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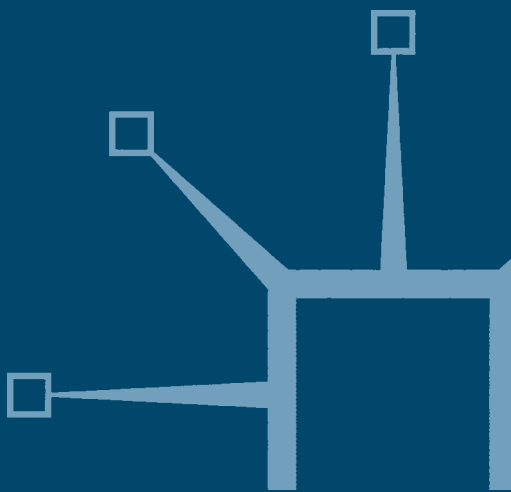
Breast Cancer Genes and the Gendering of Knowledge

Science and Citizenship in the Cultural Context of the 'New' Genetics

Sahra Gibbon



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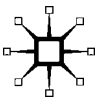

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Preface

Although the 'inherited susceptibility' genes BRCA 1 and 2 are only thought to be involved in approximately 5–10 per cent of all cases of breast cancer, risk assessment and genetic testing for breast cancer is at the vanguard of a rapidly expanding field of medicine, while the molecular genetics of breast cancer is a focus for a growing field of basic and applied scientific research. The period since the early 1990's has also seen an exponential rise in health 'activism' around breast cancer. These seemingly parallel developments warrant closer examination. Using an ethnographic approach, this book examines the way that the knowledges and technologies associated with the so called 'breast cancer genes', BRCA1 and 2, are used, received or acted upon in two contrasting social arenas (a) cancer genetic clinics and (b) a breast cancer research charity, and how a growing and diverse culture of breast cancer activism intersects with these developments. Drawing on a notion of 'co-production', the book examines the collective practices, networks and identities caught up with the knowledge and technologies associated with breast cancer genes in their passage from, to and between the lab and the wider world. It points to a powerful social form within the new genetics that powerfully aligns gender with the knowledge and technologies associated with breast cancer genes, whilst showing how the circuits of connection which link people and practices in different social arenas operate in complex non-linear ways. The entanglements engendered by the 'traffic' around the work of transmission reveal the often uncomfortable tensions and gaps in the mobile and shifting landscape where new genetic knowledge is being used and translated.

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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 2000: 236)

Although many aetiological agents have been linked to breast cancer, in more than 90 per cent of cases the cause is still essentially unknown. However, in the field of oncology, there has long been a suspected connection between family history and some cancers, including breast cancer. Although this association pre-dates the rapid developments in genetic technology that transformed genetic science in the 1970s (Gaudillière 2001), it was 'confirmed' when two'inherited susceptibility' genes, BRCA1 and BRCA2, were identified in the mid-1990s. Come to be known as the 'breast cancer genes', they have arguably become one, if not the, most public and publicised development in a raft of rapid advances in the human genetics over the last 10 years (Henderson and Kitzinger 1999).[1] They are understood to be inherited in a dominant way so that a person with a parent who carries a mutation on one of these genes has a 50 per cent chance of inheriting the same gene mutation. It is commonly thought that they are involved in about 5–10 per cent of the population who develop breast cancer. Estimates for assessing the increased lifetime risk of developing breast cancer

for carriers of mutations on these genes were originally thought to be universally high. This risk is now thought to range between 35 and 80 per cent (the 'normal' life time risk is 9 per cent).[2] Despite this recent and ongoing re-assessment of the risks conferred by carrying a BRCA mutation and the logistically complex, time-consuming, as well as costly nature of genetic testing in the UK, this service has now become available in specialist clinics for those at 'high risk' of developing the disease. More importantly genetic risk assessment for breast cancer is at the vanguard of an expanding field of clinical genetics in the UK's national service of health provision. (Wonderling *et al*. 2001).

The beginning of the 1990s saw the growth and emergence of 'preventative' public health campaigns in the UK and elsewhere emphasising the risk of breast cancer for all women and the importance of mammography screening and health awareness. It is a campaign which has itself been fuelled by and helped to inform a somewhat diverse yet growing culture of health 'activism' around the disease. Coupled with an exceptionally heightened media interest, which ensures that breast cancer is four times more likely to be headline news than any other cancer (Saywell *et al*. 2000), these developments have helped propel the public profile of the disease to an unprecedented high level.

It is the premise of this book that the intersections between these two developments are vital to understanding the emergence of breast cancer genetics as a field of medical practice and scientific research. Although these are dynamics which others have also begun to examine (Cartwright 2000; Kaufert 2003; Parthasarathy 2003), this book provides an important ethnographic perspective in examining the scope, scale and circuitous nature of the connections between these developments. It maps the practices of transmission and translation from and between patients and practitioners in cancer genetic clinics to broader public domains of health activism and fundraising within a breast cancer research charity and finally back to the space of the laboratory. Drawing attention to a process of 'co-production' at the interface between health activism and BRCA genetics, the book explores the social dynamics, cultural as well as gendered politics that are part of both these high profile developments. Challenging a linear model of technological innovation or social impact, it illustrates how the work of translation from and between the laboratory, clinic and wider world is informed by and also itself has 'up' and 'downstream' consequences for different persons and practices.

'Geneticisation' and the 'social 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. However, this work has been somewhat narrowly defined (Kaufert 2000). On the one hand, there has been a tendency to examine the psychological or social consequences of technologies, such as genetic testing, for the relatively small numbers of persons undergoing these procedures.[3] At the same time attempts to broaden the field of analysis have tended to separate the consequences of genetic knowledge and technology for patients from changes in health policy or the social context of medical practice itself (see, for instance, Marteau and Richards 1996). One of the repercussions of this demarcation has been not only a tendency to sustain the novelty of these developments, often referred to as the 'new genetics', but also a theoretical emphasis given to the notion of 'geneticisation'. Responding mostly to genetic developments in reproductive medicine, this concept has been used to posit that genetic knowledge is leading in a direct and linear way to a new reductionism and determinism about health, disease and the body (Lippman 1992, 1998; Nelkin and Lindee 1995; Hubbard and Wald 1997; Rothman 1998; Finkler 2000). Although advocating an important pre-cautionary approach, there are particular consequences in defining the parameters of a social science critique in this way. This approach to 'social impact' tends to mask the necessary involvement of multiple individuals and groups and the heterogeneous practices undertaken in the work of translation. It also obscures how the movement from or between the lab and the wider world has diverse and often contradictory consequences for those other than the relatively small group of persons undergoing genetic testing. Moreover focusing only on the downstream effects of these developments assumes that scientific knowledge is itself 'unified' and 'stable' (Irwin and Wynne 1996: 7).

The question of 'social impact' and 'geneticisation' are re-situated in this study in a number of different ways. This is achieved, in part, by extending the parameters for inquiry. But, as Layne puts it, this is not only or just about adding different perspectives but understanding 'where [and how] work is collaboratively performed' (1998). By attending to the reciprocal yet uneven exchanges caught up in the emergence of new genetic knowledge or technology, the questions these developments raise about agency, identity and power are located across a broader span of social relations. At the same time an ethnographic perspective allows moments of productivity *and* disjuncture to become more concretely located.

As a number of studies in this field have demonstrated, there is in addition also a need to consider these developments more reflexively, in a way that does not situate questions of the social only in relation to the 'downstream' consequences of scientific or medical innovation. Like others this book locates specific articulations of the social (and ethical) in the emergence of, rather than after, new genetic knowledge and technologies (Rabinow 1999; Franklin 2001a; Hayden 2003; Strathern 2004). It explores how in novel and legitimising ways social or ethical concerns, often refracted through idioms of female gender, are caught up and instrumentalised in the pursuit of scientific knowledge or the undertaking of predictive health care interventions.

These broader parameters for examining the question of social impact are used here to look at the dynamic interfaces between breast cancer activism and the communication, translation and dissemination of genetic knowledge and technologies associated with BRCA genes. This approach to the analysis of 'co-production' draws from a body of work in which there has recently been a cross disciplinary fertilisation of theoretical, conceptual and methodological approaches.

Theorising the 'co-production'

The problem of the 'black box' and the 'broader context' have been used to characterise the different ways that Science and Technology Studies (STS) and Anthropology have traditionally addressed the social construction of 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, [while conversely] the opening of 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)

Nevertheless fruitful lines of inquiry have recently begun to emerge that bring together these seemingly disparate disciplinary perspectives in examining developments in medical and health technologies, increasingly orientated around a notion of 'co-production'. In showing how, as Jasanoff points out, 'natural and social orders are produced together', this kind of multi-sited and often inter-disciplinary approach

has become an important way of 'accounting for complex phenomena' (2004: 3). It is in fact at the meeting point between anthropology and STS that this perspective is developing most fully.

The notion that 'knowledge and artefacts are culturally shaped and socially constructed' (Hess 1997: 148) is a central tenant of STS (Latour 1987). Despite some reluctance to address the 'science question' in anthropology, new interdisciplinary interest in the materiality or substance of biology and technology has begun to expand the terms and parameters of anthropological engagement. There has been a renewed effort to link a long-held interest in the culturally constituted and embodied experience of 'illness' with an attempt to address 'disease' or scientific/medical knowledge itself (Wright and Treacher 1982; Lock and Lindenbaum 1993; Lock *et al*. 2000).[4] At the same time the question of biological substance has been the focus of fresh anthropological engagement with kinship in the wake of developments in reproductive and genetic technologies (Strathern 1992a,b; Edwards *et al*. 1993; Edwards 2000). This work has brought new questions to the fore about the meaning of materiality, substance, identity and embodiment if we are now 'after' nature (Strathern 1992a), or if nature will now be 'known and re-made as technique' (Rabinow 1996).

Just as particular approaches in anthropology have been informed by the way that STS situates the 'science question', so STS has been influenced by the 'social context' and 'identity' approaches that are inimical to anthropology. The notions of 'actor networks', 'boundary objects' and 'social worlds' analysis (Strauss 1978; Callon 1986; Latour 1987; Star and Greismar 1989; Fujimura and Clarke 1992) have provided the theoretical tools for examining the ways in which intersecting circuits of action and practice inform the construction of scientific knowledge and technology from the perspective of STS. This type of analysis has now moved from examining the networks that operate inside the laboratory to explore the movement of people, practices, knowledge or technologies inside *and* outside the laboratory. Moving beyond the 'executive approach' (Clarke and Montini 1993) of earlier studies, this new type of analysis intersects with approaches in anthropology where there has long been an interest in questions of identity or subjectivity and the way these are informed by, as well as increasingly helping to shape, new scientific knowledges or technologies (Epstein 1996; Oudshoorn and Pinch 2003).

Various approaches orientated towards elucidating the 'co-production' of science and technology are, some argue, therefore casting fresh light on how questions of power, knowledge, expertise, identity, technology,

materiality and the body are sustained by or instrumental to, and themselves become interactively reproduced through, collective practices (Lock *et al*. 2000; Jasnaoff 2004).

The theoretical, conceptual and methodological approach used and developed in this book draws from and informs these intersecting disciplinary trajectories whilst also bringing new ideas and concepts to the analysis of 'co-production'. In the same way that, as Martin says, scientists and lay persons must be seen as 'co-participants' in the process by which scientific facts or artefacts 'do or do not become part of culture' (1998: 20), this study suggests that the efforts to secure as well as maintain the productivity of BRCA genetics must be understood as a collective endeavour. Examining the intersections between health activism and genetic knowledge sheds fresh light on how ideas of expertise, technology, identity and the constituent relations or parts of a lay/professional boundary are being drawn and shaped by particular gendered practices and values.

Power, predictive expertise and lay/professional entanglements

The scope of medical knowledge and practice to define has been well documented by a broad body of work in the anthropology and the sociology of medicine. Here the 'bio-power' of clinical or scientific authority in its ability to label or classify has been explored in diverse ways, from the regulatory power of population statistics (Lupton 1995) to the powerful visualising technologies used to uncover the inner workings of the (frequently female) body (Hartouni 1997). Many of these practices are evident in the social settings where genetic knowledge associated with breast cancer is being used and received, appearing to enable and facilitate new articulations of medical authority. Moreover the promise of predictive health seems to bring 'an obsession' with the 'taming of chance' into the domain of medical practice, offering the prospect of being able to 'divine our past and make that heritage in the form of genes in to omens for the future' (Lock 1998: 8). However, examining the bio-power of predictive medicine in a broader field of social relations and action, this book raises questions about the stability and scope of the kinds of medical or scientific authority seemingly propelled by the discovery and application of genetic knowledge. It demonstrates how attempts to make genetic knowledge or technology real or meaningful cannot be abstracted from the expectations or actions of patients and variously situated publics in relation to an emerging and still inchoate arena of science and medicine. As Palladino points out, the necessary 'dialogical engagement' of patients and practitioners vital to genetic

medicine, 'calls into question the stability of knowledge and a discourse of bio-power' (2002: 140).

A lay/professional distinction has been somewhat ubiquitous in social studies of medicine. It has usefully highlighted how those assumed to be subject to new forms of scientific or medical knowledge and technology make sense of them in different ways to 'professionals' who work in these novel fields of health care practice. For example juxtaposing the use of medical statistics in the practice of bio-medicine with patients 'lived experience' of disease, often serves as an exemplar for the 'gap' between lay and professional perspectives in social analysis of medical practice. Clearly this is a feature and articulation of difference and power that continues to adhere within a wide range of institutionalised medical settings, including new arenas of practice associated with genetic medicine and science (Parsons and Atkinson 1992; Richards 1996; Hallowell and Richards 1997; Sacks 1999; Rapp 1999). However, examining the dynamic nature of the interface between different 'lay' publics and medical practitioners or scientists in the context of BRCA genetics raises questions about constant recourse to both the notion of medicine as a unified monolithic entity (Mol and Berg 1998) and the dichotomous distinction between those who are assumed to be 'powerful' and those seen as 'disenfranchised' (Epstein 1996). As Stockdale points out, sociological discussion of the new genetics is in 'danger of remaining trapped in its original binary framing' and might be 'usefully exploded into a more complex mapping of cultural constructions and social relationships' (1999: 80; see also Lock *et al.* 2000). While simultaneously recognising the presence of an ongoing 'will to knowledge' (Palladino 2002) in this arena of experimental genetic medicine, this study emphasises the importance of delineating the types of 'entanglments' between lay and professional (Rabeharisoa and Callon 1998) that characterise a field of genetic knowledge and technology such as breast cancer genetics.

Adopting a less binary approach to a lay/professional distinction *and* pursuing a less unitary analysis of medical practice or culture also makes it possible to see that these developments are not without consequences for the experiences of professionals. Nevertheless the same illuminating focus that has been directed at those who are presumed to be subject to these technologies has not, for the most part, been applied to those who are generally seen as working 'upstream' of their application. Too little attention has been paid to the 'subjectivities' of these individuals (Fortun and Fortun 2005), in considering how they experience and identify with new genetic knowledge or in pinpointing and accounting for their diverse and stratified responses. Considering how a range of health care

practitioners and basic science researchers are involved in the practical management, communication and dissemination of genetic knowledge at different public interfaces, this book examines the extent to which certain 'professionals' are caught up in these developments. Attending to both their perceptions and practices brings to light the opportunities *and* challenges that subsume the pursuit and application of new knowledge of breast cancer genes for these individuals.

'Patient' agency and citizenship

Numerous recent studies exploring how 'publics' respond to or make sense of scientific knowledge or new technologies have shown how this is constituted by active, often creative engagement, rather than just a simple process of passive reception (Irwin and Wynne 1996; Kerr *et al*. 1998; Rapp 1999; Edwards 2000; Oudshoorn and Pinch 2003). Others looking more closely at 'patients' have explored the connections between subjectivity and new medical technologies, where a process biomedicalisation is 'simultaneously transforming biomedical knowledge and subjects themselves' (Clarke *et al*. 2003). On the one hand, taking Foucault's lead in examining the growing prominence of a preventative public health agenda, some have examined how power is exercised, not just through repressive means, but in the way that health care knowledge and information is increasingly internalised as part of a subjective sense of self (Lupton 1995). Others point to a more dense feedback mechanism in examining the complex ways that agency is caught up with innovations in health care. One example of this approach is work examining the recent rapid growth in 'patient movements' (Hess 2004; Epstein 2007) and the increasingly heterogeneous ways that ideas about the 'patient' are being constituted (Landzelius and Dumit 2006).

For Rabinow part of the power of developments in the field of genetic knowledge and technology, where a preventative health care ethos meets predictive information, is the way that this will become 'embedded through the social fabric at the micro level' (1996: 103); that is through quite literal re-definitions of self and identity. Agency, far from being abstracted, is from this perspective, vital or instrumental to emergent forms of genetic knowledge *and* new modes of identification he terms 'biosociality'. The kind of rich ethnographic work that might elucidate more clearly exactly how predictive foreknowledge or genetic information is being incorporated into novel sorts of identity making has only just begun to emerge (Gibbon and Novas 2007). Nonetheless early evidence suggests that the 'fit' between subjectivity(ies) and novel biological knowledge cannot necessarily be

assumed and/or is reproduced and sustained in much more uneven ways. For instance, Konrad's work on genetic testing in relation to Huntingdon's Disease demonstrates how being a 'pre-symptomatic' patient is not only an achieved and sometimes contested arena of identity making but also a fully relational one that articulates 'social anatomies of interdependence' (2004: 153). Although not examining 'lived experience' in the same detail as Konrad, this book nevertheless sheds light on the diverse and what might be described as the powerful yet diffuse biosocialties of BRCA genetics as they shape and are shaped by 'patient(s)' and different 'suffering' communities.

Rabinow's concepts have also been extended in different ways by others who have begun to examine and theorise the new forms of identity making presaged by and caught up with developments in biomedical and genetic technology in relation to governmentality. Ideas of 'biological citizenship' (Petryna 2002; Rose and Novas 2005) or 'genetic citizenship' (Heath *et al*. 2004) have been used to show how new biological knowledge is being used as a resource at the meeting point between regulatory practices, state or health policies of inclusion *and* the articulation of rights 'from below'. Rose and Novas link these emergent forms of citizenship to practices of 'ethical self formation' (2005) while Peterson and Bunton explore the kinds of government power and regulatory authority at stake in the new genetics where people 'perform their freedom in ways that cast them as responsible citizens' (2005). Although, as Lock points out, medical knowledge, in contrast to the seemingly 'purified objects' of scientific practices, has always involved issues of citizenship (2000: 234), recent research highlights how different forms of governance are increasingly caught up in the pursuit and scientific practice of genomic research and not just its political representation. This book, exploring the dynamics of citizenship emerging in relation to developments in breast cancer genetics, examines how novelty intersects with an older set of cultural categories pertaining to gender *and* long standing, yet evolving, institutional or national cultures of cancer research and health care provision.

Breast cancer activism and 'consensus' politics

Since the early 1990s 'lay' or 'patient' activism has had a profound and lasting impact in raising the public profile of breast cancer in Euro-American contexts (Kaufert 1998; Klawiter 2000, 2004). Although activism in relation to a range of health issues pertaining to women, particularly contraception and abortion, can be traced to the early 20th century (Weisman 1998), the recent upsurge in activities and interest

in breast cancer is, in part, a legacy of the feminist politics of the 1970s and the successful lobbying activities of AIDS activist groups in the 1990s (Morgen 2002). Nevertheless, as Epstein points out, it is now the scope and reach of a culture of breast cancer activism which is informing and cross cutting the recent rapid growth in a diverse range of patient movements and lay groups active around the politics of health (2007).

On the one hand, the recent visibility of a culture of activism around breast cancer has helped shape state or government instigated preventative public health campaigns in relation to cancer education, particularly in the provision of mammography screening. Yet it has also itself been fuelled by these campaigns, as Lerner points out, women have been the main targets of these initiatives emphasising the importance of health awareness and early diagnosis (2001). This collectively produced 'preventative' health agenda continues to draw attention to the 'risks' for all women of a disease now framed as an 'epidemic' (Lantz and Booth 1998). This has also resulted in a substantial increase in the funding allocated to breast cancer research, particularly in the US (Anglin 1997; Epstein 2003). A similarly vocal if differently constituted alliance of breast cancer charities and support groups have begun to have an equally strong presence in the UK, raising the public profile of the condition and contributing to significant regulatory changes in the move towards a more 'patient centred' NHS (see Allsop *et al*. 2004).

However, a straightforwardly optimistic or superficial reading of the changes brought about by the increased public profile of breast cancer and women's health issues have been cautioned against by others (Treichler *et al*. 1998; Fosket *et al*. 2000; Klawiter 2000; Potts 2000). Longstanding public health campaigns raising awareness of breast cancer as well as new inclusionary agendas around scientific research and medical provision, targetted at women, often makes it difficult to distinguish between what counts as revolutionary change and what is cooption (Epstein 2003).

This, as a number of feminist commentators have long pointed out, makes it important to examine how agency or empowerment *and* conformity intersect in this and other health care arenas (Lock and Kaufert 1998; see also Ginsburg and Rapp 1995; Haraway 1991). It is not insignificant that since the mid 1990s notions of 'resistance', in the context of a culture of breast cancer activism, have shifted towards a sphere of more consensual based politics (Kaufert 1996; Myhre 2001). Moreover paradoxes abound in an arena where calls for collective awareness of the disease have also helped to ensure the management

of risk and danger have become the 'burden' of individual women themselves (Clarke and Oleson 1999; Fosket *et al*. 2000).

The different cultures of breast cancer activism explored in this book reflect on these aspects of empowerment and agency in relation to developments in breast cancer genetics. Focusing on these specific arenas of activism raises new questions for social science inquiry. Such issues relate not only to the particular kinds of gender-inflexed modes of citizenship, that are emerging at this juncture, but also the way that gender comes to *matter* in relation to genetic knowledge and technologies.

The gendering of bodies and technologies

Despite Rayna Rapp's impressive study of the 'uneven benefits and burdens' that genetic knowledge and technology has for a diverse range of women (1999), there has been something of a 'gender blindness' in terms of the way that social scientists have analysed developments in the new genetics (Stacey 1999). Although the issue of gendering in relation to genetic technologies has begun to be addressed (Hallowell 2000; D'Agincourt-Canning 2001; Ettorre 2005), it is examined here as a complex configuration of social practices, with diverse and ramifying consequences. Focusing on an interface between gendered health activism and genetic knowledge in relation to predictive rather than reproductive medicine, this study explores what is at stake in situating women as specific kinds of citizens and how this is related to particular articulations of morality and ethics. At the same time fresh light is cast on the relationship between agency, identities and the materiality of science and the body by examining how particular cultural signifiers around gender are constituted in relation to, and how they in turn come to be inscribed into, artefacts or technologies (Wajcman 1991; Martin 1994; Oudshoorn 1994; Van Oost 2000).

The meaning of breast cancer, perhaps more than any other form of cancer, is closely associated with ideas and representations of the female body. It has and continues to be subject to and constituted by a range of historically diverse and contradictory meanings (Lacquer 1990; Martin 1989; Bordo 1993). As Yalom points out this is particularly so of the female breast, which is a 'timeless' signifier of 'sex, life and nurturance' and more recently, through the increased cultural prominence given to breast cancer, also 'death'. As a result, she points out, we are increasingly seeing the female breast as 'first and foremost as a medical problem' (Yalom 1998). Yet the meaning, experience and representation of breast cancer is inescapably caught up with powerful notions about gender

and sexuality (Klawiter 2004; Kolker 2004). Just as the meaning of breast cancer reflects and informs particular representations of women, gender and the female body are also enmeshed with recent developments in breast cancer genetics. If, as Butler argues, 'materiality' is a site at which 'gender is continuously played out' (1993), then breast cancer genes and the kinds of bodily and technological 'matter' enlisted and elicited by new genetic knowledge also have consequences for articulations of gender and practices of gendering. This is especially when issues of embodiment and lived experience, refracted through genetic knowledge and technologies are, to a certain extent, re-framed or displaced by the temporality of predictive knowledge and/or the logistics of 'distributed' patienthood.

Central to the modes of co-production explored in this account is the way therefore that particular representations, practices and moralities associated with female gender identity and the female body are caught up with developments in BRCA genetics. In this sense, the book builds on and extends Rapp's idea of women confronting new reproductive health technologies as 'moral pioneers of the private . . . at once held accountable at the individual level for a cascade of broadly social factors that shape health outcomes of pregnancy and individually empowered to decide whether and when there are limits' (1999: 317). In drawing attention to the powerful but disjunctured terrain through which different gendered configurations of knowledge and technology play out, it also illustrates how novelty meshes ways with older forms of cultural classification. That is despite the unhinging of 'natural facts' in an era of 'biosociality', idioms and practices of 'naturalised' female gender continue to provide the context for medical or scientific knowledge and practice (see Franklin *et al*. 2000).

Re-situating the social and ethical as a context for knowledge

At the same time as paying heed to the way ideas of the natural continue to infuse particular arenas of genetic knowledge and practice, a number of scholars have become aware of the need to develop a more reflexively orientated analysis of how ideas of the social and ethical are themselves being put to work in relation to scientific developments. There is a need, as Strathern puts it, to examine how society and sociality have increasingly become 'legitimating epithets', to ask in other words, 'what will count as an adequate description of society in agentive mode . . . not just there in the background but already caught up co-evolutionary with science' (2004: 56). Fisher also emphasises the need to not uncritically participate in sustaining normative ideas of 'ethics' but to actively attend

to the 'mediated and performative nature of ethical discourse itself'. This is not, he points out, in order 'to dismiss false claims but to understand the different kinds of functionalities that [ethical] claims help constitute' (2005: 379; see also Hoeyer 2001; Hayden 2003). When, as Franklin says, the idea of 'biological vs social facts is an inadequate way of describing the cultural context of the new genetics' (2003), a new orientation is required which attends to and accounts for how ideas of the natural, social or ethical become resources in an arena of genomic science and medicine.

An emphasis on understanding how the natural and social are mutually and inseparably entangled has been central to Strathern's analysis of kinship in relation to recent developments in reproductive and genetic technologies (see also Haraway 1992). Her work examines how ideas about 'nature' or 'culture' in relation to kinship and 'the family' can be used to 'domain', 'contain' or even act as a 'boundary claim' to knowledge; a process of connecting (or sometimes disconnecting) she refers to as 'merographic' (1992a: 37). It is a perspective which has been usefully extended by Jeanette Edwards in her ethnographic account of how a particular kind of 'born and bred' kinship becomes a strategic resource in response to novel developments in reproductive technologies (2000).

The conceptual tools developed in the above ethnographic work provide a theoretical and methodological orientation for examining how kinship and female gender, as both 'hybrids' of the natural and social, are subject to and produced in 'merographic' ways in the context of developments in BRCA genetics. But a key point about these 'domaining' strategies is, as Strathern points out, that while powerful they are also replete with unexpected and uneven consequences with de-stabilising 'ricochet effects' (1996: 3; see also Yanagisako and Delaney 1995). In a similar way, although the flux and movement in ideas of the natural and social explored in this book are shown to be productive, they are also partial and disjointed. The generative movement between the natural and social in BRCA genetics is balanced by an ever-present possibility of uneasy reverberating consequences for different persons and for the stability of claims to scientific expertise or medical knowledge.

Importantly a number of recent social studies of the 'new' genetics have begun to reveal more fractured aspects of these developments. Like Rabinow's notion of the 'purgatorial' (1999), Franklin's discussion of a 'genetic gap', points to what she sees as a consistent and inevitable feature of developments in this field 'built into the attempt to instrumentalise DNA for social ends' (2003: 82). Reading 'the omens'

of breast cancer genetics (Lock 1998), this study builds on this theoretical and ethnographic work of lacunae in an emerging era of genetic knowledge and technology. It pays close attention to the discontinuities that are embedded in and emerge from the collective work at stake in the translation and transmission of genetic knowledge at a range of science/society interfaces inside *and* outside the clinic. As Palladino points out, exploring the 'dialogical' spaces of new genetic knowledge and technology gives 'greater credibility to a more fissiparous and centrifugal discourse' (2002).

Mapping co-production; sites, methods and partial perspectives

It has long been acknowledged in anthropology that the positioning and identity of the researcher is always something of a negotiation that influences and to an extent informs ethnographic research. This process is heightened in research that spans numerous different persons, groups and intersecting contexts and where the anthropologist and their research are in Riles's terms, both 'inside' and instrumental to such networks (2001). Moreover, given the way that the developments of interest in this book are inseparable from, as well as having consequences for, the politics of women's health many questions are raised about the (critical) perspective of the author. As a feminist academic anthropologist I have discovered that there are no comfortable positions. Anxiety about 'medicalising' health care interventions co-exists with the recognition of long denied rights to equality of access and care in medicine or scientific research. Moreover despite the dangers of co-option, I continue to hold to a belief and hope in the potential for collective action to create change, empower individuals and create dialogue where previously none existed. The book offers no solution to these 'double binds' (Fortun 2001) but instead takes a sense of experienced unease, both my own and that articulated by those I met in the course of this research, as a resource and source of new insight and knowledge that will inform an unfolding and dynamic understanding of a particular social space in an evolving field of genetic medicine and science. In this sense, ethnography becomes not just about a shape shifting arena of science or medicine, but is also itself enmeshed with that process of emergence (Fisher 2005). Consequently it has the potential to become a powerful resource for critical engagement as a basis for further political action.

Just as the cross-cutting perspectives of work in STS and Anthropology inform the theoretical background to the analysis in this book,

a methodological approach is used that links seemingly disparate field sites and research tools (Martin 1994). In mapping the work of translation and transmission in relation to new knowledge and technologies associated with BRCA genes, my research is located at the juncture between different sites, persons and practices. As Heath posits, locating oneself at these boundary zones illustrates the way 'new meanings' appear at the 'intersections of trans-local displacements' (1998: 520). This is not only or just about following the 'object' or the 'thing' (in this case, breast cancer genes and cultures of health activism) across different public/science interfaces but exploring the relations and parts that they connect with and the spaces and gaps left in the wake of their travelling or stasis.

In responding in part to opportunities and avenues as they emerged, over a period of 18 months fieldwork, this study might be characterised in Marcus's terms as a deliberate engagement with 'thick and thin' ethnography (2005). Examining the work of transmission at different public/science interfaces, my aim has been to reflexively balance breadth and depth. To this end a range of methods have been utilised, some more appropriate to certain ethnographic arenas and moments than others. This included interviews, observations, analysis of marketing materials, texts and images, as well as more participatory research approaches with a diverse range of persons.

The research centred on two main sites, cancer genetic clinics and a breast cancer research charity. I carried out field research at two cancer genetic clinics in separate hospitals in the UK; a specialist cancer hospital and a large general hospital with a regional genetics unit attached.[5]

Despite my original intention to focus my research in relation to genetic testing, it became clear early on in my fieldwork that this was not a widespread clinical procedure. At this time relatively few mutation carriers had been identified in the UK. As a result, these patients were somewhat in demand by others carrying out psycho-social and clinical studies leading to some concerns that this group were being 'over-researched'. In conjunction with key staff in the clinics it was decided that my work would focus on a demographically larger population, who were at the time, of less interest to others carrying out psycho-social research. This group consisted of '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'. To this end I met and interviewed a group of women who fitted this profile and who were attending the clinics for the first time. Interviews were carried out in patients' homes both some weeks prior to their appointment and then once again in the weeks following their visit.

As well as carrying out formal interviews with patients, I interviewed a range of practitioners and also observed numerous different consultations in both clinics. These varied from first time to follow-up visits. Some appointments were with individuals who 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 I interviewed in their own homes.[6]

It was during the initial stages of talking to patients that I became aware of the extent to which the values and ethos of a growing breast cancer lobby were central to understanding recent developments in breast cancer genetics. As a result, I sought an arena outside the clinic in which to explore this culture of activism in more detail and its relationship to the knowledge and technologies associated with BRCA genes. It was at this time that I came into contact with a charity, a large 'grass roots' breast cancer research organisation funding basic science, which included work on the BRCA genes. My research with the organisation between late 1999 and early 2001 coincided with and was directly part of a project initiated within the charity to investigate how different 'stakeholders' perceived the organisation and the scientific research it funded. Although the time of my research saw shifts in public and media discourse in relation to genetic 'discoveries', my work with the charity was de-limited to a particular period in the history of the organisation, and was also focused on specified social dynamics and groups of persons. Although therefore not a comprehensive analysis of the charity and the work it undertakes, the analysis presented in the second half of the book does provide a window onto an emergent field of BRCA genetics in a non-clinical context by examining the social relations between particular kinds of publics and sciences in a specific breast cancer research charity. The formal components of this part of the research included in-depth interviews with staff and volunteers a particular group of so called 'fundraisers' located across the country and scientists working in the organisation's laboratory. In addition I undertook a number of focus groups with the charity's supporters in different locations across the UK, attended their rallies, and was a regular participant on the monthly visits to the charity's research centre and laboratories for these persons and others who supported it in different ways.[7]

These two places of ethnographic research are examined separately in the organisation of the book. They are situated here as simultaneously comparative spaces inside and outside the clinic or the laboratory. But

they are also social arenas where health care activism and genetic knowledge connect and ramify, such that comparison becomes an examination of cross cutting links and interconnecting practices.

