Expertise as perspectives in dialogue

Authors:

Michael Larkin (Aston University, UK) Email <u>m.larkin@aston.ac.uk</u>. ORCID 0000-0003-3304-7000.

Lisa Bortolotti (University of Birmingham, UK). Email: <u>I.bortolotti@bham.ac.uk</u>. ORCID 0000-0003-0507-4650.

Michele Lim (University College London, UK). ORCID 0000-0001-8069-0416

ACKNOWLEDGEMENTS

We wish to thank our collaborators on the Agency-in-Practice project (peer researchers, Young Person's Advisory Group members, lived experience research managers, and academic researchers) for their feedback and discussion on an earlier draft of this chapter.

This work was funded by UKRI under a Methodology call for the MRC/AHRC/ESRC Adolescence, Mental Health and the Developing Mind program. The short-form title 'Agency-in-Practice' was chosen by the Young Person's Advisory Group. The funder's project reference is MR/X003108/1.

ABSTRACT

Expertise is situated in the sense that we can scaffold or obstruct the capacity for providing expert insight and choose to create environments and relationships in which different perspectives are heard and understood, due to skilful facilitation, preparation, expectation-setting, and thoughtful configuration of systems and structures. As a result, the people providing those perspectives can be seen as experts where expertise is built upon knowledge or experience, but it arises from extensive efforts in seeking to understand

something; it is borne out of a hard-earned familiarity with the contours of a particular set of problems.

In this chapter, we examine the notion of *expertise by experience* with reference to mental health research, discussing some of the objections commonly raised against its legitimacy. The best way to characterise the integration of different forms of expertise is to describe the process as a case of *perspectives in dialogue*. A perspective is a way of referring to how something appears from a particular standpoint, which acknowledges the relevance of that standpoint to what is foregrounded. A dialogue is a means of sharing insights, carried out to support reciprocal understanding. Co-design and co-production approaches encourage perspective taking and use group processes and facilitation to support community consensus building. It is through such collaborative and relational processes that common objections against the legitimacy of expertise by experience can be addressed.

Keywords:

expertise, expertise by experience, disagreement, objectivity, subjectivity, evidence, coproduction, co-design, perspective, dialogue.

1. What is Expertise?

Philosophers and social scientists have recently turned their attention to the notion of *expertise by experience* (e.g., Dings and Tekin, 2022; Castro et al., 2019), a notion¹ that has been formulated to account for a form of expertise that does not depend on studying a particular issue but by having a particular experience.

¹ We are aware that the phrase "experts by experience" is problematic and controversial and that in some contexts other phrases are preferred, such as "lived experience advisors". In this chapter, we use the phrase "experts by experience" because we are interested in addressing recent literature that discusses the strengths and the limitations of that role, and we want to focus on the notion of expertise. However, the arguments presented in the chapter can be interpreted as an invitation to reflect on whether the phrase "experts by experience" is adequate to the purposes for which it is used.

If those who are not experts can have expertise, what special reference does expertise have? It might seem that anyone can be an expert. We say that those referred to by some other analysts as 'lay experts' are just plain 'experts' – albeit their expertise has not been recognized by certification; crucially, they are not spread throughout the population, but are found in small specialist groups. [W]e will refer to members of the public who have special technical expertise in virtue of experience that is not recognized by degrees or other certificates as 'experience-based experts'. (Collins and Evans 2002, page 238)

In the background of many discussions about expertise the following question seems to emerge: Are experts by experience *real* experts? But in this formulation the question raises a number of concerns: Why do we need to demarcate expertise in that way? How does power affect the process by which lived experience is recognised as a legitimate source of expertise? Is there an underlying assumption that there can only be a limited number of experts and thus some gatekeeping is required? Or that experts by experience can only have a well-defined, limited role in their contribution to shared knowledge and decision making? Such concerns resonate with our experience in meetings with patient and public involvement groups, where people with lived experience are often assigned a mere consultancy role, and asked to comment on a small number of issues, but are not actively engaged in the more general discussions that occur between professionals within the same meetings. This is an illustration of the idea that experts by experience are not considered as *real* experts and that their involvement is often tokenistic.

In the literature, objections raised to the notion of expertise by experience have started to be identified and addressed. These are presented either as general worries about expertise that are made more salient by the case of expertise by experience, or as concerns that are specific to the acceptance of lived experience as an epistemic resource. The general issues debated in this literature are the need to ensure the *objectivity* of knowledge, and the importance of finding effective ways to deal with *disagreement* among experts, combined with the need to integrate various perspectives in decision making. Such challenges are not unique to expertise by experience but can arise in encounters between experts trained in different disciplines, belonging to different schools of thought, or using different methodologies. The more specific issues with the legitimacy of expertise by experience can be seen as at least partially prompted by a threat to the authority of experts by training: such experts might worry that their more 'traditional' expertise is at risk of devaluation if other routes to expertise are validated. However, such issues are also conceptually grounded. One of these issues is whether contributions by experts by experience are a source of *evidence* for the claims and decisions they support. In other words, lived experience is not always recognised as a legitimate epistemic resource.

In this chapter, we acknowledge the urgency of clarifying the notion of expertise, but we consider questions about the legitimacy of expertise by experience as a lens through which key aspects of our epistemic practices come into clearer focus rather than as a problem in itself. In the course of the discussion, we start developing what we take to be a more productive way to look at the challenges of group decision-making: expertise is something that emerges from a collective and dialogical pursuit that involves a group reflection on the available evidence. That is, it arises out of collaborative discussion and critical consideration. One way to bypass the constant requirement to justify a seat at the table for experiential insights is to think of contributions as *perspectives in dialogue* rather than independent claims to expertise.

