



OPEN LETTER

# Critical qualitative research on 'madness': knowledge making and activism among those designated 'mad' [version 1; peer review: 2 approved]

Diana Rose

Research School of Social Sciences and Department of Sociology, College of Arts and Sciences, Australian National University, Canberra, ACT2600, Australia

**v1** First published: 06 May 2021, 6:98  
<https://doi.org/10.12688/wellcomeopenres.16711.1>  
 Latest published: 06 May 2021, 6:98  
<https://doi.org/10.12688/wellcomeopenres.16711.1>

## Abstract

This paper charts the background to a project which aimed to map the knowledge being generated across the world by people silenced for centuries – the 'mad': a term with derogatory historical resonances but which is now being reclaimed. The idea that those designated 'mad' can produce knowledge is novel: 'mad' people are imagined as lacking rationality, and incapable of producing knowledge; they are subject to epistemic injustice. Patient engagement in research has grown in the last 20 years but we lack methodological frameworks through which such knowledge can be surfaced. One goal of the project is to let the mad speak their knowledge, often practical knowledge. To do this we had to innovate methodology. Centrally, we refuse the distinction between theory and method for these are constantly intertwined in all research. Thus, what typically comes under 'Method' in background papers is infused with implicit conceptualisation. We carried out 48 interviews in North America, England, Australia, New Zealand, and Eastern and Western Europe. We argue all aspects of these interviews are radically different than is usual for exploratory research in this area. Psychiatry is not central here – it is present only when present in the words of our participants; situated in material and symbolic spaces. We also seek to move away from the individualising therapies of medicines and psychological treatment because they strip participants from their situated realities. Psychiatry enters also because of what it does *not do* – engage with the life world of its patients. We call then for 'recontextualisation' of madness at all levels. The project was user-led and all researchers had experienced distress and responses to it. Future papers will develop and demonstrate this approach.

## Keywords

critical theory; madness; mental illness; knowledge, power

## Open Peer Review

Reviewer Status

	Invited Reviewers	
	1	2
<b>version 1</b>		
06 May 2021	report	report
1. <b>Junko Kitanaka</b> , Keio University, Tokyo, Japan 2. <b>Mark Cresswell</b> , Bath Spa University, Bath, UK		
Any reports and responses or comments on the article can be found at the end of the article.		

**Corresponding author:** Diana Rose ([Diana.Rose@anu.edu.au](mailto:Diana.Rose@anu.edu.au))

**Author roles: Rose D:** Conceptualization, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Writing – Original Draft Preparation, Writing – Review & Editing

**Competing interests:** No competing interests were disclosed.

**Grant information:** This work was supported by the Wellcome Trust [203237].

*The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.*

**Copyright:** © 2021 Rose D. This is an open access article distributed under the terms of the [Creative Commons Attribution License](https://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

**How to cite this article:** Rose D. **Critical qualitative research on ‘madness’: knowledge making and activism among those designated ‘mad’ [version 1; peer review: 2 approved]** Wellcome Open Research 2021, **6**:98  
<https://doi.org/10.12688/wellcomeopenres.16711.1>

**First published:** 06 May 2021, **6**:98 <https://doi.org/10.12688/wellcomeopenres.16711.1>

## An initial clarification about the scope of this paper

This paper gives the background to a study aiming to surface the knowledges being generated by users of mental health services, survivors, refusers and people with psychosocial disabilities. In other words, people deemed deficient in their capacity for knowledge making. The proposal for the project stated that it would be ‘global’ in scope. This turned out to be an impossible task because of team dynamics, and particularly due to differences with regard to the Global South, where positions on racialisation became entrenched in a very strong way. This has had the consequence that a single background paper became unfeasible. This paper develops the framings and arguments which are more germane to the Global North, but including people with intersecting positionalities. I have not here discussed issues pertaining specifically to the ‘Global South’. While other members of the team contributed to the thinking behind this paper, the synthesis which this paper represents is mine and I take full responsibility for any errors. The point of this short paragraph is to be transparent about the circumstances surrounding this work. Full details of the researchers involved in the EURIKHA project can be found at [www.eurikha.com](http://www.eurikha.com).

## Introduction

Why don’t those involved with mental health research policy, researchers and members of the public themselves listen to the voice of those with ‘lived experience’, to use a topical term? Many state that they are doing this, and multi-authored research papers increasingly claim to include people with ‘lived experience’ among the authors (Holmes *et al.*, 2020). The recent *Lancet Commission on Global Mental Health* argues that “engagement of civil society with mental health should be increased, in particular of people with lived experience of mental disorders” and a recent Editorial in *Lancet Psychiatry* acknowledges that “global mental health” contains assumptions about knowledge and expertise that are inimical to the very populations it purportedly sets out to help (Patel *et al.*, 2018). Fundamentally, we must recognise that expertise comes from individuals and communities in specific social, cultural, and economic environments, rather than the world being a blank slate on which supposedly value-neutral, technocratic solutions can be imposed.” So, there have been steps forward and they are important. But in this paper I argue that they are radically insufficient because of often tacit assumptions about lack of capacity of those with mental health challenges and denial of structural inequalities. The insufficiency is with the experts this time but is deeply embedded so difficult to recognise. It revolves around the power of omission and includes not addressing the challenges which would facilitate a real voice for service users, nor the challenges which would which face survivors in making possible a real shift in how ‘mad’ people are imagined and treated. Nor do said ‘experts’ recognise themselves and their institutions as barriers to such changes. This includes their own inability to listen to the voices of experience and so prevents the inclusion of persons with mental distress in these debates. ‘Mad’ is a term with derogatory historical resonances but which is now being reclaimed by those critical

of the idea of madness as some kind of deficit of reason. We must recognise the many hurdles faced both in generating new knowledge and establishing how it can be used in mental health specifically to ground new developments. I therefore here set out an alternative, based on the developments in theory and method utilised in a project which aimed to explore the ways in which people designated ‘mad’, specifically the mentally ill, survivors and people with psychosocial disabilities, are developing new forms of knowledge about their distress, the forms of support associated with that knowledge and wider questions concerning their relations with ‘mainstream’ academic research. This alternative partly lies outside the mainstream altogether and so it is not just to ‘listen’ but with the purpose of ‘change’ – radically

## Terminology

I started this paper with the term ‘lived experience’ because it is currently topical. But it should be noted that ‘mad’ people who are changing knowledge and practice have in the past and still now use other terms. The unqualified term ‘experience’ is significant too and I shall return to it. The variety of terms is not random and they can indicate the groups’ activities, thinking, and practical positions. For example the word ‘consumer’ was used for many years in Australia whilst an activist group in the UK chose ‘Survivors Speak Out.’ This indicates a wide difference in vision and political orientation from just these two and there are many more. This phenomenon has been recounted and analysed in detail (Lyon & Mortimer-Jones, 2020). I will use ‘lived experience’ where relevant but invoke other terms if they are used in work we are citing.

The project to be discussed is called EURIKHA – Explorations in User Research, Impact, Knowledge and Activism – and all the researchers in the project team were, or had been, users of mental health services. As a group of researchers with experience of mental distress and responses to it, including those who have experienced what are commonly referred to as severe mental disorders, we were well-placed to undertake this work. What this paper aims to do is articulate some of the fundamental elements that have arisen, changed, developed, split and were revisited in the time line of the project. The research focused on the last few decades, starting in the early 70s when the modern ‘user and survivor movement’ in mental health developed (Campbell, 1985; Davar, 2013). We aimed, in addition, to compare the knowledge produced by service users to mainstream knowledge about ‘mental illness’.

Of course, we recognised that neither mental health service users or ‘mainstream researchers’ are homogeneous. Those designated ‘mad’ are not a uniform group either and attention to difference is paramount if we are to understand the complexities at stake, including the hierarchies and expertise *within* the field as well as its relation to others. The concept of intersectionality can help here, although applying it to mental health is not straightforward (Fricker, 2007; Kurs & Grinshpoon, 2018). This ‘mainstream’ – that is to say the body of accepted knowledge and those who create and legitimate – is also not homogeneous. What is taken to be knowledge varies

over time as does the status accorded it. It also varies across place, and in our approach, the local is as important as the general. Thus we aligned ourselves with Haraway's 'situated knowledge' but paid more attention than she does to the material aspects of a setting (Haraway, 1988; Nazarea, 1999). Some features of the mainstream knowledge at play here are well known. They are persons or groups with the authority to speak and write *about* us because it is assumed we cannot speak for ourselves. We argued that knowledge of the worlds of mental health and associated arenas will always be incomplete if undertaken from these mainstream perspectives. Indeed, this may be deeply flawed (Double, 2002). We aimed to find out about the kinds of knowledge people designated 'mad' are generating, their form and their content, how they are situated and what the symbolic and material requirements are for such knowledge to grow and act as an antidote to the constant 'othering' to which we are subjected. We also focused on the aspects of life that are *missing* from mainstream knowledges. Silence speaks volumes.

The paper focuses on 48 interviews from survivors in the Global North, but as will be seen these interviews are treated differently from the way interviews are usually positioned in a project. Allied to this, we did not systematically review the literature. We conducted a rapid review but this is unsatisfactory when much of the literature is not peer reviewed. Therefore we positioned the literature as part of the 'context' – immediate to an interviewee or more widely. We were attentive to things that our some participants had published, both to give us a greater sense of the contexts from which they were speaking, and also because in their interviews, they sometimes expanded, and sometimes contradicted what was in that written material. And of course some interviewees had a public profile but others did not, and were much more focused on local activism. For example, one participant talked at length about having an intersectional identity and the relation of this to activism, but their published writings are quite conventional. By contrast, another participant with a public profile spent most of the interview discussing their ambivalence about being identified as a service user. Therefore we did not confine ourselves to the peer reviewed literature and go beyond even the 'grey' literature and other forms of representation (Sexton & Sen, 2018). The rationale for this should become clear.

