Title:

How did I not see that? Perspectives of non-consumer mental health researchers on the benefits of collaborative research with consumers.

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TITLE

How did I not see that? Perspectives of non-consumer mental health researchers on the benefits of collaborative research with consumers.

ABSTRACT

Co-production of research between consumers of mental health services and other non-consumer mental health researchers is increasing. There is some research available describing consumer perspectives of this experience. However there is a notable lack of research on other (non-consumer) researcher experiences of and views about consumer involvement in co-produced research. A qualitative exploratory study was undertaken to examine perspectives of other mental health researchers about consumer involvement in research. In-depth individual interviews were undertaken with 11 other mental health researchers in Australia and New Zealand. Interview transcripts were analysed to identify major themes. There were three interacting themes: the salience of experiential difference, expanded learning and enhanced research. The dynamic between different perspectives and learning had the effect of enhancing research across the spectrum of study phases and in ensuring research was of value to different groups. The findings emphasise the important contribution consumer researchers can make to mental health research by bringing their unique

perspective and enhancing an environment of mutual learning. Findings also point to the need for foregrounding the numerous benefits of joint research between consumer and other researchers to enhance and improve clinical practice and the development of policy.

KEY WORDS

benefits,
consumer participation,
mental health,
co-production,
research,

INTRODUCTION

There is increasing emphasis in policy on the need for consumers to become active contributors to mental health research (Mental Health Commission of New South Wales 2017), complemented by more general directives on consumer and public participation in health research activities (National Health and Medical Research Council 2016; INVOLVE 2017). Consumer experiences and views are recognised as providing valuable expertise and insight (Scholz *et al.* 2017b), with clear benefits to research practice. Consumer input ensures the foci, purposes, methods and outcomes of research are connected with the diverse needs, values and perspectives of consumers (Graham *et al.* 2014; Trivedi & Wykes 2002). However, uptake of consumer research involvement by non-consumer researchers (herein referred to as 'other' researchers, particularly co-production (equal partnering of consumer and non-consumer researchers in research), is thus far ad hoc, sporadic, and often tokenistic (Staley *et al.* 2013; Wallcraft *et al.*

2009; Coney 2004), with limited examples in relevant peer-reviewed literature.

In this paper we use the term 'other' to refer to mental health researchers who do not identify as consumers of mental health services. More specifically for the purposes of this paper, 'other' researchers have professional disciplinary backgrounds and are employed on this basis, generally in universities, to conduct mental health research. We have specifically chosen this term to emphasise the expertise of consumer researchers.

Background

Consumers, carers, mental health professional groups and policy-makers all support the importance of consumer involvement in research (Mjosund *et al.* 2017), paralleling similar views about the importance of consumer involvement in mental health service decision-making and delivery (Law & Saunders 2016). The grounds for consumer participation in research are based on human rights, democratic and participative citizenship, and diversifying research to arrive at more complete and valid knowledge (Phillips 2006; Beebeejaun *et al.* 2015; de Freitas 2017). Consumer research also generates distinctive knowledge and concepts based on analyses of experience and encounters with service systems (Russo & Beresford 2015), of benefit to mental health research more broadly.

These rationales intersect closely with a complex history of multiple movements seeking to ensure the limited perspective of some mental health research, and adverse effects of this, are not repeated, continued or perpetuated (Schneider 2012; Rose 2017; Jones *et al.* 2014). Broadly, meaningful involvement of consumers in research is considered crucial to enhancing the development of recovery-focused and consumer-centred mental health services (Schneider 2012).

Several benefits of mental health consumer involvement in research have been reported, from shaping the prioritisation of research agendas to refining discrete stages of research projects (Wallcraft *et al.* 2009; Ostrow *et al.* 2017; Michalak *et al.* 2016). Consumers may be more willing to participate in research if they know a peer is part of the research team and feel more comfortable with providing frank responses during interviews when the interviewer is a peer, leading to greater validity of data (Rose *et al.* 2008; Callard *et al.* 2012). Consumers who do not have a background in research, if given opportunities for quality training in research skills, engage effectively in formal analysis with other mental health researchers (Sweeney *et al.* 2013). Consumer input in the research process is likely to maximise the relevancy and import of research to the needs of consumers (INVOLVE 2012).

