

**Ethics, Expertise and Legitimacy in the Cultural Context
of the New Genetics; The Case of BRCA Genes in Breast
Cancer**

Sahra Elizabeth Gibbon

Department of Anthropology, University College London

Thesis submitted for the Degree of Ph.D.

2003

ProQuest Number: U643516

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest U643516

Published by ProQuest LLC(2016). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

Abstract

This thesis examines the social and cultural context of new genetic knowledge associated with breast cancer, namely two inherited 'susceptibility genes' BRCA1 and BRCA2 which were identified in the mid 1990s. It looks at how this knowledge is used, received and acted upon in two key social arenas; (a) Cancer Genetic Clinics and (b) a Breast Cancer Research Charity. In relation to other recent developments in the field of human and plant genetics, BRCA genetics has generated comparatively less public or media criticism, concern or controversy. Nevertheless it is at the forefront of an expanding field of clinical genetics. By looking at how this knowledge is transmitted at key sites of social interaction, this thesis contextualises the comparative 'silence' that has accompanied these developments. It explores how the knowledge and technologies associated with breast cancer genetics are sustained through collective practices and identifications, which necessarily involves the participation of those involved. However, the circuits of connection which link people and practices operate in complex non-linear ways that involve entanglements of agency, practice and power. These fractured channels of action and interaction are revealed in examining the ways that the 'expert' and 'ethical' dimensions of this new knowledge, are being negotiated. This analysis raises questions about recourse to a normative model of 'medicalisation or 'geneticisation' in understanding the development of new genetic knowledge. In these contexts, the passivity and subjugation of patients or lay persons cannot be assumed and the ambivalent subjectivities of medical professionals or scientists must be understood. This field of genetic knowledge is also accompanied by a particular framing of the 'social'. This emergent space of 'ethics' intersects with but also challenges the collective practices that sustain BRCA genes as a legitimate field of research and clinical practice.

Table of Contents

Title Page	1
Abstract	2
List of Figures	6
Acknowledgements	7
Chapter 1 Introduction	9
1.1 Social Science and the ‘impact’ of the new genetics	10
1.2 STS and Anthropology: between the ‘black box and the broader context’	12
1.3 Lay/Professional Entanglements	14
1.3.1 ‘Lay’ agency, action and power	14
1.3.2 Predictive expertise and hidden subjectivities	18
1.4 Re-situating the ‘social’; locating ethics	20
1.5 Sites and Methods	22
1.5.1 Cancer Genetic Clinics	23
1.5.2 A Breast Cancer Research Charity	27
1.5.3 The ‘ethics’ of fieldwork	31
1.6 Chapter Outlines	32
Part One: Cancer Genetic Clinics	34
Chapter 2 Patients’ expectations; awareness and visibility	40
2.1 The morality of being aware	40
2.2 Making danger visible/being visibly a ‘patient’	44
2.2.1 Having a family history	44
2.2.2 Bodily connections (and disconnections)	51
2.2.3 The agency of genes	55
2.3 The specialism of genetics and faith in technology	58
2.3.1 The expert Clinic	59
2.3.2 Visualising danger; the mammogram	60
2.3.3 Anticipating the ‘test’	61
2.4 Conclusion	63
Chapter 3 Technologies of the Clinic; tools tests and explanatory strategies	65
3.1 Making knowledge material	65
3.1.1 Family trees, risk assessment and the tools of explanation	66
3.1.2 The materiality of prediction	72
3.2 Technologies and tools for ‘talking down’	76
3.2.1 Triage and the necessity of limits	76

3.2.2 The instability of technologies, tools and knowledge	81
3.3 Conclusion	85
 Chapter 4 ‘Care’ and the requirements of patienthood	 88
4.1 Pastoral practices	89
4.1.1 Care for the future	89
4.1.2 Care for ‘the family’	91
4.2 Patients and the care of predictive genetics	99
4.2.1 Being ‘on the books’	99
4.2.2 ‘Fractal’ patients	105
4.3 Conclusion	114
 Chapter 5 Working with BRCA genes; the ambivalence of practitioners	 117
5.1 Predictive medicine and Oncology	118
5.1.1 Genetic knowledge; from dazzle to doubt.	118
5.1.2 ‘Care’ as expertise?	127
5.2 Geneticists and the ‘hysteria’ of breast cancer	135
5.2.1 Uncertain knowledge and the demands of consumerism	136
5.2.2 Refusing ‘care’ (and knowledge) as counselling	138
5.3 Conclusion	142
 Part Two A Breast Cancer Research Charity	 144
 Chapter 6 The alchemy of loss and hope	 147
6.1 Memorial practice	147
6.1.1 Remembering and witnessing	148
6.1.2 Being ‘positive’ for the future	151
6.2 Science and the fundraiser’s quest	159
6.2.1 The need for ‘knowledge’	159
6.2.2 The promise (and problems) of genetics	163
6.2.3 Criteria for research	166
6.3 Conclusion	168
 Chapter 7 Scientists and the making of ‘monuments’ for the living	 170
7.1 Laboratory Tours; the ‘enchantment’ of science?	170
7.2 Being scientists of Breast Cancer Genetics	177
7.2.1 ‘Evidence’ of expertise	178
7.2.2 The morality charity based breast cancer research	181
7.2.3 A passion for complexity	184
7.2.4 The challenge of communicating basic science research	186
7.2.5 Being part of a ‘redemptory’ science	189

7.3 Conclusion	193
Chapter 8 Between hope and high risk	196
8.1 The balancing act of BRCA genes	197
8.1.1 Hype, heroes and the human genome project	197
8.1.2 Defining a 'post-genomic' space	202
8.1.3 Bringing treatment into view	205
8.2 Ethical strategies	209
8.2.1 The advocacy project	211
8.2.2 Gene patents	219
8.2.3 Genetic testing and insurance	221
8.3 Conclusion	224
Conclusion	226
Bibliography	237

List of Figures

Figure one: <i>Frida Khalo's My Nurse and I</i>	8
Figure two: <i>Research Sites: people and places</i>	30
Figure three: <i>Donna's family tree</i>	46
Figure four: <i>Other patients' family trees</i>	46-48
Figure five: <i>An example of a popular depiction of family genealogy</i>	67
Figure six: <i>A 'typical' clinical family tree</i>	68
Figure seven: <i>The 'Challengers' Wall</i>	150
Figure eight: <i>Campaigning image</i>	155
Figure nine: <i>Images displayed at entrance to research centre</i>	171-172

Acknowledgments

I am grateful to a number of people who helped me in a range of different ways in the writing of this thesis. First and foremost I would like to thank my main supervisor Nanneke Redclift, who has supported and encouraged me throughout all the stages of my research and offered valuable guidance and help. I have in addition appreciated the insightful comments and help of my second supervisor Murray Last.

Academic support has also come from other staff in the department during Writing Up Group Seminars, particularly Victor Buchilli and Mike Rowlands. The encouragement and friendship of fellow PhD students at UCL during these seminars and at other times has been invaluable. Special thanks go to Katherine Tomlinson, Sandra Squires, Sara Skodbo, Sadie King, Paul Basu and Susie Kilshaw. I would also like to mention fellow members of the 'GAT' group who collectively provided an exciting and supportive environment for discussion, particularly Oonagh Corrigan, Carlos Novas and Adam Hedgecoe. Thanks also to Richard Tutton and a special thanks to Claire Moynihan whose help and support has been particularly appreciated.

I am especially grateful to all my informants during the time of my field research. I hope the thesis is seen as an honest and accurate attempt to represent the time I spent with them.

In terms of financial backing, I have benefited from and would like to thank the Economic and Social Research Council for three years of funding. I also appreciate the financial help given to me by the British Federation of Women Postgraduates in the final year of writing up. A Radcliffe Brown award from the Royal Anthropological Institute also helped me to complete my research.

My family, friends and partner have helped and encouraged me in many different ways. Thank you to my parents Marie and Graham as well as the many significant others in my family. All have been unstinting in their faith and support. A special thank you to Woodie for being there throughout.



Figure one: *Frida Kahlo's My Nurse and I*

Introduction

‘Genes R us in ways that have nothing whatsoever to do with the narrow meaning of genetic determinism and everything to do with entire worlds of social practice’
(Haraway 1997: 231)

‘Where the process of purification takes place relatively smoothly- where silence resounds about any given innovation- this too is fertile ground for social scientists. In this instance, the initial task is of course to name the hybrid, for it will usually be camouflaged as though it is a natural entity. (Lock et al 2000: 236)

Although many aetiological agents have been linked to breast cancer, in more than 90% of cases the cause is essentially unknown. However in the field of oncology, there has long been a suspected connection between family history and some cancers, including breast cancer. In the mid 1990’s, this suspected link was confirmed when two ‘inherited susceptibility’ genes were identified, BRCA1 and BRCA2. These have come to be known as the ‘breast cancer genes’¹. These genes are inherited in a dominant way so that a person with a parent who carries a mutation on one of these genes has a 50% chance of inheriting the same gene mutation. Inherited genes are thought to be involved in about 5-10% of the population who develop breast cancer. According to current estimates BRCA1 mutations ‘account’ for about 40-50% of these genetically linked cases of breast cancer and BRCA2 for about 20 –30%.² Other genes, mostly unknown, are thought to be involved in the remaining 20- 40% of cases. Although the exact function of these genes in the development of breast cancer is not certain, it is ‘estimated’ that those who carry an inherited mutation in one of these two genes have an approximately 80% chance of developing breast cancer by the age of 70 (the normal risk is 9%). The genes are in this sense thought to be ‘highly penetrant’³, although population based studies suggest these risks are lower and in fact these figures are subject to constant revision.⁴ Genetic testing for these genes has now become available through specialist clinics in the NHS for those at ‘high risk’ of developing the disease and genetic risk assessment for

¹ In fact these genes have also been linked to a number of other common cancers such as ovarian and prostate cancer as well as some rarer types of cancer such as thyroid and pancreatic cancers.

² All these figures are derived from the Public Health Genetics Unit 25/07/02

<http://www.medschl.cam.ac.uk/phgu>

³ This is the likelihood that a person carrying a mutation will develop the characteristics caused by that mutation.

⁴ For instance population studies suggest that the risk is between 60-80% for those carrying a BRCA1 mutation and 40% for those carrying a BRCA2 mutation. Source as ref 2

breast cancer is at the vanguard of an expanding field of clinical genetics (Wonderling et al 2001).

The social practices and technologies which enabled genes to dominate cancer research in the late 1970's and 80's have been well documented (Fujimura 1996). As Batchelor says 'we know too little about the process of transmission of innovative knowledge from the benches of the laboratory to the bedsides of patients and the consulting rooms of medical practitioners' (1996:226). The historical narrative of 'discovery' and 'application' outlined above, suggests that in the case of BRCA genes this is something of a linear process. These developments appear to be 'forging ahead under the twin banners of probability theory and molecular genetics offering the prospect of certainty and control' (Lock 1998: 8). This thesis begins to contextualise the knowledge and technologies associated with breast cancer and their apparently smooth passage from the lab to the wider world by looking at the work involved in the transmission of this new knowledge. It draws attention to the 'traffic' (Heath 1998) that constitute this process and the 'hybrids' (Latour 1993), (Lock et al. 2000) that dot this mobile and shifting landscape.

1.1 Social science and the 'impact' of the 'new genetics.'

Questions of 'impact' have been central to the ways in which social science has begun to address developments in genetic knowledge and technology, which have now come to be seen in terms of the 'new genetics'. Kaufert notes that this work has been somewhat narrowly defined (2000). On the one hand it has been dominated by research looking at the consequences of technologies such as genetic testing for the small numbers of individual patients undergoing these procedures. There is, for instance, a significant amount of psychological literature on the consequences for individuals undergoing genetic testing for the BRCA genes. On the other hand, there is a large body of bio-ethical literature looking somewhat speculatively at the 'social, legal or ethical' consequences of developments in genetic knowledge.⁵ Even when there are attempts to broaden the field of analysis, the consequences of genetic knowledge and technology for

⁵She also notes that another body of literature mainly in the field of pre-natal testing which looks at these developments from an epidemiological or public health perspective (2000)

patients are often separated from health policy issues or medical practices (see Marteau & Richards 1996).

One of the consequences of this demarcation is the theoretical emphasis given to a notion of 'geneticisation', by those who seek to critique these developments (Lippman 1992). This is used to posit that the application of new genetic knowledge and technology is leading in a direct and linear way to a new determinism about the health, disease and the body (Rothman 1998), (Nelkin & Lindee 1995), (Lippman 1992). Yet there are other consequences of defining the parameters of social science research in this way. Focusing only on the downstream effects of developments in genetics, and predominantly on the consequences for specific individuals ensures, as Irwin and Wynne point out, that this knowledge is itself taken to be 'unified' and 'stable' (1996:7). Clearly it is important to document the 'effects' that new articulations of risk, associated with the emergence of predictive medicine, have for patients. However a narrowly defined impact approach masks the involvement of multiple individuals and groups, the heterogeneous practices undertaken in the work of translation and how these developments have consequences for those other than patients. As Kaufert says we need to broaden the 'cast of characters' that constitute social science studies of the new genetics (2000). Others have suggested that questions of social 'impact' need to be more reflexively considered, in order to examine how these issues of impact are themselves being 'built into' genetic knowledge and technologies (Franklin 2001a), (Rose 2001).

This thesis responds to such a task by looking at how a range of people and practices in key social arenas are involved in the work of communication, translation and dissemination of new knowledge associated with BRCA genes. Recent work in anthropology, which maps points of convergence (while recognising on going divergences) with Science and Technology Studies (STS), provides a theoretical background for this approach

1.2 STS and Anthropology; between the ‘black box’ and the ‘broader context’

The problem of the ‘black box’ and the ‘broader context’ have been used to characterize the different ways that STS and Anthropology have traditionally addressed knowledge or technology in science and medicine (Lock et al. 2000). That is, from the perspective of STS, anthropology ‘ignores the production of clinical and laboratory objects and procedures thus treating them as black boxes. The counter argument is that focusing only on the ‘opening of the black boxes leads to a neglect of the ‘broader context’ in which the objects of science are used and ‘translates into little interest in their fate once they leave the scientific laboratory’ (Lock et al. 2000:3). Despite these differences fruitful lines of cross and multi-disciplinary inquiry, which reflect upon these separate approaches but also trace points of connection and interconnection , have recently begun to emerge (Franklin 1995), (Franklin 1996), (Hess 1997), (Martin 1998) and (Lock et al. 2000).

The notion that ‘knowledge and artifacts are culturally shaped and socially constructed’ (Hess 1997: 148) has been central to science and technology studies. Here the idea of ‘actor networks’ (Callon 1980), (Callon 1986) and (Latour 1987) in one branch of STS, has provided a tool for examining the ways in which circuits of action and practice inform the construction of scientific knowledge. This type of analysis has recently shifted from examining the networks that operate inside the laboratory to examining the movement of people, practices, knowledge or technologies beyond it. This has brought an anthropological concern with the ‘wider world’ into focus particularly, as Martin points out, in terms of addressing ‘lay’ understanding or response to new developments in medical or scientific knowledge (1998). Since then there has been a general movement both in STS and anthropology to look at science and technology at the ‘intersection’ of different worlds and practices, that might include the space or work practices of the laboratory, but which are not confined or defined by it (Heath 1998), (Martin 1994), (Singleton & Michael 1993). This has drawn attention to more fractured circuits of action and practice. As Harvey points out, Anthropology does not just offer simply an extension of possible field sites but an understanding of technology in terms of ‘contextualised action’ (1997).

At the same time that anthropology has informed an analysis of science, technology and medicine that moves beyond the laboratory, the centrality of the 'science question' continues to challenge this discipline (Lock et al. 2000). Nonetheless after some neglect, there has been a renewed focus in medical anthropology to link a concern with the cultural context of 'illness' with an effort to address 'disease' or scientific/medical knowledge itself (Wright and Treacher 1982), (Lock and Gordon 1988) (Lock and Lindenbaum 1993).⁶ More recently particular attention has been given to the way questions of meaning *and* materiality are embedded in the technologies of health care practice (Casper and Koenig 1996). Studies of the new reproductive and genetic technologies have also brought the question of science, technology and biological substance to the centre of anthropology, where the shifting relationship between kinship, nature and gender has been examined (Strathern 1992a & 1992b), (Franklin 1997), (Franklin and Ragone 1998), (Edwards et al. 1993) (Edwards 2001). In fact these developments have led some commentators to conclude that there are seismic cultural changes underfoot, such that we are now 'after' nature (Strathern 1992a) or that in the wake of initiatives such as the Human Genome Project nature will now be 'known and re-made as technique' (Rabinow 1996). This raises interesting and demanding questions about how issues of materiality and substance will be addressed by social scientists in the context of the new genetics, particularly in relation to the emergence of predictive medicine. In placing objects and technologies centre stage, STS offers a starting point for thinking about such issues.

The theoretical and methodological approach used and developed in this thesis draws from these disciplinary intersections in an attempt to address two key themes. First, the way that power and agency are linked in the relationship between 'lay' and 'professional' persons or groups implicated in the spaces where genetic knowledge is being used and received. Second, the ways in which a concern with the social or 'ethical' is becoming 'built into' the knowledge and technologies associated with BRCA genes.

⁶ Although within sociology and medical sociology the social dimensions of bio-medical knowledge and practice have been part of the disciplinary boundaries of inquiry for some time.

1.3 Lay/professional entanglements

A lay/professional distinction has been used in a variety of domains relating to medical practice or the use of scientific knowledge in order to highlight the differing ways that those subject to technologies or forms of knowledge experience or make sense of them. This has been most usefully demonstrated in relation to risk information and figures (Douglas 1992), (Lupton 1995), (Beck 1992). For example a notion of a 'doubled discourse' (Rapp 2000) has been used to show the ways that a so called scientific or medical discourse characterized by 'rationality' is never neutral for those patients who make use of these technologies. Such differences have also been identified in relation to developments in genetic knowledge (Hallowell and Richards 1997), (Richards 1996), (Parsons and Atkinson 1992) and (Sachs 1999).

Clearly this is a feature of the social arenas examined in this thesis. However, in examining the transmission of genetic knowledge and technologies between different lay publics and professionals, this discussion raises questions about constant recourse to such a distinction. For example Stockdale points out that sociological discussion of the new genetics is in 'danger of remaining trapped in its original binary framing'. He suggests that it might be 'usefully exploded into a more complex mapping of the cultural constructions and social relationships that span numerous intersecting contexts in which genetics is an important feature' (1999: 80). In exploring how difference as well as similarity is reproduced at the interface between 'sciences' and 'publics' this thesis attempts to write 'against culture' (Abu-Lughod 1991). For example, it is important to see the ways that practitioners often require the experience of illness to reach a diagnosis or the way that patients can sometimes 'live' their illness in part through notions of 'disease', using risk classification in understanding and making sense of suffering or danger (Moll 2000).

1.3.1 'Lay' agency, action and power.

In championing a 'lay perspective', anthropological studies and others have revealed a great deal about the way that patients and other lay persons respond to new technologies and knowledge as they are applied and/or disseminated into the "wider world". Work examining new reproductive technologies has

highlighted the diverse and often creative reactions of different audiences to these health practices, whilst also retaining an awareness that such responses are informed by a stratified diversity (Rapp 1999), (Ginsburg and Rapp 1995). Although studies examining how those who are not 'patients' perceive and make sense of developments in reproductive or genetic technologies has only just begun (Edwards 2000), (Kerr et al. 1998), others exploring how 'publics' respond to science in a broader sense have shown how this is constituted by action, rather than just a simple process of passive reception (Irwin and Wynne 1996). For example, Martin's work (1994) illustrates how ideas about the immune system 'travel' and change between different publics (and sciences). Others addressing questions of identity have drawn attention to the way that the materialities of knowledge or medical practice, for instance risk figures, can become tools for identity formation, in the service of particular kinds of selves (Dumit 1997), (Cussins 1996). As Silverman points out the distinction between the 'lifeworld' [of patients] and medicine itself is problematic' precisely because of the way medical discourse has entered into 'our own accounts of ourselves' (1978:198). This is also echoed in Rabinow's discussion of the way identity might begin to be inscribed in the context of the new genetics, a process he terms 'bio-sociality'. He suggests that this is just one of the ways that genetic knowledge will be 'embedded through the social fabric at the micro level' (Rabinow 1996:103). Like others, Rabinow points out that agency cannot be abstracted from power in the domain of health, particularly when it pertains to genetic knowledge. In this sense 'resistance' can be seen in terms of the 'resistance of a copper wire to an electric current flowing through it [...] sometimes higher and sometimes lower but always enabling the current to flow through it' (Martin 1992:417), (see also Lock and Kaufert 1998).

There is a growing body of work, following Foucault, examining how individual control over health and the notion of risk is increasingly internalised as part of a subjective sense of self. This includes the increasing phenomena of 'healthism' (Becker 1997) in a Euro-American context and the importance placed on individual health awareness as part of a public health agenda (Lupton 1995). For example Rose explores the dense interconnections between active patienthood, the project of the 'self', the growth of a 'psy' discourse and neo-liberal

governmentality (1996). At the same time Kohn and McKechnie draw attention to the contradictory power of a public health model; that is giving people the ability to take care of their health also makes them also more able to question it (1999). They point out that this is a paradox which might be strongly felt where the 'boundaries' of health are expanding. This is particularly a feature of the new genetics, where a preventative health care ethos meets the emergence predictive medicine.

Breast cancer provides a particularly important context for examining the juncture between lay agency, identity and power. As Kaufert says, commenting on the feminist critique of health care practice as subjugating women, 'the model of nature as beneficent and science as malign is attractive and powerful but difficult to sustain once the subject becomes breast cancer rather than birth' (1996:167). She and others have suggested that this may in part be why reproductive technologies have been the topic of extensive examination by social scientists while breast cancer, or even the routine preventative technologies that many women are now subject to, have been given far less attention.⁷ It is not only that breast cancer is something that affects and kills thousands of women, that makes it an important topic for inquiry, but also because the heightened profile of the disease in the last 15 years in a Euro-American context can be partly tied to female health care activism (Anglin 1997),(Montini 1996) and (Kaufert 1998). This activism has helped highlight the scale of the breast cancer 'epidemic' and inform a discourse about the 'risk' of breast cancer and the need for 'awareness' (Lantz 1998). Anglin explores how in the US this has precipitated more 'patient centred' decision making and an increase in the funding allocated to breast cancer research (1997). A similar alliance of breast cancer charities and support groups has also begun to make its presence felt in this way in the UK. As such these developments could be seen as examples of the way 'choice and control' have shifted away from the medical profession to women themselves and in many ways there have been significant changes.⁸

⁷ Although cancer has been examined by some anthropologists for instance see for instance Balshem (1991).

⁸ A personal communication with a leading epidemiologists also suggested that changes in the way cancer services are offered to patients in UK outlined in policy documents such as the Calman Hine Report (1995) are also a direct result of the way the 'breast cancer lobby' has organised itself in this country.

However Potts cautions against such a straightforwardly optimistic or superficial reading of these changes (2000).

In this way breast cancer provides a space in which to 'explore patterns of resistance that are not contingent upon the withdrawal outside of medical control' but are located in complex ways within it (Kaufert 1996:174). As Kaufert points out women had to be 'convinced to become collaborators in the search for breast cancer' in the development of public health mammography screening (1996 :172). The emergence of predictive medicine in breast cancer genetics, as well as benefiting from the legacy of this public health programme, also expands a discourse about 'risk' and 'awareness' into new territory. It is likely that collusion and collaboration are going to be key features of these developments also. The practices explored in this thesis bear witness to the circuits of agency and power that are so much a part of the way breast cancer has become an increasingly high profile disease.

Clearly, breast cancer also raises questions about gender identity and the body. The female body has been and continues to be subject to range of historically diverse and contradictory meanings (Lacquer 1986),(Martin 1989) and (Bordo 1993). Yalom notes that this is particularly so of the breast, which is a 'timeless' signifier of 'sex, life and nurturance' and more recently, through the prominence given to breast cancer, 'death'(1998), (see also Lupton 1994). These contradictory meanings and the kind of ambivalence and anxieties this generates are powerfully reflected in a painting by the Mexican artist, Frida Kahlo, at the start of this thesis (see Figure One). Yalom suggests that we are increasingly seeing the breast 'first and foremost as a medical problem' (1998), in the same way that Martin's work (1989) shows how medical discourses about reproduction inform a particular powerfully normative narrative about the female body. The meaning of breast cancer therefore intersects with other narratives about female gender identity in diverse ways. For example, in her study of breast cancer narratives in the media Saywell examines the ways in which breast cancer is a 'sexualised illness' (1999). She looks at how it is made newsworthy precisely by focusing on maternal or sexualised bodies; elements of a female gender identity it also seems to threaten .

If the meaning of breast cancer reflects and informs particular representations of women it is highly likely that gender will be enmeshed in diverse and contradictory ways with developments in BRCA genetics. Rabinow points out how it is possible that developments in genetic knowledge will not mean the disappearance of older forms of cultural classification but may 'in complicated and insidious ways take on renewed force' (1996;103). This thesis looks at how particular representations of female gender identity are part of the knowledge and technologies associated with BRCA genetics, examining as other anthropologists have the 'ricochet' effect between nature, culture and gender (Collier and Yanagisako 1987), (Yanagisako and Delaney 1995), (MacCormack and Strathern 1980).

1.3.2 Predictive expertise and hidden subjectivities

The power of medical knowledge and practice to define has been well documented by a broad body of work in Anthropology and the Sociology of medicine. In the context of reproductive technologies such as amniocentesis, Rayna Rapp explores how the 'authoritative' language of the Clinic can subvert commonly held ideas such as a 'positive family history' (1995a). Others have examined how a narrative of scientific progress (Franklin 1997) or an idiom of naturalisation (Finkler 2001), (Rapp 1999), or the use of visual imaging technologies such as ultrasound pictures (Hartouni 1995), (Cartwright 1995) can all enable clinical or scientific authority. Some or all of these practices are evident in the social settings where new genetic knowledge associated with breast cancer is being used and received. Moreover developments in genetic knowledge bring new criteria for knowledge and authority to the fore, embedded in the prospect of being able to predict and control the future. In some ways this could be seen as part of the rise of probability mathematics and a 'lust' for measurement which Hacking suggests has led to the gradual erosion of determinism, since the industrial revolution (1990). Predictive genetics bring this 'obsession' with the 'taming of chance' into the domain of medical practice in new ways, facilitating an ability to 'divine our past and make that heritage in the form of genes in to omens for the future' (Lock 1998: 8). Exploring how prediction is practiced in the context of developments in breast cancer genetics enables some of this authority to be contextualised, suggesting that attempts to

make this real or meaningful cannot be abstracted from other processes. This includes the expectations of patients or lay publics and the ontological uncertainty that is so much a part of an emerging field of predictive medicine.

The new avenues these developments in genetic knowledge generate for the articulation of 'power' are also not without consequences for the professionals. Nevertheless the same illuminating focus that has been directed to those who are subject to these technologies has not been applied to those who work in these settings. This has led to a reification of professionals and their practices, whose experiences and identifications are either neglected or often subsumed within a representation of scientific knowledge as rational, statistical and normative. In particular little attention has been paid to the way these individuals experience working with new genetic knowledge (Kaufert 2000) and the extent to which this might also be characterised by a degree of diversity or dissent. There has been some attempt to understand the way that practitioners in the context of breast cancer more generally negotiate the gap between uncertain epidemiological findings and the provision of care in relation to benign breast disease (Gifford 1986) and mammography screening (Kaufert 1998). The emergence of predictive medicine in clinical cancer genetics is likely to be populated by similar disjunctures. I explore how those that work in these arenas must traverse a significant distance between knowledge and care and how this brings new requirements for expertise and caring practices.

Although those who work at the 'coal face' of scientific knowledge have not been neglected in the same way, the 'culture' or identity of scientists has nonetheless been represented somewhat one dimensionally. Actor network theory, while taking account of scientific practice, provides little sense of how scientists experience or identify with the worlds in which they work. As Martin says, the 'Latourian' scientist 'bursts upon the scene [...] forming his networks and gathering his allies, resembling all too closely a western business man' (1998: 27). Traweek's analysis of the way the 'beamtimes' that a certain group of physicists study are co-constructed alongside their 'lifetimes' is an attempt to redress this balance (1988), as in a different vein is Rabinow (1999) and Marcus's

use of extended interviews with scientists in their examination of emergent technologies and knowledge (1995a).

This thesis takes such a task seriously and within the parameters of the process of transmission adopts a 'symmetrical analysis' (Latour 1987). That is, it considers how a range of health care practitioners and basic science researchers practice and experience the dissemination of genetic knowledge at different public interfaces. I explore how this group of people are caught up with these processes in ways that are not always comfortable or easy. Attending to the working practice of professionals, their interactions with patients or lay publics *and* their reflections on this process, brings to light the 'fault lines' that subsume the transmission of new genetic knowledge for these individuals.

1.4 Re-situating the 'social'; locating ethics

There is another dimension which must be addressed in considering how genetic knowledge of breast cancer is being used and translated beyond the laboratory arena. This relates to the way an 'ethical' and a 'social agenda' is not only being made explicit in this context, but is in fact becoming instrumental to the dissemination of such knowledge. In this sense, issues of impact are already folded into and part of the practices of transmission.

The idea that the 'social' is being sidelined and undermined by the 'new genetics' is embedded in a particular critique of these developments. The claim by many is that we are witnessing a process of renewed medicalisation and 'geneticisation' across a range of areas where new genetic knowledge and particularly technologies are becoming more widespread (Lippman 1992), (Finkler 2000), (Hubbard and Wald 1997). Others have pointed out that this is a somewhat misplaced critique of the new genetics (Rose 2001) and that what needs attending to is the way the social and particularly an 'ethical agenda' is being put to work in new and novel ways. (Rabinow 1992), (Rabinow and Palsson 1999) (Heoyer 2001). This is something that Franklin suggests will require 'imaginative' and reflexive approaches from social scientists (2001a).

There has been some attempt to examine the changing and shifting nature of the 'social' or 'ethical' in relation to the new genetics. Kerr has looked at the way health care professionals make use of a particular 'flexible' model of the social which enables them to influence the dissemination of genetic knowledge but also retain their impartiality (1997). Franklin has examined the way that social concerns are literally being 'built into' the cell line in the way stem cell research is being carried out, as the bio-tech industry attempts to address certain ethical concerns associated with using embryonic stem cells (2001a). While Rose links the emergence of the 'ethics machine' in the context of new genetic knowledge, exemplified in the practice of genetic counselling, with the expansion of new forms of governmentality (2001). In a broader sense Nowotny links this form of governance to the emergence of what she calls the 'Agora'. She sees this as growing public space where 'science must increasingly meet the public and the public speaks back to science', such that good science no longer has to be only reliable but also 'socially robust' (2001: 168). In fact Rabinow's study of a specific juncture in the development of genetic knowledge and research in France offers a particular study of the expanded realm of the 'Agora'. He explores how ethics becomes part of an 'assemblage' and a form of social capital that may, for a time, help to bring new alliances and 'forms' into being (1999).

I contribute to this growing body of diverse work, examining ethics as social practice, by examining how a notion of 'care' and a concern with the 'social' are part of the work of transmission in the Cancer Genetic Clinic and a Research Charity. I explore how these feed into and inform different notions of the 'ethical'. A discourse about 'care' is clearly a euphemism in medical settings, something which is normally 'naturalised' and thus tends to fall outside questions of ethical codes (Kohn & McKechnie 1999). Sevenhuijsen points out that it is important to see discourses about 'care' as forms of social practice where people from diverse positions and perspectives exchange values (1998). However new predictive genetic knowledge involves making 'care' a more explicit dimension of medical practice, such that concerns with the social become meshed with care and ethics in ways that are instrumental to knowledge. This makes the need to 'unpack' the moral and ethical issues raised by caring

practice and discourse (Kohn and Mckenchie 1999), in the context of genetic knowledge, even more important. Nevertheless 'ethics' is not always enabling, as Rabinow's work illustrates (1999). That is, the social and ethical agendas which may seek to suppress the 'hybrids' that arise in the process of 'translation' can actually facilitate their coming into being; a process that Rabinow aptly terms 'purgatorial'.

In exploring the changing nature of the social in the communication, use and reception of knowledge and technologies of BRCA genes I draw on anthropological studies of the new reproductive technologies (Strathern 1992a & 1992b), (Edwards et al. 1993), (Franklin 1997), (Edwards 2001). This body of work has explored how Euro-American notions of kinship as a hybrid between nature and culture are used as a context for knowledge. Strathern (and others) have explored how this enables individuals to 'narrow the relevance of what they wish to consider so as to contain its implications'...[such that] their exclusions work to render certain views 'invisible'.(1993:173-174). I use this perspective to explore how 'ethical' or 'social' concerns, agendas and questions 'domain' knowledge in different social arenas associated with developments in breast cancer genetics.

1.5 Sites and Methods

Just as the cross-cutting approaches of work in STS and Anthropology inform the theoretical background of this thesis, a methodological design is used which draws from both these disciplines in order to work across 'texts, practices and contexts' (Franklin & Ragone 1998: 5). This type of approach is perhaps best exemplified in Martin's study of the notion of 'immunity' in America that links seemingly disparate field sites and research tools (1994). My research, although not quite so broad in its scope, also maps a process of knowledge communication and dissemination and hence works at the juncture between different sites, persons and practices. Heath locates herself at these boundary zones in her research; her work testifying to the way 'new meanings' appear at the 'intersections of trans-local displacements'(1998: 520) and (1997).

My initial plan had been to ‘follow the thing’ (Marcus 1995b), in this case ‘BRCA genes’, at a number of spaces and places where I anticipated the translation of genetic knowledge was being undertaken or having an ‘impact’. This was intended to include field research with patients in their homes, a GP and a ‘hereditary’ breast cancer support group. On beginning field research it became apparent that my focus on genetic testing was to a certain extent misplaced, but also that the Clinic was a more dense place for inquiry than I had first imagined. Moreover, at least two of the other intended places of research were not feasible. GPs seemed reluctant to have a researcher waiting for a patient to come in who might request or was recommended a referral to a Cancer Genetic Clinic when they might have only ‘30’ such patients a year.⁹ Equally, there were at the time no organised hereditary breast cancer support groups. Nevertheless, as is a common occurrence in the context of carrying out research, I came across another space of ‘transmission’. The work of the Breast Cancer Research Charity in obvious ways precedes the point of clinical application but, as I explore in the thesis, it is also in other less obvious ways ‘disconnected’ from this process. Consequently a somewhat subtle element of comparison was unexpectedly part of my research design.

Two main sites therefore informed my research, although the process by which I became involved in each was somewhat different and meant using a range of methods and approaches.

1.5.1 Cancer Genetic clinics

I carried out field research at two Cancer Genetic Clinics in separate hospitals in the UK; Hospital X a specialist cancer unit and a much smaller piece of research at a large general hospital named here Y.

Having ‘contacts’ in one of the hospitals made my entry into the Clinic at Hospital X, somewhat easier. I was in fact a patient at this hospital 7 years ago prior to starting research and had maintained personal contacts with a few individuals. Nonetheless, this was by no means a smooth process and I spent

⁹ This was based on personal information from a GP who I contacted in the early stages of my research.

many months honing a research design that would satisfy the demands of the hospital ethics committee, the clinical staff and other researchers already working in this area. At the time I carried out my research, ethics committee approval was only necessary in order to talk to patients.¹⁰ The deliberations over the research 'protocol', as it was termed, related therefore to the type of patient I would formally meet. Despite my original intention to talk to a range of persons attending the Clinic, including those who had had or were about to undergo genetic testing, it soon became clear that this was not a widespread clinical procedure.¹¹ In fact, these patients were somewhat in demand by others carrying out psycho-social studies and both clinical staff and psychosocial researchers expressed concern that this might be a somewhat 'over-researched' group of people. It was finally decided that my work would focus on a very specific and delimited group of individuals attending the Clinic; 'unaffected' women (they did not have and had not had breast cancer) who on the basis of initial assessment of their family history were thought to be at 'moderate risk'.¹² Demographically this was a much larger proportion of the population, but which had also been somewhat neglected by psycho-social research in this area. Half way through my period of field work I also made contact with a number of clinicians working in a Cancer Genetics Clinic, in a general hospital that was part of a larger regional genetics unit and negotiated carrying out a similar piece of research with them. This enabled me to not only expand the number of patients I met but also include a range of other practitioners whose perspective on these developments was very different.

Field research at Hospitals X and Y was therefore undertaken in a number of ways and in a range of different places. This included meeting with up to 15 women attending the Clinic for the first time, both some weeks prior to their appointment and then once again in the weeks following their visit. This relatively small sample of patients reflected my attempt to understand how genetic knowledge was being used and acted upon by a range of people and not to focus only on the 'experience' of patients. A larger sample would of course

¹⁰ I was told that observing clinical encounters, talking formally and informally to practitioners would not require formal ethical approval, although informal consent was always obtained and confidentiality assured.

¹¹ At the time of starting my research only 50 or so mutation carriers had been identified by Hospital X.

¹² See page 36 for a definition of this 'risk'

have enabled me to examine more systematically how variables such as age and ethnicity influenced the experience of patients, but this was outside the scope of my research design and was not its primary aim.

Possible interviewees were identified, based on lists of those attending forthcoming appointments. A clinician would confirm that they fitted the criteria and I would send a letter to that person asking if they would be willing to take part in the research.¹³ If they sent a reply I would then phone them to arrange a time to meet before their appointment. Nearly all the interviews took place in the homes of the women I met.¹⁴ Formal written consent to participate in my research was obtained during these first meetings. I taped all of these interviews, following a very rough interview guide and transcribed them at a later date.

However, I felt considerably constrained in my contact with patients. Meeting individuals twice seemed to me a far cry from the kind of participatory research I had envisioned at the start of my research and experienced as an undergraduate anthropologist doing fieldwork in a small village in Hungary. I was conscious that this was only a snapshot of their lives. Moreover, it was felt to be 'inappropriate' to observe their clinical appointments as well as interview them and I had been told not to discuss certain issues, such as genetic testing, unless they were raised by the patient themselves (which many did). Nevertheless, talking to people in their homes was often enlightening and sometimes interviews spilled out into more general discussions which informed and shed light on the issues being addressed. Most of those I met were more than willing to talk about their expectations or experiences and seemed to perceive me as part of the care they hoped or anticipated they would receive, as a result of their visit to the Clinic. I also sensed that for some this may have been part of the reason why they had agreed to participate in my research.

I combined this very defined piece of fieldwork with regular attendance at the both Cancer Genetic Clinics where I tried to 'sit in' on as many appointments as

¹³ I sent out approximately 40 letters and received 17 replies (2 people did not subsequently take part because of the logistical reasons of arranging interviews)

¹⁴ A few patients (4) did not want to meet up in their homes or were too busy to arrange visits, so we met either at their place of work or one occasion at the clinic itself.

possible, with a range of staff.¹⁵ This included those undertaken by oncologists who had become genetic specialists, geneticists, genetic nurse specialists and a part time GP's who saw some newly referred patients in Hospital X. Specialist nurses who worked in an adjacent Family history clinic in Hospital X saw follow up patients. The same work was undertaken, as part of the Cancer Genetic Clinic, by a part time GP at hospital Y.¹⁶ The appointments I observed ranged from first time to follow up visits. Some individuals were not considered to be at greatly increased genetic risk, on the basis of their family history, while others were offered predictive genetic testing, or were waiting for or had been given a test result. The patients I encountered in the clinics constituted, therefore, a much broader spectrum of people than those that I interviewed in their own homes.

The practice of having 'observers' in the Clinic was something that was not uncommon to either of the hospitals, although I was perhaps a more persistent and regular 'observer' than others (mostly medical personnel from other specialties or who were in training to practice in the Clinic). I would try not to take notes during appointments, but in the lull between them I would record as much as possible in a notebook before writing it up at a later date. Yet the notion of being a 'passive' observer does not convey how I felt my presence subtly affected how practitioners conducted their appointments or the way patients 'responded', to having an 'observer' sit in on their visit to the clinic.¹⁷

As well as talking and chatting informally with a range of people who worked at both the Clinics I also undertook formal taped interviews with a number of key

¹⁵ Because I began research at Hospital Y half way through my field research I sat in on comparatively less clinics, up to 10 (compared with over 30 at Hospital X). I also spent less time with the practitioners at Hospital Y

¹⁶ There were no designated 'genetic counsellors' in either of the *Cancer Genetic Clinics*. Nearly all staff had moved into the field of Cancer Genetics from a background of clinical training. Although there were genetic counsellors at hospital Y, they saw patients and families with other genetic conditions and not those with an increased cancer genetic risk.

¹⁷ For instance I felt that on some occasions consultants paid more attention to the 'social' dimensions of their practice when I sat in with them. At the same time some patients would sometimes 'use' the 'observer' (through eye contact or direct conversation) if they weren't getting the kind of response or 'care' they wanted from practitioners. Only one patient in all the clinical consultations I sat in on objected to my presence during their appointment.

personnel in the later stages of my research.¹⁸ If my contact with patients was defined in very particular ways, my contact with clinicians was much more wide ranging. I was able to combine an approach which included observation of health care encounters, practitioners' narrative reflections on such appointments, as well as their response to a range of other issues. In addition I attended a number of large events, such as meetings and conferences of those working in the field of cancer genetics, where the same clinical staff were also in attendance. I also had a more participatory role, particularly in Hospital X. Here I was perceived as part of an expanding group of 'psycho-social' researchers examining the 'impact' of genetic knowledge on the 'family'; a designated role which, as I examine in chapter 3, shed light on the 'pastoral' dimensions of clinical practice.

I therefore generated a range of data as a result of research in the two Cancer Genetic Clinics. This included transcribed interviews with patients and practitioners, noted observations of clinical encounters, formal meetings between clinicians, as well as informal discussions with them.

1.5.2 A Breast Cancer Research Charity

During the first few months of my research in the middle of my initial investigations to try and locate a hereditary breast cancer support group, I became aware of large numbers of exclusively breast cancer charities. Collectively these organisations provide information or advice mainly for those with breast cancer and their family and friends. Support for those at risk of breast cancer because of their family history or for those who found to be carry a BRCA gene mutation appeared to be subsumed within the broad remit of these charities.¹⁹ Many also seemed reluctant to allow a researcher to make contact with these individuals. There was however another organisation, named here Charity H, where there was a more direct concern with 'genetics'. This became the second 'site' for my research; a context for fieldwork which I had not quite

¹⁸ Time pressures meant that I was not able to carry out formal interviews with those in Hospital Y. However I spent a significant amount of time chatting informally with this group of practitioners between observed appointments or after.

¹⁹ There are however such groups in the US. Such as FORCE (Facing Our Risk of Cancer Empowered) which has its own web site and support network for those with a family history of breast/ovarian cancer for individuals who are known to be carriers of one of the BRCA genes.

planned and which shed light on the transmission of genetic knowledge in a way that I had not anticipated.

Charity H is a 'grass roots' Breast Cancer Research 'Charity'. The official history of the organisation documents how it was originally set up in 1991 by the husband and family of a woman who had died of breast cancer. Their aim was to establish the first dedicated breast cancer research centre; something that has recently been achieved. But the history of the organisation also links it to a bigger more general cancer research establishment as well as a number of large corporate sponsors. Nevertheless the 'grass roots' image is a strong feature of the Charity's identity. This is reflected in the way that it is in part maintained by the relatives and friends of those who have had or died from breast cancer and those with or those who have survived breast cancer. Importantly, the Charity's research work is not just dedicated to breast cancer in a general sense, but more specifically to finding out more about the 'biology of the breast' through basic science genetic research. The long term goal is the development of treatments for those 'with breast cancer'.

As the major funders of cancer research in the UK, cancer research charities, provide an important but neglected social domain for examining developments in genetic research and the relationship between lay publics and sciences. Although there has been some social science work done on 'patient groups' who may sponsor or support genetic research (Raberharisoa and Callon 1998), it is certainly not extensive. Charity H straddled both these worlds in bringing into contact those carrying out genetic research and a group of lay publics. As such it provided a unique and interesting domain outside the Clinic for my research

With an intuitive sense that this would be an interesting organisation, to at least, talk to about these developments, I met the volunteer co-ordinator who suggested initially that I undertake some voluntary work helping out in the busy publicity section, just prior to the launch of Breast Cancer Awareness Month in September 1999. After meeting others in the organisation, particularly a few members of the research services team it became apparent that there was something of a shared interest in understanding how a wide range of groups and

persons were 'responding' to developments in breast cancer genetics. Fortuitously my voluntary work with the organisation had coincided with a project to investigate how those who raised money for the Charity perceived the organisation and the research it did. This was directly linked to an attempt to increase the role of fundraisers in terms of lay advocacy. I volunteered to undertake the research that would form the basis for implementing (or rejecting) this agenda. It was agreed by key individuals that the research I generated could also be used as data for my Ph.D. research. If work with the Clinic did not always feel like 'participatory' research, fieldwork with the Charity meant 'intervening' (Downey and Dumit 1997) much more directly in the workings of the organisation.

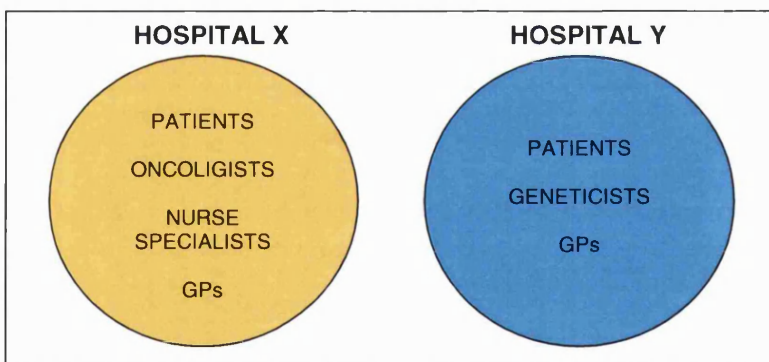
The formal components of the 'advocacy' research project, as it became known, included interviews with staff, volunteers and over 10 key fundraisers across the country. In addition I undertook (along with another staff member) three focus groups with fundraisers in different locations across the South East and the Midlands. All of these interviews and focus groups were taped and transcribed. I also attended an annual Fundraiser's Rally in the midlands where over 30 fundraisers from across the country met and was a regular 'participant' on the monthly 'laboratory tours' for fundraisers where scientists would present their work, introduce the centre and guide visitors around some of the laboratories.

In addition, an enlightened member of the research services team also felt it was important, in exploring the context for implementing the advocacy initiative, to understand how the scientists working at the Charity's Research Centre perceived the work of the organisation, their and the fundraisers role in it. As such I was able to carry out in depth interviews with nine scientists working at the centre, which were also taped and transcribed. This included both technicians or scientific officers and more senior members of scientific research teams. The scope of my research with these individuals was however fairly narrowly defined by the terms of the advocacy project. Consequently the findings presented here are not intended to provide a comprehensive examination of their 'identity' but a perspective on their experiences of working with breast cancer genes and communicating with a particular public about the research they undertake.

I also spent a significant amount of time in the headquarters of the Charity. This enabled me to talk informally with different staff about a range of issues relating to the research project, read the Charity's publicity material and document how breast cancer and genetic research were being represented in the press. I began my field research here six months prior to the announcement of the first draft of the Human Genome. Consequently I was witness to how the Charity negotiated this development as well as the more difficult public controversies over patenting and the use of genetic tests for insurance purposes which followed in its wake. A broad span of data was then generated from my work with the Charity. This included interviews with a range of individuals, such as fundraisers, staff and scientists (as well as more informal discussions with staff), observations of key events such as the rally or the laboratory tours and the analysis of publicity material produced by the organisation such as newsletters and fact sheets.

The two sites for my fieldwork are diagrammatically represented below, showing the main groups that were located in each site:

CANCER GENETIC CLINICS



BREAST CANCER RESEARCH CHARITY

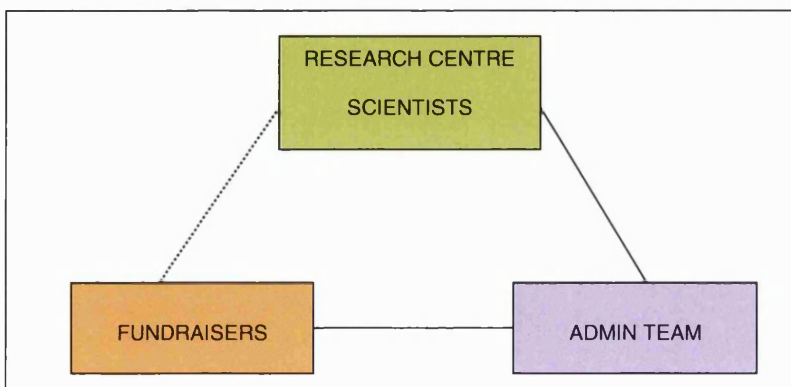


Figure two: *Research Sites: people and places*

1.5.3 The 'ethics' of field work

Questions of 'ethics' are not just the subject of analysis in this thesis but are also raised in considering how the analysis of this subject has been undertaken. As many anthropologists have noted field research which draws on participant observation as its central method inevitably raises a number of different ethical questions about informed consent and confidentiality.²⁰ These issues have increasingly come under the spot light in anthropology in the wake of a more reflexive approach towards theory and methods within the discipline (Marcus and Fischer 1986). Undertaking multi-sited research in a 'western' context at the intersection between different groups and individuals in a variety of health care and research settings, working with patients and professionals, brings these issues to the fore in particular ways.

At the time of my research formal ethical approval from local hospital ethics committees was only necessary for my interviews with patients. Here the procedures for recruiting, contacting and obtaining informed consent, of patients, were clarified and discussed. The informal permission that had been given by practitioners in both hospital settings to observe clinical appointments, talk with and/or interview practitioners as part of my research was not subject to this kind of formal 'ethical' review.²¹ Field research with Charity H was also undertaken without having to submit my proposals to ethics committees as, at the time of my research, there was no mechanism within my university or the charity for doing so.²² However I attempted to be as open as possible about my research goals in asking for the consent of those who were willing to be part of my research. I also re-assured them that I would preserve, as far as possible, confidentiality and anonymity in writing and disseminating my research. To this end the names of the people, places and organisations I worked with have been changed and information which might identify individuals removed from the text.

²⁰ See for instance Metcalfe (2002)

²¹ This situation changed in 2001 when the Central Office For Research Ethics Committees (COREC) at the Department of Health stipulated that all research involving NHS staff 'recruited as research participants by virtue of their professional role' must be subject to review by an NHS Research Ethics Committee (COREC 2001: 7).

²² This has also changed since the time of my field work. In January 2003 University College London stipulated that research involving human participants, where a UCL person is the principal researcher, must be submitted to a newly established UCL Ethics Committee. www.ucl.ac.uk/gradschool/ethics (accessed December 2002)

Nevertheless, anthropological method entails being open to the issues and themes that arise during the course of field work itself or which emerge from the issues and concerns of those encountered. As such it is not always possible to anticipate the questions and topics that will become central or arise out of a period of fieldwork or through more in-depth analysis over a longer term. Consequently the goals of research, articulated at the start of a project, may have substantially shifted and changed by the time it has reached its conclusion. Where possible I attempted to monitor any new ethical issues or problems that arose during the course of fieldwork itself. However, in this case, a form of 'retrospective' ethics may also be useful. This would involve returning to the groups and individuals who participated in research to discuss any changes in research aims or goals and whether this raises new issues for consent and confidentiality. This is something that I intend to undertake on completion of my PhD.²³ Nonetheless responding to the need for a more explicit attention to the problematic ethics of anthropological fieldwork, as well as understanding the consequences of adhering to such ethical standards, presents an on-going challenge for the discipline.

1.6 Chapter Outlines.

The thesis is divided into two parts. Part one focuses on the Cancer Genetic Clinics. I first explore the ways in which a specific group of women attending the Clinic talk about their forthcoming appointment to the clinics. How does a broader discourse about prevention in relation to breast cancer inform these narratives and what are the consequences of this for patients' expectations? The clinical arena is addressed more directly in Chapter Two looking at the tools and tests of medical practice and examining how they are used in translating and communicating knowledge about BRCA genes. How do they secure the authority of health practices and do they only or always achieve this? Chapter Three looks at the ways in which 'care' is part of clinical practice. What might 'care' mean in this context and what does it do? The second half of this chapter explores the consequences of care for patients. What kind of patient do the

²³ To this end, on completion of my thesis, communication and correspondence with the charity that I worked with has been undertaken. This has helped to clarify and confirm that the data

caring modes of 'predictive' medicine require? The final chapter in Part One looks at practitioners' experiences of working in breast cancer genetics and what the implications are for them. Are there differences in the way medical specialists identify with and experience the delivery of this genetic knowledge?

The second part of the thesis explores transmission of the knowledge and technology associated with BRCA genetics in relation to a Cancer Research Charity. Chapter Five examines the particular identity and ethos of the organisation by looking at how and why a particular group of 'fundraisers' became involved in it. How does the genetic research the Charity funds inform this involvement? Taking one event in the work of the Charity, the laboratory tours of the organisation's research centre, Chapter Six examines how the research work it funds is represented and 'performed'. The second half of this chapter explores how those who carry out basic science research for the Charity experience working in this environment and the necessary communication of their research. How are they implicated in the work of transmission? The final chapter of the thesis explores the ways in which the organisation represents the research work that it does to its supporters and the wider public. How has this changed in relation to broader developments and discoveries in genetic knowledge and how do those who work there negotiate and experience this shifting ground? The latter part of this chapter looks at how ethical concerns are increasingly becoming part of the representational and social practices of the Charity. How do ethical or social concerns inform, help or hinder the work of transmission in this context?

Part One: Cancer Genetic clinics

The evolution of a new health service

In April 2001, a few months before the last UK General Election the Secretary of State for Health gave a speech setting out the government's commitment to support an expanding genetics service in the NHS, announcing a £30 million package of new investment in the NHS genetic services (Milburn 2001). Ten months before that in the government's National Cancer Plan, cancer genetics was highlighted as key site for future research and investment, as the following extract indicated ;

Over the coming years our expanding knowledge of cancer genetics will have a major impact on our ability to predict an individual's level of risk of developing cancer; our ability to detect and diagnose cancer early and our ability to select treatments which are most likely to be effective. Ultimately the genetic revolution may lead to ways of preventing cancer (2000:89)

The situation was somewhat different a few years before these announcements, at the time when the BRCA genes were identified in the mid 1990's. Although most regional genetics services now have designated Cancer Genetic Clinics this has only really happened relatively recently (Harper 1996). Up to 1996 genetics services in the NHS were mostly focused on rare and single gene disorders. As such the system for the provision for Cancer Genetics was somewhat ad hoc and the boundaries blurred between what constituted research and what might be seen as health service provision (Wonderling et al. 2001). For example, there were a number of family history clinics dealing mostly with breast cancer in Cancer Departments in large hospitals which were often funded by research work or which had been set up by breast surgeons responding to patient inquiries. Regional genetics services did see patients as well, but were only funded in a few cases to specifically cover Cancer Genetics. Even at this time however a report published in 1996, a year and a half after the 'high profile' discovery of two breast cancer susceptibility genes, suggested that cancer related referrals to regional genetics units constituted over 20% of all referrals in a third of genetics centres (Royal College of Physicians 1996).

Partly in response to the uneven funding and provision for, as well as the significant increase in demand for these services, an expert working group was set up which made some of the first recommendations for a core service in cancer genetics in England and Wales (Harper 1996). Following a pattern outlined in the Calman-Hine report for organising and commissioning cancer services (1995), the group recommended a model that would provide a co-ordinated service at three different levels, linking primary care with cancer screening units in district and general hospitals and specialist Cancer Genetic Clinics. It recommended that primary care would be the focus for clinical cancer genetics services, especially in reassuring those at 'low risk'. Cancer units in district and general hospitals would respond to the needs of those at 'moderate risk' and those at 'high risk' would be seen by specialist Cancer Genetic Clinics. It recommended that purchasers should ensure such clinics were supported by contract funding rather than the insecure research funds that currently many depended upon. It also suggested that although the service should be seen as a 'partnership' between clinical genetics and oncology services, there should also be a movement to increase the numbers of dedicated cancer geneticists.

A study of referrals to regional cancer genetics services (Wonderling et al. 1999) suggested that the ad hoc system had begun to change, when it was noted that nearly all regional genetics centres now had dedicated Cancer Genetic Clinics. Nevertheless, this study also suggested that maintaining the tertiary system recommended in the Harper Report was not necessarily easy, particularly given the way breast cancer dominated these referrals. In a survey of 22 regional genetics in the UK, over a 4 week period, it was found that over 63% of all referrals were concerned with breast cancer (only 7% of all referral were for men). Of these large numbers were at moderate risk, and only 17.4% of new patients had cancer.²⁴

These findings in part reflect the fact that defining the guidelines for referral for women with an increased risk of breast cancer has been a subject of much

²⁴ Over half of all referrals came from GP's (Wonderling et al. 2001)

confusion. This was explicitly articulated in a Breast Cancer Consensus Report (Pharoah 1998), produced by a group of health practitioners and researchers working in this field seeking to reach an agreement on this issue. The report noted that 'there is widespread professional and public misunderstanding of the likely impact of these recent advances, particularly in breast cancer[...] this has resulted in large numbers of anxious individuals who have a relative with breast cancer approaching the primary care team' (1998:45). One indication of this is that best practice in this area has been under consideration by NICE (National Institute of Clinical Excellence) since 2001 and they are not expected to report their findings until December 2003. The following definitions for those at 'high' and 'moderate' risk and respective guidelines for referral are derived both from Eccles et al.(2000), the Consensus report of 1998 and the Public Health Genetics Unit in Cambridge(July 2002).

