

## INTRODUCTION

# CONTROVERSY, CREDIBILITY, AND THE PUBLIC CHARACTER OF AIDS RESEARCH

It was the first day of classes at Harvard Medical School in fall 1988. As students arrived for the new semester, members of the Boston chapter of ACT UP (the AIDS Coalition to Unleash Power) took positions in front of the building. Equipped with hospital gowns, blindfolds, and chains, the activists broke into a chant: “We’re here to show defiance / for what Harvard calls ‘good science’!” While some of the demonstrators poured fake blood on the sidewalk, others presented the medical students with a mock “course outline” for an “AIDS 101” class. The outline listed discussion topics like:

PWA’s [People with AIDS]—Human beings or laboratory rats?

AZT—Why does it consume 90 percent of all research when it’s highly toxic and is not a cure?

Harvard-run clinical trials—Are subjects genuine volunteers, or are they coerced?

Medical elitism—Is the pursuit of elegant science leading to the destruction of our community?<sup>1</sup>

This wasn’t a large demonstration; indeed, it was a lesser episode in the annals of AIDS activism. But it suggested the contours of a

distinctive terrain. The concepts embedded in the “course outline” were relatively opaque, especially in contrast with the graphic symbolism of the protest—the blood and the chains. These were no simple slogans of the “Up with *this*, down with *that*” variety; each cryptic item hinted at arguments of some depth and complexity. In fact, the activist agenda reflected critical engagement with the nuts and bolts of clinical research into the Acquired Immunodeficiency Syndrome and a desire to take the science of AIDS as seriously as a deadly illness demanded.

These protesters were not rejecting medical science. They were, however, denouncing some *variety* of scientific practice—“elegant” science, “what Harvard calls ‘good science’”—as not conducive to medical progress and the health and welfare of their constituency. To the uninitiated, such a challenge might well be baffling: What would “inelegant” science look like, and why should anyone desire it? What would be the alternative to the “good science” that the medical students were absorbing in their lecture halls? What precisely were the activists claiming, both about the nature of AIDS and the nature of biomedical research? And from where did they derive the authority to make their allegations and proposals?

This book is a study of how varied classes of AIDS experts, diverse conceptions of scientific practice, and distinct claims of knowledge about AIDS have all been generated out of relationships of conflict and cooperation in the United States since the early 1980s. Inside a large and often floodlit arena with a diffuse and porous perimeter, an eclectic assortment of actors has sought to assert and assess credible knowledge about AIDS: biomedical researchers and health care professionals of different stripes; activists, advocacy groups, and people with AIDS or HIV infection; health educators and social scientists; politicians and public health officials; government agencies and advisory committees; pharmaceutical and biotechnology companies; writers, journalists, and the institutions of the mainstream and alternative media. “What we know about AIDS” is the product of this elaborate, often heated, and in some ways quite peculiar complex of interactions.

I seek to identify the pathways by which specific beliefs and spokespersons have become accredited as authoritative: How is certainty constructed—or deconstructed? How are scientific controversies adjudicated? How are debates closed, and what is the character of that closure? Who becomes an “AIDS expert” and by what means? In short, how is the linkage of power, knowledge, and order forged in

the United States in the context of the AIDS epidemic? My analysis shows how knowledge emerges out of *credibility struggles*—and how the unusual politicization of AIDS in the United States has altered the conduct and resolution of such struggles.

By scientific “credibility,” I mean to refer to the believability of claims and claims-makers. More specifically, credibility describes the capacity of claims-makers to enroll supporters behind their arguments, legitimate those arguments as authoritative knowledge, and present themselves as the sort of people who can voice the truth.<sup>2</sup> Credibility is, of course, a quality that can be established in many different ways in different arenas. The credibility of a speaker can rest on academic degrees, “anointment” by the media, or the speaker’s access to esoteric forms of communication; the credibility of any knowledge claim can depend on who advances it, how plausible it seems, or what sort of experimental evidence is invoked to support it. In the case of AIDS, credibility struggles have had distinctive characteristics, and the involvement of such a large cast of characters in the controversies has important implications for the study of credibility and knowledge-making.

