Introduction: What is the Role of Lived Experience in Research?
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Experts by Experience in the context of mental health are those who have personal experience of using, or of caring for someone who uses, health, mental health, and social care services. How do people with lived experience of mental illness contribute to scientific knowledge and personal growth? This volume comprises three distinct philosophical perspectives focused on specific theoretical and practical challenges for theorising about *expertise by experience* in the philosophy of mental health research: the idea of subjectivity in 'lived experience' and the issue of scientific validation, the prospects of shared meaning-making, and the problem of injustice in 'co-production', and the philosophical role of values in navigating difference and value disagreement in psychiatry.

The philosophical concepts of 'expertise by experience', that is, expertise based on one's personal experience of some condition, and 'participatory research' are rapidly expanding areas of interdisciplinary research. Both concepts are increasingly present in medicine and mental health, and link academics, clinical practitioners, charitable foundations, and policy makers to develop an inclusive and efficient approach to mental health in the service of patient empowerment and agency. Towards the end of the twentieth century, it became increasingly clear that the scientific empiricism of modern medicine, although necessary, was not sufficient as a basis for delivering clinical care that best served the patient. The first indication of the centrality of patient values and the notion of *expertise by experience* as essential components of adequate mental health research, in reaction to the technical professionalism of medical science (and what we may think of as the contrastive concept of *expertise by medical training*), was the development of medical ethics with its promotion of patient autonomy. However, as noted by Bergqvist's contribution to this volume below, while autonomy-driven approaches went some way to reinstate the importance of the person in medical science, medical ethics itself has developed into a new form of increasingly professionalised medical science rather than offering mechanisms for empowering patients. (See also Fulford and Bergqvist, in press.) It was against this background that in the early years of the twenty-first century, concepts like person-centred

care, co-production, and shared decision-making made their appearance in medicine and related areas of clinical practice (Fulford and Bergqvist, in press). These concepts were each concerned, in different ways, with restoring the patient to centre stage in health care. Salient examples in psychiatry that centre on the individual historical person and their ecological context are found in associated models of recovery and person-centred management. Such models are geared towards the restoration of well-being and re-engagement in major social, vocational, and family roles (Maj *et al.*, 2020).

Philosophical methodologies are well positioned to address the gaps in our theoretical understanding of concepts of *quality of life* and *shared decision-making*, both of which are key to the development of an inclusive and efficient approach to participatory mental health as the gold standard for good practice. This is particularly true regarding the role of patients as experts, as real contributors of knowledge in the establishment of health literature bases, especially in areas of what is sometimes described as severe and enduring mental illness ('SMI'). Other emergent research areas in the adjacent cognate field of public mental health include how we might best improve the mental health of our populations, and how we consider incidence and prevalence of both mental illness and poor well-being. Potential tensions between mental health advocacy and public health campaigning may include the impact upon admission rates and levels of stigma if public mental health approaches were designed with the intention of reducing prevalence of mental illness rather than identifying what, if any, levels of well-being amongst populations necessitate a cohesive approach to mental health. This is especially pertinent given existing philosophical disagreement in relation to diagnosis and diagnostic precision.

How we understand our own experiences, and what insights that experience gives us into the generalisable nature of some phenomenon or other are much discussed topics in epistemology alongside the social dimension of knowledge (where the latter concerns social injustice and positionality in our knowledge-gathering capacities). Epistemological arguments have been given which indicate that lived experience, that is, first-person, direct acquaintance, with some phenomena or other provides an unrivalled insight into some specific quality of that experience. This is sometimes, though not always, associated with standpoint epistemologies (e.g., Harding, 2004; Medin,a 2013), whereby one's experiential horizon and socio-historical situatedness guides what one can know. Put in simple terms, if you are not personally acquainted with some phenomena, the standpoint theorist would argue, your knowledge of that phenomena should not have parity of importance when compared to lived experience. Even those who disagree with standpoint theory seem to agree that there is

a role – an important one – for insight derived from lived experience. When it comes to scientific research itself, notably that which focuses on the role of first-person testimony, this is no exception.

