



# EQUALLYWELL

## 2023 Symposium

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# Research with – not for – Consumers: Reflections on Co-Designing a Qualitative Study on Physical Health for People with Mental Illness

Presenters: Tessa-May Zirnsak & Judith Drake

Authors: Lyn English, Chris Maylea, Rosie Elwyn, Melanie Sherrin, Hazel Dalton, Russell Roberts

Co-Design Group Members: Michael Burge, Amrita Dasvarma, Judith Drake, Lyn English, Heidi La  
Paglia, Ailsa Rayner & Melanie Sherrin

# What is the project about, and why does it matter?

1

Develop a resource for mental health consumers to get their physical health needs met

2

Improve self-efficacy and self advocacy

3

Challenge the gap in health outcomes for mental health consumers

## Why Co-design?

- Researcher defined intentions of co-design
  - Make the resource more applicable to the target group
  - Bring on expertise like in any other research project
- Our project is not true co design, but it was much better to have members of the co-design group involved in most aspects of the research

*'it's been a process, we've gone through bit by bit about what's necessary, what's missing, the impact that it has on us; and if you have a short interview or a focus group, you can't work through all those issues, we've covered the stigma, discrimination um you know talking about it from a carer's perspective the other day so there's a lot of detail and a lot more information that's been able to be gathered doing it over a period of time' - Lyn*

# Activities the Co-Design group contributed to

- Literature review – inc substantial assessment of existing resources
- Ethics application – inc. development of essential study materials
- Recruitment pathways
- Data analysis – group discussion of quote and individual transcripts

*I felt we were included in fair bit of the process, which meant we learnt the focus of what was going on and we were able to contribute at quite a few stops through the way which was helpful' - Ailsa*

# Activities that make this (close to) co-design

- Power dynamics (difference between consultation and co-design) - one success for us is that the group think they can speak up and feel heard
- Able to have influence before a decision is made, and before it's too late to change (e.g. no being sent drafts for feedback – involvement from the beginning)
- Holding the researcher accountable – asking questions, following up, disagreeing

*it has been good to be involved in things like the lit review because you don't normally get involved in those processes, so you just get given the results and it's kind of by magic this kind of happened. Whereas when you're involved with it you can sort of see it develop a bit more, there's a bit more - I don't know if ownership's the right word - but kind of ownership of the work. - Judith*

# Obstacles to co-design

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Funding requirements vs.  
co-design vision



Requirements of the  
academic world



Recruitment of the group



Negotiating the ethics  
committee (e.g., distress  
protocol disagreement)

# Where co- designed has worked

Diversity of the group (expertise, experiences, types of knowledge)

Putting research problems back to the group who could resolve it

Being involved at stages when you are not normally involved

Membership continuity

Consumer-researcher led

Openness to listen in research team

Research reflexivity regarding timelines, meetings etc

Literature review

Want to know more about the resource? Come to our workshop!

12:30pm on Thursday 27<sup>th</sup> July – after symposium close in Seminar Room 2

# Thank you

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