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# The Coproduction of Medical Knowledge

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## Abstract

What is the relationship between experiential knowledge and the categories, etiologies, and treatment modalities of medical science? When do patients form social movements and demand participation in medical research? This article reviews trends in how medical anthropology, sociology, science and technology studies, and the history of medicine approach the coproduction of medical knowledge. Coproduction is used as a wide-ranging idiom to capture how knowledge building happens across social-material domains and as an aspirational vision for the ways that collaborative knowledge making can be intentional, improved on, and reimagined. I begin with an intellectual and social history of voluntary self-help organizations, patient advocacy movements, citizen science, lay expertise, and the era of intentionally patient-led research. I then offer thoughts about how abolition medicine and Indigenous science offer a radical vision for the coproduction of medical knowledge, especially in an era of antiscience, when strong political forces threaten public well-being.

# INTRODUCTION

Who gets to tell the truth of the bodymind? What is the relationship between embodied, experiential knowledge and the categories, etiologies, and treatment modalities of medical science? Scholarly interest in such questions since the mid-twentieth century has illuminated two helixing sociohistorical processes. On one side of the helix is the differentiation of medical knowledge and its experts from lay knowledge and laypeople, along with the concomitant professionalization of medicine [Foucault 1994, 2012; Starr 2017 (1982); Kleinman 2020]. How, when, and why have physicians asserted their singular authority to speak for the human organism? What have been the consequences, both intended and unintended, of this modern form of power? On the other inseparable side of the helix are all the ways in which the demarcation of biomedical science as discrete, totalizing expertise fails; this failure might be due to the limitations of the science itself (the failure to explain or to cure) or to sustained pressure from those treated as outside the scientific arena who demand, and make inroads into, research domains once considered the province of only authorized experts. What role do patients play in the production of knowledge when they seek out, reject, or work to transform medical care? When do patients form social movements and demand participation in research, and to what end? Because observers in medical anthropology, sociology, science and technology studies (STS), and the history of medicine have tracked this helixing motion for decades, the ethnographic study of the coproduction of medical knowledge long predates the arrival of coproduction as a discrete object of inquiry or aim of medical research. This rich corpus provides a useful lens through which to view present possibilities and conundrums for the reimagination of medicine that serves healing, equity, and justice.

Any genealogy of coproduction in medicine must necessarily be both an intellectual and a social history, though, obviously, it cannot reflect every field, trend, or study. In this review article, I am especially interested in moments and movements in which groups consolidate to influence, reject, or participate specifically in the creation of medical knowledge. A focus on consolidation will mean special attention to biosociality (Rabinow 1996). In this case, biosociality refers to the processes and relations through which people with vested interests in particular health questions become powerful agents who, often in collaboration with scientists—themselves situated actors (Haraway 1988)—change medical research and clinical practice. The literature reviewed makes clear that patient advocacy is here to stay. It is an essential part of contemporary medicine due to its often-dramatic benefits for health outcomes and because strained resources, rapacious insurance companies, and critical gaps in medical access in the Global South, which includes marginalized communities within the Global North, necessitate patient engagement. The power of patient advocacy has been nowhere more visible than in the case of postacute sequelae of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, now known as long COVID, which has depended on patient participation in research and treatment paradigms to the extent that it has been called a "patient-made illness" (Callard & Perego 2021). This review describes how we got to this moment by tracing the intellectual and social history of voluntary self-help organizations, patient advocacy movements, citizen science, lay expertise, and the era of intentionally patient-led or coproduced knowledge. I then offer some thoughts about the ways that abolition medicine, Indigenous science, and disability justice activism are pushing demands for the coproduction of medical knowledge in even more radical directions. The article concludes with a brief consideration of how we might approach coproduced medical knowledge in an era of antiscience, when strong political forces threaten to unmake public health: Can we "thread the needle," as organizer, author, and founder of Strategies for High Impact JD Davids (personal communication, 2024) puts it, and push for patient-led research when anyone on TikTok can claim to have "done the research"?

At first glance, it may appear as though the coproduction of medical knowledge has been the province of sociology rather than anthropology (authors cited in this review include many sociologists). But it is striking that the field itself is defined more by a method—ethnography—than by a specific theoretical framing. Studies of the coproduction of medical knowledge attend to what varied actors do: determining how relationships are built among patient communities or between patients and doctors, when and where citizen science reflects broader cultural and political shifts, and the operation of power across domains. They also attend to narrative: how patients and caregivers tell their stories; ways that medical knowledge always involves the collaborative authoring of stories that draw on a number of available idioms, from laboratory science to local healing traditions; and moments when large-scale narratives shift. Ethnography, which gives primacy to on-the-ground relationality across domains, has been especially well-suited to the task. This field is one in which the travels of ethnography out of anthropology into other disciplines and back again are usefully mapped. It is also a sphere in which autoethnography has flourished (Moodie 2025).