From a scientific standpoint, the sheer complexity of AIDS has ensured the participation of scientists from a range of disciplines, all of them bringing their particular, often competing, claims to credibility. But AIDS has also been a politicized epidemic, and that political character has had consequences: it has resulted in *multiplication of the successful pathways* to the establishment of credibility and *diversification of the personnel* beyond the highly credentialed. The construction of facts in AIDS controversies has therefore been more complicated and the routes to closure more convoluted. Credibility struggles in the AIDS arena have been multilateral: they have involved an unusually wide range of players. And the interventions of laypeople in the proclamation and evaluation of scientific claims have helped shape what is believed to be known about AIDS—just as they have made problematic our understanding of who is a “layperson” and who is an “expert.” At stake at every moment has been whether specific knowledge claims or spokespersons are credible. But at a deeper level, the stakes have involved the very mechanisms for the assessment of credibility: how are scientific claims adjudicated, and who gets to decide? As this study shows, debates *within* science are simultaneously debates *about* science and how it should be done—or who should be doing it.

The science of AIDS, therefore, cannot be analyzed “from the top

down.” Rather, it demands attention to what Michel Foucault calls the “microphysics 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 at every site; and the propagation of knowledge, practices, meanings, and identities out of the deployment of power.<sup>3</sup> At the same time, my analysis suggests that—as Foucault would have it—the attempt to master specialized forms of knowledge can make people “objects” of that knowledge as well as “subjects.” This is no romantic tale of resistance that privileges the “purity” of knowledge-seeking from below; rather, I argue that the cultures of experts significantly encroach upon and transform those of the laypeople who would engage with them. Nor am I interested in cheerleading, despite my strong sympathies for AIDS activism. What make the story of this engagement with biomedical expertise interesting and important are the ironies and tensions embedded in the process of forging novel scientific, political, and moral identities. This is a complicated history in which no party has had all the answers. All players have revised their claims and shifted their positions over time; all have had to wrestle with the unintended consequences of their own actions.

The immediate goal of my analysis is to shed light on the scientific and political dynamics of a health crisis of immense social import. With so many lives at stake, it behooves us to understand the configuration of interests, beliefs, and practices that determine how we come to believe what we think we know about the epidemic. However, I intend this analysis to do more. By emphasizing the role of laypeople in the production of biomedical knowledge, this study challenges approaches to the social study of science that tend to assume that knowledge-making is the province of a narrow circle of credentialed experts. And by exploring the vicissitudes of lay interventions in AIDS research, particularly on the part of grassroots activists, this study addresses some important and intractable questions about the politics of expertise and the place of science in the larger culture: What is the nature of the power wielded by experts? How does a society reconcile competing commitments to scientific autonomy and participatory democracy? What possibilities are there for laypeople to involve themselves meaningfully in the processes of “doing science,” and what are the consequences of such incursions?

In the broadest sense, the analysis that follows reflects a historical and institutional approach to the study of controversies about knowl-

edge. It is concerned with the minute details of the construction of facts, but it assumes that the dynamics of fact-making become apparent only through a more thoroughgoing examination of power, meaning, and social organization. It focuses on the institutions of biomedicine and their particular organizational features and interests, but it argues that these institutions are constrained, and in some sense constituted, by their relations to other institutions and actors, notably forms of popular resistance. Because the pattern of these interrelationships in the case of AIDS has taken shape only gradually over the course of the epidemic, the body of my analysis assumes the form of narrative history. And because the actors and institutions in the story are so diverse, I have been deliberately eclectic in my selection of the theories and concepts that give the narrative its structure. Specifically, this book unites approaches from social studies of science, the sociology of medicine and the professions, and the sociology of social movements. In so doing, the book suggests directions for the development of a more comprehensive inquiry into the politics of knowledge in modern Western societies.

## The Crisis of Credibility and the Rise of the AIDS Movement

### THE POLITICS OF TRUST AND DISTRUST

Why is AIDS research so fraught with conflict and controversy? Why is this arena of fact-making so unusually public and porous? It has been suggested that a line of scientific research is likely to be controversial when any of a number of characteristics are present: if the research has direct applications, if it challenges or threatens the "natural order," if it is relevant to some politicized social issue, if sentiment has mobilized a related social movement, or if the research is in competition for scarce resources.<sup>4</sup> Since AIDS research is marked by all five characteristics, one need not search hard for explanations of the volatility of the encounters surrounding it.

