content and form.

In China, genetic counseling and the production of a genetic risk estimate unfold through an arrangement of practices involving the establishment of a family history showing indications of genetic predisposition, blood sampling used for screening and computer programs used to establish possible risks according to specified risk categories in local guidelines. A trajectory in China unfolds at multiple sites including laboratories and outpatient clinics together with other patients seeking treatment for cancer. Genetic counseling sessions were conducted within strict timeframes allocating approximately five minutes to each consultation. Each service provided is paid for individually through a patient OOP system. Genetic counseling builds upon dialogical information and medical records from and genetic tests performed at the local hospital. Common for all trajectories, and a central finding of this study is that genetic practices are strictly focused on the individual patient, and that professionals only need to depend upon individual patients in order to produce knowledge of risk of genetic cancer.

This is in contrast to genetic counseling for cancer practices in Denmark. Here genetic cancer counseling practices rely on related practices unfolding at specialized hospital departments. These involve the establishment of a family history through means of verified information and pedigrees. Verification is done based upon information obtained from national medical record archives and databases requiring patient-family collaboration. Information is used to estimate risks using computer programs, pedigree information, and occasional blood test results. On the basis of the risk estimates, patient and families are placed within specified risk categories leading to adequate prevention trajectories in accordance with nationally established guidelines. All services are paid for through a national welfare health care budget funded by public taxation. It is common for all practices that they focus upon the individual as being a part of a family, and the practices of professionals thus come to depend upon families. Empirical illustrating these differences in China and Denmark have raised questions of how to comparatively study and understand such differences in genetic counseling practices.

Organizational conditions and a praxiographic perspective

How may we comparatively study and understand genetic counseling and the different practices in China and Denmark, respectively?

Differences in genetic counseling practices in China and Denmark may be understood as the products of specific local modes of organizing health care systems (Gammeltoft & Nguyen, 2007) . Focusing specifically upon organizational differences pertaining to guidelines for genetic cancer counseling, the financial governance of health care services, and the organization of available clinical medical record data, this research has emphasized that differences form the ways that specific genetic practices may unfold and be understood.

In China, genetic counseling services are provided as patient OOP services, whereas in Denmark services are provided as a part of the welfare system free of charge. In Denmark, genetic counseling follows nationally established guidelines; in China, guidelines are developed locally. In China, medical record information is strictly kept locally, whereas in Denmark this information is stored in national accessible databases complying with national laws.

This comparative study has offered a particular perspective on the different organizational conditions and the influence they have on genetic counseling in China and Denmark, respectively. Taking a praxiographic perspective to clinical practice in China and Denmark, mapping who does what, how, why, and through what kind of related webs of actors, the comparison has offered, "a studying down" everyday comparative account of genetic counseling (Mol, 2002).

The research has revealed how different organizational conditions influence genetic counseling in China and Denmark. In practice it may be understood as the different products of workings of often very mundane every-day webs of related non-human and human actors through which such conditions operate. Mapping the everyday mundane actors that constitute genetic counseling practices in China and Denmark has revealed, how differences in guidelines, financial governance of health care, and organization of available clinical medical record data translate into very different webs of related actors in these two countries.

In China, these webs of actors are made up of guidelines containing individual risk and prevention categories, multiple patients in out-patient examination rooms, numbers, referrals and receipt notes in both the out-patient and laboratory facilities, medical records that need to be brought along from

other hospitals by the patient if to be used and finally, professionals and individual patients. In Denmark, the web of actors are comprised of guidelines containing family risk categories and categories for preventive interventions, health laws, civil registration numbers, nationally available medical records, consent forms, common welfare system funding, professionals, patients and selected members of the patients' families.

Taking a comparative praxiographic approach to genetic counseling reveals how the form and meaning of clinical genetic counseling practice may be understood as looped through the possibilities and constraints provided by these very different webs of non-human and human actors(Cetina, 2001). This has been shown to have a fundamental impact on practices of genetic counseling in China and Denmark, respectively.

Genetic counseling and the locality of practice

What do differences anthropologically mean for the unfolding of genetic counseling practices in China and Denmark, respectively?

Following local practices from a day-to-day praxiographic perspective demonstrates how different webs of related mundane actors are joined and carve out very different spaces of clinical agency and modes of reasoning for the professionals in China and Denmark. They not only open up possible ways of conducting meaningful genetic counseling in practice, but they demand to be conducted in this way to respond to local stakes raised by the very same webs.

Analytically, the different organizational conditions in a Chinese patient OOP funded healthcare system, with locally developed guidelines and locally stored medical records, as opposed a Danish health care system with paid for health care services by a welfare system, national guidelines focused on families, and nationally accessible medical records not only open up very different possibilities for conducting genetic counseling, but also explicit demands to do so. To Chinese professionals, I have argued, there are few choices in the day-to-day productions of genetic risk estimates except to accommodate their genetic counseling practices to the every-stakes raised by such an organization.

Stakes such as delivering an adequate and equal service to an expected large number of paying patients within a constrained time period means that genetic counseling practices (and normal oncological services) are unfolded within the ideas of working fast (zuo kuai), saying enough (shuo

guole) and, most importantly, have a stringent focus solely towards that of the individual paying patient (Geren fuwu).

Though faced by different organizational conditions in Denmark, the relationship between possibilities and demanded responses to stakes by the very same web of actors hold true also for Danish professionals. To Danish professionals, the organizational conditions providing the possibility for *verifying information,* and the possibility *for producing a verified pedigree* through a dependency on the collaboration of patients' families become demanded professional practices. They do so because they serve as practical responses to the stakes raised by other actors from the very same Danish organizational conditions. If professionals neglect or refuse to verify information it could result in patients and families being sent through unnecessary surgical interventions. It could also result in welfare funding being wasted on unnecessary screenings.

This dissertation argues that each web of related actors that the organizational conditions of a health care system open up, produces its own set of related clinical professional possibilities, stakes and demanded ways of responding to these.

To the professionals in clinical genetics, the consequences of working within a Chinese as opposed to a Danish health care system is profound. It is a difference between working with genetic counseling naturally depending on individual patients as opposed to working with genetic counseling depending on a patient-family collaboration. Though sharing a common departure in a genetic science underlining social heredity, there is a difference between working with a scientific production of genetic risk estimates that inherently emerge as individual as opposed to family-orientated. With different spaces of agency opening up to professionals, different spaces of agency also open up to patients and their families.

A comparative praxiographic perspective on genetic responsibility and their investments

How may a comparison of genetic counseling practices in China and Denmark contribute to anthropology and the field of clinical genetic practice?

This research is a part of an anthropological discussion of the relationship between genetic counseling practices and the emergence of novel modes of genetic responsibility. Genetic counseling means being capable of identifying and advising at risk. It presents risks as manageable, and it also places an implicit obligation on individuals to act upon these risks (Gibbon, 2007; Konrad, 2005; Lupton, 1995; Sachs, 1999; Svendsen, 2005). It builds upon a science of genetic

pathology, allowing people to see themselves *in a pathological relation to others,* and this gives rise to genetic responsibility and demands for responsibility investments (Gibbon et al., 2010; Hallowell, 1999). Genetic responsibilities and demands for investments follow the human agencies that local genetic counseling practices carve out. They have been argued to be tied to stakes raised by cultural and state discursive ideas in which lives are lived and genetic counseling practices are unfolded.

This dissertation, however, illustrates that genetic responsibilities and demands for investments may also be understood as socially negotiated, following the local organizational conditions under which genetic counseling unfolds. Comparing the practices of genetic professionals in China and Denmark, I have argued that by being situated as actors within local webs, specific local stakes become raised to them and that this in turn demands specific responses from local clinical practice. Pursuing such responses to the different stakes raised, place patients and their families in China and Denmark, respectively with very different ideas of genetic responsibility and they thus demand very different forms of investments for these to be fulfilled.

The organizational conditions surrounding genetic counseling in Denmark leads to a specific mode of genetic responsibility. Knowledge of genetic risk not only needs to be understood as a particular social construction pertaining to a family, but also requires the interdependent social collaboration of families to provide information and participate if a genetic risk estimate is to be achieved and modes of prevention are to be offered.

Contrary, the organizational conditions surrounding genetic counseling in China strictly open up different modes of genetic responsibility and thus different demands for investments, strictly framed around the individual patient. In China, genetic risks are treated and understood as individual in clinical practice. Achieving knowledge of genetic risk and access to preventive interventions depend solely on patients investing in genetic risk estimation practices as individuals. Patients in Denmark are left with no possibility for obtaining an individual risk estimate in genetic counseling; patients in China have no other option.

Comparing genetic counseling in China and Denmark in this sense provides a salient contribution to the existing anthropological discussions of genetic counseling and modes of genetic responsibility.

Turning to organizational conditions as webs of related actors does not mean debunking cultural and state discourses in anthropological discussions of genetic counseling and their role in the emergence of local forms of genetic responsibility.

Rather it adds a different perspective to such arguments by bringing forth the actions of mundane and easily overlooked non-human actors. An example are the guidelines in China that contain categories for individual preventive offers, numbers, referrals and receipts in both out-patient clinics and laboratories as well as local medical records.

In Denmark, non-human actors included guidelines containing categories on family risk and offers for preventive interventions health laws, civil registration numbers, national medical records, consent forms, common welfare funding. Moreover, it gives insight into the role these play in genetic counseling and the emergence of local forms of genetic responsibility as either family or individually orientated.

Adding this perspective helps illustrate the role that the everyday local social organization of both human and non-human actors play in local practices, genetic risk estimates, genetic responsibilities, stakes and demands for investments.

Comparative praxiography and its anthropological and clinical perspectives

Comparisons allow multiple perspectives to be opened up simultaneously.

When comparing genetic counseling practices, they allow differences to emerge in a clinical world where genetic science among professionals is still to some extent allowed to carry a scent of universalism. Comparing two very different countries allowed me to capture the heterogeneous nature of genetic counseling and its products. It reveals how different localities impact on the practices of science. But comparisons also help to explore ideas of difference on a larger scale. They do so because they constitute contingent processes as this study reveals. Comparisons are not static entities, they are an act of making, in which questions may be asked and reformulated in novel ways (Niewöhner & Scheffer, 2010) .

