THE UNIVERSITY OF SYDNEY

Making Lived Experience Research Accessible in Recovery

FINAL REPORT FOR ONE DOOR MENTAL HEALTH

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STELLER

Supporting the translation into everyday life of lived experience research

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EXECUTIVE SUMMARY

Lived experience research illuminates the experiences of and is conducted by, people who have experience of mental health issues. The findings from lived experience research have the potential to help people with lived experience in their recovery journeys, for example by imparting wisdom and inspiring hope. However, lived experience research is often unknown to or inaccessible by people who are not, themselves, involved in research. Little is known about the potential helpfulness of direct access to lived experience research and the best ways for people with lived experience to access this research.

This study was a collaborative project between researchers with and without lived experience of mental health issues and peer workers. Its purpose was to explore the translation and usefulness of lived experience research in the lives of people living with mental health issues.

Resources were developed in consultation with designers and peer-workers. Peer workers introduced their clients to four different resources over a four week period. Using a non-randomised experimental design we investigated whether exposure to these resources increased participants' hopefulness. An anonymous survey and qualitative interviews enabled us to develop an in-depth understanding of how participants interacted with and experienced the resources.

Participants' levels of hope increased between the first and last assessments, suggesting the hope promoting properties of the lived experience resources. However, levels of hope did not improve immediately after engagement with the resources, indicating that the impact may be gradual in taking effect.

Overall, participants reported extremely positive experiences with the resources and the research project overall. For example, 93% of participants in the anonymous survey (28/30) describing their experience as "quite positive" or "very positive" and 50% of respondents had shared their knowledge of lived experience research with other people. A majority of participants found each of the resources interesting, easy to understand, and helpful. Between 85% and 100% said that they would recommend each of the resources to other people. Likewise, peer workers were positive in their descriptions of their own and participants' interactions with the resources and were enthusiastic about the potential for resources to be incorporated into peer work beyond the research project.

People's resource preferences varied. Each resource was liked most by some participants and least by others. Participants displayed diversity of opinion on the content and format of the resources, often explaining their opinions as related to their individual personalities and situations. This

indicates the need for a variety of different resources with different content and formats to cater to a broad spectrum of users.

Participants and peer workers liked and appreciated a number of aspects of the resources, with different aspects emphasised for different resources. They valued resources that: contained practical information; were relatable to their own experiences; were attractively presented; contained empowering message; gave them insight into other peoples' experiences; were straightforward and easy to digest; were creative and novel in format; were succinct; and involved hands-on engagement. They also appreciated variety across resources.

Participants and peer workers reported that some aspects of various resources could be improved. While suggestions for improvement were unique to each resource, people most frequently commented that the information in the resource could be more specific and concrete in their advice and implications.

Responses to questions about the impact of accessing each resource on various aspects of their lives were very positive with 60 to 80% of participants reporting, for each resource, that it had made an improvement in their lives. In interviews, participants described the following positive impacts from interacting with various resources: being motivated to take positive action; having an enjoyable and interesting experience in the moment; gaining new knowledge; reflecting on their journey; experiencing hope and empowerment; thinking more constructively about mental health issues; feeling less alone; and being better able to explain mental health and their experiences to other people.

Three participants in the anonymous survey and three participants in the qualitative interviews reported negative impacts of a resource on them. While these impacts occurred in the context of generally positive experiences of the study, they suggest the need for peer workers to be proactive in monitoring and addressing the impact of resources on clients.

Participants suggested additional content for future research including specific topics relating to: mental health self-care; life skills; and mental health conditions. They recommended additional formats within the broad categories of: arts-based formats; interactive activities; video; and tactile formats.

The importance of peer workers and their delivery of and support relating to the resources was emphasised, despite the resources having been initially designed to require minimal presenter input. Indeed, the role of the peer worker appeared to be critical in ensuring that participants, despite their varied needs, preferences, and backgrounds, derived optimum benefit from each resource. Features

in peer worker delivery that promoted a positive experience were: presenting the resources in the context of an existing relationship; providing clear explanation and suggesting ways to approach the resources; going through resources with the client; encouraging reflection; taking enough time; and introducing resources in a group setting. It was clear that participants had different needs and preferences for ways of interacting with resources, and that an individualised approach was ideal.

Overall, participants reported being pleased to be part of the research and to have the opportunity to share their thoughts on a topic they found to be meaningful. This makes it difficult to tease out the impact of the resources themselves from the context of being involved in a research project.

The findings suggest that lived experience research resources have the potential to be helpful for people with lived experience of mental health issues and that responses to the resources vary. This indicates a need to provide resources addressing a variety of content, with similar content being provided at different levels of detail and in different formats. The way the resources are presented and delivered was found to be important, highlighting the critical role of peer workers and their ability to deliver the resources in a flexible and individualised way.

Further research is needed to assess the usefulness of lived experience research resources in the day to day practice of peer workers and the impact of these resources on a larger number of diverse participants. It will be important to distinguish the impact of lived experience resources from the impact of being in a research project.

Background

Lived experience research in mental health is research that illuminates the perspectives and experiences of people who live with mental health issues and is conducted either by researchers with their own lived experience or in collaborative research teams that include people with lived experience (Happell & Roper, 2007; Walsh & Boyle, 2009).

The importance of people with lived experience being involved in mental health research is increasingly being recognised and is now considered expected practice (e.g., Australian Health Ministers, 2010). There are three primary arguments for this. First, consumer rights activists, using the slogan of "nothing about us without us" have argued that inclusion is a human right and a social justice issue (Epstein & Olsen, 1998; Nelson, Joanna Ochocka Kara, & Lord, 1998). Second, inclusion of people with lived experience on research teams is believed to improve the quality of the research by enhancing relevance, methodological sensitivity, accuracy of data collection, validity and user ownership of results (e.g., Faulkner, 2009; Goodare & Lockwood, 1999; Kim, 2005). Third, people with lived experience have reported positive personal consequences from involvement in research, including satisfaction, skill development, empowerment and hope (Faulkner, 2009; Kim, 2005).

Findings from lived experience research have the potential to be helpful to people in their recovery journeys. Numerous studies have reported the benefits of both learning from the wisdom, strategies and successes of others and from seeing or hearing about those who are progressing well on their recovery journeys (e.g., Davidson, 2016). One of the major benefits for people with lived experience of mental health issues of being exposed to the stories and experiences of others in similar situations is increased hope, one of the critical components of recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Observing peers recovering and reading or listening to individual narratives of recovery are important ways in which people learn from each other. However, lived experience research has the potential to bring together the stories of a variety of different people to provide a range of ideas and a bigger picture on particular issues, thus contributing to an individuals' store of resources for recovery.

While we were unable to locate research about the direct use of lived experience research by people with lived experience of mental health issues, the research team's collective experience has indicated that many who are not themselves involved in collaborative research, do not even know that it exists, let alone how to access the findings. Further, research is often presented in a way that is unappealing to a lay reader. Little is known about how useful people might find lived experience research in their daily lives, nor what the best formats are to bring it to their attention.

The purpose of this study was to explore the translation and usefulness of lived experience research in the lives of people living with mental health issues. The aims were to:

a) Develop a range of user-friendly formats to disseminate lived experience research findings.
b) Disseminate lived experience research findings to people with lived experience of mental health issues via peer-workers
c) Evaluate the accessibility and usefulness of these resources

The evaluation sought to answer the following research questions:

i. Does exposure to lived experience research increase hopefulness for participants?;
ii. How do participants perceive lived experience research resources and their relevance to their own lives?
iii. What other topics and formats should be considered for developing additional lived experience research resources; and
iv. How do peer workers experience using these resources with their clients?

Methods

a) Study design

Our research team, consisting of researchers both with and without lived experience of mental health challenges, collaborated with peer workers and final year design students to develop a suite of six resources. These were introduced to people living with mental health issues by peer workers. The intervention was evaluated using a mixed methods approach including: a quasi-experiment: an anonymous survey; qualitative interviews with participants; and a focus group and interviews with our peer worker research assistants. Ethical approval was obtained for the intervention and data collection from participants from the LHD's Human Research Ethics Committee. Ethical approval was gained from the University of Sydney Human Research Ethics Committee for interviews with peer worker research assistants.

b) Resources

We reviewed the lived experience literature to identify lived experience research papers in which the findings were directly relevant to the daily lives of people experiencing mental health issues. This was a minority of lived experience research, as we found that most was aimed at increasing the understanding or changing the behaviour of health professionals. We consulted with peer workers and other people with lived experience to find out what topics were likely to be of most interest to users. Through these processes we identified six research studies to develop into user-friendly resources. The process of translating these into user-friendly resources began with a conference workshop (Boydell, Glover, Honey, Tooth, & Gill, 2017) and a full day design lab focused on design thinking around the resources (Brenner, Uebernickel, & SpringerLink, 2016). These were attended by a range of mental health service users, peer workers, researchers, clinicians and final year design students from the University of Technology Sydney (UTS). After the design lab, the ideas and prototypes were handed over to the design students for further development. The design students designed and produced the resources with regular input and feedback on both content and format from the research team and peer workers.

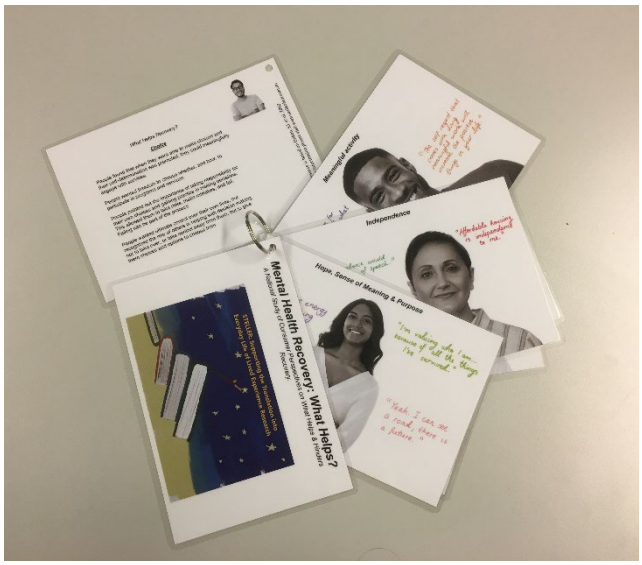
Each resource is described on the following pages.

Concepts of Recovery Podcast

Based on: *Tooth, B. A, Kalyanasundaram, V, Glover, H & Momenzidah (2003). Factors consumers identify and important to recovery from schizophrenia. Australasian Psychiatry 11 (1), 70-77. DOI: 10.1046/j.1440-1665.11.s1.1.x*

Tooth, Kalyanasundaram, Glover and Momenzadah (2003) conducted interviews with 57 people who self-identified as being in recovery to identify what they considered as important in this journey. Thematic analysis was used to identify common themes. These themes were not diagnosis specific but likely to be useful to anyone living with mental health issues. The STELLER research project created a 34-minute podcast of an interview with two of the lead authors, Dr. Barbara Tooth and Ms. Helen Glover. They discussed what inspired them to conduct the study, their experiences of the research, the findings, and their own thoughts about recovery and what it means.

What Helps Recovery

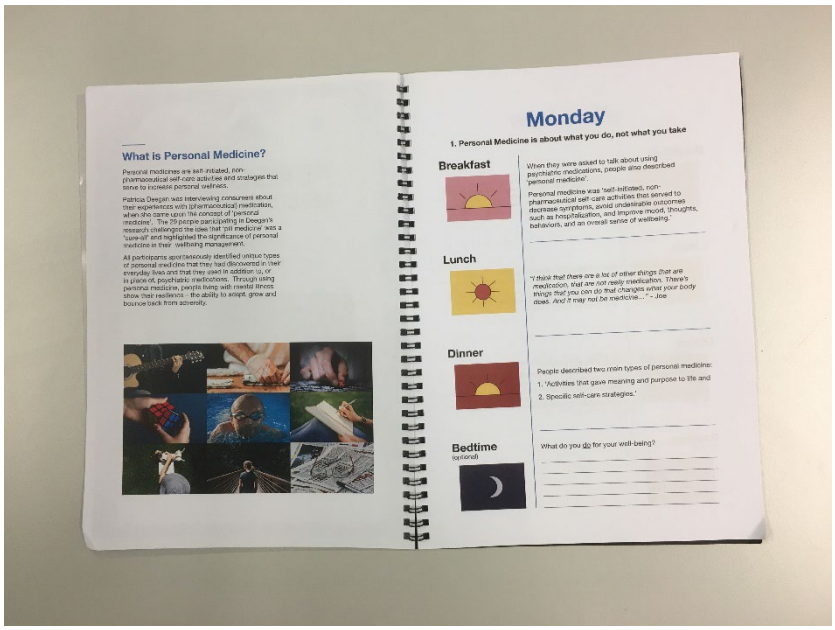


Based on: *Onken, S.J., Dumont, J.M., Ridgway, P., Dornan, D.H., & Ralph, R.O. (2002). Mental health recovery: What helps and what hinders? A national research project for the development of recovery facilitating system performance indicators. Phase one research report: A national study of consumer perspectives on what helps and hinders mental health recovery. National Association of State Mental Health Program Directors (NASMHPD) National Technical Assistance Center (NTAC), Alexandria, VA*

Onken, Dumont, Ridgway, Dornan and Ralph (2002) conducted structured focus groups with 115 people to understand what helped or hindered their recovery. The STELLER research project focussed on the findings for "what helps" to create two variations of a resource entitled "Mental Health Recovery: What Helps?". One version of the resource was developed to be viewed like an art exhibition with seven A3 sized prints. Each contained a black and white photograph of a person (stock image) along with direct quotes from the research handwritten in different colours. Next to the print was a small placard, as would also be found at an art gallery, containing the title of the theme and a description of what the research said on that theme. For example, one theme was "Hope, Sense of Meaning & Purpose" and a quote included in hand-written style text (in green) was "I'm valuing who I am… because of all the things I've survived." A smaller version of the resource was created for people who did not view the resources at the mental health unit. These were A5 laminated cards put together with a metal ring, so users could flip through the content and open the ring to remove cards of interest to display.

Personal Medicine

Based on: *Deegan, P. (2005). The importance of personal medicine: A qualitative study of resilience in people with psychiatric disabilities. Scandinavian Journal of Public Health, 33(66_suppl), 29–35. DOI: 10.1080/14034950510033345*



Deegan (2005) used a qualitative method and participatory action design following interviews with 29 people about their experiences with pharmaceutical medication. Findings revealed the concept of 'personal medicine', described as "self-initiated, non-pharmaceutical self-care activities and strategies" that serve to increase personal wellness. The STELLER research project used findings from this study to create a resource entitled the "Personal Medicine Pack", modelled on a webster pack (or pill box). The resource was an A4 booklet divided into the seven days of the week. For each day, the booklet included information and direct quotes from the study as well as prompts to encourage people to think about their own personal medicine. For example, the Monday page, entitled "Personal Medicine is about what you do, not what you take", introduced the concept, explained what personal medicine is and the two types of personal medicine, provided a quote from a participant, and asked the reader to consider what things they did for their well-being. At the end of the book were three 'personal medicine self-prescription' templates, adapted from the Living Edge KIT (part of the Living Edge program, Queensland).

Hope Box

Based on: *Yeung, W. S., Hancock, N., Honey, A., Wells, K., & Scanlan, J. N. (early online). Igniting and maintaining hope: The voices of people living with mental illness. Community Mental Health Journal. DOI: 10.1007/s10597-020-00557-z*

Yeung, Hancock, Wells and Honey (2018) asked 74 people living with mental health issues to write about an experience that had helped them to feel hopeful. They analysed responses using interpretive content analysis. The STELLER research project translated some of these findings into a unique resource we called the hope box. The hope box is a plain, circular cardboard box which contains (1) a brief overview of the study; (2) an insert summarising the classic story of hope and perseverance "Sadako and the Thousand Paper Cranes"; (3) several coloured textas to encourage participants to make the box their own by decorating or writing on it and, most importantly; (4) seven small white hollow balls labelled with a letter, indicating a day of the week. While participants were told to use the resource however they liked, opening one ball each day was a suggestion. Each ball contained a tiny hand-made colourful paper crane and a slip of paper with a key concept and quotes from the study. For example, one insert read: Acknowledge your strengths and your positive progress! "See how far I've come since first being diagnosed", "I've many other strengths including being an insightful, gracious, kind, compassionate, brave and determined person."

