Refreshing Perspectives

Exploring the application of peer research with populations
facing severe and multiple disadvantage

Part two of a series of literature reviews on severe and multiple disadvantage

By Lucy Terry with Vicki Cardwell

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Contact the author of this paper: lucy.terry@revolving-doors.org.uk.

To get in touch with our peer researchers or learn more about

Revolving Doors' coproduction work: paula.harriott@revolving-doors.org.uk

Introduction

Government and third sector bodies are increasingly willing to acknowledge that the expertise of people with direct experience of social exclusion is unique and invaluable. User involvement or coproduction approaches are increasingly sophisticated and prevalent, with examples of people with lived experience getting involved in running organisations, designing national programmes, training and recruiting staff, shaping commissioning and political influencing (Clinks and Revolving Doors, 2016).

Peer research is a distinct type of service user involvement extending the expertise of experience into research. Often, it is propelled by an academic body or third sector organisation having a particular interest in coproduction approaches. In peer research people with direct experience are involved in designing, delivering and shaping research. Peers generally take on the role of the researcher in studying the target group; they are often researching their peers. Peer or 'user led' research is regularly employed in mental health (see for example the peer research organisation the McPin Foundation; and papers such as Faulkner and Thomas, 2002; Rethink, 2009). In this paper, we will focus on peer research methodologies involving people facing common 'markers' of severe and multiple disadvantage such as criminal justice contact and homelessness.

In reviewing the peer research literature and grappling with questions such as 'validity', 'purpose' and 'robustness' we were mindful of the context in which peer research has developed. Its origins are in the broader approach of neighbourhood-based participatory research and indeed the terms are sometimes used synonymously. Both approaches have strong links to community action and social change. The research is not distant, neutral or objective, it is strongly political and presupposes a need for change (Clover, 2011; Fine and Torre, 2004). Feminist approaches to qualitative methodology such as Oakley (1981) are commonly cited in peer research literature (e.g. Sova, 2003; Revolving Doors, 2015). This challenges assumptions of objectivity in research and emphasises the need for researchers to make explicit their own subjectivity, considering how their views, thinking and conduct impact on the research process. As well as the components of subjectivity and social action, 'rapport' is key to peer research. It is argued that research which engages meaningfully with its participants is more effective, in that leads to deeper, richer and more honest data (Sova, 2003; Beresford, 2007).

Nevertheless commentators have also queried if and how peer research can meet widely recognised quality standards in research. Producing research that is valid, reliable, confirmable, reflexive, and responsible (McLeod and Noble, 2016) requires a specific skillset and ongoing training and development. Peer research goes beyond many forms of service user involvement which require service users to use their own experiences to inform policy and service delivery. It is instead about gathering and synthesising the experiences of others, which requires a degree of detachment.

Done well, peer involvement has the potential to make research more relevant and inclusive; and to change a very hierarchical practice. It offers broader benefits too: personal development and confidence, reversing marginalisation and objectification, and community activism. It can support the journeys of desistance and recovery, for which social inclusion and a meaningful and positive role are key factors (Terry, 2015).

Peer research on severe and multiple disadvantage is very much a field in development, and the scope of our review crosses very disparate sectors, remits, social contexts and geographical boundaries. This review explores some of the conceptual implications underpinning peer research and the practical and methodological considerations that arise.

This review is not authored by a peer researcher. We recognise the limitations of this. The paper will be followed by a series of case studies of peer research reviewed by members of our National Service User Forum (NSUF, forthcoming). We have also asked a peer researcher to respond in blog form.[1]

How we completed this review

Our review of peer research methodologies took place between January and April 2016. Our review was limited to examples or accounts of peer research processes by/with severely socially excluded populations, such as: people in the criminal justice system, those with experience of street homelessness, people involved in street based sex work, and those with experience of substance misuse. Our focus was on the detail of the process, not research findings. We did not include peer research done by mental health service users unless the research involved those with experience of mental illness *and* other complex needs. Some of the peer research projects we reviewed were led or included by young people as young as 16; however, we do not specifically consider the key aspects of peer

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[1] This will be available at: http://www.revolving-doors.org.uk/news--blog/blog/forum-blog/.

research with children and recognise that many of the findings will be different.

We included papers using both the term 'participatory research' and the term 'peer research' – but always with a primary focus on the involvement of marginalised populations in research. There are some possible, but underarticulated, differences between the two terms: for example levels of involvement in field research (Guta et al, 2013) but many of the underlying concepts are the same. Participatory research that is neighbourhood-based may serve to exclude populations such as prisoners or drug users who are physically or socially marginalised within a community. However, we reviewed examples of participatory research projects within prisons or homeless communities.

We put out a call for papers to 200 members of our research network on severe and multiple disadvantage, asking for examples of peer research papers which contained details of the process of carrying out peer research. We attended two seminars focusing on peer research from which we were made aware of examples. We also took examples from organisations with a history of delivering peer research, including Revolving Doors, and also Groundswell. Due to the emerging nature of this methodology much of the papers we reviewed is 'grey literature'. We are not attempting here to understand the evidence base for a specific topic. Rather we are focusing on methodology (or more loosely, approach). This is an exploratory review of an approach to research as it pertains to the severe and multiple disadvantage field. It raises key conceptual questions and practical considerations.

We used the databases Google Scholar and the British Library catalogue to continue our search for papers. Key terms included 'participatory research', 'peer research', 'user led research', combined with for example 'homelessness' 'criminal justice', 'sex work'. Reviews were assessed for their relevance to the scope of this review; papers with very little detail on the process of doing the research were excluded. We limited scope to English-language papers. In total we reviewed 27 papers.

We originally intended to assess the quality of this body of literature. However, given the disparate and multiple perspectives, remits, scopes, and contexts, an assessment of quality seemed inappropriate. Instead, we have explored the key concepts and implications for peer research delivery and design and for research into severe and multiple disadvantage.