This paper is not a research protocol. Our research is complete. Because it was an exploratory project, we could not lay down in advance the ways our approach would develop, even though some aspects grew out of work that we had used previously but not systematically. I would like this paper not just to explain why mad people are imagined as they are, but also to change dominant narratives and associated practices and to draw upon our own engagement with mental distress, variations in the ways people live and think, and the novel debates that characterise the field. I see this as a ground clearing exercise that is necessary for subsequent papers which will lay out more substantively the lineaments of this field of survivor knowledge in the early 21<sup>st</sup> Century. So, this paper is not

value-neutral but seeks to demonstrate the generative nature of knowledge making by people who may now be recognised as able to provide anecdotes and stories of their own lives, but are not believed to be capable of generating knowledge. And as for stories more generally, only certain ones will do – mostly ones of recovery made possible by a psychiatrist or medication (Costa *et al.*, 2012; Slade, 2009). This has been called 'disability porn'.

## Theory and methods

Introductory papers such as this often have a section called 'Theory' and another section named 'Methods', implying that these are at least partially distinct in a body of work. I have not divided the paper in this way because one of our central arguments, and the one to be articulated here, was that the conceptual and methodological work are intertwined throughout. Consequently, I will treat them and their interrelations together. Existing literature on 'concepts and methods' is almost exclusively statistical and gives primacy to data rather than conceptualisation in formulating conclusions (Gentle *et al.*, 2012). There is a large body of literature on the development of measurement and scales in relation to mental health, but where this does discuss theory and method the its main focus is again statistical, in the form of psychometrics. Mental health 'needs assessments' often use this approach (Rasch, 1961) as do tests of 'intelligence', 'achievement motivation' and so on (Michell, 1997). Such work claims to be 'hypothesis-free' and that the results arise from the data itself. We do not accept this view. For example, in epidemiology the categories through which information is collected puts strong constraints on what the data can tell us. An example is contemporary surveys which use socioeconomic categories in an economy that is first, primarily a knowledge economy and second, a system invented before economies characterised by austerity and zero-hour contracts came into being. Similarly, psychiatric epidemiology uses formal diagnostic categories and researchers here seem oblivious to their power. Categories such as schizophrenia or major depression function as if they were 'natural kinds' and thus go unquestioned (Kohrt *et al.*, 2014; Young, 2004), see Hacking (Hacking, 2007). Even in work that calls itself 'interdisciplinary' the focus of discussion is the *difficulty* of working in an interdisciplinary way, not arguments that would facilitate it. The whole architecture of scholarly work as constituted by 'disciplines' is taken as a given and to disturb this is unthinkable for most (Sewell, 1989). Of course, there is much critique of psychiatry, including of its categorical diagnostic structure (Haslam, 2002). But our task was to surface the positive knowledge of survivors. Some takes the form of a critique of psychiatry, while for others, psychiatry is not relevant or is to be avoided. Our project centred on the survivor perspective and therefore psychiatry itself, although exercising power at multiple levels, will be discussed only when the data or preliminary analysis demand it. Psychiatry was not our starting point; survivor perspectives are.

## The role of speaking back

Historically, the 'mad' have been written and spoken *about* but until recently there has been no voice for this

group. This is because persons designated 'mad' have been portrayed as unable to think, as lacking reason, as incapable of forming relationships: madness is an individual aberration. The 'mad scientist' is not a joke: it is a paradox. Experts such as psychiatrists and all the 'little pys', educationalists, priests and therapists have been thought to have a monopoly on what madness is, and what should be the appropriate professional and public response. People with psychic challenges are set apart from the 'normal' and can be given treatment deemed curative by professionals, even when it is often experienced very negatively by survivors. This includes treatment they do not want or which harms them in many ways. We, living under these descriptions, have no voice of our own because it has been assumed that any knowledge we create will be incoherent, lacking reason, detached from reality and severed from social significance by virtue of these attributes (Foucault, 1967; Porter, 1987; Porter, 1988). It is still the case that 'mad' people are held not to be able to give an account of their own experience, and only rarely have 'experts' tried to find meaning in their own explanations of their predicament (Kohrt *et al.*, 2014) Jaspers' General Psychopathology is a good example (Spitzer, 1988). Fricker's concept of 'epistemic injustice' is useful for our analysis (Fricker, 2007). Epistemic injustice is to define a person as not a credible source of knowledge. Fricker's original analysis was concerned with women and feminism. But Foucault made a similar point 50 years ago specifically about 'mental illness'. He writes:

"The constitution of madness as a mental illness *thrusts into oblivion all those stammered imperfect words without fixed syntax* in which the exchange between madness and reason was made. The language of psychiatry, which is a monologue of reason about madness, has been established only on the basis of that silence" (Foucault, 1967), emphasis by author

Foucault is being quite specific here. It is psychiatry that has constituted madness as a mental illness, its practice renders the 'mad' person the antithesis of reason, and on that basis the speech of the 'mad' person is not even heard, or heard only as a symptom of their madness. It is this last part of the quotation that is the most important, and often overlooked. The book – Foucault's *Madness and Civilisation* – has had many critics, for romanticizing madness whilst at the same time being not just Eurocentric but specifically French in content (Porter, 1990). But it is a place to start, a point of entry but with fluid and provisional boundaries and open to revision. A place to start but not an origin. Its significance lies in approaching madness as a space where specific knowledges break out only to be silenced, rendered illegible, invisible, for three centuries and more. The task is to trouble that silence and let madness speak.

#### Our project specifically

We will now see how this general background relates to our specific project. Although the researchers were from different disciplines, most had in one way or another or at some point

adopted the style of papers in mainstream psychiatry and psychology. These disciplines take the individual as their unit of analysis and hence there was a tendency to see what we were looking at as the property of individuals. This was a limitation which we pushed against constantly. Might it have been enriched by drawing on other disciplines? The problem is that anthropology, the humanities, social science and neurology may represent things differently, but they share central themes: madness as: bestial, possessed, dangerous and unpredictable. Since the Western enlightenment the 'mad' have been imagined as lacking reason and unable to engage in the structured activities required for society to function, such as work in the open market. We are touching a central tenet of critical theory – the valorisation and articulation of knowledge generated by marginalised groups.

Critical theory was first used as a term by the Frankfurt School, a group of East Germans of Marxist persuasion whose fundamental goal was to show the power wielded by cultural hegemony instead of relegating it to the 'superstructure' (Forchtner, 2011). The Frankfurt School concerned itself with the overall form of oppressive cultural structures and focused its analysis on social class (Geuss, 1981). There are many strands to this school of thought that can be useful. But major problems arose when diverse subjugated social groups found Marxism inadequate for understanding their specific material and symbolic situations. Instead of relying on Marxism, new theories of knowledge emerged from these new collective forms of action and resistance, and the knowledge makers were also activists - feminist, post-colonial, LGBT+ groups and more. Significant for our work was the development of critical theories and practice in the disability field. So, against the background of the Frankfurt school, we understood critical theory as knowledge produced by marginalised groups to understand, develop and change their situation. Authors in many different fields have taken this approach; feminist studies (Harding, 2008); post-colonial work (Darius *et al.*, 1993); queer theory (Butler, 2011), disability studies (Oliver, 2013) and work on intersectionality (Bell, 2010; West, 2020). The evolution of our concepts of 'knowledge' was built on some of the elements of this work. It changed over time but the trajectory of these concepts in EURIKHA is important. The original project proposal put a heavy emphasis on 'user-led research'. In a very short while we realised that this was a narrow and elite view of knowledge, both in terms of the settings where knowledge developed and in terms of ontology. Knowledge arises in the academy, it implied, and this is its natural home. Natural and prized. But most of the researchers in EURIKHA had been activists in some manner in the mental health field for many years before this project was proposed. We knew that activist and self-help groups had produced analyses of experiences that reconfigured and overturned venerated psychiatric diagnosis: eating distress and self-harm (Pembroke, 1994; Pembroke, 2005); hearing voices (Blackman, 2001; Corstens *et al.*, 2014); bipolar disorder (Martin, 2009); PTSD (Kaplow *et al.*, 2006). Most of these authors had first-hand knowledge of the descriptors they had been given. The work was innovative: its reception by mainstream psychiatry was predictable – it was usually ignored.

But for us, campaigning and self-help organisations were legitimate sites of knowledge production just as much as the academy. Another setting was peer support (Faulkner & Kalathil, 2012; Voronka, 2017). The realisation that you were not alone with your distress and that reflecting and acting together produces a different set of understandings and different subjectivities was a key moment for some. And research can be political. Indeed, the idea that most research is value-neutral is something we rejected. As our concepts of knowledge deepened and widened, we did not abandon the focus on user-led research; rather we tried to revalorise knowledge production by widening the settings included and focusing on a world beyond that which had attributed a pathology to an individual.

### Hierarchies of knowledge

There is a hierarchy of evidence *within* the academy but also a hierarchy between academic knowledge and the rest. Diversifying the sites where knowledge was produced was central to the conduct of the project. It had always been agreed that we did not want to interview a random or even representative group of participants. The people we wished to engage in our work were people and organisations who were producing new knowledge. It did not need to be high theoretical knowledge, it could be and often was practical knowledge (Telford & Faulkner, 2004). And so we set about a ‘mapping’ exercise where potential participants and their organisations were entered on a spread sheet with the single eligibility criterion being that they were actively pursuing alternative analysis of their own and others’ conditions of existence. We began with people we knew or who were well known, but through a process of snowballing the map grew until it had more than 300 names and organisations.

People with mental illness are seen as cognitively and emotionally compromised and are usually treated with medication or some form of psychological intervention. That is, they are treated conceptually and treated in practice as individuals with no social context, no social determinants that could account for their dilemmas, no focus on poverty or familial care or constraint, no focus on norms and the consequence of breaching them. Such individuating inhibits collective organising and the development of campaigning goals and understandings. This tendency to individualise is growing within societies characterised by austerity today, leaving people to subsist on few resources and with few friends (Friedli & Stearn, 2015; Lasch, 1980). Some knowledge makers in the arena of mental health are in hiding and this had important implications for their participation in this project.

This account makes the process seem one of linearity as if we were proceeding step by step. This is inaccurate as the ‘steps’ overlapped and influenced each other. Participants in the project were encouraged to revisit parts of their interview rather than give a single narration, at the time of the interview itself or later through comments.

