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The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials

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In an unusual instance of lay participation in biomedical research, U.S. AIDS treatment activists have constituted themselves as credible participants in the process of knowledge construction, thereby bringing about changes in the epistemic practices of biomedical research. This article examines the mechanisms or tactics by which these lay activists have constructed their credibility in the eyes of AIDS researchers and government officials. It considers the implications of such interventions for the conduct of medical research; examines some of the ironies, tensions, and limitations in the process; and argues for the importance of studying social movements that engage with expert knowledge.

One of the most striking aspects of the conduct of AIDS research in the United States is the diversity of the players who have participated in the construction of credible knowledge. Inside of a large and often floodlit arena with a diffuse and porous perimeter, an eclectic assortment of actors have all sought to assert and assess claims. The arena of fact making encompasses not just immunologists, virologists, molecular biologists, epidemiologists,

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physicians, and federal health authorities—but various credentialed experts plus the mass media and the pharmaceutical and biotechnology companies; it also encompasses a strong and internally differentiated activist movement along with various organs of alternative media, including activist publications and the gay press. Beliefs about the safety and efficacy of particular therapeutic regimens, and understandings about which clinical research practices generate useful results, are the product of an elaborate, often heated, and, in some ways, quite peculiar complex of interactions among these various players (Epstein 1993).

My point in stressing the breadth of participation in claims making is not simply to say that AIDS research is heavily politicized or that it has a public face. More profoundly, this case demonstrates that activist movements, through amassing different forms of credibility, can in certain circumstances become genuine participants in the construction of scientific knowledge—that they can (within definite limits) effect changes both in the epistemic practices of biomedical research and in the therapeutic techniques of medical care. This surprising result is, of course, at variance with the popular notion of science as a relatively autonomous arena with high barriers to entry.¹ It is a result that illustrates the danger of understanding the role of laypeople in scientific controversies solely in passive terms—as a resource available for use, or an ally available for enrollment, by an entrepreneurial scientist who is conceived of as the true motive force in the process of knowledge making.

In fact, activist movements can, at times, advance their own strategic goals within science, helping to construct new social relationships and identities, new institutions, and new facts and beliefs in the process (cf. Brown 1992; Cozzens and Woodhouse 1995; Cramer, Eyerman, and Jamison 1987; Di Chiro 1992; Petersen 1984; Rycroft 1991). Medicine, to be sure, is an arena more permeable to outside influence than other less public, less applied, and less politicized domains of technoscience (Cozzens and Woodhouse 1995, 538). But even here, AIDS activists did not achieve influence simply by applying political muscle of the conventional sort (although that did prove necessary at points along the way). In addition, they found ways of presenting themselves as credible *within* the arena of credentialed expertise. At the same time, these activists succeeded in changing the rules of the game, transforming the very definition of what *counts* as credibility in scientific research such that their particular assets would prove efficacious.²

Successful lay incursions into biomedicine have considerable implications for the understanding of such broad phenomena as the cultural authority of science and medicine (Barnes 1985; Nelkin 1987; Starr 1982), the public reception of scientific claims (Collins 1987; Jasanoff 1991; Wynne 1992), the boundaries between “science” and “society” (Gieryn 1983), the relationships

between doctors and patients (Cicourel 1986; Freidson 1988; Katz 1984), and the tension between expertise and democracy within complex and differentiated societies (Ezrahi 1990; Habermas 1970; Petersen 1984). By insisting that AIDS clinical trials are simultaneously sites of scientific research and medical care, AIDS activists indicate that they understand implicitly what some sociologists (Berg and Casper, this issue) have recently been asserting programmatically—that medical therapeutics cannot fully be understood separately from questions of knowledge construction and that our conception of scientific practice can be furthered by careful attention to the local details of medical work. The importance of analyzing AIDS research is heightened by the influence that AIDS activism appears to be exerting, at least in the United States, on a new wave of health-related activism—a politics of identity organized by particular “disease constituencies” such as those suffering from breast cancer, environmental illness, or chronic fatigue.

In this article, I explore how AIDS activists in the United States have established their credibility as people who might legitimately speak in the language of medical science. I focus specifically on interventions by so-called “treatment activists” into the design, conduct, and interpretation of the clinical trials used to test the safety and efficacy of AIDS drugs.³ This is an area in which activists have enjoyed great success in transforming themselves into credible players—as marked, for example, by the presence in recent years of AIDS treatment activists as full voting members of the committees of the National Institutes of Health (NIH) that oversee AIDS drug development and as representatives at the Food and Drug Administration (FDA) advisory committee meetings where drugs are considered for approval.⁴ As the National Research Council of the National Academy of Sciences noted (in a report otherwise *skeptical* about the transformative impact of the AIDS epidemic on U.S. institutions), “not since randomized clinical trials became the orthodox mode of clinical investigation have the most basic approaches and assumptions regarding research methodologies been open to searching critique in the context of an epidemic disease” (Jonsen and Stryker 1993, 111).⁵

I begin with a discussion of the study of scientific credibility in the interface between biomedical professionals and social movements. I then describe the unique characteristics of the AIDS treatment activist movement and analyze four key mechanisms or tactics that these activists have pursued in constructing their credibility within biomedicine: the acquisition of cultural competence, the establishment of political representation, the yoking together of epistemological and ethical claims making, and the taking of sides in pre-existing methodological disputes. Finally, I point to some of the implications, complications, and ironies of the activist engagement with biomedicine.

Medical Science, Social Movements, and the Study of Credibility

Scientific credibility refers here to the capacity of claims makers to enroll supporters behind their claims, to legitimate their arguments as authoritative knowledge, and to present themselves as the sort of people who can give voice to science.⁶ Credibility, therefore, can be considered a system of authority in Weberian terms, combining aspects of power, dependence, legitimation, trust, and persuasion (Weber 1978, 212-54). In his analysis of the medical profession, Paul Starr (1982, 13; cf. Cicourel 1986, 88-89) has observed that authority of this kind includes not just *social* authority rooted in the division of labor or in organizational hierarchies—the probability that a command will be obeyed, in Weber's terms—but also *cultural* authority, which rests on an actor's capacity to offer what is taken to be truth.

As Shapin (1994) has emphasized, credibility is the backbone of the cognitive and moral order in modern scientific inquiry, and trusting relationships are a sine qua non of scientific practice (see also Barnes 1985; Barnes and Edge 1982; Latour and Woolgar 1986; Shapin and Schaffer 1985; Star 1989, 138-44; Williams and Law 1980). Questions of credibility may emerge as particularly salient in fields, such as AIDS research, that are marked by extreme degrees of controversy, uncertainty, and, in particular, politicization (cf. Martin 1991, chap. 4). When various interested publics pay attention to the progress of research and expect answers, a "credibility gap" may develop if solutions are not forthcoming. Indeed, despite the suspicion of expertise that has become rampant in many quarters, people in advanced industrial societies do typically expect doctors and scientists to protect them from the effects of epidemic disease. The failure of the experts to solve the problem of AIDS quickly, as they were "supposed to" do, has heightened popular resentment and diminished the credibility of the establishment; it has also opened up more space for dissident voices.