We have split the findings of our literature review into three sections. The first discusses

underlying theoretical concepts in peer research approaches, which incorporates questions of definition, democracy, transfer of power and purpose. The second section outlines major themes of the practical application of peer research - the aspects of research that come into peer research projects, how people are trained and developed, the benefits to people involved, potential challenges, and how it can be done well. We then give an overview of the specific subject of ethics in peer research, which spans theoretical underpinning as well as practical considerations. Finally, we conclude with thoughts on where peer research on severe and multiple disadvantage can go next.

1. Key concepts in peer research

What defines a peer?

Peer research is based on the assumption that shared experiences brings a unique quality to research; an understanding and empathy that results in a higher quality and more meaningful research process. In this review we are focusing on peer research projects with people who have experienced a depth of social exclusion such that lived experience would appear to have considerable benefits in shaping research topics, access to participants and rapport between researcher and researched.

Peer researchers are therefore qualified partly on the basis of lived experiences of aspects of severe and multiple disadvantage - such as criminal justice contact, street homelessness, or street-based sex work. Most projects we reviewed identified peer researchers by one of these experiences and sometimes also considering demographic factors such as age, gender, and ethnicity (e.g. Thompson et al, 2015; Revolving Doors, 2015). However one peer research project studying young people's drug and alcohol use seemed to define 'peer' by age only (Ledden and Vickers, 2011).

However, some literature raises the potential difficulties in defining a 'peer'. Thompson et al (2015: p.13) explored this quandary:

> *"Did it matter that we were asking a 20 year old black male from London who had been homeless to understand the experiences of a 14 year old white female from Sheffield who had run away from home? Were the identities and experiences of these young people really quite different, or does the common experience of needing to find a safe place create a sufficient commonality? …. [The] peer researchers will have held multiple identities informed*

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by race, class, ethnicity, gender and many other factors all of which will have influenced the research process."

A person's experiences are shaped by multiple factors - their "dominant identity" may not be their homelessness or drug use experience (Thompson et al, 2015: p.13). Revolving Doors' National Service User Forum commented on a series of case studies of peer research projects (NSUF, forthcoming). One of their key points of feedback was that peer researchers needed to have a similar *range* of experiences for some projects - giving the example of women in prison who may prefer to speak to those of the same gender *and* with criminal justice experience.

Another point suggested in the literature is the balance between authenticity of experience and being deemed 'ready' to take on the role of peer researcher. Some peer research projects have excluded people for being too chaotic, for exhibiting behaviours associated with street survival, and for being 'difficult'. Guta et al (2013) note a possible conflict between authenticity and ability to meet fixed budgets and timelines. As they note, management may find peer research useful but will have limited patience for accommodating complexity and chaos within their projects. A peer researcher they interviewed (2013: p.446) commented on the limited empathy of the project coordinators for people taking extra refreshments from a project site to give to their friends: *"I thought [the coordinator] …. maybe could have been a little more understanding that these are real issues we have to face, and there's barriers there that you can't just – boom, solve".*

Peer researchers may require a certain degree of 'professionalism' and ability to manage time, especially to participate in peer research projects commissioned by external bodies for a specific purpose. But professionals managing peer research projects should be mindful of the purpose and ethos of peer research: that is, to give a voice to the most excluded, to challenge injustice, and to reverse power imbalances.

Concerns about tokenism and the extent to which peer researchers truly reflect the experiences of study participants can be well-founded. But Beresford (2007) points out that the representativeness of people with lived experience is often interrogated in a way that it is not for professional stakeholders, and that diversity concerns should not be used as an excuse to dismiss wholesale the benefits of lived experience. Rather, ensuring

representativeness should be built into the design and delivery of a project (see e.g. Revolving Doors, 2015). Steel (2005: pp.26-27) notes that how difficult it is to reach a group *"depends on how hard you are prepared to try"*.

Who creates knowledge?

Some of the peer research literature emphasises that knowledge is socially constructed, and that usually people from marginalised communities do not get to control or shape that knowledge. Knowledge is shaped by certain dominant frames and discourses in society, notwithstanding myths of objectivity or infallibility in empirical research (Wahab, 2003; Beresford, 2007; Fine and Torre, 2004). Research is actually shaped by "context, power and social construction" (Wahab, 2003: p.626). Put another way: what we know about the world is influenced by who gets to ask and who gets to answer questions. This is dangerous and limits our understanding. It can result in harmful stereotypes, objectification, and ignorance of marginal populations. It is a form of social inequality. Groups such as homeless people, prisoners and those involved in sex work are denied the right to create knowledge[2]; they are not recognised as experts on their own lives (Wahab, 2003); and they lack the tools and the platform necessary to create a competing narrative.

Peer and participatory research is a way to create a competing narrative. It is about creating knowledge collaboratively; challenging dominant discourses and interpretations; reversing the exclusion and objectification that means some groups are denied the right to be experts on their own lives. For this reason, peer research is argued to be ethically imperative (see e.g. de Winter and Noom, 2003), and naming peer researchers as co-authors is symbolically important (Fine and Torre, 2004).

Injustice and power is often invisible, assumed inevitable or invariable (Fine and Torre, 2004). Some peer research projects have challenged this, turning the lens of analysis onto these invisible forms of power and injustice - creating new forms of knowledge. For this reason many argue for the external validity of peer research because it focuses on issues of high relevance to marginalised groups that may have nevertheless been under-researched (Sova, 2003; Fine and Torre, 2004). Understanding what research should be looking at, and

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[2] We use the phrase 'right to create knowledge' a few times in this review and recognise it may be a contentious term. We feel this reflects the moral and ethical grounds for being able to influence the process of acquiring knowledge, as we outline in this section.

what questions researchers are not asking but should be, is a key benefit of a peer research methodology that includes peer researchers in setting the overall direction. Not all peer research projects with very marginalised populations can or do involve people with lived experience in setting the overall topic direction; many such projects still bring considerable personal and research benefits. But being able to create knowledge is a key principle and component of peer research - increasing representation of the most marginalised.

