

Brenda Happell ORCID iD: 0000-0002-7293-6583

Brett Scholz ORCID iD: 0000-0003-2819-994X

ESTABLISHING AN EXPERT MENTAL HEALTH CONSUMER RESEARCH GROUP: PERSPECTIVES OF NON-CONSUMER RESEARCHERS

Authors:

The authors report no potential or actual conflicts of interest

Professor Brenda Happell

RN, RPN, BA (Hons), Dip Ed, B Ed, M Ed, PhD, FACMHN

School of Nursing and Midwifery, and

Hunter Medical Research Institute

University of Newcastle

University Drive

Callaghan

New South Wales, 2308

Australia

Brenda.happell@newcastle.edu.au

This is the author manuscript accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/ppc.12520](https://doi.org/10.1111/ppc.12520).

This article is protected by copyright. All rights reserved.

Orcid ID: 0000-0002-7293-6583

Dr Sarah Gordon,

PhD, MBHL, LLB, BSc

Senior Research Fellow/Clinical Lecturer - Service User Academic

Department of Psychological Medicine

School of Medicine and Health Sciences

University of Otago, Wellington

PO Box 7343

Wellington South

New Zealand

Email: sarah.e.gordon@otago.ac.nz

Ms Cath Roper

BA, Dip Ed., M Soc Hlth

Academic Specialist / Consumer Academic

Centre for Psychiatric Nursing

Department of Nursing

Faculty of Health Sciences

Alan Gilbert Building

Level 6/ 161 Barry Street,

The University of Melbourne,

Victoria 3010

Australia

T: +61 3 8344 9455

E: croper@unimelb.edu.au

Professor Pete Ellis

MA BM BCh, PhD, FRANZCP

Department of Psychological Medicine

School of Medicine and Health Sciences

University of Otago, Wellington

PO Box 7343

Wellington South

New Zealand

Email: pete.ellis@otago.ac.nz

Ms Shifra Waks

BA (Hons), MIHP, B Int and Global Stud

Consumer Research Assistant

School of Nursing and Midwifery

University of Newcastle

University Drive

Callaghan

New South Wales, 2308

Australia

Shifrawaks1@gmail.com

Ms Terri Warner

Master of Culture, Health and Medicine (Advanced)

ANU Medical School

College of Health and Medicine

The Australian National University,

Canberra, 2600

ACT

Australia

Chair

ACT Mental Health Consumer Network

Genge Street,

Canberra, 2600

Australia

Terri.warner@anu.edu.au

missterrigirl@gmail.com

Dr Brett Scholz

BHSci (Hons), PhD

Research Fellow

ANU Medical School,

College of Health and Medicine,
The Australian National University,
Canberra,
Australia
ACT

Brett.Scholz@anu.edu.au

Orcid ID: orcid.org/0000-0003-2819-994X

Dr Chris Platania-Phung

BA (Hons), PhD

Lecturer

Australian College of Applied Psychology

Lonsdale Street

Melbourne

Victoria, 3000

Conjoint Lecturer

School of Nursing and Midwifery

University of Newcastle

University Drive

Callaghan

New South Wales, 2308

Australia

0401 008 447

Chris.platania-phung@acap.edu.au

Orcid ID: 0000-0001-7529-2210

Acknowledgements

The authors acknowledge the funding provided by the University of Otago and the in kind support provided by SYNERGY: Nursing and Midwifery Research Centre, University of Canberra and ACT Health.

Our sincere thanks to the participants who generously gave of their time to describe their experiences and opinions.

ABSTRACT

Purpose:

To explore views and opinions of non-consumer researchers to the concept of an Expert Consumer Researcher Group.

Design and methods:

Qualitative exploratory involving individual interviews with non-consumer mental health researchers experienced in working

collaboratively with consumer researchers. Data were analysed thematically.

Findings:

Participants viewed the concept positively, albeit with caution. Perceived advantages included: Greater visibility and enhanced access; Collegiality; Sharing and creating expertise; Broader acceptance; Making it mandatory; and Structure and location. Participants were concerned about potential tokenism and implementation barriers.

Practice implications:

Consumer involvement enhances the quality and relevance of research, potentially impacting clinical practice.

KEYWORDS

Consumer
Expert researcher group
Lived Experience
Mental Health
Research

INTRODUCTION

Comprehensive and rigorous research and evaluation is integral to ensuring mental health services are high quality, reflect contemporary trends and policies and are responsive to consumer needs (Wainberg et al., 2017). There is increasingly an expectation that

research and evaluation activities are inclusive of major stakeholders, and particularly of end users (Banfield et al., 2018; Ghisoni et al., 2017; Paul & Holt, 2017).

Increasingly mental health policy in Australia and New Zealand (Commonwealth of Australia, 2017; Mental Health Commission, 2012) and other parts of the developed world (Health Services Executive, 2018; Mental Health Commission of Canada, 2016) has articulated clear expectations of consumer participation in mental health services. To fulfil policy expectations, health services need to demonstrate that consumers are active collaborators in all aspects from design to evaluation. Collaborating with consumers in mental health research is integral to accomplishing these aims. The identified close relationship between research and the quality of services signals a pressing need for consumers to be recognised as active and legitimate collaborators in mental health research (Lawn, 2016). Lived experience expertise has been identified as contributing uniquely and positively to care mental health practice and to improving health outcomes (Bennetts, Pinches, Paluch, & Fossey, 2013; Ehrlich, Slattery, Vilic, Chester, & Crompton, 2020; McDonagh, Cummins, & Gallagher, 2014; Oborn, Barrett, Gibson, & Gillard, 2019). Consumers must therefore be genuine collaborators in mental health research to ensure this expertise is further developed and effectively utilised.