Researchers in the helping professions such as clinical psychology and psychiatry, for example, are increasingly asked to think about the role of participatory research with people with lived experience of mental illness in designing and delivering salient empirical studies and research projects. The consensus, whether driven by desires for equal participation, or for broadly applicable research findings, is that lived experience ought to have a role in how we conceive of knowledge. The same holds true for research into mental (ill) health. Mental health is itself a contested, and complex concept. Often, individuals who have lived experience of mental ill health can be considered less reliable as knowers and as agents in interpersonal settings, as irrational, or as otherwise lacking in some important virtue required to be considered an authority. This is often indicated as being in large part because of historic and enduring stigma associated with mental ill health and its association with criminality, dangerousness, and untruthfulness. Those with a diagnosis, or who are presumed to have a psychiatric disorder or condition, often are marginalised. Even without such presumptions, the role for knowledge derived from lived experience is unclear. Testimony, narratives, and anecdotes are not viewed, in many instances, as being of the same calibre as scientific testing, which is supported by repeatability, hypothesis, and quite often, large-scale trailing of pharmacological, technological or community-based intervention. This raises the question of whether knowledge derived from lived experience *should* be valued as equal to that gained via traditional scientific methodologies. Impartiality and objectivity are called into question when we attempt to generalise from our own experience. And psychiatric or psychological disorders are somewhat unique in that they affect one's experiential states. When one's own psychological systems are in some way affected by a mental illness, can that individual appraise those experiences as if an impartial bystander?

While there are many research development reports on what in the United Kingdom is known as Patient and Public Involvement (PPI)[1] and Expertise by Experience in mental

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[1] Other cognate terms to that of 'PPI' and 'EbE' (that are *not* equivalent in meaning) found in the literature surrounding shared decision-making include 'experience-based co-design' (EBCD), 'service-user engagement', 'participatory research', 'action research', 'user-led research', 'survivor-led research' – to name but a few.

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health research in the United Kingdom, this volume is unique in the ways that it both highlights the relationship between conventional areas in philosophy, psychiatry, and mental health research, and further crosses conventional boundaries in philosophy (such as social epistemology, moral philosophy, and philosophy of science) in order to understand the ethical and scientific significance of lived experience in the philosophy of psychiatry and mental health. New understandings of the role for and of lived experience in philosophical discourse, clinical practice, and more traditional mental health research, as discussed in this volume, are varied and lively. The essays contained in this collection engage with lived experience at a range of levels of the research process and propose a variety of novel views. First, by focussing on the scientific impact of patients as stakeholder experts, Experts by Experience (sometimes abbreviated 'EbE'), rather than on individual vulnerability to mental ill health and responsiveness to categorical diagnostic measures and treatment involving predictive biomarkers (as seen in the growing field of psychiatric genetics), it reframes the philosophical question of subjectivity in 'lived experience' in connection with the question of scientific validation. Second, by exposing the ways EbE contribute as knowers in articulating values as theorists, advocates, and peer-support in meeting the complex challenges of knowledge transfer in helping people make better decisions, it targets the social dimension of knowledge and epistemic injustice in received models of 'co-production'. Third, by interrogating the diversity of factors that contribute to individual people's well-being, it addresses possible conflicts between different stakeholders arising from value pluralism and a multiplicity of perspectives that often frame the use of psychopathological concepts, which often play a role in determining aspects of quality of life in mental health contexts. Below, we briefly discuss each philosophical thematic research area in turn.

Voicing Lived Experience as Scientific Knowledge
The first section of this volume examines the moral and scientific value of lived experience as scientific knowledge. Research methodologies, and present debates over 'expertise by experience', and funder recommendations (such as that of the Wellcome Trust)[2] about the