Blurring the boundaries or 'us and them'

Peer research is "*a shift away from 'top down' research where those with the most power in organisations decide how the research should be conducted*" (Sova, 2003: p.3). Steel (2005) argues that without some change in team dynamics and boundaries, the involvement of service users can only be tokenistic. If research is produced by people with lived experience, either in full or in part, this suggests some blurring of boundaries between the researchers and researched, between academics and people with lived experience, between professionals and service users. Wahab (2003) felt her participatory research project made professional boundaries seem irrelevant and artificial.

Peer researchers report benefits resulting from crossing over from being a service user to being a professional. For one peer researcher who had been homeless, it reversed "a profound experience of exclusion" (Harding et al, 2010: p.322). This also benefits participants in studies, showing them that "change is possible" (Smith, 2010: p.19). In Sova (2003) some peer researchers felt more assertive in dealing with professionals after working alongside them; the authors also suggest that peer researchers may have had a better understanding of the perspectives of professionals. It is also symbolically powerful. In Sova (2003: p.7), "*serving prisoners were granted permission to go into prisons where they were not serving and ex-offenders were also granted permission to enter/return to prisons*".

But to what degree are boundaries genuinely blurred? In many peer research projects a clear division between 'us and them' remains. Sometimes it is interrogated and reflected upon by authors, in other cases it is implicit. Papers which are written by invisible academics that write in detail about the lives and demographics of peer researchers can seem othering and not really coproduced. Research institutions which are bound to fixed structures, approval bodies and processes cannot produce entirely user-led research. Thompson et al

(2015) note that as a small charity Railway Children was able to make quick changes to their research model following peer researchers' feedback; this would be different in an academic body with an entirely separate ethics committee.

Furthermore, it may not be ethical to simply abandon all professional boundaries. Researchers working with very vulnerable populations must maintain professional responsibilities to keep people safe and well, and this has to be considered in (for example) assigning roles and administering compensation (Hayashi et al, 2012; and discussed further in our ethics section).

Fine and Torre (2004: p.17) blur the boundaries through listing the demographics of not just their prison-based researchers, but the academic researchers as well:

> *"Some of us were White, Jewish, Latina, Caribbean and African-American, some mixed. Most of us were from the mainland of this country, a few born outside the borders of the USA. The most obvious divide among us was free or imprisoned, but the other tattoos and scars on our souls weave through our work, worries, writings and our many communities."*

Still, they reflect that some divisions remained, that a peer research project could not erase or undermine gulfs of experience such as that of being imprisoned: "*half of us could go home at night, half of us were 'home'*" (2004: p.17). They reflect on the need to analyse, address and make explicit "places of disjuncture" within a peer research team (Fine and Torre, 2004: p.19). Price (2008: p.406) reflects on the paradox of doing peer research for an organisation which carried out community-based sentences on behalf of the criminal justice system, an organisation committed to monitoring and surveillance of its users.

How can boundaries shift to include lived experience?

A sense of 'us and them' will likely prevail where peer researchers are insufficiently prepared for the research process. In order to 'sit at the table', peer researchers need to have the tools, the knowledge and the language to participate as equals (Coupland, 2005; Fine and Torre, 2004). Tokenistic examples of peer research fail to sufficiently upskill people with lived experience and then use the results to dismiss the methodology as inadequate, explicitly or implicitly. More ambitious examples of peer research reflect on how people can be sufficiently supported to participate, and the resources required to do this. The required

skills may not simply be training in research methods, but understanding the policy and social context (see examples in Smith, 2010). A specialist participation or engagement worker skilled in reaching marginalised groups may also help break down social or practical barriers to inclusion (e.g. Thompson et al, 2015; Garcia et al, 2013).

Organisations themselves need to shift and change attitudes and processes in order to be more inclusive (Steel, 2005). Professional researchers must be prepared for their assumptions and deeply held beliefs to be challenged; for their favoured explanatory theories to be countered (Fine and Torre, 2006). Organisational stigma can prevent peer researchers participating (Harding et al, 2010). Wahab (2003) is a highly personal account of a participatory research project with women involved in sex work, which involved the researcher herself (a PhD student) shifting roles and crossing boundaries as she built up a strong relationship with a group of women. She reports becoming a friend, a confidant and a *receiver* of peer support: "*perhaps to the chagrin of my social work instructors, it was a place where I too received support*" (2003: p.629). Wahab's disclosure of her own experiences and personal life to women involved in sex work seems to represent professional researchers 'giving back' something of themselves. Historically, this exchange of stories has been one-way, with research requiring marginalised people to tell their story repeatedly and for other people's use. This has been criticised as unethical (see for example Oakley, 1981).

Key insights for peer research projects

There are a number of skills and qualities required for professionals to work with peer researchers, which include a willingness to be challenged and to give up one's voice, and a commitment to reducing stigma and exclusion.

Power imbalances within peer research

There were fewer repercussions for Wahab for discussing her personal life than for a vulnerable, criminalised or marginalised person (see also Fine and Torre, 2006). As she noted, her enthusiasm and dedication to a collaborative pursuit of knowledge could not simply shake off power imbalances. While she facilitated collective interpretations of the findings, her participants reminded her that they still had well-founded concerns around misrepresentation:

"While reflecting on the research process, Nancy expressed concern that I might misinterpret her report of her experiences and her opinions: […..]: 'What happens though is that two people hear things two different ways. What I can tell you about my childhood I might explain some things and you might hear it differently. So, when you hear the tape, remember that.' "
Wahab (2003: p.634.)

Peer research teams can and do replicate power dynamics in services, systems and society. Recruitment of peer researchers sometimes echoes employment practice, e.g. interview panels: *"I was interviewed by four different people in the same room, which was a bit intimidating. I must say. I felt that I was okay there, but it was intimidating having been a long time since I [had] been in a job interview"* (Guta et al, 2013: p.440).