Those at 'high risk' are thought to have more than 4 times the average 'age related risk'. It is estimated that they constitute 20- 50 families per million of the population in the UK. For example this would include those with 3 or more affected relatives with breast cancer only, with an average age of less than 40 or breast/ovarian cancer families with 3 affected relatives with an average age of diagnosis of less than 60. It is suggested that these persons be referred to specialist genetic units where a range of services including genetic testing may be appropriate.

Those at 'moderate risk' are thought to have between 3- 4 times the average 'age related risk' and make up a far larger group 47, 000 women per million of the population. Those fitting this category would include 3 first or second degree relatives with breast or ovarian cancer at any age on the same side of the family or 2 first or second degree relatives with breast cancer diagnosed under 60. The management of this group is somewhat unclear. There seems to be support for offering these individuals routine mammography screening but it is less clear whether they should be offered genetic testing or referred to a regional genetics unit

It is recommended that those at low risk should be reassured by their GP and encouraged to seek screening as part of the National Breast Screening program when they reach the appropriate age.

The diverse and uneven development of Cancer Genetic Clinics in the UK is reflected in the 2 clinics with whom I carried out research with. By way of introduction to this part of the thesis, I describe the different historical trajectories that led to their separate development and the kind of institutional and social milieu that they were each part of.

Two Cancer Genetic Clinics

The cancer hospital where I began my fieldwork is one of the largest cancer centres in Europe seeing over 30,000 patients a year who are referred from all over the UK. It is recognized world wide as a centre for excellence in terms of treatment of rare and common cancers, in research and the education and training of health care professionals.

The main entrance to the hospital reflects the impression of a place of historically grounded expertise and tradition with its imposing stone façade and steps sweeping up the main entrance, where most attending the Cancer Genetic Clinic would arrive. There is an air of quiet competence with mainly health professionals and administrative staff moving around the building. By contrast the out-patient department around the corner of the hospital in a new set of buildings is an altogether more busy and somewhat predictable chaotic hospital setting, where mostly those newly diagnosed cancer patients or those returning for routine check ups following their treatment arrive for their appointments.

For those attending the Cancer Genetic Clinic only a short trip on the lift is necessary to the 'Breast Diagnostic Unit' or BDU. The lift opens out into newly refurbished corridors and pale pink thick carpets which sign post the short walk to the reception and waiting rooms. The atmosphere is reassuringly comfortable and relaxed with newish pink toned furniture and décor. The one or two staff at the reception are rarely too busy not to be friendly and welcoming, often offering patients tea or coffee and directing them to the waiting area where there are magazines and a full range of information leaflets on a range of issues relating to breast cancer. The half a dozen consulting rooms lie off to the side along a carpeted corridor, not really in view of those sitting in the waiting rooms. The tall ash coloured doors swing back and forth when a patient leaves or when the nurse or consultant comes in or out, but the corridor is mostly fairly quiet. Inside the consulting rooms themselves, the atmosphere of comfort is continued with colour co-ordinated carpets, curtains and a number of softly furnished chairs arranged normally at right angles to a smallish table, helping to convey and reinforce the sense that these are private spaces.

The current rather luxurious location of the Cancer Genetic Clinic which runs alongside the Family History Clinic within the BDU, is a result of recent hospital and other research investment in the unit, which is the setting and co-ordinating centre for a number of key clinical trials. The Family History Clinic grew out of a 'Well Woman' unit catering mainly for the local women to whom it provided advice as well as routine mammography screening and cervical smears.

Threatened with closure 15 years ago the unit was saved, if somewhat transformed, by undertaking clinical trials and providing services only to those with a family history of breast cancer. This is still one of the main focuses of the Family History Clinic which is run mainly by specialist nurses and provides regular examination, monitoring and mammography screening (the screening unit is adjacent to the BDU) for those with a number of affected relatives in their family, who may or may not be taking part in trials. The more specialist Cancer Genetic Clinic which has in part emerged from the Family History Clinic, monitors those at 'higher' genetic risk as well as seeing new referrals. These have increased several fold in the last few years and seem to come from a fairly wide catchment area, a recognition of the esteem and expertise associated with Hospital X. A range of personnel work in this unit, including consultant oncologists trained in genetics, nurse specialists and part time GPs.

By contrast, the Cancer Genetic Clinic at the large general teaching hospital, called here Hospital Y, had a different history. The Clinic was a relatively recent but growing addition, part of a larger regional genetics unit, where clinical management, laboratory research and diagnostic testing had long been linked in addressing a wide range of genetic conditions.

Arrival at the hospital is no different from the entrance to many other general hospitals. It is busy with buses and ambulances arriving, dropping off and leaving patients and has both an array of clinical staff and patients milling around. A sprawl of corridors leads to the fairly non-descript clinical space from which the Cancer Genetic Clinic runs 2 days a week. These clinics are slotted in around other genetic clinics or different medical specialisms that use the adjacent waiting area or the consulting rooms on different days of the week. Although not uncomfortable, the space lacks the more dedicated comforts and privacy of the

Clinic at Hospital X. There is nothing on the greyish walls to identify this as a Cancer Genetic Clinic and no patient leaflets about cancer genetics.²⁵ The impersonal atmosphere is compounded by the fact that there is no dedicated receptionist. Consequently there is often a wait, for new patients seeking to confirm that they are in the right place, as the staff juggle reception duties while attending to the patients that they are already seeing. Normally one or two geneticists plus a nurse specialist would be working here seeing mostly new patients. A visiting GP would see follow up patients who might be returning for their annual checkups. As there was no Family History Clinic, the kind of special 'cancer' nurses that worked in Hospital X were not part of this cancer genetic service. Moreover, organizing a mammogram or ultrasound for follow up or new patients was much more difficult and generally had to be coordinated often months in advance, after liaising with the screening unit in the hospital.

²⁵ Later I discovered that there were leaflets given to patients by practitioners in Hospital Y during their appointment. It was thought that having information freely available would cause 'more anxiety', particularly if it was picked up by those who were not at greatly increased genetic risk.

Chapter Two

Patients' expectations; awareness and visibility

The thesis starts by considering those who have generally been at the centre of analysis in medical anthropology; 'patients' and their 'experiences' of 'illness'. I examine how a particular group of people attending the clinics for the first time talk about how their referral had come about, their perceptions of risk and what their expectations were regarding their forthcoming appointments. All who took part were 'unaffected' women. Although the age range of participants spanned those in their mid 20's to late 60's, most were between 30 and 45 years old. They had been invited to take part in my research because they were presumed to be at 'moderate risk' (see page 35), on the basis of their referral letter. Although not always easy to define, on the basis of their employment many, but not all, could be classified as 'middle class'.²⁶

In this first chapter I examine how prominent features of a public health discourse about prevention and breast cancer (Kaufert 1998), particularly notions of 'awareness' and 'visibility', are part of the way those I met talked about going to the Cancer Genetic Clinic. I explore the consequences of this for how these individuals perceive the danger posed by genes and the scope of genetic knowledge or technologies associated with its use.

2.1 The morality of being aware

Most of those I met talked about how their appointments had been set up after discussions with their GP; something which many seemed to have instigated themselves.²⁷ Regardless of how exactly their referral had come about, nearly all those I met saw their visit in terms of being 'healthier'. One woman talked about how this was linked to a broader health awareness strategy

²⁶ A number of women were or had been employed within the public sector as teachers or working for government while others worked in the media or commercial business.

²⁷ There were a few exceptions to this, one woman was already part of the Family History Clinic at Hospital X and had been referred on to the Cancer Genetic Clinic. Another woman seemed to have been encouraged to visit the Clinic as a result of the actions of her GP. I explore these women's experiences in chapter 3 looking at how their 'inactivity' in seeking a referral (or in being a patient) had particular consequences for them.

Rose/ I've just sort of said to myself well I need to start looking at me. It's all very well looking after everybody else and seeing what they're having with breast cancer and their statistics. I'm actually about a stone and a half overweight, so I think about that a lot. I don't know whether it's age or lifestyle or whatever, but I just want to get back to being a bit fitter. It's all tied in together, it's all come at once, and breast cancer is a part of it.

For Emily going to the Clinic, following her mother's treatment for breast cancer, was also part of being more aware of her health. From what she said she clearly saw this as a 'good' thing.

I've become far more aware of checking myself and looking for signs and talking to other people about it, like friends in my peer group, they talk about it. It surprises me how little they know about it, it shocks me. It's important to discuss it and it's important to go and get checked.

Both these comments imply that there was an awareness of a high profile media and public health discourse about breast cancer risk and possible preventative strategies, particularly the need for vigilance or awareness and the role of lifestyle factors such as diet.²⁸ For some, their appointments were also linked to other health care concerns such as decisions about taking HRT or Tamoxifen. More importantly, as Emily's remarks suggest, this desire for awareness carries with it a high moral value. This was illustrated in the way several women I met, who had been required to be more pro-active than many in seeking a referral, talked about how they had had to assert their moral 'right' to be seen and hence were angered by what they saw as the inappropriate response of some practitioners. One woman recounted the struggle she had undergone with different 'male' health professionals to have her concerns taken seriously, which having now obtained an appointment at the Clinic, appeared to have been vindicated

Donna/ I mean it's like hitting your head against a brick wall. The doctor, he goes to me 'well you're only in your thirties and so if you're going to get it you're likely to be in your fifties' and I think what an attitude. Another time when I was being examined I had a man doctor and I said 'what can I do to get out of this pain' and he said 'we'll put you on these tablets and try swimming'. Then he said 'well the only thing I can do is a bust reduction' and it was like oh a sort of a 'go away' attitude and I felt like oh you're a blimming man and you ain't got a pair of boobs .

²⁸ For instance a number talked about specialist diets that they were investigating or following in order to prevent breast cancer.

Another woman also talked about what she saw as the inappropriate response to her care by a (private) doctor she had seen several months prior to obtaining an appointment for the Genetic Clinic at Hospital X.

Deborah/ He was so rude and impertinent. What I was looking for is 'this is what we're going to do, you obviously have a big history we're going to monitor you and we'd like you to come back every year, or five years'. But he didn't say anything like that to me, the mammogram was it. So he took the money and at the end of it I thought well what was the point of that. I mean he said 'well we might not find anything today but it might manifest itself tomorrow and anyway you're too young and the breast is very dense so we can't tell'. So I was very much sort of dismissed out the door.

For a few women being assertive and demanding about health care was less something that they were forced to undertake and more something that was, from their perspective, simply part of being a patient. For instance, Shona pointed out that this meant you had to be, what she termed, a very 'decisive patient'. This feeling was reflected in the way she talked about dealing with another health care issue.

I basically had several unclear smear tests and I just went straight to a gynaecologist recommended to me by a friend and it was sorted within six months. I think it was partly to do with the fact that I felt I'm not going to listen to the doctor again saying 'well lets do another one in six months time and see what its like'. I was just like right, no! I'm being referred and I'm being referred today. A lot of people do have problems because they're not educated in thinking about their own health. People are very lackadaisical about their health, you know it's the age old thing, health is when you don't have symptoms.

Some women also talked about their visit to the Clinic in terms of 'not living in regret' and being 'upfront' about health issues or the need to bring 'risk' into the open, illustrating how a moral code of awareness was powerfully linked to a need for visibility. For example, one woman I met noted the difference between the time when their relatives had had breast cancer and now.

When me Nan had it, it was like whisper whisper 'the big C'. My mum found it very hard to say the word too, but now we can say the word.

But speaking about the experience of cancer in the family or personal fears of the disease, as some had been required to do with their GP or other health care professionals in order to secure an appointment, was more than just an expression of personal anxiety. A number of those I met had relatives who they

felt had been misdiagnosed or left their concerns until it was too late. For them, going to the Clinic was about making hidden danger visible in a way that their relatives had not or simply had not been able to. This rationale was illustrated in the way that Deborah talked about her reasons for wanting to go the Clinic.

I suppose it is coming out of the twitchy curtain syndrome. Women are still very frightened though, but if you close up about it you're not going to be prepared to step forward and do something about it in its early stages. I'd rather be aware of what's going on, rather than not talk about it, rather than not be monitored, I'd rather be up front and face it.

The link between visibility and awareness brings into focus how the desire for, or reason behind attending the Cancer Genetic Clinic was therefore strongly informed by a high profile preventative health care agenda.²⁹

This has become particularly salient in relation to breast cancer over the last fifteen years in Euro-American societies. Much is made of the need to identify the disease in its early stages, by encouraging individual women to be aware of their breasts or attend routine mammography screening. It is a 'preventative' agenda that has also been informed by a burgeoning growth in health activism around breast cancer which has been instrumental in raising the profile of the disease (Anglin 1997).³⁰ In her analysis of the breast cancer movement in Canada, Kaufert points out that demands for 'visibility and voice' were central elements of the 'resistance' that created this activism (1998). She notes how the breast cancer activism of the 1990s emerged from the gender consciousness raising movements of the 1970's and identity politics of the 1980's. As such the previous invisibility of the disease has increasingly over the last decade been replaced by a heightened visibility; a process facilitated by the way individual women have told their stories and talked about their experiences.³¹ In this sense,

²⁹The connection between bringing fear/anxiety into the open and prevention seemed for some of those I met to be connected to an ethos that is strongly identified with complimentary and alternative health care practice. This approach to health views the mind and body as intimately connected and 'talking' about cancer and or anxiety is advocated as a form of 'healing' practice (See Sharma 1996, Stacey 1997). For instance one woman talked about how she thought there was a 'mental' side to the development of breast cancer. For her, going to the clinic, would enable her to 'release' the anxiety she felt about developing the disease and thereby counter any 'mental' contribution she felt she might make to her risk.

³⁰ However Aronowitz notes that a 'do not delay' message was prevalent before the advent of mass screening programmes in the 1970's and 1980's suggesting that this view has been prominent for a lot longer than this.

³¹ See for instance Audrey Lorde's *The Cancer Journals* (1980)

the *morality* of awareness in relation to breast cancer is animated both by a public health ethos and female health activism.

We can see the influence of this discourse in the way patients perceive going to the Cancer Genetic Clinic as rooted in terms of a right to health and the need to bring concerns and dangers out into the open. However it is perhaps the desire and need for ‘visibility’ which has most consequences for the way those I met talked about attending the Clinic. As I explore in the next section of this chapter, this is demonstrated not only in terms of a need to be open or upfront about risk but in the ways that some individuals appear to actively participate in making their genetic risk ‘real’ before attending the Clinic.

2.2 Making danger visible; being visibly a ‘patient’

Talking with those I met about their reasons for seeking an appointment brought to the fore how many women appeared to actively participate in identifying, reproducing and making manifest a personal as well as a more general sense of genetic danger. This process of making genetic risk visible and material was apparent in a number of diverse ways.

2.2.1 Having a family history

Some of those attending the Clinic had undertaken a good deal of investigative work to explore in more detail the history of cancer in their family. Deborah talked about how after her mother’s two sisters had developed breast cancer they had then uncovered what she termed an ‘extensive’ family history.

We’ve done a bit more chipping away to see whether there has been more breast cancer back in other generations. We’d never looked into it until after her sisters [Deborah’s mother] had breast cancer and then we were like hang on a minute oh yes auntie so and so died of cancer. When everybody finally looked back it was breast cancer .

Sometimes it was what was unknown or ‘mysterious’ and therefore suspect which made a family history ‘significant’. For instance, Lucy suggested that it was the gaps in her knowledge of the history of the family which pointed to possible cases of cancer that might have been hidden unbeknown to her and others in the family

I don't know much about my mum's family, my mum doesn't really either. She says that there was an auntie who died fairly young, in her fifties, so she doesn't know if that was anything to do with it. My mum comes from a quite a big family too and her mum was Irish so they had loads of kids, so potentially there could be a lot out there that I don't know about.

However, for most it wasn't just the fact that significant aspects of family history had been recently discovered or that there could potentially be hidden cases of cancer that they didn't know about; it was more that the family history they were aware of pointed to an undeniable danger. This was exemplified in what Shona said:

It obviously is genetic to some extent although research hasn't completely definitively shown what causes it. It's just there is breast cancer down the female line on my mother's family and it just strikes me that it must be related unless it's just a coincidence that my grandmother and mother had breast cancer, which of course is possible. But they had very different lives I mean if it was just fluke it's an unlikely fluke because one lived in the country and did nothing for years and years and the other lived in the city and just worked. They had very different lives so it's more probable that it's genetic that would be the logical explanation. It just seemed that it was obvious that I am at higher risk than probably a lot of my friends.

In general when there were several cases of breast cancer in the family, those I talked to were inclined to think that it was unlikely to be just a 'coincidence'. Genes provided a comprehensible, plausible and rational explanation for the cases of cancer in the family. This was brought home during my meeting with Donna after she talked about and then drew her family history.

Donna/ It's so weird my Nan's sister is still alive, she was ninety last year. She's got all me mum's cousins they're all fine. But if you look at the tree there are two sisters, like one sister has it and my mum, who's the daughter and then the other line nothing. It's weird, it puzzles my brain?

Sahra/ I wonder would you mind drawing how you see your family history ?

Donna/ No I don't mind. Going on me dad's side, I don't think of me dad's side as related to cancer funnily enough, because me Nan [on her father's side] did have stomach cancer and me granddad did have like a brain cancer but because the daughters didn't I don't seem to relate to that side. I just see like on me mum's side there is aunt kit and there is me Nan and then me mum [has had breast cancer] just like me Nan. Do you see what I mean [pointing to the diagram] see cancer and cancer we're scared that it's going to come. See if there is a certain gene it could have missed my aunt but went to my Nan .

Donna's very visual description of her family history helped to give form to a suspicion that genes were responsible for cancer in her family, a rationale that

was reflected (and to a certain extent reproduced) by the drawing I asked her to do.

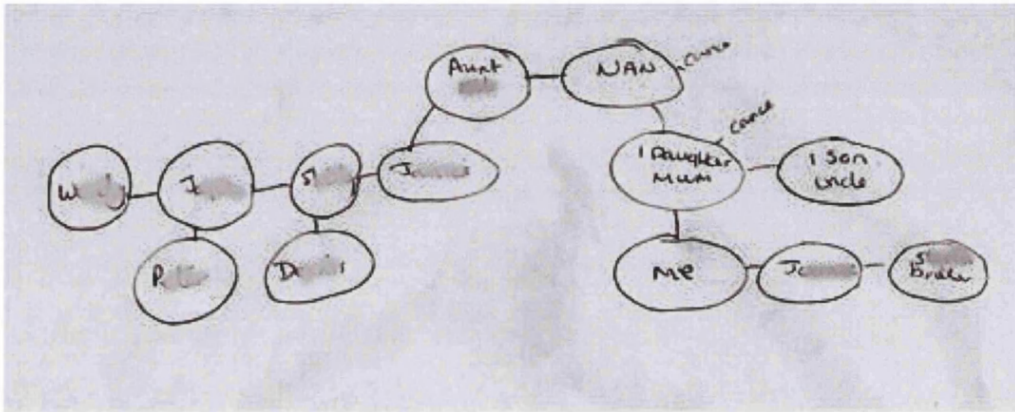
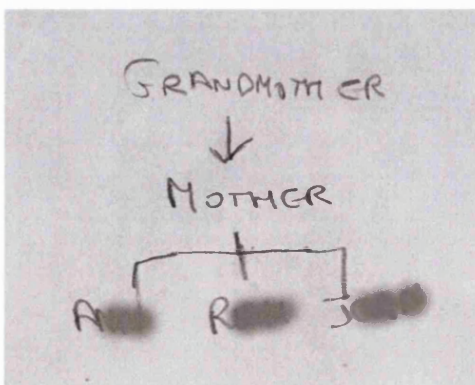


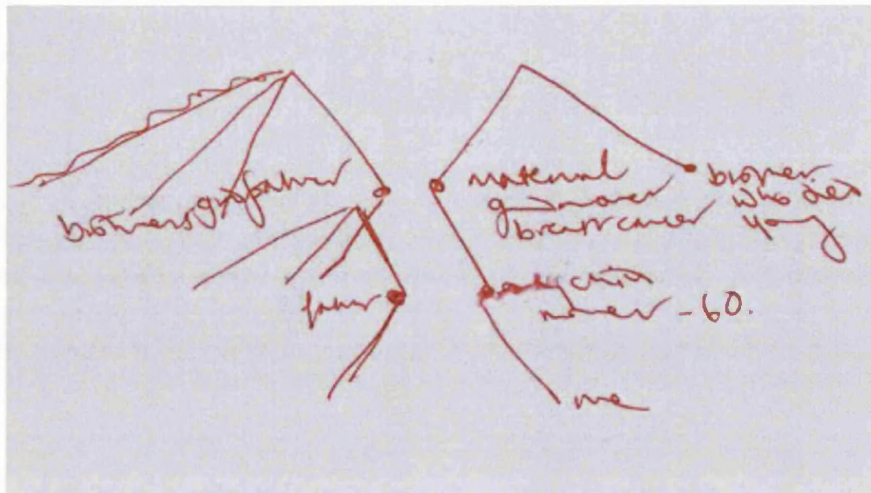
Figure three: *Donna's Family Tree*

We can see that Donna divided this depiction of her family history into two halves, as her description had suggested. This started at the juncture between her grandmother and her grandmother's sister. The linear trajectory she describes and the danger she feels this poses to her is clearly visible in the way she indicates who has had illness or cancer in the family. After this encounter I asked several other women to draw how they 'saw' their family history, copies of which are reproduced below.³²

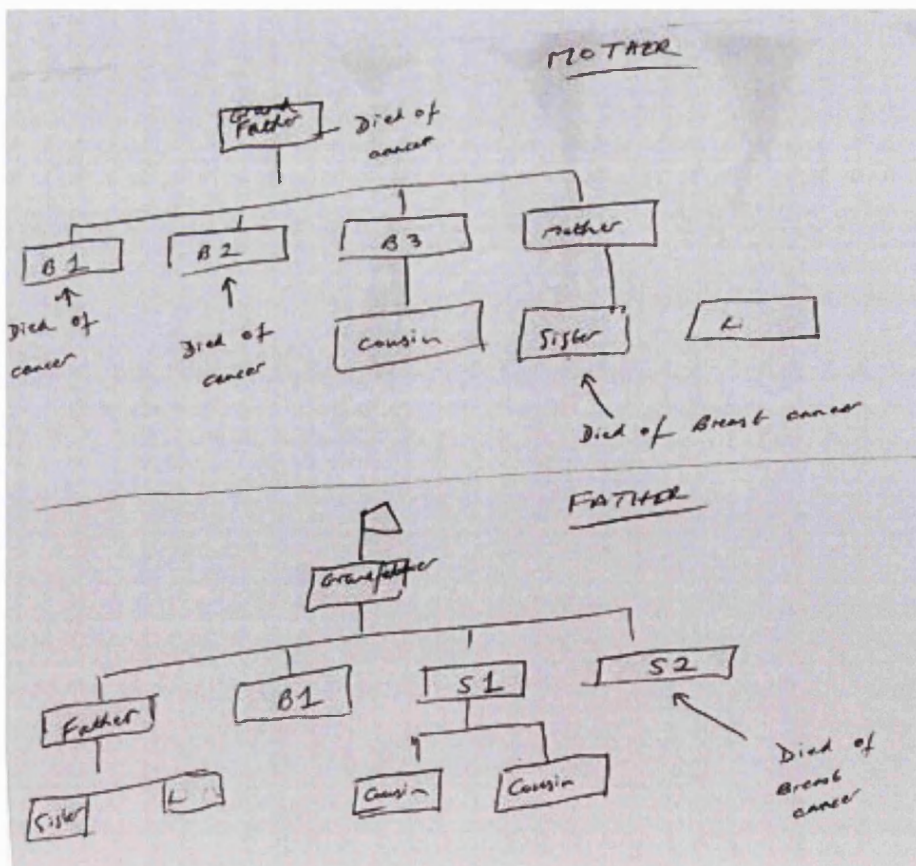


³² In all cases identifying names have been hidden

4.1 Joan's family history



4.2 Shona's family history



4.3 Leslie's family history

therefore, is how the perception of genetic risk that was apparent in discussing family history was easily visually represented, revealing the extent of a common feeling of anxiety about the dangers that this posed.

Nevertheless, these representations and discussions of family history must also be understood in relation to a practice that had to be undertaken by those attending the clinics. Before having their appointment confirmed, more than half of those I met had had to fill in a 'family history form' which involved them documenting the history of cancer and other significant diseases in the family.³³ This illustrates how those attending the Clinic *had* to be 'active' patients in the process of obtaining a referral. However completing the form, as a requirement for an appointment, also had particular consequences for how these individuals perceived and represented their family history.

In one sense it appeared to inform a sense of anxiety about the possible dangers that lay within family history. For example Joan's commented on how doing this had affected her perceptions of risk

It made you think you know yes perhaps there is something. On me dad's side there are a few brothers and sisters who have died of cancer, an uncle who had liver cancer and it wasn't drink related and an aunt had leukaemia. It just made you think oh there is cancer there, it's affecting to see who is having it and it makes you think oh perhaps they're related, who is going to be the next one if you like.

However, at the same time that completing the form may have made perceived or suspected genetic risk more real or in some instances frightening, it also confirmed to many that their family history made them 'special' or 'interesting' cases. For Donna simply having to fill out the form, suggested that her family history conferred something of a unique status, otherwise, she said 'they could be seeing everyone'. In fact many of these women were also aware that it was on the basis of the information documented on the family history form that they would receive an appointment at the Clinic. As such there seemed to be an effort to

³³ The form requests details of the family history. It asks for information about the patient themselves, the patient's children/ brother(s)/ sister(s)/mother/ mother's sister(s)/ mother's brother(s)/ father/father(s) sister(s)/father's brother'(s)/grandchildren/grandfather and grandmother. Details requested include name, date of birth, date of death (if a relative has died), where cancer was diagnosed, the site of the cancer and when it was diagnosed

represent family history in particular ways that might ‘talk up’ apparent or perceived danger in order that their family history would be seen as significant.³⁴

My interview with Emily demonstrated how difficult it is to separate a patient’s efforts or wish to be seen in the Clinic, by having a significant family history, from the effects of having to collect these details in the first place. During our first meeting I was surprised to hear what she told me about her family history.

My mother’s the oldest of the family and all her sisters have gone down with it, she’s got three other sisters and they’ve all gone down with it. It could be hereditary considering every single female is involved. It is strange that they’ve all gone down with it, at around the same age, that it is absolutely across the board, every single female member of the family.

The way Emily talked about her family history suggested that her ‘risk’ was a lot higher than others of those I had met. From what she said I didn’t think she was at ‘moderate risk’, as her referral letter had suggested and as a clinician verifying my selection of patients had also confirmed. However on our subsequent meeting a month later following her first appointment a very different presentation of her family history emerged, as she told me what had happened at the Clinic.

When I actually looked at the family history I thought oh yeah it isn’t that big a deal. We concentrated on my mother’s side of the family and really it’s just my mother, her mother and one of her sisters. If there were more than two sisters that had it then I would get worried but because there is only two it could be pure fluke. Also because my family’s so huge it just doesn’t make that much difference and all the people affected are over 45. So the statistics when you look at them don’t look that bad.

In some ways the discrepancies in Emily’s discussion of her family history before and after her visit can be explained in terms of the necessary work required to complete the family history form.³⁵ As Emily recounted she had found it a very demanding process.

I found it very difficult especially with the dates and stuff like that. So what I had to do was go back home and stay with my mother and make a series of phone calls to get it all sorted. It was a bit shocking really, the extent of cancer

³⁴ Some clinicians also seemed to confirm this when they spoke about how some patients might ‘misremember’ or ‘guess’ their family history.

³⁵ The change in Emily’s representation of her family history can also be understood in relation to the necessary clinical practice of ‘talking down’ the family history in the Clinic, when a person’s risk is not as great as they had perceived, or when testing is not possible (see Section 3.2.1).

in my family, not just the fact that there has been so much of this type of cancer, but the fact that everybody had been so sick, there seemed to be something wrong with everybody really. There was just more cancer in the family than I had thought there was.

For Emily, like Joan, completing the form had clearly made apparent the extent of illness and disease in the family which may have led to a heightened sense of danger and hence a fairly dramatic presentation of her family history at the start of our first meeting. But equally the changes in Emily's narrative about her family history must be seen in light of an awareness that it was only on the basis of having a 'significant' family history that she would receive an appointment at the Clinic. In this sense making risk visible is linked to an ethos of awareness that not only makes it important to bring the hidden dangers of family history into the open, but is also informed by an understanding that not everyone who requests a referral will be seen.

The complex interweaving of agency that characterised the process by which appointments seemed to be sought and ultimately secured was particularly palpable in the way Shona talked about her appointment as 'giving something back' to the hospital where her mother was treated.

When my mother was here I raised some money for the hospital when I was working in the city with some incredibly rich dealers and I thought oh it would be good to give something back. People aren't going to get anywhere with research unless people help out and also because although I don't know my exact risk I guess it's a lot higher than other peoples, which makes me think I'm a more interesting case.

Like Shona, others that I met also talked about their willingness to take part in clinical trials and research. Being able to participate in such an exchange was of course dependent on receiving an appointment in the first place; in being a 'case' that was of 'interest' to the Clinic. This was something that some of those I met were aware of and which their discussions or representations of family history, to some extent, reflected.

2.2.2 Bodily connections (and disconnections)

The 'obvious' and 'logical' danger of family history was also made visible in a number of more bodily ways by the women I met. For some, the sharing of physical symptoms, build and even personality or life experiences between

related individuals provided further evidence of an underlying narrative of causation that strongly suggested the involvement of genes in some way.³⁶

For instance Donna discussed the way a physical parity between family members fuelled her disquiet. For her this was linked to a shared anxiety and trauma that had passed through the lives of many generations that included her mother and grandmother.

Donna/ What makes it worse for me is the same year that me mum had the cancer that same month I found lumps in me own bust . And then there was me Gran, I must have been about 14 or 15 [when she developed breast cancer]. I can just remember it living with my mum just as it does with me and my sister.

Lucy also talked about the significance of similarities in physical build between herself and related individuals.

Lucy/ I expect to get it, that's how I feel. All the woman in my mum's family we're all very much the same sort of build my sisters and me, I just feel like I'm very much like them, built like them. I wouldn't be in the least bit surprised if I got it, I wouldn't be shocked. If I've inherited similar genes like them then I would be [more susceptible] and I'm probably more like my mum than my other two sisters.³⁷

For her, these bodily connections were more than enough evidence to convince her that there was a high probability she would develop the same condition. On another occasion, the identification of physical and psychological affinities between related individuals was used by the husband of a woman, who had been seen at the Clinic, to sustain the possibility of there still being a danger after they had been told that she was at little or no increased risk. Bob the (very vocal) husband of Alice, whose mother had had breast cancer many years previously, talked about how he was not entirely convinced by the reassurances they had received at the Clinic.³⁸

³⁶ These bodily connections could be seen as linked to a process of 'distributed' patienthood I discuss in chapter 4 and further evidence that those attending the Clinic are already participating in the reproduction of a particular kind of patient role.

³⁷ This belief seemed to be confirmed by Lucy's 'ecstatic' response to the clinician's suggestion during her visit to the Clinic that it might be possible to have a breast reduction operation. Although the clinician had, she said, pointed out that this was nothing to do with her 'risk'.

³⁸ This effort on the part of Alice's husband reveals the extent to which affinal members of a family might be equally as involved and invested in the procedures of the Clinic. In their case this was linked to a shared desire to continue to receive routine mammography screening, as part of the Family History Clinic at Hospital X, which they had been part of for some time.

Bob/ you've still got that thought why was she unlucky then, were there any pre-disposing factors that would cause her to be unlucky. Whilst there isn't a clear genetic link there, I have to say that I've still got a slight nagging doubt at the back of my mind that there isn't something in that line. The interesting thing as someone who has married into Alice's family is that Alice and her sister are almost the same physical characteristics of Alice's mother and her sister. Alice takes very much after her mother and looks quite similar, although her mum was much fatter and her sister is almost a facsimile of her aunt, they are like two peas in a pod. So maybe with the two sisters, one of them inherited some pre-disposition and the other didn't.

While physical similarities between related family members were seen by some as evidence of genetic risk, others expressed an underlying fear and uncertainty about their bodies, which must also be seen as part of their reason for seeking a referral. For example a number of women talked about the anxiety they felt about examining their breasts. For Chloe this was directly linked to her desire to be seen by a specialist Clinic.

Chloe/ That's why I asked [for an appointment at the Clinic] because I have a fear of it, because I'm quite scared of it happening. It actually makes me *not* want to check myself more. It's not right and I know it's not logical but that fear is that this will be the time that you will find something. So that's why I asked to be checked by the nurses so at least then you know I have someone doing it thoroughly.

Like Chloe, others felt distrustful not only of their own ability to examine their breasts but also of the utility of doing so, because of what had happened to relatives, as Joan pointed out.

The thing is my Nan's, when her lump was big enough to get worried about it, it was too late anyway and my mum she felt a little tiny one, but she had little growths and they were deep seated. We're all quite big and you can't feel, this is the thing at the back of all of our minds really, [for my mum] there was no sign, no feeling or change. It wasn't detected by feel, so this is something that's a big fear.

A more explicit indication of this hesitancy was the way a few women talked about how they would consider having the parts of their body, which were associated with this anxiety, surgically removed at some point in the future. Towards the end of our first interview, Faye's comments about undertaking surgery seemed to come out of the blue, suggesting this was something that had been at the back of her mind but which we hadn't explicitly discussed.³⁹ As this

³⁹ As the issue of preventative surgery was never prompted through direct questioning from myself this nearly always became apparent from passing comments or when other issues were being discussed. I had also been warned by practitioners prior to carrying out interviews not to raise issues such as genetic testing

excerpt from my interview with her demonstrates, we were initially talking about seemingly unrelated issues.

Faye/ and what is your Ph.D. in?

Sahra/ well the broad context of the Ph.D. is looking at how people deal with all the new knowledge about genetics in relation to breast cancer, I mean there are obviously lots of developments in genetics at the moment, is that something that you picked up on?

Faye/ well vaguely, not too much, I tend to read the travel pages, more than anything else, (laughing).

Sahra/ it's just very interesting to me really to see how people are responding to these new things?

Faye/ Yes I mean if someone said to me that I could have an operation, if it was cutting something off to eliminate the risk of breast cancer, I would definitely do it...you wouldn't have to think about it then.

Another woman's discussion of undertaking such a procedure also emerged in what seemed an offhand way, after I asked her about the kind of things she hoped would happen as a result of her appointment.

Deborah/ well I don't know, obviously there are these things to consider if there is a very high risk. You could almost voluntarily have a mastectomy and I know many women who've done that, get a boob job (laughing). I mean I know someone whose done it, they actually had a mastectomy then had their boobs re-built at the same time. To them they've taken away their risk of breast cancer. It seems fairly logical way round of doing it to me. I really feel like if I need to do something about it and if I have to go and have a boob job. Ill go and have it, just to get rid of the risk

Deborah's deliberate light heartedness seemed nonetheless to disguise a deeper anxiety about her risk of developing breast cancer.⁴⁰ The sense of anxiety around breast examination and the ease and readiness with which several women discussed prophylactic mastectomy as an option revealed much about the extent with some of those I met disassociated from and objectified parts of their bodies. As such, we can see that the bodily connections which served to make genetic risk manifest must be understood in relation to the articulations of

or prophylactic mastectomy both because this may be read as being 'directive' in my research and also because of their own concerns about the number of women who wanted to undertake this procedure.

⁴⁰ After being seen in the Clinic, on our second meeting, it was clear that this option was something that she was more seriously thinking about. She talked about how this was very much her preferred option compared with the threat to the 'natural' integrity of the body that drug based intervention posed.

Deborah/ I'd rather go through an operation than take a series of drugs, anything that's mucking up your system, I think its got to be juggling with nature. Rather than fill myself up with drugs if I still decided to take drastic action I would rather have a preventative mastectomy.

disembodiment with which they were connected. Fear and anxiety about the body were clearly linked to the way those I met engaged in efforts to make genetic risk visible; an entanglement of narratives and practices that must also be seen in terms of a public health discourse about the morality of health awareness.

2.2.3 The agency of genes

If a narrative of underlying genetic causation was reproduced in the way family history was discussed by patients, or the way connections were made between persons and bodies, the way in which genes were talked about also contributed to this process. Many of those attending the Clinic did talk about the possibility of other mainly lifestyle risk factors being implicated in the cases of cancer in their family such as HRT or diet. Nevertheless, the causative agency of genes predominated in nearly all cases. For instance, genes were often discussed in terms of the presence or absence of a 'bad' gene. The latter was often imbued with cancer causing potential and hence seen almost as a 'quasi pathogen' (Yoxen1982). This was demonstrated in what Joan said;

All I know is that you get so much genetic information from the father and so much genetic information from the mother and some of it is much more predominant than others. It's like a rogue gene, it's something that's there that shouldn't be, that doesn't effect everybody.

On other occasions the agency of genes was given a more concrete quality more obliquely. That is, for some, genes provided a way of understanding the cause of breast cancer that paralleled the way that other cancers had been linked to very tangible and specific environmental agents such as smoking.

Donna/ I think with other cancers it's environmental, with smoking and asbestos and things like that but with breast cancer I'm not sure. But I think if you've got the gene then you're probably likely to get it whatever, however healthy you might be.

Genes seemed to provide a certainty amidst a sea of possible risk factors and dangers. The strength of this attribution was particularly evident in my discussion with Deborah. She was one of the few women I interviewed who had family members who were already undergoing predictive testing.⁴¹ The possible presence of a 'gene' therefore took on a greater significance than it might have

otherwise done. Even so, her response to the possibility that genetic testing might prove inconclusive or even negative was to preserve the agency and possible presence of other genes in her family.

Deborah/If she's [her aunt] got it then that's obviously where it's come from and my mother would have it as well, but if she doesn't prove positive there are still genes that haven't been discovered yet. It could still be an 'outsider'. I mean BRAC1 and BRAC2 are just a tiny part of all this and there is so much more out there that they don't know about.

The attribution of agency to genes was also demonstrated in the way that 'fate' was understood and perceived as an expression or articulation of an underlying genetic presence. For two individuals, the sex of their (and their siblings) children pointed to the way 'fate' or 'genes' were operating in interconnected ways. Whilst talking about her family history and the diagram she had drawn (see page 48) Lucy highlighted the fact that she, like her sister, had had girls. For her this provided an indication that there might be a genetic risk in the family.

Lucy/ These are all my sisters' here and they've nearly all got girls [pointing to the family tree she has drawn]. There is only one boy, which is another thing I think oh you know maybe that's connected to all this. My mum's sister had two girls and the aunt that died had got three girls, so not many boys in our family but lots of girls which does make you think.

A more reassuring 'genetic' fate for future generations was identified by Donna because she had had boys, even if this did little to counter perceptions of her own risk.

I do say to myself is that why I had two boys so it could stop, I've got this terrible fear I've got the gene but at least I haven't got daughters so I won't have the worry.

Expressions of destiny were also apparent in the way Shona talked about the kind of diet she had always 'unconsciously' eaten. At the same time this reassured her she was doing everything possible to reduce her risk it also compounded a feeling that there was a genetic risk.

Shona/ It's funny really about the things that you read. I read that certain foods were anti-carcinogenic, namely green vegetables and it's funny but all my life I've always eaten loads of green vegetables, anything green I always sort of look at and want to eat. I thought this is because it's anti-carcinogenic and it's something within my body telling me because I don't really know what is anti-carcinogenic.

⁴¹ She only discovered this just before our first interview. It had emerged during discussions with her relatives about her own visit to the Clinic, in the process of filling in the family history form.

This fated 'sixth sense' about food for Shona not only confirms that she has a genetic risk, but that she is also countering it by being intuitively healthy. Her comments highlight the dense interconnections between a public health ethos of awareness around breast cancer (which often includes dietary advice) and the way those I met talked about and made visible their genetic risk. For Joan however, the expression of 'genetic' fate, she raised, was less reassuring.

Joan/ When my Nan died of breast cancer it was a big thing, but you didn't think it was going to affect anybody else. But my dad's quite religious and his view when Nan died was "sins of the father type thing" and "all this has been brought up on us". Now of course it [the cancer] is through the family. Until mum got the breast cancer we never really realised quite the link, that this is something that is going to happen again and again, pick one miss one that sort of thing simply because my mum's Nan died.

Here it seemed that the religious beliefs of Joan's father had served as a background for a growing feeling of genetic fate that fed and informed her feeling that there was a genetic risk in the family.⁴²

The desire, by those attending the clinics, to objectify or identify with having a genetic risk of breast cancer is significant. We can see that substantial efforts are undertaken to make genetic risk real by representing or talking about family history in particular ways and by pointing to physical and bodily parities. Moreover, genes are given both a more personal as well as a more general 'agenetic' character in the way they are seen as 'objects' with cancer causing potential or aligned with the expression of 'fate' in understanding the trajectory of individual and collective lives.

We can see that in examining the expectations and understandings of those attending the Clinic, it is less important to try and understand how 'illness' is 'experienced' than to examine how a de-contextualised notion of risk or danger is appropriated or applied in the effort to be identified as a patient. In her examination of the practices of the infertility clinics, Cussins argues that the objectification of patients involves their active participation in pursuit of a 'long range self', in this case the desire to be pregnant (1996). As they submit to a

⁴² As I discuss in Chapter 4 this is something that may have been given renewed emphasis by what had subsequently happened during Joan's appointment.

range of procedures she suggests that the ‘agency’ of patients, far from being curtailed by the ‘itinerization and objectification of their bodies’, may actually be pursued through these procedures (Cussins1996:576). Some parallels may be drawn in the way those I met objectified their family history or their bodies, in pursuit of a differently located ‘self’. In this case, as someone who is ‘aware’ of their health and will as a ‘patient’ be ‘seen’ and thus have their concerns addressed. Dumit, exploring the way that patienthood has become a means of articulating identity, uses a notion of ‘objective self fashioning’ to describe the way a scientific idiom may become a tool for identificatory practice, such that ‘facts and experiences are constantly tripping over each other’(1997). He suggests that this is particularly important in the context of more ‘controversial’ diseases such as M.E., where patients may have to ‘fight’ for a diagnosis. This process may also have particular consequences in relation to breast cancer where the disease is less ‘controversial’ but more ‘hidden’(Kaufert 1998), a situation which may be compounded in relation to genetic risk. For example, Lambert points out that genetic knowledge of risk may make patients more reliant on disembodied ‘scientific facts’ rather than trusting or relying upon their own embodied experience (1996)

Nevertheless I have suggested that efforts to make personal as well as a more general sense of genetic risk visible can also not be separated from a public health care agenda that is informed by and draws from an ethos of awareness and visibility in promoting a preventative approach. Such entanglements are particularly apparent in understanding the matrix of factors that underlie patients’ decontextualised representations of their family history.

2.3 The specialism of genetics and faith in technology

The final part of this chapter examines how a discourse about health awareness and visibility also has consequences for how patients perceive the expertise of the Cancer Genetic Clinic and its attendant technologies. I explore how this contributes to a sense of heightened expectation about the knowledge and technologies associated with breast cancer genes.

2.3.1 The expert Clinic

The notion that the Clinic was a place of expertise was widely held and could be contrasted with rather different feelings about other health care practices and practitioners.⁴³ As Shona said:

I'm really rather cynical about GP's anyway (laughing) I have to be really convinced that they are any good because whenever I've ever wanted anything done they've never done it. So I came straight here actually, I've just always had this belief that if there is something that you really want then go to the expert .

Like Shona many women had pursued the need for a referral either through their GP or other health care professionals, precisely because they perceived the Clinic and its practices as a place where they could benefit from the specialist knowledge and technology. Although Joan had not been as single-mindedly active in her pursuit of a referral as Shona, she also anticipated that the Clinic was a place of specialism in which she had an incredible amount of faith invested.

It's a bit like going to the mechanic. A mechanic who knows what they're doing will fix the engine but you take it to your next door neighbour and they tinker about with it they could blow the engine. They've [the practitioners at the Cancer Genetic Clinic] trained in that field, they know what they're talking about, it's the best you can't get any better advice. I feel quite lucky to have been referred you know I've got the opportunity

For a couple of those I met, referral to this specialism came about as something less expected, even though they might have been engaged in rigorous efforts to obtain some kind of monitoring or a check up of some sort. However, even when the clinical specialty to which they were referred was different to their expectations, there was a sense that genetic knowledge would provide a more skilled way of assessing risk. For instance, Rose explained how she had originally sought an appointment through her GP for a mammogram. In the process of waiting for this referral she had moved house and had then been to see a different doctor who had suggested that it would first be important to look at the 'gene aspect'. This was her response when I asked her how she felt about this unexpected referral.

⁴³ The sense of faith and hope in the expertise of the Cancer Genetic Clinic was most widely expressed by those attending the Clinic at Hospital X. This may have been linked to the fact that it was a specialist cancer hospital and hence was seen as doubly expert.

Rose/ well I thought great, because if they're actually looking down another avenue as well as just your very standard mammogram, if it's a truer picture or more efficient way of doing it, then I thought yeah lets go for it.

Sahra/so was it a shock to have to think about going to a Cancer Genetic Clinic?

Rose/ no not at all, in fact it was quite the opposite of a shock, I just thought well it's positive. I thought well there is going to be something else to detect it.

2.3.2 Visualising danger; the mammogram

As Rose's comments suggested, faith in the Clinic's anticipated expertise was closely linked to the application of technologies and most frequently associated with mammography screening. A few of the women quite openly declared that their reason for seeking a referral was to obtain a mammogram either on a one off or regular basis. For some this was because, like Rose, they were not aware of other interventions that might be possible in a Genetics Clinic. For most, however, it was because they felt emphatically that having a mammogram should be part of their visit. The conversation I had with Faye drew attention to the sense in which this outcome was anticipated and expected

Faye/I think that going to the Clinic and getting a mammogram is much more for peace of mind really rather than anything else

Sahra/So that's what you hope will happen when you go there next week.

Faye/yes just going to the hospital and knowing that you can have a check up, it does give you that peace of mind. In my head that was the whole point of going, as opposed to sitting down and having counselling really and working through my family history. I'm very well aware of my family history, I want to go specifically to have a mammogram and if I don't have that, then there is no point in going at all.

Francis also saw mammograms as an expected component of her visit to the Cancer Genetic Clinic. Her response to my question about how she would feel if she was told that this was not possible, because she might not be at sufficient risk, revealed her investment in this outcome.

If they say you're absolutely fine but I suggest that you do this, I'd feel really good, if they said you're absolutely fine, there is nothing to do, then you can go, I would be worried they're not suggesting what I should do. In my heart of hearts I suppose I haven't really crossed that bridge, to me they are always going to do something and I will get the information that I need. I do want it [a mammogram], even if I pay for it I do want it.

Many of those who expressed a sense of hope in this technique, talked about it in terms of a preventative 'mantra', very much linked to a public health discourse about screening; that is they believed that having regular mammograms would identify a possible risk or cancer before a problem took hold. When a discourse of health awareness preaches that vigilance and early detection is central to prevention and successful treatment mammography becomes the 'technological fixer; the diagnosis is made sooner, treatment begins before growth is visible or tangible' (Kaufert 1996: 178). In this sense it is perceived as an important tool for bringing hidden danger into the open, particularly when there is a certain degree of fear associated with other modes of being vigilant such as breast self examination. The desire to be on a screening program is therefore one of the crucial factors behind many women's decision to seek a referral to the Cancer Genetic Clinic, something that also becomes evident in examining clinical encounters in later chapters. But there is another technology which was more directly associated with visualising genetic 'danger'.

2.3.3 Anticipating 'the test'

Among some of those I met there was a presumption that going to the Clinic would involve genetic testing.⁴⁴ This became apparent when I asked Joan what she expected to happen when she went for her appointment. She revealed that she had many questions and concerns, however the prospect of having a 'blood test' held out the hope of more definite answers.

Joan/ I hope that we will walk away and perhaps know a bit more about the history of the family, know if it can happen to you or your aunts or your sisters, whether it can go down anywhere else in the family. To know yes you have got a possibility of contracting breast cancer or if there is anything on the medicine side of it like Tamoxifen, whether it would be good to take something like that. It's the answers to those sort of things. So I should imagine a blood test of some sort.

Sahra/ What would the blood test be for then do you think

Joan/ What I've been told is they do like a blood test which can tell once and for all whether you're likely. If you know it is a definite hereditary thing, then you can get on and deal with it a bit better.

⁴⁴ It should be noted that the examples outlined below were mostly unprompted discussions. I had been 'advised', by those working in the Clinics not to talk about genetic testing unless it was raised by the patient in the first place.

Like Joan, the prospect of going to the Cancer Genetic Clinic for Alice and Bob precipitated an anticipation that Alice would have a genetic test and hence receive more definite answers. As their comments reveal it also engendered a good deal of anxiety about the implications of any 'result' they might get.

Bob/ we had visions of a battery of blood testing (laughing)

Alice/ I think I thought I will go along there and there will be some answer to it. If they said well yes your family history shows a leaning toward it being genetic, then they would have taken the blood test and come back and said well these are the three things that you're susceptible to (Bob laughing loudly). I think I thought it would be like they would do those tests when they say 'oh you're allergic to this and this'.

Bob/ It was almost like right well how long have you got!

Alice/ No I don't think it was that bad, I think I thought that they were going to take this blood test and come back and say well you're likely to get A, B and C (laughing too)

Bob/ The annual battery of tests!

Their retrospective account about what they had expected to happen at the Clinic had of course the benefit of knowing a little more about the difficulties of undertaking testing. Nevertheless, as well as trying to reflect honestly about how they had felt about going to the genetic Clinic, they told me 'their' story with reassurance that Alice was not at greatly increased risk already in place. As such they were ironically aware of the gap between their own expectations and the reality that confronted them and so I felt didn't hold back in telling me how they had really felt before going to the Clinic. By contrast the possibility of having a 'genetic test' had been etched on Donna's mind by a programme she had seen on television.⁴⁵

Well I was watching a television programme and there was a lady on there. She had nine women through the family that had breast cancer and had a genes test done and she found out it was in the genes and so she had her bust removed. She said it's the best thing she ever did because the fear of breast cancer was affecting her life. So listening to her was like listening to myself. Unfortunately to have genes test done, it means blood from me, and blood from my mum and I lost my mum two years ago. But hopefully the records of her blood, she had so many tests it should be in her records. If they say to me yeah it's in the genes then I'll know what my options are, I would feel a relief and could get on with me life a lot better.

⁴⁵ The programme she talked about was actually called 'The Decision: living in the shadow' broadcast in 1996 and followed a group of related family members as they made decisions about having genetic testing and surgical interventions.

Even though Donna had learnt that because her mother was no longer alive genetic testing would probably not be feasible, she still anticipated and hoped that she would somehow be able to have a genetic test. For her, like others, this held out the possibility of bringing some sort of resolution to her anxieties.

For some, the expectation of a blood test had been informed by what had been done and said by other health care professionals either directly to them or to their relatives before their own referral to the Clinic, as Chloe's experiences demonstrated:

My mother, who still goes for checks once a year, she told her consultant what I was doing and he said 'if she wants to come to our hospital she can come here, if it's nearer for her, that's fine'. I think that's why he was interested (laughing) because my mum was still alive. The doctor said 'oh your mum is still alive so would she be willing to come and they would just take some cells from her cheek' or something. So it seems like a lot of people are quite keen to get people to do it. I was surprised that I was allowed to do it really, because I thought I would have to have an auntie as well, or a sister.

In this case, Chloe was aware that the interest expressed in her was linked to the fact that it might be possible to carry out some sort of testing on her mother.

These examples demonstrate how it is difficult to disaggregate the actions of GPs and other health professionals or a particular agenda in the media about genetic testing for breast cancer, from the actions, awareness and expectations of patients.⁴⁶ Whatever the source of such an expected outcome it's also clear that genetic testing provides a powerful symbol of the precision and expertise that many of those I met associated with this medical specialty. Testing for genes held out the hope of providing concrete answers in the midst of widespread fear and anxiety about the risk of breast cancer.

2.4 Conclusion

This chapter has explored the perspectives and understandings of those attending the Clinic. It suggests that patients are proactively involved in their efforts to obtain a referral, make their 'risk' real, and reproduce the Clinic as a space of expertise and knowledge. The data presented, like recent work in anthropology

⁴⁶ Henderson has explored the high profile given to genetic testing and breast cancer genes in the UK media (1999)

looking at the accounts of patients and lay persons, challenges a 'deficit model' of the public's response to new medical technology or knowledge (Irwin and Wynne 1996). A growing body of work, focusing on the downstream 'users', has revealed the multi-faceted ways that patients and lay persons deal with the 'effects' of new technologies or knowledge about health (Rapp 1999), (Ginsburg and Rapp 1995), (Martin 1994) and (Kerr et al. 1998).

The findings presented in this chapter have shed light on the agency and actions of lay individuals, not simply as recipients of such information, but as those who initiate, seek and anticipate new knowledge or technology, before even being seen in the Clinic. They are in this sense very much 'anticipatory' patients, although of a somewhat self selected variety. One of the most striking aspects of this mode of identification is the desire to make personal genetic risk real and manifest. I have suggested that such actions must in part be understood in terms of the work required of individuals prior to or in the process of securing an appointment. In fact, active patienthood must in this sense be seen as linked to a broader valorisation of health and part of a growing culture of healthism (Becker 1997), which has found particular expression in the context of breast cancer over the last 15 years (Kaufert 1998), (Anglin 1997). As such, the need to make genetic risk manifest by those attending the Cancer Genetic Clinic can not be abstracted from a prominent preventative public health care agenda that is informed by and draws from an ethos of awareness and visibility in promoting a preventative and precautionary approach.

We can already see that the 'traffic' of transmission in relation to knowledge of BRCA genes is not only flowing in ways that might not have been expected, but is already multi-directional. The expectations of patients inform this emerging field of medicine, even as this must be seen as the outcome of a discourse about awareness, prevention and breast cancer. Whatever the particular configurations of agency that lead individuals to seek an appointment at the Cancer Genetic Clinic, we can see that there is a heightened expectation about the scope of this field of health care practice. The next chapter, exploring the material practices of the Clinic, shows how such expectations have diverse implications at the interface between practitioners and patients.

Chapter Three

Technologies of the Clinic; tools, tests and explanatory strategies.

The legacy of an illness/ disease distinction (Eisenberg 1977) has meant much anthropological study has been confined to the parameters of illness rather than confront the social and cultural dimensions of 'disease' or bio-medical knowledge (Lock and Lindenbaum 1993). This has now begun to be redressed particularly in terms of a focus on medical technology (Gaines and Hahn 1985), (Lock and Gordon 1988), (Casper and Koenig 1996). It is a research agenda that has long been a key feature of work in STS, which has focused on the social production of new technology and scientific or medical knowledge (see for instance Clarke and Montini 1993), (Oudshoorn 1994). This chapter contributes to an expansion of this domain of anthropological inquiry by examining the routine practices of the Cancer Genetic Clinic and the way that transmission of genetic knowledge is undertaken at the interface between patients and practitioners. It explores the way particular visual tools and objects are important aspects of predictive medical practices. If, as one clinician put it, the goal of the consultation is about 'putting ill-defined concerns and anxieties into some kind of framework' then this chapter shows how these tools, and the discourses that accompany their use, play a crucial role in achieving this aim. Observation of clinical encounters suggest however that such objects and technologies do more than just service knowledge or expertise (Latour and Woolgar 1986) and are not 'shot through with power' in a simple or direct way (Rapp 1999). The second half of this chapter explores how the same tools are used in ways that deliberately bring contingency into play or become linked to a narrative of 'uncertainty' in ways that are less intended or controllable.

3.1. Making knowledge material

The routine practices of both the clinics where I carried out research were constituted by various practices of risk assessment, explanation and sometimes prediction. To a greater or lesser degree, all these processes involved the use of

visual tools and objects.⁴⁷ The next two sections of this chapter explore their importance not only in providing a framework for knowledge practices in the Clinic, but in the way they imbue such practices with a certain materiality. This, I suggest, might be particularly important in the context of BRCA genetics.

3.1.1 Family trees, risk assessment and the tools of explanation

The initial task undertaken by practitioners during appointments with patients visiting the Clinic for the first time is a discussion of the family history, followed by the production and presentation of a clinical family tree, or 'pedigree'. In Hospital X this was marked by the removal from personalised medical notes of an already printed family tree, which is laid on the desk in front of both practitioner and patient(s). The presented tree is a product of information sent in on the family history form by the person attending the Clinic and drawn up using specialist software by a member of the departmental staff. In Hospital Y, practitioners preferred to draw the family tree with the patient in attendance during first time appointments, although the resulting depiction was also in part a product of information written onto a family history form that patients brought to their appointments. Despite differences in the mode by which clinical trees were produced, the resulting depictions were not dissimilar.

In many ways these clinical trees replicate in visual form a widely recognized mode for representing the history of relations in the family. 'Family trees' have familiar iconic status and meaning for many outside a clinical setting, as the diagrams of those I met attending the Clinic already suggest. Tracing family history has in fact become a hugely popular activity and is part of a widespread commodity industry in a Euro-American context.⁴⁸ In their most minimal state these types of representations of family history map kin relations in 'tree' like form with documentation of the names, dates of birth and death. But more often other historical details of relatives' lives may be included such as a person's occupation(s) or place(s) of residence during their life. Some examples of the kind of popular representations of family history are illustrated in figure 5,

⁴⁷ Comparatively speaking however those in Hospital Y tended to use less visual tools than those in Hospital X, apart from the clinical family tree which was used equally.

⁴⁸ There are for instance National and International monthly publications, a vast number of clubs and societies as well as hundreds of web sites all dedicated to the pursuit of finding out about family history.

sourced from a monthly publication dedicated entirely to investigating family genealogies. We can see here that both names, pictures and places are important features of such representations.

