**Addressing deficits and injustices: the potential epistemic contributions of patients to research**

**Abstract**

Patient or public involvement (PPI) in health research is increasingly promoted as a matter of policy. In theory, PPI can contribute both to the epistemic aims intrinsic to research (generating knowledge), and to extrinsically valued features of research such as social inclusion and transparency. In practice, the aims of PPI have not always been clear, although there has been a tendency to encourage the involvement of so-called ‘ordinary’ people who are regarded as ‘representative’ of an assumed patient perspective. In this paper we focus on the epistemic potential of PPI, using theoretical work in epistemology to develop a nuanced account of patients’ experiential knowledge and how this might contribute directly to conceptual development, hypothesis generation and data interpretation. We also consider how some features of health research pose barriers to this kind of epistemic contribution. Drawing on Miranda Fricker’s idea of testimonial injustice, we explore how disciplinary indicators of credibility in clinical and academic health research contexts might be wrongly applied to those involved in PPI, undermining their potential to contribute. Finally we argue for a range of strategies to maximize opportunities for patients to engage with research teams and make epistemologically significant contributions to research.

**Introduction**

It is increasingly common for research policy, funding and governance bodies to encourage or even mandate some form of patient or public involvement (PPI) in health research. In the UK, for example, PPI is encouraged in all National Health Service funded research and by most other public and voluntary sector funders. This expectation applies to a wide range of research – including basic biomedical science, population-based surveys and qualitative investigations of healthcare experiences as well as effectiveness research. As a matter of policy, PPI is generally recommended at all stages of research, including: identifying and prioritizing research questions; commissioning research; designing, undertaking and managing research projects; disseminating findings; implementing recommendations; and evaluating research impact [1-8].

Policies encouraging PPI reflect increasing acceptance that the ‘active’ involvement of patient or public stakeholders is of value, over and above any benefit that may derive from the contributions of study participants. Currently, however, high level enthusiasm for PPI outstrips convincing evidence of practical benefits.[[1]](#footnote-1) Meanwhile, some researchers remain unconvinced of the appropriateness, value, or value for money of at least some forms of PPI [14- 16]. One reason for the paucity of evidence for its value, (and the skepticism of researchers) may be due to a failure to take account of the various aims, forms and research contexts of PPI. In particular, two broad aims of PPI – to improve knowledge, and to promote what we might term politico-moral goods such as social inclusion, accountability or transparency – are rarely distinguished despite the fact that they are likely to be achieved through very different modes of involvement. Our aim in this paper is to investigate the potential knowledge-related (i.e. epistemic) contributions of PPI to research, and to identify ways of strengthening these contributions, given the general policy commitment to PPI. To achieve this aim, we first clarify the distinction between primarily politico-moral aims and primarily epistemic aims of PPI. To date, attention has largely focused on the politico-moral aims of PPI. And although it has long been recognized that people with lived experience of health problems might enhance the quality of health research and the knowledge it generates by revealing unique insights [17-18], mechanisms for achieving this have been largely neglected. This, then, is our focus. In section 2 we offer an analysis of the particular kinds of knowledge patients have. In section 3 we explore the potential benefits of this knowledge to researchers, particularly in terms of filling hermeneutical gaps. In section 4 we consider how patients’ experiential knowledge should be harnessed, and explore the role of testimonial injustice as a potential explanation as to why there is limited evidence about epistemic benefits from this kind of PPI. In the final section we develop practical suggestions as to how these insights should inform practice, with a particular focus on skills or training for patients who are involved in research to maximize their likely epistemic contributions.

1. **The nature and aims of patient and public involvement in research**

PPI serves two broad sorts of aims: epistemic, which are intrinsic to the research itself; and politico-moral, which are extrinsic in the sense of being concerned with research as a social enterprise rather than specific instances of knowledge production. Extrinsic aims include promoting goods such as research participation, social inclusion, accountability, and improving the transparency of research processes [19-20]. These aims are typically met by including patients or members of the public on research commissioning panels, governance committees or project steering groups. In many cases the appropriateness of those involved will be judged in terms of how well they (are seen to) represent relevant populations (clinical or demographic groups, or citizens more generally) and enhance accountability. ‘Ordinary’ patients or citizens – those without particular skills or training in health-related or research fields – are often favoured for these purposes.

In contrast, epistemic aims are the aims intrinsic to the research itself: broadly the generation of new knowledge in order to improve healthcare. The epistemic aims of research are primarily served by conceptualizing problems, generating research questions, designing studies, and collecting, analyzing and interpreting data.[[2]](#footnote-2)

PPI can contribute to the epistemic aims of health research in direct or indirect ways. Direct contributions can occur when patients engage in creative intellectual processes associated with the aspects of research just mentioned. Indirect contributions to the generation of knowledge occur when PPI helps to improve, for example, the clarity and appeal of participant information sheets, or the acceptability of research processes, both of which may boost recruitment of participants and effective data collection and so contribute to the generation of knowledge.[[3]](#footnote-3)

Our concern in this paper is with the potential for PPI to make direct epistemic contributions to the generation of new knowledge in research. In the next section, we explore how this might occur, by investigating the potentially unique knowledge that patients may bring to research.