Credibility can rest on a range of social markers such as academic degrees, track records, institutional affiliations, and so on. The sheer complexity of AIDS from a scientific standpoint and the profound and differentiated impact of the epidemic have ensured the participation of scientists from a range of disciplines, all of them bringing their particular, often competing, claims to credibility. But the striking fact about AIDS is that the politicization of the epidemic has brought about a further multiplication of the successful pathways to the establishment of credibility, a diversification of the personnel beyond the highly credentialed, and hence more convoluted routes to the construction of facts and the establishment of closure in biomedical contro-

versies. The science of AIDS therefore cannot simply be analyzed “from the top down”; it demands attention to what Foucault has called the “micro-physics of power” in contemporary Western societies—the dispersal of fluxes of power throughout all the cracks and crevices of the social system; the omnipresence of resistance as imminent to the exercise of power at each local site; and the propagation of knowledges, practices, subjects, and meanings out of the local deployment of power (Foucault 1979, 1983).⁷

The Rise of the AIDS Movement

A number of studies of scientific controversies in the public arena (e.g., Mazur 1973; Nelkin 1982) have focused in useful ways on the clash between scientists or other credentialed experts and social movements. Yet few studies have explored the role of movements in the construction of credible knowledge, and few sociologists of scientific knowledge have engaged with the sociological literature on social movements.⁸ Petersen and Markle (1981, 153) have applied the “resource mobilization” perspective (McCarthy and Zald 1977) to the study of the cancer treatment movement, analyzing the structural conditions that allow such movements to “try to form coalitions, seek sponsorship, and appeal to a wider audience . . . as a means of increasing their movement resources.” And Indyk and Rier (1993) have likewise emphasized resource mobilization in their useful analysis of the particular case of alternative knowledge production in the AIDS epidemic. But there has been little attention by analysts of science to the growing theoretical and empirical literature on “new social movements” (e.g., Cohen 1985; Gamson 1992; Habermas 1981; Klandermans and Tarrow 1988; Laraña, Johnston, and Gusfield 1994; Melucci 1989; Morris and Mueller 1992; Taylor and Whittier 1992; Touraine 1985). These works describing the ecology movement, the women’s movement, the antinuclear movement, racial and ethnic movements, the lesbian and gay movement, and so on have an obvious relevance to the study of the AIDS movement.⁹

Theorists and analysts of new social movements differ greatly in their approaches to the topic, but most tend to agree that the actors within the new movements are drawn primarily from the “new middle class” or “new class” of culture producers. But as against the traditions of working-class politics, the class character of the new movements is not emphasized by the activists. They are involved not (or at least, not only) in a distributive struggle, where an overall quantity of resources is being parceled out to competing groups, but in a struggle over cultural forms—what Habermas (1981, 33) calls the “grammar of forms of life.” Their emphases tend to be on “personal and

intimate aspects of human life,” their organizations tend to be “segmented, diffuse, and decentralized,” and their theatrical protest tactics emphasize civil disobedience and a politics of representation (Johnston, Laraña, and Gusfield 1994, 6-9).

Central to the self-understanding of such movements is a focus on the values of autonomy and identity. Yet as Cohen (1985, 694) argues, the salient feature of the new social movements is not so much that they assert identities—something all movements do—but that the participants have become reflexively aware of their own active involvement in contested processes of identity construction. Although the constitution of identity may sometimes become an end in itself, Gamson (1992, 60) argues that it also serves an instrumental function in the mobilization process, influencing not only people’s willingness to “invest emotionally” in the fate of the movement and “take personal risks on its behalf” but also their choices of strategies and organizational forms.

This emphasis on identity politics has, in certain crucial respects, facilitated the capacity of AIDS activists to engage with scientific knowledge production. As Wynne (1992, 301) has noted, “the unacknowledged reflexive capability of laypeople in articulating responses to scientific expertise” is crucially dependent on their construction and renegotiation of a social identity. Furthermore, because identity politics are preoccupied with nonmaterial issues—with questions of representation and meaning—its practitioners are inclined to wage struggles over the definition of reality.¹⁰ And precisely because identity politics stand in opposition to what Foucault (1983, 211-12) has called “normalization,” such movements are highly sensitive to the imposition of norms, categories, and interpretations by outside authorities. Understanding AIDS activism as a new social movement helps explain why these activists might have a greater inclination and capacity to participate in the construction of social meanings, including forms of knowledge.

The AIDS movement is broad based and diverse, ranging from grassroots activists and advocacy organizations to health educators, journalists, writers, service providers, people with AIDS or HIV infection, and other members of the affected communities. The members of this movement are not the first group of laypeople to put forward claims to speak credibly on biomedical matters (see Dutton 1984; Shapiro 1985; von Gizycki 1987). Cancer activists in the 1970s, for example, provide an interesting counterpoint in an analogous situation (Petersen and Markle 1981), while the feminist health movement is perhaps the clearest case in point (Fee 1982). Patient self-help groups, now a common and rapidly proliferating phenomenon (Stewart 1990), also sometimes engage in the evaluation of scientific knowledge claims. But the AIDS movement is indeed the first social movement in the United States to

accomplish the mass conversion of disease “victims”¹¹ into activist-experts, and in that sense the AIDS movement stands alone, even as it begins to serve as a model for others. Its distinctive approach toward scientific and medical questions owes to a specific constellation of historical and social factors.

To some extent, the unique features of the clinical picture of AIDS have shaped the development of an activist response. AIDS and HIV have affected many young people in their twenties and thirties—a group for which there is little social expectation that they will passively await death. Indeed, those who test positive on HIV antibody tests (available since 1985) are likely to be told by medical authorities to expect some number of years of outwardly normal health before the onset of symptoms. During this period, activism not only is feasible from a physical standpoint, but seems eminently practical from a political and psychological standpoint.

Even more fundamentally, the distinctive social epidemiology of AIDS has shaped the character of the public engagement with science. From the start and up to the present day, AIDS has been understood, both in epidemiological and lay parlance, as a disease of certain already-constituted social groups distinguished by their lifestyle, their social location, or both. As a result, the very meaning of AIDS is bound up with the cultural understandings of what such groups are like, while the very identity of the groups is shaped by the perception of them as “the sort of people who get this illness.” If AIDS were not deadly, if it were not associated with taboo topics such as sex and drug use, and if the groups affected were not already stigmatized on other counts, such linkages between identity and illness might be of little consequence. As it is, the AIDS epidemic has engendered fear and prejudice and has sparked the necessity, on a mass scale, for what Goffman (1963) once called “the management of spoiled identity.”