Our aim is threefold. In section 2, we revisit the notion of expertise and ask how individuals and groups come to be seen and treated as having expertise, independent of the source of their expertise. We argue that expertise requires scaffolding and is perspectival. It is not a property of an individual or a group but a function of the relationship between an individual or a group and the world around them. As Matt Stichter says:

Deciding who to credit as an expert is not like describing a natural kind. We credit people with expert status because it serves a useful function, and we decide who to confer this status upon depending on what we want from them, and this also determines what power we choose to grant to them. So we want to avoid what some have termed an "immaculate" conception of the expert – someone who counts as an expert whether we like it or not, and to whom we must defer judgment. (Stichter 2015, page 126)

In section 3, we to consider and address some of the most common objections to the idea that lived experience is a source of expertise. How can experience give rise to knowledge if it is subjective? Aren't experts supposed to provide evidence to reach the best decisions for a group of people, whereas lived experience is always an individual experience of something in particular? What type of evidence can experts by experience provide? And what is the value of this type of evidence? We respond to these challenges, arguing that in some contexts subjective experience is exactly the type of perspective we need, and highlighting that narratives reporting personal experiences can be evidence of something worth knowing, but are not the only contribution that experts by experience can offer. Moreover, we reiterate how being able to access and use information is necessary but not sufficient for any form of expertise. If it is reflection on experience that generates expertise as opposed to experience alone (e.g., Castro et al., 2019), the complaint that all that experts by experience can offer is a first-person account of their own experience misses the point. The point is that what the experience offers is a unique perspective on the problem that deserves to be reflected upon.

In section 4, we offer some an example of how distinct forms of attaining knowledge, including expertise by experience, can be integrated in the mental health context and reflect on the process of co-design and co-production before making a concrete proposal about how the promotion of different perspectives in dialogue may be facilitated.

2. Expertise as Scaffolded and Perspectival

'Expertise' is usually defined in terms of a high level of skill or knowledge in a given field where the skill or knowledge can be attained by training, study, or practice. In this chapter, we address the notion of expertise *as knowledge* and leave aside the notion of expertise *as skill*. In addition, to make the discussion more manageable, we focus on situations where experts meet to make an informed decision or solve a problem.

Most definitions of expertise (such as the one to be found in the dictionary of the American Psychological Association, where expertise is defined as "a high level of domain-specific knowledge and skills accumulated with age or experience") present expertise as a property of an individual or a group rather than a function of the relationship between the individual or group and the world around them. Most commonly, the property referred to is *knowledge*. However, it is unhelpful to define expertise as a high level of knowledge where knowledge stands for an individual's or group's capacity to gather information pertinent to a given topic and draw upon this information when appropriate. That is because, if the availability and use of information were sufficient, then it would be very difficult not to attribute expertise to anybody who has access to a source of information, such as someone sitting in a library or searching the internet.

The literature on *distributed cognition* (e.g., Hollan et al., 2000) and *communities of practice* (Wenger, 2000) are powerful reminders that an intrapsychic view of expertise is inadequate. Both of these notions, and the research developed from them, emphasise the means through which intrapersonal knowledge is boosted, scaffolded, and augmented through dialogue with others, through structured interactions within knowledge systems (as informal as team meetings, or as formal as peer review), and opportunities to 'offload' tasks to technology (e.g., see Hollan & Hutchins, 2009). These processes apply to domains as varied as flying a plane (Hutchins & Klausen, 1996) and working in public health (Barbour et al., 2018).

An alternative, more enactive, formulation suggests that expertise is *afforded*—by people, questions, culture, expectations, power relations, and systemic structures. For example, an academic in their university office, with their colleagues across the corridor, their student asking the 'right' kinds of questions, the spines of their books on the shelves to prompt recall, and the internet at their fingertips, may feel very comfortable in their professional expertise. But the same academic may feel considerably less able to draw upon a sense of their own expertise when they are caught off guard and asked the 'wrong' sort of question in a media interview, while at a bar with friends, or in a taxi. These examples underscore that expertise is usually defined and performed in a given environment, and in that environment, it is accessed and benefits someone, either another individual or a community. Expertise is a form of *social contribution*, which is—by nature of its recognition *as* expertise—valued and, correspondingly, afforded by others.

If expertise is afforded, then this has important consequences, because affordances can be changed at the interpersonal level through skilful facilitation, preparation, and expectationsetting. A well-planned and well-chaired research meeting allows for different kinds of expertise to be heard, for example. Expertise might also be afforded via thoughtful configuration of the tools, environments, systems, and structures through which different kinds of expertise are recognised and warranted. Think for example about the conventional structures of the 'ward round' in which the patient's expertise is barely heard, while a range of professional forms of expertise are granted more time, space, and authority. Now contrast this with the kinds of patient-and-family-first discussions which characterise the Open Dialogue approach (Seikkula, 2011). In the traditional ward round, professionals talk *about* the patient. In the Open Dialogue model, the patient's concerns are the *central* focus—and no one talks about the patient unless the patient is present.

Moreover, in the complex environments in which we live, most decision-making tasks require inputs from distinct sources of information and information is attained via a multiplicity of methods, so each contribution needs to be integrated in a wider context. Consultations which incorporate perspectives from sales, user experience, marketing, and product design are needed to make decisions about new products in the business boardroom. Problem-solving in technological industries requires the input of designers, developers, software engineers, programmers, hardware managers, and moderators. Emergency responses in public health draw on the insights of epidemiologists, infectious disease specialists, psychologists, health communication experts. Each party in these situations offers valuable information despite their distinct perspectives and areas of specialty—all of which need to be carefully balanced, navigated, and integrated through dialogue, to reach a comprehensive and suitable plan. The key claim here is that people's capacity for providing expert insight can either be scaffolded or obstructed. The recognition that expertise is situated in this way opens up the possibility of creating environments and relationships in which different kinds of expertise can be heard and understood. Keeping these contextual and ethical matters in mind enables us to formulate a more useful, applied concept of expertise.