It should be noted that the idea of ‘context’ is complex. The term is central to the fields of physics and engineering but is

also of great significance in anthropology where ‘context’ functions at many levels including the interpretation of their characteristics and situations by people themselves (Dilley, 2002). We also have the idea of C-M-O (Context-Mechanism-Outcome), coming from realist evaluation (De Souza, 2013). These three approaches, using the same word, could not be further apart. In the critical realism approach, ‘context’ functions as a black box – taken for granted and never unpacked (Næss, 2004). Much science and technology studies (STS) concerns itself with physical science and information technology. But there are exceptions, for example, the work of Callon and Rabeharisoa with disabled people and marginalised groups (Callon & Rabeharisoa, 2003; Callon, 2009). But the basic point – that ‘context’ remains both central and not articulated – holds in social science too. And, it will be argued that it can resonate with the field of ‘psy’ research and practice where madness is seen as a phenomenon with no discernible context other than demographic sheets sometimes filled in by participants, in research or clinically. These are treated as independent variables in any analysis which is usually quantitative. So ‘context’ can mean many things and later I will describe how Western psychiatry treats the individual as though they had no material or social elements to their lives – everything is focused on a diagnosis or a treatment. It is true that there are many ethnographies that touch on the experience of madness, and these are rich in ‘context’. But, in common with so many fields, all these arguments are almost always made by academic or other ‘experts’. None of them include service users in the author list, and references to arguments where service users could be central to the making of new knowledge and strategies for change are absent.

### Ethics

Our approach was difficult for some to understand. For example, we applied for ethical approval, and were indeed granted such approval: (REMAS) LRS 16/17 4502. Despite this, we had to revise and resubmit to counter some misunderstandings. For example, we suggested a simple question “What triggered your interest in this field?” The response of a member of the ethics committee was to ask whether there would be a psychiatrist available. In psychiatry the word ‘trigger’ is used specifically as a cause of an episode of mental illness. The committee, reading a submission on mental health, had assumed that we were asking if the person felt ‘triggered’ by the interview setting. We had to submit a revised application to explain this and similar misunderstandings. It is hard to challenge conventions, especially in the area of mental health where expertise is thought to lie with psychiatrists by many people, especially academically

### Participants: who did we talk to?

Before proceeding with our argument, I can anticipate criticisms of the order that our work was not ‘rigorous’ or not ‘real research’ because it has a biased sample. This kind of response is nothing new: in a field that has established itself with strict rules about what counts as knowledge, introducing new ideas, and especially those emanating from a subjugated position are likely to be suppressed, ignored or co-opted. Scholars in the field of science and technology studies have

given us many detailed examples of how and why some new knowledge is suppressed whereas others will grow. In entitling his book on science *Never Pure*, Shapin demonstrates that sociability, power and value underpins much of science, and not veridicality as such (Shapin & Fuller, 2015). Research and scholarship are shaped and set by social relations and social structures. This does not imply that knowledge that survives is 'better' as Shapin makes clear. It can be quite the reverse and so an adequate theory of the production of valid knowledge would not be confined to issues of logic and syllogisms, or even reliability or validity – we need to take account of values throughout and much more besides (Ajei, 2007). Our approach, seeking explicitly to bring forward subjugated voices, necessitated us rejecting conventional ideas of sampling and representativeness, which are themselves formed within particular disciplinary structures.

The above discussion of sites and groups as settings for knowledge generation goes hand in hand with the development of the 'mapping' exercise described above. Names and organisations of potential participants were entered into an Excel spreadsheet together with some of the other relevant background information. As our conceptualisation of 'knowledge' developed so did the kinds of people we wanted to talk with and where. We made every endeavour to find out which organisation(s), if any, potential participants belonged to because of our widening concepts of knowledge and our misgivings about individuals being the sole source of knowledge, especially that which chafes the mainstream. This is not a novel observation: many have written about the foregrounding of the individual as knowledge producer in modern Western societies (Triandis, 2018). As I have said, theoretically and empirically, both psychiatry and psychology work with individuals in an almost context-free way and as such shape subjectivity so that the person becomes a 'case' (Flore *et al.*, 2019) We therefore sought out participants whose perspectives were explicitly socially grounded.

Marginalised groups are hard to contact. We tried hard to find people who were not high-profile – that is not high profile in a group already marginalised. Our success here was partial and had we had more resources the stories and persons involved would have had more detail and depth. But had we tried to find a 'representative sample' we would have amassed much less detail about the diversity of knowledge that was being produced, or at least painted a different picture. Our method of choosing participants violates every rule in the book about sampling but it was consistent with our primary goal – to understand knowledge making by people and groups who were designated mentally compromised. Those very people who are envisioned as not able to produce knowledge at all.

### Interviews and context

In keeping with our decentering of the individual, we found out as much as we could about the lives of the persons on the map, their workplaces and their identifications. We attempted to 'recontextualise' the person by placing them relative to their own and group history, the work they did whether informal

or formal, their familial situation, cultural norms, the nature and number of links with other marginalised groups and how each person saw themselves in the current moment of change, both individually and collectively. Marginalised groups are difficult to identify. In keeping with our evolving concepts of knowledge, we tried to find people in grassroots organisations as well as prominent individuals. This was an immense effort and we placed no bars on where to find information about an individual or group as long as ethical principles were followed. Sometimes an informal conversation took place before the person 'went on the record'. This differs from much qualitative research where the method of data collection is standardised, and, for example, projects specify the number of people to be interviewed each week. Commonly this is graphed – indicating the number aimed for and number actually interviewed, with the discrepancy between the two a marker of success or failure.

The prized 'outputs' in the epistemic West are peer reviewed papers. There is a growing literature on 'user-led research' but, as a consequence of our developing concept of knowledge, we did not privilege the peer reviewed literature – we also went far beyond the 'grey literature'. But many people, due to their subjugation, do not have a public profile at all. They may be important advocates and activists locally, but their work is not visible outside this in any detail. This led to a biased participant group but in a way that the term 'bias' is not commonly used. Those who were wholly or partially associated with academia were the easiest to find and to find out about, which means that this form of representing knowledge has a head start. This was an ongoing struggle in the as the initial framing of the project did not give enough weight or resources to groups for whom academia is totally irrelevant. We attempted to correct this as we proceeded but we were not entirely successful.

There is another critical point that should be addressed. Some of the people we approached to be interviewed simply refused. In the main this was a matter of trust and power. The project was situated in the leading psychiatric research and teaching institution in Europe. This was our institutional context and it was a barrier to speaking with some of the people we were anxious to interview. For them, quite understandably, we were asking for their views from the vantage point of academic elitism and salaried Western academics. One important reason seems to be that they did not trust us to understand what they had to say, that we would warp it or turn them into mere data points. So, our own institutional position constrained the information we accessed.

In sum, try as we did, our positionality meant that certain key groups of people were not represented to the degree that should have been. Either they were the most silenced group, or they were cynical about our motives or both. On the other hand, the work surrounding each interview sets this project apart from most qualitative research where at most there is a demographic form for each individual to complete. Of course, this is in some ways different from how other disciplines

and non-academics proceed, but it is the hegemonic orientation (Woods, 2011).

In formal terms, it is important to note that interviewed face-to-face gave written consent and completed a consent sheet. Those interviewed by Skype gave verbal consent, and this was properly noted and filed.

### Conducting the interviews

In our first discussions about the interviews we thought they would be amenable to an oral history approach, as it was developed in the 1970s and as in the more complex form that it now takes. A full account of oral history and its strengths and weaknesses would be another paper. But fundamentally, the goal is that the speaker has control of their narrative for they are ‘telling their story’ (Portelli, 2009). Here there is an apparent levelling of power in research, but there is controversy about this (Molden, 2016). The power relations in an oral history interview have been much discussed, especially by feminist historians, which has often been linked to the question of whether it is possible to ‘bracket out’ the researcher (Scanlon, 1993). These are important considerations, and they stand, but there is a further issue about a person simply telling their life story, if the interview seeks to capture specific moments or perspectives that are important for the project as a whole. Exploring the knowledge potential of service users’ lives and organisations thus needed to incorporate some key questions on our part. Our initial idea of using oral history had to be modified because, as we worked on the topic guide (see below) we realised that there were certain key issues that often needed prompting if we were to conduct our work so as to explore questions of marginalisation and subjugation. These themselves are not just ‘descriptions’ of events or feelings - they often become evident only if viewed from a concern with inequality and social justice. A good example again is ‘epistemic injustice’, a concept alluded to earlier to show how some groups of people are marginalised at an epistemic level – they cannot think or speak either about themselves or others and so are not credible knowers. As we describe below, we coded the interviews, and ‘epistemic injustice’ was a sub-code of ‘theorising’ in the coding frame. However, it turned out to be by far the most often used of all the sub-codes under that ‘master code’. This was not just a question of counting the number of appearances of a code, and of course people didn’t have to use the term itself: identifying epistemic injustice was an act of interpretation. So our approach was not merely one in which the coding frame drove the analysis: the interviews themselves were constantly changing the concepts used in the analysis, and its focus.

We therefore identified some questions that would make our concerns transparent. How best to hear about issues of power and knowledge, history and theorising whilst at the same time trying to observe the principle that the relation between researcher and participant should aspire to one of different expertise – different but of equal and complementary value. The complexities here were again prompted by feminist oral history research where one much discussed issue was

whether women interviewing women would elicit richer and deeper information from people and groups who often did not have a voice (Turnbull, 2000). These debates have been raised in user-led research, asking whether having someone with a history of using mental health services (or avoiding this) makes a difference to the interview (Newman & Clarke, 2018). It is suggested that if this did not fully cultivate a space of equity, it would broaden the frame of what is actually sayable (Barnes & Wistow, 1994). A similar debate exists in relation to racialised groups and oral histories of people of black and minority ethnicities (Kim, 2008).

Thus, to put the process in formal terms, interviews were guided by a topic guide, but in some cases, as normal, were tailored to the specifics of the interviewee which we had discovered during our mapping work. Interviews were all performed by members of the team, except for two (in Chile and Japan) where local interviewers were used, and translations undertaken. All interviewers were trained on the interview protocols.