Gay men, the group whose identity has been shaped most thoroughly by the confrontation and association with the epidemic, entered the era of AIDS equipped with a whole set of crucial resources to engage in the struggle over social meanings. In the recent past, gays and lesbians in the United States had achieved a singular redefinition in social status, challenging the dominant frames of homosexuality as illness or immorality and reconstituting themselves as a legitimate “interest group” pursuing civil rights and civil liberties. With the limited successes of the “homophile” movement of the 1950s and 1960s and the more substantial impact of the gay liberation movement of the 1970s, gay men and lesbians recasted social norms, constructed organizations and institutions, and established substantial and internally differentiated subcultures in urban centers throughout the United States (Adam 1987; Altman 1982; D’Emilio 1983).

By the time the AIDS epidemic was recognized in 1981, the gay movement was thoroughly engaged in projects of identity politics that linked tangible political goals to the elaboration and assertion of an affirmative group identity (Escoffier 1985). A threat to identity, therefore, was a threat that the movement could easily understand—and one against which it was quick to mobilize. Negotiation with the medical profession was not entirely foreign to this movement because a specific component of the gay liberation agenda had been the “demedicalization” of gay identity (Bayer 1981). Indeed, gay activists had long been inclined to view medical authorities with some suspicion. Furthermore, many lesbians (and heterosexual women) who would become active in the AIDS movement were schooled in the tenets of the feminist health movement of the 1970s, which also advocated skepticism toward medical claims and insisted on the patient’s decision-making autonomy (Corea 1992).

The AIDS movement, in other words, was built on the foundation of the gay and lesbian movement and borrowed from its particular strengths and inclinations. It mattered that gay communities had pre-existing organizations that could mobilize to meet a new threat, and it mattered that these communities contained (and in fact were dominated by) white, middle-class men with a degree of political clout and fund-raising capacity unusual for an oppressed group. It was crucially important, as well, that gay communities possessed relatively high degrees of “cultural capital”—cultivated dispositions for appropriating knowledge and culture (Bourdieu 1990). These communities contain many people who are themselves doctors, scientists, educators, nurses, professionals, or intellectuals of other varieties. On the one hand, this cultural capital has provided the AIDS movement with an unusual capacity to contest the mainstream experts on their own ground. On the other hand, it facilitates mediation and communication between “experts” and “the public.”

AIDS Treatment Activism

The U.S. AIDS movement encompasses a wide range of grassroots activists, lobbying groups, service providers, and community-based organizations; represents the diverse interests of people of various races, ethnicities, genders, sexual preferences, and HIV “risk behaviors”; and has engaged in a variety of projects directed at numerous social institutions (Altman 1994; Corea 1992; Elbaz 1992; Emke 1993; Gamson 1989; Patton 1990; Quimby and Friedman 1989; Treichler 1991). Treatment activism, more narrowly defined, is the province of particular movement organizations. It includes specific subcommittees of ACT UP—the AIDS Coalition to Unleash Power—including the Treatment & Data Committee of ACT UP/New York

(along with a more recent spin-off organization called the Treatment Action Group) and the Treatment Issues Committee of ACTUP/Golden Gate in San Francisco. Another key player is the San Francisco-based organization Project Inform, which lobbies for the development of effective AIDS treatments and works to educate laypeople, particularly in gay communities, about treatments. In addition, a number of independent publications, including the San Francisco-based *AIDS Treatment News* and the New York-based *Treatment Issues* (published by Gay Men's Health Crisis), have played a crucial role in evaluating clinical research and providing information about clinical trials that is considered widely credible and often relied on by doctors as well as patients.

AIDS treatment activism dates to the mid-1980s, when activists began clamoring for the rapid approval of experimental treatments and established so-called "buyers clubs," organizations occupying a gray zone of legality that imported and distributed unproven treatments to patients around the United States (Arno and Feiden 1992). Activist ire was directed largely at the FDA, whose "paternalistic" policies of drug regulation were perceived to rob patients of the right to assume the risk of an experimental treatment. By the late 1980s, however, activist attention had shifted to earlier stages in the drug development pipeline, in part because of growing concerns about the ethics of clinical research and in part because activists recognized that it was no good fighting for faster approval of drugs if there were few such drugs to be approved. This realization implied a shift in targets from the FDA to the NIH and, specifically, to the AIDS Clinical Trials Group of the National Institute of Allergy and Infectious Diseases, the bureaucratic entity responsible for administering the network of publicly funded clinical trials of AIDS treatments.

As early as 1986, John James, a former computer programmer and the editor of *AIDS Treatment News*, had sounded a call to arms:

With independent information and analysis, we can bring specific pressure to bear to get experimental treatments handled properly. So far, there has been little pressure because *we have relied on experts* to interpret for us what is going on. They tell us what will not rock the boat. The companies who want their profits, the bureaucrats who want their turf, and the doctors who want to avoid making waves have all been at the table. The persons with AIDS who want their lives must be there, too. (James 1986; emphasis added)

To "rely solely on official institutions for our information," James (1986) advised bluntly, "is a form of group suicide."

Yet how could laypeople bring such pressure to bear? Large, graphic, well-executed and well-publicized demonstrations—including one at FDA headquarters in 1988 (Bull 1988) and another at NIH headquarters in 1990 (Hilts 1990), both involving more than 1,000 protesters—helped ensure that representatives of these agencies would pay attention when activists spoke.

Yet, while demonstrations and street theater remained the signature tactics of groups such as ACT UP and attracted the attention of the media, such techniques did not lend themselves to nuanced critique of specific research practices or priorities. Although some activists opposed “sitting at the table” with representatives of the scientific and governmental elite (Wolfe 1994), most treatment activists favored a strategy of direct negotiation:

I mean, I wouldn't exaggerate how polite we were. . . . I would just say that it was clear from the very beginning, as Maggie Thatcher said when she met Gorbachev, “We can do business.” We wanted to make some moral points, but we didn't want to wallow in being victims, or powerless, or oppressed, or always right. We wanted to engage and find out if there was common ground. (Harrington 1994)¹²

But to engage fully with the project of biomedical research, treatment activists needed to undergo a metamorphosis, to become a new species of expert that could speak credibly in the language of the researchers. This was the agenda that treatment activists pursued over the next several years.