Individuals or groups we consider as experts do not merely gather and use information but understand the information at their disposal and know how to apply it in order to engage with problems and processes, or to come to a decision. They know something about *how* to use what they know. Such 'meta-knowledge' arises from prior experience and is situated. As with many situated phenomena, it will reflect certain social inequalities: you may have learned how to successfully chair a committee in such a way that it reaches decisions that you approve of; or you may have learned what information to share with (and withhold from) a health professional, in order that they suggest a treatment that you will be able to accept. In both cases, you may find that what you have learned in one domain has some utility in the other.

However, if we make the leap too quickly from saying that expertise is just 'high level knowledge of information pertinent to a topic' to saying that it is 'the capacity to understand and apply high level knowledge', then we may overlook an important feature that is especially salient in some contexts, such as health and mental health, where professionals work in multi-disciplinary teams. This critical feature is that the information *pertinent* to any topic can come from many possible sources (e.g., distinct professional and disciplinary knowledge; distinct methodologies and epistemologies), and can take many possible forms (for example, statistical patterns, experiential narratives, clinical images, organisational logics, professional standards, treatment guidelines, case studies, and so on). There are many perspectives.

Expertise is *perspectival* in a very important sense: it implies a view which is situated somewhere, and which provides—under the right conditions—depth of insight. Resolution of differences between expert views is something which occurs *dialogically* (e.g., a team talks it through and decides on balance what the best course of action is); through consultation (e.g., options are shared with a wider community and the members of that community provide feedback); or through *consensus* (e.g., stakeholders work together to co-design solutions that meet everybody's needs). The capacity and opportunity to engage in such processes is indicative of some degree of expertise, of knowing how to use what one knows. Thus, expertise is not just specialist knowledge. It is often built upon such knowledge, but in practice it is a form of reflection which arises from the extensive experience of seeking to understand something—it is a hard-earned familiarity with the contours of a particular set of problems. The ability and opportunity of an expert to draw upon familiarity with a problem in a way which is valued by others comes from the expert being in a situation where they can *reflect* upon the knowledge they have, for the benefit of others. This reflective thinking is a product of an interaction between the person's potential and capacity, and the context's affordances and scaffolding, and it is shaped to some extent by the values of the other parties who are present. In the context of health and mental health, these dynamics are captured in the popular meme:

Doctor: Don't confuse your Google search with my 6 years at medical school.

Patient: Don't confuse the 1-hour lecture you had on my condition with my 20 years of living with it. (Greenhalgh 2018)

If we conceive of expertise as situated in this way, as something that is always scaffolded and perspectival, we appreciate a number of things: that one can become an expert by many routes; that expertise is generally performed for some purpose to benefit someone; that it can be afforded or obstructed by features of the context in which that performance is sought; and that it involves offering reflective and perspectival insight into a particular problem or topic. This understanding of expertise can apply to expertise derived from (personal or clinical) experience, just as well as to expertise stemming from specialist or technical knowledge (via scholarship or research).

3. Subjectivity and Disagreement

Expertise primarily derived from specialist or technical knowledge is commonly assumed to be genuine expertise or a superior form of expertise, whereas expertise by experience is often thought to be a sort of pretend expertise or a second-class form of expertise, if recognised as expertise at all. In many disciplines dealing with the real-world effects of complexity and uncertainty (such as social science and medicine), the admission of multiple and perspectival sources of expertise is considered to be both pragmatically and conceptually sensible. However, expertise by experience is rarely acknowledged as an example of this acceptable heterogeneity, and that is due to the assumption that expertise by experience is not based on objective knowledge.

How generalisable is the significance of expertise by experience for decision making and problem solving? Expertise by experience grants us insight into things which are 'humanscaled' and thus is more likely to make an important contribution to mental health research than to climate science. But acknowledging the value of the 'human-scaled' perspective can be a useful route to reflecting on the bigger picture. Not only can a climate scientist persuade us of the urgency of the problem of climate change by sharing the intensity of their personal concerns, but experiential insights can help us better understand the complexities of the problem. For instance, they can get us to appreciate how climate change does not affect all human lives equally. There are some populations and communities who will feel its effects at an earlier stage and more dramatically than others. Experiential insights tell us something about the *human systems* aspect of climate change, even if they do not add much to our understanding of the *physical systems* aspect.

In domains like social science or medicine, practitioners often encounter situations where objectivity is unattainable or undesirable, or face problems that have irreconcilable features—under these conditions, collaborating to develop a nuanced and negotiated formulation of the problem is the way in which consensus is reached and an 'expert' view emerges. In what comes next, we focus on a specific context to make our discussion more manageable. In the recent literature in philosophy of science and medical ethics, there has been a genuine attempt to legitimise expertise by experience in the context of mental health, integrating the experience of people whose health is at stake with the views of experts by training. It is overwhelmingly plausible that a person who lives with a specific health condition acquires knowledge about the ways in which the health condition affects them (via lived experience), and also acquires knowledge about the ways in which the views of contribute to practical decisions about treatment but also to a better theoretical understanding of the health condition as such.

