

PATIENT GROUPS AND HEALTH MOVEMENTS

by

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In 1990, when I began work on a Ph.D. dissertation on AIDS research and AIDS activism, I was able to find little written from an STS or allied perspective on the politics and projects of patients groups, or on health movements more generally.¹ An article by Rainald von Gizycki about cooperation between the German Retinitis Pigmentosa Society and medical researchers, published a few years earlier in a sociology of science yearbook, had seen fit to comment on the novelty of studying any such interaction “from the point of view of the non-scientist rather than the scientist.” Distinguishing his work from all the other contributions to the volume, he proposed to “look at the conditions prevailing inside the non-scientific group which have made it possible to exert influence on scientists, rather than the other way around” (Von Gizycki 1987, p. 75).

Fifteen years later, such an intention would hardly raise eyebrows, as explorations of these topics have mushroomed. Four different journals have published special issues devoted to the epistemic and practical projects of patient groups and health movements (Bonnet et al. 1998; Brown and Zavestoski 2004; Hess 2004a; Landzelius forthcoming-b), and an edited volume also takes up this theme (Packard et al. 2004b). Several of these collective endeavors originated out of conferences that brought together scholars studying these topics in many different countries. From abortion to vaccines, from preterm babies to Alzheimer’s, from intersexuality to alternative medicine, analysts now have studied an extensive and extraordinarily diverse range of cases that span the human life cycle and shed light on nearly every conceivable aspect of the politics of health, illness, and biomedical research.

Patient associations and associated health advocacy organizations pose crucial questions for scholars in the field of STS. How do “disease constituencies” arise, how do they forge “illness identities” as a collective accomplishment, and how do they use those collective

identities as the basis for political mobilization? How do new developments in the biomedical sciences serve to “carve out” new groupings of individuals, in ways that provide unanticipated bases for identity formation or social affiliation? How do the actions of patients or their lay representatives change the way that medicine is practiced, health care services are distributed, biomedical research is conducted, and medical technologies are developed? What is the character of the experiential knowledge of illness possessed or cultivated by patient groups or health movements? What sorts of challenges do these lay actors pose to the authority of credentialed experts, and what kinds of alliances with professionals do they construct? What sorts of “politics of the body” do such groups put into practice, and how are bodies transformed as a result? When does health activism of this kind result in the extension of medicalized frames of understanding, and when does it contest such medicalization? How do patient groups intervene in the web of relationships that connect biomedical institutions both with the market and with the state? What are the effects of these groups on the vast social inequalities that characterize the field of health and health care? What conceptions of medical science do patient groups promote and contest, and what visions do they articulate of what it means to be healthy?

I will offer different vantage points for viewing this burgeoning body of literature and its answers to the questions listed above. First, I will suggest that the surge of interest in this topic within STS cannot be taken for granted, and I will consider why it might be that studies of patient groups and health movements have proliferated within STS in recent years. Second, I will look more closely and critically at the definitional question: Just what is the object of study here, and what are its boundaries? Third, I will briefly describe the different research methods that have been used by STS scholars to study patient groups and health movements. Fourth, in place of a formal typology, I will propose a number of different criteria by which we might usefully compare and contrast different patient groups and health movements. Fifth, I will consider three

key research questions that have emerged in relation to the emergence and functioning of these groups. Sixth, I will examine the effects or consequences of patient groups and health movements. Finally, I will suggest some potentially useful directions for future scholarship.

Why this, why now?

The recent efflorescence of intellectual activity in relation to patient associations and health advocacy poses an interesting question in its own right, a question in the sociology of knowledge: Why the burst of scholarly attention to this topic at this particular time? No doubt it reflects, in part, the growing prominence of the phenomenon itself. On the one hand, it is worth emphasizing that group formation and activism of this kind is by no means new. In the United States, for example, voluntary national health associations such as the National Tuberculosis Association and the predecessor of the American Cancer Society were inventions of the early years of the twentieth century (Talley 2004, p. 40) and self-help groups in the “12-step” mold, such as Alcoholics Anonymous, followed a few decades later (Rapp 2000, p. 193); while other sorts of group-specific health activism with enduring legacies, such as women’s health movements, date back to the nineteenth century (Weisman 1998). On the other hand, many commentators have noted the sheer quantitative increase in such organizing in recent years, as well as its enhanced social visibility (Katz 1993, p. 1; Kelleher 1994, p. 105; Rapp, Heath, and Taussig 2001, p. 393; Rabeharisoa 2003, p. 2127; Allsop, Jones, and Baggott 2004, pp. 738, 741).² Qualitative changes may also be heightening the salience of this social form. Rapp, Heath, and Taussig have observed the tendency toward “marriages, mergers, and traffic among these organizations” in recent years (Rapp, Heath, and Taussig 2001, p. 392); while Allsop, Jones, and Baggott, in reference to the U.K., have pointed to the diffusion of “shared values and norms across condition areas” as well as the emergence of a common discourse across groups (Allsop,

Jones, and Baggott 2004, p. 745). Although the bulk of studies to date have tracked these developments in the U.S., the U.K., and France, existing analyses suggest a trend that is, if not global, then well represented at least in many Western countries and in Japan (Matoba 2002). Indeed, the shortage of analyses of patient groups and health movements in other parts of the globe most likely reflects a research gap to be remedied more than an absence of the phenomenon on the ground. In fact, transnational alliances increasingly are connecting health advocates in the global “South” with their counterparts in the “North” (Whyte, van der Geest, and Hardon 2002, pp. 146-60; Bell 2003; Barbot forthcoming, p. {add}; Hardon forthcoming).

It is understandable, then, that this proliferation of patient groups and health movements has attracted scholarly attention, especially because of a widespread sense of their consequence—indeed, a perception that such groups often have been successful in their goals. As a number of commentators have suggested, this upsurge of health- and disease-based organizing reflects the prevalence in recent decades of more skeptical attitudes toward doctors, scientists, and other experts, trends that also have manifested themselves in new conceptions of patients’ rights and renewed concerns with bioethical debates (Brown and Zavestoski 2004, p. 682). Many scholars also have associated recent patient groups and health movements with the more general expansion of rights-based movements and of so-called “new social movements” since the 1960s (Shakespeare 1993; Kelleher 1994, p. 113; Epstein 1995, pp. 412-13; 1996, pp. 20-21; Kaufert 1998, p. 303; Layne 2003, pp. 38-39; Silverman 2004, pp. 361, 370; Blume forthcoming, pp. {add}; McInerney forthcoming, pp. {add}).³

At the same time, the fact that scholarly literature on patient groups and health movements has flourished in the past fifteen years also says something about the field of STS and its own trajectory of development. During that time scholarly work in STS has moved decisively “beyond the lab” to analyze—in all their messiness, variability, and volatility—the

broader dimensions of public engagement with science and technology. Patient groups and health movements have proven to be more than incidental objects of attention for analysts seeking to understand how and why it is that in a technoscientific world, “without public participation, things simply fall apart” (Elam and Bertilsson 2003, p. 243). Rescuing us from the vague and hopelessly undifferentiated notions of “the public” or “the public sphere” that all too often are invoked in discussions of the “public understanding of science,” patient groups and health movements are—at least by comparison—specific, concrete, and locatable entities, well available for study. Moreover, the passion and moral fervor that often animates them makes them especially interesting as exemplars of the new kinds of subjectivities that STS has encompassed within its scholarly embrace.

A range of recent work of broad significance to the overall field of STS has found it useful to focus attention on the specific phenomena of patient groups and health movements in order to make more general points. Michel Callon and Vololona Rabeharisoa have treated *associations de malades* as exemplary manifestations of “concerned groups”—non-scientists conceived of as “(potentially) genuine researchers, capable of working cooperatively with professional scientists,” whose dramatic growth in recent years has sparked new varieties of “research in the wild” (Callon and Rabeharisoa 2003, p. 195; see also Callon 2003). Similarly, Bruno Latour has pointed to the engagement of patient groups with biomedical research as emblematic of the “collective experiments” by which science policy is now generated (Latour 1998). Patient groups and health movements also figure as prominent examples in the line of STS research that Sheila Jasanoff has termed “co-production” studies (Jasanoff 2004); in the formulation of new notions of “scientific citizenship” (Elam and Bertilsson 2003; Irwin and Michael 2003); in the renewed emphasis on the institutional, structural, and political dimensions of science and the social order that Scott Frickel and Kelly Moore have promoted as “the new

political sociology of science” (Frickel and Moore forthcoming); and in the proclamation by Harry Collins and Robert Evans of a “third wave” of science studies that re-conceives of the nature and boundaries of expertise. From the rubric of technology studies, analysts have recognized patient groups and health movements as an important subtype of the “relevant social groups” described by Bijker, Hughes, and Pinch in their canonical work on how the trajectories of technological development are shaped (Pinch and Bijker 1993, pp. 30-34; Blume 1997, p. 46); while the recent scholarly emphasis on “users” of technologies has provided an additional entry point for assessing the contributions of advocacy groups (Oudshoorn and Pinch 2003). In all these ways, from all these diverse perspectives within STS, patient groups and health movements in recent years have proven remarkably “good to think with.”