The first part of the book focuses on the clinical interface and begins with the experience of those who are most readily seen as 'subjects' of developments in new genetic knowledge and technology. Drawing from my meetings with women attending the clinic for the first time, this chapter examines how ideas about 'visibility and voice' and the morality of 'awareness' inform how appointments at this specialist clinic were sought and anticipated. It looks at the consequences of and requirements for patients 'agency' in relation to the knowledge and technologies associated with BRCA genes. The clinical arena itself and its practices are addressed more directly in Chapter 2. Looking at the range of tools and tests associated with predictive medicine and examining how they are used in translating and communicating knowledge about breast cancer genes, it examines how the material practices of the clinic are used to secure the authority of predictive technologies or stabilise knowledge claims. Nevertheless when situated in relation to patients expectations or investments and the regulatory triage structure, that orients cancer genetics as a specialist service, the meaning of these tools are shown to be multivalent and mutable. Chapter 3 looks at the particular discourse of 'care' that is part of this field of predictive medicine and how it works to sustain knowledge claims and expectations across the patient/practitioner divide. Mapping how the care of BRCA genetics intersects with and draws upon an ethic of female nurturance, it outlines how powerful ideas about shared genetic substance are as important as cultural obligations between kin. At the same time these genealogical and gendered hybridities, that align nature and nurture, articulate new forms of patienthood which can have uneven, often difficult and compromising consequences for those attending the clinic and their family. The final chapter in the first part of the book looks at a range of practitioners' experiences, examining what the implications are for them of new roles as 'diviners' or 'pastoral keepers'. It draws attention to how in different yet also compromising ways they are also subjects in relation to these developments.

The second part of the book examines the work of transmission linked to the breast cancer genes and the parameters of co-production in relation to a particular high profile breast cancer research charity. The three chapters which constitute this part of the book use the social dynamics between different groups in the organisation as a lens for examining how persons situated outside the clinical arena, breast cancer

'activists', organisational actors in the charity and scientists negotiate, respond to and are implicated in BRCA genetics. Chapter 5 examines how the identity and ethos of the organisation lies precisely at the meeting point between a particular type of activism and the pursuit of genetic knowledge. Examining the narratives of 'fundraisers', it explores how the scientific research undertaken by the charity informs and sustains involvement as an act of 'memorialisation' and hope. Chapter 6 examines this culture of 'activist' investment in relation to the organisational challenge of managing hype and hope associated with gene research, through an analysis of particular marketing and campaigning materials. The second half of the chapter illustrates how specific ethical values, instrumentalised in service to this goal, have become increasingly important in negotiating the challenges of supporting and funding long term, complex basic science research. The final chapter of the book turns to the space of the laboratory to examine how a group of scientists, working at the charity's research centre on the BRCA genes, are caught up with the social relations and dynamics explored in the proceeding chapters. Here one mode of science/public communication around a particular event at the organisation's research centre, the monthly laboratory tours for fundraisers, becomes a focus for examining how scientists are implicated in a collective quest for 'salvationary' knowledge.

Bringing these two sites to bear on the analysis contained in the book serves to highlight how the question of 'social impact', which has been the focus of much social science engagement in the new genetics, must be situated in much more multi-dimensional ways. This means examining such development not only in relation to a wider range of persons or a more diverse set of practices but also a particular political economy of health and institutionalised medical and scientific cultures. This study shows how in direct and more distributed ways all these different 'actors' are incompletely, yet always partially, linked to the collective work at stake in breast cancer genetics. Starting from the perspective of 'patients' attending clinics and concluding with a group of scientists working on the BRCA genes, it is an account which traces a line not 'downstream' of developments in breast cancer genetics but what appears in circuitous ways to be a movement 'upstream'. Yet mapping the co-production of the knowledge and technologies associated with breast cancer genes suggests that unilineal effects or trajectories are not necessarily always so clearly definable and might more usefully be understood in term of the 'traffic' around the work of transmission.

Part I

Clinical Breast Cancer Genetics: Patients, Practitioners and Predictive Medicine

Since the late 1990's NHS genetic services, in particular clinical cancer genetics, have increasingly become prime targets for government sponsored research and investment. In April 2001, the then Secretary of State for Health gave a speech setting out the government's commitment to support an expanding genetics service in NHS, announcing a package of new investment (Milburn 2001). Ten months before that in the government's National Cancer Plan cancer genetics was highlighted as key site for investment linked, as the following extract indicates, to the rationality of 'patient' centred and 'preventative' health care:

> 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).

But it is the more recent Department of Health White Paper 'Our inheritance, Our Future' (2003) which has concretised the UK government's commitment to furnishing the coming 'genetic revolution' with an announcement of £50 million for genetic research, health care and the training of medical professionals. In an era of finite resources and the ever-increasing rationalisation of health services, these policies and the promise of investment they bring tie an economic rationale to the promise of genetics, where prediction and prevention are closely allied to targeted interventions.

The situation was somewhat different 10 years before these announcements, at the time when the BRCA genes were identified in the mid-1990s. Although most regional genetics services now have designated cancer genetic clinics, this has been a relatively recent development. Up to 1996 genetics services in the NHS were mostly focused on rare and single gene disorders. As such the system for the provision cancer genetic services was somewhat ad hoc and the boundaries blurred between what constituted research and what might be seen as health service provision (The Harper Report 1996; Coventry and Pickstone 1999; Palladino 2002). For example, as Wonderling *et al*. point out, at this time there were a number of family history clinics dealing mostly with breast cancer in cancer departments in large hospitals. These were often funded by specific research programmes or had been set up by breast surgeons responding to patient inquiries (2001). Regional genetics services did see cancer genetic patients at this time also, but were only funded in a few cases to specifically cover cancer genetics. Nonetheless a report published in 1996, a year and a half after the 'high profile' discovery of two breast cancer susceptibility genes, suggested that in a third of genetic centres, cancer related inquiries had come to constitute over 20 per cent of all referrals (Royal College of Physicians 1996). Even at this time, as Parthasarathy notes in her examination of the regulatory processes that brought cancer genetic services into being in the UK, 'demand' was seen as a 'problem that had to be solved'(2005: 29).

Partly in response to inconsistencies in referral practice, the uneven funding structure as well as the significant increase in referrals, 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 (The Harper Report 1996). In her examination of these developments Parthasarathy points out how the committee who produced this report, 'capitalizing' on the recent re-organisation and commissioning of NHS cancer care outlined in the Calman-Hine report a year earlier, fought to ensure that cancer genetic services were an 'integral part of these developments' linked to a 'preventative' approach (2005). The Harper Report recommended that purchasers should ensure that these services could be supported by contract funding rather than the insecure research funds that many depended upon at the time. 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. Following a pattern outlined in the Calman-Hine report, the group recommended a 'triage' model that would provide a co-ordinated service

at three different levels, linking primary care with cancer screening units in district or general hospitals and specialist cancer genetic clinics. It recommended that primary care would be the focus for reassuring those at 'low' or no increased genetic risk. Cancer screening units would respond to the needs of those at 'moderate risk' and those at 'high risk' would be seen by specialist cancer genetic clinics, thereby restricting the offer of genetic testing to those who fell into the high risk category.

A study of referrals to regional cancer genetics services (Wonderling *et al*. 2001) suggested that the ad hoc system had begun to change in the late 1990s, when it was noted that nearly all regional genetics centres had dedicated cancer genetic clinics. But this study, a survey involving 22 regional genetic centres in the UK, also noted the extent to which breast cancer had come to dominate most clinical appointments. It found that these constituted not only 63 per cent of all referrals, but that over 80 per cent of these were from currently healthy women (only 7 per cent were from men). More importantly the report pointed out that large numbers, (approximately 25 per cent) of those getting to the newly established cancer genetic clinics for breast cancer risk assessment, were 'inappropriate', involving women at low or moderate risk on the basis of their family history (see also NICE 2004; CMGS Audit 2004–2005).

It is clear from this data that maintaining the tertiary system for managing referral practice, in relation to the development of cancer genetic services for breast cancer recommended in The Harper Report (1996) and the more recent NICE guidelines (2004), has not necessarily been easy. In fact defining and implementing the guidelines for those women with an increased risk of breast cancer has been a subject of much debate and to a certain extent ongoing public and professional 'misunderstanding'.[1] The 'confusion' over guidelines and the challenges associated with referral practice cannot however be separated from the way that the 'risks' associated with BRCA genes have been and continue to be an evolving and moving target (Antoniou *et al*. 2003). A shifting terrain of medical knowledge which is examined more closely in Chapter 2.

The somewhat ad hoc emergence of cancer genetic services in the NHS are also, perhaps not surprisingly, reflected in the way they have developed in the two settings where I carried out my research.

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

research or training of health care professionals. The current location of the cancer genetic clinic, which runs alongside a more long-standing family history clinic, is a result of recent hospital and other investment from a number of clinical trials that have been set up. These have been and continue to be undertaken as part of a larger medical arena dealing with the diagnosis and treatment of breast cancer – the Breast Diagnostic Unit (BDU). Importantly the whole unit was also originally part of a so-called 'well woman clinic' catering mainly for the needs of local women to whom it had, in the past, provided advice as well as routine mammography screening and cervical smears. Although its remit has now expanded beyond a localised approach, the gendered ethic of care and ethos of rights historically associated with this kind of community-based initiative targeted at women, is something that continues to be felt in the work of the clinicians who now work in and occupy this space. Threatened with closure 15 years ago the unit was saved, if somewhat transformed, by undertaking clinical trials and providing services mainly 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 mostly by specialist nurses and provides regular examination, monitoring and mammography 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, where several consultant oncologists trained in genetics work, along with a number of nurse specialists and some part-time locum GP's, monitors those at 'higher' genetic risk. This clinic also sees new referrals – a group which had increased several fold in the few years prior to my fieldwork in the hospital.

By contrast, the cancer genetic clinic at the large general teaching hospital, where I also carried out a somewhat smaller piece of research, has evolved in a different way. Paralleling in many ways the history of the UK genetic services outlined by Coventry and Pickstone (1999), the clinic is a relatively recent but growing addition to a larger regional genetics unit. Here clinical management, laboratory research and diagnostic testing have long been linked in addressing what had, until the mid to late 1990s, been mostly a wide range of somewhat rarer single gene or monogenetic conditions. As a result, unlike the cancer hospital, the cancer genetic service in this setting was less directly connected to an integrated cancer services. Although oncology clinics operated in the hospital, they were somewhat at a remove from cancer genetics. The cancer genetic clinic runs two days a week from a fairly generic clinical space, where there is nothing to identify this medical speciality with cancer, breast care or genetics. Like the cancer

hospital, though, there is a family history clinic which monitors follow-up patients or those involved in research, run in this case by a locum GP. The more specialist cancer genetic clinic sees new referrals or those identified at high risk or who are undergoing testing. It is run by a nurse specialist and a number of clinical geneticists.

In both hospitals patients are referred to the cancer genetic clinics in a variety of ways. Although in an earlier period patients may have been able to self refer (Parthasarathy 2003), most new requests for referral now come from GPs. But letters might also come from breast screening units or family history clinics in the same or other hospitals. On receipt of such requests letters would be sent to patients either offering them an appointment or conversely explaining why they do not meet the criteria for referral.

Examining the development of cancer genetic services in France, Bourret demonstrates how regulatory practices and guidelines are 'actors' in sustaining this new and expanding field of medical intervention (2005). The chapters in the first part of this book illustrate the importance of situating such policies in relation to a more expansive set of 'actors and networks'. These encompass not only a specific regulatory yet evolving culture of national health provision, pre-existing and differently institutionalised clinical specialisms such as oncology or genetics, but also the 'activism' and investment of patients.

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The Enrolment of 'Patients': Visibility, Voice and Breast Cancer Activism

This book starts by considering a group of persons who have traditionally been situated at the centre of analysis in medical anthropology, where attending to the embodied or narrative experience of a patient's illness normally takes centre stage (Good 1993). However, as Landzelius and Dumit point out, the figure of the patient is currently 'undergoing an accelerated process of change' (2006). Responding to their calls for further 'scrutiny' and 'problematisation' of the very concept of patienthood this chapter examines the expectations and experiences of a particular group of women attending cancer genetic clinics for the first time.[1] It examines how the features of an increasingly prominent public health discourse about breast cancer and a growing breast cancer lobby become a resource for a kind of health activism and what is perceived as preventative health. It explores how, in the context of a referral to the cancer genetic clinic, the value of 'awareness' and the need for 'visibility' entail and sustain what might be seen as a form of anticipatory patienthood. This in turn has consequences for the way persons perceive the danger posed by genes and the scope of genetic knowledge or technologies associated with breast cancer.

The focus in this chapter is less therefore on the 'embodied' experience of illness than on the way danger, genes, risk and pathology are made real and material in the process of seeking to become and identifying oneself as a patient with rights and access to health care interventions. Although described here as 'patients', this is shown to be something of a contested identity in relation to an emerging arena of predictive medicine, less ascribed than achieved and reproduced in the practice of seeking and/or obtaining a referral to the cancer genetic clinic.

The morality of health awareness

The value of health awareness as a preventative strategy has become especially salient in relation to breast cancer over the last 15 years in Euro-American societies. Targeting women in particular, much has been made of the need to identify the disease in its early stages by encouraging individual women to be aware of their breasts or to attend routine mammography screening (Lantz and Booth 1998; Lerner 2001). It is an agenda that is informed by a burgeoning growth in health activism around breast cancer, instrumental as discussed in the Introduction, in raising the public profile of the disease (Anglin 1997). As a result, the previous social invisibility of breast cancer has increasingly been replaced by a heightened visibility, where the morality of health awareness has and continues to be animated both by a preventative public health message and gendered health activism around the disease. Research with women attending the cancer genetic clinics a few weeks before their first appointments illustrates how a preventative health ethos has specific consequences for expectations, anxieties and hopes about novel sorts of predictive interventions.

Most of those I met and interviewed talked initially about how their appointments had been set up after discussions with their GP. Although difficult to substantiate, it was a process of referral which many seemed to have instigated themselves. Regardless of how exactly a 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 strategy of monitoring her health:

> Rose: I've just sort of said to myself well I need to start looking at me . . . . 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 another person going to the clinic, following her mother's treatment for breast cancer was also part of an attempt to undertake preventative action:

> Emily: 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 reflect the way that those attending these clinics, are for the most part not only cognisant of a high profile discourse about the 'risk' of breast cancer but the need also to be personally active around prevention. In addition these examples illustrate the way awareness carries with it not only a perceived practical but also a high moral value. This was evident in how several women I met, a few of whom had been required to be more pro-active than most in seeking a referral, talked about how they had been angered by the reluctance of their GP to refer them and how they had subsequently asserted their 'right' to be seen. One woman, for instance, recounted the struggle she had undergone with different 'male' health professionals to have her concerns taken seriously. Having now obtained an appointment at the clinic, it was an initiative which 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 haven't got a pair of boobs.

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 cancer genetic clinic:

> 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, for 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 at least, simply part of being a patient.[2]

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, an unclear cervical smear test:

> I just went straight to a gynaecologist recommended to me by a friend and it was sorted within six months. 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' or being 'upfront' about health issues. This served to illustrate how, for these persons, a moral code of awareness and 'rights' to health care was instrumentally linked to a process of prevention. 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.

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 a celebration of a newly acquired ability to vocalise concerns or simply an expression of personal anxiety. Rather, going to the clinic seemed to be about making 'hidden danger' visible. This was especially so for those attending the clinics, who had had either 'misdiagnosed' relatives or affected persons in their family who had ignored concerns about their health for some time leading to what were perceived, by some clinical attendees, as preventable premature deaths from the disease. This was how one woman put it:

> I suppose it's 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.

From these comments and narratives it's clear that the reasoning that lay behind seeking referral to a cancer genetic clinic was often strongly informed by a high profile preventative public health care agenda and an ethic of health care rights, which the burgeoning breast cancer lobby in the UK has also been active in articulating. This is illustrated in the link made by many women between the morality of health awareness and the desire, as one woman put it, to bring dangers 'out into the open'. Part of the rallying call of feminist discourse in a different era, these demands for 'visibility and voice' (Kaufert 1996) arise from and leave particular kinds of ramifying traces in the way those attending the clinic perceive predictive technologies and actively participate in materialising genetic risk.

Making danger visible; being visibly a patient

The desire and need for awareness or activism in pursuit of prevention also has other consequences. This was apparent in the way some women appeared to actively engage in efforts to identify themselves as 'patients' whose 'pathologies' are located in anticipated and predicted risks. That is, a number worked hard to locate, reproduce and make manifest or material a sense of personal genetic danger *before* being seen in the clinic.

Having a 'family history' of breast cancer

It was apparent that a number of those I met 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.

Sometimes it was what was unknown or 'mysterious' and therefore suspect which made a family history 'significant', from the point of view of those attending the clinic. For instance, Lucy suggested that it was the gaps in her knowledge of the history of her 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. My mum comes from a quite a big family too, so potentially there could be a lot out there that I don't know about.

However, for most it was not 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 did not 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 . . . it's just there is breast cancer down the female line on my mother's family and it strikes me that it must be related unless it's just a coincidence that my grandmother and mother had breast cancer. But they had very different lives . . . 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 . . . [so] it just seemed 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, after prompting from me, 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 my 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 my dad's side, I don't think of my dad's side as related to cancer funnily enough, because my Nan [on her father's side] did have stomach cancer and my granddad did

> have like a brain cancer but because the daughters didn't . . . I just see like on my mum's side . . . 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, of course, reproduced) by the drawing I asked her to do, as illustrated below in Figure 1.1.

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 also are reproduced in Figure 1.2.

Not precluding the possibility that those I met perceived me as a 'gatekeeper', in terms of access to the clinic, it is nonetheless striking that many of the resulting diagrams were dramatically pared down and somewhat pathologised representations of family history. In nearly all cases, very few affinal relations were included, and in some cases no other consanguineous or 'blood' relatives were drawn. This was particularly so in Jane's and Shona's illustrations where hardly any other relatives were depicted that might detract from the narrative trajectory of risk they had talked about. Jane drew only the two relatives affected by cancer (her mother and grandmother), herself and her two sisters. It was only much later in the interview that she mentioned in passing that she had four brothers. Even when the depiction of family history seemed to be more balanced, or at least encompass more people, as in Julie's case, 'clues' about possible risk were also visually represented. Lucy's depiction of her family history was less obviously a narrative about 'risk' in the way the others seemed to be. There was, for instance, no indication in her drawing of who had had cancer. Nonetheless, unlike others, she had also included her children and her sister's children in her depiction of family history, where there was a gendered ratio which, for her, was further evidence of risk (see p. 40).

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. That is, before having an appointment confirmed, more than half of those I met were asked to fill in a 'family history

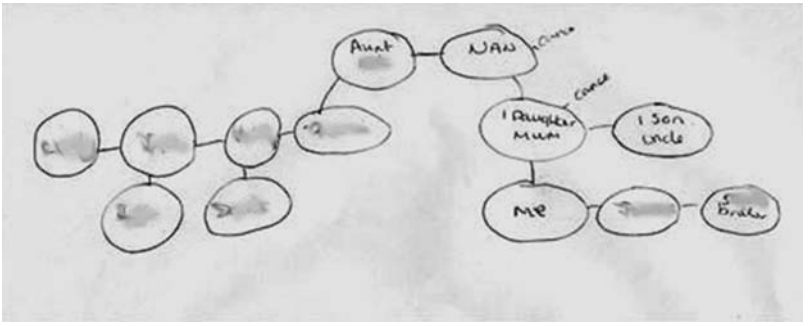
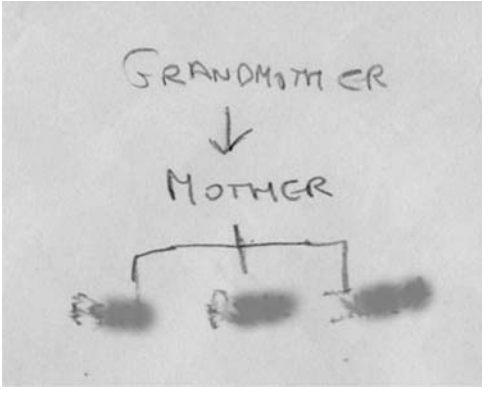
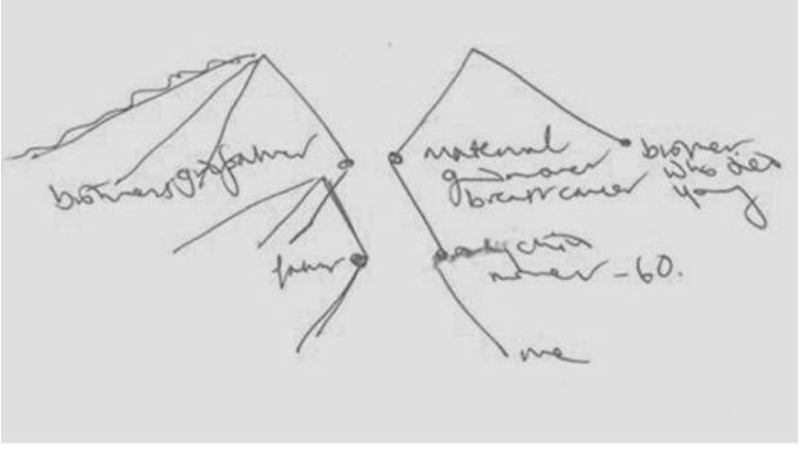


Figure 1.1 A depiction of family history

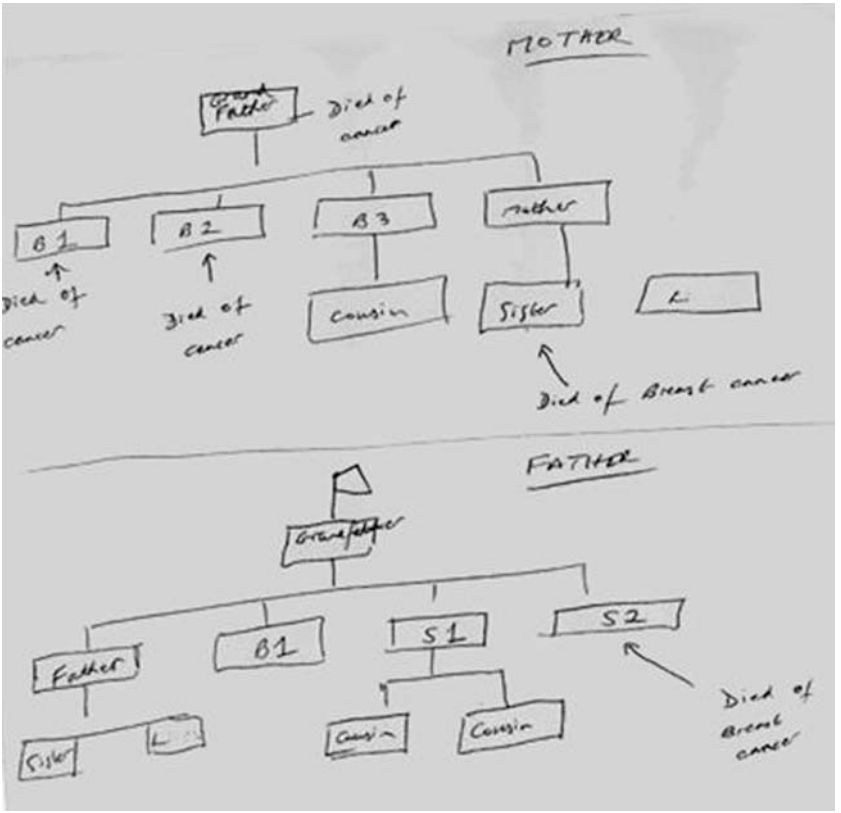


Jane's family history

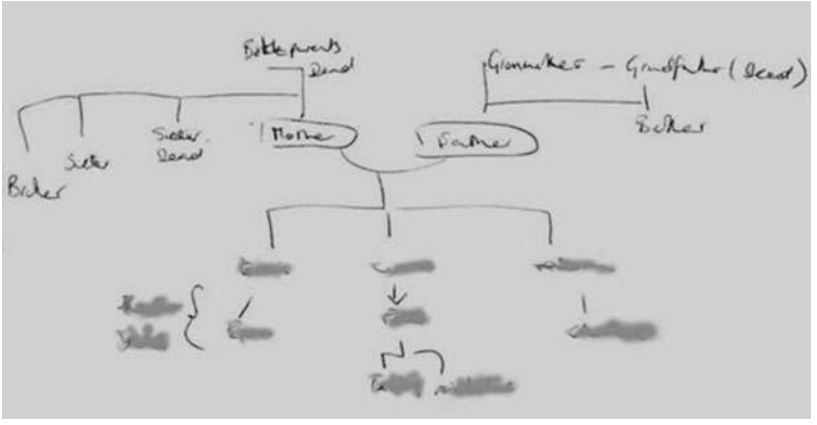


Shona's family history

Figure 1.2 Other 'patients' family trees



Julie's family history



Lucy's family history

Figure 1.2 (Continued)

form' which involved them documenting the history of cancer and other significant diseases in the family. This would then be brought or sent to the clinic prior to their first visit.[3] It is a procedure which illustrates how those attending the clinic *had* to be 'active' patients in the process of obtaining a referral or filling in the family history form, showing how recruitment is constructed in particular ways prior to appointments.

However, at the same time completing the form may have made perceived or suspected genetic risk more real, it also confirmed to many that their family history made them 'special' or 'interesting' cases.[4] For one person, simply having to fill out the form implied 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, given the finite resources in this and many specialist areas of medical practice in the NHS, it was only 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 represent family history in particular ways that might 'talk up' apparent or perceived danger in order that their family history would be seen as deserving attention. In fact, there was a sense among some of those I met that seeking and obtaining an appointment was something of an 'exchange' with particular health care or research institutions. This was illustrated in the way one woman in her early thirties, who was keen to be on some sort of screening programme, talked about her desire to be seen in the clinic in terms of 'giving something back' to the hospital where her mother was treated:

> When my mother was here I raised some money for the hospital 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.

These remarks highlight how for some persons a willingness to take part in medical research intersects with an awareness of increasingly 'rationed' health care. In other words many knew that being able to participate in acts of altruism, in 'giving something back', was dependent on being a 'case' of 'interest' in the first place. It is a set of entangled exchanges a number of women I met seemed willing and eager to be part

of; an ethos of reciprocity which was reflected in already pathologised depictions and narrative accounts of family history which made real and manifest the evidence of hidden or latent past and future risk or danger.

Bodily continuities and discontinuities; the evidence of danger

The 'obvious' and 'logical' danger of family history were also made apparent in a number of more bodily ways, helping to confirm and confer an anticipatory embodiment to perceptions of risk. Here 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; something which others examining 'lay' or patients' perceptions of genetic risk have also discussed (Richards and Hallowell 1997; Finkler 2000).

For instance, Lucy 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. 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.

For her, these bodily connections were more than enough evidence to suggest that there was a high probability she would develop the same condition. Donna also discussed the way physical parity between family members fuelled her disquiet. At the same time, this sharing of symptoms could not be separated from a sense of anxiety and trauma that had passed through the lives of many generations that included her mother and grandmother. For her, lived experiences became caught up with the anticipated danger of genes:

> Donna: What makes it worse for me is the same year that my mum had the cancer that same month I found lumps in my own bust. And then there was my Gran . . . I can just remember it living with my mum just as it does with me and my sister.

These bodily connections could be seen as akin to what Nahman, in a different arena of reproductive medicine, refers to as kind 'part/whole

telescoping of traits' across different temporal terrains and in the configuring of persons and patients (2005). The 'telescoping' work of patients in relation to breast cancer genetics operates in pursuit of, while helping to make real, an at-risk identity.

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 also informed and fed the perceived need and rationale for referral to a specialist clinic. Although a sense of connection with others' bodies might provide the background to perceptions of risk for these persons, this was less the locus of concern than a sense of detachment and feelings of pathology about their own. For example, a number of women talked about the anxiety they felt in 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. I know it's not logical but the 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, because of what had happened to their relatives, also of the utility of doing so. As Jane 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, 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 bodily anxiety was the way a few women I met mentioned in passing, and without any direct questioning or remarks from myself, how they would, as a 'preventative' measure, consider having their breasts surgically removed at some point in the future. Towards the end of our first meeting, Faye's comments about undertaking surgery seemed to come out of the blue, suggesting this was something that lay semi-consciously behind some of her anxiety:

> Faye: 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 this procedure also emerged in what seemed an offhand way, after I asked about her expectations of care following the appointment at the clinic:

> Deborah: well I don't know, obviously there are 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 who's 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 I'll go and have it, just to get rid of the risk.

Although there was a sense of flippancy about Deborah's discussion of 'boob jobs', like Faye's of-the-cuff remark, their comments seemed to disguise a deeper set of concerns about the risk of developing breast cancer. The sense of anxiety around breast examination and the ease and readiness with which several women I met discussed prophylactic mastectomy, as a possible option that they might undertake in the future, revealed the extent to which some expressed a sense of detachment and disconnection from their bodies. This might, in part, be understood in relation to the increasing routinisation and public profile of cosmetic procedures associated with the breast (Davis 2003). But it also cannot be abstracted from the way an ethic of preventive health is embedded in a message about the need for routine and regular monitoring and vigilance. Fear and anxiety about the body were clearly linked to how and why those I met engaged in efforts to make genetic risk visible, and tangible. In this sense, the bodily parities which served to make genetic risk manifest, for some, must also be understood in relation to the articulations of disembodiment with which, for others, was an equally powerful source and manifestation of anxiety.

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 and disconnections were made between persons and bodies, the way in which genes were perceived and talked about also contributed to a

narrative emplotment that highlighted the presence of risk and danger. For some, forthcoming appointments were linked to the need to clarify other health care concerns about the risk of breast cancer, such as diet and decisions about taking HRT or Tamoxifen; concerns which reflect how different mainly so-called 'lifestyle factors' have been linked with the development of the disease through a media and public health discourse. Nevertheless discussion of these issues, by those I met, intersected with perceived genetic danger in ways that mostly preserved the latters causative agency.

Like 'quasi pathogens' (Yoxen 1982), genes were sometimes discussed in terms of being either present or absent (having or not having the gene), or in terms of having a 'bad' gene, often imbued with cancer-causing potential. This was demonstrated in what Jane said when I asked her what she meant when she talked about having 'the' gene or not:

> 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 'explained' breast cancer in a way that paralleled how different 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 as causative factors appeared to provide a certainty amidst what seemed to many like a vast sea of possible risks and dangers. The strength of this belief became particularly evident in my discussion with Deborah. She was one of the few women I interviewed who had, in the process of garnering details to fill in the family history form, discovered that other relatives were already undergoing predictive testing. The possible presence of a 'gene' therefore took on a greater significance than it might have otherwise done as her response, to our discussion about the possibility that genetic testing might prove inconclusive or potentially negative, illustrated:

> 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.

If some preserved the agency of genes by highlighting the possible presence of other, as yet unknown genes, others emphasised the power of known genes, and hence the underling evidence and materialisation of personal risk and danger, in terms of the way 'fate' was understood and talked about. This is illustrated in how for two individuals I met the sex of their (and their siblings) children made evident and apparent the interconnections between genes and 'destiny'. Whilst talking about her family history and referring to the diagram she had drawn, 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:

> 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.

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 some kind of 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. 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.

This 'sixth sense' about food for Shona confirms not only her sense of genetic risk, but also that she is also countering it by being intuitively healthy. Her comments illustrate how a sense of personal danger is informed by complex connections between a public health discourse about possible lifestyle risk factors for breast cancer (which often includes dietary advice) and perceptions of genetic risk. For Jane, however, the expression of 'genetic' fate she reflected upon was somewhat less reassuring.

> Jane: 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 Jane's father had served as a background for the growing feeling of genetic fate that fed and informed her feeling that there was a risk in the family.

The desire, by many of those attending the clinics, to objectify or identify with having a genetic risk of breast cancer is striking. Substantial efforts are clearly being undertaken to make risk 'real' by representing or talking about family history in particular ways and by pointing to physical and bodily parities between related persons. Moreover, genes are given both a more personal as well as a more general 'agentive' 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 the collective lives and experiences. In these narratives, genes appear to be inextricably linked to 'being' and 'becoming' (Duden 2003) in ways that cannot be abstracted from a preventative ethos, linked to and promoted by a public health and activist discourse on breast cancer.

The modes of 'anticipatory' patienthood examined here suggest it is less important to try and understand how 'illness' is 'experienced' than to see how different signs of risk or danger, which index the possible presence of past or future disease, are appropriated or applied in the effort to be identified as a patient. The objectification of family history and bodies is central to such work. The agency of individuals

far from being curtailed by being labelled a patient from 'above' is by contrast an identity which seems actively sought and pursued in pursuit of empowerment or control and what are seen as legitimate claims to health care interventions. Here genetic pathology becomes a tool for identificatory practice. In 'fighting' for their right to have perceived danger recognised as medically defined risk, these individuals are attempting to 'author and authorise' (Landzelius and Dumit 2006) a form of anticipatory patienthood.

But the efforts and struggles of those I met to construct themselves as 'patients' are also not separable from the increased rationing and standardisation of NHS resources. In the case of cancer genetics, this ensures that only those most at risk will be seen and/or offered monitoring and specialist services. It is in fact just such services and interventions that those I met appeared to seek in pragmatically constructing themselves as particular kinds of patients, where the sorts of agency gained from objectification is directly linked to investment in specialist clinical knowledge and specific visualising technologies.

Faith in technology

If many of those attending the clinic articulate a need to identify risk and danger before a problem takes hold, the expertise and technologies associated with this medical specialty are directly connected to these efforts, in their perceived ability to pre-empt risk and danger. As the examples below illustrate, the sense that screening, monitoring and testing technologies will be able to access a certain 'truth' about the body contributes to heightened expectations about the kind of interventions that will or should be offered to those who are 'at risk'.

The expertise of clinical genetics

The notion that the cancer genetic clinic was a place of expertise was a sentiment that was widely held among those I met. Many had pursued the need for a referral either through their GP or other health care professionals, precisely because they viewed the cancer genetic clinic and its practices as a place where they could benefit from 'expert' knowledge and technology. Jane had not been as single-mindedly active in her pursuit of a referral as some of those I met. Nonetheless she also anticipated that the clinic was a place of professionalism

and proficiency, 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 if 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 some I met, referral to this particular specialism was something less expected, even though they might have been engaged in substantial efforts to obtain some kind of monitoring or a check up of some sort. However, even when the clinical speciality to which they were referred was different to their original 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:

> 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..[and].. there is going to be something else to detect it.