3.1. Objectivity

There are several notions of objectivity that have been discussed in the philosophy of science (Reiss and Sprenger, 2020). Objectivity has been interpreted as: (1) a way of looking at the world that does not depend on any perspective, but is neutral—as in Nagel (1986)'s *View from Nowhere*; (2) a way of looking at the world that is not affected by any value or normative commitment—what Kuhn (1977) denies when he talks about the *incommensurability of rival paradigms*; (3) a way of looking at the world that is not influenced by personal bias—what Feyerabend (1978) deems a misleading ideal in science. In feminist approaches to the philosophy of science and to epistemology, such accounts of objectivity are rejected on the basis of the value-ladenness of science (Longino, 1990) and the perspectival and situated character of all forms of human knowledge (Haraway, 1988; Harding, 1993).

In a recent paper, Şerife Tekin describes how patient perspectives have been excluded from the wide range of consultations leading up to the revised version of the *Diagnostic and*

Statistical Manual of Mental Disorders (DSM-5) for fear that they would compromise the objectivity of the process:

It is also important to note that in DSM-III and DSM-IV, the APA highlights that it sought the 'advice of experts in each specific area under consideration' (APA 1994, xv). 'Experts' in the DSM language refer to scientifically trained researchers or clinicians with recognized degrees who treat individuals with mental disorders. During the DSM-5 revision process, there were calls to the APA to include patients, by involving them in the decision-making process about the diagnostic criteria. However, this was not accepted by the DSM-5 Task Force, on the grounds that patient inclusion would reduce objectivity in the scientific process. (Tekin, forthcoming).

Tekin argues that the decision to exclude patients from the consultation was misguided because it was based on the wrong notion of objectivity for psychiatry, a positivistic notion where objectivity (as in the accounts listed above) is characterised either as *the opposite of subjectivity* or as *concordance*. For Tekin, there is a more useful notion of objectivity, what she calls *participatory interactive objectivity*. Inspired by feminist philosophy of science and social epistemology, Tekin sees objectivity as a product of a "participatory and interactive negotiation process" bringing together people with different forms of expertise, "the professionals trained in psychopathology and those with experiential knowledge". For Tekin, this notion of objectivity is not opposed to subjectivity and is not to be assimilated to concordance.

Tekin's contribution to the debate helps us see how key philosophical notions such as expertise and objectivity should be contextualised to the domains where they are applied. However, as a defence of expertise by experience, Tekin's proposal does not go far enough. Rather than redefining what objectivity means to legitimise the contribution of people with lived experience to the production of shared knowledge, couldn't we simply acknowledge that, in some contexts, the type of knowledge we need to access is *subjective*? If the reason why we find the contribution of experts by experience intrinsically valuable is that we need an understanding of illness as it is lived by those who are ill, what we need is knowledge of their subjective experience, a type of knowledge which training alone cannot offer. Psychiatry and psychology are examples of the kinds of applied domains which deal with very few matters that can be known objectively. In these domains, subjectivity is a feature of *many* or *all* perspectives, and the thing which distinguishes one perspective from the other is not the presence or absence of objectivity, but the kind of evidence which one draws upon. Reflection on personal experience is a source of knowledge which has an especially important contribution to make when the other available resources (e.g., clinical experience, qualitative and quantitative research evidence, professional training and ethics, pragmatic and local knowledge) are in need of a contextual interpretation.

Tekin observes that objectivity is usually posited as the opposite of subjectivity:

Such detachment or distance is thought to keep the individual observer from being overly invested in a particular outcome or fearing another, thus biasing/spoiling her understanding of the phenomenon in question. In the positivistic view, science should be based on impartial or third-person observations, not 'subjective' or first-person perspectives. (Tekin forthcoming)

If we are investigating the causes of a mental health condition or the centrality of a specific symptom for that condition, a person's report about their experience of illness will not provide all of the evidence required to come to a reasoned conclusion. But in the context of other research questions, such as "How does it feel to have depression?" or "How do people with unusual beliefs experience clinical encounters?", then we do not need evidence that is detached from the observer's standpoint, and we should not be concerned about biases spoiling the person's "understanding of the phenomenon". On the contrary, it is the person's standpoint that we need to have an understanding of, and potential biases will not spoil the object of investigation but will be integral to it. The value of lived experience comes from its subjectivity, because it provides a deeply personal, visceral understanding of the illness that goes beyond (or is at least qualitatively distinct from) any form of academic or scientific knowledge.

What is the relationship between objectivity and concordance? Again, if we are investigating the causes of a mental health condition or the centrality of a specific symptom for that condition, a person's report about their experience of illness can only be part of the evidence that we need. It will have to be integrated with other types of evidence, and gathered across a range of patient reports to identify patterns, that is, similarities and differences between individual perspectives. Discordance is not a weakness and does not give us a reason to doubt either the importance of the reports as evidence or the competence of the people who share those reports. Rather, those discordances are precisely the data we need in order to come to a better understanding of how the health condition manifests: the differences do not need to be eliminated but appreciated in a dialogic process where multiple perspectives coexist. As Tekin also suggests, when the phenomenon is complex, the "inclusion of differently trained experts", and we would add, *people with different experiences*, make the process of inquiry "interactional, collaborative, and critical".

Thus, for at least some of the relevant research questions, we need neither unbiased information from a neutral standpoint nor perfect agreement among the people who play the role of experts. We need, as Tekin puts it, a "participatory and interactive negotiation process" and there should be no pressure to brand it as a way to achieve objectivity. The view of expertise emerging from this discussion is a form of a dynamic and collaborative dialogue. Interactive participation and the ensuing negotiation processes won't guarantee objectivity but can ensure that subjective information is reflected upon and complements the existing body of knowledge on a particular issue in a way that is coherent and considered. For some research questions, objectivity is not the gold standard. In the process by which we attempt to understand and enhance patient experience of healthcare (e.g., see Green et al., 2020), for instance, the value of lived experience lies precisely in harnessing *subjectivity*, that is, harnessing knowledge of the experience of approaching services with a health condition that is perspectival, value-laden, and idiosyncratic.

