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SPECIAL ISSUE • Opening up evidence-based policy: exploring citizen and service user expertise

research

## Knowledge, evidence, expertise? The epistemics of experience in contemporary healthcare

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This paper explores how personal experience acquires the status of knowledge and/or evidence in contemporary healthcare contexts that emphasise being both patient-centred and evidence-based. Drawing on a comparative analysis of three case studies – self-help and mutual aid groups; online patient activism; and patient feedback in healthcare service delivery – we foreground: a) the role that different technologies and temporalities play in how experience is turned (or fails to be turned) into knowledge or evidence; b) the role that experts-*of*-experience, in addition to the more frequently referenced experts-*by*-experience, play in mediating how, when and why experience is turned into an epistemic resource; and finally, c) how the need to be ‘evidence-based’ remains a persistent, yet at times productive, challenge to how patient and user experiences are incorporated in contemporary healthcare policy and practice. Throughout the paper, we argue that it is necessary to look at both democratic and epistemic imperatives for including patient and service users in healthcare services and policymaking based on their experience.

**Key words** experience • experiential knowledge • experts-by-experience • evidence

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## Introduction

From clinical care to national policymaking, few people would argue against involving patients and the public in healthcare. In the UK, numerous initiatives, such as public consultations and citizen juries, have been used to increase what is variously referred to as patient and public ‘involvement’, ‘participation’ and ‘engagement’ in healthcare (Stewart, 2013; Martin and Carter, 2017). While the question of who should be included and how is a topic of ongoing debate, two logics predominate: 1) a democratic imperative to include ‘the public’ precisely because they are not experts; and 2) an epistemic imperative to include specific individuals – usually patients, informal carers or other service users – because they have particular types of knowledge.

The democratic imperative, which emphasises representativeness, diversity, transparency and public accountability, emerged as a response to a perceived democratic ‘deficit’ and declining trust in public institutions and policymaking (Warsh, 2014; Fredriksson and Tritter, 2017). The epistemic imperative foregrounds lived experience as a source of knowledge, and has emerged *inter alia* from self-help and mutual aid groups, patient activism, and the patient consumer movement (Epstein, 1995; Allsop et al, 2004; Hess, 2004). Despite different normative underpinnings and histories, these two imperatives are blurred and reinforce each other in policy and practice (Martin, 2009). This is particularly striking when considering how ‘experience’, usually of a particular condition or service, is used to justify the inclusion of ‘lay’ people – by which we mean those without academically-credentialed expertise in the topic at hand – in healthcare services and policy.

The idea that *lived experience* can constitute knowledge and expertise started to receive explicit attention in the 1970s, and then grew rapidly during the 1980s and 90s (Prior, 2003). One of the earliest definitions of ‘experiential knowledge’ – defined as ‘truth based on personal experience with a phenomenon’ (Borkman, 1976: 446) – emerged from research on self-help and mutual aid (SHMA) groups. Patient activists and health social movements have played a key role in foregrounding the epistemic dimensions of personal experience, successfully influencing healthcare policy and biomedical research through leveraging personal experience alongside the development of high levels of biomedical and scientific expertise (Epstein, 1995; Rabeharisoa and Callon, 2002). In addition to ‘bottom-up’ activities driven by patient groups and third sector organisations, the epistemic importance of experience is today emphasised in ‘top-down’ initiatives led by government, policymaking bodies and healthcare institutions (Martin, 2012). This has contributed to an ever-growing emphasis on collecting, understanding and using patient and user experience to inform and improve healthcare services and policy (Ziebland et al, 2013; Coulter et al, 2014).

Today, experience is widely recognised as a form of knowledge and expertise, as indicated by the pervasive use of terminology such as ‘experiential knowledge’, ‘expert patient’ and ‘expert-by-experience’ in policy documents and patient involvement initiatives (Greenhalgh, 2009; Noorani, 2013; Toikko, 2016). However, there is little consensus on what experience(s) should be considered knowledge (Pols, 2014; Blume, 2017). Questions about *whose* lived experience is represented, *how* and *by whom* are often raised in relation to initiatives aimed at increasing public and patient participation (Horner, 2016: 15–16). Moreover, it is widely recognised that knowledge and power hierarchies shape what and whose experiences are included in healthcare-related

decision making, with professionals and those with officially recognised credentials playing a key role in consultative practices (O'Shea et al, 2019).

