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**Doing Your Own (Patient Activist) Research**Robin McKenna
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**Abstract** The slogan “Do Your Own Research” (DYOR) is often invoked by people who are distrustful, even downright sceptical, of recognized expert authorities. While this slogan may serve various rhetorical purposes, it also expresses an ethic of inquiry that valorises independent thinking and rejects uncritical deference to recognized experts. This paper is a qualified defence of this ethic of inquiry in one of the central contexts in which it might seem attractive. I use several case studies of patient activist groups to argue that these groups often engage in valuable independent research that advances biomedical knowledge. In doing so they demonstrate the value of “lay expertise” and the epistemic as well as political necessity of not simply deferring to recognized experts. I also give some reasons why patient activist groups often produce valuable biomedical knowledge: they are examples of what I call “research collectives”. Research collectives are research communities that differ from the traditional research communities we find in universities and research institutes in that their members typically lack formal relevant scientific credentials and training. But they are similar in that they have internal structures—training procedures, norms of discussion, venues for holding discussions—that facilitate the production of knowledge. I finish by suggesting that future research into the differences and similarities between research collectives and traditional research communities is required.

The slogan “Do Your Own Research” (DYOR) is often invoked by people who are distrustful, even downright sceptical, of recognized expert authorities. While there may be those who distrust *all* experts—who “trust no one”—the more usual situation is that someone, or some group, is distrustful of the recognized experts on a particular range of issues—on climate change, on vaccine safety, on treatment protocols for a medical condition, and so on. When members of these groups invoke the slogan DYOR, their doing so may serve various rhetorical purposes—*I* have done the work; what about *you* (Ballantyne, Celniker, and Dunning 2024)? But it also expresses an underlying ethic of inquiry that, at least on its surface, valorises independent thinking (“think for yourself”), rejects uncritical deference to recognized experts, and even expresses distrust in those experts.

This paper is a qualified defence of this ethic of inquiry, at least in one of the central contexts in which it might seem attractive. As has been documented in many places, particularly in the Science and Technology Studies (STS) literature, patient activist groups often engage in independent research, motivated in part by their distrust of biomedical experts and institutions. Yet these groups have made valuable contributions to biomedical knowledge, whether into treatment or management of health conditions, clinical trial methodology, or the design of new technologies (Akrich et al. 2014; Callon and Rabeharisoa 2003; Dumit 2006; Epstein 1998; Jansky, Hendl, and Nocanda 2024; Jansky and Langstrup 2022; Rabeharisoa, Moreira, and Akrich 2014; Williamson 2010).

Patient activist groups do not just provide a convenient source of examples of the value of independent research. The healthcare context is a rich source of examples because it is a space where “pure science” meets the complex realities of lived experience. The result, I will argue, is the need to recognize that traditional biomedical expertise needs to be enriched by the insights of those who are directly affected by medical conditions. Importantly, these insights go beyond the “experiential knowledge” afforded by living with a medical condition (Borkman 1976; for relevant discussion in the medical context see Williamson 2010, chap. 5). Patient activist groups have engaged in independent research, sometimes theoretical, sometimes more applied. They have generated insights that have added to biomedical knowledge and understanding, and even produced new technologies that patients can use in managing their medical conditions.

By urging the importance of the contributions to biomedical knowledge made by patient activist groups, I aim to reshape an emerging literature within applied and social epistemology that is surprisingly hostile to the idea that laypersons (those who lack relevant credentials within a domain) can make genuine contributions to human knowledge within that domain, and to the more general idea that independent research, the results of which may lead you to disagree with, even distrust, recognized experts, can be both epistemically and politically beneficial (see e.g. Ballantyne, Celniker, and Dunning 2024; Buzzell and Rini 2023; Levy 2022).

Here is the plan for the rest of the paper. I will start (in §1) by situating my discussion within an ongoing discussion, both in and outside philosophy, of the dangers of independent research and of distrusting recognized expert.

I will then do three things. First, I will (in §2-3) argue that the literature on patient activist research groups provides several cases of communities whose members lacked the usual “expert credentials” (e.g., relevant higher degrees, institutional affiliations) yet made valuable contributions to biomedical knowledge and technology. §2 spends some time outlining Steven Epstein’s (1998) celebrated case study of AIDS activist researchers in the 1980’s and early 1990’s, which has been widely discussed in the STS literature but will perhaps not be so familiar to a philosophical audience. §3 presents further case studies which parallel Epstein’s.

Second, I will (in §4) explain the relevance of these case studies for the debate, such as it is, about the value of independent research. As I will argue, the debate should not be about the value of doing one’s own research, as an individual, in isolation from a community of others conducting similar kinds of research. While there may be rare examples of people who, working on their own, have made important contributions to human knowledge, they are the exceptions, not the rule. The debate should be about the value of what I will call “research collectives”—research communities that exist outside of mainstream scientific institutions. Patient research collectives are research communities, formed by patients with an interest in gaining and sharing relevant knowledge about their medical condition. Like scientific research communities, they involve intra-community deference, division of labour, and enjoy a degree of autonomy. But they differ from scientific research communities in that they are composed of groups of people who typically lack specialist training and qualifications, as well as other relevant credentials, in the field(s) in which they are conducting research.

