DOI: 10.1017/psa.2025.10162
This is a manuscript accepted for publication in *Philosophy of Science*.
This version may be subject to change during the production process.

The Epistemic Grounds for Lay Interference in the Conduct of Science

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Abstract. I present a heretofore untheorised form of lay science, called *extitutional science*, whereby lay scientists, by virtue of their collective experience, are able to detect errors committed by institutional scientists and attempt to have them corrected. I argue that the epistemic success of institutional science is enhanced to the extent that it takes up this extitutional criticism. Since this uptake does not occur spontaneously, extitutional interference in the conduct of institutional science is required. I make a proposal for how to secure this epistemically beneficial form of lay interference.

> If science is to serve sick people and not the other way around, we must explain to science our expectations and our needs. Our demand for the right to interfere in research processes is grounded both politically and scientifically.
>
> —ACT UP Paris, *Le Sida, combien de divisions?*

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It is common to mark a distinction among the *agenda* of science (the set of topics that are to be researched by scientists), the *conduct* of science (the process by which findings on a topic are produced), and the *application* of science (the utilisation of scientific findings in technology, policy, healthcare, etc.) (Kitcher 2001, 118, Elliott 2022, 8). In part because scientific activities are largely publicly funded, and in part because they have widespread consequences beyond their own domain, philosophers tend to believe that the public as a whole should be able to *interfere* with the agenda and application of science; they should, that is, be able to have an impact thereon that is not mediated or controlled by institutional scientists.[1] Philip Kitcher in particular has influentially argued that the agenda of science and its applications should, as a matter of democracy, be aligned with the values of the demos (Kitcher 2001). But he did not extend his argument to the *conduct* of science.[2]

Traditionally, philosophers of science viewed the conduct of science as a purely epistemic endeavour, that the uninitiated neither could nor should interfere with. More recently, many have rejected the view that the conduct of science is a purely epistemic matter (Longino 1990, Douglas 2000, 2009), and have argued that the uninitiated may have a restricted role to play in the conduct of science, specifically, in the choice of non-epistemic values used in science (Douglas 2005, 2017). Thus, there are grounds for thinking that laypeople may legitimately interfere with the non-epistemic aspects of the conduct of science.[3] There are also grounds for thinking that laypeople may *contribute* to the epistemic aspects of the conduct of science. The recent "participatory turn" (Wynne 2007) in science is fuelled by the idea that the inclusion of

[1] Interference so defined is quite weak: it simply entails that institutional scientists do not have complete control over the aspect of science at hand.

[2] Note however that in Kitcher (2011, §20), he argues à la Douglas (2009, 2017) for the involvement of laypeople in making value judgments within the conduct of science. See next paragraph.

[3] I do not presuppose that there is a sharp distinction between epistemic and non-epistemic values (Longino 1996), but I will argue that lay scientists make crucial contributions to aspects of research that are no less epistemic than those of institutional scientists.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

laypeople in research projects initiated and led by institutional scientists can be beneficial in numerous ways, including on the quality of the findings produced (Wylie 2015, Koskinen 2023). But this is not usually taken to justify laypeople's *interference* with these projects. The interference of laypeople in the conduct of science can only be desirable, it seems, when circumscribed to non-epistemic domains.

In this paper, I make a case for a specific form of lay interference in the epistemic aspects of the conduct of science. Drawing on the scientific work of people with HIV/AIDS and a group of diseases known as *infection-associated chronic conditions* (IACCs), which includes myalgic encephalomyelitis (ME) and Long COVID, I present a form of scientific activity, which I call *extitutional science*, that arises outside the confines of institutional science as a response to its failures. Extitutional science propels scientific understanding forward, I submit, not because it produces new findings, but because it can identify errors in the methods of institutional science. I explain how extitutional science is capable of identifying them and making proposals for their correction. I then argue that institutional scientists largely ignore this transformative criticism, such that their errors stand uncorrected. So, it turns out that popular interference in the conduct of institutional science is sometimes necessary for its epistemic success. The current organisation of science does not leave much room for such interference however. This suggests that, if the organisation of institutional science is to be optimised for its epistemic success, it ought to be modified in a way that promotes this beneficial form of interference. I make a proposal as to how.

I.

Let us begin with some terminology. The conduct of science primarily takes place, according to social epistemologists, within a system of institutions (universities, research hospitals, commercial research institutions, journals, professional societies, etc.) which has a complex internal organisation. I shall call scientific activity performed in one's capacity as a member of one of these institutions *institutional science.* Not all scientific activity is so performed. Sometimes, science is performed by people who are not members of these institutions, or by members of these institutions but not in their capacity as such: this is what I shall call *lay*

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

science.[4] I take the distinction between lay and institutional science to be purely sociological: what differentiates the two forms of scientific activity is that the latter, but not the former, are performed by professional scientists in their capacity as such. Using a purely sociological demarcation criterion, as opposed to an epistemic one, allows me not to settle in advance the question whether there can be "lay experts" (Epstein 1995, Arskey 1998) who may potentially have an epistemic advantage over institutional scientists in specific domains.[5]

The forms of lay science which have been identified in the literature may be divided into two kinds, based on how they relate to the conduct of institutional science. In what I shall call *community science* (after Kovaka 2021), laypeople come together to research a particular phenomenon that affects their community.[6] Although institutional scientists are sometimes asked for their input, this form of lay science remains largely separate from the conduct of institutional science. Indeed, in cases of community science as I define it, community scientists aim to produce their own findings, either for direct use by their community, or to pressure the authorities into policy changes. For instance, they may seek to evaluate food contamination as a guide for their own consumption (Kimura 2016), or to evaluate the impact of pollution on their health to extract protective policies from regulators (Allen 2017). Thus, community science takes place in relative disconnection to the complex social mechanism of institutional scientific

[4] An academic physicist who also collects ornithological data as a volunteer (Bonney 2008) is an institutional physicist and a lay ornithologist.

[5] Because they understand 'lay' in a normative sense to mean a non-expert, Collins and Evans call the expression 'lay expertise' an "oxymoron" (2002, 238), and propose to replace it with 'experience-based expert'.

[6] Karen Kovaka provides the example of a community of people in an industrial area of France who showed the deleterious impact of pollution on their health (Allen 2017); other examples include women researching the contamination of food by radiation after the Fukushima disaster (Kimura 2016), and Black people investigating the contamination of their water supply in Flint, Michigan (Carrera et al. 2023, Pauli 2019). In healthcare, community science can look like groups of people collectively investigating the effects of dietary supplements on their health (Wiggins and Wilbanks 2019).

