

# Peer workers disseminating lived experience research: a perfect match?

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## Abstract

**Purpose** – This paper aims to explore the use of lived experience research in peer work.

**Design/methodology/approach** – A suite of user-friendly and engaging lived experience research resources was introduced to consumers by peer workers. In-depth interviews were conducted with 33 consumer participants and five peer workers about their experiences. The data were analysed using qualitative content analysis.

**Findings** – The role of the peer workers appeared critical in ensuring that participants, despite their varied needs, preferences and backgrounds, derived optimum benefit from each resource. Features in resource delivery that promoted a positive experience included presenting the resources in the context of an existing relationship, providing clear explanations, going through resources together, encouraging reflection, taking enough time; and flexible delivery. Peer workers viewed the resources as potentially useful in their everyday peer work and as a valuable addition to their peer work toolkit.

**Practical implications** – The benefit of lived experience research to consumers is likely to be optimised by supportive and thoughtful delivery of the resources. Peer workers have the skills and are in an ideal position to do this. Bringing lived experience research to consumers provides peer workers with a potentially unique and helpful approach for supporting and promoting recovery and is congruent with their overall practice.

**Originality/value** – Lived experience research has the potential to benefit consumers directly but is rarely brought to their attention. This paper is the first to examine the potential role of peer workers in introducing learnings from lived experience research to consumers.

**Keywords** Peer work, Lived experience research

**Paper type** Research paper

## Background

There is increasing recognition in mental health literature of the value of lived experience. People with lived experience of mental health challenges are making critical contributions to service planning, delivery and evaluation (Byrne, 2017). Two ways in which lived experience perspectives are informing service development are through lived experience research and peer work.

Lived experience research is conducted by researchers who identify as having their own lived experience, sometimes in collaborative teams with other researchers (Walsh and Boyle, 2009). It focuses on illuminating lived experience perspectives and experiences. Advantages of lived experience research include relevance to the target population, methodological sensitivity, validity and usefulness of results to consumers [1] (Faulkner, 2009; Kim, 2005). Although lived experience research is increasingly being used to inform policy and practice, our exploratory research suggests that it also has the potential to have direct, positive impacts on the lives of people living with mental health challenges (Honey *et al.*, 2020). Consumers who were introduced to resources developed from lived

experience research reported that their interaction with the resources promoted hope, motivated helpful activities, provided positive experiences, increased knowledge, encouraged reflection, facilitated constructive ways of thinking, decreased feelings of isolation and assisted them in explaining their situation to others.

Peer workers have their own lived experience of mental health challenges and are employed in formalised roles where they draw on their lived experience to offer support to others (Health Workforce Australia, 2014). They are employed in a range of roles, including direct peer support, systemic advocacy, education and training, research and management (Health Workforce Australia, 2014). There is emerging evidence that peer-delivered supports are effective for increasing consumer engagement with services, decreasing the need for acute services, supporting active involvement in treatment and recovery, increasing consumers' sense of hope and empowerment and supporting attainment of life goals (Byrne, 2017; Gagne *et al.*, 2018; Health Workforce Australia, 2014; Productivity Commission, 2020). As a result, increasing attention is being paid by service providers and policymakers to ways in which peer workers can complement, enhance and transform existing mental health services (Byrne, 2017).

One potential role for peer workers is supporting dissemination of lived experience research to consumers. In our recent study (Honey *et al.*, 2020), participants were introduced to lived experience research resources by peer workers who were employed as research assistants. Peer workers were seen as ideal collaborators in the study because:

- they could bring their experience, both as people with lived experience and as peer workers, to the design and development of the resources;
- they could recruit participants from the people they work with; and
- they could introduce the resources to participants in a sensitive and appropriate way, given their experience in providing resources and information to consumers in their daily practice.

The resources themselves, however, were designed to require little specific or direct input, with peer worker research assistants (PWRAs) being expected to briefly explain and demonstrate each resource, then give it to the participant.

Nevertheless, while participants were not specifically asked about the role of the PWRAs in our evaluation of the resources, this role emerged in the inductive analysis of in-depth, post-intervention interviews as important to how participants engaged with the resources, suggesting a greater prominence than we had anticipated.