Credibility Tactics

As Shapin (1990, 1993) has noted in an analysis of the historical constitution of the expert/lay divide, the question of who possesses *cultural competence* is “one of the most obvious means by which we, and people in the past, discriminate between ‘science’ and ‘the public.’” The most crucial avenue pursued by treatment activists in the construction of their scientific credibility has been precisely the acquisition of such competence by learning the language and culture of medical science. Through a wide variety of methods—including attending scientific conferences, scrutinizing research protocols, and learning from sympathetic professionals both inside and outside the movement—the core treatment activists have gained a working knowledge of the medical vocabulary. While activists have also insisted on the need to bring “nonscientific” language and judgments into their encounters with researchers, they have nonetheless assumed that the capacity to speak the language of the journal article and the conference hall is a *sine qua non* of their effective participation.¹³

In a learning approach that one such activist characterizes frankly as “ass backwards,” activists often begin with the examination of a specific research protocol in which patients have been asked to participate and, from there, go on to educate themselves about the mechanism of drug action, the relevant “basic science” knowledge base (such as considerations of the viral replication cycle of HIV or the immunopathogenesis of AIDS), and the inner

workings of “the system” of drug testing and regulation including the roles of the pharmaceutical companies and the relevant government advisory committees (Braverman 1993). Although activists have benefited from the presence of a few medical and scientific professionals within their ranks, typically the leading lights of the treatment activist movement have been autodidacts who began as science novices but came from positions of relative social advantage. Like most of their scientific interlocutors, they have tended—by and large, although by no means exclusively—to be white, middle-class, well-educated men. And in the course of learning truly impressive amounts of technical information about virology, immunology, molecular biology, and biostatistics, they have also been able to parlay their other social and personal advantages into new types of credibility.

Mark Harrington, one of the young *de facto* leaders of ACT UP/New York’s Treatment & Data Committee (now with the Treatment Action Group), exemplifies the pathways to expertise among the treatment activist elite. Harrington had studied German art and film at Harvard University and had worked as a coffee-house waiter and a freelance writer. When he discovered ACT UP, Harrington was writing scripts for a film company. “The only science background that might have proved relevant was when I was growing up my dad always had subscribed to *Scientific American*, and I had read it, so I didn’t feel that sense of intimidation from science that I think a lot of people feel in this country,” Harrington (1994) recalled. Taking quick stock of his ignorance about science and the federal bureaucracy, Harrington stayed up one night and made a list of all the words he needed to understand. That list evolved into a fifty-page glossary that was distributed to ACT UP members (Handelman 1990).

Other activists explicitly use the metaphors of a foreign language and a foreign culture to describe their initiation into treatment activism. Brenda Lein, a San Francisco activist, described the first time she went to a meeting of the Treatment Issues committee of ACT UP:

And so I walked in the door and it was completely overwhelming, I mean acronyms flying, I didn’t know *what* they were talking about, I thought, oh, they’re speaking Greek and I’m never gonna understand this language. . . . Hank [Wilson] came in and he handed me a stack about a foot high [about granulocyte macrophage colony stimulating factor] and said, “Here, read this.” And I looked at it and I brought it home and I kept going through it in my room and . . . I have to say, I didn’t understand a word. (Lein 1993)

But after reading it about ten times, Lein concluded:

Oh, this is like a sub-culture thing, you know, it’s either surfing or it’s medicine, and you just have to understand the lingo, but it’s not that complicated if you

sit through it. So once I started understanding the language, it all became far less intimidating.

And indeed, the remarkable fact is that once they acquired a certain basic familiarity with the *language* of biomedicine, activists found they could also get in the doors of the *institutions* of biomedicine. Once they could converse comfortably about viral assays and reverse transcription and cytokine regulation and epitope mapping, activists increasingly discovered that researchers felt compelled, by their own norms of discourse and behavior, to consider activist arguments on their merits. Not that activists are always welcome at the table. To quote Lein (1993) again, "I mean, I walk in with, you know, seven earrings in one ear and a mohawk and my ratty old jacket on, and people are like, oh great, one of these street activists who don't know anything." But once she opens her mouth and demonstrates that she knows her stuff, she finds that researchers are often inclined, however reluctantly, to address her concerns with some seriousness.

Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases, makes clear that "there are some [activists] who have no idea what the hell they're talking about," but he is nonetheless happy to grant that "there are some that are brilliant, and even more so than some of the scientists" (Fauci 1994). Prominent academic researchers also typically acknowledge the acquisition of scientific competence on the part of key activists. "Mark Harrington is a perfect example," recalled Douglas Richman, a virologist and member of the AIDS Clinical Trials Group at the University of California, San Diego. "In the first meeting, he got up and gave a lecture on CMV [cytomegalovirus] to us that I would have punished a medical student for in terms of its accuracy and everything else, and he's now become a very sophisticated important contributor to the whole process" (Richman 1994).

A second way in which AIDS treatment activists have striven to present themselves as credible is through the establishment of themselves as *representatives*. That is, a basic "credibility achievement" of treatment activists has been their capacity to present themselves as the legitimate, organized voice of people with AIDS or HIV infection (or, more specifically, the current or potential clinical trial subject population). This point is easily missed but is important because the three groups—activists, people with AIDS or HIV, and clinical trial participants—overlap but are not isomorphic, and it is a complicated question whether in fact activists *do* meaningfully represent the diverse groups in the United States that are affected by HIV.

Over time, treatment activism has become more demographically diverse, in part through the mechanism of the Community Constituency Group (the formal organization of activists elected to sit on the committees of the AIDS

Clinical Trials Group), the membership of which is mandated by the NIH to represent all the communities affected by HIV. Nevertheless, gay men continue to play the dominant role. Even within gay communities, the question of representation can be complex, in part because the activists are often more politically radical than the gay mainstream on whose behalf they speak and in part because gay researchers and health professionals may also make plausible claims to representation. "What right do these people have to think that they are representing the gay community when I'm also here and just on the other side of the fence?" a prominent gay researcher complained (Abrams 1993).

Looking back at her experience with treatment activism, one activist who is now completing medical school reflected, "I *never* represented people with AIDS. I represented *activists*. And those are different people, you know. They are a subset of people with AIDS" (Roland 1993). Yet the extraordinary success of treatment activists (who have always been a relatively small group and whose ranks have been further depleted by burnout, illness, and death over the years) stemmed in large part from their capacity to convince the biomedical establishment not only that they spoke for the larger body of patients, but also that they could mobilize hundreds or thousands of angry demonstrators to give muscle to their specific requests. And once activists monopolized the capacity to say "what patients wanted," researchers could be forced to deal with them to ensure that research subjects would both enroll in their trials in sufficient numbers and comply with the study protocols. On the basis of their credibility, activists thus constructed themselves as an "obligatory passage point" (Latour 1987) standing between the researchers and the trials they sought to conduct (cf. Crowley 1991). Of course, by the same token, the activists *wanted* to see the trials conducted; so the point, really, is that the relationship became a powerfully symbiotic one.