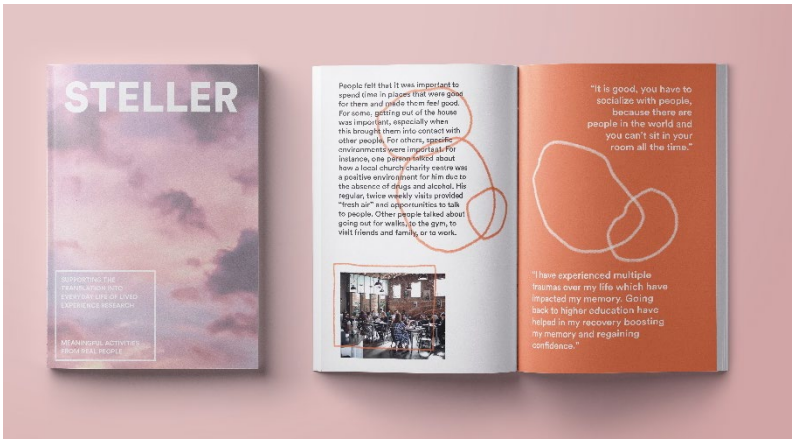
Physical Healthcare Cards

Based on: *Ewart, S., Bocking, J., Happell, B., Platania-Phung, C., & Stanton, R. (2016). Mental health consumer experiences and strategies when seeking physical health care: A focus group study. Global Qualitative Nursing Research, 3, 1-10. 2333393616631679. DOI: 10.1177/2333393616631679*

Ewart, Bocking, Happell, Platania-Phung and Stanton (2016) conducted focus groups with 31 people living with mental health issues to find out about their experiences using health services for their physical health needs, as this group often do not get the same level of physical health care that other people do. Findings included information about what people did to get better care. The STELLER research project created a set of 'physical health care cards' based on these findings. The resource was a pack of 26 cards, with a colourful design on the back, similar in size to a normal deck of cards. The graphically designed front of the cards were colour matched in pairs to allow them to be used to play a memory game. The first four cards included an introduction, overview of the study and suggested use of the resource. The remainder of the cards were separated into eleven themes (two cards per theme), with unique colours representing each theme. One card in each pair provided a description of the theme and the other included direct quotes. Reflective questions were also sometimes included. For example, the "taking time" pair included: "People said that it was important to allow enough time in an appointment to fully deal with physical concerns"; and "One person said that if he was feeling hurried or rushed, he would say: 'Well hang on a minute. I need help with this. Can you refer me to these other services?'. What else might you do or say to make sure you get the time you need with a health professional?".

Meaningful Activities Magazine

Based on: *Biringer, E., Davidson, L., Sundfør, B., Lier, H.Ø., & Borg, M. (2016) Coping with mental health issues: Subjective experiences of self-help and helpful contextual factors at the start of mental health treatment, Journal of Mental Health, 25:1, 23-27, doi: 10.3109/09638237.2015.1078883*



Biringer, Davidson, Sundør, Lier and Borg (2016) conducted in-depth interviews with ten mental health service users in the early stages of treatment (0-7 years). They used a collaborative-reflexive framework to explore what they experienced as helpful and what they had done to help themselves. Analysis revealed that one of the most important things they did was engage in activities each day that were meaningful to them. The STELLER research project translated key information from this study into the 'meaningful activities magazine'. The magazine was A5 in size and was 29 pages. It included an 'editor's note' with an overview of the study, followed by concepts and direct quotes from the study about different types of meaningful activities and how people used them. These were presented in attractive and varied text with colourful pictures, images and backgrounds created by a graphic designer. For example, one section was about music, "making a conscious choice to listen to happy music as that is a good way of changing how you feel". It also included a "brain teasers" section with a word list and Sudoku game, a section for mindful colouring and two blank pages at the end to list or sketch activities that are most meaningful to the reader.

c) Intervention

Participants chose four of the six resources that were most interesting to them based on the topics. Peer workers introduced participants to one resource per week for four weeks. The resources were designed to require brief explanation only. During peer worker training, each of the finalised resources was examined and together the peer workers and research team reached consensus on how each resource would be introduced to participants. This was flexible however, enabling peer workers to adapt their explanations and activities to be most appropriate to the needs of individual participants. The agreed upon protocols were developed into a peer worker manual for peer workers to refer to prior to introducing each resource. In most cases, the peer workers showed each participant the resource, went through part of it, explained how it was designed to be used, then gave it to the participant to take home and use in whatever way they preferred.

d) Sampling and recruitment

Site

The project was carried out in South Eastern Sydney Local Health District (LHD). The LHD employs 18 peer workers over five inpatient and four community sites, including a Recovery College (Sommer, Gill, & Stein-Parbury, 2018). The project employed five of these peer workers to recruit and provide the intervention to participants who were clients of these services, excluding the intensive care inpatient unit.

Criteria and consent

People were eligible to participate in the project if they were receiving mental health services from the LHD, were able to speak and read English, and were able to provide informed consent. Clients were excluded if they were considered by their peer worker or primary clinician to be unable to fully understand the procedures, risks and benefits of participation due to acute illness. In this research consent was considered, not a one-off event, but an ongoing negotiation between the peer worker and participant, where the primary concern was the participant's well-being. Therefore, at each research-related interaction, peer workers obtained verbal confirmation that the client was happy to continue taking part in the research project.

Participant safety

A distress protocol was designed to prevent participant discomfort or distress and manage it in the unlikely event of its occurrence. This involved: ensuring that relevant mental health centre staff were informed that a session was taking place and available to assist if necessary; ensuring that the

peer worker had a mobile phone and phone numbers of relevant staff; not commencing an assessment or intervention if a participant showed signs of elevated distress; being sensitive to signs of possible discomfort; responding to discomfort by focusing on the participants' needs, offering a break or stopping the activity; ensuring the participant had strategies to deal with any discomfort or distress; and, if necessary, contacting appropriate mental health staff.

Recruitment

Peer workers explained the study to all eligible clients that they saw in the course of their work. If a client was interested, the peer worker gave them written project materials (flyer, participant information sheet and consent form), offered to read through the forms with them, and answered any questions. Clients were given several days to read and think about the project and were invited to call the chief investigator to discuss the project further if they wished. In several days, the peer worker recontacted the client and, if they wished to participate, obtained written informed consent. Peer workers emphasised to participants that the research was voluntary, they could withdraw at any time, and their choice to participate or not would have no impact on their other interactions with the peer worker or the health service.

After completion of all intervention and assessments, the research assistants were asked, by email, whether they would like to participate in a focus group and/or interview about their experience with the resources and observations of participants' responses to them. Peer workers were assured that their choice to participate or not would not affect their future relationships with the University of Sydney or the researchers. The risk of coercion was low, as a) they were at the end of their casual employment on this project so would not perceive a risk to current employment; b) they had already expressed a wish to give their feedback on the experience and provide their insights into the usefulness of the resources; and c) the questions asked would have been asked as part of a normal exit process; including these interviews as research simply allowed the data to be used as research data.

Allocation to groups

After providing informed consent, participants were allocated to group A or group B. In most cases this was done using a coin toss, however, the staggered timing of recruitment and other peer worker commitments made it necessary for 13 participants to be allocated based on logistical issues. This also meant that the groups were uneven, with 25 participants allocated to group A and 13 participants allocated to group B.

e) Data collection

Participants completed assessments at three timepoints, each approximately five weeks apart. Participants in Group A were introduced to their selected resources between Time 1 and Time 2, while Participants in Group B were introduced to their selected resources between Time 2 and Time 3. As well as providing demographic data, participants completed the following assessments:

The Herth Hope Index (HHI) is a 12-item scale that was developed for clinical populations, takes just a few minutes to do, has good psychometric properties (Herth & Herth, 1992) and has been used with a variety of different clinical groups in at least seven languages (e.g., van Gestel-Timmermans, van den Bogaard, Brouwers, Herth, & van Nieuwenhuizen, 2010). It includes three factors of: temporality and future; positive readiness and expectancy; and interconnectedness.

Participants were asked to complete an anonymous online evaluation survey once only, after they received the intervention. Of the 38 participants, 30 completed this survey. The survey consisted of a series of fixed-choice questions about each resource to measure participants' engagement with the resource and its perceived usefulness including.

(1) How interesting they found the resource
(2) How easy it was to understand the resource
(3) How helpful they found the resource
(4) Whether the resources made a difference in their life in the areas of:
    a. Your feelings about yourself
    b. Your perspective on your own experiences
    c. Your beliefs about your future or recovery
    d. Your ability to care for yourself and your mental health
    e. Your ability to deal with the mental health system
    f. Your ability to interact with mental health professionals
    g. Your understanding of other people and their experiences
    h. Your understandings about mental illness
(5) Whether they would recommend the resource to others

Additionally, the survey included three general questions: "Are you interested in accessing more lived experience research in the future?", "Have you shared your knowledge from lived experience research with anyone else" and "Overall, how would you describe your experience of participating in this study?"

Semi-structured interviews (Rubin & Rubin, 2004) were conducted with project participants by the project manager after the intervention. An interview guide was used containing open ended questions. These asked participants to describe their thoughts and feelings about the resources, how they engaged with them, and the usefulness of lived experience research to them. Questions included what resources they liked most and least, and why; what information they remembered most and found most useful; their experiences with the different formats, ideas about how to improve the resources, and the impact on them, if any, of being in the project. The interview guide was used flexibly, allowing for conversational flow and follow-up questions to gather detail about issues that were of importance to participants (Rubin & Rubin, 2004). Interviews were conducted in person in a private room in the health service or, where the participant preferred, over the phone. Interviews lasted between 7 and 30 minutes, depending on how much participants wished to tell us, with an average of 17 minutes.

Data was collected from the five peer workers through a focus group and qualitative interviews. Three peer workers participated in the focus group, in which they were asked about their experience of presenting the resources to their clients, for example, their observed responses to different content and modalities. They each participated in follow-up interviews which focused on their own personal experiences of presenting the resources and being part of the project, and their likely use of lived experience research resources in the future. Two peer workers were unable to participate in a focus group for logistical reasons. They each participated in a single longer individual interview which combined content from both focus group and follow-up interview. The focus group went for one hour and 20 minutes, while interviews ranged between 17 and 38 minutes.

f) Data analysis

Herth Hope Index

Total scores were calculated for each of the factors (inner sense of temporality and future; inner positive readiness and expectancy; interconnectedness with self and others) as well as an overall total score. To examine change over time, paired *t*-tests were completed between Time 1 and Time 2; Time 2 and Time 3 and Time 1 and Time 3 for all participants as well as for Group A and Group B participants separately.

Anonymous survey

Frequencies were calculated and presented in visual format to understand the range of responses.

Participant interviews

Data from participant interviews were analysed using interpretative content analysis (ICA). This hybrid method combines qualitative and quantitative techniques (Ahuvia, 2001; Drisko & Maschi, 2015), enabling inductive identification of themes as well and reporting of the frequency of those themes (Bengtsson, 2016; Drisko & Maschi, 2015).

The first step in ICA is inductive coding. Constant comparative analysis (CCA) was employed, as it is a systematic, rigorous and well-established coding technique which minimises the risk of omission of data (Charmaz, 2014). In accordance with this method, segments of data, such as phrases or sentences were examined and allocated one or more code names to reflect the underlying concepts they represented. Each new segment of data was compared to others and to existing codes to determine whether it represented the same or different concepts. Accordingly, the data were added to existing codes or new codes were developed. Codes were compared to each other and refined by merging similar codes or grouping codes into higher level categories. NVivo computer software (QSR International, 2018) was used to manage the data. Two authors independently coded the first three interviews, then met to discuss coding decisions and reach consensus. Thereafter, the authors met regularly to discuss and review coding decisions. These discussions were aimed at enhancing interpretive rigour, ensuring participants' viewpoints were faithfully represented. When all interviews had been coded, and the coding list finalised, the transcripts were re-examined to ensure comprehensive coding (Drisko & Maschi, 2015). NVivo was then used to identify the number of participants who discussed each theme.

Peer worker interviews

Interviews with peer workers were analysed using qualitative content analysis (Drisko & Maschi, 2015). A coding process using constant comparative analysis was used as discussed above. However, rather than counting responses, the emphasis was on identification of descriptive themes, which encapsulated participants' views.

Results

Results are presented first according to the 4 research questions.

1. Does exposure to lived experience research increase hopefulness?
2. How do participants perceive lived experience research resources and their relevance to their own lives?
3. What other topics and formats should be considered for developing additional lived experience research resources; and
4. How do peer workers experience using these resources with their clients?

However, two additional issues emerged as relevant during data analysis and these are also examined below.

5. Peer workers' role in the delivery of the resources; and
6. The research context

Participants

64 people were invited to be part of the study and 43 agreed to participate. Five participants withdrew from the study after the first assessment and did not receive any of the resources. Participants were not required to provide explanation for not participating or withdrawing but reasons mentioned included: "limited time/too busy"; "not interested"; "couldn't be bothered"; "school commitments"; "mental health is okay"; and "anxious". No participants withdrew from the study between the pre and post intervention assessment. Thirty-four completed all three assessments, while four participants completed only the pre and post intervention assessment. Thirty-three participants participated in the qualitative interviews and 30 completed the anonymous survey. Table 1 presents the characteristics of people who participated in the study (n=38).

A limitation of the study is that 36/38 participants were living in the community. While peer workers believed that many of the resources would be useful in acute care or rehabilitation settings, logistical and staff issues meant that recruitment was primarily from the community.

Table 1. Characteristics of participants

Variable	Variable values	n (%)
Gender	Male	24 (63%)
	Female	23 (34%)
	No response	1 (3%)
Country of birth	Australia	31 (82%)
	Other (1 each from Bangladesh, Iraq, Malaysia, New Zealand, Papua New Guinea, Peru and Taiwan)	7 (18%)
Primary language spoken at home	English	30 (79%)
Marital status	Married/ co-habitating	2 (5%)
	Unmarried	30 (79%)
	Separated/divorced	6 (16%)
Indigenous status	Aboriginal and/or Torres Strait Islander	2 (5%)
Inpatient status	Acute ward	1 (3%)
	Rehabilitation ward	1 (3%)
	Community client	36 (94%)
Education	Did not complete high school	5 (13%)
	Completed high school	7 (18%)
	Trade/technical/vocational training	6 (16%)
	Some college or university	4 (11%)
	Bachelors degree	8 (21%)
	Postgraduate certificate or diploma	8 (21%)
Employment status	Employed (paid)	8 (21%)
	Unemployed	30 (79%)
Currently studying	Recovery college courses	8 (21%)
	Bachelors degree or diploma	3 (8%)
	Certificate 2, 3 or 4	4 (11%)
	Other	1 (3%)
Duration of mental health issues	<1 year	3 (8%)
	1-3 years	3 (8%)
	4-6 years	2 (5%)
	7-10 years	5 (13%)
	>10 years	25 (66%)
Diagnoses*	Schizophrenia and other psychotic disorders	22 (58%)
	Depressive disorders	9 (24%)
	Personality disorders	1 (3%)
	Trauma and stressor related disorders	3 (8%)
	Bipolar and related disorders	7 (18%)
	Anxiety disorders	5 (13%)
	Obsessive compulsive and related disorders	1 (3%)
	Eating disorders	1 (3%)
	Did not answer	5 (13%)

* 13 participants reported 2 or 3 diagnoses.

1. Does exposure to lived experience research increase hopefulness?

Table 2 presents summary statistics and change over time for the HHI. This information is also presented graphically in Figure 1. For the combined sample and Group A participants, there were significant changes between Time 2 and Time 3 and between Time 1 and Time 3 in HHI Factor 1, HHI Factor 3 and HHI Total scores. For Group B participants, the only significant change was in HHI Factor 1 score between Time 1 and Time 3.