This paper draws on empirical research in three healthcare-related contexts where the epistemic dimensions of experience are both foregrounded and contested: self-help and mutual aid groups; patient activism in an age of social media; and online feedback in the English National Health Service (NHS). Our aim is not to make normative judgements about *whether* experience *should* be considered knowledge or to suggest how it might be best included as an epistemic resource in healthcare. Taking our cue from Blume (2017), we draw out commonalities and trends across the three different cases to contribute to wider debates on how personal experience acquires or fails to acquire the status of knowledge or evidence in healthcare contexts, characterised by a simultaneous emphasis on evidence-based decision making and patient centredness.

## Methods

### *Cases and contexts*

This paper is based on three studies that employed different forms of data collection and analysis, and focused on different types of experience: of those with mental distress, who are often pathologised under the rubric of 'mental illness'; of those affected by Multiple Sclerosis (not just patients but also their family members); and of those using NHS services. All three studies had an analytical focus on how people's personal experiences were positioned as, or contrasted with other, forms of knowledge, expertise and evidence.

Case A draws on ethnographic research conducted by Tehseen Noorani (TN) of voice-hearing and bipolar SHMA groups from 2007 to 2011 (Noorani, 2013). The findings from this project are supplemented by subsequent personal communication between TN and other self-help researchers, including discussions within the self-help and mutual support interest group of the community psychology division of the American Psychological Association, and empirical literature from community psychology, sociology and public health. Ethical approval for the initial ethnographic project was received from the Bristol Frenchay NHS Research Ethics Committee (09/H0107/19).

Case B draws on qualitative research on online patient activism and experiential information sharing in relation to a controversial theory about and associated intervention for Multiple Sclerosis (MS), which received significant media, academic and popular attention between 2009 and 2014 (Mazanderani et al, 2017). Fadhila Mazanderani (FM) studied this case over an extended period (2011–2016) through different methods – qualitative interviews, document, video and text analysis. Ethical approval for the initial study was received from the University of Warwick's Biomedical Research Ethics Committee (96-03-2011 AM0).

Case C draws on multi-sited ethnographic research conducted by Farzana Dudhwala (FD) in four NHS Trusts across England in 2016–2017. This formed part of project INQUIRE, a National Institute for Health Research (NIHR) funded study to understand online patient feedback from multiple perspectives, using different methods. Engagement with the Trusts involved: interviewing and/or conversing with 60 staff members working at different levels (for example, patient experience managers, senior matrons, ward nurses); participating in patient experience and

service improvement meetings; gathering and analysing patient experience reports, dashboards and time-series data; and participating in quality improvement workshops. Ethical approval for this work was received from MS IDREC/CUREC reference R32336/RE001.

### *Combined analysis*

Three authors (FM, TN and FD) presented together on a panel that explored the shifting dynamics of experience in contemporary healthcare, with a particular focus on interrogating the notion of ‘expertise-by-experience’. This workshop prompted the authors to consider commonalities and differences across their respective areas of study. Following the workshop, each author individually wrote a summary of their case reflecting on: a) how, for whom and when experiences of a phenomenon was treated as a form of knowledge; and b) how this interacted with other forms of knowledge, evidence and expertise circulating in the field in question. We adopted a constructivist approach when writing these summaries, paying attention to how personal experiences were *turned* into knowledge in our different cases (Blume, 2017). We did not make judgements about whether we considered the experiences to be a legitimate source of knowledge (an essentialist approach) or whether they ought to be recognised as such (a normative approach).

We compared and contrasted our materials, situating our findings within a review of social science literature on the relationship between experience and knowledge in contemporary healthcare. Four cross-cutting themes emerged: a) how technologies shaped what and how experience was seen as knowledge and/or evidence; b) the temporal dimension of how and when experience was treated as knowledge and/or evidence; c) the significance of two kinds of expert necessary to translate experience into knowledge and/or evidence (the now familiar experts-*by*-experience and the rarely discussed experts-*of*-experience); d) how a wider evidentiary imperative shaped what, when and how experiences were treated as knowledge and/or evidence. Below, we provide an overview of each case, highlighting key themes in relation to the specific context within which they emerged. In the Discussion, we bring the themes together, putting our findings in conversation with wider social science literature where relevant.

## **Findings**

### *Case A: self-help and mutual aid groups*

There is great variability across SHMA groups, each of which has its own history and orientation(s) toward the larger world, including towards mainstream ‘science’ and ‘politics’. However, there are a number of significant commonalities. Broadly defined, SHMA groups are where members share common problems, benefit from reciprocated problem solving, and voluntarily attend meetings, and where groups tend towards self-directed leadership and do not oblige attendees to pay fees (Humphreys, 2004: 14). They can be distinguished from more generalised support groups offering connection, friendship, and information sharing, as they consciously seek to understand, act upon and transform the problems and experiences that have brought them together – they are, in other words, epistemic communities.

