How Users Matter
The Co-Construction of Users and Technologies

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Knowledge Is Power: Genetic Testing for Breast Cancer and Patient Activism in the United States and Britain
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When discoveries of the BRCA genes, two genes linked to inherited susceptibility for breast cancer, were announced in the mid 1990s, attention turned almost immediately to the development of related diagnostics and therapeutics (Davies and White 1995). In the United States and in Britain, groups began to develop technologies to test for mutations in the BRCA genes that predicted an inherited susceptibility to breast and/or ovarian cancer. Because genetic testing for breast cancer was the first genetic testing technology for a common disease, however, a variety of political actors, including scientists, activists, clinicians, biotechnology companies, and government officials, struggled to influence its development. This chapter examines the politics of developing genetic testing for breast cancer in the United States and Britain and specifically, the role of patient advocacy groups, in order to understand how national contexts frame how users matter in the development of a medical testing technology. How did patient advocates try to influence genetic testing for breast cancer? Did their efforts differ in the United States and Britain? How did national context figure in the activism of patient groups regarding the new genetic testing technology?

Recent scholarship in the emerging field of science and technology studies has shifted from a focus on the construction of technologies themselves to the relationships between technologies and their users. Feminist scholars have demonstrated how particular understandings of the user, such as gendered assumptions and constructions of the female body, are embedded in the very design of technologies such as household goods and even synthetic hormones (Wajcman 1991; Akrich 1995; Oudshoorn 1994). Other scholars have focused on how activist communities influenced the directions of scientific research and technological development (Epstein 1996; Kaufert 1998). Steve Epstein has shown how American AIDS activists were able to pressure the Food and Drug
Administration (FDA) to speed up drug approvals and also were able to enter the previously closed doors of peer-review committees and influence research funding decisions.

This chapter adds a comparative dimension to the study of users focusing on the influence of patient advocacy communities in the development of genetic testing for breast cancer in the United States and Britain. The United States and Britain are particularly good sites for this comparative analysis for a variety of reasons. Both the United States and Britain are English-speaking and affluent Western capitalist democracies with very close ties to one another as well as many shared political traditions. There are also a number of aspects specific to the case of genetic testing for breast cancer that make the United States and Britain rich and compelling sites for this comparative analysis. First, scientists in both countries were heavily involved in the effort to find the breast cancer genes. Researchers at US genomics company Myriad Genetics were credited with finding the BRCA1 gene, while British geneticist Mike Stratton from the Institute for Cancer Research was credited with discovery of the BRCA2 gene. Second, incidences of breast cancer (and breast cancer gene mutations) in the populations of the two countries are considered to be equally high. Both the United States and Britain have exhibited significant commitments to genetics and biotechnology research, as exemplified by their leadership in the Human Genome Project, the effort to map and sequence the entire human genome.

Despite these similarities, however, we might easily imagine that national approaches to health care could structure the politics of developing genetic testing for breast cancer in very different ways in the two countries. Britain has a government-run National Health Service (NHS) that guarantees health care to all its citizens while the United States relies on a private health insurance market for the provision of health care (Starr 1982; Klein 2001). Furthermore, many scholars have argued that the British NHS is based on principles of public health and equal access, while America's private insurance system is based on competition and consumer choice (Blume 1992; Ashmore, Mulkay, and Pinch 1989; Skocpol 1996).

This chapter begins with a brief description of the development of genetic testing for breast cancer in the United States and Britain and then explores how patient advocates responded differently to the new technology in both countries. It closes with some discussion about the relationship between national context, technology, and users and the utility of this comparative analysis for the study of users of technology. In addition, like Jessika van Kammen’s article in this volume, the chapter problematizes the relationship between activists and individuals for whom they speak.

**Developing Systems of Genetic Testing for Breast Cancer**

On September 13, 1994, Tom Brokaw opened his nightly newscast on NBC as follows: “There’s an important breakthrough in breast cancer research... A rogue gene could show the way to treatment and prevention. Scientists think the gene is responsible for one in twenty breast cancers.” (Brokaw 1994) NBC News deemed the discovery of the BRCA1 gene, which was led by a team of researchers from Myriad Genetics, a genomics company based in Salt Lake City, so important to the American public’s immediate welfare (and NBC’s ratings) that it broke a press embargo imposed by *Science* magazine (Angier 1994b; Saltus 1994; Brown 1994). Its announcement emphasized the value of the discovery for both prevention and treatment for all breast cancers. NBC’s excitement was not unique, however. Soon, news of the discovery had spread throughout the media and newspapers across the world announced the discovery on their front pages. The discovery of the second gene linked to breast cancer, BRCA2, by Mike Stratton at the Institute for Cancer Research in England in December 1995 only intensified the excitement. An article in the newspaper *The Scotsman* (Christie 1996) noted: “The discovery may result in the development of a screening test to identify those at risk of contracting breast cancer. They could then be monitored more closely, enabling the identification at the earliest treatable stage.”