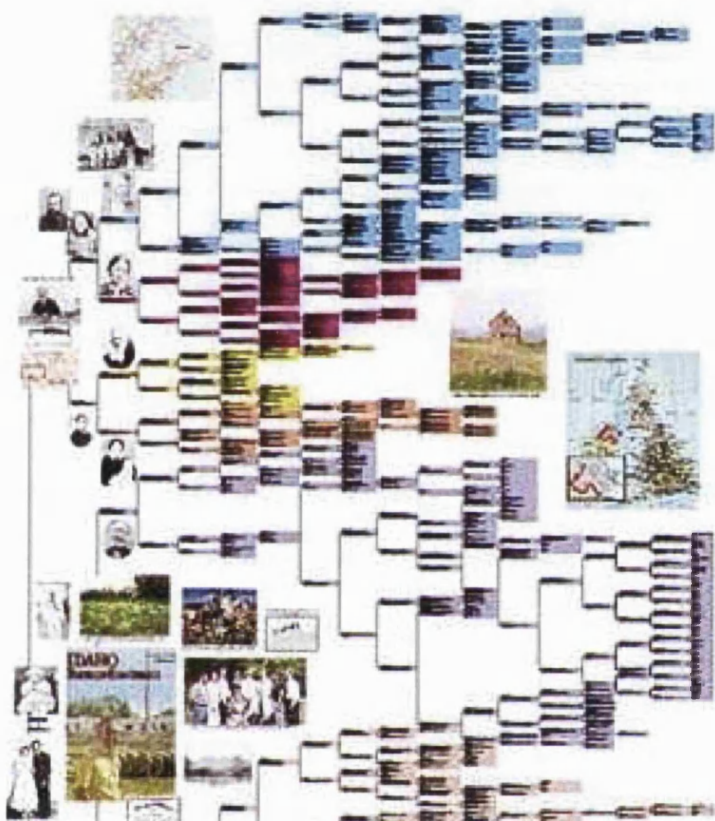


Figure five: *An example of a popular depiction of family genealogy*

By contrast clinical depictions of family history use specific icons as a shorthand for gender, illness and death in the family(see Figure 6). As such what is notable, when they are presented or drawn up at the start of the consultation, is the visual impact of a variety of shorthand symbols. These include black circles, or other half-filled or quarter-filled circles and squares representing women with breast cancer and women or men with other cancers in the family. Crossed out circles and squares represent those who have died and the white circles and squares are used to denote healthy members of a family. In the initial presentation of the clinical family tree, these symbols mostly refer to children in the family.

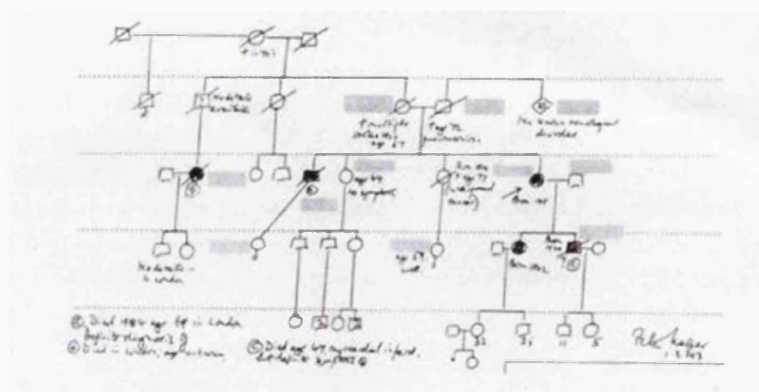


Figure six: A 'typical' clinical family tree

These somewhat stark and de-contextualised representations of family history are compounded by the fact that at the start of the clinical appointment, these trees may make little reference to other relations such as cousins, aunts, uncles and relatives by marriage and hence male relations. This is can partly be explained, at least in Hospital X, by the fact that the trees which emerge at the start of the appointment are a product of information filled in on a family history form by the patient before their appointment. There, is as I have shown in chapter 2, often a desire to present family history in particular ways, although this is also de-limited by the information requested.

The presentation and/or production of the tree is accompanied by the clinician asking the patient for verbal confirmation about the information written on the form they have filled in concerning the types of illness or age of a relative's deaths. This is an important process, as there is a widespread feeling among clinicians that the trees are at this stage sometimes 'inaccurate', because of the way patients 'misremember' or 'guess' their family history.⁴⁹ As the information is confirmed or altered and then transcribed onto the tree, questions may be asked about other relatives, both near and distant, who might not have been included on

⁴⁹ This was illustrated by what one nurse specialisat said:

Nurse/One of the things that I feel really strongly about is getting the correct diagnosis, because I know that there are inaccuracies. I am concerned about people making up their history. I mean patients have told me that their relatives have had cancer at 24 or 25 and I've looked into it and its been 40. Anybody that's told you that their relatives had breast cancer at a very young age, you need to check it out on the death certificates.

the form but whose state of health or manner of bodily illness manifestation might be crucial to the assessment of risk. Sometimes these are more directly posed. Clinicians may ask if there were any more cases of cancer on one side of the family or if a relative was young when they died, or even the manner in which a cancer first appeared or developed.⁵⁰

The specificity of these questions reflects the centrality of this tool in making accurate assessments of risk. It is on the basis of information collected and reproduced on the family tree that an initial estimate of the chance that there might be a gene in the family is undertaken, as well as the subsequent sorting or 'triaging' of patients into different risk categories (high, moderate, low). This in turn governs the type of intervention offered to patients, which may include regular check-ups, routine mammography or genetic testing. Moreover, in the frequent absence of predictive testing (see page 73) the tree is often the only tool and technology of risk assessment or prediction. It is no coincidence that during first time appointments the tree stays on front of the desk between practitioner and patient, providing a constant reference point for both parties.

The importance of the tree as a tool of assessment was reflected in the way those who worked in the clinics talked about them. One oncologist said 'sometimes I look and I think that person doesn't need to have a test to see if there is a gene in the family, you can see just by looking at the tree'. She implied that drawing up the tree sometimes enabled her, at least privately, to ascertain the presence or absence of a gene. Another practitioner pointed out 'we call them the 'blood test' because our basic investigation is with the family tree and that's what we are basing our discussion on' revealing, even if somewhat ironically, the centrality of the trees in the absence of widespread predictive genetic testing.⁵¹

⁵⁰ For instance if a relative had developed breast cancer in both breasts, this is considered to be more suggestive of genetic involvement.

⁵¹ This was apparent on another occasion also when another senior clinician reflected on the 'evidence' the family tree provided for her, if not the patient in question.

Consultant/ we had a lady in the Clinic the other day who did not want testing and she was 'affected' [had breast cancer], had a family history. The chance that she had a genetic alteration was 98% and yet for her she'd not had a blood test and that was a really important thing. So there is a psychological difference in it being absolutely there in black and white on a piece of paper that there is a genetic alteration and the *facts staring at you in the face* (my emphasis).

We can see that the trees are an important index of expertise in the Clinic in undertaking risk assessment. However, the clinical family tree is not the only visual tool used in the Clinic, others play an important role in subsequent aspects of the consultation.

Explaining the complexities of inheritance in relation to the BRCA genes typically involves the hypothetical juxtaposition of a person's family tree in relation to a number of other images and explanations. One of these consists of two circles; one with a red line and blue line in its centre and another with two green lines. This is shown to the patient and described as representing two cells, each with two copies of the gene. The red line is said to denote the 'bad copy'. Beneath this are visual representations of the possible permutations of inheritance that may ensue in terms of inheriting the 'bad copy', or not. The faulty gene is most often hypothetically described for the purposes of explanation as the 'mother's bad copy' and the one with two green lines described as representing the 'father's good copy'. This provides the starting point for what is presented as the central contingency in the explanation about genetic inheritance. That is, even though a relative might hypothetically carry one bad copy, it might not be inherited by other descendants of that relative because 'you get 50% of your genes from your mother and 50% of your genes from your father'.

Such explanations alongside the use of the family tree make biological connections explicit and 'literal' and clearly rest on a particular 'origin story' about genes, identity and reproduction that replicate a perceived Euro-American notion of kinship as predicated on bio-genetic connections. As such this 'normative' representation of genetic inheritance and risk could be seen in terms of process of 'naturalisation' (Yanagisako and Delaney 1995), that 'displaces' alternative or more complex narratives (Strathern 1992b).

A further 'displacement' is evident in the use of other tools and different explanatory strategies. For instance, according to practitioners the 'most important thing to remember is that even though there might be a gene in the family, you might not have inherited it'. In the clinics I observed this was frequently the most explicitly and consistently highlighted aspect of explanations about genetic inheritance. The

variable 'penetrance'⁵² of the BRCA gene is mentioned when explaining that it is only with 'the loss of two good copies of the gene that breast cancer will develop'. That is even if the so-called 'bad copy' is inherited 'other changes' would have to occur to the remaining 'good copy' for breast cancer to occur. These changes are not visually depicted in the same way that the inheritance of the genes are and only alluded to through words written beneath this central image, 'environmental and lifestyle factors'.

Sometimes these factors may be acknowledged as an unknown variable in response to common concerns from patients about the influence, say, of dietary factors on genetic risk. Nevertheless gene/environment interactions are not a prominent feature of the visual tools used in the Clinic or always necessarily fully incorporated into the explanations that accompanies their use. In fact the discussion of genetic inheritance as a risk factor for breast cancer stands in dramatic contrast to the lack of explanation in the Clinic about the possible aetiology of most breast cancers. These are referred to as sporadic cancers and put down to 'just bad luck' or caused by 'chance alone'. To a certain extent, this explanation reflects the current lack of knowledge about breast cancer aetiology more generally. Nevertheless it also reinforces the explanatory power of 'knowable' risk factors such as genes and sidelines more complicated questions associated with suspected but less readily identifiable etiological agents.

A circumscribed explanatory style was an approach that was used by all clinicians to a greater or lesser degree. For instance, this was reflected in the way breast cancers were talked of in terms of a tripartite division. Sometimes clinicians would explain how there were essentially three types of cancer; 'sporadic cancers, genetic cancers' and what were termed 'familial cancers'. Although it was often subsequently acknowledged to patients that this latter category constituted something of a 'grey area' (and was the category which applied to most patients), this tripartite division at least implied clear cut boundaries. On one occasion, during an appointment with a patient, the boundaries between different type of cancers were drawn even more starkly by one clinician. Talking about the importance of distinguishing between 'sporadic and genetic breast cancers' she

⁵² See footnote 3 page 9

pointed out that some breast cancers are like ‘single gene disorders.. where there is a mutation in every cell’. No breast cancer could be truly described in this way given the multi-factorial nature of all breast cancers, even where inherited genes are known to play a role.⁵³

Another visual image accompanies the discussion of exactly what DNA is. Here a computer generated iconic image of free floating , twisting piece of DNA is used. It is described as the substance that conveys ‘specific instructions to the cell’ . On the one hand it is therefore represented as inherently powerful. The iconic separation of this strand of DNA from other cellular activities appears to reinforce the agency of genes. This visual representation also intersects with a metaphoric narrative about gene mutations. Here, the emphasis is on how only ‘small things need to go wrong’ for damage to cells to be incurred. So if DNA is, as one clinician said, like an alphabet then it only takes ‘one spelling mistake’ for problems to arise. Another practitioner described a gene as ‘like a song on a tape’ in which mutations were described as a ‘wrong note’, so that ‘when the song is played, it sounds terrible’.⁵⁴

If the use of visual tools and particular metaphors or narratives help to bring a coherency and stability to explanations about genetic inheritance, the predictive practices of the Clinic also involve recourse to material practices that are used to seek similar ends.

3.1.2 The materiality of prediction

A predictive graph is another important tool used in the Clinic. This probability curve enables practitioners to be able to show what periods in persons life there

⁵³ At the end of the appointment I asked her about why she had used this description. Her reply revealed how the desire for clarity may have been behind such demarcated explanations.

Clinician/I was really trying to get across the difference between genetic and sporadic cancers and if you get into too much detail at the beginning and start talking about how these genes are dominant but recessive in terms of the phenotype then people start to lose the thread

However this attempt to make explanations coherent may also have been linked on this occasion to the fact that the patient and her family were , according to the doctor, ‘perfect’ for research. Her awareness of this may have prompted her to be more than usually categorical in her description of genetic cancers.

⁵⁴ Other metaphoric descriptions of gene inheritance were less simplistic, particularly those used by clinicians in Hospital Y. Although this could be in the pursuit of very particular ends(see section 3.2.1)

is most risk and explain how it is higher or lower at different ages.⁵⁵ This tool did not just visually facilitate explanations but was also linked to the provision of personalised risk statistics, based on a person's family history. A range of different risk figures could be provided in the consultation, including the chance that there might be a gene in the family, the 'relative' or 'absolute' risk of breast cancer. In turn this might be compared with the population risk. The language of statistics as well as the visual images that accompany their use are clearly powerful, particularly in the context of predicting risk. As Adelsward and Sachs point out, in their examination of the use of risk figures, 'statistical probabilities [...] are used in the clinical context as a metaphors, attempts to make the incredible intelligible and the invisible future manageable' (1998: 206). But the authority of numbers could be important for other reasons also, as the consultation I observed below illustrates.

The patient, a young women in her mid 20's, has been told that the Clinic can do little for her at present and won't be eligible for screening until she is older. She is clearly upset and perturbed about this. At this point the clinician proceeds to identify a point on the graph, which she has in front of her. Reading between the graph and the woman's family history, she says:

If your mother had been sixty when she had breast cancer of course we would not have been so worried but because she was 35 when she got breast cancer you can *see* [pointing to the graph] that this puts you in a higher risk category.

She then gives the woman a personalised risk figure based on the reading from this graph and talks of the programme of screening and monitoring that will be offered to her when she reaches a certain age.

In this instance, providing a personalised risk estimate which draws on the authority of a statistical approach, embodied in the visual aid provided by the graph, does much to verify the authority of the clinician's assessment of risk. This may be particularly important when there is little that can be done for patients who are young or where genetic testing is not possible and when a patient's expectations are high, as they seemed to be in this case.

There are, in fact, significant limits in relation to the technology associated with genetic testing. Predictive genetic testing is currently only generally available to

⁵⁵ The data used to produce these graphs was obtained from high risk families. Some practitioners acknowledged therefore that the figures might be subject to revision when more was known about the role

those persons in a family where a gene mutation has been identified in a living affected relative or from whom a blood sample can be obtained.⁵⁶ Moreover because both the BRCA genes are large with hundreds of different mutations, looking for unknown mutations on the gene is time consuming and difficult. During my research this meant that it was only possible to test approximately 60% of the BRCA1 gene which looked at 'hot spots' where mutations were thought to lie and it was estimated that this picked up about 65% of mutations.⁵⁷ Once a mutation has been found then predictive genetic testing for other members of the family can be done relatively simply. Consequently, for large numbers of people a test result was simply not possible. This was either because they had no living affected relatives, could take many months if not years or/and the result was frequently inconclusive. Others may have had a 'negative' test from the BRCA1 gene and were waiting for a BRCA2 test result, which was very much in its infancy at this time.⁵⁸

If genetic testing was a procedure that was not frequently undertaken or was itself uncertain, the *possibility* of testing was talked about during clinical encounters. This happened most often when a patient was young and genetic testing simply wasn't possible because the relative or relatives with breast cancer, most commonly a mother, had died many years previously. If a person's relatives had died more recently, the prospect of testing could be made more real, as discussions about finding out if some blood or tissue had been stored ensued. Even when genetic testing was impossible or unlikely, talk about this technique gave it a 'presence', holding out the hope of a certain degree of clarity in the future. Significantly, the few occasions when I observed appointments where the results of a genetic test were being given to the patients this also involved a rhetoric of certainty and closure, as well as the use of material objects. For example during one appointment, following the search for a gene mutation in the blood sample given by a relative of the patient, the clinician appeared almost to announce at the start of the appointment that 'we now know what is causing the breast cancer in your family'. She then proceeded to hand the patient the laboratory test

of genes in a larger population.

⁵⁶ This determines if the cancer in the family is associated with a BRCA mutation.

⁵⁷ Figures from the Public Health Genetics Unit, Cambridge. See also (Evans 2001)

⁵⁸ Little testing was being undertaken on the BRCA2 gene outside a research setting

report and read, with her, what had been written on the form. This physical sharing of the laboratory test report seemed an important part of the process of imparting the results of genetic testing that happened on other occasions when I observed this process. In this sense the materialities of testing seemed to extend in ways that both preceded its actual undertaking and followed it, as the prospect as well as getting a 'result' was made real by clinicians.

Collectively the visual tools and objects that are so much a part of the routine practices of the Clinic appear to give explanations of genetic knowledge and predictive practices an important material underpinning. Intentionally or not, they can help to screen off some of the 'messy' questions about the exact function and effect of mutations in the genes that have been linked to breast cancer.

A focus on how the tools and objects of 'science' are used or produced has helped to shed light on the process of knowledge formation and dissemination in one branch of STS (Callon 1986), (Latour 1987). Rapp points out that Latour's notion of 'mobiles' draws attention to the way particular objects or tools 'condense and represent an argument about causality that can be moved around and displayed to normalise individual cases and theoretical points of view' (Rapp 1997:37). The authority of 'science' and medical knowledge in the Cancer Genetic Clinic can be seen in the way family trees, visual or graphic images present a somewhat de-contextualised explanation of genetic causality helping to ground predictive practice and make knowledge real. In this sense, images and objects such as family trees 'become an argument for the credibility of scientific inferences' (Gifford-Gonzalez cited in Bouquet 1994:45).

We can see that such authority is also sustained by a certain explanatory style as well as the language of rationality and the use of a 'statistical' idiom; elements of a process of 'narrative reasoning' that Mattingley argues is part of the way clinical language pursues 'order and control' (1994). For Rapp, the power of medical language in pre-natal testing clinics is illustrated in the way a notion of 'positive family history' acts 'like an inversion which attempts the work of suppression' (1995b: 130). But power in this setting is also clearly embedded in a more symbolic realm. The 'world building' effects of metaphor (Haraway 1992)

are reflected in anthropological studies of the new reproductive technologies. This work draws attention to the importance of an idiom of 'naturalisation' and the way it can work to 'domain' knowledge (Yanagisako and Delaney 1995), (Edwards et al 1993), (Strathern 1992a and 1992b). This 'effect' is evident in the way that family trees are used or explanations about knowledge constructed. We can see that both are grounded in a particular kind of 'origin story' about inheritance and risk.

3.2 Technologies and tools for 'talking down'

However, to leave the analysis of clinical practice there is to tell only part of the story. The second half of this chapter explores how another trajectory for talking about BRCA genetics is also often a component of clinical practice. The way that objects and tools facilitate a different clinical narrative, which is not about 'order and control', reveals a 'mutability' (Heath 1998) in their use and meaning. This reflects the importance of not just talking 'up' genetic knowledge but the necessity, intended and sometimes unintended, of also talking it 'down'.

3.2.1 Triage and the necessity of limits

The assessment or prediction of risk in the Clinic is closely tied to the necessity to 'triage' patients. Asking one clinician what she felt the main aim of the Clinic was revealed how triage was more than simply sorting patients.

I think we should be seeing the highest risk patients... that was our aim in 1996 so I think the first thing is to triage off the highest risk.

As she implied, triage was not just about putting patients into different categories of risk, but making decisions about whether they were eligible for the various programmes of monitoring or interventions the Clinic could offer and at what age, or whether they should be discharged. Actively identifying those most at risk, fits a model suggested in the Harper report (1996) which recommends that those at moderate to high risk on the basis of family history, should be seen in specialist Cancer Genetic Clinics. Despite this apparently clear cut aim, in practice this was something that was not always necessarily easily achieved and

which could frequently involve a rather different explanatory strategy to that examined in the first half of this chapter.

Sometimes triage took place before a patient was seen in the Clinic. The return of the family history form from patients, as well as the referral letter from a GP or breast unit, meant those who did not fit the guidelines could be screened out before they even got to the Clinic. In such cases, patients were sent letters explaining that their family history did not suggest that they were at greatly increased risk of breast cancer. However, information received prior to an appointment at the Clinic did not always provide a clear cut assessment of the situation. The danger of triaging ‘incorrectly’ meant that this often took place in the Clinic with the patient in attendance.⁵⁹ As a result a significant amount of time was spent reassuring new or young patients that they were not at that much risk and so did not have to be on a programme of increased monitoring or perhaps would not be seen until they were in their mid 30’s.

One clinician talked about the balancing act involved in triage where resources were finite and when they were often dealing with new patients who had high expectations about what could be available to them.

I am very aware that as a service we are oversubscribed, so I try to stick fairly rigidly to the criteria. That means not starting until people are 35 and if someone’s got a mother who was 41 when she got breast cancer, then they don’t fit the criteria. I do try and stick to that but there are obviously some very anxious people who find it very difficult to cope with not fitting the criteria. So it depends on the person, say you have a person and you say you don’t fit the criteria, well *you might have to explain how it’s not a perfect system*. So I do try and do it on a patient by patient basis but also try and stick to the criteria as well. (my emphasis)

These comments suggest that an important part of clinical practice includes a more explicit strategy of ‘talking down’ genetic risk, and/or the scope of the Clinic’s technologies and knowledge. As I examine below, this could involve a rather different use of the Clinic’s visual tools and objects.

⁵⁹ This is partly because there is a danger that the most important details of the family history have not been included or recorded on the form or noted in the referral letter.

For example, in these cases, reproducing the family tree might include an effort to dilute the visual starkness of this iconographic representation. This would involve adding to the tree horizontally to include cousins, aunts, uncles and particularly those who had not had cancer or who might not have been included on the family history form by the patient. This would increase the number of 'white' circles and squares (healthy individuals) on the clinical family tree thereby blurring the lines of presumed genetic inheritance in an effort to substantiate the practitioner's reassurance to the patient that their risk was much less than they thought.

Sometimes other strategies were necessary as the consultation between, a GP who worked on a part time basis with new referrals to the Clinic, and a particularly insistent young patient illustrated.

The woman in her late 20's speaks in broken English and explains that she has recently moved here from Spain. She readily details what seems to be an extensive family history and how she has been to her doctor, because she has 'a problem' with one of her breasts. She is quite insistent that it is because of her family history she really 'needs' to have a mammogram. The doctor explains how according to the protocol run in the Clinic, mammography screening for those who fit the criteria because of family history doesn't actually start until 35 and is then yearly or 18 monthly after that. The woman appears shocked by this saying to the clinician:

What if something comes up before that, something could come up this year and then I could die.

Looking for a different approach, the doctor turns to the 'official' protocol for screening pinned to the wall in front of her desk. She points to the information written there explaining how 'we just don't screen people before the age of 35'. The woman's reading English is slightly better as she is able to pick up the information further down the page which recommends screening at 30 for some individuals. Clearly flustered by the woman's insistence, the doctor points out that 'this is only if a person's relative were much younger than yours when they got breast cancer'. She adds that of course 'the system may be different in Spain' and that 'we don't normally screen that early because we really feel it could *cause* breast cancer by having too much radiation' (my emphasis).

Nevertheless the young woman does not seem put off by this and continues to discuss the pain in her breast. Reluctantly, the GP relents and sends her for a mammogram. Later that morning the result comes back clear and the woman now seems to have no problem with the doctor's suggestion that she makes contact with the Clinic again when she is 35.

In this instance 'triage' had meant talking about one the Clinic's technologies, in this case mammography screening, in a particularly compromised way and even then it had been impossible not to accede to the patient's expectations.

Although it was the limits of mammography screening that the clinician highlighted in this case, other strategies could also be used to counter patient expectations. For example, in Hospital Y a very different metaphoric description of genetic inheritance might be used to achieve this end. Here, practitioners would talk about developing breast cancer as 'climbing a ladder' and having a BRCA gene mutation, in terms of starting a few rungs 'higher on the ladder'. The key point being that there was still a long way to go before developing breast cancer, even if you had a gene mutation. On other occasions, clinicians in this setting might explain that there had to be at least '8 changes' before a breast cell turned cancerous, of which carrying a gene mutation was just one.

A very different perspective on genetic knowledge and expertise was sought and presented therefore in the use of these descriptions, informed by a need to disenrole rather than recruit patients into the practices of the Clinic. In chapter five I explore the ways in which these differences can be linked to how various practitioners located themselves within this emerging medical field.

On other occasions, rather than giving presence to the procedure of genetic testing, triage might entail talking not just about the limits of its scope but also the potentially negative ethical ramifications associated with its use. A clinical encounter between a nurse and a regular attendee at the family history Clinic at Hospital X illustrated the way that this strategy might be utilised to offset the expectation of or, in this case, almost a 'demand' for genetic testing.

The woman in her mid 40's has been coming to the Clinic for several years. On arrival within a few seconds of sitting down she says that;

Patient/ I've been on the programme now for a long time and I'm wondering when I can have a genetics test, I thought I would have had one by now and I really want to do it soon?

The nurse seems taken aback and surprised by the request, it's obviously not something that she had been prepared for in this instance given that the woman had been seemingly happy, up to now, being a regular attendee at the Clinic.

Nurse/ Testing is a big thing with lots of ethical implications, which could take months or years. It could cause lots of problems in terms of mortgages and insurance for you, or your family .

In this scenario the uncertain technical capability as well as the ethical implications of this procedure were used in an effort to communicate to the patient that such a procedure might not be possible and the benefits were less than they might have imagined.⁶⁰

It was not just in countering the expectations of new or sometimes existing patients that made ‘talking down’ an important feature of clinical practice, but also the more difficult discharging of patients no longer thought to be at increased risk. Although this was a necessary practice in both hospitals, given the changing nature of referral guidelines⁶¹, which had become increasingly tighter and the fact that some patients had been coming to these clinics for some time, it seemed to be a particularly common feature of practice in Hospital X . Here, the long running Family History Clinic, which had and continues to manage a number of clinical trials, had ‘recruited’ patients at a time when the criteria for inclusion was much less. Following changes to the guidelines for referral over the last few years many of these patients were no longer considered to be ‘at risk’ and therefore had to be discharged.

Some indication of the nature of this challenge was illustrated in an appointment I observed between nurse practitioner and a regular attendee at the Family History Clinic in Hospital X. The patient was a woman in her early 40’s who had been coming to the Clinic on a regular basis for about five years since the death of her mother.

The familiarity between the patient and the nurse is evident from the start of the appointment as a discussion unfolds about the latest work project the patient, who is involved in a branch of the media, is doing. But as the encounter proceeds this casual intimacy is subsumed by the nurses more considered and careful attention to the family history. Irene, the nurse extends her normal offhand inquiry about whether there have been any ‘changes in the family history’. She asks the woman to confirm again the ages at which those relatives who did

⁶⁰ The issue of insurance was however most commonly raised when obtaining informed consent from patients for genetic testing.

⁶¹ See page 36 for more discussion of this.

have cancer were diagnosed. The woman attuned to the routines of the Clinic, picks up this digression and says almost half jokingly:

Now you're going to tell me that you think having a family history isn't as great a risk as you thought it was and I can't have my screening. Please don't take my screening away from me, will you? (said in mock crying voice).

The nurse, reading the underlying concern in the woman's 'pleading' tries to arrest her fears saying that 'you'll probably be ok', whilst also glancing not so reassuringly at the guidelines for referral that she has pinned to her wall.

This interchange demonstrated how difficult discharging patients might be with this group of patients. It might, for example, involve liberal use of the predictive graph, particularly when patients were older in their fifties. On these occasions clinicians would point to the downward trajectory of the curve after the age of 50. They would explain that the risk of a cancer being linked to a gene was significantly less if a relative was over 50 when they developed breast cancer. If the person in the Clinic had reached this age or was older they would similarly point out that their chances of getting breast cancer (that might be linked to a gene) were reduced.⁶² Clinicians would often say that this meant that they or their relatives had 'lived through most of their genetic risk'. Such descriptions implied a dramatic reversal in the way agency was attributed to genes and DNA at other times in clinical practice, such as those examined in the first part of this chapter.

The fact that triage is a notion used in both the military battlefield and the medical emergency room, appropriately evokes what can be a difficult aspect of medical practice. This is a particularly salient feature of breast cancer genetics, where as we have seen the expectations of patients are high. Negotiating triage meant making use of the tools and objects of the Clinic in a different way that was clearly not just about securing the authority of medical knowledge and technology but was sometimes also about drawing attention to its limits.

3.2.2 The instability of technologies, tools and knowledge

Sometimes clinical practice involved presenting the tools and tests of practice in a much more contingent light, in ways that were not necessarily linked to the triage of patients. In this section I examine how explanation, prediction and the

⁶² Although the fact that the population risk of developing breast cancer increases with age was less frequently pointed out in these situations.

tools that secure the authority of these practices can be de-stabilised at the clinical interface, in a way that clinicians do not necessarily intend. Lock points out that a number of anthropologists (Evans-Pritchard 1937), (Wikan 1990) have shown that one of the characteristic features of a practice of 'divination' or prediction, is that 'in seeking to avoid misfortune..new ambiguities and uncertainties' are created (1998:7). I explore how this is also a feature of the evolving predictive medical practices of the Cancer Genetic Clinic in relation to three appointments that I observed. The first concerned the use of risk figures and the other two related to genetic testing.

The first of these clinical encounters took place between a clinician and a couple in their mid 50's. Prior to the appointment the clinician, a consultant in Hospital X, had told me that the purpose of their visit was to give them the result of a predictive genetic test on the man's blood.⁶³ Despite the presence of seemingly conclusive information and the clinician's efforts to talk about the 'certain' interventions, that having a test result made possible, the discussion which ensued highlighted the contingency of risk information.

The consultant cuts straight to the chase at the start of the consultation, telling them almost immediately, turning to face the husband she says,

We have got your results back and they are not good, we found a mutation in your blood that is the same as your aunt who recently died of breast cancer.

The clinician then pulls out the lab test report and reads it to the couple before handing it to them. Their response is mixed, the man seems fairly relaxed and says 'it was really what I expected' whereas his partner appears more visibly shaken, drawing in a sharp intake of breath and moving her chair closer to him. The man is concerned about 'what it means for our children'. The doctor begins to explain what their lifetime risk of developing breast cancer is if they have inherited their father's mutated copy of the gene. She also talks about what their risks of other cancers could be if they have the mutation. This includes the risk of ovarian, melanoma and pancreatic cancers. This discussion is accompanied by the provision of different risk figures for each cancer. She begins to suggest that they should be entered on screening programmes for these cancers when they reach an appropriate age.

The husband then interjects wanting to know what the 'survival rates are for these cancers'. The consultant outlines in further detail a different set of figures to the above revealing sometimes quite large disparities between the figures she has given them already and information the man has asked for. In some of these the former is greater (i.e. melanoma) but in others it is the latter (i.e. ovarian). This

⁶³ An initial gene mutation search on the man's sister had uncovered a mutation which meant that predictive testing for other members of the family was possible.

leads into a more in-depth discussion between the couple about whether they should inform their children about the risk of melanoma. The man explains that, given these disparities, he is not so sure it's necessary.⁶⁴

Afterwards, at the end of a long and difficult appointment, where the demand for information from the doctor has been great, it is clear that she is not altogether happy about how the meeting has gone. When they have left the room she tells me that says she is worried by the husband's reaction, particularly his questions about risk figures and reluctance to convey all the risk information to his children.

During an interview with this consultant a few days later she brought up the same appointment in our discussion, suggesting that it had been continuing to prey on her mind.

You know I've never felt that I've had a good rapport with them. I've always felt that despite the fact that they're very educated I don't feel that I express myself well with them. I just always feel that I'm stuttering a bit and that I'm getting taken down a line of explanation that isn't working out quite right. The reason that we got into survival rates was because they had specifically asked for this at nearly every consultation and because they'd understood about the risk of developing cancer. He had hit the nail on the head really that it doesn't matter if you develop the cancer but what matters is whether you die of the cancer. Seeing 85% of women developing cancer is an awful thing but if only 20% of them are dying of cancer then it does put the risks into a different kind of perspective and that was what he really wanted to find out. This is the kind of complicated consultation I got into with them and they wanted that

We can see that this clinician's sense of unease was directly connected to the ability of this patient and his wife, in seeking out more specific details, to force her to speak about the disparities and uncertainties relating to the use of risk figures in the Clinic

Another case brought about an equally qualified presentation of a different tool of clinical practice which, at least in the first half of this chapter, had appeared to be linked to an effort to make knowledge material and real. On this occasion I was sitting in with one of the nurse specialists in Hospital X when a couple arrived for their appointment. As I describe below it was a far from straightforward appointment.

I had seen the couple, both I guessed in their late 30's, earlier in the morning, noticing the fact that they had been sitting very closely together, talking with what seemed a quiet intensity. The nurse specialist was bright and upbeat on their arrival and there was a light-hearted discussion about where they had been

⁶⁴ There is a more cursory discussion of the risks that the man now faces following this test result. Dawn suggests that he should undergo prostate screening. It's clear though that he is not keen, saying that screening could bring up lots of 'false negatives'

on holiday. But this shifted into discussing why they had made an appointment to come. The husband explains that, as the nurse knows, they had blood taken for testing several years ago, just after his wife had finished her course of treatment for breast cancer and as they have ‘heard nothing’ from the Cancer Genetic Clinic (although they were being seen regularly in the Family History Clinic for routine check-ups) they decided to make an appointment at the Cancer Genetic Clinic to ‘find out what was happening’. The woman adds that she has recently ‘heard some things on the radio about how they’d found something else on the breast cancer genes and so thought we’d better find out’. The nurse, acknowledges how sorry she is that they’ve been waiting so long. She begins to outline some of the limits to current technology, using visual tools to explain why it can be difficult to find the particular mutation affecting a family.

Pointing to an iconographic representation of a piece of DNA, the nurse explains that:

We’ve only looked at 50% of the gene and we’re looking for one little mistake. As you know a genetic test won’t pick up everything and it could be another gene, BRCA 3, 4, 5 and in some cases we never find the gene.

In this instance the difficulties of genetic testing forced the clinician to talk about genetic testing in a less than normally compromised way as she tried to square the legitimate demands and expectations of the couple with the very real limits of such a technology.⁶⁵

The validity of genetic testing was brought into question in a slightly different way during another appointment with a different couple; a husband and wife in their 50’s who had been to the Clinic to see the consultant on several occasions and who were coming for what was intended to be their final visit before making a difficult decision.

The woman is sitting with her husband in the Clinic. She had been diagnosed with breast cancer a few years ago and is now in remission, following chemotherapy and a mastectomy to remove one of her breasts. Before they come into the consulting room, the doctor tells me that they are here today to help them make a decision about whether or not to have a prophylactic mastectomy on the woman’s other healthy breast, given the woman’s family history.

They arrive clearly prepared with a folder full of cuttings and questions already planned. After responding to their queries, the consultant proceeds to talk about genetic testing. Although it hasn’t as yet been brought up by either of them, their response suggests that it’s clearly an issue that they have been discussing in

⁶⁵ This was particularly difficult for this couple because of the way it was bound up with other life changing decisions such as deciding whether to continue to try to have a baby or have the woman’s ovaries removed which would reduce her risk of breast cancer.

some depth as the woman explains how it's something she has decided not to undertake

Patient/ I think we've decided not to go ahead with the test. I mean I can quite happily walk around thinking that I am probably positive for the gene but if somebody was to say oh yes 100% you are positive for the gene then I would find that difficult and also I've got to think of my daughter, she's only 22. I don't want to place too much burden on her and she's got insurance to think about as well

There is slight pause before the patient asks the doctor in a rather worried way whether or not the hospital would only go ahead with surgery if she had a positive test. The consultant says no, they will still be willing to go ahead with it. This prompts the woman's husband to raise further questions about testing and its utility in this context.

Patient's husband/ I'm wondering about this then so if she tests positive for the gene then that doesn't mean that she is necessarily going to get it and if she tests negative for the gene that doesn't mean that she hasn't got it as well, is that right?

Consultant/yes that is right

Patient's husband/ well what is the point in that then (exasperated)

Consultant / well it would just be *neater* to have a genetic test because then if it was negative you really wouldn't have to worry so much and might then not want to go ahead with the surgery'

Making things 'neater' did not, as expected, convince the couple at the end of the appointment to go ahead with genetic testing. In this situation, where a woman had had breast cancer and was not prepared to participate in a process of attempting to obtain predictive knowledge for her or her daughter, there was very little else for the clinician to respond with. This left the doctor resorting to a description that served to compound the limits that the couple had already highlighted.

In all these examples, a narrative of uncertainty in relation to the tools and tests of the Clinic was forced by the questions, concerns and expectations of patients. This brought about a much more compromised presentation of the knowledge and technologies associated with BRCA genetics. In both the first and the last case we can see that these uncertainties were in fact used as tools for *patients* to shun the need to engage in particular predictive or precautionary practices.

3.3 Conclusion

This chapter has explored the routine practices of the Cancer Genetic Clinic and the way genetic knowledge about BRCA genes is communicated at the interface between patients and practitioners. Material objects, tools and tests have been

revealed as central to this work. Nonetheless, these are very much ‘mutable’ mobiles (Heath 1998) which do more than simply or always successfully securing the expertise of new genetic knowledge.

We can see that these objects can help to make explanations about inheritance, prediction or risk assessment meaningful to those attending the Clinic in an effort to demonstrate the authority and scope of new knowledge and technology. This strategy seems particularly important in enrolling those individuals for whom such knowledge might be relevant or ‘used’ now, or in the future. Nevertheless I have shown that objects and tools also bring a necessary discussion of ‘limits’ to the clinical encounter, when genetic knowledge and technology is considered not to be useful. These contradictory narratives must be understood in the context of the necessity to triage patients. This is a process that is particularly challenging for those working in this clinical speciality, given the heightened public profile of breast cancer where a particular discourse of awareness and visibility leads to increased patient expectation. However, ‘talking up’ and ‘talking down’ is not always a process which is containable. As the last examples of this chapter illustrate, one can seep into the other bringing a less than necessarily easy discussion of the contingency of knowledge and technology into view.

The presence of this contingency brings a new perspective to understanding the way the objects and tools of the Clinic help to make knowledge real. When an idiom of probability, risk or contingency subsume medical practice and when pinpointing genes or danger in the body of specific individuals is mostly elusive, iconic representations of DNA or the predictive graph might be particularly important. This gives foundation to Haraway’s claim that DNA is a ‘material, semiotic entity’ (1992) as well as demonstrating the vital importance of sustaining this ‘fact’ in the face of the ongoing ‘invisibility’ of genetic knowledge in clinical breast cancer genetics.

This chapter has shown how the communication of new genetic knowledge is both simultaneously enabled, but also deliberately and not so deliberately undermined by the tools and objects that constitute routine clinical practice. Such contradictory trajectories pose questions for those who would critique these

developments in terms of unilinear process of 'geneticisation'. The evidence presented here suggests that it would be hard to locate all that is done as part of routine medical procedure in terms of this description. It is also clear that the expectations of patients have ramifications for the translation and communication of new genetic knowledge. The next chapter of this thesis examines another dimension of routine clinical practice which raises further questions rather than feeds in an easy or direct way a one dimensional understanding of transmission.

Chapter Four

‘Care’ and the requirements of patienthood.

The screening out of the ‘social’ is something that both critics of the new genetics (Lippman 1992), (Rothman 1998) and anthropologists examining the cultural context of new reproductive technologies have commented upon. The latter have drawn attention to the ways in which a particular notion of Euro-American kinship as a form of naturalisation works to regulate, frame or ‘domain’ knowledge (Strathern 1992a and 199b), (Edwards et al.1993) and (Edwards 2001). This is a process we have already seen at work in the way the tools and tests of clinical practice are used. However this anthropological work also highlights how Euro-American notions of kinship, as a hybrid of the natural and social, can be used to bring the ‘social’ into focus. That is the way that individuals engage in practices of ‘literalisation, substitution or displacement’ in order to create particular contexts for knowledge or raise particular questions about the ‘impact’ of new reproductive technologies. I draw on this work to examine how ‘care’ is constituted in the Cancer Genetic Clinic. I look at the way an explicit concern with the social elements of kinship are embedded in these caring modes and in a more hidden sense are integral to the transmission of genetic knowledge itself.

The importance of examining the changing nature of the ‘social’ and ‘ethical’ in the context of developments in the new genetics has also been made by others (Rose 2001), (Franklin 2001a), (Kerr and Burley 1998). For example, Rabinow suggests that the distance between diagnostic capabilities and therapeutic interventions which characterise new genetic knowledge, as evidenced in the previous chapter, will lead to the growth of new ‘ethical’ practices to cope with the issues engendered by this gap (1996). It is suggested that these emerging modes of care can be seen as ‘pastoral practices’ which articulate power in new ways (Foucault 1977), (Rabinow 1996) and (Rose 2001). I show how this unfolds in the clinical practices of predictive breast cancer genetics and the way an explicit discourse about ‘care’ can become linked to questions of ‘ethics’ (Kohn & McKenchie 1999). The second half of this chapter examines what the

consequences of these caring/ethical modes are for being a patient suggesting that this engenders new and, for some, uneasy forms of patienthood.

4.1 Pastoral practices

Examining first how care is articulated in the Clinic, I look at two main modes of caring practice. The first is concerned with care for the future and the second with care for the family, although as the data below illustrates, the boundaries between them are relatively fluid.

4.1.1 Care for the future

Lambert points out how it is only relatively recently that a notion of care has become homologous with (primary) prevention, normally associated with health practices in the secondary or tertiary setting (1999). Clinical Cancer Genetics brings these domains together in new ways, so that prediction makes care necessarily for the future.

Even on the rare occasions when the results of a predictive genetic test provided a more 'concrete' result, no guaranteed preventative interventions could be offered to those known to be at increased risk. As such, for the vast majority of those who attend the clinics and who meet specific 'at risk' criteria, 'care' consists of regular monitoring such as physical examination or routine mammography screening. This is coupled with the frequent verbal reassurance that they would be seen on a regular basis and a promise that the future would bring better testing technologies and knowledge. Practitioners did also point out to patients that mammography was not 100% secure and impressed upon them the need to undertake breast self examination (which was often taught to new patients as well). Nevertheless, when little else can be offered to patients, it is difficult for practitioners not to present screening and particularly annual check-ups, at least at the clinical interface, as 'care' for the future.⁶⁶

⁶⁶ For others in their twenties care is a more deferred process as they are asked to return to the Clinic when they are older. The explanation for this in the Clinic, to the patient, is that the density of the breast is too great for those under 35 to benefit from regular mammography. This decision is also of course linked to the question of finite resources and services and the need to triage patients.

Sometimes a more explicitly articulated promise of care for the future was necessary as this description of an appointment between a clinician and a first time patient, who was well aware of the gap between diagnosis and therapy, illustrated.

The doctor is sitting with a new patient in her Clinic. As she undertakes the normal routine procedures of the Clinic, it is clear that the patient is well aware of her 'risk' when she talks of her 'tremendous' family history. At this point the clinician asks casually if 'anybody has been gene tested in the family'. The question almost appears to be a way of acknowledging the risk the woman clearly feels herself to be in. This appears to trigger a tirade of concerns from the patient, who points out that 'most of the family aren't that keen, especially when you think of the insurance implications'

Trying to find a point of connection with the woman, the clinician does acknowledge that there are difficulties, saying that 'even for those that do get a negative test result, this doesn't mean that there won't be a gene in the family'. The patient becomes more effusive in her comments saying 'well what re-assurance are you getting then'. The doctor speaks about her 'hope that the future will bring new developments in terms of technology and targeted treatment now that advances in genetic science are improving all the time'.

The appointment comes to a close with the practitioner still grasping at some statement that will seal the sense that the future will be less dominated by some of the uncertainties that have been raised in the course of the appointment. Optimistically she says 'well hopefully we will find things that can prevent it soon, especially with the human genome project not so very far away'. The patient, clearly not rising to the doctor's attempt to conclude in a rather more upbeat way suggests more soberly and pointedly that 'perhaps we should find the things that are *causing* it first'.

When patients themselves exposed the inadequacies of current testing technologies, this required a more concerted effort on the part of practitioners to talk about the 'care' that the future would bring.

However, talk of the future could be accompanied by another technological intervention which was often discussed in situations such as the encounter above, where testing might have been possible, but patients perceived it as dangerous or inadequate. The offer of being able to put a sample of blood 'in storage' for testing at a later date seemed to embody an ethic of future care. It could, of course, only be done if an affected relative was still alive. Yet it was presented by clinicians as an opportunity to take 'positive' action which made the hope of intervention at a later date a more real possibility.

In different ways, the promise and hope for future care constituted a routine component of clinical discourse and practice. Yet this promissory approach is clearly not just about reassuring patients, but also furthering knowledge, as the 'offer' to store blood for the future makes clear. In a climate of 'predictive' practices, ensuring that patients place their faith (and sometimes their blood) in developing technologies, or are being monitored and are therefore within the health care system and are 'available' for trials and research, is a pre-requisite to the future application of genetic knowledge.

However there is one aspect of the way that 'care for the future' is discussed in the Clinic which crosses the boundary into another mode of caring practice. Talk of the future was frequently prompted by concerns from patients about their children, some of whom may at times have been barely in their teens.

Practitioners would explain to patients that they were not at risk at the moment but would also point out that by the time they were older much more would be known about breast cancer genes. On such occasions the family tree became a useful tool for showing how care would be honoured. By including them and sometimes much younger children on the tree, such genealogies could be extended forward and backward in time. In this way the clinical trees could be used to demonstrate, like a 'contract', the Clinic's commitment to future care and re-assure (mostly female) patients that their children would be included in the Clinic's programme of care.⁶⁷ In fact 'care for the family' is another key arena for caring practice in the Clinic.

4.1.2 Care for 'the family'

We have already seen how a focus on 'the family' is part of the assessment of risk in work surrounding the discussion and depiction of the family history. Here the family tree is a tool of expertise for undertaking risk assessment and an essential visual component for presenting explanations about inheritance, while also facilitating the work of triage when dealing with those whose risk might be less than they had expected. Attending to the way that care is articulated in the Clinic illustrates how the meaning of this object 'mutates' again, at the interface

⁶⁷ This may be as re-assuring for practitioners as much as it is for patients as there are also 'risks' to them in not identifying all those potentially at risk.

between practitioners and patients. I explore below how it is used to make a concern with 'the social' a much more explicit element of medical practice.

Despite the graphic shorthand used to represent family history, reproducing the family tree is almost never a simple checklist procedure. Talking about the history of cancer in the family can frequently evoke much more than the mere recording of deaths and illnesses. For example, writing or confirming the names of those who have died can bring traumatic memories of the experiences of cancer in the family flooding back, while including the names of children on the family tree can precipitate the articulation of deep seated anxiety. Emotion can therefore seep into the dynamics of the appointment, enabling sensitive clinicians to demonstrate their 'care' for the family in empathetic ways. However, attending to the family may not only be precipitated by a patient's emotional response or their concerns about others but through active inquiry, on the part of practitioners, to find out about the health and well being of family members not present. 'Offers' may be made to the person in the Clinic to extend a program of 'care' screening or monitoring to related others. This attentiveness suggests that exploring the social context of the family is not just about demonstrating a capacity for empathy or the holism of practice⁶⁸ but, like care for the future, is vital and instrumental to knowledge. I describe how this became apparent in relation to three clinical encounters and the way I was situated as an anthropologist in the work of the cancer genetic department at Hospital X.

The first example was an appointment between a geneticist and a woman in her mid thirties at Hospital Y. I describe what happened in the moments after the clinician had drawn up the tree and given the woman an estimated risk figure along with a recommended programme of screening.

At this point the woman visibly relaxes, reflecting in an openly chatty way on the experiences of her family with cancer. In what seems an offhand passing comment, she then says that her mother was 'just like the women in that book, [a popular novel about several generations of an Irish family] always blaming the men for the deaths in her family' because her mother had 'always believed the cancer had come from her father's side.' The consultant seems surprised, saying 'is that true then' and prompts the woman for further reflections on the experience of cancer

⁶⁸ Although as I explore in Chapter Five this is certainly an element of the way a few clinicians at least in Hospital X identify with the work that they (have) to do

in the family. This is followed by renewed investigation of the paternal family history of the patient's mother and an expansion and correction of the clinical family tree. After this the clinician gives the woman a much reduced estimate of risk and a different programme of surveillance.

This encounter illustrates how identifying the hidden stories and myths about illness by considering the social context of the family is not just or only about being caring but can be essential to establishing an accurate diagnosis of risk. In this case a chance comment by the patient, in relation to 'beliefs' about cancer in the family, prompted further inquiries from the practitioner. This discussion and exploration of the social history of the family shed light on other instances of illness which, in this case, the clinician had neglected to inquire about. We can see that this revealed other cancers in the family which ultimately changed the nature of the patient's risk. In a somewhat more obviously intentional way, another appointment also highlighted the necessity of clinical practice to attend to the relational dynamics between kin.

I am sitting at the back of a large consulting room, the nurse specialist and a doctor sit nearest to the 'patient' a woman in her early 50's. Without much preliminary conversation, the clinician explains to the woman that she has the results back from the laboratory and that the sample of blood from her aunt tested positive for a gene mutation on the BRCA1 gene. A number of 'options' are then presented to the woman. Although the patient, it transpires, was already aware of her aunt's positive test result, she still seems somewhat shell shocked by the sort of health 'care' interventions being offered to her.

Her response to such options is therefore fairly subdued. She seems to want to downplay the significance of the information she is being given as the following interchange illustrates;

Patient/ all cancer is genetic in some way isn't it?
Consultant/that's true but well this type of gene mutation, if you've inherited it, is in every cell of your body.. and is there from birth.

Nevertheless the woman then explains that she doesn't want to go ahead with a genetic test, pointing out;

Patient/I don't think it would be right for me and wouldn't really suit my temperament and at the moment I get all this screening, so I'll still get it if I don't go ahead with it, won't I?

This is confirmed by the doctor. Both she and the nurse don't seem surprised by the woman's decision not to go ahead with testing. However taking the patient's cue about it being a 'personal' decision, another issue is raised by the doctor; the

'difficult' social dynamics of her family.⁶⁹ Initially there is some informal discussion about how the patient has suddenly discovered her artistic talents after being 'repressed' by her family. She has even brought some copies of her pictures with her and proceeds to show them to us all. The nurse surmises that these vividly coloured pictures, of female figures seem to be about 'a struggle for freedom'. The woman concurs with these conclusions as if to confirm that the metaphoric interpretation of her pictures is not unconnected to her own very personal decision not to go ahead with genetic testing.⁷⁰

After this discussion the doctor then turns back to examine the family tree and there is some discussion first about 'care' for other family members and then subsequently about other research being undertaken at the hospital.

Consultant/ your brother and niece would be eligible for screening, do you think they would be interested?

Patient/ I'm not sure. There has been a lot of illness in the family lately, so I don't think it would be a good idea at the moment'.

Consultant/ right, that will probably be ok because your niece is still quite young isn't she (checks the family tree again). But there is one other thing we would like to ask you. As you know the hospital undertakes a number of different research projects which you might want to get involved in, although of course this is entirely your choice and any decision you make won't in any way affect your care. The multi-million dollar question is why some people choose to go ahead with testing and others don't, so there is a study we are doing to investigate that. Of course the social context of the family is one of the key things in the way people make these decision.

Patient/ No I don't think I'd mind.

In this case the woman's decision not to go ahead with testing is rationalized by the patient mostly in terms of its limited benefits, that it would make no difference to her screening and possibly cause concern to other family members. This decision is contextualised by the *practitioners* in terms of personal relationships with the family. This serves to 'displace' the uncertainties associated with genetic testing, which are 'substituted' for an interest and concern with the social dynamics of the family. The final interchanges of the appointment reveal the extent to which knowledge and 'care' is in fact predicated on the sociality of family members. Even when the patient does not facilitate this process by agreeing to talk to her relatives, this becomes something to be investigated and used to further knowledge for the future. In this light the discussion in the middle of the appointment about the woman's paintings can in

⁶⁹ Both the consultant and the nurse were well aware of the difficulties within the family because of the number of meetings the nurse had had with this patient prior to this appointment.

⁷⁰ This connection is further underlined (by the practitioner) when the woman confirms that she wouldn't want to go ahead with testing and the nurse says 'these decisions are so personal and subjective.. a bit like your paintings really'

part be understood in terms of attempts to begin to understand such dynamics, at the same time as it clearly engendered an empathetic approach to clinical practice.

In the final example a concern for related others was even more explicit. In this instance the clinician seemed more concerned with the 'family' than with the person who had initiated the appointment herself.

The woman comes in with her partner, who are, I would guess, both in their late 30's. The clinician requests details of the family history. With some tense emotion in her voice the woman says that her father had breast cancer and her mother also, explaining that this was 'an awful fungating breast cancer, which she had left too long'. She adds that that's why I'm here, to stop it happening again'.

The woman is clearly upset by the experience of her mother's illness and could it seems, talk more about this, if prompted. The clinician does not do so on this occasion and does not therefore immediately respond to the woman's strong hints that she would like screening. Nevertheless the clinician is concerned about other members of the family, asking if her father is getting prostate screening. She explains that the fact that he had breast cancer is a rare event and so more likely to be linked to a gene. There is also some discussion about whether he would be willing to give a blood sample. The clinician adds that 'then we could see if there really is something there'. She proceeds to explain more about the genetics of cancer and the possibility of genetic testing for other members of the family if a mutation is found in his blood. Following this there is a discussion, prompted by the clinician, about the couple's teenage sons and the possibility of providing screening for them. The clinician points out that

If we find something then we can set up some screening for them because if there is they could be at risk from prostate cancer, although of course this wouldn't be until much later in their lives.

The couple seem surprised by this, it is clearly not something that they had thought about. It is only towards the end of the appointment, the clinician discusses the possibility of routine screening for the woman.

Here, the focus of the appointment seemed to shift away from the person who was in the Clinic towards related kin and a concern with their health or potential risk. The interests of the doctor suggest that genetic knowledge may have more significance for these others rather than the woman herself, although she had made the appointment because of concerns about her own risk. But it is also clear that the involvement of related kin is essential to extending and fulfilling the scope of genetic knowledge as well as reproducing 'care', not least for the woman herself whose own screening is caught up in possible interventions for others. In these last two examples, we can see that clinical discourse and

practice draws on a notion of 'care for the family' that is linked to a set of values about relating and nurturance towards related others; a morality of care that has been particularly associated with women (Gilligan 1982), (Sevenhuijsen 1998).

The importance of the social dimensions of the 'family' to health care practice also came to light in other ways as a direct result of my entry into my 'fieldwork' site at Hospital X and the way clinicians here talked about how they perceived and situated my work as 'an anthropologist'. Soon after starting research there I began to become aware that an anthropological interest in 'culture' could easily stand for 'the social dynamics of the family'. This was one aspect of my interest in this area. However I had certainly not defined the boundaries of 'culture' only in this way, in my discussions with them or the proposals I produced.

Nevertheless, this attributed identification helped to shed light on the importance a particular definition of 'culture' had for health care practices. In one sense situating my work in this way demonstrated that the clinicians in question recognised the importance of the social, cultural and ethical 'impact' of new genetic knowledge. Just as attending to the 'family' in clinical appointments is central and instrumental to genetic knowledge positioning my work in this way seemed also to be important in other ways.

This was reflected in one particular event at Hospital X in which I was also a participant. A meeting had been arranged between the department and a group of half a dozen family and friends of a woman who had died of breast cancer. They had raised funds for the Cancer Genetic Unit and had been invited to come to the hospital on an official visit to meet the staff and see some of the laboratories and research that their money had funded.⁷¹ I recall this event in my field notes below.

Staff head off from the genetics unit to the meeting room in the main part of the hospital at about eleven o'clock. Surprisingly nearly all the people along the one corridor, where most of those linked to the unit work, trickle out of their offices. This included clinical researchers, clinicians and nurse specialists, those working on trials as well as members of the 'psycho-social' research and support team, office and administrative staff. When we get to the room, tables are arranged in a circle and we join the 'guests' sitting at one section of the table.

⁷¹ Lab tours and official visits to the hospital by fundraising members of the public had happened on a few other occasions but they were not a regular occurrence here in the way that they were for the Charity, as I explore in the second half of the thesis.

The meeting begins with a presentation from the lead clinician. She welcomes the visitors, outlining to others in the room the 'personal' background of their visit and how they have come to 'see and hear about the kind of work that the department is doing.' She explains to the visitors that those in the room represent the 'cancer genetic 'team'. She then suggests that it would be 'nice if we went round the room and explained who we all were and how the kind of work that we do might be useful for *patients*' (my emphasis)

Exploring 'family dynamics' takes centre stage in presenting the team's work, alongside more obviously clinical focused research, such as a study looking at the effectiveness of MRI screening for those with a family history of cancer. Moreover, unlike the scientists who appear to struggle to answer this question⁷², those working in the 'psycho- social' field seem to have no problem outlining how this work will benefit patients. One researcher explains how 'counselling can't grow if you don't look at the social context of the family and the way stories about genetic risk and new genetic information are used'. It's a way she says of examining the 'soil' in which the 'seed' of genetic information and counselling can take root. After all those around the table have had a chance to speak, the lead clinician makes a comment about how the range of research being undertaken in the unit demonstrates the broad base of approaches encompassed in the department's work.

The presentation of the 'team' at this event was clearly intended to imply that all those in the room were part of a cohesive group which married the 'scientific' with the 'psycho-social' and hence illustrate how the clinical team was attending to the 'ethics' of care. My presence at this event as an 'anthropologist' contributed to bringing this dimension of the department's work into view.⁷³ The ethical value of incorporating this social perspective was illustrated in the way those in this psycho-social domain seemed better able to demonstrate exactly how genetic knowledge might benefit patients, than those working with the uncertain science of genetics. However, as the remarks made during the course of the meeting show, addressing a social dimension is about more than just publicly demonstrating an ethical agenda. This was illustrated in a discussion that took place in the middle of this meeting:

One of the visitors asks about whether 'Ashkenazi women come to the genetic Clinic very much' as she's heard that 'they're supposed to have a higher risk aren't they'? The clinician concurs that some women in this population are reluctant to

⁷² For instance one of the young scientists who sits at the table becomes out of necessity part of the roundtable discussion. She talks quietly in a barely audible way about some of the genetic research taking place at the lab, using a significant amount of technical language. The clinician at the meeting prompts her however to explain a little bit more about the possible 'new genetic discovery' that the work here at the centre has uncovered. She seems a little disconcerted saying that 'these are very preliminary findings at present' and 'how much work still has to be done' adding later that 'its probably something like a lifetimes work'.