The advantages of consumer contributions to research have been well established (Banfield et al., 2018; Daya, Hamilton, & Roper, 2019; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Platania-Phung, et al., 2018; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Platania-Phung, et al., 2018; Scammell, Heaslip, & Crowley, 2016). Despite this, there are major barriers to realising this potential (Daya et al., 2019; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Platania-Phung, et al., 2018). These include active resistance to consumer collaboration (Boaz, Biri, & McKeivitt, 2016; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Platania-Phung, et al., 2018; Lawn, 2016; Vollm, Foster, Bates, & Huband, 2017), power differentials (Bryant et al., 2012; Faulkner, 2017; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Scholz, et al., 2018), hierarchical and paternalistic attitudes (Happell, Gordon, et al., 2019; Landry, 2017; Patterson, Trite, & Weaver, 2014), and inflexible environments of tight deadlines and bureaucratic structures (Scholz et al., 2019). Consumer collaboration is frequently tokenistic, potentially creating the impression of being inclusive, while effectively silencing genuine consumer input (Domecq et al., 2014; Rose, Carr, & Beresford, 2018).

Consumer leadership has been identified and recommended as crucial for promoting the expertise and contribution of consumers in their own right (Happell, Gordon, et al., 2019; Stewart, Scholz, Gordon, & Happell, 2019), rather than as an adjunct to, or being dependent on, non-consumer colleagues (Russo, Beresford, & O'Hagan, 2018; Stewart

et al., 2019). Leadership from the perspective of consumers includes the facilitation of environments that build the capacity and expertise of the consumer workforce (Bennetts et al., 2013; Stewart et al., 2019). Similarly, fostering consumer leadership and the creation of environments to build the capacity and expertise of consumer researchers will be integral to the development of quality mental health research. For the purposes of this paper, the term consumer researchers refers to people who identify as having lived experience of mental health service use and have experience in, or a desire to undertake, mental health research. Consumer researchers range from the novice level to experienced researchers with doctoral qualifications and research track records.

To date, understanding of the need for, and investment in the strategic development of consumer leadership remains limited (Stewart et al., 2019). This lack of investment contributes to the identified gap in opportunities for the development of skills and expertise within the consumer workforce (Bennetts et al., 2013; Byrne, Stratford, & Davidson, 2018; Stewart, Watson, Montague, & Stevenson, 2008), and severely limits the overall growth of the consumer workforce. This provides a strong rationale for the need to invest in both consumer workforce development and organisational literacy around consumer roles (Byrne et al., 2018). Without this, consumer roles will lack 'real world impact' and run the risk of being co-opted into current medically-dominated

service delivery approaches. A clear understanding of consumer leadership within mental health organisations remains elusive and therefore poses a major barrier to consumer collaboration in research (Byrne et al., 2018; Scholz, Gordon, & Happell, 2017).

There is currently limited literature describing the development, implementation, benefits or limitations of consumer research roles (Gillard et al., 2010; Rose, 2017; Rose et al., 2018; Sangill, Buus, Hybholt, & Berring, 2019). There is a growing body of literature about roles for mental health consumers as educators and academics (which may include research components, although these are not delineated in published works) (Arblaster, Mackenzie, & Willis, 2015; Gordon, Ellis, Gallagher, & Purdie, 2014; Happell, Platania-Phung, et al., 2015; Happell, Platania-Phung, et al., 2019; Mahboub & Milbourn, 2015; McCann, Moxham, Usher, Crookes, & Farrell, 2009; Ridley, Martin, & Mahboub, 2017). Leadership roles in academia, where consumers are on staff, remain limited (Happell, Platania-Phung, et al., 2015), and other education roles are generally minimal, ad hoc, poorly funded and not well supported (Happell, Bennetts, Platania Phung, & Tohotoa, 2015; Happell, Platania-Phung, et al., 2015).

Given the very limited support for consumers to actively engage in leadership of mental health research, it is essential to harness and highlight the expertise that is currently available and to provide a mechanism for other researchers to engage with consumers. The

authors (including both consumer and other mental health researchers) have extensive experience in mental health research involving collaborative partnerships between consumer and non-consumer researchers. The barriers and limitations experienced as part of this work led to consideration of an Expert Consumer Researcher Group as a strategy to facilitate consumer leadership in mental health research through the formation of a collective structure. might well provide a potential mechanism to achieve this goal.

The aim of this study was to explore the views, opinions and perspectives of other mental health researchers regarding the idea of an expert consumer researcher group, and their ideas about how such a group might be structured and implemented

METHODS

Design

A qualitative, exploratory design (Hunter, McCallum, & Howes, 2018; Stebbins, 2001) was selected as it is particularly germane to examining areas with a limited literature base and the research team must be guided by participants with relevant expertise (Stebbins, 2001). This research was co-produced by consumer and non-consumer academics. The research team comprised equal numbers of consumers and non-consumers to facilitate equal contribution to all stages of the research process including design, implementation, design and analysis (Gillard, Simons, Turner, Lucock, & Edwards, 2012). Co-

production enhances the authenticity and applicability of research findings (Happell, Gordon, Bocking, Ellis, Roper, Liggins, Platania-Phung, et al., 2018; Roper, Grey, & Cadogan, 2018), and takes steps to redressing the historic power imbalance in mental health research.

Setting and participants

The research was conducted in Australia and New Zealand. Mental health researchers not operating from a lived experience perspective (herein referred to as 'other' researchers), with experience of collaborating with consumers in mental health research were targeted for recruitment. Purposive sampling techniques were used to recruit participants with expertise relevant to this topic (Patton, 2007). Contact was made through organisations and with other researchers known to members of the research team. Interview participants were also asked to identify colleagues that met our criteria, a process known as snowballing (Etikan & Bala, 2017). Eleven other researchers were recruited. The discipline backgrounds of participants included mental health nursing, psychiatry, psychology, and social work. Their levels of research experience varied substantially from early career researchers, to those with more established careers, occupying senior positions (e.g. Professors, Department Heads, Directors of Research Centres). Demographic data is presented in Table 1.