### Coding

Debate about specific aspects of research, and especially technical ones, runs the risk of abstraction from the approach as a whole. To consider ‘interviews’ as an isolated method loses its connection to the lifeworld of the speaker and the overall methodology. It was finally decided to blend the principles of oral history, its attention to the research relationship and power dynamics in the interview setting with a flexible qualitative methodology. This methodology entailed analysing the text of the interviews with a coding frame to assess the use of words, concepts and arguments in the accounts given by our interviewees. We built a ‘coding frame’ which foregrounded seven major categories and each had sub-categories with some ‘codes’ free floating. We used NVivo to code the transcripts and made use of the ‘annotations’ feature available. This usefully allowed us to comment, abstract and compare, both within and between transcripts. This was one way of developing theory and the use of annotations increased as we became familiar with the deep content of the transcripts. We were also able to see which codes had few or no references. That in itself was a finding and did not mean the concept was unnecessary. Rather it could challenge us so that we searched for meanings where there was a reason they might be absent. For example, when we considered one interview where very few different codes were used, it became clear that this was because the participant was completely focused on the question of what it meant to be a survivor researcher and activist. This revealed the contrast with other participants who cast this question of subjectivity intersectionally, exploring their roles in different identity groups rather than dwelling on one.

Germane to the work on the interviewer/participant relations was that all the interviewers were service users. The ‘evidence’ regarding appropriate interviewers is sparse and lacks discussion of what was of most significance to us – that it should be connected up with other aspects of the project and thus elicit perspectives on our key questions which would not surface



had the interviewer not been a service user. An example would be the ability to elicit criticisms of other strands in the user movement which some people avoided in case it was seen as a 'betrayal'. In other instances what was said by our participants was strategic in the sense of Spivak's concept of 'strategic essentialism'; those times when diversity is glossed over to pursue a particular goal (Darius *et al.*, 1993; Spivak, 1988). The 'method', including the status of the interviewer was therefore consistent with and partook of the theoretical arguments set out above.

### Instruments

The initial project specified three groups of participants: historical figures, those from the Global North and those from the Global South. These groups were not distinct, many people could be positioned in more than one. We formulated a rough interview guide for those from the Global North and piloted it. This was aligned with the project's initial aims but crafted to avoid favouring material on user research. The guide was indeed a 'guide' and this was made clear at the start. And, of course, the distinction between Global North and South has been widely critiqued (Müller, 2020)

The aim was to have the topic guides for the three groups 'mirror' each other but this proved unfeasible in terms of how people talked. They overlapped of course, but the pilot coding showed different patterns of discourse. It also showed that relations between a participant's personal history and the history of collectives they belonged to was quite complex, raising questions about what 'diversity' meant and also the nature of the relation between an individual's history and that of the collective. So some participants spoke almost exclusively about collectives in the past, whereas others recounted their current concerns with user-led research (Weedon & Jordan, 2012). We found stories of successes, failures and nostalgia in different transcripts and sometimes within the same ones. I doubt whether our participants would have been so forthcoming had the interviewer not been a service user. A second topic guide was formulated to be closer to the dominant concerns in other regions and settings, especially the Global South. In practice, background work showed that a participant had very distinctive experiences and reflections and here the 'topic guide' was quite malleable and tailored to that person.

The interviews were either conducted face to face or via Skype using the audio software, Audacity, to record the interview. The fact that English was not the first language for some participants added another layer of complexity. Within the Global North, we used interpreters three times and this was not without problems (Ingvarsdotter *et al.*, 2012). In Australia and New Zealand we conducted five interviews with indigenous people and the comparison with the interviews with people of predominantly white ethnic groups was revealing, particularly in relation to stigma: one participant told us that 'mental illness' was stigmatised by their community, not for itself, but because it was Eurocentric and alien concept (Smith, 2013). Another difference appeared when a Maori participant criticised the very idea of a 'meeting' because of the differences between Maori practices and the mainstream. They were

angered to be confined to an agenda, rules about turn taking, the 'meeting' ending 'on time' regardless of what was left to say and, crucially, the absence of food.

Transcription was checked first by the researcher who conducted the interview. Then, in order that participants could hear first-hand how they were coming across, each was provided with a copy of their interview to check that it was faithful. Participants could also add, redact or comment on their interviews. Not everybody did this so if a transcript was not returned as 'checked' (by the participant), they were sent a copy of any relevant outputs and could elect to be named, be anonymised or have the actual texts turned into a descriptive point not attributable to any individual. It was possible too for researchers to ask the participants to develop or add material. This was a very time-consuming process.

In sum, oral history turned out to be insufficient, as there were areas we wanted to be covered in each interview. At the same time, we tried to create a flexible space for participants and how they were represented. To ensure this, we gave participants as much control over their finished transcript as we could. Some made many changes and some made none at all. Nevertheless, there were without doubt aspects that we missed. As already mentioned, we decided that we would use a 'coding frame' that would be partly drawn from the theoretical work engaged in and partly with familiarity with a sub-set of texts. The software we used was NVivo 12 and we had two days of bespoke training on this. Our 'master codes' were as follows: alternative approaches; collectives; change over time; culture and norms; identity; knowledge; personal journey; power, settings; theorising; mainstream research; user-led research. Each master code had sub-codes to enable us to record particular examples or particular ways of talking about a topic.

The development of the coding frame was conducted by meeting at least twice a week for 3 months. It was painstaking. Each code was defined and the discussions were minuted. This meant that, if we were having difficulties with codes or chunks of text, we could revisit what we had done before in similar circumstances in the minutes. The length of time this took was partially for certainty but building the coding frame was not a technical exercise only; it involved complex discussions of conceptual matters as well. Once again, this emphasises the inextricable relations between theory and method.

NVivo allows for more than one code to be allocated to a text which means the analysis can be richer. However, it also has a feature called 'annotations' which is a space for reflection, suggesting relevant literature and making comparisons between and within transcripts and incorporating relevant literature. Once we had some provisional notion of the importance of a set of codes, this was developed not just through further coding but by making fuller use of the Annotation function.

Coding is often called 'mechanistic' so in the next section we will show this is not the case in our analysis of the emergence of mad knowledge.

## Critical Discourse Analysis

I will conclude by returning to the issue that we raised at the start of this paper, concerning the interweaving of theory and methods. Part of our theoretical orientation was critical discourse analysis (CDA). For some theorists CDA is a form of critical sociology. This takes an interdisciplinary approach to the analysis of societal injustices and oppressions. As pointed out earlier, this approach developed in the 1930s with a group of philosophers, cultural analysts and social scientists. It was Marxist in orientation, normative in its values, and sought social change or transformation and empowerment of the dispossessed. Some aspects of this remain valid but, as we pointed out earlier, it was criticized both in the “discursive turn” in social theory, and in the emergence of smaller groups who considered that their oppressions were distinct and could not be ‘read off’ a general Marxist analysis. Feminists, post-colonial activists and thinkers and disability activists argued in their different ways for the specificities of their subjugation and routes out of it, including the development of counter-narratives. This confluence of the emergence of specific oppressions and activisms and the ‘turn to language’ changed critical theory, such that attention was accorded to the way discourse and other forms of representation reproduced fundamental structures of disadvantage and privilege. Discourse, in this mode of argument, is not just speech but is a systematic way of representing the world or parts of it as embedded in practice. The incorporation of discourse analyses into critical theory began in the 1970s, notably in the work of Fairclough and Wodak (Fairclough *et al.*, 2011; Wodak, 2001). We sought to distance ourselves from the generalist or universalist approach of The Frankfurt School, because CDA is not just a ‘technique’. Thus, as described earlier, we drew on concepts such as situated knowledges (Haraway, 1988) or ethnocultural niches (Nazarea, 1999) and hence located ourselves in contemporary critical theory that is concerned with the knowledge and the practices of marginalised groups as understood and developed by them. Consequently, we emphasize that those who are denied a voice should have a seat at the table and speak for themselves and their organizations.

Today, those closer to the original Frankfurt School privilege the critical theory aspect of the approach whereas those whose roots are in linguistics emphasise discourse. For those coming from the ‘linguistic’ or sociolinguistic background rather than the ‘critical theory’ end, CDA functions more as a toolbox and is not a single and coherent approach (Gavriely-Nuri, 2017). There is, then, latitude in how CDA is conceptualised and functions, yet it remains the case that CDA takes a social justice approach and that the analysis of power is central (Mulderigg, 2008). Empowerment is built into the methodology. For us, CDA was useful because it has a base in critical theory but also because it enabled us to draw on concepts specific to madness and to emphasize the intersectionality that our transcripts showed early was an antidote to universalism (Crenshaw, 1991; Nash, 2008). However, the ‘subjects’ of this research are not accorded any control or power themselves.

To understand how we approached the transcripts and the literature, all three components of CDA are necessary. CRITICAL because we drew on, though modified, the approaches taken

in Critical Theory more generally. DISCOURSE, at a simple level because our material was mostly texts. Discourse analysis is a distinct form of working with texts and the term is used broadly. It concerns itself with key semiotic structures in a text, the social ‘grammar’. It is a social product and can define and redefine the meanings that it identifies in how the dominant culture (institutions, boundaries, enactment)) reproduces itself through language and this can be quite superficial or attentive to deep structures and paralanguage. It is centred on language but not usually in the full social sense of a layered embedding in practice. So, we may take a particular text, or set of texts to analyse but, in contradistinction to usual approaches, the ‘background’ work for interviews referred to above means attention to the setting where the discourse is placed is primary and power relations are central (Mayr, 2008). This is why I have argued that theory and method cannot be separated and certainly do not require distinct methods.

Many tributaries produced the kinds of work now called CDA and they are tributaries of subjugation as well as empowerment. In fact, there is much more literature on the reproduction of cultural structures than there is on new narratives. In the landscape as a whole, the attention to language itself runs from very superficial to intensely detailed. It could be said that our approach was constructivist but we gave a much larger role to the materiality in which language is set than most (Shankar & Cavanaugh, 2012). And to call an analysis CDA is to look at this embedding. Importantly, CDA is not an analysis of conversations, or dialogues, it is not conversation analysis (CA) which usually aims primarily to show how language acts as a social glue (Silverman, 2015). Power, if it appears, is interpersonal not structural. Even the body of work which calls itself Foucauldian discourse analysis, while it highlights power relations, still does so at the interpersonal level of conversations (Arribas-Ayllon & Walkerdine, 2008). But Foucault was not talking about talk! Like other critical work EURIKHA was centrally about change, and took the view that discourse does not just reflect change, it is part of the strategy for bringing it about or preventing it. While CDA aims to empower participants as individuals and groups, this presents a fundamental challenge in relation to those who, on grounds of ‘mental illness’, are considered deficient not just in their capacity to meet their social obligations, but also in their capacity for rational thought itself. To be excluded from the domain of legitimate knowledge is to concede the battle for truth to those deemed reasonable. To be deemed ‘at fault’ in one’s capacity to know renders the goal of social justice and equality unattainable. One way to start redressing these power imbalances, then, is to recognize that those deemed mad can nonetheless be ‘knowledge makers’.