However, none of this is sufficient to account for the particular emphasis on questions of biomedicine, health, and illness. Patient groups and health movements have come to be of growing interest to STS scholars not just in response to broad debates about public engagement with science, but also because of their centrality to the processes by which bodies, diseases, and life itself are being remade by the biomedical revolutions of recent years. On the one hand, the rise of interest in health activism reflects the more general movement of biomedical topics from the relative periphery to the very center of attention within STS over the past fifteen years. On the other hand, during those same years, as Adele Clarke and coauthors have described, medicine itself has been transformed “from the inside out” (Clarke et al. 2003). Through innovations in molecular biology, genomics, bioinformatics, and new medical technologies; through the intensification of clinical research practices; through vast increases in public and private funding for biomedical research; through the ascendance of evidence-based medicine and the growing prominence of techniques of standardization and rationalization in medicine; through the development of neoliberal approaches to health that promote new modes of governing bodies

and populations; through the rapid expansion of a global pharmaceutical industry constantly searching for new markets and engaging in new ways with consumers; through the resurgence of dreams of human enhancement or perfectibility by means of biotechnologies; and through the dominance in the United States of managed care as a system attempting to rationalize and ration health-care delivery; the world of medicine has to some significant degree been refashioned in ways that impinge (variably) upon the everyday experiences and practices of people around the globe (Berg and Mol 1998; Lock, Young, and Cambrosio 2000; Rose 2001; Franklin and Lock 2003; Keating and Cambrosio 2003; Timmermans and Berg 2003; Conrad 2005; Lakoff 2005).

The increasing “disunity” of medicine (Berg and Mol 1998; Barbot and Dodier 2002) makes it hard work to comprehend all these shifts. Yet an analysis of patient groups and health movements is crucial for understanding the consequences of these manifold biomedical transformations, especially including the resistances that have arisen in response to them. We live in a world characterized by what Nikolas Rose has called “vital politics,” in which “selfhood has become intrinsically somatic,” and in which “biopolitics now addresses human existence at the molecular level” (Rose 2001, pp. 16, 18). Categories of personhood are being reconstructed by new medical technologies (Dumit 1997), and new practices of research, care delivery, and risk profiling cut across (or remake) populations in widely divergent ways—sometimes shoring up, sometimes reconfiguring, profound disparities in health care and health outcomes according to social class, race, ethnicity, gender, sexuality, region, and nation. Yet as Clarke and coauthors rightly insist, new biomedical developments cannot be understood only in top-down fashion: we must simultaneously be on the lookout for “new forms of agency, empowerment, confusion, resistance, responsibility, docility, subjugation, citizenship, subjectivity, and morality” that emerge from dispersed social locations in response to such changes (Clarke et al. 2003, p. 184).

Recent biomedical developments have thrust into view new outcroppings of agency and

resistance in at least two ways that are well reflected in the new scholarship on patient groups and health movements. First, drawing on Paul Rabinow's descriptions of "biosociality" (Rabinow 1996, pp. 91-111), several analysts have expanded the concept of citizenship to describe the practices that link bodies, individuals, groups, and nations together—or that separate the biosocially privileged from the excluded—at the biological or genetic level (Petryna 2002; Briggs and Mantini-Briggs 2003; Heath, Rapp, and Taussig 2004; Rose and Novas 2005). Patient groups and health movements have been pivotal actors in the making and the unmaking of these new varieties of biological, biomedical, or genetic citizenship.

Second, the diverse politics of feminism and women's health not only crisscross the new biomedical landscape but also are implicated within the rise of patient groups and health movements to an astonishing degree. In reviewing the literature in preparation for writing this chapter, I quickly recognized what a hefty proportion of the recent research is devoted to understanding groups that concern themselves with women's bodies and women's health—particularly including breast cancer activism, which is now the most extensively researched of any health movement from an STS perspective, but also abortion, reproductive and contraceptive technologies, pregnancy loss, postpartum depression, and menopause, among others.⁴ Of course, this scholarly emphasis is indicative not only of the social centrality of these issues, but also of the distinctive impact of feminist theory and politics on several generations of STS researchers.

Thus the recent scholarly interest in patient groups and health movements reflects both the growing salience of the analytical object and the larger transformations of the biosciences and the political environment, at the same time as it tracks broader substantive shifts in emphases and concerns within STS. Although a genealogy of studies of patient groups would locate much of the earliest scholarship well outside of the field of STS (Stewart 1990; Borkman 1991; Chesler 1991; Katz 1993; Kelleher 1994; Lavoie, Borkman, and Gidron 1994), at present STS is

perhaps the largest contributor. Yet this claim is in some respects misleading, because—just as it has become harder in general to place boundaries around the field of STS in recent years—the STS scholarship on patient groups and social movements reflects creative fusions and cross-fertilizations, especially with medical anthropology, the sociology of health and illness, and the sociological study of social movements.⁵ Indeed, the new STS work on these topics may be one of the chief pathways by which the field of STS is having an influence on these other fields—as evidenced by the publication of special issues in mainstream journals of medical sociology (*Sociology of Health & Illness* and *Social Science & Medicine*). Familiar sociological and anthropological concepts such as the illness experience, the doctor-patient relationship, collective identity, and mobilization are being reworked through conversation with STS approaches; and, as Kelly Moore has observed, studies of activist challenges to medicine are proving an important exception to the tendency in social movement scholarship to presume that movements are worth studying only when they take on the state (Moore 1999). More generally and more ambitiously, the study of patient groups and health movements provides STS scholars with an appropriate vehicle for explaining to scholars in other fields the broader relevance of technoscientific developments for the understanding of important theoretical concepts, such as collective identity, solidarity, personhood, and embodiment.

What is the object?

So far I have been using the phrase “patient group” as if its meaning and referents were clear and unequivocal. Yet the body of scholarship I am reviewing here has tended to burst the bounds of the category in several ways. First, quite a few advocacy groups that have been studied under this general rubric are organized not by patients per se, but by various sorts of “proxies” for patients. These may be parents or relatives, in cases where the actual patient is too young or

too physically or mentally incapacitated to advance his or her own interests (Beard 2004, p. 798); they may sometimes be activists, who may or may not actually have the disease or condition in question, and whose interests may not precisely coincide with the larger group of patients or users of medical technologies (Epstein 1995; 1996, pp. 252-53; Van Kammen 2003); or they may be advocates speaking on behalf of broad constituencies (such as “women’s health”) whose interests transcend any specific disease (Epstein 2003a). The point is not to exclude cases of these kinds as legitimate instances of the phenomenon under study but, rather, to call attention to the very practices of representation by which spokespersons come to stand in for a group—a task for which STS is well suited. In other cases, patienthood itself may be a murky status. In her analysis of infant loss support groups, Linda Layne has observed that it is “surprisingly difficult” to say whether there is a patient present: “By the time a loss has occurred, the embryonic/fetal/neonatal patient is no more and the woman is no longer pregnant, and therefore no longer an active obstetrical patient” (Layne forthcoming, p. {2nd}). Here again, rather than quibble over who really qualifies as a patient, we would be advised to embrace elastic classifications and ask what we can learn from the juxtaposition of examples.

In practice, many analysts of patient groups simply have not found it possible or meaningful to discuss the phenomenon apart from consideration of broader categories, such as “health social movements” (Brown and Zavestoski 2004; Hess 2004b), “consumer movements” in health (Bastian 1998; Allsop, Jones, and Baggott 2004; Rosengarten 2004); the practice of organizing around “pain and loss experiences” (Allsop, Jones, and Baggott 2004, p. 738); and the political projects advanced by “communities of suffering” (Packard et al. 2004a). Furthermore, the study of patient groups shares blurry boundaries with still other sorts of phenomena: science advocacy movements pressing for research on specific biomedical topics, such as stem cells (Ganchoff 2004); movements advocating democratic participation in priority-setting for public

funding of medical research (Dresser 2001); ecological and environmental justice movements that have significant health implications (Pellow and Park 2002; Allen 2003; Brown, Mayer et al. 2003; Allen 2004; Hess 2004a, 2004c; Shostak 2004); movements for new therapeutic directions, such as efforts to advance complementary and alternative medicine (Goldner 2001, 2004; Hess 2004b); and movements that work with private-sector firms to develop alternative health products (Hess 2005). In other cases, such as the French muscular dystrophy association (AFM) studied by Rabeharisoa and Callon, affinities to social movements may be less relevant than similarities to large, formal organizations: the AFM employs more than 500 workers and has an annual budget of nearly 80 million euros (Rabeharisoa 2003, p. 2130).

On the ground, the actors participating in these collectives are defining themselves in an expanding variety of ways—indeed, there is probably a complex interaction between the spread of analytical categories, on the one hand, and of the self-descriptions mobilized by the groups and movements, on the other. Rather than attempt any exclusionary boundary work, I prefer to follow both the analysts and the actors as they increasingly think outside the box of “patient groups,” in the narrow sense of the term, so as to draw connections as well as contrasts across a diverse range of cases.⁶ In the rest of this chapter, my use of the term “patient groups and health movements” will be meant as shorthand to invoke this broader array.

Three methodological implications follow from this expansion of analytical focus. First, even while being catholic in acknowledging diverse ways of framing the conceptual object, it seems important to consider how different terminological choices affect the mapping of the intellectual terrain. According to Hilda Bastian in her analysis of the rise of consumer advocacy in health care, “people can argue for hours over whether we are ‘consumers,’ ‘users,’ ‘patients,’ ‘clients,’ or any other term from a list of favorites,” suggesting that the nomenclature is on some level arbitrary and that we can rescue words such as “consumer” from any negative associations

they might bear (Bastian 1998, pp. 3-4). Others, however, have insisted that words inevitably do bring meanings along with them. In his study of tobacco control, Roddey Reid has critically analyzed the consequences of viewing the targets of health promotion campaigns as “consumers,” arguing that the displacement of more substantive notions of citizenship by a market model of social relations is consistent with the rise of neoliberal approaches to managing the health of populations (Reid 2004). Similarly, those who consider themselves to belong to a “health movement” may be more likely to link their concerns to questions of power, participation, and democracy than those who see themselves as part of a “patient group.”