Although this research found little emphasis on family in Chinese genetic practices, it did not make a comparison break down, rather it evolved and allowed different kinds of research questions to be asked and different perspectives to be pursued. It has helped question what makes genetic counseling, a scientific practice so intrinsically grounded in practices of heredity, an individual and a family practice in Denmark but strictly an individual practice in China? Moreover, to question what makes family members and their physical participation become a natural inherent necessity in

Danish genetic cancer risk estimation practices when this is not a necessity in China? And finally to question how to study and understand such differences, and the impacts they may have on genetic counseling in practice.

This research illustrates how comparative praxiography may also contribute to anthropological studies of genetic counseling by helping to explore and challenge established cultural ideas.
In this research praxiography has challenged the established cultural dichotomies of Western individualism against Asian sociocentrism, which are often seen in societies where genetic counseling practices unfold (Kleinman 1997).
This comparative research initially expected to find genetic counseling practices in Denmark stringently to unfold within western ideas of individualism, and Chinese genetic counseling practices within ideas of social family collectivity. Taking a comparative praxiographic approach to genetic counseling, however, has revealed that genetic counseling practices unfold opposite to what was expected. Danish genetic counseling practice surprisingly revealed to unfold within ideas of social family collectivity due to its situatedness within webs of related actors caused by the organizational conditions of a welfare health care system. Chinese genetic counseling practice, on the other hand, unfolded within ideas of a strict individualism due to its different situatedness within webs of related actors caused by the organizational conditions of a partially market- and patient OOP-driven health care system.
To research aimed at genetic counseling, a praxiographic comparison provides the possibility to challenge our perceptions of “the known” but also of “the exotic” (Hastrup 2003). Praxiographic comparisons help allow different perspectives on genetic counseling to emerge, even as seen in this dissertation, looping the understandings often taken for granted.
Using this perspective to study the professionals’ everyday practices in China and Denmark, genetic risks are neither universally to be seen as the inherent products of an interdependent patient-family collaboration nor universally as the inherent product of the work with individual patients. Rather genetic risks are to be understood in the local context. They are the local products of practices unfolding within very different organizational conditions. To professionals in China and in Denmark, such comparisons demonstrate that different ways of thinking and doing genetics are possible, as genetic risk estimates as seen are fluid at best.

This research provides a platform for clinical genetic practice and offers a salient perspective specially aimed at the Danish professionals who helped initiate this project. It reveals that the current professional, patient and family collaborations in Denmark follow practices offered by a welfare organization of health care.
Comparing this practice with China demonstrates that different modes of organization lead to different genetic counseling practices and genetic risk estimates
To Danish professionals and the clinical practices from which this study departed, the comparative findings from China offer a perspective on the naturalness of Danish genetic counseling practices. They illustrate that the current practical dilemmas of working with patients and their families as opposed to working with individuals alone emerge from the organizational conditions that provide grounds for practices and meanings.
Conducting genetic counseling related to cancer in a welfare state is different from practicing in a country where such services unfold within self-paid and locally organized hospitals.

Genetic counseling could be provided in different ways, as argued in this research. It concludes that a difference in organization of health care means that different webs of non-human actors carve out different flexible boundaries for human agency. However, it should be kept in mind that such webs and agencies are fluid. Humans and non-humans relate to and influence each other. Humans have a responsibility for organizing different health care conditions through which non-human actors come to act.
The organization of guidelines, financial governance and available health care data is not static but can be made subject to manipulation. Current Danish practices are historically situated in a perception about how guidelines, economy and availability of data should function in a welfare state, and they give rise to the interdependent genetic counseling practices as seen in this research. However, this perception could change. Ideas of how a particular health care system is to be organized have been shown to change rapidly throughout history, also in Denmark (Vallgårda, 2003). In this light the presented Danish (but also Chinese) webs of related actors in this dissertation should be seen as fragile at best, and as subject to possible changes.

Human actors could change the organizational conditions and thereby the webs of actors through which they operate. Comparing Denmark and China, one of the central differences between these countries causing more challenges in Denmark than in China, is the existence of Danish national

archives of medical records made accessible through means of civil registration numbers assigned to all Danish citizens. These give rise to inherent demands for the challenging social collaborations portrayed in this dissertation.
It should also be kept in mind that the possibility for such Danish archives and civil registration numbers to form a web making verification practices necessary, comes from webs of actors as well. In this study, Danish health laws have been presented as demanding consent in return for such connections to be established legally.
Though not part of this research, it should be kept in mind that such laws are themselves also products of webs of actors enforced by humans, who currently see such connections as a legal right for professionals in Danish health care. However, such perceptions could change. If the use of civil registration number or the retrieval of information from medical records would one day be deemed illegal by Danish policymakers, the existing webs presented in this study would naturally be changed. This would result in new practices potentially limiting the current social family challenges portrayed in this research.

Yet, change is not necessarily outside the immediate reach of the Danish clinical professionals portrayed in this dissertation. Guidelines emerge through the possibilities offered by the health care organizational conditions under which clinical professionals work (Berg et al., 2000). They are nevertheless still partially the products of clinical professionals. Knowing the pressure that the clinically developed genetic risk categories and correlated prevention offers pertaining to families place upon patients and their families seeking out such services, Danish professionals could be inspired by practices in China. They could consider developing guidelines taking a strict individual focus upon risk and prevention. It would, however, mean that all offers for prevention and knowledge disclosure would depend on the individual patient alone as in China. Whether such pressure upon the individual patient can outweigh the challenges of working with families is an open question, and it would need careful consideration in a Danish context. This research hopes to contribute with knowledge that may fuel such considerations, opening possibilities for changing practice where change could be needed.

The intent of this dissertation is not to provide a comprehensive list of possible organizational conditions that could or should be changed. The examples given are examples after all.
What kind of organizational changes should be made and at what costs, is still an open question.

Answering such questions is not an easy task, nor is the practice of changing such established webs of related actors. This dissertation is not able to resolve such grand questions and make decisions on behalf of entire health care systems, nor does it intend to place the responsibility to do so on a single group of professionals. It is my hope that this research may provide a basis for further discussions in a broader group.

The point is therefore to use the contribution of this research and call out to all those professionals such as clinical geneticists, researchers, policymakers and lawmakers who all have a responsibility for current practices in the field of genetics. These professionals should come together and discuss how different ways of organizing the conditions for genetic counseling practices could meet the challenges described.

Future trends – future changes

Writing this conclusion in 2018, developments may already have begun to underline the fragility of the organizational conditions that gave rise to the genetic counseling practices presented in the dissertation. Looking back at my field studies in China in 2015, certain hints of change were already in the making. As I left China, the professionals I followed were gradually building up their own family history databases. These databases were to be used during the practice of genetic counseling in the future. Would this bring change to current practices, I wondered? Could these registers integrate families in the practices in the future, and thereby bring Denmark and China closer together? When looking at the current situation of genetic health care and health care in general in both China and Denmark, certain indications in 2018 could suggest that substantial changes very readily could be on the way in both countries.

In this dissertation, a local registry was being established, and since then establishing new broad national registers and databases has been initiated (Xinhua, Xinhua | Updated: 2017-10-31 10:54). These are to be used nationally in the health care system, it has been stated. Here DNA profiles for the Chinese population are to be stored and used to conduct research into the links between genetics and disease. The implications for genetic counseling for cancer in China may very well be substantial. If nationally accessible registers are established, the family pedigree drawing practices currently only performed as local research could potentially obtain a new position within genetic counseling and bring in families. Such changes would, however, also depend on substantial

alterations to the current system of financial governance exerting a powerful individual influence on all aspects of genetic counseling as demonstrated in this dissertation.

These alterations could also be on the way. In 2009, China took its first step towards gradually reforming its current organization of the health care system. A central theme in in this reform has been to change the current organization of financial governance of public health care. Essential to this health care reform is to provide a much broader health care coverage for the Chinese population, and importantly to limit the need for and reliance upon patient OOP at public hospitals ((Yip et al., 2012).

In 2016, the China National Health and Family Planning Commission issued a *Healthy China 2030 Planning Outline* further promulgating initiatives to provide better health care for all, while ensuring that the government increasingly covers health care costs. The combination of such initiatives will alter the current organizational conditions for genetic counseling, and potentially bring change to the current conclusions of this dissertation.

A focus upon families could be the future for Chinese genetic counseling for cancer. But does this mean then that genetic counseling in China in the future will come to mimic the situation in Denmark? This is probably less likely. Though future health care reform programs may cover genetic services and decrease the dependency upon patient OOP, no formal declaration has been made that such alterations will also automatically expand the time allocated to patients. The Chinese population is increasingly seeking out health care services, and genetic counseling in China is indeed a growing service but educated professionals are still few, and currently China is experiencing challenges with general recruitment of medical doctors (Wu, Zhao, & Ye, 2016). Thus, to imagine that professionals in the public health care sector in the future may be provided with the opportunity to meet with patients for 2-hour meetings as in Denmark, and then proceed to spend hours on meticulously mapping genetic predispositions in collaborations with whole families may speak against the reality of the Chinese health care system.

This, however, does not mean that family information may not in some way be included in future genetic counseling practices. Spending time at the laboratory at BC and listening to the stories of future practices from professionals, it seems likely that the establishment of registries containing genetic information about families may bring change and new modes of counseling with focus on families. But these new approaches will have to be adapted to the local organizational conditions, and currently very little evidence suggests that these will promote the kinds of interdependent family collaborations seen in Denmark.

When looking to Denmark, future changes are also to be seen to draw practices in a different direction. In 2016, it was decided that Denmark should implement a large-scale program for personalized medicine (Sundheds & Ældreministeriet, 2016) . New molecular tests are to be used in specific diagnostics and modes of treatment. This new initiative promises individual genetic knowledge and individual treatment.

The public program for personalized medicine is to be based on information from the known public medical record archives in Denmark, and correlated with genetic information from a selected group of the Danish population. Currently, it is estimated that samples from approximately 200,000 people will used. But the aim is not to build grand pedigrees for the population. Though still in the development and implementation phase, it has been argued that that central ways of organizing health care and conducting clinical practices will be changed accordingly (Ibid). Less focus is to be on population or group health, when organizing the provision of health care. By using genomic information to stratify Danish patients, this new program of personalized medicine promises that health care services will be organized to increasingly meet the needs of individual patients alone. Services like cancer treatment are going to be organized and delivered according to the unique genomic makeup of the individual patient, as opposed to knowledge of what works on broader patient groups (Danske Regioner, 2015).