In most SHMA groups, experiences are shared in circles, with ground rules including respect for others' interpretive frames, minimal judgement about others' experiences ('cross-talk'), confidentiality and active listening. Groups develop specific technologies that emerge over time, such as role plays that structure experience to generate insight. Knowledge formation in this context demands attending to how to make sense of and aggregate dissimilar experiences, and learning how to tell one's story in a more nuanced way. Experiences shared within group meetings count as knowledge of what has happened and as evidence of what could happen for others living with similar problems, concerns or conditions.

The temporal dimension of knowledge generation is significant as the sharing of experiences enables members to look both backwards and forwards in time. New members and those who do not share (for example, because they do not feel comfortable doing so) also shape the experiential knowledge produced. New members may ask questions that betray misunderstandings which only a more sustained engagement with similar others and/or their problems will come to reveal. Over time, these newcomers' personal stories reach back further in time, offering an ordered and often nested series of experiences and reflections regarding the central problem or issue bringing the group together.

While everyone in SHMA groups is considered to be producing knowledge through sharing and reflecting upon their experiences, individuals who have been immersed in groups for long periods are often considered to have a particular 'depth' of experiential knowledge on the basis of having heard more stories, similar and dissimilar from their own (Noorani et al, 2019). Over time, these members become known as the go-to persons to get the best advice on particular issues and, arguably, are best placed to represent the group in other forums, including policy ones, as 'experts-by-experience' (Noorani et al, 2019). However, they are not simply experts of their own experience. Through group immersion and exposure to multiple different experiences, they ideally also cultivate knowledge of others' experiences and knowledge of how those experiences are shared, differ, relate and change over time.

Conversations within SHMA groups often include experiences with and reflections on scientific claims, medical interventions and evidence, which drive further self-experimentation and reflection. Nonetheless, the experiential knowledge produced in groups is usually framed as distinct from and complementary to professional knowledge and biomedical evidence (Borkman, 1976; Humphreys, 2004; Noorani, 2013). Indeed, its epistemic value rests on the fact that it is *not* the same. Group knowledge is not only a 'know-that' kind of knowledge but also a 'know-how' – how to experiment with one's distress or problems; how to communicate what one experiences to those who do not experience it, and so on (Pols, 2014). An awareness of this difference is important when considering how to translate SHMA knowledge into policy domains that emphasise the importance of being evidence-based.

Rather than trying to intervene in policy directly, many SHMA groups have sought to provide alternatives and complements to mainstream service provision by existing 'alongside' it. Notably, over time the Hearing Voices Network (HVN) developed as an influential network contesting entrenched biomedical framings of voice-hearing, psychosis and schizophrenia, with an active website and local groups that were or were not affiliated with a national office housed at MIND (an organisation run in large part by psychologists). As emerging HVN 'leaders' began to train mental health

professionals about experiences of voice-hearing, they developed affective technologies for simulating experience (for example, voice-hearing role plays) to reverse the power dynamics in the room at the beginning of trainings, turning non-voice hearers into participants in a new kind of experience that the trainers were the experts of. Through trainings, teaming up with sympathetic academic researchers, outreach and facilitating and encouraging the setting up of myriad SHMA groups, the HVN has come to be relatively powerful without having sought institutional legitimacy or contesting institutional psychiatry head-on. Today even secure mental health units in the UK have invited the HVN to set up groups.

The HVN's influence continues to be shaped by the demands for evidence-based research and practice, with key survivor-researchers in the network publishing peer-reviewed research that draws on, works with and reflects upon the experiences of voice-hearers in the movement (for example, [www.hearing-voices.org/tag/research/](http://www.hearing-voices.org/tag/research/)). Some attempts to 'operationalise' SHMA knowledge so that it can be used in clinical and/or epidemiological research, as well as in policymaking, have been critiqued (Humphreys and Rappaport, 1994), both from within SHMA communities (for example, for failing to recognise the specificity and inventiveness of the knowledge provided by SHMA) and without (for example, questioning the validity of the knowledge and the representativeness of the expert-by-experience). One consequence of trying to adhere to the dictates of evidence-based policy is that SHMA practices are often conflated with 'self-help' more broadly, including, for example, online courses and 'bibliotherapy' (Watkins and Clum, 2008).