Finally, this is an ANALYSIS. Typically work that uses, for example, thematic analysis will speak of ‘themes emerging’ from the data’ (Braun & Clarke, 2006). This is an untenable position because the analytic work is always informed, explicitly or not, by theoretical and epistemological underpinnings. To be explicit about calling our approach CDA means it approached the data with some pre-formed social categories

that were central to the goal of the project. This is anathema to many qualitative researchers who assert that it is possible to fully analyse a text atheoretically, a position epitomised in grounded theory (Charmaz, 2014). Such a position denies that such analyses are always *interpretations*, researchers do not come to their material with a completely blank mind and let the data fill it in some unmediated way. There is a huge sociological literature on this issue of ‘bracketing out’ associated with ethnomethodology and now ‘post-qualitative inquiry’ (Gerrard *et al.*, 2017). The more appropriate strategy, especially with a new field, is to be quite explicit about the framing with which we approach the data. A ‘coding frame’, such as the one described above, is not just a set of categories and sub-categories. It is dynamic and its major categories are theoretically driven, shaped in our case by the theory we have been developing and vice versa. Like any qualitative analysis, these frames need adjustment as analysis proceeds. ‘Empty’ codes are important as I have said. They tell us that certain threads either were not important, or we defined them incorrectly which could lead to misleading interpretations. So, the analysis is informed by critical theory and looks to discourse not as a ‘representation’ of what concerns us but as dynamic, explanatory and generative. This can be at a very abstract level but can also be seen at a micro-level when talk exemplifies the knowledge we are interested in, or indeed, contradicts the original framing. In sum, coding is often called a ‘mechanistic’ approach to qualitative research. We hope to have shown that conceptual and interpretive work is central to the functioning of the analysis.

This recognition must extend to the presentation of the ‘results’. Qualitative research generally involves argument at some level ‘illustrated’ by quotations. This means that meaning units are extracted from the overall transcripts. And some transcripts did lend themselves to this, being highly structured in the way people answered questions and in how they connected these together. Conversely, some transcripts were more a free-flowing narrative and to ‘extract’ a unit of meaning from these means we lose another piece of ‘context’ – that of the interview itself. In future papers, we will take the nature of transcripts into account when comparing them and entering them into *our* interpretation, sometimes summarising what went before but also with the result that some ‘extracts’ are much longer than others. In sum, we believe it is important not to attempt to homogenise at any level but to draw attention to the patterns that result.

## Conclusions

In this paper I have introduced the thinking in EURIKHA around the knowledge produced by people subjugated on grounds of their epistemic competence, subjugated individually, ethically

and as a group. I hope that the paper introduces some important features of an approach that might be used to really give voice to the ‘lived experience’ of mental health service users. It also offers sufficient detail to orient the reader to the ways that the more substantive papers to come have a solid base in critical thinking and critical practice. The aim is to show that new knowledge is being generated from the kinds of sources explored in this paper and are part of the drive to change the variable conditions of existence of people who are ‘othered’ because they do not meet the criteria of the logical, social or moral attributes seen as necessary for society to function. To develop counter-narratives is to unsettle and trouble the privilege given to some ‘experts’ which can be harmful in the overall life of a person or persons. In that sense EURIKHA seeks to facilitate a new imagining of those of us designated mad.

## Coda

As science and technology studies has definitively shown, when a project or programme of research is made public, many things are left unsaid or glossed over. The descriptions in this paper are no exception. Many issues of power and knowledge gave rise to what I have written here but also what we have not written. To write a reflexive piece on the social and political, ethnic and gender positionalities in the team would entail making public very troubled issues and interactions. This is not unique to this project and again speaks to the power of silence. But it will be seen as no accident that the author on this paper, who was also the PI on the project, ultimately took the decision to configure the dissemination of the work. There is more to come including an examination of the counter-narratives that are being sustained despite attempts to co-opt them into mainstream research and thought. It will be up to the readers to decide if EURIKHA’s aspiration to amplify this counter voice has, at least partially, succeeded.

## Data availability

The data is not publicly available because of legitimate concerns about confidentiality expressed by some participants as a condition for their participation. While some participants wanted to be named, others were extremely worried that they would be identified and did not want to be named. Given the difficulties this presented for anonymisation, I took the decision to use full anonymisation. As participants could be identified from the transcripts of their interviews, this also meant that the transcripts could not be made available and these are the only form of data collected for this study. No view on data sharing was expressed by the Ethics Review Board. Any properly qualified researcher who wishes to access some of the data for legitimate reasons should contact the author of this paper individually to discuss access and conditions ([Diana.Rose@anu.edu.au](mailto:Diana.Rose@anu.edu.au)).

## References

Ajei MO: **Africa's development: the imperatives of indigenous knowledge and values.** University of South Africa, 2007.  
[Reference Source](#)

Arribas-Ayllon M, Walkerdine V: **Foucauldian discourse analysis.** *The Sage handbook of qualitative research in psychology.* 2008; 91–108.  
[Publisher Full Text](#)

- Barnes M, Wistow G: **Learning to hear voices: Listening to users of mental health services.** *J Ment Health.* 1994; **3**(4): 525–540.  
[Publisher Full Text](#)
- Bell C: **Is disability studies actually white disability studies.** *The disability studies reader.* 2010; 374–382.
- Blackman L: **Hearing voices: Embodiment and experience.** Free Association Books, 2001.  
[Reference Source](#)
- Braun V, Clarke V: **Using thematic analysis in psychology.** *Qual Res Psychol.* 2006; **3**(2): 77–101.  
[Publisher Full Text](#)
- Butler J: **Gender trouble: Feminism and the subversion of identity.** routledge, 2011.  
[Reference Source](#)
- Callon M: **Acting in an uncertain world: An Essay on Technical Democracy.** Harvard, MIT press, 2009.  
[Reference Source](#)
- Callon M, Rabeharisoa V: **Research “in the wild” and the shaping of new social identities.** *Technol Soc.* 2003; **25**(2): 193–204.  
[Publisher Full Text](#)
- Campbell P: **From little acorns. The mental health service user movement.** Sainsbury Centre for Mental Health (ed.) *Beyond the Water Towers.* The Unfinished Revolution in Mental Health Services 2005, 1985.  
[Reference Source](#)
- Charmaz K: **Constructing grounded theory.** New York, London, Sage, 2014.  
[Reference Source](#)
- Corstens D, Longden E, McCarthy-Jones S, et al.: **Emerging perspectives from the hearing voices movement: implications for research and practice.** *Schizophren Bull.* 2014; **40** Suppl 4(Suppl 4): S285–S294.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Costa L, Voronka J, Landry D, et al.: **“Recovering our Stories”: A Small Act of Resistance.** *Studies in Social Justice.* 2012; **6**(1): 85.  
[Publisher Full Text](#)
- Crenshaw K: **Mapping the margins: Intersectionality, identity politics, and violence against women of color.** *Stanford law review.* 1991; **43**(6): 1241–1299.  
[Publisher Full Text](#)
- Danius S, Jonsson S, Spivak GC: **An Interview with Gayatri Chakravorty Spivak.** *boundary 2.* 1993; **20**(2): 24–50.  
[Publisher Full Text](#)
- Davar B: **From mental illness to disability: choices for women users /survivors of psychiatry in self and identity constructions.** *Disability Studies in India: Global Discourses, Local Realities.* R. Addlakha. New Delhi, Abingdon, Routledge: 2013; 333–360.
- de Souza DE: **Elaborating the Context-Mechanism-Outcome configuration (CMOC) in realist evaluation: A critical realist perspective.** *Evaluation.* 2013; **19**(2): 141–154.  
[Publisher Full Text](#)
- Dilley RM: **The problem of context in social and cultural anthropology.** *Language & Communication.* 2002; **22**(4): 437–456.  
[Publisher Full Text](#)
- Double D: **The limits of psychiatry.** *BMJ.* 2002; **324**(7342): 900–904.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Fairclough N, Mulderrig J, Wodak R, et al.: **Critical discourse analysis.** *Discourse studies: A multidisciplinary introduction.* 2011; 357–378.  
[Publisher Full Text](#)
- Faulkner A, Kalathil J: **The freedom to be, the chance to dream: Preserving user-led peer support in mental health.** London: Together for Mental Wellbeing, 2012.  
[Reference Source](#)
- Flore J, Kokanović R, Callard F, et al.: **Unravelling subjectivity, embodied experience and (taking) psychotropic medication.** *Soc Sci Med.* 2019; **230**: 66–73.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Forchtner B: **Critique, the discourse–historical approach, and the Frankfurt School.** *Critical Discourse Studies.* 2011; **8**(1): 1–14.  
[Publisher Full Text](#)
- Foucault M: **Madness and Civilisation: A History of Insanity in the Age of Reason.** London, Penguin, 1967.  
[Reference Source](#)
- Fricker M: **Epistemic injustice: Power and the ethics of knowing.** Oxford, Oxford University Press, 2007.  
[Publisher Full Text](#)
- Friedli L, Stearn R: **Positive affect as coercive strategy: conditionality, activation and the role of psychology in UK government welfare programmes.** *Med Humanit.* 2015; **41**(1): 40–47.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Gavriely-Nuri D: **Cultural approach to CDA (CCDA): From theory to practice.** *The Routledge handbook of critical discourse studies,* Routledge: 2017; 120–132.  
[Reference Source](#)
- Gentle JE, Härdle WK, Mori Y: **Handbook of computational statistics: concepts and methods.** Springer Science & Business Media, 2012.  
[Reference Source](#)
- Gerrard J, Rudolph S, Sriprakash A: **The politics of post-qualitative inquiry: History and power.** *Qualitative Inquiry.* 2017; **23**(5): 384–394.  
[Publisher Full Text](#)
- Geuss R: **The idea of a critical theory: Habermas and the Frankfurt School.** Cambridge University Press, 1981.  
[Reference Source](#)
- Hacking I: **Natural kinds: Rosy dawn, scholastic twilight.** *Royal Institute of Philosophy Supplement.* 2007; **82**(61): 203.  
[Publisher Full Text](#)
- Haraway D: **Situated knowledges: The science question in feminism and the privilege of partial perspective.** *Feminist studies.* 1988; **14**(3): 575–599.  
[Publisher Full Text](#)
- Harding S: **Sciences from below: Feminisms, postcolonialities, and modernities.** Duke University Press 2008.  
[Reference Source](#)
- Haslam N: **Kinds of kinds: A conceptual taxonomy of psychiatric categories.** *Philosophy, Psychiatry & Psychology.* 2002; **9**(3): 203–217.  
[Publisher Full Text](#)
- Holmes EA, O'Connor RC, Hugh Perry V, et al.: **Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science.** *Lancet Psychiatry.* 2020; **7**(6): 547–560.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Ingvardsdotter K, Johnsdotter S, Östman M, et al.: **Lost in interpretation: The use of interpreters in research on mental ill health.** *Int J Soc Psychiatry.* 2012; **58**(1): 34–40.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Kaplow JB, Saxe GN, Putnam FW, et al.: **The long-term consequences of early childhood trauma: A case study and discussion.** *Psychiatry.* 2006; **69**(4): 362–375.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Kim SN: **Whose voice is it anyway? Rethinking the oral history method in accounting research on race, ethnicity and gender.** *Critical Perspectives on Accounting.* 2008; **19**(8): 1346–1369.  
[Publisher Full Text](#)
- Kohrt BA, Rasmussen A, Kaiser BN, et al.: **Cultural concepts of distress and psychiatric disorders: literature review and research recommendations for global mental health epidemiology.** *Int J Epidemiol.* 2014; **43**(2): 365–406.  
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Kurs R, Grinshpoon A: **Vulnerability of individuals with mental disorders to epistemic injustice in both clinical and social domains.** *Ethics & Behavior.* 2018; **28**(4): 336–346.  
[Publisher Full Text](#)
- Lasch C: **The culture of narcissism.** *Bull Menninger Clin.* 1980; **44**(5): 426–40.  
[PubMed Abstract](#)
- Lyon AS, Mortimer-Jones SM: **Terminology preferences in mental health.** *Issues Ment Health Nurs.* 2020; **41**(6): 515–524.  
[PubMed Abstract](#) | [Publisher Full Text](#)
- Martin E: **Bipolar expeditions: Mania and depression in American culture.** Princeton University Press. 2009.  
[Reference Source](#)
- Mayr A: **Language and power: An introduction to institutional discourse.** A&C Black. 2008.  
[Reference Source](#)
- Michell J: **Quantitative science and the definition of measurement in psychology.** *Br J Psychol.* 1997; **88**(3): 355–383.  
[Publisher Full Text](#)
- Molden B: **Resistant pasts versus mnemonic hegemony: On the power relations of collective memory.** *Memory Studies.* 2016; **9**(2): 125–142.  
[Publisher Full Text](#)
- Mulderrig J: **Using keywords analysis in CDA: Evolving discourses of the knowledge economy in education.** *Education and the knowledge-based economy in Europe, Brill Sense.* 2008; 147–169.  
[Publisher Full Text](#)
- Müller M: **In search of the global east: Thinking between north and south.** *Geopolitics.* 2020; **25**(3): 734–755.  
[Publisher Full Text](#)
- Næss P: **Prediction, regressions and critical realism.** *J Crit Realism.* 2004; **3**(1): 133–164.  
[Publisher Full Text](#)
- Nash JC: **Re-thinking intersectionality.** *Feminist review.* 2008; **89**(1): 1–15.  
[Publisher Full Text](#)
- Nazarea VD: **Ethnoecology: situated knowledge/located lives.** University of Arizona Press. 1999.  
[Reference Source](#)
- Newman J, Clarke J: **The instabilities of expertise: remaking knowledge, power and politics in unsettled times.** *Innovation: Abingdon.* 2018; **31**(1): 40–54.  
[Publisher Full Text](#)
- Oliver M: **The social model of disability: Thirty years on.** *Disabil Soc.* 2013; **28**(7): 1024–1026.  
[Publisher Full Text](#)
- Patel V, Saxena S, Lund C, et al.: **The Lancet Commission on global mental**

