# Who gets to study whom: survivor research and peer review processes

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## Abstract

This article explores the ways in which hidden biases against survivor research can emerge through the anonymity of peer review processes. We describe how this occurs in part because of an epistemological clash between the positivist science underpinning much mental health and psychiatric research, but also because of norms surrounding who has the right to study whom, norms that survivor research challenges. We conclude with some suggestions for ways forward.

Keywords: peer review; epistemology; survivor research; bias; positivism; researcher identity.

## Introduction

In academic research there are powerful norms surrounding who gets to study whom. Clinical researchers, social scientists and students typically study disabled people, health and social care service users and others such as children and young people on account of - or to acquire - clinical and research skills and knowledge. The discourse this creates is typically seen as objective and universal. When disabled people and health and social care service users and survivors engage in research ourselves, we are challenging these norms, and challenging our historical exclusion from knowledge generation. Hidden and open biases against our knowledge can arise, including doubts about our ability to conduct impartial and methodologically robust research. These biases have long been challenged by both traditional academics (Becker 1967) and disabled activists (Oliver 1992).

Peer review is the key process through which academic knowledge is authenticated and funding is granted. It is also the key arena within which hidden objections to the research involvement of disabled people, health and social care service users and survivors can surface. In this article we focus on our experiences of mental health survivor research to explore the epistemological base of survivor research, describe the continuing impact of the ‘double identity’ challenge, and explore how these play out in peer review processes. We conclude with some suggested ways forward.

## Experiential knowledge: The ‘I’ and the ‘we’ of survivor research

Sweeney (2016) describes how survivor’s experiential knowledge in research often stems from the ‘I’ – our personal attempts at seeking sense and meaning-making from experiences, and our search for a language to describe and communicate them to ourselves and others. In some forms of survivor research, robust methodological approaches – most notably autoethnography - are used to interrogate the ‘I’, with interconnections then sought between the ‘I’, ‘we’, and institutional, societal, and theoretical levels of understanding. Rather than seeking evidence of our own experiences, survivor researchers move reflexively between our experiences and the points of intersection and departure with others, with implications at broader levels explored. Consequently, “accusations of bias relating to the conscious shifts between ‘I’ and ‘We’ are simplistic and misleading” (Sweeney 2016).

Epistemologically, survivor research typically occupies an interpretative paradigm in which our direct experience and identity are foregrounded. Survivor research is reflexive and participatory, explicitly exploring the relationships between our positionalities and experiences, and our research activity, relationships and outputs. This impacts on all aspects of research, including the questions asked, the methods used, the nature of research relationships with participants, the interpretation of data, and the communication of findings. Inevitably then, survivor research is conducted from an explicit standpoint that is not hidden or obscured but foregrounded and interrogated. This can be seen as increasing the ecological validity of our research (Faulkner and Thomas 2002). Whilst all academics hold multiple identities - be they clinician, service user, survivor, mother, grandson, lesbian, neighbour or tennis player - having access to an identity is not sufficient to engage in critical reflexive looping. Instead, it is the way in which identity is used that is critical. Yet survivor researchers may feel the need to, or be encouraged to, downplay this aspect of their identity meaning that traditional research remains unchanged and unchallenged.

Whilst the foregrounding and interrogation of researcher identity can be seen as indicative of any high quality qualitative research study - most typically through reflexivity - there is a clash with the positivist paradigm of much psychiatric and mental health research which strives for objectivity, neutrality and distance (Beresford 2003). Of course, those operating within an interpretative paradigm assert that all research is undertaken from a particular standpoint, it is just rarely acknowledged or understood as such. However, within positivism, complexity and positionality can be lost to the trump card of objective science, creating suspicion and sometimes outright dismissal of survivor research and experiential knowledge (e.g. Russo and Beresford 2015; Sweeney 2016).

## The persistence of the double identity challenge

Over fifteen years ago, Diana Rose (2003) wrote of a double identity challenge facing survivor researchers in which we can be seen as survivors by fellow researchers, and researchers by fellow survivors, including our research participants. This means that what should be a strength – our ability to generate experiential knowledge (and more) and to translate between groups – can be lost because we are reduced to a single identity. More recently, Sarah Carr (2019) described the lack of understanding of survivor research from academics who do not identity as survivors, and the online abuse she experienced from survivor activists who feel that working in a university is a betrayal: “We are made ‘other’ by both powerful and oppressed groups of people”. Of survivor research, Carr observes:

We do not yet occupy a powerful position within academia, we have limited access to resources to enable us to pursue our own independent or user-led investigations, and we are often marginalised for various reasons – from outright pathologisation to non-service user colleague discomfort or professional competitiveness.