### *Case B: the sharing of experiences in online patient activism*

Search for almost any condition or healthcare service in the UK online and one will quickly find personal accounts, reviews, ratings, and comments shared on different platforms. Research across different conditions has shown that many people consider the experiential information they find online a source of knowledge and regard those sharing it as having expertise (Whelan, 2007; Akrich, 2009; Mazanderani et al, 2017). Moreover, digital technologies and platforms can form part of wider epistemic projects, with members forming 'epistemic communities' online (Akrich, 2009). That said, simply sharing an experience online does not mean it will be considered knowledge or evidence, or that the person sharing it will be deemed an expert. Rather, experience comes to be seen as knowledge through practices and technologies that differ between interactions, groups and communities.

To illustrate how this plays out in relation to online patient activism, we focus on a case study on the sharing of experiences of a contested intervention for MS – modified venous angioplasty (Zamboni et al, 2009). Within a week of the publication of a scientific paper that suggested MS was associated with venous abnormalities – termed Chronic Cerebrospinal Venous Insufficiency (CCSVI) (Zamboni et al, 2009) – people affected by MS were discussing it online. They quickly sought interventional radiologists willing to test them for venous abnormalities and, if deemed necessary, to perform venoplasty. A small number of patients, initially in the US, but quickly followed by those in other countries, had the intervention (Rhodes, 2011). Many reported positive results across digital technologies such as YouTube, patient forums, Facebook, blogs and in the mainstream media.

Indeed, one of the main reasons CCSVI galvanised patient support so rapidly was the large number of positive accounts people shared online soon after the publication of initial research studies. Experiences shared through video and other visual media and technologies (images, scans and charts) were particularly influential when it came to informing other patients' decision making (Mazanderani et al, 2017). In the early days of the controversy people searching for the intervention were likely to find numerous positive experiences that reinforced each other. While people did share neutral and even negative experiences, positive ones tended to be more highly ranked in Google and YouTube searches (Mazanderani et al, 2013). There are many reasons for this. There is a general bias towards sharing news about seemingly successful medical treatments; private clinics offering the treatment quickly posted advertisements in the guise of experiential accounts; and online practices of linking and liking can percolate popular (in this case positive) videos to the top of search results (Gerlitz and Helmond, 2013). Community dynamics also played a role. People who had less positive experiences were sometimes reticent to share them, as they did not want to dash others' hopes, while some even feared being verbally attacked by advocates of the intervention. Thus, both the technologies people used to share their experience and the time at which they shared it influenced whether others would see it and use it as an epistemic resource.

Certain individuals emerged as opinion leaders through a combination of sharing their own experiences, engaging with medical research and terminology, being active in online communities and supporting others. It is important to note that they rarely claimed to be experts. Individuals posting their experiences repeatedly stressed that they were specific to them and that people should always consult a suitable medical expert. Despite this, other patients often interpreted these experiences as evidence for the (at least potential) efficacy of the intervention. Moreover, while these opinion leaders' starting point were their own experiences, they, like members of the SHMA groups discussed earlier, actively engaged with other people's experiences – for example, through providing support online or by attempting to collect experiences more systematically. They, in other words, developed expertise in responding to and collating others' experiences. They were also often proficient in medical terminology, played a mediatory role between patients and medical experts, and in some cases went on to be patient representatives in research and policymaking arenas.

While the biomedical community was frequently criticised, and some posters made claims that contradicted biomedical orthodoxy in relation to MS, medical knowledge, authority and evidence was rarely abnegated wholesale. Medical research was discussed and interpreted (albeit in ways that many scientists and clinicians would have challenged), and sympathetic experts were actively engaged with. In recognition of the need to be 'evidence-based' in order to be taken seriously by policymakers, biomedical researchers and healthcare practitioners, some patients tried to aggregate their experiences in more 'scientific' ways (for example, through a tracking thread on one forum and a special tracking service on a website). The aim here was to systematise experiential accounts into something that would be more recognised by the scientific community. As with the SHMA groups discussed above, these attempts met with a mixed response. They were seen as a valuable attempt at engaging with scientific methods to build up an evidence base that, while not necessarily scientifically robust, could inform other patients and galvanise further research. But they were also

deemed insufficiently rigorous, opening up the community to further criticism from scientific experts.

At the time of writing, the prevailing opinion of the biomedical establishment is that there is no association between CCSVI (if such a syndrome exists) and MS, and no benefits in treating MS with venous angioplasty. Yet this case shows that experiential information shared online can: influence patient decision making; contribute to the formation of people who are seen as experts by virtue of their own experiences and through representing others'; put considerable pressure on national and regional healthcare services, policymakers and clinicians; and play a role in shifting research funding agendas (Laupacis and Slutsky, 2010; Chafe et al, 2011; Pullman et al, 2013).