This program of personalized medicine focusing upon information obtained from the genome of the individual patient, as a point departure for both diagnostics, counseling and treatment, was already a topic discussed when I did my fieldwork at DCG. From talks with professionals, this is expected to have an influence upon genetic counseling possibly in a direction away from the current family-focused practices.

It is, however, only one tendency towards increased focus on individuality in Danish genetic counseling. As seen in chapter 7, obtaining a greater cost efficiency is a great concern to administrators in the Danish health care sector. Each department is expected to perform better each year while still cutting costs. During my stay at DCG, discussions of how optimize time with patients, and time spent on risk estimation were already topics heavily debated in the management. Talking to professionals in late 2015, the time allocated for meeting patients had already been cut by 30 minutes and more streamlining was expected to come. Among several professionals I talked to, a greater reliance upon screening and computer estimation programs using information from

individuals rather than families was therefore expected to be the future of genetic counseling in Denmark due to constant organizational and economic rationalization.

Considering such changes, many questions are still unanswered concerning the impact upon genetic counseling tendencies in both China and Denmark.
It is, however, safe to say that current and potential future changes of the organizational conditions in the Danish and Chinese health care systems, will very likely result in the surfacing of novel webs of actors. When compared to the practices and products presented in this dissertation, this could mean that new and different genetic counseling practices could be emerging and with them new genetic responsibilities and demands for investments.
Taking these new tendencies into consideration could very well be to reverse the current conclusion: Chinese genetic counseling becoming increasingly orientated towards families and Danish genetic counseling towards individuals. Both counseling practices would, however, still have a unique local form and meaning due to their situatedness within specific local organizational conditions.

English summary

This PhD dissertation compares local cancer genetic counseling practices in the health care sector in Denmark and China, and the role that local cancer genetic counseling practices play in the emergence of novel forms of genetic responsibility. The project was initiated in a collaboration between health professionals in Denmark, China and researchers from DEFACTUM (a research unit in Central Denmark Region).

Genetic counseling and the use of elaborate genetic technologies make it possible for clinical professionals to estimate whether patients and families sharing DNA are at risks of developing specific cancer diseases such as breast and/or ovarian cancer. Obtaining a risk estimate may allow patients and families to pursue relevant risk management strategies.

However, in order to produce a risk estimate through means of genetic counseling, professionals rely on the willingness of patients and their families to collaborate, by sharing knowledge and participating in clinical genetic interventions. In the clinical literature, such social genetic counseling practices have been described as giving rise to a plethora of clinical challenges for professionals. Discussions have taken place on how to best handle the rights of individuals and families when conducting genetic counseling.
For patients and the families who participate in genetic counseling it means that they increasingly become interdependent on having to collaborate to achieve what ultimately emerges as socially shared genetic risk estimates.

In anthropology, such genetic counseling practices have therefore been argued to give rise to novel forms of genetic responsibility within families seeking out genetic counseling. Genetic counselling practices not only make individuals responsible for their own health but also for the health of their family. Only through the collaborative responsibility of patients receiving genetic counselling, the knowledge of risks capable of saving the life of patients and genetically related kins can become a reality. Having to responsibly manoeuvre between individual rights to bodily knowledge and moral obligations towards a genetic family thus becomes the reality for patients and their families when participating in genetic counseling.

This dissertation departs in a comparison of cancer genetic counselling in China and Denmark. It specifically studies the role that locality plays in giving rise to different cancer genetic counselling practices and how these result in the emergence of different forms of genetic responsibility for patients and their families. Empirically, the dissertation departs in data from two consecutive fieldworks in China and Denmark in which very different genetic counselling practices and very different degrees of patient and family collaboration were encountered.

The study theoretically departs in the anthropological literature that sees genetic counselling as social practices and genetic responsibilities between patients and their families as the products of social negotiations within specific local clinical contexts.

When comparing differences between Chinese and Danish cancer genetic counselling, this PhD argues that these differences may be seen as the products of practices socially unfolding within two very different local ways of organizing health care systems. This different organisation gives rise to very different forms of local genetic responsibilities between patients and their families.
This PhD theoretically departs in a Science and Technology Study approach. It takes its central inspiration from the framework of *Body Multiple* and the method of *praxiography* developed by the anthropologist Annemarie Mol. Departing in Mol's framework, the study shows how the organization of health care systems may be approached, studied and understood as local conditions promoting unique webs of related human and non-human actors that make specific local everyday cancer genetic counseling practices both possible, necessary, and meaningful.
The material for the comparative praxiographic analysis was based upon qualitative data obtained through participant observation and interviews.

Comparing the organizational conditions surrounding Chinese and Danish cancer genetic counseling practices reveals notable differences in the organization of guidelines for genetic counselling for cancer, the financial governance of the health care system, and the organization of available health care data. This PhD argues that these conditions provide very different grounds for clinical practice.
The PhD demonstrates how the combination of locally developed guidelines for cancer genetic counselling in China, an increasing market orientated health care system in which each local hospital depends on patient out-of pocket payments, and a system where medical health record data is only accessible at the local hospital level, promotes local webs of related human and non-actors to clinical practices. These actors include guidelines containing individual risk and prevention categories, multiple patients in out-patient examination rooms, numbers, referrals and receipt notes in both the out-patient and laboratory facilities, and medical records that need to be brought along from other hospitals by the patient if to be used. To Chinese professionals, these webs of actors give rise to specific local highly time-constrained genetic counselling practices such as assessment of family histories, genetic tests, and risk estimation practices with a stringent focus upon delivering services solely to the individual paying patient. For patients participating in these practices, the result is that genetic counseling and genetic risk estimates emerge as orientated strictly towards them as individuals, leaving no need of but also no room for families within these practices.

This is in opposition to Danish practices. Here the combination of nationally developed guidelines for cancer genetic counselling, a welfare-based health care system in which genetic counselling is financed through a public taxation system, and a system of medical record archives that may be accessed by using Danish civil registration numbers, promotes local webs of human and non-human actors. These actors include guidelines containing family risk categories and categories for preventive interventions, health laws, civil registration numbers, nationally available medical records, consent forms and a system of welfare funding. To Danish professionals, these specific webs of actors give rise to counselling practices such as assessment of family histories using verified information based on information from national databases, genetic tests and risk estimation practices that all become highly dependent on the collaborative capabilities of patients and their families. It also means that the risk estimates that these practices produce have a stringent focus on families rather than individuals. For patients and their families this means that participation in Danish genetic counselling practices leave individual members of a family within an interdependent relationship with their other family members and with little room for individual autonomy.

These results demonstrate the formative role that different local organizational conditions of health care plays in the emergence of different cancer genetic counselling practices. They illustrate how local organizational conditions in China and Denmark provide different spaces of agency in which cancer genetic counselling practices may be negotiated among professionals, patients and their families, and how this results in very different genetic responsibilities between patients and families to become articulated in clinical practices in these two countries, respectively.

The PhD argues that by comparing cancer genetic counselling through a lens of organizational conditions using a comparative praxiographic approach, an important day-to-day practical perspective on clinical practice is provided. – a perspective that helps illustrate the profound roles of easily overlooked mundane human and non-human actors that such conditions operate through.

It also helps to provide new explorations and challenges to established cultural ways of thinking about family and individuals when studying genetic counselling and genetic responsibilities in western and non-western countries. The PhD demonstrates how a strict focus upon individuals in Chinese genetic counseling and a focus upon families in Danish genetic counseling effectively challenge traditional dichotomies seeing non-western countries as “sociocentric” and western countries as “individualistic”. It illustrates how taking a departure in specific practices and webs of actors may bring forth a different perspective to such established ideas, ensuring that genetic responsibilities become acknowledged as complex, contingent and also very strictly tied to the specificity of the individual practices at hand. The dissertation concludes that genetic counseling needs to be critical to such established dichotomies in future studies.

To clinical professionals working in China and Denmark, the comparison in this dissertation reveals the contingency and fluid nature of genetic practices and its products. It also shows how such practices leave professionals with a window of agency allowing possibilities for changes to be made.

The PhD concludes that although cancer genetic counseling practices are determined by the webs of related human and non-human actors that specific ways of organizing health care systems promote, it does not mean that the role of human actors should be underestimated Professional human actors, it argues, rather need to acknowledge the key role they play in defining the organizational conditions under which cancer genetic counseling may be unfolded.

The dissertation ends by looking to the future where recent developments could indicate that such changes in the organization of cancer genetic counseling could be on the way.

Danish summary

Denne ph.d.-afhandling sammenligner lokale cancergenetiske rådgivningspraksisser i sundhedssystemerne i Danmark og Kina samt den rolle, disse spiller i fremkomsten af nye former for genetisk ansvarlighed. Projektet bygger på et samarbejde mellem sundhedsprofessionelle i Danmark og Kina samt forskere fra DEFACTUM (en forskningsenhed i Region Midtjylland, Danmark).

Genetisk rådgivning og brugen af nye genetiske teknologier gør det muligt for kliniske professionelle at estimere, om patienter og familier, som deler DNA, er i risiko for at udvikle specifikke cancersygdomme såsom bryst- og/eller ovariecancer. Et sådant risikoestimat kan give patienter og deres familier muligheden for at opsøge relevante forebyggelsestiltag.

Men for at kliniske professionelle kan tilvejebringe et risikoestimat i den genetiske rådgivning, kræver det, at patienter og familier i fællesskab arbejder sammen med den professionelle. Dette sker i fællesskab ved at dele genetisk viden og ved at deltage i klinisk genetiske interventioner. I den kliniske litteratur er sådanne genetiske rådgivningspraksisser blevet beskrevet som givende anledning til mange kliniske udfordringer. Litteraturen har her lagt særligt vægt på at diskutere, hvordan klinikere bedst håndterer både individuelle og familiære rettigheder i klinisk genetisk rådgivningspraksis.
For de patienter og familier, som deltager i genetisk rådgivning, betyder det, at de i stigende grad bliver gensidigt afhængige af at kunne samarbejde for at opnå det, der bliver et socialt-genetisk risikoestimat.