At the same time, both the controversies enveloping AIDS research and the invasion of the domain of science by outsiders presuppose a specific historical moment—one in which the authority of experts has extraordinary cultural centrality yet seems possessed of a curious fragility. Certainly there is no avoiding reliance on experts who are crucial transmitters and translators of technical knowledge to the lay

public.<sup>5</sup> Increasingly, science is the resource called on to promote consensus, and experts are brought in to “settle” political and social controversies. Yet this “scientization of politics”<sup>6</sup> simultaneously brings about a “politicization of science”: the fact that political disputes tend to become technical disputes means that different parties rally their own experts to support them in a controversy, much like lawyers offering to the jury a parade of expert witnesses. Ironically, the outcome is that the very reliance on experts to adjudicate disputes tends to undercut the authority of expertise in general, “[highlighting] their fallibility [and demystifying] their special expertise.”<sup>7</sup>

Growing distrust of established experts is magnified by our culture’s ambivalent attitude toward the institutions of science and their technological products. To be sure, science remains in relatively high esteem, especially considering the overall decline in confidence in many social institutions in the United States in recent decades.<sup>8</sup> Yet science has been subject to attack from a range of points on the political spectrum, and the powers and prerogatives of the expert technocracy have been called into question.<sup>9</sup> Postmodernist perspectives have unseated an Enlightenment confidence in the forward march of history, raising troubling questions about the role of science in a world stripped of the old warrants of reason, truth, and progress.<sup>10</sup> And in a post-Hiroshima world, each passing technological disaster—DES, asbestos, Three Mile Island, Chernobyl, the space shuttle *Challenger*, the *Exxon Valdez*—heightens the perception that the fruits of scientific discoveries may be bitter as often as they are sweet. Overpromising by scientific experts, and claims of certainty that must later be watered down or retracted, are other instigators of “flip-flop thinking” on the part of the public—a tendency to alternate between mythologizing and demonizing scientists.<sup>11</sup>

Medicine, as the most visible—and indeed most popular—form of applied science, has been a particularly important target of recent critiques of science.<sup>12</sup> Doctors, in the words of Paul Starr, “serve as intermediaries between science and private experience.”<sup>13</sup> More profoundly than the abstract sciences, medicine seems to entrap its consumers in a fierce love-hate relationship, a tight nexus of need and fear. Over the course of the nineteenth and early twentieth centuries, doctors rose to positions of privilege in the United States, able to reap substantial social rewards on the basis of their authority. This authority, according to Starr, rested on the twin pillars of legitimacy and dependence: people believed that medical knowledge could help them,

and they felt that only doctors possessed that special knowledge and the skill to use it. The victory of medical authority therefore required the popular abandonment of an earlier, Jacksonian belief that the healing arts were accessible to "common sense" and the acknowledgment, on the contrary, of medicine's "legitimate complexity": no longer could everyone be his or her own physician.<sup>14</sup>

In the 1950s, as Starr notes, "medical science epitomized the post-war vision of progress without conflict"—but this vision faltered in the 1960s and 1970s.<sup>15</sup> Leftists advanced a thoroughgoing critique of the "medical-industrial complex": lurking behind the white coats and the reassuring smiles were profit lust and the dominance of large corporations.<sup>16</sup> While conservatives and liberals argued that medical costs were out of control, feminists strove to take back control over their own bodies, criticizing medical science as a patriarchal institution. Revelations of past abuses in medical experimentation on human subjects led to an expanded emphasis on "informed consent," premised on the notion that the patient's trust in a physician is not automatically granted but "must be earned through conversation."<sup>17</sup> At the same time, these revelations prompted the emergence of new institutions and bureaucratic structures designed to safeguard the interests of patients and research subjects vis-à-vis their own doctors.<sup>18</sup>

The AIDS epidemic has magnified these various misgivings about doctors and researchers. Indeed, in the face of death and disease, popular ambivalence about biomedicine has undergone a peculiar amplification: distrust has been accentuated, but so has dependence. Despite their suspicion of expertise, people in advanced industrial societies typically expect doctors and scientists to protect them from illness and death. Yet, a decade and a half into the epidemic, researchers have not found an effective cure or vaccine. Scientists insist this is not surprising, given the complexity of AIDS and the "normal" rate of progress in biomedical investigations. Nevertheless, the failure of experts to solve the problem of AIDS quickly, as they were "supposed to," has heightened popular resentment and sparked a "credibility crisis."<sup>19</sup> This in turn has opened up more space for dissident positions, both among scientists and doctors and within the lay public.