A major barrier to expanded and deepened consumer involvement in mental health research is negative attitudes and systemic prejudice towards consumers (Dabby *et al.* 2015). Resistance to including consumers in research may be due to the view, implicit or explicit, that the knowledge of conventional researchers and professionals should be privileged over the expertise of experience (Scholz *et al.* 2017a). Further, health professionals may equate people with their diagnosis or symptoms (Kopera *et al.* 2015), failing to appreciate that people are capable and keen to engage in research and contribute substantially to it (Faulkner 2017). In addition, the philosophy of co-production challenges familiar conventional power relations, presenting a challenging paradigm for many other mental health professionals and researchers (Happell & Scholz in press). The literature also points to further barriers to co-production, including the protracted length of time required to complete projects in partnership, and the lack of support by research organisations in terms of funding and incentives (Lawn 2016; Staley *et al.* 2013).

To inform decisions and strategies designed to increase and strengthen co-produced mental health research, it is important to gain an understanding of the actual views and experiences of stakeholders in such research collaborations. While there is some literature on consumer perspectives relating to research (Case *et al.* 2014; Patterson *et al.* 2014), there is considerably less available describing the experiences of other mental health researchers. Research internationally has typically focused on other researchers qualitative reflections on a single research project and/or group (Case *et al.* 2014; Schneider 2012), sometimes in conjunction with guidelines and process models on how to undertake collaborative research (e.g. Fothergill *et al.* 2012). Other researcher views and experiences have also been sought through surveys (Lawn 2016; Staley *et al.* 2013). To build on this important literature, there is a great need for full qualitative research studies into the views of other researchers on the benefits of coproduced research and what dynamics in the research process contribute to those benefits. This research gap is particularly salient in Australia and New Zealand, where no in-depth study of this issue has been published.

Aim

The aim of this study is to enhance knowledge and understanding of the benefits that other mental health researchers have identified from collaborating with consumers in research activities in Australia and New Zealand.

METHODS

Design

As there is limited published literature articulating the experiences and opinions of other mental health researchers' views on consumer involvement

in research, we conducted a qualitative, exploratory study (Stebbins 2001) of the views of other mental health researchers within Australia and New Zealand experienced in conducting research with consumer researchers.

Setting and participants

Organisations and specific other researchers known to be involved in mental health research involving collaboration with consumers were invited to participate. Participants were other mental health researchers in Australia and New Zealand, primarily affiliated with universities. The disciplinary backgrounds included psychiatry, psychology, mental health nursing and social work. The sample ranged from mental health researchers in the early stage of their research careers to those in senior positions (e.g. Professors, Department Heads, Directors). A total of 11 other researchers participated in an individual interview.

Procedure

Potential participants were identified through the professional social network of the research team as well as relevant mental health research institutes, and sent an invitation with a background to the research project.

Two experienced other (non-consumer) mental health researchers conducted the interviews. Both had extensive experience in conducting qualitative research, especially in the area of health services and health professional education. They did not identify as consumers, although both have considerable expertise in working with consumers as researchers. The interviews took place in June of 2017. Semi-structured, one-to-one interviews were conducted. Interview questions broadly sought information about what experiences other researchers have had researching with consumer

researchers, what led to such collaborations, the benefits and limitations, and views about how consumer involvement in research may be further enhanced. The current analysis focuses on the responses to the following question: What do you see as the main benefits/ strengths/ advantages to working with consumers in research?

Interviews were between 33 to 75 minutes, with a median length of 48 minutes. All interviews were audio recorded. Audio recordings were transcribed by an external transcription service.

Ethics

This study was reviewed and approved by the University Committee for Ethics in Human Research [name omitted to facilitate anonymous review].

Interested parties were provided with an overview of the research, furnished with a copy of the Plain Language Statement and consent form. Interview times were arranged with those who agreed to be involved, and participants were requested to return the consent form prior to interview.