In the United States, four very different providers began to develop BRCA testing services on a large scale immediately after the gene discoveries in the mid 1990s. While their services varied considerably, each used an approach that had roots in the American biomedical context. As a research laboratory at an academic medical center, the University of Pennsylvania’s Genetic Diagnostic Laboratory offered individuals who visited a genetics clinic at an academic medical center access to an experimental method of analyzing the BRCA genes. Oncor, a start-up biotechnology company with close ties to the medical genetics community, offered high-risk individuals access to its laboratory analysis services through research protocols organized by itself or other investigators. The Genetics and IVF Institute, a reproductive services clinic, offered both clinical care and laboratory analysis of the BRCA gene mutations common among the Ashkenazi Jewish population under one roof. Finally, Myriad Genetics, another start-up biotechnology company who had been
credited with finding the first BRCA gene, offered BRCA testing like any other medical test: individuals could use its DNA analysis service through any physician. Of these four, Myriad Genetics developed the largest-scale testing service. By allowing access to any individual who received a referral from any physician, Myriad ensured that the potential market for its service was quite large—it was available to anyone who could afford it.

In contrast to the variety of providers that developed BRCA testing services in the United States, BRCA testing services in Britain were provided on a regional basis through the state-run National Health Service. Its shape was reminiscent of other specialist services in the NHS, involving both risk assessment and triage. Individuals interested in testing would first provide their family history of breast and ovarian cancer to a primary or secondary care physician in their region. Then, using a standard that had been developed in consultation with geneticists across the country, these physicians would classify individuals into low-risk, moderate-risk, and high-risk categories and offer services accordingly. Only individuals classified at high risk would be allowed to visit a regional genetics clinic and access both counseling and laboratory analysis. BRCA testing services were actively being developed in both countries.

**Patient Advocacy in the United States**

Breast cancer advocacy groups, who had been particularly powerful in the United States since the early 1990s, immediately got involved in influencing the development of BRCA testing in the United States. After securing a six-fold increase in federal research money devoted to breast cancer in 1991, the National Breast Cancer Coalition (NBCC), a Washington-based advocacy group, had ushered in an era of breast cancer activism where advocates were frequently invited to join government advisory committees, speak at congressional hearings, and sit on peer-review committees where decisions about research funding were made (Stabiner 1997; Love 1995). With regard to NBCC's presence in biomedical policy making, one member noted: "I think for the Coalition, I just think that we have a much more reasoned, analytic way of looking at problems. And I think we have, I know we have the respect of many people on the Hill, when they have a breast cancer issue, they call the Coalition to see what we have to say." (interview with National Breast Cancer Coalition representative 1999). Breast cancer activists were now called upon by both the media and government to comment on breast cancer advances, health-care controversies, and funding debates alike.

The discoveries of the BRCA genes and development of genetic testing for breast cancer were no exception.

Despite the excitement expressed in the media regarding the promise of BRCA testing, most breast cancer advocacy groups took a particularly cautious approach toward the new technology. They first spoke out vociferously in the media, arguing that the new information would not create the panacea that the media predicted and test providers promised. Nancy Evans, a representative of ECA was quoted in an article published immediately after the first gene discovery, saying, "It's a very mixed blessing to have this knowledge... It's the first step in a long journey, and the journey is probably across a minefield." (Angier 1994b) Fran Visco of NBCC expressed concern as well, noting that "women will have to be very careful... You're talking about giving them a test telling them they have an 85 percent chance of getting a disease that we don't know how to prevent, and for which there is no known cure." (Angier 1994a) Both groups argued that providing genomic information without effective therapeutics was potentially dangerous as it made women anxious while providing them with no avenues to relieve their worry. They felt that the new technology had unknown implications and required additional care by test providers, health-care professionals, and patients alike. Overall, they constructed BRCA testing as potentially dangerous and requiring caution in its integration into health care, while arguing that women needed protection and did not have the right to simply demand testing.