Visualising danger – the mammogram

As Rose's comments indicated, faith in the clinic's anticipated expertise was closely linked to screening technologies, particularly the now routinised mode of screening for breast cancer through mammography. In fact there was a more widely and often openly declared rationale that the primary reason for seeking a referral was to obtain a mammogram either on a one-off or regular basis.

For some this was because they were not aware of other interventions that might be possible such as predictive genetic testing. For

most, however, it was because they felt emphatically that having a mammogram was an important and necessary 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. 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. Her response to my question about how she would feel if she was told that this was not possible, if she wasn't at sufficient risk, revealed much about her investment in this outcome and the actions she was prepared to undertake to secure this.

> 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. Then they're not suggesting what I should do . . . 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 and faith in this visualising technology talked about it in terms of a health care 'mantra', very much linked to a public health discourse about the need and value of preventative action. Reflecting and reinforcing this message, they believed that having regular mammograms would identify a possible risk or cancer before a problem took hold. Treichler *et al*. suggest that the heightened visibility of women's health that has emerged since the early 1990s is closely tied to the application and use of various 'screening' technologies particularly in the context of breast and cervical cancer (1998). It is not perhaps surprising then that when a discourse of health awareness preaches that vigilance and early detection is central to the prevention and successful treatment of breast cancer, mammography becomes the 'technological fixer; the diagnosis is made sooner, treatment begins before growth is visible or tangible' (Kaufert 1996: 178). As numerous recent controversies over the value of mammography screening attest, these are not unproblematic perceptions.[5] Subsequent chapters examine how these perceptions have particular ramifications in the dynamics of

clinical encounters with consequences for the way patients and practitioners manage the distance between knowledge and care in BRCA genetics. Nonetheless for many of those attending the clinic, mammography is perceived as an important tool for bringing hidden danger into the open (see also Hallowell 1997). This is particularly so when there is a certain degree of fear, for at least some women, associated with other modes of being vigilant, such as breast self-examination. The desire to be on a screening programme is therefore one of the crucial factors behind many women's decision to seek a referral to the cancer genetic clinic, which for a significant number often appears to be a way of obtaining mammograms.

Not surprisingly some women also talked about another technology which was more directly associated with visualising genetic danger.

Anticipating 'the' test

For a significant few people there was an automatic assumption that going to the clinic would either involve or somehow enable them to have genetic testing. For example, when I asked Jane what she expected to happen when she went for her appointment, she revealed that she had many questions and concerns about her risk. Nevertheless the prospect of having a 'blood test', as she put it, held out the hope of providing more definite answers.

> Jane: 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?
>
> Jane: 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.

Like Jane, for Alice the prospect of going to the cancer genetic clinic informed an assumption that she would have, as she put it, 'a battery of blood testing'. In this way she hoped to have more definitive answers about her risk as these comments illustrated when she reflected, in retrospect, on her initial expectations:

> 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'. I think I thought it would be like they would do those tests when they say 'oh you're allergic to this and this' . . . to come back and say 'well you're likely to get A, B and C'.

For Donna the possibility of having a 'genetic test' had been etched on her mind by a programme she had seen on television.[6]

> 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 she had a genes test done and found out it was in the genes. 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 . . . 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 my life a lot better.

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. Nevertheless the expectation of a blood test had also been informed by what had been done and said by other health care professionals either directly to those I met or to their relatives, 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. So it seems like a lot of people [doctors] 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 very much linked to the fact that it might be possible to carry out some sort of testing on her mother.

It's clearly difficult, in some cases, to disaggregate the effect of patients expectations and desires for testing, from the actions of GPs and other health professionals and/or a even particular agenda in the media about genetic testing for breast cancer (see Henderson and Kitzinger 1999). At the same time the possibility cannot be discounted that anticipating a genetic test was perceived as simply part of or necessary to being a patient who would be seen, screened and generally looked after on a routine basis. Whatever the source of such anticipated interventions, genetic testing clearly provides a powerful symbol of the precision and expertise that many of those I met associated with this medical speciality, holding out the hope of providing concrete answers in the midst of widespread fear and anxiety about the risk of breast cancer.

In championing a 'lay perspective', anthropologists have revealed a great deal about the way that patients and other 'lay' persons actively respond to new technologies and knowledge as they are applied and/or disseminated into the 'wider world'. Focusing mainly on the downstream 'users', this growing body of work has revealed the multi-faceted ways that patients and others deal with the 'effects' of new technologies or knowledge about health (Rapp 1999; Finkler 2000). Exploring the experiences of a particular group of persons attending the cancer genetic clinic not only challenges a 'deficit model' of the public's response to new medical technology or knowledge (Irwin and Wynne 1996) but also raises new questions about the agency and actions of lay individuals. The findings presented here suggest that many are proactively involved in efforts to obtain a referral, make their 'risk' real at the same time as reproduce the clinic as a space of expertise and knowledge.

These persons are in this sense very much 'anticipatory' patients with strategic investments in pathologising their potential risk. But the activeness this entails must also be understood in relation to a valorisation of preventative health or individual vigilance which, since the early 1990s, has found particularly strong expression in the context of breast cancer. Here an ethos about health awareness and the rhetoric of visibility, targeted and promoted by the breast cancer lobby, has been foundational. In contrast to Parthasarathy's conclusions (2005) the evidence presented in this chapter suggests that a consumerist ethos about health care interventions and services, in relation to breast cancer genetics, is not confined to countries without a national health service. It is possible that new consumer-tinged demands among patients within an NHS setting is emerging because of, rather than despite, increasingly rationed and rationalised health care provision.

The activism and articulations of empowerment explored here, tied to neo-liberal values and practices of self-actualisation, associated with preventative and a newly emerging arena of predictive health care, could be framed in terms of 'biological citizenship' (Rose and Novas 2005; Peterson and Bunton 2005). From this perspective, the kind of anticipatory patienthood sought by those attending the cancer genetic clinic helps to sustain disciplinary power internalised and expressed as health awareness. Subsequent chapters critically examine these claims by examining the challenges raised by these developments for medical practice and practitioners working in a specialist NHS service such as cancer genetics, predicated on triage and also in relation to the experiences of patients who are unwilling or unable to act on predictive foreknowledge. In this way issues of biological citizenship become more institutionally embedded even as these modes of identification are unevenly mobilised.

The work of patients explored in this chapter illustrates how the transmission of genetic knowledge and technology is not only flowing in ways that might not have been expected, preceding the clinical interface, but is already multi-directional. In the same way that, as Palladino points out, patients have been 'constitutive figures' in the emergence of another arena of genetic medicine (2002), this chapter has illustrated the extent to which the expectations and actions of patients also inform clinical breast cancer genetics. Whatever the particular configuration of agency and power that lead or impel individuals to seek an appointment, there is clearly a heightened expectation about the scope of this field of health care practice. The next chapter, exploring the technologies and material practices of the clinic, shows how such expectations have diverse implications in the social dynamics of health care encounters.

2
Technologies of the Clinic: Tools, Tests and Explanatory Strategies

The constituting and transformatory role of technology in the development of different clinical and medical specialties has been central to science studies (Casper and Koenig 1996; Mol and Berg 1998). This perspective stands in contrast to what has been a somewhat more reluctant approach within anthropology to examine the material practices of bio-medicine itself (Lock and Lindenbaum 1993). Drawing on recent work situated across these disciplinary divides, which have begun to produce new kinds of inquiry at the intersection between technology, patienthood and a variety of health care specialisms or practices, this chapter examines the routines of the cancer genetic clinic. In attending to how genetic knowledge is communicated at the interface between patients and practitioners, it explores how certain clinical narratives along with both old and new material or visual technologies are important tools for predictive practices. Like other 'boundary objects' (Star and Griesemar 1989), these devices are reproduced and sustained in part through the 'co-production' of patients and practitioners. In this sense they are not 'shot through with power' (Rapp 1999) in a simple or direct way and do more than just, or always successfully, service medical knowledge or professional expertise. This chapter explores how the power, mutability and ultimately also the inherent instability of tools and technologies must be understood in relation to the collective, conjoined, yet differently situated investments that meet at the juncture of this clinical domain.

Making knowledge material

As a number of studies have highlighted, various different material practices and objects have been central to evolving research agendas

and clinical perspectives and practices within cancer research (Austoker 1988; Löwy 1997) and cancer genetics specifically (Fujimura and Clarke 1992; Gaudillière 2001; Palladino 2002). Some have even pointed to the centrality of genetic testing to the development of this specialism in relation to breast cancer (Parthasarathy 2003). By contrast plotting the emergence of this clinical speciality in France, Bourret sees the BRCA mutation as 'key player', both a 'clinical tool' and a 'research entity', helping to construct a new arena of health care practice (2005). While these authors acknowledge that the provision of clinical genetic testing for breast cancer risk in the US or France has not been a simple or linear process of translation, there has been less examination of how other tools and technologies central to a predictive approach are utilised or also came to constitute this field of medicine. The data presented in this chapter illustrates how the challenges of genetic testing might make these other tools and techniques especially significant in the dynamics of clinical encounters.

In the UK, testing is currently generally available only to 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. Moreover, because both the BRCA genes are large with hundreds, if not thousands, 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 per cent of the BRCA1 gene, looking at 'hot spots' where mutations were thought to lie. It was estimated that this technique picked up about 65 per cent of mutations.[1] Once a mutation had been found, then predictive genetic testing of other members of the family could be done relatively simply. But for large numbers of people referred or attending the clinics, a conclusive test result was difficult. This may be because they had no living affected relatives, or because they were still waiting for a result (which could take many months if not, in some cases, years) and/or because the result was inconclusive, linked to an inability to test all the gene. Others may have received 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.

In sum because of the logistical, technical and economic constraints that characterised genetic testing in the NHS, gene mutations and hence BRCA 'carriers' were, and in many ways continue to be, fairly elusive or indefinable entities and identities. This was no more evident than in the fact that only 50 carriers of a BRCA mutation had been identified at the time of my research in one of the hospitals where I worked.[2]

More recent data suggests that these figures are still not exceptionally high and that the majority of mutation screening tests in NHS labs produce negative results (NICE 2004). In light of the challenges of positively identifying those carrying gene mutations, the tangibility and materiality of genes become not only more important but also depend on a range of other techniques and tools. This chapter, expanding beyond a narrow analysis of predictive testing per se, explores how, at the same time the *prospect* of testing and/or the *possibility* of identifying deleterious mutations have a sustained presence in the clinic, other tools, and techniques and materialities are also an essential component of this medical arena.

The routine procedures of both the clinics where I carried out research are constituted by various practices of risk assessment, explanation and prediction. To a greater or lesser degree, all these processes involve the use of visual frequently paper tools and techniques that relate family history to epidemiological risk data. In performing regulatory functions around triage and risk assessment, these objects are directly linked to the 'conditions of possibility' for genetic knowledge of breast cancer genes (Bourret 2005). Yet in the face of the technological limits, the lengthy timescale and complexity of genetic testing for BRCA mutations, these tools and tests also bring an important materiality to medical practice.

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'. This is most frequently 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.[3]

In many ways, these clinical trees replicate in visual form a widely recognised 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 outlined in Chapter 1 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 (Bouquet 1994; Basu 2006). In their most minimal state, these representations of family history map kin relations in 'tree' like form with

documentation of the names, dates of birth and death and sometimes also a person's occupation(s) and or place(s) of residence.

By contrast, clinical depictions of family history use specific icons as a shorthand for gender, illness and death in the family. 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, which represent gender and the type of cancer in the family. Crossed-out circles and squares represent those who have died and the white circles and squares are used to denote healthy relatives. In the initial presentation of the clinical family tree (Figure 2.1), these symbols mostly refer to children.

These somewhat stark and seemingly 'geneticised' visual 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 can partly be explained 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. Despite being circumscribed by the categories on the form there is, as we have seen, also a desire to identify risk through reductionist representations of family history.

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 death. This is an important process, as there is a widespread feeling among clinicians that the trees are at this stage

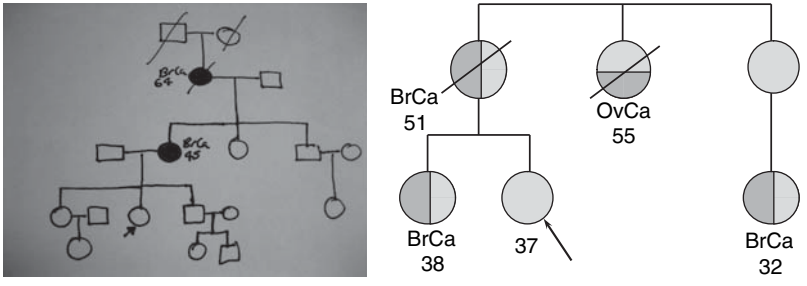


Figure 2.1 Clinical family trees

sometimes 'inaccurate', because of the way patients 'misremember' or 'guess' their family history.[4] As the information is confirmed or altered and then transcribed on to the tree, questions may be asked about other relatives, both near and distant, who might not have been included on the original form or first draft of the family tree but whose current state of health, or past trajectory of ill health, might be crucial to the assessment of risk. Sometimes these questions 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.

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 mutation in the family and the subsequent sorting or 'triaging' of patients into different risk categories (high, moderate, low) is undertaken. This in turn governs the type of intervention offered to patients, which may include regular check-ups, routine mammography and/or genetic testing. In the absence of widespread predictive testing, the tree is often the only tool of risk assessment or prediction. Consequently it is no coincidence that during first-time appointments the tree stays on 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.

The clinical family tree is then an important index of expertise in the clinic in undertaking risk assessment. However, it is not the only visual tool used here, 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 visual 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 uncertainty in the explanation about genetic inheritance. That is, even though a relative might carry one bad copy, it might not be inherited by other descendants of that relative because 'you get 50 per cent of your genes from your mother and 50 per cent of your genes from your father'.

At the same time that such explanations are undertaken in part to show that an individual might *not* be at risk, used in conjunction with the clinical family tree, they also can help to make biological connections explicit and 'literal'. The authority and power of such statements would seem in part to be derived from a particular 'origin story' about genes, identity and reproduction which replicates a perceived Euro-American notion of kinship as predicated on bio-genetic connections (Schneider 1980; Finkler 2000). In this sense the explanatory idiom of 'naturalisation' in the use of these descriptions literalises kinship and genetic knowledge. Alongside a notion of genes in terms of 'good' and 'bad' copies, these 'merographic' framings help to contain and work as a 'boundary zone' (Strathern 1992a) to the contingency and complexity that subsumes the practices of prediction in clinical BRCA genetics.

This process of 'containment' is also evident in the use of other tools and different explanatory approaches often undertaken in the clinic. In contrast to the most frequently highlighted aspect of explanations about genetic inheritance, that 'even though there might be a gene in the family, you might not have inherited it', the variable 'penetrance' of the BRCA gene seems to be a less explicit dimension of clinical encounters.[5] Practitioners do point that it is only with 'the loss of two good copies of the gene that breast cancer will develop' and 'other changes' would have to occur to the remaining 'good copy' for breast cancer to occur. However, these are not visually depicted in the same way that the inheritance of genes are and are only alluded through the words 'environmental and lifestyle factors' written at the bottom of the page

of one visual aid. Sometimes these factors may be acknowledged as unknown variables 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 this setting nor always necessarily fully incorporated into the explanations that accompany the use of such images.

In fact the discussion of genetic inheritance as a risk factor for breast cancer stands in dramatic contrast to the lack of explanation about the possible aetiology of most breast cancers. These are often referred to as sporadic cancers and put down to 'just bad luck' or caused by 'chance alone'. To a certain extent, these explanations directly reflect the current lack of knowledge about most factors and causative agents which might lead to the development of breast cancer. Nevertheless silence about these aspects also reinforces the explanatory power of 'knowable' factors such as genes and sidelines more complicated questions associated with suspected but less readily identifiable etiological agents. In this sense the notion of 'gene penetrance' serves less as a tool to ameliorate the tension between the accounts of patients and practitioners (Palladino 2002) and more a means of acknowledging, without fully explaining, the effects of other factors, cellular, lifestyle and environmental, in relation to BRCA mutations.

A circumscribed explanatory style was an approach that was used by all clinicians at different times 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 attending the clinics), these distinctions at least implied clear-cut boundaries. On one occasion, during an appointment with a patient, the differences between types of cancer were drawn even more starkly by one clinician. Talking about the importance of distinguishing between 'sporadic and genetic breast cancers', she 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 the disease, even where inherited genes are known to play a role, yet the clinician in this instance clearly felt impelled to describe genes in this way.[6]

Another visual image accompanies the discussion of exactly 'what DNA is'. Here a now familiar computer-generated iconic image of free floating, twisting piece of two-stranded DNA is used, described as the substance that conveys 'specific instructions to the cell'; a depiction of agency which is visually re-inforced by the separation of this strand of DNA from other cellular activities. But this representation also intersects with a metaphoric narrative about gene mutations where 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'.

If the use of visual images and particular metaphors or narratives help to bring a coherency and stability to explanations about genetic inheritance other technologies, more directly linked to the work of prediction, also involve recourse to more epidemiologically orientated paper tools that are used to serve similar ends.

The materiality of prediction

The rise in importance and relevance of epidemiological data to medicine and the way this intersects with the move towards so-called 'evidence based medicine' has been observed in a number of arenas of medical practice (Löwy 1997; Timmermans and Berg 1997). Statistical probabilities are, as Adelsward and Sachs point out, used in the clinical context, as 'metaphors, attempts to make the incredible intelligible and the invisible future manageable' (1998: 206). More specifically, Fosket outlines the 'organisational embeddedness' and 'legitimation' work of particular epidemiological models of breast cancer risk in helping to construct the idea of the 'high-risk woman' in relation to the uncertainty and controversy surrounding novel chemo-prevention strategies for breast cancer (2004). Predictive medicine also reproduces the language and power of statistics and epidemiological data in new ways, often 'eliding a discourse of risk with the abstraction of probability' (Lock 1998; see also Konrad (2005) and Bourret (2005)).

It is perhaps then no surprise to find that another paper tool is an important technology in clinical breast cancer genetics which brings epidemiological data to the fore; the basis on which individual estimates of risk and further intervention or care is predicated. A probability curve enables practitioners to be able to show at what periods in a person's life there is most risk and to explain how it is higher or lower at different

ages. This tool does not therefore just visually ground explanations but is also linked to the provision of personalised risk statistics, based on a person's family history. In practice, a range of different risk figures might be given to the patient in the consultation, including the chance that there might be a gene in the family, as well as the 'relative' or 'absolute' risk of breast cancer which can then be compared with the population risk of the disease. The language of statistics as well as the visual images that accompany their use are clearly powerful in these instances.

As the consultation outlined below illustrates, the authority of numbers represented and reproduced on a predictive graph could be particularly important:

> The patient a first time visitor to the clinic – a young woman in her mid 20's, has been told that the clinic can do little for her at present and she won't be eligible for screening or routine appointments at the hospital until she is older. She becomes clearly upset and agitated by this prospect. 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 and underline the authority of the clinician's assessment of risk. But a broader reading of this encounter implies more is at stake. 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, these tools can be particularly important. As this encounter suggests they can help to allay anxieties, by *confirming* in this case a perception of increased risk.

Even though genetic testing was a procedure that was not frequently undertaken or could be a lengthy procedure which often yielded inconclusive results, the hope of being able to carry out more routine genetic

testing 'sometime in the future' was talked about by clinicians during meetings with patients. This happened most often when a patient was young and genetic testing simply was not possible because their relatives with breast cancer had died many years previously. If a person's relatives had died more recently, then discussions about finding out if some blood or tissue had been stored ensured that the prospect of genetic testing was made more real, even if ultimately this proved to be impossible. Even when genetic testing was not feasible or at least uncertain, talk about this technique therefore gave it a certain 'presence', holding out the hope of clarity in the future.

In this sense the objects and tools of genetic medicine appear to '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 clinical explanations and practices seem in part to be sustained by a certain explanatory style where the language of rationality and the use of a 'statistical' idiom become linked to a process of 'narrative reasoning'; a practice that Mattingley argues is a routine feature of the way clinical language pursues 'order and control' (1994). However, it is not just discursive practices which are important to the legitimacy of medical practices but also visual objects and graphic images, giving foundation to the notion of DNA as simultaneously a 'material, semiotic entity' (Haraway 1992). The use of family trees or explanations about genetic inheritance and causality illustrate how paper objects and technologies help to support explanations of genetic causality or 'naturalise' predictive practices, grounded as they are in a particular kind of 'origin story' about reproduction, identity, inheritance and risk (Strathern 1992a). But perhaps most importantly in an arena of predictive medicine, subsumed by ongoing challenges associated with genetic testing and the problems of identifying the particular gene mutations affecting the family, they help to make genetic knowledge real and tangible, giving explanations and predictive practices an important material underpinning. Intentionally or not, these tools, appear to screen out some of the 'messy' questions about the exact function and effect of mutations in the genes that have been linked to breast cancer. As a result power in this setting is embedded in a mutually constituting symbolic realm of language and materiality where images and objects become part of the argument for the 'credibility of scientific inferences' (Gifford-Gonzalez cited in Bouquet 1994: 45). This appears to be the case not just for practitioners, but in different ways for patients also, sustaining collective hopes and expectations of care and knowledge.

Mutable mobiles; contingency, triage and 'code-switching'

Nevertheless this analysis of clinical power and authority is, only part of the story in understanding the use of paper tools and techniques. The practices elicited by and through the predictive techniques of the clinic must also be understood in relation to a broader nexus of co-production. This not only includes patients' desires to engage in practices of awareness or surveillance, but also takes account of the regulatory governance of cancer genetics and the inherent contingencies of predictive interventions themselves. The collective negotiation and management of these tensions during clinical encounters ensures these tools and technologies, rather than being 'immutable mobiles' (Latour 1987), can in fact become and are sometimes deliberately positioned by practitioners as mutable and somewhat unstable. When these tools are just as essential to the work of re-assuring inappropriately referred and unnecessarily anxious patients or in discharging those not at greatly increased 'genetic' risk, they participate in a very different clinical narrative. In contrast to the work explored in the first half of this chapter, the aim here is to 'talk down' and make claims to predictive knowledge considerably less certain or viable. These are 'code switching' practices in which the visual or paper tools of clinic also have a crucial part to play.

Triage and the necessity of limits

The assessment or prediction of risk is, as earlier sections of this chapter show, closely tied to the necessity to 'triage' patients into different risk categories. In practice, however, triage is not just simply concerned with putting patients into different categories of risk, but about making decisions about whether they are eligible for the various programmes of monitoring or interventions the clinic could offer, at what age, and whether or when patients should be discharged. Actively identifying those most at risk fits a model suggested in The Harper Report (1996) and the subsequent more comprehensive NICE guidelines (2004), which recommends that those at moderate to high risk on the basis of family history should be seen in specialist cancer genetic clinics and those at low risk re-assured by their GP. Despite an apparently clear-cut aim, in practice this was something that was not always necessarily so easily achieved, particularly when the pressure for guidelines had grown in part from a rise in the number of inappropriate referrals to these specialist centres. In fact the historical evolution and institutional location of both clinics meant

that there were also many 'low' risk patients 'on the books' as a result of previous clinical trials investigating family history.

Sometimes, and perhaps most ideally from the clinicians perspective, triage took place before a patient was seen by a specialist service. 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 for referral could be screened out before they even got to the hospital. 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 but they should continue to practice routine self-monitoring, or depending on their age, participate in the national mammography screening programme. However, information received prior to an appointment did not always provide a clear assessment of the situation, and the danger of triaging incorrectly often meant that meetings with the patient were essential to ensure accurate risk assessment. As a result, a significant amount of practitioner time was spent reassuring new or young patients, some in their 20s and early 30s, 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 in a specialist genetics clinic or offered mammography screening until they were older.

One clinician talked about the balancing act involved in triage. She pointed out the challenges this posed where resources were finite and when clinicians were often dealing with many new and, despite guidelines for referral that suggested otherwise, often patients with low or moderate risk who had high expectations about what would 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 [mammography screening or follow up appointments] 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 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.

These comments draw attention to a sentiment widely expressed by a number of practitioners that the clinics were being overwhelmed by referrals, for people who were at low or little increased risk. In these cases, a more explicit strategy of 'talking down' genetic risk and/or the

scope of the predictive technologies and knowledge could be particularly important. This would mean reproducing family trees in ways that diluted the visual starkness and the seemingly geneticised quality of these iconographic representations. It might 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 increased the number of 'white' circles and squares (healthy individuals) on the clinical family tree, 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 and a particularly insistent young patient illustrate:

> The woman in her late 20's readily outlines the history of cancer in her family and how she has been to her doctor, because she has 'a problem' with one of her breasts, insisting that, as a result, she really 'needs' to have a mammogram. The doctor explains how according to the protocol in the clinic, mammography screening for those who fit the criteria because of family history doesn't actually start until 35. 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 explaining again how 'we just don't screen people before the age of 35'. The woman however is able to pick up 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', adding that 'we don't normally screen that early because we really feel it could cause breast cancer by having too much radiation'.
>
> The young woman does not seem put off by this and continues to discuss the pain in her breast. Reluctantly, the practitioner appears to relent and sends her for a mammogram in the adjacent department. 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 it is evident that 'triage' had meant recourse to the paper protocol pinned to the wall and talking about screening technologies, in this case mammography, in a particularly compromised way. Despite these efforts, it seemed impossible, at least in this instance, not to accede to the patient's expectations.

In contrast to explanations about gene mutations that characterised some clinical appointments, very different metaphoric description of genetic inheritance might then be used in the work of re-assuring low risk patients. In these situations, practitioners would talk about developing breast cancer in terms of 'climbing a ladder' or having a BRCA gene mutation, in terms of simply 'starting a few rungs higher on the ladder'. On another occasion, a clinician explained to a patient that there had to be at least '8 changes' before a breast cell turned cancerous, of which carrying a gene mutation was just one. The key point being in all these cases that there was still a long way to go before developing breast cancer, even when a person was known to be a gene mutation carrier.

Rather than discussing the future scope of genetic testing, triage might also mean discussing the potentially negative ethical ramifications associated with testing. An encounter between a nurse and a regular attendee at the family history clinic at one of the hospitals 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

> 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 patient had been seemingly happy, up to

now, being a regular attendee at the family history clinic. Responding she points out how,

> 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 might have been imagined.

However, 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 task of discharging patients no longer thought to be at increased risk. Given the changing nature of referral guidelines (which had become increasingly more narrowly defined in recent years) and the fact that some patients had, in some cases, been attending these clinics for some time, this was a challenging feature of practice in both hospitals. In each case, long-running family history clinics, which had and continued to manage a number of clinical trials, had 'recruited' patients at a time when the criteria for inclusion were much less stringent. Following changes to the guidelines for referral over the last few years, many of these patients were no longer considered to be at sufficient 'risk' to warrant medical surveillance and therefore had to be discharged.

Some indication of the nature of this challenge was illustrated in an appointment I observed between a nurse practitioner and a regular attendee at the family history clinic in the cancer hospital. The patient was a woman in her early 40s who had been having follow-up appointments on a regular basis for about five years since the death of her mother from breast cancer.

> The familiarity between the patient and the nurse is evident from the start of the appointment as a discussion unfolds about the latest work the patient is doing. But this casual intimacy is subsumed by the nurse's more considered and careful attention to the family history, following her normal offhand routine query about whether there have been any 'changes in the family history'. She then asks the woman to confirm again the ages at which those relatives with 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 allay 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. In these cases the use of tools such as the predictive graph were invaluable. For instance, when patients were older, in their 50s say, clinicians would point to the downward trajectory of the curve. 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. In a similar way, if the person in the clinic was 50 or over they would point out that their chances of getting breast cancer (that might be linked to a gene) were much reduced. On these occasions clinicians might say that this meant that they or their relatives had 'lived through most of their genetic risk'. At the same time as these descriptions obscured the fact that the population risk of breast cancer increases with age, they also implied a dramatic reversal in the way agency was attributed to genes and DNA at other times in clinical practice.

A very different perspective on genetic knowledge and expertise was also sought and sustained therefore in the use of these narratives and visual tools, informed by a need to *disenrole* rather then recruit patients into predictive practices. Negotiating triage meant making use of these technologies in ways that was not just about securing the authority of medical knowledge but was sometimes also about drawing attention to its limits. It is somewhat apposite that triage is a notion used more commonly in both the military battlefield and the medical emergency room, as it fittingly evokes what can be a difficult aspect of clinical breast cancer genetics. The necessity of 'code switching' had, as might be expected, particularly uneasy and challenging consequences for practitioners; an ambivalence which is explored further in Chapter 4.

The instability of containment; contingent knowledge and technology

The diverse strategies for undertaking the triage of patients outlined in this chapter, whether in efforts to enrol appropriate patients or discharge

those considered at low risk, were however not always containable. That is, the narrative explanations and the tools that secure the authority of current or future predictive practices can be de-stabilised at the clinical interface, in ways that clinicians do not always intend. As Margaret Lock points out, extensive work in anthropology has demonstrated how a characteristic feature of a practice of 'divination' or prediction is that 'in seeking to avoid misfortune . . . new ambiguities and uncertainties' are created (1998: 7). The 'rub' in predictive medicine is, that 'there is no such thing as prognostic information per se, only different categories of information that generate different prognostic fields for the moments of potential knowledge disclosure' (Konrad 2004: 84). The way that this contingency infiltrates medical practice in relation to breast cancer genetics is explored by examining three appointments in which 'divination' raised challenges for all concerned. These encounters demonstrate how the kind of 'code-switching' practices and strategies of containment, to which paper tools and technologies are central, are not always effective or necessarily stable.

The first of these clinical encounters took place between a clinician and a couple in their mid-50s. Prior to the appointment, the clinician, a consultant in the cancer hospital, 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, following an initial identification of a BRCA mutation in the man's sister. Despite the presence of seemingly conclusive information, 'confirmed' in this instance by the presence of another paper technology – the lab test report – and the clinician's efforts to talk about the 'interventions' that a test result made possible, the discussion which ensued highlighted the ways that risk information was rife with uncertainty.

> The consultant tells them the news almost immediately at the start of the appointment, turning to face the husband she says,
>
> > We have got your results back and I'm afraid 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 inherited the same mutation. This includes the risk of ovarian, melanoma and pancreatic cancers. She begins to suggest that they should be entered on screening programmes for these cancers when they reach an appropriate age.
>
> The husband interjects querying the risk figures he is being given and wanting to know what the 'survival rates are for these cancers'. The consultant outlines in further detail a different set of figures revealing sometimes quite large disparities between the figures she has given them already and information the man has asked for. This leads into a more in-depth discussion between the couple about whether they should inform their children about the risk of these other cancers. The man explains that, given these disparities, he is not so sure it's necessary.
>
> 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 information to his children.

During an interview with the consultant a few days later, she brought up the same appointment in our discussion, suggesting that it had been exactly this which had been the source of her unease about the meeting when she pointed out:

> 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 . . . 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 . . . [so] this is the kind of complicated consultation I got into with them.

It seemed that in seeking out more specific details about risk probabilities the couple had forced the clinician to speak about the disparities and uncertainties relating to the use of risk figures in the clinic.

In fact risk data linked to the so called 'penetrance' of the BRCA genes was at the time of my research, and has subsequently, been the

subject of much re-assessment. As the number of mutations identified on the BRCA genes has risen so the penetrance estimates have fallen (Kaufert 2003). The commonly and widely held understanding of BRCA gene carriers having an 80 per cent lifetime risk of developing breast cancer (Ford *et al*. 1994) is now thought to be anything between 30 and 85 per cent (Antoniou *et al*. 2003). As Bourret points out, the claim which has been the 'cornerstone of the field', that mutation carriers have a 'very high risk of developing cancer', has in fact been brought 'into question' (2005: 51). Morever there is also now an increasing recognition of the need to examine the effect of 'modifying factors' on these genes using large-scale population-based epidemiological studies (Pharaoh 2002; NICE 2004: 23).

If risk figures constitute one shifting ground, another appointment illustrated how the timescale and challenges of genetic testing could contribute to a different type of discomfort concerning uncertainty. As the appointment below illustrates, visual tools might be singularly ineffective in attempts to contain or stabilise this type of contingency:

> The nurse specialist was bright and upbeat on the arrival of a couple in their early 40's and there was a light-hearted discussion about where they had been on holiday. But this soon shifted into discussing why they had made an appointment to see the cancer geneticist when they were being seen regularly for routine check ups in the family history clinic. The woman reminds the nurse that she had blood taken for testing several years ago, after she had finished her course of treatment for breast cancer and as they have 'heard nothing' from the cancer genetic clinic they decided to make an appointment to 'find out what was happening'. She adds that she has recently 'heard something 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 for a result. Using visual tools she proceeds 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, using 'a needle in a haystack analogy' explains that:
>
> > We've only looked at 50 per cent of the gene and we're looking for one little mistake. As you know also a genetic test won't pick up everything and it could be another gene, BRCA 3, 4, 5. In some cases we never find the gene.

In this instance, the difficulties associated with genetic testing forced the clinician to talk about this technology in a highly compromised way, as she tried to balance the legitimate demands and expectations of the couple, the extremely difficult consequences of living with this uncertainty with the very real technical and logistical challenges of such a procedure.

The validity and value of genetic testing was questioned in a slightly different way during an appointment with a husband and wife in their 50s, who had been to the hospital on several occasions and who were coming for what was intended to be their final visit before making a difficult decision.

> The woman sitting with her husband in the clinic has 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, because of the woman's family history, they are here today to help them make a decision about whether or not to have a prophylactic mastectomy on the woman's healthy breast.
>
> 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 as the woman explains:
>
> > 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 you are 100 per cent 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 seems to prompt the woman's husband to raise further questions about the value of testing.
>
> > Patient's husband: I'm wondering about this then, so if she tests positive for the gene 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!