Second, it becomes important to take the hybrid and boundary-crossing character of patient groups and health movements as an explicit object of study—much as researchers increasingly have been doing. Many such groups are hybrid insofar as they blur the divisions not only between “expert” and “lay,” but also between “civil society,” “the state,” and “the market,” and—of course—between “science” and “politics” (Epstein 2001). Observation of patient groups and health movements reveals, on the one hand, cases of patients and activists behaving like scientists or doctors (Epstein 1996; Anglin 1997; Myhre 2002) and, on the other hand, cases of scientists or doctors behaving like activists (McCally 2002; Frickel 2004) or like patients (Mykytyn forthcoming). In still other cases, such as the abortion rights movement in the United States, the movement itself encompasses both lay and professional actors (Joffe, Weitz, and Stacey 2004). McCormick, Brown, and Zavestoski have proposed the term “boundary movements” to describe such blurrings (McCormick, Brown, and Zavestoski 2003), thereby usefully connecting the study of these characteristics of patient groups and health movements to related STS concepts concerned with boundaries (Gieryn 1983; Star and Griesemer 1989; Guston 2000). Somewhat similarly, I have proposed that Mark Wolfson’s concept of “interpenetration” (developed in his study of the anti-tobacco movement) is helpful in describing those cases where

it is systematically unclear “where the movement ends and the state begins” (Wolfson 2001; Klawiter 2005; Epstein Forthcoming).⁷ Though not using the term, analysts have revealed state/movement interpenetration to be a defining characteristic of a number of national health advocacy groups in the U.S. in their formative relationship with specific branches of the National Institutes of Health (Fox 1989; Talley 2004, p. 58). A recent example is the intimate relationship between the Genetic Alliance (a super-group of genetic support groups) and the NIH’s Office of Rare Diseases, established in 1993 (Rayna Rapp, personal communication).

The third methodological implication of the move beyond any narrow consideration of patient groups is the importance of locating multiple patient groups and health movements in relational terms, both diachronically and synchronically. Sometimes this has been done by examining the “diffusion” or “spillover” effects of one movement upon another (Meyer and Whittier 1994; McAdam 1995)—analyzing how emergent groups adopt and adapt the frames, strategies, or action repertoires of previous movements or organizations (Epstein 1996, pp. 12, 347-48; Karkazis 2002, ch. 9; Brown et al. 2004, pp. 65, 68) In other cases, STS scholars have examined the simultaneous impact of different patient groups or health movements on the same issue, as in Stefan Timmermans and Valerie Leiter’s analysis of how FDA hearings on the revival of thalidomide as a legitimate treatment brought into competition the perspectives of the Thalidomide Victims Association of Canada, HIV/AIDS activists, women’s health advocates, and representatives of people with leprosy (Timmermans and Leiter 2000; for a different example see Clarke and Montini 1993). Most ambitiously, a number of scholars have sought to locate patient groups and health movements within “fields” of activity (in some cases borrowing on Bourdieu’s general theorization of fields of practice (Bourdieu 1985) and in other cases adopting Raka Ray’s more specific concept of “fields of protest” (Ray 1999)). For example, Nick Crossley has analyzed the relatively autonomous “field of psychiatric contention” in the UK,

within which “organisations variously compete, co-operate, agree, disagree, debate and take up positions relative to one another” (Crossley forthcoming, pp. {add}); Maren Klawiter has described the different “cultures of action” present within the field of breast cancer activism in the San Francisco Bay Area (Klawiter 1999; Klawiter 2000), as well as transformations in the institutional field of mammography screening (Klawiter 2005) and syntheses across the fields of cancer activism and environmental activism (Klawiter 2003); and Chris Ganchoff has located embryonic stem cell movements and counter-movements within a larger “field of biotechnology,” understood as “an imagined space within which various politicized collective illness identities exist” (Ganchoff 2004, p. 760). In all these ways, scholars have been moving beyond the analysis of the patient group in isolation to examine the institutional and cultural webs in which they are multiply entangled.

Methods

STS researchers studying patient groups and health movements have been employing an increasingly diverse mix of data sources and specific research techniques (Brown and Zavestoski 2004, p. 690). These include single- and multi-sited ethnographic methods, content analysis, questionnaires, focus groups, and textual analysis. A few researchers have taken a biographical approach that emphasizes the stories of key individuals (Lerner 2001; Klawiter 2004); and a few have employed computerized tools of network analysis (Rabeharisoa forthcoming).

Not surprisingly, given the growing significance of the internet for the formation and maintenance of patient groups, there has been a parallel interest in obtaining and analyzing various forms of online data. While mostly this research has consisted of online ethnographic observation of listserves and newsgroups (Goldstein 2004) or content analysis of websites (Novas 2005), others have taken less typical approaches. In her study of a breast cancer

organization that emphasized web-based communication, Patricia Radin also analyzed server logs and interviewed the webmistress by phone, email, and in person (Radin forthcoming). Scholars also have begun to experiment with the use of computerized information tools to manage the massive quantities of data available online in sources such as newsgroup archives (Dumit forthcoming, pp. {add}).

For a number of scholar/activists, the study of patient groups and health movements has raised important methodological (and ethical and political) questions about conducting forms of research where the analyst is also an actor in the movement or organization. For example, in her study of the transnational controversies surrounding new contraceptive technologies, Anita Hardon “wore both hats, participating in debates [as a women’s health advocate] and taking meticulous notes on the actions and reactions as a researcher.” In her written text, Hardon noted each occasion on which she participated as an advocate (Hardon forthcoming, pp. {add}n8). Layne also has considered such issues in her recent work on infant loss support groups (Layne 2003, forthcoming). Layne’s analysis was based on extensive field research, but it also reflected her personal experience of having miscarried as well as her emerging role as an activist in the movement (Layne forthcoming).

Typologies, typologies

In an attempt to impose order on the mix of collectivities encompassed under the rubric of patient groups and health movements, researchers have suggested a number of helpful (if potentially competing) typologies. One set of distinctions that has been widely cited is that drawn by Phil Brown and coauthors between *health access movements* concerned with the equitable provision of health-care services; *constituency-based health movements* that focus on the health agendas of large, socially visible groups, such as those defined by gender, race,

ethnicity, or sexuality; and *embodied health movements* that “address disease, disability or illness experience by challenging science on etiology, diagnosis, treatment and prevention” (Brown et al. 2004, pp. 52-53; see also Zavestoski, Morello-Frosch et al. 2004). This classification is useful especially for shining a spotlight on the third category—embodied health movements—which in practice has been the primary concern of STS scholars.⁸

The question is how well these categories serve to distinguish specific movements. Brown and coauthors note that their terms are only ideal types, and they acknowledge that some health movements may have characteristics of more than one category (Brown et al. 2004, p. 53). Still, it is striking how many real-world examples cross the typological lines. For example, Layne has described how the infant loss support movement, while in many ways emblematic of what Brown and coauthors would call an embodied health movement, has also been concerned with extending the movement to “underserved communities”—thereby taking on tasks associated with health access movements and constituency-based health movements (Layne forthcoming, pp. {add}). Similarly, Alondra Nelson’s excavation of the little-known history of the Black Panther Party’s involvement in health activism has depicted a movement whose forms of engagement with health issues cut across the tripartite division described by Brown and coauthors (Nelson 2003). The risk, then, is that an overly rigid adherence to this typology could conceivably lead to oversimplified and inaccurate understandings of internally diverse social movements or a truncation of their complex histories—for example, imagining that “embodied” AIDS activists were not also concerned with issues of access to health care (Hoffman 2003).

By contrast with Brown and coauthors, the typology proposed by Rabeharisoa and Callon is concerned less with the structural characteristics of groups and more with their orientations toward biomedical partnerships. Rabeharisoa and Callon divided patient associations into three kinds (all of which, however, might be seen as subtypes of embodied health movements):

Auxiliary associations support the biomedical research process but either leave it up to credentialed experts to decide which topics to research or else “[set] about acquiring the necessary knowledge to be able to enter into discussion with them” about research priorities.

Partner associations play a more substantial role in the organization of medical research in ways that often include, but go beyond, directly raising funds for research. And unlike the other types, *opposing associations* simply want nothing to do with medical specialists (Rabeharisoa and Callon 2002, pp. 60-63). This typology is also helpful, although the somewhat elastic definition of auxiliary associations to encompass groups that acquire their own medical expertise leaves it a bit unclear exactly how they can be distinguished in practice from partner associations.

With both of these typologies, there is also the risk that taking disease-specific groups as the unit of analysis can falsely incline us to imagine an internal homogeneity and to disregard crucial, cross-cutting divisions by other categories of identity, such as race, class, gender, and sexuality. It may sometimes be quite problematic to assume “that disease is the great leveler,” as Lisa Cartwright has warned, since “the experiences and cultures of illnesses... are always lived through identity positions and arenas of public and professional discourse that exceed the frameworks and cultures of disease” (Cartwright 2000, pp. 121-22).