In this paper, we use data from in-depth interviews with study participants and PWRAs to explore the intersection between peer work and lived experience research. We answer the following questions:

Q1. How did participants view the role of PWRAs in their introduction to lived experience research resources?

Q2. How did PWRAs see the resources as applicable in their everyday peer work practice?

## Methods

### *Study design*

This paper is a collaboration between researchers with and without lived experience and PWRAs. It reports selected findings from our resource evaluation, using data from qualitative interviews with study participants and PWRAs. We present findings that emerged about the roles PWRAs played in participant engagement with the resources and the potential usefulness of the resources for peer work. Ethical approval was obtained for the

intervention and participant data collection from Human Research Ethics Committees at the relevant local health district (LHD) and for PWRA interviews from The University of Sydney.

### *Intervention*

In collaboration with five PWRA employed at the LHD and four final-year design students, we translated six lived experience research papers into user-friendly resources (for details, see [Boydell et al., 2021](#); [Honey et al., 2020](#)). The resources are described in [Table 1](#).

Participants chose four of the six resources, and PWRA introduced them to one per week for four weeks. The resources were designed to require only brief explanation before being given to participants to take home and use in whatever way they preferred. PWRA and researchers discussed and reached consensus on how each resource would be introduced. Protocols were developed to be used flexibly, enabling PWRA to adapt their introductions to address individuals' needs. When they next met, PWRA asked participants general questions to encourage them to reflect on the resources (e.g. "How do the messages in the resource align with your own lived experience?").

### *Sampling and recruitment*

Consumers were invited to participate in the research by the PWRA. They were given time to consider whether they wanted to participate and assured that their choice would not influence their relationship with the peer worker or the service. All provided written informed consent.

Having expressed a wish to give formal feedback on their experiences, PWRA were invited to participate in an interview via an email from the lead researcher at the end of the study. They would have been interviewed as part of the normal exit process; providing informed consent simply allowed their insights to be used as research data. However, they were assured that their choice to participate would not affect their future relationships with the University of Sydney or the researchers.

### *Data collection*

Semi-structured interviews ([Rubin and Rubin, 2004](#)) were conducted with consumers after they had received all four resources. Interviews took place in person in a private room at the

**Table 1** Resource descriptions

<i>Topic</i>	<i>Citation</i>	<i>Resource description</i>
Meanings of recovery	<a href="#">Tooth et al. (2003)</a>	A 34-min podcast of an interview with two authors of this seminal study about lived experience perspectives on the meanings of recovery
What helps recovery	<a href="#">Onken et al. (2002)</a>	A set of black-and-white portraits with direct quotes depicting a theme from a research study about what helps recovery. Each is accompanied by a placard containing a description of the theme
Personal medicine	<a href="#">Deegan (2005)</a>	A workbook about "personal medicine" ("self-initiated, non-pharmaceutical self-care activities and strategies"), in a blister-pack design
Hope	<a href="#">Yeung et al. (2020)</a>	A box containing seven small, white, spherical canisters, each of which contain a tiny handmade colourful paper crane and a slip of paper with a key concept and quotes from the study
Physical health care	<a href="#">Ewart et al. (2016)</a>	A pack of 26 graphically designed cards about obtaining good physical health care. These are colour matched in pairs, with one card describing a study theme and the other including direct quotes and, sometimes, reflective questions
Meaningful activities	<a href="#">Biringer et al. (2016)</a>	A 29-page, A5 magazine depicting meaningful activities illuminated in the research, via graphically designed, colourful images, and participant quotes from the research

health service or by telephone, depending on participant preference. They were 7- to 30-min in length, averaging 17 min. An interview guide was used, containing open-ended questions which focused on participants' perceptions of the resources, such as which resource they liked most and which the least. The guide was used flexibly to allow follow-up on issues of importance to participants (Rubin and Rubin, 2004); however, no questions were included about the PWRAs' role in their experience.