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[2] The Wellcome Trust identifies mental health as on of its three key research funding priorities and further defines the very concept of 'mental health research' in co-productive and participatory terms. As they express their position; 'We are committed to the meaningful involvement of lived experience experts in the direction and decision making of the mental

very concept of mental health research as research with 'lived experience experts' agree that there is an important role for individual testimony in research. But, given the contentious way in which lived experience is viewed, particularly in terms of its (lack of) scientific status as validated evidence, inclusion of those with lived experience in research into mental health requires a careful approach to mediating different, and sometimes opposing, values. Mental ill health is linked in important ways to one's social positionality, and relative degrees of privilege, and belonging to a particular community, create inextricable links with values and accepted understandings of important concepts. What does it mean to be 'ill'? How ought society treat those with a psychiatric diagnosis? What is the legitimacy of psychiatry as a discipline of medicine in the philosophy of science in relation to other social movements such as mental health 'survivor' activism (Rashed, 2019) and what Peter Segwick (1982) calls psycho politics? How an individual engages with such questions, and the view they ultimately take, will depend on such values. These guide decisions individuals make, or preferences that an individual may have, when making judgements or decisions about their own care. The role of lived experience in such participatory research approaches in clinical psychology and psychiatry is not a substitute for but is complementary to 'traditional science'. Perhaps, others argue (Tekin, 2011, 2019), self-understanding as guided by social positionality requires that lived experience be used in ways which may not be considered science *proper*, but which nonetheless allow shared understanding and knowledge advancement to take place. Might phenomenological tools, or accounts of aesthetic value, allow us to further our understanding of psychiatry and psychiatric diagnosis?

There are many, of course, who contest the very notion of psychiatric diagnosis whilst simultaneously recognising that support for those in distress is, in most all cases, dependent upon such diagnoses. Making room for different, and competing, understandings of how our social notions of normal psychological function, illness, and dependency may affect the weight assigned to one's testimony is argued, by some, to be a necessity in making room for lived experience. Power dynamics, historic institutionalisation of those considered deviant from the accepted norm, and institutional arrangements, including those prevalent in higher

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health team; the projects and research that we fund; and in the field of mental health science.' See: https://wellcome.org/what-we-do/mental-health

education and research culture, privilege voices considered expert. The notion of lived experience as qualifying one as an expert based on experience (EbE) is an attempted redress of such historic inequities. As the essays in part I illustrate, although the concept of *expertise by experience* has been introduced into the literature and also clinical practice, it has so far done little to allay the philosophical concerns regarding the asymmetry and disparity of weight assigned to knowledge credential offered by those with traditional expertise in comparison with the voices from individuals with lived experience.

Co-Producing Meaning

Person-centred medicine seeks to mediate such differences in knowledge credential, stakeholder voice, and power by creating space for lived experience and individual value preferences in what is known as 'shared-decision making'. Genuine involvement of those with lived experience of mental health concerns, particularly regarding mental ill health prevention, mental health and well-being promotion, and collaborative treatment design, raises a whole host of questions about the prospects of shared decision-making and co-production that are both theoretically and practically important. In addition to the doubts regarding credibility of individuals with lived experience – as noted above – *how* EbE ought to be included in discussions, in planning, and in implementation of public mental health approaches is a contentious topic. Research has indicated that thus far, even well-intentioned researchers exclude the views of EbE in producing summary reports and policies, raising the question: if the narratives of those with lived experience are ignored, how are we to truly consider any approach to mental health to be 'co-produced'?

Related and relevant further questions include: what might the impact be upon individuals of being considered at risk of being mentally ill? Are there positive duties that clinicians and those implementing mental health as a public health approach must empower patients? What is the moral significance of the first-person perspective? And how do epistemic violence and social injustices impede or impact upon our sense of self in living with a mental health condition? Given recent focus upon public campaigns promoting discussion of mental ill health, additional questions focus upon access to mental health support services resulting from health promotion campaigns. Should peer support services be viewed as sub-clinical and less effective? Who is responsible for ensuring population mental health? How should the 'othering' of EbE be countered in designed to achieve a genuinely collaborative public mental health strategy?