⁷³ In explaining my work at this event and responding to the need to outline how my work would benefit 'patients' I did participate in the reproduction of this agenda. I explained how my work was 'in part' examining the 'expectation and experiences' of a particular group of patients.

attend adding that 'this is exactly why we need the sociological and psycho-social perspective on these issues.'

This event highlighted, therefore, not only how attention to the social context of the family is supported and promoted by many of those who work in this domain, but how it is an essential aspect of medical practice.⁷⁴

Exploring the pastoral practices of the Clinic has brought to the fore how 'care' makes genetic knowledge viable in ways that are both affective and effective (Kohn1999). That is clinical discourse about care for the future and care for the family help to make predictive knowledge more explicitly synonymous with 'care' in a euphemistic sense associated with all hospital or medical practice. At the same time this brings ethical values into play, such as 'care' for 'the family' and the morality of a notion of 'nurturance' towards 'bio-genetic' kin. We can also see that these pastoral modes are instrumental to the utility and value of genetic knowledge itself.

Highlighting the promissory nature of BRCA genetics through rhetoric or the presentation and provision of particular technologies makes explicit the extent to which care is for the long term. This is an ethic of care which must also be understood in relation to the means required to fulfil the 'promise' of predictive health in breast cancer genetics; this necessitates the lengthy involvement of patients. Care is also focused 'on the family'. This is expressed in terms of a particular concern with the social at the interface between practitioners and

⁷⁴ Another event early on in my field work also suggested that 'care for the family' and the promotion of a 'social' approach might be more instrumental to knowledge practice. A month or so after starting my research and beginning regular 'observation' sessions in the Clinic I was invited out to dinner with a few members of the clinical team in Hospital X, in honour of few visiting American researchers.

We are having dinner at a nearby restaurant and discussing the latest piece of research the two American researchers have been working on together. One, a social scientist is currently engaged in a project exploring 'family dynamics' and breast cancer genetics. The second visitor has a more eclectic background, having been a geneticist for a number of years, she explains that she has now moved into the field of 'public health genetics' and increasingly is becoming interested in psycho-social research and family dynamics. They both talk about the joint project they are working on, a research tool which can be used to look at 'social dynamics within families'. The multi-coloured map they show us looks something akin to a family tree but instead of only visually mapping the genetic connections, it also diagrammatically represents social networks in the family. They explain how it will be an incredible 'aid' to the consultation, enabling the clinician to visually depict 'who is closest to who, who talks to who most and who doesn't communicate in the family or which stories get told to which family members'. At dinner the two members of the clinical team seem relatively enthusiastic about this proposed device and the prospect of their upcoming research more generally, pointing out how important it is to examine how this information is 'impacting' on the family.

patients. Taking care of ‘the family’ is more vital than just being attentive to the social, psychological or ethical consequences of genetic knowledge. Information about kin and their involvement is crucial to the accuracy of prediction and the utility of genetic knowledge and, in some cases, the care of the person in the Clinic. In this sense kinship ‘regulates’ knowledge in a way that is very different to that explored in the Chapter Three. It relies on a notion of the family as a domain not only of biological ties but enduring and affective kin ties that are maintained through ongoing sociality and a desire to nurture the health and well being of others. I suggest that this is a component of how the emerging pastoral practices of predictive medicine articulate power in new ways; a modality of care which, as the next section explores, is not without consequences for patients.

4.2 Patients and the care of predictive genetics

Drawing from the ‘follow up’ interviews I carried out with the same group of women discussed in Chapter Two the second half of this chapter explores what ‘care’ means for being a patient. Novas has explored how a moral discourse relating to the development of predictive testing for Huntington’s Disease helps construct the identity of those at risk as ‘uncertain subjects’ (2000),(see also forthcoming). In a similar way I show how the caring practices Breast Cancer Genetics inform the kind of patienthood required by individuals attending the Clinic.⁷⁵

4.2.1 Being ‘on the books’

Most of those I met were told that although they were at some risk they were not at greatly increased risk, as one woman put it: ‘we are slightly more at risk than the next door neighbour, because we’ve got two women in the family who’ve had it, but we are at no real grave danger.. but the risk is there’. Although some individuals had been given precise risk figures, these did not seem to mean a great deal other than confirming that they were at some risk and hence eligible for screening.⁷⁶

⁷⁵ Meetings were undertaken anything from 1- 3 weeks after these individuals had been for their first time appointments at the Cancer Genetic Clinics.

⁷⁶ This is something confirmed in Adelsward and Sachs study also (1998)

Consequently few were offered genetic testing⁷⁷ but nearly all were or would be included in a program of monitoring and surveillance. Depending on their age and their family history this included either yearly or 18 monthly check-ups at the Clinic and/or mammography screening. We have already seen that for many being 'monitored' and receiving a mammogram was one of the prime motivations for seeking an appointment. Several individuals had indicated their desire to be 'on the books', as one woman said;

Deborah/ I'd really rather be given some sort of structured timetable really. That somebody was watching my progress, so I'm not having to worry and think about what I should be doing but somebody tells me what I should be doing.

When this had been set up following their appointments, the response of many was predictably positive, as this excerpt from my interview with Penny indicated.

A good thing that came out of it, is that I've already got my appointment for the genetics Clinic for 2002, so I won't be forgotten about. I'm going to be monitored now, so my risk is going to be less. If it is going to be there, I'm going to be checked out anyway and it will be discovered. Other people sitting at home might think 'oh shall I go to the GP or not' and then they have the whole process of the GP checking them out and then whether they will send them on to the hospital or not

Receiving mammograms or being on program of monitoring made real a hoped-for future in which many felt they were being taken care of. As a result, being monitored was not seen, by the majority, as something that was negative or in any way a burden, but quite the opposite; it conferred a 'special' or 'lucky' status.⁷⁸ This seemed to be the case even when some individuals were too young to undergo regular routine mammograms or check-ups and had been asked to

⁷⁷ As well as not being at high risk this could also have been linked to the fact that in some cases there was no living affected relative, which made genetic testing unfeasible.

⁷⁸ This sentiment was implicitly conveyed towards the end of my meeting with Deborah, who compared it to another time when she had been an 'at risk' but 'special' patient. She tells me that it was

Like the time when I had the second baby, I was in my forties and they thought I was 'high risk' and they really paid attention (starts laughing). It was funny because they put a big red dot on front of my medical records; you know I was special, just because I was a bit older.

A more subtle articulation of this sense of being special and lucky as a result of being recruited into a particular future orientated form of patienthood can be identified in the use of the expression 'fluke'. This was widely used by a number of persons to describe the history of cancer in the family after they had been to the Clinic and been told that they were at less risk than they originally assumed. This expression was used to convey the sense that what had been assumed to be the consequence of a genetic fault with was now probably just 'chance'. But the use of this expression also references a notion of 'luck' which was, I would suggest, implicit in this description.

come back when they were older. Emily was in this position as she told me on our subsequent meeting.

They sort of said to me I don't need to start worrying until I'm 30 or 35. Because I'm on their list or their records either I'll contact them or they'll contact me then. So I'm happy just to sort of leave it in limbo at the moment. In five years time maybe I'll start making some decisions to go back and go through the information that they've got and then make a plan.

For Emily being in a sort of patient 'limbo' did not mean then that she didn't feel reassured because she knew she could return to the Clinic at some point in the future. However, from other things that she said, it seemed that this kind of patient status also involved a certain commitment on her part. For instance she pointed out that;

If I could do trials to help that would be good and also then in the future when I become more at risk at least my name will be out there and I'll be on a special list. So yeah if in the future they need people [for research] then I'm up for it definitely.

Her comments suggest that she was fully aware of the requirement on the part of patients to be part of a health care institution for the long term, which she seemed to see as an act of exchange. However this willingness to be part of research may have been made more acute precisely because of her 'limbo' status.

If most appeared happy, in the weeks and months following their appointment to do this, one of the women I met was more hesitant. I examine her experiences in detail, drawing on her different response to shed light on the norms and necessities of patient participation in the breast cancer genetic Clinic.

Leslie was in her late 40's and worked part time. She had been a regular attendee at the Family History Clinic at the Hospital X for a number of years. Although she was not receiving any extra screening she was seen in this clinic for an examination each year. Consequently she was a little confused about her forthcoming appointment. This had come about after the nurse had told her that she was probably not at sufficient risk to be maintained on the hospital program of monitoring but that in order to confirm this she should go and see someone in the Cancer Genetic Clinic. During our first meeting it became clear that the context of her referral to the Genetic Clinic was also different in other ways .

For example she explained how she didn't want to take the drug 'Tamoxifen' that was part of the trial she had been recruited into when she first started attending Hospital X. In fact she described her recruitment into the trial at this time in terms of looking after 'people who had lost a relative to breast cancer'.⁷⁹ Her ambivalence about preventative drugs was also evident in the way she discussed her reluctance to take HRT, which her GP was keen to prescribe for her. More revealing of this underlying hesitancy about a 'precautionary' approach to health care was the way she talked about the possibility of genetic testing.

Leslie/ If they said we could do a genetic test, and if you're in the high risk group, there is a strong chance that you will get cancer and we can do A, B or C to reduce the risk, then I can see the point of taking the test. But if they said well we can do the test and we can tell you whether you're in a very high risk but there is nothing we can do about it, it's just to forewarn you, then I don't think I'd want to. Why be told something that might never happen and worry about it, if you can't do anything about it. I would rather not know, it would just be years of worry and paranoia, every time I got the slightest thing.⁸⁰

Unlike others I had met, Leslie seemed reluctant to engage in future orientated preventative strategies; she did not want to be 'forewarned' or 'prepared in the same way. However, the sequence of events set in motion following her visit meant doing just that. She explained how the Clinic had confirmed that the one case of breast cancer in her family probably meant that she was at less risk of breast cancer than originally thought. Nevertheless because of the few cases of bowel cancer amongst some of her male relatives, the Clinic had felt it would be 'sensible' for her to go and have a colonoscopy, something that she was not entirely happy about.

⁷⁹ It had apparently been agreed that she could still be part of this trial by attending for regular check ups without taking Tamoxifen.

⁸⁰ Towards the end of the interview Leslie launched into a broad and wide-ranging discussion about the dangers of 'scientific knowledge' that included recent developments in genetics and nuclear power. The suddenness of this change in perspective suggested that such issues did not seem unconnected to her own sense of anxiety about the benefits of 'knowledge' in the context of breast cancer genetics. Her discussion of these 'dangers', seemed resonant with a less articulated sense of concern that her appointment at the Cancer Genetics Clinic seemed to have engendered, as the following comments imply.

Nuclear fuel is a wonderful thing but what about all the waste. I don't like the thought of it being buried underground and left, that's just storing up problems for a future generation. To me they should have solved that problem first before they started using nuclear fuels and I wonder whether the same is with the genetics yes they can find cures for this that and the other but are there going to be other side effects that they can't control, we don't know what the consequences are.

Leslie/I almost feel that it's snowballed out of control. There is absolutely nothing wrong with me and now there is so much being done. My hope is that I'll go and see this gentleman and he will say well there is no need for you to have this colonoscopy and it's just diet and lifestyle. Hopefully that will be the end of that. But if someone is prepared to do a check to see, it would be silly to turn it down

Sahra/is that reassuring then for you then?

Leslie/Umm (pause) I'm not bothered by it, but it's just trying to fit in all the appointments (laughing). I just sort of feel at the end of the day, I'm wasting everyone's time because there is nothing wrong with me. But then you read so many cases about people who have got a problem and because of where they live or because of over-work in the hospital, they don't get the treatment they need, and it seems stupid not to take the advantage when it's frankly handed to you on a plate. So if they recommend a colonoscopy I'm going to have it, even though I don't really want to. I suppose prevention is better than cure. I just hope that I don't turn into a hypochondriac (laughing). I'm having all these things suggested to me and I've never thought about them, so I suppose that's one danger. I could see how it maybe could happen, in being overcautious, you're more susceptible and could make you more inclined [to develop cancer].

Despite being told that she was 'probably' not at very high risk for breast cancer, the precautionary and preventative approach on which clinical practice is predicated entailed further more intrusive bodily investigation. Although others attending the Clinic seem to experience (admittedly less intrusive) screening interventions as comforting, this was not the case for Leslie, as her somewhat uncertain response illustrates. This may in part, of course, have been because she was already being seen (but not screened) at the Family History Clinic where she had been going for regular consultations for many years. Yet, unlike others that I met, she clearly struggled to choose between being a 'good' vigilant patient preparing for the future and becoming as she put it a 'hypochondriac'. She even implied that her anxiety about having to have screening could possibly induce disease as much as it appeared to be part of a preventative strategy.

In their study of predictive health practices Adelsward and Sachs see the use of risk analysis as part of a 'moral technology' where 'awareness of risk necessarily means providing for and being disciplined by the future'(1998: 197). I have explored how a discourse about care for the future is part of such practices. We can see that care requires a commitment to being part of a health care institution for the long term. This an 'exchange' that many appear willing to be part of. For the most part, the inadequacies of genetic testing did not upset or disconcert those I met because of the promise of 'care' through monitoring or

screening that was being offered to them instead. For many, this was precisely what they were looking for in actively seeking to obtain a referral to the Cancer Genetic Clinic.

However it is also possible that the commitment and promise to be ‘in the system’ for the long term intersected with the sense of bodily disconnection those I met expressed before attending the Clinic. When fear of self examination had in part impelled many women to seek a referral, being on a programme of routine check ups and/or mammography screening may have reduced or removed this *immediate* fear. In the long term it may also have done little to counteract the sense of disassociation with their bodies that many had expressed, despite efforts on the part of practitioners to explain in detail how breast self-examination should be undertaken. For others, being part of a programme of surveillance may have entailed a sense of ‘body anticipation’, as those enlisted prepared for a time when they might become ill or might develop breast cancer. Kaufert, in her examination of routine mammography for those over 50 in Canada as part of a national program of health care prevention, argues that screening changes the way the body is experienced and the nature of disease (1998). The long term experience of being ‘on the books’ over many years for much younger ‘genetically’ at risk women is clearly an area that requires further investigation.

Nevertheless, we can see that the development of BRCA genetics is informed and furthered by the way many individuals seen in the Clinic interpret their own sense of agency and identity as persons who adopt a preventative approach to their health care. A conjunction which is, I have suggested, particularly salient in this context because of the culture of ‘activism’ and ‘awareness’ around breast cancer.

One woman’s hesitancy about what being a patient involved suggests that not all of those attending the Clinic are necessarily comfortable with the kind of future orientated or precautionary patienthood genetic knowledge necessitates. Yet asserting a different kind of agency to decline preventative health care

interventions is obviously not an easy option.⁸¹ This implies that there may well be differences in the way those attending the Clinic respond to these interventions. Research with larger groups of patients would enable further exploration of how class, age, education and religion inform the diverse or stratified ways that persons respond to the requirements of predictive health care, as Rayna Rapp's work has demonstrated in relation to amniocentesis (1999). At the same time, the lack of such evidence in my research suggests that enrolment into these arenas of health care is already defined in particular ways. As others have shown, it is in the main white middle class women who are most often amenable to preventative health care interventions (Martin 1989),(Rapp 1999), (Kaufert 1998).⁸²

4.2.2 'Fractal' patients

If a commitment to being monitored for the future seems to be a necessary component of being a patient, there is another aspect of patienthood entailed in the Clinic's handling of care

I use a notion of 'fractal' identity here as a heuristic device to explore this emergent and changing aspect of patients' roles in the light of developments in predictive genetics. This concept has been used and developed in studies of personhood in 'non-western' contexts, which have shown how the supposedly 'western' idea that the person is the locus of a unique inner identity is not universal (Marriott 1976).⁸³ For instance studies of personhood in Melanesian societies suggest that it would be more appropriate not to see persons here in terms of separate individuals but as 'dividuals' or 'partible persons' constituted through the exchange of properties, goods and substances shared with others

⁸¹ As Hallowell points out in constructing genetic risk as a 'moral' issue, in terms of responsibility for their health and the future health of others, women attending Cancer Genetic Clinics 'relinquish the right not to know'(1999).

⁸² As mentioned previously, (see page 40) although I did not specifically ask those who I interviewed for demographic information, all were 'white' and based on what they did tell me about their jobs or sometimes education, the majority (but not all) might be defined as middle class.

⁸³ More recently Konrad (1998)has examined how a notion of partibility may be applicable to understanding the narratives of women who donate ova to infertile recipients. She suggests that such a comparison is possible because of older ideas of the person and body in western culture that have since been eclipsed.

(Strathern 1988). I explore in this section how these ideas might help to illuminate a particular aspect of patienthood in the Cancer Genetic Clinic.

A shared right to health care was often part of the process by which those I met had received or obtained their appointments. A number of women talked about how the impetus to ask for or pursue an appointment at the Clinic had in part arisen from the experiences and health care practices of related others, as Penny's comments imply.

Well it started off my sister had breast cancer, and then all the other sisters thought well we ought to go and get ourselves checked out, so I went to the GP who referred me.

This collective involvement was also evident in the way that one woman talked about the work that had been undertaken to fill in the family history form.

Deborah/ I didn't do it, because I don't know enough about it. My mother and her sister did it. I thought it was very important that I got them in on it, it was more accurate that way. Also I thought we really ought to get this down and then get a copy for my daughter, because if anything did ever happen to me and she had questions. They're very keen, my generation. All my cousins go and do something about it, they're all under somebody, I was the only one who didn't so I thought I'd better. It's something I will discuss with them when I've had the experience of it myself. So some of us are and some of us aren't but we're trying to get everybody on it.

In this case a group of cross generational relatives were already enrolled and implicated in each others health care practices. This was a sociality which had clearly contributed to their, as well as Deborah's, efforts to be seen in a specialist Clinic. Like others I met who had children this 'family' involvement was also about looking out for and making sure a younger future generation would be looked after when they got older.

If getting to the Clinic was to a certain extent dependent on or the consequences of actions and health care practices of other members of the family, being seen in this arena often precipitated a new found determination to demand and inquire about others shared rights to care. This was the case for one of Penny's sisters who had had breast cancer, as she told me when we met after her first appointment.

Apparently my other sister had said to the consultant why are they going to the genetics Clinic and not her and he said to her that because she was the one

with the cancer she didn't need to. Although now, she is going to ask if she can have a mammogram on the breast that isn't removed, she's going to talk to the consultant next time she goes, so it has got people thinking.⁸⁴

When concern for others was less sought and more unexpectedly raised by practitioners, many I talked to saw this as evidence of care. It was care which went, as one woman put it, 'a bit deeper' because it was 'taking into consideration the whole family'. This was also the case for Lucy, who referring to the form she had filled in, talked about how impressed she had been by the attention paid to others in the family; 'it wasn't just me going, it was like everyone was going, everyone down on that sheet of paper [the clinical family tree] was part of it'. Donna also commented on the interest which had been paid to her sister's health and well-being by the clinician she had seen; 'What I thought was good was that she was concerned about my sister and what she was doing about it. They didn't have any need to be concerned but they showed complete care'.

Despite the comments by some of the *individuals* attending the Clinic that taking care or attending to 'the family' was a good thing, the penumbra of patienthood was not always easily extended by all those that I met or necessarily gratefully received by their kin. Sometimes this was apparent in the activities required to produce the family history form, which often involved and implicated others. Mostly, though, it was the consequences of being seen in the Clinic which drew attention to the difficulties of being or extending fractal patient status to others. I explore this by examining the experiences of three of the women attending the Clinic who had to address, in different ways, the implications of 'distributed' patienthood.

Emily

During our first meeting Emily, a young woman in her 20s completing her academic studies, talked about her forthcoming visit to the Clinic as a means through which she could impart information and care to others in the family;

If, with my scientific background, I can get the facts right then I can talk to all my cousins about it.

⁸⁴ Sometimes, as in Penny's case, this revealed awkward disparities in the monitoring available to those who might be at risk of breast cancer compared with those who had had breast cancer.

But she also pointed out that many family members did not at the moment want to be involved. This awareness was sharpened and given a more real hue after her visit to the Clinic, as Emily explained when we met for a second time;

The doctor explained that there are various options. One would be having a genetic test so my mother would be tested to see if she's got a gene then to see if I've got it as well. The other one was that they could take my mother's blood and freeze it and keep it there so possibly in the future she could have a genetic test or if something really bad happened at least we would have a sample of her that we could test. So I thought all that was good and a brilliant suggestion. But I went home and spoke to my mother and she got in a right state. The way she feels is that she just wants to ignore the fact that it ever happened and she doesn't want to be tested for the gene she doesn't want to have blood taken. Now that puts me in a difficult position.

Despite this impediment to shared or future care Emily continued to identify as a patient in a relational sense; something that, for her, held out the hope that some intervention might be possible at a later date.

Emily/ My mother's got more sisters and if another one of them went down with it or if something happened to sort of like my nieces, then I think we'd have to seriously start thinking about investigating it. I think I'd want to go back to my mother and see if she'd donate blood. They [the Clinic] said they've got new methods of testing coming out and if in the future maybe one of my cousins wants to get involved they [the Clinic] said that's all cool. One member of the family gets involved then the whole family gets involved, which sort of means that my entire family would be well looked after.

Sahra/ have you talked to any of them about doing that?

Emily/I've spoken to a couple of my female cousins and they're sort of in complete denial. Because neither of them has got a mother who has been through it and so they're sort of 'oh no I'll be fine don't worry about it'. But if in the future they feel they want more information they know that I've got a contact so they are sort of safe. But the cousin of my mum's mum is also in complete denial, I don't think it's worth pursuing because she's not in the frame of mind to want to listen about it.

Emily's own care, even after her mother had declined to donate blood for storage, was still predicated therefore in part on the future health and involvement of others. The strength of her identification with a distributed notion of patienthood might also have been linked to her 'limbo' status (see page 100), which meant she could not at the moment have regular mammography or check ups as she was too young. Clearly Emily saw her involvement in the Clinic in terms of 'caring' for her family, even if they continued to be more reluctant participants to this exchange of rights and obligations.

Margaret

The implications and requirements of distributed patienthood were different for Margaret was in her early 60's and continued to work part time. In the first instance, the context and manner of her referral had not involved a great deal of effort or initiative on her part, as she explained during our first meeting:

Yes it was my GP's suggestion, and I thought 'Ok I'll try it'. When I sort of said to her [the GP] that my brother has got to have a mastectomy next week, she said oh we must get you on to this hereditary thing, or whatever you call it. So the next time I went for an appointment she had got it all sorted out. I don't know whether I would have asked for it if my GP hadn't suggested it, because I hadn't really heard enough about it

It seemed that on hearing that her brother had recently had a mastectomy following a diagnosis of breast cancer, several years after Margaret's sister had died of breast cancer, the response of her GP was to refer her to the genetics Clinic.⁸⁵ Although somewhat unprepared and unsuspecting of her appointment to the Clinic, she was clear on one thing:

I just hope if I do get, or if they say to me, well I've got more chance of getting it, then I hope they say that I can have mammograms more frequently.

Margaret was aware that at 65 she would no longer be routinely called by the National Breast Cancer Screening programme. She explained that by having extra screening she hoped to avoid the kind of 'surgical' intervention, arising from developing breast cancer, that would exacerbate her biggest health concern, her heart. During our first meeting she also talked about her brother's response to her referral to the Clinic.

Well, he doesn't want to talk about anything unfortunately. I don't think he had considered the fact that I might be affected by it in a way, the inheritance. I don't think he'd thought about it, he doesn't really want to know about it. It's funny because we grew up somewhere you don't talk about your illnesses, I mean cancer wasn't a word that you used in my childhood. My brother didn't even tell his daughters when he first got diagnosed, until he had the operation and then they knew at the same time as I did.

In Margaret's case, therefore, it was obvious that the kind of sharing of information and rights that might have led others to seek a referral at the Clinic was not present. This was apparent at the start of our first meeting when Margaret explained that she wanted to ensure what she said to me would be anonymized because she didn't want anything getting back to her brother, as

⁸⁵ She did however add that she 'wouldn't mind if they get benefits from knowing more about cancer' suggesting that she hoped to benefit from some exchange of knowledge for 'care'.

relations between her and her brother were not really that good. The silence of her brother about his illness and Margaret's feelings about this also seemed to be connected to and informed by the lack of communication with another set of relations, in particular her brother in law's response to his wife's (Margaret's sisters) illness and death.⁸⁶ However it was the actions precipitated by Margaret's visit to the Clinic which had the most significant implications for relations with her family. She described what had happened following her appointment at the start of our second meeting.

Margaret/ When I went for the appointment I looked at it with the view of whether I was going to get it, that's all that I had thought about. I didn't know if they were going to get any research out of it. But because it's rarer in men, the nurse said that it was probably worth looking into. It's more likely to be hereditary if you've got two relatives and one is a man, so my brother is going to have a blood test. I spoke to him yesterday, and he's got the letter, he's got to go to the surgery and get the sample which will be sent back here for analysis. I think if they find that he's got a hereditary gene they will ask me for a blood sample to see if I've got a hereditary gene. He's got two daughters who are in their thirties, so they might be interested in having a test if he has the hereditary test, but the first step is for him to have the test

The actions precipitated by Margaret's visit to the Clinic clearly initiated a dramatic reversal in the level of communication between her and her brother, such that both they and others were now actively involved in each others health care. This new development was brought sharply into focus in the way she contrasted how she had initially thought of her visit to the Clinic, in terms of her own care, and what was now actually happening. More importantly this scenario of shared health care, which implicated many family members, was now underpinned and informed by an exchange of rights and obligations, as Margaret's discussion of how her brother had responded to this new situation highlighted:

Sahra/How does your brother feel about all this now then?

Margaret/well he's not really bothered (laughing). He can't really see the point of it. But he said that if I wanted him to, he would do it. When I first told him, you know I rang him and I said were you willing to have a blood test, he said you know you'd just find it from the lump you would find it, and he couldn't see the point in having the test. Anyway he said that if I wanted to go ahead with it, he said that he wouldn't mind having it.

⁸⁶ This situation appeared to at one time have been linked to a sense of guilt that she should have been there when her sister died and anger that her sister's husband hadn't told her exactly how serious the illness was.

Given the pre-existing social relations between her and her brother it was an exchange that was evidently somewhat reluctantly undertaken and not necessarily warmly welcomed. But it was not just her brother who was now implicated in this process, as Margaret pointed out when I asked her if she or the nurse had talked about her nieces during the appointment.

Margaret/Yes in fact I said about the daughters and she said that was another reason for having his blood test. If the family had sort of finished with my brother and me, then there may not have been the same reason for doing it, because of my age. But she was saying that for the sake of his daughters it would also be useful, if they wanted to.

Although Margaret had wondered if her nieces could be 'at risk', this possibility was confirmed during her visit when it was pointed out by the nurse as one of the reasons for going ahead with genetic testing. It was the risk to these individuals which from the nurse's perspective then made such intervention important and urgent rather than the risk to Margaret herself, underlining her status as a patient only in relation to the prospective patient status of others. I was interested to know if Margaret was happy about this new involvement in her family's health, given the sense of loss and anger she had talked about earlier when she had been excluded from important family events such as her sister's death and its aftermath. When I asked her about this, she talked about how she might get in touch with one of her nieces

Margaret/ I might tell her that there is this opportunity and if she wants to follow it up. But the other thing that came to my mind since then, I was reading through some insurance form and it wasn't something that I was going to go into but it just said have you ever had a genetics test and what was the result. I didn't realise they went into that, and presumably it could put up insurance premiums. I mean I'm not going to take out life insurance, but my nieces would, they've got young families, so they might not want to go into knowing.

At the same time that the events precipitated by the Clinic did involve and entail renewed contact between family members Margaret did not seem completely convinced that the consequences for others would necessarily all be good. In addition Margaret's own care was now much further down the line than she might have thought as the following excerpt from our discussion demonstrates:

Sahra/Did you talk about what the risks were for you at the Clinic at all?

Margaret/No not until she gets the results. I think she [the nurse] just wanted to know about whether there was a hereditary gene. She said until they know the results of these tests, they can't promise me any more screening.

Joan

During our first meeting, Joan, who was in her early 50's, talked about how she had completed the family history form. Like many people attending the clinics, there were gaps in her knowledge of the family history, as her description of this process demonstrated

Well I spoke to mum and dad obviously and brothers and sisters. They're all quite close so I know what's going on with that side of the family. The others I haven't seen them for years and I wouldn't even know where they live. On me mum's side, I don't know. On her father's side I know nothing, she doesn't even know who her father was. All she knows is that it was a married man in the 1920's but that's all. So there is no one else on her side of the family alive apart from some distant cousins who don't even live in this country any more.

However, following Joan's visit to the Clinic, it was clear that this somewhat fuzzy detail concerning her mother's father had greater significance than she had thought. This was revealed in the first few moments of our second interview when I asked her to tell me about what had happened at the Clinic.

Joan/ well, everything is fine. I've only got a very low risk of a hereditary gene. Although they picked up, my mum, as I explained to you I think, was illegitimate. Well her father was a Russian Jew. I don't know anything about him only that he was Jewish and married and owned some warehouses up in London

Sahra/Oh right so how did this come up then?

Joan/ well, her Gran told her who he was and mum sort of said over the years, we've all got Jewish blood in us. All these sort of jokes come out. Anyway I happened to mention to the nurse, she was asking if I knew anything on that side of the family, and I said well I don't know anything about that side of the family apart from the fact that he was a Russian Jewish immigrant. She said 'oh that's quite interesting because that puts a slightly different slant on the hereditary [aspect]'. Apparently there is a slightly different gene that comes through on the Jewish side. So mum has agreed to have her DNA tested and she's given permission to have her medical notes to be looked at, to see if there is any link that way. There may be something being passed on that side of the family, so we'll wait and see.

In the course of our discussion Joan talked about how the medical interest in this aspect of her family history had impacted on her and her family and the range of issues it had raised

My mum thinks she knows the name [of her father] but she's not even a 100 percent sure on the name. It's not even on the birth certificate or anything. I think the general view of everybody is well we didn't know him, so it doesn't matter (laughing). All be it perhaps a little tiny bit of him is in all of us. Now that we know that perhaps there was something that he could have passed through it makes us feel that perhaps he's a little bit more important. Years ago I was thinking about having AID, because we couldn't have any more children. I would have jumped at it. But Eric said no, because we've got one and he

didn't feel all that comfortable with a child with father unknown type of thing. It makes you think then well, if I had of done, what sort of genes would that child have had. So it's quite a wide thing it could open up. Suddenly there is a grandfather that has got a lot of importance in our lives, or could have a lot to do with things that happened to us. Everybody has said oh he was just someone who went with my grandmother, but he is a bit more important than just a fly by night if you like.

It was evident therefore that this 'new thing' had opened up many issues. I have already discussed how Joan's fathers belief in predestination helped make tangible for Joan and others in the family the possibility of dangerous genetic inheritance in the family (see page 57). Although not explicit in what Joan had said, it is possible that the reappearance and sudden significance of this figure from the past may have provided renewed focus and force for such beliefs and given vent to further feelings of guilt or anxiety among different family members. There was evidence from our previous interview that a discourse of 'guilt' was present among family members as a result of another condition that both her husband and her son had.⁸⁷ Some of this unease was conveyed in her final comments when I asked Joan whether she felt overall her appointment had been a good thing to do, given that regular screening had been set up for her and other investigations were underway with her mother.

Joan/Overall I would say that its settled a lot. The only thing is it's thrown up the thing with the Jewish ancestry, that's the only thing. I'm hoping that it won't be years before we get an answer from that and that if it is something, a gene on that side of the family, if it's there then start dealing with that. It's a new thing that's come in and there are no answers to it.

If you have a look at this letter, [reaches for follow up letter sent to her from the Clinic after being seen there] I think it's on the third page [reads from letter], 'there is a low chance of finding a mutation in BRCA 1 or 2'. But you see because of the Jewish link, it worries me more, because it is more prevalent. [Reads from letter again] 'if we do find a fault in the blood sample and testing may make take many months or years and it would mean that anyone in the family who wished to know their genetic status could have a genetic test after counselling'. But they don't say what it would be, I presume it would just be a blood test. I do remember reading that there is something that affects the Jewish population, I think they get blisters. I seem to remember reading or hearing about some disease, it's a bit like black people get sickle cell anaemia, that affects the black population or the African. So I wondered whether there is anything else, but I should imagine that it's just the breast, because I went about the breast cancer. It's just well hopefully we will get answers, because if we have to wait a year, you'll be worrying. It's the unknown, that's the only doubt now.

⁸⁷ This was illustrated in some of what Joan said;

We've already got problems with my husband whose got hypercholesterolemia and the sons got it as well and the chances are that he's passed it on. That causes its own problems and there is quite a sort of guilt trip because they've passed it on. I think that's what's frightening is that you can pass something to those that you love.

The new significance given to a shadowy figure from her grandmother's past had obviously reverberated through Joan's family. Although this might have given renewed vent to older issues, her comments also suggested that it had also raised new and other troubling questions.

The three case studies outlined here show how patients not only had to be proactive in getting to the Clinic but also in involving others. For someone like Margaret who did not fit this 'active' model, we can see that the inclusiveness of being a patient for herself and others was something less expected. But even for someone like Emily, who saw her active participation in terms of being a 'good' aware patient, fulfilling this notion of patienthood was thwarted by the reluctance of her mother to participate in her daughter's preventative goals. The work the pastoral practices of the Clinic precipitated and required of such individuals and their related kin was not always necessarily perceived in terms of 'care' by all. Although I did not have the opportunity to talk to related others, from what was said by these individuals, it was clear that this could engender or exacerbate tension among family members. The case studies presented here show how unknowing, reluctant, or in Joan's case, essentially unknown relatives, became entangled in each others medical care in ways that resituated risk, rights and responsibilities between related individuals.

4.3 Conclusion

A notion of 'selves in relation' has been used by others to describe how those attending Genetic Clinics perceive their actions in terms of responsibility to others or how predictive practices entail shared involvement(Hallowell 1999), (Kenen 1994) and(Armstrong et al 1998). My research supports such findings but suggests that this articulation of patienthood arises at the intersection between the expectations of patients (for themselves and others) and the pastoral practices of the Clinic. That is 'care for the family' (and 'care for the future')in making 'ethics' explicit *and* helping to ensure the utility and viability of genetic knowledge, have material consequences for patients.

In this context, a notion of 'fractal' patienthood or the 'dividual' does shed new light on what being a patient in a Cancer Genetic Clinic means. I am not suggesting that this is a necessarily fixed or widespread property of identity in 'western' arenas. In fact it may be at odds with a more 'ego' centred form of personhood (McFarlane 1978) or even the reflexive project of the self (Giddens 1981), (Rose 1996). That is awareness of one's own health in getting to the Clinic might conflict with a much more distributed notion of patient identity required as a result of such a visit, as some of the case studies in this chapter suggest. Others might interpret this aspect of being a patient as simply another expression of individuality; that is the centredness of the person in a nexus of social relations (Edwards 2000:37). However we have also seen that the person in the Clinic is not necessarily always at the centre of such a network and may actually not be considered the 'patient' or the most important 'patient' by clinicians. Nonetheless Hallowell points out the notion of a 'relational self', considered to be a property of female 'nurturant' identity (1999)(see also Gilligan 1982), could be particularly enabling in the context of predictive genetics. I have suggested that it is also something which the practices of the Clinic rely on and, to a certain extent, reinforce.

Just as attention to exchange relations in anthropological work on personhood has helped to illuminate a seemingly radically different understanding identity in non-western contexts, so attending to the dynamics of exchange in the Clinic also draws attention to a very different dimension of patienthood. An idiom of 'gift' exchange is evident in the way clinicians talk about the necessary involvement of multiple related kin as 'care for the family' or 'care for the future' and the way some of those attending the Clinic perceive of their actions as caring for others. Although this is a gift exchange that not all attending the Clinic are necessarily willing to extend or which related others want to participate in. The 'dream' of relations and relating being somehow a 'good thing', although a powerful idiom in the context of talking about 'the family'(Yanagisako and Delaney 1995) is, as Strathern points out, just that; 'everyday kinship practices are as much about dividing and excluding as they are about connecting'(1996: 530).

The concern with the 'social' demonstrated in the pastoral practices of the Clinic poses a challenge to those who would critique developments in the new genetics as a necessarily leading to a form of 'medicalisation'. Describing the nature of this authority, Finkler, in her study of the 'experiences' of women attending Breast Cancer Genetic Clinics, writes that;

DNA is devoid of morality or affect, the hallmark of family and kinship relations..[it] does not impose, express, or insist on responsibilities, obligations or love, other than requiring living relatives to furnish blood samples in order to establish genetic markers on chromosomes' (2000: 187).

My analysis suggests quite the opposite. I show how the transmission of knowledge and care in breast cancer genetics is embedded and predicated on 'the combinatory power of substance and code [...]at the heart of a notion of blood relative' (Carsten 2001:50). Nevertheless this is a morality of connection, obligation and responsibility which is not always or necessarily shared among related kin. The next chapter examines how the 'bi-directional affective entanglements' (Rose 2001) that arise from predictive health care practices have consequences, not just for kin relations, but also for those who work in these clinical arenas.

Chapter 5

Working with BRCA genes; the ambivalence of practitioners

A lay/professional distinction has been used to draw attention to the way patients and other lay persons 'experience' of new technologies and knowledge is constituted within their 'lifeworld' (Rapp 1999). This has, however, meant that the 'experiences' of those who must work with new technologies have been somewhat neglected or equated with a clinical or scientific idiom of rationality. There has been some investigation of the challenges faced by medical practitioners who have to negotiate the distance between epidemiological knowledge and clinical care in other domains of health practice (Kaufert 1998), (Gifford 1986), (Singleton & Michael 1993), (Silverman 1987). This omission has, nonetheless, been particularly marked in the context of social studies of the 'new genetics' (Kaufert 2000). Although Bosk has examined the practices of genetic counselling in the world of pre-natal clinics (1992) there has been little sustained exploration of how those who work in other specialties experience these developments. As Lenaghan points out, health services for the diagnosis of disease are going to have to develop in very different ways in dealing with a new domain of 'probability' (1998). As such, it is particularly important to understand how new roles as 'diviners' (Lock 1998) or 'pastoral keepers' (Rabinow 1996), (Rose 2001) engendered by developments in predictive medicine may intersect with old roles in different ways, depending on the disease in question and the historical or social location of clinical practice.

We have already seen in both chapters 2 and 3 that the *practices* undertaken by health professionals are crucial to reproducing breast cancer genetics as knowledge and care. This chapter, based on interviews and informal discussions with practitioners examines the *experience* of those who undertake these practices. It draws attention to the ambivalence of those who are like patients caught up in the traffic of transmission and the challenges they face in negotiating the distance that currently exists between knowledge and care. The experiences of those who worked in hospital X and Y are examined separately,

drawing attention to the differences in the way health care practitioners approach, make sense of and reflect upon working with BRCA genes.

5.1 Predictive Medicine and Oncology

I first explore how those who worked in Hospital X, the cancer hospital, discussed working with the knowledge and technologies associated with BRCA genetics. Although for many this had been part of, and emerged from long involvement in the field of cancer or breast screening, there were disparities in the way different persons talked about working in this setting and the predictive and caring modes that were part of their practice.

5.1.1 Genetic knowledge; from ‘dazzle to doubt’

One of my first meetings with one of the cancer geneticist who worked at Hospital X, to discuss my research, drew attention to how central the ‘potential’ of genetic knowledge was to how some of those who worked in this setting talked about the work that they did.

Eve greets me in the hospital corridor where we have managed to arrange a meeting in her busy schedule early one morning. Sitting opposite each other in the hospital canteen having breakfast, we talk about the possible directions that my Ph.D. work could take in the Clinic. At this stage of my fieldwork I am, of course, keen to find out exactly how much genetic knowledge and technology is actually ‘impacting’ on clinical practice. Eve tells me that;

‘Gene array and chip technology means that it’s going to be possible to do testing soon without having to go through different relatives and this is going to lead eventually to targeted drug treatments for cancer patients’.

She has a copy of Nature Genetics with her and proceeded to show and discuss with me an article about ‘chip’ technology as if to prove how real these things are or could be. Surprised and excited by the speed at which she suggests things are moving, I launch confidently into discussing with her the details of my planned research, which at this stage is orientated around the impact of genetic testing. At this point Eve stops me and points out that not many people have actually been tested for the gene and that as yet no BRCA 2 testing has been done outside a research setting.

The real scope of genetic testing stood in stark contrast to the way Eve had initially talked about the imminence of these developments. Nevertheless, the ‘dazzle’ (Strathern 1999) of her remarks were reflected in discussions and

interviews I had with this particular clinician throughout my research, as an excerpt from another interview with her illustrated.

Eve/ the thing that does increase referrals is for example if we had found another gene, say BRCA3, that would have had a tremendous impact on families. And if, although we probably know now that it's not the case, but if we had located BRCA3 and it was very large and lots of mutations in it, we would have been really pushed to cope with the numbers. It would have been a very real problematic health care issue.

Sahra/ but that's unlikely to happen now, is that right?

Eve/ It's unlikely to happen now because we would have found it by now if another large gene was there. That doesn't mean that there isn't a BRCA 3, 4, 5 out there, it just means that it's going to be much more complicated. This means that we do have a slight window whereby we can start to train people up, getting ready to deal with this and getting people [health professionals] into breast units so that they'll be ready when BRCA 3, 4 and 5 are found and gene chip technology will be available. So then you can develop the chip to do it all together.⁸⁸

On another occasion she pointed out that; 'the very exciting thing about genetics is how big this is going to get. You could almost reach the situation where you could prevent so much that people actually start to think well this is never going to happen to me.' Although I soon learnt, as my fieldwork progressed, that her concerns were at least currently somewhat misplaced, her comments brought home how the 'potential' impact of BRCA genes was an important part of the way Eve identified herself as a practitioner. In fact her participation in this clinical field had been a product of long term professional involvement moving from oncology and many years in cancer genetic research. She had, therefore, in her career thus far seen a substantial shift in genetic knowledge of breast cancer and witnessed its translation into clinical practice. She also continued to be involved in numerous research studies related to this field, both scientific and clinical. It was, she said, something she had become 'completely fascinated by' and with which her career was strongly connected.

One particular discussion with Eve in the Clinic illustrated the extent to which her hopes for genetic knowledge were closely linked with her own sense of professional and even personal identity .

⁸⁸ There were some caveats at the end of this discussion however which suggested that Eve did acknowledge some problematic dimensions to this area of medicine, when she said 'then genetic testing might become much more mainstream and then we've just got the ethical issue and the counselling issues'. As I explore in the next section she did concede that this challenged the development of predictive practices.

It is near the end of the Clinic after a long afternoon of appointments. Nevertheless, Eve is still full of enthusiasm and seeming energy. She asks me how my research is going. Although early on in my analysis, I point out the extent to which some people appear to find their visit to the Clinic something of a 'positive' experience. Before I can fully explain Eve interjects. She concurs that this does happen and warming to my theme about genetic knowledge being apparently for some a 'good thing' she takes the opportunity to reflect on the way that knowledge of a genetic heritage has been enabling and illuminating for her.

She explains that she used to find it surprising how at home and relaxed she feels when she goes to Greece, each year on holiday, but explains that this feeling now makes sense to her because of the discovery of 'European ancestry' in her family.

Almost immediately following this revelation she talks about how in the future it might be possible to use genetic testing to tell who is 'really Jewish', because doing a genetic test would, she says, make it possible 'to see if they had an Ashkenazi mutation'.⁸⁹ Failing to see the kind of 'truth' that Eve is suggesting genetic testing may reveal, I say that this wouldn't be possible without asking them about whether patients would believe this to be a evidence of a 'hidden' ethnicity or religious identity. 'That is just the point' Eve continues, 'you wouldn't have to ask about their perceptions at all, it would just depend on what was being encoded in their genes'. A few moments later, the nurse comes in and begins to talk about her last patient of the day. Although not aware of the conversation we have just had, she says that she suspects she might be Jewish, 'given her personality which was very straight forward and down to earth'. Her comments seem to provide further proof of a belief and hope in an underlying reality that Eve seemed to see genes as providing.

The incident revealed not only the way that genetic knowledge was closely tied up with Eve's own sense of identity, but the way this was incorporated into and informed a belief and faith in a more hopeful future where genes would reveal a kind of truth. The importance of a 'vision' of the future has been commented on by others who point out that such claims are very much part of a discourse on the new genetics (Franklin 2001a). Nevertheless, the sense of total faith in achieving these predictive goals that this practitioner talked about was not necessarily commonly shared by all those in Hospital X, other practitioners were more equivocal.

⁸⁹ This topic of discussion may have been prompted by the fact that earlier in the day along with another colleague I had been part of discussion with Eve about how sometimes even though a patient might deny that they were Jewish there were strong suspicions that sometimes people 'must have' Jewish ancestry because of certain stereotyped character traits.

One of the younger members of the cancer genetics team, Dawn, who was in her early 30's, had been working as a consultant in Oncology for a number of years and had only recently moved into cancer genetics. During the beginning of a long interview with her, she described how she had initially become involved in this area as result of deciding to do a Ph.D.

I wanted to do a scientific lab based Ph.D., completely out of the Clinic, which is of course what I'm not doing now but that was the original plan. I wanted to do science as my research initially, understanding how all these things work. I wanted something completely different to what I was doing on a day to day basis. I also didn't want to do a clinical Ph.D. because they're fraught with patient recruitment and running studies, everything that I now have a problem with (laughing).

Her hesitancy about working in *clinical* genetics emerged more clearly however in the gap between her practice and the way she talked about the challenges of working in this particular field.

Her appointments were some of the longest clinical appointments that I observed; first time visits by patients, as well as other clinical encounters could take anything up to an hour. This was because she was particularly fastidious in giving information which could sometimes take up more than three quarters of her appointments. She herself acknowledged that it was a misnomer really to call what she did 'genetic counselling', when the bulk of her contact with patients involved imparting information.⁹⁰ For instance, more than others in the Clinic, she also seemed willing to use risk figures in her appointments. But her attention to detail and apparent ease with which she made recourse to the use of risk figures was belied by her comments about the challenge of conveying risk information.

Dawn /It's about trying to find a balance. It's about putting the information in context but also in a way that there doesn't end up being so much information they can't see the wood for the trees. You try to explain what a gene is, how you inherit it and the penetrance and you can see people go blank. I think when you start talking about other genes coming in and acting and affecting the penetrance and it's all very complex and even though you express it may not mean breast cancer will develop

⁹⁰ She took great care, for instance, to make it clear what was meant by the statement that 'a cancer is genetic'. She would often explain to the patient that this 'could be confusing because in a sense 'all cancer is genetic' or a product of 'cell and gene interaction'. But 'genetic cancers' were she said 'different' as these were linked to 'inherited mutations present in every cell of the body' and not just 'a breast cancer cell'.

Sahra / but that is what is happening isn't it ?

Dawn/ it is what is happening but it's a case of do you try and give someone a bachelor of science degree or do you try and just give the salient points which would be the important. It's the most difficult part of the work, expressing risk in a meaningful manner, particularly when we don't really understand what the risks are. I just feel that you do have to try and say something and there is no point in not saying anything at all, otherwise there is no point in them coming.

Of course it may in part have been her awareness of these limitations which made her more than normally rigorous about imparting risk information. Nonetheless, the use she made of a particular description during one appointment, as well as her comments afterwards, seemed to illustrate her *need* to provide coherent explanations.

The woman sitting in the Clinic is here on her first visit. It is a lengthy appointment, in part because a gene mutation has been identified in a relative and Dawn spends much time outlining the 'choices' available to her. There has also been some discussion prompted by the patient about the limits of undertaking the procedures being offered to her. Nevertheless Dawn concludes the appointment on a suitably upbeat note saying;

'your aunt choosing to have this genetic test, is a *legacy*. If she hadn't done that then we wouldn't be able to know for certain that you could be at risk, it explains things. The information is not going to go away and will always be here as a resource to use when you and your family want to.' (my emphasis)

After the patient has left Dawn talks to me about how 'easy' and 'straightforward' the consultation was because 'when you know that there is a gene in the family you can offer definite things and provide them with real options.'

Judging by the patient's response, these options did not necessarily generate such easy or straightforward answers. However, the encounter highlighted the desire of practitioners to talk in more concrete terms. It may have been because definitive answers were mostly elusive that, on this occasion, Dawn felt impelled to describe genetic testing almost as a 'gift' when the relatively rare opportunity arose to provide a patient in the Clinic with what seemed like more concrete options. Her eagerness for clarity was also reflected in the way she experienced obtaining family history.

My experience of taking histories from any patient is that it's a long and laborious process, particularly when you're talking about family history. Some of them will take you straight to the quick but most of them will take you down this long and laborious path of Auntie Sue was married to Uncle George and did they have any children... and it takes for ever. It's also not accurate and you could spend your whole hour drawing a family tree and then they have to go back and check the details and it's not right

Her frustration about taking family history was also illustrated somewhat indirectly in the way she responded to one clinical encounter when a mother and daughter had brought in their own home-made genealogy to the appointment. In this case they had included detailed information directly applicable to the assessment of risk, such as the types of illnesses relatives had had and the dates they had been diagnosed. To Dawn's obvious delight this made producing the clinical family tree much simpler and quicker with substantially less discussion about the family history than would have normally been required.

Both these scenarios were, however, the exception to the rule. Opportunities for achieving clarity in the Clinic were in fact rare, something which appeared to compound Dawn's ambivalence about working in this domain. For example, this was the way she talked about how she saw the future of cancer genetics:

I think it's going to get more and more complex as we get to know more about it and then how do you actually translate that into patient care. I think there are two different levels of genetics; the first as in identifying risks or identifying families at risk and then the second is understanding how cancer develops as a result of genes and then having that information to have better therapy. *I think that the second thing is fantastic* and I hope that we just continue down that route and we will find something more effective to replace what we have at the moment. (my emphasis)

Here we can see how her sense of unease in relation to the complexity associated with predictive genetics contrasted with an enthusiasm for genetic knowledge that might ultimately 'treat' cancer.⁹¹ A contrast which clearly intersected with her own desire to, as she put it, 'spend the rest of my life doing oncology' and her obvious reluctance to work in a field where translating predictive knowledge into patient care was complex, difficult and tenuous.

Others working at Hospital X also expressed doubts about predictive practices of BRCA genetics, although these were articulated in slightly different way. Irene was one of the senior nurses who worked in the Family History Clinic. Having

⁹¹ Dawn's desire to provide 'treatment' was also evident in the way she talked about one of the key dilemmas of work in the Cancer Genetic Clinic, addressing the care of related others.

Dawn/ Although we do see families its sometimes easy to forget that we need to deal with the individual in front of us as well. I came across that the other day, I gave someone their genetic test results and I started talking about what screening is suitable for the family and the woman said, ' what about screening for me, what kind of screening do I need to do'. She was the concerned one in the first place.

worked in the unit the longest (over 15 years) she had developed a specific expertise in addressing the physical symptoms of breast pain and the anxiety about breast cancer that afflicted many of those she saw. The fact that she addressed some of these persons as ‘cancerphobics’ brought home the extent to which Irene saw this as an illness and not just simply about the ‘anxiety’ of the ‘worried well’.⁹² Her skill in examining patients and aspirating benign cysts was widely acknowledged among other staff in both the Family History and Genetic Clinics and something that she was proud of. Significantly, unlike the others who worked in the BDU, she had a room that she used nearly all the time which had her own ‘personal’ touches on the walls. It was also dominated, in the way the other consulting rooms were not, by the placing of an examination table in the middle of the room.⁹³ This enabled her to move expertly on both sides of the table and to conduct physical examination and needle aspiration.

The feeling that her skill lay in this domain was demonstrated on one occasion when, sitting waiting in the Clinic, she told me she had an ‘interesting case’ and that I should come and sit in on her appointment. In fact the issue of ‘interest’ had nothing to do with genetic knowledge or family history, but because she had discovered a suspicious lump on the breast of a follow up patient. On another occasion I asked her about why she didn’t seem to draw family trees when the patient came for their appointment in the way that I had seen all clinicians as well as the nurses in the family history Clinic undertake. With a touch of irony in her voice she said ‘oh no I leave that to the young ones, all those new fangled things’, suggesting that she felt her skills lay elsewhere. Her feelings about the movement towards more predictive practices, that she had witnessed over the course of the last 5 years, emerged in conversations and interviews with her during my research.

⁹² This was brought home one day when she pointed out her annoyance that a colleague in another department had said that she dealt with the ‘worried well’.

⁹³ Although nearly all the consulting rooms had examination tables, most of the rooms used by the cancer genetic staff were generally larger rooms where examination tables were placed at the side of the room. This reflected the fact that physical examination was not the first or most important activity undertaken by these practitioners. Whereas for the nurses that worked in the Family History Clinic who saw follow up patients it was a routine procedure, that they were experts in undertaking, and part of the way they provided ‘care’.

Reflecting on her professional history and on the way she and other nurses in the Family History Unit had developed a unique set of skills she said,

Having been fairly pioneering I suppose, from the nursing point of view, it was nice to see how far we could go and I think we are about the top of what we can do, because we do needle tests, guided needle aspiration, under protocol, obviously.

Nevertheless, the identification of the BRCA genes had led to a series of changes in the guidelines for referral to the Clinics. She commented on this and the sense of frustration this had generated for her.

In the days when it wasn't so tight on age [of affected relatives] over half of those who came here didn't have any family history at all and compared to nowadays would have been taken as not at risk at all.[...]It may be that you'll get to the stage where they'll tell us that you can't define them as high risk unless they've got a gene already! (laughing). I'm sorry that sounds frivolous, but you know that the age [of a referred person's affected relatives] might go down to thirty or something, it seems to change with the wind.

The increasingly narrowly defined criteria for seeing patients had particular consequences for Irene. Having been there the longest she had to bear the brunt of discharging patients who might have been recruited earlier as part of clinical trials but, according to the tighter criteria for inclusion in the hospital's programme of screening, were no longer considered to be at risk. Some of these challenges were hinted at by one of the consultants who worked in the Cancer Genetic Clinic.

Dawn/ If they get breast cancer at fifty it's because they're at population risk not because of their family history risk, so they should be part of the population screening risk program just like everybody else. That's it in scientific terms but it's very hard in emotional terms for a woman who has been seen, is discharged and then comes back two years later with breast cancer and says if I had been seen on a yearly basis this wouldn't have happened.

Others like Irene who worked at the sharp end of this process found it more difficult to separate emotion from science, as the following comments indicated.

Irene/ I had a patient who asked me that the other day, cos they're not stupid these women, she said 'I thought as I got older it got worse', so I said 'well yes it does but thank you and goodbye!' You know what I would like, is that the people who make the rules come and tell the patients because we've had to discharge patients at 70. Personally I have quite a few problems with it. I find that where we go wrong here is that it's supposed to be black and white but it's a lot of grey.

Irene's remarks imply the difficulties of triage were also linked to the circumscribed or narrow basis on which risk was assessed. This was something that others were also, aware of as was demonstrated in a discussion I had with a member of the cancer genetic team about the complexity of the risk information provided in the Clinic

Jane/They could have a population risk of 8% and then a 20% lifetime risk, and then I might write to a patient that there is less than a 10% chance that there is a gene in the family and a lot of those people may have more or less hormonal risk, because of the pill or whatever

Sahra/ but that's not calculated is it in those figures

Jane/ No that's right it's not calculated ! That's why I'm saying to you that we're calculating it on a purely genetic thing.⁹⁴

Referring to the narrowly defined basis on which risk was calculated in the Clinic Irene talked about the kind of research agenda this focus seemed to support and other avenues or research that might, as a result, be obscured.

Irene/You know it's amazing to think that we are at least 40 or 50 years down the road with research but we are not really much further down the road. What fascinates me is that how come we haven't found out why it is that in China or Japan there is much less breast cancer, but if you move the family to America then the second generation get the same statistics as the Americans. Now what does that tell us, its got to bloody tell us something. I'm amazed that we haven't got anything from that!

However, it was perhaps the lack of proven interventions for at-risk patients which most disturbed her. For instance in contrast to the way patients expressed their 'faith' in the various technologies of the Clinic, particularly mammography screening, Irene (and other nurses) talked about it in terms of a very 'muddy crystal ball' which provided 'no guarantees'.⁹⁵ A similar sense of hesitancy was apparent in the way she talked about genetic testing and the consequences of predictive knowledge:

⁹⁴ There are different models for calculating breast cancer risk, some of which do include other lifestyle 'risk factors' however the one used in the Cancer Genetic Clinics was based solely on a person's family history.

⁹⁵ Another nurse talked about the way mammography was perceived by patients and the difficulties this generated for her and others working in the Clinic

Karen/ It's almost like a relief. They feel that they've been given a clean slate for the next year, so I was ok on that day. I can breathe easy now, for the next six months or however long. It's very difficult to try and get them away from that way of thinking because it is literally a snapshot. What you try and say is that this isn't a let off from examining themselves or keeping an eye out themselves because yes there are interval cancers.