1. **The particular knowledge that patients have**

In light of our focus on epistemic goals, we start by noting that PPI is most likely to contribute directly to the intrinsic knowledge-generation aims of research if those involved are people with first hand personal experience of the health condition of interest, rather than lay people or members of the public more broadly construed. We call these individuals ‘patients’[[4]](#footnote-4) for convenience. In what follows we develop an account of patient knowledge and sketch out the conditions in which it might fruitfully be harnessed for research.

It is natural to describe the difference between patients’ knowledge of their condition and the knowledge of others in terms of first and second hand knowledge. While most patients lack disciplinary training in health-related fields, their first-hand knowledge of what it is like to have particular health conditions or receive particular treatments is a unique resource. Others (including most medical specialists) have only second-hand knowledge about the experience of ill health and associated interventions.[[5]](#footnote-5)

Bertrand Russell coined the term ‘knowledge by acquaintance’ to refer to a particular type of first-hand knowledge – the pre-conceptual awareness associated with experience. In his words:

[W]e have *acquaintance* with anything of which we are directly aware, without the intermediary of any process of inference or any knowledge of truths. Thus in the presence of my table I am acquainted with the sense-data that make up the appearance of my table—its colour, shape, hardness, smoothness, etc.

In addition to sense-data, knowledge by acquaintance also includes memories and introspection. Once the agent has conceptualized or formulated a description of an experience, memory or introspection, the processed content becomes what Russell termed ‘knowledge by description’. The distinction is thus between raw or unprocessed knowledge associated with experience, memory or introspection and processed content that is ready to be conveyed to others.

Knowledge by acquaintance includes both the first-hand experiences people have of their bodily states such as pain (i.e. self-knowledge) and pre-reflective awareness of objects in the external world. Neither self-knowledge nor knowledge of the external world is regarded as straightforward by philosophers. Sellars, for example, criticizes what he calls ‘the myth of the given’ - the idea that there is an unproblematic relationship between objects in the world and our perceptions of them, while many philosophers and psychologists have questioned the apparent infallibility of self-knowledge. While accepting that these are contentious issues, it remains meaningful, and indeed useful, to distinguish the raw awareness characteristic of first-personal experiences (knowledge by acquaintance) from the content of conceptualizations of these experiences (knowledge by description).

Patients’ knowledge by acquaintance of their health conditions includes self-knowledge of their symptoms and the effect of treatment (tiredness, pain, changes in mood and so on) as well as more contingent knowledge of the context in which these occur. To illustrate: a patient can have a rich awareness of her bodily experiences during an episode she describes in terms of “feeling faint and dizzy”, and she can also have a rich awareness of context in which this occurs, which she might describe, for example, by saying “It was a hot day and I hurried up the stairs feeling anxious about missing the bus”). The descriptions of both bodily experiences and contexts might only partially capture her awareness.

It is thus highly plausible that knowledge by acquaintance offers something unique in the context of health research because of its completeness (notwithstanding the particularly evocative nature of some descriptions). However, knowledge by acquaintance must be communicated if it is to inform the research process, and this requires some kind of conceptualisation. It is likely that any particular experience admits various conceptualizations which could differ in emphasis and content while remaining accurate. Both subsequent experiences and prompts from others (e.g. in the form of questions and comments) might lead to reassessment and additional processing of knowledge by acquaintance, and enhance the potential for this to be communicated. . However, it is likewise plausible that what is potentially valuable in knowledge by acquaintance may be difficult to communicate, for various reasons. First, it can be particularly difficult to conceptualize experiences that do not conform to current knowledge. Second, communication may be hampered by moral and political issues associated with the reception of testimony, as Miranda Fricker has recently highlighted. We return to these issues later in the paper [sections 3 and 4].

In comparison with what patients can, in principle, know, clinicians’ and researchers’ knowledge about a condition they have not experienced has two limitations. First, it incorporates and builds on only those aspects of the experience that are identifiable from an external perspective, or have already been observed or articulated by those who have the condition (which may of course, be considerable). Second, it might thus neglect aspects of the condition or intervention that are important for patients and potentially a source of further knowledge development. For these reasons, we believe that patients’ experiential knowledge represents a partially untapped epistemic resource for research. This may be of value in making breakthroughs in conceptualizing problems or generating hypotheses, especially when shared in a genuine spirit of enquiry with others [26].