I antropologien er genetisk rådgivning blevet set som givende anledning til fremkomsten af nye typer genetisk ansvar blandt medlemmer af de familier, som deltager i sådanne praksisser. Genetisk rådgivning gør ikke blot individer ansvarlige for deres egen sundhed, men også ansvarlige for familiens sundhed. Kun gennem en gensidigt ansvarlig deltagelse i genetisk rådgivning kan viden, som potentielt kan redde både patienten og dennes genetiske familie, blive opnået. Denne gensidigt ansvarlige deltagelse betyder imidlertid, at patienter og deres familier må lære at manøvrere mellem hensyntagen til deres egen individuelle kropslige autonomi og det sociale ansvar for andres kroppe, som deltagelse i genetisk rådgivning kræver.

Denne afhandling tager udgangspunkt i en komparation mellem cancergenetisk rådgivning i Kina og Danmark. Den studerer specifikt den rolle, som lokalitet spiller i udviklingen af forskellige rådgivningspraksisser, og hvordan disse giver anledning til udviklingen af meget forskellige former for genetisk ansvarlighed for patienter og deres familier.

Empirisk tager afhandlingen sit udgangspunkt i to feltarbejdsperioder i henholdsvis Kina og Danmark, hvor to meget forskellige typer af genetisk rådgivningspraksis med meget forskellig deltagelse af patienter og deres familier blev observeret.
Teoretisk tager studiet sit udgangspunkt i den antropologiske litteratur, hvor genetisk rådgivning ses som social praksis, og genetisk ansvar mellem patienter og deres familier som et resultat af sociale forhandlinger i specifikke lokale kliniske kontekster.

I sin komparation af forskellene på genetisk rådgivning i Kina og Danmark argumenterer denne ph.d.-afhandling for, at sådanne forskelle skal ses som produktet af, at disse sociale praksisser udfolder sig i sundhedssystemer, som på lokalt plan er organiseret meget forskelligt. Disse forskellige former for organisering af sundhedssystemer giver anledning til udviklingen af meget forskellige former for lokale genetiske ansvar, hvad angår patienter og deres familier.
Denne afhandling tager sit teoretiske udgangspunkt i en *science and technology studies*-tilgang. Den tager sin centrale inspiration fra det teoretiske begrebsapparat *body multiple* og metoden *praxiography* udviklet af antropologen Annemarie Mol. Med udgangspunkt i Mols begrebsapparat viser dette studium, hvordan organiseringen af sundhedssystemer kan studeres og forstås som særlige lokale betingelser, der fremmer unikke net af relaterede humane og non-humane aktører, og hvordan disse danner rammer for fremkomsten af mulige, nødvendige og meningsfulde lokale genetiske rådgivningspraksisser.
Den komparative praksiografiske analyse bygger på kvalitativt datamateriale, som er indhentet via etnografisk deltagerobservation og interviews.

I sammenligningen af de organisatoriske betingelser, under hvilke kinesisk og dansk genetisk rådgivning udfoldes, afsløres bemærkelsesværdige forskelle i organiseringen af retningslinjer for cancergenetisk rådgivning, i den finansielle styring af sundhedssystemerne og i organiseringen af sundhedsdata. Afhandlingen argumenterer, at disse forskellige organisatoriske betingelser skaber grundlaget for meget forskellig klinisk praksis.
Afhandlingen demonstrerer, hvordan kombinationen af lokalt udviklede retningslinjer for cancergenetisk rådgivning i Kina, et sundhedssystem baseret på stigende markedsvilkår, hvor hvert enkelt hospital er afhængig af *out-of-pocket*-betaling, og en organisering af sundhedssystemet, hvor journaldata kun er tilgængelige på et lokalt hospitalsniveau, fremmer lokale net af relaterede humane og non-humane aktører i klinisk praksis. Disse aktører omfatter lokale retningslinjer indeholdende risikokategorier og forebyggelsestiltag rettet mod den individuelle patient, multiple patienter ad gangen i ambulatoriets undersøgelseslokaler, nummersedler, henvisningsnoter og kvitteringer i både ambulatoriet og i laboratoriet samt journaler fra andre hospitaler, der skal medbringes af den enkelte patient, hvis de skal bruges i rådgivningen. For de kinesiske professionelle fremmer disse net af relaterede aktører specifikke lokale strengt tidsbegrænsende

rådgivningspraksisser såsom udredning af familiehistorien, genetiske tests og risikoestimerings-praksisser, som alle tager et strengt fokus på den enkelte patient, som har betalt. For patienter, som deltager i disse praksisser, er resultatet, at den genetiske rådgivning og det genetiske risikoestimat bliver strengt orienteret mod dem som individer, og der efterlades hverken noget behov for eller plads til familien i disse praksisser.

Dette står i kontrast til dansk praksis. Her eksisterer en kombination af nationalt udformede retningslinjer for cancergenetisk rådgivning, en velfærdsbaseret finansiel styring af sundheds-systemet gennem offentlige skatter, et system af patientjournaldatabaser og arkiver, som kan tilgås via et dansk civilregistreringsnummer (CPR). Dette fremmer særlige lokale net af relaterede humane og non-humane aktører. Disse aktører omfatter retningslinjer indeholdende særlige familierisikokategorier og kategorier for forebyggelsestiltag, sundhedslove, civile registrerings-numre, nationalt tilgængelige patientjournaler, samtykkeerklæringer og velfærdsbetalinger. For danske professionelle fremmer disse net af aktører specifikke lokale rådgivningspraksisser. Disse indbefatter udredning af familiehistorien ved hjælp af verificerede data indhentet i nationalt tilgængelige patientjournaldatabaser, genetiske tests og risikoestimeringspraksisser, der alle bliver særligt afhængige af patienter og deres familiers evner til at samarbejde. Det betyder også, at disse praksisser får et særligt fokus på familien. For patienter og deres familier betyder deltagelsen i genetisk rådgivning i Danmark, at individer efterlades i et gensidigt afhængighedsforhold til deres familie med ringe plads til individuel autonomi.

Disse resultater demonstrerer den formative rolle, som forskellige organisatoriske rammer for sundhedssystemet spiller i udviklingen af forskellige genetiske rådgivningspraksisser. De illustrerer, hvordan lokale organisatoriske rammer for sundhedssystemet i Kina og Danmark muliggør forskellige rum for agens, hvori cancergenetisk rådgivning kan blive forhandlet mellem professionelle, patienter og deres familier. De viser samtidig, at dette resulterer i fremkomsten af meget forskellige former for genetisk ansvar mellem patienter og deres familier i disse to lande.

Afhandlingen argumenterer for, at man ved at sammenligne cancergenetisk rådgivning gennem en linse af organisatoriske rammer for sundhedssystemer og ved brug af en komparativ praksiografisk tilgang opnår et særligt dagligdagsperspektiv på klinisk praksis. Et perspektiv, som hjælper med at illustrere den gennemgribende rolle, som hverdagsagtige humane og non-humane aktører, som sådanne organisatoriske rammer opererer igennem, spiller for klinisk praksis.

Denne afhandlings tilgang til genetisk rådgivning tilbyder også et udfordrende og eksplorerende blik på ellers etablerede måder at tænke om patienter og familier på i studier af genetisk rådgivning og genetisk ansvarlighed i vestlige og ikke-vestlige lande. Afhandlingen demonstrerer, hvordan et

strengt fokus på individer i kinesisk genetisk praksis og et særligt fokus på familier i dansk genetisk praksis kan udfordre traditionelle dikotomier, som ofte fremstiller ikke-vestlige lande som "sociocentriske" og vestlige lande som "individualistiske". Den viser, hvordan man ved at tage udgangspunkt i specifikke praksisser og net af aktører kan fremme et alternativt perspektiv på sådanne etablerede idéer. Et perspektiv, der sikrer, at genetisk ansvarlighed bliver anerkendt som et komplekst og foranderligt fænomen, som er strengt knyttet til de enkelte praksisser. Afhandlingen konkluderer, at fremtidige studier af genetisk rådgivning bør være kritiske over for sådanne dikotomier.

For professionelle i Kina og Danmark afslører afhandlingens komparation den genetiske rådgivnings foranderlige og flydende natur. Den viser også, at sådanne praksisser tilbyder rum for agens, som kan resultere i fremtidige forandringer.
Afhandlingen konkluderer, at skønt cancergenetiske rådgivningspraksisser er determinerede af net af relaterede humane og non-humane aktører fremmet af specifikke måder at organisere sundhedsvæsener på, så bør man være varsom med at undervurdere menneskers rolle heri som helhed. Professionelle bør snarere anerkende, at de som humane aktører kan spille en fremtrædende rolle i at definere de organisatoriske rammer, som fremtidige cancergenetiske rådgivningspraksisser kan komme til at udfolde sig i.
Afhandlingen afsluttes med et blik mod fremtiden. Den illustrerer, hvordan nylige udviklinger i måden, hvorpå sundhedsvæsenet organiseres i Kina og Danmark, kan betyde forandringer i eksisterende cancergenetiske rådgivningspraksisser.

References

Anagnost, A. (2004). The corporeal politics of quality (suzhi). *Public Culture, 16*(2), 189-208. doi:10.1215/08992363-16-2-189

Atkinson, P. (1995). *Medical talk and medical work*. London: Sage.

Bak, A. H. (2012). *Danmark får internationalt genom-forskningscenter [English: Denmark opens an international genome-research center]*. Retrieved 01/25, 2015, from http://nyheder.ku.dk/alle_nyheder/2012/2012.2/bgi_gensekvensering/

Barad, K. (2007). *Meeting the universe halfway : Quantum physics and the entanglement of matter and meaning*. Durham: Duke University Press.

Beck, S., & Niewöhner, J. (2013). Localising genetic testing and screening in Cypruss and Germany: Contingencies, continuities, ordering effects and bio-cultural intimacy. In P. Atkinson, P. Glasner & M. Lock (Eds.), *Handbook of genetics and society. mapping the new genomic era* (pp. 76-93). New York: Routledge.

Bell, D. A. (2008). *China's new Confucianism. politics and every day life in a changing socioety*. Oxford: Princeton University Press.

Bell, C. (1992). *Ritual theory, ritual practice*. New York: Oxford University Press.