### *Case C: patient and service user experiences as feedback in the NHS*

Our final case study is of patient and service user experiences collected through different methods across services in NHS England. Previously, a lot of patient experience was collected via paper questionnaires or written letters, and there was a time lag for this experience to get to the right people. Thus, it was much easier to 'contain' the experience if thought to be inconvenient or irrelevant. Over the past 20 years, there has been an increased emphasis on using digital technologies to collect and respond to patient experiences of NHS services, sometimes in real time (Dudhwala et al, 2017). As a result, people can now comment, rate and review their experiences of NHS services across a range of platforms. This includes: feedback mechanisms run by or closely linked to the NHS in England, such as the Friends and Family Test ([www.england.nhs.uk/fft/](http://www.england.nhs.uk/fft/)) and the NHS Choices website ([www.nhs.uk/](http://www.nhs.uk/)); dedicated third-party healthcare feedback platforms such as Care Opinion and iWantGreatCare; and more generalist commercial ratings and reviews platforms such as Yelp and Google reviews. Both the timing of and technology used for patient feedback shape what and whose experiences are incorporated, used and responded to and in what ways.

Digitally mediated feedback systems enable Trusts to meet national regulations and legal requirements, adhere to Care Quality Commission targets and meet NHS targets for the collection of patient experience. It promises to reshape organisational policy and practice. Nevertheless, three key factors shape the likelihood of an experience becoming a source of data that can be used to generate evidence and be turned into knowledge. Firstly, whether the experience has been *sanctioned* by being shared through a medium approved by the relevant NHS Trust as an official feedback channel. Secondly, whether the experience has been *solicited* from a healthcare practitioner or patient experience monitoring service. Thirdly, whether the experience has been deliberately *sought* with the specific intention of being used for a particular purpose. Any one or all of the above serve as preconditions for an experiential account to be used as evidence in the wider NHS service user feedback landscape (Dudhwala et al, 2017).

Beyond these factors, an experience shared on a publicly available and accessible forum that gains media or political attention will often prompt a Trust to take it more seriously and openly engage with it. Thus, when experiences are in the public domain, there is a responsibility on the Trusts to take them into account, especially given the contemporary emphasis on patient-centred care and the patient voice.



Moreover, the public availability of online digitally-mediated feedback extends its reach: there is now the potential for thousands of people to be following a feedback story, while also keeping track of the response by the Trust. Consequently, Trusts not only feel pressure to improve their services as a result of the feedback, but also to leave a public account of having done so. We are reminded here of [Button and Sharrock's \(1998: 75\)](#) idea that social actions 'are not only done, they are done so that they can be seen to have been done'.

Certain types of patients and their experiences face significant challenges in being listened to or taken seriously as an epistemic resource. In the case studied, the experiences of patients with mental health difficulties were seen as particularly difficult to incorporate and respond to (for more on the implications of 'sanism' on the experiences of people with mental health conditions being seen as having epistemic value see [Poole et al, 2012](#)). At the same time, there are questions to be asked about *whose* experience is relevant, especially when it comes to children and older patients, where a family member, rather than the patient, may be the person providing feedback, and where opinions and experiences can vary considerably between the patient and their family members regarding what counts as quality care.

Within the world of healthcare service feedback, significant importance is attached to *patterns* and *trends* in the changing patient experience. People working as patient experience leads and data analysts (titles and roles vary) in NHS Trusts and the healthcare service more generally do much of the work involved in quantifying individual narratives. Their work involves filtering, aggregating, collating and isolating patient experience as it comes in through the various sources. They are often the ones responsible for creating patient experience dashboards – which mediate patient experience for Trusts. Very few members of staff other than those on the patient experience or quality improvement teams have the permission or expertise to access or use the raw patient experience data.

Meetings regularly start with the sharing of an emotive 'patient story', aimed at generating empathy and relatability with patients, staff and patient-facing clinicians. While focused on an individual's experiences, these accounts are chosen by a staff member for being illustrative of a broader issue. These staff members usually do not have direct experience of the event, but are familiar with the case in question and have seen examples of similar experiences. Staff members working with patient experiences, therefore, develop skills and proficiencies at selecting and retelling them where appropriate, turning them into evidence through processes of codification, aggregation and analysis. They may not be experts-by-experience, but develop expertise in relation to working with, extracting and sharing digitally-mediated experiences within the specific institutional contexts of the NHS and the demands for evidence-based policy and practice therein.