## TERMINOLOGY AND INTERDISCIPLINARITY

I use "coproduction" as a general descriptor for several different approaches to medical knowledge creation. First explored in the work of economist Elinor Ostrom in the 1970s, who argues that public goods and services cannot be produced without active participation from citizens, coproduction reflects the insight that policy spheres are not separate from other social spaces. Goods and services are always coproduced across domains (Ostrom 1996). Ostrom's argument is largely descriptive, but it is also an argument that supports this form of knowledge production. In general, social scientists have retained Ostrom's double valence, in which coproduction both captures something important about the relationship between science and society, and also serves as an aspirational model, not only for the subjects of study but for the operation of social science itself. Reflecting this double valence, Jasanoff (2004) uses coproduction as an "idiom" that enables interdisciplinary conversations within the social sciences based in the proposition "that the ways in which we represent the world (both nature and society) are inseparable from the ways we choose to live in it" (p. 2). In recent years, with the rise of participatory, community-based, and activist scholarship, coproduction has been used to describe an "epistemic praxis" that "seeks to contest knowledge claims and recognize the legitimacy of different types of expertise" (Perry 2022, p. 349).

One is less likely to see the term coproduction in the United States and Canada than in the United Kingdom. Labels such as "participatory," "participatory action research," or "collaborative" (Lassiter 2005) are more commonly in use. "Slow research" is a related idea that stresses local starting points, the "often incalculable mosaic of evidence," and iterative research processes that unfold without pregiven timeframes (Adams et al. 2014). It is also common to hear references to "community-engaged," "community-led," or "community-based research partnerships" (CBRP), which is the most formalized version within medical research itself (Israel et al. 1998, Minkler 2005, Wallerstein et al. 2019). All these approaches call for community input at every stage of the research process: choice of research question, data collection, analysis, and dissemination, as Grinker et al. (2012) note in their study of autism research in South Korea and South Africa. Since the arrival of COVID-19, it has become more common to see projects referred to as "patient-led"; these are focused especially on the elaboration of research hypotheses, data collection and analysis, and the dissemination of treatment knowledge often developed through self-experimentation or social media–based group discussion (McCorkell et al. 2021).

I use "coproduction" to retain the double valence and invoke features of all these discussions in the same discursive space: the idea that knowledge is (intentionally or not) always produced socially, that is, jointly, across social milieus and nonhumans and apparatuses that bring it into being (Barad 2007, Haraway 1997, Latour 1987, Livingston 2012, Mol 2002); and the idea that projects of collaborative making can be intentional, improved on, and reimagined. Because coproduction is about the creation of knowledge across domains, it requires an interdisciplinary view. While I highlight anthropological contributions, my account does not stay put within the annals of anthropology. Rather than signaling a lack of interest among anthropologists, the fact that coproduction does not stay neatly within the discipline shows that ethnography is essential to the study of the coproduction of medical knowledge. Some have argued that anthropologists have a unique role to play in medical coproduction, from researchers producing the early studies of public health efforts pushing for "community incidental services" (Paul & Miller 1955, p. 11) to those ethnographers who were called on during the 2014–2016 Ebola outbreak (Martineau et al. 2017, Orton et al. 2019). The presence of anthropologists and scholars of coproduction on COVID-19 research teams, especially in the United Kingdom, Europe, and Scandinavia, may signal an even greater role in the future, but it is undeniable that anthropologists have been among those coproducing medical knowledge all along.

## VOLUNTARY SELF-HELP GROUPS

After World War II, the United States became the main engine of global medical science (Lock & Nguyen 2011). But the history of US medical practice has always been one of contestation and "boundary work" (Gieryn 1983). Beginning in the late nineteenth century, enormous discursive and material resources went into separating, institutionalizing, and professionalizing physicians' unique claims to authority, away from medicine's more democratic roots in the local and home-based treatment of ailments [Starr 2017 (1982)]. Some areas, such as obstetric medicine, were the object of intense intrusion (Martin 2003), due to widespread eugenic ideas (Oparah & Bonaparte 2015). While this demarcation was largely successful, medicine did not attend to everyone equally; medical interest was often driven by military agendas (Terry 2017, Wool 2020).