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

research, and any links between community science and the conduct of institutional science are tenuous.

By contrast, in what I shall call *participatory science*,[7] laypeople are invited by institutional scientists to take part in the scientific research they conduct.[8] It takes place on a spectrum of lay involvement: on one end, volunteers perform mere data collection for a professionally designed and run project,[9] and on the other end, lay scientists are "full research collaborators", who "help … to shape research questions, study methods, conclusions drawn, and all the other decisions made along the way" (Potochnik 2024: 51). But even in the case of "full collaborat[ion]", the emphasis is always on how "members of the participating public" (Dunlap et al. 2021, 287) can "help" (Potochnik 2024, 51) or be "included" (Potochnik 2024, 50) or "participate" (Evans and Potochnik 2023, 13) in the research that "professionally trained researchers" (Dunlap et al. 2021, 287) or "scientists conduct" (Evans and Potochnik 2023, 12). Participatory science may involve lay researchers to various degrees, but it takes place under the purview of institutional science: the initiative and decision-making roles belong to institutional scientists.

These two forms of non-professional science are not jointly exhaustive: people living with HIV/AIDS and IACCs have been involved in scientific activities that do not fall under either of the two kinds surveyed so far. They have independently established the existence and characteristics of their disease when institutional science remained oblivious to it.[10] They have collated, summarised, and spread the subsequent findings of institutional science on their

[7] Dunlap et al. (2021), Evans and Potochnik (2023), and Potochnik (2024) use this term to refer to all scientific activities performed by laypeople, including what I am here calling "community science". I borrow their term but use it in a narrower way, to refer only to those instances where lay scientists actually participate in institutionally-run research projects.

[8] In the medical context, participatory science falls under the banner of *public and patient involvement* (McCoy 2019, Frith 2023).

[9] Data collection by volunteers is known outside of STS as *citizen science*, but in STS, the term usually refers to what I call *community science* (Kimura and Kinchy 2016). Sometimes, the term is also used to discuss any form of lay science. I use other terms throughout the paper to minimise confusion.

[10] See Callard and Perego (2021) on the case of Long COVID.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

diseases; but much more than that, they have collectively analysed, criticised, and disputed almost all of its aspects: from conceptual questions (diagnostic criteria, symptom definitions), to clinical trial methodology (eligibility criteria, control type, outcome measures, posology, statistical analysis), to research into disease pathophysiology (theory building, hypothesis generation, research methodology). In response to a scarcity of correctly run trials, they have sourced medications outside formal channels, run underground trials, performed experiments on themselves, and used the knowledge acquired in this way to demand changes to the way institutional science was producing findings on their disease. In other words, they have left no stone unturned in the collective criticism of what they have considered to be the inadequate research pursued by institutional science as a whole.[11]

These cases cannot be understood as forms of participatory science. As we have seen, participatory scientists are invited to perform some specific set of tasks, such that their activities are decided on by institutional scientists. By contrast, the groups of sick people at hand have not been sought out or pre-emptively invited to participate in institutional-run research, but have initiated and run their own projects without institutional oversight. Thus, unlike participatory scientists, their scientific activities cannot be said to fall under the purview of institutional science. But these cases cannot be understood as forms of community science either. For unlike community scientists whose scientific activities are aimed at producing their own findings, the groups of sick people I am discussing here seek to exert modifications on the way in which institutional scientists produce their findings: they direct their efforts towards altering the course of institutional research. The scientific activities under discussion are thus neither subsumed under institutional science, as participatory science is, nor separate from it, as community science is. A new theoretical model for understanding these activities is therefore needed.

Lucas Dunlap et al. (2021) argue that understanding lay science requires a sense of why people engage in it. They discuss, for instance, the fun and educational aspects of participatory science for participatory scientists, and conclude that one of its benefits might be to increase public trust in science (see also Potochnik 2024, Potochnik and Jacquart 2025). The sick people I have been

[11] In neither case has this criticism extended to *all* institutional scientists working on the condition. See e.g. fn. 26.

writing about, however, do not engage in their activities primarily because they find them interesting (though many do), but because they desperately want a safe and effective treatment that will allow them to survive and/or regain some quality of life. In a context where they see institutional science as systematically producing errors, such that no safe and effective treatment exists on the horizon, they feel compelled to make institutional science change course: "it is by *reaction* that organisations of sick people were created" (ACT UP Paris 1994, 95, emphasis added). The kind of science I have been describing, therefore, has two core features. Firstly, it emerges as a response to the failings of institutional science, such that these failings constitute the reason for its genesis.[12] And secondly, it is neither subordinate to (like participatory science) nor separate from (like community science) institutional science, but characterised by sustained critical engagement with it. By virtue of these features, it can be viewed as a kind of lay counterpart to institutional research, and called *extitutional science.*[13]

II.

> The FDA sins by commission; it is doing the wrong things, and they are deadly wrongs.
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> —FDA Action Handbook, ACT UP New York

The epistemic success of extitutional science must be accounted for, and there are immediate difficulties: extitutional scientists tend to have very little scientific training, and no access to the kinds of resources necessary for the production of meaningful scientific findings. The source of their competence must instead reside in their experience of living with the condition at hand, but the mere fact of living with a particular condition cannot possibly give one direct insight into its biomedical aspects. What needs to be developed then is an explanation of how the lived experience of extitutional scientists indirectly provides the kind of competence that can propel scientific understanding of the condition forward. We saw that extitutional science has two

[12] Some instances of community and participatory science may share this feature: often, community science emerges from a dearth of institutional science on the topic of interest, and participatory scientists may be motivated to participate in institutionally-run research projects by what they perceive to be failings in the way these projects are conducted.

[13] See McKenna (ms) for further examples of extitutional science.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

characteristics: it emerges as a response to the failings of institutional science, and it consists in a form of sustained critical engagement with it. This suggests that the contribution of extitutional scientists is not primarily additive but critical: their most successful activities consist not in the production of new findings, but in the criticism of existing ones. In other words, extitutional science is successful because it is able to detect and correct errors committed by institutional science; or so I shall argue in this section.