**3. What might patients’ knowledge by acquaintance contribute?**

Even if patients do have access to unique knowledge, it does not automatically follow that this will be useful to health researchers. We contend that patient knowledge might be useful in two ways: (1) bringing to light previously ‘unknown unknowns’ about the health condition in question; and (2) informing judgments about the significance of aspects of the condition for the research. These correspond to different aspects of the research process, with the former potentially suggesting research questions or fruitful lines of enquiry and the latter feeding into priority setting and research design.

There are many readily identifiable unknowns in healthcare, such as how new combinations of drugs will interact and whether or not new surgical devices are more effective than their predecessors. These form the bedrock for research. In addition, however, there are ‘unknown unknowns’ – gaps in knowledge of which people are unaware and so do not set out to address.[[6]](#footnote-6) One reason for ‘unknown unknowns’ is what Miranda Fricker describes as ‘hermeneutical deficits’. These occur when a society does not have the concepts needed for the articulation of particular experiences [28 p6]. This is not uncommon in healthcare, as new conditions emerge or understanding of existing diseases change. Post traumatic stress disorder (PTSD) related to military service provides an example of this phenomenon. Symptoms and experiences now associated with PTSD have been described throughout military history (for example, ‘shell shock’ in World War 1), but were not understood as PTSD until the Vietnam War era [29]. Of course a hermeneutic gain requires more than a change in terminology. World War I era publications on shell shock indicate a lack of conceptual clarity, with opinion divided over whether the condition was physical or psychiatric. Perhaps because psychiatric conditions were closely connected with malingering and mental weakness, even clinicians who regarded shell shock as primarily psychiatric and involuntary focused on finding quick fixes for the physical manifestations such as muteness and tremors, and on returning patients to active duty. Part of the barrier to understanding PTSD in earlier times may have been the difficulty of reconciling a psychological disorder with widespread beliefs about soldiers and military courage. It was literally inconceivable that brave men might be psychologically damaged by exposure to war. Lack of a fully developed or articulated concept for a condition poses a significant challenge to health care, due to the role such concepts play in the ability to communicate about and solve the associated problems.

Hermeneutical deficits limit research progress because hypotheses and research questions are framed explicitly on the basis of existing knowledge and currently perceived unknowns. Researchers have few avenues for investigating problems and possibilities that have not been somehow conceptualized and defined.

Patients’ knowledge by acquaintance may provide one route for discovering researchers’ ‘unknown unknowns’; it is a repository of untapped insights which could, if successfully accessed, facilitate the conceptualization of hitherto unknown experiences, and thereby plug a hermeneutical gap.

Gulf War Syndrome (GWS) provides an evolving example of some of these issues. Gulf War veterans presented to health care providers with an unfamiliar constellation of symptoms [30]. The syndrome was recognised only because veterans articulated their bodily experiences; that is, its identification was based upon the knowledge by acquaintance of those affected. The symptom cluster was then subject to medical scrutiny which confirmed that this was indeed a novel phenomenon rather than a known condition.[[7]](#footnote-7) Researchers are now following up various likely causes for GWS, such as exposure to biological agents, or toxic gases, or sand, or smoke from burning oil stacks [32]. In investigating possible causes, researchers are hampered by their lack of first hand experience of the contexts of the Gulf War and thus of potential causative agents. It is quite possible that a breakthrough in understanding GWS will be predicated upon both veterans’ knowledge by acquaintance (bodily experiences, memories and pre-reflective awareness of the environmental context) and their subsequent descriptive knowledge of circumstances that may be associated with GWS (for example, combinations of smoke exposure and vaccinations, or dehydration, fever, or a particular brand of flea collar[[8]](#footnote-8)).

Different forms of knowledge are at stake here. Patients’ knowledge by acquaintance of experiencing GWS is susceptible to the problems highlighted by Fricker, but important due to the absolute inaccessibility of some of these phenomena to non-sufferers. Patients’ descriptive knowledge of the Gulf War Context includes specific features of the environment or experience in which the disease originated, but this knowledge, although important, may not be unique to sufferers of GWS. Different kinds of breakthrough might be likely from the descriptive recollection of ‘connections’ as opposed to the more experiential recollection of the symptoms.

Clearly some conditions, interventions and contexts are less conceptually developed and understood than others. The potential of patients to make an epistemic difference will depend in part on how well the index health condition or intervention has already been researched and the extent of any unknown unknowns, as well as the impact of historical biases etc. to existing understanding of the disease as per PTSD. For example, patients might contribute significantly to knowledge generation if included in exploratory discussions intended to support research agenda setting around newly emergent or poorly understood conditions, but be less likely to make much of an epistemic contribution to established research projects that have already incorporated (other) patients’ experiences in some detail.