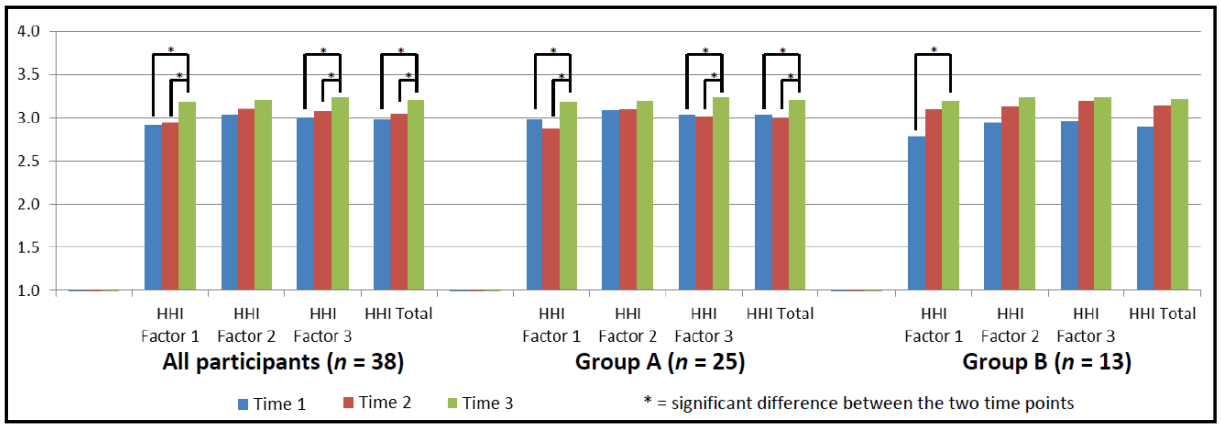
Table 2. Summary statistics and change over time for the Herth Hope Index, all participants and by group allocation

	Time 1	**Time 2**	**Time 3**
	Mean (SD)	**Mean (SD)**	**Mean (SD)**
All participants	***n* = 38**	***n* = 38**	***n* = 34**
HHI Factor 1	2.9 (0.5)[§]	2.9 (0.5)[‡]	3.2 (0.4)[‡§]
HHI Factor 2	3.0 (0.5)	3.1 (0.4)	3.2 (0.4)
HHI Factor 3	3.0 (0.6)[§]	3.1 (0.5)[‡]	3.2 (0.5)[‡§]
HHI Total	3.0 (0.5)[§]	3.0 (0.4)[‡]	3.2 (0.4)[‡§]
Group A	***n* = 25**	***n* = 25**	***n* = 21**
HHI Factor 1	3.0 (0.5)[§]	2.9 (0.5)[‡]	3.2 (0.5)[‡§]
HHI Factor 2	3.1 (0.4)	3.1 (0.5)	3.2 (0.4)
HHI Factor 3	3.0 (0.6)[§]	3.0 (0.5)[‡]	3.2 (0.6)[‡§]
HHI Total	3.0 (0.5)[§]	3.0 (0.5)[‡]	3.2 (0.4)[‡§]
Group B	***n* = 13**	***n* = 13**	***n* = 13**
HHI Factor 1	2.8 (0.6)[§]	3.1 (0.5)	3.2 (0.4)[§]
HHI Factor 2	2.9 (0.7)	3.1 (0.4)	3.2 (0.4)
HHI Factor 3	3.0 (0.7)	3.2 (0.4)	3.2 (0.4)
HHI Total	2.9 (0.6)	3.1 (0.4)	3.2 (0.4)

Notes:

SD = Standard Deviation; HHI = Herth Hope Index; HHI Factor 1: Inner sense of temporality and future; HHI Factor 2: Inner positive readiness and expectancy; HHI Factor 3: Interconnectedness with self and others.
[†] Significant difference ($P < .05$) between Time 1 and Time 2 (NB: there were no significant differences between Time 1 and Time 2)
[‡] Significant difference ($P < .05$) between Time 2 and Time 3
[§] Significant difference ($P < .05$) between Time 1 and Time 3

Figure 1. Change in Herth Hope Index over time, all participants and by group allocation



Initially, these results appeared counter-intuitive, especially for Group A who received the resource between Time 1 and Time 2. The initial hypothesis was that participants would report improved hope after engaging with the resource (i.e., Time 2 for Group A). This was not the case as there were no significant differences between Time 1 and Time 2 for Group A. However, there were significant differences in Factor 1, Factor 3 and HHI Total Scores between Time 2 and Time 3 as well as Time 1 and Time 3. This result could suggest that more time is required (perhaps to integrate learnings from the resources into everyday life) before the impact of the resources are seen in relation to Hopefulness. This interpretation would also be supported given the lack of significant change between Time 2 and Time 3 for Group B. Perhaps if Group B completed the HHI a month following engaging with the resources (i.e., one month after Time 3), then significant changes may have been observed.

It is also possible that the hope scores for Time 1 were artificially inflated through the process of recruitment and consent relating to the research project. As discussed in section 6, our qualitative data indicated that people may have derived hope from finding out about lived experience research and the research project, and being asked to be part of it. It may well be that levels of hope, if measured before the project was explained to participants (a hypothetical possibility only) may have been lower, suggesting that the change between Time 1 and Time 2 that relates to the resources may be underestimated.

2. How do participants perceive lived experience research resources and their relevance to their own lives?

Feedback about the resources was overwhelmingly positive in both the anonymous survey (n=30) and the interviews (n=33). By looking at the two types of data together, we can triangulate

responses and gain a fuller picture that includes not only a quantitative summary of opinions, but additional detail on how people experienced the resources and, importantly, what can be improved for future iterations. By using open ended questions and inductive analysis the interviews ensured collection of participants' own perspectives unrestricted by pre-defined responses and provided richness and depth through probing and clarification of answers. The anonymous survey provided comparable data and reduced risk of acquiescence and social desirability bias.

Findings are presented under the following subheadings:

- Overall opinions on the resources
- Participant resource preferences
- Desirable features for resources
- Aspects to improve
- How participants used the resources
- Impact of resources on participants

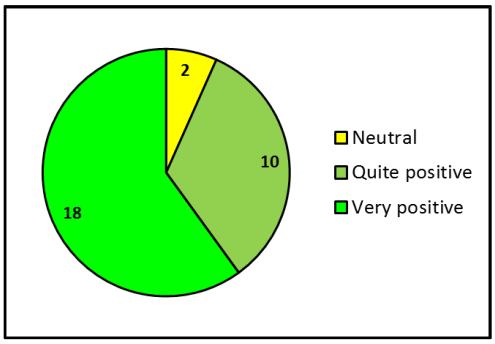
a) Overall opinions on the resources

Participants reported high levels of satisfaction with the program overall with 93% of participants in the anonymous survey (28/30) describing their experience as "quite positive" or "very positive" (Table 3; Figure 1).

Table 3. Overall experience with the program

Overall, how would you describe your experience of participating in the study?	
Response	**n (%)**
Negative	0 (0%)
Neutral	2 (6.7%)
Quite positive	10 (33.3%)
Very positive	18 (60%)

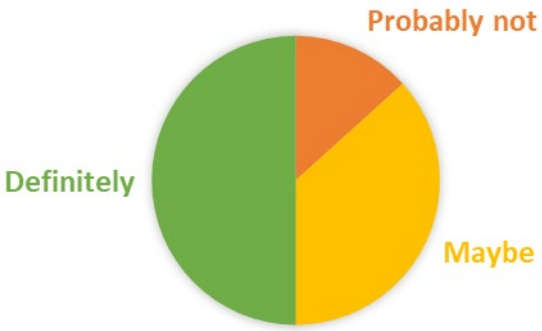
Figure 1. Overall experience with the program



Participants were asked about whether they wanted to engage with more lived experience research resources in the future, to which only 4 participants (13.3%) indicated that they were not. Results are presented in Table 4/ Figure 2.

Table 4/Figure 2. Future engagement with lived experience research

Are you interested in accessing more lived experience research in the future?	
Response	**n (%)**
Probably not	4 (13.3%)
Maybe	11 (36.7%)
Definitely	15 (50.0%)



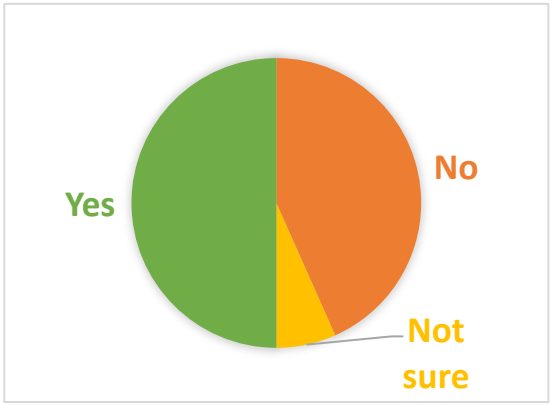
It is interesting that the number responding 'definitely' was far fewer than those who found resources interesting, had a positive experience or would recommend them to other people. It may be that people were unsure about how they might access such resources if not in the context of a project such as this.

b) Sharing the resources

In the anonymous survey, a full half of participants stated that they had shared the resource with other people as shown in Table 5.

Table 5/Figure 3. Sharing the resources

Have you shared your knowledge from lived experience research with anyone else?	
Response	**n (%)**
No	13 (43.3%)
Not sure	2 (6.7%)
Yes	15 (50.0%)



Eleven people brought this up in the qualitative interviews: nine said that they had shown the resources to or discussed them with other people, while two intended to do so.

P26: It did stimulate conversation with my friends and family

P19: My kids want to look through it with me

Two people talked about discussing the resources with other people who had participated in the study, which they found beneficial. Six people showed resources to relatives, with one commenting that she felt her mother had gained some insight about her condition as a result. Others simply commented that their relatives also liked the resources, or that they discussed them together. One participant talked about using material from the resources to help others.

P06: Some of the examples and things I also share with other people because I help people that have challenges in their life... So, I incorporate some things into it to help. Not just the activities or the stories. Also the wordings of things because I can say things in one way that they might not be relatable as well. So it's learning different key words that I could use to say the same thing, so that it is more understandable for more people.

Several peer workers also commented on the positive benefits that came when participants shared resources with others, including friends, family, and other clinicians and health workers involved in their care.

PW02: One consumer, in particular, lives with her parents and her three sons and she would have them on the coffee table and I think it became an interactive part of the family home while it was continuing.

PW03: One of my consumers actually called me back before I even had a chance to call her and said, "This was amazing. I even showed my mum and we really got it. We really like it." ... they've both got lived experience, so she was like, "It was really nice to look at it with my mum and see what was good about it. "

Three peer workers reported that some participants had even requested additional resources to give to others they believed could benefit from them. When participants shared their resources with others, it appeared to reflect that they perceived value and interest in the resource. Beyond that, however, sharing resources with others also provided participants with more opportunities to engage with the resource and reflect on its meaning.

PW02: From my perspective, I think these resources are best engaged with someone else. . . I think some of my consumers are a bit more isolated on their own whereas I found from people that live with someone else, or had a lot more interaction with other clinicians or whatever at the service, engaged a little bit more.

c) Opinions on individual resources

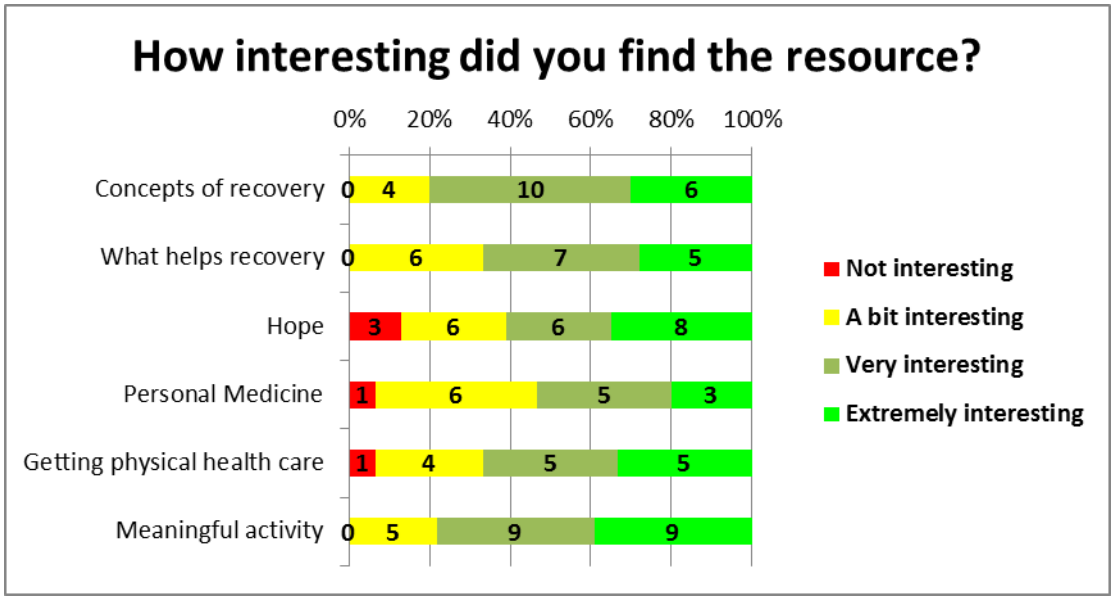
Participants also provided feedback in the anonymous survey about their opinions about each of the resources. They were asked to rate how interesting, easy to understand and helpful they found each resource. Perhaps the most important element of this feedback was the response to the final question: "Would you recommend the resource to others?" Responses for all resources were positive. These results are summarised in Table 6 and presented individually in graphical format in Figure 4. Highlights are:

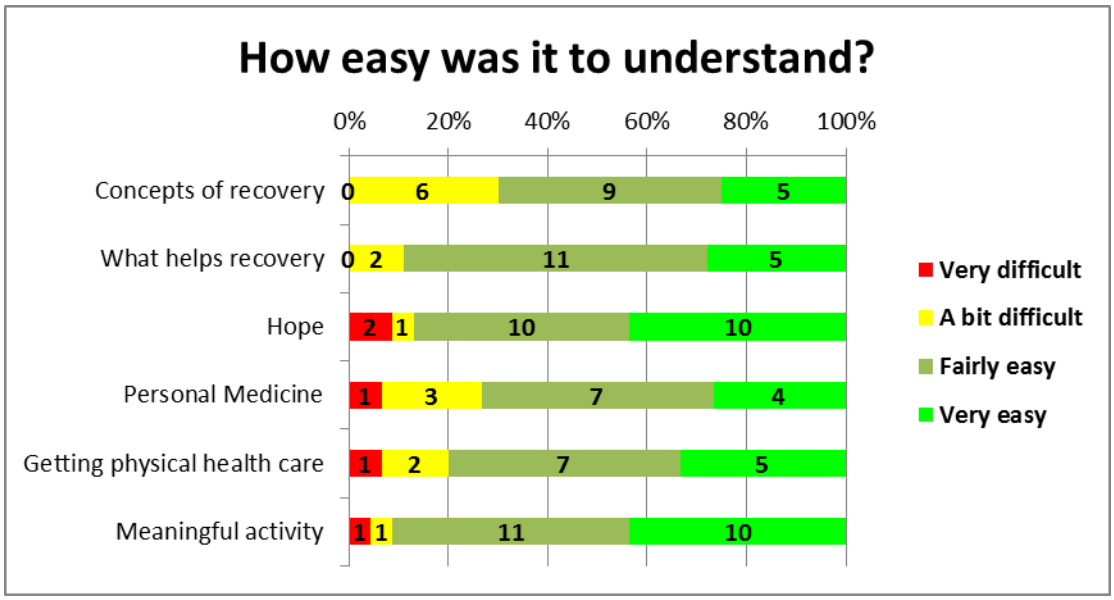
- Most participants (53% - 80%) found each resource 'very interesting' or 'extremely interesting'. The two modules rated as most interesting were "Concepts of recovery" and "Meaningful activities".
- Most participants (70%-91%) said that each resource was fairly easy or very easy to understand. The modules rated as easiest to understand were "Meaningful activity" and "What helps recovery".
- The perception of the helpfulness of resources varied more. While 75% of participants found the concepts of recovery podcast very helpful or extremely helpful, only 46% of people gave those ratings to the physical health cards (40% 'a bit helpful'). The modules rated as helpful for the largest proportion of participants were "Concepts of recovery" and "Hope".
- The vast majority of participants, however, (85%-100%) said that they would recommend each of the resources to other people, which is supported by the data above, that 50% of people had already shared the resources with others.