To be honest with you I have a problem with it. If you're going to tell someone that they've got whatever gene and you can give them a pill and say fine right that's it, but we can't. I feel, the cart has gone before the horse. If we are going to tell people that they're at 90% risk, then let's offer them something that takes away the whole thing, I mean the only thing that we can offer is a mastectomy and is that even foolproof ? Not to my knowledge[...]I think what I find frightening is that one day you're not at high risk and then the next day you are. Not for my generation obviously but I'm talking about the youngsters whose mothers haven't reached forty who are all carefree and the like and then the next minute we tell them they're at risk of breast cancer.

Changes in the guidelines for admitting patients had meant that it was increasingly this group of persons, those thought to be at high risk of carrying a gene, who were being enrolled into the Clinic; a basis for medical practice which she clearly felt uneasy about.

We can see that a sense of hesitancy about the predictive approach entailed in BRCA genetics is unevenly distributed and somewhat diffusely articulated in Hospital X. For some, the uncertainties that arise from working in this context are circumvented by investing their faith in yet-to-be-developed knowledge and technologies, which, at least for one clinician, had been part of a long term career involvement in genetic research. Others were more open in articulating their doubts about this. For both Irene and Dawn, this seemed to be linked to a sense of loss in the skills they had acquired as oncologists or as specialist nurses in treating the physical ailments of disease or the 'illness' of anxiety. Their experiences and comments give a very different reading to the tools of 'authoritative' knowledge, such as the use of risk figures explored in Chapter 3. We can see here that the use of risk statistics at the clinical interface masks the controversy and doubt experienced and articulated by medical practitioners outside this arena (Gifford 1986). However, predictive medicine also provides the chance to identify as new kinds of practitioners, as 'keepers of the pastoral' (Rose 2001). This is an 'opportunity' which, as I explore in the next section, has equally uneven ramifications for those in Hospital X.

5.1.2 'Care' as expertise ?

We have already seen the way that certain pastoral modes are central to clinical practice in ways that are affective, but also effective or instrumental to knowledge. From some in Hospital X, attending to the 'social' context of the

family seemed to enable them to demonstrate the 'caring' ethic at the heart of their practice. As one clinician said, it meant being able to be 'holistic' about somebody's care. This was reflected in the way Eve talked about the intuitive almost innate counselling type skills and abilities that were necessary to undertake work in this setting.

Eve/ I must admit I don't think it's something that can be taught, you either have it or you don't. What you can't teach is somebody to have the perception to pick up the clues and non verbal communication, that extreme perception. It's interesting, some alternative practitioners have it, and you know they're considered to be psychic. I don't actually think they are psychic but they are just very sensitive to the clues that they are getting back. So this is part of the practice of counselling, which is obviously different to a normal consultation, although most medical consultations should bring that aspect of counselling in, not that they always do. But in fact that's the way that I was trained, that if you listen hard enough the patient should tell you what is wrong and this is what old style physicians always used to do. Of course in a genetic counselling context you're trained to do that and you have much more time to go into things. So you don't say just consider whether there is a genetic mutation or if they've got a clinical problem but you're also looking at the effect that might have on the family and the interactions with other members of the family .

The ability to 'listen' to the patient is therefore seen somewhat nostalgically, from Eve's point of view, as part of an older type of clinical practice. In contrast to others who seemed to 'mourn' the loss of physically treating patients she suggests that an older kind of caring value might be regained through the 'counselling' approach required of practitioners, where it's possible to consider the person as a 'whole'.⁹⁶ As we have seen, this is not so much an option as a necessity; a sentiment reflected in the way Eve sees this as an intuitive 'skill' that cannot necessarily be taught.

Jane, the nurse specialist, was in fact considered to have this special ability, that Eve talked of, in large supply. She herself interpreted the trajectory of events and experiences which had led her to work in this field as a form of 'fate', because of the way her own family had been affected by cancer. Jane's role was in fact unusual. She traversed the role of nurse and genetic specialist in a way that was unique, compared with other health professionals in this area. With a background in community nursing, then genetic research with families before

⁹⁶ At the same time her discussion of the 'holism' of clinical cancer genetics was also resonant with an ethos more common to alternative health care practice. Her suggestion that alternative practitioners' 'psychic abilities' were akin to counselling practices seemed like an attempt to convey a different kind of legitimacy.

undertaking some clinical cancer genetic training, her role was very much located in terms of 'care for the family'. This was evident in the response she gave when I asked her what she felt the most enjoyable aspects of her work were:

I suppose being there for people, particularly for young people who need a lot of help or support understanding the genes. I suppose I find it very rewarding knowing that I can actually help someone, have the knowledge and help those families. You only have to work with families where they've had so many early deaths to know that they are very destroyed families, you know it's so awful for some of them. I feel whatever I can do to help them the better, so I do enjoy all that I do.

An ability to empathise and deal with families was not only a source of Jane's expertise, but also informed the expertise of the Clinic, where the negotiation of family dynamics is vital to facilitating the work of prediction, risk assessment and care. This made her role central and essential to clinical practice.

Her skills were particularly evident in the way that she approached and encountered patients, for instance, when dealing with some of the young girls who came to the Clinic who in their mid to late 20's had often lost mothers and other female relatives to breast cancer early in their lives. The tone of these meetings was friendly and often intimate, there was much sharing of information about recent developments in patients' lives such as a new boyfriend, job or the birth of a baby or a recent wedding or christening in the family. It was clear that Jane found this aspect of her work fascinating, as she said to me at the beginning of a so called 'Carrier' clinic (patients who have already been identified as carrying a mutation) one afternoon, 'this Clinic isn't really as interesting because a lot of the emotional work has already been done'. But she also undertook the task, like the rest of the team, of doing many follow up appointments, for those patients and families who might be undergoing different treatment interventions such as surgery or genetic testing. The rapport and empathy she built up with them developed not only through numerous appointments or through travelling to patients homes but also in the frequent phone calls she made to patients, in order to find out how they were. This happened most often with those families where genetic testing was happening, whom she felt required a great deal of 'support' while waiting for an initial result of a search for a gene mutation or after taking blood for predictive testing.

A discussion I had with her concerning the use of clinical family trees seemed to demonstrate the extent to which she identified with her pastoral role when I asked her a somewhat provocative question:

Sahra / I sometimes wonder when the trees are brought out, whether you think they actually make people think there is more of a risk because suddenly they see this very stark picture and all these cancers which of course may not be connected.

Jane/ well I think it's a very interesting question Sahra and I've thought a lot about it. It's a very painful and emotional experience for a lot of people talking about their mothers or sisters that might have been ill or died. To that extent I think if the tree is already there, you've got the information there before you've started about what is generally going on with the family. So you can adjust the way you handle the situation and *allow for time for that person to be upset*. Yesterday I had a very young girl and we had the tree all drawn up and she needed the time to cry if you like, she needed that time. I can see what you're saying. Its sort of like a ritual and geneticists have always done this. But nurses always do things in certain ways. We are always very keen to explore the emotional side of the situation as much as the practical side, even more so than our medical colleagues, you know that's where we come from. That's not to say that the medical side of things isn't important, but on the whole our decision making process hasn't been diagnostic or in a different form. So I think overall I feel completely comfortable about all that work with the trees. (my emphasis)

Her response to the possibility that a tool, as she saw it, of 'care' which facilitated 'empathy' might actually have quite the opposite consequences illustrated the importance of maintaining her clinical practice within the space of ethical care giving. This meant rationalizing the use of an already drawn tree ready in terms of providing 'more time' to explore the emotional dimensions of coming to the Clinic. The boundaries of care were also maintained by drawing an explicit contrast between what a 'geneticist' would do as standard practice and the way she felt the trees were used by her and her other colleagues in Hospital X who were either nurses or cancer specialists.⁹⁷

⁹⁷ This need to maintain work within the boundaries of care was also reflected in the way another member of the Cancer Genetic team commented on the effectiveness of mammography screening. Although nearly all the nursing staff in Hospital X had drawn attention to the limits of this procedure this was acknowledged in a less open way by those who worked in the Cancer Genetic Clinic at Hospital X. As this excerpt from my interview with Dawn demonstrated when I asked how she felt about the uncertain value of mammography screening for those at increased genetic risk?

Dawn/ There are 2 schools of thought about screening. I think you have to take breast and ovarian screening separately. Ovarian screening is completely invalidated. We don't know if there truly is an early stage in which you can pick up these things. There has to be really for a screening programme to be effective. So I think that is a problem.

In terms of mammography screening, there is a lot of data to validate it in the general population, but there are still some people who disagree with it strongly and don't think its an effective tool. I have to say that most of our patients are anxious anyway and I don't see how the screening makes them any more anxious. It actually makes them feel

It was also striking that Jane, in acknowledging the limits of knowledge and technology in breast cancer genetics, to a certain extent circumvented such questions by talking about how, despite the limitations in this field, there was still significant psychological value for patients.

You know you have to let people know that there are limitations to what we can do and also compensate that. But those people have still got to live with that, they've got to live with their fears. I think it's a therapeutic factor that they actually want access to, something at some institution and some persons that they can talk to. I do think that we do serve our purpose in that way.

Although she did accept that there were difficulties these were, to a certain extent, subsumed by the 'therapeutic' value of the interventions offered to patients. Nonetheless these limits could not always be circumvented by pastoral 'care'. For instance, she talked about an appointment which had particularly disturbed her.

You get some very anxious people in here who get things all out of perspective. I mean this girl that I saw yesterday, she had decided not to have children because she was so terrified of getting breast cancer, so that upset me a great deal that. It wasn't for me to step in and say don't feel like that, but I did say well lets have a think about it and maybe over time you might feel that you want to have a baby.

When Jane's 'care' work was concerned with the sociality between family members, the decision by an individual to curtail the social networks that constitute 'the family', *because* of genetic knowledge, were experienced by her as intensely uncomfortable.

The double edge of embracing a role as a pastoral keeper was also apparent in the way that Jane had to deal with the consequences of uncertainty in relation to

less anxious because they feel like they're being looked after, whether or not it's doing them any good is another matter.

It's quite hard but I actually feel quite strongly that you can't test people and say they're at risk and then not give them something for that risk. So I feel that the screening is there and I'm happy to offer it. I don't think that anyone within genetics feels that its an unreasonable thing to offer screening, apart from people who are generally opposed to screening who aren't necessarily geneticists

These remarks suggest that those working in the Cancer Genetic Clinic appeared to be willing to accept the limits of certain other types of screening (which I hadn't asked about) while refusing to be drawn more explicitly on the problems of mammography screening. This suggested that such an admission compromised an effort to provide care, particularly given the institutional context of Hospital X and when few other interventions could be offered and mammography was seen in terms of care by patients.

genetic testing and the effects this had on individuals and families. This emerged during one appointment when a couple who had been waiting many years for a test result returned to find out what was happening. No result could be provided but they also had yet to make a decision about whether to remove the woman's ovaries, an issue which generated a considerable amount of tension during the appointment, but which I was surprised to see that Jane did not address as she usually did in such situations. The reason for the tension became apparent after they had left, when I commented on this. Jane pointed out that me that 'they used to be a lot worse because you see they were trying for a baby and not succeeding' . It might have been precisely the challenges to care which on this occasion had made Jane wary or unwilling to engage with the tensions and emotions this raised for these individuals by having to wait so long for a genetic test result; something which had clearly been discussed in the past. This seemed to be confirmed in what Jane said when talking about the difficulties of her job one day:

It's the demands really that get me down. The amount of phone calls from the past, you know I saw somebody a few years ago and they want to know what's happening. It's understandable, if I'd seen somebody years ago I'd want to know what's happening too.

It was not just the timescale of procedures such as genetic testing which challenged caring practices but also the pressures and dilemmas generated by the necessity to attend to and facilitate a degree of 'sociality' between related members of the same family. Although for a practitioner like Jane (and to a certain extent the follow up nurses in the Family History Clinic) this was part of their domain of expertise, it could also be fairly fraught for them because of the way they were involved with families. For example, Jane talked about one particular family where the lack of communication between relations had resulted in an outcome that she at least felt uneasy about.

There is one family where I'd originally seen the daughter of a mother who got breast and ovarian cancer. Well the family dynamics I wasn't sure about but the next thing I heard was that this woman's sister was going into have a prophylactic mastectomy. This particular woman, she refused to see the psychologist and the mother's genetic test was sort of half being done but not there yet. The thing is they were all sort of separate, so they'd all been seen in different places and times and *it was about how to get them all to come in and have a joint appointment*. Somebody as young as that girl going in and having major surgery, when perhaps a mutation would be found in the mother would

mean that she might not have to have all this⁹⁸. But sadly in this particular case a mutation wasn't found. So those sort of traumas in the family where one person goes into have surgery which her sister did, and we'd never seen her in genetic counselling. I used to lie awake worrying about it you know, or I used to, so I do worry a lot about all these families. (my emphasis) .⁹⁹

Care work with families was something that others also expressed concerns about even though some had talked about this necessary aspect of their work as linked to the caring ethic at the heart of their practice. For example, Dawn pointed out she found the issue of 'conflicting rights' between family members problematic. Her feelings about this seemed in part to be tied up with the 'stress' caused to patients in having to inform and speak with relatives. However she also recognized that there was a responsibility on practitioners' parts to provide 'care' and let others know of their risk, as she said 'how can you not let these other people know that there is a problem either and have the opportunity to seek advice or screening. For her this situation was incredibly challenging . As she said it was a scenario which, 'I haven't resolved in my own head as yet'.

Even Eve conceded that this was a delicate area of work in the Clinic. She talked about the difficulties that the need to maintain confidentiality between related individuals posed, particularly when family members were being treated by different hospitals.

I think the most difficult thing is, that I find it very hard to reconcile within myself, the issue we have on confidentiality between centres. I understand that patients have to have their confidentiality respected. You know the information has been given to you by one person and if you're passing it on to help the management of a family in another centre, then in theory then you should be doing nothing but good. I can see that genetics is different because you've got information about others, but we've got to get around this because otherwise something dangerous is going to happen. We're starting to have this battle between the rights to know of the people who are at risk versus the rights to confidentiality of those who already have at risk information.

⁹⁸ This would have enabled the daughter to have a predictive test and if it proved negative, she would not have been at risk and hence would have no need to undertake surgery.

⁹⁹ Once again these challenges were somewhat circumvented by Jane in the way that she associated these difficulties with 'problem families'.

I think the difficulties have been when the family dynamics and patients are trying to manipulate you, where they've fallen out with the relatives, and the relatives have given a blood sample and then she doesn't want to do it and you have to throw the whole thing back into the family. For example we actually had a woman in the other day . She'd sent a letter in and her sister had actually had a blood test and wanted the result of that blood test for herself but under no circumstance could I tell her other sister. I think that's when it's difficult, is when you get families who are manipulative and difficult with each other and then they try and manipulate you.

I've had two families, where I've had people saying 'I don't want information about my case or bits of information disclosed to other family members.' However you may warn them that they should have screening. So we've sent out letters that we've given the patients to give to relatives saying that because of the family history, which we cannot disclose, you should have regular screening. In both cases it's caused a huge amount of problems. Other members of the family have been to see a different geneticist and given a different family history and the geneticists have written to us and said 'why does this person need screening this is crazy' and then what do you do? So you have this terrible dilemma where you can't disclose but on the other hand you've been given a family history which is strong. Interestingly another geneticist who was caring for one of the relatives wrote to say that I would also be very alarmed to receive such a letter from the genetics department, so the 'duty to warn letter' that had quite rightly been written was actually decried by another very senior geneticist and so we've got this problem now about who's at fault

Although Eve claimed previously that work with the family was bringing about an older style of medical practice that could be linked a more 'holistic' approach, from what she said here it was obvious that the necessary work with families compromised an ability to act expertly.¹⁰⁰ These difficulties also highlighted how the 'counselling skills' and a focus on 'the family' that someone like Jane championed but which others also *had* to adopt were absolutely essential to medical practice. This was something that those working in Hospital Y were also only too reluctantly aware of as I examine in the second half of this chapter.

The pastoral practices of the Cancer Genetic Clinic 'impact' in different ways for those working in Hospital X. On the one hand the 'care' work that genetic knowledge necessitates provides the opportunity for some to excel in a different form of expertise where dealing with the social dynamics of the family is central. For some, this meant they could incorporate the necessary 'talking down' work explored in chapter 2 as part of their expertise. This can only be understood in relation to the way attending to the family in Hospital X is presented as a mode of clinical practice which is in itself seen as 'holistic' or 'ethical'. However embracing this as an element of their expertise also meant that they were particularly challenged by the problems of confidentiality and consent that care work with families engendered, as these later examples illustrated.

¹⁰⁰ In this instance working with the family tree became an embodiment not of holistic care, but potential ethical danger, as Eve's said:

It [the issue of confidentiality] is going to become an issue when we try to computerise our records and we start to put the tree on the system. We have to decide are we going to gate the tree, so that only certain people have access and other centres won't be able to see the tree without the patients written permission.

These contradictory representations of care work with the family and the hesitancy with which the difficulties of prediction were highlighted suggest that such an admission was somewhat compromising for those working in this clinic. Focusing only on cancer genetics and particularly breast cancer genetics in a cancer hospital, within a specialist breast unit, means that those working at Hospital X are closely associated with the uncertain knowledge of BRCA genes in an institutional setting where there is a strong expectation of expertise and also of benevolent 'care'.¹⁰¹ In addition, the evolution of the Cancer Genetic Clinic from a Well Woman unit contributes to an ethos, still felt by those who work there now, which supports the (female) patient's right to knowledge, information, and care. This is a right which is not always possible to fulfil, but may make the requirement to do so more strongly felt and compound practitioners reluctance to bring their doubts directly into view.

5.2 Geneticists and the 'hysteria' of breast cancer.

Talking to members of the cancer genetics team, mostly geneticists, in the general hospital where I carried out a much smaller piece of field research, it became obvious that their perspective and experience of developments in BRCA genetics were of a different order to those who worked in an oncology setting.¹⁰² I explore here the way that they articulated a sense of ambivalence about the work of prediction and the caring modes this required of them.

5.2.1 Uncertain knowledge and the demands of consumerism

Breast cancer, and cancer more generally, was of course only one of a number of conditions that the geneticists in Hospital Y addressed in their clinical work. It is

¹⁰¹ The comments of one nurse suggested that working in this domain in a cancer hospital was not always easy.

Karen/I think there is a degree of conflict within the hospital about the way that it's [the family history unit] is perceived. I don't know that it's always well received. I think your working in a cancer hospital full of very ill patients and it does come back to this thing of should we be spending resources on screening a lot of women who we'll perhaps pick up a cancer and balance that against the cost of doing all the screening.

¹⁰² There was also a nurse specialist working in the Clinic at Hospital Y whose experiences I don't recount here. Her responses were more hesitant, much like those in Hospital X. With a role similar to Jane's she was very much identified with the necessary 'care' work with families. It was not insignificant that she also identified herself, as coming from a background in oncology.

a relatively recent but rapidly growing area of their practice and increasingly, to their chagrin, the condition for which they have most referrals. Feelings about the increase in referrals for breast cancer became apparent during an informal discussion with a geneticist and nurse specialist before a clinic one day, when the geneticist highlighted the 'severity' of breast cancer in relation to other conditions that they had to deal with.

Mary/ It's just not that bad when you compare it with other things really and at least 75% of breast cancers are curable nowadays. I mean I've got one woman later on today and it's just awful. She's got this condition which affects young adults and teenagers who really don't know that they've got it until they drop down dead, but she now has a baby and has insisted that her child be tested so that she knows what to do. It's such a terrible condition and knowing that your child could die at any moment, it's absolutely dreadful.

A similar sentiment emerged during the early stages of fieldwork in the second hospital, during a lull in the Clinic that I had been sitting in on with a different geneticist. Partly in response to some discussion of my research, the geneticist begins to talk about dealing with patients at risk of breast cancer in the Genetic Clinic

Elizabeth/ There is just this huge hysteria about breast cancer and in a way I feel partly responsible.¹⁰³ I mean it's not such a nasty disease, not like all those other things that people come here about. Sometimes we are telling women they have a 1 in 8 chance of developing breast cancer which isn't much more than the population risk so it seems ridiculous that people are coming here. Bowel cancers are more interesting and least there is more you can do for them; at least we can offer them screening that might work. What can we offer women who come here worried about their breast cancer risk? Screening which is unproven and sometimes ineffective or having your breasts cut off or chemo-prevention which might make you ill. All not very nice options really and so many things can go wrong with the re-constructions.

The diffuse and isolated concerns that those in Hospital X had about the scope of prediction in relation to BRCA genetics contrasted with the litany of doubt that was reflected in these remarks, which seemed to bring the whole edifice of such practices into question. The sense of limits to knowledge and technology was compounded by what this geneticist saw as a certain degree of 'panic' in relation to breast cancer that was out of all proportion to the severity of other conditions, the numbers of people affected and the scope of possible

¹⁰³ Although I didn't pursue exactly why she might feel partly responsible, I understood such an admission to be linked directly to the way Breast Cancer Genetics had emerged at the forefront of Clinical Genetic Services, which as a geneticist she would have been involved in facilitating.

interventions. These concerns and the challenge this posed for the work they did was reflected in the way another geneticist commented on the language a patient had used in responding to his assessment of her risk:

The patient in the Clinic is already on the NHS Screening Programme, having reached 50. The appointment proceeds with the geneticist reassuring the patient that she is at much less risk than she thought. Near the end of the appointment, the consultant asks her how she feels now that she has learnt that she is probably not at that high a risk, but is going to be receiving extra screening. 'Well' she says 'I suppose it's a bit of a concession'. Giving his own feelings away during the appointment, he says to the patient that he finds her choice of words 'interesting'. After she has left he makes no attempt to disguise his exasperation. Drawing attention to her use of language he points out how it confirms his feeling that the Clinic is being overwhelmed, inappropriately, by unnecessarily anxious and demanding patients.

Others spoke more generally about the demands that were placed on them by patients although given that these remarks were made in the context of a previous discussion concerning the 'hysteria' surrounding breast cancer, the two were clearly not unconnected.¹⁰⁴

Elizabeth/ Expectations are just so high now with patients it's difficult to know if you can do anything right. What's wrong with rationing? We've always had rationing. I mean people have always died. They've had treatment and maybe it didn't work but the expectation now is for it to work, whatever. I mean people think it's a shop that you can come and buy or choose from, but the NHS is not a shop, it's a service run by government.

These comments draw attention to the difficulties that practitioners in Hospital Y experienced in dealing with patients concerned about their risk of breast cancer who expected much more than the Clinic could technically and economically provide.¹⁰⁵ The pressure of such expectations emerged in one particular

¹⁰⁴ Those in Hospital X were aware of this pressure but presented it slightly differently, as one member of the team pointed out.

Jane/ I think a lot of the people coming in are what I would call 'control type' characters wanting testing and things. They feel that they want to know these answers and its getting that message over to them that we haven't got clear cut answers that I find quite difficult

The main focus was not on the problems of knowledge itself or even a broader issue of 'consumer demand' in health care but the 'psychological' propensity of some individuals to control their health.

¹⁰⁵ This stance also had consequences for the way they dealt with discharging patients particularly those that were older where there seemed to be a more straightforward approach toward letting patients go that contrasted with the somewhat agonising experience of those in Hospital X. As one geneticist said 'there really aren't the resources there to deal with these kind of patients and you can't be soft and give in and then start giving them screening because then they start worrying unnecessarily so then its not fair on them either'.

appointment which elicited a fairly qualified public and private assessment of the kind of expertise that could be provided in these situations.

Peter is seeing a female patient in the Cancer Genetic Clinic. After going through the family tree, he tells her that she is not at greatly increased risk because the breast cancers are on different branches of the family. The woman seems relieved adding that 'coming here had made me feel like the sword of Damocles was hanging over my head'. After the woman has left Peter seems agitated by the woman's use of language and the kind of scenario she had anticipated.

Peter/I can't understand why people use that expression. I don't think people really know what it means when they use it. I mean do you know what it means?

Sahra/I'm not sure, does it mean your fate is sealed?

Peter/ There you are you see, you got it wrong as well. It actually means your fate hangs in the balance, things aren't decided either way in terms of your life and death. It's just so ridiculous to use that to describe coming here. It's as if we are deciding the fates of these people. It's as if I was a heart surgeon or could tell if someone is going to live or die, which I can't of course.

At the same time as the geneticists remarks at the end of this appointment reflected his frustration at having to deal with so many expectant and demanding patients, it also drew attention to what he saw as an overly prescriptive assessment of what geneticists did or could do.¹⁰⁶ Although the fieldwork that I carried out in the general hospital was not extensive, the sense of ambivalence expressed by geneticists about working in the context of BRCA genetics is clearly palpable in the examples discussed above. Yet openness about this hesitancy was not confined to just the doubt about the limited scope of expertise, but also included a sense of unease about what these limits meant for the work 'care' required of them, as well as patients.

5.2.2 Refusing 'care' (and knowledge) as counselling.

A reluctance to embrace the kind of pastoral practices that at least some of those in the Hospital X saw as a central feature of their work was evident during clinical appointments that I sat in on with these geneticists. One indication of this was the way that appointments tended to be generally shorter here and

¹⁰⁶ This was something that may have not only been linked to the limits to knowledge in relation to breast cancer but the way that geneticists were perceived more generally. For instance one clinician pointed out how she felt 'geneticists often have a bad press from other professions'. She explained how she knew one GP who had refused to refer a patient on to a geneticist because 'he thought that all geneticists do is stop people having babies'.

involved less time attending to 'family dynamics'. A more explicit sense of this disinclination to embrace the role of 'pastoral keepers' and all that this entailed was illustrated in the comments one geneticist made after an uncharacteristically 'counselling' like appointment.¹⁰⁷

Before the woman, who is in her late 40's has arrived, the geneticist points out to me that the referral letter had implied she was particularly 'anxious'. The consultation seems, for the most part, to be fairly routine. This included mapping the family history, establishing that there is a moderately increased risk of there being a gene in the family and finally indicating who is eligible for screening. Having completed this assessment, Peter begins somewhat unusually to ask questions about the family.¹⁰⁸ A difficult family situation gradually begins to trickle out into the space of the consultation following several fairly probing questions. The woman reveals that she has recently nursed her father through his last dying months from cancer and is now looking after her sister who has been recently diagnosed with breast cancer. Further questions and discussion prompted by the geneticist show that these experiences appear to be the source of the woman's 'anxiety'.

After the woman has gone, Peter reflects on this encounter. He seems initially pleased and excited to have picked up the woman's underlying anxiety, 'there was certainly more going on there than I thought.' I say I am surprised at the way he pursued this with the patient. This prompts more discussion about whether he should be 'counselling' patients.

Peter/ is that the role we should be taking here? I mean it's a can of worms this work, it's raised all those issues for that woman and I just wonder if that's what we should be doing. I don't know if it's our role to do counselling. I know some people think it is.

Sahra/ Do you think it is?

Peter/ No I don't think so ..I think it should just be information giving myself

Peter's response in this situation indicated the extent to which he felt the emphasis in the clinics should be on straightforwardly outlining current knowledge, providing information and screening. As such there seemed to be less attention paid to the difficulties patients encountered when contacting

¹⁰⁷ In both Cancer Genetic Clinics there were no non-medically trained counsellors. There were genetic counsellors in hospital Y. These were long standing members of the genetics unit, however they didn't work with the cancer genetic team but worked alongside the geneticists when dealing with other conditions such as families with Huntingdon's disease. There was however a nurse specialist who worked in hospital Y who had a role similar to Jane's in Hospital X, whose experiences and reflections I don't include here.

¹⁰⁸ I sensed that this may have been more for my benefit and perhaps in an effort to demonstrate how he could address this area if required to do so. This seemed to be confirmed in the fact that Peter also picked up at the start of the appointment the fact that woman had written 'Indian' on the family history form. He asks the woman for some clarification about what she means when she writes 'Indian'. Again this somewhat unusual way of beginning the consultation may have been a demonstration on the geneticists part of how socially 'aware' he could be.

relatives for information or in order to pursue a procedure such as genetic testing. When this created an impasse in the ability to provide care or further knowledge, this consequently could be experienced as deeply dissatisfying for all concerned. A sense of frustration about having to deal with 'families' was openly expressed by several members of the clinical team. For instance, during a discussion I had with a geneticist and a nurse specialist one afternoon, a senior geneticist talked about some of the difficulties she had confronted earlier in the day in facilitating 'care' for other members of a family.

I had a situation this morning in fact where it was possible to do a genetic test for the family for colon cancer actually. It just seemed so logical in this situation, because if you have a mutation then you can have regular screening and if you have routine screening to see if you develop a polyp then this can be treated. Anyway I explained all this and then said to the patient do you think your brother would like to be told about the possibility of having this screening and he just said 'no I don't think so'. So then I said well what about your cousin, 'no I don't think I'll contact her', it's just so difficult that you can't do anything to change that, can you? ¹⁰⁹

One of the most direct indications of the sense of reluctance and unease those working in Hospital Y felt about having to pursue knowledge and care in a way that relied on the social dynamics of the family, was in the policy changes they discussed concerning the referral guidelines. A number of members of staff had mentioned, in passing, how they felt the 'ethical' challenges this work posed could be reduced by radically altering referral protocols and current guidelines. One geneticist said 'we should be starting with the affected people first (those with breast cancer) before we even see others in the family and then when we find a mutation we can offer testing to other family members'. In the changes some of those working in Hospital Y proposed, the families and relations of an affected individual would only be seen in the Cancer Genetic Clinic if and when a mutation had been identified in the family. Risk would then be *known* rather than probable, and interventions could be appropriately offered to related others. The situation they currently found themselves in, where 'concerned' relatives of those with or who had had breast cancer requested a referral, could necessitate much difficult and time consuming 'counselling' work with a family. This could happen long before knowing if

¹⁰⁹ However she does go on to say that she understands the ambivalence many have around contacting relatives in relation to genetic testing and breast cancer, pointing out that in this case the 'choices are that much more difficult'.

genetic testing was possible (or desired by others in the family), let alone whether a mutation had been found.

One particularly clinical encounter in Hospital Y, and the geneticists response to this situation, seemed to bring home why such changes might be so strongly felt by this group of practitioners.

The three members of the family that arrive for their appointment with Elizabeth come into the consulting room. This includes an older woman in her fifties, her daughter and a young child in a pram. They all sit in front of the large desk behind which the geneticist, after introducing herself, then sits.

The geneticist had already filled me in a little on the background before they arrived explaining that one of the other younger daughters had recently been diagnosed with breast cancer in her late 20's, but at the moment her tumour was not responding to treatment. However, the situation had clearly worsened. This was evident not only from the subdued way that the mother responded to Elizabeth's questions, but also from what her more talkative, yet seemingly numb, other daughter said. She explained how the family had, a few days ago, been told that 'it's gone to her liver' and that she now had 'tumours everywhere'.

Elizabeth seems slightly shocked but responds, not by openly engaging the family in discussion about how they are coping, but by adopting a very straightforward matter of fact approach to the consultation and outlining what action they need to take. As the discussion unfolds it becomes apparent that they are here mostly at the instigation of their dying young relative who wanted them to do something about what she perceived as the risk to the family. After setting up some more frequent screening for the mother, whom Elizabeth suggests is most at risk, and examining her privately in the room that lies off to the side of the consulting room the appointment concludes with plans to arrange for the woman's very sick daughter to give blood for genetic testing in the next few days.

After they have gone, despite the down to earth approach adopted by Elizabeth during the consultation she seems to want to reflect on the encounter. In fact from what she says and does, it seemed that she found it a particularly difficult meeting. Talking about how upset the mother was in the examination room she says

She just wanted to die really and seemed to be bursting with guilt about it all. I can't imagine having a daughter going through this really. It is just so terrible the situation they are in and now they might have to deal with the implications of genetic testing too. I don't know why they were sent here now of all times.

At this point Elizabeth decides she needed to take a break and goes off alone to make a cup of tea obviously still, it seemed to me, disturbed by the whole encounter.

The appointment illustrated exactly the kind of dilemmas this group of geneticists openly drew attention to and which the policy changes they discussed

sought to avert; that is the 'ethical' challenges of dealing with the social dynamics of the family in the context of limited and uncertain knowledge. In this instance although the geneticist acknowledged that the family's visit to the Clinic may have been some comfort to the woman who was dying, she was also acutely aware that that there was no guarantee that the repercussions of the appointment, i.e. taking blood for genetic testing, would generate useful knowledge or ease the trauma for others in the family.

The geneticists in Hospital Y appeared to have no problem in openly articulating their sense of ambivalence about current genetic knowledge in relation to breast cancer. For them, this was compounded by the unrealistic demands placed on them from an expectant and demanding group of patients. There also seemed to be a deep reluctance to embrace the kind of 'care work' that genetic knowledge required of them. Their responses can, in part, be understood in terms of the fact that they worked within a regional genetics centre where hereditary breast cancer is one among other genetic conditions. As such, they are not necessarily totally defined by the uneasy entailments of BRCA genes in the same way as those in Hospital X were.

5.3 Conclusion

This chapter has explored the experiences of those who work with BRCA genetics in two Cancer Genetic Clinics. We have seen how the medical practices required and entailed by this knowledge have ramifications for these individuals as well. There are clearly differences, however, in the way that those in Hospitals X and Y identify with predictive practices, articulate their ambivalence and embrace or reject the pastoral modes required by new genetic knowledge of breast cancer. These differences suggest that the knowledges and technologies associated with BRCA genetics have differing implications for health care practitioners, depending on the historical and institutional context of their use and development. As Moll points out, new technologies 'have to make room in already full worlds' (2000).

The most striking indication of this difference is the way in which practitioners respond to the need to attend to the 'social' context of the family which, as I have shown, is a pre-requisite for knowledge, prediction and, in some cases, care. Some of those in Hospital X seem to embrace this new role as 'pastoral keepers' in a way that defines dealing with the family in terms of 'holism'. However, this 'nostalgic' yet powerful representation of their work has to confront the 'always present effect' (Strathern 1995) of family relations - something which all working in both hospitals acknowledged as challenging and frustrating in some way. The distance between knowledge and care may be particularly 'purgatorial' for those in Hospital X who are caught between a need to provide benevolent 'care' and a demand for expertise. These expectations are informed both by their specialist location and the way an ethic of gendered 'rights' is embedded in the history and ethos of the unit in which they work and the values which many who work there share. Like the GP's in Singleton and Michael's study of the development of the UK cervical screening programme, they stand in position of 'enrolment' and 'betrayal' (1993), acutely aware of the paradox of health awareness in breast cancer genetics.

Those who work in the emerging field of clinical cancer genetics are clearly deeply conscious of and reflective about the uncertainties of genetic risk information and the limits on their ability to act as health 'care' practitioners. The ways that these practitioners experience working with predictive medicine within their 'lifeworld' raises questions about the utility of a normative lay/professional distinction, if this equates their experiences in terms of narrative of rationality. Although this might be one feature of their work at the clinical interface, this chapter has drawn attention to the need to contextualise such practices. Examining how professionals are caught up in the transmission of new knowledge of breast cancer genes and the evolution of predictive health care has shown how their experiences can be as diverse and disjunctured as the patients who are 'subject' to such developments.

Part Two

A Breast Cancer Research Charity

The second part of this thesis looks at BRCA genetics in the context of a Breast Cancer Research Charity, named here Charity H.

In the UK, in contrast say to the US, charities are one of the major sources of funding for cancer research, alongside pharmaceuticals. There is a degree of government funded cancer research, however the charitable sector is by far the largest financial supporter of such research. Walker also notes that the government cut backs on funding for scientific research, including cancer research, since the 1980's has forced agencies and charities into large partnerships with industry (2000). He points out that these arrangements are not always made known to a wider public who support research 'charities'. This funding situation has a significant effect on the co-ordination of cancer research which, in this country, is dominated by 3 major charities (although there are also over 600 smaller cancer research charities). The organisation where I worked is closer in terms of its profile and size to the upper end of this scale, but unlike these three very large general charities, is a single disease focused organisation looking only at breast cancer.

Charity H was, in part, set up in 1991 with this goal in mind and in response to what was seen as lack of focused research on breast cancer. The founder of the Charity was an American man who lost his wife to breast cancer. He and his family decided to set up, in her memory, a charity with the aim of building the first research centre dedicated solely to breast cancer. They succeeded in recruiting others who had gone through similar experiences, as well as key members of the research community in the UK and other corporate financial backers. This has gradually expanded to become a national organisation with numerous fundraising branches across the country. Although the Charity is partnered with another large general cancer charity, its identity as 'a grass roots'

organisation focusing on breast cancer is unique in the field of cancer research in the UK.

The success of the organisation is a product of and testament to the way breast cancer, under the aegis of a loose coalition of breast cancer organisations and charities, has become an issue of some import over the last decade. Although not quite so tightly aligned and organised as the co-ordinated breast cancer activism that has emerged in the US or Canada (Anglin 1997), (Kaufert 1998), a range of charities and organisations have emerged in the UK over the last ten years. Some of these cater to the varying and different needs of those with breast cancer, or their family and friends, while others focus on lobbying parliament on different issues related to breast cancer. All are active in raising awareness about breast cancer, embodied in the now annual national event, Breast Cancer Awareness Month. This event, started first in the US, has transposed easily to the UK and has been running here since the early 1990's. Potts notes, however, that this event is not just a product of grass roots activism, but also pharmaceutical involvement and sponsorship (2000).

Charity H is very much part of the heightened profile of breast cancer in the UK and has a unique space in it. This is not just because of its focus on research, as opposed to practical 'care' for those with breast cancer, but also because of the kind of research it funds. The target of raising 15 million pounds to build the first dedicated breast cancer research centre was fairly quickly met by supporters and sponsors. Although the centre opened in 1999, the Charity began funding research projects several years before this. This is ostensibly basic science research focusing on molecular genetics of breast cells and breast cancer. At the time of my research, there were a number different teams working in the research centre. More than half of those were focused on investigating the function of the BRCA genes. In fact several key members of the current research teams funded by the Charity were involved in the work that identified the BRCA 2 gene.

The Charity has succeeded, therefore, in setting up a research centre focusing on basic science research but with a something of an 'activist' identity. A model which is fairly unique in terms of cancer research in the UK. A measure of its

success is the way a number of other cancer research organisation focusing exclusively on men's cancers have recently been set up in the UK, which seem to be very much in the mould of Charity H.

Chapter Six

The alchemy of loss and hope.

There has been extensive analysis of the role of activist patient or consumer groups in relation to AIDS and HIV (Epstein 1996), but relatively little research looking at the role of lay or patient groups who 'fund' genetic research (Rabeharisoa and Callon 1998), (Rabinow 1999), (Stockdale 1999). This chapter explores how a group of 'lay' individuals classed as 'fundraisers' are involved in a breast cancer research Charity that supports basic science genetic research. We have already seen that patients attending Cancer Genetic Clinics must be understood as active agents in relation to the transmission of new genetic knowledge. The people examined in this chapter, in a rather different way, must also be seen as proactively involved in this process. Like patients, the agency of fundraisers is linked to the way breast cancer has become a high profile disease in the last 15 years, itself a product of a gendered health activism. One of the goals of the growing coalition of support groups and networks that has come to be known as the 'breast cancer lobby' has been funding for more breast cancer research (Anglin 1997). In this sense, the Charity must be seen as a product of such activism. In this chapter I explore the agency of fundraisers by drawing on anthropological work on memorials (Forty 1999) to look at how the identifications of these individuals are informed by, but also have implications for, the genetic focus of Charity H. The data presented here is based on research I carried out in relation to the 'advocacy' initiative (see page 29) and analysis of the Charity's publicity literature, particularly the newsletters for the many thousands of the Charity's supporters and fundraisers.¹¹⁰

6.1 Memorial practices

In a recent collection, Adrian Forty suggests that successful memorials and monuments always reproduce a tension between remembering and forgetting, which can entail a more or less explicit separation between these two elements. (1999). I examine here how these processes are at the centre of how a group of people who fundraise for a Breast Cancer Research Charity identify with the

organisation, their role in it and the work it funds, before examining in section 6.2 how this intersects with the genetic research focus of the organisation.

Talking to fundraisers about how they first become involved with the organisation, and what it was about it that motivated them to support it in its activities, begins to shed light on the nature of these ‘memorial’ practices

6.1.1 Remembering and witnessing

On first meeting fundraisers, one of my initial aims was to find out how they had become involved; to ask for ‘their story’. It quickly became apparent that this seemingly innocuous opening question was one that was loaded with significance and emotion. This was the way that Betty who was in her mid 50’s responded to my query.

Just over eight years ago my daughter died of breast cancer. She was 28 when she found out that she had got breast cancer and she died about 2 and half years later. I used to do a lot of reading to her when she was in hospital, and I happened to read about this new research centre that was only going to research into breast cancer, but we never spoke about it again. Unbeknown to me she made instructions that upon her death she didn’t want any funeral flowers, except from the family, but that donations should be to this new breast cancer research Charity that was about to be set up. So that’s how I became involved in it, when we first came up to the Charity with all the cheques from the flowers.

Another woman, Jan, who was in her mid 30’s, told me about how she had first started fundraising, a practice which she admitted had ‘completely taken over her life’ but which she ‘loved’.

It was my sister in law that introduced me to the Charity. She lived in Birmingham and sent me a Christmas card with their logo on it. She had had breast cancer and had a mastectomy in her 40’s. We went up to hers one Christmas. I said I loved the card and I said ‘what’s this organisation’ and she said ‘they’re a Charity and they do a £1000 challenge, why don’t you have a go?’ I felt a £1000 was a bit steep because at that time I was teaching full time and had two small kids. But she was very inspirational was Liane and she led me on. I went home and got my sisters and friends round with a bottle of wine. We said we would do a ball and would sink or swim on the first occasion. We organised the ball, that took about 10 months. That was my initiation ceremony. We raised £7000 first off and so exceeded all our expectations. After that Liane died. The ball was in October and Liane died in the February. She was only 44. Going to her funeral and seeing her daughters so devastated had a profound effect. I didn’t do anything more for a while and then we moved house and I found some letters from Liane. One was a lovely thank you after the ball and saying that it may be too late for her but for her daughters sake please keep fighting because research is the only way forward.

¹¹⁰ It is also available to a larger public either on the internet or in other places where public information about breast cancer is accessible

Both these narratives, which were not untypical, suggest that remembering relatives and loved ones was at the root of an identification with the Charity. In fact market research carried out by the organisation in 1998 showed that more than two thirds of fundraisers had *not* had breast cancer themselves. However 9 in 10 had some 'personal connection' with those who had developed the disease. This research and other anecdotal evidence suggested that many fundraisers had a relative or someone close to them who had or had died from breast cancer. For them the Charity provided an opportunity to do something in memory of these persons.

One of the ways that remembrance could be given a permanent expression in the context of the Charity's work was the opportunity for those who raised a £1000 or over to have a 'name' displayed on a dedicated space within the organisation's recently built research centre, known as the 'Challenger's Wall'.¹¹¹ Although this name could be their own, given the demographic constitution of the Charity it was equally likely that the name chosen was of the person who was being remembered in the act of fundraising. One woman, a co-ordinator for a group of fundraisers in Lancashire, pointed out that the motivation for fundraising was, for many, what she termed 'a remembering or a remembrance'. This was she said linked to the possibility of having a 'name' written on the 'challengers wall':

I think when people have said you know you can have a 'memorial' at the centre then they seem more interested, because then they feel it's tangible to them.

Another fundraiser told me that her original motivation for coming to see the research centre was, as she put it, 'to see the names on the wall'. In fact this six foot plaque is strikingly noticeable at the entrance to the organisation's research centre. This is not only because of its mirror like glass appearance, but also because in contrast to other visual displays, it is densely scripted with small writing. Closer inspection reveals that there are in fact thousands of names listed. When fundraisers came to visit the centre, they would often initially gravitate to the wall, picking out the names that they recognised and hovering there for some

¹¹¹ It's difficult to know what the exact model is for this kind memorial. Of course it may have precedents in the acts of remembrance that have arisen out of AIDS activism also, such as the making of 'quilts' (Epstein 1996)

time. Sometimes they stood there in silence in a way that indicated they were physically moved, clasping the hands of friends or relatives who had come with them. During official visits to the research centre by fundraisers, the story would also be told of the Charity's founder; an act of re-telling that implicitly acknowledged the multitude of other personal experiences of trauma and loss silently embodied on the challenger's wall.



Figure seven: *The 'Challengers' Wall'*

However, the names on the wall are not just of those who may have had or died from breast cancer. They also include the names of young children of both those who have had the disease or their relatives. This suggests that it is not just remembrance or the witnessing of loss that provides the motivation to fundraise for many, but the need for a more hopeful future.

6.1.2 Being 'positive' for the future

These other reasons for fundraising were illustrated in the way a group in the Midlands introduced themselves and talked about how they had initially got involved in the organisation at the start of one of the focus groups undertaken as part of my research.

Person A/ well it's about investing in all our futures and as far as I see it the best investment plan there is

Person B/ I had breast cancer when I was 29 and then did the £1000 challenge after that. I've got two daughters as well and really want everything to be better for them

Person C/ My mum died of breast cancer and I have a daughter and granddaughter to think of.

The sense of working towards a better future for themselves and a younger generation was also illustrated in a way that one woman talked enthusiastically about how she had got involved with the Charity and the activities she was now immersed in.

Jackie / It was 1992 when I got involved. It was something positive coming out of it all, I think many people got started that way. We've had some quite large events like a ball and Faberge lunch and dinner and my school that I teach in has been continually supportive. Most years we do a marathon or a ladies walk and then we try to do a dinner, so one or two big events a year.¹¹²

Not insignificantly, Jackie's reference to the fact that she had had cancer was somewhat implicit in this account. She made a passing reference to this before launching into a description of the activities and community which had now become part of her life. It was only later in my discussion with her that she talked about this experience more explicitly.

I find since I've had breast cancer, the Charity has been fantastic, because it's been a focus and a way of keeping going and looking to the future

Like Jackie, others suggested that the work the Charity did was a way of looking beyond the experience of breast cancer. This was articulated more clearly in what another fundraiser said.

¹¹² Jackie pointed out that it was this orientation to the future which marked Charity H out from other organisations and made it particularly appealing to her and others.

It's strange, I feel now as though I haven't had it. I've had the all clear and I think more about what I'm doing now than the past. You know, you put it to the back of your mind and now the Charity has become a way of life too.

Mildred, who was in her late 50's, clearly did not feel the need to dwell on her own experience of breast cancer. By contrast, she seemed entirely comfortable talking openly about the fact that her niece had had breast cancer at 35.

Moreover she concluded our meeting by saying that her work was 'for the children; everybody's daughter and occasional son'. This forward looking dimension that focused on a younger generation implies, at least for some of those who have had breast cancer, a kind of 'forgetting', but it is also obviously a way of moving on from the trauma and tragedy of the disease.¹¹³

The interface between 'remembering' and 'forgetting' which is part of a process of memorialisation was also reflected in the way 'testimony' was published in the Charity's newsletter. The experience of fundraisers was a regular feature of the monthly newsletter produced by the Charity. Entitled 'My Story', it provided an opportunity to document how individuals had got involved in the organisation. When the experience being recounted was that of a relative or relatives of a person who had died of breast cancer, such narratives created a space for the witnessing of loss which could be shared amongst others with similar experiences. However, these published narratives were not only symbolic acts of remembrance, but were also nearly always overlaid with a sense of 'positive' hope.

This was illustrated in one particular personal story, renamed for the edition of a newsletter as 'our story'. The article recounted the experience of a group of sisters who had lost another sister to breast cancer. Their involvement began when the sister, who had been diagnosed with breast cancer, told the others that she wanted to support the Charity because it offered 'hope for the future'. The article recounts how after fundraising through concerts and football matches and raising over £12,000 'in memory of their sister Barbara' who died at the age of 32, the three

¹¹³ This was also apparent at the start of the tours. Although many fundraisers shared the experiences of having lost relatives to breast cancer or the even having had breast cancer, experiences which were the source for the memorial intentions of their activities, this never appeared to be a time for the verbal sharing

sisters visited the research centre and the Challenger's Wall. The article concludes by saying;

The sisters have 9 names on the challenger's wall, those of Barbara, her three children, her parents and three nieces. [...] all their fundraising is in her memory- they know it's what Barbara would have wanted[.] the family intends to carry on fundraising for Charity in the hope that Barbara's children will grow up in a world where breast cancer is no longer something to fear.

A sense of investment was also evident when it was the experience of those who had had breast cancer that was being told in the newsletter. One story recounts the experience of an older fundraiser who had been raising money for the Charity since in 1991, the same year that she had been diagnosed with breast cancer. This published narrative, mostly in the third person, does not dwell on her experience of that illness or her subsequent mastectomy, but on the work she undertakes to raise money for the Charity, selling knitted toys. It concludes by saying that her 'main motivation for supporting the Charity is wanting a cure for breast cancer for the future of her daughters and granddaughters'. When the focus was on those with or recovering from breast cancer, the emphasis in these publicised narratives seemed to be on what they had achieved since being diagnosed, such as the story of one woman's dream to complete the London Marathon.¹¹⁴

The importance of these published testimonies to those who fundraised for the organisation was demonstrated in the way one group of women in the Midlands talked about how much they enjoyed the personal narratives in the 'my story' section of the Charity's monthly newsletter.

Person1/This last month's one with the personal stories is particularly good.

Person 2/This gentleman who had lost his wife to breast cancer and he and his little girl really took it on. Then his little girl was killed. But he is still supporting the Charity though

Person 1/Yeah, and the one before when there were the three sisters and one had died and the other three kept raising the money.

Person3/Those are the kind of stories that are great for [Charity H] but they are also the sort of ones that we want to see in Woman magazine and Cosmopolitan...
(Lots of agreement from others in the group)

of such experiences. Humorous or impressive stories of fundraising activities were commonly shared, but personal testimony of trauma and loss was mostly silently witnessed

¹¹⁴ Each edition of the newsletter also comprises a two page 'diary' listing and describing, with numerous photographs, various fundraising events that have taken place across the country. This reinforces the importance of fundraiser's personal achievements in raising funds for the charity.

These remarks highlight the importance for 'fundraisers' of hearing and reading about the ways in which people like themselves, who had experienced tragedy as a result of breast cancer had, through involvement in the Charity, transformed this into something much more positive. They also clearly felt that it was necessary to counteract what they saw as 'negative' coverage of breast cancer reflected in the way that testimony was represented and reproduced in the newsletter.¹¹⁵ One woman's reference particularly to 'Womens' magazines' draws attention to another element of these testimonies that seems to be central to the identity of the Charity as a whole and its forward looking ethos.

I have already suggested that a notion of 'awareness' has been at the forefront of 'feminist' health activism in relation to breast cancer, contributing to the heightened profile of the disease over the last 15 years. A gendered ethos about health was certainly an element in the way the Charity had succeeded in mobilising support for a Research Charity focused exclusively on breast cancer. This was reflected in the demographic constitution of the organisation. Although, many other charitable organisations are predominantly supported by women market research suggested that this was even more marked in this case.¹¹⁶ More importantly, gender provided an ongoing rallying point for articulating the values and identity of the Charity. For instance, published excerpts from the newsletter pointed out how 'breast cancer is the scourge of women everywhere' and how the opening of the new research centre would be 'something that will prevent women having to face the indignity of breast cancer'. However it is not just that 'women' were represented as cohesive and unified in the fight against breast cancer, but that

¹¹⁵ This need for positive representations of breast cancer in a broader public domain was also reflected in another discussion with a different fundraising group. They talked about a recent story in the long running Radio 4 drama 'The Archer's', where one of the younger women had recently been diagnosed with breast cancer.

Person1/Has anybody been listening to the Archers about ? She's a young women and so of course it could be worse for her. But I'm worried what's going to happen. If she recovers then people will sit back and think oh its just breast cancer, but if she dies then its really going to upset people.

Person2/I actually wrote to them and said she shouldn't die of breast cancer. People with breast cancer get such a negative press.

Person3/The press always talk about the dark side of it

Person 1/But it worried me when she got breast cancer on The Archers because I thought oh are they going to do away with her

particular images of women and female bodies are given a high profile in the literature of the Charity than others. As the examples below demonstrate, these are representations which reflect the complex and contradictory meanings of the breast and breast cancer (Yalom 1998)(see also Yadlon 1997).

The importance of an image of 'natural' female nurturance was illustrated in a campaign insert in the middle of one of the newsletters in 2001. On one side is an advert for ways of leaving a legacy for the Charity in a will. The image shows an older woman's hand holding a small baby's hand and is accompanied by the following text; 'the most precious thing I can leave my granddaughter is the hope of a cure for breast cancer'. On the other side of the advert is information for participating in a 'crocus walk', an annual national fundraising event for the Charity. This is joined by the logo of the Charity, an iconic image of a crocus, alongside the following text; 'mothers day is a celebration of the lives of the women who are closest to us, and an opportunity to remember those who have lost their lives to breast cancer'.

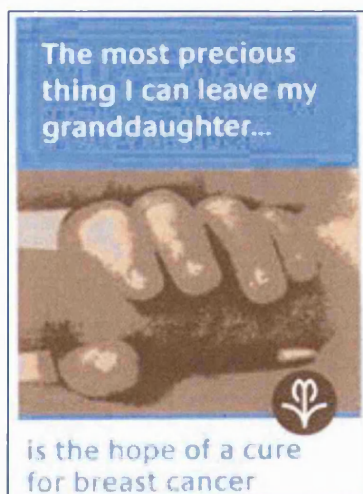


Figure eight: *Campaigning image.*

The leaflet highlights a certain representation of female gender which draws its force from the way women are perceived as inherently and almost 'naturally' relational; both nurturer and nurtured. We have already seen how this is a strong element of published testimony, and the way those who fundraise for the Charity talk about their involvement. That is in terms of a remembrance of those who

¹¹⁶ Market research, carried out by the organisation a few years ago, suggested that the supporter base is extremely female; comprising over 90% of all supporters. Almost half are 45 or under.

have died, often mothers or sisters, or for the future, frequently seen in terms of daughters or granddaughters. It is an image of gender identity that clearly draws and informs the morality of breast cancer as a predominantly female disease, which can and does tragically negate the ability to continue to nurture or be nurtured as it blights women's lives and those around them. But, as Ginsburg has shown in relation to the fiercely contested issue about abortion in America, nurturance is a powerful image of female gender identity, which helps to 'naturalize' particular positions (1987).¹¹⁷ Saywell, in her analysis of breast cancer narratives in the media, also notes how these are dominated by notions of 'nurturance' and 'motherhood'; the latter couched in terms of 'martyrdom' or 'self-sacrifice'. As a result, she says, 'feminine worth is pre-ordained and what is at stake fits neatly into a moral order' (1999: 49) (see also Seale 2002).

However, there is another important facet of the way women are represented in the publicity literature of the organisation which intersects more directly with a 'positive' forward-looking ethos. The Charity is continually involved in so called 'celebrity' events and receives support from public figures in particular national campaigns involving the fashion industry. This not only enables them to maintain a high profile in the public domain, but also means that many of the images used in the publicity literature are of well known figures from the world of television and fashion, particularly models. This use of a certain standard 'normalised' even 'glamorised' bodies in the marketing of different products highlights a particular representation of women as 'healthy, young and beautiful'. This can be understood as a part of a broader marketing strategy, as Saywell says, breast cancer is a 'sexualised' illness where the 'sexiness of the breast is used to sell breast cancer' (1999:39).¹¹⁸ Clearly the use of these images is complex and not reducible to one meaning, however this image of glamorised normality or

¹¹⁷ One staff members comments seemed to reinforce the view that it was this particular image of female gender identity, which pre-dominated in the Charity and which provided some of the motivation for fundraisers.

Vicky/ I think there is something about breast cancer that makes it a really devastating disease. Not that other cancers are any less devastating. I just really think it seems to strike families really hard, whether it's mother or not I don't know .

¹¹⁸ This practice has however been somewhat controversial as one commentary in a national newspaper about the Charity's attempts to make breast cancer 'sexy' suggested. It stands in contrast to the way other more radical breast cancer activist groups, particularly in America, have campaigned to make images of a 'breast cancer body' more visible (Cartwright 1998).

'perfection' can also be linked to a more optimistic vision of the future; a vision which is central to many fundraisers' involvement in the organisation and their hopes for 'daughters and granddaughters' .

I conclude this section by examining a high profile narrative which featured in a one-off publication by the Charity during Breast Cancer Awareness Month in 1999. It seemed to powerfully reflect, as well as inform, how fundraising was part of a memorialising process. The story of Ruth Picardie, a young woman in her early 30's whose experience of breast cancer was recounted in diary form for over a year in a weekly national newspaper column until her death in 1997, would have been familiar to many fundraisers. The article in the Charity's publication was written by her sister. It first recounts the experience of Ruth's illness and then her own and others' sense of grief and desolation following her death. The excerpt below talks about how she became involved in the Charity's work:

Now two and half years after her death, that cancer colonised world no longer seems quite such a blighted place. It's not that time heals all, the wound of Ruth's death will never disappear, but I have slowly become aware of not simply of a community of shared grief, but also of shared compassion, even hope. The work of Charity H is, for me and others, both an emblem of these emotions and a very practical demonstration of the power of positive thinking. [...]

The kind of positive thinking embodied in [the Charity..] has its roots in the experience of FG¹¹⁹, whose wife, a talented and vivacious actress died of breast cancer in 1986. FG like so many others before him grieved and suffered and struggled with his own life after death. But he also did something very remarkable; along with this oldest son, he decided to raise enough money to fund a new centre for breast cancer research[...].The money came from a huge variety of sources; from FG's own pocket, initially and his family and friends and then from different donors and thousands of individuals have all pledged to raise £1,000 or more.

This narrative shows then how the Charity's work has become a source of strength for a 'community' of people affected by breast cancer, illustrated in the way the experiences and hopes of the founder of the Charity are recalled and linked to the stories of others. More importantly, through its focus on research, it provides a sense of positive hope in the face of apparently meaningless tragedy.