Until the early nineteenth century, it was widely believed that scientific outputs were always true, and therefore that science progressed through the mere accumulation of new findings. But developments in the sciences began to reveal that science was fallible: it could produce errors. A new philosophical tradition emerged, most closely associated with Charles Sanders Peirce, which accounted for this fallibility whilst maintaining that science was epistemically successful: the trick was to argue that, although science produces errors, it can also correct these errors. In other words, scientific progress came to be seen as requiring not only the production of new findings, new theory, etc. but also the correction of any errors that had been introduced. In that sense, science could be seen as *self-corrective*, and therefore progressing towards the truth: "inquiry … has the vital power of self-correction and of growth" (Peirce 1898, 47).[14]

One way to parse this claim draws on the work of Helen Longino (1990, 2002). Longino begins from the observation that the interpretation of data and the evaluation of hypotheses based on them requires making a number of what she calls *background assumptions* (1990, ch. 3). Indeed, data can never settle the truth or falsity of a more general hypothesis on its own, and background assumptions are required that bridge this inductive gap. These background assumptions can be empirical, conceptual, metaphysical, or even political: they are "substantive and methodological hypotheses that … form the framework or proximate intellectual context within which inquiry is pursued" (2002, 127). She then argues that different scientists are liable to make different background assumptions, therefore conducting scientific inquiry in different ways, and even drawing different conclusions based on the same data. Progress in science therefore requires not

[14] See Laudan (1981) for an account of this historical development. The idea that science is successful to the extent that it is self-corrective has been popular in recent years; see e.g. Ioannidis (2012), Romero (2016), Vazire and Holcombe (2021).

only the collection of new data, but also a "collective give-and-take of critical discussion" (1990, 79) which enables the identification and correction of errors in background assumptions (1990, ch. 4). What she calls the "transformative criticism" (1990, 76) of background assumptions therefore has a central role to play in scientific progress, for the "conflict and integration of a variety of points of view" (1990, 69) comes to increase the epistemic quality of the outputs of science.[15]

Scientific communities in which background assumptions are routinely subjected to thorough criticism, and which are responsive to this criticism, are thereby more self-corrective, and yield epistemically better outputs. This, I submit, is how we should understand the primary contribution of extitutional scientists: it is by providing extensive and profound transformative criticism on the background assumptions made by institutional scientists that they have improved the scientific understanding of the pathophysiology of their disease, and enabled the discovery of effective treatments. This, to be sure, is a bona fide scientific activity. Evaluating the conceptual, methodological, and other background assumptions against which data is rendered meaningful is a core part of what enables the production and correction of scientific results. Extitutional scientists are indeed doing science. But if they propel science forward by providing this kind of transformative criticism, it must be explained how they are able to notice errors committed by institutional scientists and to make proposals for correcting them. It must be explained, that is, where their scientific competence springs from.

Standpoint theory (Hartsock 1983, Harding 1986, 1991, Collins 1986, Haraway 1988) can be read as providing this kind of explanation. According to feminist standpoint theorists, the sexist ideology that pervades our culture impacts the background assumptions that institutional scientists adopt. For instance, misogynistic assumptions about the supposed passivity and weakness of women led scientists to assume that the egg plays no active role in the process of fertilisation, such that they focused their attention solely on the role of the sperm, and produced erroneous theories of fertilisation (Martin 1991). Because it is so pervasive, people of all genders

[15] Longino puts this in terms of increased 'objectivity'. I use the more general ideas of scientific progress or epistemic improvement so as to avoid complex questions about the notion of objectivity which are not particularly relevant to the present context.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

tend to absorb some measure of sexist ideology, and are thus susceptible to this kind of error. However, those targeted by sexist ideology may have an inchoate sense that this ideology does not accurately describe their own lives, and for this reason, may be motivated to form social movements through which it becomes possible to collectively pierce through sexist ideology, and produce what is known as a feminist *standpoint*: an integrated and comprehensive understanding of gender and gendered oppression. The production and adoption of a feminist standpoint allowed feminist biologists to recognise sexist ideology where it appeared, and therefore, to spot the errors that it had engendered in the practice of science. They were able to see that extant theories of fertilisation were erroneous by recognising the sexist background assumptions that led to them for what they were, and to produce non-sexist, epistemically superior accounts of fertilisation that identified and described the active role that the ovum plays in the process.

This kind of mechanism is at play in our illustrative cases. For instance, homophobic assumptions led some scientists to deny that HIV is the cause of AIDS, defending instead the so-called *immune overload* hypothesis, according to which AIDS is caused by a 'gay lifestyle': people with AIDS have supposedly subjected their bodies to so many stressors, in the form of non-HIV sexually transmitted infections and use of recreational drugs, that their immune systems have simply given up (Epstein 1996: ch. 1). Similarly, ableist and misogynistic assumptions continue to cause some institutional scientists to argue that IACCs are essentially forms of hysteria: according to them, IACCs are perpetuated, not by organic disease, but by 'maladaptive cognitions and behaviours' caused by 'psychosocial factors' and the unconscious desire for the 'secondary gains' of illness (Geraghty et al. 2019, Hsu 2024). In these cases, it is the lived experience, not of the disease itself, but of the social meanings and forms of oppression and marginalisation associated with the disease, that provides the grounds for people to see through these erroneous political background assumptions. Since, people with HIV and people with IACCs have formed close-knit communities in which their political situation is collectively analysed, it is clear how they might have communally produced a standpoint from which these ideological posits can be seen for what they are.

However, the transformative criticism that extitutional scientists have levelled at institutional science has not been confined to these fringe, if dangerously influential, ideas baked in active bigotry. Instead, much of their criticism has been targeted at institutional scientists who, on the

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face of it, are not particularly prone to ideological assumptions and are actively working to solve the health crises at hand. The background assumptions they have criticised have, on the whole, not been of an obviously political nature: they have been methodological and conceptual assumptions which one would tend to classify as epistemic. Since, on standpoint theory as it was developed by feminists in the 1980s and 1990s, it is ideological distortions which introduce error, and the shared experience of the associated form of oppression which allows piercing through it, this classic form of standpoint theory cannot explain the epistemic advantage of extitutional scientists. But a looser form of standpoint theory can perhaps be articulated which retains the idea that those theorised about can collectively detect error in their theorisation, on the basis of their lived experience.

III.