Finally, I will (in §5) identify some questions for further research. The case studies I discuss raise a series of interesting questions about patient research collectives. Most pressingly, to what extent do the structures we find within these communities parallel the structures we find within scientific research communities? To the extent that they parallel these structures, what does this tell us about the problems that often arise within patient research collectives, and patient activist communities more generally? While I will not be able to answer these questions here, they are important questions for future work.

# Setting the Stage

We are—some say—living through a “crisis of expertise” (Collins and Evans 2009; Gil 2019; Nichols 2024). The problem, we are told, is that nobody trusts experts anymore. Or, at least, many people do not trust the *recognized* experts—the people who are recognized as experts by the others in their field. Indeed, , the problem with many who claim to distrust experts is that they simply replace uncritical deference to recognized experts with uncritical deference to “alternative experts”—people, often with some relevant credentials, who are not recognized as experts by others within their field and/or take stances that put them at odds with the recognized experts in their field (Lewandowsky and Cook 2020; Sunstein and Vermeule 2008).

Are we living through a crisis of expertise? I do not want to take a stand on this question, though I suspect that the crisis is often over-stated (for relevant empirical data see Cologna et al. 2024). I want to focus on a slightly different question. Those who claim we are living through a crisis of expertise usually point to examples of distrust in recognized expert authorities which they presume—usually correctly—that their audiences will view as *unjustified*. For example, they talk about the prevalence of climate change denial, or scepticism about the efficacy and safety of widely used vaccines (Ballantyne, Celniker, and Dunning 2024; Levy 2022; Matheson 2022). But what about examples of *justified* distrust of recognized expert authority? There clearly are such cases; recognized authorities are sometimes wrong, and it is not hard to think of examples of groups that have been mistreated, often very badly, by expert authorities. (The biomedical context is, of course, a rich source of examples. For relevant philosophical discussion see Biddle 2018; Furman 2020; Goldenberg 2021).

In a recent paper Neil Levy (2022) argues against laypersons doing their own research, based on worries about the dangers of distrusting experts. But he is aware of the potential dangers highlighted above:

There are also sometimes important social benefits to doing one’s own research. For example, the acquisition of genuine understanding, and the capacity to speak in the technical vocabulary of a discipline, may be necessary for marginalized voices to be heard and given due weight. One famous example involves AIDS activists, who discovered they needed to be able to use the language of virology to have their voices heard (Epstein, 1995). By acquiring genuine competence with the relevant science, they were able to exercise genuine influence, and make research more inclusive of the whole population of sufferers (p. 356)

Levy sketches a way of incorporating the value of this sort of independent research while avoiding what he sees as the dangers of distrust (the italics are Levy’s):

While discouraging people from doing their own research will tend on average to protect the knowledge of lay people and slow the generation and promulgation of unwarranted, and sometimes dangerous, conspiracy theories, these are significant costs, both to individuals themselves and to the broader community. Matheson may be right that we need to combine research with deference, but how, exactly, are we to do this, such that we maximize the benefits and minimize the risks? I doubt there is any risk-free way to pursue one’s own research. But there is a way to minimize the risks without eliminating the benefits. We ought to encourage *exploratory* inquiry, aimed at understanding, rather than the *truth-directed* inquiry that is the royal road to the loss of knowledge (ibid).

Levy’s suggestion is that we distinguish between two kinds of research. The first kind, which is appropriate for those who are genuine experts in a field, is truth-directed inquiry: inquiry aimed at the generation of new knowledge. When a scientist conducts research in their field—when a climate scientist designs a new model, when a physicist devises a new theory—their aim is to advance, if only a little, the state of scientific knowledge. The second kind, which may be appropriate for laypersons in a field, is exploratory inquiry: inquiry aimed at understanding the knowledge produced by experts. When a layperson reads a textbook, or has a go at reading a journal article, their aim is to understand the current state of scientific knowledge, not to advance it.

While this is a useful distinction, I do not think it helps with the example Levy cites as a problem for his view of the value, or lack thereof, of layperson research. Levy’s example is based on Steven Epstein’s (1998) study of AIDS activists in the 1980s and 1990s. But, as Epstein tells it, these AIDS activists played a crucial role in reshaping the production of scientific knowledge by advocating for patient involvement and questioning the authority of established scientific institutions. Crucially, these activists were not just involved in the setting of research priorities but in the “nuts and bolts” of research into the treatment of, and to a lesser extent the causes, of AIDS. They were participants in the construction of a body of biomedical knowledge. But this means that, on Epstein’s telling, these activists went beyond exploratory inquiry—inquiry aimed at understanding the then-current state of biomedical knowledge—and engaged in a truth-directed inquiry aimed at contributing to the then-current body of biomedical knowledge.

If Epstein’s AIDS activists were an outlier—if there were no other documented examples of patient activist groups engaging in truth-directed inquiry and contributing to biomedical knowledge—then we would simply have an exception to a sound general rule about the appropriate division of labour in biomedicine, and between experts and laypersons more generally. But—as I will show in the next two sections—it is not an outlier. There are several other case studies in the literature that, at least in broad outline, tell a similar story to Epstein’s study: they feature patient activist groups engaging in truth-directed inquiry and making contributions to biomedical knowledge.