Navigating Values and Difference

What guides the design of a participatory mental health approach, and indeed the inclusion of those with lived experience in mental health care design and treatment methodologies, is dependent upon mediation of differing values. Mental ill health is commonly cited as being largely caused by social factors, and accordingly, individuals and differing social community groups prioritise different values and goals dependent upon their experience. Values-based medicine and related person-centred approaches to health care purport to offer ways of competing values being accommodated, and several practical guides exist, offering support for clinicians adopting a person-centred approach. However, clinicians and those with lived-experience disagree often, leading to debates around values and how best to proceed with preventative and recovery-focused interventions. For instance, how should public mental health accommodate the positive experience reported by many with the lived experience of a severe and enduring mental illness (SMI) of their symptoms? Philosophers have contributed to the debates surrounding the 'Mad Activism' movement, and these and related areas are addressed by several authors in this volume below.

The volume's experience-led philosophical focus, incorporating a co-production approach, considers the communal, shared aspects of identity and experiences beyond recording patient values from a culturally neutral, single management perspective. Special attention is placed on the role of contested concepts and on alternative interpretative approaches based on value pluralism and diverse storied experiences to understand the mechanisms by which shared decision-making can play a transformative role in creating healthier societies. For example, how can peer support assets to build the capacity for self-management support societal well-being? What is the role of intersectional (for instance as articulated by the black feminist Patricia Hill Collins, 1990), contextualised experiences and needs of persons with lived experience including their self-identified social networks, such as family?

Other important questions concern what is permissible to value. How do differing cultural attitudes and approaches to psychopathology and spirituality differ in their perspectives on the goals of mental health prevention? Should narratives which report a positive experience of symptoms be dismissed in light of credibility doubts regarding the mental health of speakers? Finally, how should we think about value shifts, particularly in mental health, where certain illnesses have been proven to distort individual beliefs and desires?

Future Practices

Going forward, there is much scope for research in philosophy of psychiatry and medicine to shape future education, training, and procedures in medical colleges nationally. This potential lies not only in the ability to recommend best practices, and to highlight the ethical risks of co-produced approaches to mental health care, and to public mental health, but also in terms of maximisation of public benefit. However, currently, measures of efficacy of public mental health approaches and of treatment interventions are based largely on quality-of-life assessments, on cost-benefit analyses, and on minimisation of disability and related financial costs. Such evaluative practices are commonplace in public health more generally. However, they raise substantive questions about future recommendations. How might we ensure equality in participatory mental health approaches, for instance, when disparities in mental ill health are so often resultant from existent societal, racial injustices? Is it possible to standardise quality of life assessments relative to mental ill health? Relatedly, what if anything, do such assessments tell us about the efficacy of public mental health strategies?

Part of the theoretical complexity concerns value pluralism and different health priorities between different stakeholder experts (including EbEs and carers, psychiatrists, policy makers, regulators, economic beneficiaries, academics, *etc*.) of a given mental health intervention. Different groups prioritise different metrics of value measurement and often *disagree* about which measure is the most important and why. Philosophy, conversely, has an exceptionally well-established literature relating to contested ways of measuring mental health and well-being. Philosophical scrutiny of *quality of life* and *shared decision-making* in received methodologies in measuring of mental health, including Stewart-Brown's Warwick-Edinburgh scale (discussed extensively in Burgha *et al*., 2018, *Oxford Textbook of Public Mental Health*) and other 'self-assessment' techniques, reveals the theoretical significance of the complexities in measuring what is, to many, a subjective 'felt' concept. Such analysis includes discussions surrounding fallibility in personal evaluations, i.e., phenomenological experiences of mental health – both poor and robust.

Part One of this volume focuses on the scientific value of 'expertise by experience' by engaging with issues of art, self-description, as well the role of, and barriers to lived experience as an important dimension of knowledge. The papers in this section examine, in various ways, tensions, opportunities, and analogies that are useful in understanding how lived experience can be voiced in ways which could be termed 'science'.

Panayiota Vassilopoulou's essay, 'Art and the Lived Experience of Pain' is the first paper which picks up on this issue. Arguing that art, particularly works which publicly share the lived experience of pain, can contribute to public mental health and holistic approaches to care, Vassilopoulu's discussion of the role of aesthetic experience in understanding and communicating about pain – even that which is not felt physically – highlights the interplay between the private and the public, the personal and the universal. Vassilopoulu emphasises the potential of art to create communal spaces for reflection, much in the same way as scientific research allows the advancement of common understanding.