Voluntary self-help organizations for individuals who were born with or acquired disabling medical conditions and their families grew rapidly in the mid-twentieth century (Traunstein & Steinman 1973). While these often focused on forms of daily support and mutual aid, they also strove to impact the direction of medical research. Rapp shows that parent organizations for children with Down syndrome changed their focus strategically. Initially concerned with helping families cope with practical challenges, organizations moved more toward an engagement with medical science. This engagement took the form of funding specific research projects, raising money and awareness, and counseling families as they entered the heavily medicalized world of disability (Rapp 2000; see also Ginsburg & Rapp 2024). Silverman (2011) shows how caregivers for people with autism compiled empirical data—daily logs, medical documents, records of symptom progression over time—that were taken seriously by the medical professionals with whom they worked through patient advocacy organizations. Rising affluence, a greater focus on women's domestic roles (especially around children), and a growing social tolerance for disability and physical difference necessitated by the large numbers of wounded veterans attempting to reintegrate into their families and communities also enabled the establishment of organizations such as United Cerebral Palsy, which specialized in raising funds for relevant research (Carey et al. 2020). Some of this parent activism and "telethon fundraising" would eventually be called into question as objectionable and offensive by disability rights movements led by adults with disabilities, due to their objectifying hyperfocus on cure (Shakespeare 1993). But for a history of coproduction in medicine, it is important to note that in labs and clinics and teaching hospitals across the United States, research scientists and doctors were responding to the desires and demands of affected populations, in many cases taking funding directly from patient organizations. In some fields, such as genetic conditions, physicians had long acceded that their work was impossible without family and patient input at every step (Heath 1998, Rapp et al. 2001). Often treated as apolitical or outside frameworks of advocacy and social movements, this engagement with medical science, and particularly the push for coproduction, belies the extent to which self-help groups were, in fact, having impacts far beyond the individual (Blume 2017).

## THE RISE OF PATIENT ACTIVISM AND CITIZEN SCIENCE

In this section, I describe studies of several historical conjunctures when the explicit politicization of citizen science in medicine was highly visible. Many of these movements have crystallized around specific diagnoses (or lack thereof); I have roughly followed this pattern in my presentation. The examples selected are meant to be illustrative rather than exhaustive, and there are overlaps and continuities over time; for instance, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) sufferers in the 1980s worked with HIV/AIDS activists (Rogers 2024), and both ME/CFS and HIV/AIDS activists have played an important role in patient activism around long COVID (Brier et al. 2023). While I have attempted to frame a global swath of citizen science movements, examples from the United States, United Kingdom, and the rest of the Anglophone world predominate due to my own linguistic limitations, though it is notable that even when studies have been carried out in France, for instance, authors often choose to publish their findings in English. I have confined myself to cases in which citizen science per se is explicitly at issue, which in itself shows a geographical clustering in the Anglophone West, though exceptions are discussed below.

### Women's Health

Most histories of the rise of citizen science in medicine begin with the US-based women's health movement for good reason. Organizing efforts such as the Boston Women's Health Collective (1971) enshrined in *Our Bodies, Ourselves* achieved enormous gains beginning in the late 1960s. Individual health care practice (e.g., the warming of a speculum before a pelvic exam or the return of midwifery) and the direction of policy (especially policies related to abortion and individual consent) changed rapidly and dramatically (Davis 2007; see also Davis-Floyd 2022, Martin 2003). The mostly white, middle-class women associated with the movement went into medicine in larger numbers, and they were able to influence research priorities and practices, though they remained stymied by sexist understandings of women's health and reproductive science (Clarke 1990, Dusenbery 2018). We must remember, however, that the gains of this movement were always unevenly distributed—rates of infant and maternal mortality among Black women would rise in the ensuing decades—and that understandings of what constitutes a feminist approach to health vary (Goode & Katz Rothman 2017). In the same era as *Our Bodies, Ourselves*, Black feminists wrote of their work for abortion rights and against sterilization abuse in the Combahee River Collective Statement as achieving gains despite, not because of, white feminism (Combahee River Collective 1977). Black women's relationship to medical science is haunted by histories of slavery and forms of gynecological violence (Bridges 2011, Cooper Owens 2017) that have ongoing reverberations for Black birthing people in particular, even as they fashion new, life-affirming modes of birth and mothering that we might consider coproduced practices of healing (Davis 2019, Hager et al. 2024, Nash 2021, Oparah et al. 2018). Indigenous and Latinx women also rejected conventional medicine and identified little with mainstream women's health activism as they faced institutionalized medical abuse and forced sterilizations (Lawrence 2000, Torpy 2000). It might be more accurate to think of this time period as an era of women's health movements (plural); while most of these movements opposed biomedical science in some way, their modes and meanings varied significantly, and each deserves careful consideration of its role in the rise of coproduction.