Data were collected from the five PWRAs through a focus group and semi-structured interviews, which were transcribed verbatim for detailed analysis. Three PWRAs participated in the focus group lasting 80 min. They were asked about their perceptions of the resources and strategies they found more useful or less useful for presenting resources. Follow-up individual interviews focused on PWRA's personal experiences of presenting the resources. The two PWRAs who were unable to attend the focus group participated in a single extended individual interview covering all content. Interviews ranged between 17 and 38 min.

### *Data analysis*

Interviews were analysed using qualitative content analysis (Drisko and Maschi, 2015). Inductive coding was carried out using constant comparative analysis, a well-established coding technique (Charmaz, 2014). Each chunk of data (e.g. phrase or sentence) was examined to identify the ideas or meanings it exemplified, and each meaning was represented by a succinct code name. New pieces of data were compared to existing codes and added, or a new code developed. Codes were compared with each other to identify conceptual similarity, and like codes were merged or grouped into categories. To enhance interpretive rigour, three interviews were coded independently by two researchers who discussed and reached consensus about the coding. Subsequent interviews were coded by one analyst and checked by and discussed with at least one other researcher. Emerging findings were discussed with PWRAs, who aided in interpretation. This paper, co-authored by three of the PWRAs, reports findings that emerged around how the resources were presented.

### *Participants*

Of the 38 consumers who interacted with the resources, 33 completed the qualitative interviews. The remaining five were unable to be contacted. Table 2 presents the characteristics of consumers who participated in interviews ( $n = 33$ ).

All five PWRAs (two male and three female) employed on the project participated in the study; these PWRAs had been peer workers for between six months and six years. PWRAs introduced the resources to between six and nine consumers each.

### **Results**

Participants expressed very positive views overall about the resources (Honey *et al.*, 2020). It was apparent from participants' interview data, however, that the PWRAs played an important role in their experiences. While PWRAs individualised their presentation of the resources to some degree, this was limited by the research context. Interviews with PWRAs indicated that they saw value in using lived experience research in their day-to-day practice and the potential to provide more tailored experiences.

#### *How did participants see the role of PWRAs in their experience with the resources?*

Although not asked how their interactions with the PWRA influenced their engagement with the resources, 24 of the 33 participants mentioned this. While different people had different preferences, common ways that PWRAs were thought to facilitate or have the potential to

**Table 2** Characteristics of consumer participants

Variable	Variable values	n (%)
Gender	Male	10 (30)
	Female	23 (70)
Country of birth	Australia	26 (79)
	Other	7 (21)
Mental health service setting	Acute inpatient unit	1 (3)
	Rehabilitation unit	1 (3)
	Community services	31 (94)
Duration of mental health challenges	<1 year	2 (6)
	1–3 years	2 (6)
	4–6 years	2 (6)
	7–10 years	4 (12)
	>10 years	23 (70)
Diagnoses*	Schizophrenia and other psychotic disorders	19 (58)
	Depressive disorders	8 (24)
	Bipolar and related disorders	7 (21)
	Anxiety disorders	4 (12)
	Trauma and stressor related disorders	3 (9)
	Eating disorders	1 (3)
	Personality disorders	1 (3)
	Did not answer	4 (12)

**Notes** \*10 participants reported two or three diagnoses

facilitate a positive experience included introducing the resources in the context of an existing relationship, explaining the resources clearly and suggesting ways to use them, taking enough time, going through the resource in detail, encouraging reflection and using the resources in a group setting.

*Introducing resources in the context of a relationship (n = 10).* Participants indicated that their overall relationship with their PWRA influenced their experiences with the resources. For several participants, their relationship with the peer worker was important to them agreeing to engage with the resources at all. They may have had no particular interest in lived experience research but were willing to try something their peer worker suggested due to the relationship of respect or trust.

*P14:* I was working with [PWRA] for many months, and she introduced it to me, and she said, “I’ve got some resources here, that might help you” [. . .] So, I just said, “Okay, yeah, I don’t mind” [. . .] and I really like some of them.

Others explained how their peer worker’s enthusiasm and endorsement of the resources was important in their engagement.