Many of these advocacy groups did not stop at comments in the media and issued more methodically argued and organized position papers, press releases, and articles through their newsletters, criticizing the rapid provision of BRCA testing as a commercial service by organizations such as GIVF and Myriad Genetics. "Because much more needs to be researched about the sensitivity, specificity, and reliability of the genetic tests," NBCC recommended (1996b), "and because not enough is known about the effectiveness of genetic education and counseling, genetic testing should only be available within peer-reviewed research protocols." Though BCA stopped short of recommending access to the test only through research, it too suggested that "no one should be tested without access to education and counseling concerning all benefits and risks of genetic susceptibility testing" (Breast Cancer Action 1996). The National Action Plan on Breast Cancer, a public-private partnership funded by the NIH but including activists and scientists, also recommended that BRCA testing only be made available in the context of research (National Action Plan on Breast Cancer 1996). The perspective of this public-private group
was not unexpected, however, because an investigative testing system would surely benefit researchers funded by the NIH by increasing both funding and freedom to conduct research in this area while satisfying advocacy groups by ensuring a cautious approach to testing.

Advocacy groups defined BRCA testing as a new technology to which women had a right to controlled access as well as a right to be protected from bad medical choices. They suggested that individuals should only be given choices among good medical options, as opposed to options simply defined by the market, such as Myriad’s BRACAnalysis service. Instead, they argued, citizens and patients deserved protection by health-care professionals and the state against potentially dangerous technologies.

As they enlisted the help of government and the biomedical community, activists also presented themselves as appropriate authorities that could distinguish between good and bad medical options. As BCA methodically detailed reasons why testing was dangerous, for example, it displayed its own ability to distinguish between good and bad science: “It is equally clear that the BRCA1 test for genetic susceptibility is not the early detection tool we need . . . a positive result from the BRCA1 test does not mean that the person tested will develop breast cancer. (Nor does a negative test mean she is not at risk.) And, even if a positive test meant a woman would certainly develop the disease, there is currently no known effective method of preventing breast cancer. . . .” (Brenner 1996) Like the AIDS activists Steve Epstein describes in his research exploring how the AIDS community gained power in biomedical policy making, these activists tried to develop their credibility by emphasizing their scientific expertise.

Even more explicitly, NBCC specifically identified itself as an expert in the definition of good science: “Together we can make certain we get the data we need. Too many medical recommendations in breast cancer—on how to treat women, what tests to give them—are made without a basis in good science. We must not add genetic testing and its followup to this category.” (National Breast Cancer Coalition 1996a) Not only was commercial BRCA testing not in the category of good science, activists argued, but individuals should not be in the position of deciding what types of health care were best for them. Instead, they argued, individuals should be advised and protected by the state, physicians, and even knowledgeable activists about the appropriateness of particular health-care options.

As they advocated limited choice to BRCA testing, breast cancer activists distanced themselves from the individuals they represented. They claimed a combination of scientific training and expertise in the patient experience that authorized them to distinguish between health care based on good science and a technology that was potentially dangerous. Meanwhile, they argued that their constituencies did not have a mastery of scientific knowledge and needed to be protected by them as well as physicians, test providers, and the government.

Both scientific and professional organizations and breast cancer activists suggested alternatives to the testing service marketed by Myriad. They called attention to the uncertain nature of BRCA gene information and argued that the test should be cautiously integrated into health care. Moreover, they offered a new definition of empowerment, arguing that women had a right to be protected from bad knowledge and that genomic information had the potential to be disempowering without effective therapeutics.

**Empowering the Individual**

The efforts of breast cancer advocacy groups to protect women from the new BRCA testing technology might sound surprising considering not only their history of encouraging women to take charge of their medical care but also a broader context of patient advocacy which always seemed to lobby for greater access to innovative medical care. However, the breast cancer advocates’ attempts to protect women from BRCA testing technology was by no means unprecedented. In fact, this episode highlights the complicated definitions of empowerment, choice, and protection among patient advocacy movements that had emerged in the United States since the 1960s.

Although the American women’s health and disease-based social movements that had developed in the late twentieth century advocated increased access to knowledge, medical care, and new technologies in order to empower the patient through additional knowledge about their bodies, they also fought against the use of knowledge and technology that they considered dangerous. Both of these efforts were considered empowering. A 1973 edition of *Our Bodies, Ourselves*, the book that launched a generation of women’s health activism and popularized the phrase “Knowledge is power,” emphasized the importance a woman’s control over her body through knowledge, particularly in the face of what the authors perceived to be a paternalistic medical establishment: “Finding out about our bodies and our bodies’ needs, starting to take control over that area of our lives, has released for us an energy that has overflowed into our work, our friendships, our relationships with men.
and women, and for some of us, our marriages and parenthood.” (Boston Women’s Health Book Collective 1973) As activists in the 1970s emphasized power through knowledge, then, they also lobbied for additional government regulation over drugs and medical devices. During this period, activists blamed the government, and specifically the FDA, after learning that diethylstilbestrol (DES) and the birth-control pill had caused serious side effects even after approval by the FDA (Ruzek 1978). Although they argued that women were capable of making decisions about their own bodies and lives, they also sought protection against what they perceived as dangerous medical interventions.