## Discussion

### *Technologies for turning experience into knowledge and evidence, aggregation and personalisation*

Digital platforms and social media use provide clear examples of how technologies mediate experience (Cases B and C). By taking a wider view of technology as techniques aimed at shaping experience in specific ways, we can add the sharing of

stories in the SHMA groups of Case A. Indeed, across our case studies and wider literature, arguably *the* most dominant ‘technology’ for articulating experience, and hence a crucial steppingstone for turning it into knowledge, is the sharing of experiential accounts or narratives.

As illustrated in each of our case studies, the technologies through which an experience is articulated and shared – a story in a mutual aid group, a posting on an online forum, or a review on a feedback platform – plays a crucial role in shaping whether, how, and by whom that experience acquires the status of knowledge or evidence. Nonetheless, a common thread is that technologies for turning experience into knowledge or evidence look to reconcile the subjective, personal and emotive aspects of experience with a need to go beyond individual ‘opinion’. To do this the patient and service users across all three cases developed strategies and tactics for moving between the specificity of individual experience and its general applicability (see also [Moreira, 2014](#)). Various norms and rules shape how they achieved this, but a crucial commonality was they all employed some mechanism (explicit or implicit, informal or codified) for *both* aggregating *and* personalising experience.

In Case A, stories shared in SHMA groups converge and diverge in overlapping ways such that long-term group members can distinguish commonalities from idiosyncrasies. This is tied to group culture and the approach the facilitator takes, but usually the way people come to know others’ stories is through their own. We see with Case B how this can happen in online forums and social media – for example, through the creation of dedicated forum threads, practices of cross-referencing, linking and liking, all of which serves to create agreed-upon, mutually reinforcing patterns within particular groups. Sometimes this emerges out of a confluence of factors, from community dynamics to platform architectures, but it can also be a result of the active policing and moderation of platforms ([Ziewitz, 2017](#)). In Case C, patient experiences are processed through automated technologies and algorithms deployed by different professionals, such as health experience leads and data analysts, while, at the same time, individual stories are drawn on for their emotional power.

### *The temporal dimensions of when experience becomes knowledge or evidence*

On the one hand, experiences entail immanent temporalities and on the other, they are mobilised into different temporalities in the process of becoming knowledge and evidence. In Case A, the sharing of experience evidences what has happened and could happen. Transforming experiences into knowledge requires reflexive practices of telling, hearing and retelling stories. Experiences reported in SHMA groups grow over time for the sheer reason that no member’s journey is complete, and others’ stories provide new lenses through which to view one’s own. The stories of SHMA group old-timers unsettle and enfold prior moments of certitude, revealing traps in knowing and the dangers of divorcing knowledge from ongoing practice. Collective knowledge is durative and operates within its own unfolding present, as different group members can offer mutually exclusive but compelling perspectives or interpretive frameworks.

In Case B, temporality is built into the narratives mobilised through patient and service user activism; experiential accounts shared online move backwards and forward through time, with the past, present and future of those affected presented in different

ways. Knowledge is generated in part through embedding experiences within patients' wider biographies. Due to experiencing what is an incurable condition, both patients and their families stress the immediacy of the issue, arguing that their experiences should be taken seriously precisely because of the lack of suitable scientific evidence on experimental therapies. In addition, social media platforms allow for the rapid – some would argue dangerously so (Gafson and Giovannoni, 2014) – sharing of experiences that can go viral.

Temporalities of progress are most evident in Case C, where experiences are typically captured as data 'snapshots', with temporality being constructed post-data collection to produce diagnostic narratives evaluating services, institutions and policies. The point of collecting data about experiences is to improve the operations and policies of health services. While in all the cases experience cannot be obsolete or irrelevant if it is to be considered knowledge, here the reduction of the time lag between experiences and their remediation as evidence is particularly important. Case C also illustrates how the temporal cycles of media and policy attention play a role in how and what experiences become used as evidence. The activism of Case B also invokes temporalities of progress through a focus on finding a cure, while in both A and B we sometimes (but not always) find that emphasis is placed on identity associated with a specific set of experiences that those living with a condition both share and are distinguished by.

### *Moving from 'experts-by-experience' to an increased recognition of 'experts-of-experience'*

Questions about the legitimacy of patient representatives in healthcare persist, with concerns regularly raised about the narrowness of the selection of representatives and the role of professional (or professionalised) representatives (Caron-Flinterman et al, 2005; Horner 2016; O'Shea et al, 2019). Becoming proficient with biomedical knowledge enabled AIDS activists in North America and Western Europe to intervene in biomedical research and policymaking. However, it also caused tensions between 'lay' experts (non-credentialed activists with significant experiential and biomedical knowledge) and 'lay' activists embedded in the grassroots (Epstein, 1995: 429).