The next essay by Sofia Jeppsson, 'A Wide Enough Range of "Test Environments" For Psychiatric Disabilities', focuses upon the barriers and issues requiring redress such that we can gain an understanding of the impact of social and environmental factors on individuals' likelihood or predisposition of experiencing psychiatric disability. Using schizophrenia as an example, Jeppsson considers a range of socio-ecological test environments which emphasise that addressing disclosure rates and stigmatisation alone would likely be insufficient to engender an environment whereby all neurodivergent identities were able to openly embrace their ways of being without backlash. Picking up on key social issues, including racism, poverty, and academic job precarity, Jeppsson calls for a range of societal improvements that go beyond anti-stigma campaigns and increases in funding to lessen the impact of broader socio-political factors which heighten the propensity of poor mental health.

Sam Fellowes continues the discussion of the role of socio-political factors in affecting self- and scientific understanding with the essay 'Self-Diagnosis in Psychiatry and the Distribution of Social Resources'. Fellowes discusses the ways in which recognised and scientifically validated psychiatric and neurodevelopmental diagnoses, despite concerns regarding nosological legitimacy, affect what 'social resources' individuals are deemed entitled to or else deserving of. Whilst advocating for some of the potential benefits of self-diagnosis, Fellowes emphasises the need for further research focusing on the outcomes for those who self-diagnose, and for an assessment of which social resources unofficial or self-ascribed diagnosis permits an individual to access, have, or take part in. As Fellowes' essay illustrates, lived experience is in many contexts taken as a supplement to, and not a substitute for, 'science'. The challenge, as research into the philosophy of psychiatry has shown, is that psychiatry has been repeatedly challenged itself as being science *proper*.

The section concludes with Zsuzsanna Chappell's essay 'In Defence of the Concept of Mental Illness'. Written from a lived experience perspective, Chappell argues that we should

not abandon the term 'mental illness' because it is a useful way of understanding a type of human experience, because and is so far as the term (i) is apt or accurate, (ii) a useful hermeneutical resource for interpreting and communicating experience, and (iii) can be a good way for at least some of us to establish a liveable personal identity within contemporary Western social and political culture. Chappell's counterargument in favour of the concept of mental illness also responds to salient psycho political objections to the notion of self-identifying as 'mentally ill' on the grounds that it is important that we continue to accept that mental illness experiences do exist and must be named in order to treat people justly or morally. Such identity recognition is part and parcel of what it is to 'treat persons as persons' (Spelman, 1978), especially as a lack of recognition of their suffering is very threatening to those who suffer (Wilkinson, 2005). Chappell calls for better clarity in distinguishing the concept of 'illness' from both that of 'disease' and 'sickness', arguing that that there is a phenomenon that we experience as illness-like that is usefully described as illness-like within our culture and that there are people who can benefit from identifying, either personally or socially, as someone having or living with mental illness. As Chappell's essay illustrates, through an illness identity it is possible to make a claim on others for a positive caring relationship.

Part Two of this volume addresses the topic of lived experience and its role in research practice by looking at co-production. Viewed as a gold standard of participatory research by many, co-production is framed as a desirable and well-received research methodology.

Lucienne Spencer and Ian James Kidd's jointly written essay, '"The Hermeneutic Problem of Psychiatry" and the Co-Production of Meaning in Psychiatric Healthcare' discusses how meaningful communication between patients and clinicians in clinical settings is affected by both contingent factors and by features intrinsic to psychiatric or mental ill-health problems themselves. Spencer and Kidd draw out the ways in which power dynamics and institutional barriers can affect meaningful communications, as well as note the inherent features of many episodes of mental ill-health – the ways in which individual self-expression and understanding can go awry. Analysing a range of methods by which clinicians might incorporate phenomenological tools to make sense of what they are experiencing might, Spencer and Kidd argue, improve meaning-making by empowering patients. Addressing contingent features of clinical interactions such as power, marginalisation of minoritized individuals, and institutional barriers, the authors claim, is key to improve understanding and treatment of those with mental ill health impairments.