More generally, it may be wise to be skeptical of the idea that any single, unidimensional typology adequately can capture the variation of patient groups and health movements: each well-posed research question about patient groups will generate a unique classificatory scheme that chops up the universe of cases in a distinctive way. The point, then, is to consider what some of those important questions might be, and by that route to examine the key dimensions along which patient groups and health movements may vary. Several examples are worth considering:

- *Relationship to medicalization:*⁹ Patient groups and health movements can be categorized according to their orientation toward the extension of medical frames of

understanding. One fascinating family of cases that has been well represented in the recent literature concerns conditions such as chronic fatigue (Barrett 2004; Dumit forthcoming), fibromyalgia (Barker 2002; Barrett 2004), multiple chemical sensitivity (Kroll-Smith and Floyd 1997; Dumit forthcoming), Gulf War Syndrome (Zavestoski et al. 2002; Brown, Zavestoski et al. 2003; Zavestoski, Brown et al. 2004), post partum depression (Taylor 1996), sick building syndrome (Murphy 2004b), and repetitive strain injuries (Bammer and Martin 1992; Arksey 1994, 1998). These “illnesses you have to fight to get,” as Joe Dumit aptly terms them (they have also been characterized as “contested emergent illnesses” (Packard et al. 2004a, p. 26) and as “medically unexplained physical symptoms” (MUPS) (Zavestoski, Brown et al. 2004)) have in common the demand on the part of sufferers that their mysterious conditions be publicly acknowledged as being legitimately of a medical nature. As Kristin Barker has suggested, sufferers of such conditions find themselves in a state of “epistemological purgatory”—an anxiety-provoking experience “in which they question their own sanity precisely because of their certainty about the realness of their experience in the face of public doubt” (Barker 2002, p. 281). Often accused of having problems that are really just “in their head,” these putative patients “cling to the biological” as a tactic of legitimization, insisting upon the “realness” of their illnesses in biological terms (Taylor 1996; Dumit forthcoming, pp. 17-18).

At the same time, a different and equally intriguing cluster of patient groups and health movements repudiate medicalization or seek to demedicalize their conditions. Studies of Deaf activists who oppose the use of cochlear implants as an assault on Deaf culture (Blume 1997, 1999); of lesbian and gay liberationists who rejected the definition of homosexuality as a mental disorder (Bayer 1981); of intersex activists critical of pediatric specialists who insist on surgically resolving cases of “ambiguous” genitalia among newborns (Karkazis 2002, ch. 9); of African-Americans with sickle-cell anemia who resisted the racialization of the disease and the

consequent pathologization of their racial identities (Fullwiley 1998); of the sector of the mental patients self-help movement that has embraced a position of “anti-psychiatry” (Morrison 2004; Crossley forthcoming); and of fat acceptance activists who challenge the discourse of an obesity “epidemic” and question epidemiological claims about the unhealthy effects of being overweight (Saguy and Riley 2005) demonstrate the range of cultural resources that the unwillingly medicalized may bring to bear, in the hope of casting off the yoke of medical definitions and interventions and the normalizing judgments that underpin them. Studies of disability activism likewise have been keen to demonstrate the formation of new collective identities that partially or wholly reject the normalizing judgments of biomedicine about how human beings are supposed to look or behave (Shakespeare 1993, 1999; Dowse 2001; Rapp and Ginsburg 2001).

Other demedicalizers, including various descendants of the feminist women’s health movement, may be less concerned with resisting medical diagnoses or treatments than with asserting the capacity of women to exercise control over their own bodies (Copelton 2004; Murphy 2004a). Still other groups seek neither to claim an illness identity nor to reject one but rather to question or repudiate specific medical practices, such as vaccination (Blume forthcoming) or vivisection (Elston 1994). Thus while medicalization and demedicalization as distinctive goals are useful terms for considering patient groups and health movements, in practice each term may encompass quite disparate examples. Moreover, many groups seeking to demedicalize their conditions nonetheless may invoke biomedical data and frameworks as part of their political argumentation —a tension that Heath, Rapp, and Taussig rightly label productive (Heath, Rapp, and Taussig 2004, p. 158). Conversely, groups that do not dispute the overall relevance of a biomedical framework for understanding their issue of concern—and that may accept that medical science “is the only (or most powerful) game in town” (Thompson 2005, p. 238)—may still challenge particular medical projects or tendencies (Epstein 1997a; Thompson

2005; Hardon forthcoming). Yet another tricky case is that of advocates for complementary and alternative medicine, who may accept medical definitions while rejecting conventional medical therapies (Goldner 2001, 2004; Hess 2004b). “Medicalization” and “demedicalization” capture something of what these various groups are up to, but the terms should be used with caution.

- *Constitution of the group:* A different way of categorizing patient groups and health movements looks critically at the group formation process: What is the pathway by which a group’s “groupness” comes into being? In some cases, groups emerge out of previously existing communities—such as military veterans in the case of people with Gulf War Syndrome (Zavestoski et al. 2002; Brown, Zavestoski et al. 2003; Zavestoski, Brown et al. 2004) or gay communities in the case of many early AIDS activist groups (Epstein 1995, pp. 414-15; 1996, pp. 10-14)—and their capacities to mobilize and their forms of engagement may be shaped significantly by those previous associations. In other cases, individuals with no previous connection to one another are inducted into group membership via biological, biomedical, or biotechnological processes that construct new biosocial grouping—for example, associations formed by family members of people with genetic disorders (Rapp, Heath, and Taussig 2001), or by the surviving kin of organ transplant donors (Sharp 2001). Still other cases show the influence of corporations and markets in the constitution of groupness. For example, Carlos Novas has described how pharmaceutical company websites may deliberately “emulate the ‘look and feel’” of sites produced by patient organizations, in an attempt to “create a sense of ‘community’ between affected persons and the company” (Novas 2005); while Kane Race (2001) and Marsha Rosengarten (2004) have analyzed the ways in which makers of antiretroviral drugs seek to shape the personal and collective identities of people with HIV/AIDS through “lifestyle” advertising. Finally, nation-states may sometimes play an important role in molding the identities of groups organized around illnesses (Larvie 1999). These examples suggest the importance of studying the

“looping effects” (Hacking 1995, p. 34) by which external attributions about a group are taken up by the group and become constitutive of its members’ identities. In addition, these examples suggest that collective illness identities are rarely stable over long periods of time. Not only do identities often evolve as groups embark on different biomedical and political projects, but the group’s definition may itself be a stake in health controversies. For example, in her analysis of lesbian health advocacy, Sarah Wilcox has argued that that the debate over lesbian health priorities in the 1980s and 1990s coincided with an equally heated debate over the boundaries of the category of “lesbian” (Wilcox 2000).

- *Social organization:* As already suggested by my discussion of what “the object” is, patient groups and health movements vary considerably in terms of the size of membership and finances; the geographic scope (local, national, or transnational); and the degree of formal organization, bureaucratization, and professionalization. In addition, some groups coexist or compete with different groups addressing the same condition, while others have the playing field to themselves. Still others, such as the various genetic disease support groups, may form organizational coalitions across genetic conditions (Heath, Rapp, and Taussig 2004). These basic differences have (at least loose) implications for how groups are governed, how leadership is constituted within them, how practices of participation and representation function within them, and how (or whether) new alliances are established across them.

- *Independence:* To what degree does the group maintain an autonomous standing, and to what degree is it dependent upon, or fused with, other organizations, such as private firms, state agencies, professional associations, funding agencies, or non-governmental organizations? For example, Orla O’Donovan has described a continuum of relations between patient groups and the pharmaceutical industry that includes such diverse orientations as “corporatist,” “cautious cooperation,” and “confrontational.” As O’Donovan’s research in Ireland suggests, these varying

degrees of cooperation with, or autonomy from, industry have implications for patient group practices and sensibilities, though by no means in any automatic fashion (O'Donovan 2005).

- *Militancy and oppositionality:* Yet another way of classifying patient groups and health movements focuses on the degree to which they mount militant challenges or seek to oppose the status quo. While many support groups adopt deliberately non-confrontational styles and comply with the advice of medical professionals, others practice “organized noncompliance” (Emke 1992) and cast their opposition in ways that Debbie Indyk and David Rier termed “self-help with a vengeance” (Indyk and Rier 1993, p. 6). Often, militancy may be a consequence of urgency, as when a group confronts a fatal disease and perceives itself to be engaged in a life-and-death struggle. The oppositional character of a patient group or health movement also may conceivably depend on the degree to which professionals dominate within the movement (Von Gизycki 1987, p. 85; Joffe, Weitz, and Stacey 2004); the extent to which the group is organized in a professionalized and bureaucratic fashion (Staggenborg 1999); whether the group distances itself from the frameworks of Western allopathic medicine (Goldner 2001, 2004; Hess 2004b, 2005); and whether it articulates a clear alternative vision rather than simply rejecting the status quo (Hess 2004c). In addition, organizations with a genuine grassroots base may adopt a more oppositional repertoire than those with elite sponsorship—sometimes called “grass-tops” or “astroturf” advocacy (Dimock 2003; O'Donovan 2005). In the end, the choice made between agonistic and consensual approaches may greatly affect the kind of scientific citizenship that activists help forge (Elam and Bertilsson 2003; see also Landzelius forthcoming-a).

An important question here concerns the circumstances in which militancy is perceived as efficacious. For example, the AIDS activist group ACT UP became known for its radical politics and confrontational style, even if much of its success in transforming medical science stemmed from the melding of militant “outsider” and cooperative “insider” tactics (Epstein 1996).