Berg, M., Horstman, K., Plass, S., & Heusden, M. V. (2000). Guidelines, professionals and the production of objectivity: Standardisation and the professionalism of insurance medicine. *Sociology of Health and Illness, 22*(6), 765-791.

Bernard, H. R. (1994). *Research methods in anthropology : Qualitative and quantitative approaches* (2. ed. ed.). London: SAGE.

Bharadway, A. (2003).
Why adoption is not an option in India: The visibility of infertility, the secrecy of donor insemination, and other cultural complexities *Social Science & Medicine, 56*, 1867-1880.

Bharadway, A. (2008). Biosociality and biocrossings: Encounters with assisted conception and embryonic stem cells in India. In S. Gibbon, & C. Novas (Eds.), *Biosocialities, genetics and the social sciences. making biologies and identities* (pp. 98-116). New York: Routledge.

Blomqvist, A., & Qian, J. (2008). Health system reform in China: An assesment of recent trends. *The Singapore Economic Review, 53*(1), 5-26. doi:10.1142/S0217590808002811

Blumenthal, D., & Hsiao, W. (2005). Privatization and its discontents - the evolving Chinese health care system. *The New England Journal of Medicine, 353*(11), 1165-1170.

Bougie, O., & Weberpals, J. I. (2011). Clinical considerations of *BRCA*1- and *BRCA2*-mutation carriers: A review. *International Journal of Surgical Oncology, 2011*, 1-11. doi:10.1155/2011/374012

Bourdieu, P. (1977). *Outline of a theory of practice*. Cambridge: Cambridge University Press.

Shenghuo. BTV, B. D. (Director). (2015, April 21st. , 18.30-18.45).[Motion Picture] Beijing, China

Burke, W., Daly, M., Garber, J., Botkin, J., Kahn, M. J. E., Lynch, P., et al. (1997). Recommendations for follow-up care of individuals with an inherited predisposition to cancer: II. *BRCA1* and *BRCA2*. *Jama, 277*(12), 997-003. doi:10.1001/jama.1997.03540360065034

Callon, M. (1987). Society in the making: The study of technology as a tool for sociological analysis. In W. Bijker, T. Hughes & T. & Pinch (Eds.), *The social construction of technological systems* (pp. 83-103). Cambridge: MIT Press.

Candea, M. (2009). Arbitrary locations: In defence of the bounded field site. In M. Falzon (Ed.), *Multi-sited ethnography. theory, praxis and locality in contemporary research* (E-Book ed., pp. 25-46) Ashgate.

Cao, A., Huang, L., & Shao, Z. (2017). The preventive intervention of hereditary breast cancer. In E. Song, & H. Hu (Eds.), *Translational research in breast cancer. advances in experimental medicine and biology* (1026th ed., pp. 40-57). Singapore: Springer.

Cao, W., Wang, X., & Li, J. (2013). Hereditary breast cancer in the han Chinese population. *Journal of Epidemiology, 23*(2), 75-84. doi:10.2188/jea.JE20120043

Cetina, K. K. (2001). Objectual practice. In Schatzki,T.& Cetina, K. & Savigny, E.V. (Ed.), *The practice turn in contemporary theory* (pp. 175-188). London: Routledge.

Clarke, A. E., Shim, J. K., Mamo, L., Fosket, J. R., & Fishman, J. R. (2003). Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine. *American Sociological Review, 68*(2), 161-194.

Cox, S. M., & McKellin, W. (1999). 'There´s this thing in our family': Predictive testing and the construction of risk for huntington disease. *Sociology of Health & Illness, 21*(5), 622-646.

dAgincourt-Canning, L. (2001). Experiences of genetic risk: Disclosure and the gendering of responsibility. *Bioethics, 15*(3), 231-247. doi:10.1111/1467-8519.00234

Danish Board of Health. (2007). *Rapport for specialet klinisk genetik. [English: Report for the medical speciality clinical genetics]*. Copenhagen: Sundhedsstyrelsen.

Danish Health Law Chapter 5 §15;
LBK Nr 1202,(2014) Retrieved from Www.Retsinformation.Dk 25.08.2017

Danish Health Law Chapter 5 §16, Stk 2;
LBK Nr 1202, (2014). Retrieved from Www.Retsinformation.Dk 25.08.2017

Danish Health Law Chapter 9 §42a;
LBK NR 1202, (2014). Retrieved from Www.Retsinformation.Dk 25.08.2017

Danske Regioner. (2015). *Personlig medicin og individualiseret behandling. oplæg til en samlet dansk indsats.[English: Personalized medicine and indvidualized treatment. A call for a joint danish program]*. Copenhagen: Danske Regioner.

Davis, d., & Harell, S. (Eds.). (1995). *Chinese families in the post-mao era*. US: University of California Press.

DBCG. (2014). *Guideline 19 arvelig cancer mammae - ovarii retrieved from www.dbcg.dk/DBCG%20Retningslinier.htm*. Online: DBCG.

De Laet, M., & Mol, A. (2000). The zimbabwe bush pump mechanics of a fluid technology. *Social Studies of Science, 3*(2), 225-263.

Dean, M. (1999). *Governmentality : Power and rule in modern society*. London: Sage.

Döring, O. (Ed.). (2009). *Ethical governance of biological and biomedical reseach: Chinese-european co-operation. TEXTBOOK. life sciences in translation - A Sino-european dialogue on ethical governance of the life sciences* (Second Edition ed.) Sixth Framework Programme, BIONET.

DSMG. (2009). *Praktiske retningslinier for og kvalitetssikring af genetisk udredning og rådgivning [English: Practical guidelines and quality assurance of genetic elucisdation and counseling] retrieved from ww.dsmg.dk* (Guideline No. 1). Online: Dansk Selskab for Medicinsk Genetik.

Dupré, J. (2008). What genes are, and why there are no genes for race. In B. A. Koenig, S. Lee & S. Richardson (Eds.), *Revisiting race in a genomic age,* (pp. 39-55) Rutgers University Press.

Easton, D. F., Ford, D., & Bishop, D. T. (1995). Breast and ovarian cancer incidence in *BRC*A1-mutation carriers. breast cancer linkage consortium. *American Journal of Human Genetics, 56*(1), 265.

Easton, D., Narod, S., Ford, D., & Steel, M. (1994). The genetic epidemiology of *BRCA*1. *The Lancet, 344*(8924), 761-761. doi:10.1016/S0140-6736(94)92256-X

Edwards, J., Franklin, S., Hirsch, E., Price, F., & Strathern, M. (1998). *Technologies of procreation. kinship in the age of assisted conception* (2nd ed.). New York: Routledge.

Eggleston, K., Ling, L., Qingyue, M., Lindelow, M., & Wagstaff, A. (2008). Health service delivery in China: A literature review. *Health Economics, 17*(2), 149-165. doi:10.1002/hec.1306

Falzon, M. (2009). *Multi-sited ethnography : Theory, praxis and locality in contemporary research*. Farnham, England: Ashgate.

Featherstone, K., Atkinson, P., Bharadway, A., & Clarke, A. (2006). *Risky relations. family, kinship and the new genetics* (first edition ed.). Oxford / New York: Berg.

Featherstone, M. (1991). *Consumer culture and postmodernism*. London: Sage.

Feidson, E. (Ed.). (1989). *Medical work in America. Essays on health care*. New Haven: Yale University Press.

Finkler, K. (2001). *Experiencing the new genetics. family and kinship on the medical frontier*. Philadelphia: University of Pennsylvania Press.

Finkler, K., Skrzynia, C., & Evans, J. P. (2003). The new genetics and its consequences for family, kinship, medicine and medical genetics. *Social Science & Medicine, 57*(3), 403-412. doi:10.1016/S0277-9536(02)00365-9

Fodor, F. H., Weston, A., Bleiweiss, I. J., McCurdy, L. D., Walsh, M. M., Tartter, P. I., et al. (1998). Frequency and carrier risk associated with common *BRCA1* and *BRCA2* mutations in Ashkenazi jewish breast cancer patients. *The American Journal of Human Genetics, 63*(1), 45-51. doi:10.1086/301903

Foucault, M. (1994). *Viljen til viden. seksualitetens historie 1* [English: The will to knowledge. The history of sexuality ver.1] (2nd ed.). Copenhagen: Det Lille Forlag.

Franklin, S. (2001). Biologization revisited: Kinship theory in the context of the new biologies. In S. Franklin, & S. Mckinnon (Eds.), *Relative values. reconfiguring kinship studies* (pp. 302-328). US: Duke University Press.

Franklin, S. (2006). Origin stories revisited:IVF as an anthropological project. *Culture, Medicine and Phsyciatry, 30*(4), 547-555.

Freedman, M. (1979). *The study of Chinese society*. Stanford, CA: Stanford University Press.

Gammeltoft, T., & Nguyen, H. T. T. (2007). Fetal conditions and fatal decisions: Ethical dilemmas in ultrasound screening in Vietnam. *Social Science & Medicine, 64*(11), 2248-2259. doi:10.1016/j.socscimed.2007.02.015

Gao, X., Xu, J., Sorwar, G., & Croll, P. (2013). Implementation of E-health record systems and E-medical record systems in China. *The International Technology Management Review, 3*(2), 127-139.

Geiger, T. (1935). *Samfund og arvelighed en sociologisk undersøgelse* [English: Society and heredity. A sociological study]. Copenhagen: Martins Forlag.

Gibbon, S. (2007). *Breast cancer genes and the gendering of knowledge. science and citizenship in the cultural context of the 'new genetics"* . New York: Palgrave Macmillan.

Gibbon, S. (2008). Charity, breast cancer activism and the iconic figure of the *BRCA* carrier. In S. Gibbon, & C. Novas (Eds.), *Biosocialities, genetics, and the social sciences.making biologies and identities* (pp. 19-37). New York: Routledge.

Gibbon, S. (2013). Ancestry, temporality, and potentiality : Engaging cancer genetics in southern Brazil. *Current Anthropology, 54*(S7), 107-117. doi:10.1086/671400

Gibbon, S. (2011). Family medicine, ?la herencia? and breast cancer; understanding the (dis)continuities of predictive genetics in Cuba. *Social Science & Medicine, 72*(11), 1784-1792. doi:10.1016/j.socscimed.2010.09.053

Gibbon, S., Kampriani, E., & Nieden, A. z. (2010). *BRCA* patients in Cuba, Greece and Germany: Comparative perspectives on public health, the state and the partial reproduction of 'neoliberal' subjects. *BioSocieties, 5*(4), 440-466. doi:10.1057/biosoc.2010.28

Gordon, D. (2014). It takes a partuclar world to produce and enact BRCA testing: The us had it, italy had another. In S. Gibbon, G. Joseph, J. Mozersky, A. Zur Nieden & S. Palfner (Eds.), *Breast cancer gene research and medical practices* (pp. 109-126). Oxford: Routledge.