In this manner, these activists described their empowerment objectives in two very different ways. First, they were empowering patients by advocating increased access to new knowledge and technology, arguing that they had the right to make choices about how their bodies should be treated and medical care provided. Second, they tried to limit their empowerment objectives by arguing that women should only have access to “good” science and medical care, as “bad” knowledge or technology could be potentially disempowering. Here, activists considered themselves expert to make these distinctions between good knowledge that could be empowering and bad knowledge that was potentially disempowering.

When breast cancer advocates recommended limited access to genetic testing for the disease, they were also defining the individual’s agency by arguing that individuals would be hurt by access to useless genomic information and should only be provided with access to “good” medical options as defined by the state, the biomedical community, and activists. They argued that the average woman was not capable of making the distinction between “good” and “bad” choices and needed to be protected. While these activists focused on “empowering people to deal with the issues raised by a breast cancer diagnosis,” NBCC advocated access only in research, and BCA stated that “we should be a long way from offering a test to anyone who wants it” (Breast Cancer Action 1997; Brenner 1996). Attempts by activist groups to limit access to testing not only highlighted this complication of empowerment but also demonstrated the distance between advocacy groups and their constituencies. As they limited and altered their definitions of empowerment, activists emphasized their own position as authorities determining the welfare of the uneducated public.

The conflicting empowerment objectives of the women’s health movement (and subsequently the breast cancer movement) were also particularly clear as some women’s health advocates explicitly disagreed with some of the breast cancer advocacy groups with regard to the provision of BRCA testing. In 1996, the NIH’s Advisory Committee on Research on Women’s Health (ACRWH), which was made up of doctors, scientists, lawyers, social scientists, and public health officials primarily concerned with women’s health issues, reviewed the availability of pre-symptomatic genetic testing for breast and ovarian cancer. Although it initially resolved to restrict testing to the research context and bar unlimited availability, some committee members criticized what they considered to be a paternalistic approach to medical care. Marjorie Schultz, a law professor from the University of California at Berkeley and a member of the committee, asked: “Can you imagine yourself saying to a woman who comes to a center to do testing, ‘No you can’t unless you’re a research subject?’” (Pinn and Jackson 1996) The committee eventually recommended that testing be conducted in the context of counseling, rather than recommending that breast cancer testing be restricted within research protocols. Empowerment had a multiplicity of meanings, even among the advocacy community, and each of these definitions had different implications for both understanding the appropriate use of the technology and the representation of the patient community in the politics of biomedicine.

Responding to US Patient Advocacy Groups

How did test providers respond to such criticism from patient advocacy groups? Myriad Genetics, the largest testing provider, tried to gather support for its testing service by playing on the importance of empowerment rhetoric not only among patient advocates but also the public.

Myriad started to publicize its vision of a BRCA testing system immediately after the discoveries were announced. It defined itself as a commercial diagnostic laboratory providing women with the opportunity to inform themselves about their genetic status. Its 1996 annual report characterized testing as a life-saving technology that was important “for thousands of women who will soon gain access to genetic testing that can enhance and extend their lives” (Myriad Genetics 1996a). In an article published immediately after the discovery of BRCA1, Mark Skolnick, who led the winning University of Utah—Myriad Genetics research team, asserted that the diagnostic test would provide “knowledge that can allow [women] to make an appropriate choice about cancer detection and treatment” (Volland 1994). Genomic knowledge as provided by Myriad, the company argued, could help women make choices about their own health care. Mark Skolnick reiterated these sentiments at a conference on breast cancer genetics attended by both activists and scientists in 1996, stating that
BRCA testing should be as commonly available as a Pap smear (Brenner 1996). The company argued that it was providing an important technology that could help women make their own decisions, and invited both scientists and activists to join in this process of empowerment.

Using what Bruno Latour (1986) has called an “I want what you want” strategy, the company argued that women had the right to determine their own destiny. Myriad told women that it was providing them with power through information, an oft-cited demand of the women’s health movement. Articulated by a number of women’s health activists and championed in Our Bodies, Ourselves, “Knowledge is power” had become synonymous with women’s empowerment. Now Myriad was using this rhetoric that was once solely in the domain of women’s movements to develop a market for its new genetic testing technology. By convincing women that BRCA testing would provide information to help them take power in making decisions about their own health care, Myriad might be able to encourage them to use its service.