Consequently, a number of groups, such as chronic fatigue activists, have styled themselves after ACT UP's militancy, though not always with the same success (Barrett 2004). Other groups explicitly have sought to distance themselves from the aggressive image of ACT UP on the assumption that less “in-your-face” tactics would be *more* effective: these include mainstream breast cancer advocacy groups in the United States, which stressed their “ordinariness” and “moral worthiness” vis-à-vis “the public stereotype of the AIDS patient, gay, male, and radical” (Kaufert 1998, p. 102; see also Myhre 2002); parents of premature infants, who adopted metaphors of “generativity and affinity” in place of ACT UP’s militaristic imagery (Landzelius forthcoming-a, p. {add}); and advocacy groups for assisted reproductive technologies, which adopted a style of “motherly activism” that appeals both to the left (“reproductive choice”) and to the right (“family-building”) (Thompson 2005, pp. 238-39). The point is not that either being militant or being unthreatening are universally efficacious tactics. Rather, different actors will perceive different strategic advantages accruing to these orientations, depending on the constraints that they face, as well as the specifics of the disease or condition in question, the stage in the movement’s development, its perceived relationship to other visible movements within the “field,” and the particular historical moment.

- *Goals:* As a final example, it might be possible to construct a typology of patient groups and health movements based on the various sorts of goals that they pursue. The diverse goals of such groups include finding (or rejecting) medical cures; improving the quality of life of ill people; cultivating practical advice for the management of illness; raising funds for research; changing scientific and medical practices, priorities, or orientations; rejecting technoscientific approaches; opposing stigmatization and exclusion; and changing more diffuse cultural codes related to the meanings associated with health, illness, the body, and expertise. Needless to say, many if not most groups adopt more than one of these goals.

Key research questions

Three sets of questions about patient groups and health movements stand out for the amount of attention they have received from STS scholars. These are: (1) What kinds of social and technoscientific developments are implicated in the rise of patient groups and health movements? (2) How do particular aspects of the disease or condition affect the rise and trajectory of patient groups and health movements? And (3) What conceptions of knowledge do these groups employ, how do they put their knowledge to use, and what kinds of expertise do they develop? I will address these in turn.

- *Social and technoscientific developments:* In understanding the rise of individual patient groups and health movements, several researchers have stressed the importance of studying “opportunity structures”—the political or cultural factors (more or less) external to the group itself that present it with opportunities or threats (Nathanson 1999, p. 423; Goldner 2001). These might include economic transformations and the rise of new technologies in the workplace (Bammer and Martin 1992; Pellow and Park 2002); the spread of political ideologies, such as neoliberalism (Crossley forthcoming); changes in social and medical norms (Saguy and Riley 2005); or changes in gender relations and gendered meanings (Montini 1996; Klawiter 1999; Klawiter 2000; Zavestoski, McCormick, and Brown 2004; Gibbon forthcoming). Not infrequently the emergence of patient advocacy is linked to specific historical advances in biomedicine—for example, Patrick Fox pointed to a “shift [in the 1970s] in the biomedical conceptualization of Alzheimer’s disease that allowed the inclusion of greater numbers of potential victims” as a crucial precursor for the development of national advocacy in relation to the disease in the U.S. (Fox 1989, p. 59), while Landzelius has identified as a necessary precondition of the “parents of preemies” movement the relatively recent ability of neonatologists to push back the limits of the

viability of fetuses to earlier and earlier gestational ages (Landzelius forthcoming-a, p. {add}). It is worth noting that developments within academia *outside of* medical fields have rarely been considered for their potential to prefigure or shape group formation. An interesting exception is Karkazis's analysis of how the founder of the Intersex Society of North America made use of the critiques of sex and gender categories that had been published by scholars such as Anne Fausto-Sterling, Suzanne Kessler, and Alice Dreger in order to contest the use of sexual surgeries in infancy to "treat" intersexuality (Karkazis 2002, ch. 9).

One implication of attending to opportunity structures is that location matters. Several scholars have invoked Alexis de Tocqueville's well-known claims in the nineteenth century about the American propensity to form voluntary associations as part of an argument for why patient groups are so widespread in the United States (Talley 2004, p. 41; Layne forthcoming, p. {add}). By contrast, Allsop, Jones, and Baggott have argued that the more centralized character of British political institutions, including the National Health Service but also a "centrally-regulated charity sector," have "encouraged the use of conventional channels" on the part of health consumerism in the U.K., such as cooperative work with professional associations and close attention to the mainstream political process (Allsop, Jones, and Baggott 2004, pp. 751-52).

But in a globally wired world, location doesn't *always* matter—at least not always to the same degree—and the birth and development of the internet is another crucial background condition that explains much about how and why patient groups and health movements have taken the particular forms that they have in recent years (Gillett 2003; Loriol 2003; Novas 2003; Goldstein 2004; Radin forthcoming). Landzelius has gone so far as to call the parents of preemies movement a "direct descendant" of the internet because of its historical dependence on the latter's "capacity to engender (virtual) community and to geographically-untether information/disinformation" (Landzelius forthcoming-a, p. {add}). Dumit has emphasized how

the asynchronous character of internet communication comes to the advantage of people suffering from conditions that make face-to-face, real-time communication more problematic (Dumit forthcoming, p. {add}). Indeed, the advent of web-based communication may even lead to a decline in face-to-face group formation and the disappearance of “non-virtual” groups, as Layne has documented in her study of the infant loss support movement over time (Layne 2003; forthcoming, p. {add}). Web-based interactions can have other powerful effects as well. Patricia Radin has described how specific features of a breast cancer advocacy website “gradually transform casual visits—’thin trust’—into the kind of ‘thick trust’ that generates social capital” (Radin forthcoming, p. {add}); and Diane Goldstein has analyzed how internet-based support groups generate “their own separate and distinct medical culture” (Goldstein 2004, p. 127). At the same time it is important to recall that not just access to the internet but also the meaning that it acquires for users can vary considerably: Heath, Rapp, and Taussig, while observing how the internet has transformed an older identity politics around health, also have warned of “the potential for a widening of the ‘digital divide’ in which expansion of technoscientific literacy among many increases the exclusion and isolation of those without access in both rich and poor countries” (Heath, Rapp, and Taussig 2004, p. 156).

- *Aspects of the disease or condition:* In addition to the impact of background conditions, many factors specific to the group, or specific to the illness or social problem, can be quite important in determining the likelihood that a patient group takes shape, mobilizes, and attracts resources and public attention. The trajectory of a patient group or health movement can be shaped by whether those affected by the condition are numerous in the population or isolated and scattered; able-bodied or infirm; young or old; and socially privileged or disadvantaged (Epstein 1995, p. 414; 1996, p. 10; Stockdale 1999; Rabeharisoa 2003; Allsop, Jones, and Baggott 2004; Layne forthcoming). Moreover, not every disease is equally likely to promote patient organizing.

In some cases, an outbreak of illness can spark a “biographical disruption” that motivates affected individuals to become active; in other cases—Allsop, Jones, and Baggott point to the example of circulatory disease—illness “does not appear to arouse feeling of anger and resentment, or pose a threat to identity” in such a way as to promote group formation (Allsop, Jones, and Baggott 2004, pp. 741, 744; see also Shim 2005, p. 429). At the same time, we have little understanding of why a given illness will motivate some people, but not others, to join groups or movements. Clearly, not every sufferer is equally likely even to claim an illness identity, let alone want to be enrolled in a condition-appropriate movement, yet few scholars have attempted to compare those who join patient groups to those who do not (for a partial counter-example, see (Rapp 2000, pp. 202-4)).¹⁰

Case studies have presented poignant depictions of the particular dilemmas confronting those who seek to organize around certain conditions. For example, Chloe Silverman has described how the stigma of autism often spills over onto the parents of autistic children to the detriment of their organizational efforts: they may be perceived as incompetent parents whose advocacy on behalf of their children therefore cannot fully be credited as reasonable (Silverman 2004). And Renee Beard has analyzed the peculiar plight of people with Alzheimer’s disease who, even when mentally competent and functional, are presumed incapable of advocating for themselves (Beard 2004). Others have tried to generalize across cases to suggest broader patterns. In the introduction to their edited collection, Randall Packard and coauthors concluded that the rapidity of the social response to an emerging illness may depend on a range of factors, including the epidemiological significance of the condition, the availability of an unequivocal diagnostic test, the social class of the sufferers, the degree of activism, and the extent of media coverage (Packard et al. 2004b, pp. 22-23). In their article on embodied health movements, Brown and coauthors extracted a series of predictions: that sufferers of not-yet-medicalized conditions like chronic fatigue will face an uphill battle compared to those with medically accepted diseases; that

those with links to previous social movements will have an easier time mobilizing than those without such links; that members of socially disadvantaged groups, such as women and minorities, may be more inclined toward activism while being less likely to have access to the requisite resources; and that, everything else being equal, the absolute numbers of people touched by an illness will affect the chances of successful mobilization (Brown et al. 2004, pp. 73-74).

Much work also suggests that patient groups can solidify their claims to authority when they succeed in constituting themselves as an obligatory passage point (Latour 1987, p. 132) through their control over access to a resource desired by researchers, whether that be the bodies of patients who might enroll in clinical trials (Epstein 1995, p. 420), blood and tissue samples (Taussig, Rapp, and Heath 2003, p. 63), information about family genealogies (Nukaga 2002, p. 59), or funding to conduct research (Rabeharisoa 2003; Kushner 2004). However, Emily Kolker is right to point out that scholars have tended to emphasize the potency of the structural resources available to patient groups and health movements while underplaying the significance of cultural resources, such as the development of distinctive, “culturally resonant frames to persuade audiences” (Kolker 2004, p. 821; see also Epstein 1997b).