# Patient Activist Research: AIDS activism

Let me start by going into Epstein’s case study in some detail, as it is the most celebrated and widely discussed study of patient activist research in the literature. Epstein provides a detailed account of how AIDS activists in the 1980s and 1990s helped shape the then-emerging field of HIV/AIDS research. He documents how activists, lacking any formal medical training or credentials, played an important role in the production of biomedical knowledge, a role which “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” (p. 5). As Epstein argues, these “activist-experts” formed an “alternative basis of expertise” (p. 9) that sought to not just “reform science by exerting pressure from the outside but also to perform science by locating themselves on the inside” (p. 14).

Epstein particularly emphasizes the role that activists played in research into the treatment of HIV/AIDS. He tells us that they:

challenged the formal procedures by which clinical drug trials are designed, conducted, and interpreted; confronted the vested interests of the pharmaceutical companies and the research establishment; demanded rapid access to scientific data; insisted on their right to assign priorities in AIDS research; and even organized research on their own, with the cooperation of allied professionals. (p. 33)

Activists did not just try to change the “politics” of biomedicine. Yes, prominent activists ended up occupying powerful roles on committees at the National Institutes of Health (NIH) and Food and Drug Administration (FDA). They, as Epstein puts it, confronted vested interests of the pharmaceutical industry and the biomedical research establishment, and argued for a more patient-centric approach to HIV/AIDS research. But they also challenged the “formal procedures” of scientific research and even, at least to an extent, involved themselves in “pure science”.

Epstein particularly highlights the criticisms that activists made of the then-prevalent methodology of clinical trials of drugs to treat HIV/AIDS (see in particular Chapters 5 and 7). Simplifying quite a bit, activists argued against a fixation on “clean” trials (trials where there were strict rules surrounding participation criteria) and double-blind trials (trials where participants did not know if they were receiving the drug or a placebo). Their argument was that people with HIV/AIDS had too many incentives to “cheat” and break the rules, for example by lying about their current state of health to get on a trial in the first place, or by procuring drugs when they learned they were receiving the placebo rather than the drug being tested. This meant that the results of trials were less clear than researchers supposed.

Crucially, the argument was *not* just that it was morally wrong to deprive people of drugs that might save or prolong their lives. The argument was that insistence on “pure” trials made for *bad science* because, whatever the aspirations of researchers, their trials were *not* pure. As Epstein puts it:

how do researchers anticipate the actions of patients understandably anxious about the possibility that they were squandering their remaining days swallowing sugar pills? … reports of ‘noncompliance’ raised serious questions about just how ‘objective’ the much-vaunted double-blind trials really were. Those seeing only the tidy graphs and reading only the crisp prose in the *New England Journal of Medicine* might conceive of such trials as the essence of scientific rigor and, hence, the most solid basis for forming clinical and regulatory judgments. Those observing the conduct of a trial ‘from the inside’ might conclude that knowledge was resting on something rather less solid than bedrock, and they might wonder why the research establishment chose to fetishize this mechanism for establishing biomedical truth (p. 205).

It is important to recognize that, while the “lived experience” of people with HIV/AIDS provided the basis for these criticisms of trial methodology—they knewtrial participants and they knew that they were acting in ways that contravened the design of the trials—the criticisms, and the contributions they made to understanding of trial methodology, went beyond the expression of the experiential knowledge that comes from living with a health condition.. Making these criticisms required activists to have acquired a form of “lay expertise” (p. 18, p. 333). You can hardly critique clinical trial methodology without understanding how the trials were supposed to work.

One might wonder, though, how far this “lay expertise” extended. The way that Epstein tells the story, it extended beyond clinical trial methodology:

AIDS treatment activism was becoming increasingly more *complex* … The established treatment activists knew about much more than clinical trial methodology and design—by this point they could speak fluently about a host of technical issues that were surfacing in research on AIDS treatments. These activists had become experts of a sort, and they could engage with researchers, government health officials, and pharmaceutical companies (p. 288).

But, other than acquiring a large amount of relevant biomedical knowledge, what did they achieve? Epstein highlights the role that activists played in shaping the aims and direction of basic research, which typically took the form of trying to “hurry it along”, ensuring the patient perspective was adequately considered, and playing a co-ordinating function in “connecting up” different researchers (see pp. 322-3). Some, though by no means all (more on this later), activists became “insiders”, working with biomedical researchers on standard research projects, and bringing their unique skill sets to bear where appropriate.

At this point the philosophical reader might be demanding more conceptual and terminological precision. Let me try and satisfy this demand. First, I have been talking in a loose way about “experts” and “laypersons”. Expertise is, of course, relative to a domain: any individual is, at most, an expert in a small number of domains. An expert in, say, biomedicine will not be an expert in most other domains (physics, climate science, economics, etc.). Expertise also comes in degrees: you might be more of an expert in biomedicine than your friend, but you might be less of an expert than someone working in the field. When we describe someone as an expert *simpliciter* we typically mean that their level of expertise is above a threshold. Similarly, when we describe someone as a layperson, we typically mean that their level of expertise falls under a threshold. So, in discussing Epstein’s case study, I have been talking about experts and laypersons within the field of biomedicine, by which is meant people that fall above or below this threshold.