3.2. Experience as evidence

Objectivity and evidence are intimately related in the philosophical literature: for the logical positivists, and more generally in the philosophy of science, an objective inquiry is an inquiry that is driven by evidence and that makes it possible to reach agreement across multiple perspectives (Feigl 1953). So, it should not be a surprise that a standard objection to thinking of lived experience as a source of expertise, and to drawing upon the first-person accounts of people with lived experience, is that lived experience can only contribute

personal narratives of illness. Given that these narratives, by being personal, are both partial and subjective, they are thought to be of limited relevance to understanding the illness more generally. The traditional approach is to emphasise the sharp distinction between the *narrative paradigm* and the *argumentative paradigm*, where only the latter provides evidence and contributes to rational argumentation (see Fisher, 1984). But this dichotomy neglects the possibility that stories can serve as evidence for rational arguments and as a window into another person's or another group's valuable perspective.

In the domains of qualitative research, phenomenology, narrative psychology, and intersectional epistemology, there are a number of counter-arguments rejecting claims that experiences can only produce narratives (e.g., see Høffding et al., 2023); that the narratives (and other structures of experiential knowledge) of one person cannot have relevance to other people's experiences (e.g., see Finfgeld-Connett, 2010); that partiality can be avoided in any form of knowledge; and that subjectivity or perspectivity is always a form of epistemic deficit (e.g., see Grant & Kara, 2001). Some of these defences of lived experience as a form of expertise arise from the literature which explores the different forms through which experience can be accessed and represented by research participants and researchers (e.g., see Thomsen & Brinkmann, 2009; Boden & Eatough, 2014); from methodological work on 'transferability' and 'theoretical generalisability' (Kuper et al., 2008) as tools for conceptualising the ways in which knowledge always requires contextualisation and interpretation in order to be applied in a new domain (e.g., see Konradson et al., 2013); and from the examination of the inescapability of a 'standpoint' for human knowledge (e.g., Bacevic, 2023), or of the way in which specific standpoints can grant insights and capabilities that others may not.

These responses suggest that the objections to lived experience as a source of evidence are based on misleading assumptions. We already saw in the previous section that a description of the events can be valuable, and sometimes also essential to answering some research questions, even when it is not obtained from a neutral point of view or is not agreed upon. Arguably, the value of lived experience is precisely that it enables a particular perspective to be shared with people who would not otherwise have access to it. People are often biased when they self-report and confabulate reasons for their actions in contexts as diverse as consumer choice, politics, and morality (see for instance, Bortolotti, 2018; Stammers, 2020; Murphy-Hollies, 2022), and this is especially true when people report events that are emotionally salient and personally significant to them. This applies to experts and novices, and experts by training and experts by experience in equal measure.

However, people's 'subjective' ways of telling their stories, sharing their knowledge, or explaining their actions are not a confounding variable, but part of the evidence we need when we appeal to lived experience. Stories are *curated* versions of the events and the curation itself can be evidence of the impact of the events on that person. The effects of the curation may be more obvious when information is presented in a narrative form, but other expert views are also the product of a process of selection and reconstruction of the data that can add or detract from their value depending on the aims and context of the exercise. When experts by training offer their advice, for instance, some information may be foregrounded and other information passed on quickly, and these curatorial choices can determine how the expert view is received and assessed and what impact it has on decision making.

Another related assumption is that lived experience can *only* produce personal narratives, where the narrative is the beginning and the end of the process. Instead, personal narratives are only one way to communicate a person's experience, and often they are just the starting point of a process of reflection and elaboration. Experiential insights may well be communicated via narrative, but qualitative and phenomenological researchers know that they can also be expressed and represented in the form of metaphors, concepts, images, emotion or network maps, atmospheres, sounds, invariant structures, themes, and touchpoints. Many of these forms do not rely on core features of a narrative (such as temporality and causality), and they allow us to understand experiential knowledge along a number of different dimensions (such as intensity, quality, tone, connectedness, pattern, and essence). Substantive bodies of literature in qualitative research draw upon these sources of experiential insight as *data*. Thus, the claim that experience is only communicated via narratives cannot be supported.

Narratives can be a helpful form of knowledge. The blanket claim that personal narratives cannot be evidence is deeply unsatisfactory. In deciding whether a piece of information can be evidence, we need to agree on what we are gathering evidence *of*. A narrative of a person's experience of depression may not be a reason to believe that the next person with

depression will have a similar experience, but it is evidence that depression can be experienced in that way. Although personal narratives may not always help us understand what caused an event or predict how likely that event is to happen again in the future, the elements of curation that make the story unique, how emphasis is used, what roles different actors and events play in the story, and what the narrative arc includes and excludes, provide powerful evidence of how the narrators see and interpret being in certain situations, of how those situations make them feel (Murphy-Hollies and Bortolotti, 2021; Bortolotti and Jefferson, 2019).

4. Expertise by Experience in Mental Health

There is an extensive literature which describes the harnessing of lived experience expertise for conceptual and evidential insight in mental health. As a source of data, participants in qualitative research studies, or in projects which use 'expert consensus' methods (such as Delphi surveys, or nominal group techniques), provide accounts of—and from—their lived experience. These accounts inform the theoretical and conceptual understanding of topics right across the disciplinary spectrum.