In addition, some types and stages of research are more likely than others to be conducive to epistemic contributions from patients. Involvement for epistemic reasons might require the presence of patients only when they can make an important difference [14]. This is likely to be during periods of intellectually creative work on the conceptualization of problems, generation of research questions, study design, and generation, analysis and interpretation of data.

The view we have presented of the potential for patients’ knowledge by acquaintance to make direct contributions to conceptual breakthroughs may be somewhat optimistic. Examples are hard to identify, although this may be as much due to lack of recollection on the part of researchers as to the absence of such contributions. Researchers may, for example, fail to recollect conversations with patients that triggered particular ‘hunches’ or lines of inquiry. Iain Chalmers has noted that the link between diethylstilbestrol in pregnancy and subsequent cancer in female children was first suggested by the mother of an affected patient; likewise the mother of a child affected by trisomy 18 suggested that low maternal serum α fetoprotein might be a prenatal marker for the condition [18].[[9]](#footnote-9) It seems reasonable to postulate that these breakthroughs occurred because women with affected children ‘racked their brains’ to try to identify anything about their pregnancies that might be associated with the disorders. Similarly, women with Crohn’s disease were instrumental in identifying metronidazole as a treatment, after reporting improvements in their Crohn’s disease while taking the antibiotic for an unrelated disorder. This triggered exploration of the causal role of bacteria in Crohn’s disease, and of antibiotics as a treatment [16]. Contributions of this sort may be rare, and even more rarely formally acknowledged, but are notable because of the significance in prompting breakthroughs.

The potential of patients to make direct epistemic contributions to research is, furthermore, not limited to the possibility that they might articulate or gesture towards new concepts or theories drawn from their knowledge by acquaintance of their condition and/or the contexts in which it might have arisen. The relevance of already-articulated features of the condition may be underestimated, and thus neglected in researchers’ thinking. Such patterns in thinking about a condition could be challenged. Thus a more modest and potentially more frequent epistemic contribution from patients is insight into the relevance of some aspect of the condition that has not appeared significant to researchers, and which then triggers expanded or ancillary research hypotheses and questions.

1. **How can patients’ knowledge by acquaintance be harnessed for research? Concerns about hierarchies and testimonial injustice in PPI**

Given the potential for patients’ knowledge to contribute to the epistemic goals of health research, we may wonder why there is so little concrete evidence of such benefits, especially as patients now have a place at the table in many research studies. The paucity of examples of epistemic contributions might imply that patient knowledge by acquaintance does not have much to contribute. Alternatively, it may be that its potential is not well harnessed. There are several reasons for taking this second explanation seriously. We argue that there are good reasons for concern that, despite policy support for PPI, patients’ potential to make direct epistemic contributions to research are typically limited by social status, and by the prejudices of both researchers and patients.

In thinking about barriers to patients’ contributions, Fricker’s account of epistemic injustice offers relevant insights. Fricker identifies two forms of epistemic injustice: testimonial and hermeneutical, both of which are pertinent. In the previous section we identified hermeneutical deficits and how these might be delineated by patients’ knowledge. In themselves, hermeneutical deficits are not necessarily unjust: our knowledge will always be patchy. However, hermeneutical *injustices* arise if members of marginalized groups suffer because society lacks the concepts that would allow them to articulate the nature of their concerns, particularly where this absence may be attributed to their unfair lack of power in structuring social understandings [28 p. 147].

It is worth asking, then, whether the under-conceptualisation of some health-related experiences reflect (or lead to) hermeneutical injustices. Both PTSD and GWS might be candidates, insofar as soldiers are often considered vulnerable because of the intensely hierarchical structure of the military, which fosters a culture in which junior personnel are expected to defer to and obey their superiors without question or complaint [33], and in which it has been unacceptable to admit psychological consequences from warfare or that otherwise brave soldiers may have this vulnerability.

Conceptualising previously unarticulated aspects of health conditions is epistemically valuable. If there are injustices at play, then there are also equity-related reasons to support strategies that will promote conceptual development, as well as knowledge and health-related reasons. In such circumstances, involving patients in order to improve knowledge also serves a moral aim.

A second kind of epistemic injustice, relating to a failure to take seriously patients’ accounts of symptoms, may help to explain why hermeneutical gaps arise. According to Fricker [28], ‘testimonial injustice’ occurs when unfair credibility judgments occur based upon wayward indicator properties. Credibility refers to others’ perceptions about whether or not an individual is knowledgeable and worthy of intellectual respect in a particular domain. Thus it is possible that a patient may possess relevant knowledge without being accepted as credible. Such a patient suffers ‘testimonial injustice’.