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 however 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 did not see the benefit, hence was not prepared to participate in a process of seeking predictive knowledge for her or her daughter, the clinician seemed to be left floundering for appropriate reasons to proceed with genetic testing. Ultimately she resorted to a rationale that served to compound the limits that the couple had already highlighted.

All these examples illustrate how a narrative of uncertainty in relation to epidemiological tools, predictive tests and explanatory narratives of the clinic was forced by the questions, concerns and/or the expectations of patients. This precipitated a considerably more compromised presentation of the knowledge and technologies associated with BRCA genetics than any of the clinicians had intended. It is striking that in both the first and the last case we can see that these uncertainties were used by patients to shun the need to engage in particular predictive or precautionary practices, such as genetic testing, whilst still retaining an 'at-risk' identity. This strategic management of the uncertainties of predictive information enabled some individuals to still be recipients of much desired ongoing monitoring such as mammography screening.

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 material, often paper objects, tools or tests, and the discourses that accompany their use, play a crucial role in trying to achieve this aim. However, the complex dynamic of the clinic where 'code switching' is essential to containing and stabilising newly emerging predictive medicine, as well as negotiating the delicate triage of patients, demonstrates the mutability of these tools. They do more than simply or always successfully secure the authority or expertise of new genetic knowledge.

These objects can help to make explanations about inheritance, prediction or risk assessment meaningful to patients and practitioners, seeming to secure the authority and confirm the scope of new genetic

knowledge and technology. Such practices seem particularly important in enrolling persons deemed at sufficient risk and for whom genetic knowledge may have some relevance now, in terms of offering other interventions such as genetic testing or, as is more usually the case, in the future. However when an idiom of probability, risk or uncertainty subsume medical practice and when pinpointing genes or danger in the body of specific individuals is mostly elusive, paper objects and visual aids such as the family tree or the predictive graph are central to clinical interventions for other reasons. Given the ongoing 'invisibility' of gene mutations in the routine work of practitioners and for the vast majority of those patients attending the clinics, metaphor *and* materiality play a crucial role in sustaining the facts of BRCA genes. In this sense, the tools and technologies of the clinic, like the regulatory practices Bourret explores (2005), do not simply organise, rationalise or legitimise practices but quite literally help to bring specialist services such as breast cancer genetics into being.

Nevertheless the same objects and tools also involve and help to raise a discussion of 'limits' within the clinical encounter, when genetic knowledge and technology is considered to be inappropriate or irrelevant. These contradictory narratives must be understood in relation to the oversubscription of services and heightened expectations of patients which have to be managed through triaging appropriately, in accordance with regulatory guidelines and increasingly rationed specialist health care services in the NHS. However, as the last section of the chapter illustrates, 'talking up' and 'talking down' are, perhaps unsurprisingly, not always containable. Sometimes one can seep into the other, entailing a less than easy discussion about contingency.

Although the communication of new genetic knowledge is powerfully enabled by the tools and objects that constitute routine clinical practice, it is apparent that in attempting to shore up uncertainty they also sometimes elicit and compound such effects. The ethnographic account outlined in this chapter suggests that it would be hard to locate all that is done in the clinic in terms of the 'bio-power' of predictive medicine, where the expectations of patients have ramifications for the translation and communication of contingent genetic knowledge.

3

Constructing Patienthood: The 'Care' of Predictive Medicine and Female Nurturance

Continuing an examination of the kinds of collective work of patients and practitioners at the clinical interface, this chapter examines how 'care' is constituted in predictive medicine. It examines what care means for being a patient and how particular cultural values, long associated with female identity, are central and essential to the 'pastoral' practices of cancer genetics. It explores how managing the ongoing distance between diagnostic capabilities and therapeutic interventions involves particular modalities of care and articulations of patienthood. Bringing together ethnographic observations of clinical practice, discussions and interviews with patients and practitioners, this chapter builds on and also contrasts with the work of others exploring what it means to be a 'pre-symptomatic patient' in an era of promissory health and how the 'ethico-temporal' dimensions of this novel health care arena are informed and inform ideas and practices of kinship and the family (Finkler 2000; Konrad 2005). Exploring the way ideas long associated with female identity, such as 'care' or responsibility towards related others are refracted through predictive interventions, it examines how gender is embedded in particular sorts of 'distributed' patienthood. While powerful, the configurations of genes, gender and genealogy this entails are unevenly and uneasily mobilised across the field of social relations that constitute clinical practice. In this sense the experiences recounted here point to some emerging tensions between the values and ethics of individual health awareness and the kinds of requirements for collective action and involvement in a particularly 'feminised' arena of novel medical intervention. This raises questions about the kinds of biosocialities being reproduced and sustained in context of breast cancer genetics, where predictive medicine, consanguinity, gender, patienthood and citizenship are closely interconnected.

Pastoral practices and the pursuit of genetic knowledge

In negotiating the gap between knowledge and care in predictive medicine, Novas and Rose point to the growth of new kinds of ethical/medical practices, which they term 'pastoral' (2000). The first half of this chapter examines these pastoral dimensions in relation to clinical breast cancer genetics and the way they are used to configure ideas of 'care' in terms of 'the future' and 'the family'. It illustrates how 'care work' not only shores up the 'gaps' in predictive medicine but also shapes and informs these spaces in specific ways.

Care for the future

It is only relatively recently that the notion of medical 'care' has begun to become homologous with (primary) prevention, normally associated with health practices in the secondary or tertiary setting (Kohn and McKechnie 1999). Clinical breast cancer genetics, while building on an ethos of preventative health, is in fact situated in relation to a more promissory if uncertain world of medical intervention, such that prediction makes care necessarily for the future.

For the majority of those who attended the cancer genetic clinics where I conducted research and who met specific 'at risk'criteria, 'care' consists of regular monitoring such as physical examination by a health professional or routine mammography screening. This coupled with the frequent verbal reassurance from practitioners that they will be seen on a regular basis, and the promise that better technologies are in development, situates care in a temporal trajectory in which the future takes on an active structuring presence. On the relatively rare occasion that predictive testing is offered and/or undertaken by a patient, the time-consuming nature of such procedures and the possibility of an inconclusive result still propel 'care' giving into the realm of the future. Moreover the variable penetrance of the BRCA genes, coupled with the lack of full-proof preventative interventions, or often even any kind of positive result, situates care and prediction as co-determined aspects of each other.

Practitioners do point out to most attending the clinics that the technologies of surveillance available, such as mammography, are not entirely full proof, impressing upon those attending the clinic the need to undertake breast self-examination. However, when little else can be offered, it is difficult for practitioners *not* to present the limited interventions available, in terms of promissory care. The following observation of an appointment between a clinician and a first-time patient illustrates

how the presence of this 'therapeutic gap', highlighted in this case by the patient, informs clinical discourse about the 'future care' of predictive intervention.

> The doctor is with a new attendee. As she undertakes the normal routine procedures, it is clear that the woman in the clinic is well aware of her 'risk' when she talks of her 'tremendous' family history. At this point the clinician seemingly a little overwhelmed by this barrage of knowledge from the patient asks casually if 'anybody has been gene tested in the family'. The question almost appears, at least to me, to be a way of acknowledging the risk the woman clearly feels herself to be in. Nevertheless this triggers a tirade of concerns from the patient, who points out that 'most of the family aren't that keen, especially when you think of all the implications in terms of the insurance questions'.
>
> The practitioner does acknowledge that there are difficulties currently with procedures such as genetic testing, saying that 'even for those who get a negative test result, this doesn't mean that there won't be a gene in the family'. This seems to provoke even more effusive comments from the patient who asks 'what re-assurance are you getting then'. The doctor begins a long, if by now slightly hollow sounding, narrative that the future will bring new developments in terms of 'technology' and what she calls 'targeted' treatment adding 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 responding 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'.

Although this was a somewhat more uncomfortable than normal encounter for the practitioner concerned, it also demonstrates the extent to which a discourse about 'care for the future' is not just a routine but essential dimension of clinical discourse. This is particularly so when it is patients themselves who expose the inadequacies of current testing technology. Although not undertaken on this occasion, during similar appointments where there was a reluctance, for whatever reason, on

the part of patients to engage in predictive testing, offers might also be made to 'store' a sample of blood for testing at a later date. Although this procedure could only generally be done if an affected relative was still alive, it was presented by clinicians as an opportunity to take 'positive' action, making the hope of some kind of interventions at a later date a more real possibility. It is a process which in many ways seems to epitomise the ethos of future care that dominates the cancer genetic clinics.

In different ways, promissory and hopeful care is a key component of clinical discourse and practice; a temporal framework linked to a culture of expectation which is structuring claims to knowledge in a broader field of developments in genetic and the life sciences (Brown *et al*. 2000; Ganchoff 2004). It is a clinical discourse which is clearly not just about reassuring patients, but also sustaining the viability of a newly emerging field of predictive medicine. In a climate of emerging predictive medicine ensuring that patients agree to be monitored or participate in research but also place their hopes faith (and sometimes their blood) in developing technologies is a pre-requisite for the future application of genetic knowledge.

Talk of 'the future' in the clinic intersects however with another dimension of pastoral practices, often brought to the fore by concerns from patients about their children. Practitioners would sometimes explain to patients that they were not at risk at the moment, pointing out by the time they were old enough to be at risk much more would be known about the breast cancer genes. On such occasions the family tree became a useful tool for showing how care for these persons would, like a contract, be honoured in the future. Including younger members of a family in the tree was used to demonstrate and re-assure those in the clinic that their children, when they reached an appropriate age, would be included in a programme of monitoring and surveillance. In fact, like a discourse of future care, ensuring the well-being of kin forms a much more explicit aspect of the pastoral *and* knowledge practices of clinical BRCA genetics.

Care for 'the family'

As outlined in Chapter 2, a focus on 'the family' is part of risk assessment in work surrounding the discussion of family history where the clinical tree is an important tool of expertise in estimating risk, presenting explanations about inheritance or in facilitating the necessary yet difficult triage of those at low or not substantially increased risk. We have already seen how paper tools and technologies derive their authority

and power in part from the way they reproduce and sustain a particular reductionist idea of kinship, genetics and genealogical connection. Examining how care is constructed in terms of 'the family' and in relation to a particular articulation of female gender identity illustrates how the meaning of these tools and technologies 'mutates' again. Family trees in predictive medicine are far from 'univocal' (Palladino 2002; see also Gibbon 2002) but are in fact put to work in variety of ways. That is, these tools are tied to a discourse about care that is subject to and a locus for traffic between the natural and the social in which a particular kind of 'born and bred' kinship (Edwards 2000) powerfully intersects with naturalised and socialised ideas of female nurturance.

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 flooding back, while including the names of children on the 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 patients in the clinic, who are mostly women, to extend a programme of 'care' screening or monitoring to include relatives. In fact attentiveness to the social context of the family, and the provision of care for others is not just about demonstrating a capacity for empathy or the holism of practice but is, like care for the future, vital and instrumental to predictive knowledge, as a number of clinical encounters outlined below illustrated.

The first was an appointment between a geneticist and a woman in her mid-30s at the General Hospital. This excerpt demonstrates 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 in the family. This is followed by renewed investigation of the paternal family history of the patient's mother and an expansion of the clinical family tree, with some correction of cases of cancer which had been drawn on one side of the family After this the clinician gives the woman a much reduced estimate of risk and a different programme of surveillance.

This encounter exemplifies how identifying the hidden stories and myths about illness by considering the social dynamics or context of the family is not just about empathetic care-giving but is vital to establishing an accurate diagnosis of risk. Here a chance comment by the patient, in relation to 'beliefs' about cancer in the family, prompted further inquiries which shed light on other instances of illness which, in this case, the clinician had neglected to enquire about.[1] This revealed other cancers in the family, which ultimately changed the calculation of the patient's risk.

In another appointment a concern for related others in the family was made explicit in a way that seemed to come as something of a surprise for the person(s) in the clinic.

> The woman comes in with her partner, who are, I would guess, both in their early 40s. 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 clinician does not immediately respond to the woman's strong hints that she would like screening, but is concerned about other members of the family. She asks if the woman's father is getting prostate screening, explaining that breast cancer in men is a rare event and so more likely to be linked to a gene. There is then 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 in the future, if something is found, adding that this 'of course wouldn't be until much later in their lives'.
>
> The couple seems surprised by this, it is clearly not something that they had thought about. It is only towards the end of the appointment that the clinician discusses the possibility of routine screening for the woman.

In this instance the clinician seemed more concerned with the 'family' than with the person who had initiated the appointment; the focus of the meeting shifting towards related kin and a concern with their health or potential risk. Even though it was the woman herself who had made the appointment because of concerns about *her* risk, the interests of the doctor suggested that genetic knowledge may have more significance for related others. When the logistics of genetic testing mean that an initial gene mutation must be identified in the relative with cancer, the involvement of related kin is vital to extending and fulfilling the scope of predictive knowledge, as well as reproducing 'care' for those who may have had initial concerns about their risk. In this sense knowledge and care is predicated on the shared actions and obligations by those considered most likely to yield predictive foreknowledge for the family or conversely those considered most at risk because of such foreknowledge. Situated as gatekeeper and moral guardian for the health of others, 'care' for the woman in the clinical encounter outlined above, perceived by her in terms of more regular mammography screening, is, as a result of her visit, now complexly caught up in other possible interventions by and for her father and two sons.

The final example illustrates how the kinds of mutual entanglements and exchanges of responsibility and obligation between kin that genetic information requires is reflected and also reproduced through the language of one clinician:

> 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, who has also been seen in the same hospital and the doctor spends much time outlining the 'choices' available. The meeting is also characterised by some discussion, prompted by the patient

in this case, questioning exactly how beneficial genetic information might be for her and her family. Nonetheless the doctor seems to feel compelled to conclude 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 the doctor 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'. Nonetheless these comments seemed to sit in tension with the patient's less than enthusiastic response, for whom these options did not necessarily generate such easy or straightforward answers.

The language used by the clinician to describe the kind of choices and entailments involved in pursuing predictive information are telling. A notion of 'legacy' references not only the extent to which relational kin are essential to these novel medical interventions but also how morality and value cross cuts the pastoral *and* predictive dimensions of clinical practice. It is a descriptive terminology which, in this instance, is used somewhat unsuccessfully to suture the gaps that are a characteristic feature of this field of medical practice.

Exploring the 'pastoral' dimensions of the clinic, brings to the fore how 'care' makes genetic knowledge viable in ways that are not just affective but also effective (Kohn and McKechnie 1999). On the one hand clinical discourse or practice about the family and the future helps to make predictive medicine more explicitly synonymous with 'care' in a euphemistic sense associated with all hospital or medical practice. At the same time these pastoral modes are also instrumental to the utility and pursuit of genetic knowledge itself, where an orientation towards the idea of the patient as the family and notions of female nurturance as care towards others are both implicitly assumed. As a result the promissory, familial and gendered modalities of pastoral care, so central to clinical breast cancer genetics, articulate particular kinds of patienthood. Nevertheless these are requirements for the status of patient which are more easily and/or willingly fulfilled by some of those attending the clinic than others.

Patients and the care of predictive genetics

Drawing mainly from 'follow up' interviews carried out with the same group of women attending the clinic for the first time, whose expectations and practices were explored in the first chapter, this section examines what the 'care' of predictive genetics means for the experience of being a patient. This parallels the work of Carlos Novas who has explored how a moral discourse relating to the development of predictive testing for the disease helps construct the identity of those at risk as 'uncertain subjects' (2005) and Monica Konrad who examines the how 'pre-symptomatic persons' and 'inter-generational relations' are constructed by the 'ethico-temporal' aspects of pre-emptive knowledge (2005). Exploring how a certain group of persons respond to and participate in certain pastoral modalities relating to the future, family and gender makes visible the diverse and sometimes fractured pathways by which persons become patients in this clinical speciality.

Being 'on the books'

Most of the persons I met and interviewed were at moderate or in some cases low risk and so were told that although they were at some potential genetic risk, this was not greatly increased by their family history. As one woman put it, referring to her family: 'we are slightly more at risk than the next door neighbour . . . we are at no real grave danger . . . but the risk is there'. Although some individuals had been given more precise risk figures, these did not seem to mean a great deal to most of those I met other than confirming that there was some risk. Hence, although most were not eligible on the basis of the UK triage guidelines for genetic testing, nearly all were or would be included in a programme of ongoing surveillance. Depending on their age and their family history this included either yearly or 18 monthly check-ups and/or mammography screening. This was a programme of monitoring which, for many, had been the prime motivation for seeking a referral in the first place. As Deborah put it:

> '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 demonstrates:

> Penny: A good thing that came out of it, is that I've already got my appointment for the genetics clinic for next year, 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 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 the books', as one woman put it, 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. 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 come back when they were older. Claire 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 one woman, 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; something she situated as an act of exchange that would identify her as a special case worthy of attention and monitoring. This is an exchange

of care, resources and needs that I've already suggested appears to characterise the recruitment of women into clinical cancer genetics, where many are acutely aware of finite and rationed nature of NHS services.

If most of the first time visitors to the clinic who I met and interviewed, the majority of whom were at low or moderate risk, appeared reassured by the promissory and future orientated dimensions of predictive care, there were nonetheless a few who were more hesitant about the implications of further if more intrusive interventions. I examine one woman's experiences in detail, drawing on her more reluctant response to shed light on the norms and necessities of patient participation in the breast cancer genetic clinic.

Julie was in her late 40's and worked part time. She had been a regular attendee at the family history clinic at the cancer hospital for a number of years, after being recruited during a time when the criteria for inclusion in research was very different. Although she was not receiving any extra screening she was seen in this clinic on a routine basis for a physical 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 programme of monitoring but in order to confirm this she should go and see someone in the cancer genetic clinic. During our first meeting it became clear that, compared to others I met, she seemed somewhat more ambivalent about the kinds of predictive interventions, seen by others I met, as a necessary part of precautionary approach. This was evident in her reluctance to contemplate taking HRT or Tamoxifen and also reflected in the way she talked about the genetic testing.

> Julie: 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 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.

Unlike others I had met, Julie seemed hesitant about engaging in future orientated health care strategies; she didn't seem to want to

be 'forewarned' or 'prepared in the same way as others I met had (although she was of course, unlike these others, already being seen on a routine basis by someone in the specialist family history clinic). However this situation changed following her visit to the cancer genetic clinic. She explained the clinic confirmed that the one case of breast cancer in her family probably meant that she was at less risk of this cancer than she originally thought. Nevertheless because of the few cases of bowel cancer, amongst some of her male relatives, the doctor had felt it would be 'sensible' for her to go and have a colonoscopy. An intervention that she was not entirely happy about.

> Julie: 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. [. . .] 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 overwork 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! 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 which characterises cancer genetics meant further more intrusive bodily investigation for Julie. Somewhat significantly, this was not for breast cancer but colon cancer. Although others attending the clinic seem to experience (admittedly less intrusive) screening interventions, such as mammograms as comforting, this was not the case for Julie, as her more uncertain response illustrates. This may in part have been because she was already being seen 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.

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. This implies that there may well be differences in the way those seeking predictive or preventative health care respond to these interventions. This may be not only in terms of class, age, education and religion, as Rayna Rapp's work demonstrates (1999), but also in terms of how persons are being recruited into these health care arenas. That is the extent to which they are already on a routine programme of monitoring and the perceived degree of bodily intrusiveness of a variety of screening interventions. In fact analysis of those 'at risk' persons who decline an offer of a referral from a GP or who never seek a referral in the first place is neglected, but much needed, in social science enquiry of the 'new' genetics.[2] At the same time the lack of large scale stratified diversity among most of the women I met and interviewed and the willingness of the majority to undertake so-called 'precautionary and preventative health care practices', such as monitoring and screening, suggests that enrolment into these arenas of health care is already defined in particular ways. As others have shown, it is mainly white, middle class women who are most amenable to new health care technologies (Martin 1989; Kaufert 1998; Lantz and Booth 1998; Rapp 1999); a profile that appeared to fit many of those attending the cancer genetic clinic. Julie's struggle to refuse these interventions suggests that, for some, asserting a different kind of agency, to decline certain preventative health care interventions, is not always an easy option.

In her analysis of predictive medicine in the context of Huntingdon's Disease, Monika Konrad argues that it is precisely the temporal gap between diagnosis and prognosis that defines the making of the presymptomatic person (2005). Her examination of how this temporal distance is experienced shows how it is wracked with limboed uncertainty. It is significant that the same kind of foreknowledge, in breast cancer genetics, replete also with 'ethico-temporal' disjunctures, is mostly more readily and willingly embraced. Here being disciplined by a promissory future seems a source of care and security, an 'exchange' many of those I met seemed willing and keen to undertake. For the most part, the inadequacies or impossibility of genetic testing did not upset or disconcert because of what was perceived as an actual or a promise of

future 'care', offered through monitoring, screening or genetic testing now or at a later date. It is a perspective which is sustained in the way many interpret their own sense of agency and identity as persons who adopt a preventative 'future' orientated approach to their well-being; that is as 'patients in waiting', who have secured certain rights to health care interventions.

Further research would shed important light on how the 'temporal gap' that Konrad examines in relation to Huntingdon's Disease, is lived over the long term for those identified at increased risk because of a history of cancer in the family. These apparent differences nonetheless suggest that emerging areas of genetic medicine must be examined in relation to specific diseases with their own unique medical, social and cultural history. In the case of clinical breast cancer genetics, this includes a location within and association with an arena of biomedicine, *cancer* research and treatment, in which novel and experimental therapies are often viewed as 'state of the art care' (Anglin 1997; Löwy 1997). It also includes a mode of co-production that aligns gendered patient activism and the neo-liberal values of preventative and predictive health care.

Distributed patienthood

If one kind of caring practice orientated to the future seems to sustain what Konrad describes as the productive 'ambiguity' of the pre-symptomatic patient (2005), there is another modality of care in 'BRCA' genetics which can, for some, lead to quite literal fissuring of social relations and sometimes thwart a much desired attempt by some *individuals* to secure patient status. The first half of this chapter has shown how the social context and dynamics of the family are central and essential to clinical cancer genetics, where, the 'practice of medicine are the practices of the family' (Kenen *et al*. 2003). Others have begun to explore the uneven consequences of this orientation to patienthood when as Konrad puts it, 'intergenerational relations . . . as divergent moral agents encounter and negotiate their status as pre-symptomatic patients' (2005: 25), see also Featherstone *et al*. (2005). This next section explores these ramifications by examining how ideas of female nurturance intersect with the requirement for being, what might be described as, a more distributed 'patient'.

The perception and sense of a shared 'right' to health care was sometimes part of the process by which those I met had received or obtained their appointments. For instance a number of women talked about how the decision to ask for or pursue an appointment at the clinic had in part

arisen from the experiences and health care practices of related female others. As one woman said:

> 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 female relatives were already enrolled and implicated in each other's health care practices. This was a sociality which had clearly contributed to their, as well as Deborah's, efforts to be seen by a specialist. 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 for some getting to the clinic was to a certain extent dependent on or the consequences of others' actions, for others being seen seemed to precipitate a new found determination to demand and enquire about 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.

When concern for others was less sought and more unexpectedly raised by practitioners, many I talked to also saw this as evidence of care, even if, as this example also illustrates, this sometimes revealed awkward disparities in how screening was being made available. Nevertheless 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.'

The sentiments expressed by these women illustrate how particular kinds of gendered values in relation to female nurturance are embedded in and inform responses to and the requirements for care and knowledge in breast cancer genetics. That is, if being seen in the clinic is for some pursued in terms of naturalised obligation to 'take care of the family', it also becomes a way of laying claim to health care 'rights' that can be collectively claimed. As Nina Hallowell points out, women attending these clinics are only too willing to locate themselves as 'selves in relation' (1999), such that there is a 'gendering of responsibility to inform' and also 'manage risk' (d'Agincourt-Canning 2001). It is a willingness that must in part be linked to culturally valorised idea of female nurturance (Gilligan 1982; Sherwin 1992). As the second half of the book also illustrates, this is an ethical discourse which has more recently been directly drawn upon as a resource by breast cancer activist groups themselves.

Nevertheless at the same time that these gendered values and idioms appear to help sustain and reproduce the requirements for patienthood in the clinic, they are not always so easily or readily fulfilled by all. The kind of responsible, self-actualising individualism of preventative health, which both arises from and is strongly propelled by cultures of activism and awareness in relation to breast cancer, can come into conflict with the sharing of responsibilities required by predictive medicine. That is the trajectory between 'anticipatory' to 'distributed'

patienthood can at the very least be convoluted and is more often than not ambivalent. These tensions are examined below in relation to the experiences of three women. In each case the penumbra of patienthood is not always readily extended or necessarily gratefully received by their kin, with uneasy ramifying consequences for different persons.

Emily

During our first meeting Emily, a young women 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.

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, as Emily described 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 . . . 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'.

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. Clearly Emily saw her involvement in the clinic in terms of 'caring' for her family, even if they continued to be more reluctant participants in this exchange of rights and obligations.

Molly

The implications and requirements of distributed patienthood were different for Molly, who was in her early 60s, and semi-retired. 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'. 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.

It seemed that on hearing that her brother had recently had a mastectomy following a diagnosis of breast cancer, several years after Molly's sister had died of breast cancer, the response of her GP was to refer her to the genetics clinic. Although seemingly therefore not as aware of the new arena of predictive medicine as some of those I met, she was clear on one thing:

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

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. 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 Molly'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. However it was the actions that arose as a result of Molly's visit which had the most significant implications for social relations with her family. She described what had happened following her appointment at the start of our second meeting.

> Molly: 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. 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.

The actions precipitated by Molly's appointment 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. It was a scenario of shared health care which was now underpinned and informed by an exchange of rights and obligations, as Molly's response to my question about how her brother had responded to this new situation illustrated:

> Molly: 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 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.

Given the nature of 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 Molly pointed out:

> Molly: I said about the daughters and she [the nurse] said that was another reason for having his blood tested. 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 Molly 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 made such intervention important and urgent rather than the risk to Molly herself, underlining her status as a patient only in relation to the prospective patient status of others. Talking about how she might now get in touch with one of her nieces she pointed out that:

> Molly: I might tell her that there is this opportunity and see if she wants to follow it up. But the other thing that came to my mind since then . . . 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 require renewed contact between family members, Molly did not therefore seem completely convinced that the consequences for others would necessarily all be good. In addition Molly's own care was now much further down the line, as she pointed out 'until

they know the results of these tests, they can't promise me any more screening.'

Jane

During our first meeting, Jane, 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 she casually pointed out in describing how she had filled in the form:

> 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 my 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.

Following Jane'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 during the consultation:

> Jane: 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.
>
> . . . 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'. 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.

In the course of our discussion Jane 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:

> I think the general view of everybody is well we didn't know him, so it doesn't matter . . . all be it perhaps a little tiny bit of him is in all of us . . . now that we know that perhaps there was something he could have passed through . . . 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. For example earlier we saw how Jane's father's belief in predestination helped make tangible for Jane and others in the family the possible dangers of genetic inheritance in the family (see p. 40). Although not explicit in what Jane 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 anxiety among different family members. There was at least some evidence from our previous interview that a sense of what Jane called 'guilt' was present among family members as a result of another condition, hypercholesterolemia, that affected both her husband and her son. Some of this unease was conveyed in her final comments when I asked Jane 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.

> Jane: Overall I would say that it's settled a lot. The only thing is it's thrown up the thing with the Jewish ancestry, that's the only thing. It's a new thing that's come in and there are no answers to it . . . because of the Jewish link, it worries me more, because it is more prevalent. 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. 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.

> The new significance given to a shadowy figure from her grandmother's past had obviously reverberated through Jane'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 case studies presented here illustrate how those individuals being referred to the cancer genetic clinic have to be pro-active not only in seeking an appointment but also in involving others. For someone like Molly who did not fit this 'active' model of enrolment, the need for such activism on her and/or the part of related others came as something of a surprise. But even for someone much younger like Emily, who saw her participation and activism in seeking health care interventions for herself and others within a morality of taking preventative and pre-emptive action, fulfilling the requirements for being a patient in this context was thwarted by the reluctance of her mother to participate in her daughter's preventative goals. In different ways, unknowing, reluctant or, in Jane's case, essentially unknown relatives became caught up in each other's medical care in ways that resituated risk, rights and responsibilities between related individuals. Although I did not have the opportunity to discuss these issues with relatives of these persons, from what was said by the individuals I did talk with, it's clear that mutual and collective involvement in health care could engender or exacerbate tension among family members. The demands for involvement and participation precipitated and required by predictive medicine were not always necessarily perceived in terms of 'care' by all. When 'heredity' translates into what Konrad calls 'social anatomies of interdependence' new affiliations required and sustained by predictive medicine do not necessarily divide neatly along lines of shared genetic inheritance (2004: 153).

This chapter has explored the pastoral practices which are central and essential to clinical breast cancer genetics and the way this brings a certain set of moral claims and values into play. Focusing on two modalities of care and how they orient around the future and the family, it illustrates how 'care work' not only shores up the 'gaps' in predictive medicine but also shapes and informs these spaces in specific ways.

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 future. This must also be understood in relation to the means required to fulfil the 'promise' of predictive health in breast cancer genetics which necessitates the

lengthy involvement of patients. Yet there is also a focus 'on the family' expressed through and orientated by an idiom of female nurturance and care towards related others. However 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.

Kinship therefore 'regulates' clinical knowledge and practice in a way that is very different from that explored in Chapter 2, raising further questions about a critique of these developments only in terms of a reductionism and/or argument about unilinear geneticisation. Ethnographic observation and analysis of different health care encounters illustrate the extent to which predictive medicine 'puts kinship [and gender] to work' (Edwards 2000) in ways that productively blur the boundaries between the natural and the social in configuring genes, female nurturance and family history. That is the collective pursuit of care and knowledge relies on a notion of the family as a domain not only of biological ties but enduring and affective kin ties which are maintained through ongoing sociality and a presumed desire and ability of those attending the clinic, who are mostly women, to nurture the health and well-being of others.

Nevertheless these pastoral modes entail different articulations of patienthood that can pull in tension against one another. Important work has been done challenging certain bio-ethical analysis of recent developments in genetic knowledge and technology, raising questions about the 'myth of pre-emptive individualism' often embedded in these type of approaches (Konrad 2005). Yet individualist orientations have a structuring presence in breast cancer genetics, in helping to recruit 'patients' into this arena. As Bourret points out clinical BRCA genetics is constituted in terms of an oscillation between the individual and the family (2005). This chapter has explored how having to be both 'anticipatory' *and* 'distributed' patients is sometimes uneasily achieved. The case studies presented here point to a disorientating flux in which awareness and pursuit of one's own health in going to the clinic can conflict with the necessarily more collective notion of patient identity required as a result of such a visit. Such tensions must I suggest be situated in a broader cultural frame. That is they arise from and have consequences for notions of patient and citizen constituted at the interface between a neo-liberal ethic of being pro-active in relation to one's own health and the naturalised and socialised moralities associated with

'the family'. Specific articulations of female gender identity link these two domains, connecting the values and practices associated with individual vigilance and health awareness, which has been so much a part of a growing arena of breast cancer activism, to broader cultural ideas of female nurturance as inimical with care and concern for others.

These genealogical and gendered dimensions raise important and interesting questions about how men are and will be implicated in these developments. There has been little research into how male persons identified as being at 'genetic risk' or passing on a genetic risk, or even male relations and partners of those attending these clinics, perceive, understand and respond to developments in BRCA genetics (see however Hallowell *et al*. 2004; NICE 2004: 21).[3] The indirect evidence, illustrated by the few case studies presented in this chapter, and the little research which has been done suggest that they are less subject to or willing to participate in the collective activities necessary to secure their own care or to maintain the care of others. While confirming a thesis about the value of female nurturance presented in this chapter, this also raises further questions about the centrality of women in realising the 'revolution' in predictive health care.

In her examination of kinship in the context of amniocentesis, Rayna Rapp draws attention to the contrast between the 'powerful ethnoscience' of bio-medical genetics and 'kinship reckoning' which speaks 'a related and alternative language of possibility and truth' (2000). 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).

Differences in so-called 'lay' and 'expert' configurations will of course continue to be one feature of new arenas of medicine such as predictive breast cancer genetics. This may be particularly so in relation to the experience of patients *living* with the foreknowledge of predictive genetics (Konrad 2000). Nevertheless analysis of the dynamics between patients and practitioners suggests that there is a much more complex interweaving of meaning and morality in relation to and/or between medical and lay ideas of heredity.

My research points to a much more slippery connection between the science of prediction and ethical values or moralities associated with the family and female nurturance in configuring care and knowledge. In fact, these 'merographic' connections (Strathern 1992a) are as much about the limits of predictive medicine as its scope, further demonstrating the complex and unpredictable ways that ideas of shared sociality or obligation among kin are used as resource in this setting.

The next chapter examines how the sorts of 'bi-directional affective entanglements' (Rose 2001) predictive interventions require and entail have consequences not just for patients and their kin, but also for those who work in these clinical arenas.

4

Diviners and Pastoral Keepers: Working in Clinical Breast Cancer Genetics

The ubiquity of a 'lay/professional' distinction in much medical sociology and anthropology has often produced a somewhat reified analysis of the relationship between doctors and patients, contributing to a description and perception of medicine as unified or monolithic (Mol and Berg 1998). Although this distinction has been useful in highlighting how patients' 'experience' of new technologies and knowledge is constituted within their 'lifeworld', constant recourse to this difference has also meant that the 'experiences' of those who work with new technologies have been neglected, or are often presented in a one dimensional way. This has now begun to be re-dressed (see for instance Lock *et al*. 2000). However it is an omission which has been particularly marked in social studies of the 'new genetics' (Stockdale 1999; Kaufert 2000).