Procedure

Individual interviews were conducted by two experienced other mental health researchers. The interviewers had substantial expertise in qualitative research methods in general and mental health in particular. In-depth, semi-structured, individual interviews were conducted either in person or via Skype or telephone, according to locality. An interview guide was utilised to ensure that the interviews elicited participants' opinions and perspectives related to working collaboratively with consumer researchers. The guide was prepared collectively by the research team (comprising both consumer and other researchers), and included questions about participants' experiences of working with consumer researchers, perceived advantages and barriers, and suggestions for strengthening collaboration. Towards the end of the interview, participants were invited to share ideas about ways the capacity and expertise for consumer researchers might be enhanced or facilitated. An Expert Consumer Researcher Group was presented as a potential strategy and participants were asked their opinions about this concept and if appropriate how it might best be structured and developed.

Participants were not provided with a clear definition of an Expert Consumer Research Group. This was intentional and reflected the exploratory nature of this research. A definition of the group may have influenced participants' thinking and potentially limiting

opportunities for creative ideas to be considered and expressed. To provide some focus, participants were asked if they believed there would be any value in having a group of expert consumer researchers that might be available for people who want advice, are seeking consumers as co-researchers, or seek to facilitate consumer-led research, for example. Interviews were audio recorded and transcribed verbatim by an external transcription service to provide a full and accurate transcript.

Ethics

Ethics approval was obtained from the University Committee for Ethics in Human Research [name omitted to facilitate anonymous review]. Potential participants were given a brief verbal description of the study and provided with a copy of the Plain Language Statement and consent form. They were invited to ask any questions or seek clarification. A mutually agreeable interview time was organised. Participants were advised to return the signed consent form before the interview. Participants were informed that participation in the study was voluntary and they had the right to not participate or to withdraw at any stage. Confidentiality and privacy were assured.

Data analysis

Data were analysed thematically, utilising the framework described by Braun and Clark (2006; 2019). Two members of the research team independently undertook data analysis. Each

researcher read and re-read the transcripts several times to achieve familiarity with the content and meaning. Data coding was undertaken, with codes grouped together according to common content. The codes were represented diagrammatically and used to develop draft themes. At the conclusion of this process the two researchers met to discuss their draft findings. Themes were compared and iteratively developed into the thematic model presented below. The draft findings were then reviewed by the full team, including consumer and other researchers.

FINDINGS

Participants discussed the concept of the Expert Researcher Group with consideration and enthusiasm and their responses produced considerable in-depth data. The data analysis process led to the development of five main themes related to the Expert Consumer Researcher Group:

- Greater visibility and enhanced access
- Collegiality, sharing and creating expertise
- Broader acceptance
- Making it mandatory
- Structure and location

These themes will now be briefly described and illustrated with quotations from participants.

Greater visibility and enhanced access:

Participants viewed the concept of an Expert Consumer Researcher Group as potentially beneficial in enhancing the profile of mental health consumer research and facilitating an environment that would support a stronger collective presence of this important expertise:

There's a lot of value in having greater visibility. So if a group helps to give that, a sense of a mass, and also several voices, I think that would be a great and rich resource (Participant 11).

The participants had all experienced collaborative relationships with consumer researchers. As a result they were aware of the important work consumers are undertaking, often in solo positions or very small teams. Due to the limited number of consumer researcher positions, they did not enjoy the same levels of collegiality and opportunities for collaboration as other researchers:

We're aware of consumers in academic positions in Australia and New Zealand, and overseas, do some amazing stuff largely working in isolation, most of them (Participant 7).

The group could potentially provide a point of focus for other researchers who wish to work collaboratively with consumer researchers and without such a group are finding it difficult to identify consumers with appropriate expertise and mutual interests:

I know that there's a lot of allies out there that really would love to engage with consumers, but within their particular university, or their health service, or wherever they're coming from, there isn't really anybody to engage with. I'm sure it happens, that those people don't pursue that because they don't know how to, they don't know where to start. A group like that could be really useful in terms of helping people to get started (Participant 7).

Similarly:

I've spoken to other people who have said, that's so interesting, the research you do ... then it kind of ends there. If you had this organisation ... I can say ... these are the details, contact these people and there might be somebody you could work with for this (Participant 9).

The group might also provide the opportunity to expose other researchers to the value of consumer perspective and for consumer researchers to increase their own research capacity and research networks which is particularly important given the limited number of positions at present:

There's a very strong tendency to want to inadvertently potentially burn out some people in this position, because we want them to do everything (Participant 7).

Participants frequently made reference to the changing trends in relation to funding expectations and the likely future necessity of including collaboration with key stakeholders. Such an expectation would encourage researchers to seek consumer research expertise, perhaps becoming an important function of the proposed group:

Increasingly ... a lot of the major funders are ... expecting collaboration with major stakeholders, and if you've got those networks [consumer expert researcher group] ... it's going to potentially enhance all kinds of applications to do research (Participant 1).

Collegiality, sharing and creating expertise:

Participants, through their individual and collective experience, were aware that there is extensive important work being undertaken by and in collaboration with consumer researchers and that in current circumstances much of the work is being undertaken in isolation.

People with lived experience and academic allies are doing some fantastic work, but we're doing it in quite siloed spaces, just by the nature of our institutions and our locations (Participant 8).