Myriad also tried to initiate a dialogue with the patient advocacy community about their concerns regarding the provision of a commercial testing service. The company reached out to advocacy groups, recognizing that these groups had tremendous control not only over their constituencies, but also among Washington players and media outlets. The company organized meetings with activists and consumer groups to “get good relationships with advocacy groups, to make sure we heard what they were thinking, get the tone of what the advocacy groups are thinking” (interview with Myriad Genetic Counselor 2000) and to explain its own position.

Many advocacy groups (including NBCC and BCA) refused to attend these meetings or even speak to Myriad representatives. A member of the National Alliance of Breast Cancer Organizations (NABCO), however, eventually agreed to sit on the company’s clinical advisory board in an ad hoc capacity while helping the company develop educational materials (interview with National Alliance of Breast Cancer Organizations 2000). While the NABCO representative’s participation allowed Myriad to include a visible patient advocate in their discussions, most advocacy groups continued to refuse contact with the company.

As the futility of efforts to convince activist groups, groups of scientists, and groups of health-care professionals became clear, Myriad largely gave up and began to market its testing service directly to individuals potentially interested in testing and physicians. By distinguishing between individuals potentially interested in testing and physicians and their representatives, the company hoped to stabilize its testing service.

Myriad began to market its testing service to the public by advertising in the mainstream media as well as sending targeted brochures and videos to physicians and individuals who requested them directly. Advertisements for Myriad’s testing service appeared in such diverse locations as the New York Times Magazine, the USAirways in-flight magazine, and a Broadway playbill. This strategy suggests that Myriad defined its market as the entire population of American women. In order to develop this market, Myriad relied on the “Knowledge is power” strategy. Through advertisements in newspapers and magazines and promotional videos, the company told women that their BRACAnalysis services would empower them by providing information about their bodies. An advertisement in the New York Times Magazine, for example, showed a woman boldly staring straight at the camera and declaring “I did something today to guard against cancer.” By taking the accurate and informative genetic test, Myriad argued, this woman would be empowered to take charge in the delivery of her own health care.

Educational materials distributed through physicians or sent to individuals who contacted the company expressed similar sentiments. The cover of one brochure sent to women curious about their BRCA risk states “Given a choice, would you rather deal with the known or the unknown?” The back of the brochure offers “answers” (Myriad Genetics 2000). The company promised women both the information and the opportunity to deal with the unknown risks of breast cancer. An educational video put out by the company (Myriad Genetics 1999) made the message clear: a woman who had undergone testing stated “Knowledge is power.”

Myriad also tried to garner public support by developing a reimbursement structure for its expensive technology. Indeed, the only way for it to expand the market for testing was to develop a procedure for insurance reimbursement. While Myriad emphasized the woman’s right to choice, this choice was severely constrained by economics. Myriad’s testing services cost anywhere from $500 to $4,000, with the most common full sequence analysis of both genes costing about $3,000. The company recognized that the costs might be prohibitive if promoted as an unnecessary service, and worked with insurance companies through the Myriad Reimbursement Approval Program (MRAP) to encourage insurance reimbursement.

The company publicized this effort by reiterating its commitment to improving health-care choices. Announcing an agreement with a leading health insurance company, Myriad stated: “We are pleased that Aetna US
Healthcare is taking this step to provide women at risk of developing cancer with access to a test that provides information that might save their lives.” (Myriad Genetics 1998) Although many women were still reluctant to ask their insurance companies to reimburse BRCA testing for fear of discrimination, Myriad used publicity from these insurance services to emphasize not only providing a state-of-the-art clinical service but also empowering women through genomic information (interview with US Geneticist 1999). Indeed, as the company developed its testing system, it defined a pivotal role for insurance companies who became responsible for maintaining the individual’s right to demand BRCA testing.

The company’s strategy clearly demonstrated an effort to entice interest in the new technology by contextualizing the testing system within the efforts of the women’s health movements of the late twentieth century which had likened empowerment to increased access to knowledge. Realizing that it would be unlikely to gain activist support, it used empowerment rhetoric to convince average women to use its testing system. While Myriad tried to divide activists and their constituencies by capitalizing on a particular definition of empowerment, activists continued to work against the company by encouraging women to be careful about their BRCA testing decisions and to use testing only in the context of clinical care. Press releases, position papers, and statements on BCA and NBCC’s web sites suggested an ongoing effort to strengthen an alternative approach to testing.