## Disability, Deinstitutionalization, and Medical Abuse

Erratum >

Another formative moment for today's coproduction models (one rarely mentioned in histories of popular health mobilization, perhaps due to the complex relationship between disability activists and biomedicine or perhaps due to the sidelining of disability histories in general) was undoubtedly the anti-institutionalization movement. As media exposés beginning in the 1960s and flourishing in the early 1970s brought to light appalling conditions in "schools" such as the infamous Willowbrook institution in Staten Island, New York, efforts began to reform, if not abolish, forms of medical incarceration for people with intellectual disabilities and mental illness (Ben-Moshe 2020, Hylton 2024, Rothman & Rothman 2005). At the same time, revelations about medical experimentation in other contexts emerged. The horrific violence inflicted on Black men in the Tuskegee syphilis study came to light and resulted in the Belmont Report, which recommended creation of Institutional Review Boards for Human Subjects Research (Jones 1993). Later research also confirmed that a similar experiment had been carried out with the support of the US government in Guatemala (Reverby 2009). The Black Panther Party openly supported antipsychiatry movements and "believed that the overmedicalization of disability, illness, and disease depoliticized and individualized these experiences" (Schalk 2022, p. 48; Nelson 2011).

The disability rights and antipsychiatry movement of the late 1970s gave people with a variety of physical and mental conditions a sense of common identity and agency (Newnham & LeBrecht 2020, Shakespeare 1993) and launched a stringent critique of the "medical model of disability" with its focus on cure (Oliver 1990). Resistance was especially strong from adult D/deaf activists who identified as a linguistic community rather than as a disabled constituency, even as (some) parents of D/deaf children continued to argue for medical intervention and technological innovation (Bauman & Murray 2014). The fight against institutionalization and for disabled independent living can be seen as an origin for community-based, or coproduced, participatory research that not only demands "respect for persons" (one of the basic principles identified by Belmont), but takes it "to a whole new level. . .[where] not only do research subjects participate voluntarily, but they also participate *actively* in research design, data collection, analysis, implementation, and dissemination" (Brown et al. 2012, p. 246, emphasis in original). After all, the slogan "Nothing about us without us" comes from this era (Charlton 2004, Nielsen 2012).

## HIV/AIDS

Perhaps the most in-depth and oft-cited study of the rise of patient activism is Epstein's (1996) *Impure Science: AIDS, Activism, and the Politics of Knowledge*, a close-hewn ethnography of the early days of patient outrage, fear, and organizing when it became clear that a new virus was making people extremely sick, that gay men seemed to be especially at risk, and that the virus was largely being ignored by the medical establishment. Epstein attends carefully to the shifting strategies through which HIV/AIDS activists came to speak with medical authority. Among these strategies was the creation of organizations devoted specifically to monitor, disseminate, and then create scientific knowledge, such as the Community Research Initiative of the People with AIDS Coalition (Merton 1990). By taking part in the research process itself, some HIV/AIDS activists challenged who counted as an expert and who counted as a layperson, recreating themselves as "lay experts" (Epstein 1996, p. 171). Whether embracing medical collaboration or maintaining a strong hermeneutic of suspicion toward scientists, HIV/AIDS activism "redefined the roles that are normally played by people with or at risk for serious diseases" (Indyk & Rier 1993). Initially composed largely of gay, white, middle-class men in urban centers—a group that, Epstein argues, already had a shared identity deriving from the gay liberation movement as well as access to resources—the movement grew more diverse and decentralized over time. The movement's insistence that those most at risk should have the largest say in the direction of medical research, its rejection of gatekeepers, and its critique of medicine-for-profit have arguably weakened the boundary between scientific and lay knowledge across the globe (Callon 1999). For example, this model of patient activism shaped "action-research" for women in the Democratic Republic of the Congo in the same era (mid-1980s) (Schoepf 1993) and continues today as "high risk" sex workers in Kenya "intervene in the technical aspects of knowledge production by launching dissent from within scientific frames of reference" (Lorway 2020, p. 400).

## Environmental Illness

A huge swath of coproduction in medicine has been born from local attempts to document, enumerate, and share the embodied effects of environmental toxicity due to polluting industries, radioactive exposure, and dangerous consumer chemicals (Brown 2007). Ethnographers have studied how poisoned communities fight for the recognition and treatment of environmental illness in Bhopal, India (Fortun 2009); Chernobyl, Ukraine (Petryna 2013); Woburn, Massachusetts (Brown & Mikkelsen 1990); Love Canal, New Jersey (Blum 2008); Fukushima, Japan (Kimura 2018); and Hanford, Washington (Cram 2023). Among the practices that have been developed are "popular epidemiology" to identify and enumerate leukemia clusters (Brown & Mikkelsen 1990) and the careful documentation of symptoms dubbed "intimate activism" (Grandia 2020, Tironi 2018). Two of the most potent, ground-shifting arguments made by environmental illness activists are that, first, embodied experience constitutes valid medical evidence (Brown et al. 2004) and, second, that illness and health are public issues (Kroll-Smith & Floyd 1997). As Kroll-Smith & Floyd (1997) argue

> In theorizing their somatic distress, the environmentally ill, in particular, are locating the sources of their troubles outside of themselves, in the practices and habits of intimate and institutional others. They are claiming to know something biomedical about the body and environments that is at once an explanation of chronic somatic distress and a representation of imperfections in the body politic—at once, in other words, a theory and a social criticism. (p. 7)

This element of "social criticism" is crucial to later developments in coproduction because it highlights the potentially transformative power of decentering science-as-usual.