Kaufert points out that the use of testimony and narrative which was so much a part of female identity politics in the late 1970's and 1980's was consequently

easily adopted, in subsequent years, as a tool of shared identification and awareness raising by breast cancer activist groups (1998). The range of testimonies explored here, both published and personal, show how it is also an important tool for making fundraising part of a memorialising process. Examining the growing cultural visibility of testimony in Euro-American societies, a recent collection explores how such narratives are often a way 'out' of, rather than simply a way of recounting traumatic or tragic experiences (Ahmed & Stacey 2001). As Phelan says, 'testimony as something made from the echoing vibrations of loss, is distinct from the trauma itself' (2001: 27). This creative aspect of testimony is something that Caruth highlights. Drawing from Freud's work on mourning, she suggests that witnessing trauma is a 'repeated suffering of the event but is also a continual leaving of its site' (1995: 10) and as such constitutes an act of 'survival.' This analysis echoes in the way both the individuals I met told me their story and the way the organisation reproduces narratives in its publications, which collectively reinforce the Charity as a locus for a process of 'memorialisation.'

In this sense, 'positively' focused individual or published testimony is not so much about a process of 'forgetting', but rather contributes to a process of 'transcendence'. That is, involvement in the Charity seems to provide a way of acknowledging grief, loss or tragedy but is also a way of moving on from it by focusing on the future, a younger generation or life 'after' breast cancer. As an editorial in the newsletter said the Charity is about 'turning the devastation caused by breast cancer into hope for the future'. This could be seen to parallel the way that Rowlands sees war memorials providing a way out of 'melancholia' for the living (1999). He points out that what all war memorials share in working to resolve the suffering for survivors is an attempt to ameliorate a sense of negativity or powerlessness, through a collective validation of a higher positive ideal. One of functions that memorials 'for the living' must satisfy is, he says, 'the transformation of a sense of trauma and loss into an object of passion and devotion' (1999:144). I explore in the next section how the alchemy of loss and hope embedded in fundraising as a 'memorial practice' is informed by and links to the genetic research focus of the organisation in diverse ways.

¹¹⁹ These are the initials (based on a pseudonym) of the founder of the Charity.

6.2 Science and the fundraisers' quest

Many of those who raise money for the Charity had, not surprisingly, given the trajectory of their involvement, very strong feelings about the kind of 'knowledge' they hoped their activities would help fund. The genetic research focus of the Charity informed this in different ways at the same time that the fundraisers 'quest' had consequences for the requirements of gene research they helped fund.

6.2.1 The need for 'knowledge'

A demand for information about breast cancer and breast cancer research was evident in talking to a number of women, who described how they consulted numerous different resources in an effort to find out more. Jackie talked about how this need to know as much as possible developed after her own experience of breast cancer. It was a desire that seemed to be partly satisfied and perpetuated by her decision to get involved with the Charity, as she said; 'that's partly why I'm so interested in what they are doing'. Sometimes the need for information specifically about the research activities of the Charity was driven by a long standing investment, as Betty's response to my question indicated.

Sahra/ is it important for you to keep in touch with what's going on in terms of the research work of the Charity?

Betty/ oh definitely yes. Oh heavens yes. After being, shall I say, from when it didn't even have a name to now, then you must understand my very strong feelings about it. I mean eight and a half years is a hell of a long time to be on a Charity.

For most, however, it wasn't simply that fundraisers wanted information about the research being carried out by the organisation they supported, but evidence that 'knowledge' was being reproduced. This was reflected in the way one woman criticised the response she had received from a member of the Charity's staff on inquiring about how the money she and others had raised would be used.

Janet/ In the past I have phoned the Charity and they have said a computer! Quite honestly, that is not what they [the fundraisers] are looking for. If they are sitting alongside someone dying of breast cancer they do not want to hear that you're going to buy a computer

A desire for more than just 'information' was more explicitly articulated in the way fundraisers talked about the kind of research work the Charity should be supporting. This was brought sharply into focus in the context of one woman's response to the possibility, suggested by another participant in a focus group, that the Charity should look at inequities in the provision of treatment for breast cancer.

No, the Charity's work is to crack the disease. I wouldn't want them to do that and leave out other things that were vital. I think you can spread yourself too thinly.

Others I met concurred with this. One woman said that the Charity should be about, 'stopping it in the first place not messing around with treatment', while another added that it has got to continue to 'make sure that it keeps ahead of the field' and that they 'find a cure and what the cause is'. One particular event brought home the strength of many fundraiser's feelings about this; the Charity's annual rally for fundraisers in June 2000 when about 40 key supporters from across the UK came together for a few days.

The place for this event, a country house in the Midlands, seemed a suitably auspicious setting for a yearly rally. Here, people from different regional groups came to meet other fundraisers as well as the Charity's staff. It was also an opportunity for the organisation to thank fundraisers and give them renewed enthusiasm for future money generating ventures. Talking to several fundraisers informally in the evening before the day's main events highlighted the extent to which the research activities of Charity H were at the heart of their own identification and investment as fundraisers. As one woman said 'The research, well that's what we're all here for isn't it, and why we are doing what we are doing'.

The following morning events, began well enough. The head of the fundraising section in the Charity started the meeting by first recalling what had been achieved in the last year, namely the much awaited opening of the dedicated research centre. He nevertheless reminded participants that the next stage of the work of the Charity, maintaining the research at the centre, was likely to be 'hard work'. The rest of the day's activities focused first on the use of publicity to raise awareness which was followed by a somewhat less inspiring session concerning health and safety issues during fundraising events. After this

particularly downbeat workshop, what appeared to be required, at the end of the weekend, was a rallying and resounding endorsement about how the work they did to fundraise had and would continue to contribute to the research work of the centre.

The closing speech of the day, billed as the 'Past and Future of Breast Cancer Research', at the very least held out this promise. I recall in my fieldnotes the content of this talk from a member of the research services department in the Charity:

The talk starts with an explanation about how the Charity's research strategy is focusing on the 'causes' of breast cancer. The speaker (a member of the research services team) initially points out that historically what has been thought to cause breast cancer has changed dramatically. For the next 20 – 30 minutes he examines the different ways that this has been understood and the way that treatments have been linked to these changing beliefs and knowledge. He plots what seems like a linear historical trajectory. This includes earlier notions that breast cancer is caused by 'black bile in the body' which has to be 'purged', to the idea that breast cancer is a 'local disease' that has to be 'cut out'. At this point, he intersperses his talk with fairly graphic black and white drawings of 18th century practitioners undertaking mastectomies. He then moves onto more recent notions of breast cancer as a disease of cells that can be treated with chemicals or radiation, but is careful to point out the 'timelag' between knowing that radiotherapy could be an affective agent to developing a suitable means of administering this as treatment. Reaching the 1970's and the period of rapid generation of molecular knowledge, he explains how the focus is now towards the 'mechanism of the cells and genes'. But on reaching the end and apex of his presentation instead of expanding on the kind of results that such research will generate, he poses a more cautionary rhetorical question; 'does more research mean less breast cancer? Well not necessarily'. He adds that current knowledge about genes and breast cancer is 'not likely to impact on patients very much as yet.' It is only in the closing moments of his presentation that the work at the research centre is mentioned.

In the weeks and months following this event many of the fundraisers, who had been at this rally, felt the need to comment on this talk in my meetings with them where we discussed their hopes and expectations for the Charity's research. One woman who lived in Lancashire described how she and her friend had felt short-changed by this event.

Pat/ We would have liked a lot more about the research and what was going, not just say the health and safety aspects which we were all fully aware of! Yes we will raise your funds, yes I will go out to Lancaster every night of the week, yes have your 'jollies', yes I'll be part of that but if you want me to be committed to doing that, then educate me so that when I go out there I'm spreading the right message and the kind of message that then does you some good and that would give me the incentive to continue to fundraise

Another fundraiser was also led to reflect on the way the talk had been unsatisfactory for her and others who had attended the event;

Mildred/ The groups meeting..that was a little disappointing really, a bit breast cancer as it used to be. I wanted to know what was happening. One of my other ladies was disappointed as well. That was one of the main reasons why she went. She kept saying she must go and find out what's going on. But she came back a bit unhappy.

There was also another different dimension of the talk which some fundraisers had found more than just disappointing, as one person in a focus group in the midlands pointed out.

I didn't necessarily want to hear about history of surgery and left feeling a bit flat because we didn't hear what was going on now and the year before it had all been so enthusiastic. I thought it was a bit insensitive as well, all those mastectomies for any ladies that had had surgery recently

Although the intentions behind this speech might have been to draw a dramatic contrast between medical practices in the past and the precision of current research on genetics, for at least one fundraiser this imagery brought the reality of the disease flooding back. When part of the attraction of the Charity for many was precisely its forward positive looking ethos, which often provides a way out of the experience of breast cancer, the somewhat brutal images and descriptions of how mastectomies had been carried out in the past did little to facilitate this process. If the use of these images was difficult for some fundraisers it was in general the lack of upbeat information or discussion of the research work of the Charity that most found disappointing.

The fundraisers' responses to the rally illustrated not only a collective desire for 'knowledge' but the need for the research that they helped fund to be somewhat promissory. There was little talk of a 'cure' during this presentation of the work of the Charity; something that was clearly a central feature of the fundraising quest and many individual's memorialising activities. This desire for a particular kind of science intersected in diverse ways with the genetic research the Charity pursued.

6.2.2 The promise (and problems) of genetics.

For some a need for a particular kind of ‘promissory’ knowledge appeared to be met by simply knowing that genetic research was a central aspect of the science they helped fund. For instance the research supported by the Charity was frequently described by fundraisers as ‘very exciting’ and an ‘important way of looking at the causes of breast cancer’ and even something that was so otherworldly to be ‘almost beyond the reach of the normal lay person to understand.’

This sense of fulfilment and faith in genes was reflected in the way one woman talked about the causes of breast cancer and the kind of knowledge she hoped the Charity’s research work would generate.

Jackie / We don't really know what does cause it, do we? I don't think it's genetic in our family because we haven't got anyone else with breast cancer, but obviously things like the small percentage of family related, genetic breast cancers would be one of the known causes[...]. I would hope that by identifying a gene that would have some influence on the way breast cancer develops that we would be able to find some means of intervening, it might be a drug or a test or whatever. I would like to think that there would be some way of combating the defective gene. I just think that what they are doing is excellent. It was very exciting when the team identified the BRCA2 gene.

For Jackie although genes didn’t provide an obvious answer in understanding the breast cancers that had affected her family, she was still ‘excited’ by this research. She saw this as addressing one of the few ‘known’ causes which held out the hope of treatment intervention. For some fundraisers, the fact that there was a clinical application associated with the BRCA genes fuelled a sense of hope and faith in the research work of the organisation which many knew was focusing particularly on these genes. This was reflected in what one woman said during a focus group discussion when asked about the Charity’s research focus.

Do you think it will mean there could be a fairly simple blood test for one of my daughters that could say whether she will or she won't be at risk?

The way that the genetic research of the Charity could be associated with predictive testing and an identifiable clinical realm meant that, at least for some, the research could be readily linked to a notion of potential ‘care’ and hope for the younger generation. As Finch points out, social obligation within the family

is often seen as grounded in 'biology', especially that from parent to child 'where the offer of support is seen as part of human nature (1993: 36).

For other fundraisers it was precisely this association with the clinical application of BRCA genetics which caused them to express their concerns about the research work of the Charity. A sense of hesitancy was apparent in what one woman said:

Rita/ I know there is a big question mark over genetic research.[...] I know it opens up very difficult questions, you know, should the family then be tested for this gene. Then what do you do with the knowledge that you acquire. I know that in breast cancer this is causing a lot of problems at the moment.

For some the current clinical application of BRCA genetics raised many questions and potential anxieties. As one fundraiser talking about the predictive testing for the BRCA genes said; 'We haven't moved far enough to say what can be done once when we have identified the people at risk, all we have done is said we can identify them'.

At the same time that being able to link the genetic research of the organisation to a particular clinical application might be a source of investment and hope for some fundraisers, for others this association raised more difficult questions. One woman reflecting on this difference talked about how fundraisers might have divergent interests in or perceptions of the research work of the Charity.

Referring to those with breast cancer who became involved in the Charity she said;

Pat/ Obviously they want answers but for them the answers aren't too late. If they're cured they don't want any depth and if it's too late they don't want to know any more because it's not changing their outcome is it. If you're a woman of forty with breast cancer and you've got a child of eight you wouldn't really want to be going there either would you? It will be the families that might ask the questions, rather than the people that are sick.

For those fundraisers with breast cancer or recently recovered from the disease there were, as these comments suggest, specific concerns about genetic research. For instance, one woman talked about what she saw as the 'narrowness' of this research focus and the need to balance and expand the Charity's agenda for research. This fundraiser, in her late 40's, who had become very active in the

Charity, had not long finished her treatment for breast cancer.¹²⁰ I met her initially at the Fundraisers' Rally, where she made clear her wish to bring a treatment agenda to the fore in the work of the organisation. There she told me how she was very keen that the organisation address 'post-code prescribing' in relation to 'new cancer drugs', such as 'Taxol'. 'New drugs' she said, 'should also be a big issue for research'. But it was during an interview with her that this issue became more clearly defined.

Asking Janet the standard questions that I had asked others about how she perceived risk factors for breast cancer and what she knew about research demonstrated, like others, she had a strong demand for knowledge and was well informed about research. For her, this had led to a growing awareness of the work of breast cancer research charities more generally, which had precipitated a number of concerns about the Charity's genetic research.

It's something that never ceases to amaze me, how many small projects are going on. I would be very interested to know how if the Charity get involved with risk factors and that type of research. For example, I came into contact with a little charity which is entirely for action against secondary breast cancer and why some people survive after the initial treatment and some don't. Having had breast cancer myself, this is obviously something I am very interested in. I've been to two funerals last week of members of the fundraising groups, so it is really hard when you sit back and think why am I alive and she is not. Given that I would think a large proportion of Charity's supporters have either directly or indirectly been affected by breast cancer, it is very close to most people's heart. Obviously the gene research is going to take many years and it's comforting in the long-term that something is going to be done, but in the short-term there are research projects that, while I know they will take 4 or 5 years to complete, will come to fruition before the gene research results. The gene research is going at such a pace now but how many years nobody ever says do they, other than it is very long-term – that could be 3 years or 300!

Concerns about what seemed like a narrow focus on gene research were obviously particularly acute for those with breast cancer who were also sometimes, like Janet, very aware of the very long term nature of this work.¹²¹

Despite some sense of disquiet from some fundraisers, for the majority a sense of 'faith' in the research work of the Charity dominated in a way that appeared to

¹²⁰ It was perhaps significant that unlike others she did not seem adverse to talking openly about her experience of breast cancer. This may have been because, compared with others that I met, it had been a relatively recent experience.

override any anxiety about its genetic focus. This was reflected in the way some of those I met talked about how genetic research was an arena where lines could be drawn, as Mildred pointed out.

Mildred/ Things are a bit frightening when you think about it. But I think that people are always frightened by anything new aren't they. They feel they'd rather stick with the old and be safe, I don't like playing around with life either I think that all the publicity and press does frighten people, the cloning and that sort of thing, you know.

Sahra/ So do people say that about the research work of the Charity?

Mildred/ No, no not at all, people think that's very important

6.2.3 Criteria for 'research'

We can see that a widespread desire and demand for 'knowledge' is met, for the majority of fundraisers, through the gene research work of the Charity, which is widely perceived in terms of working towards a 'cure' for breast cancer.

Although some have concerns about the narrow specificity of the Charity's work, many clearly invest and perceive the 'science' the organisation funds within a domain of expertise and skilled practice, which is powerfully linked to a more hopeful future. Alongside this widespread enthusiasm and support about the research work of the organisation, there were a few more widespread concerns regarding scientific research more generally. One of the women I met talked about how fundraisers often quizzed her about this

Pat/ They want to know if a lot of people are working toward the same goal and who selects what is a good project to research. We need more information about this. It would be nice to know why that focus has been chosen, is it just because someone has got a superb interest in that? Or is it because that is where the answer probably lies?

Related concerns about the duplication of research, or how research was regulated, were also evident in the comments of another fundraiser:

Rita/ research can sometimes be a bit about empire building. We have discovered this and we aren't going to tell you. That isn't what research should be about. The only way to move things forward is for people to communicate and share projects so that millions of pounds are not wasted on exactly the same sort of research in different places.

¹²¹ Other fundraisers who were health care professionals talked about the need for research that was also more treatment focused.

Questions about the replication of research were therefore linked to the fear that scientists were driven by ‘individually’ orientated career motivation and not a more collective pursuit of knowledge, where information could be shared. Expressing her anxiety about how a wider public perceived breast cancer research, another fundraiser drew attention to an article in a magazine that seemed to confirm this widespread fear:

Janet/I got information sent from the Economist on breast cancer and they suggest that a lot of money is wasted and the scientists are there for their own benefit. It's all a load of tosh, but very frightening. This is the kind of thing that the Charity has to rise above as they have been doing for the last five years.

Although Janet didn't seem to believe the findings, she did point out how this was something the Charity must not be associated with. Fundraisers' anxieties about ‘competition’ were also apparent in the findings of a consultation exercise in which the Charity had participated. The organisation had been asked to consult supporters about the possibility of setting up a national co-ordinating body for cancer research in the UK. The concerns fundraisers voiced about competition pointed to their desire for such a national body, as some of those who responded to this consultation indicated. Others took a different stance, opposing the formation of a national body. Nevertheless, the reasons for doing so were identical to those who were in favour of this policy. For instance, one respondent had said that having a national co-ordinating body could make scientists ‘more competitive about their careers, rather than the pursuit of cures’. Different responses to this proposal were subsumed by similar concerns about competition.

These remarks and responses suggest that there is a widespread set of concerns among fundraisers about the detrimental effect of research that might be about the ‘careers of the few’, rather than pursued for the ‘good of all’. This may be the legacy of a high media profile given to genetic research, particularly the international ‘competition’ to sequence the human genome, during the time of my fieldwork. However this requirement for knowledge also reveals how the fundraisers' perceptions of the kind of research work the Charity *should* be doing is also connected to the way they participate in the organisation as part of a memorial practice. We can see that this makes the work of the Charity

incompatible with research that does not appear to be part of what might be seen as a 'redemptory' science.

6.3 Conclusion

I have suggested that a process of memorialisation is at the heart of how a group of individuals who fundraise for a Breast Cancer Research Charity identify with the organisation, their role in it and the work it funds. We have seen how fundraisers' involvement is linked both to a need to remember and witness the loss of loved ones or to acknowledge their own experience of breast cancer. At the same time, this involvement enables loss to be transformed into a more positive hope and faith in the future. These identifications are also furthered and perpetuated by the activities of the Charity in the way they make use of published testimony or a particular image of female gender identity. In fact, fundraising for a Breast Cancer Research Charity, as part of a memorial practice, can also not be abstracted from the wider processes which have led to breast cancer becoming a high profile disease; the activities explored in this chapter are both informed by and help to reproduce this 'breast cancer' agenda.

For many, the Charity's work looking at the causes of the disease provides a powerful image of a more hopeful future. It informs an expectation that this research will lead to not just 'information' but real 'knowledge' and a 'cure for cancer'. For some fundraisers genes are at forefront of this elusive quest. In this sense, the much hyped 'alchemy' of gene research links the transformation of personal lives with an expected transformation in the treatment of breast cancer. This is powerfully symbolised for many fundraisers in the way they talk about their experience of visiting the Charity's research centre for the first time and seeing 'the names' on the 'challengers' wall'. As Rowlands points out in his examination of the war memorials 'it is the remembering of names as real events that constitutes the 'sacrificial act'[of the living to the dead] compressing both the past and future into the present' (1999:144). This was conveyed in one woman's description of this moment which seemed to reflect something of these transformatory processes:

I was just so in awe of it, I couldn't take it in, it was so upsetting standing there in front of my mother's name and it just sort of really threw me.

For others, particularly those with breast cancer or those who had recently finished their treatment, genetic research is potentially more troubling in its apparent narrowness or lengthy timescale. These contradictory and potentially conflicting perceptions of the genetic research are embodied in the way genetic testing is seen by some fundraisers as holding out the hope that their children will be cared for in the future, while for others it suggests danger rather than care. Regardless of these differing views it is clear that the fundraisers' quest requires that the research they support is unsullied by competition or is somehow ego driven. The next two chapters show how this criterion for research is something that reverberates through the organisation with implications for the genetic research it funds.

Chapter Seven

Scientists and the making of ‘monuments’ for the living.

The role of scientists, from the analytic perspective of some in Science and Technology Studies has, as Traweek notes, been somewhat limited given the way there is a tendency to focus on ‘agonistic encounters’ or present the ‘self’ only in terms of ‘autonomy and initiative’ (cited in Martin 1998:28). Anthropological studies have done something to redress this (Traweek 1988). Nevertheless, the experience of scientists, who increasingly must communicate or work with publics, patient or lay groups beyond the confines of the laboratory, has only just begun to be explored (Heath 1997), (Rabinow 1999). This chapter offers one perspective on this process by exploring how scientists who work for a Breast Cancer Research Charity participate and are implicated in the transmission of genetic knowledge. Taking the monthly laboratory tours for fundraisers at the recently built research centre as a starting point, I explore how the genetic research undertaken by the Charity is represented and communicated during this event; a process which is nominally undertaken by the scientists. The second section of this chapter explores the consequences of this involvement for the scientists in more detail by examining how this group of people experience the communication of new genetic knowledge in the context of working for Charity H.

7.1 Laboratory Tours; the ‘enchantment’ of science

During the time of my research the ‘lab tours’ had recently become a regular event in the work of the Charity. They took place with a group of 15-20 fundraisers at the recently built centre each month and were normally carried out by one or two scientists who worked at the centre, with a few members of the Charity’s staff in attendance.

The setting that greets fundraisers when they arrive, normally early on a weekday morning, is an impressive one. An array of high tech publicity material on perspex panels cover the walls of entrance. Situated to the right of the reception desk in the centre of one of these publicity dense panels is what is known as ‘the

challenger's wall', which, as I have discussed in chapter 5, is a powerful emblem of the thousands of acts of remembrance which constitute the Charity. If remembering appears to be an important visual element at the entrance to the research centre, another temporality is suggested in the display of other images. Here, spanning the length of one side of the wall, approximately 10 metres, are photographic representations of the back or sides of a number of bodies (see Figure 6). A number are recognisably female and include both young and old, but they are not in any way visibly ill or 'cancerous'. More significantly they are mapped and criss-crossed with superimposed geometrical lines and computer generated patterns of DNA or chromosomal structures, along with attendant explanations. The visual meaning conveyed by such images is that science is or will uncover knowledge about the inner workings of the body.¹²²



¹²² Given that the Charity's research centre is linked to a larger more general cancer research establishment the source of funds for such images could have come from here also or the involvement of other corporate sponsors.

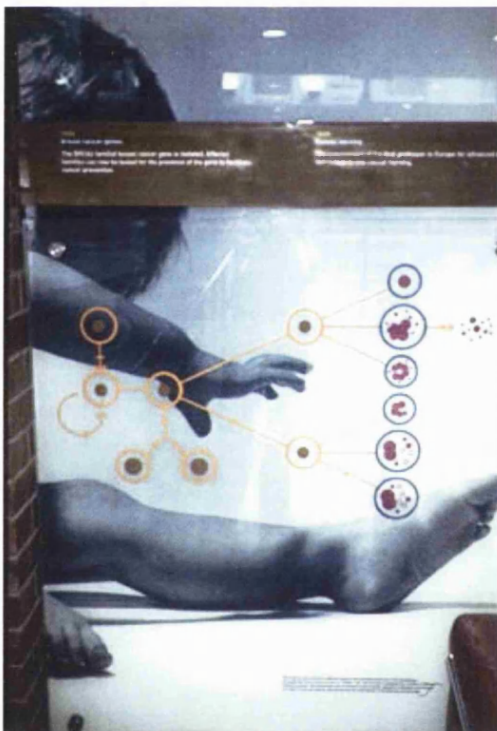
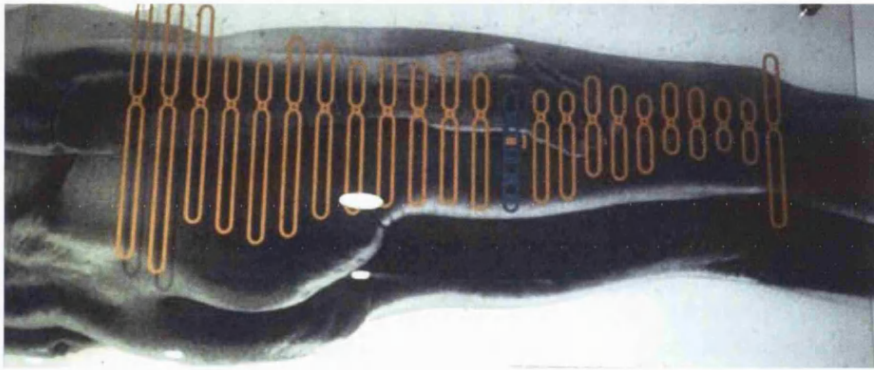


Figure nine: *Images displayed at entrance to research centre*

This vision of the future is given a more verbal presence in the short introductory speech to fundraisers in the reception area before entering the laboratory. After recounting the familiar but still numbing roll call of annual statistics of death from breast cancer, a member of the Charity's staff talks briefly about the research taking place at the centre. There is a strong emphasis on the importance of examining genes in the research setting, often described as getting to the 'root' of the problem. Ample reference is also made to the future potential of the Human Genome Project and the way that the laboratory will be ready to

exploit the benefits of that knowledge when it does emerge. Much is also made of the bridge being built between this yet to emerge information and the future clinical application of genetic knowledge. For instance, the project examining the function of the two BRCA genes was nearly always described in terms of hopefully leading to uncovering the 'pathway of all breast cancers', rather than the 5% that are thought to be linked to inherited mutations on the two identified genes.

Hope for the future takes on a greater presence during the course of the tours. Following the introductory talk given by a member of the Charity's staff, the movement into the 'inner sanctum' of the centre is precipitated by the arrival of the one or two scientists who guide the tour. They lead the way past the security check into a network of newly built pristine corridors, which lead off into work rooms and laboratories.

The event is essentially structured around a series of visits to see a range of objects and tools that are used in the laboratory setting. The first port of call for the tour is either the 'walk in fridge' where samples and experiments are stored or the smaller, but nevertheless impressive fridges which, on opening, divulge huge amounts of liquid nitrogen. This display at the start of the tour is clearly intended to engage the 'awe factor' among the fundraisers. It was an outcome that was nearly always guaranteed, met with either impressed silence or comments from supporters that it 'was exactly like on the television'. Moving through different corridors the tour groups are shown other objects which, like the fridges, are pointed out not just for their novelty, utility or cost value, but because it seems they embody something of the 'magic' of scientific practice. This includes a photo imaging booth, described by a scientist as 'a bit like a tardis', that develops films in a matter of minutes, but which you have to literally walk through with the films. The scientists also often pointed out the lab coats which were casually hanging in the corridor. Although clearly not impressive in themselves, attention was drawn to the small sensors attached to the coats which they explained would 'tell' the person wearing them when they might have been subjected to too much radiation.

Moving into one or two of the laboratories themselves, the tour groups are guided through past the laboratory benches. Sometimes when the rooms were relatively empty of scientists, any object or person 'doing' science was interesting. On one occasion, fundraisers were introduced to the activity of a scientist who was feeding rows of sampled DNA into a specialist piece of equipment attached to a computer. The computer screen then displayed the different levels of gene expression that had been read by the equipment. It was not, however, the complexities of gene expression in relation to breast cancer which were flagged by the scientist concerned, but the fact that the sampled DNA 'changed colour', demonstrated in his display of samples after they had been read by the computer.

Although the focus is mostly on the tools of science a significant amount of 'wonder' was also reserved for talking about DNA. For most of the tour this is an invisible substance. Nevertheless, there is plenty of animated talk from the scientists about DNA and what it does. It is presented as something that is at the very least 'special' and on one occasion referred to as the 'stuff of life itself'. Such descriptions resonate with the way genes are associated with a certain 'mystical power' (Nelkin and Lindee 1995). As Haraway points out 'discourses of genetics [...] are especially replete with barely secularised Christian figurative realism at work' (1997:10). More importantly the agency of genes is preserved and extended, if the reality of the complex role they play in the development of any breast cancer is simplified, when scientists highlight how it only requires small things to go wrong or 'just one letter out' in the nucleotide sequence, to precipitate the changes that lead to breast cancer. These representations might well be commonplace in the media accounts of genetic knowledge, but the appearance of such descriptions in the context of working practices where the complexities of this chemical substance are part and parcel of daily life is significant.

Collectively these representations, descriptions and displays reveal much about how the scientists in the context of the tours participate in a particular 'public' presentation of genetic knowledge that can be seen as 'enchanted' (Gell

1992).¹²³ This image of technological awe and wonder could be understood in terms of what Gell refers to as the ‘halo’ effect of technical difficulty and the power that technological processes have in ‘casting a spell over us’. The silence of fundraisers in response to such a display and during most of the initial part of the tour suggested that it was an effect which had been achieved.

Nevertheless, this representation involves a displacement; both the complexity of gene research and the current somewhat uncertain and narrow application of BRCA genetics are discreetly left out. The final stages of this event bring these somewhat hidden elements more directly into view. Although not a working lab and virtually empty at the moment, while waiting for new scientists to be recruited, the ‘show lab’ is presented at the end of the tour and therefore appears, perhaps unintentionally, as the apex of the whole event.¹²⁴ Until now fundraisers have been shown a series of disparate objects or technologies, performing or being used in different experiments. The show lab brings these together in a particular way.

The objects of interest, in fact almost the only objects in the fairly empty room are lined up along one side of the bench. Closest to the door is a mammogram or x-ray picture showing, for the first time on the tour itself, a readily identifiable outline of a breast with a compact white dot in the centre indicative of a cancerous lump; an image which has now become an iconic representation of breast cancer. Next to this are several brightly coloured and enlarged cytology slides of normal and cancerous breast cells. Scientists nearly always moved quickly past these two sets of objects, openly displaying their ignorance of them. On one occasion one scientist pointed out to fundraisers that ‘you probably know more about these than I do’, while another reluctantly tried to guess at what was being depicted on the cytology slide. However, hesitancy would be displaced by open excitement as the scientists moved toward the objects at the other end of the bench, a PCR machine and the computer screen. It was the slow but steady appearance of the letters on a computer screen which generated the most

¹²³ I am grateful to Sara Skodbo for introducing me to the work of Alfred Gell.

¹²⁴ The very fact that it was clearly a ‘show lab’ and not a ‘working lab’ and that copies of the Charity’s newsletter for fundraisers could be seen on the shelves too, seemed to confirm this as the domain of the Charity rather than the scientists. It appeared to be their decision locate the end of the tour here.

excitement for the scientists. They would explain how this indicated that the DNA sequence was being read by the PCR machine. One scientist pointed out how it was possible to 'see mutations in the gene'. This was indicated by the gaps in the sequence where a letter was missing. This was then, from the scientists perspective, the 'enemy' in full view; letters being churned out on a computer screen.

Understandably, this did not generate a similar level of excitement for all those attending the tour. Fundraisers, having being introduced to the computer screen, and what it revealed gravitated back to more closely inspect the mammogram or the cytology slide. For many, these seemed to be much more immediate and animated depictions of breast cancer and 'the enemy'.¹²⁵ But it was in the content of the questions that normally flowed at this point in the tour that not only disappointment but also doubt about the research could be discerned as more direct challenges about the use value of genetic knowledge were made. The intrusion into the research setting of the 'sick body' represented by the mammogram and cytology slide, as well as the linear narrative that was suggested between basic research and clinical practice through the juxtaposition of these objects, prompted difficult questions from fundraisers.

Scientists' responses differed to common variants of the question that was most often raised at this point in the tour, 'what good is it to know about these letters?' Many answered quickly, before couching their answers in terms of the contingency, which is of course the 'life blood' to their work. So one scientist making a reference to the human genome project, said that knowing these genetic sequences would enable comparisons to be made between 'normal' and 'abnormal' DNA. He quickly added that, 'of course normal DNA would have some mutations in it anyway so the comparison wouldn't be that clear cut.'

Another scientist made a more offhand comment, in response to a question about 'what exactly the benefits are of having identified the two BRACA genes', before making more explicit efforts to backtrack on his answer:

¹²⁵ On one occasion a women actually picked up the cytology slide and carried it around with her into the refreshment area, determined to pick the brains of the scientists about the research via this tool.

Well, it would be important for a woman to find out if she definitely had a BRCA mutation by having a genetic test because then she might want to have a prophylactic mastectomy. Of course she might not have inherited the mutation even if it was present in other family members, in which case she wouldn't develop breast cancer and of course the actions of genes was quite complex. In fact we don't really know what BRCA 2 does yet.

The show lab therefore raises many difficult issues. It brings the contingency of the present rushing up to meet the scientists, who in their responses appeared singularly unprepared to meet these demanding and currently unanswerable issues about the use and utility of genetic knowledge.

For the most part the 'performance' of the laboratory tours draws attention to the awe or wonder of science and technology and the way hope is pinned to the future clinical application of basic science research. The display of objects and tools helps to present and communicate the research work being undertaken by the Charity as authoritative and 'expert'. In this sense, the tour serves to reproduce the genetic research not so much in terms of memorialisation, but more as 'triumphalist and celebratory' 'monument' for the living (Dante cited in Rowlands 1999: 130), which helps to facilitate the fundraisers' needs and desire for 'transcendence'. But we can see that this is a product of collective action, that requires the participation of the scientists. The final part of the tour suggests that this representation of 'expertise' is not necessarily always easy for these individuals to maintain, given the uncertainties and contingencies generated by the current clinical application of BRCA genes. The next section of this chapter explores further the consequences for the scientists of involvement in the work of the Charity.

7.2 Being scientists of Breast Cancer Genetics

Based on interviews with a group of 10 scientists¹²⁶, as part of the 'advocacy' project, I examine how this group of persons talked about their experiences of working at the research centre, communicating with fundraisers, as well as participating on the tours themselves. These findings suggest focusing on breast

¹²⁶ Individuals I met worked in a range of capacities at the research centre, some were technicians others leading members of one of the several research teams, while others were completing their Ph.D.'s or clinicians who had taken some time off to carry out basic science research. With a few notable exceptions most were young, under 35 and had come to work at the centre in the last few years since it had been built.

cancer genes in the context of being funded by a ‘grass roots’ based Breast Cancer Research Charity in some ways provides evidence of expertise or confers moral value to basic science research. As some parts of the tour had suggested, this made communicating the work they did to fundraisers fairly straightforward. Nevertheless those same elements that facilitated the transmission of new knowledge also meant there was little immunity for these individuals from the current limits to the *clinical* application of such knowledge. Moreover fundraiser’s hopes for a redemptory science had, I suggest, particular and somewhat uncomfortable consequences for these scientists.

7.2.1 The ‘evidence’ of expertise

Most of those I met were working in a variety of ways with projects associated with the BRCA genes.¹²⁷ Not unsurprisingly, therefore, when I asked them to tell me a bit about their research, it was the role of genetic factors in the aetiology of breast cancer that was highlighted. For some, being able to talk about their work in terms of a group of very specific genes that had recently been identified and which were already having an impact in a clinical setting was, to a certain extent, enabling.

For example, asking scientists the same question I had asked fundraisers about what they perceived as the main risk factors for breast cancer elicited what seemed like similar responses. Like fundraisers, some scientists initially responded by drawing a sharp contrast between ‘possible and ‘known’ risk factors.

Andrew/The main thing is basically we don't know, unless it's a hereditary predisposition and an inherited mutation in those genes[...] just in terms of thinking of the high penetrance of those genes there is 85% certainty where as the other things aren't as certain.

The way that genes provided a concrete avenue for researching the causes of breast cancer was also mirrored in what Anna said, one of a few scientists I met who had had personal experience of breast cancer in her family.

¹²⁷ There were one or two other teams in the research centre looking at different aspects of basic science research, such as the effect of oestrogen on breast cells and since this time other teams have been set up that are less exclusively focused BRCA genes. However the molecular science focus of the research work of the Charity remains predominant.

Well there has been lots of research looking into diet and whatever and all kinds of environmental things. On their own they don't give rise to breast cancer they have to be combined with genetic changes

The importance of examining genetic changes was also demonstrated in the way that genes were imbued with a great deal of agency by scientists. This seemed to be illustrated in the quick retort of one scientist when I commented on something he had said about cancer being linked to a range of genetic factors. His reply seemed to confer a certain animistic quality to genes.

Yes that's right, one from each group has to give up the ghost eventually.

In fact the agency of genes was preserved in other ways. For example, factors 'internal' to the cell, or genes or bodies were represented by some of these scientists as the most important elements of breast cancer research. This became apparent during a interview with one scientist when I asked if he was aware of other research looking at breast cancer. As this excerpt from my interview with him shows, this prompted something of an indignant response:

Andrew/ what do you mean? Do I think about it, ..um I'm for it ! In fact I would think of the question in a broader sense, I get the impression that this is a common misconception that if you work on breast cancer you're not working on any other cancer. But the BRCA2 gene is mutated in other cancers not just breast cancer.

Sahra/ so you would see the work at the centre connecting with other types of research looking at cancer genetics rather than say research looking at diet, environment and lifestyle.

Andrew/For me the diet and lifestyle research ..well...of course there are good scientists and bad scientists, but if you really want to understand that research whether it's actually complete rubbish or not, you have to have a very good understanding of the field. You're talking more about prevention than cure, once you've got cancer you're not going to cure it with things like diet. So really I suppose this work [at the centre] doesn't impinge on lifestyle stuff.

His redress to my query was to suggest that gene research would impact on other cancers and not just breast cancer, rather than making connections with a broader field of research, which I then proceeded to define. At the same time, he sidelined, and to a certain extent undermined research examining 'external' risk factors. This displacement was also evident in the way he talked about the difficulties of incorporating lifestyle factors into risk assessment.

Andrew/ as you can imagine it's very difficult to study things like lifestyle, to do a proper study. But for these genetic factors you just do people's family trees, you can't factor in food to that or it's not easy to see how you might do it.

My discussion with Andrew drew attention to how some scientists simultaneously preserved the agency of genes and, by extension, their research work by presenting genetic factors, or things internal to cells or the body, as the most important or feasible areas of research. This could be seen as akin to a process of striving for 'universal de-contextualisation' that Oudshoorn has noted in the way scientists involved in researching sex hormones 'naturalise' their research by defining it in certain ways (1994). However the reference in Andrew's comments to a tool, the family tree, normally reserved for clinical practice, suggests that genes also provided 'evidence' of expertise for some scientists in other ways. This was demonstrated in his response to one of the first questions I asked during my interview with him.

Sahra/ How you would explain the kind of work that you are doing here for the Charity?

Andrew/ Ok well I think about 5% of breast cancers are due to inherited susceptibility. So we've been busy just trying to find out just what it [BRCA2] does because if you can find out what it does we might be able to use it so that the people who have got the mutation can get therapies. It's work like this that will provide the cure .. because then you can tailor therapies .

Although my question did not require a 'medically' orientated reply, he seemed keen to provide one, illustrating his desire to draw attention to the clinical end point of the work he was doing. For some scientists, working on the BRCA genes provided an apparently obvious connection to a clinical world and hence further proof of the utility and worth of genetic knowledge. However, it was not just that a clinical domain could be incorporated into descriptions of basic science research in this setting, but that working with these genes meant connections could also be made to a particular realm of social relations. For example this was the way one scientist described the project he was involved in:

Tim/ It's really looking into how we think about BRCA2. It's normal function is to keep our genetic template clean and intact. But when it's not working and there are permutations in the gene, then the ability to keep the genetic code accurate from *mother cell, to daughter cell and granddaughter cell all along the line becomes damaged and therefore you start passing on the bogus blueprint to your daughter*. So it's looking at how that actually happens. (my emphasis)

Here, a genealogical idiom was used as a way of describing genetic changes at the cellular level.¹²⁸ This description not only indexes a notion of gendered inheritance but also brings into view the social relations and values of nurturance that lie at the heart of the 'identity' of the Charity. As I examine in the next section, scientists were aware of the social dimensions of their research and drew upon this in talking about their work showing, as Fleck did in the 1930's, that particular cultural ideas are used as 'resources' in scientific research (1937) or in this case its representation

7.2.2 The morality of Charity based breast cancer research.

Several individuals talked about how working in this area of basic science had a particular 'value' compared to other areas of research.

Gillian/ I didn't select it because it was breast cancer, I didn't choose it but I am glad I did as it is good to know you are doing something to help everyday. It has meaning to it rather than just working in a lab.

Andrew/ I used to be a developmental biologist, but I just I wanted to do something less esoteric. I wanted to do something useful and just think it made more sense

The 'value' or 'meaning' of working in the field of breast cancer research was apparent in other ways. Many of those I met were aware of the degree of public or media criticism and concern that had been directed towards other types of genetic research, particularly in relation to GM food, or Pre-natal genetic testing. From the perspective of some of these scientists, the ethical value of being part of a Breast Cancer Research Charity secured a certain immunity from such concerns, as Tim's comments suggested:

I think if you were to say to the public in Britain whether they think we need to use this kind of technology to develop new strategies and then link it to breast cancer research, I would be very surprised if anybody, or a significant proportion of people say I have a problem with that. I think people will do anything to make advances in the treatment of cancer.

Probing these issues with one scientist initially elicited a more flippant reply, which also revealed the extent to which he, like others, felt breast cancer and

¹²⁸ The incorporation of established idioms of genealogy into representations of a different kind of science is also something discussed by Helmreich (1998)

cancer research more generally would not have to face the kind of problems other areas of genetic research had been subject to.

Sahra/ So from what you're saying, it seems as if you find the work that you do here very exciting. I just wondered if there is anything you find worrying about the genetic research focus of the Charity?

Andrew/Every now and again I think if we cure cancer then maybe we'll have over-population! (laughs) What kind of worries do you mean?

Sahra/ I mean are you concerned about the possible knock on effect of the controversies over GM food say on things like human genetics

Andrew/ Oh right I see what you mean. That may be true with some things but I think you're relatively safe with cancer because it's so obviously a good thing to do. For example if you want to get into genetically engineered babies, say you find you have a BRCA2 mutation but you want to have children and you want to make sure that you don't pass it on, is it not completely reasonable that you might want to get rid of that mutation in your sperm or your ovaries. I think you can't argue with that. I think done reasonably I wouldn't have a problem modifying babies.

In this case we can see the extent to which some scientists felt breast cancer was exempt from fears associated with other areas of genetics, with this individual implying that the somewhat controversial practice of pre-implantation diagnosis might be acceptable in the case of breast cancer. The morality of the basic research work they were associated with was also highlighted in the way a few of the scientists talked somewhat angrily about some of the other controversies that were emerging at this time.¹²⁹

Christine/ What is the point in patenting? Is it to get the glory of finding the gene? 'I own that gene, I found it, therefore it is my gene'. I don't know why people would want to patent genes to be honest. It's all about the fame and money. Pharmaceutical companies are obviously going to do that and go away and work on it and then make extremely expensive drugs. But surely something like that should be a big huge co-ordinated effort.

Discussing the patenting of genes provided another mode by which the worth of the research work they were undertaking could be defined more clearly. As Christine's comments suggest, a contrast could be drawn between research that was orientated toward a collective good, and that which was commercially or 'ego' orientated; as part of a Breast Cancer Research Charity their work could be

¹²⁹ Although some of the staff were embroiled in the patenting problems associated with BRCA2, this was only directly mentioned by one of those I met. What most scientists I met were keen to point out was the immorality of patenting genes; drawing explicit attention to this involvement might have compromised this argument.

firmly located in the former.¹³⁰ Nevertheless it was perhaps the response of a leading scientist to a query during a presentation to another group of researchers at a different scientific institute about the work at the centre which illustrated how the morality of Charity funded breast cancer research made the value and legitimacy of this work self evident.

Having finished his presentation the scientist responds to several questions from the audience. One member of the audience asked him how he deals with 'scepticism' about this research. Seemingly prepared for such a query the scientist, with a wry smile, puts up a slide of a newspaper article referring to him and the Charity. The article appeared in conjunction with a campaign in large daily tabloid newspaper to raise money for cancer research. He reads the caption underneath the picture to the audience; 'the most important man on earth'. Laughing with the audience he says 'I don't think it will be a problem in this case'.

These comments and descriptions suggest that working in *breast cancer* research that is *charitably* funded produced value and meaning in such a way as to confer a certain in built resistance to potential challenge or doubt associated with genetic research. This was powerfully brought home during an event that happened in the course of the tours one month.

On the way towards the final part of the tour, the group often passes a small room that houses a substantial bank of tissue samples from women who have been treated for breast cancer in the area. It is one of the very few times when, at least indirectly, bits of 'bodies' and, in this case quite literally, 'sick bodies' were potentially at least visible (in fact all that could be seen were the hundreds of small compartments where the samples were stored). However, it did not seem a designated highlight and was omitted altogether on more than half of those tours I attended.

¹³⁰ Notably, one scientists, the youngest member of the group suggested that the ethical goal of sharing information was not so widely held and accepted.

Gillian /There is a lot of backbiting. There are probably six or seven groups working on exactly the same thing, because everyone wants to be there first and be the first to get their name on something, everyone is being very selfish and wants the limelight for themselves.

Her comments seemed to confirm the fundraisers worst fears about scientific research; that such work was bound up with competition and the pursuit of careers rather than a cure for breast cancer. Significantly on reading these comments a member of the staff in the research services department of the Charity, responded with shock and dismay. This suggested that even if elements of this were true it was important not to bring this into the open and preserve the ethical and moral parameters in which breast cancer gene research in the Charity appeared to be located.

Others did, at least in passing, flag the room and its contents. They pointed out that this is where the hundreds of samples that had been ‘donated’ by women who’ve had breast cancer in the area were stored. I was intrigued by both the decision to show this room, when others had not, and the use of this term to describe the stored samples. I asked during one tour if consent had been given to use the samples for different aspects of the research. The scientist I had asked was off hand and almost indignant;

That would be ridiculous if every time you wanted to use a sample you had to ask permission.

Her reply, in full view of other fundraisers, suggested that the domain of breast cancer was not dogged in the same way by new and troubling ethical issues about consent that had arisen in the aftermath of a number of controversies in recent months.¹³¹ The description of these samples as a ‘donation’ could be understood as both a reflection of this sense of immunity at the same time that it re-inforced it.¹³² Implicitly this wording also created a parity between the ‘gift’ that fundraising bestowed with an act of sacrifice that bodily donation so readily evoked. In this way, the morality of breast cancer research was enmeshed in a circuit that could be read back and forth between the activities of the fundraisers, the ‘donated/sacrificed’ bodies of those who had had breast cancer and the work of the scientists. Nevertheless, subsequent sections of this chapter suggest that this was a circuit of connection that was not necessarily always so helpful for those carrying out basic science research.

7.2.3 A passion for complexity

We have seen that some scientists talked about their research with BRCA genes in terms of a process uncovering knowledge that would lead in a linear direction towards patient care. A rather different picture began to emerge in talking to others or as initial conversations with individuals slipped into more detailed discussions of research. These discussions revealed how it was precisely the

¹³¹ Particularly the public controversy and media attention around the retention of deceased children’s organs in Alder Hay, Liverpool in 2000.

¹³² Her reply also implied that this work was not contaminated by the muddy ethical waters that other clinical based research and practice had to confront, revealing (somewhat unintentionally perhaps) the distance between science and its clinical application.

circuitous and difficult nature of this area of basic science research which fascinated and motivated them in the work they did.

Gillian, one of the younger scientists on the team, had already confessed that she wasn't entirely sure what the Charity did, revealing a certain lack of awareness of the agenda and ethos of the organisation. This became even more apparent when I asked her what she would say if she was asked by a 'lay person' to explain the research being undertaken.

Gillian/ I think people know that DNA is the genetic code of life, DNA determines everything about you, all the physical things anyway. But it is very difficult, you then get into how does the gene get switched on, what switches the gene on, you have two copies of the gene in each cell and only one of them is switched on at any one time. It's very difficult to explain it really, it's very complicated it's not all black and white.

Although she began her explanation fairly confidently, the different dimensions of genetic research soon began to emerge; a complexity that was very much part of the work that she did. A more multi-faceted representation of gene research was also illustrated in the way another scientist talked about her work.

Alsana/ What I'm doing is basically trying to work out the function of the protein both for BRCA1 and BRCA2. We know that they are probably involved in DNA repair within normal cells, but nobody has actually elucidated the exact function and where they lie in whichever DNA repair pathway that they are involved in. Nobody knows exactly which molecules they're binding to and interacting with. It's not a human cell line [I'm working on] so the direct relevance I mean it's not directly relevant to the tumours in human beings per se at the moment.

Following this, I asked Alsana how she felt this work could be described to a lay audience. Her normally lengthy and fluent answers were characterised by disjunction and hesitancy (as indicated below), suggesting that like Gillian, this was a particularly challenging question for her to answer.

Alsana/ Very difficult, it's difficult to explain in layman's terms because it's so connected with knowing what DNA is. I don't think you can really explain it very well unless you have the background knowledge, unless you explain what the other things are like DNA. What would I say... I would say a gene was a.....[long pause at least 10 seconds] a factor in the cell that controlsthat controls or codes.....and determines the inheritance ofa protein or a specific functionit's an inheritable factor.....it controls the expression of...

Moreover her discussion of risk factors also demonstrated that she did not necessarily position genetic factors as the most important causative agents, in the same way that other scientists had.

Alsana/ well it's very difficult to pinpoint a specific risk factor it's not like lung cancer where 99% is a result of smoking . It's not as clear cut as that and I don't think it ever will be. I don't think it's ever going to be one specific factor per se. It's not only the fact that you can get tumours in various different organs but the fact that each organ can have tumours of different types. This is what makes pathology *fascinating*. I think there are going to be many things that interact with each other. I don't know whether it's pollution whether it's diet, hormone changes related to lifestyle. I suppose they all or the majority of them contribute in some way (my emphasis).

In the depth and breadth of what Alsana talked about it was evident that, like Gillian, it was precisely this heterogeneity which absorbed and compelled her in the work that she did. For Alsana it seemed to be the driving force behind her decision to work more in the lab having previously worked full time as a clinical pathologist. In talking about the intricacy and detail of their work, these scientists therefore presented a more complex multi-dimensional picture of breast cancer aetiology. For them, this seemed to be at the root of what they did and, for some, was linked to a sense of passion for and fascination with genetic research. As might be expected, this complexity had more difficult consequences for the communication of their research given the context in which they worked and the current limited clinical application of the knowledge and technologies associated with BRCA genes.

7.2.4 The challenges of communicating basic science research

We have seen that, for some, being able to link BRCA genetics to a clinical field provided evidence of expertise. Others pointed out that this raised more difficult issues, as the events of the show lab on the tour had already suggested. One of these challenges related to the timescale of genetic research; as one scientist succinctly put it, if you are working on breast cancer and one or two genes it's not straightforward and doesn't mean you'll cure it. Others were similarly honest in their discussion of the process by which this knowledge would benefit patients.

Gillian/ I think in translating the research we do here in the labs to the Clinic or patients - it's a long process, you can't just try something. I don't have that much knowledge of the application of our research to patients, but I can't see it being that direct, at least not immediately.

Some even went so far as to point out the *need* for a broad approach to research that did not have a therapeutic result as its immediate goal.

Tim/ I recognise that often you can't be too narrow minded about it and can't always look for the therapeutic results. You often have to think laterally and broadly about basic science and mechanisms behind breast cancer pre-disposition before you can home in on a target for treatment, there has to be a lot of research that isn't directed specifically at treatment. You have to have a wide range of research before you can know what you want to target the drug at.

It was striking also that several scientists, who had initially been keen to claim and show the clinical benefit of genetic research (talking hopefully about how this would impact on patients and lead to the development of therapies), seemed more hesitant during later stages of what were sometimes lengthy interviews. For instance, Andrew had talked confidently about the link between the research focus of the lab and therapy at the start of my interview with him (see page 179). This contrasted with what he said when later I asked him more specifically about the work that he was doing.¹³³

Andrew / People think that we are experimenting on therapies and we are not at that stage of the game yet. The stuff that's happening here isn't going to affect anybody's tumour in the next ten years.

The contradictory way that Andrew talked about the clinical interface for basic science research on BRCA genes implied that there was at least a degree of unease about being able to associate the work they did with a newly emerging field of predictive medicine. This was more clearly articulated in the way that Christine discussed the gap between diagnosis and therapy and the clinical domain that she and other scientists was associated with because of the research work they undertook.¹³⁴

Christine/ Obviously scientifically it is a good thing. But for your average man in the streets going for jobs is that information going to be available to your future employer, 'by the way I've got a mutation in my BRCA2 gene therefore I might get breast cancer', I think people find it quite scary that sort of knowledge. To be able to run something off a computer and find a gene that causes a disease is incredibly exciting. But I don't know whether people want to know that they are genetically pre-disposed, do they want to know that they are going to get Hodgkin's in their forties?[...] But we can't slow down progress. We've already got the technologies to sequence the whole entire

¹³³ It's possible that the disparities and contradictions in the way these two scientists had talked about their research could have been related to how at least their initial presentation of this work was circumscribed by what they felt 'should' be said in 'publicly' talking about their research.

¹³⁴ This association might have been compounded for Christine because she was part of the team who had identified the BRCA 2 gene.

genome and we can't stop now, it's on a roll now. We can't say oh we've done that but it's not a very good idea. I mean we are in frightening period where we can say to somebody yes you've got this gene your going to get such and such but unfortunately although we know your going to get it we can't actually cure you yet. In about twenty years' time we might be able to do something about it. I just hope some bright spark does come up with something some fantastic young scientist that does another 'Crick and Watson' !¹³⁵

For some scientists the ability to associate the work they did with a clinical realm worked in quite the opposite way. Given the potentially problematic diagnostic application of breast cancer genetics and the limited therapeutic interventions for those at risk, it was an association that was not always welcomed. Others pointed out that such an association was more than just problematic, but had in fact particular implications for them and the Charity in the way it raised expectations about the research work they did. This was reflected in the way that a few individuals talked about the importance of getting a 'result'. As one scientist said; 'I think we need to keep giving people a carrot or whatever and I would think the first big result we get out of here will be a huge boost'. Another scientist pointed out how a 'result' might be particularly important for Charity H compared with other research charities. At the same time that he implied that it was important not to be 'too honest' about the timescale of such a result.

Tim/The research is so fundamental it is actually an awful long way from basic science to the clinic. Obviously it's important not to rush this process and throw things into the clinic before you understand them or before there is a reasonable basis for doing so, but this has to be the end goal of the research strategy for this Charity. Some of the charities who are larger are able to say we need to have a large section of our research which is very fundamental in the hope that some if will filter through and be relevant to all types of cancer. But organisations like that are less targeted at therapies in the way that Charity H needs to be.[...]Of course there is no point in being terribly honest and saying we won't have any results for 25 years or people will say why give money to Charity H when the other cancer charities get results every 2 months, I guess it's just finding a balance.

Some scientists were fully aware that the complexity of the research work they were involved in, as well as being a source of fascination and motivation for

¹³⁵ The anxiety this generated for Christine also seemed to be confirmed in the way she drew a parallel between the work of the centre and new foray into the 'treatment' field by the Roslin Institute, who had been involved in the controversial practice of nuclear transfer or cloning which had led to the production of 'dolly' the sheep.

Christine/ I noticed the other day that the Cystic Fibrosis gene they found years ago, well now the group from Scotland who are doing the 'dolly' work are building a whole new programme to generate drugs from that gene. That's what they're doing with that gene, so I don't see why we can't do the same.

them, had difficult ramifications for the Charity, in terms of fundraising. As Andrew put it; 'it's is a long game and that's why I imagine it's difficult for *you*.' (my emphasis). His remarks suggested that he felt the scientists were not caught up, in the same way that the organisation was, with these challenges. The final part of this chapter illustrates how such boundaries are 'leaky' in the way that the scientists are in fact directly implicated and in some ways affected by these challenges .

7.2.5 Being part of a 'redemptory' science

We have already seen how the scientists participate in reproducing a particular image of genetic research through their participation on the tours. In this section, I examine their experience of this event in more detail to illustrate the dense interconnections between the scientists, BRCA genetic research and the fundraisers' quest.

The difficulties of the tours for the scientists became apparent fairly early on in my research, during informal discussions with some of the Charity's staff. Talking about the very first tour that had taken place, Susan told me how many of the scientists had been anxious about the way in which fundraisers would respond and were worried that they might, as she put it, 'burst into tears or get upset or ask when they would find a cure for cancer or why they hadn't already'.¹³⁶ In-depth interviews with scientists as well as discussions with them during and following the tours enabled the nature of this anxiety to be explored further. For example, a number of scientists talked about the 'mixed' feelings they had about this event.

Elaine/I'm not sure how good they actually are, in some ways. I've taken a few people around and it's quite difficult to know what to say. These people, they've obviously had relatives who've... and they obviously want to do something and raise money. So you take them around and show them these pieces of equipment and say they cost thousands of pounds and they've only raised 2,000 pounds. They're going to go away and think it's not enough.

Andrew/I don't know what they want out of it. I enjoy people coming around to show them what's going on but I always wonder what people get out of it. It's nice for them to see the building and know that it exists but as to what they

¹³⁶ Nevertheless she recalled that 'in fact although a few people did get upset, it went surprisingly well and the scientists afterwards said they were grateful that they'd been given a chance to talk to people and to see how much difference it made to their work'.

take away from that or how much they want to take away from that. I guess the bottom line is when are we going to see a cure. At least that is what I would want to know if I had a relative with the disease or I was at risk, those would be the mental calculations I would be doing as I was going around the centre. Even though nobody ever says that, I guess that's what they want to know and that's enormous.