In theory, science is a quintessentially public enterprise. As Yaron Ezrahi notes, every scientific finding is legitimated by the notion that it is "grounded in impersonal non-private reproducible procedures through which it can be certified by anyone who cares to do so, provided he has the competence and the patience."<sup>20</sup> In fact, as Steven

Shapin and Simon Schaffer have described it, the evolution of modern science is an ironic story of the construction of "a public space with restricted access." The consequence is that "a form of knowledge that is the most open in principle has become the most closed in practice."<sup>21</sup> Scientists themselves are often anxious to police the boundaries of their professional domain and keep out unqualified interlopers or traffickers in "pseudoscience."<sup>22</sup>

Yet the experts themselves ruefully acknowledge that the traditional conception of scientific autonomy is little in evidence in the case of AIDS. "We are no longer in that period of splendid isolation in science," the director of the National Institutes of Health (NIH), Dr. James B. Wyngaarden, remarked in 1989. "AIDS has politicized research, brought scientists face to face with many social issues and disaffected individuals, and gotten the attention of an activist community."<sup>23</sup> If, as some have sought to argue, the "purity" of science is guaranteed by its insulation from external pressures,<sup>24</sup> then AIDS research is a clear-cut case of impure science.

#### THE DISTINCTIVE CHARACTER OF THE AIDS MOVEMENT

Perhaps the most striking feature on the landscape of AIDS politics is the development of an "AIDS movement" that is more than just a "disease constituency" pressuring the government for more funding, but is in fact an alternative basis of expertise. The members of this movement are not the first laypeople to put forward claims to speak credibly on biomedical matters. But this is indeed the first social movement in the United States to accomplish the large-scale conversion of disease "victims" into activist-experts. In this sense, the AIDS movement stands alone, even as it begins to serve as a model for others.<sup>25</sup>

The movement is broad based and diverse, ranging from grassroots activists and advocacy organizations to health educators, journalists, writers, and service providers; it cuts across the various communities and constituencies affected by the AIDS epidemic, and includes gays and lesbians, people with hemophilia, injection drug users, and members of many hard-hit African-American and Latino communities. Over the course of the epidemic, members of the AIDS movement have taught themselves the details of virology, immunology, and epidemiology. They have criticized scientific research that seemed to be fueled



by antigay assumptions, defended speculation about alternative theories of AIDS causation, asserted that community-based AIDS organizations have the expertise to define public health constructs such as “safe sex,” demanded scientific investigation of potentially useful treatments, established a grassroots base of knowledge about treatments, conducted their own “underground” drug trials, and criticized the methodologies employed in AIDS clinical research. They have established their credibility as people who might legitimately speak in the language of medical science, in particular with regard to the design, conduct, and interpretation of clinical trials used to test the safety and efficacy of AIDS drugs.

Medicine is, to be sure, a more likely target of lay intervention than other, more private and remote domains of scientific practice. On a national level, biomedical politics constitute “one arena of science-government relations” where interest groups flourish and “where ordinary people get some of what they want.”<sup>26</sup> On a more intimate scale, the health of one’s body is an issue of considerable salience to most people in a way that, say, astrophysics or oceanography typically is not. And individuals have much easier access to at least the frontline institutions of biomedicine—hospitals, clinics, and so on—than to the inner sanctums of science. Indeed, there is a substantial, if recent, history of political challenges to the doctor-patient relationship and of the emergence of the “educated patient”—a history that prefigures the claims-making projects of the AIDS movement. Patients with chronic illnesses such as diabetes, multiple sclerosis, and arthritis may be particularly inclined to become expert in therapeutic options and even the theories about underlying disease mechanisms.<sup>27</sup>

Of course, the expertise of the individual educated patient is not likely to “travel” far beyond a restricted domain. But as patients begin to organize and exchange information, the breadth and durability of their lay expertise is enhanced. Such organization can take a variety of forms. Creation of patient self-help groups—a rapidly proliferating phenomenon particularly in the United States—is an important step in the development of an organized base of alternative expertise.<sup>28</sup> A different kind of example is the attempt made by groups of cancer patients in the 1970s to promote access to unapproved therapies, such as use of laetrile; their efforts resulted in public hearings and Supreme Court rulings.<sup>29</sup> Perhaps most consequential for the cultural redefinition of relations between medical experts and lay consumers was the emergence in the 1970s of the feminist health movement. Linking a

systematic critique of patriarchal institutions to a concrete praxis of self-help, the feminist health movement sought, in Sheryl Ruzek's words, to "[reduce] the knowledge differential between patient and practitioner, [challenge] the license and mandate of physicians to provide certain services, [reduce] professionals' control and monopoly over related necessary goods and services, . . . and [transform] the clientele from an aggregate into a collectivity."<sup>30</sup>