## Contested Illnesses

Though in some ways overlapping with environmental illness, "contested illness" refers to any symptom set that does not have an agreed-upon biological origin verified by a broad scientific consensus or "conditions whose causes are either unexplained by current medical knowledge or whose purported environmental explanations are in dispute" (Brown et al. 2012, p. 18). They can include orphan diseases (rare or understudied by scientists), autoimmune conditions, and genetic diseases (rare and otherwise) as well as tick-borne, viral, and mast-cell-activated illnesses. Dumit (2006) describes the way that the "intractable uncertainty" that surrounds such illnesses leads to constant competition over facts; rather than "settling" matters, facts are the terrain on which the debate happens (Dumes 2020). Struggles over what Dumit calls "illnesses you have to fight to get"—indeed, whether they are recognized as illnesses at all—have significant material effects for patients (Sherman 2025).

Those living with contested illnesses are often left to fend for themselves, especially when seeking effective medical treatment. In addition to older-style patient voluntary self-help groups that continue to expand and multiply, online spaces have become especially important sites for the creation and transmission of scientific knowledge not only about the origin or diagnosis of an illness, but also about how to live with it (Diedrich 2024). This space has proven to be a rich arena for recent digital ethnography, with studies of groups related to fibromyalgia (Barker 2008), rare genetic diseases (Vicari & Cappai 2016), ME/CFS (Brea 2017, Rogers 2024), childbirth (Akrich 2010), running injury (Campbell 2021), and cluster headaches (Kempner & Bailey 2019), among others. Members of these digital fora, such as Patients Like Me, The Mighty, #MEAction (the Myalgic Encephalomyelitis Action Network), and the Body Politic Long COVID Support Group, as well as thousands of Facebook groups and listservs, are most often organized by diagnosis; participants may find that they also share poor treatment at the hands of conventional medicine (Hodgkin's International, for instance, has guidance for patients facing medical gaslighting; The Mighty has a discussion group on "PTSD caused by doctors") (Tempini 2015). There is also a strong push to identify chronic illness with disability justice to reject the dominant fantasy of "cure" (Diedrich 2024, Moodie 2020, Wendell 2001).

Some contested illness support spaces become politicized in ways similar to those described above for other movements. They lobby government bodies and interact with the media to bring attention to their struggles. But precisely because they lack clear diagnostic biomarkers (Rogers 2024), those with contested illnesses stress finding strategic ways to challenge and/or engage medical science. For example, Panofsky (2011) shows how members of patient advocacy organizations (PAOs) with rare genetic diseases use "sociability"—literally, friendships with doctors that develop over time—to attract scientists and influence the direction of research. In her ethnography of a French organization for those living with muscular dystrophy, Rabeharisoa (2003) argues that a new partnership model emerged as the organization subordinates specialist activities to patient initiatives and creates "mutual learning between patients and specialists who, together, produce knowledge" (p. 2128). Ushiyama's (2020) study of eczema sufferers in Japan describes similar partnerships, driven by the lived needs of those most affected and working with clinicians who become sympathetic. In many cases, as Dumes's (2020) detailed study of controversies over Lyme disease shows, the relationships between the chronically ill and scientists remain a mixed bag. Scientists and doctors retain the ability to exercise "symbolic domination" through diagnoses and insurance codes (Dumit 2006), and activists are faced with what Rogers (2022) calls "recursive debility," in which the fight for recognition and treatment actively makes chronically ill people more unwell.

## COPRODUCTION OR COOPTATION? WHO IS A LAY EXPERT?

Social scientists demonstrate how lay expertise becomes possible, even necessary, with the unsteadiness of the boundary between science and society (Gieryn 1983); they also stress that the meaning of this expertise is shifting and contested. "Lay expert" is a term that comes from Epstein's (1996) work on HIV/AIDS advocacy, with important antecedents in the "amateur science" of voluntary organizations (Silverman 2011). This shift in medical authority can be heralded, as it has been by some, as the democratization of science and part of its progressive development as a system of knowledge. Yet, at the same time, for all the reasons cited above—revelations about medical abuse and highly publicized battles over environmental toxicity, as well as insights into the operation of racism, sexism, ableism, and trans- and homophobia in medicine—public distrust in medical knowledge has grown apace with coproduction. For every patient activist group running a survey they intend to turn over to researchers at a university lab, there are self-proclaimed medical experts extolling the virtues of fad diets and expensive supplements or, conversely, convincing parents it is dangerous to vaccinate their children against childhood diseases. These logics reassert older models of science and its dissemination, as in the idea that one will not get vaccinated until more scientific research has been conducted (Briggs 2024).