Second, what sets this threshold? Following Collins and Evans (2009), we can distinguish between *realist* and *relational* (perhaps better, deflationary) views of expertise. These views agree that “being an expert” is a social status; it is afforded to people who meet certain criteria, where those criteria are the result of, broadly speaking, social negotiation and agreement. But the views differ in that, on the relational view, there is nothing over and above the social status—to be an expert is simply to have the status—whereas on a realist view expertise has a substantive basis in the skills, knowledge, and competences that are supposedly possessed by those who are afforded the social status. Thus, for the realist, it makes sense to say, of some individual, that they really are an expert (they possess the relevant skills, knowledge, and competences) but are not recognised as such whereas, for the relational view, it is—at the very least—less obvious that it makes sense to say this.

Applying this distinction to Epstein’s case study, it might look like Epstein goes back and forth between the realist and the relational views. In some places he describes his activists as laypersons; in others he describes them as experts, although he typically qualifies this description—“lay expert”, “alternative basis of expertise”, and so on. This slippage makes sense given the aims of his study. He wants to challenge the view that biomedical knowledge is produced by credentialed experts, so he needs the sociological distinction between those with the credentials (biomedical researchers) and those without them (his activists). But he also needs the *epistemological* distinction between those who possess certain skills, knowledge, and competences (both biomedical researchers and certain activists) and those who don’t. Does this mean that Epstein is himself a realist about expertise? I am not sure. But, for my purposes, what we really need is the distinction between viewing expertise as a *social* status and viewing it as an *epistemic* status. What Epstein’s case study, and the studies I discuss below, highlight is that the relationship between the social and the epistemic status is complicated and is mediated by a complex web of politics—the politics of knowledge.

Third, Collins and Evans also make a valuable distinction between different forms of expertise. Most importantly for my purposes, they distinguish between *interactional* and *contributory* expertise. Put roughly, interactional expertise within a field is an advanced form of verbal fluency; someone with interactional expertise can understand and use key concepts of a field, talk to researchers in the field, understand their work, ask questions, even offer criticisms. What they cannot do is contribute to knowledge and practices within the field (conduct experiments, develop new theories, implement new practices). Making contributions to a field requires contributory expertise. Importantly, interactional expertise is part of—or, perhaps better, required for—contributory expertise, but the converse does not hold. Imagine someone who can “hold their own” in conversation with a physicist but would be all at sea if asked to conduct an experiment themselves or do a bit of advanced mathematics. This person has interactional but not contributory expertise.

Returning to Epstein’s study, his activists developed a high level of interactional expertise. Epstein repeatedly emphasizes their ability to engage in high-level discussions with practicing researchers in the field. But at least some activists went further and developed contributory expertise, as evidenced by the contributions they made to knowledge and practices within HIV/AIDS research, for example clinical trial practices (for relevant discussion see Collins and Evans 2009, chap. 2).

This point parallels the point I made earlier about exploratory and truth-directed research. Someone with (mere) interactional expertise may be able to engage in an advanced form of exploratory inquiry (inquiry aimed at understanding the current state of knowledge). But, because they cannot make real contributions to the field within which they are inquiring—because they lack contributory expertise—it is unclear whether they can engage in genuine truth-directed inquiry (inquiry aimed at advancing the current state of knowledge). On the other hand, someone with contributory expertise can engage in truth-directed inquiry because the whole point of making contributions to the field is to advance, in however small a way, the state of knowledge in the field. At least some of Epstein’s activists went beyond simply understanding and being able to talk to biomedical researchers and made genuine contributions to biomedical knowledge and practices. This required contributory expertise, not just interactional expertise, and engaging in truth-directed research.

# Patient Activist Research: Further Case Studies

Epstein’s study of AIDS activists is the most celebrated study of patient activism in the STS literature. But there are other studies in this literature, as well as a wealth of research in related fields on the valuable contributions to biomedical knowledge made by patient activists. In this section I will provide brief summaries of some studies, highlighting the ways in which they parallel Epstein’s study, and some important differences.

*Example 1: Radiotherapy Action Group Exposure*

My first example closely parallels Epstein’s case study. Charlotte Williamson (2010) details the activities of the Radiotherapy Action Group Exposure (RAGE) in the UK in the 1990s and 2000s. Briefly: in the 1970s and 1980s women who had been given radiotherapy for breast cancer reported a range of symptoms that they suspected were due to radiation damage. They were often dismissed by doctors, even branded as hysterical and neurotic (see pp. 84-5). These women formed a group, RAGE, which produced data showing that “there were clusters of severe [radiation] damage in some hospitals and in some years but not in others” which they argued “suggested that differences in total dose, or in fractionation regime or in technique, not in individual patients’ different sensitivities to radiation damage, had been responsible” (p. 85). This prompted the Department of Health to fund an audit, which was conducted by two members of the Royal College of Radiologists. But the outcome of the audit was mixed, at least from perspective of RAGE members. A member of RAGE, Margaret King, wrote a detailed critique of the audit, highlighting what she saw as errors in the data, gaps in the literature review, misleading presentation of data, and conclusions that were not warranted by the evidence (pp. 85-6).

