

Service-user engagement and leadership in mental health research

Findings from an occupational therapy supported project

Presented by

Dr Nicola Hancock

Faculty of Health Sciences



Overview of Presentation

- Background to our project
- Methods to examine ourselves/process
- Taster of some Findings
- Relevance to Occupational Therapy



Acknowledgement: many of these slides were developed by the consumer research team and presented various conferences – they are happy for me to share them with you

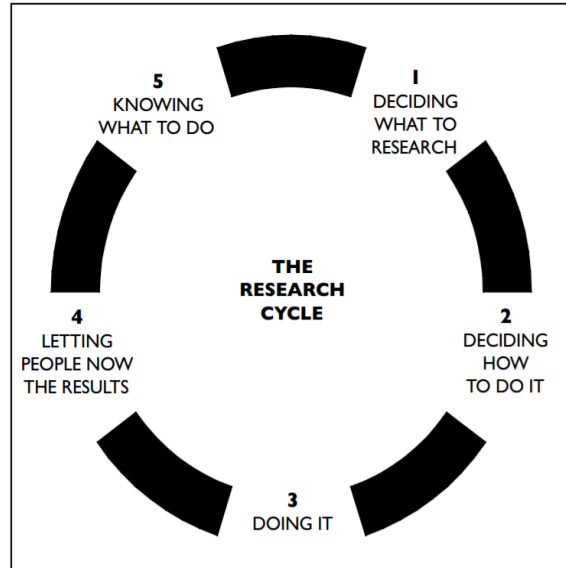
Background:

- NSW Non-Government /Community Managed Organisation
- Wanted to do something different with their evaluation budget
- Independent **consumer-led evaluation**
- University academic team – to facilitate this to occur

- Increasing evidence of this occurring (and some published evidence)
- BUT:
 - mostly co-production
 - little ‘guidance’ on consumer-led – particularly supporting it
 - mostly post reflections

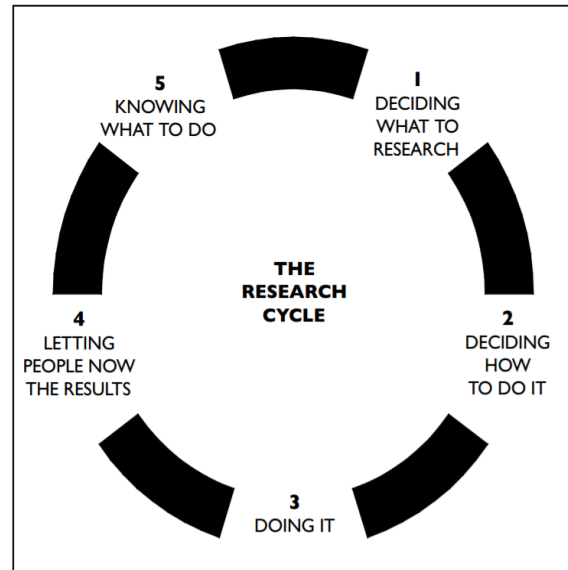
Our Research Team & Project:

- 3 consumer researchers and 3 academic or ally researchers
- 1 day a week for 18 months



Our Research Team & Project:

- 3 consumer researchers and 3 academic or ally researchers
- 1 day a week for 18 months



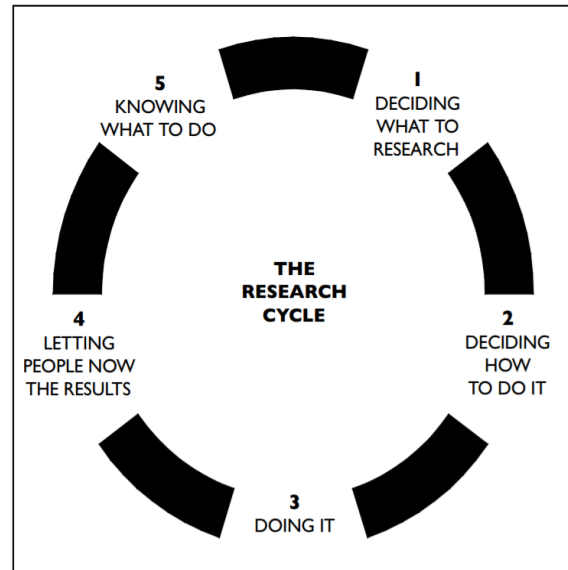
Service (PIR)
evaluation –
experiences of
service users



PROCESS
evaluation –
experiences of
consumer-led
research

Our Research Team & Project:

- 3 consumer researchers and 3 academic or ally researchers
- 1 day a week for 18 months



Service (PIR)
evaluation –
experiences of
service users



PROCESS
evaluation –
experiences of
consumer-led
research

Collaborative Auto-Ethnography

What is it?

