



When “all researchers are equal but some are more equal than others”: Collaborating with consumers in mental health research

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Research team

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Background

- ▶ Contemporary mental health policy (Australia and New Zealand) promotes active consumer involvement in all aspects of service delivery including evaluation.
- ▶ Active involvement of consumers in mental health research and evaluation has been limited, despite evidence supporting benefits.
- ▶ Understanding the views and opinions of 'other' mental health researchers is imperative to progressing this agenda.

AIM

- ▶ To enhance understanding of the views and opinions of non-consumer mental health researchers who do not identify as consumers of about including consumers as part of research teams.

Methods

- ▶ Qualitative exploratory
- ▶ In-depth individual interviews were held with mental health researchers from the disciplines of nursing, psychiatry, psychology, and social work in Australia and New Zealand
- ▶ Purpose sampling of participants with experience of working with consumers as researchers.
- ▶ Thematic data analysis was undertaken to elicit the main themes.

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POWER STRUGGLE

You need to make it clear who is in charge right from the start.

Sub-themes

- ▶ Tokenism
- ▶ Undermined potential
- ▶ Critical mass
- ▶ Denying power differences
- ▶ Awareness of power differences



Tokenism does not change stereotypes of social systems but works to preserve them, since it dulls the revolutionary impulse.

— *Mary Daly* —

AZ QUOTES

Tokenism

- ▶ Tokenism was seen by most participants as reflecting the systemic power differences and prejudice (sometimes overt, sometimes subtle) on the part of other researchers towards consumer researchers:
- ▶ *“... it depends on how on board the other members of the team are in terms of the levels of involvement; whether it’s a tokenistic...versus a co-lead, co-produced...often there is a potential for them to still have that bias of, I am better because I’m a professional and you are a service user.”*

Tokenism

- ▶ Power relations were sometimes evident through the selection process for consumers. Power was deployed behind-the-scenes in deciding who would be present at the table in the first place:
- ▶ *“In the [government health agency] they would involve people with lived experience or potential end users, they would hand pick them according to people who they would see as supportive of the work, so somebody who was a strong advocate, and a critic of the policy or the strategy would not be invited to be at the table.”*
- ▶ Participants described similar occurrences in research.

Undermined potential

- ▶ Involving consumers in research is not of itself sufficient to realise the potential benefits of consumer participation:
- ▶ *“I think power comes into it very much, and a lack of insight into that. And a sense that there’s a lack of appreciation and a lack of experience in working with end users, ... a lack of valuing potential, so it becomes a tick box exercise of yes, there was somebody round the table with that voice, rather than appreciating the possibilities of – or the richness of – or the better quality that will result from the outcome. ...”*

Critical mass

- ▶ The presence of a solitary or small number of mental health consumers was identified as an issue of power:
- ▶ “...*the power of numbers. So maybe it's not appropriate to only have one person who's holding up the flag ... critical mass might be important.*”

Denying power differences

- ▶ Participants described power differences as often ignored, with statements like *we value everyone's opinion*, although possibly well meaning, shifts focus from existing inequities and minimises attempts to address and reduce inequities in power
- ▶ *“Power is often brushed aside by, we're all equal here, we value everybody's views - and so in a sense it doesn't allow for power to be talked about.”*

Awareness of power dynamics

- ▶ The existence and potential consequences of power need to be placed front and centre at the outset of the relationship:
- ▶ *the imperative is for the non-lived experience health researchers to put the conversation about power on the table really early on and using it as a point of critical reflection throughout the working relationship. I don't think that means that people with lived experience researchers won't experience power differential, but I think given that usually we have more power by our role and our own life course that it's our responsibility to be putting it on the table and talking about it and to create the conditions for lived experience researchers to talk about when power is not working and it's not okay.*

Awareness of power dynamics

- ▶ A 'declaration of power' was suggested as a potential tool to establish frankness at the table that consumers and other mental health researchers are positioned quite differently in terms of power and how to go about navigating that difference:
- ▶ *"...power is incredibly pervasive and it's the main thing that we have to address. We almost need to have a declaration of power at the beginning to say – "This is where we've got, this is what you've got, we know it's not the same, what can we do to make it not any worse, and hopefully better"*



"SURE IT'S A PARTNERSHIP, ELWOOD, BUT IT'S A LIMITED PARTNERSHIP, AND YOU'RE THE ONE WHO'S LIMITED."