By the mid-1990s, radiotherapy practices in the UK had improved, and Williamson provides some evidence that this was partly due to the activities of RAGE (p. 86). Still, there were concerns about wide variations in radiotherapy regimes, and members of RAGE, including King, criticised new protocols for standardising doses and fractionation regimes. Williamson highlights that these criticisms drew on the “new knowledge” that members of RAGE had acquired from their activities as patient activists. This “new knowledge” included experiential knowledge, drawn from members’ experiences of different radiation regimes, and specialist knowledge gained in other fields, especially the law. But it also included scientific and clinical knowledge about the costs and benefits of different dosing and fractionation regimes that members of RAGE had gained from their research (see p. 87).

The story Williamson tells differs from Epstein’s in that RAGE was less successful in shaping biomedical knowledge than his AIDS activists were. But this lack of success was more due to lack of uptake than a lack of expertise on the part of RAGE members. Williamson’s study still demonstrates the ability of patient activist researchers to “use new knowledge to judge whether clinical trials are scientifically and ethically acceptable”, “pick up weaknesses in the design and conduct of research”, “challenge … clinical and scientific assumptions and conclusions,” and conduct “‘quick and dirty’ research that suggests lines of enquiry” (p. 88). This means that RAGE activists like King engaged in truth-directed, not just exploratory, inquiry and demonstrated contributory expertise, not just interactional expertise.

*Example 2: French Muscular Dystrophy Association and “evidence-based activism”*

My second example parallels some aspects of Epstein’s study, though perhaps not all of them. In several papers Vololona Rabeharisoa, Michel Callon, and collaborators discuss the activities of the French Muscular Dystrophy Association (AFM) (Callon and Rabeharisoa 2003; Rabeharisoa and Callon 2004; Rabeharisoa, Moreira, and Akrich 2014). AFM was founded in the late 1950s by the families of people affected by muscular dystrophy (MD). MD is a group of genetic disorders, the key characteristic of which is progressive weakness and degeneration of the muscles that control movement. MD varies widely in severity, age of onset, and the muscles it affects, with some forms being fatal.

After its foundation, AFM established itself as a force for both scientific research and patient advocacy. It is an example of what Callon and Rabeharisoa (2003) call a “partner organization”. Partner organizations differ from “opponent organisations” is that they try to establish links between patients and specialists rather than setting themselves up against specialists. But they also differ from “auxiliary organizations” in that they aim to establish a form of parity between themselves and specialists, rather than accepting a mere auxiliary, supporting role. From its inception, AFM pursued a dual strategy, one focused on providing daily care and support for patients, the other focused on funding and directing research, leading it to become, as Callon and Rabeharisoa put it, a partner in the “co-production of scientific knowledge” (p. 196).

A central part of AFM’s work is its emphasis on the complementarity of patients’ experiential knowledge and specialist medical knowledge. AFM’s activities demonstrate that these two forms of knowledge are “not contradictory but complementary” (p. 196). Rabeharisoa et al. (2014) refer to this as “evidence-based activism”, which is a form of activism where patient groups collect and integrate experiential and specialist medical (“credentialed”) knowledge with the aim of influencing the understanding and treatment of health conditions, and so of reshaping political and scientific agendas. AFM members used tools such as photos, films, and written accounts to document their experiences with MD. These patient-created resources were vital in “creating formal, transportable, cumulative, and debatable knowledge,” which, in turn, shaped the direction and scope of laboratory research (Callon and Rabeharisoa 2003, 197). For example, photos of children with spinal muscular dystrophy were essential in developing a knowledge base for a form of MD that was not fatal in the short term but was still degenerative in the longer term.

It is important to highlight that evidence-based patient activists do not simply “add” experiential knowledge to an existing basis of specialist medical knowledge. Rather, they are “engaged in collecting and confronting” these two forms of knowledge, with “translating people’s experience into the language of science and medicine and vice-versa” (Rabeharisoa, Moreira, and Akrich 2014, 117). The result is a “seamless web” of experiential and specialist medical knowledge that provide a focal point for activists’ activities. Rabeharisoa et al. (2014) cite several examples of patient groups, not just AFM, to make this point: patient groups fighting for recognition of ADHD and other “illnesses you have to fight to get”, like chronic fatigue syndrome (Dumit 2006) and childbirth activist groups (Akrich et al. 2014). Part of the point of integrating experiential and specialist medical knowledge is to construct interdisciplinary communities invested in understanding a condition like MD, ADHD, or other medical conditions that are not adequately understood or researched.

The story that Rabeharisoa, Callon, and collaborators tell differs from Epstein’s study in that, while FMR did contribute to the body of biomedical knowledge about MD, this contribution was more about bringing existing patient experiential knowledge to bear on biomedical research. But, as was highlighted above, bringing experiential patient knowledge to bear on biomedical research is not a simple task and itself requires interactive expertise in Collins and Evans’s sense. Whether this qualifies as a form of contributory expertise depends on how exactly we understand contributory expertise (what must one contribute, what must one contribute it too, and how responsible must one be for the contribution?). What matters more for my purposes is that members of FMR were clearly engaged in a kind of truth-directed inquiry because their aim was to identify, and then fill, zones of “undone science” (Hess 2009). Filling these zones of undone science required developing partnerships with researchers and biomedical institutions, which is why Rabeharisoa, Callon, and collaborators spend some time on the stance that AFM took towards these institutions. This part of their story closely echoes Epstein’s case study, which also emphasizes the ways in which some AIDS activists and activist groups became partners with, rather than opponents to, or mere supporters of, the biomedical establishment.