A third credibility tactic employed by treatment activists consisted of *yoking together methodological (or epistemological) arguments and moral (or political) arguments* so as to monopolize different forms of credibility in different domains. A good example was the activist insistence that clinical trial populations should be more fully representative of the different social groups affected by the epidemic (Eigo et al. 1988, 29-31). In AIDS trials, as elsewhere, the subject populations early on tended to consist largely of middle-class white men. AIDS activists argued that people from all affected populations— injection drug users and people with hemophilia, women and men, whites and minorities, heterosexuals and homosexuals—must be given access to trials.

One impetus here was the notion (which was itself somewhat new and controversial) that access to experimental treatments was a social good that must be distributed equitably. Most debates about the ethics of clinical trials

in the United States in the last quarter century have focused on issues of informed consent and the right of the human subject to be protected from undue risk. AIDS activism has shifted the discourse to emphasize the right of the human subject to *assume* the risks inherent in testing therapies of unknown benefit (Edgar and Rothman 1990) and, indeed, to become a full-fledged partner in the experimental process (Feenberg 1992). Once participation in clinical trials came to be viewed, in this sense, as a benefit rather than a burden, the question of equal access to trials assumed centrality.¹⁴ At the same time, activists pressed the claim, backed by some biostatisticians, that to generate data about drug safety and efficacy that is fully generalizable, one's subject population must be broadly representative of those who will be receiving the drug (Cotton 1990). Activists therefore pushed simultaneously for a *morally* credible policy promoting fair access to experimental drugs and for a *scientifically* credible policy for acquiring generalizable data. Between these two lines of approach, AIDS treatment activists had plenty of room to play; such trials not only would be fairer, they would also be better science. Defenders of the opposing notion that a clean trial required a homogeneous research population, by contrast, found themselves increasingly on the defensive.

A final credibility technique is the *taking of sides in pre-existing debates* over how clinical research should be done. That is, many of the positions taken by treatment activists are not arguments that they dreamed up; rather, activists have seized on pre-existing lines of cleavage within the biomedical mainstream.¹⁵ I illustrate this point with a brief analysis of how activists promoted a "pragmatic" approach to clinical trials in reaction to researchers' insistence on the need to perform "fastidious" trials to generate clean data.

For most clinical researchers, the best way to obtain clean results about drug efficacy was to perform randomized, controlled, clinical trials according to carefully delineated methodological precepts. Activists supported the goals of this research but also recognized that one primary motivation of the actual research subjects was access to otherwise unobtainable and potentially helpful therapies. The perception of activists was that, in the name of clean data, people with lab test values or demographic characteristics outside of a specified range, or those who were currently taking other medications or had taken them in the past, were finding themselves excluded from study protocols. Similarly, those enrolled in studies who took other medications without explicit permission were sometimes threatened with expulsion. The practical effect, activists argued, was that in some cases trials were unable to recruit subjects because the treatment options that were offered were too unattractive. In other cases, people were lying in order to get into trials of potentially helpful therapies or were cheating on the protocols while trials were under

way. That is, in the context of a life-threatening illness among a savvy group of patients, the very emphasis on clean data was itself helping to produce some decidedly messy clinical trials.

Terry Sutton was an activist who wanted to be a research subject in a trial of a drug that he believed might keep him from going blind from cytomegalovirus retinitis (a common opportunistic infection in people with AIDS). Sutton was considered ineligible for participation because he had previously taken another drug for the same condition and the research protocol excluded such patients out of concern with statistical bias. Sutton was quoted in the gay press in 1989, shortly before his death:

The idea of clean data terrifies me, because it punishes people for trying to treat early. My roommate . . . has made the decision not to treat early because of the pure subject rule. What he says is “I want to be a pure subject so that I can get access to the best protocol once it starts to move.” You only get to be a pure subject once. (Kingston 1989, 4)

In the activist way of looking at the world, at least circa 1989, the particular ways in which trials were designed, with their emphasis on specific strategies of ensuring methodological purity and cleanliness, reflected a dangerous abstractedness from pressing social realities. In developing this critique, activists seized on a pre-existing debate between two competing understandings of the very purpose of clinical trials—a debate with a history independent of AIDS or AIDS activism. This history goes back to the beginning of formal clinical research early in the century (Marks 1987), but one might reasonably begin with a 1983 article in the *Annals of Internal Medicine* by Alvan Feinstein, a professor at the Yale University School of Medicine and an authority on clinical trials.

Feinstein (1983) had distinguished between two warring conceptions of such trials, which he called the “pragmatic” and “fastidious” perspectives. Proponents of the first perspective look to trials to answer pragmatic questions in clinical management. The trial design, in their view, should “incorporate the heterogeneity, occasional or frequent ambiguity, and other ‘messy’ aspects of ordinary clinical practice” (Feinstein 1983, 545). Those who approach clinical trials with the perspective that Feinstein calls fastidious “fear that [the pragmatic] strategy will yield a ‘messy’ answer. They prefer a ‘clean’ arrangement, using homogeneous groups, reducing or eliminating ambiguity, and avoiding the spectre of biased results” (p. 545).

Feinstein’s distinction between fastidious and pragmatic clinical trials was described by Robert Levine (1986), a professor of medicine and ethicist at Yale University, in a 1986 book; from there, it made its way into the working

vocabulary of John James (1988), the editor of *AIDS Treatment News*, who discussed it in the pages of that publication. The pragmatic perspective made sense to the activists, as it did to the community physicians with whom they were often allied. In their view, clinical trials are experiments, to be sure; but they are not the kind of laboratory experiments where the variables can be controlled neatly, and it is self-deceptive to pretend otherwise. They should be designed not to answer ivory tower theoretical questions, but to inform day-to-day clinical practice and help patients and doctors make meaningful decisions when confronted with treatment dilemmas. Indeed, the trials with the most elegant designs may not be the ones that provide the most useful information if they fail to reflect the actual treatment regimens prescribed by doctors and consumed by patients.

Treatment activists then pushed the critique of fastidious trials even further to raise questions suggested by Terry Sutton's comment. Did "clean" data come only from "pure" subjects? Was "messy," "impure" science necessarily worse science? As one prominent treatment activist told a Senate health subcommittee, people with AIDS are not in awe of that "strange and abstract god, clean data" (Marshall 1989, 345). Similarly, James (1989) argued that "good science, like God, patriotism, and the flag, are rhetorical devices designed to be impossible to argue against—devices often used in the absence of a good case on the merits."¹⁶ Academic researchers could be counted on to come up with "elegant" research designs, but were these the ones that would answer the burning questions most effectively? The metaphors of cleanliness, elegance, and so on varied from the realm of hygiene to that of social status, but the implication in each case was similar: the defense of science put forward by mainstream researchers was an *ideology* designed to promote *the kind of science they happened to do* as the only kind that could be called science.