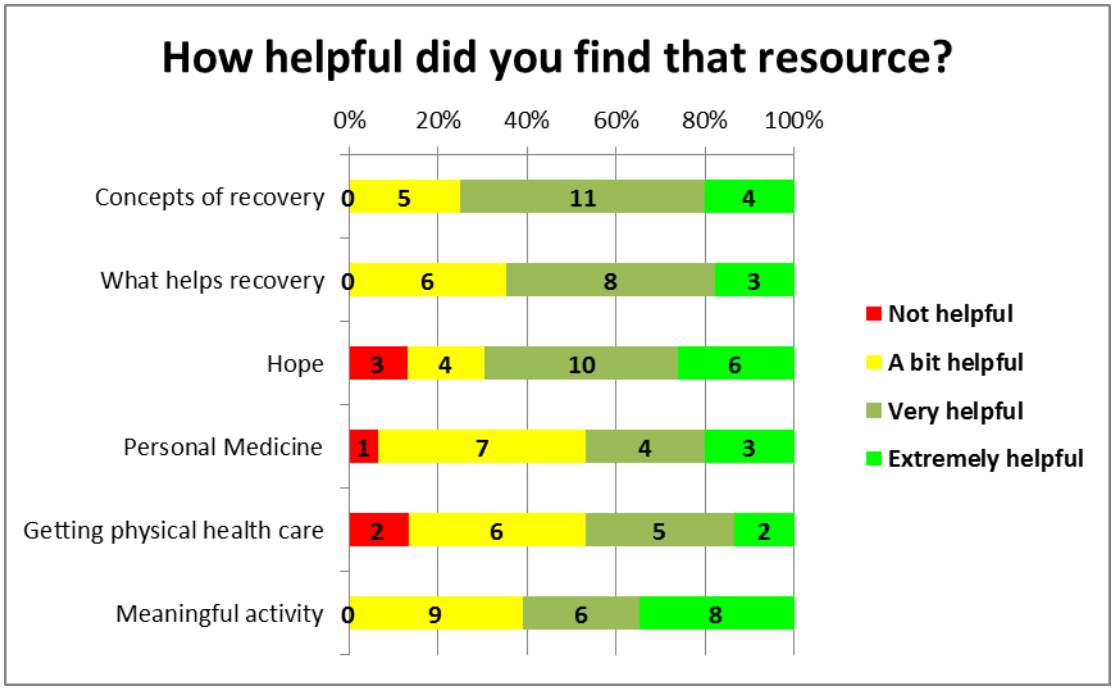
Table 6. Participant feedback about individual resources

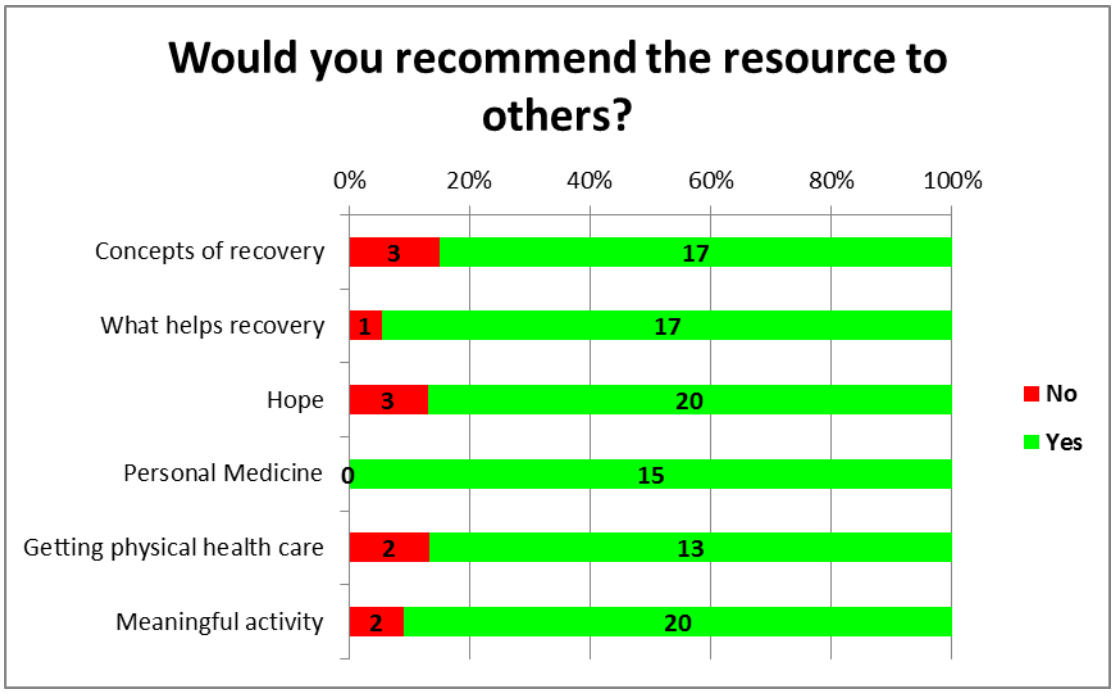
	Concepts of recovery (*n* = 20)	What helps recovery (*n* = 18)	Hope (*n* = 23)	Personal medicine (*n* = 15)	Looking after physical health (*n* = 15)	Meaningful activity (*n* = 23)
How interesting did you find the resource?						
Not interesting	0 (0%)	0 (0%)	3 (13%)	1 (7%)	1 (7%)	0 (0%)
A bit interesting	4 (20%)	6 (33%)	6 (26%)	6 (40%)	4 (27%)	5 (22%)
Very interesting	10 (50%)	7 (39%)	6 (26%)	5 (33%)	5 (33%)	9 (39%)
Extremely interesting	6 (30%)	5 (28%)	8 (35%)	3 (20%)	5 (33%)	9 (39%)
How easy was it to understand?						
Very difficult	0 (0%)	0 (0%)	2 (9%)	1 (7%)	1 (7%)	1 (4%)
A bit difficult	6 (30%)	2 (11%)	1 (4%)	3 (20%)	2 (13%)	1 (4%)
Fairly easy	9 (45%)	11 (61%)	10 (43%)	7 (47%)	7 (47%)	11 (48%)
Very easy	5 (25%)	5 (28%)	10 (43%)	4 (27%)	5 (33%)	10 (43%)
How helpful did you find that resource?						
Not helpful	0 (0%)	0 (0%)	3 (13%)	1 (7%)	2 (13%)	0 (0%)
A bit helpful	5 (25%)	6 (35%)	4 (17%)	7 (47%)	6 (40%)	9 (39%)
Very helpful	11 (55%)	8 (47%)	10 (43%)	4 (27%)	5 (33%)	6 (26%)
Extremely helpful	4 (20%)	3 (18%)	6 (26%)	3 (20%)	2 (13%)	8 (35%)
Would you recommend the resource to others?						
No	3 (15%)	1 (6%)	3 (13%)	0 (0%)	2 (13%)	2 (9%)
Yes	17 (85%)	17 (94%)	20 (87%)	15 (100%)	13 (87%)	20 (91%)

Figure 4 – Participant feedback about individual resources






How helpful did you find that resource?
0%
20%
40%
60%
80%
100%
Concepts of recovery
0
5
11
4
What helps recovery
0
6
8
3
Hope
3
4
10
6
Personal Medicine
1
7
4
3
Getting physical health care
2
6
5
2
Meaningful activity
0
9
6
8
Not helpful
A bit helpful
Very helpful
Extremely helpful


Would you recommend the resource to others?
0%
20%
40%
60%
80%
100%
Concepts of recovery
3
17
What helps recovery
1
17
Hope
3
20
Personal Medicine
0
15
Getting physical health care
2
13
Meaningful activity
2
20
No
Yes

d) Participant resource preferences

Participants were asked in the interviews which resources they liked most and least. Their answers were diverse. It can be seen from Table 7 that each resource was liked most by some and least by others. Eleven people could not decide on a 'least liked' resource, stating that they liked them all. The hope box was rated as favourite by the largest percentage of those who chose it. The most controversial resource appeared to be the personal medicine pack, which was liked most and least by equal numbers of people.

Table 7: Resources liked most and least

Resource	# Selected resource (total)	# Selected resource (interviewed)	Liked most #*	Liked most %	Liked least #*	Liked least %
Concepts of recovery	21	19	7	36.8%	3	15.8%
What helps	31	26	6	23.1%	1	3.8%
Hope	28	24	14	58.3%	3	12.5%
Personal medicine	21	19	6	31.6%	6	31.6%
Physical health	19	16	4	25.0%	2	12.5%
Meaningful activity	32	28	13	46.4%	6	21.4%
Can't decide/ unclear			2		13	

* Columns do not add up to the total interviewees (n=33) because some people chose two most or least favourites.

Diversity in participants' preferred resources was also reflected in the varied observations of peer workers, who nominated different resources as the overall favourites of their participants. Like some participants, peer workers tended to be hesitant to nominate their own favourite resource as they could identify the unique beneficial features of each resource.

> *PW01: I think all of them have their merit, all of them have their strengths and they all offered something really different. So they're all kind of unique in their own right.*

The diversity of opinion highlights that different resources are more suitable for different people. For this reason, peer workers appreciated having a diverse range of resources to draw from. Participants and peer workers discussed how aspects of participants' own personalities and situations influenced their reactions to the content and format of the resources.

Content

How much people connected with particular content, and the impact it had on them depended on their unique personal circumstances and histories. Their existing knowledge was an important factor. Some people enjoyed being reminded of information they already knew. For example, P05 commented that she liked the personal medicine pack because:

> *P05: "I could read all about it and answer all the questions. Finished it in half an hour. I already knew what was in that."*

For others, however, familiarity of content meant that it was not as interesting or useful, while new information was valued.

> *P28: Oh, [Meaningful activity], there was just nothing new in it. It's what we've heard many times over.*

> *P07: The content was different. That was what highlighted it for me, to what is my normal things that I read about recovery.*

These thoughts were echoed by one peer worker.

> *PW01: I guess it's probably down to their own personal experiences and what they've been through. So if someone's really interested in physical health and well-being, they would have been more likely to pick the cards, if that was an essential part to their experience. I guess it just really ties into their own kind of experiences. Although, I guess it could actually swing the other way where people might have picked something different that they wanted to find out more about, that they didn't know much about.*

Participants also preferred different amounts of depth and detail. Many liked resources to be succinct and simple, while others liked more detail.

> *P03: I sort of found that these are good, but it'd be a bit nice to have a bit more depth. But then you'd probably find 85% of the people are saying it's maybe even too deep as it stands.*

Some people found the podcast too long, while others thought that the length was fine. Many liked the succinctness of the hope box, but others felt that it lacked detail.

At times, peer workers attributed differences in preferred depth and detail of information to participants' literacy, comprehension, and attention skills. One peer worker commented that this may explain why some did not engage readily with the personal medicine booklet:

PW04: For some of the participants, literacy would be an issue. If it's content heavy as far as reading or comprehension at times. For some of the participants it was [too content-heavy].

In some cases, personal circumstances, needs and history made a resource more or less useful, as shown by the following two comments about the physical health cards.

P25: Just because I don't have a problem with meeting my physical health needs with my treatment team… I didn't find those as beneficial for me, but I can see how they would be beneficial for other people.

P28: The cards. They were particularly useful… It's a big problem that when mentally ill people come into a place like this their physical health gets extremely neglected. And speaking from experience, I've had long periods in these facilities, as a result my knees have gone, walking is painful simply because I had so much to worry about. I just ignored my ongoing physical deterioration.

For others, an influential factor may be how well the information gels with their existing beliefs and values. For example, P28 disliked the Meaningful Activity resource because it "focused on distraction rather than rehabilitation" and emphasised social interaction when "ultimately, we all need to solve our own problems." Others appreciated resources that reinforced and emphasised existing priorities and goals or reflected their feelings and experiences.

P01: The most I remember … getting out there and all that kind of stuff that we heard in the podcast… it clicked to me, because it's something that I do, it was something I always wanted to do.

P23: Sometimes it's just the way you're feeling, the emotions at the time. And then you may look at one part of it and thinking "Oh that's like me now."

On the other hand, peer workers identified that some participants' negative experiences with pharmacological medicine regimes affected their initial interest in the resource about personal medicine.

PW04: They're like, "Oh, I don't like medication. I want to get off of it." It still provided a lot of opportunities to talk about, "Well, this doesn't have anything to do with medication. . . This is you taking control and being able to self-administer to decide what you need and

when." So once I explained it, there was a couple of people that really enjoyed it, but it took a lot more work to see if that is something that they would like to engage with.

A couple of participants emphasised how different content would be experienced differently and appeal to different people at different times in their lives.

P29: Depending on your age and where you're at, it just highlights the similarities that are essential in life ... For me it was really good because in my youth it was all about drinking and drugging and working and, now, I don't do any of that.

P15: It's a great tool but it's important to know when it's needed.

Peer workers often linked participants' content preferences to their stage of recovery and noted that the needs and situations of people in acute care varied significantly from those living in the community. Resources such as the hope box, with its succinct messaging, was believed to be immediately applicable to most people, whereas resources such as the meaningful activity journal, physical healthcare cards, and personal medicine were seen as more suitable for those who were living in the community. One peer worker remarked:

PW03: Different times in their life and different points of recovery. Because I [work] in community [settings] and so a lot of them have gotten past the acute stage and they're on that recovery process. Some of the stuff that I presented, they were kind of like, "Oh, I want something more." So that's why I could see with my resources which ones were going well and which ones weren't. Because some of them were a bit too basic.

Another peer worker, who worked with many people in inpatient care observed:

PW04: So that same resource for somebody that's out in the community and has adjusted and they've got their housing and their life in order, they may get a lot more out of [the personal medicine booklet]. Somebody that's just come in, and if I offered it up to somebody in inpatient, they may have only been in hospital for a couple of weeks. There's a lot going on in their heads. And they're bombarded with forms and instruments to gauge how happy you are, how hopeful you are. So in the hospital setting, in the clinical setting, they're exposed to so many forms and [if you presented the personal medicine booklet] they'd just go, "Oh, no. . . Too much. Too much." So it just depends on where they're at in their recovery.

It is also important to be aware that almost any content may be experienced as distressing depending on an individual's unique history.

P26: I have trauma around seeing doctors. So the physical health care thing was unexpectedly triggering for me…. I wasn't expecting it and [the peer worker] wasn't expecting it. It just sort of came out from the blue.

Format

It was very clear that different people engaged more with different resource formats. For example, P08 liked the podcast best because "I liked that medium", while it was P10's favourite because "there wasn't really any reading in it." For others, however, it was less preferred.

P01: I liked them all. The least, I would say, the podcast… the other resources were more interesting… with the podcast, it was more just listening the whole time.

P12: It's like me talking on the phone. I can't fully understand, or it might not, it just doesn't sink in properly.

Participants and peer workers alike recognised that format preferences were very individual and depended on their unique experiences, traits and learning styles.

P21: Because I'm a touchy feely, I'm a kinaesthetic type of personality. I actually learn by doing.

P28: Well the cards appealed to me simply because I'm a mad poker player. Anything that reminds me of that makes a good first impression.

PW04: It was very individual. There wasn't a common thread throughout it. . . So some people, it's just a tactile thing. I don't like the feel of that. I didn't want to have to open something. Other people loved having the book, other people - "I don't want to read something."

Participants and peer workers commented on appreciating the variety in the format of resources so that diverse people's needs were catered for.

P04: I liked the idea of different formats because everyone learns differently and if you do one particular format, you're going to miss certain people's learning experiences.

P29: Some people can't read and write, so those are things to consider, too.

P14: It's good to have the range of things there, that different people can relate to, sort of thing.

PW05: While I say that the hope box was probably received the best, and the podcast the least, it doesn't mean that I think that everything should be delivered in a box. I think that the differences in formats is actually quite interesting, and of course some people responded to different things. While that was the experience that I had with myself and my participants, I actually liked that there was quite a diverse range of things on offer.

e) Valued features of the resources

While different people preferred and emphasised different aspects of the resources, there were a number of features that were commonly valued and appreciated. Table 8 below presents, for each feature, a description, examples and the number of participants who related the feature to each resource. It should be noted that numbers represent participants who brought up each feature in response to open ended questions (i.e., the 24 people who did not mention attractive presentation did not necessarily find the resources unattractive). Participants' comments were echoed by peer workers; while peer workers opinions *are not* included in the counts, some of their comments are included in the examples.