Data analysis

The thematic approach outlined by Braun and Clark (2006) was adopted to guide analysis of the transcript data. This framework is designed to identify the main themes. The transcripts were repeatedly read, closely analysed for patterns across the data, and coded with the purpose of identifying and classifying themes and their inter-connection.

The data analysis process was undertaken independently by two members of the team. The findings were compared and adjustments made

until consensus reached. The analysis was then cross-examined by the full team, including consumer researchers.

RESULTS

Three main themes were identified through the analysis: (1) salience of experiential difference, (2) expanded learning, and (3) enhanced research. Figure 1 presents the thematic structure. Salience of difference and expanded learning were 'higher order' processes based on relationship building between consumers and non-consumers. Salience and expanded learning led to enhanced research, which had subthemes linked to aspects of research projects such as recruitment and data analysis.

Insert figure 1 here

Salience of experiential difference

Several other researchers emphasised the *salience* of the difference of perspective provided by consumer partners. Even participants who had experienced mental health difficulties themselves suggested that no level of awareness, or mindfulness, or formally learned knowledge in higher education or clinical experience could replace the direct lived experience particularly of compulsory mental health service use (e.g. seclusion, non-voluntary medication). For instance, one researcher stated:

"...we may all of us have mental health issues from time to time...and some of them will be quite serious, and debilitating, and I don't think that's the same as having your rights stripped...I've never been forced to have any kind of treatment, or anything against my will, so I think, it's just absolutely no comparison in itself."

The salience of difference in perspective and insight of consumers was observed to make positive impacts on various aspects of research, whether tied to a particular stage of a research study, or more broadly in terms of the underlying assumptions of the research and how resulting knowledge is relevant to end users. One participant argued that interests and sensitivities of other researchers could not replace abilities that come out of the direct experiences of consumers, applied in the research process:

"...I collected a whole heap of data...coding it with a few colleagues, one of whom is a consumer researcher... there was certain aspects that I wouldn't have been able to pick up in their coding of the data...and this is even coming from somebody who, I'm really interested in this area... I might have that mindset, I still haven't experienced that...that's brilliant, and was...almost a feeling of why did I not see that...now that you've pointed it out to me, I just think that's so important and it became the central part of the analysis..."

Expanded learning

Mutual learning during research was raised in most of the interviews. This had positive implications, not just for immediate research studies and their specific outcomes, but also for the growth of consumer and non-consumer researchers. Learning expanded in the sense of realisation of other viewpoints. Consumers became mentors and gained new or strengthened research skills through co-productive activities. Important to several researchers was how consumers facilitated their learning in terms of going beyond a singular viewpoint and looking holistically across viewpoints, for instance:

"...working with somebody as a service user in research means that I'm the learner; so I learn from that, because I learn about what my own

biases and assumptions might be...it also, yeah, makes sure that the research is considering multiple perspectives and joining those perspectives together rather than just necessarily framing things up in a particular way."

Dialogue with mental health consumers therefore provided a new vantage point that stimulated learning. A participant reflected on working with consumers in research activities, as well as in teaching and conferences, and described their learning process:

"...they'll always give you something more than what you started with. So, there's a lot of learning...you do all your background reading ... and then suddenly you've got some new perspectives that you hadn't thought of...sometimes there'll be a statement made that makes me think, okay, so my view of that needs to be reviewed and revised. It might be about language, often about language. Or it might be about you know a perspective on something...And I think, okay, so that's learning for me because that's not my experience."

For most participants, realisation of how consumers facilitate learning was noticed after first meeting as teaching colleagues. Evaluative research of the education experience itself would be the conduit into consumer and other researcher collaborations:

"So I was employed in the department, [name] works in ... My teaching role...and [name] had started doing some work redeveloping that to introduce formal recovery concepts."

Learning was also expansive in the sense of being multidirectional. . For instance, in one research study, consumer researchers adopted mentoring roles, especially for junior researchers on the team:

"I think it's often had a really good effect on other researchers in the project who haven't – who don't necessarily have a lived experience, but there's a sort of mutual mentoring...[for] the field work in that project, she [young consumer researcher] learned a lot from having consumer researchers working alongside her. And they learned a lot from her. So there was that really great mutual exchange. And I keep up with her, and I see her having benefited in the long term around that."