However, neither self-help groups nor cancer activists nor even the feminist health movement has had much success in extending its critique of medical *practice* into an engagement with the methodologies of biomedical *research*. Examples of this sort of lay intervention are few and far between, although analysts have described some intriguing parallel cases. For example, in the late 1980s the RSI (Repetitive Strain Injury) Association in the United Kingdom not only produced patients who were "better informed about the disorder than their treating physician" but also played a role in the very conceptualization of this new illness within the biomedical establishment.<sup>31</sup> The German Retinitis Pigmentosa Society, founded in 1977, encouraged scientists to pursue specific lines of research that otherwise might not have been investigated, judging from the absence of such research in other European countries.<sup>32</sup> Yet even these examples pale when compared to the breadth, depth, and, certainly, the *militance* of the AIDS movement.

What gives AIDS activism its distinctive character? To some extent, the unique features of the clinical picture of AIDS have shaped the development of an activist response. First, AIDS has affected many young people in their twenties and thirties who are little inclined simply to lie down and wait to die. Second, 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—years in which activism is not only feasible from a physical standpoint but may seem eminently practical from a political and psychological standpoint. Indeed, AIDS activism, as opposed to many other activist projects, holds out the promise of some profoundly tangible immediate rewards, most notably access to potentially life-prolonging medications.

Even more fundamental, the distinctive social epidemiology of AIDS has shaped the character of the public engagement with science. Unlike many other diseases, which affect the population in a relatively random fashion, AIDS has had a strikingly uneven impact, being dis-

proportionately prevalent within specific groups, subcultures, and communities. This may seem an obvious point, yet its significance cannot be overemphasized. 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.<sup>33</sup> The result is that the very meaning of AIDS has been bound up with the cultural understanding of what such groups are like, while the very identity of the groups has been 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 massive scale, for what Erving Goffman has called “the management of spoiled identity.”<sup>34</sup>

Gay men, the group whose identity has been most thoroughly shaped by the confrontation and association with the epidemic, entered the era of AIDS equipped with a whole set of resources crucial for engagement in the struggle over social goods and social meanings.<sup>35</sup> In the recent past, gays and lesbians in the United States had achieved a singular (if incomplete) redefinition of social status, challenging the dominant conceptions 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 and gay rights movements of the 1970s, gay men and lesbians challenged social norms, constructed organizations and institutions, and established substantial and internally differentiated subcultures in urban centers throughout the United States.<sup>36</sup> By the time the AIDS epidemic was recognized in 1981, the gay movement was deeply engaged in projects of “identity politics”—the linkage of tangible political goals to the elaboration and assertion of an affirmative group identity.<sup>37</sup> A threat to identity, therefore, was a threat that the movement could easily understand and one against which it was quick to mobilize.

An engagement with the medical profession was not entirely foreign to this movement either, since a specific accomplishment of gay liberation had been to “demedicalize” homosexuality by removing it from the official list of psychiatric illnesses. Indeed, while gay activists

on the margins of U.S. society had developed an oppositional stance regarding many social institutions, they had for some time been particularly inclined to view medical authorities with suspicion.<sup>38</sup> And 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 likewise advocated skepticism toward medical claims and an insistence upon the patient's decision-making autonomy.<sup>39</sup>

Thus, in its emergence and mobilization, the AIDS movement was a beneficiary of "social movement spillover":<sup>40</sup> it was built on the foundations of other movements and borrowed from their particular strengths and inclinations. Most consequential was the link to the lesbian and gay movement of the 1970s and early 1980s: It mattered that gay communities had preexisting organizations that could mobilize to meet a new threat; these community organizations and institutions also provided settings for the face-to-face interactions that are so important in drawing individuals into activism.<sup>41</sup> It mattered, too, that these communities included (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. And it was crucial that gay communities possessed a relatively high degree of "cultural capital"—that they had cultivated a disposition for appropriating knowledge and culture.<sup>42</sup> Within these communities are many people who are professionals, artists, and intellectuals of one sort or another—not to mention many doctors, scientists, educators, nurses, and other health professionals. On one hand, this has provided the AIDS movement with an unusual capacity to develop its own "organic intellectuals"<sup>43</sup> and contest the mainstream experts on their own ground. On the other hand, it has afforded important sources of intermediation and communication between "experts" and "the public."