- Qualitative method
- Involved occupying dual roles – researchers and research participants - process of studying ourselves
- Used own experiences (diaries + focus groups) as pooled data
- Focused on experiences of consumer-led research

Example of diary questions:

- What aspects of this week facilitated consumer led or consumer directed moments/research?
- What aspects compromised consumer led or consumer directed moments/research?

- Thematic analyse of data
- Cyclical process – discussed emerging themes in focus groups



Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS



+

INTERNAL TEAM ASPECTS/DYNAMICS:



Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS:

- Flexibility and time
- Resources – enough \$ and consumer control over this
- More than one consumer researcher
- More than one academic voice
- Skilled consumer research team
- Consumer researchers networking beyond the team



Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS:

- Flexibility and time
- Resources – enough \$ and consumer control over this
- More than one consumer researcher
- More than one academic voice
- Skilled consumer research team
- Consumer researchers networking beyond the team



Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS:

- More than one consumer researcher

I feel very grateful to my co-researchers for taking on jobs I feel less comfortable with – such as some of the more communication... aspects, while I can focus on literature... The team dynamic continues to be a good one (from my perspective)...we all listen to each other and respond to each other's needs. (CR1 – diary)



Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS:

- More than one consumer researcher

I feel very grateful to my co-researchers for taking on jobs I feel less comfortable with – such as some of the more communication... aspects, while I can focus on literature... The team dynamic continues to be a good one (from my perspective)...we all listen to each other and respond to each other's needs. (CR1 – diary)

Bridget has taken on the brave initiative of starting the ethics proposal of the main PIR evaluation. I am glad Bridget has put up her hand and the whole ethics process really intimidates me. (CR2 – diary)



Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS:

- More than one consumer researcher

I feel very grateful to my co-researchers for taking on jobs I feel less comfortable with – such as some of the more communication... aspects, while I can focus on literature... The team dynamic continues to be a good one (from my perspective)...we all listen to each other and respond to each other's needs. (CR1 – diary)

Bridget has taken on the brave initiative of starting the ethics proposal of the main PIR evaluation. I am glad Bridget has put up her hand and the whole ethics process really intimidates me. (CR2 – diary)



The process of working in this setting with 2 other people with lived experience of mental illness have been nothing short of amazing and impressive... I definitely prefer being part of a team of consumers. There is a real level of openness and understanding in our whole team and that has been truly unique. (CR3 – diary)

Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS:

- More than one academic researcher voice

Although this is consumer led, we need to be informed and know the different options. So to hear the different options, and you guys don't agree, so ... all cards are on the table, we can say... where we wanted to go with that. (Consumer1 – FG)



Aspects that ENHANCED the consumer-led nature

STRUCTURAL ASPECTS:

- More than one academic researcher voice



Although this is consumer led, we need to be informed and know the different options. So to hear the different options, and you guys don't agree, so ... all cards are on the table, we can say... where we wanted to go with that. (Consumer1 – FG)

we are presented with different suggestions, advice, options etc. from the academics... I am confident that options are a good thing and as a consumer team leading and saying yes and no to certain suggestions is possible!
(Consumer2 – Diary)

Aspects that ENHANCED the consumer-led nature

INTERNAL TEAM ASPECTS/DYNAMICS:

- Respect and Positive group dynamics
- Team communication
- On the same page - values & vision
- Enough team time



Aspects that CHALLENGED the consumer-led nature

STRUCTURAL ASPECTS



INTERNAL TEAM ASPECTS/DYNAMICS:



+

Aspects that CHALLENGED the consumer-led nature

STRUCTURAL ASPECTS:

- Time limitations
- Systemic barriers
- AR career aspirations



INTERNAL TEAM ASPECTS/DYNAMICS:

- AR - more research experience
- AR blunt - phrasing as direction not suggestion
- CR – tendency to defer