Extitutional science, I have argued, propels scientific understanding forward by correcting the (non-ideological) errors of institutional science. This raises the question of how extitutional scientists are able to detect these errors. In order to answer this question, let us examine two examples of extitutional science.[16]

> *1-HIV/AIDS*: After HIV was discovered to be the cause of AIDS, institutional scientists focused heavily on slowing and reversing HIV-induced immunodeficiency, which they saw as the upstream and therefore most important aspect of the disease. It was widely understood among institutional scientists that progress on antivirals

[16] These two examples were chosen because they are easy to understand and have been important struggles waged by extitutional scientists working on HIV/AIDS and IACCs. But there are hundreds of further examples that could have been chosen to illustrate my points. The reader curious to know more about the work of extitutional scientists working on HIV/AIDS in the late 1980s and early 1990s may appreciate the writings of Epstein (1995, 1996) and Schulman (2021). Unfortunately, the work of extitutional scientists working on ME and Long COVID has not yet been recorded in a systematic fashion. I encourage the interested reader to look into the Patient-Led Research Collaborative (McCorkell et al. 2021), who published the first landmark study on Long COVID (Davis et al. 2021), and whose review of Long COVID science remains the most cited paper in the field (Davis et al. 2023).

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

would be met with widespread acclaim.[17] In their early trials for HIV antiretrovirals, institutional scientists borrowed methodological background assumptions from other medical fields, according to which trial data could not be 'tainted' by concurrent medication use: any data which was obtained in this way would count as 'impure' and not be taken to reliably inform the trial hypothesis. In both the intervention and the control arm, participants were therefore required to stop any and all medication. This included all medications for the control of opportunistic infections.

Extitutional scientists argued against these methodological assumptions. They were acutely aware that a narrow focus on immunodeficiency at the expense of its downstream effects in the form of opportunistic infections and cancers was inadequate: "to die of AIDS is always to die of an [opportunistic disease] … It is opportunistic diseases which kill people with AIDS" (ACT UP Paris 1994, 156). Not only did trials which forbade the concurrent use of medication risk hastening the death of those enrolled in the trial (an ethical consideration), they would also fail to inform the hypotheses that needed evaluating (an epistemic consideration): these trials would produce results that would not be applicable to a population which made extensive use of these medications, and would thus be unable to inform AIDS healthcare. Although institutional sceintists initially resisted this criticism, they eventually changed their ways. (For more details on this example, see Epstein 1996, 253–256.)

2-IACCs: All people with ME and many people with Long COVID have a markedly reduced capacity to perform a range of activities.[18] On the milder end of the spectrum, people are unable to exercise; on its most severe end, they are fully bedbound, unable to tolerate light and sound, and need to be tubefed. Many

[17] "Everyone knows that the Nobel Prize will be awarded to the scientist who discovers an effective antiviral, not to those who will have improved the treatment of mycobacteria" (ACT UP Paris 1994: 157).

[18] It is usually said that ME represents a particular phenotype of Long COVID. Thus, some (but not all!) people with Long COVID have ME. Extitutional science on Long COVID exists for ME and for non-ME phenotypes.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

institutional scientists designing clinical trials for these conditions have parsed this functional impairment in the familiar-to-them terms of 'fatigue', and have assumed that interventions would be effective to the extent that they reduce fatigue. Accordingly, the outcome measures (ways of evaluating the impact of an intervention) of some of the most prominent trials for IACCs have been assessments of fatigue intensity.[19]

The sick people at hand have argued against these conceptual-methodological assumptions. They have pointed out that the symptoms underpinning their functional impairment go far beyond fatigue, and also include pain, orthostatic intolerance, cognitive dysfunction, and more (see e.g. the #NotJustFatigue campaign). More importantly, they have insisted that the primary factor in their functional impairment is not the intensity of their symptoms but the looming threat of what is known as *post-exertional malaise* or PEM: an exertion-induced, often-delayed, dangerous, and debilitating pathophysiological state, during which their functional capacity is markedly reduced and their symptom load is significantly increased. Because PEM carries the risk of temporary or permanent disease progression, it is essential that people refrain from whatever level of activity induces it (see e.g. the #StopRestPace campaign).

Accordingly, extitutional scientists working on IACCs have argued that clinical trials targeting functional impairment in people with PEM that use fatigue scales as outcome measures do not accurately capture disease-induced functional impairment. As a result, these outcome measures may fail to accurately identify intervention effects and produce false negatives (Goxhaj et al. ms). Instead, extitutional scientists

[19] Examples include the Rituximab trial for ME (NCT02229942, Fluge et al. 2019), whose primary outcome measure was a self-reported fatigue score; the Ampligen trial for Long COVID (NCT05592418), whose primary outcome measure was the fatigue subscale of the PROMIS questionnaire; and the BC007 trial for Long COVID (NCT05911009), whose primary outcome measure was the fatigue subscale of the FACIT questionnaire. Note that not all trials for IACCs use fatigue scales as outcome measures; quality of life scales are also popular. These have been less criticised by extitutional scientists.

> have been promoting the use of functional capacity questionnaires, such as the FUNCAP (Vogel et al. 2024, Goxhaj et al. ms). The FUNCAP, which was co-produced by non-sick and sick researchers with feedback from thousands of sick people, evaluates not symptom intensity, but the post-exertional consequences of performing a range of activities (Sommerfelt et al. 2024). To date, numerous trials continue to use fatigue scales as outcome measures,[20] and the only trial for an IACC which uses the FUNCAP is sponsored by the Open Medicine Foundation, a non-profit largely funded by sick people and their kith and kin (NCT06366724, Meadows et al. 2025).

These two examples share a common structure: institutional scientists made erroneous conceptual and/or methodological background assumptions, extitutional scientists detected these errors and argued for their correction, and institutional scientists resisted uptake of this criticism.[21] In this section, we shall examine what enabled extitutional scientists to detect errors; in the next, we shall turn to institutional scientists' reaction to this criticism.

In both examples, institutional scientists new to so-far immature fields adopted erroneous conceptual and/or methodological background assumptions. In the HIV/AIDS example, this is the methodological assumption that trial results are only reliable if they disallow the concurrent use of other medications. In the IACC example, it is the conceptual assumption that functional impairment must be parsed in terms of fatigue, and the attendant methodological assumption that fatigue scales are an adequate outcome measure. In both our examples, extitutional scientists were able to notice and correct these errors, despite their lack of training and resources. This

[20] Ongoing trials for IACCs using a fatigue scale as primary outcome measure include NCT05430152 (Naik et al. 2024), NCT06128967, and NCT05710770 (Preßler et al. 2024).