Consensus process to decide module content





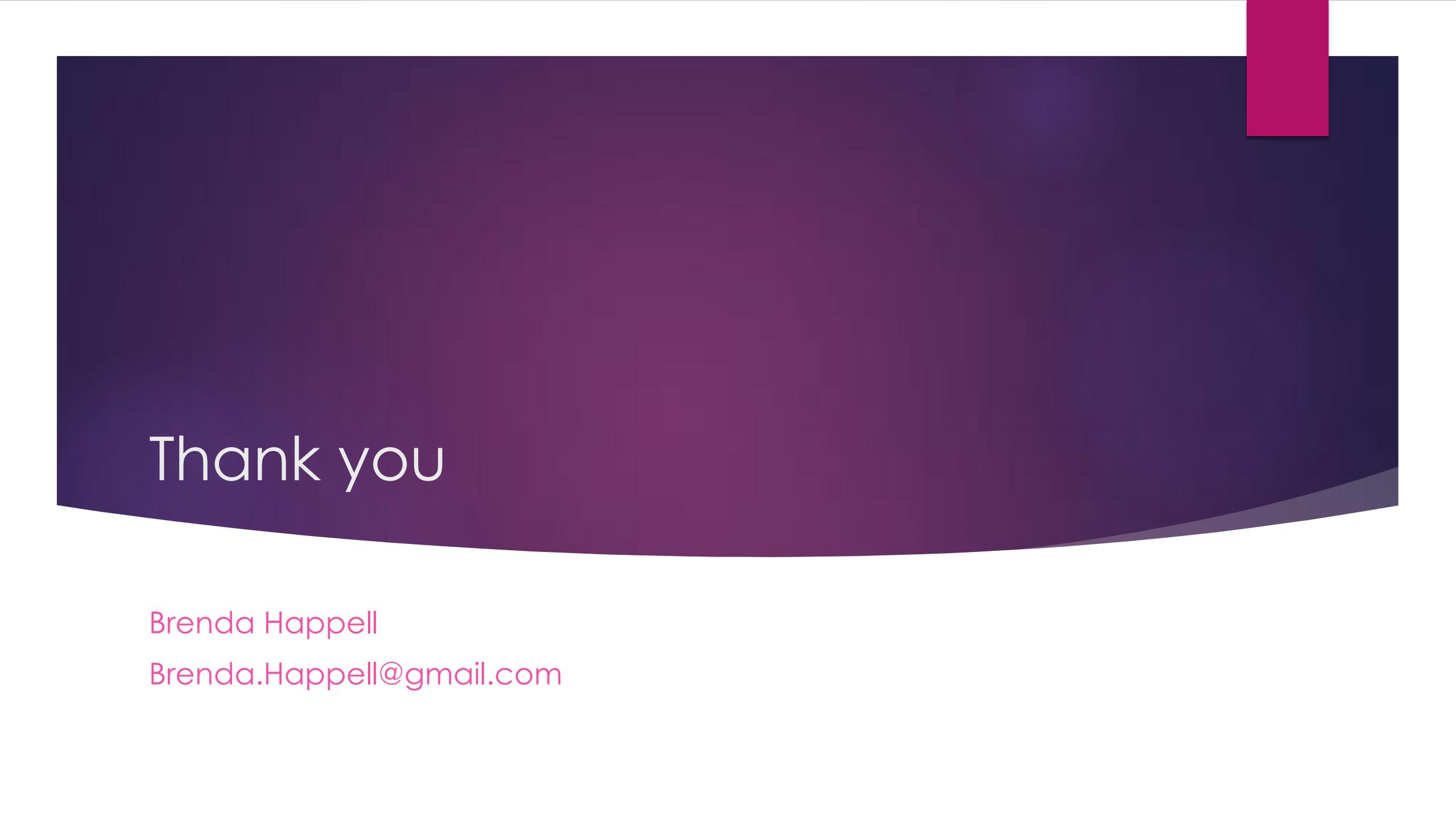
EQUALITY



EQUITY

Discussion and conclusions

- ▶ Power differentials pose a major barrier to working in partnership or having meaningful involvement with consumers in research
- ▶ Power is often dismissed or underplayed through the veneer of mutual respect and valuing all contributions
- ▶ If power is not acknowledged and addressed its impact will be stronger and likely impenetrable
- ▶ Indeed by presenting an inaccurate sense of equality, the discriminate is likely to be far greater



Thank you

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