There have been some indications that certain health care practitioners are uneasy about the 'hype' associated with new genetic knowledge and/or the potential for the medicalisation and or geneticisation of health (Holtzman and Marteau 2000; Melzer and Zimmerman 2002). In addition some studies have begun to examine the novel professional collaborations and alliances developing in some areas of predictive medicine (Bourret 2005). There has nonetheless been little sustained exploration of how those who work in these emerging medical specialisms experience and make sense of developments in genetic medicine. This research seems particularly important when the normal 'ellipsis' of prognosis in medical practice and education (Christakis 1999) appears to be forced centre stage by these developments. It is vital to understanding how seemingly novel arenas of medical practice ramify and connect with pre-existing clinical specialities or older orientations to medical care and expertise.

If the work undertaken by health professionals have in previous chapters been shown to be crucial to reproducing breast cancer genetics as knowledge and care, this chapter, based on interviews and informal discussions with a range of practitioners, examines the experience of those who undertake this work. It demonstrates how new personal and professional identities are implicated in predictive practices. Drawing attention to the ambivalence of those who, like patients, are caught up in the work of transmission, this chapter highlights how new roles as 'diviners' (Lock 1998) or 'keepers of the pastoral' (Rabinow 1996; Rose 2001) intersect with old roles in particularly stratified ways. If new technologies 'have to make room in already full worlds' (Mol 2000) the differences outlined here point to the importance of understanding the diverse professional and institutional cultures in which a clinical speciality such as breast cancer genetics is emerging.

These differences are illustrated by using a more detailed case study approach in examining the experience of those who worked in two separate cancer genetic clinics in a cancer hospital and a general hospital.

Predictive medicine and oncology

In her anthropological work on medical oncology in the US, Good draws attention to two cultural features of the clinical dynamics between patients and practitioners in this field of medicine, what she calls the 'political economy of hope' (1995) and the 'bio-technical embrace' (2001). Both, she argues, characterise the way oncology, in the face of a disease which often makes it impossible to salvage health and or life, is managed by patients and practitioners in relation to a clinical discourse about hope, optimism and faith in medical technology and knowledge (see also Löwy 1997). The first half of this chapter explores how this ethos affects the way that practitioners in a cancer hospital experience working in clinical cancer genetics. It traces the stratified and uneven lines that connect the practices of oncology to predictive medicine in a cultural and institutional locale that invests in promissory knowledge and technology. It also maps how the historical evolution of this clinical speciality and the career trajectories of a number of health professionals, support the values and ethics of certain kind of gendered health activism. These intersections have varying consequences not only for the way that predictive knowledge and patient care is perceived by practitioners but also how those who work in this arena identify with the roles and professional identities brought about by developments in BRCA genetics.

From 'dazzle to doubt'

In the initial stages of my research at the cancer hospital at the beginning of my field work, when I was trying to abstract a 'hype' fuelled media discourse about the BRCA genes from actual clinical practice, I had an initial meeting with one of the cancer geneticists. The discussion I had with her illustrated how, for some of those who worked in this setting, it was difficult to disaggregate hype from a more hope-filled future:

> 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 research work could take in the clinic. 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 proceeds 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, orientated in these initial stages around the 'social 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 no BRCA2 testing has really been done outside a research setting.

The gaps in the scope of genetic testing that emerged somewhat indirectly in this discussion stood in stark contrast to the way Eve also talked about the imminence of these developments. Despite criticism by some clinicians of the overblown rhetoric, that was often associated with predictive genetics, it seemed that at least some clinicians still continued to hold strongly to ideas of future potentiality in relation to genetic knowledge and technology. The 'dazzle' of her remarks were reflected in other discussions and interviews I had with this particular clinician throughout my research, as an excerpt from another interview with her illustrated when we were discussing the

overwhelming number of inappropriate referrals that the clinic was receiving:

> 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 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, so that they'll be ready when BRCA 3, 4 and 5 are found and gene chip technology will become available.

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, given the problems associated with identifying carriers of BRCA mutations, somewhat misplaced, her comments brought home how the *potential* impact of genetic knowledge was an important part of the way some practitioners identified with working in this arena. In fact the participation of this particular clinician had been a product of long-term professional involvement in oncology and then cancer genetics. It was, she said, something she had become 'completely fascinated by', having witnessed the transition of genetic knowledge into the clinical setting and been involved in research within this field for some time.

For one cancer geneticist therefore genetic knowledge appeared to be closely tied up with a sense of professionalism that was incorporated into and informed a belief and faith in a more hopeful future where genes would reveal a kind of truth; an orientation that was not dissimilar to the perspective of very many 'patients' attending such clinics. The 'bio-technical embrace' of oncology and cancer care (Good 1995, 2001) that routinises what are often experimental and uncertain interventions (Löwy 1997) appears here to be refracted through a 'vision' of the future which is very much part of the discourse of the 'new' genetics (Brown

et al. 2000; Franklin 2001a). Nevertheless, the sense of total faith in achieving the predictive goals that this practitioner talked about were not necessarily commonly shared by all; other practitioners were more equivocal about this.

One of the younger members of the cancer genetics team, Dawn, who was in her early 30s, 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 through a desire to complete her PhD.

> I wanted to do a scientific lab based Ph.D., completely out of the clinic, which is of course not what I'm not doing now. I wanted to do science as my research initially, understanding how all these things work . . . 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 cancer genetics, as a result of pursuing her PhD research, emerged more clearly however in the gap between her practice with patients and how she talked about the challenges of working in a field of predictive medicine.

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. She was particularly fastidious in her explanations to the patient about genetic inheritance and in imparting detailed figures about actual or potential risk information. She acknowledged that it was a misnomer to call what she did 'genetic counselling' when the bulk of her contact with patients involved imparting information. But her practices contrasted somewhat with her comments about the challenge of conveying risk information:

> Dawn: 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. 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.
> Sahra: but that is what is happening isn't it?

> Dawn: it is, 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 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. There is no point in not saying anything at all, otherwise there is no point in them coming.

Her comments suggest that it may in part have been her awareness of these limitations which made her more than normally rigorous about conveying risk information. Her eagerness for clarity was also reflected in the way she experienced obtaining family history. During one of her appointments a mother and daughter had brought in their own home-made genealogy with detailed information about 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. This contrasted with her normal routine experience of obtaining family history which was from her perspective 'a long and laborious process' where accuracy was crucial and sometimes, to her frustration, difficult to achieve. As Dawn pointed out, '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'.

Opportunities for achieving the kind clarity Dawn felt she had achieved in this appointment were however mostly rare. This seemed to compound her ambivalence about working in this domain as she pointed out in a discussion about 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.

Dawn's sense of unease in relation to the complexity associated with *predictive* genetics contrasted dramatically, not only with the style of her clinical appointments, but also with her enthusiasm for genetic knowledge that might ultimately 'treat' cancer. Her sense of ambivalence seemed to be strongly associated with her own desire to, as she put it,

to '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 in the cancer hospital also expressed doubts about a newly emerging arena of genetic medicine. These were however articulated in a slightly different way, products of different institutional and professional histories.

Irene was one of the senior nurses who worked in the much longer running family history clinic that was closely aligned with the cancer genetic unit. Having worked in the unit the longest (over 15 years), she had developed specific expertise and skill in addressing the physical symptoms of breast pain and the 'disease' like 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 what, to her irritation, other colleagues termed the 'worried well'.

On one occasion I asked her about why she did not seem to draw family trees when the patient came for their appointment in the way that I had seen all clinicians, as well as other 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', confirming that for her, she felt her skills lay elsewhere. Nevertheless a sense of discomfort about the movement towards more predictive interventions, that she had witnessed over the course of the last 5 years, emerged in conversations and interviews with her during my research.

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 pointed out that this meant they were 'fairly pioneering' and that they were at the 'top of what we can do'. Nevertheless, the identification of the BRCA genes had led to a series of changes in the guidelines for referral and seeing patients, both in the family history and cancer genetic clinic. Commenting on these changes she pointed out that,

> in the days when it wasn't so tight on age, 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 in these specialist units 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 increased genetic risk. Some of these challenges were hinted at by one of the consultants:

> 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', in meeting the strictures of changing and evolving guidelines for referral. As she pointed out:

> 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 implied that the difficulties of triage were also linked to the increasingly circumscribed or narrow basis on which risk was assessed; a product of new guidelines and governance structures that had emerged at this time seeking to standardise practices and manage the rapid rise of inappropriate referrals. But the difficulties of enrolling some patients and discharging others was also linked to the fact that the calculations of risk which informed guidelines were, and to some extent still are, products of limited epidemiological knowledge. This is of course a challenge to clinical practice not unique to cancer genetics (Gifford 1986; Singleton and Michael 1993; see also Timmermans and Berg 1997). Many in the cancer hospital were uncomfortably aware of

this, as the following discussion I had with a member of the cancer genetic team highlighted:

> Jane: well, they [the patient] could have a population risk of 8 per cent and then a 20 per cent lifetime risk, and then I might write to a patient that there is less than a 10 per cent 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 the figures you give to the patient is it?
> 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.

If the fact that there were different epidemiological risk models which produced numerous and often contradictory figures posed one challenge to clinicians[1], for others it was the lack of proven interventions for at-risk patients that was also disturbing.

In contrast to the way patients expressed their 'faith' in the various technologies of the clinic, particularly mammography screening, practitioners in the cancer hospital talked about it, during interviews at least, in much more contingent terms. It was a 'very muddy crystal ball', according to one nurse, which provided 'no guarantees'. Yet the incongruity of not being able to offer effective and proven interventions to those identified at increased risk was particularly difficult for this group of practitioners, as the comments of one clinician highlighted:

> It actually makes them [the patients] feel 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 [cancer] genetics feels that its an unreasonable thing to offer screening.

These remarks suggest that, at least for some who worked in cancer genetics, the re-assurance mammography screening provided for patients was sufficient, despite its uncertain medical benefits. At the same time one of the nurses who worked in the family history unit implied that the use of finite resources such as mammography screening services was not always well received by others in the cancer

hospital. Pointing out that 'there is a degree of conflict within the hospital about the way that it's [the family history unit] perceived', she said:

> I think you're 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.

Of course other technologies such as predictive genetic testing provided another possible means of intervention. But as we have already seen, this is a technique replete with logistical, technical and ethical challenges, which many in the cancer hospital were fully aware of. Some were however more vocal about this than others. The comments outlined below draw attention to the context and nature of one practitioner's hesitancy:

> Irene: To be honest with you I have a problem with it. I feel, the cart has gone before the horse. If we are going to tell people that they're at 90 per cent 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 potential carriers of gene mutations, young enough to benefit from monitoring and surveillance, who were being recruited into cancer genetics; a basis for medical practice which Irene clearly felt uneasy about.

The sense of hesitancy about the predictive expertise of BRCA genetics is diffusely and unevenly distributed and articulated by those who work in the cancer hospital. The uncertainties that arise from working in this context are, for some, circumvented by investing their faith in yet-to-be-developed knowledge and technologies, linked to long-term career involvement in cancer genetic research. Others are more open in articulating their doubts about the value of predictive medicine, linked to a sense of loss in the skills they had acquired as oncologists treating

physical disease or as nurses dealing with the 'illness' of anxiety. These accounts give a very different reading to the tools and technologies of predictive knowledge examined in Chapter 2. As Gifford's work demonstrates, the use of risk figures and statistics at the clinical interface masks the controversy and doubt experienced and articulated by practitioners outside these arenas (1986).

Nevertheless the scope of predictive medicine also provides the chance to articulate new kinds of 'ethical' expertise, as 'keepers of the pastoral' (Rose 2001). For some this means an opportunity to connect an ethic of 'care' and 'hope', that has long been associated with oncology and which is also powerfully rooted in the history of the unit as a Well Woman clinic, to predictive practices. For others this modality of care giving brings challenges and concerns.

'Care' as expertise?

As the previous chapter has demonstrated, certain pastoral modes are vital to clinical practice in ways that are not only affective, but also instrumental and essential to the production of predictive knowledge. Attending to the way care giving practices are experienced suggests that, for some practitioners in the cancer hospital, the 'social' context of the family enables them to demonstrate, experience and bring a certain degree of holism to their medical practice. This was reflected in the way one cancer geneticist talked about the intuitive, almost innate, counselling type skills and abilities that were necessary to undertake work in this setting:

> 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. But 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 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.[2]

The ability to 'listen' to the patient, so central to cancer genetics, is situated here in somewhat nostalgic terms where it is seen as part of an older and now lost set of skills associated with 'listening to the patient'.

In contrast to others who seemed to 'mourn' the loss of treating patients' physical symptoms, this practitioner implies that an older kind of caring value might be regained through a required counselling approach, which makes it possible to consider the patient as a 'whole'. But as the previous chapter illustrates, this is not so much an option as a necessity. It is a sentiment perhaps reflected in the way this practitioner situates her practice, as a cancer genetic specialist, in terms of an intuitive 'skill' that cannot necessarily be taught.

One of the nurse specialist was in fact considered to have this special ability, which others talked of. 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 her own personal experiences of 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, 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:

> Being there for people, particularly for young people who need a lot of help or support understanding the genes. I find it very rewarding that I can have the knowledge and help those families, where they've had so many early deaths to know that they are very destroyed. I feel whatever I can do to help them the better.

An ability to empathise and deal with families was not only a source of Jane's expertise, but also in turn informed the expertise of the clinic, where the negotiation of family dynamics is essential to facilitating the work of prediction, risk assessment and care.

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 20s had often lost mothers and other female relatives to breast cancer early in their lives. The tone of these meetings was often intimate and friendly sometimes involving much sharing of information about recent developments in patients' lives such as a new job or the birth of a baby, a wedding or a 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 having a gene mutation on either of the BRCA genes) 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 monitor their well-being. 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.

Although like others I met working in the cancer hospital, Jane acknowledged the limits of predictive interventions in breast cancer genetics, she also to a certain extent circumvented this issue, as her comments below suggested:

> 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.

Despite the problems associated with the limited interventions available in cancer genetics, for her there was still significant psychological, if not proven clinical, value for patients. Jane firmly located this medical specialism as part of the *solution* to the problem of anxiety. Nonetheless the personal and professional challenges linked to predictive health interventions could not always be avoided.

The double edge of having expertise in the realm of pastoral care was particularly acute in dealing with the consequences of uncertainty in relation to genetic testing and the effects this had on individuals and families. This emerged during an appointment I observed when Jane was faced with a woman and her husband who had been given an inconclusive gene mutation test and had yet to make a decision about whether to remove the woman's ovaries, thereby perhaps reducing some of the woman's risk of recurrent breast cancer. Although this was an issue which clearly generated a considerable amount of tension for the couple, I was surprised to see that Jane did not seem to address this, as she usually did in such situations. The reason for the tension became apparent after they had left, when Jane pointed out to 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 situating predictive information as care which, on this occasion, had made Jane wary or unwilling to engage with the tensions and emotions raised by having to wait so long for a genetic test result. The difficulties of dealing with the social and emotional fall-out of inconclusive test results 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, I saw somebody a few years ago and now they want to know what's happening. It's understandable . . . I'd want to know what's happening too.

It was not therefore 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, such scenarios 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 difficult 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'd 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 in to have a prophylactic mastectomy. The sister 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. So those sort of traumas in the family where one person goes in to have surgery which her sister did, and we'd never seen her in genetic counselling. I used to lie awake worrying about it, so I do worry a lot about all these families.

For some these challenges were circumscribed within the space of what were termed 'problem families' or 'control type characters', reduced to the pre-existing social dynamics in the family that pursuing

predictive knowledge and care had to somehow manoeuvre. Other clinicians were more explicit about the difficulties of having to provide care to the person in the clinic, in ways that meant treating many of the patient's kin as potential patients.

This was reflected in one doctor's articulation about the struggle to negotiate 'conflicting rights' between different persons. Her feelings about this were in part tied up with the 'stress' caused to patients in having to inform and speak with relatives. However, she also recognised that these scenarios impacted on her as a practitioner in uneasy ways. On the one hand, there was a responsibility on her part to inform family members of potential risks, 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'. But she also recognised the need to provide care and health interventions for those persons who had initially sought or been referred in the first place:

> 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.

With a background in oncology and having had a number of years experience treating individual patients *with* cancer, the necessity for 'distributed' medical intervention in pursuit of predictive knowledge was somewhat problematic for this practitioner; something which she said, 'I haven't resolved in my own head as yet'.

Even those who were generally more enthusiastic about the future potential of predictive medicine conceded that this was a delicate area of work. Eve talked about the difficulties posed by the need to maintain confidentiality between related individuals when family members were being treated by different hospitals:

> I think the most difficult thing that I find very hard to reconcile within myself, is the issue we have on confidentiality between centres. I can see that genetics is different because you've got information about others, but . . . 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.

> 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. 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.

Although Eve claimed previously that work with the family was bringing about an older style of medical practice that could be linked to a more 'holistic' approach, from what she said here, it seemed that the necessary work with families could compromise an ability to act expertly. These difficulties also demonstrate how the 'counselling skills' and a focus on 'the family' championed by some, but which others also *had* to adopt, were vitally important aspects of this arena of medical practice.

Geneticists and the 'hysteria' of breast cancer genetics

Talking to members of the cancer genetics team, mostly geneticists who were part of a regional genetics unit attached to a general hospital, where I carried out a smaller piece of field research, it became obvious that their perspective and experience of developments in BRCA genetics were somewhat different to those who worked in an oncology setting.[3] The sense of ambivalence they articulated about the work of prediction and the caring modes this required of them are explored in relation to discussions I had with this group of persons and observations of their clinical encounters.

Predictive uncertainty and the demands of consumerism

Breast cancer, and cancer more generally, is only one of a number of conditions that the geneticists addressed in terms of the broad remit of their clinical work. At the time of my research, cancer genetics, particularly in relation to breast cancer, was a relatively recent but nevertheless rapidly growing area of their practice and increasingly the condition for which they had most referrals. Feelings about the increase in the numbers of persons being seen, as part of a process of genetic risk assessment for breast cancer, became apparent during discussion before a clinic one day, when the geneticist I was with contrasted the

'severity' of this disease in relation to other conditions that the genetics unit routinely had to deal with.

> Mary: It's just not that bad when you compare it with other things really and at least 75 per cent of breast cancers are curable nowadays. I've got one woman later today and 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! It's such a terrible condition and knowing that your child could die at any moment, it's absolutely dreadful.

A similar sentiment emerged among others working in this arena, during a lull in the clinic that I had been sitting in on, one day. Partly in response to some discussion of my research, the geneticist begins to talk about dealing with patients at risk of breast cancer:

> Elizabeth: There is just this huge *hysteria* about it [breast cancer] and in a way I feel partly responsible.[..] 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 circumscribed concerns that many of those in the cancer hospital had about the scope of predictive interventions contrasted with the open and vocal litany of doubt that was reflected in these remarks. The juxtaposition of so many different concerns in this practitioners comments seemed to bring the validity of a predictive approach to breast cancer into question; a sense of limits to knowledge and care which was compounded by what this geneticist saw as a certain degree of 'panic' in relation to breast cancer. For her this was out of all proportion to the severity of other conditions, the numbers of people affected and the scope of possible interventions. Such concerns were reflective of not only the rapid rise in referrals for breast cancer but also the large numbers of people referred who were at no or low

increased genetic risk. According to some reports this constituted as much as 25 per cent of all referrals to cancer genetic clinics at this time (Wonderling *et al*. 2001). These feelings of frustration were reflected in the way another geneticist commented on the language a patient had used in responding to his assessment of her risk:

> The appointment begins with the geneticist reassuring the patient that she is at much less risk than she thought and reminding her that, being over the age of 50, is she already on the NHS screening programme for breast cancer. After assessing her family history he concludes that her risk is moderately increased and he puts her on programme of increased mammography screening. Near the end of the meeting, the consultant asks her how she feels about this assessment and programme of intervention. '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 somewhat persistant and expectant patients.

While those in cancer hospital described the 'demands' of patients in terms of anxiety or the problems of 'control type characters', the geneticists I met, spoke more generally about the consumerist style requests that were placed on them by certain groups of patients:

> 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 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 highlight the difficulties that these practitioners experienced in dealing with patients concerned about their risk of breast cancer, who they felt expected much more than specialist services such as cancer genetics could provide. As one geneticist pointed out, standing firm against such pressure was also about countering the anxiety that the availability of predictive interventions seemed to fuel: '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'. The strain for these clinicians linked to patients heightened expectations also emerged after one particular appointment which, elicited a fairly terse response from one geneticist:

> Peter is seeing a women who has just been referred for the first time. After going through the family tree, he tells her that she is not at greatly increased risk because the incidences of breast cancer among her relatives are spread across different sides 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 saying:
>
> 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 geneticist's remarks at the end of this appointment reflected his frustration at having to deal with so many expectant and demanding patients, they also drew attention to what he saw as an overly prescriptive assessment of what geneticists did or could do. Although the fieldwork that I carried out in the general hospital was not as extensive as that in the cancer hospital, the sense of ambivalence expressed by this group of practitioners, concerning the recent rapid translation of BRCA genetics into a clinical service, is clearly palpable in these examples. It was a sense of hesitancy which was not confined to just doubt about the limited scope of expertise in the face of patients' expectations, but also included a sense of unease about what this meant for the 'care' work required of them, as well as patients.

Refusing 'counselling' as care and knowledge

It was notable that among these practitioners there was a more general marked reluctance to embrace the kind of pastoral work, which at least some of those in the cancer hospital, seemed to see as part

of their professional practice. One indication of this was perhaps the way that appointments tended to be generally shorter in the general hospital's clinics. Although this may have been to do with a different allocation of resources and or a particular patient/practitioner ratio that was less easy to manage, there certainly seemed to be less time taken in attending to the social dynamics and context of family relations. A more explicit sense of this disinclination to embrace the role of 'pastoral keepers' was illustrated in the comments one geneticist made after an uncharacteristically 'counselling' like appointment.

> 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. A difficult situation gradually begins to trickle out, 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 linked to, if not 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 concerns, 'there was certainly more going on there than I thought'. This however also prompts more discussion about whether he should be 'counselling' patients in these clinics:
>
> > 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 . . . I think it should just be information giving myself.

Peter's response in this situation indicated how he felt the emphasis in the clinics should, to the extent that it was possible, be on straightforwardly outlining current knowledge, providing information and screening. In the appointments I observed in this cancer genetic clinic,

there did seem to be less attention paid to the difficulties patients encountered when contacting relatives for information in order to assess their own risk or to pursue a procedure such as genetic testing. When this created an impasse in the ability to provide care or seek out predictive knowledge this could, as in the cancer hospital, be experienced as deeply dissatisfying for all concerned. Nevertheless it was a sense of frustration which seemed to be more openly and widely expressed by this clinical team. This was illustrated during a discussion I had one afternoon with a senior geneticist. She talked about some of the difficulties she had confronted earlier in the day in facilitating care for a family where a gene mutation linked to an increased risk of developing a form of colon cancer had been identified:

> I had a situation this morning where it was possible to do a genetic test for the family. 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 she 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?

One of the most direct indications of the sense of reluctance and unease this group of practitioners felt about having to pursue knowledge and care, in a way that relied on and implicated multiple family members, was in the policy changes they discussed with me concerning referral guidelines to cancer genetics for those at increased risk of breast cancer. A number of clinical staff had mentioned, in passing, how they felt the 'ethical' challenges this work posed could be reduced by radically altering current referral protocols and guidelines. As one geneticist explained, '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 they discussed, 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. This stood in contrast to the current situation, where it was often the concerned and anxious relatives of those with or who had had breast cancer who sought or were referred to cancer genetic clinics. This, as we have seen, necessitated

difficult and time-consuming 'counselling' to know if a genetic test was possible or desired by the 'affected' individual or others in the family, far in advance and frequently in the absence of knowing if a mutation would been found.

One particular clinical encounter in the cancer hospital, and the geneticists' response to this situation, seemed to highlight exactly 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 the geneticsts come into the consulting room; an older woman in her fifties, her daughter and a young child in a pram.
>
> The geneticist had already filled me in a little on the background before they arrived explaining that one of the other younger daughters had been diagnosed with breast cancer in her late 20's. She suspected that they were here because the prognosis had clearly worsened, something confirmed by the family in the clinic who gave a lengthy account of her recent rapid deterioration. Although the doctor, it seems to me, is slightly shocked she responds not by openly engaging the family in discussion about how they are coping, but by adopting a very 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 other daughter, who wanted them to do something about what she perceived as the potential risk to the family, including her own children. After setting up some more frequent screening for the mother, whom Elizabeth suggests is most at risk, 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 straightforward practical approach adopted during the consultation the clincian seems to want to reflect on the encounter, suggesting she had found it a particularly difficult meeting. Talking about how upset the mother was she says
>
> > She seems 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 the geneticist 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 was, not surprisingly, a particularly emotional one for all concerned. Nevertheless it also illustrated exactly the kind of dilemmas this group of practitioners highlighted and which the policy changes they discussed, sought to avert. That is, the 'ethical' challenges of having to pursue uncertain predictive interventions in relation to the social dynamics of the family. In this instance, although the geneticist acknowledged that the family's visit may have been some comfort to the woman who was dying, she was also, uncomfortably aware that that there was no guarantee that the actions set in motion now to search for a gene mutation in the relative with breast cancer would generate useful knowledge or ease the trauma for others in the family. The 'therapeutic' salve that some practitioners talked of in the cancer hospital, for the most part, did not assuage the concerns of the geneticists I encountered.

This chapter focusing on the experiences of those who work with the knowledge and technology of breast cancer genes in two cancer genetic clinics has shed light on a neglected arena of the 'new' genetics. It has shown how the medical practices required and reproduced by this knowledge have different yet also equally problematic ramifications for these individuals. However, there are clearly variations in the way that practitioners identify with this new field of medicine, articulate their ambivalence and embrace or reject the specific kinds of expertise required by predictive interventions associated with cancer genetics in relation to breast cancer. Historical studies of the emergence of other arenas of clinical cancer genetics (Palladino 2002), as well as an analysis of the emergence of breast cancer genetics in different national health care arenas such as France (Bourret 2005) or in comparative studies between the UK and the US (Parthasarathy 2003), have also emphasised the importance of examining the 'institutional configuration' in which genetic diagnosis is 'expressed and managed' (Nellis 2000: 214). These dynamics have been mapped in this chapter by examining the stratified responses to new roles as 'diviners' and 'pastoral keepers' in two different health care cultures and settings involved in the provisioning of cancer genetic services within the UK.

Although for many working in the cancer hospital breast cancer genetics had been part of, and emerged from, long professional involvement in the field cancer care or breast screening, there were disparities in

the way different persons talked about the kind of expertise this constituted and the practices necessitated by predictive interventions. This ranged from expectant and almost hype-filled images of imminent technological interventions to more ambivalent renderings of the currently limited scope of genetic testing and preventative interventions offered to those at risk. By contrast the geneticists I met were vocal in their articulation of the problems associated with this arena of medical intervention. This was compounded by the unrealistic expectations placed on them from what were perceived as a relatively demanding group of patients.

But there are also differences in the way in which practitioners respond to what is a pre-requisite for knowledge, prediction and the care of the patient(s); the need to attend to the 'social' context of the family. Some of those in the cancer hospital embrace this new role in a way that defines dealing with the family in terms of 'holism' – an approach which taps into what are perceived as the unique and special skills possessed by those that have a background in oncology. At the same time, embracing this as an element of expertise does not preclude this group of practitioners from having to deal with the problems of confidentiality and consent that care work with families in predictive medicine requires. Although it was acknowledged by all that this was a challenging dimension of clinical practice there was a much deeper reluctance to embrace the kind of care work that the field of BRCA genetics required among the geneticists I met.

The geneticists' openness about the difficulties engendered by the rapid emergence of this clinical speciality might, in part, be understood in terms of working in a regional genetics unit where hereditary breast cancer is one among other genetic conditions. This ensures that they are not necessarily totally defined by the uneasy entailments associated with predictive interventions linked to breast cancer. By contrast the associations between professional practice or identity and new predictive interventions are less easily circumvented by those professionals in the cancer hospital. This is in part because their focus is only on cancer genetics within a specialist breast unit. But it is also because their professional practice is part of a culture of oncology in which novel, uncertain and often unproven medical or technological interventions become entangled with hope, such that they are often perceived by patients and/or presented by practitioners as 'state of the art care' (Anglin 1997; Löwy 1997). In addition the evolution of the unit from its origins as a 'Well Woman Clinic' contributes to an ethos, still felt by those who work there now, which supports the (female) patient's right to knowledge,

information, and care. In continuing to defend this ethic these practitioners, perhaps more than the geneticists I met, stand in a position of 'enrolment' and 'betrayal'.[4] That is they help to facilitate, whilst also being witness and themselves subject to the uneasy ramifications of, a gendered rights based culture of activism and awareness being played out in the pursuit of uncertain predictive knowledge.

Focusing on the narratives and experiences of those on the professional front line of clinical BRCA genetics brings an important ethnographic perspective and stratified diversity to Christakis's reading of doctors as 'reluctant prophets' (1999). Those who work in clinical breast cancer genetics are clearly deeply conscious of and reflective about the uncertainties of genetic risk information, the gap between knowledge and care and the limits on their ability to act as health practitioners. Although a narrative of bio-medical rationality and expertise might be one feature of this arena of health interaction, as the data in Chapter 2 suggests, contextualising this discourse in relation to the dynamics of the clinical encounters and the perceptions or experiences of a range of practitioners reveals a much more complex context for the reproduction expertise, professional identity and identification. Given these findings, the possibility that the new divinatory practices of predictive medicine might actually 'reduce the weight of responsibility' for clinicians (Konrad 2005: 84) seems somewhat contested and at the very least something that must be subject to further empirical examination. Outlining how professionals are caught up in the transmission of new knowledge of breast cancer genes highlights how, whilst being productively central to this work, they are also, like patients, subjects in relation to these developments.

Part II

A Breast Cancer Research Charity: Science, Activism and the Quest for Knowledge

Moving outside the clinical arena and the specific dynamic between patients and practitioners, the second half of this book examines the knowledge and technology associated with breast cancer genes in relation to a very different science/society interface. Informed by the idea that the viability of scientific research is inseparable from social or institutional organisations and relations (Fujimura and Clarke 1992) and their particular 'scientific-body language' (Wynne 1991), Chapters 5–7 explore the dynamic interface between gendered health activism and the BRCA genes in the context of a breast cancer research charity in the UK.

Although the boundaries between charity, patient organisations, state institutions and corporate interests are increasingly often difficult to separate (King 2001; Allsop *et al*. 2004), UK charities are one of the major sources of funding for cancer research, with a long and highly successful history. Several large cancer charities have had a major if not *the* primary influence in overseeing cancer research in this country through the 20th century. As Austoker notes in her historical study of one of these charities (now merged with another major UK cancer charity) the ICRF (Imperial Cancer Research Fund), from its inception in the 1930s to the mid-1980s, was, like other large cancer charities, given a 'mandate by the public to dictate the pattern and direction of research' (1988: 317). She points out how this has had a significant effect not only on the funding of cancer research, with correspondingly low input of government funds into cancer research, but also on the co-ordination of such research. Although there are over 600 much smaller cancer research charities in the UK (Walker 2000), the field of charitably funded cancer research is dominated by a few major organisations whose scale of operation is 'comparable with that of most commerical firms' (Austoker 1988: 318). As Porter

notes, there have been comparable kinds of relationship between science and publics throughout the course of the 20th century, illustrated in the campaigns against TB and Polio (1997: 694). Nevertheless the 'war' on cancer has proved to be not simply a resilient cultural metaphor in relation to cancer (Sontag 1991) but also a reflection of sustained public support and investment in cancer research. When, as Karakasidou points out, the disease itself is constituted as a 'subversion of modernity' (2005) it is perhaps not suprising to find that the science of cancer research has been, and in many ways continues to be, situated as a 'modernist' project, articulated in terms of quest for a 'cure' (see Löwy 1997).

In the UK the character of this 'war' on cancer, through scientific research, and the nature of public support in fighting it, has been and continues to be refracted and forged through the history and social institution of charity. As this chapter illustrates, it is an institutional context for cancer research which has wide-ranging consequences for the kinds of public/science relations that characterise the social dynamics surrounding breast cancer genetics.

Scientific research focused on breast cancer has come to occupy an increasingly prominent space in cancer research over the last 15/20 years, partly in response to the burgeoning growth in gendered health activism around the disease. This has also led to the proliferation and expansion of breast cancer organisations in the UK. Some of these cater to the varying and different needs of those with breast cancer, or their family and friends, while others participate in lobbying parliament, increasing patient advocacy or fundraising for research. All are active in raising awareness about breast cancer, embodied in the now annual international event, Breast Cancer Awareness Month. This event which been running since the early 1990s, marked by the selling of 'pink ribbons', has now come to constitute something of a consumer industry. As King points out, these developments index the success of a range of breast cancer organisations, and highlight the increasingly dense interconnections between cancer research, corporate philanthropy and raising funds for charity as an individual 'lifestyle choice' (2001).

In general specific support and information for those at risk of breast cancer because of their family history or for those found to be carrying a BRCA gene mutation was and continues to be subsumed within the broad remit of an array of breast cancer charities. In the UK there are no specific organisations aimed exclusively at those identified as being at increased risk because of their family history or as a result of predictive genetic testing; a situation which makes evident the need to explore the wider bio-social terrains which BRCA genetics are implicated in and

which they are also helping to inform. There is however a breast cancer charity in the UK which, at the same time as being very much part of the heightened public profile of breast cancer, has a particular space within the institutional culture of charitable research and also the field of genetic science and knowledge. This is not just because of the organisation's somewhat unique 'grass roots' identity but also because of its single disease focus on breast cancer *research*, as opposed to immediate practical 'care' for those with the disease. Although the stated long-term goal is in developing 'treatments' for breast cancer the research it has funded, from its inception, has been orientated towards 'basic' science. This has included, although not been totally defined by, research on the BRCA genes. This is part of a programme of research which is collectively orientated towards finding out more about the 'biology of the breast', in working towards what is described as a future 'free from the fear of breast cancer'.