For both Elaine and Andrew, the tour evidently brought them face to face with the expectations and motivations of fundraisers in a way that was not always comfortable, given the complex and long term nature of the research they were engaged in. The very personal consequences of this unease was brought home in a discussion I had with one individual about her concerns regarding the fundraiser's 'impression' of them on the tour.

Christine/ I think they think that we are all highly motivated, highly driven and we are all going to make them much better. I would just hate to let them all down, we won't, but it's not going to happen probably in their lifetimes. I think they're all impressed by the building, it is an incredibly impressive building. I imagine that most people haven't even been into a lab before and they are probably just a bit over-awed by that really

Sahra/ Yes that's true, but my feeling is that often the scientists seem fairly relaxed in the labs?

Christine/Well it isn't always like that but to a certain extent it has to be. Do you think that impresses them or do you think they think we should be running around?

Sahra/No I suppose the 'TV image' of scientists is really different

Christine/ I hate that and we've all got high foreheads and lab coats buttoned up to here (laughing). But do you think they want to see people with big foreheads, and spectacles beavering away?¹³⁷

My discussion with Christine suggested that the expectations of fundraisers had implications for the way scientists presented themselves on the tours. Another member of the research team suggested that this event also had consequences for the way they presented their work, pointing out that the fundraiser's 'expect to see bucket loads of DNA lying around'. This was more clearly articulated by one scientist, in pointing out how the structure of the tours served to present a somewhat one dimensional view of their work.

¹³⁷ This anxiety was also reflected in what another scientists said:

Elaine/ If I was going to see a scientist I would expect to see people in lab coats rather than playing music and chatting. I don't know people have this idea of scientists having a solitary existence tucked away in the corner with their lab coats on doing their own thing.. and its not like that at all.

I don't know, just to wander around how useful that is, because one science lab is going to look the same as any other and they're just not going to have any idea what we are doing or what we are researching into just by looking at test tubes on the bench. But maybe what they want to see differs from what we might want to show them. A lot of the time what they want to see might be the hardware which their money has bought, say the microscopes or the micro-injector. That's something physical and something incredibly expensive which actually takes a lot of hard work to raise the money to buy. This is different perhaps from what we want to show them which is a few cells in a tiny plastic dish which is much more important to us. I mean the hardware is just a means to an end. A PCR machine is perhaps a bit like a microwave, its got no essential interest on its own, you can't do your 'cooking' without it. But for us it's the food at the end of the day which is important rather than the machinery or microwave or whatever that you 'cook' it with.

Alsana's comments highlighted how the focus on the objects and tools of science during the course of the tours prevented the scientists from highlighting the less visible aspects of their work. From what she said it seemed these less visible aspects were deeply connected with their 'ideas'. She implied therefore that these events required a certain presentation not only of their work but also of themselves; a display that involved a certain loss of subjectivity. This was echoed in what Andrew said about the first ever tour that had taken place at the centre.

There was a strong emotional response to seeing this thing and a lot of them had been involved from the beginning and it was quite a big thing. So I wasn't to them an individual, I was just part of this whole thing that this money had created.¹³⁸

These comments implied that some scientists experienced the tours in terms of something of a negation of their work and their 'identities', particularly when this was defined by an interest in and a 'passion' for complexity. This was not only because of the way this event focused on the objects of science, but because they themselves and the genetic research they undertook were situated as objectifications of the fundraisers pursuit of a 'redemptory' science.

¹³⁸ Although initially flummoxed when I asked him how this 'made him feel', he rallied after pausing for a few moments with what he clearly felt was an 'appropriate' response. This nonetheless revealed much about the not necessarily welcome obligations of being a scientist in this domain of research.

Andrew/ Oh I don't know I didn't really think about it... no hold on let me think back it gives you a feeling of responsibility... because it reminds you that this money why they raised this money and what it means to them and that you've got a responsibility to use this money.

Their reluctance to being reproduced as embodied objects of expertise was sometimes apparent during the tours as two 'rare' moments of fractious interchange between the scientists and the fundraisers illustrate.

I am with a group of fundraisers walking around the various labs. We have just been through one of several that appear to be empty at the moment. Nicole, the research administrator, begins to talk about the amount of money needed to continue to fund the research now that the centre has been set up. She says that the centre is going to need about '5 million per year' for the next few years during which the labs should start to fill up with scientists. One of the fundraisers asks her if this money is already there or if they raised more money would that fill the labs up more quickly. Nicole's response is terse. She explains that 'no that's not really the issue here'. She explains that it's about getting the right people in. 'You see' she explains 'it needs to be an attractive place for them to work, we have to encourage them to want to work here. It's not just the fact it's a Charity for them, it's about their careers as well.' She points out how, as a result, recruitment will take place over the next 2-3 years and just can't be any sooner than that.

In this example the sharp reply to the fundraiser's query threw into relief the agency and individuality of the scientists in a way that ran counter to the way they were normally perceived by fundraisers and represented in the Charity or on the tours.¹³⁹ It was an explanation that also seemed directly linked to the unease some scientists had privately expressed about how they experienced the laboratory tours.

The second instance concerned a fracas over something seemingly innocuous, lab coats. As well as having a very practical function in the labs associated with health and safety, these objects are also an iconic symbol of authority within the scientific and medical community. It was perhaps the former that was at the forefront of the scientists mind at the start of the tours when they made their

¹³⁹ The Charity also participated in this process. For instance the Charity's research centre brochure used particular imagery and discourse about the scientists. In the information about donating to the Charity at the back of the brochure, the cost of various 'objects' used in scientific practice is listed, which, as we have already seen in the context of the tour, are treated as objects of awe and wonder. However, next to the cost of these objects, the cost of funding a scientist for a year is also listed. This sense of 'objectification' is further reinforced by the imagery on the front cover of the brochure. This comprises of a series of 12 graphic images spread out across covers and representing a time line from when the Charity was first set up and plans for the centre made to when the first scientists started work there. The first image consists of a few black and white lines. As these images transform across the page, the first becomes recognizable as an empty room in a lab. This is gradually transformed into a recognizable science space, with the tools and the objects of science. The final colour image is of a young female scientist pipetting some liquid. In this representational sequence on the brochure cover, scientists seem to be represented as the apex of an end goal, embodiments themselves of knowledge and expertise.

appearance in their white coats, as if hot off the lab benches. However, it was the absence of a lab coat on a 'working' scientist during the course of this event which upset one fundraiser and prompted this revealing interchange.

It is near the end of the tour, there is a question and answer session. One fundraiser says that she was 'worried' by the person in the lab without a white coat adding that 'having worked in a laboratory myself in the past I know how essential it is that those working in the lab wear coats at all times'. The staff from the offices of the Charity are suitably placatory, pointing out that the particular scientist in question had been wrong in neglecting to do this. However, in an aside out of earshot of one of the fundraisers, the scientist conducting the tour was outraged. She says that the particular task the scientist was completing did not require a lab coat and that if there were any concerns about health and safety they should have been directed at the female fundraiser who had brought her baby into the laboratory.

At one level this minor dispute seems to be about a relatively petty issue. But, I would suggest, the scientists' unwillingness to concede the terms on which lab coats should be worn also reflected a feeling that their subjective right to define the terms of their expertise was often denied to them in the course of this event and in relation to the research work of the Charity more generally.¹⁴⁰ These tense but rare encounters draw attention to the uneasy consequences for scientists and the work that they did in being caught up in a 'quest' for knowledge of a particularly redemptory kind.¹⁴¹

7.3 Conclusion

The experience of scientists who increasingly must communicate with 'patient' or 'lay' groups beyond the confines of the laboratory, has only just begun to be explored in social and anthropological work. Heath's discussion of the 'traffic'

¹⁴⁰ Another attempt to counter their sense of objectification seemed to be demonstrated in the way that the atmosphere within the labs themselves was sometimes almost deliberately relaxed, against the background of the formal structure of the tours. Music would often be playing and scientists chatting to each other in what appeared to be a conscious attempt to counteract the enforced formal representation of expertise that the tour required. This was also reflected in what one scientist said about the opportunity the tours provided to show fundraisers what a lab, scientists and science was 'really' like.

Gillian/ I think it is good for them to come and see what a lab is like, because many people have misconceptions about labs and lab scientists. I think it is good for them to see that we are relatively normal.

¹⁴¹ This was also illustrated in the way there was a demand for the scientists to be 'committed' to their work. For instance one fundraiser meeting the scientists more informally over coffee after the tour treated one of the scientists almost semi-reverentially talking about how she really admired their 'dedication' and couldn't understand the kind of 'commitment' this work required. This was also demonstrated in an appeal leaflet, produced by the charity which used a notion of the scientists 'dedication', described in terms of them 'giving 150%', as a baseline for what was needed in terms of funds from the public.

that flows between a group of patients with Marfan Syndrome and the scientists in the US who research the disease draws attention to the 'contradictory connections and divisions that describe the networks linking [the] laboratory researcher to wider worlds' (1997: 79). She explores how patient groups desire for a therapeutic outcome is 'disturbing' for those involved in basic science research and how they express a need to be 'autonomous' in the work that they do (1997). Similar discontinuities (as well as dissimilar continuities) characterise the relationship between 'lay/patient' groups and researchers carrying out basic science genetic research in the social arena of a Breast Cancer Research Charity. Here there is an expectation of not just or simply 'therapy' but 'cure'.

This nexus of connection and disconnection has been explored here in particular ways. Taking one key event where the communication of the genetic research is central I have initially examined how the monthly laboratory tours reproduce a particularly 'enchanted' image of scientific research. That is for the most part 'knowledge' is maintained as authoritative and expert. The 'show lab' suggests however that this 'performance' is subject to slippage.

Exploring the experiences of one group of participants in this event, the scientists, the second half of this chapter has drawn attention to the contradictory consequences of being involved in the transmission of new genetic knowledge associated with breast cancer. Carrying out basic science research on BRCA genes helps to make knowledge and expertise 'tangible'. This is a context for knowledge some scientists reproduce by talking about 'genes' in particular de-contextualised ways (Oudshoorn 1994), thereby preserving the importance of a molecular approach to breast cancer research. But scientists also make use of a 'social dimension' drawing on the 'morality' of breast cancer to highlight the value of their work both informally and more 'publicly'. Others talked openly about the complexity of the gene research they worked on and the way that it was precisely this feature of basic science work which fascinated and motivated them. However, we can see that admitting to or acknowledging the complexity of this work also draws attention to the timescale of translational research and the current limited clinical application of BRCA genetics.

Although some scientists suggested that this might pose problems for the *Charity*, the final section of this chapter, exploring the scientists' experience of the tours, suggests they are not so easily separated from such consequences. Coming face to face with the expectations of fundraisers during this event, particularly in the context of the show lab, not only made many uncomfortable, but also precipitated concerns about how they should present themselves and their work. In fact, I have suggested that some scientists experienced the tour in terms of a denial of personal subjectivity and agency, because of the way they are identified by the fundraisers (and reproduced by the Charity) as embodied objects of expertise. This presents an interesting twist to the claim in Science and Technology Studies that the 'agency' of objects must be recognized in understanding the social production of scientific knowledge (Callon 1986). Here, the agency of persons, in this case scientists, appears to be denied through a process of objectification. The pursuit of a 'redemptory science' clearly implicates scientists. Many struggle to remain faithful to the real nature of their work in the attempt to produce good enough 'monuments for the living'.

Fundraisers and scientists are caught up in the transmission of genetic knowledge in complex ways. The role of the organisation in this process can also not be discounted as the use of published testimony in chapter six or the inclusion of the 'show lab' on the tours demonstrates. The final chapter of this thesis examines how pursuing gene research necessitates different representational strategies for Charity H that delicately mediate the expectations of fundraisers and the current scope of genetic knowledge.

Chapter 8

Between Hope and High Risk

The notion that institutions are necessarily stable or consensual (Douglas 1986) has been superseded by studies which highlight the way organisations can also be constituted by more fractured, local practices that involve different groups and individuals (Wright 1994). This is something that a recent collection draws attention to in examining how western organisations provide a rich arena for anthropological inquiry (Gellner & Hirsch 2001). We have already seen the extent to which Charity H as an organisation is made up of different groups between which there is a degree of disjuncture and tension. The final part of this chapter examines how the administrative component of the organisation negotiates the communication, dissemination and promotion of the work it funds to fundraisers and a wider public.

Rabinow's examination of the temporary 'assemblages' that formed between different groups and organisations in pursuit of genetic knowledge in France, in the late 1990's, offers one model for addressing the role of organisations in the context of developments in the new genetics (1999). By highlighting the shifting and partial nature of these alliances and the emergence of what he terms 'form/events' he illustrates how the response of organisations to these developments is fluid and changing. This shifting ground is reflected in the communicative practices of Charity H. Drawing on analysis of a range of publicity materials from 1997 to 2002 (newsletters, fact sheets or the research centre brochure), produced for fundraisers and a wider public, I explore the way transmission is mediated through the use of particular representations or by highlighting certain areas of research and omitting other aspects. These practices are contextualised and understood in relation to a number of interviews and conversations I had with various members of staff, which reveal the delicate nature of these representational practices. The second half of this chapter investigates how making an ethical or social agenda explicit is an important part of how the transmission of genetic research is negotiated. This is a process that can be linked to what Nowotny et al sees as the increasing need for 'science' to demonstrate a 'context' dependency (2001). I explore how incorporating

‘ethics’ in the Charity arises from the difficulties posed by long term contingent basic science research and the need to show that BRCA genetic research can be associated with the ‘good’, defined in a range of different ways. But embracing ‘ethics’ also changes the parameters of the organisation’s work in a way that is not necessarily easily countenanced by all or which precipitates new and in some ways more problematic challenges for the Charity.

8.1 The balancing act of BRCA genes

I first examine the way that genetic research was represented in publicity materials in the years leading up to the announcement of the first draft of the human genome project and the official opening of the Charity’s research centre, which rather felicitously coincided within six months of each other between 1999 and 2000. A changed and changing mode for representing genetic knowledge could be discerned in the months immediately preceding these events and the years that followed. These shifting representations are understood in relation to how those who work in the organisation talk about their perceptions of the Charity’s research, the expectations of fundraisers and the challenge of communicating genetic research more generally.

8.1.1 Hype, heroes and the human genome project

The fact that the organisation had started to fund genetic research was apparent in publications which sought to explain and outline some of the first projects undertaken by the Charity in 1996/7, two years after the BRCA genes had been identified. The centrality of basic science research to the Charity’s work and identity was illustrated in an excerpt from a ‘fact sheet’ about some of the projects they funded at this time.

[The Charity] funds research which focuses on basic science - going back to the laboratory, looking at how breast cells actually work, and how they become cancerous. It is through understanding the basic biology of cells and learning more about the disease itself that major steps forward in the fight against breast cancer will be made possible.
142

¹⁴² It went on to say that

Rapid advances in technology have assisted in the identification of some of the genetic abnormalities which convert a normal cell into a cancer cell. In the last two years this has resulted in the identification of four genes responsible for familial (inherited) breast cancer, and it is predicted that in the next five years, the majority of genes which cause breast cancer will be identified

A more widely distributed discussion of this research work was reproduced in an article in their quarterly newsletter in 1997. Entitled 'The Nuts and Bolts of Research' it set out to present a rationale for the work that was beginning to be funded by Charity H. Here the significance of 'knowing' about genes is evident in the preliminary discussion about the 'causes' of breast cancer

Cancerous lumps are now known to be due to an unusual increase in the number of cells in a particular part of the body.[...]We now know that this is because there are many different types of genes which cause cancer and produce abnormal growths of cells in the breast and other parts of the body

Although described as a 'multi-factorial disease' it is the role of genes that are highlighted as another excerpt from the same article illustrates, which is structured as an interview between a reporter and the then director of the Charity' research.

Interviewer/It's such a huge field, how do you decide where to start?

Research Director/ It's hard, we can't do everything so we have to focus on the topics which appear to be the most relevant [...]For instance we now know that approximately 10% of breast cancers are due to the 2 abnormal genes that are inherited BRCA1 and BRCA2. The next step is to understand the function of these 2 genes and why they produce breast cancer.

We'll also focus on identifying other genetic abnormalities that are responsible for breast cancer in 90% of cases that are not due to inherited factors. Within 5-10 years I wouldn't be surprised if we could identify all the genes that are involved in breast cancer.

Interviewer/ have there been any major developments recently ?

R.D/An enormous number, [...], there have been great advances in our understanding of breast cancer. A lot of this has happened through the development of modern technology and molecular biology which has enabled people to really start dissecting the causes of the disease.

The discovery of BRCA1 and BRCA2 that I've already mentioned has been the most important step forward since Tamoxifen was first used in clinical trials in 1971. [The Charity] has already been associated with these discoveries in a major way, even though it has invested only a relatively small amount of funding so far.

The way that BRCA genes and other possible but unknown genetic factors are singled out as being the 'most relevant' aspect of research or the most significant

Notably the use of the 'responsible' and 'cause' to describe the action of hereditary breast cancer genes is now no longer widespread, within the Charity or beyond. It has been replaced by language with a less linear association such as 'linked'. Moreover little now is said about the prediction to identify all genes involved in breast cancer. This not only reflects changing knowledge but also the desire on the part of the Charity, at this time to express the agency of genes and the expertise of research.

‘major development’ in the field of breast cancer research reveals how the feasibility of gene research is being represented and reproduced in the Charity’s publications. At this time the discovery of the BRCA genes was firmly linked to the Charity and the question of ‘ownership’ of the gene treated as a success story.¹⁴³ Moreover, discussion of the Charity’s gene focused research was also linked to a much larger high profile project, as an excerpt from a different article written to profile the new research director in a newsletter demonstrates;

The centre is opening at an ideal time. A new world-wide initiative called the Human Genome Project is working to identify all the 100,000 genes that determine the way cells working the human body[...] This will be one of the most exciting events to happen in the history of medical research. (1999)

The project to identify and sequence all genes in the human body therefore provided an opportunity to link the research focus of the Charity with a much larger ‘international’ initiative. These linkages not only furthered the authority and legitimacy of the research focus undertaken by the Charity but also enabled a certain degree of ‘hype’ to be incorporated into the discussion of its own and other genetic research projects. For example, this was the way that other gene ‘discoveries’ were announced in the newsletter.

American scientists discover new gene involved in breast cancer at Stanford university

The gene called TSG101 was found to be defective in half of the breast cancer the scientists studied according to the scientific journal[...]. It is not yet known whether the mutation or defective gene pre-disposes cells to become cancerous or encourages existing cancer cells to become more aggressive. Once this is known then testing for abnormalities in the gene could serve as a tool for diagnosing or predicting disease progression, scientists say.
1997

On this occasion the application of genetic knowledge for diagnosis or therapeutic intervention is talked about in the same breath as the discovery of another gene helping to sustain a somewhat hopeful presentation of the scope of genetic knowledge. A similar upbeat narrative was apparent in a particular metaphoric description of ‘gene mutations’ that appeared in a short news article in the newsletter in 1997.

¹⁴³ This openness about the organisations involvement with the discovery of the BRCA 2 gene contrasts with much more widespread silence about this issue in later publications.

Gene mutations- the secret battle [Charity H] funds important new research.

We've all heard of Teenage Mutant Hero Turtles. The huge turtles battle through murky underworld of sewers, fighting forces of darkness and evil. But what about mutated genes? What exactly do they do?

We know that mutations in some genes cause cancer. Cells normally know when to stop growing but sometimes mutations in genes confuse them and tell them to keep growing when they should stop, this is the basic cause of cancer. Now, thanks to major new research funded by [Charity H] we may well find out more about this complicated process. [Charity H] is funding a project studying mutations in one of the genes known to be responsible for breast cancer BRCA1

The parallel between the well known cartoon figures and the gene research of the Charity could be read as an attempt simply to engage readers on what might appear to be a difficult scientific issue, 'gene mutations'. However, in the context of a broader narrative of hope, hype and promise, this description could also be interpreted as an attempt to locate gene research, like the heroic mythical cartoon characters, at the forefront of a 'good' fight against the disease of breast cancer. In light of the fact that the Charity was focusing on BRCA genes in their research, where mutations on these genes were linked to *causing* breast cancer, using metaphors which suggested a more positive application might have been especially important.¹⁴⁴

Van Dijck (1998) and others (Nelkin & Lindee 1995) have examined how a 'genetic imaginary' is an important tool in the public presentation of such research; as Franklin says you cannot 'factor out hype' because 'it is precisely the importance of imagining a future yet to be that fundamentally defines the whole issue of the new genetics and society' (2001a:347). In these earlier examples of publicity literature, prior to the announcement of the first draft of the

¹⁴⁴ A similar example of this was the way a possible function of BRCA genes, at odds with the normal representation of these genes as 'causing' cancer, were discussed in excerpt from an interview with the research director in an article in 1997.

Interviewer/ we've seen some reports that BRCA1 might be capable of slowing up the progress of breast cancer and even reversing it, can you give us your opinion'

RD/The evidence is contradictory[...]but there is some indication that the function of BRCA1 might be to control the rate of growth of breast cells[..]this raises the hope that BRCA1 and the proteins it produces might be used in the future for the design of new treatments for prevention.

In this context the knowledge that mutations in BRCA genes might not just be 'responsible' for certain breast cancers is conjoined by the possibility that normal BRCA genes might actually be active in 'preventing' breast cancer.

human genome project and the official opening of the research centre, we can see how genes and genetic research are embedded within a story of potential or soon to be realised expertise. This upbeat presentation promised and implied fulfilment of expected and anticipated authoritative medical knowledge

During the initial stages of my fieldwork, this vision of the future seemed to be part of the way at least some of those, who worked for the organisation at the head office, also talked about the genetic research it funded. For instance, one woman said that the human genome project 'really blew her mind'. Another talked about how learning about genetics in breast cancer was about starting from the 'roots' and part of a rational approach to research that worked like 'building blocks' in understanding more about the disease and working towards understanding the 'cause' and the 'cure'. This linear and logical trajectory was exemplified in the way that a member of the research services team, with whom I was later to work closely, also presented the research work of the organisation in the first few weeks of my fieldwork.

Well there is strategy to co-ordinate very closely with the Human Genome Project so that we will be first off the mark when genes are identified. There are really four stages to it all; identifying and sequencing the genes that have been identified in the relation to breast cancer, then seeing their function or the proteins that they code for, then seeing how things like hormones affect these genes, then seeing how all this could be translated into clinical practice.

Her remarks suggest that the genetic research focus of the Charity was perceived as part of a rational approach to researching breast cancer that aligned expertise with a positive and forward looking ethic. Nevertheless, in the following months, as I became more immersed in the work of organization, this upbeat linear narrative seemed to belie her and others' concerns about the genetic research focus of the Charity. The 15 months of field research, that I undertook with the Charity, also witnessed dramatic 'discoveries' in genetic science and new questions about the use of such knowledge and information. I explore in the next section of this chapter how this had implications for the representational strategies of the organisation.

8.1.2 Defining a 'post-genomic' space

A changed and changing trajectory for presenting genetic knowledge could be discerned in the months that immediately preceded and followed the genetic 'discoveries' that were announced in June 2000. I examine this in relation to two leading articles about the Charity's research.

The first article was written to coincide with the opening of the research centre. It profiled the new research director and his 'vision' of the work that was going to be undertaken there. After outlining the fact that the focus of the research was linked to the identification of BRCA1/BRCA2, the interviewer posed questions which prompted discussion of these discoveries in a way that was somewhat different to the way they had been previously represented.

Interviewer/ Does this mean that if genes are involved in breast cancer, all breast cancers are inherited?

Research Director/ No, only around 5% of all breast cancers are hereditary[...]. mutated genes in the other 95% of breast cancers are only present within each tumour. With several different types of breast cancer, this makes our job more difficult. We may well find that there are a dozen different genes involved with each tumour type and there are numerous different types of breast cancer. [...] Breast cancer can be compared to an engine which runs too fast (cancer occurs when cells multiply and grow out of control). At the moment we only know how a few of the engine's components (genes) work.

Interviewer/ When will we see results from the research?

R.D/ Breast cancer is a complex disease, if it was an easy problem it would probably have been solved by now[...]. Our research programme is part of a long-term strategy to beat breast cancer- identifying the genes implicated in breast cancer is just the beginning, albeit a necessary one.
December 1999

The second article produced a year later (2000) in a newsletter which marked the 10th year of the Charity's existence was entitled 'The importance of gene research in breast cancer'. A superimposed image of laboratory test tubes and what appeared to be combination bike locks accompanied the article written by a member of the research services team. As was befitting the occasion, he began his discussion in a suitably upbeat way.

Ten years ago our mission was to establish the UK's first centre dedicated to breast cancer research, and thanks to our incredible supporters, a decade later the research centre is open and home to pioneering research looking at the very chemical building blocks of life to understand the disease.

Alongside this upbeat and celebratory rhetoric another message was identifiable.

The last decade has seen a revolution in our understanding of what cancer is and how it progresses, although big improvements in treatments have not come as quickly as we would like. [...] The widely publicised announcement of the first draft of the human genome is an indication of the progress that has been made - however even the completion of this enormous task is just a first step in understanding how genes function, and how defects in specific genes can lead to cancer.

At the same time as maintaining a sense of potential about gene research, both these articles contain elements which hint at a more cautionary presentation about the scope of this work, particularly in relation to the timelag between the discovery of genes and their clinical application. A more tentative message was also discernible in a letter from a supporter which was published in the Charity's newsletter. The fundraiser explains in her letter that she is going to give a speech and wants to use an analogy she has heard comparing the complexity of gene research to AIDS research in order, as she put it: 'to show how far they've come and how far they've got to go in terms of breast cancer research. The printed reply from the Charity's health correspondent reinforces the scale of the task pointing out how, 'with the AIDS virus we know that there are nine genes involved but there are possibly 200,000 oncogenes and up to 30,000 genes active in any one cell.'

Conversations and interviews with staff undertaken six months after starting my fieldwork with the Charity and during the time in which these articles appeared, provided a context for understanding these subtle shifts in tone. For instance, those who worked closely with fundraisers talked about their anxieties regarding the pursuit of such long term research.

Vicky/I think research is slow moving and after a couple of years I think they will want to know what the results are and what we're finding. My fear is that it's going to take far longer than we think it will because now we're at the beginning. We say that the scientists think they can make a significant difference within the next twenty years, but my fear is that it's going to take so much longer than that.

Others who worked in the publications department talked about the challenge of conveying what was increasingly acknowledged as the lengthy timescale for translating genetic research into medical care.

Helen/ It's very difficult to communicate. It takes decades potentially. That's very hard to understand and secondly it's difficult for us to tell people that,

because it's not very exciting, for us to say we need your money for twenty more years please. But of course the press want more immediate dramatic kind of thing, so that's a problem and I think our role is awkward in that we end up saying a lot of the more boring responsible stuff

One event which seemed to highlight the challenge of communicating the timescale of genetic research was the fundraisers rally, an event already discussed in some detail (see page 158). We have seen how the talk by a member of the Charity's staff generated disappointment and frustration among the fundraisers precisely because so little was said about the future potential of the research work in his speech. Talking to the person who had given this talk at a later date, I asked him about why he had chosen to present his speech about research in the way that he had and if this was an attempt express a more cautionary note about genetic research. Initially surprised by my question he says:

Well the specific point that just because there is more research doesn't mean there is less breast cancer has been made by a number of cancer charities. For example when we [the Charity] talk about breast cancer now, we talk about 'reducing the fear' of breast cancer, as opposed to 'eradicating' breast cancer, which used to be our old mission statement.¹⁴⁵ It's changed [because] it's not necessarily clear how you can eradicate breast cancer, because that implies that you can stop it happening in the first place and I don't know whether anyone knows whether you can stop it happening [...]. Also at this point the research is still just getting going [...] but it may take a long time to really make a difference.

We can see how he appeared to concede that the decision to structure his talk in this way was in some respects to talk down the heightened expectations about the scope of genetic knowledge. However not all were so convinced that this was necessarily the best strategy. On hearing about this talk, mainly from the way fundraisers had expressed their disappointment, another member of the research services team expressed her frustration at this decision. She pointed out that it made talking to fundraisers about the research more difficult and said it would have been better to focus more positively on the future consequences of gene

¹⁴⁵ In 1997 the Charity's mission statement was linked to the language of 'cure' and the 'eradication of the disease'. By 1999 this had been changed as the full context of the new mission statement revealed.

Despite [Charity H's] achievements since our launch in 1991, there is still a long way to go in breast cancer research. The establishment of the [Charity H's] research centre is the beginning of a long journey toward our ultimate goal - a future free from the fear of breast cancer

research.¹⁴⁶ Her comments suggested that a strategy of ‘talking down’ might itself be risky for the Charity, who had to square the need to communicate the real timescale of genetic research with meeting the expectation and hopes of fundraisers.

8.1.3 Bringing treatment into view

However, alongside an attempt to address the issue of timescale in relation to basic science research, and reduce the ‘hype’ associated with genetic knowledge, there was another seemingly contradictory feature about the way the Charity’s work was talked about at this time. This was apparent in the way certain slogans began to appear in the Charity’s publicity material, as an excerpt from the Research Centre Brochure illustrates.

[Charity H] believes in ‘*the bench to bedside*’ approach. We take seriously our responsibility to ensure new findings are used for the benefit of people with experience of breast cancer

We are approaching the problem from several different angles and adopting a ‘*micro-macro*’ approach, micro meaning the molecular biology of breast cells’ (healthy or cancerous) and macro meaning collaboration with clinicians to improve the way in which breast cancer is diagnosed and treated. (my emphasis)¹⁴⁷

The use of these particular descriptive mottos draws attention to the way a clinical endpoint was highlighted in relation to the Charity’s research. Alongside a message which implied the timescale for the fruits of genetic research was likely to be long, there was also an effort to make sure that a hoped for clinical interface was a consistent element of discussions of Charity’s research work.

Nonetheless, this clinical domain was circumscribed in particular ways. It is not until 2001 that the current application of genetic knowledge in relation to breast cancer, predictive genetic testing, is mentioned. Up until that point there seemed to be a marked silence about this technology, which was of course directly associated with the discovery of the BRCA genes.¹⁴⁸ For instance, in an article

¹⁴⁶ It was significant that when the opportunity arose during the focus group research when fundraisers pressed us to ‘tell them more about the research’, or when more problematic issues had already been raised about the current utility of genetic knowledge, Susan did not hold back in ‘talking up’ the hopes and expectations associated with the research at the centre

¹⁴⁷ In the centre brochure much is also made of the connections with the specialist cancer hospital that stands in close proximity to the research lab.

¹⁴⁸ There was one exception to this prior to 2000. This was a letter from a woman who had a large family history of the disease, had decided not to go ahead with testing for the BRCA genes but explained that she

in a 1999 edition of the newsletter looking at the 'Role of key breast cancer health professionals' there is no mention of the role of geneticists, genetic oncologists or genetic counsellors, although the role breast surgeons, cytologists, radiographers, radiologists, oncologists, breast care nurses are discussed. There was also an elision of the somewhat drastic interventions that could be offered to women at genetic risk of breast cancer. This helps to explain, in part, why discussion of the clinical application of BRCA genetics was avoided.

In contrast to huge numbers of articles in the popular press and women's magazines that appeared during the time of my research, particularly during Breast Cancer Awareness Month (see also Henderson 1999), the Charity chose for the most part not to publicly discuss the issue of prophylactic surgeries; the 'preventative' interventions available for those at high risk because of their family history or where a BRCA mutation had been positively identified.¹⁴⁹ This silence was exemplified in an article that appeared over two editions of the newsletter in 2002 looking at 'breast reconstruction'. The first edition examined the procedures and clinical options available and the second edition examined this issue from a more personal perspective. In both articles no mention was made of healthy women who might, because of their at risk status, voluntarily decide to undertake such surgery. Some indication of how this unproven, yet high profile, 'treatment' procedure for 'healthy' women might be problematic to the Charity was apparent in the introduction to the second article.

A woman's fundamental sense of self is affected by the alteration to her breasts, one of the main symbols of female self image. The breast is about who you are as a woman..sexual, maternal and nurturing.

was concerned about the fact that other younger members of her family were not being offered routine screening because of their risk. Published in 1997 this letter drew attention to the need for regular screening for those at risk because of their family history and therefore, at least potentially, the limits of resources and the necessity of triage in clinical cancer genetics. The official editorial reply to this letter sidelined this difficult and complex issue when it was simply acknowledge that the woman's daughter had every right to request a referral and get screening. Nevertheless publishing the article illustrated the dangers inherent to addressing this particular aspect of BRCA genetics.

In 2000 the discovery of the BRCA1 and 2 genes was cited as 'an important tool for predicting the risk of breast cancer for women who come from families with a high incidence of the disease' However no mention is made about the reliability of predictive testing or the 'treatment' interventions available to those who test positive for one of the BRCA genes.

¹⁴⁹ This was apart from a small news item in the 'parliamentary matters' of the newsletter in 1997. This small news item highlighted the need for a register to monitor the number of women choosing to go ahead with this 'radical' and 'drastic' measure. A positive response to this item was printed the following month in letter sent in by a fundraiser.

Significantly there was a comment in the science section of a different newsletter on prophylactic Oophorectomy, the surgical removal of a woman's ovaries to reduce the risk of breast and ovarian cancer in healthy women. However, the author pointed out that there was much 'uncertainty' surrounding this intervention, and seemed keen to move the issue forward to examine how the clinical research associated with this procedure would lead to new ways of *treating* breast cancer.¹⁵⁰

Saywell, in her analysis of breast cancer narratives in the media, notes that mastectomies for those who have had breast cancer are constructed as a 'violation of femininity'. That is, because the breast is an iconic 'image of idealized femininity, the asymmetry of mastectomy or lumpectomy represents an assault on beauty and perceptions of normality' (1999: 43). It is perhaps then not surprising that prophylactic surgeries or removal of the organs of 'nurturance' in *healthy* women were somewhat problematic for Charity H. The issue of prophylactic surgeries drew attention to the drastic and limited 'treatment' available to those at genetically high risk of the disease. More significantly as an intervention arising out of genetic knowledge, it was a procedure that threatened the Charity's image of genetic research as a symbol of hope for the future. This was a symbol that was represented in liberal use of 'normative' gendered representations of young, healthy and female bodies in the organisation's publicity literature. These displacements and omissions bring attention to what a number of feminist cultural commentators have long pointed out that the body is not simply 'neutral' matter for the inscription of gender (Gatens 1996), (Grosz 1994).

¹⁵⁰ As an excerpt from the article illustrates

Readers may have seen press coverage claiming that surgical removal of both a woman's ovaries can reduce the risk of breast cancer by up to 70% - there is no need to be alarmed by these claims. This research looked at a small group of women who have a mutation in the BRCA1 gene, and are therefore considered to be at high risk of developing breast cancer. Even for these women, it is very unlikely that such a drastic and permanent measure will become a routine therapeutic options[...]What is most interesting about this research is that it shows that drugs which block oestrogen may be useful in preventing as well as treating breast cancer. From this we can look at the ways in which drugs work and therefore find non-surgical methods of reducing the risk of breast cancer (2000)

The clinical dimensions of genetic knowledge were therefore demarcated in the Charity's publicity literature in ways which highlighted future treatments for those with breast cancer rather than risk being associated with uncertain interventions for 'healthy' women.¹⁵¹

The personal difficulties engendered by the association between the research work of the Charity and current clinical application of BRCA genes, for those who worked in the Charity, became apparent one afternoon in discussing the other aspects of my research with Susan. An event I recall in my field notes.

We are sitting in the rest area having a cup of tea together. There is a copy of an article from a women's magazine about a woman who has chosen to go ahead with testing lying on the sofa. Alongside the story is a picture of the women's family tree and a small box with some figures about risk. Susan picks it up and, looking at the page with these visual representations on, says that it must be 'difficult to take in all that information' for those women who go to the Clinic. Thinking that she is referring to the risk figures, I agree saying something about how figures mean different things to different people. She agrees but says that 'actually I was thinking about the tree...they're all so 'dark' with those black circles'. I explain that a black circle means that a person has had breast cancer and that they are used all the time in the Clinic. Surprised she says,

They're just so frightening I mean why would people want to be tested in the first place, is it because of their children. I get quite a lot of phone calls from people worried about their risk and asking about genetic testing'.

Warming to her theme I point out that many people coming to the Clinic have high expectations about genetic testing when in fact it's technically a very difficult procedure and can sometimes take years to get a result. She seems surprised saying,

The impression you get is that you go in have a blood test, they whizz it around and then give you the result in a few days, I didn't realise that it was such a long haul.

Talking to her about other misconceptions about genetic research I tell her about a recent event I had been involved in where a scientist had referring to a newspaper article to show that genetic testing could 'improve a person's quality of life'.

¹⁵¹ It must also be noted that in the last few years a new possible treatment end point for the molecular based research being undertaken at the research centre has emerged. This is illustrated in a small excerpt from the Research Centre brochure, which points out;

In the near future we hope to diversify in various ways, by perhaps looking at other factors such as diet which might trigger genetic mutations, with a view to influencing *complementary* therapies in the widest sense.

Making connections with the area 'complementary health' and not just clinical bio-medicine is something of a new development and can be seen, in a different way, as part of an effort to make explicit how genetic knowledge will be useful in terms of a slightly different definition of 'care'.

I tell her that the story he talked about was about a woman, who had been about to undergo an operation to remove her breasts because of her family history. A few weeks before this surgery was about to go ahead, a gene mutation had been discovered in a blood sample from one of her relatives enabling her to have a predictive test. This revealed she was not a carrier and didn't have to go ahead with a prophylactic mastectomy.

I was keen to point out to Susan how in fact testing is not always as conclusive or as definitive as the scientist has suggested. Susan's concerns are different;

I'm more worried about what that kind of story does for women who do test positive, I mean does that mean that they should go and have a prophylactic mastectomy?

This informal encounter revealed how a member of the research services team associated genetic testing with a certain degree of anxiety and concern. This suggested that at least for some of those working in the Charity this was personally a problematic dimension of the research the organisation they worked for was involved in. Others indicated more clearly how this was dangerous territory for the public face of the Charity. Helen, who was directly involved in writing the copy for publications such as the newsletter, talked about how the media tended focus on this aspect of BRCA genetics and the consequences of this for how the organisation presented such knowledge.

Helen/ the whole family history thing has just been so overplayed. It really all needs to go the other way. It seems like if people have any family history now they immediately assume the worst and think that they will get breast cancer. There are some 'incredible stories' in the media. There are more stories in the press about bilateral preventative mastectomies than there are about other things. So talking about focusing on genetics makes our research scope sound quite narrow, it sounds like just one area where as it's actually a huge area with such huge implications.

The importance of situating genetic research in a broader frame of reference, while also implying that such research was still about making connections with a clinical arena(which wasn't associated with the uneasy consequences of predictive medicine), was apparent in the way Helen told me about a new piece of publicity material.

We've been working on a more up-to-date version of the research centre brochure to mark its opening. There have been some changes about how we talk about genes, because we were worried that people would think that we were only looking at inherited genes. We now say how all breast cancer is genetic in some way and there is much more about the clinical connections we're making with Hospital D.

If it was important to dissociate the Charity from the current application of BRCA genetics one particular ‘treatment’, a drug for those with breast cancer, was given an extremely high profile in the Charity’s publications. ‘Herceptin’ is one of the first drugs to be derived from molecular based knowledge of breast cancer.¹⁵² From 1999 to 2001 the drug was mentioned in six different articles in the newsletters of the Charity. Three of these referred to the fact that the Charity had made recommendations to NICE (National Institute for Clinical Excellence) to support the licensing of the drug during the time when it was being assessed for use in the UK. Talked about in the popular press in terms of a ‘vaccine’ for breast cancer, the Charity acknowledged in the first issue of the newsletter in which Herceptin was mentioned that the story was as ever ‘a little more complex’ than this. The article pointed out that it is suitable for only around 30% of women with breast cancer, not always successful and, at the time of my research, only available in the US. Nonetheless, this was subsumed in subsequent articles by a much more upbeat assessment.

Herceptin is exciting because it's the first treatment created from research investigating genetic changes that cause breast cancer[....] with continued research into genetic changes associated with breast cancer we hope to make even more progress towards eradicating the disease' (2000)

During an interview with a member of the research services team I discussed the way Herceptin had been talked about in the publicity literature of the organisation and asked him whether this was the kind of ‘result’ that the Charity would like.

Henry/Oh, absolutely. Here is a drug that may have great benefit in specific cases, we can do a test for people that have a lot of Her2 on the their tumor cells so you know who to target.

He seemed to concur with my assessment that Herceptin was a treatment which could be used to demonstrate the validity of the Charity’s basic science approach. However, talking about Herceptin with Henry also raised other issues about developing therapeutic agents from molecular knowledge:

If the drug [Herceptin] is never used in this country, then you could make the argument well why bother doing the research and certainly in some ways that is

¹⁵² It has been in development for over 10 years and is essentially an antibody for those women who over express a particular protein ‘Her2’ (Human epidermal growth factor receptor). It is licensed to a large American pharmaceutical company.

part of the campaigning issues we are doing because we see that as a responsibility to deal with that end of it as well. I don't think there is any question about whether it's medically valuable in some cases but NICE have to make a decision weighing that against the cost as well. Herceptin is an expensive drug and these drugs tend to get more expensive with time as opposed to less expensive. Also you have to remember the time lag between the actual discovery of the 'Her2' protein and the making of a therapeutic agent that actually works. It would have been certainly more than a decade. So even if you discover something today there is still going to be that considerable timelag for it to go through clinical trials.

The cost, as well as the timescale, of treatment derived from molecular knowledge highlighted another potentially problematic aspect of gene research.¹⁵³ As Henry's comments, implied these challenges may have made it particularly important to publicly support the licensing of the drug in the UK.

Analysis of publications such as the newsletter demonstrates the extent to which 'talking up' genetic research in earlier publications has subsequently been accompanied by a more difficult and necessary precautionary approach. The need to define a post-genomic context for gene research is demonstrated in the tone of these later publications as well as the comments and concerns of staff working within the organisation. We can see that there is also a concomitant effort to bring to the fore a clinical dimension, although the dangers of the current clinical application of BRCA genetics is only all too obvious, as certain omissions in the Charity's publicity material make clear. Another drug treatment, Herceptin, provides a valuable example of the future application of genetic knowledge. Nevertheless, publicly lobbying for the licensing of this drug also made social and ethical issues, in this case supporting the needs of breast cancer patients, a more explicit part of Charity H's work. I explore this emerging agenda in the social practices of the Charity in the next section of this chapter.

8.2 Ethical strategies

Irwin points out that a concern with ethics is part of a newly evolving paradigm in the governance of 'science' in the UK and Europe (2002) while Nowotny

¹⁵³ The problems of cost was further confirmed in an interchange with Susan who pointed out how the pharmaceuticals perceived basic genetic research as 'high risk' and were generally much more inclined to invest in 'something like a new cancer drug, because obviously there is market out there'. The problem was she said 'the likely costs of these diagnostic and prognostic tests for predictive medicine enormous, and I don't know where the money is going to come from..it would probably mean something of a two tier system of state and private health care'. Despite this somewhat pessimistic assessment she did add that 'this doesn't make it a good reason not to pursue basic research though'.

has noted how increasingly important it is for those institutions and companies engaged in basic science research to demonstrate an awareness of the 'social' (2001). It is perhaps not surprising then that in various ways attending to 'ethics' was something that the Charity had begun to address during the time of my research. I explore in this section how ethics is being incorporated in this context as a result of concerns which arise from the pursuit of genetic research in terms of three 'case study' scenarios. First, the way a specific project was initiated in the organisation which explicitly mobilised an ethical agenda and then how two particularly challenging issues pertaining to the pursuit of genetic research, were negotiated by the organisation.

8.2.1 The Advocacy Project

The 'supporter advocacy project', as it was first known provided the basis for my involvement and research work in the Charity. This project to investigate the possibility of involving fundraisers more directly in the organisation and the work that it did was obviously directly linked to an emerging ethical agenda associated with accountability and inclusion that has become a key feature of neo-liberal governance (Irwin 2002), (Strathern 2000). It was apparent fairly early on that this was very much a 'top-down' initiative, comparable to recent moves towards 'inclusion' in a range of government initiatives. There has, for instance, been much discussion of 'deliberative democracy', particularly in relation to health care, where taking account of 'stakeholders views' is increasingly held up as a gold standard for organisational and institutional practice. However, the move to address and possibly implement 'supporter advocacy' had a very particular meaning in the Charity. This was because they were an organisation with a history of 'grassroots' fundraising activism for basic science research on the causes of a widespread and common female disease, that had its own gendered morality.

The particularities of this context became apparent during a meeting with several members of the research team when we met to talk about the research I was going to undertake. One person was uncertain about exactly how advocacy would work in practice, as well as its value. It was a question which prompted

other participants to talk about the history of the Charity and why this made such a project important but also challenging.

Henry / I'm just not sure how patients could talk to the scientists about molecular biology

Monica/ But that's not the point, it's their money they should say how the money is being spent, where it should go and what the implications might be, we have a duty to allow people to do this. The Charity is unique in many ways, it's not a medical body although we fund medical and scientific research. We don't, like other cancer charities, provide a 'service' per se, we don't have 'customers or clients'. But we do have this unique history; set up by a charismatic founder and are seen as a 'grass roots' organisation. So the way we involve patients perhaps requires a unique approach that hasn't yet been done before. If we ignore supporters' views about the research, we do so at our peril.

Monica's response suggested that there was another, more urgent and practical, reason for instigating this policy. From talking with others, there was an implicit sense that such an initiative would help in the challenges posed in pursuing long term, complex and currently contingent genetic research. This became apparent in the way a possible hypothesis for undertaking the research work associated with advocacy project was proposed; in terms of 'how women invest in research'. A section of a document which outlined this hypothesis is copied below

Investing in research

High Risk High Return	Medium Risk Medium Return	Low Risk Low Return
Long-term	Medium –term	Short term
(Hard to communicate)	(Easy to communicate)	(Easy to communicate)
Basic Science e.g. genetics Epidemiological studies	Translational research Clinical Trials Development of new imaging techniques	Palliation of symptoms Organisation of care
Output Magic bullet/cure	Output Small % increase in survival	Output Pain reduction
Understanding causes	Identification of high risk groups	Reduced depression Increased Quality of life

We can see from this that there is an assumption that those who fundraise for the Charity see basic science research as a 'high risk/ high return' domain. If it was a high risk investment for the fundraisers, it was also 'risky' for the organisation, as the document pointed out. In this sense, implementing supporter advocacy

was not just about being seen to be 'ethical' but also about finding possible solutions to funding research that was 'long term' and 'hard to communicate'. What perhaps could not be anticipated was the way this initiative and the prospect of it being instigated challenged and threatened an established nexus of social relations between 'lay' and 'expert' which had been so central to the success of the organisation.

The initial 'in-house' report on the research I undertook with fundraisers was fairly positive about how fundraisers had responded to the possibility of lay advocacy.¹⁵⁴ However, a much fuller understanding of the significance of the data was gained after further analysis and in connecting these findings to other events and issues that arose throughout the period of my field research. This revealed a more complex and ambivalent picture. It is true to say that there were a few people who were enthusiastic about the idea of supporters becoming more involved in the research, particularly from those who had had breast cancer.¹⁵⁵ Even for these individuals, this was undercut by a sense of hesitancy, as Jackie's comments illustrate

Jackie/ Obviously the scientific people on such a committee would be the ones with the background knowledge, it would only be a layman's point of view that I would be putting forward. You would want to make sure that they were mostly scientists, the people involved wouldn't you.

Another fundraiser who had expressed enthusiasm initially about the idea, conveyed her concerns about the effect of such involvement pointing out that 'I think if you open it out too wide there is a danger the research will not be as concentrated.' Although one supporter said it was important to have scientists and supporters 'either talking or listening' and that 'we need to have it both ways', it seemed that ultimately the scope of her and others' involvement was fairly narrowly circumscribed. As she said 'I can't think what else we could do, because we're not

¹⁵⁴ The summary of the findings was written by another member of staff, based on the analysis of the findings undertaken in the weeks and months after completing the interviews. Although it was also noted that 'not everyone would want to be involved in this way and some felt 'that there would be people better qualified', the tone of the summary was generally that supporters were keen for some kind of advocacy. I would suggest that the simplified presentation reflected not only a feeling amongst some members of staff that supporter advocacy should be implemented but also that the Charity needed to be seen to be implementing this, given the kind of research they undertook.

¹⁵⁵ It was pre-dominantly fundraisers who had had breast cancer or who worked in a health field who were most vocal in expressing their opinions and concerns about the research the Charity funded as I have examined in section 6.2.2

professional people, so we just do what we can'. In other cases, the strength of an identification with being a 'fundraiser' seemed to preclude discussion of any other role, particularly one that was so radically different as being an advocate for the Charity. Nevertheless, it was the extremely adverse reaction of some fundraisers which brought home the difficulties and dangers this project posed. For instance, this was the response of one focus group to the possibility of developing supporter advocacy after I and another member of staff tried to elicit their views about risk factors as part of a research exercise which they knew was linked to its implementation:

Person A/ You're saying that you're not testing us but you are. Surely you should be telling us what the risk factors are?

Susan/ We're just trying to find out what you think because there is a feeling sometimes that scientists might get too narrowly focused on one particular thing

Person B /I for one wouldn't dream of going down that route. I mean I have every faith in the scientists

Susan/ well we're just trying to build a better relationship between the scientists and the supporters?

Person C/ What can we contribute, apart from saying it could be to do with stress, you're asking us to do the impossible really.

Another fundraiser was equally nonplussed and vociferous in her response to my queries about the prospect of advocacy.

Sahra/ what sort of things do you think the research should be focusing on?

Betty/ for the ordinary person like myself, who knows

Sahra/Do you think it's important for the Charity to have supporters involved in different ways in the organisation, not only as fundraisers?

Betty/personally speaking I don't think that anybody knows where the money for research should be going. That's for the scientists. I mean lets face it they are the people that know what they want to help their research. We don't. Or I wouldn't. So personally I don't think that people have got the experience or the know how to sit round a table and discuss 'Lets spend so many thousands of pounds in buying this'. I think it's up to the scientists.

Sahra/ do you think if people had training that might be a possibility

Betty/ No. No. No! I don't think that training could do it. You're talking about years of experience hands on. No, definitely not. It's a waste of time and a waste of money. To actually put people through training to find out that. I mean why should one actually do that when the scientists are there anyway. That's what they're being paid for. To know what equipment they want and to know

what research is necessary in what field. If you can't put faith in them then you can't put faith in anybody

Both these strongly felt responses illustrated how the prospect of advocacy for a significant number of fundraisers threatened to bring about changes that challenged a perception of the research work the Charity funded as an arena of skilled practice. This perspective, as we have seen, was very much a part of the fundraiser's motivation to be part of the organisation

The ambivalence expressed by fundraisers was also echoed in the way both scientists and some staff responded to this initiative. Although there was widespread recognition by many staff and scientists of the 'rights' of supporters to have a 'say' in the way that the money they raised was used, there was also uncertainty and hesitancy about how this might be done. The 'official' findings of the advocacy research with the scientists did not really draw attention to this aspect.¹⁵⁶ But this was not the whole picture. A number of scientists, as the summarised report suggests, did recognise what they saw as the rights of the supporters to be more involved in the research. As one scientists pointed out:

Andrew/ They are the punters and obviously we need to tell them what we've done with the money and they should be able to talk to the scientists.¹⁵⁷

But even fairly positive comments such as this were subsumed by those who expressed anxiety about how this 'ethical' goal might be implemented; concerns which one scientist tried to articulate at the same time as suggest something of a solution.

¹⁵⁶ This is based on the findings of an internal report on the advocacy project written up by another member of staff. Although she and I had discussed some of the tensions among scientists about this initiative, the internal politics of the organisation meant there was an imperative not to bring into the open too many of the difficulties the scientists had talked about. The discussion in the report re-inforced this upbeat presentation, as this excerpt demonstrates:

Scientists showed a willingness for supporters to be engaged in discussions about research and the need for them to be well informed about what their donations are being used for

¹⁵⁷ Others also felt that this could also ultimately have benefits.

Gillian/ I think it is important they have a more active role to a certain extent. Maybe that science them and us thing would reduce and we would be a less kind of sheltered institute. I think that if you want someone to carry on supporting something then you have to accommodate them as well and inform them as to where their money is going.

Tim/ Cancer used to be a taboo subject, it is no longer taboo, in fact it is becoming an obsession and given that is changing I think that cancer research organisations need to recognise that people want to have lots more information. I don't necessarily think this means that one's research strategy should be superficial because it reflects what people currently understand about cancer or what is discussed about cancer in the media. [...] My concern would be that you could end up with a poorly informed, but populist research strategy. But if you had a lay body of supporters who had some kind of training so that people understand it and people's main concern is not about overhead power lines. I think if that is the case we will have good funding, good research and good understanding by supporters

Although Tim recognised that the Charity needed to address the increased awareness among lay groups about cancer, his remarks also suggest that he found the prospect of lay advocacy somewhat threatening, fearing it might lead to a 'populist' research strategy. Significantly, it was only when lay persons had been provided with 'training and education' that he felt such an initiative could be workable.

Scepticism and fear were also identifiable in the way that some staff talked about this issue. Discussing how different research programs in the US had sought to involve 'lay' people, one staff member pointed out the difficulties of imagining how such a project might work in this context.

Henry/ One of these examples would be clinical research where the people that are actually being researched on are the people with breast cancer. So they can have input into things that the people designing these studies wouldn't necessarily see. For example one of the things would be how many appointments does somebody have to have to be part of the trial. But when you look at basic research do you actually want people coming in and saying your looking at the wrong gene! The point is we are not starting with a blank sheet.

But it was perhaps one of the scientists who best illustrated the way the prospect of advocacy was particularly challenging for this organisation.

Andrew/ The question is do the people who aren't scientists do they really understand all the issues of what should be done. [If advocacy was implemented] I would envisage a situation in ten years where people are asking well you found the BRCA mutations why isn't there a cure, it's just going to take a long-time. I think it's a difficult thing cos I think they should have some say but I don't know how, it's just it really is hard to understand this stuff.

The necessity and danger of supporter advocacy highlighted by this scientist was also recognized by Helen, a member of the communications team. She initially responded positively to this possibility, but then on reflection also pointed out

that the greater awareness this facilitated might also not be such a good thing for the Charity and the work it did

Yeah that would be good so that supporters had a clearer understanding of the timescales or the money involved or the cautious nature of science. That's all so difficult to understand if you're not directly involved. [But] if people realised that we need five million every year for lets say twenty or thirty years that might be off-puttingly big. They might think no we want to see more immediate results or we want to know more about other areas of research. So it might not be in the Charity's interests..it's hard to know, because there are other charities out there as well.

On the surface the incorporation of the goal of advocacy appeared to mobilise an ethical agenda, provide an opportunity for inclusion, with the potential to facilitate greater understanding about the scope and timescale of genetic research. However, it soon became clear that the prospect of this initiative exposed how people identified with and perceived the Charity, their role in it and the expertise associated with the genetic knowledge it pursued.

This 'ethical' initiative was not easily or readily countenanced by fundraisers. The policy of advocacy did recognise and capitalize on the supporters' demand for 'knowledge'. It also shifted the onus for the reproduction of that expertise away from those and that which had been its sole repository and source; the skills of the scientists and their research. For some supporters it threatened the ethos and identity of the Charity, which had provided the inspiration for their initial involvement and which was constantly being reproduced through fundraising practices. It appeared to cut into an established 'gift' relationship between lay and expert which had been so central to the Charity's foundation and the fundraiser's pursuit of a 'redemptory' science. Although the scientists resisted being cast as objects of 'expert' science, it was clear that the 'ethical' goal of advocacy posed a different threat that, from their perspective, held out the possibility of more open challenges to their research. These contradictory responses can only be understood in relation to the contingent and currently limited nature of genetic research itself. At the same time as providing a possible solution in terms of facilitating greater understanding the prospect of advocacy could, as the responses of the scientists and staff indicated, also bring the reality of complex and long term gene research more clearly into view.

If the prospect of advocacy was something that many seemed unwilling to participate in, for different reasons, the way the organisation responded to two other events engaged less discussion and a more open embrace of what was more obviously an 'ethical' agenda. This signalled a new locus of activity for the organisation that like advocacy arose from but also fed into the transmission of the genetic research they funded in complex ways.

8.2.2 Gene patents

The fact that the Charity had been involved in the work leading to the identification of the BRCA 2 gene was something that was openly discussed in earlier issues of the newsletter (see page 199). However, in the months leading up to the announcement of the first draft sequence of the 'Human Genome' in June 2000, the question of 'ownership' of genetic knowledge became increasingly a more delicate issue. This was particularly after the 'competition' between the 'public' and 'private' venture to complete the first draft of the human genome began to subsume media coverage of this event and legal claims by an American bio-tech company to the patent on BRCA2 gene were used to highlight the negative consequences of patenting genes.¹⁵⁸ This latter development drew direct and somewhat uncomfortable attention to the fact that certain leading members of the Charity's scientific team were intimately connected to these developments.

The problems this posed were indicated by an informal conversation I had with a member of the research services team six months before the announcement of the first draft of the human genome. Susan had just returned from a meeting with other members of her team, as well as some of the scientists. Positively buzzing with news about the fact that the patenting question is 'about to be blown sky high' she explains that the problem is the Charity simply doesn't have a 'policy' position on this issue adding 'I can't begin to think about how we could discuss this issue in the newsletter, it's so vast'. Her remarks suggested that the patenting debate posed difficulties for the Charity. When the work of the Charity was very much associated with the 'enchantment' of science, as hope for the future, the patenting

¹⁵⁸ See for instance 'Your Life in Their Hands' The Guardian November 15th 2000 or 'US Firm double costs of UK cancer checks' The Guardian January 17th 2000.

of genes, forced an engagement with the 'politics of disenchantment' in to play(Strathern 2001).