Peer researchers worked alongside health workers in a participatory action research project with injecting drug users in Australia. While both groups were inexperienced in research and were supervised by university researchers, the health workers seemed to become "de facto supervisors" in the researchers' absence (Coupland et al, 2005: p.195). The health workers were also initially sceptical about the ability of peer researchers to participate, doubting their ability to maintain confidentiality. However, overall this project went some way towards tackling stigma and prejudice: towards the end health workers acknowledged that peer researchers had many skills to offer.

Price (2008) believes his peer research findings were dismissed as unhelpful and weak because they did not suit or reflect management interests. As a counterpoint, a pragmatic approach to peer research which addresses issues which can realistically be changed and which are of concern to management may be more likely to have an impact (Revolving Doors, forthcoming). However, Guta et al (2013: p.443) highlight how peer research can be a tool to serve management concerns: *"community bonds [are] mobilised for the purpose of extracting community knowledge"*. In the project they discuss, peer researchers with experience of homelessness and drug use were required to maintain a balance between authenticity and professionalism. Community links and insider knowledge was useful, but those whose behaviour was too difficult, inefficient or 'chaotic' were dismissed. Some of the literature raises the importance of transparency and open discussion, especially in

contentious decisions and rules (Hayashi et al, 2012), and also recruitment (Smith, 2010).

Promoting social change

> *"I found [the project] whilst being in a meeting at a probation office. I was looking for ways*
> *to change the criminal justice system as many people who were involved in it were having*
> *their lives destroyed and being dismissed by society."*
> A peer researcher in Revolving Doors (2015: p.10).

Much of the peer research literature highlights that peer research has strong links to 'action research' and so should be driven by the needs of the community to effect positive change for that community (Hayashi et al, 2012; Clover, 2011; Fine and Torre, 2004; Garcia et al, 2013). It is "inherently political" (Beresford, 2007: p.308).

Disseminating research and using it for action is a major part of the peer research process. Peer research is not solely about getting marginalised voices into professional research contexts. It is often a tool to serve community action, which may or may not involve professional researchers; it is also used in service evaluation and service improvement, driving change in professional contexts (e.g. Revolving Doors, 2014a and 2014b). Its origins in the political, bottom-up process of participatory action research are key to understanding the methodology, how it has evolved and how it should be judged (Clover, 2011; Beresford, 2007). Fine and Torre facilitated a prison-based participatory research project: they were "*obligated (and honoured) to join the… political struggle of prisoners' rights*" (2004: p.20). They highlight the unique ability of participatory research to centre injustice and oppression: to show "*the keys to how institutions seamlessly benefit those in power"* (2004: p.24). Clover (2011) discusses the "explicit aim … to better the lives of women" in her account of a feminist, arts based participatory process.

Many of the peer research projects discussed in the literature include activity like campaigning, peer support, service improvement and community organizing, including Groundswell (2010), Garcia et al (2013) and Fine and Torre (2004). Hayashi et al (2012) describe how their project with injecting drug users in Thailand involved promoting a harm reduction service to more users. Peer research can precipitate informal, ad hoc peer support and advice as well (Sova, 2003; Hayashi et al, 2012; Clover, 2011) – including from those with lived experience to professionals (Wahab, 2003). It also has the potential to

challenge stigmatizing and limiting views:

> *"Providing peer workers with opportunities to demonstrate their skills and abilities may prove more effective in challenging negative attitudes towards IDUs* [injecting drug users] *than attempting to resolve these issues in the context of a training programme."* Coupland et al (2005: p.196.)

Who and what is peer research for?

Understanding the origins of peer research in community action reminds us to take care when considering by which yardstick to measure its success. Is peer research about improving the quality of research, through richer qualitative data (Harding et al, 2010)? Is it about increasing the relevance and validity of research by widening the lens of analysis (Fine and Torre, 2004)? Or is it about dismantling power structures, stopping professionals from always speaking on behalf of others; or about and improving conditions for oppressed people (Fine and Torre, 2004; Beresford, 2007; Wahab, 2003)? Wahab (2003: p.637) suggests a possible tension between goals of empowerment and requirements of research institutions. She discusses introducing traditional qualitative analysis methods to her project and the accompanying sense of "betrayal" she felt, that she had diminished the impact of a collaborative approach:

> *"Because I was asked to "analyse" the data, I feared that dissecting the whole narratives into smaller pieces, coding, assigning themes might compromise the integrity and spirit of the narratives as they stood in their entirety."*

When judging peer research against quality metrics, its core values and principles of self-advocacy, democracy and inclusion must also be borne in mind. Nevertheless, as we detail below, peer research does have positive implications for research quality - both conducting field research and breadth of interpretations in the research team.

2. Practical considerations of peer research

Which stages of the research process do peers get involved in?
In most of the projects we reviewed, peer researchers were involved in varying degrees in

designing and delivering research; and in promoting its findings. Some ways people were involved in designing the research included: deciding the research question, the method of enquiry, the interview questions, and how to recruit participants. Peer researchers (co)delivered research through acting as interviewers, analysing data, drawing up recommendations, and writing reports. Peer researchers did not always get involved in data analysis, and this is sometimes reported as challenging (e.g. Thompson et al, 2015). However this is not inevitable:

> *"While transcribing the data the peer researchers were asked to make notes about possible arising themes. These themes were then used to go back and code, and order, the data – with new themes and sub themes emerging. An initial linking of themes was done by Mike Seal* [facilitator and trainer of this project]*, which the group then discussed and revised, which then was used to go back and analyse the data."*
> Revolving Doors (2014a: p.6).