Originally set up in 1991 in response to what was seen as lack of focused research on breast cancer by the family of a woman who had died of the disease, the charity has been highly successful in recruiting support and securing financial backing for its cause from the public, the broader cancer research establishment, but also other major corporate funders. This has lead it to become a national organisation with numerous fundraising branches across the country and enabling it to meet the target of raising £15 million to build the first dedicated breast cancer research centre within the short space of 10 years. The rapid rise and expansion of the charity to become one of a handful of extremely successful cancer charities in the UK with a national profile is a product of and testament to the way it has succeeded as a research charity focusing on basic science but with a something of an 'activist' identity – a model which, until fairly recently, had been unique in terms of cancer research in the UK.

It is not insignificant that the growth and success of the organisation, particularly from the mid- to late 1990s, has coincided not just with the expansion of breast cancer activism but with the identification of the BRCA genes. As I explore in subsequent chapters the 'hype' and 'hope' that built up around these 'discoveries' and the larger international project to identify and sequence all the genes in the human body, although a feature of a diverse set of public, scientific and social science discourse at this time, has also informed the work of the organisation in particular ways. At the time of my research in 1999 to early 2001 there were a number of different teams working in the research centre. However a number of high profile groups were focusing on investigating

the function of the BRCA genes and in fact several key members of the current research teams funded by the charity, were involved in the work that identified the BRCA2 gene. Although the type of research undertaken by the charity has now expanded well beyond a focus on BRCA genes per se, its work continues to be directly associated with long-term basic science research examining the 'molecular pathways' thought to be involved in developing breast cancer.

The second half of the book examines therefore the work of transmission and translation of genetic knowledge and technology in a domain outside the clinical setting by exploring the social and cultural dynamics that constitute one particular high profile breast cancer research charity in the UK. This journey out of the clinic towards specific 'sciences' and 'publics' highlights how seemingly disparate arenas are caught up in mutually evolving ways in the co-production of breast cancer genes.

Chapters 5–7 map the matrix of social relations that constitute one particular breast cancer research charity exploring the connections that work to reproduce, as well as the challenges to sustain, an alignment between fundraising, genes and the pursuit of and quest for scientific knowledge of breast cancer.

5
The Alchemy of Loss and Hope: Fundraising as Memorialisation

Recent expansion and developments in the bio-sciences have been accompanied by the growth of a diverse and fairly heterogeneous range of 'patient organisations', who increasingly have some sort of stake in the direction and outcome of different arenas of scientific or medical research (Epstein 1996, 2007; Brown *et al*. 2004). Such developments are also now reflected in the field of genetics (Rabeharisoa and Callon 1998; Rabinow 1999; Stockdale 1999). While many emphasis the novelty of these new alignments between public and science and the 'research in the wild' that this can engender (Callon and Rabeharisoa 2003) others have questioned the innovativeness of these alignments. Hess points out that there is a long history of 'generative exchange' between social movements and scientific research (2004). In fact the history of lay or patient and public involvement in science stretches from the voluntary, charitable or philanthropic health associations of the 19th century in the US and the UK, to the 'public' health campaigns against TB or the fundraising initiatives aimed at eliminating polio in the 1950s (Porter 1997), cancer at various times during the course of the mid and late 20th century (Austoker 1988) and more recently AIDS in the 1990s (Epstein 1996).

Of interest here however is the way the broad, diverse and long history associated with the 'politics of women's health' has informed and continues to influence the growth and character of a variety of different patient organisations and movements (Epstein 2007). The feminist identity politics and grass roots activism of the 1970s and 1980s brought to the fore a range of health issues relating to women including contraception, abortion and child birth. The most recent, vocal and public manifestation of women's activism around health has been in relation to breast cancer (Weisman 1998; Morgen 2002). The

growth and emergence of a breast cancer lobby throughout the 1990s has been instrumental in transforming the *public* identity of the woman with breast cancer from 'tragic victim to heroic survivor' (Klawiter 2004). Such success nevertheless belies the fact that there are not only many different cultures of activism around this disease but also diverse experiences and perceptions of breast cancer (Myhre 2001; Blackstone 2004; Klawiter 2004; Kolker 2004).

Focusing on one particular arena and type of breast cancer activism, that closely intersects with and arises from within the long history of charitable funded cancer research in the UK, this chapter examines how a group of 'lay' persons, individually and collectively classified by themselves and others as 'fundraisers', come to identify with a breast cancer charity. Based on research undertaken with a specific group of persons involved in the charity, it examines how this form of breast cancer 'activism' is refracted through gender, the work of 'memorialistion' and the hopeful pursuit of science.

Female nurturance, memorials and the power of testimony

In the same way that the agency of persons attending cancer genetic clinics examined in Chapter 1 is caught up with how particular idioms and values associated with gender are embedded in and have been mobilised by a growing breast cancer movement, the 'activism' of persons involved in a breast cancer research charity is also situated at the intersection between neo-liberal citizenship and the goals and values of preventative public health. A gendered ethos about health was certainly a dimension of how the charity had succeeded in garnering support for its research work. This is reflected in the demographic constitution of the organisation. Although many other charitable bodies are predominantly supported by women, market research carried out by the organisation in the late 1990s suggested that this is strikingly so in this case, with over 90 per cent of supporters being female and more than half under 45. But the kind of gendered civic engagement articulated in the values, ethos and work of fundraising or supporting a breast cancer research charity is more than simply demographics.

Before turning to reflect more specifically on the narratives of those persons who raise money for the charity, the particular gendered values and representations reproduced by the organisation, in its promotional material and fundraising campaigns, are examined. This brings to the fore the kinds of 'looping' (Hacking 1986) mechanisms that connect

certain marketing devices to the making of 'activists' as fundraisers in a breast cancer research charity. Here, specific 'ontologies' of gender provide an ongoing rallying point for garnering support and recruiting individuals, in ways that might be seen as unifying or normative. For instance, published excerpts from newsletters and supporters have pointed out how 'breast cancer is the scourge of women everywhere' and how the opening of the charity's new research centre will be 'something that will prevent women having to face the indignity of breast cancer'. However it is not just that 'women' are represented as cohesive in the fight against breast cancer, but that particular images of women and female bodies are given a higher profile in this literature than others.

This is reflected in the way women are often visually or verbally represented in 'relational' terms, as mothers, daughters, sisters or aunts. This 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 an annual national fundraising event which takes place in and around 'Mothers Day', 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'.

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. It is an image of gender identity that clearly derives from 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 by others, as it blights women's lives and those around them. Ideas about female nurturance are, as others have pointed out, powerfully mobilised across diverse cultures of gendered health activism (Ginsburg 1987). This is particularly evident in the case of breast cancer where the 'moral worthiness of the breast cancer victim has become part of the sub-text' (Kaufert 1998: 102; Kolker 2004). In her analysis of breast cancer narratives in the media, Saywell *et al*. points out how these are dominated by idioms of 'nurturance' and 'motherhood', often 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' (2000: 49; see also Seale 2002).

However, there is another important facet of the way women are represented in relation to campaigning messages about breast cancer within certain sectors of the diverse activist culture around this condition. The scale of fundraising for research and care in this area means that breast cancer now receives support from many public figures and celebrities in particular national campaigns, especially those involving the fashion industry. This is also the case for the charity in question, which not only enables them to maintain a high profile, 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 and celebrities. Others examining these developments in relation to public discourse or media representation argue that this contributes to the 'sexualisation' of breast cancer (Fosket *et al*. 2000; Zavestoski *et al*. 2004). From this perspective 'race, age and beauty' are key to understanding the emerging (consumerist) politics of breast cancer (Cartwright 2000) where the 'sexiness of the breast is used to sell breast cancer' (Saywell *et al*. 2000:39).[1] Clearly the use of these images is not reducible to one meaning. Standing in relation to and often in tension with the valorisation of female nurturance, they illustrate the contradictory meaning of the breast and breast cancer (Yadlon 1997; Yalom 1998). However the frequent use of glamourised normality rather than visibly ill or cancerous bodies across a broad range of institutional arenas, in relation to fundraising for breast cancer, is significant in thinking about how the disease is being gendered in particularly normative ways.

If specific representations of female gender are instrumental in raising awareness, and garnering public or charitable funds, support and resources for breast cancer, it is not surprising to find that certain person who support the charity talk about their involvement in ways that reflect the morality and ethical value associated with particular articulations of female gender. As the narratives of some of these persons outlined below illustrate, this mode of involvement and identification, traced through the ideas and values of sociality and female nurturance, helps situate fundraising for scientific research in term of what might be described as a process 'memorialisation'.

On first meeting some of the charity's supporters, one of my initial aims was to find out how they had become involved and what it was that motivated them to be part of the activities of the organisation. It quickly became apparent that this seemingly innocuous opening question was not only one that was, for many, loaded with significance and emotion but one that situated them and the 'activist' work they did

in specific relational ways. As Kolker points out, part of the culture and success of recent mobilisation around breast cancer activism is the way it has cast a 'net wide enough to encompass breast cancer survivors and their families' (2004: 831).

For instance, this was the way that Alice who was in her mid-50s 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. Unbeknown to me she made instructions that upon her death she didn't want any funeral flowers 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, Lois who was in her mid-30s, 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. 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 Caroline, and she led me on. I went home and got my sisters and friends round with a bottle of wine. We organised the ball, that took about 10 months . . . and raised £7000 first off and so exceeded all our expectations. After that Caroline died. The ball was in October and Caroline 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 Caroline. 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.

Both these narrative accounts of involvement bring a particular activist profile to the fore in relation to fundraising activities within the organisation. In fact research carried out by the charity in the late 1990s revealed that more than two-thirds of those who participated in the work of the organisation, mostly through fundraising, had *not* had breast cancer themselves but had some 'personal connection' with those who had developed the disease. Although the profile of the charity's supporters has changed somewhat in the last few years, following the merger with a high profile advocacy group, at the time of my research this articulation of involvement was not untypical. In this sense these narratives illustrate how, for many, remembrance of persons who had had or who had died from breast cancer, relationally positioned as mothers, sisters or daughters, was at the root of an identification with the charity and the work it did in raising funds for scientific research. For them the organisation provided an opportunity to do something in memory of these persons.

One of the ways that remembrance could be given a permanent expression was the opportunity for those who raised a £1000 or more to have a 'name' displayed on a dedicated space within the recently built research centre. Although this name could be their own, given the charity's demographic constitution, it very often transpired that the name chosen was of the person who was being remembered in the act of fundraising. One woman, a coordinator for a group of fundraisers in Lancashire, pointed out that the motivation for many was linked directly to the possibility of having a name written on this dedicated wall, as she said:

> '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'. This six-foot memorial 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 supporters 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 time. Sometimes they stood in silence in a way that indicated they were

physically moved, clasping the hands of friends or relatives who had come with them. During these official visits to the research centre the story of the charity's founder would also be told. An act of re-telling that implicitly acknowledged the multitude of other personal experiences of trauma and loss silently embodied on the wall.[2]

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 children, young relatives of persons who had had the disease or the children of those who were fundraising in their memory. 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, often expressed in terms of looking out for and ensuring the future health of daughters or granddaughters. These other reasons for being 'active' in raising funds for breast cancer research were illustrated in the way a group of supporters in the Midlands introduced themselves and talked about how they had initially got involved in the organisation:

> Person A: well it's about investing in all our futures and as far as I see its 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 evident in a way that one woman talked enthusiastically about how she had got involved 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.

Not insignificantly, Jackie's somewhat implicit reference to the fact that she had had cancer was somewhat subsumed in this account. She made a passing mention of this before launching into a description of the activities linked to a community of fellow fundraisers, who had become

part of her life. As she pointed out later in our discussion, 'the charity has been a focus and a way of keeping going and looking to the future'.

Like Jackie, others suggested that the work they did was a way of looking beyond the experience of breast cancer, as this woman's comments implied:

> 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 50s, also 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, that at least for some of those who have had breast cancer, involvement in this arena of 'activism' is also a way of moving on from the trauma and tragedy of the disease.

These narrative accounts and descriptions point to the way being active in a breast cancer research charity is articulated in terms of raising funds in remembrance of those who have died, often mothers or sisters, or for the future, mostly seen in terms of a younger generation. It is exactly just such narratives of loss and hope that also characterise the individual and collective testimonies which dominate the publicity literature of the charity.

The narrative experience of those involved in the charity was a regular feature of the monthly newsletter produced for supporters. This section of the newsletter 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, these 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 collective mourning, but were also, like the accounts outlined above, nearly always overlaid with a sense of 'positive' hope for the future.

One such story 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 Sandra', who died at the age of 32, the three sisters visited the charity's newly established research centre and the memorial wall. The article concludes by saying:

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

The importance of these published testimonies to those who fundraised for the organisation was demonstrated in the way one group of women I met talked about how much they enjoyed the personal narratives in this section of the charity's monthly newsletter. They commented that these were 'the kind of stories that are great for the charity, but they are also the sort of ones that we want to see in Woman magazine and Cosmopolitan'. Such remarks reflect 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, 'positively' transformed or been themselves changed by this experience. 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.

Personal narrative and testimony are clearly powerful in this context. It seems that this is something that has easily and usefully been adopted as a tool of shared identification and awareness-raising by breast cancer activist groups, following its use in the context of feminist identity politics in the late 1970s and 1980s (Kaufert 1998). It continues to be a powerful, yet complex tool of 'female empowerment' across a range of different health care arenas (Taylor 1996). In the testimonies explored here and the symbiotic relationship between those published by the organisation and those recounted by supporters, it is possible to see how this device helps to facilitate the public witnessing of loss and suffering. In this context published testimonies and narrative accounts are very much part of 'the looping' mechanism by which the identity of activists as fundraisers become reproduced.

In their examination of what they term 'biological citizenship', Novas as Rose suggest that in relation to these new modes of activism and identification, 'claims' are being made 'in terms of the vital damage and suffering of individuals and groups and their vital rights as citizens' (2005; see also Petryna 2002). The kinds of activism at stake in fundraising for a breast cancer research charity, through what might be described as the work of memorialisation, suggests that a carefully contextualised approach is required in understanding the specific sorts of biological citizenship being mobilised in particular social arenas. In this instance it must include understanding how the 'proxy' suffering of those affected, if not afflicted, by breast cancer powerfully connects an articulation of individual and collective identities to the pursuit of scientific research.

Yet at the same time, this particular manifestation of breast cancer activism also cannot be separated from its institutional embeddedness in the UK's long-standing culture of charitable fundraising for cancer research, it must additionally be understood in relation to particular gendered articulations of citizenship. Berlant argues that different spheres of public life, the intimate, private or even sentimental are being increasingly and powerfully utilised across a wide range of institutional arenas, especially where issues of identity, civic participation and belonging are at stake (1998).[3] As a number of commentators suggest, it is a process of what might be seen as 'feminisation', that resonates diversely yet strongly in relation to a growing culture of breast cancer activism (Klawiter 2004; Kolker 2004). In the practices examined here, it is made manifest in the way female nurturance, expressed in terms of remembrance or hopes for past and future (mostly) female relatives, is linked both individually and collectively to the work of fundraising as memorialisation.

Genes and the fundraisers 'quest'

Examining the use of published testimony and personal narratives of involvement, it's clear that fundraising is also a means of 'transcending' suffering, focused as it is on the future, a younger generation or life 'after' breast cancer. As an editorial in one newsletter put it, the work of the charity is about 'turning the devastation caused by breast cancer into hope for the future'. The location of the memorial wall at the entrance to the research centre gives some clue as to the object of this necessarily transformatory work. In fact the alchemy of loss and hope embedded in fundraising as a 'memorial practice' is informed by,

whilst also having consequences for, the pursuit of basic science genetic research being pursued in this setting.

'Knowledge' not just information

A desire to 'know' about breast cancer research was evident in talking to a number of women who supported the charity through fundraising. They described how they consulted numerous different resources in an effort as one woman put it, '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 about the importance of keeping up to date with the work of the charity indicated:

> Betty: oh definitely 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 involved in a charity

However, it was not simply that most of this group of supporters wanted more information about the research being carried out, 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 organisation should be supporting. This was brought sharply into focus in terms of one woman's response to the possibility, suggested by

another participant in a focus group, that they 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.

Others I met concurred with this. One woman said that the research should be about 'stopping it in the first place not messing around with treatment', while another added that the charity 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 fundraisers' feelings about this: the annual rally for fundraisers in June 2000 when about 40 key supporters from across the UK came together for a few days. It was an event which I also attended and recount in some detail below, as it starkly illustrated how investment in research was linked to the act of fundraising.

The place for this meeting, 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 to thank fundraisers and give them renewed enthusiasm for future money-generating ventures. Talking to several women informally in the evening, before the day's main events, highlighted the extent to which the research activities of the charity 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. The rest of the day's activities focused first on the use of publicity to raise awareness, followed by a somewhat less inspiring workshop session concerning health and safety issues during fundraising events. What appeared to be required at the end of the weekend was a rallying and resounding endorsement about the research being funded by the organisation. The closing speech of the day, billed as the 'Past and Future of Breast Cancer Research' and recounted in my field notes below, at the very least, held out this promise:

> The talk starts with an explanation about how the research strategy of the centre 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. He plots what seems like a linear historical trajectory. This includes earlier notions that breast cancer is caused by 'black bile in the body' to the idea that breast cancer is a 'local disease' that has to be 'cut out'. At this point, however, 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 cells and genes'. But on reaching the end of his presentation, instead of expanding on the kind of results that such research will generate, he poses a more cautionary rhetorical question and answer saying; '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 a brief and fleeting single slide outlining the main projects being funded.

In the weeks and months following this event many of the fundraisers, who had been at this rally, felt the (unprompted) need to comment on this talk in my meetings with them in discussing their hopes and expectations for the research they were helping to fund. One woman who lived in Lancashire described how she and her friend, who had made the trip to the meeting, had felt somewhat let down by this event.

Pat: We would have liked a lot more about the research and what was going on, not just say the health and safety aspects which we were all fully aware of! Yes we will raise your funds . . . 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 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: It 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 and 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 dimension of the talk, which some fundraisers had found more than just disappointing:

> I didn't necessarily want to hear about history of surgery . . . I thought it was a bit insensitive as well, all those mastectomies for any ladies that had had surgery recently . . . and we didn't hear what was going on now and the year before it had all been so enthusiastic.

As these responses demonstrate 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 or trauma associated with breast cancer, the attempt to draw a dramatic contrast between relatively crude medical interventions of the past and the precision of current research, did little to facilitate or fuel this mode of identification. If the somewhat ill-judged inclusion about the history of breast cancer treatment was difficult for a few fundraisers, it was the general lack of upbeat information or discussion of the research work that most found disappointing. The fundraisers' responses to the rally illustrated therefore not only a collective desire for 'knowledge' but the need for the research that they helped fund to be somewhat promissory. Nevertheless more detailed discussion with fundraisers revealed how, although for very many basic science *genetic* research did occupy this hope-filled space, and thereby help to fuel collective expectations about the use and value of this research, for others it was a scientific focus which also raised or provoked questions and concerns.

The promise (and problems) of genetics

For many a need for a particular kind of hope-filled 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'. These sentiments mirrored the way that genetic research was framed in publicity material associated with the organisation; that is in terms of a 'success' story. This was

particularly so in its formative years, as I explore in Chapter 6, where hype and hope about basic science research was entangled with the discovery and clinical application of BRCA genetics and imminent announcements of the Human Genome Project.

Faith in the research work of the charity was strongly upheld by many of those who supported and raised funds for the charity. This was reflected in the way one woman talked about the genetic research in terms of dealing with some of the 'known' causes of breast cancer, even when she did not see such research as directly explaining or intervening in the health of her own family:

> Jackie: I would hope that by identifying a gene 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. . . . 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 [my emphasis]

Although for Jackie, genes did not provide an obvious answer in understanding the breast cancers that had affected her family, she was still 'excited' by this research which in focusing on a 'known' risk factor held out the hope of future treatment intervention. For some however it was precisely the fact that there was a *clinical* application associated with the BRCA genes which fuelled a feeling of hope and faith in the research work of the organisation. In fact there was often a productive slippage in the narratives of those I met between the activities of memorialisation for future generations through fundraising, a sense of faith in scientific knowledge or research as a means of 'cure' or 'prevention' of the disease and the value of predictive knowledge associated with genetic testing for the BRCA genes. This was reflected in what one woman said during a focus group discussion when asked about what she thought of the organisation'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 organisation could be associated with and translated into an identifiable clinical realm meant that, at least for some, the science they helped fund could be easily linked to a promissory future where foreknowledge was constituted as preventative care. For fundraisers, like patients attending the cancer genetic clinics, pursuing genetic research and caring for future generations were closely related. This was perhaps not surprising given that many who supported the charity often became involved in the work of fundraising after a relative had contracted the disease. Nevertheless these productive slippages, reflected in narrative comments such as the ones above, do provide some illustration of how investment and attachment to genetic knowledge can become mobilised through the relatively more diffuse 'bio socialities' associated with the BRCA genes.

But this flexible, yet powerful bio-social intersection, could also raise more troubling concerns. For other fundraisers, it was precisely the link between the charity's research focus and clinical intervention associated with the BRCA genes, that caused them to express some concerns about this research focus. A sense of hesitancy which was apparent, in this woman's comments:

> 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 therefore clinical applications, such as genetic testing associated with BRCA genetics, raised many questions and potential anxieties. As one fundraiser 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'.

Others articulated their concerns about a focus on genetic research in a different way. For instance, one woman talked about what she saw as the potential 'narrowness' of this work and the need to balance and expand an agenda for research. In her early 50s, and having just finished her treatment for breast cancer, she had only recently become active in the political lobbying work of the organisation. I met her initially at the Fundraisers' Rally, where she made clear her wish to bring a different agenda for research to the fore. 'New drugs', she pointed out, 'should also be a big issue for research'. But it was during a later interview with

her that these concerns became more clearly defined, when she talked about how following her diagnosis of breast cancer she had become very interested in research:

> Janet: 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 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! . . . [. . .] I would be very interested to know how, if the charity get involved with [other]risk factors. Having had breast cancer myself, this is obviously something I am very interested in. 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.

Concerns about what seemed like a narrow focus on genetics 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 provoking an interest in other areas of scientific inquiry. This gave her a strong interest in different avenues for scientific research.

Another woman, reflecting on the varied ways that the organisation's focus on genetic factors were interpreted by the supporters of the charity, pointed out that this might be difficult for some, particularly those currently suffering from breast cancer:

> Pauline: obviously they want answers but for them the answers can't be 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 would you? It will be the families that might ask the questions, rather than the people that are sick.

She implied therefore that it was the 'relatives' of those who had had or died from breast cancer who might be more interested and perhaps supportive of the genetic research associated with the BRCA genes. This was the group of persons who constituted, as we have seen, the vast majority of the organisations' supporters. Nevertheless despite a sense of disquiet from some fundraisers, for the majority of those I met, there

was a dominant sense of 'faith' that overrode anxiety about research focussing mainly on genes. This was a field of inquiry which, as one fundraiser pointed out, lines could be drawn:

> Mildred: 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

A widespread desire and demand for 'knowledge' is met therefore for the majority of fundraisers, through the gene research work of the organisation, which is generally perceived in terms of working towards a 'cure' for breast cancer. Although some did have concerns about the narrow specificity of this work, many clearly invested and perceived the 'science' the organisation funds within a domain of expertise and skilled practice, which was linked to a more hopeful future.

Exploring the dynamics between novel genetic knowledge of breast cancer and gendered health care activism in the particular institutionalised arena of a breast cancer research charity, this chapter has examined how a group of individuals classified as fundraisers identify with the organisation, their role in it and the work it funds. The evidence presented here suggests that it is a form of 'activism' in which gender, citizenship, genes and science are strongly, yet complexly aligned.

The involvement of fundraisers' has been shown to be part of a collective narrative and shared identification in which the need to remember and witness the loss of loved ones is accompanied, through investment in the research work of the charity, by a transformation of that experience into a sense of positive hope and faith in the future. These identifications are also sustained and reproduced in the way the organisation itself makes use of published testimony and mobilises a particular image of female gender identity. In this context loss, trauma, hope or faith become instrumental too and themselves effects and products of the practices that are 'making up' persons as fundraisers, supporters and variously constituted activists. At the same time the power of these modes of identification can also not be abstracted from wider shifts and changes in the way breast cancer activism is altering the public profile of the disease (Klawiter 2004; Blackstone 2004) and the

increasing 'corporatisation' or 'branding' of breast cancer that is taking place across a wide range of institutional practices (King 2001).

For many, the charity's work looking at basic science research and the so-called '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 many, but not all fundraisers, genes are at the forefront of this elusive quest; material manifestations of scientific 'knowledge' which powerfully fuel collective action. In the distributed, yet powerful biosocialities at work in the charity, gene focused science connects issues which are qualitatively different in scale and scope. Here the much hoped for 'alchemy' of scientific research links the transformation of personal lives with an expected transformation in the treatment of breast cancer. This is symbolised for many fundraisers in the way they talk about their experience of visiting the research centre for the first time and particularly in seeing 'the names on the wall' at the entrance to the labs. One woman's description of this moment seemed to reflect this process, in witnessing the conjunction between her own very personal act of remembrance and the work being undertaken in the laboratory she had helped to establish through fundraising:

> 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.

Here 'awe' appears to simultaneously connect memory, trauma or loss and the pursuit of science. It reflects the way the wall, located at the entrance to the research centre, is a focus for these powerful conjunctions; a kind of memorial to and monument for the witnessing of loss, the pursuit of science *and* the hopes of the living. Some parallels might be drawn here with the construction of war memorials. As Rowlands points out, the visual and physical symbolism of these kinds of monuments and memorials often have to balance recognition of the 'sacrifice' made by the dead with providing a way out of 'melancholia' for the living (1999). In other words 'the transformation of a sense of trauma and loss into an object of passion and devotion' must be achieved through the 'collective validation of a higher positive ideal' (Rowlands 1999: 144).

While for some, a focus on basic science genetic research fulfils this ideal, providing a powerful motivation or a rationale for involvement in the charity, for others the quest to sustain fundraising as memorialisation

is not so readily or easily aligned with what seems like a narrow focus on genetic research. For a minority of persons with breast cancer or those who had recently finished their treatment, fundraising intentions can be differently constructed.[4] As a result, for some, the focus on basic science research (which includes work on the BRCA genes) is potentially more troubling in its apparent narrowness or lengthy timescale. This is especially so when there is an urgency regarding treatment and/or a need to think about a broader or different range of 'preventative' interventions. Although these stratified responses point to the diverse ways that those who support the charity position themselves and their responses to its research work, there is nevertheless a widely shared hope-filled and faith-infused investment in the scientific research being undertaken by the organisation. It is a measure of support which also cannot be abstracted from the widespread respect and trust garnered by and bestowed upon the institutional culture of charitably funded cancer research in the UK (Austoker 1988).

Examining the specific social dynamics of the same cancer research charity, the next two chapters demonstrate how the demand for science as knowledge, situated here in relation to gendered forms of health activism and the pursuit of genetic science, does in fact reverberate through the organisation in uneasy ways. We see how this has consequences for the articulation and representation of 'pre' and 'post' genomic science, advocacy, ethics and the experience of being a scientist in a breast cancer research charity.

6

Between Geno-hype and the Post-Genomic: The Management of Science and Ethics

An organisation funded in the name of mothers, sisters and daughters and dedicated to fighting breast cancer by focusing on the microbiology of the breast, appears to powerfully align the witnessing of loss and the value of female nurturance with a hunt for, what is seen by many who support the charity, in terms of a 'cure' for breast cancer. This chapter moves beyond an exclusive focus on the particular character of this form of activism, to examine how sustaining and reproducing this in relation to a programme of molecular focussed research has been managed in the public discourse and practice of the charity. It examines how during a particular de-limited time frame, a hopeful, yet high risk field of science inquiry was communicated, disseminated and promoted to those who supported the charity and a wider public.

Franklin and Lock point out how examining the 'promissory work' surrounding novel fields of scientific research is an important part of social science engagement with these developments, because they say 'at risk in an effort to separate reality from hype are all the dense reciprocities and economies of co-production through which they emerge and perform in tandem' (2003: 15). Focusing on publicity material in the charity's newsletters and other campaigning leaflets, this chapter examines the 'representational politics' (Epstein 2003) that characterised a shifting temporal terrain from the mid-1990s to the period following the announcement of the first draft of the human genome in the year 2000. It is a period which is now described by some in terms of 'pre' and 'post' genomic eras. The final sections of this chapter examine how these representational practices have become linked to, what might be seen in terms of, articulating emergent 'ethical' spaces. Mobilising ethics is, as others have pointed out, an increasingly prominent and instrumental feature of recent developments in the

life sciences (Rabinow 1999; Hoeyer 2001; Hayden 2003). When the quest for genes that linked research focusing on the basic science of BRCA genes to large international projects, in the earlier years of the organisation, have begun to be replaced by the messier business of functional genomics and epi-genetics, these are practices which seem particularly important. Nevertheless deploying ethics in an attempt to ameliorate the challenge of post-genomic knowledge has its own repercussions, made operational in a dynamic public/science interface, that is itself fluid and shifting.

The balancing act of BRCA genes

Despite a distortion of the actual doing of science, Brown *et al*. point out that ideas about a 'promissory future' have become inimical with the public discourse around genetic science, where the 'breakthrough' motif has itself become 'ubiquitous' (2000; see also Bubela and Caulfield 2004). Like other media but also scientific and social science discourse at this time, what might be termed 'genohype' was a readily identifiable element in the publicity literature of the charity in the mid- or late 1990s, 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. However, a changed and changing mode for representing genetic knowledge could be discerned in the same material in the months and years immediately surrounding and following these events. The representational and discursive challenge of communicating genetic science to fundraising publics are explored here by juxtaposing close analysis of publicity material alongside discussions and interviews undertaken at this time with a number of those who worked in the organisation.

Hype and the human genome project

The genetic focus of the research was strongly emphasised in some of the first publications to explain and outline the projects being undertaken in 1996/97, two years after the BRCA genes had been identified. The importance of 'basic' science was illustrated in an excerpt from a 'fact sheet' about some of the projects being 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 . . . In the last two years this has resulted in the identification

> of 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.

At the same time that breast cancer was often described in this literature as a 'multi-factorial disease', it was nevertheless the role of genetic research which was consistently highlighted. The importance of genes both known and yet to be discovered was highlighted in another article published in a newsletter for supporters at this time, constructed as an interview with a researcher at the centre:

> Scientist: We have to focus on the topics which appear to be the most relevant [. . .] For instance we now know that approximately 10 per cent of breast cancers are due to the 2 abnormal genes that are inherited BRCA1 and BRCA2 . . . [. . .]
>
> the discovery of BRCA1 and BRCA2 has been the most important step forward since Tamoxifen was first used in clinical trials in 1971. 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 per cent of cases that are not due to inherited factors.

The reference to the recent discovery of the two BRCA genes was a development which, as Henderson and Kitzinger have pointed out (1999), had received a significant amount of attention in the popular and broad sheet media at this time. Of interest here, however, is the way that BRCA genes and other possible but unknown *genetic* factors are singled out as being the most 'relevant' aspects or the most significant 'step forward' in breast cancer research; a description which shows how the feasibility of gene research was being reproduced and sustained at this time. It was an emphasis that was reinforced by firmly linking the *discovery* of the BRCA genes to the organisation. This was less vocally expressed in the wake of public concerns, that arose in later years, around the ownership and patenting of genes. But, as an excerpt from a different article written to profile the new research director in a newsletter demonstrates, discussion of genetic research was also linked to a much larger high profile project:

> 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 work in 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 the genes in the human body' provided an opportunity to link the research focus of the charity with a much larger 'international' initiative. This seemed to both further the authority and legitimacy of its own research focus and enable a certain degree of 'hype' to be incorporated into the discussion of this arena of scientific investigation.

Van Dijck (1998) and others (Nelkin and Lindee 1995) have examined how a 'genetic imaginary' is an important tool in the public presentation of genomic and genetic research. A rhetorical discourse of 'potentiality' (Ganchoff 2004) was clearly evident in the examples discussed here, where genes and genetic research are embedded within a story of technological expertise and impending or soon to be realised transformatory knowledge. This upbeat presentation promised and implied fulfilment of expected and anticipated authoritative medical knowledge, fuelling, sustaining and reproducing the activities of fundraising as memorialisation that were embedded in the founding ethos and growing success of the charity.

During the initial stages of my fieldwork in early 1999, this vision of the future seemed to be shared in the way at least some of those, who worked for the organisation at the charity's administrative offices, also talked about the research that was being funded. This was exemplified in the way that a member of the research services team talked to me about the 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 the 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 suggested that the genetic research focus of the charity was perceived as part of a rational and linear 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 organisation, this upbeat linear narrative seemed to belie her and others' concerns about the genetic focus of the charity. This was also a time of new 'discoveries' in genome science which, rather than providing more concrete answers, raised further questions about the current value of genetic knowledge and information, with implications for the public representation of genetic research.

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 announcement of the first draft sequence of the 'Human Genome' in June 2000. For instance this news was accompanied by the finding that there were far fewer genes in the human body than were originally thought and a more vocal acknowledgement that translating this knowledge into useful and viable health care interventions was likely to be a much more time-consuming and complex problem.[1] The way the charity publicly responded to this emerging 'post-genomic' context is examined in relation to two leading articles published in the newsletter several months following these developments.

The first article was written to coincide with the opening of the research centre at this time, profiling the 'vision' of the work that was to be undertaken there by interviewing a leading scientist from the centre. 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 in the publicity literature.