Enhanced research

Participants suggested that diversity of views within a research group created significant improvement to the research. The unique perspective provided by consumers enhanced the breadth and quality of all aspects of the research:

"...unless you've got a good team to have multiple lenses on the issue, working away on it, it's just a no-brainer that you just get different perspectives, different insights into what's going on, different interpretation of the data, different discussions around the issues involved, and what you end up coming up with is a far more integrated and probably valuable output in relation to what you're producing, and it['s a] good process, rigorous process, but an enjoyable process as well."

Increased awareness

Engagement with consumer researchers brought about an increase in awareness in other researchers. The heightened awareness was driven by

hearing from consumer perspectives, rather than clinical academic literature or an academic worldview in general:

"... for me it's kind of about that thing of being made aware of issues and of the significance of issues that I wouldn't otherwise be aware of, or not as keenly [and]... that you don't get from your own reading and writing and academic discussions, that kind of thing. So, there's a whole area of understanding that you're just not exposed to until you talk to service users."

For one mental health researcher, the focal point of more awareness was to do with questioning, revisiting and revising assumptions on a range of fundamental matters. Through their particular experiences, consumer researchers contribute to results in research methods and interpretations of data that would not take place if it were solely health professionals undertaking the research:

"...one of the real advantages of partnering with consumers in terms of research is that they'll come up with questions that you wouldn't otherwise come up with, whether they would be research questions, whether that be specific interview questions, or specific bits of data that you'd want to get from a study.... because they have lived through those experiences and have had experiences of their own, they actually realise things that are important [e.g. what a desirable outcome would be] or assumptions that are just completely unfounded and things that are more valuable to focus on because they reflect more accurately what those experiences are without the assumptions of health professionals."

Ethical standards

Critical thinking by consumers was a valuable contribution to ethics review processes. One participant reported that an ethics committee, which oversaw many research projects, found consumer review of applications picked up numerous ethical issues that would otherwise be overlooked. In some cases, proposed studies were not approved and consumer input improved communication of the ethical grounds for why the research could not proceed:

“And a lot of people who have applied to the research [ ] committee have found the kind of feedback they’ve got very helpful...and sometimes knocking them back. But then being able to really articulate why we’re not proceeding with the research.”

More effective and appropriate recruitment and data collection methods

Participants recounted how discussing research plans with consumers made them reconsider their original design. For instance, one researcher in a co-produced project about a confronting topic explained how dialogue with consumers shaped decision-making on research methods. The consumer input led the researchers to discard a recruitment method that was deemed ineffective:

“...it became clear through what people were telling us...that the usual methods of making a time and going out and visiting someone and having a yarn with them, which would be more the kind of research I do, wouldn’t work. So even though I think that’s relatively informal and it’s more relational interviewing...it was really clear from their perspective that people probably won’t even be there but what’s in it for them. So through that we then thought about what would make this potentially worthwhile for people to participate in without it being coercive from an ethics point of view, and so we came up with

ideas about [visual-oriented communication]. So we really had to step outside it and then start to consult people who were researching in those ways."

Another participant reflected on two projects about young people diagnosed with mental illness. Detailed advice from young mental health consumers was valuable in refining the recruitment and data collection techniques :

"... the old chooks who're running the project, just advising them about using language that might be more accessible...improving the interview guide...not changing the questions themselves, but just how you might phrase things, and the kinds of prompts you might use.... They had a lot to say about that."

This participant added that consumer involvement increased retention of participants. Research participants had a more positive experience by virtue of the presence of a consumer researcher and "engagement" taking place, and were thus more likely to continue participating. Participant retention was considered a strength by funding bodies particularly for longitudinal studies that typically find attrition a challenge:

"...it was easy to make it convincing, because it's National Health and Medical Research Council (NHMRC) funded. So you really had to use a lot of evidence in your project proposal around everything that you were going to do, and it was really easy to find the evidence that, if we had a consumer researcher, our potential for retention of participants in a longitudinal study was going to be enhanced."