- *Conceptions and uses of knowledge, development of expertise:* Patient groups and health movements have been especially fertile sites for studying the manufacture and deployment of various sorts of informal knowledge and for the development of alternative bases of expertise. Drawing on concepts such as “local knowledge” (Geertz 1983), “subjugated knowledges” (Foucault 1980, pp. 80-85), “situated knowledges” (Haraway 1991, pp. 183-201), and “ways of knowing” (Pickstone 2000)—as well as on classic STS studies of knowledgeable lay groups (Wynne 1992)—scholars (too many to list by name) have explored in considerable detail the capacities of organized collectives of lay actors to assess medical knowledge claims and engage with the practices of biomedical knowledge production.¹¹ Some of this work has emphasized how

formal medical knowledge is often parasitic on patient experience. For example, Emma Whelan's analysis of attempts to develop standardized pain measurement tools for endometriosis has revealed that such tools can render comparable only "*accounts* of pain, not the pains themselves"; and the ineliminable character of patients' experiences has promoted "epistemic cooperation" between endometriosis support groups and researchers (Whelan 2003, pp. 464, 477).

More generally, much work has examined how being the sufferer of an illness can serve as epistemic grounding for developing distinctive, embodied knowledge claims. Similarly, a number of scholars (many of them building on Brown's concept of "popular epidemiology" (Brown and Mikkelsen 1990; Brown 1992)), have described the deployment of local knowledge by community groups concerned about environmental health risks (Di Chiro 1992; Clapp 2002; Allen 2003, 2004; Frickel 2004; Spears 2004). Such studies raise important questions about the character and utility of knowledge that grows out of the lived experience of sufferers of health risks. On the one hand, the literature amply demonstrates the practical benefit of incorporating the experiential knowledge of the patient, not only within the doctor-patient relationship but also within the researcher-subject relationship. On the other hand, most work to date has been insufficiently critical of the tendency to valorize or romanticize lived experience as a basis for reliable knowledge, or to treat experience as a sort of bedrock resistant to critical interpretation (Scott 1991). As Michelle Murphy has observed in a study of occupational health, "'experience' is a category of knowledge that is just as historical as other forms of knowledge.... It is only through particular methods rooted historically in time and space that experience becomes a kind of evidence imbued with certain truth-telling qualities" (Murphy 2004b, p. 202).

In addition to, or instead of, mobilizing experiential knowledge, patient groups and health movements also have laid claim to the formal knowledge more typically monopolized by credentialed experts, sometimes through systematic practices of self-education or community-

based education (Epstein 1995; Dickersin and Schnaper 1996; Anglin 1997; Dickersin et al. 2001; Myhre 2002). As opposed to groups that are dismissive of formal knowledge, those that learn the biomedical science relevant to their condition adopt (according to Paula Treichler, in an early analysis of AIDS treatment activism) “not...a resistance to orthodox science but...strategic conceptions of ‘scientific truth’ that leave room for action in the face of contradictions” (Treichler 1991, p. 79; see also Treichler 1999). The term “lay expert” (Arksey 1994; Epstein 1995) has been widely used to characterize the liminal or boundary-crossing qualities of those who succeed in establishing this sort of claim to formal knowledge. However, some have objected that “lay expert” is effectively a contradiction in terms (Prior 2003), and that once patients have “crossed over,” they should simply be classified as experts, though perhaps of a different sort. For example, Harry Collins and Robert Evans have suggested that patient groups may often acquire “interactional expertise” (“enough expertise to interact interestingly with participants”) and may sometimes acquire “contributory expertise” (“enough expertise to contribute to the science of the field being analysed”) (Collins and Evans 2002, p. 254).

In practice many patient groups and health movements have combined experiential knowledge with varying degrees of mastery of formal knowledge, often producing interestingly hybrid or “translocal” (Heath 1997, pp. 81-82) ways of knowing or varieties of expertise. As Rabeharisoa noted in the case of the AFM, sustained interaction between the patient group and specialists meant “that ‘experiential’ knowledge and scientific knowledge on the disease ended up forming an indivisible whole, jointly influencing clinical profiles and trajectories of life with the disease” (Rabeharisoa 2003, p. 2133). Recent work has been particularly helpful in focusing attention on the specific tools and technologies employed by patient groups and health movements in their epistemic work. For example, Yoshio Nukaga has described how genetic support groups “collect family narratives, genealogical inscriptions and family trees...., which

are first translated by genetic counselors and researchers into various forms of medical pedigrees for clinical and laboratory work, and then circulated as published pedigrees among lay and medical practitioners” (Nukaga 2002, p. 59). In her analysis of the feminist women’s health movement, Murphy has shifted attention away from their ideologies and toward their practical technologies, such as the plastic speculum and the menstrual extraction kit (Murphy 2004a, p. 347; see also Wacjman 2004, pp. 123-24); while in her analysis of sick building syndrome, she has analyzed how office workers “rematerialized” the office through efficiency analyses, surveys, and other techniques (Murphy 2004b, p. 196). Callon and Rabeharisoa have reconstructed the “primitive accumulation of knowledge” by AFM members who have used “proto-instruments” that include “cameras, camcorders for taking films and photos, accounts written by patients or their parents in the form of books for the general public, requested testimonies, spontaneous letters, and lectures given by patients or their relatives.” As these latter scholars note, such tools permit the production of knowledge that is “formal, transportable, cumulative, and debatable”—characteristics associated with the products of more traditional biomedical research. By this pathway, laboratory research and research conducted “in the wild” are brought together in the form of new cross-fertilizations (Callon and Rabeharisoa 2003, pp. 197-98).

However, these successes on the part of activists in creating and employing hybrid and translocal expertise may be accompanied by a “scientization” of the social movement that can have unanticipated consequences for its trajectory. The case of AIDS treatment activism suggested that the emergence of a specialist group of activist-experts accentuated various existing divisions within the movement through the creation of a new cleavage—that between the new “lay experts” and the “lay lay” (Elbaz 1992, p. 488) activists “left behind” in the knowledge-acquisition process (Epstein 1995; 1996, pp. 284-94). To the extent that facility with scientific and technical knowledge or tools becomes a de facto criterion for leadership within a movement,

then scientization may reshape the movement, potentially reducing its participatory potential. In addition, scientization may raise the barriers to entry, making it harder to recruit new members and replenish leadership positions—an especially critical issue for health movements, sadly, as leaders not infrequently are at personal risk of illness or death (Epstein 1996, pp. 327, 350-53).

Effects and consequences

No review of patient groups and health movements would be complete without discussion of the results that they bring about, and STS researchers have considered this issue in some detail.¹² To be sure, it is important not to exaggerate the effects of patient advocacy, which may well be limited in many cases (Stockdale 1999, p. 594). Still, scholars have identified a range of ways in which these groups contribute to social and biomedical change:

- *The conceptualization of the disease:* Howard Kushner has described how the U.S. Tourette Syndrome Association played an influential role in promoting the conception of Tourette's as an organic disease—by contrast with France, where, in the absence of a strong group of patients and their family members, Tourette's is understood within a psychodynamic framework (Kushner 2004). In another example, Stella Capek showed how a grassroots self-help group called the Endometriosis Association helped reorient conceptions of etiology away from purely endogenous causal factors and toward “a more holistic view that explores connections between the human body and a chemically toxic environment” (Capek 2000, pp. 345, 351-52).

- *Patients' management of their illnesses:* Although it has become common to speak of the “educated patient,” only a few studies systematically have investigated how the activities of patient groups changes the ways in which patients engage with their physicians, their medications (Akrich and Meadel 2002), or their bodies. The work of Janine Barbot and Nicolas Dodier is exemplary in delineating how different HIV/AIDS groups in France have been associated with

different “pragmatics of information gathering” (Barbot and Dodier 2002) and strategies of illness management (Barbot forthcoming) on the part of patients. In a recent article, Barbot constructed a typology of four varieties of educated patients—the patient as illness manager, the empowered patient, the science-wise patient, and the experimenter—and correlated each type with a different French HIV/AIDS support or advocacy group (Barbot forthcoming, p. {add}).

- *Attitudes and practices of health professionals:* In some cases, health movements have inspired a greater sensitivity on the part of physicians and researchers, for example in their judgments about people who are overweight (Saguy and Riley 2005; Boero n.d.). In other cases, patient groups and health movements have brought about concrete changes in physician practice—though as Karkazis has noted in her analysis of intersex activism, physicians may sometimes be unwilling to concede that their embracing of new policies had anything to do with outside pressure (Karkazis 2002, ch. 9). Finally, in cases where the social movement is itself built on an “uneasy alliance” between lay activists and medical professionals, as in the abortion rights movement, activism can result in important changes at the level of professional associations and medical education (Joffe, Weitz, and Stacey 2004, p. 784).