Beresford (2007) highlights potential user involvement in research beyond the more common avenues:

- Commissioning research
- Dissemination
- Managing research
- Seeking funding
- Deciding follow up actions

This reminds us of the broad, yet often unrealised potential of peer research. Often peer researchers are involved in a fairly easy-to-manage role: commenting on topic guides or carrying out interviews under supervision. Rarer is an example of a peer research project where the overall topic, ethical framework, or the training programme for researchers is done with lived experience input. Involvement in promoting the findings of research and ensuing policy recommendations *is* more common (e.g. Garcia et al, 2013; Hayashi et al, 2012). Peer researchers can and have been involved in disseminating research findings, often in creative and innovative ways.

In both Hayashi et al (2012) and Thompson et al (2015) divisions of labour and delegations of responsibility to academic researchers were agreed and discussed with peer researchers. In both cases it was agreed that academic researchers would lead on data analysis. Sova (2003: p.9) took a democratic, coproduced approach to writing up the final report:

"The Research Manager took responsibility for the initial writing up of the results. However once each section was complete the peer researchers were asked to examine the end product alongside the coded data [and feedback on its accuracy]"

Sova's approach reflects the democratic principles of peer research and also ensures a more reliable, rigorous research process by bringing in multiple interpretations of the data.

> **Key insights for peer research projects:**
> Certain avenues of funding e.g. grants allow a more flexible approach where the research question is designed with people with lived experience. Full coproduction of design and delivery are not always possible, but peer research projects should build in democratic or consensus seeking approaches throughout.

Legacy and dissemination

Peer research has origins in community action, suggesting that it must leave a legacy of positive change for marginalised communities. To make sure the research is helpful, then, findings are often disseminated in targeted and creative ways. In Revolving Doors (2015) a group of peer researchers delivered training on relapse prevention to a group of probation officers and established working groups with commissioners. Another organisation disseminated the key findings of its peer research project into routes out of street homelessness through local peer support groups:

"Groundswell piloted Escape Plan peer support groups, run by peer facilitators, using the Escape Plan Notebook to go through each week and commit to one small action per week" Groundswell (2010: p.6)

This disseminated the research findings and simultaneously implemented a key recommendation around the importance of social networks.

> **Key insights for peer research projects:**
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> How can projects use the expertise of experience to disseminate the findings? Possible approaches include user-led training, public speaking, and community organising.

Which stakeholders should be involved in peer research?

'Pure' peer research suggests an entirely user-led process in which those with lived experience have control and final say over all aspects of the process. However, some note that involving professional stakeholders is both pragmatic and effective. Examining an issue which commissioners, managers or policymakers have identified as a key concern could mean study findings are taken seriously and effective change on that issue is more likely (Revolving Doors, 2016, forthcoming). Price (2008) discusses a participatory research project for a community-based rehabilitation organisation working with offenders, which Price feels was dismissed outright by management as it was a threat to their power. However the scope of Price's research covered a broad range of issues and problems, many of which the organisation would have been unable to do little about. Including a wide range of stakeholders is arguably also grounded in the principles of peer research: professionals and other stakeholders might be part of the community which a wider participatory project should seek to engage (Fine and Torre, 2004; Price, 2008).

Later on in the process, interviewing a wide range of stakeholders in order to answer the research question is identified in the literature as beneficial. Groundswell (2010) spoke to people who had escaped homelessness and also two 'significant others' identified by 'escapees' as key to their journey out of homelessness. Revolving Doors' peer researchers (Revolving Doors 2014a and 2014b) spoke to probation officers as well as their peers on probation; and as a result found some interesting similarities and differences between staff and service users – including common frustrations! Interviewing a diverse spectrum of individuals also avoids the tendency to focus explanations and findings on individual behaviour, and is more likely to reflect the dynamic relationship between structure and agency which influences people's lives (Fine and Torre, 2004).

Key insights for peer research projects:

Before commencing delivery of a peer research project, peer researchers could hold scoping sessions with key stakeholders to identify areas of concern or importance. Depending on what is being studied, this should include relevant staff at frontline and management levels, and funders/commissioners.

How does peer involvement bring about benefits to research?

"Personal involvement is more than just dangerous bias. It is the condition under which people come to know each other and to admit others into their lives."
Oakley (1981: p.5).

Peer research is theorised to lead to higher quality data and a broader and more diverse sample of participants, through the commonality of experience between researcher and researched. This commonality of experience leads to an initial trust that is useful for grounds for study participants to be more honest and go into more depth. Harding et al (2010: p.326) argue that peer interviewing specifically is about "doing qualitative research …. properly". Initially, the presence of a peer should relax the participant, knowing that the interviewer understands what they are going through. This should improve the reliability and honesty of the data. As the interview process continues, peer researchers have the 'insider knowledge' to ask the right follow up questions, understand slang and particular terminology, and to "judge the interviewee's honesty and truthfulness" perhaps probing where necessary (Smith, 2010: p.17). One peer researcher in Guta et al (2013: p.442) expressed the benefits of insider knowledge:

"I mean not to say that we are special, but we have special skills. To be able to go out and talk to somebody in the language of the street and understand what they're talking about, and be able to put it back into a language where everybody else could understand it."

Thompson et al (2015: p.15) show the benefits of shared language: in one interview, a peer researcher's use of the word 'random' in a question seemed to "*trigger a shared*

understanding and a very honest response" in which the participant disclosed their experiences of possibly unwelcome sex while staying at other people's houses.

Peer expertise can also improve research at design stage, helping to shape a topic guide or survey. It ensures the language used is accessible and appropriate for participants (Smith, 2010; Byng et al, 2012). In Smith (2010: p.10), peer researchers working on a homelessness research study in Portugal "*[improved] some questions relating to housing questions that were unclear or incomplete. Otherwise the questionnaire would have failed on the housing trajectories.*"

Peer research also brings particular expertise post-field research, at analysis stage. It can enhance trustworthiness of analysis by increasing the breadth of perspectives analysing the data (Coupland et al, 2005). As feminist research emphasises, all researchers bring their own biases and preconceptions to a process. Having the expertise of lived experience at this stage *"helps contextualize, communicate and apply findings"* (Devotta et al, 2016: p.3).