Deepened data analysis

In reflecting on their experiences, participants described how there was often similarities with consumer researchers in analysing data however non-consumer academics may be disconnected from the particular *import* the phenomena, topic or issue has for consumers, and therefore overlook important information if consumers are not included as part of the team:

"We're looking at some [source] data and the service user who's been involved in that with us made ... commentary on what she was seeing in the data which was similar to what the academics was seeing, but was kind of articulated in a more ... forceful and committed way ... You know, so you were getting that kind of sense of the significance of things."

Ensuring relevancy of overall research

Consumers also contributed to enhancement of research in terms of its relevance, value, and acceptability to consumers and other stakeholders. This could not be readily achieved by team comprising solely of other researchers. As one participant stated:

...you end up with a product that has got far more application, and far more value across the sector to multiple stakeholders really."

Similarly:

"I'm particularly interested...in whether the work we do, the service we provide, the models of care that exist, whether those work. A key way of answering that is to ask the people are being given those services...What is their appraisal of it? Often the best investigator to have to assist you with that, or to do that, or to even potentially lead that, would be somebody who's aligned with that person's perspective."

And another participant saw diversity of experiences in the research team as integral to the big picture of how research makes a difference. Without this diversity the relevance of the research would potentially be compromised and the integrity of the research subject to question and critic:

“We should be looking for all sorts of people with all sorts of experiences who are able to bring those experiences to their academic world in order to provide a rich and varied source of research for us to develop clinical practice on. And ultimately, you know, the question to ask is what's the point of what you're doing? And essentially the answer for all of the research I do is to improve the capacity of people to live better lives.”

DISCUSSION

Research participants were overwhelmingly positive about collaborating with consumer researchers, each highlighting several benefits and emphasising the overall value of including consumers as researchers. A strength of the current study was that it centred on the stories and views of other researchers who have first-hand experience of working with consumer researchers, in some cases, for multiple research projects. Their views affirm what has been found in other studies on improvements to discrete aspects of research such as higher reflexive awareness (Veseth *et al.* 2017), better framing of questions for research participants (Case *et al.* 2014), ensuring ethics in research, new angles in data analysis (Mjosund *et al.* 2017), and upscaled relevancy to end users (Wallcraft *et al.* 2009; Phillips 2006; Clark *et al.* 2004; Michalak *et al.* 2016; Faulkner 2017). Collaborative research between people with and without lived experience of mental illness has been found to facilitate learning for both consumer and non-consumer researchers (Barber *et al.* 2011). The findings of this study were broadly consistent with this literature.

Earlier research has reported learning as a key process in shared research between consumers and other mental health researchers (Ochocka *et al.* 2002; Barber *et al.* 2011). The current findings stress the relational dimension to learning, and that it was expansive by way of diverse perspectives and its multidirectional nature. Participants often contrasted what they learn via academic activities, such as reading the literature, with what they learned from conversations with consumer research partners. Other researchers often described the interpersonal collaboration as irreplaceable in gaining understanding of the crux of matters from a consumer's lived experience viewpoint.

Researchers who rely on academic or clinical knowledge alone cannot really "know it all". The insight, knowledge and expertise derived from saliently different lived experience is one of the capacities that consumers contribute to research. As for consumers, participants believed learning might be in acquiring or strengthening research skills building confidence in doing research, and mentoring less experienced researchers. This finding is consistent with consumer researcher own views of their research journeys (e.g. Bryant *et al.* 2012).

As depicted in Figure 1, the expanded learning enabled through collaborative research benefiting from saliently different experiences had a positive bearing on several discrete features of research projects (e.g. ethics review, data analysis). Overall, while it is claimed that consumer research provides multiple benefits to mental health research (e.g. Ennis & Wykes 2013), the current findings emphasise how expanded learning depends on the conjoining of quite different viewpoints and experiences, a process that is perhaps most likely through co-productive research.