- *The research process:* Examples of the impact of patient groups and health movements on biomedical research already have been suggested throughout this chapter. Patient groups have raised funds for research and have doled it out to support the lines of research they deem most important; gained a “seat at the table” to make decisions about research directions; promoted ethical treatment of participants within clinical trials; attempted to police perceived ethical abuses such as conflicts of interest in research; challenged the techniques for conducting and interpreting clinical trials; helped create disease and treatment registries; organized conferences; coauthored publications; and pioneered new models of participatory research that joins the efforts of lay citizens with those of experts. Other effects are less tangible but no less significant. Callon and

Rabeharisoa have hinted at the new “entanglements” between patients and researchers by quoting the words of a young girl with spinal muscular atrophy speaking to a biologist: “I’m with you in your laboratory since you’re working on my genes” (Callon and Rabeharisoa 2003, p. 201). As David Hess has suggested, there are a range of alternative pathways along which such entanglements may proceed, including conversion experiences by researchers, biographical transformations of activists who become lay researchers, or the creation of “network assemblages” in which activists “help weave together networks of patients, funding sources, clinicians and potential researchers” (Hess 2004b, pp. 703-4).

- *Technological trajectories:* A growing body of literature has shown how patient groups and health movements, acting either as users of technologies or as their representatives, can intervene in the path of technological development. Scholars have examined these dynamics especially in relation to contraceptive technologies and abortifacients, showing how women’s health advocates and organizations have altered technological scripts while asserting the priorities of bodily integrity and social justice (Clarke and Montini 1993; Clarke 1998; Clarke 2000; Dugdale 2000; Bell 2003; Van Kammen 2003; Hardon forthcoming). A different sort of example of engagement with technology was provided by Lisa Jean Moore, who, analyzed how sex workers were configured by latex technologies but also configured their clients into new, “safe sex” users of these technologies (Moore 1997).

- *State policies:* Johnson and Hufbauer’s work, several decades ago, on how bereaved parents convinced the U.S. Congress to fund research by passing the Sudden Infant Death Syndrome Act of 1974 (Johnson and Hufbauer 1982) is just one example of how patient groups have sought to influence public research funding priorities. But patient groups and health movements also have brought about other sorts of formal changes in state policies. Constance Nathanson has shown the significant effect of the tobacco control movement in the United States

on legislation and regulatory policy (and has contrasted it with the limited impact of the gun control movement) (Nathanson 1999); Allsop, Jones, and Baggott have described how the health consumer movement has pushed the British government to develop new procedures for cases where patients claim harm by health professionals (Allsop, Jones, and Baggott 2004, p. 752); Saguy and Riley have shown how the fat acceptance movement prompted the U.S. Food and Drug Administration to postpone its approval of a kind of weight-loss surgery (Saguy and Riley 2005, p. {add}); and I have described how a diverse coalition of health advocates in the U.S. successfully pressed for new federal policies on the inclusion of women, racial and ethnic minorities, children, and the elderly as research subjects, as well as for the creation of federal offices of women's health and minority health (Epstein 2003a, 2004, Forthcoming; see also Auerbach and Figert 1995; Weisman 1998).

- *Corporations and markets:* Probably the most frequent corporate target of patient group activity has been pharmaceutical companies. Activists concerned about issues such as drug pricing and research ethics have been able to wrest concessions from drug companies on occasion (Epstein 1996); and recent global debates about access to medications such as antiretroviral drugs have suggested the efficacy of transnational linkages of patient groups and health movements in affecting the marketing practices of drug companies as well as their ability to enforce their patents (Whyte, van der Geest, and Hardon 2002, pp. 146-60). However, these are not the only ways in which patient groups have affected market relations. Sometimes, as in the patenting of the PXE gene described by Heath, Rapp, and Taussig, patient groups have successfully claimed intellectual property rights for themselves (Heath, Rapp, and Taussig 2004, pp. 163-64). In addition, Hess has examined the productive ties between civil society organizations and companies promoting alternative health products under the banner of "nutritional therapeutics" (Hess 2005). Such work may be suggestive of broader patterns by which patient groups affect the

organization of industrial fields, for example through their alliances with start-ups.

- *Cultural effects:* Some of the most profound and enduring effects of patient groups and health movements may sometimes be among the most diffuse and hardest to pinpoint. Such groups may have an important cultural impact simply by exposing prevailing norms and power relationships and making them available for public critique (Gamson 1989; Löwy 2000, p. 74). For example, as suggested by the disability movement and the intersex movement, health activists may seek to establish the legitimacy of different sorts of bodies or bodily experiences (Shakespeare 1993, 1999; Dowse 2001; Rapp and Ginsburg 2001; Karkazis 2002). Or, patient groups and health movements may enact public performances of bodies and diseases in ways that challenge conventional cultural codes about appropriate gender roles or sexualities (Klawiter 1999). They also may reinterpret the historical record, for example by attributing disease prevalence in certain groups to historical legacies of social oppression (Nelson 2003, ch. 4). Several scholars have emphasized the “memorialization” work of advocacy groups—for example, Sahra Gibbon has described how breast cancer advocates perform acts of memorialization that connect the witnessing of loss to a new conception of research as redemption (Gibbon forthcoming); while Lesley Sharp has shown how groups representing the surviving relatives of organs transplant donors have used cultural forms such as donor quilts and Web cemeteries to challenge transplant professionals’ tendencies to “obliterate donors’ identities” (Sharp 2001, p. 125). In these various ways, patient groups and health movements, like social movements generally, are involved in both reconstructing the “cultural schemas” that define the rules of the game by which key social institutions operate (Polletta 2004).

- *Incorporation and cooptation:* While documenting in considerable detail the transformative effects of patient groups and health movements, the scholarly literature mostly has been careful to avoid an uncritically celebratory tone. In fact, a hallmark of recent work has been

the attempt to make sense of the multivalent politics of incorporation, whereby the insights and legacies of patient advocacy are channeled back into institutionalized biomedical practice, and of cooptation, where the radical potential of an activist critique is blunted or contained. Biomedical institutions are highly flexible and resilient (Löwy 2000, p. 73)—one might say omnivorous—and the peculiar thing about the phenomenon of incorporation is that it may be hard to judge in principle whether it should be counted as victory or defeat: Does it mark the successful transformation of biomedicine by outside forces, or the taming of a radical challenge, or even both at once (Goldner 2004, p. 727)?¹³ Similarly, when activists come to moderate their critiques or adopt more conventional biomedical understanding, it is often hard to say whether they have allowed themselves to be co-opted or have made a well-advised shift in tactics.

Scholars have pointed to instances of outright manipulation of patients in order to co-opt them, for example through the creation by pharmaceutical companies of “front groups” masquerading as patient advocacy groups that are intended to build demand for a company’s products or garner support for drug approval (Zavestoski, Morello-Frosch et al. 2004, p. 274). However, this extreme case is one end of a continuum of relations to pharmaceutical companies, described by O’Donovan, that also includes many other instances in which patient groups receive pharmaceutical industry financing. O’Donovan rightly has cautioned against any automatic assumptions of a creeping “corporate colonisation,” calling for detailed study of whether corporations indeed have increased their influence over patient groups’ “cultures of action” (O’Donovan 2005).

Scholars also have identified cases where activist intentions were co-opted in the process of partial implementation of their concerns—for example, as Natalie Boero has analyzed, surgeons’ adaptations of the arguments of the fat acceptance movement in order to promote weight loss surgery; or, as Theresa Montini has described, the passage of breast cancer informed

consent laws in the United States in ways that “actually advanced and protected the professional autonomy of physicians at the expense of patient rights” (Montini 1991, p. vii; see also Montini 1996). A more ambiguous case is the “quid pro quo” worked out between twentieth-century birth control advocates and reproductive scientists, as analyzed by Clarke: reproductive scientists agreed to devote their energies to developing birth control technologies, but only on the condition that they would emphasize basic research on “modern,” technologically-advanced forms of contraception, to the exclusion of scientific attention to more simple, chemical and mechanical means of preventing pregnancy (Clarke 1998, pp. 163, 200). Another tricky case—for which blunt and accusatory terms such as “cooptation” appear unhelpful—is that of AIDS treatment activists, many of whom began to soften their critiques of clinical research and regulatory practices as they learned about the complexities involved: “The more we learned, in some ways the less we were able to ask for,” was how one activist expressed it (Epstein 1996, p. 328). By one measure, these activists became more conservative as they became inculcated within biomedical frameworks; by another measure, they changed tactics appropriately in response to an evolving political environment and as the research trajectory, and their own understanding, advanced (Epstein 1996, pp. 325-28, 342-44; 1997a). At a minimum, their example suggests the benefits of studying expert knowledge in broadly Foucauldian terms—not as an inert tool to be acquired, but rather as something that reshapes the subjectivities of those who become subject to it (Foucault 1980).

At the more benign end of the incorporation spectrum, Joffe has remarked on the legacy of key feminist principles within present-day medical practice: “Many of the ideas about abortion and other reproductive health services that were promoted by women’s health activists of the 1970s—ranging from the simple (warming the gynecological instruments) to the more complex (seeing the patient as a fully participating partner)—have now been incorporated into practice at

many facilities—even those that do not think of themselves as ‘feminist’” (Joffe 1999, p. 32). A related example is the mainstream medical incorporation of breastfeeding, a practice that health activists once had to defend (Ward 2000). While these cases might seem closer to what could simply be called victory, it is worth reflecting on the deletions of authorship and historical process that typically accompany even beneficent incorporations (Arksey 1994, p. 464). Who remembers, decades later, that what has become the ordinary standard of care was once a radical innovation promoted by activists? Yet this act of historical forgetting may indeed have consequences: it limits the capacity of subsequent generations of activists to benefit from examples of past struggles and be inspired to imagine how current conditions might be otherwise.