*Example 3: #WeAreNotWaiting and “patient-led innovation”*

Type 1 diabetes (T1D) is an autoimmune disease where (simplifying a lot) the pancreas does not produce insulin. Insulin is a hormone that regulates blood glucose levels. Without sufficient insulin, glucose stays in the blood, leading to high glucose levels and, eventually, death. Consequently, people with T1D need to administer insulin through injections, a pump, or via some other means. While diabetes technology has improved greatly since the discovery of insulin, access to new technologies is restricted due to a combination of factors, including geographical location, high costs (especially in countries without socialized healthcare), regulatory barriers, and disparities in healthcare access.

This led to the #WeAreNotWaiting movement, which is an online movement, started in 2013, with the aim of giving more people with T1D access to technologies for administering insulin, such as insulin pumps, and managing blood glucose levels, such as constant glucose monitors (CGMs) (“The #WeAreNotWaiting Movement Is Helping People with Diabetes Improve Their Health Now, Not Later” 2016). Members of this community, who were typically people with T1D, no formal medical training or credentials, but some technological know-how, repurposed and re-engineered CGMs, insulin pumps, and various proprietary and community-developed apps. Examples include Nightscout, which makes data about blood glucose levels from a CGM called Dexcom available online and was designed by the parents of children with T1D, and Tidepool, which collects data obtained from various devices in one place, making it easier for people with T1D to manage the condition. Most impressively, Dana Lewis created, with her partner, an open-source automated insulin delivery system which allowed people with T1D free access to a technology that made managing the condition significantly easier (Lewis 2019; for discussion see Jansky, Hendl, and Nocanda 2024).

The work of the #WeAreNotWaiting movement is an example of what Jansky, Hendl and Nocanda (2024) call “patient-led innovation”, which “starts with someone identifying a therapeutic gap or problem” and is then “followed by an—often collective—development of a solution” (not final number p. 3). The solution is typically made freely available for community members to use, meaning that patient-led innovation produces technologies that are not only tailored to the specific needs of patients but are also far more accessible than the products manufactured and sold by pharmaceutical companies and other medical technology providers. As might be expected, patient-led innovation is often viewed with suspicion by doctors and other healthcare professionals, with many users of these open-source technologies reluctant to tell their doctors what they are doing (Jansky 2024, 60).

Jansky and Langstrup (2022) argue that the #WeAreNotWaiting movement is quite different from Epstein’s study of AIDS treatment activists, or Rabeharisoa’s evidence-based activists, because “it is not about making established actors in the biomedical sphere aware of one’s health needs and trying to participate in research: Engaging in the #WeAreNotWaiting movement has an immediate advantage to one’s self-care” (p. 516). People in this movement are not engaged in basic research into the causes or treatment of T1D; they are engaged in work at the boundary of science and technology.

While Jansky and Langstrup are right to highlight these differences, some common themes remain. While using these open-source technologies may not require much special medical or technical knowledge, creating them in the first place requires a combination of specialist medical knowledge (of the human endocrine system) and serious technological know-how, in particular coding skills. The people driving these patient-led innovations, like Dana Collins, are therefore lay experts of a sort, though their expertise is a good deal more applied than the expertise of Epstein’s activists. It is perhaps fair to say that the expertise of Dana Collins and other “device activists” (Jansky and Langstrup 2022) is more on the technology side of science and technology. But creating new technologies still requires a form of expertise. Importantly, the form of expertise it requires is clearly *not* a form of interactive expertise in Collins and Evans’s sense as it has little too do with verbal fluency or ability to hold a conversation with a practicing scientist. Rather, it involves the application of skills, knowledge, and competences to create a concrete product that people can use. We could perhaps call this “technological expertise”.

In this section I have presented three further examples of the research contributions made by patient activist groups. I will now shift to discussing some of the implications of the studies I have already presented, particularly in regard to what we should say about the value of independent research.

# Patient Research Collectives

Let me start by returning to the theme of DYOR (doing your own research) and the ethic of inquiry this slogan expresses.

One of the lessons of social epistemology is that knowledge production is a social process. Individuals can of course produce bits of knowledge on their own: I look outside, see that it is raining, and come to know that it is raining. Perhaps individuals sometimes produce more interesting bits of knowledge on their own: I, working in splendid isolation, prove a result in group theory (not likely, but still). However, by and large, bodies of knowledge, especially bodies of technical knowledge—mathematical knowledge, scientific knowledge, legal knowledge, medical knowledge, historical knowledge, etc.—are the products of communities working together.

To be sure, the members of these communities all know a lot. But there are limits to what any individual can know, and—within more practical fields—to what any individual can do. Communities pool these resources and, to do so, they develop norms governing the exchange and consumption of information, gathering of evidence, and so on. Some of these norms govern intra-community testimony and the forms of deference that are appropriate, perhaps even required, within the community. If a community is going to be epistemically functional—produce knowledge that is of value and interest to its members, and to others as well—these norms need to be followed and enforced, at least to an extent. (There may not be a simple relationship between how functional the community is and how often the norms are followed; things are likely more complicated than that).