An example is women’s ‘undefined’ disorders [34]. These are characterised by constellations of symptoms without an accepted diagnosis. The women who experience them suffer not only from the symptoms but also from: the distress of remaining undiagnosed; the trivialisation or dismissal of symptoms; and associated failure to provide relief [34]. Malterud thinks that women are systematically disadvantaged in the interpretation of their symptoms as signs of disease. Testimonial injustice occurs when the testimony of women patients in clinical contexts is discounted or dismissed because of views about the credibility of women or the seriousness of their complaints. Such discounting reflects women’s relative lack of power (in medicine and in society), with a subsequent paucity of research into diagnosis or treatment.

In addition to testimonial injustices patients may experience in the clinical context, it seems important to explore whether patients suffer testimonial injustice when involved in health research in a PPI capacity, as this may explain, at least in part, the paucity of concrete evidence for the epistemic benefits of accessing patients’ knowledge by acquaintance. Attentiveness to the possibility of testimonial injustice may help to identify potential barriers to epistemic PPI and suggest better strategies for learning from patients.

One cause of testimonial injustice relates to hierarchical arrangements between social groups, where individuals are denied credibility based merely on their position within a hierarchy, rather than their competence [28]; this is a potential factor impeding epistemic contributions in PPI. Relationships between patients and health professionals are largely hierarchical. Clearly, health professionals have privileged knowledge which patients seek to access, but it is not so clear that this justifies the nature and extent of existing hierarchies. Of particular concern, there is evidence that inequalities in patient-professional relationships can significantly impede patients’ willingness and ability to speak up and be listened to, even when they have concerns [38]. Similar hierarchies are replicated in relationships between various health professionals and members of research teams [35-37]. However they are even less justified in research, where patients are not seeking advice and treatment, but rather are involved on the basis of their unique knowledge (as we discuss below). Given the power of oppressive hierarchies to silence patients who have concerns about their own health, we may worry that patients qua PPI participants may be likewise silenced in research contexts, where they may have less personal interest in speaking up, and so be less likely to strive to contravene perceived hierarchies.

Despite changes in practice and society that tend to reduce the hierarchical knowledge and power differentials between patients and health professionals, these differentials continue to exert influence upon the beliefs and behaviours of both health professionals and patients. Furthermore, in health research, the hierarchies of healthcare intersect with those of academia, where possession of a PhD is regarded as a bare minimum measure of research competence. Some academics struggle to welcome patients with no formal disciplinary knowledge or training in research skills into the research process as peers, or to adjust their communication and working patterns to accommodate them [39]. Thus whether research is conducted by academics, clinicians or some combination of these, patients are likely to be regarded by other members of the research team as lacking relevant training and skills, and, as we discuss below, to concur with these perceptions.

Fricker offers further useful insights into the nature of credibility judgments and how they can fail. In simple cases indicators of credibility do not come apart from the content of claims. For example, if someone routinely gives bad directions, others quickly learn that they are not credible in this domain. In more complex domains, however, it becomes impractical or impossible for most people to independently verify the claims of a purported expert; the knowledge in question may rely upon years of training. In such cases, credibility is tracked by reference to ‘indicator properties’, which are proxies for independently verifying the conclusions drawn. In the case of health professionals, indicator properties include their qualifications and practicing rights in a recognized healthcare institution. Often such indicators are fairly accurate, and deferral to those thereby identified as experts is legitimate. So, for example, Fricker’s insights are consistent with the commonsense idea that surgeons generally know more about removing an appendix than patients [28]. In other cases, however, people may rely on indicator properties which are poor proxies for the abilities they are supposed to track, reflecting features, such as wealth or social power: being a titled aristocrat is for example, no guarantee of wisdom.

Knowledge relevant to health research can be variably distributed among people with backgrounds in different subjects and methodological domains. Members of research teams all have gaps in their knowledge as well as potential to make unique contributions. Depending upon the specifics of the project, teams include health practitioners, methodologists and statisticians, bench scientists and so on. The indicator properties relevant to credibility judgments for these individuals will almost certainly differ; for a surgeon, professional qualifications and experience in surgery are relevant, while an appropriate degree and research track record are relevant indicators for a health research methodologist. Despite these differences, the researchers are likely to share some indicator properties, such as scientific and medical literacy, considerable tertiary education, and research experience.

In this situation, how might credibility judgments apply to patients? The earlier discussion suggests that patients can possess knowledge by acquaintance with the potential to make epistemic contributions to research. They might thus be considered as one more group bringing relevant expertise to the table. Just as researchers in surgical trials recognize and respect the specialized knowledge of surgeons and statisticians regarding surgery and statistics, so too should the expertise of patients be respected regarding their knowledge of the internal and contextual dimensions of health conditions. In principle, then, patients can contribute their own specialized knowledge in similar ways to other members of the research team.