Is bias a problem for peer research?

Although there appear to be considerable methodological benefits, peer research projects have recorded some examples of bias and unreliable techniques. Establishing rapport does not translate into ability to carry out a research interview (Devotta et al, 2016). People are qualified based on their personal experience but without training this could lead to them biasing interviewees with leading questions and a focus on their own priorities. This means the views and experiences of participants (who may be more marginalised than peer researchers) are lost. An example of a leading question and unreliable research technique:

> Interviewer: *Do you think it would be a nice idea if the jobs that we do, they could combine them even say in the gardens…. if they started doing an NVQ that combined with the job?"*
> Part of an interview transcript quoted in Sova (2003: p.11.)

Thompson et al (2015: p.14) reflect on possible ways in which their peer research group may have biased the findings:

> *"Were the differences in questioning styles really just mistakes? Was the emphasis on*

relationships [in the findings on young people's experiences of running away from home] partly created by working with peer researchers who were at the end of their journey, where rebuilding relationships is a key factor?"

But it is a myth that peer researchers are *uniquely* unreliable as if other biases do not also influence the research process (Beresford, 2007). Professional researchers have "multiple blind spots" due to their lack of lived experience (Devotta et al, 2016: p.3) - and have biases which they too need to be aware of when carrying out research and reporting on findings. Peers are not hugely different from inexperienced professional researchers who require training and ongoing feedback on reliability in the research process. Furthermore, institutions govern the direction and findings of research and evaluations in ways which are not as obvious - and are therefore more effective - than the bias of peer researchers. An advantage of peer research may be that the potential bias and how it could affect the data is quite clear.

Improving quality: validity and access

Much of severe and multiple disadvantage research, especially service evaluations but also research into processes such as desistance and recovery, relies on the participation of those who choose to engage with services (Terry, 2015). But peer researchers can improve the diversity of the sample through linking research to their networks of more marginalised, excluded and/or isolated people. This can highlight particular issues faced by the very marginalised and ensure their voices are not lost. For example, in Lemos and Crane (2015), Groundswell carried out a peer-led survey which reached more street homeless people than the professional researchers' study that was more likely to rely on people in hostels and supported housing. In Hayashi et al (2012) the peer research team reached over 250 injecting drug users in one month, many of whom were not previously known to the harm reduction service where the project was based. Duff et al (2013) studied sex-for-crack exchanges and associated effects on health and risk among women involved in street based sex work. To identify where the study would carry out outreach and recruitment, a peer research team carried out a mapping and sampling exercise. Peer researchers also offer practical and logistical guidance for accessing certain spaces; Sova's (2003) peer researchers with prison experience advised the research manager on personnel who could help with on conducting research in prison.

Peer researchers also increase the external validity of research. Involving new, unheard perspectives widens the lens of analysis to focus on issues that are important yet under-examined (Fine and Torre, 2004, Sova, 2003; Ledden and Vickers, 2011). It is about knowing which things to measure and what broad topics to explore: influencing the overall direction of research. However, training in policy and sociological theories may be necessary for peer researchers to understand crucial context to any issues, alongside research training (Smith, 2010).

Key insight for peer research projects

Many areas of social policy enquiry would benefit from access to a more diverse sample and participants who do not necessarily engage with services. Peer researchers can be involved in recruitment through for example identifying sites to recruit participants or interviewing their friends and acquaintances.

Training and development

"If it is possible for …. Peer Workers to develop a sufficient competency in qualitative methods to conduct a needs assessment in such a limited time frame, this raises the question of what could be achieved with additional training, ongoing support and continued collaboration."

Coupland et al (2005: p.197.)

Some literature seems to treat the limitations of peer research as an inherent inadequacy - but arguably it is an indication of a training need. Developing skills and knowledge is essential to fully realise the principles of people's right to create knowledge and be seen as experts on their own lives. Training should cover similar ground to that provided to junior researchers: topic guides, interviewing techniques, data analysis and concepts such as validity and reliability (Smith, 2010) – as well as the process of policy change (Garcia et al, 2013). Role-plays and ongoing feedback can be particularly helpful in improving interview techniques (Smith, 2010). More broadly, training should cover the purpose of research and how different methods are appropriate depending on what questions you wish to ask. It should of course cover ethics, including the importance of informed consent and keeping

personal data safe (Smith, 2010). While much training for peer researchers will be similar in content to that provided to junior researchers, it may require a different technique that takes into account, for example, low literacy rates and lack of formal education (Revolving Doors, forthcoming). However, it should not assume a 'deficit model' but should rather draw out the natural strengths and interests of a group unlikely to have realised their own potential (Garcia et al, 2013).

As well as formal training, ongoing support and development work is necessary to help people continue to participate. While not exclusive to peer researchers, they are perhaps particularly likely to need support on dealing with disturbing or upsetting disclosures during research that may trigger traumatic or upsetting memories in their own lives. Groundswell (2010: p.11) sent two peer researchers with experience of homelessness on a self-reflection training programme, "*designed to better equip the researchers to cope with [revisiting] many of the issues connected with their own episodes of homelessness*".

Many of the projects we reviewed include specialist participation workers (or organisations) who may not have any research expertise themselves but who bring particular skills in engagement and involvement (e.g. Ledden and Vickers, 2011; Garcia et al, 2013; Revolving Doors, 2015). These workers have a background in engaging marginalised groups and will be familiar with some of the key techniques needed to recruit and maintain participants. Depending on the nature of the project, they may have specialist expertise in youth work (Smith, 2010; Garcia et al, 2013; Thompson et al, 2015). They may already have links to existing networks from which to recruit participants and will have a good idea of what training will be needed and which aspects of the process peer researchers can participate in - for example they will be aware of literacy levels. They can provide emotional support to people who are juggling multiple difficulties and problems, and are aware of the importance of working assertively and flexibly, keeping an open door for those participants who cycle in and out of the project; and of ensuring people are safe and well, not at risk of harm because of the project.