Greenhalgh, S. (2009). The Chinese biopolitical: Facing the twenty-first century. *New Genetics and Society, 28*(3), 205-222. doi:10.1080/14636770903151992

Greenhalgh, S., & Winckler, E. A. (2005). *Governing China's population : From leninist to neoliberal biopolitics*. Stanford, Calif.: Stanford University Press.

Groth, L. (2015). *Patient records and clinical overview - the creation of clinical overview among physicians in daily clinical practice*. (Doctoral Dissertation, Arts, Aarhus University).

Hall, J. M., Lee, M. K., Newman, B., Morrow, J. E., Anderson, L. A., Huey, B. C., et al. (1990). Linkage of early-onset familial breast cancer to chromosome 17q21. *Science, 250*(4988), 1684-1689. doi:10.1126/science.2270482

Hallowell, N. (1999). Doing the right thing: Genetic risk and responsibility. *Sociology of Health and Illness, 21*(5), 597-621. doi:10.1111/1467-9566.00175

Hammersley, M., & Atkinson, P. (1995). *Ethnography : Principles in practice* (2. edition ed.). London: Routledge.

Hannerz, U. (2003). Being there... and there... and there! reflections on multi-site ethnography. *Ethnography, 4*(2), 201-216. doi:10.1177/14661381030042003

Harper, P. S. (2004). *Practical genetic counselling* (6th ed ed.). Oxford: Oxford University Press.

Hastrup, K. (2003). Introduktion. den antropologiske videnskab. In K. Hastrup (Ed.), Ind i verden. En grundbog i antropologisk analyse. [English: *Into the world. an introduction to anthropological method*] (pp. 9-34). Copenhagen Hans Reitzels Forlag.

He, A. J., & Qian, J. (2016). Explaining medical disputes in Chinese public hospitals: The doctor-patient relationship and its implication for health policy reform. *Health, Economics, Policy and Law, 11*, 359-378.

Hesketh, T., Wu, D., Mao, L., & Ma, N. (2012). Violence against doctors in China. *British Medical Journal,* , 345-355.

Himes, D. O., Clayton, M. F., Donaldson, G. W., Ellington, L., Buys, S. S., & Kinney, A. Y. (2016). Breast cancer risk perceptions among relatives of women with uninformative negative *BRCA*1/2 test results: The moderating effect of the amount of shared information. *Journal of Genetic Counseling, 25*(2), 258-269. doi:10.1007/s10897-015-9866-0

Hodgeson, S., Milner, B., Brown, I., Bevilacqua, G., Chang-Claude, J., Eccles, D., et al. (1999). Cancer genetic services in europe. *Disease Markers, 15*, 3-13.

Hodgson, S. V., Foulkes, W. D., Eng, C., & Maher, E. R. (Eds.). (2014). *A practical guide to human cancer genetics*. London: Springer - Verlag.

Holhmann, K. (2014). *Flere danskere gentestes for arvelige sygdomme*
TV2 - nyheder
[English: More Danes are genetically tested for hereditary diseases]
TV2- news. Retrieved October, 19th, 2014, from http://nyheder.tv2.dk/samfund/2014-10-19-flere-danskere-gentestes-for-arvelige-sygdomme

Hou, X., & Xiao, L. (2012). An analysis of the changing doctor-patient relationship in China. *Journal International De Bioéthique, 8*, 83-94.

Hougaard, J. L., Østerdal, L. P., & Yu, Y. (2011). The Chinese healthcare system : Structure, problems and challenges. *Applied Health Economics and Health Policy, 9*(1), 1-13. doi:10.2165/11531800-000000000-00000

Hylland Eriksen, T. (1998). *Små steder - STORE SPØRGSMÅL. innføring i socialantropology* [English: Small places - LARGE QUESTIONS. Introduction to social anthropology]. Oslo: Universitetsforlaget.

Jiongtu, T. (2014). Yinao: Protest and violence in China's medical sector. *Berkeley Journal of Sociology,* , 15th January 2018.

Keating, P., & Cambrosio, A. (2006). *Biomedical platforms:Realigning the normal and the pathological in late-twentieth-century medicine* (1 edition ed.). Cambridge: The MIT Press.

Keenen, R. (1994). The human genome project:Creator of the potentially sick, potentially vulnerable, potentially stigmatized? In I. Robinson (Ed.), *Life and death under high technology medicine* (pp. 49-64). Manchester: Manchester University Press.

Keller, E. F. (2000). *The century of the gene*. London: Harward University Press.

Kenen, R., Ardern-Jones, A., & Eeles, R. (2003). Living with chronic risk: Healthy women with a family history of breast/ovarian cancer. *Health, Risk & Society, 5*(3), 315-331. doi:10.1080/1369857031000160700 3

Kleinman, A. (1997). *Writing at the margin. discourse between anthropology and medicine*. Berkeley: University of California Press.

Koch, L. (2000). *Tvangssterilisation i danmark 1929-1967* [English: Forced sterilization in Denmark 1929-1967]. Copenhagen: Gyldendal.

Koch, L. (2010). *Racehygiejne i danmark 1920-1956* [English: Racial hygiene in Denmark 1920-1956]. Copenhagen: Informations Forlag.

Koch, L., & Svendsen, M. N. (2005). Providing solutions-defining problems: The imperative of disease prevention in genetic counselling. *Social Science & Medicine, 60*(4), 823-832.

Konrad, M. (2005). *Narrating the new predictive genetic:Ethics, ethnography and science*. Cambridge: Cambridge University Press.

Lash, S., & Urry, J. (2002). *Economies of signs and space*. London: Sage.

Latour, B. (2000). When things strike back: A possible contribution of 'science studies' to the social sciences. *The British Journal of Sociology, 51*(1), 107-123. doi:10.1080/000713100358453

Latour, B. (2007). *Reassembling the social : An introduction to actor-network-theory*. Oxford: Oxford University Press.

Law, J. (2008). Actor-network theory and material semiotics. In B. S. Turner (Ed.), *The new Blackwell companion to social theory* (3rd Edition ed.,). Oxford: Blackwell.

Law, J., & Mol, A. (2008). The actor-enacted: Cumbrian sheep in 2001. In C. Knappett, & L. Malafouris (Eds.), *Material agency. Towards a non-anthropocentric approach* (pp. 57-77). New York: Springer.

Lee, A. V., Oestereich, S., & Davidson N.E. (2014). The molecular biology of breast cancer. In J. Mendelsohn, Howley P.M., M. A. Israel, J. W. Gray & Thompson C.B. (Eds.), *The molecular basis of cancer* (4th ed.,) Saunders -Elsevier.

Liebman, B. L. (2012). Malpractice mobs: Medical dispute resolutionin China . *Columbia Law Review, 113*

Lock, M., Lloyd, S., Sharples, R., & Freeman, J. (2006). When it runs in the family: Putting susceptibility genes in perspective. *Public Understanding of Science, 15*(3), 277-300.

Lock, M., & Nguyen, V. (2010). *An anthropology of biomedicine*. Chichester, West Sussex: Wiley-Blackwell.

Lou, S., Petersen, O. B., Jørgensen, F. S., Lund, I. C. B., Kjærgaard, S., Danish Cytogenetic Central Registry Study Group, et al. (2017). National screening guidelines and developements in prenetal diagnosis and live births of downs syndrome in 1973-2016. *Acta Obstetricia Et Gynecologica Scandinavia, 97*, 195-203.

Lupton, D. (1995). *The imperative of health : Public health and the regulated body*. London: Sage.

Marcus, G. E. (1995). Ethnography in/of the world system: The emergence of multi-sited ethnography. *Annual Review of Anthropology, 24*(1), 95-117. doi:10.1146/annurev.an.24.100195.000523

Miettinen, R. (1999). The riddle of things: Activity theory and actor□network theory as approaches to studying innovations. *Mind, Culture and Activity, 6*, 170-195.

Mol, A. (2010). Actor-network theory: Sensitive terms and enduring tensions. *Kölner Zeitschrift Für Soziologie Und Sozialpsychologie, 50*(Sonderheft), 253-269.

Mol, A. (2002). *The body multiple : Ontology in medical practice*. Durham: Duke University Press.

Nahman, M. (2008). Synecdochic ricochets: Biosocialities in a Jerusalem IVF clinic. In S. Gibbon, & C. Novas (Eds.), *Biosocialities, genetics and the social sciences. making biologies and identities* (pp. 117-135). New York: Routledge.

Nicolini, D., & Monteiro, P. (2017). The practice approach: For a praxiology of organizational and management studies. In Tsouaks, H. & Langley, A. (Ed.), *Handbook of process organizational studies* (pp. 110-126). London: Sage.

Nielsen, H. (1991). *CPR- Danmarks folkeregister. [English: CPR- denmarks public peoples register]*. Copenhagen: CPR-Kontoret.

Niewöhner, J., & Scheffer, T. (2010). Introduction thickening comparison: On the multiple facets of comparability. In J. Niewöhner, & T. Scheffer (Eds.), *Thick comparison : Reviving the ethnographic aspiration* (pp. 17-42). Leiden: Brill.

Novas, C., & Rose, N. (2002). Genetisk risiko og fødslen af det somatiske individ. *Slagmark, Nr. 35 (2002)*, 99-130.

Offit, K., Groeger, E., Turner, S., Wadsworth, E. A., & Weiser, M. A. (2004). The "duty to warn" a patient's family members about hereditary disease risks. *Jama, 292*(12), 1469-1473. doi:10.1001/jama.292.12.1469

Olejaz, M., Nielsen, A. J., Rudkjøbing, A., Birk, H. O., Krasnik, A., & Hernandez-Quevedo, C. (Eds.). (2012). *Health systems in transition, Denmark: Health system review* (vol. 14, No. 2 ed.). Copenhagen: University Of Copenhagen.