Table 8: Valued features of resources

Valued feature	Example quote	C	W	P	H	PH	M	G	T
Practical information	People valued information that had practical implications and was relevant to their recovery. It was really useful because in the early days I tried to get help for my physical body, but I didn't know where to start, how to go about it. But those cards provide all of that. With them alone you can make up a bit of a plan to sort out your physical issues. [Physical Health – P28] They're the sort of things, resources, that for me I would rely on or lean on in times of difficulty and times of low, or feeling low. [General comment – P15] [My participants] weren't just like, "This is amazing." But they were like, "Oh, that's what I want to do." Or, "That's what I would do." There was a very good response with the actual content of the cards. [Physical Health – PW03]	1	9	7	1	7	2	13	**21**
Relatable	People strongly articulated that they identified with the information presented and that it resonated with their own lived experiences. Just people's feedback, really… just to hear it all and see it all written down on the paper and all that sort of stuff. I could relate to it a lot. [General comment - P02] They actually put into words what you think in your head. [Physical Health - P24] They resonated with me, so it was very easy for me then to offer them up and to really say that, "Look, this does have meaning for some people." [General comment – PW04]	1	4	4	5	2	5	12	**21**
Attractive presentation	People appreciated resources that they saw as aesthetically pleasing, attractive and well-thought out.		4	5	11	1	6	1	**19**

Valued feature	Example quote	C	W	P	H	PH	M	G	T
	I felt that it was a lot of time and effort had gone into making it and preparing it. A lot of thoughtfulness... I was actually a little bit emotional when I first opened the resource. [Hope – P15] That one was cool 'cause all the pictures and different things like that [Personal medicine – P32] It's so beautiful. I was worried when they wanted to just put the staples in. I was like, oh my gosh, it's going to look so cheap but then I saw it and I'm like, "It's amazing." [Meaningful activity – PW03]								
Empowering messages	People valued where resources contained empowering, positive and recovery-oriented messages, role models and language. What they said about your life transforming as a result of having a mental illness [..]It's a very positive message that it doesn't have to be a negative experience. It can be the opposite. [Concepts of recovery – P07] It was very empowering, some of the things that they said [What helps – P01]. [People said that] it helped them reflect on how far they've actually come in their own journey. And that they do have strengths that they didn't think they did, such as resilience, empowerment, strength. And that they do have choices as well. [General comment - PW01]	7	7	4	4		1	1	**18**
Others' experiences	People prized seeing and hearing perspectives from other people with lived experience, especially in their own words. I found that really helpful too, like I said, that's hearing about other people's experiences. [What helps – P12] I liked that it was people's experiences, and you could relate to that and go, "Aw, yeah, that's me." And even the ones you didn't relate to you were like, you could still get it, and it still made you think. I found it very engaging. [General comment – P04] It was good to see that other people had gone through these experiences. I think that was a big takeaway, people said it was good to see and to feel that they weren't alone. And that so many other people have had to go through this journey. [What helps – PW01]	4	6			1	4	15	**18**
Straightforward	People appreciated information being presented in a way that was straightforward and easy to understand and read. The way these people have written it is very easy to read. I'm not very good at reading. I read the whole thing; I understood the whole thing [Meaningful activities – P22].	3	6	2	1	3	5	5	**16**

Valued feature	Example quote	C	W	P	H	PH	M	G	T
	It was really well done. I mean all the examples were great. Really well put together and easy to understand. [General comment – P11] I thought all the products were quite easy to utilize and explain. [General comment – PW03]								
Creative and novel	People found that their attention and imagination was captured by resources that were creative, novel and innovative. I did find it creative, and I get attracted to creative stuff. [Hope – P14] The cards are a novel way to convey information. [Physical Health – P28] It's a really creative way of engaging with people and getting them to learn about recovery principles in a creative way. Because people, as you can imagine, can get bored very quickly if you're not engaging them in this kind of creative way. So I think these resources was fantastic because people were actually learning stuff without them even realizing that it was an educational thing as well. Because it was just so fun [General comment – PW01]	1			10	2	2	8	**14**
Variety	People liked that there was a variety of different content and formats within and across the different resources. I like the magazine one the most. It has a different ways of sharing, or providing that information. The visual, the information, the activities, the quotes and stories. And so it has a mix of everything. [Meaningful activities – P06] [I liked] all of them really, but see all of them had a different purpose. [General comment - P23] It's interesting because when you give them that many to choose from, I never had anybody that went, "I didn't like any of them." So it's interesting when you still gave them a variety, they might have thought I liked that, I didn't like that. They didn't go, "The whole thing was a waste." . . . Because everybody was able to find something. [General comment - PW04]		1			1	3	8	**10**
Succinct	A number of people described liking the resources that were relatively short and succinct. It's not so much writing at the time and you can just relate to it like that. [Hope – P33] It outlines all the things I can do. I don't need to think about, I just read through the page and I find out what I can do. [Meaningful activities – P16] Some people actually did ask roughly, how long did I think that the resource would take them to look at. So time was a factor for some people. [General comment – PW01]		2	1	3		3		**7**

Valued feature	Example quote	C	W	P	H	PH	M	G	T
"Like a present"	People who received the hope box tended to enjoy opening the box, then the balls, to reveal the crane and message. They described experiencing anticipation and surprise and feeling like they had received a present. Just the little gifts that you gave. Then I took it home and I did what they say, like with the little... It's little balls, and the crane. Each day, I wouldn't open it early. I'd just do each day. [Hope – P12] They really liked the design, the mystery, the kind of surprise and hope that it brought I suppose in terms of reading the messages and opening it up and some of them just jumped straight into it. Some of them opened one per day. [Hope – PW05]				7				**7**
Hands on	People commented positively on resources that involved doing. The hope box required people to open the balls and invited them to decorate and personalise the box, while the personal medicine pack had questions to complete. I loved that, because it was hands on. I liked the fact that it was practical activity. [Hope – P04] I find that I like that one, I did the whole booklet and also that you could direct something every day like a diary. [Personal medicine – P33] From my personal preference, and of course everyone is so individual, but I really like the personal medicine and the meaningful activity. Where there's space to jot down your own responses and kind of make it your own. I think I learn that way. More of that I think. Interactive stuff. [General comment – PW03]			3	6			1	**6**

C = Concepts of recovery podcast
W = What helps portraits
P = Personal medicine pack
H = Hope box
PH = Physical health cards
M = Meaningful activities magazine
G = General comments relating to multiple resources
T = Total number of people represented in this data

f) Aspects to improve

Overall, participants' comments about the resources were very positive, and 20 people stated that there was nothing they did not like. However, some did note things that they did not like or suggested ways of improving the resources and these are worth considering in detail.

Concepts of recovery podcast (n=12)

- Two people felt that the podcast was too long, however others, when asked, disagreed and enjoyed the depth. Peer workers observed that some participants struggled with the length of the podcast and taking in larger chunks of information. The podcast contained a suggested break in the middle, but perhaps having 2 separate files would encourage people to listen on two different occasions. Alternatively, it might be possible to have 2 versions – one briefer and one more in-depth.

- Two people found that it was not engaging or "boring".

- Two people suggested that the podcast would be improved adding a visual element: making it into a video of the speakers as this would be more engaging. Several others, when asked, agreed that a video was a good idea.

- Three people found it difficult to hear, though this may have been related to the devices they listened on. It may be possible to improve sound quality or ensure that people have access to reasonable quality equipment. This problem would also be alleviated by the idea of adding visuals, as lip movements and other non-verbal cues may make interpretation easier.

- Peer workers identified that for some people, access to the required technology (i.e., tablet devices, internet) and lack of requisite skills with technology may be a barrier to them being able to access this resource effectively. One peer worker commented: "Some of them couldn't get access with their phones. And so it was a technological thing. And so that's why I had to do a lot of in-house listening. Purely because some of them just have basic Nokias or they don't have the internet, or they don't have a computer and all that kind of stuff. That was a barrier for them, I think."[PW03]

- Two people suggested that some kind of summary, whether at the beginning of the podcast or in an accompanying hand-out would be useful to provide an overview of/orientation to what would be covered. A third, who had taken notes of her own accord, suggested that instructing people to take notes would help them to concentrate.

- One person found the podcast less practical than other resources: “I'm looking more for the practical things. So that was more of the theory and theoretical type thing, aspect of it.” (P06)

- Two peer workers pointed out that listening to a podcast may be potentially triggering for participants who experience symptoms of human voices, which may require specific support from peer workers to navigate.

What helps portraits (n=3)

- One participant described this resource as “quite wordy” but again, suggested that it be presented with an instruction of “don’t feel like you have to read it in one go”.

- Another felt that it was “a bit too vague” and needed more depth and detail.

- A third participant did not like this resource as much because “the content was stuff I really knew”.

One peer worker felt that this resource was too similar in terms of content and not as professionally presented as the other resources.

Personal medicine pack (n=7)

- Three people mentioned that they had been put off by the title “personal medicine”, thinking that it was referring to pharmaceutical medication. These comments were backed up by peer workers who reported needing to explain the concept in greater detail to many participants. It is likely that, despite the written explanation provided when participants chose resources, other participants did not select this resource because of the same misunderstanding. In fact, several weeks into the project we noticed that few participants were selecting this resource, so peer workers were asked to explain to participants that it was not about medication and encourage them to choose it, after which it was selected more frequently. It may be wise to consider changing the name of the resource, or at least making its (non) relationship to pharmaceutical medication clearer.

- Two people did not like the layout of the workbook, which had content and activities divided into seven sections labelled from Monday to Friday, imitating a Webster pack. They found it confusing and one also said that it was 'repetitive and condescending'. One suggested that: "It might have been useful maybe having at the front the instructions or what it means". Peer workers also commented that the layout of the book was not intuitive to many participants and required greater explanation. While an introduction to the concept of personal medicine and the research was given in the front of the book, an explanation and rationale for the format was not, which seems, in retrospect, an oversight.

- One participant found the actual information confusing and a fourth felt that it "could have been more thorough".

Based on the above, for some people, this resource may be unsuitable or may need additional explanation and support from a peer worker. An alternative and more straightforward format may be appropriate for some people.

Hope box (n=5)

- Two people found the plastic balls difficult to open. Some team members also felt uncomfortable with this resource in an environmental sense, so it may be prudent to investigate other, more environmentally friendly and easier opening alternatives. One participant also suggested that the balls could be decorated if they were made of a different material, such as cardboard.

- Three people also felt that the inserts were "very generalised" and lacked specificity: "I didn't quite know what to do with it. Like I had to sit with the recommendations and I had to figure it out for myself". One peer worker said that some participants found the hope box "too basic." Another felt the resource could be "very, very useful" if better explained and discussed.

- One participant found the advice about spending time with friends distressing because she was experiencing difficulty in that area. This is discussed further below in Section 2h.

Physical health cards (n=5)

- Four people suggested that the information could benefit from more detail and specificity: “I found that could have been a bit more elaborated on. I found that very helpful, actually. It could've been a bit more extended in the information.” As with other resources, however, we were somewhat limited by the content of the research, which focused more on negative experiences than personal strategies (which were seen as more helpful). One of these participants felt that, given that many people living with mental health issues neglect their physical health, the focus should be one step back – helping them to see the need to look after their physical health. This probably speaks to the need for another resource entirely.

- One person thought that the information was “a bit ambitious, and it's just a bit idealistic” because being able to access good physical health care “certainly isn't happening at the moment as far as I know, and I get the impression it's a long way off.” (P08)

- Another participant found the card game format “a little bit over-earnest and facile when I played it with my family and friends”. However, this perspective was not echoed by other participants who said they enjoyed using it as a game. This same participant found the content distressing due to previous experiences with doctors. This is discussed further below in Section 2h.

- One peer worker reported that participants required extra explanation in order to understand how to play a game with the cards, and what the point of that was. However, they noted that once explained, participants readily engaged with the resource.

Meaningful activities magazine (n=4)

- Two people commented on the graphics – one said that a picture was too “harsh”, while another felt that the colour of the page on medication was too dark, so that it might look ‘sinister’. One of these participants also commented on the layout, suggesting re-ordering of some of the pages, for example, so that the activities are in the middle rather than at the end of the book.

- Two participants suggested additional ‘features’ or inclusions, such as a recipe, and a wider variety of puzzles, such as quiz/trivia questions.

- In contrast, another participant felt “annoyed” by having puzzles at all as they “served no purpose”. Overall, they found the meaningful activity magazine to have little purpose as it was “focused on distraction rather than rehabilitation”, contained no new information and was presented in a “condescending” style (P28).

g) How participants used the resources

Participants often talked about how they had used particular resources. Their responses are presented separately for each resource, as the anticipated use of each resource was different.

Concepts of recovery podcast (n=8)

Most people had listened through the concepts of recovery podcast once, with their peer worker, though one had listened to it while she went for a walk. Two participants said that they had taken notes while listening, and a third said that they had stopped and started the podcast repeatedly because there “seemed to be a lot of points”. Two participants planned to listen to the podcast again and another stated that she had it downloaded on her phone. One participant had recommended that her parents listen to the podcast as well.

One peer worker presented the podcast in a group setting. Other peer workers said that they sat with participants while they listened to the podcast in order to assist with using the technology (e.g., if the participant wanted to rewind and listen again to sections of the audio).

What helps portraits (n=10)

Ten people commented on what they had done with the ‘What helps’ portraits. Six appeared to have just read through the resource once, though two were keeping them on their coffee tables and one had definite plans to revisit this resource. One participant had taken notes while reading them. One participant had put one of the portraits on her fridge, and two others reported having looked at them multiple times: one had read them on the train, tried to memorise them and put them in different orders, while the other stated:

> *P23: I went back to the ring one… because lately I've been quite stressed and stuff and there was other issues as well, and I kept coming back to [that] all the time.*

Hope box (n=19)

All but one participant who talked about how they had used the hope box had opened all the balls and read the messages. The remaining participant had opened some and planned to open the rest the day of the interview. Eight reported opening all the balls at once, while six said that they "paced it out", opening them each day or at intervals. Most people did not seem to have decorated the box, though one planned to use it as a haberdashery box. One peer worker reported that a participant had added her own messages in her hope box and planned to put photos of her family on it. Four participants reported that they had gone back to the box and reread the text, while seven said they planned to do so, either as a review or when they are "feeling a bit down". Four participants had made notes about the content while they read it. One person had hung the cranes out as a mobile. Two participants had showed the box to their parents and another one was planning to go through it with her children. Another participant had requested a box for a friend:

P12: Straight away I was like, "Oh, can I get another one? I know somebody I can give to. They're really suffering."

Personal medicine pack (n=12)

All participants who talked about their use of the personal medicine pack said that they had read through the workbook, with four having read it more than once. Three participants said they had filled out all of the optional spaces in the workbook, two had completed some, and one planned to fill it out in the future. Five participants described prescribing themselves personal medicine, and starting to follow those prescriptions.

P16: I prescribed to myself. I use a diary and I use the diary very often now.

Physical health care cards (n=4)

Only four people describe how they used the physical health care cards. One had only gone through some of the cards with the peer worker but planned to go back and look at the rest; one read through them once. Two participants played the card game a couple of times with others and one also used the material to stimulate conversations with family and friends.

Meaningful activities magazine (n=16)

Sixteen participants talked about how they used the meaningful activities magazine. Five people appeared to have just read through the magazine once, while six reported that they also did at least some of the puzzles and activities and one took notes. Five people said that they had gone through the magazine multiple times, one reporting that she was keeping it in her handbag: "I've actually kept it with me and referred back to it a lot". A further two planned to look through it again later but

had not so far. Two people had showed it to friends or family and another three stated definitely that they planned to keep the magazine.

P02: It was mad. Yeah, I'll keep that book.