These debates are indicative of a pervasive tension in the inclusion of patients and service users based on personal experience. They are expected to provide first-person testimony, literally embodying the issue under discussion, while representing a wider community or group: they are not simply 'experts-by-experience' but experts of others' experiences. Indeed, members of successful patient organisations draw on their own experiences and develop sophisticated techniques for working with others' (Rabeharisoa and Callon, 2004). However, the relevance of expertise of experience has received little explicit attention within healthcare service and policy research. Both Case A and B illustrate the importance of expertise for turning experience into different forms of knowledge and evidence, which is reinforced and extended by findings from Case C.

As experience is increasingly foregrounded as a valuable resource in and for healthcare, there has been a growth in professionals specifically tasked with researching and managing people's experiences (Case C). Much work has focused on developing methods to turn experiences into epistemic resources in a context that

foregrounds understandings of ‘evidence’ that do not sit easily with the embodied, specific, and emotional dimensions of patients’ experiences (Robert and Cornwell, 2013; Ziebland and Hunt, 2014; Robert et al, 2015). Various healthcare workers, researchers and policymakers develop this form of expertise as at least one aspect of their work, working alongside patient experience managers and data analysts. They, like patient representatives, cultivate expertise centred on the management and articulation of experience, albeit of a different kind. With some exceptions (Moreira, 2014), there is a dearth of social scientific literature on the emergence of new experts of experience within healthcare services and policymaking, an area that deserves further exploration.

### *Experience and evidence: the implications of a wider evidentiary imperative in healthcare*

Traditionally, patient experience and the kinds of knowledge accruing from it have been seen as subjective and individual. It is precisely this subjectivity that made this form of knowledge distinctive and valuable (Borkman, 1976). As illustrated in all three case studies, this remains the case today, where despite the prevailing epistemic climate of evidence-based medicine and policy, it is often individual, publicly shared, and highly emotive experiences that end up gaining attention and shifting policy agendas (Woods et al, 2019). When it comes to bringing about changes to practices within NHS Trusts (Case C), experiences shared on publicly available and accessible forums are often the most successful, even more so when mainstream media broadcast the story. Similarly, patient activists whose stories gain media and popular attention often go on to more formalised roles, becoming *de facto* spokespersons for a given issue (Case B).

Yet, across our case studies, personal accounts needed to be supplemented and supported by other forms of evidence for them to be taken seriously in a climate that emphasises ‘objective’ scientific decision making in healthcare. Patient groups, activists, communities and organisations have actively responded to the call for evidence, giving rise to what has been conceptualised as ‘evidence-based activism’ (Rabeharisoa et al, 2014). An acceptance of and even active engagement with this evidentiary imperative is present in online health-related communities (Case B), with different groups developing systematic processes for aggregating experience to provide evidence for advocacy and other purposes, such as convincing researchers and policymakers of the validity of a particular treatment or intervention. This entails working closely with other forms of knowledge and expertise, such as the selective collaboration between patient and user groups with ‘friendly’ disciplines and experts, a recurring theme in Cases A and B and the wider literature.

The evidentiary imperative played out in multiple ways in our case studies. Experiential knowledge and associated technologies can become loosely interpreted, with emphasis placed on aspects that can be more readily operationalised (for example, through clinical trials) in a bid to meet the requirements of ‘evidence-based research’ while maintaining that subjective experience is being valued (Case A). Relatedly, quests for coherence can result in certain accounts and experiences dominating, while others are silenced, either unintentionally or due to political expediency (Mazanderani and Papparini, 2015; Horner 2016; Woods et al, 2019). Sometimes, when patient activists work on systematising experiential accounts, hoping to make them

more ‘scientific’, they can end up being critiqued for doing ‘bad science’. By contrast, a powerful personal narrative shared through certain media can be very effective at getting them heard (Case B).

Rather than reading this as a failure of experience-based knowledge to meet the standards of evidence-based policymaking, we suggest it is indicative of the entanglement of the sometimes-reinforcing, sometimes-contradictory democratic and epistemic rationalities at play even in cases where ‘objective’ evidence is supposedly prioritised (Horner, 2016). A focus on which narratives get heard complements long-standing concerns regarding which individuals get ‘a seat at the table’ (O’Shea et al, 2019). How these narratives then play out once ‘at the table’ depends on various factors. For instance, disembodied stories presented by patient experience leads and managers can be used to support specific agendas, amounting to the person who shared the experience paradoxically both getting a virtual seat at the table and being silenced (Case C). By contrast, an established member of a SHMA group who brings a (albeit bounded) heterogeneity of experiences with them may be more able to question the assumptions made in ensuing discussions that purport to take up certain narratives as evidence for particular policy changes (Case A).