> Interviewer: Does this mean that if genes are involved in breast cancer, all breast cancers are inherited?
>
> Scientist: No, only around 5 per cent of all breast cancers are hereditary [. . .] mutated genes in the other 95 per cent 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. At the moment we only know how a few of the engine's components work.
>
> Interviewer: When will we see results from the research?

> Scientist: 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.

The second article produced a year later 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.

As well as maintaining a sense of potential about gene research, both these articles contained elements which hinted at a more cautionary message about the scope of this work, particularly in relation to the time lag between the discovery of genes and their clinical application. Notably the use of notions such as 'responsible' and 'cause' to describe the action of hereditary breast cancer genes was now no longer widespread, replaced by the notion of genes as being 'linked' to the disease; a description with a less obvious linear association.

Informal conversations and interviews with staff at the charity undertaken six months after starting my fieldwork, 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 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. 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 a 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 in the summer of 2000. As explored in the previous chapter, the talk by a member of the charity's staff generated disappointment and frustration among some of the fundraisers precisely because so little had been said about the current research or more importantly its future potential. Talking to the person who had given this talk, several months later, I asked him about his presentation and his decision to demonstrate how translating breast cancer research into effective or safe health care interventions was complex and lengthy. Initially surprised by my question he said:

> 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.[2] 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.

He conceded therefore that the decision to structure his talk in this way was, in some respects, part of broader effort to address heightened expectations about the scope of genetic science. However, not all who worked within the charity were convinced that this was a good strategy. On hearing this talk, mainly from the way fundraisers had expressed their disappointment, another member of the research services team expressed her concerns. She pointed out that this kind of strategy might itself be risky, particularly when there was a need to square the real timescale of genetic research with meeting the expectation and hopes of fundraisers.

Displacing contingency; bringing treatments in (and out) of focus

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 shift in representational practices at this time. This was illustrated in the appearance of certain slogans in the publicity literature. This included an emphasis on the science undertaken being orientated towards a 'bench to bedside' or a 'micro-macro' approach; 'micro' meaning the molecular biology of breast cells and 'macro' meaning collaboration with clinicians to improve the way in which breast cancer is diagnosed. The emphasis was squarely on ensuring that, as the charity's publicity literature put it 'new findings are used for the benefit of people with experience of breast cancer'. In sum, at this juncture discussion of a clinical endpoint to the research being undertaken became a much more consistent feature of the publicity literature. Alongside a message which implied the timescale for the fruits of genetic research was likely to be long there was also therefore a message about its likely clinical application; narratives which pulled somewhat in tension with and against one another.

Nonetheless, the parameters of the 'clinical interface' being articulated in this context was circumscribed in very specific ways. For example, although the discovery of the BRCA genes was highlighted and also promoted a few years earlier, it was not until 2001 that the *current* application of this genetic knowledge, predictive genetic testing, was talked about in any great detail. Up until that point, there was what appeared to be something of marked silence in the publicity literature about this kind of intervention; a procedure which had been associated

with the discovery of the BRCA genes.[3] For instance, in an article 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. Perhaps more strikingly there was also an elision of one treatment intervention prophylactic mastectomy, that could be offered to women at genetic risk of breast cancer.

In contrast to huge numbers of articles in the popular press and women's magazines that appeared during the time of my research about 'genetic risk', particularly during Breast Cancer Awareness Month, the charity chose, for the most part, not to publicly discuss the issue of prophylactic surgeries; the so-called 'preventative' interventions available for those at high risk because of their family history or where a BRCA mutation had been positively identified.[4] 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.

The issue of prophylactic surgeries not only highlighted the lack of proven 'treatment' available to those at genetically high risk of the disease identified but, as a medical intervention directly linked to knowing about genes, it was a procedure that also perhaps threatened an image of genetic research as a symbol of hope for the future. As Saywell *et al*. point out, it is because the breast is an iconic 'image of idealized femininity' that the 'asymmetry of mastectomy or lumpectomy' represents 'an assault on beauty and perceptions of normality' (2000: 43). When 'normative' gendered representations of young, healthy and female bodies become the dominant image in a particular arena of breast cancer activism, re-inforcing a message that, as one article put it, 'the breast is about who you are as a woman . . . sexual, maternal and nurturing', it is perhaps not surprising that discussion of prophylactic surgeries in currently *healthy* women might be a somewhat problematic issue.

Some indication of these challenges was confirmed in discussions and interviews I undertook with those whose job was to manage, through publicity material, the communication of the research being undertaken by the charity. For instance, Helen, who was directly involved in writing the copy for publications such as the newsletter, talked about how the

media tended to focus on some aspects of recent developments in genetics, as apposed to others:

> Helen: the whole family history thing has just been so overplayed. It really all needs to go the other way. It seems 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 large area with such huge implications.

The importance of situating genetic research beyond a narrow focus on certain aspects of BRCA genetics, while also building real and rhetorical bridges between the research work of the charity and a clinical interface, was apparent in the way Helen talked about a new piece of publicity material she had been involved in.

> We've been working on a more up-to-date version of the research centre brochure. 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.

If it was important to situate the research work of the charity in a broader frame of reference, beyond the media fascination with 'predictive' genetic techniques such as genetic testing and/or drastic interventions such as prophylactic mastectomy, one particular 'treatment', a drug for those with breast cancer, received much more attention in the publicity material of the organisation. From 1999 to 2001 the drug 'Herceptin', one of the first drugs to be derived from molecular-based knowledge of breast cancer, was mentioned in six different articles in a range of newsletters.[5] Three of these referred to the fact that the organisation had made recommendations to The National Institute for Clinical Excellence (NICE) to support the licensing of the drug. Talked about in the popular press in terms of a 'vaccine' for breast cancer, the charity acknowledged that the story was 'a little more complex' than this, pointing out in one article how it was only suitable for only around 30 per cent of women with breast cancer.

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 talked with one person about how this drug was being discussed and he concurred 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, as he pointed out;

> 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 . . . also you have to remember the time lag between the actually discovery of the 'Her2' protein and the making of a therapeutic agent that actually works. . . . 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 part of the campaigning issues we are doing because we see that as a *responsibility* to deal with that end of it as well. [my emphasis]

His comments suggest that the cost, as well as the timescale, of treatment derived from molecular knowledge drew attention to the potentially problematic aspects of pursuing gene research. These challenges may actually have made it especially important, as his comments implicitly suggested, to publicly support the licensing of the drug in the UK when clear evidence for the treatment benefits of a molecular approach to breast cancer research were in short supply.

Analysis of publications such as the newsletter demonstrate the extent to which 'talking up' genetic research, in earlier publications, has subsequently been accompanied by a more difficult and necessary precautionary approach; a practice which mirrors the necessary 'code-switching' undertaken by practitioners in the cancer genetic clinic. In both cases a growing awareness of the complexity of the relation between genetic research and clinical outcome, necessitated a delicate management

of the hype, hope and expectations associated with predictive knowledge and/or genetic research. In the charity the efforts to define a post-genomic context for gene research was evident in the changed content, tone and phrasing of certain publications, as well as the comments and concerns of staff working within the organisation. Certain omissions and silences make clear the dangers associated with articulating too clearly the current clinical application of BRCA genetics. At the same time, another drug treatment for those with breast cancer, Herceptin, provides a valuable example of the future application of yet to be discovered molecular knowledge.

Publicly lobbying for the licensing of drugs such as Herceptin also made social and ethical issues, in this case supporting the needs of breast cancer 'patients', a more explicit part of charity's work. This was a context for situating genetic research which was in fact being shaped and articulated, within the charity at this time, in a number of diverse ways.

Situating ethics; accountability, legitimacy and advocacy

According to Irwin, ideas and practices associated with 'the social' or those which might be defined as 'ethical' are part of a newly evolving paradigm in the governance of 'science' in the UK and Europe (2002). Others have been more explicit in identifying ethics and developments in the life and biological science as increasingly co-determined aspects of each other, where being 'socially robust' becomes an important criterion for success in scientific research (Nowotny *et al*. 2001). The second part of this chapter explores the politics, production, as well as the consumption, of some of these new agendas for accountability and legitimacy, in the context of a charity pursuing basic science research which includes work on the BRCA genes. It examines how particular ethical and social concerns were increasingly being made explicit and incorporated, the kind of legitimacies being sought in this process and the 'double binds' (Fortun 2001) this often also entailed. As Fisher points out, there is a need for studies that 'engage science as domains in which ethics are worked out' not in order to 'dismiss false claims but to understand the different kinds of functionalities that [these] claims help constitute' (2005: 379).

Gene patents

The involvement of certain scientists at the research centre in the work leading to the identification of the BRCA2 gene in the mid-1990s was something that as I've already suggested was publicly celebrated in the formative years of the organisation. However, in the immediate months

leading up to the announcement of the first draft sequence of the 'Human Genome' in June 2000, and particularly following this event, the question around the 'ownership' of genetic knowledge became an increasingly more visible dimension of media discussion about these developments. Stories abounded concerning the so-called 'competition' between different 'public' and 'private' ventures to complete this project, with rhetoric about 'patents' on 'life' much in evidence. These issues were directly related to the claims being made by an American bio-tech company, Myriad Genetics, on the patenting rights for the BRCA genes over the claims of others. This included another cancer research charity in the UK which also claimed to have 'discovered' the gene.[6]

The problems this posed for the charity in question were indicated by an informal conversation I had with a member of the research services team a few months before. Returning from a meeting with other members of this group, Susan was agitated and also animated in relation to the fact that the issue about patents was, as she said, 'about to be blown sky high'. The problem was, she explained, that the charity had not yet developed a public policy stance on these development, adding that 'I can't begin to think about how we could discuss this issue in the newsletter, it's so vast'. When the work of the charity was very much associated with science as 'hope for the future', the patenting of genes forced an engagement with complex issues of ownership, commerce and control, in relation to scientific knowledge and technology. In the words of one MP, in a parliamentary debate about gene patents at this time, gene patents were 'the dark horses of the genetics revolution' (Hansard Papers Jan 2000). The existence of patented genes therefore constituted a somewhat challenging topic for the charity. It was an issue that focused attention on questions of ownership and control of scientific knowledge, or what has been described in terms of the 'politics of disenchantment' (Strathern 2001).

Over the course of the next few months, gene patenting became an increasingly central topic of public and media debate. 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, a stance on patenting was made more public during a TV news studio debate about this issue (Channel 4 News July 2000). 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 enabled companies to 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 government should also '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 who were likely to fund and help realise the treatment goals of genetic research. Nevertheless, given the public and media debate about patents 'on life', it was clearly also important to align genetic research within an ethical domain by supporting concerns, expressed by representatives of the NHS, that patenting claims would compromise 'patient' care. The locus of these concerns focused in relation to a particular ethical 'community', constituted here in terms of 'patients', was further re-inforced in the public response to another issue where ethics and scientific knowledge were also being co-produced.[7]

Genetic testing and insurance

The use of genetic test results to help establish the level of premiums for life and health insurance was a debate that increasingly became the focus of much media and public discussion, in the wake of high profile announcements around developments in genetic knowledge and technology at this time.[8] Guidelines issued by the Association of British Insurers (ABI) had undergone a series of permutations in the preceding years. A three-year moratorium on the use of genetic testing was issued in 1997, but in 1999, the ABI ruled, somewhat prematurely as it turned out, that predictive tests could be used for a limited number of conditions, which included breast cancer, before the Genetics Advisory Insurance Committee (GAIC), 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 public 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 Genetics Commission to launch a public debate about the use of genetic testing information.

> 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 are deterred from being tested for fear of unfair discrimination in obtaining insurance or employment.

The 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 on 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 on this issue within the charity signalled therefore a new zone of activity, where explicitly addressing the 'social and ethical' impact of genetic knowledge became instrumentalised. The reasons for this emerged during an interview with one of the research services team a few months before, when one of its members talked about how the charity might begin to address this question, and the complex set of issues that informed this decision.

> 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 . . . [that] 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 a prophylactic mastectomy and there is some evidence that this 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. I mean we are a medical research charity right now, but we have been involved in

> campaigning, helping patients and lobbying governments and maybe even more so in the future. [So] does the charity want to deal with the social implications of the research that it funds?

His comments suggested that the rationale behind the decision to oppose the use of genetic tests for insurance purposes was caught up in a variety of issues and concerns. This included a real sense that the 'social' consequences of genetic testing were being neglected by key parties in this debate. But, from what this person said, it was also tied to an acknowledgment that the organisation 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 medical research charity. Henry was clearly aware of the complex consequences of embracing this agenda in the public presentation of gene research, as he pointed out:

> 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.

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, were now brought centre stage. The limited predictive value of genetic testing was now, as a result, at the forefront of an effort to demonstrate how inappropriate the use of such tests was 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 the entanglements and entailments sustained by publicly opposing the use of genetic information for insurance purposes 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 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 research 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 which involved treading something of a fine line. Embracing 'ethics' meant focusing on a fairly narrowly defined community of 'at-risk' persons. At the same time it meant being much more explicit about the limited utility of current genetic knowledge both for these persons and a wider community. In the case of patenting and insurance, something of a trade-off was undertaken between a hyped and hopeful image of genetic science and raising concerns about the negative social or ethical impact of such knowledge. The former currently met the expectations of most fundraisers. Although the latter made issues about patient 'care' more tangible in relation to the research work of the charity, given supporters' desire for the science they funded to be 'redemptory', it was potentially a somewhat delicate and difficult shift of focus.

Developing lay expertise and advocacy

But there was also another attempt at this time to articulate and form an ethical space in relation to the genetic research undertaken by the charity. The 'supporter advocacy project', as it was first known, was initially a research project to investigate the possibility of incorporating fundraisers more directly in the organisation and the work that it did through the developments of what has been called 'lay expertise'.

It has been suggested that inclusionary initiatives have become a key feature of neo-liberal governance over the last five years, associated with the need for accountability in different institutional arenas (Strathern 2000; Irwin 2002). In the field of health care, notions of 'the patients charter' and the 'expert patient' have become obligatory ethical passage points for new and emerging health care policy (Newman 2001; Daly 2003). Others have raised questions about the moves to take account of 'stakeholders views' as a gold standard for organisational and institutional practice, asking if policies of deliberative democracy are a

cause for celebration or are rather part of a process of co-option and hence dilute more radicalising agendas (Epstein 2003). Whatever the particular locus of agency at stake in these processes they are, like the incitements to 'give back' that Cori Hayden's work explores, not just 'channels' for democratising initiatives but actively 'construct and give shape' to these practices in unexpected and not always enabling ways (2003). The moves to address and possibly implement 'supporter advocacy' had and continues to have a very particular meaning in relation to an institution which is part of a broader culture of charitably funded cancer research, but where there is also a unique conjunction between 'grassroots' fundraising as a form of gendered 'activism', fuelled and formed by and through the pursuit of basic science research.

The complex questions that advocacy raised were apparent when I met several members of the research services team in the charity during the initial stages of my investigations. One person was uncertain about exactly how advocacy would work in practice, as well as its value, stating that he was not sure 'how people could talk to scientists about molecular biology'. It was a question which prompted another participant to talk about the history of the charity and why this made it an 'ethically' important yet also a somewhat challenging undertaking:

> 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 . . . 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 people perhaps requires a unique approach that hasn't been done before. If we ignore supporters' views about the research, we do so at our peril.

This response pointed to the necessity *and* problematic task of undertaking advocacy in this context. But there were also different reasons for this policy. From talking with others who worked in communicating the research to fundraisers and supporters, there was an implicit sense that such an initiative would actually help in the challenges posed in pursuing long-term, complex and currently contingent genetic research; described by some as 'high risk/high return' domain. In this sense, implementing supporter advocacy was not only about being seen to

be 'ethical' but also about finding possible solutions to funding and communicating complex and long-term genetic research.

The initial 'in-house' report was fairly positive about how fundraisers had responded to the possibility of lay advocacy.[9] However, a much fuller understanding of the significance of the data was gained after further analysis, which revealed a more complex and ambivalent picture.

It is true to say that there were a few supporters of the charity who were enthusiastic about the idea of becoming more involved in the research work of the organisation, particularly from those who had had breast cancer. However, even for these individuals, this was undercut by a sense of hesitancy, as one woman's comments illustrated:

> 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.

A different fundraiser who had expressed enthusiasm initially about the idea conveyed her concerns about the effects of 'lay' involvement pointing out that 'I think if you open it out too wide there is a danger the research will not be as concentrated'. Equally 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 professional people, so we just do what we can.' In these cases, the strength of an identification with being a 'fundraiser' seemed to preclude discussion of any other role, particularly one that was it seemed 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. This was illustrated by an excerpt from an interview with one woman, who was particularly vociferous in her response to my queries about the possibility of developing advocacy in the organisation:

> 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.

This and other equally 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 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. Such reactions chime with the work of others who demonstrate how responses to the development of lay expertise or advocacy are directly linked to pre-existing perceptions of organisational roles and identities. That is self-identified 'activists' tend to think of themselves as knowledge 'producers' and 'volunteers' tend to think of themselves as knowledge 'consumers' (Eliasoph 1998).

The ambivalence expressed by some fundraisers was also echoed in the way both staff and a number of scientists reacted to this initiative. Although there was widespread recognition by many, 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. For example, discussing how different research programmes in the US had sought to involve 'lay' people, namely patients, in relation to the design of clinical trials, one staff member pointed out the difficulties of imagining how this might work in relation to the charity: '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 both the necessity and problems of supporter advocacy which was also recognised by Helen, a member of the communications team within the organisation. She initially responded positively but on reflection was not so sure it would be that helpful in relation to the charity's work:

> Yes 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 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 be linked to ethical legitimacy and accountability, providing 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 threatened how supporters and fundraisers identified with and perceived the organisation and their role in it. This raised further questions about how the hope-filled expertise associated with genetic research would be maintained.

Defining advocacy as a 'performance of ethics in anticipation of the future', Kim Fortun explores the contradictions at stake in the social dynamics of new inclusionary agendas in a very different cultural arena (2001). Nevertheless tensions and unexpected consequences are also apparent in the development of advocacy explored here. The possible implementation of this policy did recognise and capitalise on the supporters' demand for 'knowledge'. However, it also, at least potentially, redistributed the onus for the reproduction of that expertise away from those and that which had been and continued to be a powerful symbol for fundraisers – 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 as an act of memorialisation. In this sense, it appeared to 'cut' an established 'gift' relationship between lay and expert, which had been so central to the organisation's identity and the fundraiser's pursuit of a 'redemptory' science. Although advocacy offered a possible solution, in terms of facilitating greater understanding, it also threatened to highlight the reality of complex and long-term gene research.

Questions of resistance and empowerment are clearly difficult to disentangle in the pursuit of, and in fundraisers response to, advocacy. We might read their less than enthusiastic support as a lack of radicalism;

a legacy in part of the close alignment between patient organisations and the state in the UK, particularly notable in the context of charitably funded cancer research (see Allsop *et al*. 2004). Nevertheless when accountability and inclusion became a mode of governance across a range of institutional arenas, such that it becomes difficult to discern what is 'co-option' and what is a cause for 'celebration' (Esptein 2003; Hess 2004), sustaining more clear cut boundaries between science and publics might ultimately provide more scope for critique and greater political engagement. Conclusions are perhaps premature in this regard, given that the kind of 'enunciatory community' (Fortun 2001) formed in response to a particular history of gendered health care activism has in many ways yet to be stabilised and the legitimacies at stake in funding long-term and complex research are still evolving.[10]

This chapter has explored the 'multi-representational politics' (Epstein 2003) of pursuing charitably funded basic science research, that includes work on the BRCA genes, by examining the way one organisation manages the public communication and translation of this science. It has shown how in the formative years of the organisation this was mediated by the use of particular message of 'promissory hope' and in highlighting certain areas of clinical application and omitting other aspects. However, there has also been an increasing need to define a 'post-genomic' space, as the timescale of genetic research becomes apparent and the hunt for genes slips into a more contingent and less hype filled arena of epigenetics and functional genomics. Nevertheless, 'hope' is still maintained through a focus on 'treatment', demarcated in ways that encompass 'drugs' derived from molecular-based knowledge, but which include the current clinical application of BRCA genetics. This suggests that maintaining the intersection between gender, activism and memorialisation, that constitute and fuel supporters investment in research, means focusing on future treatments for those with breast cancer, rather than being associated with uncertain interventions for 'healthy' women.

From this perspective it is possible to see that the transmission of genetic knowledge is something of a balancing act which has required a changed and changing set of responses. Yet we have also seen that these organisational and institutional reponses take place in relation to a shape shifting arena of genetic research. In his study of a particular attempt in France 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 the attempt to make explicit, incorporate or build a social and ethical agenda into the charity signals not only a new locus of activity but also feeds into the work of transmission around genetic knowledge, shifting the parameters of this task in ways that are not always comfortable or necessarily enabling.

It is perhaps instructive to again reflect on the challenge of seeking appropriate memorial forms in a broader cultural arena. Contemporary monument making and memorial practice suggest that it is often the presence given to 'absence', through the literal reproduction of the negative space of so-called 'counter-monuments', which most successfully mediates the inevitable tension between memory and forgetting, embedded in the memorial form (Young 1993). In a similar way it may be that it is 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 in a breast cancer research charity, rather than the complexity generated by their actual materialisation.

The next chapter, continuing to track the circuitous routes, gaps and disjunctures that map the social dynamics and spaces of breast cancer genetics, enters an arena normally seen as distanced from the issue of 'social impact'. In exploring the interface between fundraisers and scientists, in relation to particular events within the space of the laboratory, it illustrates how the social and technological are also being collectively cohered in this 'upstream' arena.

7

Scientists and the Making of Genomics as Monuments for the Living

Although the practice of scientists has been central to social studies of science, the experiences, identities and subject positions of scientists themselves has been the subject of far less attention. There has been a tendency, as Traweek notes, to focus on 'agonistic encounters' or present the 'self' only in terms of 'autonomy and initiative', with little sense or understanding of how scientists experience or identify with the worlds in which they work (cited in Martin 1998: 28). Some studies have begun to re-dress this, giving 'voice' to the narrative experience of this group of persons by examining how the 'imaginaries' of scientists are caught up in various arenas of scientific and technological innovation (Traweek 1988; Marcus 1995; Heath 1998).

This avenue of inquiry seems particularly pressing given the rapid and fast-moving science of genetics. Margaret Lock suggests that it is behoven on social scientists to grasp and communicate this new and rapidly changing terrain of genetic science (2005). I would point to a concomitant need for social scientists to engage with this shifting terrain of scientific understanding from the perspective and experience of those science communities, as well as a variety of publics. This seems especially important in the light of a growing demand that scientists and research institutes communicate and work with publics, patients or lay groups. This expanded 'agora' of knowledge/science production (Nowotny *et al*. 2001), conjoined to an 'experimental' arena of molecular research, bring new entanglements to the fore, which raise further questions about the tenability of a discourse of bio-power in relation to developments in the field of genetics (Rabinow 1999). Instead as Kim and Mike Fortun point out, a new set of questions about science as 'civic engagement' must be

posed, in which the 'ethical character of [scientific] subject formation' is central to the analysis (2005).

This chapter provides a window on these shifting public/science dynamics by examining how scientists, who work for a breast cancer research charity, participate and are implicated in the communication and dissemination of emerging genetic science of breast cancer to the those who fund and support this research. Taking the monthly 'laboratory tours' for fundraisers at the recently built research centre as a starting point, this chapter outlines how science was communicated and constituted during these interactional encounters, before reflecting on the consequences for scientists of being part of a collective 'quest' for scientific knowledge.

The 'enchantment' of science: Laboratory tours for fundraisers

The 'lab tours', as they were commonly known, were a regular event at the research centre, during the time of my research with the charity. In general 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 data presented here is based on research undertaken between late 1999 and early 2001, during which I attended eight laboratory tours. It should however be noted that the structure and form of these events is now somewhat differently constituted.[1]

The setting that greets fundraisers when they arrive, normally early on a weekday morning, is an impressive one. An array of high-tech publicity materials 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 memorial wall'. As discussed earlier, this is a powerful emblem of the thousands of acts of remembrance which constitute the organisation, helping to reproduce the research being funded as 'hope for the future'. This is further sustained by the display of another set of images which visually articulate this temporal orientation. 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. A number are recognisably female, include the bodies of 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.

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 organisation's staff talks briefly about the research taking place. There is a strong emphasis on the importance of examining genes, 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. The kind of bracketing and containment strategies identified in the publicity literature of the organisation, are therefore mirrored in these introductory speeches.

Hope for the future takes on a greater presence during the course of the tours themselves. Following the introductory talk, the movement into the 'inner sanctum' of the centre is precipitated by the arrival of one or two scientists, normally in lab coats 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 liquid nitrogen. This display at the start of the tour is clearly intended to engage the 'awe factor'. 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 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 which were highlighted by the scientist concerned, but the fact that the samples had 'changed colour'. A science in action effect, particularly sought after by fundraisers, demonstrated in the 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 essentially 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'. 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 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.

Collectively these representations reveal much about how, in the context of the tours, scientists participate in a particular framing of genetic research. This is not, it seems, just about preserving an idea of gene action or agency that distracts from 'inchoate' science (Fox-Keller 1995) but about actively sustaining a perception of wonder; linked in this case to the 'halo' effect of technical difficulty and the power that technological processes have in 'casting a spell over us' (Gell 1992). However, the particular discourse of genetics, which has been described as being richly 'replete with barely secularised christian figurative realism' (1997: 10) or associated with a certain 'mystical power' (Nelkin and Lindee 1995), intersects in this arena with ideas of technological awe. Such representations might well be commonplace in the media accounts of genetic knowledge, but the appearance of descriptions like these, in the context of working practices where the complexities of this chemical substance are part and parcel of daily life, is significant.

The silence of fundraisers in response to these displays, and during most of the initial part of the tour, suggested that it was an effect which had been achieved. Their 'awed' response seemed to indicate a degree of success in relation to the collective endeavour during the lab tours to construct scientific and genetic research as an object of 'passion and devotion'; something of an obligatory passage point as Rowland notes, in the creation of memorials and monuments for the living (1999).

At the same time there is a displacement involved in these displays. Both the complexity of gene research and the current somewhat uncertain and narrow application of BRCA genetics are discreetly left out. They are however brought more directly into view towards the end of the tour. The 'show lab', as it was called aligns what, up until now, have been a series of disparate objects or technologies performing or being used in different experiments. Although not a working lab and virtually empty at the moment, while waiting for new scientists to be recruited, this room is presented at the end of the tour and therefore appears, perhaps unintentionally, as the apex of the whole event.[2]

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 something of an iconic media 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 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 normally 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; on one occasion a women actually picked up the cytology slide and carried it around with her into the refreshment area, determined it seemed to pick the brains of the scientists about the research with this picture in hand. The intrusion into the research setting of the 'sick body' represented by the mammogram and cytology slide, coupled with the linear narrative that was suggested between basic research and clinical practice, through the juxtaposition of these objects, seemed to prompt difficult questions from fundraisers. 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 value of genetic science were made.

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 recourse to awareness and knowledge which reflected a less than linear relationship between scientific research and clinical application. So one scientist making a reference to the human genome project, said that knowing these genetic sequences would make it possible to 'compare normal and abnormal DNA. Pausing for reflection 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 more specific question about 'what exactly the benefits are of having identified the two BRACA genes', before making uneasy efforts to backtrack on his answer:

> 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 is quite complex. In fact we don't really know what BRCA2 does yet.

The show lab therefore 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 helps to present and communicate the research work being undertaken as authoritative and 'expert', while drawing attention to the awe or wonder of science and technology. The promissory hope of genetic research refracted and reproduced in the interactional space of the lab tours, ensures that the future takes on an instrumental structuring presence in this arena. Through the collective and active participation of the scientists the tour helps to facilitate the fundraisers' needs and desires for a transcendent science that will honour the memory and help to protect and care for past and future female relatives. The final part of the tour suggests however that it is representation of 'expertise' not necessarily always easy for the scientists to maintain. The experiences and narratives of this group of persons outlined below illustrates how they are directly caught up in representing and reproducing the BRCA genes as 'hope-filled' science.

Being scientists of breast cancer genetics

Talking about communicating their work to fundraisers, as well as participating on the tours, the discussions undertaken with a group of scientists working at the centre, revealed a dense nexus of reciprocities in their relationship with fundraisers, the charity they were funded by and the kind of science being pursued.[3] The second section of this chapter explores the uneven 'benefits and burdens' for those carrying out basic science genetic research, who are funded by a specific disease-focused research charity with its own unique historical, and institutional links to a culture of gendered breast cancer activism.

The 'evidence' of expertise

Most of those I met were working in a variety of ways with projects associated with the BRCA genes.[4] 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. Although they rejected the hyped media reductionist representation of genetic knowledge, there was nonetheless a tendency among some of those I met to give greatest causative weight to genetic factors. Moreover for some the fact that the BRCA genes had now been fully incorporated into clinical practice was not only exciting but gave scientific expertise, through an association with clinical application, a certain material efficacy and ethical validity.

Like fundraisers, some scientists, in responding to my initial query about what they saw as the main risk factors for breast cancer, drew a sharp contrast between 'possible and 'known' risk factors, pointing to 'genes' as providing a more concrete avenue for researching the causes of breast cancer.

> Simon: The main thing is basically we don't know, unless it's a hereditary pre-disposition and an inherited mutation in those genes [. . .] just in terms of thinking of the high penetrance of those genes there is 85 per cent certainty where as the other things aren't as certain.

The importance of examining genetic changes was also emphasised in the way that factors 'internal' to the cell, genes or bodies, were represented by some of these scientists as the 'most important' aspects of this field of inquiry. A practice of 'black boxing . . . anything external to the material body' that Margaret Lock also notes in her examination of certain scientific orientations towards the genetic aspects of Alzheimers Disease (2005). This became apparent during an interview with one scientist when I asked what he thought about other research looking at the aetiology of breast cancer more broadly. As this excerpt from my interview with him shows, the question prompted something of an indignant response:

> Simon: 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.
>
> 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.

As these comments highlight, his response to my query about the narrowness of a genetic focus 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 inquiry. At the same time, he sidelined and somewhat dismissed research examining risk factors 'external'

to the gene; a rebuff that might in part be understood in the way he talked about the 'do-ability' of genetic research compared with examining other risk factors.

> Simon: 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 this person 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 simultaneously the most important and feasible areas of research. However the reference in Simon's comments to a tool, the family tree, essential to *clinical* practice, suggests that genes also provided 'evidence' of expertise for some scientists in ways that paralleled how clinicians also made use of the genealogical and gendered configurations of 'the family'. This was demonstrated in his response to one of the first questions I asked, about how he would describe the work he did at the centre:

> Simon: Ok well I think about 5 per cent of breast cancers are due to inherited susceptibility genes. 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, it was significant that Simon 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. As Löwy notes in her examination of innovation in cancer technology, actual as well as symbolic and representational links between the worlds of 'healing' and 'investigation' are an increasingly important mutual resource for both clinicians and researchers in what continues to be very much an experimental field of knowledge and care (1997). However, it is not just that the reference to a clinical application and endpoint situates scientific research in the 'ethical' space of the cancer care but that reference to a specific

medical technology, with its own hybrid configuration, also means certain social relations became important in talking about doing research on the BRCA genes. For example, this was the way one scientist described the project he was involved in:

> John: 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 you start passing on the bogus blueprint to your daughter*. So it's looking at how that actually happens. (my emphasis)

Using genealogy as an index of social relations is not an uncommon metaphorical mode in talking about the transfer of hereditary substance in certain areas of scientific research (Bouquet 1994; see also Helmreich 1998). Although for some scientists use of these metaphors might illustrate some of the more troubling ramifications of working with BRCA genes, for others they reproduced and reflected the gendered social relations that lay at the heart of the identity of the charity. In fact many scientists were very aware of the social, political and ethical context of their research and drew upon this in talking about what they did at the research centre.

The morality of breast cancer research

Several of those I met, discussed how working in this particular area of basic science had a particular moral 'value' compared to other areas of research. This was linked, in part, to the public profile of cancer research, particularly breast cancer research, which conferred a certain significance to the science they studied:

> 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.

The '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 Robin'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, said 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 also revealed the extent to which he, like others, felt breast cancer and cancer research more generally would not have to face the kind of problems other areas of genetic research had been subject to:

> Sahra: I was wondered if there is anything you find worrying about the genetic research focus of the charity?
> John: 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 suppose I mean are you concerned about the possible knock on effect of the controversies over GM food say on things like human genetics.
> John: 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 BRACA2 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?

Some scientists clearly felt breast cancer was exempt from fears or the controversies that had, at the time of my research, been so readily associated with other areas of genetics. Working in an arena of breast cancer research, which is charitably funded and which is mobilised by and helps to sustain an ethos of gendered health activism, appears in many ways to confer a perceived sense of in built resistance to potential challenge or doubt more readily associated with other areas genetic research. This was powerfully brought home during an event that happened in the course of one laboratory tour.

On the way towards the final part of this event, the tour 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 'sick bodies' were potentially, at least indirectly, 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 of these events and was omitted altogether on more than half of those tours I attended.

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 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. Perhaps somewhat indelicately I asked, in full view of fundraisers, during one tour if consent had been given to use the samples for different aspects of the research. The scientist I had asked was offhand and almost indignant:

> That would be ridiculous if every time you wanted to use a sample you had to ask permission.