This has implications for what it would mean to DYOR. As Ballantyne et al. (2024) put it (the italics are theirs):

In one literal sense of “do *your own* research”, there is no way to do that. Doing your own research is like driving your car on *your own* highway – impossible. In the same way drivers depend on the planners, surveyors, engineers, and construction crews who design and build the highway, your competence to do research depends on what we call scaffolding – again, a set of facts about cognition, embodiment, technology, society, and culture that support perception, presupposition, thought, and action behind research. No matter who you are, doing your own research means relying on some scaffolding and thereby on the social world. In seeking knowledge, people have no escape from dependence on others (pp. 8-9, not final pages).

There is a bit of exaggeration here: someone *could* build their own highway and then drive on it. Similarly, someone *could* do their own research without the scaffolding provided by membership within a community of other inquirers. But—and this is the more important point—the bodies of knowledge that shape the world we live in are *not* the product of individuals doing their own research in the literal sense. They are the product of individuals working within communities of inquirers. This means that the “cognitive scaffolding” provided by these communities is an essential part of the story behind the construction of these bodies of knowledge.

The cognitive scaffolding metaphor is useful because it helps explain why some—including Ballantyne et al., but also Levy (2022) and Matheson (2022)—seem to be sceptical of the value of research conducted by those who are “outside” traditional research communities (universities, research institutions, etc.). Here are Ballantyne et al. again:

How do beginners transform into competent researchers? By being embedded in, and engaging with, the social world. The novice scientist enrolls in courses, completes homework problem sets, asks the instructor questions when something is unclear, and spends hours in the laboratory. Some of what she picks up is explicit teaching – information and models in lectures and textbooks, feedback on tests, and so on. But other elements shaping the novice scientist’s development are implicitly embedded in the situation and go unnoticed. These are the environments in which the novice scientist’s skills for acquiring and evaluating evidence are formed by the particular pedagogical methods of her discipline (p. 8).

While this passage focuses on the “training stage” of becoming a competent researcher, the general point is clear: membership in a scientific community provides the cognitive scaffolding required to do competent, perhaps even valuable, research. Ballantyne et al. contrast this with the *lack* of cognitive scaffolding provided by membership in, say, a YouTube community devoted to conspiracies about vaccines (pp. 9-10). This lack, they say, means that a member of the YouTube community is not able to conduct competent research. Importantly, on their view the difference between a scientist and a member of the YouTube community is *not* that the member of the YouTube community is less intelligent, more irrational, prone to bias, or gullible than the scientist. The problem is that the community they are a member of lacks the structures and norms that are required to be epistemically functional and are conducive to competent research.

While I think that the contrast between scientific research communities and YouTube communities of conspiracy theorists is too simplistic—what about YouTube communities, or other online communities, that don’t go in for conspiracy theories? can they do competent research? – Ballantyne et al. provide a helpful framework for thinking about what makes a community of inquirers epistemically functional and positions them to conduct competent research. An epistemically functional research community needs to provide sufficient cognitive scaffolding: sufficient training, norms that facilitate the production, transfer, and dissemination of knowledge, structures that ensure sufficient compliance with those norms, and so on. I suspect that some—certainly not all—online communities will meet these conditions and I am therefore less sceptical than Ballantyne et al about the value of research conducted in online communities.

Returning to patient research groups, the lesson I take from §2-3 is that, while patient research groups stand outside of traditional research institutions, and their members typically lack (relevant) scientific training, they provide exactly the sort of cognitive scaffolding required to conduct competent research. As Epstein highlights (see e.g. pp. 230-2), the AIDS activist communities he studied provided training in relevant fields of biomedicine, organized events with similar structures to academic conferences, attended academic conferences, and members of these communities published in periodicals and even scientific journals. While this is clearly not *identical* to the scaffolds provided by formal scientific training and membership of the scientific community, Epstein’s study demonstrates that the result was an epistemically functional community—a community with the social and institutional structures required to produce valuable research and advance the state of knowledge about HIV/AIDS. Something similar can be said about the other activist groups discussed in §3, especially RAGE, which provided structures that in many ways parallel those provided by Epstein’s AIDS activist groups.

I am *not* saying that there are no differences between the research communities formed by patient activist groups and traditional research communities. To mark the difference, I propose that we call research communities like those formed by patient activist groups “research collectives”. A research collective is similar to a traditional research community in some ways. Most fundamentally, research collectives, like traditional research communities, are communities of inquirers that produce bodies of knowledge. Like traditional research communities, they have structures in place that provide training for their members, norms governing the production, sharing and dissemination of knowledge, and venues (sometimes shared with traditional research communities) for the sharing and dissemination of this knowledge.

But there are also important differences. A research collective, by definition, stands outside of traditional research institutions, like universities, and its members typically lack relevant training and credentials in the fields in which they conduct research, though they also often have credentials in other fields, or outside of the academy. Patient activist groups do not usually have the luxury of spending years, even decades, “training up” their members. (This is, unsurprisingly, a particularly salient feature of Epstein’s case study). Where traditional research communities are—at least, historically, and ideally in the view of many of their members—invested in “pure research”, in “knowledge for knowledge’s sake”, research collectives are typically invested in research that bears on the interests of the collective and its members. This means that research collectives will typically have a narrower, and more applied, focus than traditional research communities. In some cases, such as #WeAreNotWaiting, the focus may be entirely on technological innovations rather than pure research. In other cases, like RAGE, FMR, or the AIDS activists, the focus is on pure research insofar as it is relevant to the interest of members of the collective.

