

# Enhancing Practice

## 2022 Conference

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*20:20 Vision – Transforming Our Future  
Through Person-Centred Practices*

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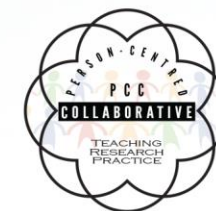
**WEDNESDAY 6 – FRIDAY 8 APRIL 2022**  
**SAGE HOTEL WOLLONGONG, NSW AUSTRALIA**

**#enhancingpractice2022**



**iPDe**

working together  
to develop practice



# Consumers as researchers, an inclusive approach: the challenges and celebrations in pursuit of person-centred research

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## Aims & objective

Provide evidence in relation to adjustment after stoma surgery

Role of nurse facilitated support groups


Describe the trajectory of adjustment that occurs after stoma surgery over the first nine months

Identify important supports that exist currently

Identify gaps in support that can facilitate adjustment

Inform ongoing care of the person with a new stoma for the first nine months

# Stoma Adjustment Study

Phase 1: Stoma adjustment study	Phase 2: Focus group study	Phase 3: Patient interview study
Quantitative	Qualitative	Qualitative
6 time points From discharge to 9 months	Members of Illawarra Ostomy Information Group	New stoma patients 3-6 months post surgery
Ostomy adjustment inventory (OAI-23)	2-3 groups of 6 to ask about their participation in the support group	10-15 ostomate interviews
	Thematic analysis by researcher 	Ask about their adjustment experience Explore ostomy group/peer support
N=230 at endpoint of nine months	With consumers: examine the preliminary analysis of the focus group data  Co-design patient interview study	Interviews conducted by consumers with researcher alongside

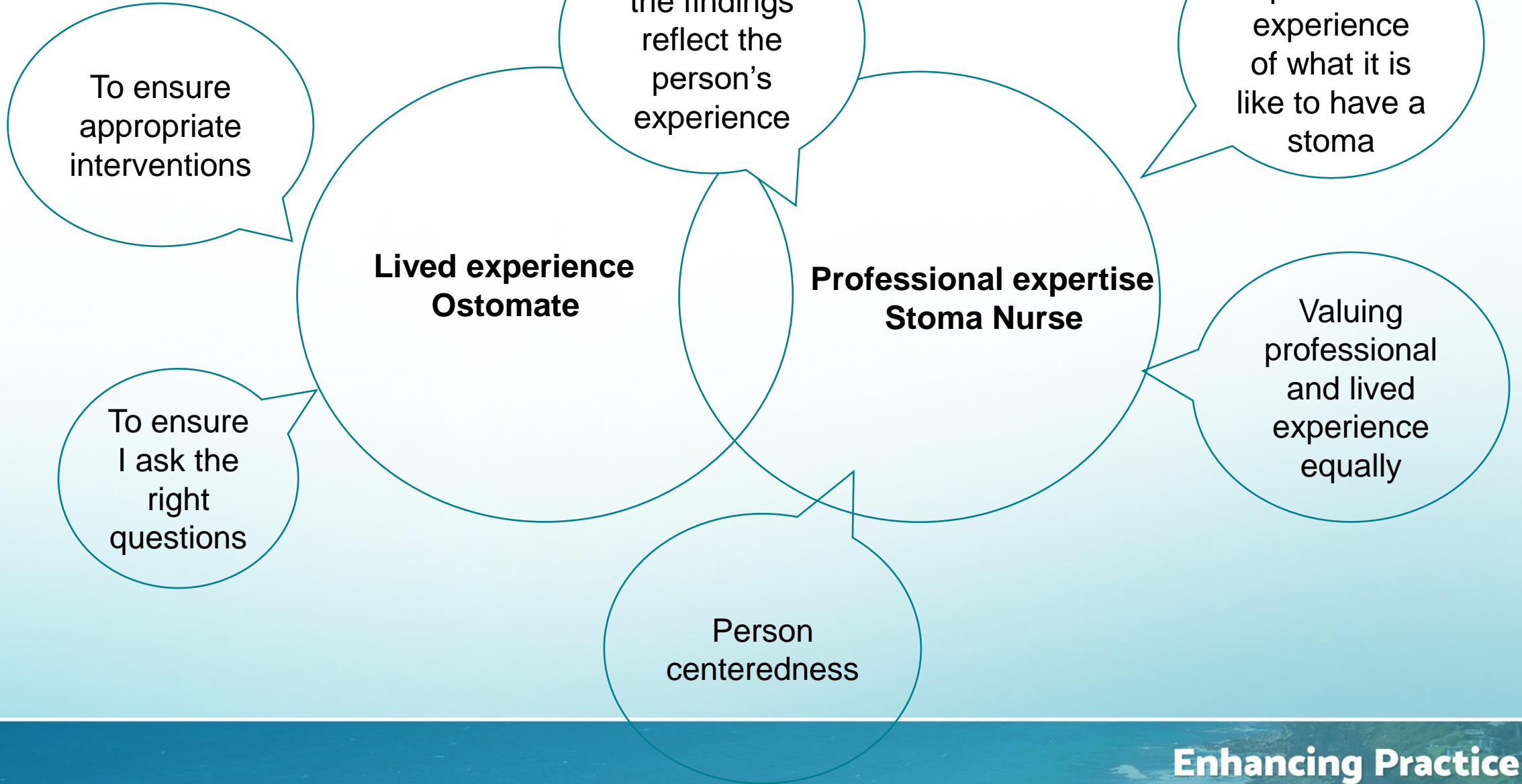
# What is Co-design?