Our contention, however, is that patients sometimes (perhaps often) experience testimonial injustice in the health research context because all parties (including at times, patients themselves) fail to recognize what they have to offer. This injustice has two causes. The first is inadequate recognition of the potential value of experiential forms of knowledge for health research. The second is the likelihood that judgments about patient credibility are tracking irrelevant indicator properties, such as the status of the patient in medical contexts, and the lack of formal scientific, medical and research literacy – the indicators likely to be shared by other members of the research team. This can lead to the unjust denial of credibility.

This view is empirically supported by studies showing that both researchers and patients tend to give only limited recognition and respect to patients’ knowledge [13]. Two recent qualitative studies suggest that patients are treated as lacking credibility when speaking about what is seen as an expert domain. Some scientists in these studies apparently accepted a traditional medical-scientific hierarchy rather than taking account of the specific kinds of knowledge that patients can contribute.[[10]](#footnote-10) And comments by patient representatives indicated that they had internalized similar views, making them fearful of appearing foolish when speaking.[[11]](#footnote-11) Patients do sometimes sell themselves short [21, 40] by internalizing and reinforcing the hierarchies and wayward indicator properties that lead others to commit testimonial injustices against them, and thereby perpetuate these injustices against themselves [15].

Overcoming hierarchical barriers to the uptake of patients’ epistemic expertise within health research requires a certain humility and willingness to listen on the part of researchers, as well as self-belief on the part of the people who might contribute as patients. Given what Knowles et al have referred to as the ‘disruptive’ role that patient insights might play by contributing potentially surprising and transformative insights, it is especially important that patients embrace the source and scope of their epistemic credibility, recognising its differences from that of other members of the research team. Patients need to be able to participate on terms that are both equal and, at the same time, respectful of the unique nature of the experiences and knowledge that they – as well as other contributors - bring.

1. **A way forward**

According to our analysis, patients could play important roles as partners in health research processes, including in question setting and the conceptualization, design and conduct of health research. However, to attain epistemic benefits from patients as research partners, it is important to challenge existing hierarchies that contribute to testimonial injustice, and ensure that all members of the research team see patients as credible contributors. In addition, it might help for the patients in question to have some level of research-context and scientific literacy as well as particular skills in, for example, navigating group dynamics, or communicating effectively with people from diverse backgrounds. This is in contrast to the “ordinary citizen” participant favoured by PPI with principally politico-moral aims. As we discuss below, we anticipate that this would increase the effectiveness of patient contributions to the research. In addition, it will help addressing the credibility deficit of those involved in PPI. In this section we make suggestions about the relevant skills and knowledge that might address questions of patient credibility and thereby facilitate epistemic contributions.

Making explicit salient aspects of patients’ knowledge by acquaintance depends on a range of patient skills, as well as appropriately supported opportunities to exercise those skills. Relevant skills include interpretation and communication, in addition to bodily and emotional awareness – the ability to reflect on, conceptualise and articulate what it is like to have a condition, undertake an intervention, or use a service. The skills involved are more complex than those required in ordinary interactions, such as describing symptoms during a medical consultation, or conversing about illness experiences with family or friends. To participate in health research in relevant and timely ways, patients need to be able to understand what the rest of the research team are talking about– to know that paraesthesia is pins-and-needles, for example, and to make sense of the context of the discussion. What this requires will depend on the nature of the research and the role of the patients, but could include basic scientific literacy, specific clinical knowledge about the condition, or knowledge of the issues that affect judgements about the quality of research, such as research methodology.

Ensuring patients have the knowledge and skills to maximize their contribution will often require careful selection processes for those involved in a PPI capacity in research, or providing relevant training. We note that doing this is likely to have practical benefits in addressing the credibility deficit noted in the previous section. While it might be morally justifiable to place the onus on other members of the research team to take seriously the knowledge of patients, from a practical perspective this process can be facilitated by fostering scientific literacy in patients involved in research teams.. Such scientific literacy may have the added benefit of building patients’ confidence in their contribution.

Examples in which non-clinical people contribute to medical knowledge often involve a process of becoming scientifically literate. For example Sharon and Patrick Terry played a major role in research on pseudoxanthoma elasticum (PXE), founding an organization that funds and undertakes research into the rare genetic condition, after their two sons were diagnosed with the disease. Their knowledge by acquaintance of contextual aspects and close and sustained observations of the effects of the disorder were complemented by educating themselves about PXE and participating in the search to discover the associated gene; a contribution recognised by their naming as co-inventors on the patent for the gene [41].