[21] In our two examples, these errors arise in clinical trial design. But institutional scientists make conceptual and methodological background assumptions throughout the whole spectrum of research, from fundamental research to the construction of clinical guidelines. It follows that the mechanism described here could operate at all levels of scientific research; and indeed, the activities of extitutional scientists have spanned the whole gamut from basic to applied research (see §I).

requires an explanation, and ours shall be two-stepped. Identifying an error in the conduct of institutional science requires two things: it requires knowing precisely how such science is conducted, and it requires independent knowledge of the phenomenon against which to spot error therein.

Let us begin with the first requirement: that extitutional scientists know how institutional scientists conduct their research. We have seen that extitutional scientists are invested in their scientific activities because they seek an effective treatment for the condition that brought their community together. When an effective treatment fails to materialise, they have an incentive to inquire into why, and thus to investigate in detail how institutional scientists are conducting their activities. Moreover, institutional science is governed, inter alia, by the *communist norm*, according to which scientists must widely share the details of their work (Merton 1942, Heesen 2017). Now, understanding the relevant details of scientific work requires training. Communities of sick people therefore often make up what Robin McKenna (ms) calls "research collectives" whose activities include educating one another and the community at large about scientific issues, with the aim to provide everyone with the capacity to understand the crucial aspects of scientific research being done on their condition.[22] To summarise: the failure of institutional science to produce the desired outcomes provides extitutional scientists with an incentive to inspect the details of its conduct, its communist norm ensures that these details are available to extitutional scientists, and the internal organisation of extitutional science ensures that the details are widely understood therein. It is easy therefore to see how extitutional scientists would have detailed knowledge of the conduct of science.

This brings us to the second requirement: that extitutional scientists have independent knowledge of the phenomenon against which to spot errors. Extitutional scientists are part of communities which have produced a collective understanding of the disease's clinical picture (what it presents as, how it evolves, what treatments it's responsive to and how) that is the result of the structured amalgamation of ample and detailed evidence. This understanding is constructed from the ground up: the "research collectives" (McKenna ms) that sick people make up have a more or less formally structured internal organsisation, wherein individuals share aspects of their disease

[22] See e.g. Schulman (2021, 39) on teach-ins about clinical trials in ACT UP New York.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

experience, and which enable the "clashing and meshing", in Longino's terms (1990, 69), of these various experiences. Through the activities of research collectives, a picture emerges of what the clinical features of the disease are. Since there is significant variation in individual experiences of disease, this kind of collective triangulation is essential. On the one hand, it allows noticing particular aspects of the disease that might otherwise have eluded perceptual attention: it is common for the gathering of people with similar inchoate experiences to facilitate or even enable the articulation of these experiences.[23] On the other hand, it enables the generation of a general picture of the condition—of what exists and what doesn't, of what is systematic, what is common, and what is rare, etc.—which requires many data points.

Thus, in virtue of their incentives, experience, and collective organisation, extitutional scientists have two characteristics: they have a detailed grasp of the conduct of science, and they have robust knowledge of the condition's clinical features against which to spot error therein. I contend that these two characteristics endow extitutional scientists with the ability to correct the errors of institutional science and thereby propel science forward. Note that this ability does not require extensive formal biomedical training or resources.[24] Its first step, understanding the way in which science is being conducted, does require a sufficient grasp of research methodology and some disease-specific scientific knowledge, but this can be achieved by any research collective with an incentive to make out why institutional science is not making sufficient progress. And its second step, detecting the errors of institutional science, requires a robust understanding of the condition as it impacts the lives of those who have it. This is made possible, not by formal study, but by the collective organisation of sick people.

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[23] This is most discussed in the literature on *consciousness raising*, a method associated with the women's liberation movement of the 1970s United States. In consciousness raising groups, women came together to share their inchoate experiences of discontent and collectively transformed these into a robust characterisation of their situation under patriarchy (MacKinnon 1985, ch. 5). A similar phenomenon has been studied in the case of specific disabilities, see e.g. Vizuete and Barbarrusa (2024).

[24] Some extitutional scientists have developed serious expertise in e.g. virology, immunology, etc. but it is unclear whether they have an epistemic advantage over institutional scientists in these domains. I do not take a stance either way.

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Thus, in one sense, the capacity of extitutional scientists to detect error resembles the ability of political collectives to pierce through ideological formations, as theorised by standpoint epistemologists. For in both cases, it is the collective articulation of a group's experience which reveals errors in the way this experience has been theorised by others. But in another sense, extitutional scientists' activities differ from ideology-busting activities. For as we have seen, the errors of institutional science that extitutional scientists are able to detect are not particularly ideological: they are conceptual or methodological errors that one could only class as epistemic. We thus have a mechanism, related to but distinct from that theorised by standpoint epistemologists, which explains the capacity of extitutional scientists to detect the errors of institutional science.

IV.

If institutional science is liable to commit critical errors, and if lay scientists have the capacity to detect them and emit proposals for their correction, the epistemic success of science will be enhanced to the extent that the criticisms of lay scientists are taken up by institutional scientists. An obvious reaction would be to argue for an increase in *participatory science*: if lay scientists were invited to participate, as research collaborators, in the design of studies including clinical trials, the errors committed by institutional scientists would be overcome and the findings from these studies would be more reliable. In this way, participatory science would provide an epistemic benefit to institutional science: it would allow institutional science to produce more accurate and useful results. The fact that participatory science can procure epistemic benefits to institutional scientists is not widely recognised in the philosophy of science literature. For example, Angela Potochnik and Melissa Jacquart (2025, 10) list five rationales for engaging in participatory science (increasing scientific understanding among laypeople, improving the way science relates to personal and social identities, increasing lay trust in science, improving access to science, and demonstrating science's value to laypeople), none of which amounts to an epistemic benefit for institutional scientists. Those who do discuss the epistemic benefits of participatory science for institutional science tend to focus on the benefits to institutional scientists of lay-performed data collection (Elliott and Rosenberg 2019, Bedessem and Ruphy

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2020).[25] Alison Wylie is an exception: she argues that scientific collaborations between institutional and indigenous archaeologists have yielded many epistemic benefits to the former, "not only adding useful detail but generating new questions and forms of knowledge" (2015, 192, see Koskinen 2023 for discussion).