Issues relating to co-production, however, are not present solely at the level of individual interactions. Alana Wilde, in her essay 'Structural Oppression in Public Mental Health', focuses on analysis of epistemic injustice in co-production as a kind of systemic oppression, diverging from the common consensus that injustices arise at the level of interactions themselves. Drawing on the framework of epistemic oppression, the paper highlights the tensions at play, such as the dismissal of EbE knowledge as 'expert' and the way in which research paradigms perpetuate exclusionary practices. Wilde emphasis the need for fundamental revisions in our epistemological systems to allow a role and to make room for the valuing and inclusion of knowledge of EbE. Wilde's analysis underscores the challenges in overcoming entrenched norms and calls for a shift towards more equitable research practices.

The challenges of injustice in co-production sets the scene for Edward Harcourt and David Crepaz-Keay's essay 'Co-production is Good, but Other Things are Good Too'. This essay critically engages with the complex dynamics at play in participatory research that have contributed to co-production becoming a much-discussed and much-used methodology in academic psychiatry and mental health research. By drawing on a range of illustrative case studies, the authors show that there are proven and effective means of delivering positive change in mental health care, treatment, and service-design which, though not befitting of the label 'co-production', have nevertheless had success and demonstrated the role and benefit of progressive, innovative means of revolutionising existent processes. As do many of the chapters within this volume, Harcourt and Crepaz-Keay keenly engage with both methodological and empirical questions about the merit of solely focusing upon equalisation of power in research.

Part Three of this volume picks up on themes that Harcourt and Crepaz-Keay touch upon, namely the role of values in navigating difference and disagreement in psychiatry. Bergqvist's 'Shared-Decision Making and Relational Moral Agency: On Seeing the Person Behind the 'Expert by Experience' in Mental Health Research' explores the role assigned to lived experience, in terms of both moral and scientific value, arguing for a relational approach which considers patient perspective equal to, as opposed to lesser than, clinical narratives. Bergqvist argues that shared decision-making promotes a dynamic partnership, balancing patient self-knowledge with clinical expertise, ultimately arguing that a holistic understanding of the personal self which encompasses agency, history, perspective, and identity is required. Supporting the assimilation of lived experience and personal accounts

into mental health research as an equally valuable source of knowledge, Bergqvist argues, would allow the integration of such narratives into clinical practice.

Mohammed Abouelleil Rashed's essay 'Mad Pride and the Creation of Culture' takes this notion of novel contributions that lived experience provides, highlighting the ways in which Mad Pride activism looks to add conceptual understandings of experiential states to our shared narratives which are non-pathologizing. This, Rashed claims, is akin to creating a new culture of madness.

Through a range of poignant examples, Rashed shows how the revisioning and revaluing dimension of madness as a form of cultural identity recognition requires transformations in the basic concepts constitutive of current mental health narratives. Drawing on the concept of the self, and the phenomena of thought insertion to illustrate this claim, Rashed gives new means of understanding how lived experience might work to shift our shared understandings of what madness *is* and how we ought to understand it societally.

The central role of individuals and the psychiatric significance of the personal self (Sadler, 2007) in health care is what motivated the appearance of a new resource for tackling contested values, called values-based practice (Fulford *et al*., 2012). This practical resource for shared decision-making is the focus of K.W.M (Bill) Fulford and Ashok Handa's chapter 'Values-based Practice: A Theory-Practice Dynamic for Navigating Values and Difference in Health Care'. Values-based practice is a process – rather than an outcome-driven methodology that works in partnership with evidence-based practice in 'linking science with people' (Fulford *et al*., 2012). The authors argue that the central difference between the two modalities, evidence-based practice and values-based practice, is found in the corresponding methodological process element. Where evidence-based practice relies on meta-analyses of the results of high-quality clinical trials to inform a consensual model of decision-making, values-based practice builds on learnable clinical skills and other process elements to inform an open-ended and ongoing *dissensual* model of decision-making, rather than seeking to overcome value-conflicts in reaching consensus based on the stakeholder dynamic and treatment circumstances presented by the health care situation in question.

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