Recently, the Lancet Psychiatry sought to create a pool of service users to review research papers; people with research training were excluded. In an open letter to the Lancet Psychiatry, a diverse group of international survivor researchers and organisations welcomed the move to include service users in peer review, but raised concerns about the ‘overly simplistic dichotimization…and ‘deeply entrenched hierarchies of epistemic authority’ (Building User/Survivor Research Capacity and Leadership, 2018).

As well as demonstrating our continued reduction to single identities – survivor or researcher - the exclusion of survivor researchers in this context may also reflect dominant beliefs regarding who has the right to study whom and in what way. In arguing for survivor inclusion in knowledge generation, survivors and allies have made methodological, epistemological and ethical arguments (e.g. Russo and Beresford, 2015). Of these, ethical arguments are perhaps hardest to counter, particularly in public forums, and objections are typically confined to the spoken word with a few notable exceptions (Rose 2009). Tyrer (2002) for instance argues that: *There is a real danger that the engine of user initiatives in mental health services, although positive in principle, will accelerate out of control and drive mental health research into the sand*. (Tyrer, 2002, p406). In an open critique of experiential knowledge in medical sociology, Prior (2003) comments that such knowledge is ‘invariably limited and idiosyncratic’, refers only to one ‘case’ and fundamentally, ‘lay people can be wrong’.

Such fears and rejections in part rest on the epistemological clash between positivist research and survivor research’s position within the interpretive paradigm, our critical reflexive looping between the ‘I’ and the ‘we’. And whilst this rejection is often hidden, confined to the spoken word, it can be brought to life through the anonymity of peer review.

## Funding and authenticating knowledge

Peer review is a key part of the academic system, authenticating knowledge and granting access to research funding. As we’ve described, survivor research’s foregrounding of researcher identity contravenes dominant (positivist) epistemological frameworks, subverting norms around who gets to study whom. Our identity is fundamental to how we propose to conduct research, and how we write the findings; it cannot be hidden. One direct consequence of this is that peer reviewers can consider our work inherently biased and methodologically weak; our ability to understand the experiences of research participants is seen as flawed, rather than enhanced. In addition to this, many mainstream journals are unlikely to publish qualitative, survivor-generated experiential knowledge that challenges not just dominant epistemologies, but often the taken-for-granted knowledge base.

To secure peer review of academic papers, editors seek reviewers based on their profile in the research community and published body of work. Whilst editors are ultimately able to take final decisions, for various reasons, few journals have editors who identify as survivor researchers (with some notable exceptions).

We are not claiming that survivor research is denied publication, that any bad review is a biased review, or that there is a blanket rejection of our work - we have experienced reviews that warmly welcome survivor presence in knowledge generation too, and the vast majority of peer reviews serve their intended purpose of raising reporting quality. Instead, we are describing the judgement that what has been (or will be) produced through survivor research is (or will be) fundamentally flawed on account of our identity. These rejections are at times presented angrily, with implicit or explicit personal attacks. This complicates our access to funding and publication, preserves the status quo regarding who has the right to study whom, and stifles methodological innovation. There are likely to be additional exclusions for independent researchers who are not based within universities, or survivors who are researching from LGBTQ+, and/or black and minority ethnic and other positionalities. Invisible whiteness (King 2016) bestows privilege in many ways, and this is likely to be one such way.

## Conclusion

Inequitable access to knowledge authentication and funding has a circularity to it, confirming who is a legitimate knower, whose voice is to be heard, and who has the right to study whom, both now and in the future. This can be seen as a form of epistemic discrimination or injustice that denies people as “legitimate knowers” (Liegghio) and which mirrors the silencing of survivors within psychiatric service encounters (e.g. King 2016; Russo and Beresford 2015). To begin challenging this situation, survivors and allies could consider:

* Engaging in peer review; however, survivor researchers are often overwhelmed with the task of managing our emotional wellbeing, for instance within complex academic systems that demand too much of people (e.g. Carr 2019).
* Developing our own journals (this idea is floated from time to time).
* Ways of referencing our experiential knowledge so that it is not lost because it is not conventionally published.
* Encouraging editors to draw on quality criteria for survivor research (e.g. Faulkner 2004; Ormerod et al 2018).
* Encouraging journals to ask reviewers to consider key aspects of participation in the study under review, as standard (as is common practice in funding applications).
* Further developing the epistemological arguments underpinning our role as knowledge producers, continuing the work of survivor researchers such as Beresford (e.g. 2003) and Russo (2012), and drawing on these arguments to situate our work.

Once our knowledge is consistently judged on equal grounds, rather than narrowly through our identity, our position in the research landscape will be more secure. Until then, academic research will continue to privilege knowledge that contains and controls the people the research intended to benefit.

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