What is to be done in such a situation, when those who are living with debilitating conditions cannot not want the benefits of scientific research? Is part of the answer in defining lay expertise?

Callon's (1999) essay, "The Role of Lay People in the Production and Dissemination of Scientific Knowledge" points to the crisis of trust produced by "the great divide between specialists and nonspecialists" in modern science (p. 82). He outlines three models of participation that can develop in this divided condition. What he calls *M*1 (for "Mode 1") is "Public Education," in which designated intermediaries convey simplified versions of scientific knowledge. Though traditional models of the dissemination of scientific knowledge have been critiqued for how well they capture the messiness and ongoing contestation involved in research and research communication (Arksey 1994, Hilgartner 1990), public education is an idealized model, for instance in the training of medical students (Good & DelVecchio Good 1994). Callon's (1999) *M*2, "Public Debate," begins from the premise that "laboratory-produced knowledge cannot absorb the full complexity and richness of the world" (p. 85); therefore, scientists can learn from local communities or impacted individuals. There are risks in this model, however: that scientists will continue to exercise "symbolic domination" (Dumit 2006) or that patient narratives will become commodified objects that end up serving the priorities of medical research (Mazanderani et al. 2013, Renedo et al. 2018). *M*3 is the "Co-Production of Medical Knowledge," in which knowledge is "the common by-product of a single process in which the different actors, both specialists and nonspecialists, work in close collaboration" (Callon 1999, p. 90). While *M*1 and *M*2 share, according to Callon, an "obsession…[with] demarcation" (p. 90), *M*3 is an intentional practice of coproduction and entanglement between science and society.

Though perhaps honored more in the breach, *M*3 is clearly, today, an aspirational vision. But Callon's description does not make clear how nonspecialists know or what kind of knowledge they possess, issues that will obviously occupy those engaged in these processes. Lay expertise documented by ethnographers can take several forms. Perhaps the most common is when the experience of laypeople is treated as a particular (i.e., separate) form of knowledge that necessarily—and rightly—supplements medical knowledge. Lay expertise is "research in the wild" (Callon & Rabeharisoa 2003), which can also be called "experiential knowledge" (Rabeharisoa et al. 2014), "knowledge in action" (Pols 2014), "clinical knowledge" (Pols 2014), or medicine with patients as "knowledge partners" (Hsu et al. 2025). Other authors stress knowledge as "what is done in practice" (Mol 2002) or the performance of daily expertise in the seizing of affordances (Dokumaci 2023). More pejoratively, patient knowledge is called "belief" (Prior 2003).

In some cases, patients study and learn medical science on a par with their doctors and engage more as colleagues (Epstein 1996). It is also increasingly the case that affected individuals enter science with the aim of studying their own conditions. For example, the lead scientist on the Medical University of South Carolina's gene study of hypermobile Ehlers-Danlos Syndrome (hEDS), Cortney Gensemer, also lives with the condition (Donovan 2023). Ableist assumptions within debates about who does science—the failure to imagine doctors with disabilities, for instance (Iezzoni et al. 2021)—reflect ableist attitudes in academia and STEMM (science, technology, engineering, math, and medicine) more broadly (Brenner & Dahlberg 2024, Brown & Leigh 2018, Dolmage 2017). We should be wary of the implicit suggestion that researchers are never disabled or patients themselves.

As Epstein (2011) warns, however, too much nearness to science can also lead to questions about representativeness. Are only some patients experts on their conditions, for instance (Blume 2017)? Too much science can lead to accusations of cooptation, as when highly medically literate HIV/AIDS activists were challenged for their increasing participation in projects with the National Institutes of Health (Epstein 1996). Furthermore, questions about lay expertise seem especially vexed in moments of strong antiscience (Berlivet & Löwy 2020). The status of lay knowledge was certainly called into question in the immediate aftermath of spurious claims that vaccines were leading to autism in children (Prior 2003); at the time of this writing, a similar storm may be brewing, with dangerous forms of what traditional medicine sees as "snake oil" being embraced through official bodies across the globe (Tan 2021).