*P18:* It was the person that I was with that was enthusiastic by it, which made me more enthusiastic with it as well.

A couple of consumers commented that it was good to have the material presented to them by someone who was a “point of contact, always accessible” and who “touched base” with them about the resources.

*Explaining resources clearly and suggesting ways to approach them (n = 6).* For some consumers, it was important that the PWRA explained the resources well, including providing suggestions on how to use them.

*P09:* I think [PWRA] guided me very well [. . .] she explained everything like what I have to do and things.

Where a resource was in an unfamiliar format or use unfamiliar concepts, additional explanation was needed. For example, three people mentioned that they had been initially put off by the title “personal medicine,” until this was explained by the PWRA.

*Taking enough time* (n = 8). Some participants felt that the time frames of presenting the different resources (one resource per week for four weeks) was important. Some felt it was enough time, whereas others felt they needed more time, and that the resources would be more beneficial if covered across a longer time period.

P12: [PWRA] gave me time to process all of that and then I was asked the questions and stuff. So she was really good.

P03: We basically did it reasonably quickly. I probably felt [...] a little bit bombarded with different things.

Busy participants sometimes found it difficult to find time and appreciated the flexibility of PWRAs in enabling meetings around their schedules.

*Going through the resources with the consumer* (n = 11). It was apparent that some participants may have gotten more out of the resources if the peer worker had spent more time with them and gone through the resources with them, rather than giving instructions and examples only before giving them the resources to take home. Some reported not taking the time at home to really go through the resources, only engaging while they were actually with the PWRA. Others felt they needed more support to understand the resources or to figure out how to get the most out of them.

P18: I reckon what we should change [...] if you're getting someone to try and look at those activities and those things, maybe look at them together.

P09: I actually haven't had a chance to look at too much of [the physical health care cards], but me and [PWRA], we did have a look at like seven, eight cards.

*Encouraging reflection* (n = 10). Participants tended to find it helpful to be given the opportunity to reflect on the resources and their connection with their own lived experience.

P07: I think that [answering the questions] kind of helped me clarify what I was learning [...] I think that was really important for me [...] I think I was, what's the word, concentrating more to kind of see what aligns with my lived experience. I think I got more out of it.

*Using resources in a group format* (n = 6). While our PWRAs were free to introduce the resources to more than one participant at once, in most cases, this was done individually to fit individual consumers' time schedules. However, a number of participants suggested that looking at the resources in groups would be beneficial, as it would promote discussion and allow them to hear more ideas, thus facilitating enhanced learning for participants.

P14: I would have benefitted if there was a big group of us candidates, who could have discussed it on a bigger level. In a group environment. That would've been helpful.

*Individualising engagement*. The data overall indicated that different participants had different preferences and needs in terms of what helped them to best engage with the resources. This uniqueness was confirmed by other project data. For example, participants' answers to questions about which resources they liked most and least varied greatly; every resource was liked most by some people and least by others. Further, most participants explained their responses to particular resources by referring to specific aspects of their own lives or acknowledged these differences. P04 summarised this:

P04: Everyone learns differently and if you do one particular format, you're going to miss certain people's learning experiences.

As P27 pointed out, these unique consumer preferences and learning styles can be taken into account by the person introducing the resource.

P27: If you've got a good team of nurses and a good team of peer support workers that can cater for that, then you don't have to individualise it so much in the format.

### *How did PWRA's see the resources as applicable in their everyday peer work practice?*

While PWRA's presented the resources to consumers in the context of a research project, they all indicated a belief that disseminating lived experience research to consumers would be useful in their everyday practice and that of other peer workers.

*PW01:* I'd actually probably like to use all of them. I mean, depending on the context and situation and what they'd like to get out of it, I think all of the resources are really useful and can be used in different situations, like for different recovery principles.

*PW02:* I do think it's definitely a useful tool for peer workers to have. It's definitely something that I would encourage them to use and I think they'd be very open to using in their practice.

Having this new set of tools was seen as useful to both support and differentiate peer workers.