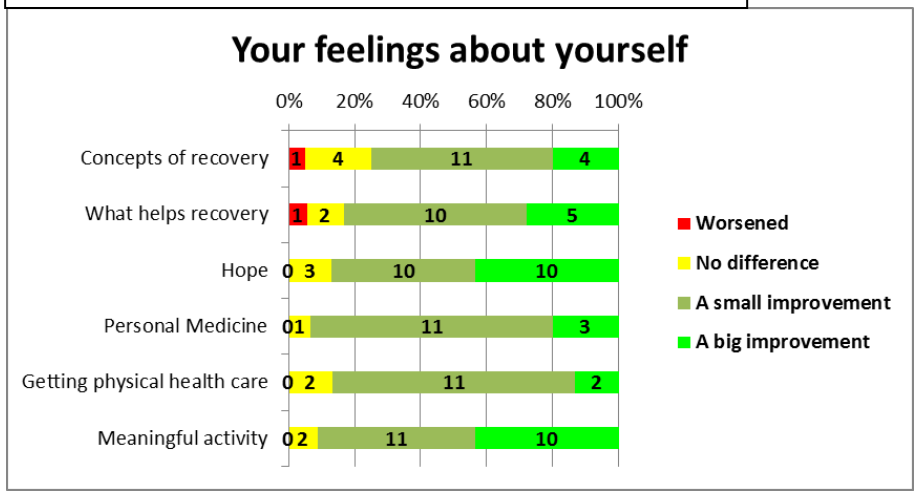
h) Impact of resources on the participants' lives

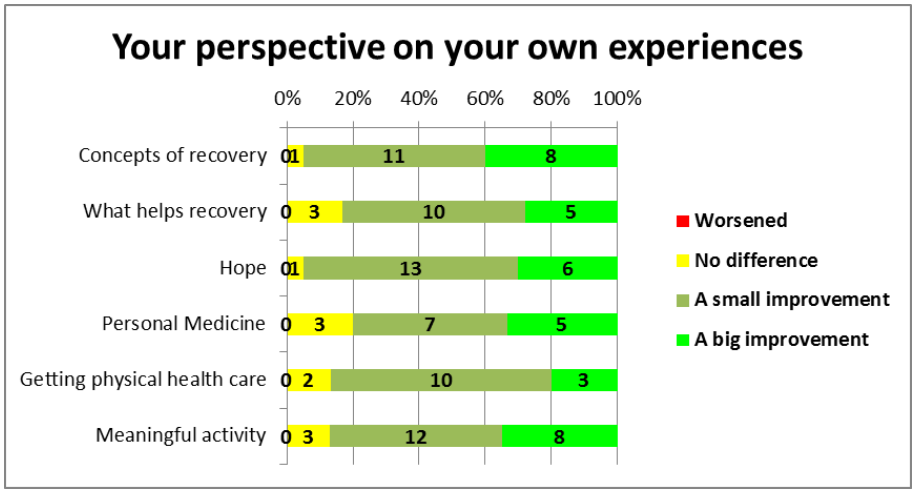
Participants in the anonymous survey were asked about the impact of accessing each resource on various aspects of their lives. Responses were very positive with generally 60 to 80% of participants reporting the resources had made a small improvement or a big improvement in their lives. Unsurprisingly given the nature of the resources, the areas that the resources tended to have somewhat less positive impacts were in the areas of "ability to deal with the mental health system" and "ability to interact with mental health professionals", although over 60% of participants generally reported that there were improvements in these areas. For easy comparison, results are summarised in Table 9 and presented in graphs on the following pages in Figure 5.

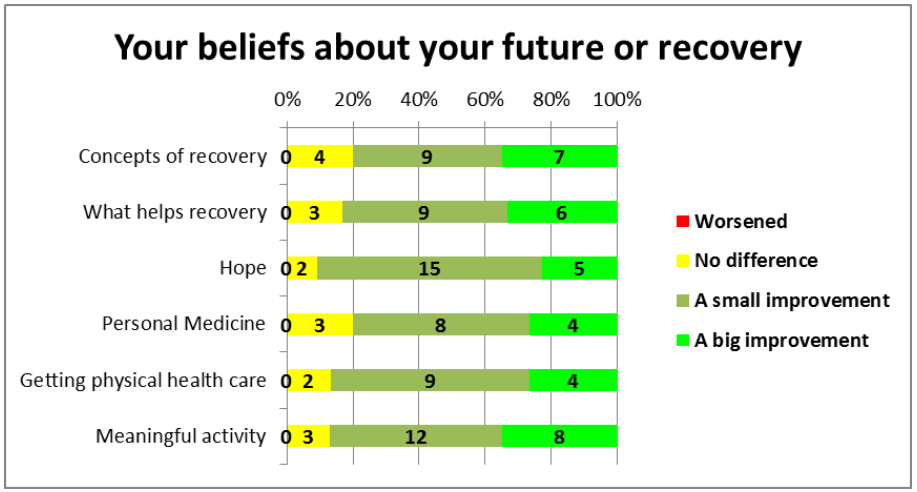
Table 9. Impact of individual resources – anonymous survey

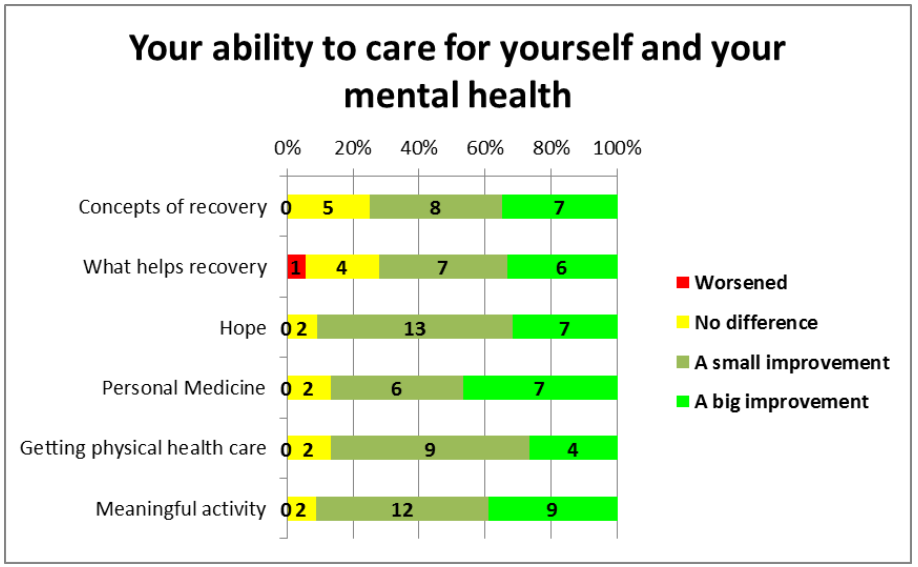
Has accessing the resource made a difference in your life in terms of:	Concepts of recovery (*n* = 20)	What helps recovery (*n* = 18)	Hope (*n* = 23)	Personal medicine (*n* = 15)	Physical health (*n* = 15)	Meaningful activity (*n* = 23)
Your feelings about yourself						
Worsened	1 (5%)	1 (6%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	4 (20%)	2 (11%)	3 (13%)	1 (7%)	2 (13%)	2 (9%)
A small improvement	11 (55%)	10 (56%)	10 (43%)	11 (73%)	11 (73%)	11 (48%)
A big improvement	4 (20%)	5 (28%)	10 (43%)	3 (20%)	2 (13%)	10 (43%)
Your perspective on your own experiences						
Worsened	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	1 (5%)	3 (17%)	1 (5%)	3 (20%)	2 (13%)	3 (13%)
A small improvement	11 (55%)	10 (56%)	13 (65%)	7 (47%)	10 (67%)	12 (52%)
A big improvement	8 (40%)	5 (28%)	6 (30%)	5 (33%)	3 (20%)	8 (35%)
Your beliefs about your future or recovery						
Worsened	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	4 (20%)	3 (17%)	2 (9%)	3 (20%)	2 (13%)	3 (13%)
A small improvement	9 (45%)	9 (50%)	15 (68%)	8 (53%)	9 (60%)	12 (52%)
A big improvement	7 (35%)	6 (33%)	5 (23%)	4 (27%)	4 (27%)	8 (35%)
Your ability to care for yourself and your mental health						
Worsened	0 (0%)	1 (6%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	5 (25%)	4 (22%)	2 (9%)	2 (13%)	2 (13%)	2 (9%)
A small improvement	8 (40%)	7 (39%)	13 (59%)	6 (40%)	9 (60%)	12 (52%)
A big improvement	7 (35%)	6 (33%)	7 (32%)	7 (47%)	4 (27%)	9 (39%)
Your ability to deal with the mental health system						
Worsened	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	6 (30%)	6 (33%)	5 (23%)	5 (33%)	3 (20%)	8 (35%)
A small improvement	9 (45%)	7 (39%)	12 (55%)	7 (47%)	7 (47%)	8 (35%)
A big improvement	5 (25%)	5 (28%)	5 (23%)	3 (20%)	5 (33%)	7 (30%)
Your ability to interact with mental health professionals						
Worsened	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	7 (35%)	7 (39%)	8 (36%)	5 (33%)	3 (20%)	11 (48%)
A small improvement	6 (30%)	5 (28%)	8 (36%)	8 (53%)	6 (40%)	5 (22%)
A big improvement	7 (35%)	6 (33%)	6 (27%)	2 (13%)	6 (40%)	7 (30%)
Your understanding of other people and their experiences						
Worsened	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	2 (10%)	0 (0%)	3 (14%)	0 (0%)	3 (20%)	3 (13%)
A small improvement	7 (35%)	8 (44%)	11 (50%)	10 (67%)	6 (40%)	10 (43%)
A big improvement	11 (55%)	10 (56%)	8 (36%)	5 (33%)	6 (40%)	10 (43%)
Your understandings about mental illness						
Worsened	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
No difference	4 (20%)	4 (22%)	5 (23%)	3 (21%)	2 (13%)	3 (13%)
A small improvement	9 (45%)	7 (39%)	10 (45%)	7 (50%)	8 (53%)	12 (52%)
A big improvement	7 (35%)	7 (39%)	7 (32%)	4 (29%)	5 (33%)	8 (35%)

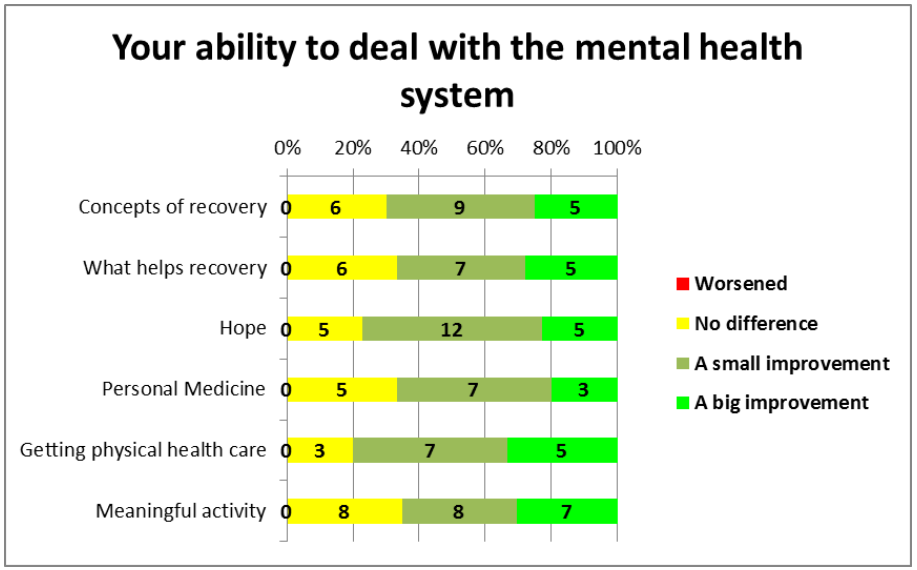
Figure 5: Impact of resources

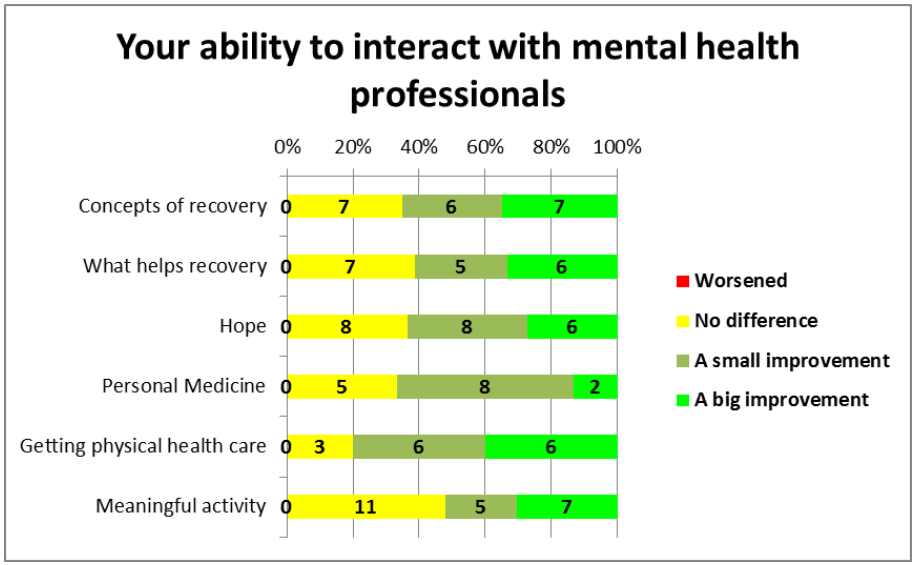


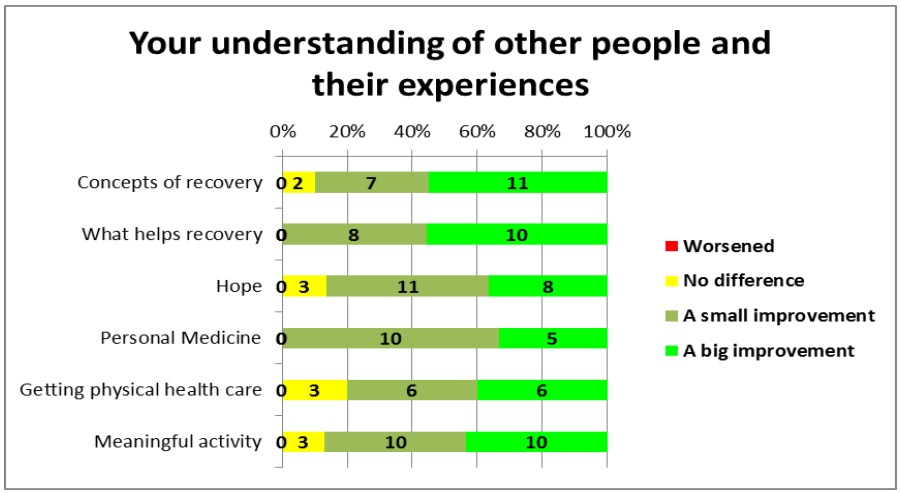


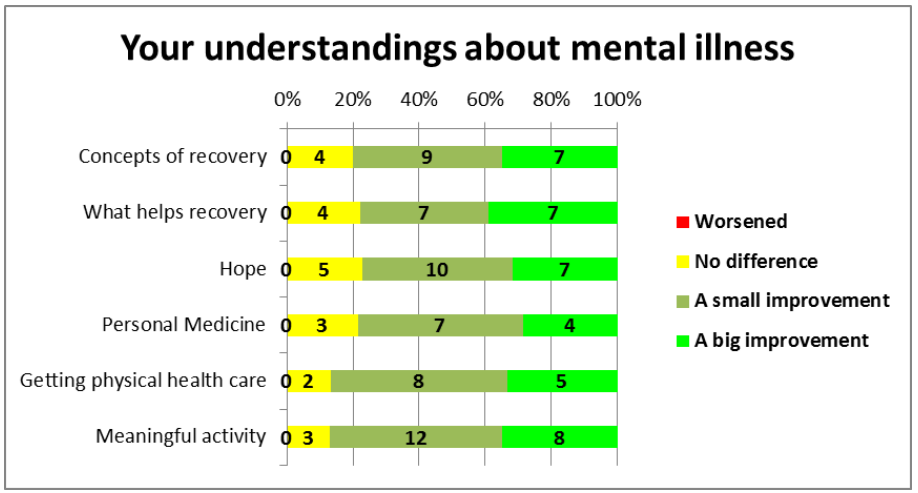





Your ability to deal with the mental health system
0% 20% 40% 60% 80% 100%
Concepts of recovery 0 6 9 5
What helps recovery 0 6 7 5
Hope 0 5 12 5
Personal Medicine 0 5 7 3
Getting physical health care 0 3 7 5
Meaningful activity 0 8 8 7
Worsened
No difference
A small improvement
A big improvement


Your ability to interact with mental health professionals
0% 20% 40% 60% 80% 100%
Concepts of recovery 0 7 6 7
What helps recovery 0 7 5 6
Hope 0 8 8 6
Personal Medicine 0 5 8 2
Getting physical health care 0 3 6 6
Meaningful activity 0 11 5 7
Worsened
No difference
A small improvement
A big improvement


Your understanding of other people and their experiences
0% 20% 40% 60% 80% 100%
Concepts of recovery 0 2 7 11
What helps recovery 0 8 10
Hope 0 3 11 8
Personal Medicine 0 10 5
Getting physical health care 0 3 6 6
Meaningful activity 0 3 10 10
Worsened
No difference
A small improvement
A big improvement


Your understandings about mental illness
0% 20% 40% 60% 80% 100%
Concepts of recovery 0 4 9 7
What helps recovery 0 4 7 7
Hope 0 5 10 7
Personal Medicine 0 3 7 4
Getting physical health care 0 2 8 5
Meaningful activity 0 3 12 8
Worsened
No difference
A small improvement
A big improvement

The in-depth interviews allowed participants to state their perspectives on the impact of the resources that mattered to them. Overall, 30/33 participants stated, when asked specifically, that they had benefited from being part of the study. Of the remaining three, two answers were unclear and one was not sure if they had benefited. This participant, P31, also reported that nothing had changed for them as a result of the study. With the exception of P31, all other participants described some positive impact in subsequent discussion from interacting with the resources.