As a source of direct expertise, people with lived experience may lead and publish their own academic scholarship (e.g., Milton, 2012), may provide insightful personal reflections (e.g., Barnsley, 2023), or may work as part of a collaborative research team (e.g., see Bond et al., 2022). They may be the source of insights driving an experience-based co-design process (EBCD) (e.g., Springham & Robert, 2015), or inform the general direction and ethos of a large project, through their contributions to an advisory group (e.g., Weich et al. 2020). Across all these roles, as we have discussed above, people's experiential expertise, and their capacity for reflection, can be supported by the surrounding context, or obstructed. Considerable guidance exists to help researchers and other decision-makers to create supportive contexts (e.g., see NSUN, 2015). Much of the guidance focuses on practical matters such as establishing clear aims; allowing adequate time and preparation for people to contribute; agreeing on processes and terminology which are inclusive; providing payment or other forms of appropriate recognition and recompense, and so on.

4.1. An example from our work: developing the agential stance

In some of our own recent work, we have been reflecting on how best to support experts by experience in engaging with the substance and detail of research data, in order to develop interpretations arising from, and useful for, a range of disciplinary perspectives.

Our project aimed to investigate whether the sense of agency of young people was safeguarded in mental health clinical encounters. To address this issue, two groups of researchers worked together to analyse the research data. One was a group of six people with backgrounds in philosophy, psychology, psychiatry, clinical communication, clinical practice, and public involvement in research. The other was a group of five young people with experience of mental healthcare services (the "experts by experience"). As it happens, there were experts by experience in the first group and experts by training in the second group, so the divide was not as neat as it may sound. All the researchers brought their training and experience to the table.

What was the data to be analysed? The data consisted of filmed interactions between young people in a mental health crisis and practitioners in mental health emergency services. We watched the videos and with the help of the members of the team who are trained in conversation analysis, we examined interactions that went well, where the young person felt heard and shared information with the practitioner in a fruitful exchange; and interactions that did not go well, where the practitioner either dismissed the young person's perspective or excluded the young person from the decision-making process leading to the identification of further support.

To begin with, both groups met separately, facilitated by the member of the team specialising in public involvement in research, who also had lived experience of receiving mental health care. The analysis conducted by the group with lived experience was fed back to the academic group. The analysis informed the selection of subsequent video clips in an interactive research process. In turn, observations from the group with academic expertise informed selection of video clips and the agenda of the meetings of the group with lived experience. Preliminary themes were identified by the group of researchers with academic expertise based on the data analysis sessions and these themes were then brought to the group of researchers with lived experience for open discussion and further interpretation of meaning and significance. This dialogue *first* within groups, and *second* between them, and *third* as one more integrated group, led us to identify a particular attitude, *the agential stance* that practitioners can adopt towards young people in a mental health crisis to make sure that the young person feels heard and has an opportunity to participate in the decisions to be made about further support (Bergen et al., 2022). The agential stance is made of five key steps: validation, legitimisation, avoidance of objectification, affirmation of the capacity for positive change, and involvement in decision making. Agreement on the key steps of the agential stance—including what the steps are, how best to describe them, what benefits and risks they have, how best to implement them in communication—was achieved via a process of reflection, discussion, and negotiation occurring within each group of researchers and across the two groups.

For instance, a choice driven by considerations brought to the table by experts by experience was to focus on how the practitioner can affirm the young person's capacity to contribute to positive change rather than talking about the young person's taking responsibility for their own health journey. In the psychological and philosophical literature, agency is usually associated with the notion of responsibility, and responsibility is in turn associated with blame and praise. However, in the context of a young person who is experiencing a mental health crisis, it was found that it is better to acknowledge that there is something meaningful and helpful that the young person can do to contribute to their progress rather than describe them as responsible for what happened to them or for how their health journey is developing. It is good to stress the young person's agency, but it is also important to identify the pressures and constraints they are experiencing due to the surrounding environment. Future health prospects are never entirely in the agent's own hands and this becomes even more salient in the case of young people seeking emergency support for their mental health.

This is just one illustration of the many negotiations that occurred in the course of the analysis. Once the analysis was completed, members of both groups participated actively in public engagement and dissemination activities, and co-authored the project's outputs.

4.2. Integrating perspectives in dialogue

With our collaborators, we have learned a lot about how to elicit, integrate, and apply different kinds of expertise within a project. Here we mention four useful places to start.

a. Providing scaffolding

People need an accessible route into the problem. This is as true for an expert by training who is working outside of their disciplinary comfort zone as it is for an expert by experience working with academics and clinicians. Effective collaboration is often scaffolded when all parties are willing to use terminology and concepts in ways that are respectful and support mutual understanding. In well-managed projects where experts by experience advise on the management of programmatic research, for example, this arises from taking care to introduce key concepts, and then agreeing on shared terminology.

In collaborations focused on the interpretation of data—as in our own brief example above—this may arise from finding an accessible means of *presenting* those data (for example, video recordings rather than transcripts). In each case, it is important to think ahead, and discuss *how* the next steps will work. 'Talking about how we will talk about it' is thus a simple and important component of supporting the kinds of collaboration which can afford the expression of expertise from a range of perspectives.

b. Accepting partiality

Empirical approaches which accept reflexive practices as responses to the 'problem of reflexivity' are helpful here (Jamieson et al., 2023). That is, if all parties begin from the position that *everyone* is likely to have some bias, and that they will all have some learning to do, then it becomes possible to begin to reflect together on what each party can bring to the project (both in terms of bias and insight), and what they have yet to understand. In experience-based co-design work, for example, these reflections often arise at the 'feedback stage' of a project, where different stakeholder groups learn about the differences and overlaps between their own insights, and those that have arisen from *other* stakeholder groups. These kinds of conversations encourage perspective-taking and can make people aware of their own assumptions and preconceptions (Larkin et al., 2015).

c. Cultivating epistemic humility and curiosity

One practical feature, which links epistemic humility with scaffolding, is the *timing* and *scope* of the involvement of experts by experience. If all parties accept that they have something to learn from each other (and we argued that they should), then it is important to ask experts by experience the right questions at the right time. This means moving away from a model of occasional consultation, and instead sustaining a dialogue with experts by experience *throughout all the stages of the project*.