This tendency to work in isolation was considered to prevent the development of concentrated expertise. Participants noted that there was no easy mechanism for people to become informed about initiatives already being undertaken:

So that people aren't constantly reinventing the wheel. So you do get this bank of people that are all supported and part of a network and that kind of stuff. And that would be great, I think (Participant 10).

The group structure would also potentially provide the framework for important peer support that is often difficult to organise, particularly given the limited numbers of consumer researchers:

[there is] much value ... in peer support, and particularly for people who have had maybe quite a bit of adversity, to have an experience of others who understand that adversity as well, and sharing it ... having a group together, and people learning together, ... solving problems together, I would say that's ideal. ... (Participant 11).

Broader acceptance

Participants were of the opinion, based on their own experiences, that this initiative would be well supported by many other mental health researchers and expected some would be enthusiastic about accessing the expertise available:

I've spoken to people who think that kind of research that I do, and partnering with consumers and writing papers with consumers ... they have an interest in it ... Having said that, if there was such a group and it was easy to access ... I imagine

that it would be something they would be interested in (Participant 9).

Other participants anticipated mixed responses from colleagues, with some actively embracing the concepts while others were likely to ignore or avoid the group:

I'm sure many of my colleagues will think that this sort of thing would be extremely valuable and a bunch of my colleagues would think this is nothing to do with me (Participant 5)

Similarly:

There would be some that ... would say, "Thank goodness, this has finally come along, I know now how to pursue my own interest in this work,". There would be some that would do everything that they could to ignore it, and ... would say, "Universities are about academic pursuits, and that's not academic" (Participant 7).

The idea of consumers actively participating in mental health research was considered likely to be threatening to some other researchers, and therefore a reason to resist, sometimes actively, engagement with an Expert Researcher Group:

Sometimes people are just not really that willing to allow a consumer group that looks quite powerful to be powerful... I

don't want them to have anything to do with my thing that I'm doing ... A program of research is something everyone builds ... and they get pretty protective of that, and don't necessarily want somebody else to be that powerful (Participant 11).

Some participants expressed the view that current trends would make it increasingly an expectation of granting bodies that consumers are involved in mental health research, which will ultimately impact the popularity of an Expert Researcher group:

I know people that I work with would probably endorse it ...

I think, there's enough genuine potential buy-in ... For those people that are reluctant, the hand in the future is going to be a little bit forced (Participant 1).

Making it mandatory

In discussing the concept of an expert researcher group, participants considered whether collaborating with consumers should be mandatory for mental health research. They contemplated what the impact on the viability of the group might be and how it might reflect the broader expectations of mental health research if collaborating with consumers was made mandatory:

If there was some kind of requirement ... of the need to demonstrate that you've partnered with consumers ... I think

people would definitely be interested because it's in their best interests (Participant 9).

Other participants were more ambivalent about the likely outcomes should consumer participation in mental health research become compulsory with particular reference to the possibility of tokenism and potential pressure on consumer researchers to acquiesce to the dominant research agenda:

I've got mixed feelings about funding bodies dictating that people have to have a consumer ... in the long run, it would probably be a good thing, in the short term, I think there'd be an enormous amount of tokenism ... You'd have to be a pretty brave consumer to say, "No. I'm not going to sign that because I haven't had enough input," it would be very easy to be influenced by, "Well, I know this isn't right, but I'll get such a hard time if I don't do it." You can hope that better things might grow, so I wouldn't say no to it, but, I think, it does need to be taken carefully (Participant 4).

Structure and location:

When considering where an expert researcher group would best be located, all participants identified the university environment as the

most appropriate. At the same time there was a strong sense that the independence of the group would need to be protected:

Should it be in the university? or should it be independent? I'd like to see it both. I'd like to see a university take responsibility, house it, support it, and be proud of it, and I'd like to see them hands off as much as you can possibly ever expect a university to be, and allow it to be collaborative. And that['s] really challenging, because I've been at a few universities and I've seen their attempts to be collaborative that don't often work that well ... That's why ... it needs to be supported by allies who are prepared to advocate for that work, and help that grow by engaging with it, by working in a coproduced way, or even a consumer-led way, to advance their own research. It's complex, it wouldn't be easy ...What you really need is one university to say, "We want to be the ones that are known for supporting consumer participation in mental health research." (Participant 7).

Deliberation about university or not as the most appropriate setting was only part of the broader issue. The broader discipline environment would likely impact on the success or otherwise of the initiative:

It makes sense for it to be a university ... the hub of where independent research is conducted. But they're also weird little

fields on their own, each university... it is just as important what faculty, what school in a university would be the right place for it, rather than whether the university is a good place (Participant 4).

Some reasons for preferencing the university environment were pragmatic in nature, for example providing the infrastructure for the administration of research funding:

if they sit in a university then there's the capacity to manage should grant funding or other sources of funding dry up, and in a way that may not be the case outside of university (Participant 5).

One participant suggested that locating the group exclusively in one university would not be viable. Cross institutional collaboration would be required, particularly in the early stages, and that would likely cause some difficulties in facilitating a cohesive and collaborative environment:

I think initially it has to be probably cross institutional ... I'm not sure that departments as a whole work that well across institutions... We've got three clinical schools within the same medical program and it's hard enough to get them to agree what they're going to teach about heart sounds let alone a mutual collaboration on research and at a departmental collaboration level as opposed to individuals (Participant 4).

Concern was also raised about the possible interference from the broader university with the need to ensure consumer researchers continued to lead the group:

I do wonder about university agenda ... whether it's in line with what they [consumers] think is the best direction for it ... if it is based at a university, then having guidelines around what that means and how it operates (Participant 6).