Ong, A., & Collier, S. J. (2005). *Global assemblages : Technology, politics and ethics as anthropological problems*. Malden, MA: Blackwell Publishing.

Ormond, K. E. (2008). Medical ethics for the genome world: A paper from the 2007 william beaumont hospital symposium on molecular pathology. *Journal of Molecular Diagnostics, 10*(5), 377-382. doi:10.2353/jmoldx.2008.070162

Ortner, S. B. (1984). Theory in anthropology since the sixties. *Comparative Studies in Society and History, 26*(1), 126-166. doi:10.1017/S0010417500010811

Pálsson, G. (2007). *Anthropology and the new genetics*. Cambridge: Cambridge University Press.

Pan, Y., Yang, X. h., He, J. P., Gu, Y. H., Zhan, X. L., Gu, H. F., et al. (2015). To be or not to be a doctor, that is the question: A review of serious incidents of violence against doctors in China from 2003 to 2013. *Journal of Public Health, 23*(2), 111. doi:10.1007/s10389-015-0658-7

Parthasarathy, S. (2007). *Building genetic medicine. breast cancer, technology, and the comparative politics of health*. Cambridge: MIT Press.

Peshkin, B. N., Alabek, M. L., & Isaacs, C. (2010). *BRCA*1/2 mutations and triple negative breast cancers. *Breast Disease, 32*(0), 1-9.

Pickering, A. (1995). *The mangle of practice : Time, agency, and science*. Chicago: University of Chicago Press.

Pickering, A.,ed., & Guzik, K.,ed. (2008). *The mangle in practice : Science, society, and becoming*. Durham, NC: Duke University Press.

Potter, A. L. (1988). The cultural construction of emotion in rural Chinese social life. *Ethos, 16*(2), 181-208.

Rabinow, P. (2005). Artificiality and enlightenment. from sociobiology to biosociality. In Inda, J. X. (Ed.) *Anthropologies of modernity : Foucault, governmentality, and life politics.* (pp. 179-193). Malden, MA: Blackwell Pub.

Rapp, R. (1999). *Testing the woman, testing the fetus. the social impact of amniocentesis in america*. New York: Routledge.

Rapp, R. (1994). Women's response to prenatal diagnosis: A sociocultural perspective on diversity. In K. Rothenberg, & E. Thomson (Eds.), *Women and prenatal testing: Facing the challenge of genetic technology* (pp. 219-234). Ohio: Ohio State University Press.

Rapp, R. (2014). Foreword. In S. Gibbon, G. Josph, J. Mozersky, A. Zur Nieden & S. Palfner (Eds.), *Breast cancer gene research and medical practices.* (first ed., pp. xvi-xx). London: Routledge.

Richards, M. (1996). Families, kinship and genetics. In T. Marteau, & S. Richards (Eds.), *The troubled helix. social and psychological implications of the new human genetics.* (pp. 249-273), Cambridge: Cambridge University Press.

Riley, B. D., Culver, J. O., Skrzynia, C., Senter, L. A., Peters, J. A., Costalas, J. W., et al. (2012). Essential elements of genetic cancer Risk Assessment, counseling, and testing: updated recommendations of the national society of genetic counselors. *Journal of Genetic Counseling, 21*(2), 151-161.

Roberts, E. F. S. (2007). Extra embryos:The ethics of cryopreservation in Equador and elsewhere. *American Ethnologist, 34*(1), 181-199.

Roberts, E. F. S. (2008). Biology, sociality and reproductive modernity in ecuadorian *in-vitro* fertilization: The particulars of place. In S. Gibbon, & C. Novas (Eds.), *Biosocialities, genetics and the social sciences. making biologies and identities.* (pp. 79-97), New York: Routledge.

Roberts, E. F. S. (2011). Abandonment and accumulation: Embryonic futures in the United States and Ecuador. *Medical Anthropology Quarterly, 25*(2), 232-253. doi:10.1111/j.1548-1387.2011.01151.x

Rogoziska-Szczepka, J., Utracka-Hutka, B., Grzybowska, E., Maka, B., Nowicka, E., Smok-Ragankiewicz, A., et al. (2004). *BRCA1* and *BRCA2* mutations as prognostic factors in bilateral breast cancer patients. *Annals of Oncology : Official Journal of the European Society for Medical Oncology / ESMO, 15*(9), 1373-1376. doi:10.1093/annonc/mdh352

Rose, N. (2011). Biological citizinship and its forms. In E. Zhang, A. Kleinman & Weiming (Eds.), *Governance of llife in Chinese moral experience*. (pp. 237-265) New York: Routledge.

Rose, N., & Novas, C. (2005). Biological citizenship. In A. Ong, & S. J. Collier (Eds.), *Global assemblages. technology, politics, and ethics as anthropological problems* (pp. 439-463). Malden, MA: Blackwell.

Rouse, J. (1996). *Engaging science : How to understand its practices philosophically*. Ithaca, N.Y.: Cornell University Press.

Rudiger, M. (2003). *Statens synlige hånd.om lovgivning, stat og individ i det 20 århundrede* [English: The visible hand of the state: About law, state and individual in the 20th Century]. Gylling: Narayana Press.

Sachs, L. (2014). Medikalisering av cancerfamiljer ger framtida skuggor. [English: Medicalisation of cancer families gives future shadows] *Tidskrift for Forskning i Sygdom Og Samfund, 20*, 47-57.

Sachs, L. (1999). Knowledge of no return: Getting and giving information about genetic risk. *Acta Oncologica, 38*(6), 735-740. doi:10.1080/028418699432888

Sachs, L. (2004). The new age of the molecular family: an anthropological view on the medicalisation of kinship. *Scandinavian Journal of Public Health, 32*(1), 24-29. doi:10.1080/14034940310007987

Sleeboom-Faulkner, M. (2010). Reproductive technologies and the quality of offspring in asia: Reproductive pioneering and moral pragmatism? *Journal Culture, Health & Sexuality an International Journal for Research, Intervention and Care, 12*(2), 139-152.

Sleeboom-Faulkner, M. (2014). *Global morality and life science practices in asia. assemblages of life.* UK: Palgrave Macmillan.

Skolnick, M. H., Frank, T., Shattuck-Eidens, D., & Tavtigian, S. (1997). Genetic susceptibility to breast and ovarian cancer. *Pathologie-Biologie, 45*(3), 245-249.

Spradley, J. p. (1979). *The ethnographic interview*. US: Wadsworth.

Spradley, J. P. (1980). *Participant observation*. US: Wadsworth.

Stafford, C. (2000). Chinese patriliny and the cycles of *yang* and *laiwang*. In J. Carsten (Ed.), *Cultures of relatedness. new approaches to the study of kinship* (pp. 37-54). Cambridge: Cambridge University Press.

Stockman, N. (2000). *Understanding Chinese society.* Cambridge: Polity Press.

Strathern, M. (1992). *Reproducing the future. anthropology, kinship, and the new reproductive technologies* . New York: Routledge.

Struewing, J., Tarone, R., Brody, L., Li, F., & Boice, J. (1996). BRCA1 mutations in young women with breast cancer. *The Lancet, 347*(9013), 1493-1493. doi:10.1016/S0140-6736(96)91732-8

Sui, S. (2009). The practice of genetic Counselling—A comparative approach to understanding genetic counselling in China. *BioSocieties, 4*(4), 391-405. doi:10.1017/S1745855209990317

Sui, S. (2010). *Vulnerable populations and genetic disorders: A socio-science approach to the application of genetic technology in china*. (Doctoral Dissertation, University of Amsterdam).

Sui, S., & Sleeboom-Faulkner, M. (2010a). Genetic testing for duchenne muscular dystrophy in China: Vulnerabilities among chinese families. *Frameworks of choice. predictive and genetic testing in asia* (pp. 167-182). Amsterdam: Amsterdam University Press.

Sui, S., & Sleeboom-Faulkner, M. (2010b). Choosing offspring: Prenatal genetic testing for thalassaemia and the production of a 'saviour sibling' in China. *Culture, Health & Sexuality, 12*(2), 167-175.

Sui, S., & Sleeboom-Faulkner, M. (2007). Commercial genetic testing in mainland China: Social, financial and ethical issues. *Journal of Bioethical Inquiry, 4*(3), 229-237. doi:10.1007/s11673-007-9062-5

Sui, S., & Sleeboom-Faulkner, M. (2015). Commercial genetic testing and its governance in Chinese society. *Minerva. A Review of Science, Learning and Policy, 53*(3), 215-234.

Sundheds & Ældreministeriet. (2016). *Personlig medicin til gavn for patienterne. klar diagnose, måltettet behandling, styrket forskning. national strategi for personlig medicin 2017-2020. [English: Personalized medicine to benefit patients. clear diagnosis, precision treatment and strengthened research. national strategy for persnonalized medicine 2017-2020]*. Copenhagen: Sundheds & Ældreministeriet.

Surbone, A. (2011). Social and ethical implications of BRCA testing. *Annals of Oncology, Supplement 1*, 60-66.

Svendsen, M. N. (2005). Pursuing knowledge about a genetic risk of cancer. In R. Jenkins, H. Jessen & V. Steffen (Eds.), *Managing uncertainty. ethnographic studies of illness, risk and the struggle for control*. Critical anthropology 2nd edit. (pp 93-122), Copenhagen: Museum Tusculanum.

Svendsen, M. N. (2004). *The space in the gap - A study of the social implications of cancer genetic counselling and testing in Denmark*. (Doctoral Dissertation, Department of Social Sciences - University of Copenhagen).

Svendsen, M. N. (2006). The social life of genetic knowledge: A case-study of choices and dilemmas in cancer genetic counselling in Denmark. *Medical Anthropology, 25*(2), 139-170.

Tibben, A., Duivenvoorden, H. J., Niermeijer, M. F., Vegter-van der Vlis, M., Roos, R. A., & Verhage, F. (1994). Psychological effects of presymptomatic DNA testing for huntington's disease in the Dutch program. *Psychosomatic Medicine, 56*(6), 526-532.

Vallgårda, S. (1999). Rise, heyday and incipient decline of specialization. hospitals in Denmark 1930–1990. *International Journal of Health Services, 29*, 431-457.