This can ensure that research plans are developed for projects that are meaningful to all parties, and decisions are reached as a result of the collaboration. Cultivating genuine curiosity in the other parties' perspectives can contribute to avoiding the dangers of merely bringing expertise by experience in to validate or rationalise plans and decisions that have already been made. Openness and flexibility can make space for a more bottom-up methodology in the identification of both key issues and solutions.

d. Supporting constructive dialogue

In our experience, the process of 'building up a picture' of a problem and its possible solutions, arises from relationships of trust.² It takes time, goodwill, resources, and effort to develop trusting relationships between parties who may experience inequities of power and social-political capital. This is one important dimension on which collaboration with experts by experience is often *not* like collaboration with experts from other disciplines.

Here, collaborations benefit from researchers first taking care to think about—for example how less powerful people will be heard, and how differences will be accommodated. This

² In political philosophy, there is a literature on trust and expertise, focusing on the conditions in which the public trusts the experts, especially epistemic authorities with scientific expertise (see for instance, Whyte and Crease 2010). We recognise the relevance of this literature for the notion of expertise more generally, but also think that there are special considerations concerning trust that apply to the way in which experts whose source of expertise is different interact with each other in group discussion and decision making and that is our focus here.

will include consideration of practical issues too, for example, time, money, childcare, and safety. In user-led or user-centred research, trusting relationships can be nurtured when other parties provide skilful facilitation, additional support, learning opportunities, supervision, problem-solving, and access to resources. In more traditionally structured research, we may need to think harder—and use more resources—to create safe and sustainable spaces in which experts by experience can both make their contributions and develop a dialogue with other experts.

To sum up, in this chapter we took the lively discussion about the merits and limitations of expertise by experience as an invitation to reflect on expertise more generally. We argued that expertise is scaffolded and perspectival, and we offered some examples in the area of mental health research where different forms of expertise have been brought together as perspectives in dialogue. In order for people to be experts, knowledge of the subject matter, attained via training or experience, and the capacity and opportunity to reflect on their knowledge are both required. But they are not sufficient: people also need to be in an environment where their knowledge can be accessed, used, and valued by others. To make the exercise of integrating expertise from multiple sources genuinely productive, we need our social environment to be structured in a such a way as to support constructive dialogue, and the people involved to be open to alternative perspectives, exercising their humility and curiosity.

References

Bacevic, J. (Accessed March 2023) "Philosophy Herself": An Essay. *The Philosopher* 110: 1. Available at: <u>https://www.thephilosopher1923.org/post/philosophy-herself</u>

Barbour, L., Armstrong, R., Condron, P. and Palermo, C. (2018). Communities of practice to improve public health outcomes: a systematic review. *Journal of Knowledge Management* 22 (2), pp. 326-343. <u>https://doi.org/10.1108/JKM-03-2017-0111</u>

Barnsley, S. (2023). OCD, metaphor, and me: the horse that can't eat apples. *The Lancet Psychiatry* 10 (3), 170-171.

Bergen, C., Bortolotti, L., Tallent, K., Broome, M., Larkin, M., Temple, R., Fadashe, C., Lee, C., Lim, M.C, McCabe, R. (2022). Communication in youth mental health clinical encounters: Introducing the agential stance. *Theory & Psychology* 32:5, 667-690.

Boden, Z. & Eatough, V. (2014). Understanding More Fully: A Multimodal Hermeneutic-Phenomenological Approach. *Qualitative Research in Psychology* 11:2, 160-177, DOI: 10.1080/14780887.2013.853854

Bond J, Kenny A, Mesaric A, Wilson N, Pinfold V, Kabir T, Freeman D, Waite F, Larkin M, Robotham DJ. (2022). A life more ordinary: A peer research method qualitative study of the Feeling Safe Programme for persecutory delusions. *Psychol Psychother* 95(4):1108-1125. doi: 10.1111/papt.12421.

Bortolotti, L. (2018). Stranger than fiction: Costs and benefits of everyday confabulation. *Review of Philosophy and Psychology* 9 (2), 227-249.

Bortolotti, L. and Jefferson, A. (2019). The Power of Stories: Responsibility for the use of autobiographical stories in mental health debates. *Diametros* 60, 18–33.

Bueter, A. (2021). Public Epistemic Trustworthiness and the Integration of Patients in Psychiatric Classification. *Synthese* 198 (Suppl 19), 4711-4729.

Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2019). Patients' experiential knowledge and expertise in health care: A hybrid concept analysis. *Social Theory & Health* 17(3), 307–330. <u>https://doi.org/10.1057/s41285-018-0081-6</u>

Collins, H.M., and Evans, R. (2002). The Third Wave of Science Studies: Studies of Expertise and Experience. *Social Studies of Science* 32/2, 235–296.

Feigl, H. (1953). The Scientific Outlook: Naturalism and Humanism. In H. Feigl and M. Brodbeck (eds.) *Readings in the Philosophy of Science*, New York: Appleton-Century-Croft.

Feyerabend, P.K. (1978). Science in a Free Society, London: New Left Books.

Finfgeld-Connett, D. (2010). Generalizability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing* 66: 246-254. <u>https://doi.org/10.1111/j.1365-</u> 2648.2009.05250.x

Fisher, W.R. (1984). Narration as a Human Communication Paradigm: The case of public moral argument. *Communication Monographs* 51 (1): 1–22.