Her necessarily public reply suggested that the domain of breast cancer research was not dogged in the same way as other areas of scientific inquiry might be, by new and troubling ethical issues about consent that had arisen in the aftermath of a number of recent controversies surrounding the storage and use of human tissue in a few UK hospitals. Her reply implied that this work was not 'contaminated' by the muddy ethical waters that other clinical-based research and practice had to confront. Although at other times, at the start of the tours for instance, these boundaries were *presented* at least as distinctly blurred, this exchange revealed and reflected an ongoing distance between the fields of scientific research and clinical application in relation to BRCA genetics. At the same time that the description of these samples as a 'donation' could be understood as both a reflection and reproduction of some sense of immunity, the sentiments conveyed might also be seen as a microcosm of the social dynamics that existed more broadly in the charity. Used in the context of the tours, these remarks suggested that there was a parity between the financial donation or 'gift' that fundraising bestowed with an act of sacrifice that bodily donation so readily evoked. In other words, from the perspective of some scientists the morality of being a scientist in charitably funded breast cancer research meant being enmeshed in a circuit where the act of fundraising could be read back and forth between the 'donated/sacrificed' bodies of those who had had breast cancer and the research work itself. It was nonetheless a cycle of reciprocity that also

had more challenging and personal ramifications for some of those carrying out working in this setting.

A passion for complexity and the challenge of long-term research

Although some scientists talked about their research with BRCA genes in terms of a process of 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 revealed how it was precisely the complex, difficult and uncertain nature of this domain of basic science research which fascinated and motivated them in the work they did.

A much more multi-faceted representation of the kind of science being undertaken at the centre was evident in the way that one scientist talked about the research she was doing:

> Alsana: I'm 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.

Moreover her discussion of possible risk factors for breast cancer 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 per cent 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 it 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 or hormone changes related to lifestyle. I suppose they all or the majority of them contribute in some way.

In the depth and breadth of what Alsana talked about, it was evident that it was precisely this heterogeneity which absorbed and compelled her in the work that she did. It was 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 some scientists therefore presented a more multi-dimensional and uncertain picture of breast cancer aetiology; a complexity that fuelled a sense of passion for and in Alsana's words 'fascination' with scientific research.

As the events of the show lab on the tour had already suggested, this more complex rendering of the research at the centre raised particular challenges in communicating science to an expectant and hopefilled public, such as the fundraisers. One of these challenges related to the timescale of genetic research; as one person 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.

> Alison: I think in translating the research we do here in the labs to the clinic or patients – it's a long process. 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.

> John: 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 research that isn't directed specifically at treatment.

It was striking also that several scientists, who had initially been keen to claim and show the clinical benefit of genetic research (by 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, Simon had talked confidently about the link between the research focus of the lab and therapy, at the start of my interview with him. This contrasted with what he

said when later I asked him more specifically about the work that he was doing:

> Andrew: People think that we are experimenting on therapies [but] 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.

These contradictory modes for talking about research implied that there was at least a degree of unease about associating the work they did with a newly emerging field of predictive medicine. This was more clearly articulated in the way that another scientist discussed the current gap between diagnosis and therapy in relation to this field of medicine. Her comments implied that it was a gap she could not entirely disassociate herself from.

> 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'. 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 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 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'!

For some scientists, the association between the work they did with a clinical realm was not productive in a simple or direct way but also generated more ambivalent responses and consequences. Such contradictory effects might, in part, be understood in terms of how a culture of clinical and scientific experimentation has long characterised the field of oncology. As Löwy's work demonstrates the boundaries between clinic and laboratory have, since the development of novel chemotherapy treatments in the 1970s, always been somewhat blurred (1997). The evidence presented in this chapter suggests that the flux and movement

between the clinical and scientific realm continues to be on-going feature of novel arenas of genetic research and clinical practice, such as BRCA genetics.

Other scientists I met suggested that the current disjunction between diagnostic knowledge and clinical application, in this field of research, might have particular implications for the charity. As one scientist said, 'I would think the first big result we get out of here will be a huge boost'. Another pointed out how this end point might be particularly important for this organisation, compared with other research charities. At the same time he implied that this also made it important not to be 'too honest' about the likely timescale for 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 of it will filter through and be relevant to all types of cancer. But organisations like that are less targeted at therapies in the way that the charity 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 when the other cancer charities get results every 2 months'

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 them, also had difficult ramifications for the charity, in terms of fundraising. As Andrew put it, 'it's a long game and that's why I imagine it's difficult for you' [meaning the charity]. His remarks also implied that he felt the scientists were not caught up, in the same way that the organisation was, with these challenges. However scientists experience of the tours and their feelings about the prospect of developing supporter advocacy suggested that these boundaries were not always easy to maintain.

Being part of a 'redemptory' science

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,

I was told about how many of the scientists had been anxious about the way in which fundraisers would respond and were worried that they might, 'burst into tears or get upset or ask when they would find a cure for cancer or why they hadn't already'. In-depth interviews with scientists, as well as discussions with them during and following these events 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'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.
>
> Simon: I don't know what they want out of it. 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 Simon, 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 work. 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, but I suppose the 'media' image of scientists is quite 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 bevearing away?

Christine's comments in this discussion, suggested that the expectations of fundraisers had implications for the way scientists presented *themselves* on the tours. 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, especially when she said fundraisers 'expect to see bucket loads of DNA lying around':

> 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. 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 more hidden, less visible dimensions 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 sentiment 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.[5]

In sum the comments of the scientists suggest that some experienced the tours in terms of something of a negation of their work and their ideas,

particularly when this was defined by an interest in and a 'passion' for the complexity of genetic science. This was not only because of the way events such as the tours focused on the objects of science, but because scientists themselves and the genetic research they undertook were situated, in the social dynamics of the charity, as objectifications of the fundraisers pursuits.

The prospect of developing supporter advocacy in the charity offered the opportunity in part to redress this problem. It held out the hope of facilitating greater understanding for the fundraisers between hype and the actual scope or timescale of genetic research. In talking to the scientists about this initiative, a number did recognise what they saw as the rights of the supporters to be more involved in the research. As one scientist pointed out:

> Simon: 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.

But even fairly positive comments such as this were subsumed by a sense of anxiety about how this 'ethical' goal might be implemented; concerns which one scientist tried to articulate at the same time as suggesting something of a solution.

> Ian: 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 Ian recognised the need 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' did he feel that such an initiative could be workable. Even therefore as advocacy held out the hope of better understanding about the science being pursued it also, according to some scientist, threatened to undermine the current research focus and agenda. As the contradictory and complex responses of the scientists suggest, advocacy was from this perspective, in Rabinow's sense, a somewhat 'purgatorial' solution to the challenge of long-term and complex gene research.

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 relationship between a group of patients with Marfan Syndrome and 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). Yet scientists are in fact increasingly implicated in what Nowotny *et al*. call the 'agora' of scientific knowledge production (2001). As the narratives and practices explored in this chapter also illustrate, they are no longer excluded but are instead constituting figures in the evolving representational politics of the emergent science and medicine of breast cancer genetics. One powerful illustration of this is the way that the profiling of *individual* scientists and the work they undertake is a growing feature of the publicity literature in the charity. Increasingly their 'dedication', described in terms of 'giving 150 per cent', is used as a model and metaphor for encouraging further campaigning work around fundraising for science and research.

The expanded 'agora' of knowledge production where scientific institutions and scientists are increasingly being called upon to demonstrate their awareness and social accountability has particular ramifications in an organisation where there is an expectation not simply of treatment but somewhat salvationary knowledge or a 'cure' of breast cancer. The nexus of interests and investments this constitutes has been examined with particular reference to one key practice, the lab tours. This illustrates how meeting the fundraisers' requirements for knowledge in the communication of genetic research is not always easy for the scientists.

Exploring the experiences of these persons draws attention to the contradictory consequences for them of being involved in the transmission of new genetic knowledge associated with breast cancer. Carrying

out basic research on the BRCA genes helps to make the science being pursued 'tangible'; a context for knowledge some scientists reproduce on occasions by talking about genes, or a hoped for clinical application in particular de-contextualised ways. Yet scientists also locate the value of their work, both privately and in the more public context of the tours, in relation to a 'social dimension', drawing on a discourse about the 'morality' of breast cancer. Others talked openly about the complexity of the gene research and the way that it is precisely this feature of basic science work which fascinates and motivates them. However, 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. The final section of this chapter, exploring the scientists' experience of the tours, and their response to the prospect of developing supporter advocacy, suggests they are not so easily separated from the uneasy consequences arising from these developments.

Despite the injunction for scientists to 'open the blackbox' of science by talking about and making explicit the contingency and uncertainty associated with different arenas of scientific research (Collins and Pinch 1998), the challenges this poses, are clear. In the particular science/public interface that operates in a breast cancer research charity, coming face to face with the expectations of fundraisers made some scientists uncomfortable, precipitating concerns about how they should present themselves and their work. In fact a number experienced the tour in terms of a denial of personal subjectivity and agency, because of the way they were identified by the fundraisers (and reproduced by the charity) as 'embodied objects' of expertise. If understanding the social production of scientific knowledge in Science and Technology Studies is predicated on recognising the 'agency' of objects (Callon 1986), here it seems more important to recognise the ways that the agency of persons, in this case scientists, is situated and even denied through a process of *objectification*. In sum the pursuit of a 'redemptory' or 'hype' and 'hope' filled genetic research implicates the scientists in unanticipated and uneven ways. Negotiating their relationship with fundraisers, many struggle to remain faithful to the real nature of their work in an attempt to reproduce genetic science in terms of a lasting legacy or what might be seen as good enough memorials and monuments for the living.

Conclusion

The practices explored in this book suggest a diverse number of cultural arenas, encompassed by and which connect to breast cancer, offer a particularly potent 'social form' (Rabinow 1999: 89) for the development and legitimisation of new genetic knowledge. As Margaret Lock points out the emergence of predictive genetic testing for breast cancer is in many ways a striking case of the way that 'possible probabilities, based on poorly constructed studies, have been constructed into certain probabilities and then into certainties' (1998: 8). In examining how genetic knowledge associated with the BRCA genes is being translated, received and acted upon at the interface between different sciences and publics, this account demonstrates how the efforts to secure and maintain the 'legitimacy' of breast cancer genetics must be positioned as a collective endeavour. In fact the circuits of action and practice which link, differently situated 'publics' and 'sciences' in the co-production of 'new' genetic knowledge and technology operate like Martin's figure of the rhizome, in 'discontinuous, fractured and non-linear ways' (1998:31).

If, as Batchelor *et al*. points out, the 'career' of a medical discovery undergoes a process of 'translation' when it becomes part of everyday medical practice (1996: 250), this study of innovation and application within, between and beyond both the clinic and the laboratory points to a more complex multi-directional field. The interdisciplinary trajectories of approaches in STS and Anthropology have been used here to re-think how knowledge, technology, networks, lay/professional identities and the discourses as well as the materialities of gender, genes, kinship and the body are collectively implicated in the work of translation and transmission. Two main sites, cancer genetic clinics and a breast cancer research charity have provided the expanded parameters for exploring the co-production of breast cancer genetics. Showing how action, meaning and effect ricochet both

up and downstream with consequences for scientific discovery and clinical application does not remove or make issues of 'social impact' or 'geneticisation' any less relevant. It does, however, re-cast these issues. Adopting this approach highlights the need for analysis which not only attends to a more multi-dimensional field of social relations and practices but also raises new questions about how we should understand and locate the kinds of 'biosociality' and 'genetic' or 'biological citizenship' at stake in these developments.

Lock *et al*. point out that 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). Reading and locating 'subjects' across different 'lay/professional' contexts of interaction, one particular dynamic has been of central interest; the growing yet diverse breast cancer movement in the UK and the knowledge and technologies associated with breast cancer genes. Tracing and tracking the points of enablement and the more difficult gaps and tensions generated by or which arise at this interface, brings to the fore how gender and practices of gendering are deeply implicated in the way that breast cancer genetics has, is and continues to be at the forefront of developments in genetic knowledge and medicine.

This is perhaps most immediately apparent in the effect of certain values and ethics mobilised by the breast cancer 'movement', in helping to enroll women into cancer genetic clinics or in the recruitment of fundraisers for a breast cancer charity funding basic science genetic research. Here a prominent discourse about health awareness, activism, visibility and female nurturance informs a presumed and perceived sense of agency in the way women articulate their experiences or expectations and variously participate in reproducing and sustaining the knowledge and technology associated with the BRCA genes.

Seeking, attending and being seen in the cancer genetic clinic is for the most part an active process that is embedded in a moral code of awareness and vigilance, which requires and elicits a form of 'anticipatory patienthood'. This has consequences for how many of those who come to the clinic participate in, perceive or make manifest a sense of genetic risk, evident in the agency which many attribute to genes and their expectations of the clinic's capacity to make 'hidden' danger visible. Although less focused on those who, for whatever reason, do not become enrolled in these arenas of health care, the different experiences of a few women in the clinical arena who are more reluctant to be active or 'forewarned patients', suggest that there are diverse responses to developments in predictive medicine. At the same time the obscured

and hidden nature of these different responses suggests that there is something of a productive 'fit' between an ethic of prevention and the value of prediction that informs recruitment into and helps to sustain this emerging field of medicine.

The second half of the book, examining how a specific sort of breast cancer 'activism' interfaces with the pursuit of genetic knowledge, outside the dynamic of clinical encounters, widens the scope of this analysis. Examining how a community of people 'affected', if not always afflicted by breast cancer, have become involved in fundraising for a breast cancer research charity illustrates how gendered and gendering health 'activism' is entangled with and fuelled by cancer research focused on molecular knowledge of breast cancer. The 'multi-representational politics' (Epstein 2003) of fundraising for a breast cancer research charity in the pursuit of basic science research are powerfully caught up here in what might be described as a process of 'memorialisation'. This enables loss or trauma to be both individually and collectively witnessed while holding out the hope of transcending tragedy through both a hope and hype filled science. Although there have been powerful alignments between publics and science, via the mechanism of charity, throughout the course of the 20th century, of interest here is the particular *gendered* configuration of this meeting point and the way that *genetic* science is situated as part of a quest for 'redemptory' knowledge. Although a potent and in many ways highly successful public–science meeting point, this is not a uniform or necessarily stable juncture. While long-term basic science genetic research fuels this kind of 'activist' identity or mode of identification within a cancer research charity, for most this is not the case for all and may not remain so in a post-genomic era.

Nonetheless in an important sense the actions and practices undertaken by different 'lay' persons, in relation to developments in genetic knowledge and technology, suggest that reproducing BRCA genetics as 'expert knowledge' is not just the preserve of practitioners or scientists, but also actively involves patients and publics. The 'black boxing' of genetic knowledge and technologies, normally thought to be part of the practice of science or the preserve of medical practitioners, is in fact reproduced here by the actions of patients before and at the clinical interface, sustained by an investment in predictive knowledge as a kind of health prevention. Similarly the memorialising intentions embedded in the act of fundraising not only act to de-contextualise genetic research and science but also serve to constitute the scientists as objectified parts of the collective quest for knowledge. This raises interesting questions

about what comes to constitute the materiality of genetic science or medicine, how it is being collectively reproduced and also how in turn 'those materialities work to fuel collective action' (Rabeharisoa and Callon 1998).

These developments cannot therefore be abstracted from and are very much part of a new 'visibility' around women's health, particularly in relation to breast cancer. The agency constituted by this activism is, however, not about empowerment in an obvious or direct way but is instead caught up with a more contradictory set of consequences and entailments. When renewed calls by 'identity' based movements have the potential for the co-option and appropriation (Epstein 2003, 2007; Hess 2004), there is a need to explore and be critically attentive to the particular view of women's health 'sanctioned' by new female-focused scientific research and/or a gendered health agenda (Eckman 1998). More importantly the health activism involved in these developments arises alongside a particular mode of civic engagement where the neo-liberal values of activism and awareness in relation to preventative health are particularly salient. But the analysis outlined in this book suggests that these modes of engagement must also be located in relation to the politics and ethics of a (increasingly rationed) national health service *and* a long-standing yet evolving culture of charity in relation to cancer research in the UK. This re-situates the parameters for considering biological citizenship far beyond considerations of how those individuals undergoing genetic testing or identified as carriers of a BRCA mutation respond to and participate in these developments. Although the representational iconicity of the 'BRCA carrier' or the 'gene mutation' are powerful in both settings, the interconnecting fields of action and practice explored in this book make the case for engagement with a much more diffuse, yet potent, field of bio-social entanglements and entailments (see also Gibbon and Novas 2007).

If it is the position of different 'lay' persons, patients 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 I have suggested also makes for an important part of the analysis.

The medical or predictive scope, authority and expertise of genetic knowledge has been explored in relation to the practices undertaken by a range of professionals, scientists and medical practitioners. This includes the use of visual tools, often paper technologies or objects, a 'risk' discourse that draws on statistical authority, as well as de-contextualised explanatory narratives which have the potential to 'talk up' or even 'hype' genetic knowledge. An ethnographic approach makes it possible to see

that these are very much 'containment' strategies which serve to stabilise and make knowledge 'real'. Imparting an important tangibility to an emergent science and medicine of genetics, these tools and techniques express and articulate the scope and reach of new genetic knowledge associated with the BRCA genes.

However, the 'bio-power' of breast cancer genetics is not only inseparable from the investment, expectations, faith and hope of different publics, but is itself belied by the inherent contingency of genetic knowledge as predictive medicine and care. As examination of social dynamics during clinical encounters illustrates or as events such as the laboratory tours suggest, disjuncture, gaps and lacunae are an inescapable aspect of BRCA genetics as medical or scientific practice. This can result in uncomfortable scenarios for some health professionals or scientists, sometimes fuelling efforts by these persons to make genetic knowledge more tangible and promissory in disseminating this information to an expectant public. Nevertheless in contrast to patients' perceptions of the visualising power of testing technology or the fundraisers' desires to materialise memorials through genetic research, it is, as the reflective comments of different professionals suggest, the inescapable 'invisibility' of BRCA genes, which for these persons is most problematic and troubling. The inability to pinpoint gene mutations in the bodies of most of those who attend the clinic or the admission on the tours that the function of the BRCA genes is 'not yet known' reflects the challenges confronting these practitioners and professionals in their dynamic relationship with different publics.

At the same time, negotiating the shifting and mobile landscape of genomic and post-genomic knowledge and managing the ongoing gap between knowledge and care means that alongside a practice of 'talking up' genetic knowledge there are also in both these settings explicit, if demarcated, modes of 'talking down'. This then is also part of the work of transmission linked to the institutional and regulatory requirement to 'triage' those attending cancer genetic clinics or sustain long-term investment in complex, hard-to-communicate genetic science in a breast cancer research charity. The necessity for 'code switching' practices raises further questions about how professionals are assumed to be sustaining the authority or legitimacy of genetic knowledge and technology and the kinds of bio-power at stake in these developments. There is, for example, a degree of unease and ambivalence for some professionals about the work they do as medical practitioners or scientists. For many this is closely tied to an awareness that although gendered health activism recruits women into predictive health care practices or fuels hope and

faith in a particular area of scientific research, as a 'cure' for breast cancer, there is also a more hidden mismatch between these heightened expectations and the current scope of genomic and post-genomic knowledge and technologies associated with BRCA genetics. Reflexive engagement with the subject positions of professionals brings new insight to the 'gendering' of breast cancer genetics and the circuitous and complex ways that health care practitioners and scientists are implicated in and affected by these developments.

Rabinow points to the untenableness of a 'hermeneutics of suspicion' in the shifting landscape of experimental genetic science and given the increasingly close links between science, ethics and politics (1996). Whilst recognising the new precariousness of professionals in an era of genetics, it is important to retain an understanding of how 'a will to knowledge' (Palladino 2002: 155) and more 'structural' factors continue to be facets of these developments, in ways that do not reduce 'specificity to contingency' (Sunder Rajan 2005). This study has shown the complex role that diverse 'lay' publics play in fuelling a drive towards experiment *and* knowledge. It has also highlighted how shifts in the locus of power/knowledge and the 'bio-power' of breast cancer genetics must be understood in relation to the values, ethics and practices of pre-existing institutional and national cultures of health care provision and a long history in the UK of charity funded cancer research. It is not so much therefore that a lay/professional distinction does not continue to be an important component of medical or scientific developments in the cultural and social context of breast cancer genetics, but that there is a need to understand how these boundaries are dynamically constituted, in relation to an emerging field of genomic medicine and science.

The complexities around the gendering of genetic knowledge are not only apparent in the (re)-configuring of a lay/professional interface but also in the way ideas of the 'natural', 'social' and 'ethical' are strategically mobilised by diverse range persons. Refracted through particular idioms associated with kinship, the family and female gender in both ethnographic sites, these 'merographic' practices provide a legitimising context for genetic knowledge.

Discourse about and representations of female nurturance are particularly important in communicating and disseminating new genetic knowledge associated with BRCA genes, linking the morality of obligation between kin, in the charity, with a discourse about care for the family in the clinic. By reinforcing and relying on a notion of women as relational, in caring for others, these representations and modes of identification appear to assist the sociality necessary to the dissemination of risk information

in clinical cancer genetics. At the same time the figure of 'the nurturing woman' provides a powerful representation and mode of identification for memorial practice in raising funds for breast cancer research. In this setting she is a symbol of what has been lost *and* hope for the future. Although in both ethnographic contexts notions of the social and the natural pertaining to the family or ideas of female nurturance are put to work in 'flexible' ways, there are in fact differences of emphasis with varying points of enablement and disjuncture; contrasts which themselves illustrate the diverse ways that the biological and social are made operational in relation to BRCA genes.

This is evident in the use of family trees in the clinic, which are as much a product of both patient investment in this arena of predictive health care, as they are used as a tool of explanation or prediction by practitioners. In both instances the authority of rights to care or claims to knowledge would seem to rest on a seemingly objectified or de-contextualised representation of family history. Yet alongside this particular representation or reproduction of family history, there is also an explicit discourse about 'care for the family'. In fact clinical knowledge is fundamentally dependent on a presumed sociality between kin. This requires clinicians to engage with the 'social' dimensions of the 'family', and for those (mostly women) attending the clinic to participate in a form of distributed patienthood articulated in terms of the sharing and exchange of obligations and responsibilities between female relatives. In this sense, the 'care' of predictive medicine is predicated on ideas of kinship and female nurturance as a hybrid zone reflecting 'the combinatory power of substance and code . . . at the heart of the notion of the blood relative' (Carsten 2001: 50), in ways that productively connect and collectively produce kinship, DNA and female gender.

Although sociality and nurturance is a powerful idiom in the context of talking about 'the family' and female gender, everyday kinship does not in practice always enable the enactment and fulfilment of these cultural ideals (Yanagisako and Delaney 1995). These gaps and lacunae point to the paradoxical nature of health awareness in the predictive arena of BRCA genetics, where it is not always easy to reconcile the agency or activism of individuals in getting to the clinics and the more distributed patienthood predictive knowledge entails. Even as this may be experienced most acutely by 'patients', it is also acknowledged as challenging by practitioners. The different ways that the requirement for a 'pastorally' orientated approach to predictive interventions are received and acted upon by medical professionals point to a need to

understand how new health care technologies intersect with pre-existing medical specialities and institutional cultures.

In contrast to the clinic it is the morality of social relations between kin which make, rather than 'cut', the networks that link kinship and female nurturance to promissory genetic knowledge in the charity. Here fundraising as a form of memorialisation for past and future female relations underpins and sustains the pursuit of a long-term, high risk, basic science research strategy. Female nurturance constituted in terms of obligations and responsibilities to related others informs the powerful moralities that lie behind such activities. Although the kind of biosocialities linked to the BRCA genes are seemingly more distributed in the field of social relations that constitute the charity, mapping the points of enablement or slippage between the practice of fundraising through a process of memorialisation and the pursuit of 'redemptory' genetic knowledge illustrates the in-direct power of these bio-social junctures. Paradoxically in this instance the fault line and point of tension lies in making the bio-genetic component of kin relations explicit and literal, something brought centre stage by the advent of predictive genetic testing for the BRCA genes.

Now that the quest for genes has been replaced by the messier business of functional genomics other contextualising strategies in terms of articulating and making explicit what is 'social' and 'ethical' about these developments have become as important as mobilising ideas of female nurturance in the pursuit of scientific knowledge. While seeming to pose solutions to the challenge of genetic research, incorporating an 'ethical' agenda raises other questions and sometimes more troubling issues. Even as these strategies become linked to new modes of accountability or legitimacy they also rebound and ricochet across pre-existing social relations.

In examining how notions pertaining to female gender identity and/or the family are used as a 'context' for knowledge, we have seen how different social, ethical or political agendas are being 'built into' translational practices in the clinic and the charity. Important questions for social science engagement with 'science' are raised when notions of the family or female obligation, responsibility and nurturance became as important in sustaining the knowledge and technologies associated with breast cancer genes as the naturalising idioms they also continue to be associated with. Exploring and naming the 'hybrids' of breast cancer genetics brings a new reading to the issue of gendering at the intersection between different sciences and publics inside and outside the space of the clinic and the laboratory. It is not just that these are

women are, as a result of these developments, positioned in Rapp's terms as 'moral pioneers of the private' (1999) with uneven repercussions but that, in the case of BRCA genetics, new fields of genetic knowledge and technology require and are themselves sustained by these gendered moralities. In this sense, social scientists need to be reflexively attentive to how gender, sociality and ethics are put to work in the pursuit of particular kinds of legitimacies by persons differently implicated in the transmission of new genetic knowledge and technologies.

Preserving the emergent aspects of one particular arena of an expanding field of genomic medicine and science, the analysis outlined here has examined how powerful but not always enabling gendered values and practices are central to the work of transmission and translation. This book is an effort to map these discontinuous connections as a basis for further intervention, action and transformation in the evolving politics of breast cancer and genomic science.

Notes

Introduction

1. The BRCA genes have also been linked to a number of other common cancers, including ovarian and prostate cancer, as well as some rarer types of cancer such as thyroid and pancreatic cancers. However this book delimits its inquiry, to a focus on the social and cultural context of the discovery and developments associated with the BRCA genes in relation to breast cancer.
2. According to current estimates BRCA1 mutations 'account' for about 40–50 per cent of these genetically linked cases of breast cancer and BRCA2 for about 20–30 per cent. Other genes, mostly unknown, are thought to be involved in the remaining 20–40 per cent of cases (Public Health Genetics Unit 25/07/02 http://www.medschl.cam.ac.uk/phgu).
3. There is, for example, a significant amount of quantitatively focused psychological literature on levels of anxiety or perceptions of risk for individuals identified as carriers of one of the two BRCA genes. See for instance Lerman *et al*. 1997.
4. Although within sociology and medical sociology the social and political dimensions of bio-medical knowledge and practice have been part of these disciplinary boundaries of inquiry for some time.
5. I was in fact a patient at one of these hospitals 7 years prior to starting research and had maintained personal contacts with a few individuals that I'd met there which served as a starting point for my research.
6. At the time of my research formal ethical approval from local hospital ethics committees was only necessary for my interviews with patients, a situation which has subsequently changed (see COREC 2001).
7. In-depth interviews were undertaken with a total of 30 persons. This included supporters or fundraisers, scientists at the research centre and staff working at the charity. Three focus groups were also undertaken across the UK with various groups of fundraisers. In addition I attended 8 laboratory tours over the course of more than a years fieldwork. Each of these would involve anything from 6 to 15 visitors and 2–4 scientists.

Part I Clinical Breast Cancer Genetics: Patients, Practitioners and Predictive Medicine

1. For further discussion of this, see the Report of the Consensus Meeting for the Management of Women With a Family History of Breast Cancer (London: Wellcome Trust Monday 12 January 1998). Sponsored and organised by the R&D Office of the Anglia & Oxford NHS Executive and the Unit for Public Health Genetics, Cambridge http://www.phgu.org.uk/info_database/public_documents/breastcaconsen.html (accessed 06/07/2006).

1 The Enrolment of 'Patients': Visibility, Voice and Breast Cancer Activism

1. In total 17 women were interviewed for this component of the research. All were 'unaffected' women (i.e. they did not and had not had breast cancer), most were between 30 and 45 years old and were presumed to be at 'moderate risk' on the basis of their referral letter.
2. A feature of breast cancer referrals noted by GPs more generally (Ruston 2004).
3. The forms used asked 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.
4. For some completing these forms appeared to inform a sense of anxiety about the possible dangers of family history. For example, are woman commented on how doing this had impacted on her perceptions of risk:

   > 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.

5. See for instance 'New Concerns Over Breast Screening' 18th October 2001 http://news.bbc.co.uk/1/hi/health/1607113.stm.
6. The programme she talked about was actually called 'The Decision: living in the shadow' broadcast on Channel 4 in 1996.

2 Technologies of the Clinic: Tools, Tests and Explanatory Strategies

1. See GAIC, Report Department of Health 2004.
2. Recent data from the CMGS 2004–2005 audit suggested that nationally this figure is still not exceptionally high. In this audited period 11,000 tests had been undertaken but of these only 94 confirmed the presence of a mutation. Although difficult to confirm definitively, a more personal communiqué with a leading oncologist in the field in 2006 suggested that although approx 25,000–30,000 genetic tests (predictive and mutation screening combined) had been undertaken in the UK, to date perhaps as few as 1200 carriers of BRCA mutations have been positively identified.
3. In the General Hospital, practitioners preferred to draw the family tree with the patient in attendance during first time appointments.
4. See 'Women Faking Cancer Histories' accessed August 23, Web page 21st April 2005 http://news.bbc.co.uk/1/hi/health/4466313.stm which suggested that a small percentage of women (1 per cent) were inventing family history in order to have treatment.
5. This is the likelihood that a person carrying a mutation will develop the condition.
6. Her response to my query acknowledged that this was an oversimplification but she pointed out 'people start to lose the thread if you start talking about how these genes are dominant but recessive in terms of the phenotype'.

3 Constructing Patienthood: The 'Care' of Predictive Medicine and Female Nurturance

1. This may have been due to the fact that the relatives of interest were on the paternal side of the family – a dimension of risk assessment which was, according to some practitioners often neglected.
2. See Callon and Rabeharisoa (2004) for an examination of how declining to take part in predictive interventions constitutes a different kind of 'ethical' behaviour that represents a challenge to social science inquiry.
3. See Hallowell *et al*. (2004) for an examination of men's involvement in BRCA testing. There is also some evidence to suggest that men who are potential gene carriers are less likely to be tested than women (NICE Guidelines 2004 p. 21).

4 Diviners and Pastoral Keepers: Working in Clinical Breast Cancer Genetics

1. There are a number of different models for calculating breast cancer risk, some of which include other lifestyle 'risk factors' (e.g. Gail *et al*. 1989); however, the one used in the cancer genetic clinics was generally based solely on a person's family history (e.g. Claus *et al*. 1994).
2. Significantly there were no designated 'genetic counsellors' for those at risk of breast cancer in either of the cancer genetic clinics where I carried out research. That is to say nearly all staff I encountered had moved into the field of cancer genetics from a background in clinical training.
3. There was however one nurse specialist whose clinical background was similar to those who worked in the cancer hospital, and who was, as a result, more concerned with the 'pastoral' dimensions of clinical practice.
4. The notion of 'enrolment' and 'betrayal' is used in Singleton and Michael's (1993) discussion of practitioner ambivalence in the UK Cervical Screening Programme.

5 The Alchemy of Loss and Hope: Fundraising as Memorialisation

1. This stands in contrast to different breast cancer activist groups, particularly in the US, who have campaigned to make images of the 'breast cancer body' more visible (Cartwright 2000).
2. It's difficult to know what the exact model is for this kind memorial. It may have some grounding in the acts of remembrance that have arisen out of AIDS activism, such as the making of commemorative 'quilts'. See Layne 2003 for further discussion of memorial practices in relation to pregnancy loss.
3. See also Chloe Silverman (2007) who has examined the generative nature of 'affect' in the context of a different culture of patient activism linked to autism and scientific research.

4. Following the merger with a breast cancer advocacy organisation, a few years ago, the charity's supporters have become more diversely constituted with many women with breast cancer now involved who are directly interested in political lobbying activities, rather than only fundraising.

6 Between Geno-hype and the Post-Genomic: The Management of Science and Ethics

1. See for instance 'Caution urged over genome hype' BBC News 10th April 2000 http://news.bbc.co.uk/1/hi/sci/tech/708261.stm.
2. 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 to a 'future free from the fear of breast cancer'.
3. There was one exception to this in 2000 when 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.
4. This was apart from a small news item in the 'parliamentary matters' of the newsletter in 1999 highlighting the need for a register to monitor the number of women choosing to go ahead with this 'radical' and 'drastic' measure.
5. Herceptin is the first humanised monoclonal antibody for the treatment of HER2 positive metastatic breast cancer, designed to target and block the function of HER2 protein.
6. See for instance 'US Firm double costs of UK cancer checks' The Guardian January 17th 2000.
7. The way different kinds of 'moral communities' have been used to legitimise positions in debates about patenting, are discussed further in Gibbon (2005). See also Parthasarathy (2003) for analysis of the relationship between breast cancer activism and gene patenting in the US and the UK.
8. See 'MP's slam insurers on genes' The Guardian May 2001.
9. A summary of the findings arising from this work was written by another member of charity's staff.
10. See note 4 Chapter 5.

7 Scientists and the Making of Genomics as Monuments for the Living

1. I had the opportunity to attend a tour in early 2005 where it was clear that there was a much more wide-ranging discussion of the science being undertaken at the centre and many more opportunities for discussion about the uncertain and long-term nature of this research. The 'show-lab' was no longer a feature of these events.

2. The very fact that it was clearly a 'show lab' and not a 'working lab' seemed to confirm this as the domain of the charity rather than the scientists whose decision it had been to locate the end of the tour here.
3. The 'scientists' I met worked in a range of capacities at the research centre, some were technicians, others were completing their Ph.D.'s, or clinicians who had taken some time off to carry out basic science research. The majority were young, under 35 and had come to work at the centre in the last few years.
4. 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. In the years following the completion of my research other teams have been set up that are less exclusively focused on BRCA genes. Nevertheless the focus on 'molecular pathways' remains predominant.
5. Although initially flummoxed, he rallied after pausing for a few moments with what he clearly felt was an 'appropriate' response saying . . . 'because it reminds you why they raised this money and what it means to them and that you've got a responsibility to use this money'.

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