More generally, the point is that, despite these differences, at a high level of analysis patient research collectives have structures in place that serve similar functions to the structures we find in traditional research communities. They facilitate competent research, contributions to biomedical knowledge, and even the production of new technologies. What exactly those structures are, how exactly they differ from the structures we find in traditional research communities, and the problems that may arise within patient activist groups due to these structures, especially when they create hierarchies within the patient activist group, are questions for further research (see §5).

# Further Issues and Questions

In this paper I have argued that patient research collectives—Epstein’s AIDS activists, RAGE, FMR, #WeAreNotWaiting—embody an ethic of inquiry that valorises doing your own research rather than simply deferring to recognized biomedical expert authorities. Because these are research *collectives*, though, what is valorised is not individualresearch—“thinking for oneself”—but rather a *community* of inquirers, members of which typically lack the usual expert credentials, looking into matters that concern them, producing new knowledge, and finding ways to translate that knowledge into action that will benefit the members of the collective. The patient research collectives I have discussed do not just embody this ethic of inquiry; they have made helped advance biomedical knowledge and innovated in the design of new technologies that can now be used by patients.

At various points in the discussion, I have deferred certain issues and questions. Let me finish by taking up some of them and pointing towards some avenues for future research. Many of these questions call for an interdisciplinary approach. I hope that, at the very least, I have persuaded a philosophical audience of their interest, and of the necessity of answering them.

First, I have acknowledged that problems and tensions can arise within patient research collectives, but I have not said anything about this. That problems and tensions can arise within patient research collectives is, of course, not surprising; patient research collectives are, if you like, the “research arm” of patient activist groups and the politics of activist groups is famously fractious. In his study Epstein highlights some of the problems that arose within the AIDS activist groups he was looking at:

What particularly complicated the internal battles of the AIDS movement was the additional overlay of the politics of expertise. It was not simply that some people were working on the inside while others were outside—just as important, those who were on the inside were increasingly mastering specialized forms of knowledge with which their fellow activists on the outside did not come into contact. There resulted what Gilbert Elbaz, in an analysis of ACT UP/New York, has nicely described as a gap between the “lay expert” activists and the “lay lay” activists. Stratification by gender, race, class, and education helped to structure access to the “lay expert” identity (p. 293).

There are often hierarchies within activist groups, with some members having more power and influence than others, and these hierarchies often reflect hierarchies within society more generally. It is therefore not surprising that the activists who feature most prominently in Epstein’s study tend to be male, highly educated, and white—people with a high amount of social capital, even if they typically lack relevant medical credentials. This leads to the first question for future research: is this a common feature of patient research collectives? There is some reason to think that it is also a feature of #WeAreNotWaiting. Jansky et al. (2024) cites some data from Braune et al. (2021) about the homogeneity of the diabetes online community: 91% of the users of opensource automated insulin delivery systems are from Europe or North America, 83% of the adults involved in the community have a first degree or higher, 26% have an IT background, and 25% have a household income over U.S. $100.000 per year. More research into other patient research collectives is needed, but it would not be at all surprising if this were a general feature of these groups.

Second, in their study Rabeharisoa, Collin and collaborators describe FMR as a “partner organization” rather than an auxiliary or opponent organization. Roughly, this means that FMR sees itself as a co-producer, with established biomedical institutions, of relevant biomedical knowledge, rather than as an opponent to or a mere auxiliary of these institutions. This leads to the second question for future research: is this an accurate description of other patient research collectives? One way of reading Epstein’s study, and thinking about the splits within AIDS activist groups discussed above, is that some activists became partners with established biomedical institutions whereas other activists preferred to be opponent organizations. In Williamson’s study, while RAGE pursued a “partnership strategy”, it seems that their attempts to establish themselves as a partner organization did not fully succeed. It is less clear what to say about #WeAreNotWaiting here, as this is a movement that has quite different aims to researchers working on T1D and T1D treatment. At any rate, this is a question that would merit further study.

Third, I have talked a bit about how patient research collectives have internal structures that facilitate competent research and the production, transfer, and dissemination of biomedical knowledge. While I have identified some relevant aspects of these structures—for example, AIDS activist groups had systems in place for training their members, and #WeAreNotWaiting creates open-source technologies that anyone can access and use—a lot more could be said here. This leads to two more questions: when we look at examples of patient research collectives, what structures do we find? And: how do these structures compare to the structures we find within more traditional research communities? One thing worth exploring here is the extent to which the structures within patient research collectives embody and perpetuate existing hierarchies within the group. For example, do we find that powerful members of the group play a disproportionate role in setting the research agenda of the group? In the philosophy and sociology of science literature there is an extensive debate about the need to *democratise* science, and about what, exactly, that would mean (Jasanoff 2007; Kitcher 2001; Longino 1990). It is therefore worth looking into the extent to which patient activist groups are democratic organizations, and the extent to which they embed power hierarchies that we find in society more generally.

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