## LONG COVID AND DIY HEALTH

In April 2020, accounts of lingering, diffuse, and sometimes worsening symptoms subsequent to infection with SARS-CoV-2 COVID-19 began appearing in news outlets and spreading widely across social media; those impacted had not necessarily suffered severe cases of initial infection or been hospitalized. Some of these accounts were patient authored, while others were more conventional journalistic reportage that drew on patient accounts. But something was clearly different: The first-person stories—Fiona Lowenstein's *New York Times* op-ed of April 13, 2020, "We Need to Talk about What Coronavirus Recoveries Look Like," being one of the most widely read—were, perhaps for the first time in the history of Western medicine, being treated as legitimate scientific evidence in themselves (Lowenstein 2020). By May 2020, when Italian scientist Elisa Perego first used the hashtag #LongCovid on Twitter (as a shortening of "long-term COVID illness"), she was intentionally challenging the biphasic disease pathway view that was common to conventional medical science (one is sick and then becomes well) in order to point out the diversity, complexity, and mystery of COVID-19 sequelae. It was already clear to her, as well as to coauthor Felicity Callard, that patients were not just giving a cute, tweet-able name to a pre-extant phenomenon but were, in fact, "making" long COVID (Callard & Perego 2021) and its related descriptor "long-haul COVID" (survivors began to refer to themselves as long haulers). While illness narratives have long played a role in clinical medicine (Charon 2006, Kleinman 2020, Mattingly & Garro 2000), first-person accounts of long COVID were being circulated not only to describe lived experience of a disease or to make sense of complicated new realities, though they did accomplish these goals. Rather, patients were penning case studies that met wide audiences, "expand[ing] knowledge of symptoms. . .and [making] demands" (Callard & Perego 2021, p. 2). Indeed, after Lowenstein's op-ed, millions of people viewed and shared information about long COVID from the Body Politic COVID-19 Support Group, which started on WhatsApp and moved to Slack when it became too large for the first platform. The first full-length book about living with long COVID came from these same activists and their networks (Lowenstein 2022).

The Patient-Led Research Collaborative grew out of Body Politic, composed of some members who had academic training and research experience and some who did not. The Collaborative launched and completed the first thorough survey of long COVID symptoms (their diversity, complexity, duration, and incidence); it was widely cited by governments and public health officials across the globe and in subsequent academic literature (Assaf et al. 2020). Additional findings were subsequently published in *EClinical Medicine* (Davis et al. 2021). Recognizing the need for patient input not only at the data collection stage, but in the generation of hypotheses, Patient-Led Research made wide-ranging suggestions for future research directions and built a first-of-its-kind template for patients to use to propose research questions based on their own scientific research. These would be vetted by the Collaborative and then published quarterly.

In the case of long COVID, "patient-made" is not a criticism but a badge of honor. The movement has certainly faced setbacks since 2023, including an acute lack of funds, which forced Body Politic to shut down; antivax and antimask movements; etc. But it has also made huge gains in the acceptance of coproduced medical knowledge. Previous ethnographic studies cited above shed light on why patient-led research might have been especially effective during the early years of the ongoing COVID-19 pandemic. First, in a situation of "heterogeneous and complexly unfolding symptoms" (Callard & Perego 2021, p. 1), the rate of communication and publication for patient-led groups is much faster than traditional peer-reviewed routes. The first to talk about what was happening got to direct the conversation, as we also see in Epstein's study of early HIV/AIDS activism. As Lowenstein (2022) says, it was "[t]he actions of long-haulers themselves that triggered a global response to this illness" (p. 8). Furthermore, some of the same personalities—particularly Anthony Fauci, head of the US National Institute of Allergy and Infectious Diseases for decades and the presidential medical advisor from 2021 to 2022—played a role in both pandemics; Fauci knew from difficult experience the value that patient-driven communication could have (Epstein 1996). Long COVID activists also worked with the support of well-respected mainstream journalism early on. Yong's articles in *The Atlantic* were widely read and circulated; he was already an esteemed science writer by the time of these publications and later won the Pulitzer Prize for his reporting on long COVID (Yong 2020). In addition, clinicians, nurses, and hospital staff featured in larger-than-proportional numbers among the first and most badly stricken with the virus and its sequelae. Therefore, doctors were often those writing about their symptoms; several boldly explained their horror at being told by a colleague that their neurological or cardiac symptoms were just a result of mass hysteria and stress (Fearnley 2021, Yong 2020). Some of the early New York City activists were also writers and filmmakers, which gave them access to means of communication. A final condition of possibility for the making of long COVID was the preexistence of decades of organizing around contested illnesses, in particular ME/CFS, which seems to share many features with long COVID (some even argue that the latter can develop into the former). #MEAction's website quickly had resources for long haulers, and many activists realized the potential benefits of joining forces. POTS (postural orthostatic tachycardia syndrome) and hEDS advocates suspected early on that hypermobility was a risk factor for long COVID, which was later confirmed in studies (Eccles et al. 2024). There were, in other words, many languages and channels of biocommunicability (Briggs & Hallin 2007).