Some participants viewed the Expert Researcher Group as potentially a small step towards a larger goal of establishing a centre or other identified academic discipline as a potential long term goal of this initiative:

To be able to look to a spot where there's a concentration of people who do have expertise as lived experience researchers, and to be able to join that ... For there to be a recognisable critical mass of scholars in that space. I think that would be useful. And that would be a place that would really draw people for capacity building (Participant 11).

Similarly:

I would love to see a centre, a centre of excellence ... for consumer participation in research ... as both a tangible thing, so it existed as a building and able to work remotely as well ... I'd like to see it have a director, and staff ... realising that it would

probably start very small ... I'd quite like to see a role in that, or a space in that for allies ... allies are very important to the consumer movement, so long as they know their place and know that they're there to support rather than direct ... It would need to be present in a way that people could find it, and could interact with it, at whatever level they are at and wherever they are. And also for then somebody who is just starting out, they're doing their PhD, something to do with mental health and they think, maybe I should actually involve and they would be able to get some advice. Now that's a huge ask, and that would take a lot to do, but that's ultimately what I'd like to see (Participant 7).

DISCUSSION

Participant responses in this study suggest strong support for the development and implementation of an Expert Consumer Researcher Group. Although real-world examples may be few, promoting consumer expertise has been described in the literature as a crucial step in supporting its growth (Banfield et al., 2018; Happell, Scholz, et al., 2018; Rose, 2017; Wallcraft et al., 2011; Wallcraft, Schrank, & Amering, 2009). The findings of the current study extend such understandings, emphasising that *greater visibility of and enhanced access to consumer researchers* would be a major benefit of such a researcher group.

The theme: *Collegiality, sharing and creating expertise*, suggests if such a group were to be developed, it would become a visible entity and resource for other researchers wishing to collaborate with consumers. Creating an identifiable group of consumer researchers could potentially enhance interactions between consumers and other researchers and if successful, potentially lead to an increase in co-produced and consumer-led research, and the development of a critical mass of consumer researchers who are recognized as contributing their own unique expertise (Bennetts et al., 2013; Happell, Gordon, et al., 2019; Russo et al., 2018; Stewart et al., 2019). Our findings contribute to a growing knowledge base about the importance of consumer expertise and leadership to the mental health field, by demonstrating, that an Expert Consumer Researcher Group could provide a starting point for consumer expertise in mental health research being seen as an essential component of research quality.

Participants expressed the view that reactions from colleagues to an expert researcher group would likely be mixed. The likely positive attitudes from some colleagues would reflect the reported benefits of consumer involvement in research (Banfield et al., 2018; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Platania-Phung, et al., 2018; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Platania-Phung, et al., 2018; Scammell et al., 2016). At the same time there were expectations of resistance and negative attitudes in line with previous discussions of

the consequences of unequal power, tokenism and hierarchical views about research (Happell, Gordon, et al., 2019; Landry, 2017; Patterson et al., 2014)

Mixed views were expressed about whether or not a mandatory requirement for consumer participation in mental health research would be beneficial. Some participants believed it would provide an important impetus, similar to the Patient and Public Involvement directive in the United Kingdom (Kalathil & Jones, 2016). Others felt it may lead to tokenism, with consumers invited onto teams to 'tick a box' rather than providing consumer expertise that would be fully engaged with by others (Bennetts, Cross, & Bloomer, 2011; Gee, McGarty, & Banfield, 2016; Happell, Gordon, Bocking, Ellis, Roper, Liggins, Scholz, et al., 2018; Patterson et al., 2014) and that this would require mitigation if such a group was established. While tokenism may pose a barrier initially should consumer researcher collaboration be required, this may change over time through the influence of the consumers and their allies.

The university environment was considered by most participants to be the most appropriate place to locate a consumer researcher group, although there were concerns about maintaining integrity and independence. Consumer researchers have identified traditional mental health research as hierarchical and supporting the status quo (Happell, Gordon, et al., 2019; Landry, 2017; Patterson et al., 2014).

Once again, promoting and recognising consumer leadership would be fundamental to the success and achievements of an Expert Consumer Researcher Group in a university environment (Bennetts et al., 2013; Happell, Gordon, et al., 2019; Russo et al., 2018; Stewart et al., 2019). This is a highly complex issue which requires further consideration. Alignment with a progressive School or Department could avoid issues of inter-professional tribal territory disputes. Losing independence may be a risk of this approach, however it may enhance the local impact of the group. As a separate existence, such as an independent research unit with its own infrastructure and within the larger university, risks isolation and only having influence outside the nominal host university.

Crucial to the success of any Expert Consumer Researcher Group would be how it is received and interacted with by other researchers. For those without prior experience in working with consumers as colleagues and partners this will require a fundamental re-conception of relationships with consumers. Other researchers will therefore need to consider how they will approach their own needs for capacity development in working with consumers (Gillard et al., 2010; Roper et al., 2018).

To ensure consumer perspectives and knowledge are as valid and valuable to the research process as possible, other researchers must position themselves as learners and acknowledge consumer partners as leaders. In this sense, working together as collaborators and

building capacity becomes not just about consumers learning research skills or learning the language of academics or other disciplines, it's also about other academics becoming steeped in the consumer discipline, consumer writing, concepts and ideas. (Roper et al., 2018). Establishing this environment of mutual valuing of expertise and collaborative learning would enhance a respectful and constructive working relationship.

The perspectives of non-consumer researchers as presented provide an important contribution to the literature on this topic. This information is however, a starting point to a broader research agenda. The consumer voice must be central to the development of an Expert Researcher Group. A qualitative study of the experiences and perspectives of consumer researchers is the logical next stage of the broader research agenda. Any progress with the Expert Researcher Group concept must also include a rigorous evaluation framework to ensure the group development and composition functions as planned.