*PW05:* I guess it gives peer workers a real tool under their belt and a real point of difference from clinicians because it's a different approach and it's a different kind of therapy, I suppose.

*PW01:* I think they're amazing prompts as well for peer work, because usually we're just thrown into the deep end with not many resources.

PWRA's talked about wanting to use the resources in one-to-one sessions and in groups both in the community and inpatient settings. They saw the lived experience resources as a useful means to build rapport, engage and learn more about consumers.

*PW03:* It's a good way to start conversations as well about other things, like, things to do with the topic. But then you can kind of, like once the conversation starts then you can kind of gauge maybe they would like to go to the beach, where you thought they would like to go to the library.

PWRA's anticipated that using the resources as part of daily peer work practice would be similar in some ways to their experience in the research project, but different in other ways. Like consumers, PWRA's recognised that the way they approached the resources was important to consumers' engagement and often talked about using their professional skills to individualise their presentation for each consumer.

*PW04:* It's getting back to who I'm with and listening to them and going "okay", when I present it, listening and watching how are they responding to it [. . .] not assuming, because something may have changed since the last time that we [met], so they normally like to read things but all of a sudden something's happened. So when I present that resource, is to kind of watch and just be mindful.

One PWRA noted that she had further developed this skill through her involvement with the project:

*PW01:* It's strengthened [my skills in] how to introduce new concepts and new resources. And also how to be mindful of people's different learning styles and how to approach that. And also how to accommodate for that.

PWRA's also described the importance of being mindful of the potential for resources to be experienced as uncomfortable or even distressing, even though they were developed with lived experience input and great attention to avoiding potential harm to participants. Thus, it was important to monitor and work with consumers' individual responses to the resources.

*PW04:* It's also a great opportunity to be with somebody [. . .] and let them go through it or to find the support [. . .] if they're in a safe space in these conversations, well that's recovery.

However, PWRA's felt that outside the research study's timelines, assessments and protocols, they would tailor resource presentation even more. For example, they could

introduce a resource when they considered it most suitable for the individual consumer, leave as much time in between resources as needed and include whoever was interested and available at the time in groups and discussions. PWRA's agreed with consumers that many would benefit from the opportunity to go through resources with them in more depth.

*PW02:* I wonder for future use, if the peer worker for some consumers can go through the entire resource with the person, depending on their learning style. I think that could be helpful for certain individuals that the peer worker can sit with them to go through it in more detail maybe. And they might be more inclined to take on more information.

As noted above, the PWRA's thought that the resources would be helpful for the practice of a wide range of peer workers. Three PWRA's mentioned that peer workers were in a unique position to bring lived experience research to consumers.

*PW05:* I think that [the resources] will be received quite well by consumers because it is being delivered by a peer worker and there is that level of relatedness and it's, "Here's something I find really helpful. Maybe it will help you too." And that's kind of a pass it forward thing. Then if they find benefit they might be able to help someone else. And that's really powerful.

## Discussion

In this paper, we used qualitative data from consumers and peer workers to explore an emerging role for peer workers – the dissemination of lived experience research. The importance of the person delivering lived experience research resources emerged as an important theme in the evaluation of the resources themselves; it was brought up spontaneously and repeatedly by consumers. Findings indicated that the way lived experience research resources were presented was important to consumers' experiences and the benefits derived, and that peer workers saw lived experience research resources as usable in their daily practice. They suggest that peer workers taking the lead in disseminating lived experience research could be beneficial, both for consumers' engagement with lived experience research and for peer workers' professional development and recognition within the mental health workforce.

Our research has suggested that engaging with the findings from lived experience research can be beneficial to consumers in their daily lives (Honey *et al.*, 2020). It is apparent that peer workers have the skills, attitudes and experience to take a leading role in bringing these findings to consumers. For example, it was clear that consumers' needs varied greatly. Some engaged with the resources with little input, while others wanted the opportunity to go through the resources with the peer worker. Some needed more explanation than others, and the preferred pace and format varied. PWRA's also described the importance of tailoring their approach to suit individual consumers. The relationship developed between the consumer and the PWRA, and the facilitation of reflection on the relevance of materials to individuals' daily lives were also important to many consumers. These findings suggest that having a person supporting engagement with the resources with whom the consumer has rapport, and who understands their needs, is important to ensure that the resources can be used in a flexible manner that is individualised to each consumer's needs, preferences and learning styles. These person-centred, relationship-based and participatory approaches are hallmarks of peer work (Miyamoto and Sono, 2012).