However, as Briggs also notes, communicability always generates forms of incommunicability, or groups who are seen as outside, beyond, or undermining medical science. It is telling to contrast sympathetic coverage of long COVID activists [arguably a movement of DIY (do-it-yourself) citizen science], many of whom are white, with portrayals of African American communities who were seen as "resisting" COVID-19 vaccination (Briggs 2024), also harkening back to racialized ways in which women's health, deinstitutionalization, environmental illness, and other popular movements were characterized. Is one person's desire for coproduction another's medical noncompliance? These questions must be asked as models for participatory science are built, especially with the assistance of social science (Benjamin 2013).

## ABOLITION MEDICINE

How do we ensure that those most impacted have a voice in the priorities and practices of medical science? One promising line of praxis and theorizing is coming from abolition medicine. While "abolition medicine" is a new term, it is grounded in a rich history of abolitionist movements against slavery, incarceration, and policing. Tied to W.E.B. Du Bois's [2013 (1935)] "abolition democracy," it is a call to deepen the examination of the role of anti-Blackness and racism in medicine and an end to medicine as we know it (Carter 2021). Rather than reforming from within, and risking the cooptation described by Epstein (1996) or reproducing carceral logics of "safety" over "healing" in medicine (Martinez & Mukerjee 2025), abolition medicine asks those invested in health equity to build up systems that support a healthier and more just society (Iwai et al. 2020). It centers narrative medicine practices that honor "the role of story in the health care encounter," challenges "organized abandonment," and demands medical education that attends to "upstream police and racial carceral violence" (Khan et al. 2022). Community-led, coproduced medical knowledge can be central to this new imagination of health and healing.

Relatedly, in the field of trans health, there is a strong push toward what Hanssmann (2023) calls "care without pathology," a move to center questions around what is needed to survive and thrive, rather than around diagnosis or illness (p. 6). This might mean a shift toward mutual aid and do-it-yourself approaches (August-Rae et al. 2024) or "economized epidemiological biographies" (Hanssmann 2023, p. 148) to counter risk-dominant, austerity-based actuary logics about the cost of essential health services. In all these cases, agendas are driven by those most impacted.

Intentional coproduction (Epstein 2021) is not necessarily easy to achieve. In their in-depth discussion of antioppressive research methodologies as practiced in the Chihuum Piiuywmk Inach/A Gathering of Good Minds (Serrano/English) project, McMullin et al. (2023) ask important questions about what actually constitutes a decolonizing, antioppressive methodology. While many community-based studies provide for consultation or create an advisory board, McMullin's team asked what it would mean to implement Indigenous epistemologies and create collaboration among researchers, health officials, and tribal members at every stage of the research process. Data analysis—the viewing and coding of interviews—proved especially challenging because those undertaking the analysis did not always share values, and the relative benefits of participation were unevenly spread (academics do research professionally, whereas community participants were fitting in their participation around livelihood and family). However, in being transparent about these struggles at every step, in taking the time to discuss, listen, and, importantly, redesign the study as they went, McMullin et al. (2023) felt that capacities and skills were honed on both sides for "now and in the future" (p. 68). Given that a large part of the project focused on the health effects of historical trauma, this element of temporality transformed conventional research standards. They were eventually able to communicate an important message to physicians treating Native communities:

> The person sitting in front of them is much more than a patient with a physical problem to be solved. That person brings a long history and lived experience that is partly informed by a history of trauma and knowledge of strengths from their ancestors. (p. 73)

## CONCLUSION

One of the suggestions recurring throughout the literature on the coproduction of medical knowledge is that anthropology—and specifically its method and genre, ethnography—might have a special role to play in both its study and its implementation. As a method that allows the researcher to center on-the-ground action, to map relationality and the operations of power, and to attend closely to narratives of all kinds (from patients, doctors, and caregivers), ethnography has been and will continue to be wrapped up with the coproduction of medical knowledge, whether it happens within the disciplinary space of anthropology or not. It is the necessary supplement to medicine's own obsession with imaging technologies, double-blind gold-standard research, and statistical regularities and norms, a fact being increasingly recognized within medicine itself—again, the shift among research funders to demand patient input and social science participation signals a strong role for ethnographers to play (Fortun et al 2014). As a related final thought, I note that as ethnographers author first-person accounts that acknowledge or describe their own experiences with medical trauma, disability, disease, and complex chronic illness, they open up new vistas on medicine, activism, and ethnography itself (Davis 2019, Atkins 2010, Cram 2023, Greenhalgh 2001, Jain 2013, Martin 2007, Moodie 2025, Murphy 2001, Walley 2013). Whether or not this is a special role, it is perhaps a unique one, as anthropologists are trained to connect the stuff of personal stories—including one's own—to broader processes of culture and history. How we participate in the coproduction of medical science in the future is a question of commitment and imagination in which we are all, for better or worse, deeply implicated.

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