Crystallised our Understanding



Ultimately coining a new phrase

CONSUMER LED COLLABORATION

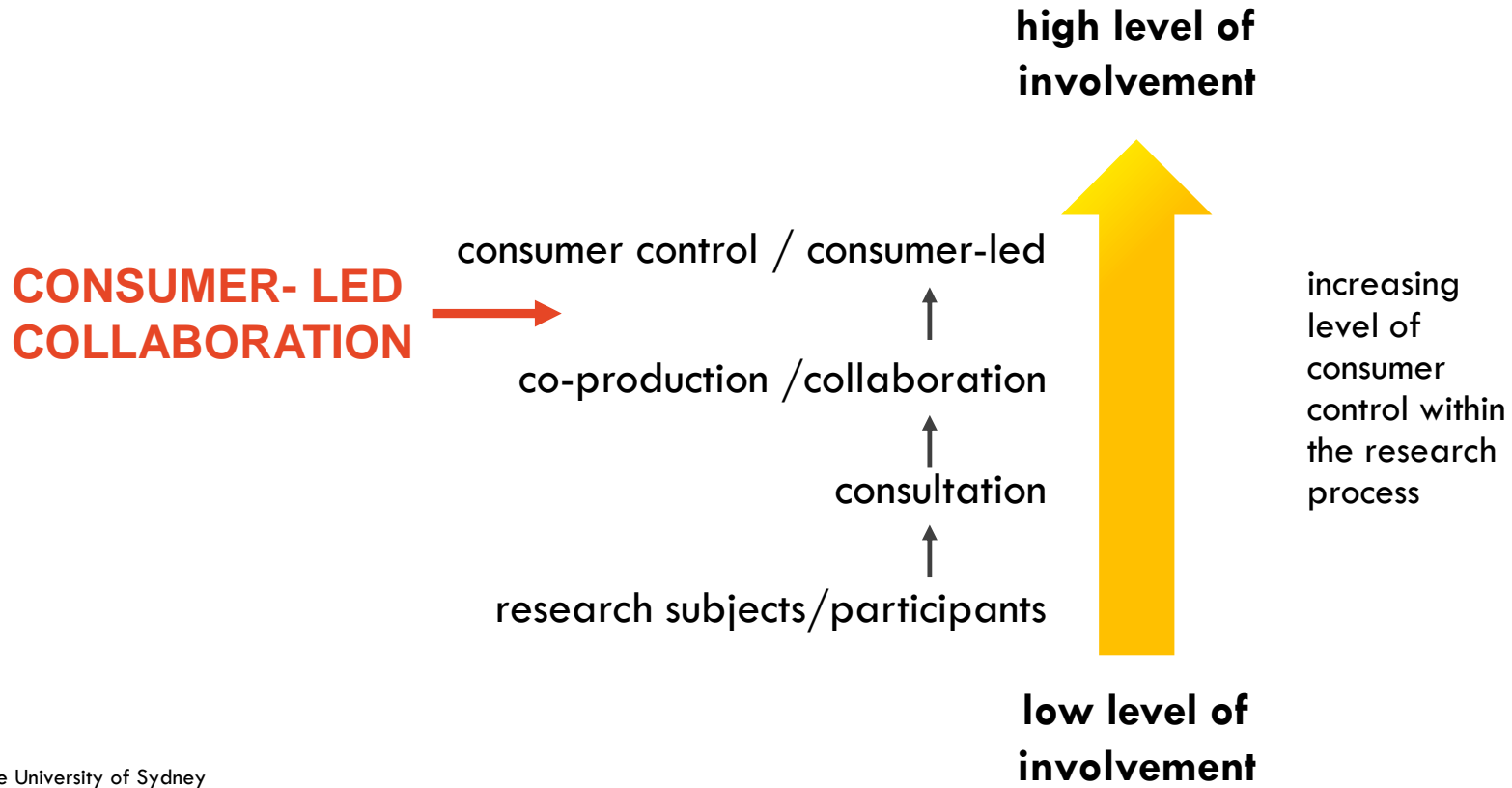
Consumer researchers have a **leading role across the research process:**

research questions; research design; data collection; data analysis, and interpretation
and dissemination of findings

Make the final call but we are a committed resource to draw on

Our role: 'guides on the side' – expert knowledge and experience for the team to
draw upon whenever they need or want it

Levels of Engagement or Participation



Thank you

Nicola Hancock

E: nicola.hancock@sydney.edu.au

T: +612 93519379

M: 0425 254 306



THE UNIVERSITY OF
SYDNEY