The positive impacts people described fall into a number of broad categories, described and exemplified in Table 10. Counts of people mentioning this impact in relation to a specific resource, the resources more generally, and in total, are provided. As previously, these impacts emerged as responses to open questions, so a participant not mentioning an impact does not guarantee that they did not experience it.

Table 10: Self-perceived positive impact of resources

Impact	Example quote	C	W	P	H	PH	M	G	T
Motivated helpful activities	Participants often talked about the resources prompting or motivating them to do things that were beneficial for them. This was through reminding them of helpful strategies, suggesting new strategies, or showing what had helped other people. *I've been a bit unwell, so I'm scaling back my hours and it's the reason for that is basically I don't have the time to do the self- care things I need to do. I really connected with that book because as I was reading it and I thought "These are the things I need to do". [Meaningful activities – P04]* *I knew these sorts of things anyway, but it was just a matter of when I was going to activate them in my head, to sort of act on them... [the resources] did, they prompt you. [General comment – P14]*			8	1		10	16	**21**
Positive experience in the moment	A number of participants talked about how interacting with the resources was a positive experience at the time, for example, it was enjoyable and interesting. *The little booklet's very relaxing. [Meaningful activities – P24]* *The first podcast was interesting to listen to. [Concepts of recovery – P10]*	6		1	4	1	3	11	**19**
Gaining knowledge	Participants talked about gaining new knowledge from the resources, such as information about mental health issues and strategies to try. *Just opening my eyes to a lot of things I didn't know about [General comment – P13]* *I got a lot of ideas and suggestions that really made sense to me, such as how to stay well, when to recognize you're not feeling well. [General comment – P13]*			3	3		2	13	**19**

Impact	Example quote	C	W	P	H	PH	M	G	T
Reflecting on my journey	Commonly, people talked about how engaging with the resources made them reflect on their own experiences, strengths and journey. *But it does make you think about what you've gone through. [General comment – P23]* *I understand myself a little bit better with what's going on. [General comment-P24]*		2	4	4	1	4	13	**18**
Feelings of hope and empowerment	Many participants described how interacting with the resources made them feel more hopeful, positive and empowered. *I just had a little bit of light bulb moment saying, 'Well, these things help these people feel better and all these ideas', so it gave me a bit of understanding and hope for my future. [Meaningful activities – P13]* *Seeing other people's experiences, and that's really helped to know 'I can do that too'. [General comment-P12]*	2	5	4	4	1	3	10	**17**
Thinking constructively about mental health issues	Participants discussed how the resources reinforced or promoted positive or useful perspectives and ways of thinking about and conceptualising mental health issues. *There was a few things that stood out and actually made me think that mental illness is not something that you should be really afraid of. [General comment – P13]* *It makes my belief in recovery much stronger. [General comment-P18]* Some of these participants reported that, after using the resources, they were able to articulate their experience or condition to other people in a better way. *So it's learning different key words that I could use to say the same thing, so that it is more understandable for more people. [General comment – P06]* *I wasn't so clear about what schizophrenia is in other people's eyes. They (the resources) help me understand about stigma and how I will cope with others and how I can explain to others. [Concepts of Recovery – P16]*	2			1			15	**15**

Impact	Example quote	C	W	P	H	PH	M	G	T
Feeling less alone	As noted in the section above, many participants noted that the resources resonated with their experiences. Relatedly, ten people noted that interacting with the resources made them feel that there were people who shared their experience and who understood them, which made some feel less alone and more supported. *I would say that I did feel a sense of support. I haven't felt that really, like I've felt it with friends, but to feel more understood, more just that people understood, and people that do care, that people's mental health experiences and are living well. [General comment – P15]* *I just kind of feel like they cared for me. So it was quite good getting the resources and then realizing that you're not alone as well. There's other people going through things as well. [General comment – P32]*							11	**11**
Explaining to others	Some people talked about how they were able to use the resources to start conversations with others. For some this was about using the resources and information to help others. For example, one participant who worked as a peer worker said: *It was more of helping me so that I can help myself, and help others more for understanding what's out there, and options for people, and how to speak to them in a way. [General comment – P06]* For other people, the resources helped them to explain their experiences to other people so that they understood better. *"Well, I showed them to my mother, who's living with me at the moment, and I think it gave her a little bit of insight. [General comment – P08]*	2		1		3		3	**7**

C = Concepts of recovery podcast
W = What helps portraits
P = Personal medicine pack
H = Hope box
PH = Physical health cards
M = Meaningful activities magazine
G = General comments relating to multiple resources
T = Total number of people represented in this data

Negative impacts

While most of the impacts participants described were, as seen above, very positive, a couple of participants reported negative impacts.

In the anonymous survey, two different people reported that accessing a specific resource had a negative impact in one or two of the specified areas. In the context of the anonymous survey, the reasons for these impacts are difficult to interpret, however the responses were considered alongside the same participants' responses to other questions about the specific resource and the resources more generally.

The first participant reported that the concepts of recovery podcast had worsened their feelings about themselves. However, they also reported that:

- The concepts of recovery podcast also lead to a small improvement in other areas: their beliefs about their future or recovery; ability to deal with the mental health system; understanding of other people and their experiences.
- They found the concepts of recovery podcast 'very helpful' overall; however they said that they would not recommend it to others.
- They rated the overall experience of participating in the study as 'very positive'.

The second participant reported that the what helps portraits had worsened their feelings about themselves and their ability to care for themself and their mental health. They also reported that:

- The what helps portraits also lead to: a small improvement in 'your perspective on your own experiences'; and a big improvement in understanding of other people and their experiences.
- They found the what helps portraits 'very helpful' overall and would recommend this resource to others.
- They rated the overall experience of participating in the study as 'quite positive' and in the comments box stated: "keep up the research".

Participants were also asked whether there were any other impacts of the research apart from those specified. A third participant reported that the Hope Box had resulted in a worsening of another aspect, however they did not choose to specify this aspect or explain this negative impact. They also reported that:

- The hope box also lead to: a small improvement in 'Your feelings about yourself' 'Your beliefs about your future or recovery', 'Your ability to care for yourself and your mental health', and 'Your understandings about mental illness'; and a big improvement in understanding of other people and their experiences.
- They found the hope box 'very helpful' overall and would recommend this resource to others.
- They rated the overall experience of participating in the study as 'very positive' and in the comments box stated: "I liked being part of this program!".

The above issues suggest that there is a possibility that lived experience research can have a negative impact on some aspects of people's lives, however, these do appear to be within the context of a wider positive experience of the resources. It may also be possible that learning new information and perspectives can make one look critically at oneself which, although challenging in the short term, may still have the potential to be helpful in the future.

The qualitative interviews also revealed some negative impacts of the resources and provide more detailed information. Three participants reported experiencing some distress from interacting with the resources. It is not possible to tell whether these are the same participants who reported the negative impacts in the anonymous survey.

Two participants said that they found the content of specific resources distressing because of their past experiences and life circumstances.

> *P26: I have trauma around seeing doctors. So the physical health care thing was unexpectedly triggering for me… It just sort of came out from the blue.*

> *P26: Just some of the recommendations [from the hope box] felt like a stab in the gut. Something that I couldn't do in my own life… the one about spending time with friends because I felt that I'd lost friends during my hospital stay.*

> *P19: Personal medicine was, I didn't want to use at all. I just didn't anticipate it. I just, I actually had an upset because I'm an astrologer. I have my own personal way of looking at life… I don't want to have more psychology stuff.*

The third participant described feeling upset from hearing about other people's experiences, but did find them ultimately hopeful.

> *P13: There were a few things, things that these participants had, reading about them and saying that they have the negative thoughts sometimes. It made me feel a bit sad because then I thought that I'm going to have to deal with this for the rest of my life and made me feel a bit upset from that reading it, and that the struggles that these people go through was real…Some of what the participants were experiencing, I experienced those symptoms and I thought it is upsetting. But with what they've set their hope in things to do, it also made me think, well, then I can still feel hopeful about the future.*

While two of these participants did not appear to have discussed their reactions with their peer workers, P26's peer worker reported providing support to this participant. Each of these participants

ultimately described an overall positive experience from being in the research. However, this experience of distress highlights the importance of being aware that unanticipated negative impacts can occur. Having peer workers or others who are experienced in dealing with distress involved in disseminating the research and checking in with people about their reactions to it is advisable. For people who are more vulnerable, it may be wise for the peer worker to actually go through the research with them, rather than providing it as a stand-alone resource. This issue is discussed further in section 5.

3. What other topics and formats should be considered for developing additional lived experience research resources?

Participants and peer workers were asked to consider other topics that they would be interested in seeing lived experience research resources about. They were also asked for their suggestions of other user-friendly, attractive and engaging formats they thought would be helpful to deliver lived experience research in the future.

a. Content

Twenty-one participants and four peer workers made suggestions of additional content that they would like to see lived experience research resources address. These were quite individual, but fell into the areas of mental health self-care, life skills and mental health conditions.

Mental health self-care (n=14 participants; 3 peer workers)

Seventeen people suggested additional resources dedicated to managing their mental health. Ideas were diverse; for those mentioned by multiple people numbers are noted:

- navigating the mental health care system;
- navigating NDIS;
- help with hoarding;
- changing thinking in depression (n=2);
- communicating with friends and family to improve their understanding;
- pampering yourself as self-care;
- mindfulness (n=2);
- meditation;
- spirituality;
- self-confidence and self-esteem;
- coping with medication and its side effects (n=5);

- weight control;
- how getting out and keeping active can improve your mood;
- communicating with mental health workers (n=2);
- reaching out for help;
- step-by-step advice for preventing a psychotic episode, dealing with anxiety, and responding to symptoms;
- recognising strengths;
- reconnecting with feelings;
- emotional regulation;
- use of language and stigma around mental health

Life skills (n=8 participants + 1 peer worker)

Nine people wanted resources focused on general life skills to help them with their daily lives. The most commonly mentioned topic was empowerment/ autonomy (n=5).

> *P07: I think self-determination and, how do people find choice in their lives, and autonomy, empowerment. These are all the same topic is what I'm saying. That's an important one.*

> *P26: I think that empowerment would be a good one to address specifically. Because the whole experiences I've been finding it very disempowering even though I've been getting a lot of help.*

Other possible topics were building or regaining identity (n=2); life meaning; socializing and making friends; transitioning out of hospital and into life; and employment.

> *P28: I'd like to see just vocational training and 'what area do you want to work in, is your resume up to date?' … if you can get out and get a job, have a job, once you're out, then it's really going to make a huge difference.*

Mental health conditions (n=4 participants + 1 peer worker)

Five people said that they would like to hear more about specific mental health issues, especially in a richer and more diverse context. For example, one participant suggested including information about diversity such as different cultures, dual diagnoses, and co-existing disability. Others suggested resources explaining specific experiences: hearing voices; childhood and other trauma; and stigma.

P29: People really need to learn about childhood trauma so they can learn to understand themselves.

P08: Why am I getting [voices]? And will they ever go away? And should I speak back? and all of this sort of taboo questions that you just don't ask. I'm curious.

b. Format

Seventeen participants made suggestions for additional formats. Participant recommendations included arts-based formats, interactive media and videos.

Arts based formats (n=5 participants + 1 peer worker)

People highly valued the creative formats of the resources and said that they would like to access more resources based on creative/non-traditional approaches. Three participants suggested using visual art like painting, drawing or pottery to convey the messages, while two recommended poetry or creative writing.

P33: The other format that they [can consider] is an artwork, a painting or something that they need to fill in some colours, and what it means to them after the completion of that artwork.

P05: I love writing. Poetry and creative writing can be another approach.

Two participants suggested music or movies as a format to start discussion and reflection.

P30: Maybe you could, I don't know, whether just a recording or a DVD or whatever, or some sort of music. Music's, I think, a big thing, you know?

P01: Different songs from different artists, and then get us to analyse how that song relates to us. Or a movie. It could be a movie that we liked, and maybe ask us to tell you our favourite movie, and why we like it, and why it entices us.

Interactive activities (n=5 participants + 1 peer worker)

Five participants and one peer worker suggested having more interactive, activity-based resources. Some interactive resources would involve more input from the peer workers (see section 5) as the peer worker would need to guide an individual or a group (which may include other people with lived experience or family/friends) through the activity. Participants suggested that this would facilitate "active learning rather than passive learning" and pointed out that regardless of the content, the interaction is also beneficial for people.

P06: A resource that could be more activity based and that.

P18: What about "how are you feeling at the moment?" … Like what's going on in your world and, ready to get them to write a journal about what that feeling, or something.

P10: Maybe something interactive… would be good. Yeah, like an interactive web page.

Video (n=5 participants + 2 peer worker)

Seven people suggested video as a potential format. This could be accessible to a wide range of people through their computers or smart phones and at their own time, especially if it is uploaded to YouTube. And since learning through video also a common way of learning, it will require less guidance for the participants.

P28: I mean things like short little training things through YouTube can take us through a lot of areas.

P32: A format that you haven't tried, a little video even you could try, like a YouTube video or, TED talk are pretty good also. That's another form that you could try.

Tactile formats (n=2)

People appreciated having physical, tangible resources, something that they could interact through the sense of touch. Two participants suggested more tactile resources to foster learning and distract people from their thoughts.

P07: Something tactile that you still learn from but, I don't know, you can feel something.

P27: Something that they can touch and feel and take the focus off the bad thoughts.

4. How do peer workers experience use these resources with their clients?

Peer workers were unanimous in describing positive experiences in delivering the resources to participants. Peer workers were convinced that participants benefited from engaging with the resources and particularly enjoyed seeing participants' enthusiastic responses.

PW02: I really enjoyed meeting with my consumers and being able to provide them with the resources and the fact that they could keep it and then getting their feedback and like

overall it was very positive feedback from the consumers that I recruited. So that was really nice to see.

Aside from participants' positive reactions, four peer workers were also boosted by positive comments about the resources from other health care workers and clinicians. These colleagues had sought additional information about the research study, requested additional resources for themselves, or made observations about the positive impact that the resourced had appeared to have had on the participant.

Peer workers were especially motivated to participate in this study by their belief in the potential value to service users. Peer workers saw involvement in this study as an opportunity to use their own lived experience of mental health problems to benefit others.

PW04: *And their natural curiosity made me feel at ease to present it because I believed in it. Otherwise, I wouldn't have been part of the project. It's a waste of my time, or if it's not going to be something that's helpful, or offering somebody hope because that's really a lot of the core part of my job is really I love being able to be a living example of what recovery or hope could look like.*

Peer workers said that they generally felt confident in presenting resources to participants, although they may have experienced initial uncertainty when first starting out. Peer workers said that the training and support provided by the research team, along with opportunities to contribute in the design process gave them sufficient opportunities to become familiar with the resources and their key messages.

All peer workers saw real potential for the future use of these resources with their clients in day-to-day peer work outside of the research project and hoped to see the wider distribution of these resources across the sector. One peer worker commented that these resources addressed a clear need for tailored resources in peer worker toolkits that were engaging and interesting to service users.

PW01: *Usually we're just thrown into the deep end with not many resources. . . But I remember when I was just a straight peer worker but not a peer educator, there was just only limited resources you could go through with people, like, such as a wellness plan or goal setting and that kind of got boring and old really quickly.…So I think these resources are incredible. And it's made me think of how you can do peer support using these resources and how you can make it fun, engaging and interesting for people.*

Peer workers were convinced that their colleagues would be open and enthusiastic to using these resources as part of their work, although one peer worker noted that appropriate training would be imperative to get the best impact:

> PW05: *I guess I think it'd be important for them to receive some training on how the resources come to be. Where these resources actually come from in terms of, there's research that exists, we picked out ideas and themes, we had discussions around what that should look like. So having an understanding of kind of from the ground up where this resource has come from, someone hasn't just picked it from thin air. And then knowing what messages we're trying to convey and learning how to deliver that; I think would be quite helpful. But yeah, I'd really liked to see this kind of rolled out on a larger scale because I think that it could be quite helpful to a lot of people.*

5. Reflections on peer worker's role in the delivery of resources

When we designed this project, we conceptualised stand-alone resources that did not require specific input from peer workers. Peer workers were required to introduce the participants to the resources, explain their use, answer any questions and then give the resource to participants. When they next saw participants, peer workers asked some general questions (e.g., What stands out for you? How do the messages in the resource align with your own lived experience?). This was not recorded as data but designed to encourage participants to reflect and help peer workers to get a feel for how participants were responding to the resources.