This particular historical conjuncture has given birth to a movement that is uniquely inclined and empowered to challenge the scientific and medical establishments. In some respects, the AIDS movement resembles other social movements that have challenged scientific authorities in the recent past—movements that have focused on issues as diverse as evolutionary theory, IQ testing, nuclear power, fetal tissue research, and recombinant DNA research. However, while there often are similarities among these oppositional groups, even across the political spectrum,<sup>44</sup> the differences in how they approach science are striking.<sup>45</sup> Some movements are essentially negative, confining themselves

to the politics of distrust: "We don't believe you when you claim that fluoridation is harmless." Others ultimately just want to show that science and truth are on their side. They seek to acquire for themselves the cachet of scientific authority by finding the expert who will validate their given political stance: "Low level radiation is dangerous"; "the greenhouse effect isn't a serious threat." Members of a third category, typified by some advocates of mysticism and "New Age" philosophies, reject outright the scientific way of knowing and advance their own claims to expertise from some wholly different epistemological standpoint.

Perhaps the most interesting of the social movements that position themselves in relation to science are those which try to stake out some ground on the scientists' own terrain. These activists wrangle with scientists on issues of truth and method. They seek not only to reform science by exerting pressure from the outside but also to perform science by locating themselves on the inside. They question not just the *uses* of science, not just the *control over* science, but sometimes even the very *contents* of science and the *processes* by which it is produced. Most fundamentally, they claim to speak credibly as experts in their own right—as people who know about things scientific and who can partake of this special and powerful discourse of truth. Most intriguingly, they seek to change the ground rules about how the game of science is played.

The AIDS movement can best be compared with the relatively short list of movements that neither simply enlist experts nor attack them but, rather, undergo the process of "expertification." A participant in such a movement learns the relevant knowledge base so as to become a sort of expert; more broadly, such participants transform the very mechanisms by which expertise is socially constituted and recognized. Phil Brown, for example, has studied the engagement of citizens of Woburn, Massachusetts, in the determination of health risks from toxic waste. Brown characterizes their efforts as "popular epidemiology," in which "laypersons gather scientific data and other information and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease."<sup>46</sup> Such movements, as Susan Cozzens and Edward Woodhouse note, are not "anti-science" but "pro-knowledge": they seek "to re-value forms of knowledge that professional science has excluded, rather than to de-value scientific knowledge itself."<sup>47</sup>

AIDS activism is distinctive, however, in the duration of intense

working relationships between the movement and the research community. And AIDS activism is unusual in the extent to which activists necessarily depend on the energy and goodwill of their own interlocutors. Antinuclear activists who master the technical jargon of nuclear engineers have the luxury of treating those experts as the enemy. AIDS activists, by contrast, have no illusions about their ultimate dependence on the biomedical enterprise for the discovery and testing of treatments. Although some community spokespeople endorse New Age therapeutic methods ranging from “creative visualization” to healing crystals, most activists accept that a solution to the deadly AIDS epidemic will arrive via some variety of scientific process, if it arrives at all. They are caught, as Ronald Bayer puts it, “between the specter and the promise of medicine.”<sup>48</sup>

## Analyzing AIDS Controversies

### CREDIBILITY AND TRUST IN SCIENTIFIC FACT-MAKING

The sociology of scientific knowledge is particularly well suited to shedding light on such phenomena as scientific controversy, credibility crises, and the public trust and distrust of experts: this body of work identifies credibility and trust as the very underpinnings of scientific knowledge-production. Not just relations between laypeople and experts, but also relations among scientists themselves are enabled by the social organization of trust and the construction of credibility.