One option for increasing the number and range of patients with relevant literacy is to provide training opportunities for patients. This already occurs successfully in some areas; the 2004 TRUE Project report included various examples in the UK such as training for multiple sclerosis patients to review funding applications, and research skills training for people living with disabilities [42].[[12]](#footnote-12) The TRUE Project report indicates that training not only improved participants’ skills in the areas covered by the training but that participants also reported increased confidence in their ability to contribute to the research process [42], which is critical in terms of remedying testimonial injustice. Even so, the authors of the report note that “the relationship [between patients and researchers] needs careful attention and care if this confidence is not to be eroded”, [42 p. 13] echoing concerns raised earlier.

Some researchers have worried that as patients become more scientifically literate, they may be less likely to make disruptive and transformative epistemic contributions. Thompson *et al* [15] see the professionalization of patients on research teams as a process through which patients cease to truly represent their experiences, in part because they internalize the norms and views of the researchers (including wayward indicators for credibility), and as a result of this, adopt a lowly or submissive position within established professional hierarchies. These are important concerns, but they identify the wrong target if the worry is that scientific and medical literacy in itself is problematic. The form of testimonial injustice described above can occur whether or not patients accept as relevant the indicator properties they are judged to lack. Knowledge or training may make patients more aware of the existence of these indicators, but failing to provide training will not solve the problem. Moreover, in cases where wayward indicators are operating, a patient with relevant knowledge or training will be regarded as more credible, and is thereby more likely to make an epistemic contribution than a patient who lacks relevant skills and knowledge and whose testimony is thereby disregarded.[[13]](#footnote-13)

Increasing the scientific literacy of patients may have practical benefits in terms of overcoming biases, but it will not address the underlying problem which is a failure of researchers (and sometimes patients themselves) to recognize that the indicators at play are inappropriate. To solve the problem of wayward indicators, judgments of credibility must be made explicit and the judgments that flow from them shown wanting. This may be achieved by, for example, using ‘tests’ and tools to raise awareness of and help overcome team members’ perhaps unconscious biases.[[14]](#footnote-14)

A different sort of problem may emerge with a shift to recruiting scientifically literate patients for some forms of PPI. Doing so may mean that “those with the economic, cultural and social capital will remain more likely to get involved in research” [21 p. 77]. Patient-initiated activity tends to be led by relatively well resourced patients. Forms of researcher initiated participation which favour the recruitment of (already) scientifically literate patients could be seen as biased, especially if they lead to the disproportionate representation of members of particular demographic groups.

In considering this issue, it is worth noting first that unequal representation of some groups is more of a problem for the extrinsic politico-moral goals of PPI than for the epistemic goals that are our focus [46]. However, our proposal that people who have both relevant illness experience and scientific literacy are more likely to be able to make direct epistemic contributions to research may tend to favour social groups that are better off in terms of education, resources or social power, and therefore lead to or compound existing injustices, especially if some health conditions or the implications of some treatments or services manifest differently in different demographic groups. Deliberate training of participants (rather than recruiting those who are already scientifically literate) might alleviate this concern, while selective training might improve the inclusion of marginalized groups, as well as facilitating the achievement of knowledge-related goals of PPI.

Another way of mitigating selection effects, while still accessing patients’ first-hand experience is to make use of interviews or group discussions with diverse patients at the exploratory and design stages of research, with one or two members of a research team ‘bridging’ between conversations primarily with and among patients (who might be more and less scientifically literate) and conversations among the primary research team.[[15]](#footnote-15)

As well as providing support by training in scientific literacy, the processes of engagement are important to harness the epistemic potential of patients’ knowledge-by-acquaintance while avoiding epistemic injustice. Various strategies might be used to promote interactions that are likely to stimulate new thinking, creative leaps or breakthroughs. A key element to concept and hypothesis formation is the process of reflecting on relevant information with a problem in mind. Participation in dynamic exchanges – such as conversations, research meetings or focus groups – can bring about the relevant kinds of reflection. As Levit notes: “a thing or fact may become evidential only when selected, organized and interpreted along with other facts and ideas in a situation and for a purpose” [47 p. 202]. Thus meetings between patients and researchers should be structured to: allow sufficient time and flexibility so that meaningful exploratory dialogue can take place; encourage research team members to talk about what the problem looks like or what a solution might look like from their perspective; mandate plain speaking from all members of the research team (avoiding unnecessary jargon etc.); and create plenty of opportunities for all present to contribute and to consider previously unanticipated/unexplored lines of discussion.

**Conclusions**

Patients have extensive raw and incompletely conceptualized knowledge of their health conditions, health care interventions and services that may not be well understood by researchers. Such knowledge may be a valuable epistemic resource in addressing hermeneutical deficits in the conceptualization, design and implementation of health research.

There are several barriers to accessing patients’ knowledge, including those related to testimonial injustices caused by existing professional-lay hierarchies. We have suggested that these could be overcome at least to some extent by creating the conditions in which patients can be treated as credible, and developing opportunities for intellectually creative interactions in research-related discussions.