Vallgårda, S. (1992). *Sygehuse of sygehuspolitik i Danmark. et bridrag til det specialiserede sygehusvæsens historie 1930-1987* [English: Hospitals and hospital policy in Denmark. A contribution to the history of of specilized hospitals 1930-1987]. Copenhagen: DJØF's Forlag.

Vallgårda, S. (2003). *Folkesundhed som politik. danmark og sverige fra 1930 til i dag.* [English: Public Health as Politics. Denmark and Sweden from 1930 until today]. Aarhus: Aarhus Universitetsforlag.

Vos, J., Menko, F., Jansen, A., Asperen, C., Stiggelbout, A., & Tibben, A. (2011). A whisper-game perspective on the family communication of DNA-test results: A retrospective study on the communication process of BRCA1/2-test results between proband and relatives. *Familial Cancer, 10*(1), 87-96. doi:10.1007/s10689-010-9385-y

Wadel, C. (1991). *Feltarbeid i egen kultur : En innføring i kvalitativt orientert samfunnsforskning* [Fieldwork in Own Culture:An Introduction to Qualitative Orientated Societal Research]. Flekkefjord: SEEK.

Waldby, C. (2009). Biobanking in Singapore: Post-developmental state, experimental population. *New Genetics and Society, 28*(3), 253-265. doi:10.1080/14636770903151943

Wen, J. Z., You, J. G., Qing, B. L., & Dan, X. (2006). Breast cancer in China: Demand for genetic counselling and testing. *Genetics in Medicine, 8*(3), 196-197.

Wolcott, H. F. (2005). *The art of fieldwork*. UK: Altamira Press.

Woolgar, S., & Lezaun, J. (2013). The wrong bin bag: A turn to ontology in science and technology studies. *Social Studies of Science, 43*(3), 321-340.

Wooster, R., Neuhausen, S., Mangion, J., Quirk, Y., Ford, D., Collins, N., et al. (1994). Localization of a breast cancer susceptibility gene, BRCA2, to chromosome 13q12-13. *Science, 265*(5181), 2088-2090. doi:10.1126/science.8091231

Wu, Q., Zhao, L., & Ye, X. C. (2016). Shortage of healthcare professionals in China. urgent action is needed to increase recruitment and improve staff retention to cope with the rising demand for healthcare. *British Medical Journal, 354*

Xinhua. (Xinhua | Updated: 2017-10-31 10:54). *China to create gigantic DNA database.* Retrieved 02.20, 2018, from http://www.chinadaily.com.cn/china/2017-10/31/content_33930020.htm

Yan, Y. (2009). *The individualization of Chinese society*. Oxford: Berg.

Yip, W. C., Hsiao, W. C., Chen, W., Hu, S., Ma, J., & Maynard, A. (2012). Early appraisal of China's huge and complex health-care reforms. *The Lancet, 379*(9818), 833-842. doi:10.1016/S0140-6736(11)61880-1

Yu, a., Hongyan, C., Li, J., Bailin, W., & Daru, L. (2013). Genetic counseling training in China: A pilot program at Fudan university. *North American Journal of Medical Science, 6*(4), 221-222.

Zhang, L., Stone, T., & Zhang, J. (2017). Understanding the rise of yinao in China: A commentary on the little known phenomenon of health care violence. *Nursing and Health Sciences, 19*(2), 183-187.

Zhang, L., & Liu, N. (2014). Health reform and out-of-pocket payments: Lessons from China. *Health Policy and Planning, 29*(2), 217-226. doi:10.1093/heapol/czt006

Zhang, Y., Feng, Y., Qi, Y., & Zhan, S. (2014). Current situation and challenge of registry in China. *Frontiers of Medicine, 8*(3), 294-299.

Zhao, X., Wang, P., Tao, X., & Zhong, N. (2013). Genetic services and testing in china. *Journal of Community Genetics, 4*(3), 379-390. doi:10.1007/s12687-013-0144-2

Zhu, J. (2013). Projecting potentiality: Understanding maternal serum screening in contemporary China. *Current Anthropology, 54*(7), 36-44.

Appendix 1 – Danish risk categories & recommendations for prevention

Genetic risk categories for families used by DCG during my fieldwork. These are in accordance with *Danish Breast Cancer Cooperative Group (DBCG) 2014*. (My own English translation)

Mutation positive (HBOC, +mutation)

Families with identified high penetrant mutation causing a risk of breast and ovarian cancer (most often a mutation in *BRCA1* or *BRCA2*)

High risk of breast and ovarian cancer (HBOC, - mutation)(The term "HBOC, obs. pro" was used during my fieldwork)

Families, where the occurrences of breast and ovarian cancer substantiates that a high penetrant mutation is being inherited, and where a first-degree relative to an afflicted family member will have a lifetime risk of breast cancer>30% or for ovarian cancer>10%. This includes families where *BRCA1* and *BRCA2* have been screened but no mutation has been identified and families where this analysis has not been conducted.

High risk of breast cancer (HBC, high risk)

Families where the occurrences of breast cancer substantiates, that a highly penetrant mutation is being inherited, and where a first-degree relative to an affected family member would will have a life time risk for breast cancer>30%

Moderate risk of breast cancer (HBC, mod. risk)

Families where the above is not the case, but where the occurrences of breast cancer indicates that a first-degree relative to an affected would have a risk of breast cancer of 20-29%

Corresponding Prevention Recommendations:

Screenings for breast cancer

Mutation positive (HBOC, +mutation)

<50 years of age: Yearly clinical mammography from the age of 30

50-69 years of age: Yearly clinical mammography
>69 years of age; Mammography screening every two years

These recommendations apply for women who are affected, women that carry the pathogenic mutation, women that are unaffected first-degree relatives to an affected or to a carrier of the pathogenic mutation, and women that are unaffected second-degree relatives to an affected or to a carrier of the pathogenic mutation via a man.

High risk of breast and ovarian cancer (HBOC, - mutation) and high risk of breast cancer (HBC, high risk)
<50 years of age. Yearly clinical mammography from the age of 30
50-69 years of age. Mammography screening every two years
>69 years of age. Mammography not recommended

These recommendations apply for women who are affected, unaffected first-degree relatives to an affected person, or unaffected second-degree relatives to an affected person via a man.

Moderate risk of breast cancer (HBC, mod. risk.)
<50 years of age: Yearly clinical mammography from the age of 40
50-69 years of age: Mammography screening every 2 years
>69 years of age: Mammography not recommended

These recommendations apply for women who are affected and for women that are unaffected first-degree relatives to an affected person.

Prophylactic mastectomy is generally not recommended, but may be performed in women with a >30% lifetime risk of breast cancer.

Surveillance for ovarian cancer

Mutation positive (HBOC, +mutation)

Women with a dominant hereditary disposition to ovarian cancer may chose vaginal ultrasound screenings and CA125, yearly from the age of 30

Women with a dominant hereditary disposition to ovarian cancer may chose oophorectomy.

This apply for women who are affected, women who carry a pathogenic mutation in *BRCA1* or *BRCA2*, women that are unaffected first-degree relatives to an affected person or to a carrier of a pathogenic mutation, women that are unaffected second-degree relatives to an affected person or to a carrier of a pathogenic mutation via a man.

High risk of breast and ovarian cancer (HBOC, - mutation)

Women suspected of a dominant hereditary disposition to ovarian cancer may chose vaginal ultrasound screenings and CA125, yearly from the age of 30

Women with a dominant hereditary disposition to ovarian cancer may be recommended oophorectomy.

These recommendations apply for women who are affected, women that are unaffected first-degree relatives to an affected person, and women who are unaffected second-degree relatives to an affected person via a man.

Appendix 2 – Danish patient information letter

Patient information letter (page 1)

midt
regionmidtjylland

Arvelig risiko?

Information inden samtalen i Klinisk Genetisk Afdeling

Du er henvist til samtale for at få vurderet, om der er en arvelig sygdom i din familie.

Formålet med samtalen er:

- At informere om muligheden for at vurdere, om du eller nogle i din familie har en arvelig sygdom.
- At informere om, hvad det betyder for dig og din familie.
- At begynde udredningen med at tegne et detaljeret stamtræ over din familie.
- At informere om muligheden for fosterdiagnostik.
- At aftale det videre forløb.

Hvordan foregår udredningen?

Der er flere redskaber, der kan være med til at belyse, om du eller andre i din familie har en arvelig sygdom:

- Optegnelse af din families stamtræ (anvendes altid).
- Undersøgelse af blodprøver for forandringer i et eller flere gener (arvemateriale). Det er en mulighed i nogle tilfælde, men ikke i alle.

Stamtræet

- Stamtræet danner altid grundlag for, hvordan vi vurderer en families risiko.
- Stamtræet tegnes og opdateres i et samarbejde mellem dig og Klinisk Genetisk Afdeling.
- På stamtræet skrives, hvilke sygdomme familiemedlemmer har. Vi vil altid sørge for at få detaljerede oplysninger om sygdomme i familien. Oplysninger finder vi i journaler og andre databaser.

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Patient information letter (page 2)

Blodprøve

- Hvis lægen skønner, at det er relevant at lave en gentest, er det dig, der bestemmer, om du ønsker det. Samtalen kan hjælpe dig til at træffe det rette valg.

Samtalen

- Vi tilbyder to samtaler:
  - Indledende samtale
    - Personlig samtale
  - Svarsamtale
    - Personlig samtale, telefonsamtale eller brevsvar
      (sammen aftaler vi, hvordan du får svar)

Tilladelse

- Vores tilbud rettes til personer, der skønnes relevante for udredningen.
  Det er personen selv, der underskriver tilladelsen.
  For børn under 15 år udfylder forældrene tilladelsen, og for ældre udfyldes tilladelsen af nærmeste pårørende.

Hvor lang tid går der?

- Ved samtalen aftaler vi, hvordan du får svar på udredningen.
- Tidsrammen er afhængig af flere faktorer, men du vil få at vide, hvor længe vi tror, det tager at få en konklusion.
- Når du har fået svar, sender vi et brev til den, der har henvist dig og til din praktiserende læge, med mindre du frabeder dig dette ved samtalen.

Har andre i din familie været til genetisk samtale?

- Hvis du mener eller ved, at andre i din familie har været til en genetisk udredning, kan det være en vigtig information for os.

Venlig hilsen

Personalet
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