The incorporation of the peer worker role into the design of resources can also allow for greater creativity and safety. The resources used in this study were designed to stand alone, with little support required. However, more creative and interactive translation formats may be possible if future resources were designed for peer workers to take a more active part in the delivery of information. This would also ensure that if participants encounter something that they find uncomfortable or distressing, they can be supported on

the spot. Individuals' recovery journeys can hold experiences, realisations and memories that elicit discomfort, and potential exists for any piece of information to be triggering, or cause distress (Substance Abuse and Mental Health Services Administration, 2014). Experienced and well-trained peer workers are in a good position to help consumers work through these issues and locate other necessary supports (Health Workforce Australia, 2014). The involvement of peer workers in co-production of resources is critical, ensuring the relevance and usability of the resources (Bennetts *et al.*, 2013; Health Workforce Australia, 2014).

Disseminating lived experience research is a new and innovative role that could benefit not only consumers but also the peer workforce. While peer workers presented the resources to consumers in the context of a research project, they indicated that disseminating lived experience research to consumers would be a useful addition to their everyday peer work practice. They also reported using the research to further their relationships with the people they worked with and their own professional knowledge. Involvement in research dissemination can diversify and enhance existing peer worker roles. Upskilling in research knowledge may provide peer workers with an avenue for professional development and provide opportunities for career pathways and progression that are limited at present (Byrne, 2017; Productivity Commission, 2020). Peer workers have expressed interest in being more involved in research (Wyder *et al.*, 2021), yet often report a sense of role ambiguity as one of the greatest challenges facing the workforce (Health Workforce Australia, 2014; Myrick and del Vecchio, 2016). Roles in lived experience research dissemination may also serve to draw attention to the evidence base underlying peer work and provide a unique opportunity to integrate the experiential evidence base with the empirical evidence base. Research into the role of peer workers in lived experience research dissemination may help build a stronger evidence base for the profession and could provide clarity and additional direction for emerging roles in peer work.

The findings from this study should be considered with due regard to several limitations. Data were collected for the purpose of evaluating the resources, not the role of peer workers in disseminating them, limiting the analysis to participants' spontaneous discussions. While PWRA's discussed using their lived experience when presenting the resources, consumers talked about the impact of the PWRA's as individuals; interviews did not explore whether they saw the PWRA's lived experience as important. Further, the research protocol allowed less flexibility in the presentation than would otherwise be the case. Additional research is needed to ascertain whether disseminating lived experience research could be done equally well by other support workers and to explore the usefulness of lived experience research resources in peer workers' daily practice.

Nevertheless, the findings suggest that disseminating lived experience research to consumers is a promising emerging role for peer workers. The authors are currently working to make the resources freely available to peer workers as "do-it-yourself" kits that can be downloaded and printed locally and are accompanied by a training manual to guide their use. In addition, development of online training modules for an interactive training experience and a range of additional resources addressing topics that are of value to consumers are planned by the authors. Our research implies several recommendations. First, lived experience researchers and co-designed research collaborations are encouraged to conduct research focused on topics that are relevant to the daily lives of consumers and to both publish those studies and consider ways of presenting them as peer worker resources. To enable this to happen, funding bodies must recognise the value of such research and its direct applicability and usefulness in consumers' lives. Health services should support peer workers to undergo professional development around the use of lived experience research in their work, including training and other learning and development strategies such as journal clubs. This research highlights the great potential for lived experience research and peer work to come together to benefit the profile and practice of both.

## Note

1 In this paper, the term “consumers” is used to describe people with lived experience of mental health challenges who use mental health services. While we acknowledge that terminology is imperfect and controversial, this term is commonly accepted in Australia and frequently used by peer workers.

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