Since its inception in the 1970s, the sociology of scientific knowledge has argued that scientific fact-making is a collective process amenable to sociological investigation.<sup>49</sup> As Steven Shapin explains, “no scientific claim ‘shines with its own light’—carries its credibility with it. . . .” Analysts of science have therefore “become intensely interested in the specific processes of argumentation and political action whereby claims come to be accepted as true or rejected as false.”<sup>50</sup> In practice, a range of theories has been offered as to how the credibility of knowledge claims is secured.<sup>51</sup> For Bruno Latour and his colleagues and collaborators, credibility is the stake in an agonistic struggle. In this approach, science is “politics by other means,” and the credibility of a knowledge claim depends on the play of power: the scientist who can appear to make nature “behave” in the laboratory, whose rhetoric is more persuasive, who is able to summon up the more compelling

citations, and who is able to enlist more allies, patrons, and supporters by “translating” their interests so that they correspond with the scientist’s own is the one who constructs credible knowledge and gains access to further resources as a result. The most effective claims are those which become “obligatory passage points”: the journal article that all must cite to justify their own work, the technology that all must employ to accomplish their own research—in general, the way stations through which other scientists, patrons, or members of the public necessarily must pass in order to satisfy their interests or achieve their goals. The more well traveled such passage points, the more fully institutionalized the knowledge claims become.<sup>52</sup>

Alternatively, analysts such as Barry Barnes, Harry Collins, and Steven Shapin, while emphasizing the role of conflict, also understand scientific credibility as emerging from the nexus of cooperative relationships that constitute scientific communities.<sup>53</sup> Since no one can “know” all or even a fraction of the corpus of scientific knowledge through direct experience, science is made possible through the allocation of trust. “Trust and authority,” writes Barnes, “are the wires of a great system of communication which makes the specialized knowledge of society widely credible and widely usable.”<sup>54</sup> Clearly, laypeople are almost always in the position of having to trust what experts tell them is true. But trust is crucial even to the relationships among scientists, as Collins demonstrates in his arguments concerning the phenomenon of “experimenters’ regress”: “The competence of experimenters and the integrity of experiments can only be ascertained by examining *results*, but the appropriate results can only be known from competently performed experiments.”<sup>55</sup> Independent replication of a finding does not resolve the dilemma of whether to believe, because no two experiments are ever exactly the same in all details, and so the status of an experiment as a replication must also be socially negotiated. In order, then, for any finding to be accepted, scientists cannot be utter skeptics. Either they must trust that the experiment was competently performed (thus granting credibility to the result) or they must trust the result (thereby conceding that the experiment was competently performed). At any given moment, *some* knowledge must be taken on faith, if science is to proceed as a social institution. Even expressions of distrust are “predicated upon a background of trust,” explains Shapin: a scientist cannot distrust a particular finding or person except against the background of other shared knowledge which is unproblematically trusted.<sup>56</sup>

These conceptions of the social relations that govern scientific knowledge-production have several implications for understanding cases such as AIDS research. First, these analyses suggest that scientists, other professionals, and laypeople alike find themselves frequently in the business of assessing the credibility of knowledge claims and claimants, and asking who or what they should trust and believe. The difficulty is that—for laypeople and to a considerable extent for experts as well—such assessments can usually be made only indirectly, through the scrutiny of external markers of credibility. Who conducted the study? Where was it published? What does the *New York Times* have to say about it? What does my doctor think? Even such everyday iconography as the diploma on the wall serves an important signaling function within a social system stitched together by assertions and assessments of credibility.<sup>57</sup>

Second, this understanding of credibility implies a special role for certain face-to-face interactions, such as those between doctors and patients. In a world significantly organized by impersonal bureaucracies, doctors serve as “‘access points’ . . . at which ‘faceless institutions’ present a particular human face to those who encounter and pass through them.”<sup>58</sup> Doctors are among the experts that laypeople are most likely to encounter firsthand; their credibility can be read in their words, body language, and “bedside manner.” This social location gives practicing physicians a distinctive function in controversies involving doctors, patients, and scientists.

Third, since trust and credibility may be fragile resources, scientists, doctors, and other experts are keenly attuned to potential disruptions in the social circulation of credibility. In effect, scientists barter their credibility for the extension of resources by patrons and the public, who typically stand back and respect the autonomy of scientists, allowing them to determine the specific division and allocation of research funds, judge one another’s work, and police abuses.<sup>59</sup> One consequence of this arrangement for the expert claims-maker is that maintaining legitimacy (both one’s own and that of science in general) becomes of paramount importance: when legitimacy is threatened, the credibility of one’s claims is in jeopardy, and with it, the availability of resources and the maintenance of professional autonomy.<sup>60</sup> Like other professional groups, scientists frequently participate in shoring up their legitimacy,<sup>61</sup> including engaging in public relations work and attempts to manage the presentation of scientific findings in the mass media.<sup>62</sup> This labor is made difficult by the number of factors that can