The array of positive contributions of consumer researchers is important to emphasise when addressing the prevailing marginalisation of consumer

participation in research. A significant factor holding back the enhanced involvement of consumers in research are negative or ambivalent attitudes of other mental health researchers (Wallcraft *et al.* 2009; Rose 2015). Attitudes are shaped by biomedical and clinical perspectives and their focus of symptoms, where a deficit framing is commonly held (Kopera *et al.* 2015). This may translate into views that people experiencing (and/or recovered/recovering from) mental illness do not have the wherewithal to engage in research and have little to contribute meaningfully to the research process. Interviewees expressly provided many examples that counter such beliefs.

The benefits pointed out in this study, as well as in the broader literature (Clark *et al.* 2004; Schneider 2012; Ennis & Wykes 2013), could be galvanised by all stakeholders so that opportunities to gain collectively from the advantages of joint research, such as co-production, are not missed. Partnerships that highlight the strengths of consumer research should be prioritised to further explore avenues for increasing willingness, readiness and subsequent valuing of consumer involvement in research by other mental health researchers.

Research limitations

The sample was small and selected by convenience for having previous experience working collaboratively with consumer researchers. Generalization to the broader population of other mental health researchers, most of whom have not experienced working with consumer researchers, cannot be assumed, even within the same geographic region. In addition, the high diversity of mental health topics and issues of research projects that were discussed (e.g. recovery, evaluating courses, mental health of young people) meant there was insufficient data to systematically compare stated benefits by topic.

DIRECTIONS FOR FUTURE RESEARCH

The findings suggest significant benefits result from consumers becoming an integral part of research teams, highlighting the substantive potential of consumers becoming recognised stakeholders in mental health research, and thereby contributing to the realisation of policy goals. However, in light of the negative attitudes of health professionals towards consumer participation, considerable work is required before consumers are recognised as legitimate members of research teams. A national survey of other mental health researchers, could provide useful baseline information regarding their views and opinions about the desirability, benefits of, and barriers to consumers becoming active members of mental health research teams. This information could subsequently be utilised to consider strategies to influence the development of more inclusive attitudes.

Furthermore, while literature supporting the benefits of consumer involvement in research is emerging, research specifically focusing on how this involvement translates into improved research outcomes is essential and should be the focus of future research. Building a tailored evaluative component using qualitative and quantitative methods to measure this impact would be advantageous in achieving this aim.

CONCLUSIONS

This paper highlights positive experiences of other mental health researchers in working collaboratively with consumers in research teams. Through their experiences they observed consumer researchers contributing significantly to enhancing research across the spectrum of research activities. These collaborations were identified as strengthening the quality and relevance of research with heightened learning for all, through the contribution of

significantly different experiential perspectives. It was evident that the lived experience consumers brought to the team provided insights and perspectives that could not otherwise have been derived and were therefore invaluable.

RELEVANCE FOR CLINICAL PRACTICE

Research is integral to mental health practice. The findings presented in this paper suggest that collaboration, in the view of other mental health researchers, enhances this domain of research. Through successive policy documents, consumers have been clearly identified as major stakeholders in all aspects of mental health services. It follows logically that consumers must have active involvement in all aspects of mental health research. This paper provides important insights based on the experiences and opinions of other mental health researchers. Collaborating with consumers in research has been identified as transformational in terms of research design, process and outcome. With that in mind partnerships of this kind should not be considered as a duty or policy directive, but as a way research can be transformed for the better.

Acknowledging the goal to increase consumer participation in all aspects of mental health services, including research, the findings presented herein provide a basis to influence other researchers who have not worked with consumers in this way. Firstly, the positives of this approach are highlighted; secondly endorsement by experienced other researchers that working with consumers is a valuable experience; and finally, examples provided would demonstrate specific aspects of the research project where consumers could participate, including research design, data collection and data analysis.

Figure 1. Themes and their inter-relationships.

**Salience of Experiential
Difference**

Expanded Learning

Enhanced Research

Increased awareness

Ethical rigour

More effective/appropriate
recruitment & data collection

Deeper data analysis

Ensuring relevancy

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