Over the course of the next few months, gene patenting became an increasingly central topic of public and media debate.¹⁵⁹ Although the Charity was active, through a parliamentary breast cancer lobbying group in calling the government to oppose gene patenting, there was little discussion of this issue in their newsletter. Nevertheless, the Charity did make their stance on patenting more public during a TV news studio debate about this issue.¹⁶⁰ The discussion involved the chief executive of the Charity and a leading spokesperson for a number of bio-tech companies. Predictably the latter was keen to point out how patenting insured that companies could recoup their costs and argued that, contrary to popular perception, 'it did not stop competition'. The Charity's representative, on the other hand, presented a more complex position. She pointed out that 'while companies need to protect their investment' the Charity felt that the government 'should intervene for *patient* good'.

This somewhat conciliatory stance drew attention to the delicate balance the Charity sought to achieve. This involved being careful not to alienate future investors and supporters of those who were likely to fund and help realise the treatment goals of genetic research. Given the outcry over gene patenting that followed the announcement of the first draft of the human genome in June 2000 it was clearly also important to align the Charity within an ethical domain by supporting concerns expressed by the NHS about how patenting claims would compromise 'patient care'. However, there was little appeasement towards a different 'industry' in the way the organisation 'publicly' responded to another 'ethical' issue.

¹⁵⁹ Parliamentary debates in January 2000 referred to gene patenting (along with the issues around the use of genetic testing for insurance purposes, discussed in the next section) as the 'dark horses of the genetics revolution'. Another parliamentary member pointed out that these issues must be addressed by parliament if the 'progress of medical research' was not to be impeded and the focus of gene research would be transferred from the 'lab to the courtroom'. (Source Hansard Papers January 2000)

¹⁶⁰ This was a Television News Debate in July 2000

8.2.3 Genetic testing and insurance

The use of genetic test results to help establish the level of premiums for life and health insurance was also a debate that increasingly became the focus of much media and public discussion at this time.¹⁶¹ ABI (The Association of British Insurers) guidelines about this issue had undergone a series of permutations in the preceding years. A three year moratorium on the use of genetic testing was issued in 1997. In 1999 the ABI ruled that predictive tests be used for a limited number of conditions, which included breast cancer, before GAIC (the Genetics Advisory Insurance Committee, set up by the government to deal with this issue) had completed its report. It was following this somewhat controversial decision by the ABI that the Charity made a decision to take a more public stance on this issue.

The organisation's opposition to the use of these tests for insurance purposes was demonstrated in an article that appeared in the newsletter in December 2000.

The article was a response to the decision by the Human Genetic Commission to launch a public debate about the use of genetic testing information, that included the use of genetic testing for insurance purposes.

This is a very important debate for women with breast cancer.
[...]There are serious implications if the results of genetic tests are allowed to be used for purposes other than those that they were taken. We are concerned that the potential benefits of genetic testing might be lost if women were deterred from being tested for fear of unfair discrimination in obtaining insurance or employment.

Their decision to oppose the use of testing for insurance purposes appeared to be vindicated when in September 2001 the ABI proposed a three year suspension of the use of such tests. Commenting on this decision in the newsletter the organisation noted that;

This is a very positive step forward, decisions will not be made about the use of genetic tests for insurance purposes until the wider social and ethical issues have been fully considered (September 2001)

The interventionist stance that the organisation adopted on this issue signalled therefore a new zone of activity examining the 'social and ethical' impact of genetic knowledge. The reasons for this emerged during an interview with one of

the research services team a few months before the Charity made their position on this issue more public when Henry talked about how the organisation might begin to address this issue.

Henry/ There is a committee that's meeting to decide whether the test should be used [for insurance purposes] based on clinical and actuarial relevance. But they don't have the ability to look at the social impact. One of the concerns is that people wouldn't come forward for genetic testing, because they would be afraid of the affects on their insurance. In the case of breast cancer where there is something that you can do, it would mean denying themselves potential medical treatment. But there are additional things to consider. If you have a test for BRCA1 or BRCA2 you can have prophylactic mastectomy and there is some evidence that that will bring your risk of dying of breast cancer down to the normal population. Then the question becomes how do the committee actually take that into account, or do the committee take that into account. Do you only give it to people who have the procedure and if you do, is that not then a financial incentive for people to have prophylactic mastectomies. So it's a very complex issue[...].

But because we are in part funding research to find new genes, you could make the argument that we also have the responsibility to deal with the success of actually finding those genes[....]It's also about the external impression of the Charity. Medical research charities view us as a patient organisation rather than a medical research Charity. I mean we are a medical research Charity right now, but we have been involved in campaigning and we are involved in certain activities, helping patients and lobbying governments and maybe even more so in the future. [So the question is] does the Charity want to deal with the social implications of the research that it funds?¹⁶²

These comments suggested that the rationale behind the organisation's later decision to oppose the use of genetic tests for insurance purposes was caught up in a range of issues and concerns. This included both a real sense that the 'social' consequences were being neglected by key parties in this debate. It was also linked to a feeling that Charity H had a responsibility to deal with the 'impact' of the genetic knowledge it funded, whilst also making efforts to maintain its external 'impression' as a 'grass roots/patient' focused organisation. It was also clear from what Henry said that embracing this issue meant talking about the current clinical application of BRCA genes, particularly the limitations of testing technology and treatment interventions. Henry was clearly aware of the complex consequences of this as he reflected on how championing this social agenda might intersect or conflict with the scope of genetic knowledge

¹⁶¹ See for instance 'MP's slam insurers on genes' The Guardian May 2001

¹⁶² The issue of genetic testing and insurance arose after I raised a finding from my research with him, that some fundraisers had talked about the need for a more 'balanced' research approach. His interpretation of 'balance' enabled him to talk about what he perceived as the 'responsibility' Charity H had to address the 'impact' or social and ethical consequences of genetic knowledge.

Henry/Of course there are ethical reasons against using certain criteria for insurance purposes which might include race and religion. Although actually being a certain race is a relatively good predictor of likely disease susceptibility. But then I would imagine as we get more knowledge about the genome, race isn't necessarily going to be such a useful tool.¹⁶³

In fact the Charity's decision to oppose the use of genetic testing for insurance purposes had very immediate consequences in terms of the way that issues which had hitherto been omitted in the publicity material of the Charity were now brought centre stage. The limits of predictive genetic testing were now at the forefront of an effort to demonstrate inappropriateness of the use of such tests for insurance purposes, as this excerpt from a newsletter illustrates:

The Charity is opposed to the use of these tests for insurance purposes[...] Women may be deterred from taking tests for fear of increased insurance premiums. In any case all that a positive test for a mutation in either the BRCA1 or BRCA2 gene tells us is that there is a pre-disposition to breast cancer, not that a woman will necessarily develop the disease. Similarly a negative result will not guarantee that a woman will not get breast cancer.

It was these entanglements and entailments which another member of the research services team seemed to be alluding to when she expressed her concerns about the apparent eagerness of some in the Charity to proceed on this particular path:

Susan/ I'm just not sure it's the right line to go down. What about other things that might come out of the centre about BRCA carriers. That just might make our current position on this very difficult.

The organisation's stance on the patenting of genes and the use of genetic testing for insurance purposes signalled then a new arena of activity for them. But this involved treading a fine line. Embracing ethics, at least in the context of questions about the use of genetic testing for insurance purposes, aligned the Charity's work much more explicitly with the current application of BRCA

¹⁶³ The way that future genetic knowledge posed challenges in making decisions about the use of genetic tests for insurance purposes was clarified in further discussions with Henry.

Sahra/Isn't part of the problem that there aren't that many people who've had a predictive test, and certainly not that many carriers who have actually been identified ?

Henry/In a way that's the whole problem, because you can't know how many people are not coming forward. Unless you do a very thorough population study, it's a very difficult to find out. What's really worrying is what will happen when we find other genes that are involved that are likely to be low penetrance genes acting in conjunction with one another, how is it going to work then. How are we going to know what the difference is between a common polymorphism and a mutation, how do you know if its significant or not?

genetics. It focused concerns on a fairly narrowly defined group of 'at-risk' persons and involved being much more explicit about the limited utility of current knowledge. In the case of patenting and insurance, something of a trade off was undertaken between a hyped and hopeful image of genetic knowledge, and raising concerns about the negative social or ethical impact of such knowledge. The former currently met the expectations of most fundraisers, but the latter brought issues about patient 'care' (for a few) into the remit of the Charity's work. Given the fundraiser's need for the science they funded to be 'redemptory', it was potentially a somewhat dangerous shift in focus, as the response of some fundraiser's to the advocacy project suggested.

8.3 Conclusion

This chapter has explored the way one organisation negotiates the transmission of genetic knowledge and research associated with BRCA genes to its supporters and a wider public. We have seen the way representations of genetic research have shifted over the course of a five year period. Initially these were encompassed by a degree of 'hype' but have subsequently been overlaid by a more cautionary message. Entwining analysis of the Charity's publications with the experience and comments of those who work for the organisation reveals how there has been an increasing need to define a 'post-genomic' space, as the timescale of genetic research becomes apparent and in the wake of the announcement that the first draft of the Human Genome. Nevertheless, 'hope' is still maintained through a focus on 'treatment' and discussion of a 'clinical' interface for gene research, although this is defined in particular ways that encompass 'drugs' derived from molecular based knowledge, but excludes current clinical application of BRCA genetics. From this analysis we can see that transmission of genetic knowledge is a something of a balancing act for Charity H which has required a shifting range of responses.

The second half of this Chapter has explored how ethical and social concerns are being put to work in this process; an approach that can be linked to strategies of governance that are being implemented across a range of institutional and political arenas (Irwin2002), (Nowotny 2001), (Rose 2001). In his study of a particular local attempt to put 'capital and science' in service to 'the social'

Rabinow shows how this brings about the emergence of ‘partially new sites and forms that catalyse actors, things and institutions into new modes of existence and assemblages that make things work differently’ (1999: 13). In a similar way Charity H’s attempt to make explicit, incorporate or build in a social and ethical agenda, as a component of the basic science research they support, also shifts the parameters of this task in ways that are not necessarily or always enabling.

Conclusion

This thesis has explored some of the social practices involved in the transmission of new genetic knowledge and technologies, associated with BRCA genes, beyond the confines of the laboratory setting. Highlighting the need for such research, Batchelor points out that the ‘career’ of a medical discovery undergoes a process of ‘translation’ when it becomes part of everyday medical practice (1996: 250). The findings presented here suggest that ‘traffic’ of transmission is more complex than this. We have seen that action, meaning and effect ricochet both up and downstream, not only of medical practice, but also scientific research itself. This brings new complexity to questions of ‘impact’, which have been so central to social science studies of the new genetics. It points not only to a need to expand the people and practices caught up in this process, but a fundamental re-thinking how the question of ‘impact’ is itself part of the work of translation.

In understanding the ways in which the knowledge and technologies associated with BRCA genetics are being used, received and acted upon, this thesis has raised questions about the boundaries and constituent parts of a normative lay/professional distinction. In the first instance we have seen that activism and initiative are central features of how ‘lay’ people, in this case patients in Cancer Genetic Clinics, and ‘fundraisers’, in a Breast Cancer Research Charity, are involved in the work of transmission.

Patient enrolment in the Clinic is an ‘active’ process that is embedded in a moral code of awareness and a need to make danger visible. This has consequences for how those who come to the Clinic perceive and make manifest their own and a more general sense of genetic risk, the agency they attribute to genes or genetic knowledge and their perceptions of the Clinic’s capacity to make ‘hidden’ risk visible. Such practices raise questions about how the materiality of BRCA genetics are reproduced, or ‘black boxed’ by patients before being seen in the Clinic.

We have also seen how a different group of 'lay' people, classed as fundraisers in a Breast Cancer Research Charity, actively participate in the transmission of genetic knowledge. Their role as 'fundraisers' can be seen as part of a 'memorial practice'. In this sense, involvement in the Charity enables loss to be witnessed while also holding out the possibility of transcending tragedy and trauma by placing faith and hope in the research work of the organisation. For many (but not all) the gene research focus of the Charity fuels this identification. Situating genetic research as part of a memorial practice also entails that it must, to a certain extent, be 'redemptory'; that is associated with 'cure' and for the 'collective good'. Interesting questions of agency and materiality are also raised here. For instance, we have seen that fundraisers' expectations inform a perception of the scientists, at least in the context of the tours, as embodied 'objects' of knowledge.

The kind of lay involvement that is part of the Clinic and the Charity also cannot be separated from the legacy of burgeoning health awareness and gendered activism in relation to breast cancer. This has been explored in relation to patients' discourses about 'visibility' and fundraisers' use of testimony. Despite the location of 'lay' agency within this nexus of power, the case is strongly made for re-considering questions of 'impact'. We can see that reproducing BRCA genetics as 'expert knowledge' is not just the preserve of practitioners or scientists but actively involves lay individuals and groups. As Lock et al. say it is 'in part because the subjects of technologies are themselves situated at [particular] intersections [...] that their co-production of technological practices makes for an important part of the analysis' (2000: 11).

If it is the position of lay individuals or groups at particular intersections which makes their role significant, it is the neglected subject position of 'professionals', situated at different but sometimes equally precarious intersections which also makes for an important part of the analysis.

We have seen that the medical or predictive scope, authority and expertise of genetic knowledge is sought or secured by scientists, practitioners and the Charity in a number of different ways. This includes the use of visual tools,

technologies or objects, a 'risk' discourse, as well as de-contextualised explanatory narratives that 'talk up' or 'hype' genetic knowledge. All of these, in different ways, serve to make knowledge 'real' and 'material'. However, such practices cannot be separated from the expectations, faith and hope of lay groups or individuals and the ontological uncertainty of genetic knowledge itself. In fact, the essential 'invisibility' of genes in the social context of BRCA genetics, such as the inability to pinpoint gene mutations in the bodies of most of those who attend the Clinic or the fact that scientists can't 'show' fundraisers their 'ideas', powerfully reflects the contingency of knowledge and expertise. I have suggested that this may make the need to make genetic knowledge tangible and promissory even greater.

Alongside a practice of 'talking up' genetic knowledge there are also in both these social arenas explicit if demarcated modes of 'talking down'. These practices must also be seen as components of the work of transmission, linked to triage in the Clinic or attempts to convey the timescale for basic science research in the Charity. This mode of communication can equally not be separated from the heightened expectations of fundraisers/patients, or the limits to knowledge and technology. I have explored how these contradictory discourses are part of the need for different 'professionals' to negotiate the ongoing gap between knowledge and care in breast cancer genetics. The presence of this distance engenders a certain degree of ambivalence for those who work with BRCA genes in a clinical or a research arena, illustrated in the disjuncture between public presentation and private or personal reflection.

This analysis suggests that it is not so much that a lay/professional distinction is not important in the context of developments in genetic knowledge but that there is a need to understand the particular ways that this boundary is constituted, shifts and changes within specific social spaces of the 'new genetics'.

In exploring the work of transmission in breast cancer genetics, this thesis has argued that questions of 'impact' must also be re-addressed in other ways. That is, the ways in which concerns about 'care' or 'social and ethical consequences', are being 'built into' the knowledge and technologies associated with BRCA

genes, so that the 'question of biological control is re-figured as one of social relationality' (Franklin 2001a:335). As Strathern points out 'like technology culture is also a source of innovation and a means of bringing forth' (1992b:7). In this thesis these processes have been explored in relation to the pastoral practices of the Clinic and the way ethical practices and social concerns are being incorporated into the work of the Charity. We can see that this not only raises questions about the ways in which the 'science' question is to be addressed by social scientists, but also has other consequences for patients, individuals or lay groups and professionals.

My discussion of this aspect of transmission has drawn, in part, from anthropological work on the reproductive technologies looking at the way Euro-American notions of kinship as hybrid of the natural and social is used as context for knowledge .

The way kinship works to 'domain' knowledge practices associated with breast cancer genetics in the Clinic is exemplified in the use of family trees. The use of seemingly objectified or de-contextualised representations of family history, as a tool of explanation or prediction, would seem to draw on and reproduce an idiom of naturalisation that mimics Euro-American understanding of bilateral and bio-genetic kinship. An explicit clinical discourse about 'care for the family' would also appear to reinforce this. In this sense, the practices of explanation, prediction and care link kinship as naturalisation to knowledge. However we have also seen that care and knowledge is fundamentally dependent on a presumed sociality between kin. This requires clinicians to attend to the 'social' dimensions of the 'family' and gives clinical family trees a very different meaning. As part of the pastoral practices of the Clinic they become 'contracts' for future care and important tools for investigating the dynamics of the family.¹⁶⁴

¹⁶⁴ In this sense its too simple to say that a clinical genogram only or simply reinforces blood ties (Armstrong 1998),(Finkler 2001) or even that the 'patient' always wants to 'tell the story of the family' or that the 'doctor' always wants to tell the 'story of the disease'(Sachs1999). This is something that I explore further in Gibbon (2002)

A parallel can be drawn here between these 'hybrid' practices and Bouquet's examination of the emergence of a genealogical method in anthropology at the turn of the century (1994). In the same way that the 'aesthetic' devices of family pedigree were excised from River's genealogical diagram, so too they are in clinical family trees. Yet Bouquet points out that River's 'transformation' of popular genealogical notions of 'pedigree' into a more universal notion of 'genealogy' was only an apparent negation of an earlier class of family trees. Similarly, we have seen that clinical practice rely on a more socially contextualised understanding of the family, as well as the patient's own active participation in finding out about their genealogical 'roots'. In both cases, the 'fundamental vision remains arboreal' (1994: 62). Just as the real meaning of anthropological trees are only understood when the social relations to which they refer are known, the reproduction of clinical family trees and the 'knowledge' they are used to pursue, is secured or sought only by attending to and engaging with the social context of the family.

In this sense 'care' in the Clinic is predicated on kinship as a hybrid zone that powerfully aligns notions of substance *and* code. This necessary incorporation of the 'social' into a range of clinical technologies such as reproducing family trees or genetic testing raises new questions about how the meanings of science, biology, DNA and genes are being re-configured in this context (Franklin 2001b). It also has more immediate consequences for patients giving, I have suggested, new significance and meaning to a notion of 'blood relatives'.

In this way the pastoral practices of the Clinic would seem to have consequences for patients that recall a notion of 'impact' in a more normative sense. Drawing on a radical different understanding of 'non-western' personhood, I have highlighted how this cannot necessarily be understood only in terms of an increased individualization, as proponents of an 'impact' thesis hold (Lippman 1992). We have seen that the sociality and participation required between family members in the Cancer Genetic Clinic not only means that being a patient necessitates a certain degree of activity but also means being a patient in a more 'distributed' or 'dispersed' sense. For some of those attending the Clinic, attention to and concern with their family is experienced as, or points to, the

evidence of caring practice. However, given that connections amongst 'kin' are not always about relating, let alone pursuing 'health' collectively, but also about 'cutting' such networks (Strathern 1996 and 1997), patients can experience their own 'care' in unexpectedly compromised ways. This is particularly when the pastoral modes precipitated by the requirements (and limits) of predictive medicine re-situate rights, responsibilities and obligations between family members.

Attending to 'the family' also has contradictory consequences for practitioners. Some embrace this new identification as 'pastoral keepers', pointing to their skill in this area as evidence of holism and an ability to attend to or deal with 'ethical' concerns engendered by predictive medicine. In this way some of the limits of genetic knowledge are circumvented, by becoming 'experts' of a different sort. This could also be interpreted as an appropriation of a valorized notion of female 'nurturance', an ethos which has been central to the heightened public profile of breast cancer (Saywell 2000), in order to further a clinical discourse about 'care for the family' and 'care for the future'. This can be seen as akin to the way Potts suggests breast surgeons have, in responding to the concerns of an earlier breast cancer 'activist' discourse about the mutilating effects of surgery, circumscribed and appropriated an image of 'feminine wholeness' in a discourse about breast re-construction (2000: 5). In this way we can see that the 'traffic' that surround clinical breast cancer genetics (as well as the treatment of breast cancer) is very much multi-directional.

Nevertheless other practitioners feel uneasy or contest these pastoral modes as a basis for knowledge and care. These differences point to the need to understand how new health care technologies intersect in particular institutional settings and how the social or historical context of diverse practitioner roles influence the integration of such knowledge into routine practice.

Kinship as a hybrid of the natural and social also has implications for understanding how social and ethical concerns are part of the transmission of genetic knowledge in the Charity. Here relations of obligation and responsibility mostly between kin are at the heart of how a group of individuals, classed as

fundraisers, support and identify with the work of the Charity. This confers a certain morality to the pursuit of genetic research which the organisation colludes with and also makes use of. As a number of anthropologists have demonstrated, new technologies are more likely to be supported if relations can be shown to be created or sustained because 'then we can breathe a sigh of relief that the social dimensions of people's lives are still in place'(Strathern1997:23), (see also Hirsch and Silverstone 1992). In contrast to the Clinic, it is the obligations and responsibilities between kin which make, rather than 'cut', this network. For the Charity, the fault line in working with BRCA genes lies in making the bio-genetic component of kin relations explicit.

Young points out that national monuments have always traditionally sought to provide a naturalising point for memory where he says 'a state's ideas and founding myths aim to be as naturally true as the landscape in which they stand'(1993: 6). From this perspective, a research centre funded in the name of mothers, sisters, and daughters and dedicated to fighting breast cancer by focusing on the micro biology of the breast would seem to have found the perfect naturalising locus for memorial practice by focusing on genes; an apparently potent source of transcendent humanity. In the initial early years after the formation of the organisation this was a research agenda that was closely aligned with the ethos of the Charity where talk of looking for a 'cure' was prominent.

The current clinical application of BRCA genetics does not sit easily with such a goal. In fact, the quest for genes that linked the work of the Charity with the Human Genome Project in earlier years has now been replaced by the messier business of functional genomics. The challenge of seeking appropriate memorial forms is, of course, far reaching. Many have suggested that the reluctance to reach closure in the anti-redemptory aesthetic of the Vietnam War memorial, or the presence given to absence through the literal reproduction of the negative space in a number of so-called Counter-monuments, built to mark the Holocaust, most successfully mediate the inevitable tension between the memory and forgetting, that any monument must address (Young 1993). The next few years will reveal to what extent it is in a similar way the hunt for and hopes of half glimpsed yet-to-be discovered genes or the immanence of genetic knowledge

which best facilitates the need to witness *and* transcend loss, rather than the complexity generated by their actual materialisation. It is clear that the current clinical application of BRCA genetics poses a danger for the Charity because of the way such knowledge aligns code with substance. That is, bringing bio-genetic connections between kin into focus, with the attendant spectre of uncertain predictive medicine and limited 'treatment' interventions, potentially undermines the pursuit of a 'redemptory' science predicated on obligations between kin.

The Charity has been active in attempting to offset the dangers posed by the clinical application of BRCA genes by making 'ethical' concerns a more explicit part of the organisation's activities. Such initiatives are not however necessarily enabling. I have shown that the prospect of fundraiser advocacy re-defines the 'gift' relationship between lay and professional in a way that is not always welcomed by fundraisers or others. In other instances, making ethics part of the work of the Charity has entailed a trade off between a hopeful 'curative' science for 'all' (part of the 'obligation' to relatives lost and those yet to be born) and support for the plight of a few. That is those who are subject to the potentially negative ethical ramifications that arise from the clinical application of BRCA genetics. While seeming to pose solutions to the challenge of genetic research, we can see that incorporating an 'ethical' agenda raises other questions and sometimes more troubling issues; a situation that is in Rabinow's sense 'purgatorial'(1999)

The way that a social and ethical agenda is used as context for knowledge in the Clinic and the Charity also highlights the need for reflexivity in examining questions of 'impact'. As Strathern says, referring to the kind of 'impact' discourse that subsumed discussion of reproductive technologies, we need to look at not just 'the immediate kinship dilemmas but forms of cultural knowledge mobilized in and around such practices'(1993: 178). In this way, what 'suggests kinship as a domain of inquiry [enhances] our understanding of a process of domaining itself and broadens the field of what kinship can be used to analyse'(Strathern 1993: 198). With this in mind it is important to understand what it means or does to say 'the new genetics is a family issue' (Richards 1993)

or how and why the anthropologist's interest in 'culture' might be demarcated by others in terms of 'the family' or readily incorporated into a project to develop lay advocacy. It means being reflexive about how social scientists are already part of the 'New World Order' (Haraway 1997) and caught up in what Irwin sees as the 'mutual embedding of science and science policy' (2002)

Not unsurprisingly, given the way the female breast and breast cancer is informed by representations of female identity, gender has also been shown to be part of the work of transmission and the effort to make social and ethical concerns more explicit. In some ways, the reinforcement of pre-existing social categories, that Duster notes in relation to genetic knowledge and sickle cell, would also seem to be apparent in relation to gender and the communication or reception of knowledge and technologies associated with BRCA genes. We have seen that images of 'natural' female nurturance are particularly powerful in these contexts linking the morality of obligation between kin, in the charity, with a discourse about 'care' for the family in the clinic. This image assists the sociality necessary to knowledge or dissemination of risk information in the Clinic by reinforcing and relying on a notion of women as 'selves in relation' (Hallowell 1999). It also provides a powerful image for memorial practice in the Charity; a symbol of what has been lost and hope for the future. Nevertheless we have also seen that normative representations of female gender identity do not always further the translation and distribution of genetic knowledge but challenge it in new ways. As an emblem of the Charity's identity, the notion of female nurturance also makes BRCA genetics a potentially dangerous arena for research because of the 'treatment' interventions so prominently associated (mostly by the media) with the clinical application of this knowledge. That is, prophylactic mastectomies for 'healthy' women threaten the image of hope which is so central to the organisation. Similarly, despite motivating many to attend the Clinic, the consequences of predictive medicine may do little to nurture and provide 'care' for others in the family and in some instances have quite the opposite effect.

Like much work in anthropology addressing gender, kinship and the reproductive technologies, we can see that there are 'ricochet effects' (Strathern 1992b:3)

between gender, nature and culture in the way that 'care', kin relations and gender are being configured in breast cancer genetics. As Hess notes, documenting these effects opens not just the 'black boxes' of STS but a 'rainbow of other boxes'; showing that 'the interpretation of meaning is as important as a sociological explanation of the content of science' (1997:160).

In examining how new genetic knowledge is being translated, received and acted upon at the interface between different sciences and publics, this thesis has shown how the efforts to secure as well as maintain the 'legitimacy' of BRCA genetics has to be viewed as a collective endeavour. As Martin says 'scientists and lay persons must be seen as co-participants in the process by which 'mobiles' [i.e. scientific 'facts' or technological artifacts] do or do not become part of culture' (1998: 20). Understanding the 'impact' of new genetic knowledge in this sense is not so much about expanding the locations of research to understand a phenomenon from different perspectives, but about 'seeing where work is collaboratively performed' (Layne 1998:6). It is also about recognising that the circuits of action and practice which link people and places in the 'co-production' of BRCA genetics operate like Martin's figure of the rhizome in 'discontinuous, fractured and non-linear ways' (1998:31)

Rabinow documents how the alliances between a patient group, a government research institute and a bio-technology company provided the best (although ultimately unsuccessful) way of attempting to meld '*zoe*' and '*bios*' within the rationality of genomics.¹⁶⁵ For Rabinow one of the key issues generated by developments in molecular knowledge is the 'social form or forms' that are to be given to 'molecular information, sequencing machines, gels, data banks, tissue collections and patient groups avid co-operation' (1999 :89). Cancer, and particularly breast cancer, would seem to offer a particularly potent arena for the development and legitimisation of new genetic knowledge. As Margaret Lock says, this is a striking case of the way that 'possible probabilities, based on poorly constructed studies have been constructed into certain probabilities and

¹⁶⁵ Rabinow points out that these two terms were used by the ancient Greeks to express what is meant by the term life. The first *zoe* referred to 'the simple fact of being alive and applied to all living beings' the second *bios* 'indicated the appropriate form given to a way of life of an individual or group (1999:15)

then into certainties'(1998:8). We have seen that 'women' who have had or are at risk from or are left behind as a consequence of breast cancer lend an 'ethical accountability' to emerging genetic knowledge and practice, linked in diverse and complex ways to a notion of female nurturance. But this is a fragile alignment that is subject also to challenge and contestation. Moreover like the blood donor system in France, cancer care or research would seem also to be almost the epitome of '*bios*', symbolized in the 'beneficence' of the NHS or 'Charity' funded medical and scientific research. Given the continuing distance between knowledge and care, sustaining the legitimacy of the knowledge and technologies associated with BRCA genes is likely to engender further challenges , as well as innovative social practices, such those examined in this thesis.

Bibliography

Abu- Lughod. L. (1991) ' Writing against culture'. In Fox. R (ed) *Re-capturing Anthropology; working in the present* Santa Fe NM: School of American Research Press, pp 137- 162

Adelsward, V. & Sachs, L. (1998) 'Risk discourse: Re-contextualisation of numerical values in clinical practice' *Text* 18 (2) pp 191-210

Ahmed, S. & Stacey, J. (2001) 'Testimonial Cultures: An Introduction' *Cultural Values* Vol 5 pp 1 –6

Anglin, M. K. (1997)'Working from the inside out; implications of breast cancer activism for bio-medial policies and practices' *Social Science and Medicine* Vol 44 No 9 pp 1043-1415

Armstrong, D., Michie, S. & Marteau, T. (1998) 'Revealed identity: a study of the process of genetic counselling'. *Social Science and Medicine* Vol 47 No 11 pp 1653-1658

Aronowitz, R. A.(2001) ' Do not delay: breast cancer and time, 1900- 1970' *Milbank Quarterly* Vol 79, No 3 pp 355- 386

Balshem, M. (1991) 'Cancer, Control and Causality; talking about cancer in a working class community' *American Ethnologist* 18 pp 152-172

Batchelor, C., Parsons, E. & Atkinson, P. (1996)'The career of a medical discovery' *Qualitative Health Review* Vol 6 , No 2, pp 225-255

Becker, G. (1997) *Disrupted Lives*, Berkeley: University of California Press.

Beck, U. (1992) *Risk Society: towards a new modernity* , London: Sage.

Bordo, S. (1993) *Unbearable Weight: Feminism, Western Culture and the Body*, Berkeley: University of California Press.

Bosk, C.L. (1992) *All God's Mistakes: Genetic Counseling in a paediatric Hospital*, Chicago: University of Chicago Press.

Bouquet, M. (1994) 'Family trees and their affinities : the visual imperative of the genealogical diagram' *MAN: Journal of the Royal Anthropological Institute* (N.S) 2, pp 43- 66

Callon, M. (1980) 'The State and technical innovation: a case study of the electrical vehicle in France' *Research Policy* No 9 pp 358- 76

Callon, M. (1986) 'Some elements of a sociology of translation: Domestication of the scallops and fisherman of St. Brieuc's Bay'. In *Power, action and belief: A new sociology of knowledge?* Sociological Review Monograph no. 32, John Law, ed. Keele: University of Keele Press.

Calman- Hine (1995) 'A policy framework for commissioning cancer services'. A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales *Department of Health and Welsh Office*.

Carsten, J. (2001) 'Substantivism, Anti-Substantivism, and Anti-Anti-Substantivism' in Franklin, S. and McKinnon, S. (eds) *Relative Values: new directions in Kinship Study*, Durham, NC: Duke University Press. pp 29-53

Cartwright, L . (1995) *Screening the Body: Tracing medicine's visual culture*, Minneapolis: University of Minnesota Press.

Cartwright, L. (1998) 'Community and the public body in breast cancer media activism' *Cultural Studies* Vol 12 No 2 pp117- 138.

Caruth, C. (ed) (1995) *Trauma: Explorations in Memory* Baltimore: John Hopkins University Press.

Casper, M. & Koenig, B. (1996) 'Bio-medical technologies: re-configuring nature and culture: intersections of medical anthropology and technology studies' *Medical Anthropology Quarterly* 10 (4) pp523- 536

Clarke, A and Montini, T. (1993) 'The many faces of RU- 486: tales of situated knowledges and technological contestations' *Science, Technology and Human Values* vol 18 no 1 pp 42-78

Collier, J. & Yanagisako, S. (1987) *Gender and Kinship: essays toward a unified analysis*. Cambridge: Cambridge University Press.

Central Office for Research Ethics Committees (COREC) (2001) 'Governance arrangements for NHS Research Ethics Committees' UK NHS *Department of Health* (www.corec.org.uk)

Cunningham-Burley, S. & Kerr, A. (1999) 'Defining the 'social': towards an understanding of scientific and medical discourses on the social aspects of the new human genetics'. In Conrad, P. and Gabe, J. (eds) *Sociological Perspective on the New Genetics* Oxford: Blackwell Publishers. pp 149 –171

Cussins, C. (1996) 'Ontological Choreography: Agency through Objectification in Infertility Clinics' *Social Studies of Science* Vol 26 pp 575 – 610

Department of Health (2000) 'Investing in the future: research and genetics' *The Cancer Plan: a plan for investment, a plan for reform* NHS pp 86- 91

Douglas, M. (1986) *How Institutions Think*. Syracuse: Syracuse University Press.

Douglas, M. (1992) *Risk and Blame: Essays in cultural theory*. London: Routledge.

Downey, G. & Dumit, J.(eds) (1997) *Cyborgs and Citadels; Anthropological Interventions in Emerging Sciences and Technologies*. Sante Fe, New Mexico: School of American Research Press

Dumit, J. (1997) 'A digital image of the category of the person: PET scanning and objective self-fashioning' in Downey, G. L. & Dumit, J. (eds) *Cyborgs and Citadels; Anthropological Interventions in Emerging Sciences and Technologies*. Sante Fe, New Mexico: School of American Research Press pp 83-103

Duster, P. (1997) 'The prism of Heritability and the sociology of knowledge' In Nader, L *Naked Science: Anthropological inquiries into the boundaries of power and Knowledge*, London: Routledge pp 119-130

Eccles, D., Evans, D. and Mackay, J. (2000) 'Guidelines for a genetic risk based approach to advising women with a family history of breast cancer', *Journal of Medical Genetics*, 37: pp 203- 209

Edwards, J., Franklin, S., Hirsch, E., Price, F. & Strathern, M. (1993) *Technologies of Procreation. Kinship in the Age of Assisted Conception*. London: Routledge.

Edwards, J. (2000) *Born and Bred. Idioms of Kinship and New Reproductive Technologies in England*. Oxford: Oxford University Press

Eisenberg, L. (1977) 'Disease and Illness: Distinctions between professionals and popular ideas of sickness' *Culture, Medicine and Psychiatry* No 1 pp 9-23

Epstein, S. (1996) *Impure Science: AIDS, Activism and the Politics of Knowledge*. Berkeley: University of California Press.

Evans, J.P. (2001) 'The complexities of predictive genetic testing' In *BMJ* :322 pp 1052- 1056.

Evans-Pritchard,E.,E. (1937) *Witchcraft, Oracles and Magic among the Azande*, Oxford: Clarendon Press.

Finch, J. & Mason, J. (1993) *Negotiating Family Responsibilities*. London: Routledge.

Finkler, K. (2000) *Experiencing the New Genetics*. Philadelphia : University of Pennsylvania Press.

Fleck, L.(1937)(1979) *Genesis and the Development of a Scientific Fact*. Chicago, Illinois: University of Chicago Press.

Forty, A and Kuechler, S (eds) (1999) *The Art of Forgetting*. Oxford, New York: Berg Publishers

Foucault, M. (1972) *Birth of the Clinic: An Archaeology of the Clinical Gaze* London: Tavistock

Franklin, S. (1995) 'Science as culture, cultures of science. *Annual Review of Anthropology* 24: pp163-184

Franklin, S. (1996) 'An excellent prognosis' *Medical Anthropology Quarterly* vol 10 no 4 p 683- 685

Franklin, S. (1997) *Embodied Progress. A Cultural account of assisted conception*, London and New York: Routledge.

Franklin, S. & Ragone, H. (1998) *Reproducing Reproduction: Kinship, power and the technological Imagination*, Pennsylvania: University of Pennsylvania Press.

Franklin, S. (2001a) 'Culturing biology: cell lines for the second millennium'
Health Vol 5 No 3 pp 335- 354

Franklin, S. (2001b) 'Comment' *Current Anthropology* Vol 42 No 2 pp 235- 263

Fujimura, J. (1996) *A socio-history of the Quest for the Genetics of Cancer*,
Cambridge: Harvard University Press

Gaines, A. & Hahn, R (1985) (eds) *Physicians of western medicine:
anthropological approaches to theory and practice*, Dordrecht, Lancaster: D.
Reidel.

Gatens, M. (1996) *Imaginary Bodies: Ethics, Embodiment and Corporeality*.
New York , London: Routledge.

Gell, A. (1992) 'The technology of enchantment and the enchantment of
technology' In Coote, J. & Shelton, A. *Anthropology, Art and aesthetics*. Oxford,
New York: Clarendon Press pp 40- 63

Gellner, D. and Hirsch, E. (eds)(2001) *Inside Organisations. Anthropologists at
Work*. Oxford: Berg Publishers.

Gibbon, S.(2002) 'Family trees in Clinical Cancer Genetics: Re-examining
Geneticisation' *Science as Culture* Vol 11 No 4 pp 429-457

Giddens, A. (1991) *Modernity and Self-Identity: Self and Society in the Late
Modern Age*. Stanford, California: Stanford University Press.

Gifford, S. (1986) 'The meaning of lumps: a case study of the ambiguities of
risk' In Janes, C. R., Stall, R., Gifford, S. *Anthropology and Epidemiology:
Interdisciplinary Approaches to the Study of Health and Disease*. Dordrecht:
Reidel Publishers pp 213- 246

Gilligan, C. (1982) *In a Different Voice: psychological theory and women's development*. London: Harvard University Press.

Ginsburg, F. (1987) 'Procreation stories; reproduction, nurturance and procreation in life narratives of abortion activists'. *American Ethnology* pp 623-634

Ginsburg, F. & Rapp, R. (1995) (eds) *Conceiving the New World Order: The Global Politics of Reproduction*, Berkeley: University of California Press.

Grosz, E. (1994) *Volatile Bodies: Toward a Corporeal Feminism*, Sydney, AU: Allen and Unwin

Hacking, D. (1990) *The Taming of Chance*, Cambridge: Cambridge University Press.

Hallowell, N. (1999) 'Doing the right thing: genetic risk and responsibility'. In Conrad, P. & Gabe, J. (eds) *Sociological Perspective on the New Genetics* Oxford: Blackwell Publishers pp 97-120

Hallowell, N. (2000) 'Reconstructing the body or reconstructing the woman? Perceptions of prophylactic mastectomy for hereditary breast cancer risk' In Potts, L. *Ideologies of Breast Cancer*, London: Macmillan pp 153-180

Hallowell, N. & Richards, M. (1997) 'Understanding life's lottery: an evaluation of studies of genetic risk awareness' *Journal of Health Psychology* 2 (1) pp 31-43.

Haraway, D. (1992) 'The Promises of Monsters: A Regenerative Politics for Inappropriate/d Others' In Grossberg, L., Nelson, C. & Treichler, P. *Cultural Studies*, New York: Routledge pp 295-337

Haraway, D. (1997) 'Mice into wormholes: a comment on the nature of no nature' In Downey, G. L. & Dumit, J. (eds) *Cyborgs and Citadels; Anthropological Interventions in Emerging Sciences and Technologies*. Sante Fe, New Mexico: School of American Research Press pp 209- 243

Harper, R. (1998) 'Genetics and Cancer services.' *Report of the Working Group for the Chief Medical Officer, Department of Health*.

Hartouni, V. (1997) *Cultural Conceptions: On Reproductive Technologies and the Remaking of Life*. Minneapolis: University of Minnesota Press.

Harvey, P. (1997) 'Technology as skilled practice: approaches from anthropology, history and psychology' *Social Analysis* Vol 41:1 pp 3-14

Heath, D. (1997) 'Bodies, Antibodies and Modest Interventions' . In Downey, G. & Dumit, J. (eds) *Cyborgs and Citadels; Anthropological Interventions in Emerging Sciences and Technologies*. Sante Fe, New Mexico: School of American Research Press pp 67-82

Heath, D. (1998) 'Locating genetic knowledge: picturing Marfan syndrome and its travelling constituencies' In *Science, Technology and Human Values* Vol 23 No 1 pp 519-539

Helmreich, S. (1998) 'Replicating Reproduction in Artificial Life: Or , the essence of Life in the Age of Virtual Electronic Reproduction' in Franklin, S. & Ragone, H. (eds) *Reproducing Reproduction: kinship, power and the technological imagination* Pennsylvania: University of Pennsylvania Press pp 207- 234

Henderson, L. & Kitzinger, J. (1999) 'The human drama of genetics: 'hard' and 'soft' media representations of inherited breast cancer'. In Conrad, P. & Gabe, J.(eds) *Sociological Perspectives on the New Genetics* Oxford: Blackwell Publishers pp 59-78

Hess, D. J. (1997) 'If your thinking of living in STS. A guide for the perplexed'. In Downey, G. & Dumit, J. (eds) *Cyborgs and Citadels; Anthropological Interventions in Emerging Sciences and Technologies*. Sante Fe, New Mexico: School of American Research Press pp143- 164

Hirsch, E. & Silverstone, R. (eds) (1992) *Consuming Technologies: Media and Information in Domestic Spaces*, London: Routledge.

Hoeyer, K. (2001) 'Exchanging blood and ethics: Commercial genetic research and the negotiation of rights and responsibility in Northern Sweden' Paper presented Symposia *Re-visiting Concepts of Gift in the New Genetics* at Lancaster University February 2001.

Hubbard, R. & Wald, E. (1997) *Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Lawyers, Insurance Companies, Educators and Law Enforcers*. Boston: Beacon Press.

Irwin, A. and Wynne, B. (eds) (1996) *Misunderstanding Science? The Public Reconstruction of Science and Technology*. Cambridge: Cambridge University Press.

Irwin, A. (2002) 'Science and Democracy in the 21st Century: Reconstructing the Scientific Citizen' Paper presented at *EASST* July 2002 York University.

Kaufert, P. (1996) 'Women and the Debate over Mammography: An Economic, Political, and Moral History'. In Sargents, C. F. & Brettell, C. B. (ed) *Gender and Health: An International Perspective*, Upper Saddle River, N.J.: Prentice-Hall pp 167-86.

Kaufert, P. (1998) 'Women, Resistance and the Breast Cancer Movement' In Lock, M. & Kaufert, P. (eds) *Pragmatic Women and body Politics* Cambridge: Cambridge University Press pp. 287- 309.

Kaufert, P. (2000) 'Health Policy and the new genetics'. In *Social Science and Medicine* 51 pp 821-829

Kenen, R. (1994) 'The Human Genome Project: creator of the potentially sick, potentially vulnerable and potentially stigmatized? In Robinson, I. (ed) *Life and Death Under High Technology Medicine*. Manchester: Manchester University Press pp 7-21

Kerr, A., Cunningham-Burley, S., Amos, A., (1997) 'The new genetics; professionals discursive boundaries' *Sociological Review* Vol 45 No 4 pp 1- 30

Kerr, A. , Cunningham- Burley, S. Amos, A. (1998) 'The new genetics; mobilizing lay expertise' *Public Understanding of Science* 7 pp 41-60

Kohn,T. and McKechnie, R (eds)(1999) *Extending the boundaries of care:medical ethics and caring practices*. Oxford, New York: Berg.

Konrad, M (1998) 'Ova Donation and Symbols of Substance: Some Variations in the the Theme of Sex, Gender and the Partible Person' *Journal of the Royal Anthropological Institute* Vol 4 pp 643-667

Lacquer, T. (1996) *Making sex, the body and gender from the Greeks to Freud*, Cambridge, M.A: Harvard University Press.

Lambert, H. (1999) 'Caring for the Well: Perspectives on Disease Prevention' In Kohn,T. & McKenchie, R.(eds) *Extending the boundaries of care:medical ethics and caring practices*. Oxford, New York: Berg Publishers pp. 111-134

Lambert, H. and Rose. H (1996) 'Disembodied Knowledge? Making Sense of Medical Science'. In Irwin, A. and Wynne, B. (eds) *Misunderstanding Science? The Public Reconstruction of Science and Technology*. Cambridge: Cambridge University pp 65-83

Lantz, P. & Booth, K. (1998) 'The social construction of the breast cancer epidemic' *Social Science and Medicine* Vol 46 No 7 pp 907- 918

Latour, B. (1987) *Science in Action. How to follow Scientists and Engineers Through Society* Cambridge, Mass.: Harvard University Press.

Latour, B. (1993) *We Have Never Been Modern* (trans.) C. Porter, London: Harvester Wheatsheaf.

Latour, B. & Woolgar, S. (1986) *Laboratory Life: the social construction of scientific facts* Princeton: Princeton University.

Layne, L. (1998) 'Introduction' *Science, Technology and Human Values*, Vol 23 No1 pp 4-23

Lenaghan, J. (1998) *Brave New NHS? The impact of the new genetics on the health service*, London: Institute for Public Policy Research.

Lippman, A. (1992) 'Led Astray by genetic maps: the cartography of the Human Genome Project and Health Care' *Social Science and Medicine* 35 no 12 pp 1469 - 1476

Lock, M. (1998) 'Breast Cancer: reading the Omens' *Anthropology Today* Vol 14 No 4 pp 7- 16

Lock, M. & Gordon, D. (1988) *Bio-medicine Examined* Dordrecht, The Netherlands: Kluwer Academic Publishers.

Lock, M. and Lindenbaum, S. (1993) *Knowledge, Power and practice: The anthropology of medicine and everyday life* Berkeley: University of California.

Lock, M. & Kaufert, P. (1998) *Pragmatic Women and Body Politics* Cambridge: Cambridge University Press.

Lock, M., Young, A. and Cambrosio, A. (2000) *Living and working with the new medical technologies. Intersections of inquiry*, Cambridge, New York: Cambridge University Press.

Lorde, A. (1980) *The Cancer Journals* San Francisco: Spinsters Book Company

Lupton, D. (1995) *The Imperative of Health: Public Health and the Regulated Body* London: Sage.

Lupton, D. (1994) 'Femininity, responsibility and the technological imperative: discourses on breast cancer in the Australian press' *International Journal of Health Services* Vol 24 No 1 pp 73 – 89

MacCormack, C. & Strathern, M. (eds) (1980) *Nature, Culture and Gender* Cambridge: Cambridge University Press.

McFarlane, A. (1978) *The Origins of English Individualism. The Family, Property and Social Transition*, Oxford: Basil Blackwell

Marcus, G. (1995a) *Technoscientific Imaginaries; conversations, profiles, memoirs* Chicago: Chicago University Press.

Marcus, G. (1995b) Ethnography In/Of the world system: the emergence of multi-sited ethnography. *Annual Review of Anthropology* 24 pp 95- 117

Marcus, G. & Fisher, M.M.J. (1986) *Anthropology as cultural critique: an experimental moment in the human sciences*. Chicago: University of Chicago Press.

Marriott, M. (1976) 'Hindu transactions: diversity without dualism' In Kapferer, B. (ed) *Transaction and Meaning*, Philadelphia: ISHI Publications pp 130 - 146

Marteau, T. & Richards, M. (eds)(1996) *The Troubled Helix: Social and Psychological Implications of The New Human Genetics*. Cambridge University Press: Cambridge.

Martin, E. (1989) *The Woman in the Body*, Cambridge: Open University.

Martin, E. (1992) 'Body Narratives, Body Boundaries' In Grossberg,L., Nelson,C., & Treichler, P. *Cultural Studies*, New York: Routledge pp 409- 421

Martin, E. (1994) *Flexible Bodies. Tracking immunity in American Culture from days of Polio to the age of Aids*. Boston: Beacon Press.

Martin, E. (1998) 'Anthropology and the cultural study of Science' *Science, technology and human values*'Vol 23 No1 pp 24- 44

Mattingley, S. (1994) ' The Concept of Therepeautic 'Emplotment'. *Social Science and Medicine* 38 pp 811- 822

Metcalfe, P. (2002) *They Lie, We Lie; Getting on with Anthropology* London: Routledge.

Milburn, A. (2001) Speech by the Secretary of State for Health at the Institute of Human Genetics, International Centre for Life, Newcastle Upon Tyne 19th April

Moll, A. (2000) ' Pathology and the Clinic: an ethnographic presentation of two atheroscleroses' in Lock, M.,Young, A., Cambrosio, A. (eds) *Living and working with the new medical technologies. Intersections of inquiry*, Cambridge, New York: Cambridge University Press pp 82 - 102

Montini, T. (1996) 'Gender and emotion in the advocacy for breast cancer informed consent legislation' *Gender and Society* Vol 10 No 1 pp 9-23

Nelkin, D. & Lindee, S. (1995) *The DNA Mystique: The Gene as Cultural Icon*, New York: WH Freeman.

Novas, C. & Rose, N. (2000) ' Genetic risk and the birth of the somatic individual' *Economy and Society* Vol 29 No 4 pp 485 – 513

Novas, C. (*forthcoming*) 'Ethics as practice: the epistemic and the normative in implementing predictive genetic testing in medical genetic clinics' In Redclift, N. (ed) *Future Perfect: ethnographies of contested moral worlds*. Palgrave/Macmillan

Nowotny, H., Scott, P. & Gibbons, M.(2001) *Re-thinking Science: Knowledge and the Public in an age of Uncertainty*. Cambridge: Polity Press.

Palsson, G. & Rabinow, P. (1999) 'Iceland. The case of a national human genome project' *Anthropology Today* vol 15 No 5 pp 14- 18

Oudshoorn, N. (1994) *Beyond the Natural Body: An Archaeology of Sex Hormones*, London: Routledge.

Parsons, E. & Atkinson, P. (1992) ' Lay constructions of genetic risk' *Sociology of health and Illness* vol 14 pp 437- 453

Pharoah, P., Mackay, J. & Zimmern, R.(1998) 'Report of Consensus Meeting on The Management of Women with a Family History of Breast Cancer'. *Anglia and Oxford NHS Executive and the Unit for Public Health Genetics, Cambridge*. [Http://www.medschl.cam.ac.uk/phgu](http://www.medschl.cam.ac.uk/phgu) (accessed January 2000)

Phelan, P. (2001) ' Converging glances: a response to Cathy Caruth's Parting words in Testimonial Cultures' in Ahmed, S. & Stacey, J. *Testimonial Cultures* in *Cultural Values* vol 5 No 1 pp 27- 40

Potts, L. (ed) (2000) *Ideologies of Breast Cancer*, London: Macmillan

Raberharisoa, V. & Callon, M. (1998) 'L'implication des malades dans les activités de recherche soutenues par L'Association Française contre les Myopathies' *Sciences Sociales et Santé* 16 No 3 pp 41-65

Rabinow, P. (1996) 'Artificiality and Enlightenment; from socio-biology to bio-sociality' in Rabinow, P. *Essays on the Anthropology of Reason*, Princeton: Princeton University Press pp 91- 112

Rabinow, P. (1999) *French DNA: Trouble in Purgatory*. Chicago, I.L: Chicago University Press.

Rapp, R. (1995a) 'Constructing Amniocentesis. Maternal and Medical Discourses' In Ginsburg, F & Rapp, R.(eds) *Conceiving the New World Order: The Global Politics of Reproduction*, Berkeley: University of California Press pp128- 141

Rapp, R (1995b) 'Heredity or revising the facts of life' In Yanagisako, S. & Delaney, C. (eds) *Naturalising Power: Essays in Feminist Cultural Analysis*, New York, London: Routledge pp 69- 86

Rapp, R. (1997) 'Real time Fetus': The role of the Sonogram in the Age of Monitored Reproduction'. In Downey, G. & Dumit, J.(eds) (1997) *Cyborgs and Citadels; Anthropological Interventions in Emerging Sciences and Technologies*. Sante Fe, New Mexico: School of American Research Press pp 31-48

Rapp, R. (1999) *Testing Women, Testing the Fetus: the social Impact of Amniocentesis in America*. New York: Routledge.

Rapp, R. (2000) 'Blue tulips and extra chromosomes: medico-familial conversations'. In Lock, M., Young, A., Cambrosio, A. (eds) *Living and working with the new medical technologies. Intersections of inquiry*, Cambridge, New York: Cambridge University Press pp 184-208

Richards, M. (1993) 'The new genetics; some issues for social scientists'.

Sociology of Health and Illness No13 pp 567- 586

Richards, M. (1996) 'Lay and Professional knowledge of genetics and

inheritance' *Public Understanding of Science* No 5 pp 217-230

Rose, N. (1996) *Inventing ourselves: Psychiatry, power and personhood.*

Cambridge: Cambridge University Press.

Rose, N. (2001) 'The Politics of Life Itself' *Theory, Culture and Society* Vol 18

No 6 pp 1-30

Rothman, B.K (1998) *Genetic Maps and the human imagination: the limits of science in understanding who we are.* New York, London :Norton Press

Rowlands, M. (1999) 'Remembering to Forget: Sublimation as Sacrifice in War Memorials' in Forty, A and Kuechler, S (eds) (1999) *The Art of Forgetting.*

Oxford, New York: Berg Publishers pp 129- 145

Royal College of Physicians (1996) '*Clinical Genetics into the 21st Century*'

Sacks, L. (1999) 'Knowledge of No Return: Getting and giving information about genetic risk' In *Acta Oncologica*, No 38: 735- 741

Saywell, C., Beattie, L. & Henderson, L. (2000) 'Sexualised Illness: the Newsworthy Body in Media Representations of Breast Cancer' in Potts.L (ed) *Ideologies of Breast Cancer*, London: Macmillan pp37- 62

Seale, C. (2002) 'Cancer heroics: a study of news reports with particular reference to gender' *Sociology* Vol 36 No1 pp 107-126

Sevenhuijsen, S. (1998) *Citizenship and the ethics of care: Feminist considerations on justice, morality and politics.* London: Routledge

Silverman, D. (1987) *Communication and Medical Practice: social relations in the Clinic*. London: Sage

Singleton, V. & Michael, M. (1993) 'Actor Networks and Ambivalence: General Practitioners in the UK Cervical Screening Programme' *Social Studies of Science* No 23 pp 227- 264

Stacey, J. (1997) *Teratologies. A Cultural study of cancer*. London: Routledge.

Stockdale, A. (1999) 'Waiting for the cure: mapping the social relations of human gene therapy research' In Conrad, P. & Gabe, J. (ed) *Sociological Perspective on the New Genetics* Oxford: Blackwell Publishers pp 79-97

Strathern, M (1988) *The Gender of the Gift: Problems with Women and Problems with Society in Melanesia*, Berkeley and Los Angeles: University of California Press

Strathern, M. (1992a) *After Nature. English Kinship in the late twentieth century*, Cambridge: Cambridge University Press.

Strathern, M. (1992b) *Reproducing the Future: Anthropology, kinship and the new reproductive technologies* Manchester: Manchester University Press.

Strathern, M. (1993) 'Regulation, substitution and possibility'. In Edwards, J. , Franklin, S., Hirsch, E., Price, F. & Strathern, M. (1993) *Technologies of Procreation: Kinship in the age of Assisted Conception* , London: Routledge pp 171 –201

Strathern, M. (1995) 'Nostalgia and the new genetics' in Battaglia, D. *Rhetorics of self making*, Berkeley, London: University of California Press pp 97- 120

Strathern, M (1996) 'Cutting the network' *Journal of the Royal Anthropological Institute*. Vol 2 No 3 pp 517- 535

Strathern, M. (1997) 'A return to the native' *Social Analysis* No 41 (1) March
pp 15-27

Strathern, M. (1999) *Property, Substance and Effect: Anthropological Essays on
Persons and Things*. London: Athlone Press.

Strathern, M. (2000) *Audit Cultures. Anthropological studies in accountability,
ethics and the academy*, London, New York: Routledge.

Strathern, M. (2001) The Patent and the Malnggan *Theory, culture and society*
Vol 18 No 4 pp1-26

Traweek (1988) *Beamtimes and Lifetimes: the world of high energy physicists*.
Cambridge, Mass: Harvard University Press

Traweek, S.(1993) 'An introduction to cultural and social studies of science and
technology' *Journal of culture, medicine and psychiatry* No 17 pp 3- 25

Van Dijck, J. (1998) *Imaginations: popular images of genetics* New York: New
York University Press

Walker, M. (2000) 'Your Money and Your Life: Britain's Cancer Charities
shirking responsibility' *The Ecologist* September pp 6-27

Wikan, U. (199) *Managing Turbulent Hearts: A Balinese Formula for Living*:
Chicago: Chicago University Press.

Wonderling, D., Hopwood, P., Cull, A., Douglas, F., Watson, M., Burn, J.,
McPherson, K., (2001) 'A descriptive study of UK Cancer genetics services: an
emerging clinical response to the new genetics' *British Journal of Cancer* Vol 85
No 2 pp 166- 70

Wright, S. (1994) *The Anthropology of Organisations* London, New York:
Routledge

Wright, P. & Treacher, A. (1982) *The Problem of Medical Knowledge: Examining the Social Construction of Medicine*, Edinburgh: University of Edinburgh Press.

Yadlon, S. (1997) ' Skinny women and good mothers: the rhetoric of risk, control, and culpability in the production of knowledge about breast cancer' *Feminist Studies*, Vol 23 No 3 pp 645- 677

Yalom, M. (1998) *A History of the Breast*. London: Pandora.

Yanagisako, S. & Delaney, C. (1995) (eds) *Naturalising Power: Essays in Feminist Cultural Analysis*, New York, London: Routledge

Young, J. E. (1993) *The Texture of Memory: Holocaust, Memorials and Meaning*, New Haven, London: Yale University Press.

Yoxen, E (1982) 'Constructing genetic diseases' in (eds) Wright, & Treacher, *The Problem of Medical knowledge; examining the social construction of medicine*.