The focus of the interviews was the resources themselves and people's experiences with them, not on how the peer worker delivered the resources. However, it was apparent from the data that peer workers played an important part in participants' experiences.

Things that appeared to facilitate a positive experience for participants or that participants thought peer workers could do to facilitate a more positive experience are described below. Numbers refer to participants only, though peer worker comments are included.

Present resources in the context of a relationship (n=10)

For several participants, their relationship with the peer worker was important to their agreeing to participate in the study and engage with the resources. 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 [peer worker] 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.

P30: Oh, just, I met [peer worker] and I got along well with him, so I thought, "Ah, you know, that'd be a good idea." I thought, "Why not?" You know?

Others also 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.

P01: She was very enthusiastic, so it really helped.

Peer workers themselves acknowledged the critical role that they played in encouraging participants to engage with resources. One peer worker particularly reflected on how peer worker engagement would be important in acute settings:

PW04: If you're unwell on the unit and there's something sitting around, unless you're really bored, [you're not going to read it]. But if you can bring it to their attention and say, "What do you think?"

A couple of participants 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.

As discussed above, a few participants found aspects of the resources uncomfortable or distressing. In such situations, it is helpful for peer workers to having an existing knowledge of participants and how best to support them. For instance, one peer worker described how she was vigilant in monitoring a participant in case he had a negative reaction to the podcast:

PW02: When he experienced symptoms of human voice, it kind of comes out of his mouth a little bit. And I was observing that was happening for him. While we were working together, he was also having quite intensive psychology sessions, or CBT for psychosis... I wanted to make sure he was okay and not too distressed or anything.

Because it is probably not possible to produce a helpful resource that can be guaranteed not to be triggering for anybody ever, having the peer worker available to debrief and assist in the unlikely event of such a reaction is also likely to be important.

Explain resources clearly and suggest ways to approach them (n=6)

For some, it was important that the peer worker explained the resources and what to do with them well.

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

Where a resource was in an unfamiliar format, participants sometimes found it confusing. P06 suggested more written instruction on the resource, however for others who prefer to minimise reading, additional instruction and explanation from a peer worker may be an additional option.

P06: The personal medicine one, the format of it, I couldn't really relate to it. How it was laid out. I didn't really understand how the days align with the different questions and things like that. It was more confusing for me on that.

As previously discussed, the content of some resources were unfamiliar and required more explanation before participants were inclined to engage with it. This was most evident with the personal medicine resource where, as noted above, peer workers' explanations of what personal medicine was, and its relevance to the participant was paramount to them engaging with the resource.

Go through the resources with the client (n=11)

It was apparent that, for some participants, they 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, while others felt they needed more support to understand the resources or to figure out how to get the most out of them.

P18: I guess that the ones that we did look at was when [peer worker] and I looked at it together... the ones I didn't get to look at was the ones that … I have to really look at it myself. So I think if, I reckon what we should change, which is slightly, it's just that maybe you should get, if you're getting someone to try and look at those activities and those things, maybe look at them together.

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

P13: [Re personal medicine pack] I just found that some of it I didn't understand properly… it would be a little bit hard. [Interviewer: Do you think maybe that one would need extra support to understand and to get the best value out of it?] Yes… Try and break it down.

P07: The way we did it, [peer worker] gave them to me and I just put them on a table and we didn't stick them up anywhere. It just felt like reading a bunch of paragraphs.

Peer workers agreed that some participants may have benefited 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.

Similarly, one peer worker remarked that some participants may be unlikely to go through resources independently without additional support from their peer worker. When asked what advice she would give to other peer workers presenting resources to participants, she said:

PW03: Probably do it with them. So with the physical healthcare cards, have a meeting, like one of your regular meetings, and just block out like part of the time and do the game, so they're learning. And the same with the personal medicine, like do it with them. Because I think some of them could be interactive, but there's a lot of loneliness in community so they might just kind of like look at it and be like, 'Oh, okay, I'll do that later' or whatever.

In some cases, there was a mismatch between client and format, for example, where a client had difficulty reading and had chosen a written resource. Literacy could be addressed within resource format, but some mismatch can also be compensated for by additional help from the peer worker.

P05: When I went onto the podcast [peer worker] had to help me… I had to clarify some things with [peer worker] because I have learning difficulties.

PW04: They might want to read that but they're a little bit ashamed that it's a bit maybe harder or it could just be their medication at the moment is affecting them in a way, that I can then say, "Yeah. We can go through it together."

While this was not the case for everyone, spending more time with the peer worker going through each resource in detail would clearly make the resources more accessible for some clients.

On the other hand, many people also appreciated being able to take the resources home with them (n=8). This enabled them to interact with the resources how and when it suited them, and to keep them to use again later.

P04: I liked the idea that you could keep these things… I liked that idea because it's something that obviously you can use later on. I think those little cards, I'll definitely use it again.

P08: You gave me the resources and I could take them home and whatever and I wasn't overloaded with information each session, it was manageable. There was no triggering.

P14: They were also a good present from [peer worker]. Yeah, they were just a good little guide to sort of be my best friend for the day, you know?

P26: I was walking [when I listened to the podcast]… I just think that maybe listening to it at your desk or something wouldn't have been as engaging.

The What Helps resource had two different formats. The intended primary format was a series of pictures to be presented in the form of an art gallery, with portraits displayed around a room at the mental health centre. The alternative, for people who did not come into the centre, was a set of laminated cards containing the same pictures and information. Two peer workers believed that this resource would be best used in gallery format, however, several of those who saw the pictures (accompanied by the peer worker) stated that they would have preferred the take-home resource.

P03: I tend to like to mull things over, so probably the take home thing is a good thing.

P02: The cards would have been mad. Yeah. I mean, whether or not people want to take it home and do what they want to do with it, that's up to them, but I think for someone like me that really takes this on board, I think that'll be an awesome idea.

As noted above, the resources were designed to stand alone, without much explanation or support required. However, a couple of participants suggested that resources could be more activity and interaction based (n=4). Additional creativity in terms of translation format may well be possible in future if resources were designed to include (trained) peer workers taking a more active part in the delivery of information. Peer workers going through resources with participants would also mean

that if participants encounter something that they find uncomfortable or distressing, they can be supported on the spot.

Encourage reflection (n=10)

Participants tended to find it helpful to reflect on the resources and their connection with participants' own lived experience. Peer workers have the capacity to encourage this kind of reflection.

> *P02: [Peer worker] said, "I've got a podcast I'd like you to listen to," and she didn't say whether I could take notes or not. So that's why I sat there with a piece of paper and I was taking notes. [Interviewer: You found that was helpful for you?] Yeah, yeah, yeah, yeah. Just writing down what I could understand and get out of it. Yeah. So I think if [peer worker] was to say that everyone take notes it'll be a bit different, rather than trying to recall the information afterwards off the top of your head.*

> *P33: Maybe a little bit of preparation. Not too much, but a week ahead or something, just say the topics you've chosen, um, think about, a little bit of brainstorming I guess... I guess it's a little bit of your own, your own awakening and thinking about how to go on about when you do read it.*

One peer described the resources as vehicles that created opportunities to have discussions about a range of topics related to an individual's recovery journey and encouraged them to reflect on their own lived experience.

> *PW04: Now, anything that we do as peers is, and this is just my take on it, this is how I love to see my role, is the fact that it's not about the game. It's about an opportunity to have discussions. . . A lot of my interactions [with consumers] are just an opportunity to have a discussion. So the whole [hope] box for me was fantastic because it brought up lots of opportunities because that's the theme of this is hope.*

Peer workers were instructed to ask participants a couple of questions after each resource to encourage them to reflect and to give the peer worker an idea of their responses. While most did this in conversation, one of the peer workers gave her participants written questions so that they could write responses if they wished. Some participants found this useful to help them reflect.

> *P07: How does it fit with your lived experience, or did you learn anything new? I think there were only two questions, and I know [peer worker] did say to me,*

"You don't have to do it." She said it, but I really wanted to … I think that 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.

P01: I enjoyed doing the questions, and the analysing, and afterwards then putting my own story and comparing it to what I heard… I used my own lived experience to answer the questions that were asked afterwards. And I really enjoyed answering the questions at the end of each resource… and using my lived experience to compare it to all the other people that were in the resources.

One participant suggested that it would be of benefit to use a combination of resources to develop a personal plan of things to do. This follow-up and encouraging of enacting of learning could be another role for peer workers.

Take enough time (n=8)

Some participants felt that the time taken by the peer worker to explain and discuss the resource and the time between giving different resources 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: Concentration is a bit hard. It might not click. And then I read it again. So she 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, even though I said it's not enough depth, a little bit bombarded with different things.

P02: On a weekly basis. Yeah, I think that was good. So a time to reflect and think about what you're going to say next, and stuff.

P01: Maybe space them out. A resource could be what the quote says on one ball, and then the next week do the other one.

Busy participants sometimes found it difficult to find time to look closely at the resources and appreciated the flexibility of peer workers in enabling meetings around their schedules.

Try it in a group format (n=6)

While our peer workers were free to introduce the resources to more than one participant at once, in most cases this was done individually to fit people's time schedules. However, a number of participants and peer workers 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 benefited 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.

P22: Maybe you do it as a group. So, say the whole group goes and together and does something out of sitting and talking about this.

PW01: It was really good in the small group setting because we did learn a lot from a discussion. So people were able to bounce their ideas off each other, which was really good.

Individualising presentation

The comments above, along with the prolific data that indicates that different people needed to engage with the resources in different ways, suggest the importance of the peer worker in individualising their presentation so that each client can get the most out of it. While it may be possible to present information in alternative formats, this can never address the multitudes of preferences and learning styles of potential clients. P27 put it best:

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 individualize it so much in the format. I think you could get away with it, but I think training is required with these resources to be able to distribute them effectively for the best possible outcome.

Peer workers recognised that it required strong professional skills to individualise the presentation of resources.

PW04: It's not about the resources. 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... But just watching their response and not assuming, because something may have changed since the last time that we had, 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 peer worker noted that she had further developed this skill through the progress of the research study:

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.*

6. Reflections on the research context

Participants

Participants engaged with the resources, not simply as part of their everyday interactions with their peer workers, but in the context of a research project. The participants generally reported a positive experience of being in the research project. However, their comments were not just in relation to interacting with the resources. Participants appreciated being asked for their opinions about the resources and valued being able to contribute to a piece of research that they saw as valuable. Some reported being pleased to know that people with lived experience were doing research and found this hope inspiring.

P25: *So I really valued being able to, like, participate and do something worthwhile.*

P15: *I felt stronger because of it, like there's people that care and people that are making an effort to try and help and improve the lives of others.*

P08: *I felt positive about the fact that someone gave a shit enough to ask someone with lived experience what they thought… I felt good feeling at the end.*

A lot of participants (n=12) reported that they had agreed to participate in the project because of a desire to make a positive contribution to their community and to the mental health system.

P09: *I actually wanted to contribute, I just felt that I should contribute.*

P26: *Currently, an important personal medicine of mine is this research project: knowing I'm contributing to a wider world of knowledge is very important to me, and even though I am struggling to balance domestic tasks against each other, my mind can still soar and have something worth saying.*

Others (n=10) were interested in research and wanted to find out more about research in general and lived experience research in particular.

> *P08: The resources were, they're primarily developed by people with lived experience. I think that attracted me to it and just generally trying to spread my wings a bit in the mental health world.*

> *P18: I just wanted to know what it'd be like to go through this study. So it just sounded really interesting to me.*

Peer workers echoed similar observations about the benefits derived by participants. Peer workers believed that contributing to this research provided participants with an opportunity to be a part of something greater, be recognised for their expertise as someone with lived experience, and reinforced participants' sense of self-worth, value, and accomplishment. The fact that participants received financial reimbursement (in the form of gift vouchers) for their time was also seen as appropriate and highly meaningful by peer workers.

> *PW03: We're dealing with people that have just been through a life crisis that are in the hospital and have to get out and live in the community again. They may go in, may go out, may go in, may go out. But these are people that can be highly intelligent and researchers or have amazing jobs. They're just in a rut. And I think what's good about the project is, it's a research project. So even me, I was like, research? That sounds amazing. So when these people are given an opportunity to contribute to a research project, it probably makes them feel like, "Oh, yeah. I am smart. I can do this. I can contribute." And within the whole project it might give them a little bit of self-esteem to be able to actually go back into the community and be what they were before because they're just in a rut at the moment.*

The participants' comments about being part of the research project and their initial motivations for being involved with the research were gratifying, but also suggest a potential confounder in terms of the study findings. It was impossible to disentangle participants' experiences of the resources themselves from their experiences of being a participant whose opinions and experiences were being sought for a research study which ultimately aimed to help improve the lives of other people who experience mental health challenges.

A number of participants and each of the peer workers expressed the hope that the STELLER project would continue into the future.

P04: I think [peer worker] was really good. I hope it keeps going.

P14: I just hope something, you guys are able to elaborate on, give more of it, the research, to people. I think it's really good, because it could save someone's life. So, I just think, just keep going with it.

Conclusions

- Lived experience research resources have the potential to be helpful for people with lived experience of mental health issues. The research suggests the utility of making lived experience research available to a wider cohort of service users and peer workers.
- Different people, at different times in their lives will identify with different content, different levels of detail and different formats. It may be appropriate to provide similar content in different levels of detail and formats.
- The way the resources are presented and delivered is important. While some people will engage with the resources with little input, others may not. Peer workers are in a good position to deliver these resources and to be flexible so that the way the resources are delivered is individualised. This will minimise and manage any risk of negative impacts.
- Lived experience research resources are regarded as relevant and helpful in the peer work role and usable within current practice.
- While peer workers believed that many of the resources would be useful in acute care or rehabilitation settings as well as in the community, and the response from the two participants not living in the community supported this, it needs to be examined in future research.
- Further research is needed to assess the usefulness of lived experience research resources in the day to day practice of peer workers and the impact of these resources on a larger number of diverse participants. Because it was difficult to tease out the impact of the resources from the impact of being in the research project, the resources need to be evaluated outside of a research project context. This is, of course, difficult, but may be achieved by conducting research with peer workers – for example, training a larger number of peer workers and then asking them about how they used the resources and how their clients responded.

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Research dissemination

The research has been disseminated in several conference presentations and two journal articles are currently in preparation. Presentations include:

Honey, A. (2019). *STELLER: Supporting the translation into everyday life of lived-experience research.* Invited paper presented at the One Door Annual Symposium, 18 May, UTS Aerial Function Centre, Sydney.

Honey, A., Glover, H., Boydell, K., Gill, K., Tooth, B., Hines, M., Coniglio, F., Dunn, & Scanlan, J. (2019). Making lived experience research accessible: Co-creating and testing resources based on evidence. Paper presented at the Society for Mental Health Research (SMHR) Conference, November 29, RACV City Club, Melbourne. Awarded Best Research Involving Consumers.

Tooth, B., Gill, K., Honey, A., Boydell, K, Coniglio, F., Dunn, & Scanlan, J. (2019). The STELLER Study: Supporting the translation into everyday life of lived experience research. Paper presented at The Mental Health Service Conference (TheMHS), August 29, Brisbane.

Honey, A., Glover, H., Gill, K., Coniglio, F., Boydell, K.M. & Tooth, B. (2019). STELLER: Supporting the translation into everyday life of lived experience research. Paper presented at the 2019 International Symposium on Public Involvement in Health Research, February 21, University of Sydney, Lidcombe.

Honey, A., Glover, H., Gill, K., Coniglio, F., Boydell, K.M. & Tooth, B. (2018). The STELLER Study: Exploring experiential wisdom in mental health. Paper presented at the Society for Mental Health Research Annual Conference, November 30, Sofitel, Noosa.

Honey, A., Glover, H., Gill, K., Coniglio, F., Boydell, K.M. & Tooth, B. (2018). STELLER: Supporting the translation into everyday life of lived experience research. Paper presented at the 2018 Occupational Therapy Research Showcase, October 17, University of Sydney, Lidcombe.

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