It is much more common in the medical field to recognise that participatory science can yield major improvements in the outputs of institutional science (see e.g. Sacristán et al. 2016). Yet participatory science has either not existed or not sufficed to ensure the uptake of lay criticism in early HIV/AIDS research or in ongoing IACC research. This can be gleaned from the very existence of extitutional science: had institutional science organised the correction of its own errors by inviting lay scientists at scale and taking up their insights, sick people would not have been spurred to attempt to correct them from the outside. In fact, both examples presented above reveal that early HIV/AIDS researchers and IACC researchers have also been reluctant to incorporate the criticisms levelled at its conduct by extitutional scientists. So, not only has institutional science failed to seek out the insights of lay scientists, but it has actively resisted taking them up when they were presented to them. Although isolated instances of spontaneous course-correction in response to requests by lay scientists with interactional expertise have occured,[26] these have been exceptions. This reveals a *reluctance*, on the part of institutional scientists, to take up lay criticism.

Since the success of science depends on the correction of its errors, this reluctance to take up lay criticism impedes scientific progress and must be overcome. Increasing participatory science will not suffice to secure the uptake of criticism, since participatory scientists are by definition

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[25] Elliott and Rosenberg do however conclude with the more general claim that "in many cases, citizen science provides one of the best avenues for achieving scientific goals and moving scientific research forward." (2019, 9).

[26] For instance, a recent Long COVID clinical trial was run entirely remotely, in response to a request by lay scientists who had been invited to collaborate on the design and analysis of the trial (Sawano et al. 2025). This opened up participation to people who are housebound or bedbound by the disease, thereby ensuring that the data was also collected on more severely affected people.

subordinated to institutional scientists: it is characteristic of participatory science that participatory scientists can offer their opinion but have no decision-making power. If institutional scientists want to ignore the criticism of lay scientists, as many manifestly do, a mere increase in participatory science will not succeed in ensuring responsiveness to it. This reveals that lay scientists must be able to *interfere* with the conduct of science; they must be able to exert at least some degree of control on its activities, or in other words, to have an impact thereon that is not mediated by institutional scientists. In accordance with this analysis, in response to the manifest lack of interest in their criticism, HIV/AIDS activists proclaimed they had a right to "*ingérence"*: interference, intrusion, or immixture in the conduct of science (ACT UP Paris 1994, 66); and as we shall see, their success in propelling science forward can be attributed to their exercising this right.

Steven Epstein explains the initial reluctance of institutional scientists to take up extitutional criticism in the case of HIV/AIDS by appealing to the fact that institutional scientists initially did not recognise extitutional scientists as *experts* (1995, 1996). It is true that the question of who had expertise loomed large in early struggles over HIV/AIDS science: Robert Gallo, an institutional scientist who played a major role in the discovery that AIDS is caused by HIV infection, initially viewed AIDS activists as incompetent: "I don't care if you call yourself ACT UP, ACT OUT, or ACT DOWN, you definitely don't have a scientific understanding of things" (cited in Epstein 1996, 116). In reaction to this kind of attitude, Mark Harrington, a prominent treatment activist, argued that "we have to break down the cult of the expert in every area of this society. People with AIDS are the experts in this disease" (Hubbard 2012, 49:50). The failure on the part of institutional scientists to recognise the expertise of extitutional scientists stemmed, according to Epstein, from the fact that extitutional scientists did not speak the 'language' of science (1995, 1996). As a result, Epstein claims that "the most crucial avenue pursued by treatment activists in the construction of their scientific credibility has been … learning the language and culture of medical science" (1995, 417). In the same lineage, Harry Collins and Robert Evans argue that the construction of "interactional expertise" (roughly, their capacity to interact with institutional scientists) is what eventually enabled the recognition of the extitutional scientists' expertise (2002, 2009).

If this explanation were complete, the success of the HIV/AIDS movement would be attributable in its entirety to the fact that some extitutional scientists did become fluent in the language of science, and the general problem of how to ensure the responsiveness of institutional science to extitutional criticism would be solved by enhancing extitutional scientists' interactional expertise. But as Collins and Evans themselves note, there is an air of "naïveté" to the suggestion that the development of interactional expertise is sufficient to provoke a change in the behaviour of institutional scientists (2002, 262). In line with this, accounts of HIV/AIDS activism emerging from the collective analysis of AIDS activists (Schulman 2021) have attributed its success to what is known as the *inside/outside strategy*: one arm of the movement made up of extitutional scientists was collaborating with institutional scientists, "working with them, cajoling them, proposing solutions, having intimate interactions, and creating identification" (Schulman 2021, 86), and another arm was exerting pressure through antagonistic protest and direct action. The aim of this outside pressure was to force institutional scientists (and other targets of the movement, such as government officials) to absorb and respond to the criticism that extitutional scientists were levelling at them. As Sarah Schulman explains, "it was the movement's analysis that the reason change didn't happen was that there was no pressure on people in power to make change. So the strategy was to bring things out into the open so that people would be horrified, and so that the people in power would be embarrassed and would make change out of that embarrassment" (2021, 122).[27] In other words, the inside/outside strategy was successful because the inside arm could emit criticism, and the outside arm could enforce its uptake.

Let us summarise. Extitutional scientists have the capacity to detect errors in the conduct of institutional science, and to make proposals for their correction. In this way, they have the capacity to propel scientific understanding forward. Yet their criticism is not spontaneously

[27] Epstein does recognise that direct action on the part of the outside arm of the HIV/AIDS movement played a role in securing the uptake of extitutional criticism from institutional scientists (e.g. 1996, 253), but this is comparatively deemphasised in his analysis. And yet, even Anthony Fauci attributes it great significance. He explains that institutional science was "reluctant to incorporate input from nonscientists [sic]; and so, the activist community became disruptive and confrontative. This response triggered [him] to actively engage the community and listen carefully to their concerns and demands [which] ultimately led to the availability of … safe and highly effective … treatment and prevention" (Fauci and Folkers 2025, 1077–1078).

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taken up. The progress of science thus depends on the possibility of interfering with the conduct of institutional science to secure its uptake of extitutional criticism. The HIV/AIDS movement achieved this by exerting significant and sustained pressure on institutional scientists, making the continuation of error more costly than its correction. This suggests that, if we want to ensure the responsiveness of institutional science to extitutional criticism, and thereby enable scientific progress, we would do well to find a way to make refusing to engage with extitutional scientists more costly than the opposite.

V.