The ultimate aim of promoting consumer collaborations in mental health research is to influence practice and more positive health outcomes for people accessing mental health services. There is some evidence to support the benefits of lived experience knowledge in this regard (Bennetts et al., 2013; Ehrlich et al., 2020; McDonagh et al., 2014; Oborn et al., 2019). Understanding the implications of

consumers as researchers must be therefore be integral to future evaluation work.

Limitations

The qualitative exploratory approach taken with this research limits its generalisability to a wider population of other mental health researchers. Furthermore the participants were purposely selected due to their experiences of working collaboratively with consumer researchers meaning their opinions and perspectives cannot be assumed to represent the views of other mental health researchers more broadly. This manuscript presents data from only one stakeholder group. Further data collection is required that is inclusive of other key stakeholders, most notably consumer researchers.

CONCLUSIONS

Genuine collaboration with consumers in the development and delivery of mental health services cannot be fully realised without their involvement in mental health research. The establishment of an Expert Consumer Research Group has been advanced as a strategy to recognise and promote consumers as researchers in their own right rather than as an adjunct to the prevailing agendas of other mental health researchers. This initiative has the potential to draw upon consumer leadership to create an environment of collegiality, and to enhance opportunities for collaboration between consumer

researchers and other mental health researchers. Notable barriers such as tokenism and power differentials will need to be addressed for the full potential of this initiative to be realised. General support for the concept of an Expert Reference Group by non-consumer researchers, while an important beginning point, represents the beginning of this process. A co-produced study involving in-depth interviews with consumer researchers is the essential next stage.

IMPLICATIONS FOR NURSING PRACTICE

A solid research base is integral to the delivery of high quality mental health services. Consumer collaborations in mental health research are associated with increased quality and relevance of research findings and their application, ultimately contributing to positive practice change. Nursing as a profession has a central role to play in promoting and facilitating consumer collaborations. The establishment and advancement of a Consumer Expert Researcher Group may potentially facilitate these relationships and ultimately create opportunities for quality and relevant research with an increased capacity to influence clinical practice. Capturing the experiences, perspectives and opinions of consumer researchers must be included before this potential initiative is progressed.

REFERENCES:

- Arblaster, K., Mackenzie, L., & Willis, K. (2015). Mental health consumer participation in education: a structured literature review. *Australian Occupational Therapy Journal*, 62(5), 341-362. doi: 10.1111/1440-1630.12205
- Banfield, M., Randall, R., O'Brien, M., Hope, S., Gulliver, A., Forbes, O., Morse, A. R., & Griffiths, K. (2018). Lived experience researchers partnering with consumers and carers to improve mental health research: Reflections from an Australian initiative. *International Journal of Mental Health Nursing*, 27(4), 1219-1229. doi: 10.1111/inm.12482
- Bennetts, W., Cross, W., & Bloomer, M. (2011). Understanding consumer participation in mental health: Issues of power and change. *International Journal of Mental Health Nursing*, 20(3), 155-164. doi: 10.1111/j.1447-0349.2010.00719.x
- Bennetts, W., Pinches, A., Paluch, T., & Fossey, E. (2013). Real lives, real jobs: sustaining consumer perspective work in the mental health sector. *Advances in Mental Health*, 11(3), 313-326. doi: 10.5172/jamh.2013.11.3.313

Boaz, A., Biri, D., & McKeivitt, C. (2016). Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom? *Health Expectations*, 19(3), 592-601. doi: 10.1111/hex.12295

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589-597.

Bryant, W., Parsonage, J., Tibbs, A., Andrews, C., Clark, J., & Franco, L. (2012). Meeting in the mist: key considerations in a collaborative research partnership with people with mental health issues. *Work*, 43, 23-31. doi: 10.3233/WOR-2012-1444

Byrne, L., Stratford, A., & Davidson, L. (2018). The Global Need for Lived Experience Leadership. *Psychiatric Rehabilitation Journal*, 41(1), 76-79. doi: 10.1037/prj0000289

Commonwealth of Australia. (2017). *The Fifth National Mental Health and Suicide Prevention Plan*. Canberra: Australian Government.

Daya, I., Hamilton, B., & Roper, C. (2019). Authentic engagement: A conceptual model for welcoming diverse and challenging consumer and survivor views in mental health research, policy, and practice. *International Journal of Mental Health Nursing*, 29(2), 299-311. doi: 10.1111/inm.12653

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Dabrh, A. M., & Murad, M. H. (2014). Patient engagement in research: a systematic review. *BMC Health Service Research*, 14, 89. doi: 10.1186/1472-6963-14-89

Ehrlich, C., Slattery, M., Vilic, G., Chester, P., & Crompton, D. (2020). What happens when peer support workers are introduced as members of community-based clinical mental health service delivery teams: a qualitative study. *Journal of Interprofessional Care*, 34(1), 107-115.

Etikan, I., & Bala, K. (2017). Sampling and sampling methods. *Biometrics & Biostatistics International Journal*, 5(6), 00149.

Faulkner, A. (2017). Survivor research and Mad Studies: the role and value of experiential knowledge in mental health research.