health and sustainable development. *Lancet*. 2018; **392**(10157): 1553–1598.

[PubMed Abstract](#) | [Publisher Full Text](#)

Pembroke LR: **Eating Distress: Perspectives from personal experience.** Survivors Speak Out London. 1994.

[Reference Source](#)

Pembroke LR: **Self Harm.** Chipmunkpublishing Ltd. 2005.

[Reference Source](#)

Portelli A: **What makes oral history different.** *Oral history, oral culture, and Italian Americans*. Springer: 2009; 21–30.

[Publisher Full Text](#)

Porter R: **Mind-forg'd manacles: A history of madness in England from the Restoration to the Regency.** Harvard University Press. 1987.

[Reference Source](#)

Porter R: **A social history of madness: The world through the eyes of the insane.** 1988.

[Reference Source](#)

Porter R: **Foucault's great confinement.** *Hist Hum Sci*. 1990; **3**(1): 47–54.

[Publisher Full Text](#)

Rasch G: **On general laws and the meaning of measurement in psychology.** *Proceedings of the fourth Berkeley symposium on mathematical statistics and probability*. 1961.

[Reference Source](#)

Scanlon J: **Challenging the imbalances of power in feminist oral history: Developing a take-and-give methodology.** *Women's Studies International Forum*. Elsevier. 1993; **16**(6): 639–645.

[Publisher Full Text](#)

Sewell WH: **Some reflections on the golden age of interdisciplinary social psychology.** *Annu Rev Sociol*. 1989; **15**(1): 1–17.

[Publisher Full Text](#)

Sexton A, Sen D: **More voice, less ventriloquism- exploring the relational dynamics in a participatory archive of mental health recovery.** *Int J Herit Stud*. 2018; **24**(8): 874–888.

[Publisher Full Text](#)

Shankar S, Cavanaugh JR: **Language and materiality in global capitalism.** *Annu Rev Anthropol*. 2012; **41**: 355–369.

[Publisher Full Text](#)

Shapin S, Fuller S: **Never Pure: Historical Studies of Science as if It Was Produced by People with Bodies, Situated in Time, Space, Culture, and Society, and Struggling for Credibility and Authority.** *Aestimatio: Critical Reviews in the History of Science*. 2015; **8**: 97–100.

[Publisher Full Text](#)

Silverman D: **Interpreting qualitative data.** Sage. 2015.

[Reference Source](#)

Slade M: **Personal recovery and mental illness: a guide for mental health professionals.** Cambridge University Press Cambridge. 2009.

[Reference Source](#)

Smith LT: **Decolonizing methodologies: Research and indigenous peoples.** Zed Books Ltd. 2013.

[Reference Source](#)

Spitzer M: **Karl Jaspers, mental states, and delusional beliefs: A redefinition and its implications.** *Psychopathology and philosophy*, Springer: 1988; 128–142.

[Publisher Full Text](#)

Spivak GC: **Can the subaltern speak?** Springer. 1988.

[Reference Source](#)

Telford R, Faulkner A: **Learning about service user involvement in mental health research.** *J Mental Health*. 2004; **13**(6): 549–559.

[Publisher Full Text](#)

Triandis HC: **Individualism and collectivism.** Routledge. 2018.

[Reference Source](#)

Turnbull A: **Collaboration and censorship in the oral history interview.** *Int J Soc Res Methodol*. 2000; **3**(1): 15–34.

[Publisher Full Text](#)

Voronka J: **Turning Mad Knowledge into Affective Labor: The Case of the Peer Support Worker.** *American Quarterly*. 2017; **69**(2): 333–338.

[Publisher Full Text](#)

Weedon C, Jordan G: **Collective memory: theory and politics.** *Soc Semiotics*. 2012; **22**(2): 143–153.

[Publisher Full Text](#)

West NM: **Another Lesson from the Outsider Within: The Transcendent Relevance of Black Feminist Thought.** *J Stud Aff Res Pract*. 2020; **57**(4): 371–385.

[Publisher Full Text](#)

Wodak R: **What CDA is about—a summary of its history, important concepts and its developments.** *Methods of critical discourse analysis*. 2001; **1**: 1–13.

[Publisher Full Text](#)

Woods A: **The limits of narrative: provocations for the medical humanities.** *Med Humanit*. 2011; **37**(2): 73–78.

[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)

Young TK: **Population health: concepts and methods.** Oxford University Press. 2004.

[Publisher Full Text](#)

# Open Peer Review

Current Peer Review Status:  

---

## Version 1

Reviewer Report 26 July 2021

<https://doi.org/10.21956/wellcomeopenres.18428.r44955>

© 2021 Cresswell M. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



### Mark Cresswell

Bath Spa University, Bath, UK

Diana Rose's Open Letter in the Wellcome Open Research series outlines a completed research project ('EURIKHA') of great significance for critical studies of mental health. EURIKHA interviewed activists who have been exploring alternative forms of knowledge of 'madness' beyond conventional psychiatric paradigms. Rose's outline focuses on that part of the project which dealt with the Global North including 48 interviews with activists in North America, England, Australia, New Zealand, and Europe. Outputs resulting from this research are eagerly anticipated.

The editorial team of this review process have asked me to focus upon five questions in response to Rose's letter:

1. Is the rationale for the Open letter provided in sufficient detail?
2. Does the article adequately reference differing views and opinions?
3. Are all factual statements correct and are statements and arguments made adequately supported by citations?
4. Is the Open Letter written in accessible language?
5. Where applicable, are recommendations and next steps explained clearly for others to follow.