Grant, A. & Kara, H. (2021). Considering the Autistic advantage in qualitative research: the strengths of Autistic researchers. *Contemporary Social Science* 16:5, 589-603, DOI: 10.1080/21582041.2021.1998589

Green T, Bonner A, Teleni L, Bradford N, Purtell L, Douglas C, Yates P, MacAndrew M, Dao HY, Chan RJ. (2020). Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review. *BMJ Qual Saf.* 29(1):64-76. doi: 10.1136/bmjqs-2019-009570. Epub 2019 Sep 23. PMID: 31548278.

Greenhalgh, T. (2018), Twitter status on 26th May, 10:30am, accessed at https://twitter.com/trishgreenhalgh/status/1000308119115915264?lang=en

Haraway, D. (1988). Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*, 14(3): 575–599. doi:10.2307/3178066

Harding, S. (1993). Rethinking Standpoint Epistemology: What is Strong Objectivity? In *Feminist Epistemologies*, L. Alcoff and E. Potter (ed.), New York, NY: Routledge, 49–82.

Høffding, S., Heimann, K. & Martiny, K. Editorial: Working with others' experience. Phenom Cogn Sci 22, 1–24 (2023). <u>https://doi.org/10.1007/s11097-022-09873-z</u>

Hollan, J., Hutchins, E., and Kirsh, D. (2000). Distributed cognition: toward a new foundation for human-computer interaction research. ACM Trans. Comput.-Hum. Interact. 7, 2 (June 2000), 174–196. <u>https://doi.org/10.1145/353485.353487</u>

Hutchins, E., & Klausen, T. (1996). Distributed cognition in an airline cockpit. In Y. Engeström & D. Middleton (Eds.), Cognition and Communication at Work (pp. 15-34). Cambridge: Cambridge University Press. doi:10.1017/CBO9781139174077.002

Jamieson, M. K., Govaart, G. H., & Pownall, M. (2023). Reflexivity in quantitative research: A rationale and beginner's guide. *Social and Personality Psychology Compass*, e12735. <u>https://doi.org/10.1111/spc3.12735</u>

Kirkegaard Thomsen, D. and Brinkmann, S. (2009). An Interviewer's Guide to Autobiographical Memory: Ways to Elicit Concrete Experiences and to Avoid Pitfalls in Interpreting Them. *Qualitative Research in Psychology* 6:4, 294-312, DOI: 10.1080/14780880802396806

Konradsen, H., Kirkevold, M., & Olson, K. (2013). Recognizability: A strategy for assessing external validity and for facilitating knowledge transfer in qualitative research. Advances in Nursing Science, 36(2), E66-E76.

Kuper, A., Lingard, L., Levinson, W. (2008). Critically appraising qualitative research. *BMJ* 337: a1035 doi:10.1136/bmj.a1035

Kuhn, T. (1977). Objectivity, Value Judgment, and Theory Choice. In T. Kuhn (ed.) *The Essential Tension. Selected Studies in Scientific Tradition and Change*, Chicago: University of Chicago Press: 320–39.

Larkin, M., Newton, E., Boden, Z. (2015). On the brink of genuinely collaborative care: reflections on the use of an adapted form of 'experience-based design' as a mechanism for translating qualitative research into service development. Special Issue of *Qualitative Health Research* on Knowledge Translation; doi: 1049732315576494.

Longino, H.E. (1990). *Science as Social Knowledge: Values and Objectivity in Scientific Inquiry*. Princeton, NY: Princeton University Press.

Milton, D. E. (2012). On the ontological status of autism: The 'double empathy problem'. Disability & society, 27(6), 883-887.

Murphy-Hollies, K. (2022). Self-Regulation and Political Confabulation. Royal Institute of Philosophy Supplements, 92, 111-128. doi:10.1017/S1358246122000170

Murphy-Hollies, K. and Bortolotti, L. (2021). Stories as Evidence. *Memory, Mind & Media* 1, E3. doi:10.1017/mem.2021.5

Nagel, T. (1986). The View From Nowhere. New York, NY: Oxford University Press.

NSUN National Involvement Team (2015). Involvement for Influence: 4Pi National Involvement Standards. Available at <u>www.nsun.org.uk/resources</u>

Reiss, J. and Sprenger, J. (2020). Scientific Objectivity. In E. Zalta (ed.), *The Stanford Encyclopedia of Philosophy*. URL =

<https://plato.stanford.edu/archives/win2020/entries/scientific-objectivity/>.

Seikkula, J. (2011) Becoming Dialogical: Psychotherapy or a Way of Life? The Australian and New Zealand Journal of Family Therapy Volume 32 Number 3, 179–193

Springham N, Robert G (2015) Experience based co-design reduces formal complaints on an acute mental health wardBMJ Open Quality 2015;4:u209153.w3970. doi: 10.1136/bmjquality.u209153.w3970

Stammers, S. (2020). Confabulation, Explanation, and the Pursuit of Resonant Meaning. *Topoi* 39, 177–187. <u>https://doi.org/10.1007/s11245-018-9616-7</u>

Stichter, M. (2015). Philosophical and Psychological Accounts of Expertise and Experts. HUMANA.MENTE Journal of Philosophical Studies 8(28), 105-128. Retrieved from https://www.humanamente.eu/index.php/HM/article/view/83

Weich S, Fenton S-J, Staniszewska S, Canaway A, Crepaz-Keay D, Larkin M, et al. Using patient experience data to support improvements in inpatient mental health care: the EURIPIDES multimethod study. *Health Serv Deliv Res* 2020;8(21)

Whyte, K.P., Crease, R.P. (2010). Trust, expertise, and the philosophy of science. *Synthese* 177, 411–425. <u>https://doi.org/10.1007/s11229-010-9786-3</u>