Building on concepts such as Feinstein's notion of pragmatic trials, activists hinted at (although never fully described) what they saw as a preferable kind of science, which would be more accurate, more useful, and more responsible. This science would be less preoccupied with the formal rules that prevent "contamination" and more open to the varying of experimental design in recognition of practical barriers, ethical demands, and other "real-world" exigencies. "The truth is that [clinical trial] research is muddy, and people need to start acknowledging that," one activist explained:

You can't get good clean answers; the world does not work that way. Patients tend to not work that way unless you totally manipulate them. And this is not a population that is going to be easily manipulated. So you either have muddy research that you *know* is muddy, and you can at least say, "This is where it's

muddy,” or you have muddy research and you don’t even know how muddy it is. (Roland 1993)

One way of understanding this critique is to recognize that a chief goal of the treatment activist movement has been to find methodological common ground that will satisfy competing ethical concerns. On the one hand, activists have often criticized clinical trials from the vantage point of the rights of research subjects; on the other, researchers have defended the trials with utilitarian arguments about the larger benefit to society. But as Rebecca Smith of ACT UP/New York explained in a letter published in *Science*, the solution was precisely to find points of convergence between “the immediate short-term needs of people with AIDS” and the “long-term goals of medical research” (Smith 1989, 1547). To the extent that methodological solutions could be engineered that would make all parties comfortable—and that would affirm the “dual role” of clinical trials as both scientific experiment and health care (ACT UP/New York 1989, 2)—people with AIDS and HIV infection would willingly participate in the trials and conform to the protocols, and scientific knowledge would be advanced.

In large part because this agenda was consistent with certain pre-existing stances within clinical medicine, bioethics, and biostatistics and because activists were able to enroll allies from those domains (see Byar 1990), they succeeded in endowing the pragmatic perspective with additional credibility. In so doing, activists won support for a number of modifications in trial design including the use of broader entry criteria, more diverse subject populations, and concomitant medication.¹⁷ But here it is important to point to the subsequent history, which is somewhat ironic.

Over time, as activists themselves have become experts—as they have absorbed the vocabulary and cultural frames of mainstream biomedicine—many of them have come to voice an increasing faith in the formal principles of the clinical trial. Indeed, as the hope of a rapidly available cure has faded, and as the precise benefits of the existing anti-viral therapies have become ever more subject to dispute, at least some of the key treatment activists, particularly on the East Coast, have now swung over to something closer to the fastidious perspective in the hopes of acquiring at least some “hard data” that can serve as ground beneath their feet. At the same time, there are other activists who now oppose what they label as “conservatism” on the part of their peers, sometimes suggesting that those activists have become detached from the constituencies they claim to represent and seduced by the aura of science.¹⁸ Such debates have overlapped with strategic disputes within the movement about the risks of co-optation and with resentment of the perceived greater access to the governmental and research elite by white male activists

(Corea 1992; Wolfe forthcoming). These tensions have been contributing factors in formal splits in AIDS activist organizations in several U.S. cities (Dobson 1990; Raphael 1990). While there is little or no evidence to suggest that activists pursuing “insider” strategies have in any fundamental sense been “co-opted,” it is nonetheless noteworthy that these activists are currently more invested in the notion that controlled experimentation is the path to medical progress and are more likely to suppose that success will lie with pharmacological products as opposed to “natural” or “alternative” therapies.

In the end, it has remained somewhat unclear precisely what kinds of science activists would like to see practiced. Are AIDS activists really just trying to “clean up” science by eliminating “biases” that the academic researchers are introducing? Or are they trying to supplant “clean science” with something that answers to different epistemological and ethical aspirations? It may be the tension between these conflicting and ambiguously defined goals, more than anything else, that characterizes the AIDS activists’ engagement with the science of clinical trials. Certainly, activists have rejected a narrow positivist conception of the clinical trial as a laboratory experiment pure and simple. Neither have they endorsed a fully relativist approach to clinical trials, as some SSK analysts have done.

For example, in her absorbing analysis of the controversy between Linus Pauling and more orthodox researchers over whether Vitamin C can help cancer patients, Richards (1991, 204) argues against “the myth of the ‘definitive’ clinical trial and the neutral evaluation it supposedly entails,” which serves the primary interest of professional legitimation. Rather than worship this false god, Richards suggests, we might be better off abandoning the formal apparatus of the randomized clinical trial, choosing instead “to learn to live with the reality of uncertainty” and to introduce political, ethical, and subjective criteria into the evaluation of treatments (pp. 232-34). This “implies a more prominent role for nonexperts, for patients and the public at large, in the processes of assessment and decision making” (p. 5). Quite similarly, AIDS activists have emphasized the artifactual and historical character of the clinical trials methodology, and they have placed a spotlight on the perceptions of the patient as a genuine participant in clinical research and not just the object of study. Yet, perhaps as they have become more enculturated into the biomedical research process, most AIDS treatment activists share with doctors and researchers a profound investment in the belief that the truth is, in principle, knowable through some application of the scientific method. Although many in the AIDS movement have, at particular moments, argued in favor of tolerating uncertainty as the necessary trade-off for access to experimental drugs, in the end, few activists, and perhaps few people with AIDS or HIV infection, are fully sanguine about the prospect of

“[living] with the reality of uncertainty.” This is not surprising because activists, and people with AIDS and HIV, are confronted daily by a burning need to know whether given treatments “work” or not, and such need does not typically take comfort in relativism. The activist critique of the randomized clinical trial unseats that methodology from the pinnacle on which it is sometimes placed, but it also assumes a greater role for such trials than analysts such as Richards would recommend.