My answers to 1 and 4 are an unqualified 'yes': a full and lucid account of the research has been provided including reference to many fascinating issues and dilemmas. Rose provides thoughtful guidance about how to reflexively approach a difficult and under researched area and this will benefit any researcher investigating 'lived experience' and political activism as well as mental health. These issues require no further comment. I also do not intend to respond to the many methodological questions that the project raised. Although Rose writes at length about methodology, I thought that the combination of purposive sampling and a modified oral history approach involving the 'coding' strategies of qualitative research was persuasive. So, in the rest of this review I will concentrate on questions 2 and 3, about which I have some critical comments to make. These concern the definition of 'knowledge', the role of 'practice', the relation of universities to social movements, some remarks on Foucault and, finally, cultural change within psychiatry in the period which the project's interviews cover (that is, since 1970). I have not answered question

5 as the project is completed and it is for the EURIKHA team to decide the next steps.

### Knowledge(s)

This was the central theoretical category of the project's research. Yet it seems under-developed in Rose's outline. Key components in a theory of social knowledge - that it labels and classifies human experience in the context of a significant claim to truth - are under-emphasised. The metaphor of surface and depth is employed, instead, to illuminate the core goal of the project: 'to map the knowledge being generated across the world by people silenced for centuries', with 'surface' being used in its verb rather than its noun form ('our task was to surface the positive knowledge of survivors' [ibid: 4]). But this runs the risk of undermining what Rose otherwise insists on: the socially constructed condition of knowledge. The weakness of the metaphor of surface and depth - together with the narrative of 'silence' and 'voice' which accompanies it - is that it sets up a false dichotomy. On the one hand, we have a socially constructed psychiatry represented by its textual 'bible, the *Diagnostic and Statistical Manual of Mental Disorders* (DSMs) (for example, American Psychiatric Association [APA], 2013<sup>1</sup>); but, on the other hand, there is a newly liberated 'mad' knowledge of indeterminate content. Surprisingly, given the aspiration to unleash 'positive knowledge', Rose defines this more in terms of its conditions of subjugation than its actual content; thus, 'mad people are imagined as lacking rationality...tacit assumptions about lack of capacity' etc. (ibid: 1 & 3). Later, discussing the theoretical framework of critical discourse analysis (CDA), Rose admits that the research team approached the interview data with 'pre-formed social categories' (ibid: 11) but this only concedes what could hardly be denied with the employment of *any* interpretative framework - that the researchers were analysing the data partly in terms of the theory. This, though, leaves undescribed the actual conditions of possibility of survivor-knowledge, except we are informed that it has now 'surfaced'.

It could be objected here that the 'positive knowledge of survivors' will be fully described as 'situated knowledge' in future EURIKHA outputs and not just referred to generically, as it is here, as having 'form' and 'content' with 'symbolic and material requirements' (ibid: 4). But it would have been useful to have seen some practical examples. Without that, even in outline, the danger is that the tendency to 'valorise' survivor-knowledge overrides the need to analyse its emergence with as much acuity as we readily apply to the DSMs. Both survivor-knowledge and the DSMs are socially constructed. This is just another way of insisting that the two forms of knowledge are epistemologically equal and should be treated as such.

### Practice(s)

Rose takes it as a given that both the subjugating (psychiatry) and the subjugated (the 'mad') phenomena are forms of knowledge and therefore that the central issue at stake is knowledge(s). Is that true? It has to be partially true insofar as 'activist...groups had provided analyses of experiences that reconfigured...venerated psychiatric diagnosis' (ibid: 5) and Rose rightly references the activism of Pembroke and the re-articulation of '*deliberate* self-harm' as just 'self-harm' in the late 1980s/early 1990s. But interpreting this as a contestation just at the level of knowledge misapprehends lived experience. Pembroke was concerned with a set of abusive practices - for example, the mistreatment of individuals who self-harm in emergency departments in England - and their replacement by an alternative set of practices (reforming attitudes, pioneering 'harm-minimisation' approaches etc.). There seems to be confusion about the temporality of the process of experience>knowledge>practice: Rose posits an experience which

becomes knowledge and is then enacted as a practice' (for example, 'self-help groups' [ibid: 5]). However, it is unlikely that the relation of experience/knowledge/practice is linear: if an experience comes first then it is certainly possible that an alternative practice may predate the articulation of knowledge which then creates the conditions of possibility for a new experience etc. The relation of knowledge to practice in the sequence experience>knowledge>practice is empirical: it may only be determined through specific historical inquiries, and it is to be hoped that forthcoming EURIKHA outputs shed new light on this process. This reviewer is not convinced that the centrality of the concept of 'knowledge' facilitates that. Rather, a focus upon social practice that embodies knowledge rather than articulating it, may help break the dichotomy between knowledge and practice. Such a concept is found, for example, in the 'habitus' of Bourdieu's (1980)<sup>2</sup> sociology and has been elaborated for mental health social movements in the UK in the academic work of Crossley (2004)<sup>3</sup> and his notion of 'oppositional habitus'. I am not suggesting here that EURIKHA took a wrong theoretical path – just that the emphasis on knowledge needs to be tempered by an equal attention to practice(s).

### Universities and Social Movements

Mention of Crossley's work on mental health social movements raises the question of the relation of EURIKHA to the academy. Rose notes this issue but underplays its complexity. The 'positionality' of the EURIKHA researchers does seem unique: activists with lived experience of mental distress researching the knowledge-production of activists within mental health social movements whilst located in an elite university which Rose characterises as, 'the leading psychiatric research institution in Europe' (Rose, 2021: 7). Almost a decade ago, when Spandler and I (Cresswell and Spandler, 2013)<sup>4</sup> considered similar issues, we thought that such a position entailed what we called 'lived contradictions.' The researcher was simultaneously: 1) treating their research subjects as agents of change but objects of knowledge; 2) expressing solidarity with those they researched whilst employing certain 'outputs' to increase academic prestige; 3) respecting the knowledge of activists whilst yet imposing a theoretical framework upon them. Confronting such contradictions, we argued, involves academics who are engaged with the social movements they study entering into complex relations with those movements. But as we pointed out, specifically referencing Rose's work, 'the survivor academic who is doubly located' - within the university but also within the movement - 'faces a number of highly specific 'lived contradictions' which we do not address here, but which deserve to be considered in their own right' (Cresswell and Spandler 2013: 152<sup>4</sup>). We did not address them because we did not have the experience to do so. Perhaps it could be the case that the conclusion of the EURIKHA project provides an occasion to address some of these issues by academic-activists who do have direct experience of these contradictions?

### Foucault

I have two brief remarks on Foucault. The first is scholarly. I agree that it remains important to keep using his work as a launchpad for inquiry in mental health studies. Where this is the case, we now have the full unabridged translation of his *History of Madness* (2013)<sup>5</sup> and I think this should be the sourcebook used rather than the earlier, abridged translation, *Madness and Civilization* (1967).

The second remark concerns the limitations of the narrative of 'silence' and 'voice'. Rose employs *History of Madness* to establish the historical silencing of madness by psychiatry. Later, in the first volume of his *History of Sexuality*, Foucault makes a different point about 'sex'; unlike, madness,



which has been silenced, sex has been the object of a 'discursive explosion' (Foucault, 1978: 17<sup>6</sup>) since at least the 19<sup>th</sup> century. I wonder if we could not say the same about 'mental health' today. It is spoken of everywhere – in higher education, sport, social media, for example – so that cultural change within the mental health system has been notable in the time period covered by EURIKHA's interviews. It may be the case, then, that the narrative of 'silence' and 'voice' needs to be supplemented by a focus upon a cultural milieu in which mental health-talk is ubiquitous. One example would be the anti-stigma campaign Time for Change; ostensibly, this was a progressive intervention, but it has been critiqued as tacitly reinforcing the epistemology of the DSMs because the notion of 'mental disorder' that underpins its activism goes unchallenged (see McWade, 2019<sup>7</sup>). The issue here is not about 'silencing' but, rather, permitting the expression of 'voice' only within constrained limits. This brings me on to a final point about cultural change within psychiatry and society within the timeframe that the EURIKHA project covers.

### **Cultural change and psychiatry**

EURIKHA's objectives are wide in scope including the aspiration 'to compare the knowledge produced by service users to mainstream knowledge about 'mental illness' (Rose, 2021: 3). This assumes an awareness of mainstream knowledge – but Rose provides little indication that EURIKHA was up to date with this. Their outline still refers to 'mental illness' which was not even in operational use as far back as DSM-I in 1952 (APA, 1952<sup>8</sup>). In fact, the mental health system has undergone profound change in the period covered by EURIKHA including: 1) the move from an asylum regime to one of community care; 2) the expansion of the DSMs particularly in terms of the 'common mental disorders' (anxiety and depression); 3) a pharmacological revolution especially in terms of the prescription of anti-depressants and anxiolytics; 4) an explosion of media representations of distress especially since the advent of social media; 5) political transformations including the emergence of survivor-led social movements which is one of EURIKHA's main themes. Not all of these transformations have taken place within psychiatry; many, such as the explosion of social media representations of mental distress, refer to wider cultural change. Without referring to these transformations it is unclear how EURIKHA could compare mainstream and survivor knowledge. Whether they can meet that objective remains to be seen.

My final point concerns the heterogeneity of service users within the mental health system, which I think Rose under-emphasises. In terms of England, nearly 3 million people were in contact with secondary mental health services in 2019-20 (NHS Digital, 2021). This number subsumes a wide range of diagnoses and experiences, ranging from the provision of psychotherapy to detention under the Mental Health Act (1983). Given this heterogeneity, I still feel a little unclear about who EURIKHA actually interviewed. They do not discuss it in the way that mainstream qualitative research establishes 'inclusion' and 'exclusion' criteria. Rose (2021: 4) does clearly state, disparagingly, in discussing the 'stories' of service users experiences that 'only certain ones will do – mostly ones of recovery made possible by a psychiatrist or medication.' I assume from this that their 48 interviewees had experienced psychiatry negatively, been harmed by it, and were part of the user/survivor/mad movements. But Rose never actually says so directly and it would have been useful for them to do so. It would have oriented the reader more specifically and prepared them for the outputs to come.

Despite these criticisms, EURIKHA remains a landmark study and its future outputs are keenly awaited. Ironically, given the criticism of universities outlined above and echoed in some of my work, it is unlikely that such a wide-ranging, resource-intensive project could have been brought

to fruition without the involvement of a mainstream funder and an elite university. EURIKHA's ultimate goal, 'to lay out...the lineaments of survivor knowledge in the early 21<sup>st</sup> century' is one many survivors and academics will be eager to see achieved.