Disability and Society, 32(4), 500-520. doi:

10.1080/09687599.2017.1302320

- Gee, A., McGarty, C., & Banfield, M. (2016). Barriers to genuine consumer and carer participation from the perspectives of Australian systemic mental health advocates. *Journal of Mental Health*, 25(3), 231-237. doi: 10.3109/09638237.2015.1124383
- Ghisoni, M., Wilson, C. A., Morgan, K., Edwards, B., Simon, N., Langley, E., Rees, H., Wells, A., Tyson, P. J., Thomas, P., Meudell, A., Kitt, F., Mitchell, B., Bowen, A., & Celia, J. (2017). Priority setting in research: user led mental health research. *Research Involvement and Engagement*, 3, 4. doi: 10.1186/s40900-016-0054-7
- Gillard, S., Simons, L., Turner, K., Lucock, M., & Edwards, C. (2012). Patient and public involvement in the coproduction of knowledge: reflection on the analysis of qualitative data in a mental health study. *Qualitative Health Research*, 22(8), 1126-1137. doi: 10.1177/1049732312448541
- Gillard, S., Turner, K., Lovell, K., Norton, K., Clarke, T., Addicott, R., McGivern, G., & Ferlie, E. (2010). "Staying native": coproduction in mental health services research. *International Journal of Public*

Sector Management, 23(6), 567-577. doi:

10.1108/09513551011069031

Gordon, S., Ellis, P., Gallagher, P., & Purdie, G. (2014). Service users teaching the recovery paradigm to final year medical students. A New Zealand approach. *Health Issues*, 113(Summer), 15-17.

Happell, B., Bennetts, W., Platania Phung, C., & Tohotoa, J. (2015). Consumer involvement in mental health education for health professionals: feasibility and support for the role. *Journal of Clinical Nursing*, 24(23-24), 3584–3593. doi: 10.1111/jocn.12957

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Platania-Phung, C., & Scholz, B. (2018). Mental Health Researchers' Views About Service User Research: A Literature Review. *Issues in Mental Health Nursing*, 39(12), 1010-1016. doi: 10.1080/01612840.2018.1475524

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Platania-Phung, C., & Scholz, B. (2018). How did I not see that? Perspectives of nonconsumer mental health researchers on the benefits of collaborative research with consumers. *International Journal of Mental Health Nursing*, 27(4), 1230-1239. doi: 10.1111/inm.12453

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Scholz, B., & Platania-Phung, C. (2018). Turning the tables: Power relations between consumer researchers and other mental health researchers. *Issues in Mental Health Nursing, 39*(8), 633–640. doi: 10.1080/01612840.2018.1445328

Happell, B., Gordon, S., Bocking, J., Ellis, P., Roper, C., Liggins, J., Scholz, B., & Platania-Phung, C. (2019). "Chipping away": non-consumer researcher perspectives on barriers to collaborating with consumers in mental health research. *Journal of Mental Health, 28*(1), 49-55. doi: 10.1080/09638237.2018.1466051

Happell, B., Platania-Phung, C., Byrne, L., Wynaden, D., Martin, G., & Harris, S. (2015). Consumer participation in nurse education: A national survey of Australian universities. *International Journal of Mental Health Nursing, 24*(2), 95-103. doi: 10.1111/inm.12111

Happell, B., Platania-Phung, C., Scholz, B., Bocking, J., Horgan, A., Manning, A., Doody, R., Hals, E., Granerud, A., Lahti, M., Pulli, J., Vatula, A., Koski, J., van der Vaart, K., Allon, J., Griffin, M., Russell, S., MacGabhann, L., Bjornson, E., & Biering, P. (2019). Changing attitudes: The impact of Expert by Experience involvement in Mental Health Nursing Education: An international survey study..

International Journal of Mental Health Nursing, 28(2), 480–491.

doi: 10.1111/inm.12551

Happell, B., Scholz, B., Bocking, J., Platania-Phung, C., Gordon, S., Ellis, P., Roper, C., & Liggins, J. (2018). "I don't think we've quite got there yet": The experience of allyship for mental health consumer researchers. *Journal of Psychiatric & Mental Health Nursing*, 25(8), 453-462. doi: 10.1111/jpm.12476

Health Services Executive. (2018). A National Framework for Recovery in Mental Health 2018-2020.. Dublin.

Hunter, D. J., McCallum, J., & Howes, D. (2018). *Defining Exploratory-Descriptive Qualitative (EDQ) research and considering its application to healthcare*. Paper presented at the Proceedings of Worldwide Nursing Conference.

Kalathil, J., & Jones, N. (2016). Unsettling disciplines: madness, identity, research, knowledge. *Philosophy, Psychiatry, & Psychology*, 23(3), 183-188. doi: 10.1353/ppp.2016.0016

Landry, D. (2017). Survivor research in Canada: 'talking' recovery, resisting psychiatry, and reclaiming madness. *Disability and Society*, 32, 1437-1457. doi: 10.1080/09687599.2017.1322499

Lawn, S. (2016). What researchers think about involving consumers in health research. *Australian Journal of Primary Health, 22*, 483-490. doi: 10.1071/PY15089

Mahboub, L., & Milbourn, B. T. (2015). Modernising occupational therapy teaching, research and practice in mental health. *Australian Occupational Therapy Journal, 62*(5), 363. doi: 10.1111/1440-1630.12236

McCann, T. V., Moxham, L., Usher, K., Crookes, P. A., & Farrell, G. (2009). Mental health content of comprehensive pre-registration nursing curricula in Australia. *Journal of Research in Nursing, 14*, 519-530. doi: 10.1177/1744987109347041

McDonagh, S., Cummins, M., & Gallagher, A. (2014). Peer work sharing of lived experience in mental health settings: A qualitative study. *Health Issues*(112), 25.

Mental Health Commission. (2012). *Rising to the challenge: The mental health and addiction service development plan 2012–2017*: Wellington, New Zealand: Ministry of Health.

Mental Health Commission of Canada. (2016). *Advancing the Mental Health Strategy for Canada: A Framework for Action (2017–2022)*. Ottawa, ON: Mental Health Commission of Canada.