Reflecting the multiple and complex needs of those included in these peer research projects, much of the literature notes the need to build in extra time for projects to account for absence, setbacks and personal commitments (e.g. Clover, 2011). In a project described by

Hayashi et al (2012) research training for injecting drug users had to be repeated due to absence; and the field research shifts were short in recognition of people's drug use patterns. Meeting basic needs – providing food and drink – helps sustain participation (Clover, 2011). Finally, people claiming welfare benefits may need help in declaring any income received from peer research.

> **Key insight for peer research projects:**
> A comprehensive training programme will be needed: note the importance of ongoing 'on the job' training and 'refresher' courses. Helping people practically and emotionally to stay involved is also key.

Recruitment of peer researchers

How peer researchers are recruited is not always explicitly outlined in the literature - yet it is significant to wider themes such as power dynamics, divisions between professionals and people with lived experience, and inclusivity. Often recruitment is done via various forms of social care and support providers; the strength of this is the presence of support staff to ensure peer researchers have a source of emotional and practical support where necessary. However, reliance on access to services can limit the breadth of perspectives and also exclude the most marginal. More creative forms of recruitment are sometimes found, for example via waiting rooms at probation or substance misuse services (Revolving Doors, 2015). Recruitment also takes place via existing service user forums or groups.

The recruitment process is formalised in some cases: including an "application and interview, to reflect real-life job search" (Thompson et al, 2015: p.6). This would seem appropriate for a commissioned piece of research or a service evaluation, but overtly exclusionary practices in recruitment can serve to undermine the principles of coproduction and empowerment (Guta et al, 2013).

Practical consideration for peer research with marginalised groups include over-recruiting, to plan in advance for drop-outs (Revolving Doors, 2014a). Risk assessment as a part comes into play especially where peer research is done in sensitive locations such as probation (Revolving Doors, 2014a and 2014b).Recruiting for a range of experiences can reflect the point that people hold multiple identities and may relate to others based on a similar

combination of experiences (Thompson et al, 2015).

Personal Benefits

"The peer research group has enabled me to practise life skills, and has increased my confidence no end. Although I have had the ability to speak in a group, I sometimes lacked the courage of my convictions. So the group structure of the project was a massive boost for anyone who is trying to gain full time employment."
Peer Researcher in Revolving Doors (2014a): pp.4-5

Peer researchers report considerable improvements to their self-confidence and skills as a result of carrying out peer research. For those who have been disenfranchised and 'voiceless' for much of their life, peer research is a unique opportunity to be experts on their own lives (Wahab, 2003) and can reverse profound social exclusion (Harding et al, 2010). Peer research offers a chance to connect with other people with similar experiences and goals, as well as engaging with wider society. de Winter and Noom (2003: p.327) note that longitudinal studies show that young people develop much better *"in a social atmosphere that invites them to actively participate – where they feel connected, wanted, welcome and necessary"*. Where peer researchers are studying or evaluating services, the process of working with these professionals in a different capacity may give people more confidence to deal with bureaucracy and agencies (Sova, 2003).

Peer research has the potential to support journeys of recovery and desistance from crime. Social exclusion is a significant barrier to successfully exiting drug use and crime - therefore mechanisms which promote the social and community 'integration' of people facing multiple and complex needs have the potential to support people's journeys towards positive change. Peer research projects can also help people develop a positive identity (Clover, 2011) including as a 'role model' (Smith, 2010).

Effective engagement with people with lived experience should build on 'raw' abilities they already have and make them see their strengths and potential (Garcia et al, 2013; Revolving Doors, 2015). Skills developed through peer research include participating in civil society, critical thinking and social responsibility (de Winter and Noom, 2003); knowledge of

services and interventions, ability to talk to new people (Coupland et al, 2005); teamwork, and empathy for different cultures and experiences (Smith, 2010). Certification and accreditation may help improve self-esteem and employability (Hayashi et al, 2012). Experience of peer research can build a CV (Sova, 2003) and possibly provide a professional reference (Harding et al, 2010). Peer research also benefits professionals too: for example by exposing them to new viewpoints and explanatory theories (Fine and Torre, 2004).

Peer researchers often allude to the empowering nature of peer research (Revolving Doors, 2015). We should be mindful of Steel's caution that "the idea that we can empower others is a contradiction in terms" (2005: p.22). Professionals managing peer research projects cannot cause other people to be empowered- but they can hinder that empowerment. This reinforces that peer research projects should be properly resourced so people have the tools to sit at the table (Thompson et al, 2015; Fine and Torre, 2004; Coupland, 2005). Peer research could also be dispiriting in cases where people are researching injustice and are made aware of the slow nature of political change (Fine and Torre, 2004; Garcia et al, 2013).

3. Ethics in peer research: a theoretical underpinning and a practical consideration

An ethical stance

Peer and participatory research is an intrinsically ethical process; it is an "ethical stance" (Fine and Torre, 2004: p.26). Broadly, the right to participate is enshrined in human rights law – for example, the UN Convention on the Rights of the Child (Thompson et al, 2015; de Winter and Noom, 2003). As noted already, it is a way to challenge inequality and misrepresentation. While peer research cannot dismantle power dynamics entirely, it is a tool of social justice, challenging stereotypes and promoting political and social inclusion (Fine and Torre, 2004; Coupland et al, 2005). Therefore those who seek to benefit from peer research must consider how to involve the most excluded:

> *"We find it troubling that Bernadette was dismissed from a project that purported to address the needs of women like her, for being too much like one of them"*
> Guta et al (2013: p.446).