The potential for patients to make direct epistemic contributions to research has long been recognized and acknowledged as an important justification for some forms of PPI. However, to achieve the intrinsic epistemic potential of PPI, it must be considered distinctly from the external PPI aim of promoting politico-moral goods. Both the skills of individual patients and the circumstances in which they engage with other research team members require attention, so as to facilitate communication which is supportive of the kinds of knowledge creation that may be possible.

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1. Systematic reviews of PPI show little or inconclusive evidence of the impact of PPI [9-13]. [↑](#footnote-ref-1)
2. Elsewhere in the literature [21] authors distinguish ethical, political, and methodological aims. Of these, the first two fit into our ‘extrinsic’ category, whereas the third fits our ‘intrinsic’ category. Similar distinctions have been made by others, e.g. [16]. p. 2576; [14]. p. 2. It is worth noting that some benefits fall into a grey area. For example, involvement of patients in research design with the aim of improving the experience of the research participants by ensuring that their experience is pleasant, not inadvertently undermining of dignity, not too difficult etc. obviously has extrinsic value (i.e. ethical value of improving the experience of participants) but might also impact on comprehensiveness of data collection by increasing the number of respondents or completers, or improving the accuracy or richness of what they say. Conversely, there are moral reasons for promoting the epistemic benefits of PPI (for example doing so will lead to better utilization of health resources) and, as we will discuss, moral or ethical issues can arise in relation to the pursuit of PPI for epistemic aims. [↑](#footnote-ref-2)
3. Examples of such indirect benefits are reported in [22]. [↑](#footnote-ref-3)
4. We recognize concerns expressed elsewhere that the term ‘patient’ can suggest sickness, passivity and disempowerment [12], although the term is claimed by some patient activists. We prefer ‘patient’ to ‘consumer’, which seems to refer more broadly to someone who is or might be a user of various health-related services, and is also suggestive of a particular kind of (economic) relationship (a point made by Angus Dawson [23]). [↑](#footnote-ref-4)
5. Groups with other perspectives (such as carers or clinicians) might also have unique forms of knowledge that could enhance the conceptualization, design and conduct of health research. Such questions lie beyond the scope of this paper, but some of our arguments, relevantly modified, might apply to other groups. [↑](#footnote-ref-5)
6. This terminology is courtesy of Donald Rumsfeld, who said: “There are known knowns. These are things we know that we know. There are known unknowns. That is to say, there are things that we know we don't know. But there are also unknown unknowns. There are things we don't know we don't know.” As David Logan observes [27], Rumsfeld’s comments gesture towards an idea that is useful in the context of scientific knowledge. [↑](#footnote-ref-6)
7. Although we note that there is ongoing controversy over whether or not GWS is caused by an unknown medical problem (for example related to immune function) or whether it is psychogenic [31]. [↑](#footnote-ref-7)
8. Gronseth [31] reports that some veterans wore pet flea collars to repel insects. [↑](#footnote-ref-8)
9. Chalmers does not reference this claim, therefore we are unable to provide further details. [↑](#footnote-ref-9)
10. For example, one biomedical scientist said: “Patients should not interfere in processes of which they know nothing about.” [16 p. 2576]. [↑](#footnote-ref-10)
11. For example, Thompson *et al* quote a patient involved as a research collaborator as saying: “You need to put brain into gear before opening mouth. You can’t just sit and waffle… [health researchers don’t] suffer fools gladly” [15 p. 613]. [↑](#footnote-ref-11)
12. The Project LEAD® institute also provides intensive science course for breast cancer advocates in the USA [43]. [↑](#footnote-ref-12)
13. Some forms of indirect epistemic contribution may benefit from those involved in a PPI capacity lacking technical knowledge or skills, for example the ability to identify that ordinary patients will not understand an information sheet due to jargon, or sensitivity to how those with limited understanding of research will react to various recruitment protocols. [↑](#footnote-ref-13)
14. The website of Harvard’s “Project Implicit” includes such resources for combating implicit bias generally, although the details are not specific to implicit biases in the health research context [45]. [↑](#footnote-ref-14)
15. The possibility of using focus groups suggests a related but less direct way that patients’ first-hand knowledge of their health conditions might lead to epistemic breakthroughs. That is, when researchers make detailed use of qualitative studies of patient experiences. Careful analysis of already articulated patient experiential knowledge might stimulate new ideas when considered by researchers in light of their existing knowledge and research questions. Although not strictly a case of patient involvement, this is worth noting here because it seems a natural extension of our account of the role of experiential knowledge in achieving the epistemic goals of health research. Further examination of the potential of forms of qualitative research such as in-depth interviews and focus groups seems warranted. This point reinforces earlier recommendations along these lines [17]. [↑](#footnote-ref-15)