Participatory Knowledge Making in Biomedicine

My analysis of these techniques for establishing credibility suggests that certain particular kinds of social movements, when pursuing certain distinctive strategies, can acquire credibility within certain specific domains of scientific practice. It mattered that biomedicine is relatively more open to outside scrutiny than are other arenas of science and technology (Cozzens and Solomon 1994). This is especially true of clinical trials, where people with AIDS or HIV were constituted as participants from the start and thus could claim to have a unique and important perspective on the process—that is, they could generate “situated knowledges,” to use Haraway’s (1991, chap. 9) term for “partial, locatable, critical knowledges” generated by social actors on the basis of their social location. But it also mattered that activists were able to master the technical *arcana* in ways that even credentialed experts found impressive; that they were able to make effective use of existing differences of opinion among credentialed experts; and that they were able to weave back and forth between epistemological, methodological, political, and ethical claims to construct powerful arguments that proved effective in both specialized and public arenas.¹⁹

Once activists succeeded in establishing their credibility, they were able to gain representation on NIH and FDA advisory committees, on institutional review boards at local hospitals and research centers, on community advisory boards established by pharmaceutical companies, and, most recently, on a national board created by the Clinton administration and charged with overseeing the entire course of AIDS research. Of course, some researchers and government officials have deemed it strategic to incorporate activists into the process. As Fauci (1994) put it, the assumption was that “on a practical level, it would be helpful in some of our programs because we needed to get a feel for what would play in Peoria, as it were.” But, in general, this recent reconfiguration of the boundaries (Gieryn 1983) between the “inside” and the “outside” of biomedicine has been the outcome of struggle. Such activism

is “self-help with a vengeance,” as Indyk and Rier (1993, 6) put it nicely; the projects of these activists surpass, in scope and character, those of more typical patient self-help groups (Stewart 1990; von Gizycki 1987).²⁰ By introducing new “currencies” of credibility into circulation, and by succeeding in establishing a value for those currencies within the scientific field, activists in effect have transformed the field’s mechanisms of operation (Bourdieu 1990). In certain respects, they have transformed how biomedical knowledge gets made (Epstein 1993).

Of course, the capacity (or desire) of activists to pose genuinely epistemic challenges to biomedicine has been limited. For the most part, activists have been more interested in participating in science—or asserting the simultaneous importance of values *other than* the pursuit of science—than they have been in transforming the practices by which science constitutes knowledge. Still, the arguments of AIDS activists have been published in scientific journals and presented at formal scientific conferences (Barr, Harrington, and Lipner 1992; Delaney 1989; Smith et al. 1992); their publications, as Indyk and Rier (1993) argue, have created new pathways for the dissemination of medical information; their voice and vote on review committees help determine which studies receive funding; their efforts have led to changes in the very definition of AIDS to incorporate the HIV-related conditions that affect women (Corea 1992); their interventions have led to the establishment of new regulatory and interpretive mechanisms by the FDA and the NIH (Jonsen and Stryker 1993; Edgar and Rothman 1990); and their arguments have brought about shifts in the balance of power between competing visions of how clinical trials should be conducted. Although activists have never established absolute jurisdiction over any contested scientific terrain, they have, to use Abbott’s (1988) term, won the rights to an “advisory jurisdiction,” analogous to the relation of the clergy to medicine or psychiatry. Of course, as Abbott notes, advisory jurisdictions are characteristically unstable, “sometimes a leading edge of invasion, sometimes the trailing edge of defeat” (pp. 75-76).

The Broader Impact of AIDS Treatment Activism

Does the story of this particular social movement have implications, either practical or theoretical, beyond the case of AIDS? On the one hand, if one looks at the extent of lay participation in different dimensions of AIDS research, it is clear that this is not the typical case in science. On the other hand, if one considers experiences elsewhere in *biomedicine*, the potential impact of the credibility struggles in AIDS research might be great. Consider some vignettes from recent history in the United States:

- At an international conference on Lyme disease held in Arlington, Virginia, in 1992, several presentations that had been rejected by the organizers were reinstated at the last minute. The program changes came in response to “popular demand” by support groups of Lyme disease patients. One program committee member who “wasn’t even consulted” about the change described himself as “damn annoyed”: “There is science and there is nonscience, and nonscience doesn’t belong at a scientific meeting,” he told *Science* magazine (Barinaga 1992, 1385).
- In 1991, more than 180 U.S. advocacy groups came together to form the National Breast Cancer Coalition. “They say they’ve had it with politicians and physicians and scientists who ‘there, there’ them with studies and statistics and treatments that suggest the disease is under control,” read a prominent account in the *New York Times Sunday Magazine* (Ferraro 1993, 26). The debt to AIDS activism was widely noted by activists and commentators alike (Krieger 1991). “They showed us how to get through to the government,” said a Bay Area breast cancer patient and organizer. “They took on an archaic system and turned it around while we have been quietly dying” (Gross 1991, 12). Another activist described how she met with the staff of *AIDS Treatment News* to learn the ropes of the drug development and regulatory systems (Gross 1991, 12).
- When a drug manufacturing company violated its promise to continue supplying an experimental drug to chronic fatigue patients following the termination of the clinical trial in which they participated, the research subjects found their way to a Project Inform board member, who helped them prepare a lawsuit. The board member told the gay press in 1991 that if it had been an AIDS drug trial, there would have been a political uproar (Kingston 1991, 8).

In fact, the past few years in the United States have seen an upsurge of health-related activism of a distinctive type: the formation of groups that construct identities around particular disease categories and assert political claims on the basis of those new identities. To be sure, not every such group owes directly to AIDS activism, although the tactics and political vocabulary of organizations such as ACT UP would seem, at a minimum, to be “in the wind” (see Wachter 1992). Thus far, none of these groups has engaged in epistemological interventions that begin to approach, in their depth or extent, AIDS treatment activists’ critiques of the methodology of clinical trials. But what most such groups appear to share is a certain suspicion of biomedical claims making; an emphasis on empowerment and a repudiation of “victim” status; a push toward greater equality in the doctor-patient relationship; and the demand for a greater role for patient groups in determining research priorities, assessing research findings, or making regulatory or policy decisions on the basis of those findings.

To varying extents, these groups challenge the hierarchical relations between experts and laypeople and insist on the rights of those affected by biomedical science to participate in its production. As opposed to those

movements that confront expertise by finding their own experts to represent them—what Gaventa (1985) has called the “hired gun” approach—these movements seek “to break down the distinction between the researchers and the researched, the subjects and objects of knowledge production by the participation of the people-for-themselves in the process of gaining and creating knowledge” (p. 35).

Here, however, it is important to stress some complications to this story. Given the preceding account, it should be clear why such activism, no matter how broad ranging it becomes, will face an uphill battle in thoroughly transforming the kinds of knowledge-based hierarchies that structure complex and differentiated societies. In fact, my analysis suggests a significant tension in the AIDS movement’s relation to its project of democratizing expertise. On the one hand, by pursuing an educational strategy to disseminate AIDS information widely, activists have promoted the development of broad-based knowledge empowerment at the grassroots. On the other hand, as activist leaders have become full-fledged experts, they have often tended to replicate the expert/lay division within the movement itself by constructing what Elbaz (1992, 488), in an analysis of ACT UP/New York, describes nicely as a divide between the “lay expert” activists and the “lay lay” activists. Arguably, it was not possible for the core treatment activists to become experts on clinical trials and sit on the NIH committees without, in some sense, growing closer to the worldview of the researchers and without moving a bit away from their fellow activists engaged in other pursuits. Similarly, activists themselves seem torn about whether mechanisms of participatory democracy are automatically of value in the struggle to develop effective therapies or whether scientific “progress,” however understood, might indeed be facilitated by an “antidemocratic” reliance on relationships of trust and authority and by the delegation of science to “the experts,” now understood to include a smattering of autodidact activists.