## Conclusion

The inclusion of patients and service users in healthcare-related decision making, from service redesign to policymaking, continues to grow in the UK and many healthcare systems around the world. Doing so is both a democratic and epistemic imperative as service users have considerable knowledge about the conditions they live with and the services they use. Yet incorporating people’s experience into healthcare remains challenging. Rather than providing solutions or guidance about how to tackle these challenges, we have unpacked some of the complexity involved. Through comparative analysis of three case studies, we have drawn attention to a number of key themes of relevance to scholars and practitioners working on and in the inclusion of patients’ and service users’ experiences in healthcare. It is not our intention to be prescriptive; indeed one of the contributions of this paper is to argue against one-size-fits-all approaches to what are contextually-embedded processes. However, with that in mind, below we reflect on some of the wider implications of our analysis for research into, and practical initiatives to increase patient and service user involvement in, healthcare.

We have drawn attention to the role different technologies and temporalities play in (re)mediating experience as knowledge and/or evidence. Extant research has already stressed the constructed and performative dimensions of knowledge, including that of an experiential kind. However, as we have shown across all three cases, the specifics of the technologies and temporalities involved significantly impact how, what and when experience(s) are treated as knowledge or evidence, and consequently who gets included in decision-making processes. Shifting the focus to *how* and *when* experience gets treated as knowledge, as opposed to *whose* experience is included, can, we hope, contribute to shifting the terms of the debate from an emphasis on what Annemarie Mol has called the ‘politics of who’, to a ‘politics of what’ (Mol, 2002: 7). This is becoming increasingly salient as the contemporary emphasis on incorporating patient and service user experiences in healthcare is often allied with the deployment of ever more complex technologies and platforms, bringing in their own histories, logics and commitments.

We have highlighted the paradoxical situation where the power of experiential accounts to enact change is often premised on their individual, subjective and emotive dimensions yet, at the same time, is subject to the wider evidentiary imperative shaping what counts as valid knowledge in healthcare. Again, this is not a new finding. Scholars interested in community participation and co-production have repeatedly flagged up how hierarchies of knowledge, often associated with long-standing power differentials between experts and ‘lay’ people, continue to persist (Horner, 2016). This situation is particularly heightened in the context of mental health research and service delivery (Rose and Kalathil, 2019), but remains common in other areas of healthcare where patients and members of the public wanting to effect change often lack the resources, training and funding needed to produce the kind of evidence deemed necessary by decision makers. Clearly, this places significant constraints on service user involvement, especially in cases where they are challenging the status quo. However, we have also shown that patients and service users find creative ways to both resist and work with this evidentiary imperative.

Just as there are knowledge and power differentials between community groups and the institutions and organisations they seek to change, so too are there differences in the distribution of knowledge and power within community and patient groups. In cases A and B, we drew attention to how certain individuals gained particular recognition because they were deemed to have a certain depth and breadth of relevant knowledge. Attempts have been made to legislate for the inclusion of such knowledge (Matzat, 2006) – what has elsewhere been called ‘deep experiential knowledge’ (Noorani et al, 2019). While this may not be possible or even desirable in every case, it flags up the importance of not only including people who have experience of a phenomenon, but also those that are aware of both the commonalities within, and the differences across, the constituencies they represent. This highlights the need for increased scholarly attention to be given to emergent practices, technologies, and expertise aimed at turning experience into different forms of knowledge and evidence – what we have called expertise *of* experience; for example, the growing contingent of healthcare researchers and policy professionals (some more, some less professionalised) – such as patient experience leads, managers and data analysts – for whom a considerable portion of their jobs involves working with service user experiences. Social scientists have been at the forefront of the drive to take patients and service user experiences seriously and are therefore in an excellent position to do this critical work. A key part of this involves being reflexive, avoiding an overly-simplistic emphasis on the democratic necessity of including experience, while simultaneously paying attention to how epistemic practices (including social scientific ones) and power dynamics shape what ends up counting as knowledge, evidence or expertise.

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### Research ethics statement

Formal institutional research ethics was received for all the three case studies presented here.

Case A received ethical approval from Bristol Frenchay NHS Research Ethics Committee (09/H0107/19). Approval received 22/03/2009.

Case B received ethical approval from the University of Warwick's Biomedical Research Ethics Committee (96-03-2011 AM0). Approval received 16/01/2012.

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### Contributors

FM, TN and FD conducted, analysed and wrote up the three case studies. ZTK contributed to the literature review. All authors contributed to the analysis and writing of the paper.

### Conflict of interest

The authors declare that there is no conflict of interest.

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