### References

1. American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders. 2013. [Publisher Full Text](#)
2. Bourdieu P: The Logic of Practice. *Stanford University Press*. 1980.
3. Crossley N: Not being mentally ill. *Anthropol Med*. 2004; **11** (2): 161-80 [PubMed Abstract](#) | [Publisher Full Text](#)
4. Cresswell M, Spandler H: The Engaged Academic: Academic Intellectuals and the Psychiatric Survivor Movement. *Social Movement Studies*. 2013; **12** (2): 138-154 [Publisher Full Text](#)
5. Foucault M: History of Madness. 2013. [Publisher Full Text](#)
6. Foucault M: The History of Sexuality: Volume 1. *New York: Pantheon Books*. 1978.
7. 10. Madness, Violence, and Media. 2019. 150-164 [Publisher Full Text](#)
8. American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders. 1952.

### Is the rationale for the Open Letter provided in sufficient detail?

Yes

### Does the article adequately reference differing views and opinions?

Partly

### Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Partly

### Is the Open Letter written in accessible language?

Yes

### Where applicable, are recommendations and next steps explained clearly for others to follow?

Not applicable

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** Sociology

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

Reviewer Report 04 June 2021

<https://doi.org/10.21956/wellcomeopenres.18428.r43764>

© 2021 Kitanaka J. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



**Junko Kitanaka** 

Department of Human Sciences, Faculty of Letters, Keio University, Tokyo, Japan

Professor Rose's paper is a very welcome addition and significant contribution to our understanding of the current state of user-led research. It sketches out, step-by-step, the actual processes of how to perform user-led research from the viewpoint of a veteran in the field. It clarifies the theoretical stance of the "Mad Studies", destabilizes some of the assumptions implicit in academic research, and critically investigates the power differentiation between the academics and non-academics in the politics of scientific knowledge production. The paper reads as a testimony to the many challenges one must contemplate before embarking on this kind of research. It is thus a guiding light, particularly for scholars outside the immediate circles of user-led research in the UK, US, and Canada, including those who attempt user-led research in the so-called Global South.

Thus, while it is certainly an important paper that accomplishes what it sets out to do, it is also rather curious in that it neglects to incorporate or highlight much of the significant progress in the field over the last few decades. Instead, Professor Rose begins her theoretical section by drawing on Foucault and the Frankfurt School to argue that the voices of the "mad" have been historically silenced and are still silenced today. While that may still be true to an extent, much has changed since the time of Foucault, and this is in large part thanks to the work of people like Professor Rose and her colleagues. The curious lack of recognition of this progress seems problematic not only because it paints a lopsided view of Mad Studies (the 'mad' have been listened to, but her paper does not give that impression), but also because it likely leaves other researchers wondering what to think about this progress: what they have overcome, what issues still remain, and how they are dealt with in the current EURIKHA project.

There are three areas of progress in particular that I'd like to point out with regard to the famous ECT research done by Professor Rose *et al.*, published in *BMJ*<sup>1</sup>. First of all, this work was epoch-making in the sense that it destabilized the politics of evidence. It problematized how the narratives (voices) of the people with mental illness had been treated as mere "anecdotes" and placed at the bottom of the hierarchy in the order of scientific knowledge. Their voices were suppressed and/or marginalized partly because they were seen as irrational, emotional, and too subjective. Secondly, the ECT research demonstrated how science, by neglecting users' subjective voices, produced quasi-scientific knowledge that simply failed to explain and/or understand users' lived experiences. By closely investigating how science failed—for instance, by asking patients about their "satisfaction" when they were feeling most vulnerable and pressured to answer positively (such as right after they were given ECT)—Professor Rose *et al.*<sup>1</sup> showed why some scientific findings might be at odds with users' lived experiences. Third, the ECT research offered innovative methodologies by showing how to collect users' own voices as a bundle and turn them into a form of evidence, a sign of scientific objectivity. In other words, the ECT research democratized scientific research by showing how the "mad" can be the agents of scientific knowledge production.

Of course, some of these insights are reflected in Professor Rose's paper on EURIKHA. For instance, the paper raises the fundamental questions of what is good science and whom science is for. It elaborates on the continued elitism in science, deconstructs the process of ethics-review where such power dynamics are inscribed, and points to the sensitive uses of terminology. Yet, instead of a celebratory tone, what one gets from this paper is an overwhelming sense of the painstakingly difficult labor involved in this kind of research. It conveys the message that the attempts to fully listen to diverse opinions, to try to include as many voices as possible, to attend to the complexities can be a truly daunting task. The resulting levels of emotional woundedness seem like they could thoroughly exhaust the researcher. And perhaps, the most important and delicate question remains unanswered: what to do with a certain sense of sacredness that comes with users' lived experience, their vulnerability, and trauma?

I wonder if Professor Rose's ambivalence and a certain silence around these issues may in fact be a product of progress in the field. That is, the progress made from the time when it was enough to criticize science and medicine, to the current time when that critical gaze is turned back on social scientists themselves. Social scientists, just as their natural scientist cousins, also tend to prioritize reason, avoid bare emotion and passion, and/or mold them into scientifically appropriate forms. As David Mosse (2018)<sup>2</sup> has pointed out with regard to PPI, what gives people's illness narratives the power they have—their subjective, specific aspects—easily gets lost when reformulated and presented in a scientific manner. Further decontextualized as data, such narratives may also lose some of their appeal, ceasing to be the kind of knowledge that could have the power to transcend science.

Another tension that comes from scientificizing user-led research may also be the politics around positionality and power dynamics. More specifically, what to do with the all-too-powerful view of a scientific expert who also speaks for and as the victim. At least in Japan, the context that I am most familiar with, there is an increasing presence of expert-users, doctors who have themselves experienced a psychiatric illness (such as developmental disorders, depression and dementia) and have come out as scientist/clinician/users. While they are highly praised for their courage, and appreciated for their unique expertise, they sometimes seem to evoke ambivalence among other users because these expert-users' voices may carry almost too much power and moral weight. Some may see that, merely by the fact that they have obtained M.D. and/or Ph.D., they do not really know what it is like to live with an illness and stigma. Their elite position may even be seen as a sign of arrogance that disqualifies them as true messengers in the first place. Particularly in the era of SNS, when some people may no longer need an "expert" to represent them, when the figure of the "patient" has changed radically from that of a passive silenced existence to an active agent who can access medical knowledge, what do such divisions mean and how have they changed the dynamics of user-led research and/or the possibilities for scientific knowledge production?

Lastly, I wonder if Professor Rose could elaborate a bit more about both the divide and also bridges between the Global North and the Global South. It is unfortunate that results from the so-called Global South were not incorporated in this report, particularly because the effects of previous user-led research are already apparent in some areas (Sugiura et al. 2020)<sup>3</sup>. There are also other unique attempts of user-led work called *tojisha kenkyu* (self-support research) that have emerged locally in Japan (Ishihara 2015)<sup>4</sup>, where practitioners are beginning to compare their work to what has been done in the UK. In Japan, for instance, people with dementia are increasingly speaking up, writing monographs, using SNSs, and their opinions are actively sought

after by the government and corporations seeking to create universal designs and dementia-friendly cities in a super-aging society (Kitanaka 2020)<sup>5</sup>. The same can be said for people with developmental disorders, whose growing presence in schools and workplaces has challenged the way people think about mental health in general (Kumagaya 2016)<sup>6</sup>. People with schizophrenia in Hokkaido, at a place called Bethel, have surprised the public by performing “hallucination/delusion contests” (where the person with the most hilarious and/or moving delusional experience gets the first prize) and have turned the act of talking about illnesses into public performance, a source of empowerment, and a space of mutual laughter and shared experience (Nakamura 2013)<sup>7</sup>. Some of these people have since sought ways to turn their knowledge into scientific evidence. People like Shinichiro Kumagaya, one of the leaders in the tojisha movement, are also expanding their insights about their vulnerabilities into projects for the “majority” to study themselves, creating personnel-developing projects for universities and corporations. Especially during the COVID-19 pandemic, they have begun to effectively challenge “mainstream” people to imagine what it is like to live with disabilities, and to ask themselves what we need to do when everyone is found to be vulnerable in some ways.

Given these new developments, I hope that Professor Rose might consider, in this EURIKHA report, including at greater length recent advances that have been made, assess where they have succeeded in changing the way scientific knowledge is produced, and what issues we still face in creating future directions for user-led research.

### References

1. Rose D, Fleischmann P, Wykes T, Leese M, et al.: Patients' perspectives on electroconvulsive therapy: systematic review. *BMJ*. 2003; **326** (7403): 1363 [PubMed Abstract](#) | [Publisher Full Text](#)
2. Mosse D: Can the Experience of Participatory Development Help Think Critically about ‘Patient and Public Involvement’ in UK Healthcare?. *Sociological Research Online*. 2019; **24** (3): 444-461 [Publisher Full Text](#)
3. Sugiura K, Mahomed F, Saxena S, Patel V: An end to coercion: rights and decision-making in mental health care. *Bull World Health Organ*. 2020; **98** (1): 52-58 [PubMed Abstract](#) | [Publisher Full Text](#)
4. Ishihara K: Learning from tojisha kenkyu: Mental health “patients” studying their difficulties with their peers. *T. Shakespeare (Ed.), Disability Research Today International Perspectives*. 2015. 27-42
5. Kitanaka J: In the Mind of Dementia: Neurobiological Empathy, Incommensurability, and the Dementia Tojisha Movement in Japan. *Med Anthropol Q*. **34** (1): 119-135 [PubMed Abstract](#) | [Publisher Full Text](#)
6. Kumagaya S: Individual impairment vs. disability that depends on location and era: Research on autism spectrum disorder. *Japanese Journal of Developmental Psychology*. 2016; **27** (4): 322-334
7. Nakamura K: A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan. *Ithaca: Cornell University Press*. 2013.

### Is the rationale for the Open Letter provided in sufficient detail?

Yes

### Does the article adequately reference differing views and opinions?

Yes

### Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

**Is the Open Letter written in accessible language?**

Yes

**Where applicable, are recommendations and next steps explained clearly for others to follow?**

Partly

**Competing Interests:** No competing interests were disclosed.

**Reviewer Expertise:** medical anthropology

**I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.**

---