People with AIDS are going to take over the [FDA]
and run it in our own interests.
—Gregg Bordowitz

Since Robert K. Merton (1973), it has been well-understood that institutional science is a *credit economy*. Institutional scientists are motivated by the prospect of receiving grants, being published in prestigious journals, and other markers of recognition; and their activities are oriented towards this quest for credit. This suggests that, if we want to make refusing to engage with extitutional scientists more costly than its opposite, we could intervene on the credit economy in such a way as to reduce the amount of credit that scientific work which fails to take on extititional criticism receives. In this section, I make a proposal for one way in which this could be achieved. I do not purport to provide any more than a sketch, and further work is obviously required to work out the proposal in detail. Nor do I claim that my proposal is the only possible solution to institutional science's failure to take up extitutional criticism, though it does have the benefit of chiming with the demands of extitutional scientists themselves. My aim here is simply to show that there exists a possible way to secure the interference of extitutional scientists within the current institutions of science, and that it does not immediately fall victim to major objections.

I propose to call on extitutional scientists to serve as reviewers for scientific publication and grant/funding awards.[28] This proposal has precedents: the use of lay scientists as reveiwers has

[28] In the same vein, one could also give a veto power to extitutional scientists on decisions concerning disease definition. The longest campaign waged by ACT UP New York was the

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been suggested by extitutional scientists (Fitzgerald et al. 2024) and philosophers (Santana 2022)—in the latter case, only for the review of grant applications. It is also an existing practice, for instance at the *British Medical Journal*, where it is known as 'patient and public review'. My proposal would have this nascent practice become systematic where extitutional science exists.[29] It would give extitutional scientists significant power to prevent a particular finding from being published, project from being funded, or clinical trial from taking place. In this way, it would create a strong incentive for institutional scientists to ensure that their research does not contain the major errors that extitutional scientists have highlighted, which in turn would promote the engagement of institutional scientists with the work of extitutional scientists, including by inviting them to collaborate as participatory scientists on their own research projects.

The proposal to grant extitutional scientists a right of interference may be thought to pose certain *epistemic risks* (Biddle and Kukla 2017). Participatory science, despite the fact that, unlike extitutional science, it proceeds "under the supervision of professional scientists" (Bedessem and Ruphy 2020, 633), such that institutional scientists have complete control on what participatory contributions influence the research project, has already been argued to carry risks of introducing errors or weakening the error-correcting mechanisms of institutional science, thereby making science less objective (Elliott and Rosenberg 2019, Bedessem and Ruphy 2020, Koskinen 2023; drawing on Koskinen's 2020 account of objectivity). The intensity of these risks would soar

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campaign to change the definition of AIDS, to include AIDS-defining illnesses which tended to present in women. Their most famous slogan was: "Women don't get AIDS, they just die from it." See Shotwell (2014). Including PEM as a necessary symptom in disease definitions of ME has been a core part of the activism of ME extitutional scientists, and the struggle to ensure both ME and non-ME forms of Long COVID are recognised is ongoing. These issues of definition are extremely important, for they impact who can participate in clinical trials, who can have access to healthcare, but also which features of the disease are studied and which are disappeared.

[29] My proposal is to grant extitutional scientists the right to serve as reviewers. But since extitutional science emerges as a reaction to the errors of institutional science, there may not exist any extitutional scientists in fields where few errors are committed. In such cases, my proposal does not issue a recommendation: it does not, for instance, mandate the use of lay reviewers.

under my proposal, since the power dynamics are inverted: on my proposal, it is lay scientists who exert control over the outputs of institutional scientists, rather than the other way around. In the remainder of this paper, I survey a number of potential risks and argue that they are minimal.

1-Risk of granting interference rights to science deniers. Lay groups which do not share the standards of institutional science, such as some anti-vaccination activists, would likely be interested in gaining the right to interference that I propose to grant extitutional scientists. These groups may in some cases have lived experience of the condition for which they are advocating (e.g. AIDS denialism in ACT UP San Francisco). But extitutional scientists are defined by their sustained and precise critical engagement with institutional science. This critical engagement presupposes shared standards: extitutional scientists aim to show that institutional science falls short of its own aims (e.g. producing an effective treatment), because of errors that itself can and should recognise. This is profoundly different from the activities of anti-vaccination activists, and from those of AIDS denialist HIV/AIDS activists, who by and large fail to engage comprehensively with institutional science, and who do not share its standards. I propose to grant interference rights only to extitutional scientists.

2-Risk of granting interference rights to unrepresentative laypeople. Lay scientists may fail to represent the interests of the community for which they advocate. Those who have garnered scientific credibility from institutional scientists tend to be less marginalised, and may fail to represent the interests of the more marginalised within the group—a phenomenon known as *elite capture* (Táíwò 2022). For instance, there was criticism from the floor of ACT UP New York that those who communicated with institutional scientists did not take seriously enough the issues specific to people of colour, drug users, and women (Schulman 2021). But if the competence of extitutional scientists stems from their being embedded in communities where a collective process takes place to distil and collate myriad personal experiences into a comprehensive account of the condition's presentation, laypeople who fail to live up to this standard will not count as extitutional scientists, and should therefore not be granted interference rights.

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These two risks highlight the importance of accurately identifying extitutional scientists. In order to detect and correct the errors of institutional science, extitutional scientists must closely and comprehensively engage with institutional science, and be responsive to the concerns of the community as a whole. If an individual fails to meet either of these criteria, they do not count as an extitutional scientist under my definition, and therefore should not be granted interference rights under my proposal. Applying my proposal thus comes with a practical challenge: it requires editors, funders, and state agencies, as well as institutional scientists, to find bona fide extitutional scientists to serve as reviewers. Note firstly that this does not require tracking down extitutional scientists among the undifferentiated mass of the public: since extitutional scientists seek, by definition, to correct the conduct of institutional science, they must make themselves known to institutional scientists (either individually or, more commonly, through organisations like ACT UP or the Patient-Led Research Collaborative) in order to achieve their goals. Finding extitutional reviewers thus only requires determining, of any candidate lay reviewer, whether they are an extitutional scientist or not. Initially, this can proceed by trial and error. If a review betrays a lack of competent engagement with institutional science, editors/funders should dismiss the review and commission a new one. If a review promotes the interests of a greater number of groups concerned by the piece of research at hand, editors/funders should prefer this review over another, and may want to commission this reviewer again. Eventually, some individuals and collectives of extitutional scientists become well-established as such, and editors/funders can rely on their recommendations to find further reviewer candidates. Thus, the reviewer-vetting process becomes more reliable as it unfolds.