**Patient Advocacy in Britain**

Although Britain did not have a long tradition of patient activism like the United States, patient advocates in Britain had just begun to gain strength and visibility around the time of the BRCA gene discoveries. This was particularly evident as a number of groups tried to get involved in the development of BRCA testing. Unlike their American counterparts, however, most British activists supported the widespread availability of BRCA testing and wanted to get involved in ensuring its integration into health care. Wendy Watson, a middle-aged woman from Derbyshire who had a prophylactic double mastectomy (preventive removal of both breasts) in 1991 after learning of her extensive family history of breast and ovarian cancer, was particularly vocal in support of widespread development of genetic testing for breast cancer after the discoveries of the BRCA genes in the mid 1990s. Immediately after the discovery of the BRCA1 gene in September 1994, she was relieved by the promise of new technologies that she thought would be able to identify inherited susceptibility: “If there had been a test for me I would definitely have had it. But I thought at least now it might be available for people like my daughter.” (Rogers 1994) Watson argued that the development of testing was particularly important because it would help women like herself who would otherwise be sick with worry to take action to deal with the inherited risk. When describing her decision to have a prophylactic mastectomy to the *Times* of London, she said: “Once I thought that [about the possibility of surgery], no one could have shaken me because my overriding worry was of dying of cancer. I went into hospital, had the operation, woke up and thought: ‘Thank goodness for that, it’s done, that’s the gamble off.’ I felt absolutely fine.” (Laurance 1996)

By May 1996, Watson had begun the Hereditary Breast Cancer Helpline to provide information to individuals concerned about their family history of breast cancer. Funded initially by the UK Department of Health, Watson received thousands of calls a year from individuals anxious about their risk of breast or ovarian cancer, curious about how to access genetics services, and uninformed about their options after learning they tested positive for a BRCA mutation (interview with Wendy Watson, 1998). Bolstered by these interactions with individuals worried about their BRCA risk, Watson began to lobby for increased availability of genetic services. In an article in *The Scotsman* (Christie 1996), she noted: “Every woman has the right to discuss her future with informed and sympathetic professionals. . . I think its ludicrous to say we cannot afford to fund these genetics clinics.” Watson was a strong proponent of BRCA testing services across the United Kingdom. She argued that it had played such an important role in her health and happiness that other women should have the right to have access to the same services. This strong support of BRCA testing, of course, was in stark contrast to the position of American activists who characterized the new BRCA technology as useless and genomic information as potentially dangerous. Moreover, while Watson argued that women had the right to access genetics services, American patient activists limited this right to medical advancements that they classified as good science.

Like Watson, the Genetics Interest Group also sought to become involved in the development of BRCA testing services in Britain. Much like NBCC in the United States, GIG was founded in 1989 by a group of voluntary organizations and disease support groups who wanted to “coordinate action” on the issues they had in common. By the mid 1990s, GIG was issuing position papers and reports on a variety of issues related to
genetic disease. Its approach to genetic testing for breast cancer was very similar to Watson’s, supporting the development and wide availability of these services across the country. A GIG representative summarized its position as follows: “Now our view on testing is, everything is subject to the informed consent of participants, if somebody has reason to suspect that they may be at risk from a genetic disorder, then they should have access to services. . . . That testing should be done in a context where information is provided, where counseling is provided before, and after the testing process. . . .” (interview with Genetic Interest Group representative 1998) While American activists saw testing as a dangerous and uncertain technology from which the government should protect citizens, GIG lauded the potential benefits of the proposed British system. Supporting the risk-assessment and triage system helped GIG potentially carve out a new and powerful role for the disease advocacy community in Britain.

In fact, GIG specifically supported the idea that care by provided according to an individual’s family history: “Because it is possible to say by drawing up certain protocols whether you are as an individual, at high, medium, or low risk. And it’s inappropriate to waste health-care resources, testing people for whom there are no prior indications. As it is inappropriate to avoid using resources to ensure that people who fulfill the criteria do actually get that help and support. But it’s a rational thing.” (interview with Genetic Interest Group representative 1998) Not only did GIG advocate this risk-assessment-based testing system, but it argued that such a system provided a perfect opportunity to assure equal access within the NHS. It was inappropriate to waste scarce resources on individuals at low risk, they agreed, when testing high-risk individuals could confer significant benefits.

British Patient Advocates Making a Difference

What difference did British patient activists make in the development of BRCA testing? Advocacy group representatives sat on advisory committees and attended meetings where the appropriate provision of genetic testing was discussed, and lobbied NHS purchasers to buy genetic testing services for their regions. The Genetic Interest Group (GIG) had a representative sit on the committees that developed national standard of risk assessment and triage for BRCA testing. A representative from the Genetic Interest Group that represented all individuals with genetic disorders commented: “I think people are realizing that the benefit will come by virtue of treatments for rare disorders being piggybacked onto the technology that cracks common disorders.” (interview with Genetic Interest Group representative 1998) Indeed, GIG often called members of its constituency who had rare genetic disorders by arguing that its initiatives specifically with regard to common diseases such as breast cancer would improve their efforts to influence genetics policy. Discussion about the appropriate provision of genetic testing for breast cancer was taking place at the highest levels of the Department of Health and the NHS, and could provide advocates with the opportunity to demonstrate their importance in the biomedical policy-making process. The Genetic Interest Group and Wendy Watson were the most vigorously involved in discussions about BRCA testing. Both strongly advocated access to testing, but they also supported the national standard involving risk assessment and triage. Rather than challenging the triage system and its limitations, they lobbied NHS purchasers to accept and provide BRCA services within this framework.