Certainly, however we understand these complexities, the experience of AIDS activism suggests the need for social analysts to attend to the particular strategies pursued by lay actors in their attempts to speak credibly about science and medicine. Negotiations over credibility in AIDS research (and perhaps often elsewhere) are multilateral in the sense of involving many different players. They are also multilayered in that those negotiations help determine *who* is credible, *which knowledge claims* are credible, and *which ways of doing biomedical research* are credible. A full-fledged analysis of the negotiation of credibility in such cases entails a broadening of our understanding of medicine and science to encompass actors who are more typically ignored—the producers of subjugated knowledges, to borrow a phrase from Foucault. In this particular case, I have emphasized the need to pay specific

attention to the role of a social movement; and, in fact, while the analysis of social movements has been commonplace elsewhere, it has been relatively underdeveloped in both the sociology of medicine and the sociology of science. The case of AIDS treatment activism suggests that so-called “new social movements” have distinctive forms of engagement with science and that the engagement with science shapes such movements in quite distinctive ways. An extended study of the relation between biomedicine and social movements could provide for a deeper and more comprehensive analysis of the construction of medical knowledge and the transformation of medical practice.

Notes

1. Indeed, many analysts, including founders of the sociology of science such as Merton (1973, 257-60) but also contemporary theorists such as Bourdieu (1975, 1991), have located the practical efficacy of science precisely in its insulation from external pressures.

2. This conceptualization is intended to echo Bourdieu's (1990) theory of agonistic social action within “fields” (*champs*). However, Bourdieu (1975, 1991) himself pays scant attention to the role of laypeople in his depiction of the scientific field. For a general critique of Bourdieu's characterization of scientific practice, see Knorr-Cetina (1982).

3. On the history and politics of clinical trials in general, see Marks (1987), Meldrum (1994), and Richards (1991).

4. On the role of scientific advisory bodies in the construction of “regulatory science,” see, more generally, Jasanoff (1990). On drug regulation, expertise, and trust, see also Abraham (1994).

5. On the engagement of AIDS activists with biomedical research, see also Altman (1994), Arno and Feiden (1992), Corea (1992), Crowley (1991), Horton (1989), Indyk and Rier (1993), Patton (1990), Treichler (1991), and Wachter (1991).

6. This conception of scientific credibility has affinities with Cozzens's (1990) definition of scientific “power” as enrollment capacity plus legitimacy.

7. Bibliometric analyses (Elford, Bor, and Summers 1991; Lyons et al. 1990; Self, Filardo, and Lancaster 1989; Sengupta and Kumari 1991) and co-citation analyses (Small and Greenlee 1990) of AIDS research, however valuable, miss this crucial point. They begin with the unwarranted assumption that the domain constitutive of knowledge about AIDS can be delimited by reference to the professional journals. On the unusual pathways of influence in AIDS research and publication, see Indyk and Rier (1993). The “social worlds” approach to the study of science (Clarke 1990; Fujimura 1992; Star and Griesemer 1989) may be particularly helpful in conceptualizing the politics of knowledge in the case of AIDS. Drawing on the interactionist tradition in sociology, the proponents of this perspective analyze the “negotiation of order” in the encounter between different “social worlds,” or “groups with shared commitments to certain activities sharing resources of many kinds to achieve their goals” (Clarke 1990, 18). Within this frame of reference, the science of AIDS can be viewed precisely as the product of the encounter—or clash—between members of many different social worlds.

8. But see Brante, Fuller, and Lynch (1993), Indyk and Rier (1993), Kling and Iacono (1988), Moore (1993), and Petersen and Markle (1981).

9. On the AIDS movement (or, more specifically, ACT UP) as a characteristically “new” social movement that engages in a representational politics to resist “normalization,” see Gamson (1989).

10. Much like scientists, doctors, and the media, social movements are actively engaged in the construction of reality through the imposition of organizing "frames." See Gitlin (1980) and Snow and Benford (1988).

11. On the AIDS activist repudiation of the "victim" designation, see Navarre (1987).

12. In this sense, AIDS treatment activists differ from groups such as animal rights activists (Jasper and Nelkin 1992), who will have no truck with "the enemy" in their confrontations with medical research.

13. Whether the adoption of the language of science compromises the capacity of activists to speak in "their own voice" is a question to which I return later in this article.

14. Of course, some groups, such as African Americans, who have been subject to abuses in scientific experimentation in the recent past may be far less inclined to desire entry into such experiments than will middle-class, white gay men. On the legacy of the Tuskegee syphilis study in influencing African American perceptions of AIDS research, see Thomas and Quinn (1991).

15. Similar dynamics in the relation between intra-expert controversy and social movements have been noted by Balogh (1991, 307) in the case of antinuclear activists.

16. Clearly, there is an implicit critique here of the incorporation of cultural metaphors of "cleanliness" and "purity" into scientific discourse. On the cultural significance of metaphors of purity, see Douglas (1979). On the "sacred" character of "pure science," see Restivo (1990).

17. Many such changes were already in place in clinical trials for cancer therapies, as biostatisticians who had moved from cancer research to AIDS were well aware (Ellenberg 1994). In this sense, too, activist victories depended heavily on the existing balance of forces within biomedicine. I am grateful to Evelleen Richards for discussion of these issues.

18. With regard to certain issues, such as the use of placebo controls in randomized clinical trials, many activists now characterize their initial stances as naïve. Thus although activists wrote in 1988 that "it is unethical to use any placebo in a group of seriously ill subjects" (Eigo et al. 1988, 24), nearly all treatment activists now endorse the use of placebo controls when no therapy has been found to be efficacious for a condition (Harrington 1994).

19. To the extent that the capacity of activists to participate in AIDS knowledge making has been linked to the special role of patients as necessary participants in clinical research, it will be interesting to see what happens as AIDS treatment activists increasingly focus their attention on basic research. This movement has been spurred by the perception that existing antiviral therapies are relatively ineffective and that the development of better treatments presupposes a clearer understanding of the immunopathogenesis of HIV infection (Gonsalves 1993). In focusing on basic research, however, it is less clear whether activists possess a special vantage point from which to contribute to the production of knowledge despite the fact that some of them have begun spending time as observers in immunology labs at NIH (Fauci 1994).

20. A closer analogy would be the "popular epidemiology" practiced by some groups within the toxic waste movement (see Brown 1992). See also Di Chiro (1992) on lay expertise in the environmental justice movement.

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