But, even if extitutional scientists are accurately identified, some epistemic risks may remain with using them as reviewers.

> *3-Risk that extitutional scientists trespass beyond their domain of expertise.* Extitutional scientists, I have argued, are able to detect errors based on collective experience-based knowledge. This knowledge has limits: some specific technoscientific points, for instance, may lie beyond its scope. Accordingly, there likely are aspects of research papers and proposals which extitutional scientists are

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not competent to review.[30] It is unlikely that extitutional scientists would seek to have these aspects of the research amended, for it is unclear what reason they could have to do that. But if they did, editors could easily detect it by looking at the criticism provided in the review: if the criticism is not ultimately grounded in collective experience, there is no reason to take it seriously enough to compel uptake. This is not to say that such comments are to be automatically dismissed however, since many extitutional scientists develop serious competence about non-experiential aspects of the topic at hand. But because extitutional scientists do not have an epistemic privilege over institutional scientists when it comes to these non-experiential aspects, this criticism cannot have the same weight, and its uptake need not be enforced.

4-Risk that the activist values of extitutional scientists unduly influence science. Extitutional scientists are driven by the value of ending the crisis that brought their communities together. Since this activist value is clearly aligned with the goals of science, it is not an inherent risk. Individual extitutional scientists may also have personal values, in the same way that institutional scientists, who may also be activists (Hauswald 2021), also do (Longino 1990, Douglas 2000, Solomon 2001). These can be prevented from leading science astray through the same mechanism that applies to institutional peer-reviewers: scientists hold a diversity or plurality of values and, through a 'collective give-and-take', edit out inadequate values (Longino 1990, Solomon 2001).

This concludes my survey of the epistemic risks associated with granting extitutional scientists the power to review for publication and funding allocation.

VI.

We are now in a place to conclude. It is widely thought that laypeople may only interfere in non-epistemic aspects of science: in agenda setting, in decisions regarding applications of scientific

[30] Note that different reviewers routinely have expertise over different parts of the same work. Extitutional reviewers are not special in this respect.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

findings, and, if one believes that non-epistemic values are involved in the conduct of scientific research itself, in decisions regarding these values. Yet, I have argued, the interference of some lay scientists in the specifically epistemic aspects of the conduct of science can be crucial to scientific progress. I came to this conclusion by establishing the following claims: 1) in response to epistemic errors on the part of institutional science, laypeople with an interest in their correction sometimes come together to attempt to have institutional science correct these errors: this is called *extitutional science*; 2) extitutional scientists are able to detect errors and make proposals for their correction in virtue of their collective experience-based knowledge; 3) this criticism is not spontaneously taken up, which shows that the uptake of extitutional criticism is currently not secured by the norms and reward system of science; and 4) changing the reward system of science by using extitutional scientists as reviewers is one possible way to incentivise the uptake of extitutional criticism and increase the epistemic success of science.

This argument was made in reference to two specific cases, both medical. This raises a question about the scope of extitutional science: Is extitutional science restricted to the medical field, or can it also occur in other sciences? Extitutional science requires those who engage in it to have a direct interest in the correction of erroneous background assumptions, and to be embedded in communities of people or 'research collectives' whose collective experience stands at odds with these background assumptions. These two requirements are easily met in the biomedical sciences, hence our two case studies. And although they presumably cannot be met in non-applied sciences like theoretical physics, they can in non-medical fields with a direct application to human life, such as environmental science. Consider for instance the struggle waged by the Black inhabitants of Diamond, an unincorporated community located next to a Shell plant in Louisiana (Ottinger 2010). Regulators had posited that only ongoing, low-level, long-term exposures to toxic chemicals could affect human health. Accordingly, only the long-term concentration of these chemicals was monitored. But residents also connected short-term spikes in air pollution levels to health events such as shortness of breath and eye irritation. They began taking their own air quality measurments and argued that the air was unsafe based on these. Gwen Ottinger explains that, in so doing, they challenged the background assumption made by institutional scientists to the effect that short-term spikes in pollution are irrelevant to human health. In other words, their collective experience allowed them to detect and emit proposals for the correction of errors made by institutional scientists: they were doing extitutional science.[31] It follows that extitutional science is possible outside of the biomedical sciences.

When extitutional science does arise, what can we hope for? Remember that the existence of extitutional science points to the presence of error in institutional science, for it is in response to error that extitutional science arises. As such, the very existence of extitutional science can be used to gauge the success of institutional science. This suggests a horizon for extitutional science. We have seen that the uptake of extitutional criticism corrects institutional errors and furthers the progress of science. If this uptake could be secured, through my proposal to use extitutional scientists as reviewers or otherwise, the *raison d'être* of extitutional science would disappear. For institutional science would cease to commit errors, and the need for extitutional science to correct them would be dispelled. Thus, the goal that extitutional scientists pursue is the *abolition* of their own activity: not its disregard or repression (clearly), but a change in underlying circumstances that would render it obsolete. In fact, now that HIV/AIDS research proceeds with broadly correct background assumptions, extitutional scientific activity in the field has decreased significantly.[32] The pursuit of epistemic success in science should lead us to compel institutional science to take extitutional criticism so seriously that extitutional science disappears.

Acknowledgments. I am very grateful to Daniele Lorenzini, Nick Makins, Robin McKenna, Felipe Romero, and Mal Uher for discussion of these ideas and/or comments on previous drafts, as well as to Nicolas Côté who generously organised a pre-read workshop on a draft of this paper at the University of Glasgow, which yielded particularly helpful comments from himself as well as Rory Aird, Adam Carter, Christoph Kelp, Jinxi Luo, Jack Lyons, and Mona Simion. I would

[31] In fact, they were engaging in two types of lay science simultaneously. On the one hand, they produced data which the community could use to make decisions about protective measures; thus, they were doing *community science*. On the other hand, they constructed an argument to the effect that the assumptions of institutional science were erroneous; in that sense, they were doing *extitutional science.*

[32] The political struggle to end the HIV pandemic however is still ongoing.

https://doi.org/10.1017/psa.2025.10162 Published online by Cambridge University Press

also like to thank two anonymous referees whose probing questions led to a real improvement in the paper, and an anonymous Associate Editor for very helpful suggestions.

Funding statement. None to declare.

Declarations. None to declare.

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