GIG was not alone in its involvement in trying to influence policies for genetic testing for breast cancer. Wendy Watson also supported the proposed BRCA testing system. Like GIG, Watson lobbied for increased access to testing. She sat on a variety of advisory committees and even gave seminars to NHS purchasers across the country. Watson involved herself directly in the decisions of NHS purchasers, arguing that BRCA testing offered not only life-saving benefits for patients but cost-saving opportunities for the NHS: “I . . . explain to them about the advantages of purchasing genetic services, how much money it saves them. In my family, genetic testing saved the NHS 68,000 pounds. Simply because four of us had the genetic test before we had breast cancer or anything like that. Three of us got faulty genes, and all of us had preventive surgery at a cost of between 2,000 and 4,000 pounds. My sister hasn’t had a preventive mastectomy, but she didn’t have to. So she didn’t have a 3,000-pound operation that would have been unnecessary.” (interview with Wendy Watson, 1998)

Watson took a more extreme position than GIG, however, arguing that every woman should have a choice of the test as well as subsequent medical options: “Everyone should have the right to have a genetic test and take whatever action is necessary to save their lives. . . . So that’s been very important, to be able to empower people, give them the information, and then they do what they want whether it is nothing, screening, preventive surgery, even radical preventive surgery. Whatever they choose, it should be their option and they should be fully supported.” (ibid.) This advocacy of unlimited choice did not appear consistent with the restricted risk-assessment model. Instead, Watson adopted a position
somewhat similar to Myriad: advocating limited choice for individuals who desired access to a potentially life-saving test. As she advocated this strategy, which appeared extreme in the British context, she proactively lobbied on the part of regional cancer genetics clinics in support of the national standard. For her, the more access to BRCA testing, even within the NHS’s risk-assessment and triage model, was better than no access at all. As mentioned earlier, however, she was advocating access to a technology that was very different than Myriad’s.

Watson and GIG’s involvement in discussions about breast cancer risk-assessment services helped to encourage regional purchasers to fund cancer genetics clinics. Watson reported, for example, that her perspective has been received very well. Regional health authority officials were interested in hearing what she had to say, and she often inspired them to begin funding BRCA testing in their region. She recalled, “At the end of my speech [at a regional health authority] last week, I was inundated with people who wanted to chat to me and then someone from the health authorities said that they were mortified that they haven’t had ‘somebody pleading the case, because people are worrying. I find it mortifying that I haven’t already purchased the service, and I should be doing it with a matter of urgency.’ So I’m not greeted as being not knowing what I’m talking about.” (Interview with Wendy Watson, 1998) Her activism on behalf of BRCA testing certainly influenced awareness and purchasing decisions among NHS officials.

While proponents of the NHS standard had initially excluded potential test users and their representatives from discussions about BRCA testing, Watson and GIG forced themselves to be recognized as legitimate participants in stabilizing the testing system. They could be important contributors to the policy-making processes, they argued, lobbying with health-care professionals on behalf of the public for more funds. Even though proponents of the NHS standard largely ignored them, these activist groups became quite relevant in the development of BRCA testing in Britain.

Why did these British patient activists take such a different position to the provision of genetic testing for breast cancer than their American counterparts? These are a few possible reasons. First, patient activists in each country were reacting to a very different provider of the new technology. While British activists were responding to the provision of BRCA testing by the trusted, state-run NHS, American activists were worried that commercial providers such as Myriad and GIVF would stifle research and offer testing as any other consumer product rather than a new and uncer-
tain technology. In addition, the testing systems themselves differed in the two countries. Breast cancer advocates in the United States were reacting largely to the prospects of commercial services such as Myriad’s that required no specialized counseling. In Britain, on the other hand, counseling was an important part of the BRCA testing services that the NHS offered. Second, American and British activists were operating in two very different health-care systems. American activists worried that within a market-driven system that encouraged the rapid availability of new technologies and the growing biotechnology industry, there were few mechanisms that would regulate or even monitor development of the new technology. In Britain, on the other hand, BRCA testing was going to be a provided by a trusted state-run system that was extremely popular among the citizenry. Finally, the histories of patient activism were quite distinct in the two countries. In the United States, patient activists had been steadily gaining power since the women’s health movements of the 1970s. Their opposition to Myriad’s genetic testing system would be unlikely to seriously jeopardize the power and credibility that breast cancer activists had gained since the early 1990s. British activists, on the other hand, had not yet become major figures in biomedical politics. As a result, they would be much less likely to oppose NHS practices of powerful clinicians. Also, patient activists in the two countries had traditionally been oriented toward slightly different goals. While AIDS and breast cancer activists, for example, had lobbied for increased research money, patient advocates in Britain usually worked for better access to services within the NHS. Indeed, while BRCA testing was not offered in the context of research in Britain, only US activists raised this as a major issue in their lobbying efforts.