Is institutionalization possible without some measure of “capture and control” (Hess 2004b, p. 705; see also Hess 2005)? Landzelius goes so far as to conclude her story of “parents of preemies” in two different ways, first suggesting the practical benefits of the movement’s cooperative approach, then “pivoting” to highlight “the ways in which it embeds normative ideologies about maternity and likewise is comfortably embedded within and cocooned by them” (Landzelius forthcoming-a, pp. {add}). Another useful way forward in analysis has been suggested by Melinda Goldner, who took up the question of institutionalization by combining social movement perspectives with institutionalist approaches within sociology. In her analysis of the “dynamic interplay” between the complementary and alternative medicine movement and Western medicine, Goldner rejected any simple conclusion about incorporation by showing how distinctive outcomes on the ground mapped onto a typology of diverse institutional responses to external challenge (Goldner 2004).

Directions for future research

Studies of patient groups and health movements have reflected and propelled a creative

synthesis of STS perspectives, medical anthropology and sociology, social movement scholarship, and other fields. Having risen to prominence within STS as a means to reconsider problems of expertise and resituate the locus of scientific work, the topic of patient groups and health movements has proven a fruitful path to consider such diverse issues as embodiment, vital politics, biomedicalization, and scientific citizenship. I have emphasized how the study of patient groups and health movements successfully has built on concepts derived from a variety of intellectual sources. But it is also important to say that this body of work now has something to offer back to scholars in other domains. For example, insofar as the constitution of groups and collective identities is a central issue in social theory, it would be valuable (though beyond the scope of this chapter) to think through the implications of studies of patient groups and health movements for general theoretical work on that topic: How does the intermingling of humans and non-humans affect the pathways by which groupness and identity take shape and evolve? How do the politics of expertise complicate the politics of alliance and division? Having absorbed so much from so many other fields, it will be important for practitioners in this research domain to reformulate their conclusions in ways that allow them to be brought back to, and illuminate, other domains of theorization and empirical research.¹⁴

I began this chapter by raising a series of questions about patient groups and health movements—among others, how they form and organize, what kinds of expertise they develop and deploy, how they affect the practice of medicine and biomedical research, and how they reshape the nexus of relations linking biomedical institutions to the market and the state. This review has suggested that scholars already have shed considerable light on these questions. I conclude with some brief suggestions of useful avenues of future research, particularly with the goal of addressing existing gaps:

- *Case comparisons:* Most work on patient groups and health movements has taken the

form of detailed case studies. Yet many of the questions that I have raised in this review—about efficacy; about the virtues of typologies—could best be answered by close comparative analysis. Models of comparative work—both between different health conditions in the same country and between the same health condition in different countries—have been suggested by Barrett with the cases of fibromyalgia and chronic fatigue syndrome (Barrett 2004), Dimock with breast cancer and prostate cancer (Dimock 2003), Kushner on Tourette Syndrome in the U.S. and France (Kushner 2004), Nathanson on anti-smoking versus gun control (Nathanson 1999), Parthasarathy on breast cancer in the U.S. and Britain (Parthasarathy 2003), and Brown and coauthors on Gulf War Syndrome, asthma, and environmental causes of breast cancer (Brown et al. 2002; see also Zavestoski et al. 2002).

- *Globalization and transnationalism:* It seems problematic that most analyses of patient groups and health movements to date have confined themselves within national borders—and all too often within the United States or Western European countries. Only a few studies have sought to analyze the diffusion of activist frames from one country to another (Kirp 1999), to consider the development of explicitly transnational health advocacy (Whelan 2003; Barnes 2005; Landzelius forthcoming-a; Radin forthcoming), or to locate patient groups and health movements in a global geopolitical context in relation to the North-South divide (Whyte, van der Geest, and Hardon 2002, pp. 146-60; Bell 2003; Barbot forthcoming, p. {add}; Hardon forthcoming).

- *Movement/counter-movement dynamics:* Social movement scholars know that movements often provoke counter-movements, and the complex engagement between the two often shapes movement trajectories in significant ways (Meyer and Staggenborg 1996). These dynamics are worthy of further study. Examples in the existing literature on patient groups and health movements include the pro-choice and pro-life movements (Joffe 1999; Joffe, Weitz, and Stacey 2004), the gun control movement and its well-organized opponents (Nathanson 1999), the

LGBT health movement and the Christian right (Epstein 2003b), and the movements for and against stem cell research (Ganchoff 2004).

- *Periodization:* So far only a few scholars systematically have tracked patient groups and health movements through distinct phases of their evolution. Useful models include the work of Barbot (2002) and of Layne (forthcoming), who describe different generations or phases of advocacy within a movement. A more ambitious concept is Klawiter's understanding of the relation between health movements and successive "disease regimes" (Klawiter 2004).

- *Insiders and outsiders:* Goldner has called for more detailed study, especially from activists' perspectives, of precisely how members of patient groups and health movements negotiate being simultaneously an insider and an outsider vis-à-vis biomedical, state, and market institutions: "How does gaining institutional access blur the boundary between movements and mainstream organisations, and how does this ultimately impact upon the movement?" (Goldner 2004, p. 730; see also Epstein 1996; Moore 1999; Hess 2004a, p. 424; 2005).

- *Inequalities and health disparities:* Scholars have not made as much as they might of the implications of the activities of patient groups and health movements for the reproduction or overturning of deeply-rooted inequalities—by gender, race, ethnicity, sexuality, nationality, and religion, among other markers—with regard to exposure to health risk, access to health care, or social rewards more generally. (Here the work of Brown and his collaborators, and of Rapp, Heath, and Taussig, stand as exceptions, as do the various studies of environmental health and environmental justice.) While the co-production of gender and technoscience is a relatively frequent theme in the literature (Gibbon forthcoming), there has been much less consideration of other dimensions of difference and inequality, such as race (Nelson 2003; Epstein 2004; Reardon 2004; Shostak 2004; Klawiter 2005; Epstein Forthcoming). Nor has there been much analysis of how the absence of universal access to health care in countries such as the United States affects

the agendas of patient groups and health movements. Finally, the stark social and health inequalities at the global level between “North” and “South” undoubtedly have a profound influence on the shapes, goals, and successes of patient groups and health movements emerging in different parts of the world. Consideration of these issues in future analyses would help flesh out the depiction of biomedical citizenship that has been emerging in the literature by linking it to the diverse struggles over rights and inclusion in the domain of health.

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Notes

¹ Existing sources that I encountered were Bayer 1981; Petersen and Markle 1981; Bayer 1985; Von Gifycki 1987; Hoffman 1989; Petersen and Markle 1989; Brown and Mikkelsen 1990. Sources that I failed to learn about until later were Johnson and Hufbauer 1982; Fox 1989.

² Group formation of this general sort has been visible enough in recent years to be represented in popular culture in diverse ways: for example, lay contributions to research on rare diseases were celebrated in the 1992 film *Lorenzo's Oil*, while self-help groups were satirized as an escapist addiction in the 1999 film *Fight Club*.

³ “New social movements” is a problematic term if meant to describe a wholly unprecedented and distinct social form (Pichardo 1997), but it is a useful concept if invoked to refer to certain tendencies and preoccupations that arguably have been more visible among movements in recent decades, including a reflexive concern with identity construction, a focus on the politics of the body, and a commitment to cultural transformation.

⁴ As Abby Saguy has suggested to me (personal communication), women’s bodies and women’s health may also be heavily implicated in the work of movements that are less overtly gendered, such as the fat acceptance activists whom she has studied.

⁵ Because a chapter of this volume (by David Hess, Steve Breyman, Nancy Campbell, and Brian Martin) focuses specifically on social movements, I have refrained from defining the term social movement, reviewing key schools of social movement scholarship, or providing references for key concepts in the social movement literature.

⁶ My approach here is consistent with, and influenced by, that taken by Kyra Landzelius (forthcoming-b) in her introduction to the special issue in *Social Science & Medicine* that she organized with and Joe Dumit. Landzelius introduces the concept of the “patient organization movement” while rendering problematic each of the three constituent terms. I am also grateful to

Volo Rabehariso for her reflections on these conceptual and definitional issues.

⁷ More generally, on the interpenetration of social movements and state institutions, see Goldstone 2003, pp. 1-24, esp. p. 2.

⁸ An overlapping typology has been suggested by Judith Allsop and coauthors, who distinguished between “population-based” groups, “condition-based” groups, and “formal alliance organizations” (Allsop, Jones, and Baggott 2004, p. 739). A somewhat more complex breakdown has been offered by Hilda Bastian (1998, p. 11), who identified six broad “strands” of consumer activism in the domain of health.

⁹ Medicalization refers to the process of taking a phenomenon not previously considered a medical issue and defining it in medical terms, adopting a medical framework to understand it, or licensing the medical profession to treat it (Conrad and Schneider 1980; Conrad 2005).

¹⁰ Within the broader field of social movement scholarship, Doug McAdam has emphasized the importance of comparing participants to non-participants (McAdam 1988).

¹¹ Another large body of literature, particularly in medical anthropology and medical sociology, has examined how *individual* lay actors, such as patients—or sometimes the public at large—assesses and apprehends medical knowledge claims. A review of that literature would be the topic of another chapter.

¹² The theme of the effects of social movements also has received renewed interest in the broader social movement literature. See, for example, Giugni, McAdam, and Tilly 1999.

¹³ I am grateful to Andrew Feenberg for past discussion of these issues.

¹⁴ I am grateful to Michel Callon for his suggestions regarding these issues.

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