Peer researchers may wish to stay anonymous for a variety of valid reasons – but this should not be assumed. The agency of peer researchers who choose to participate must be respected (Wahab, 2003) and so must their consent to be named. Where peer researchers make an informed choice, breaking their anonymity and naming them as authors, co-authors and contributors is personally beneficial and symbolically powerful (Fine and Torre, 2004).

Keeping peer researchers safe and well

Anyone new to social research, or indeed support or therapeutic work, will find it difficult to handle "sensitive information" that is disclosed to them (Smith, 2010: p.4). This is particularly pertinent for peer researchers who may find hearing about experiences of trauma, exclusion and addiction upsetting, even triggering (Harding et al, 2010). Building in emotional support for peer researchers is ethically demanded. Harding et al (2010) offered debriefings to their ex-homeless peer researchers after each interview; Thompson et al (2015) recruited peer researchers from projects where support from a named worker could be guaranteed. Researchers of social exclusion and 'marginal' experiences may find themselves interviewing people who are under the influence, or mentally unstable, which can be difficult to know how to cope with – and this applies to peer researchers too (Smith, 2010). Training and emotional support is necessary (Groundswell, 2010).

Less obvious but still potentially damaging is that researching injustice and manifestations of inequality can be demoralising, depressing and shocking:

> "We have had to build in processes before, during and after […field research] visits so students can document inequity without losing their souls, spirits or their sense of hope"
> Fine and Torre (2004: p.28).

And when using research findings to make policy change, learning about the "*slowness of change and the many setbacks that can occur along the way*" (Garcia et al, 2013: p.25) is necessary – but possibly dispiriting.

Personal safety and risk of harm are raised in the literature fairly frequently. Peer research projects record that sometimes peer researchers are at risk of harm, harassment or

retaliation because of their participation (Clover, 2011; Fine and Torre, 2004; Sova, 2003; Hayashi et al, 2012). Fine and Torre (2006) report the hostility prison-based researchers encountered from staff, their cells searched and their personal papers destroyed. Hayashi et al (2012) highlight their concerns of giving cash to people based in a community of drug users, possibly vulnerable to being robbed.

Doing peer research ethically

Peer researchers themselves must be able to keep their peers safe, respect their privacy, and ensure consent precedes participation. Training in things like the importance of securing informed consent and what to do if someone discloses a threat to safety or health is necessary ahead of field research (Smith, 2010). Peer researchers are often studying members of the community where they live and socialise – sometimes in a confined space, such as prison. This has implications for confidentiality (Sova, 2003). Smith (2010) discusses one peer research project in which people were deliberately allocated to study people working in different areas. However, this does take peer research away from its origins in community-based participatory research, used as a tool to improve conditions for people in that community.

Prison-based work is a particular challenge for confidentiality, as personal data and interview transcripts cannot easily be kept in a secure environment, thus preventing peer researchers from fully participating in the analysis process (Fine and Torre, 2006).

Implications for payment and compensation

Paying people is considered ethically important but practically and ethically fraught in some situations, for some client groups. Some of the quandaries raised in the literature include: payment to those on welfare benefits, which risks disrupting any welfare benefit income (Sova, 2003; Smith, 2010); and payments to people who may be particularly at risk of robbery or relapse (Hayashi et al, 2012). But paying people is often seen as necessary to compensate for their time, skills, and effort (Smith, 2010). Harding et al (2010) also raises the issue of intellectual property, and who should and does own the outputs of peer research.

4. Conclusion: Where next for peer research?

This paper has considered the key concepts and applications of peer research particularly as they pertain to the most marginalised populations in society. It has highlighted the multiple purposes of peer research, noting its core values of community action and social change- and, in a particular call to action for academics, changing who creates knowledge and who gets to decide which issues are deemed worthy of examination, critique and debate. This paper has noted the potential of peer research to 'blur the boundaries' - while also recognising the challenges therein.

Peer research also has practical benefits to the research process. In qualitative research, eliciting trustworthy and rich data is something that peer researchers can help to achieve. People with lived experience can improve the rapport between researcher and researched, so that field research has the potential to go further in depth, tackle sensitive subjects, and produce more honest accounts. Peer researchers also bring a greater breadth of perspectives to research design and data analysis. This increases the quality, including the external validity, of research findings.

Some of the important practical and ethical considerations of peer research in this field include the need to upskill and support people with very few formal qualifications (Bramley and Fitzpatrick, 2015) to carry out research in an ethical and reliable way. People involved may need to balance multiple, urgent demands on their time with their participation in a research project. Taking part in the project could affect their psychological state or safety. Professionals and teams running, managing, funding or involved in a peer research project may have stereotypes and prejudices and unhelpful power imbalances, which they need to address or dismantle in order for lived experience in research to be effective. Academics and researchers wanting to involve peers should be aware that engagement and participation of the most excluded is a specialist skill that they may not have.

This paper, we hope, has moved the debate on from 'is peer research worthwhile' to 'how should peer research be done'. But in order to fully answer this question, there is a need for more active involvement of peer researchers in exploring the process of peer research - the

absence of direct quotes and co-authorship was notable in a number of reviews of peer research projects. There are also further potential avenues to bring in lived experience to the research process. Including different perspectives widens the lens of analysis, highlighting what should be examined and 'troubled' (Fine and Torre, 2004). Therefore, peer research is not just for qualitative research. Just as service users in mental health have highlighted the need for a greater focus on unwanted side effects of treatment in clinical trials (Service User Research Enterprise, 2002), peer research could influence what 'counts' in trials of social policy interventions; i.e. peer researchers deciding what outcomes are measured.

Peer research is ethically imperative – and should be done in an ethical manner. This includes transparency, and professionals taking care to avoid excluding difficult voices and /or being tokenistic in how and why people are involved. In this sense, peer research echoes wider considerations of service user involvement. At its most ambitious it can challenge power dynamics, bring considerable personal benefits to peer researchers themselves and create powerful new knowledge in the field of multiple disadvantage research.

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