Conclusion

This comparative analysis has demonstrated how national specificities played a very important role in the responses of patient advocacy groups to the development of genetic testing for breast cancer in the United States and Britain. While the user of health care might seem a first glance to have uniform interests worldwide such as a desire for high quality care and access to services for which there is a demonstrated clinical need, this chapter has shown that national contexts shape the response of the user to the development of a new medical technology. In the United States, patient advocates’ distrust of commercial providers and power in biomedical politics led them to take contrary positions toward the new genetic testing technology. Their positions might even be considered
risky, as they reinterpreted women’s empowerment goals in terms of protection. In Britain, on the other hand, where the health-care system was more trusted by the public and there was virtually no history of patient activism, patient advocates supported development of BRCA testing.

Comparative analysis provides us with important insight into the role that national specificities play in the relationship between medical technologies and users. Of course, the case studied here is particularly stark because BRCA testing was provided by a private company in the United States and offered by the NHS in Britain. Both the US and Britain offer other specialized health-care services in contexts which might lead to more similar experiences for the user in the two national contexts—consider the provision of cancer care services paid for by private insurers in Britain or by health maintenance organizations in the United States. Both local and national contexts frame the interests and experiences of the user of health-care services.

It is also important to keep in mind that this is a comparative analysis of patient advocacy groups, rather than individuals who actually had their blood analyzed for mutations in the BRCA genes. In fact, this analysis has emphasized the distinction between these two groupings. Patient advocacy groups in the United States, for example, adopted a protective stance toward the individuals they represented and also emphasized a knowledge gap between advocacy groups and individuals interested in testing. An NECC representative made this distinction even clearer when describing the advice of NBCC staff when their constituent grassroots advocates visit Washington for “Advocacy Day” once a year:

…we try mostly to look at issues, and it’s hard to do, but kind of take a step back and take the individual out of the issue, and look at it in more of a global public policy way. So when we have our advocacy day and we have advocates from around the country and a lot of them are people who haven’t even been to Washington, they haven’t been to Capitol Hill, and they certainly haven’t been in to meet with their member of Congress, and we really try to drill into them that when you go up there, this is not about your breast cancer, and your specific treatment, and your specific disease and your family, this is about breast cancer. (Interview with National Breast Cancer Coalition representative 1999)

In addition, test providers in both the United States and Britain took advantage of the differences between patient advocacy groups and individuals interested in testing. This analysis forces us to question how we should understand advocacy groups in the context of user studies and perhaps more broadly, consider what makes a “user.”

In recent years there has been a growing consensus among researchers, policy makers, funding agencies, and women’s health advocates that the future users of contraceptive methods should be involved in the development process. The 1990s witnessed a major shift in the field of contraceptive research and development, from the paradigm of population control to this new paradigm. This culminated in the Program of Action adopted at the 1994 United Nations International Conference on Population and Development in Cairo. For the first time people’s reproductive health and rights were placed center stage. During the decade, major organizations in the field of contraceptive development, such as the World Health Organization and the Population Council, took a number of initiatives in order to follow up the ICPD recommendation that “users, in particular women’s, perspectives and women’s organizations [sic] should be incorporated into all stages of the research and development process.” Meetings between contraceptive developers and women’s health advocates were organized, policy was formulated, and social scientific research into the needs and preferences of users was intensified in order to develop what was called “the integration of users’ perspectives” (ICPD 1994). At the heart of this new strategy lay the conviction that users had not previously been taken sufficiently into account by contraceptive developers (Bruce 1987; WHO/HRP 1992; Population Council 1990; Cottingham and Benangiano 1997). But while there was wide agreement about the need to involve users in the research and development process at an early stage, no specific strategies for achieving this had been developed.

In this chapter, I analyze how the integration of users’ perspectives took place in the case of immuncontraceptives. These new birth-control methods are an especially interesting case, because the coordination of research into such methods is done in part by the same institutions that