Oborn, E., Barrett, M., Gibson, S., & Gillard, S. (2019). Knowledge and expertise in care practices: the role of the peer worker in mental health teams. *Sociology of Health and Illness*, 41(7), 1305-1322. doi: 10.1111/1467-9566.12944

Patterson, S., Trite, J., & Weaver, T. (2014). Activity and views of service users involved in mental health research: UK survey. *British Journal of Psychiatry*, 205(1), 68-75. doi: 10.1192/bjp.bp.113.128637

Patton, M. Q. (2007). Sampling, qualitative (purposive). *The Blackwell encyclopedia of sociology*.

Paul, C., & Holt, J. (2017). Involving the public in mental health and learning disability research: Can we, should we, do we? *Journal of Psychiatric and Mental Health Nursing*, 24(8), 570-579. doi: 10.1111/jpm.12404

Ridley, S., Martin, R., & Mahboub, L. (2017). Learning from Mental Health Lived Experience and the Influence on Students' Practice. *Australian Social Work*, 70(3), 372-380. doi: 10.1080/0312407X.2016.1235718

Roper, C., Grey, F., & Cadogan, E. (2018). Co-production: Putting principles into practice in mental health contexts (Vol. 2019). Accessed October 3, 2019 from:

https://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0010/2659969/Coproduction_putting-principles-into-practice.pdf.

Rose, D. (2017). Service user/survivor-led research in mental health: epistemological possibilities. *Disability and Society*, 32(6), 773-789. doi: 10.1080/09687599.2017.1320270

Rose, D., Carr, S., & Beresford, P. (2018). 'Widening cross-disciplinary research for mental health': what is missing from the Research Councils UK mental health agenda? *Disability and Society*, 1-6. doi: 10.1080/09687599.2018.1423907

Russo, J., Beresford, P., & O'Hagan, M. (2018). Commentary on: Happell, B. & Scholz, B (2018). Doing what we can, but knowing our place: Being an ally to promote consumer leadership in mental health.. *International Journal of Mental Health Nursing*, 27, 440-447. doi: 10.1111/inm.12520

Sangill, C., Buus, N., Hybholt, L., & Berring, L. L. (2019). Service user's actual involvement in mental health research practices: A scoping review. *International Journal of Mental Health Nursing*, 28(4), 798-815.

Scammell, J., Heaslip, V., & Crowley, E. (2016). Service user involvement in preregistration general nurse education: a systematic review.

Journal of Clinical Nursing, 25(1/2), 53-69. doi: 10.1111/jocn.13068

Scholz, B., Gordon, S., Bocking, J., Liggins, J., Ellis, P., Roper, C., Platania-Phung, C., & Happell, B. (2019). There's just no flexibility":

Ecosystemic impacts on collaborations between consumer and other researchers.. *International Journal of Mental Health*

Nursing., 28(4), 899–908.

Scholz, B., Gordon, S., & Happell, B. (2017). Consumers in Mental Health Service Leadership: A Systematic Review. *International Journal of*

Mental Health Nursing, 26(1), 20-31. doi: 10.1111/inm.12266

Stebbins, R. (2001). *Exploratory research in the social sciences:*

Qualitative research methods: Volume 48. London, England:

Sage.

Stewart, S., Scholz, B., Gordon, S., & Happell, B. (2019). 'It depends what you mean by leadership': An analysis of stakeholder perspectives

on consumer leadership. *International Journal of Mental Health*

Nursing, 28(1), 339-350. doi: 10.1111/inm.12542

Stewart, S., Watson, S., Montague, R., & Stevenson, C. (2008). Set up to fail? Consumer participation in the mental health service system.

Australasian Psychiatry, 16(5), 348-353. doi:

10.1080/10398560802047367

Vollm, B., Foster, S., Bates, P., & Huband, N. (2017). How best to engage users of forensic services in research: literature review and recommendations. *International Journal of Forensic Mental Health*, 16(2), 183-195. doi: 10.1080/14999013.2016.1255282

Wainberg, M., Scorza, P., Shultz, J., Helpman, L., Mootz, J., Johnson, K., Neria, Y., Bradford, J.-M., Oquendo, M., Arbuckle, M., Wainberg, M. L., Shultz, J. M., Mootz, J. J., Johnson, K. A., Bradford, J.-M. E., Oquendo, M. A., & Arbuckle, M. R. (2017). Challenges and Opportunities in Global Mental Health: a Research-to-Practice Perspective. *Current Psychiatry Reports*, 19(5), 1-10. doi: 10.1007/s11920-017-0780-z

Wallcraft, J., Amering, M., Freidin, J., Davar, B., Froggatt, D., Jafri, H., Javed, A., Katontoka, S., Raja, S., Rataemane, S., Steffen, S., Tyano, S., Underhill, C., Wahlberg, H., Warner, R., & Herrman, H. (2011). Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. *World Psychiatry*, 10(3), 229-236. doi: 10.1002/j.2051-5545.2011.tb00062.x

Wallcraft, J., Schrank, B., & Amering, M. (2009). *Handbook of service user involvement in mental health research*. Chichester: Wiley.

Table 1 – Participant Demographics

Participant No.	Country	Discipline	Employer	Position	Gender
1.	New Zealand	Mental health nursing	University	Professor	Male
2.	New Zealand		Non-Government Organisation	Project manager	Female
3.	New Zealand	Psychology	University	Senior Lecturer	Female
4.	New Zealand	Psychiatry	University	Professor	Male
5.	New Zealand	Psychiatry	University	Senior Lecturer	Male
6.	New Zealand	Mental health nursing	University	Senior Lecturer	Male
7.	Australia	Mental health nursing	University	Professor/ Director	Female
8.	Australia	Social work	University	Associate Professor	Female

9.	Australia	Psychology	University	Post-doctoral research fellow	Male
10.	Australia	Social work	University	Senior Lecturer	Female
11.	Australia	Mental health nursing	University	Associate Professor/ Director	Female