Key concepts of Community Based Participatory Research (CBPR) have been summarised into four stages:

1. building trust,
2. co-creating the project design and co-learning,
3. increasing the capacity of the community and acting together and
4. disseminating the findings and sustaining the project (Bomar, 2010).



# Why Co-design?



# Focus group study

3 focus groups

13 participants

Tape recorded



transcribed

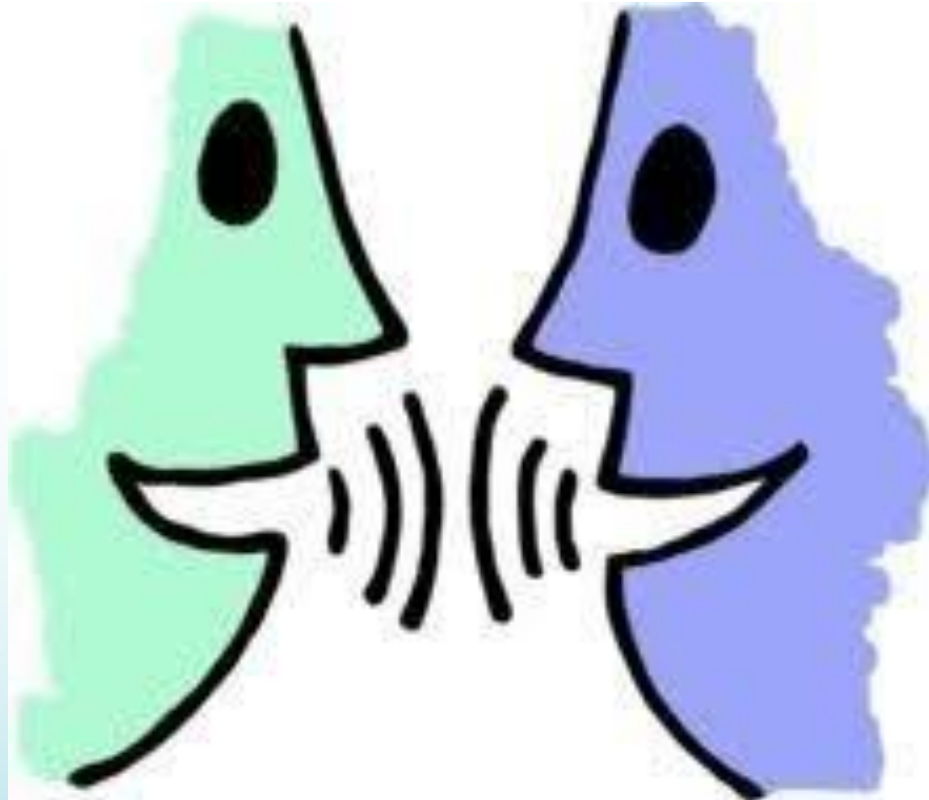


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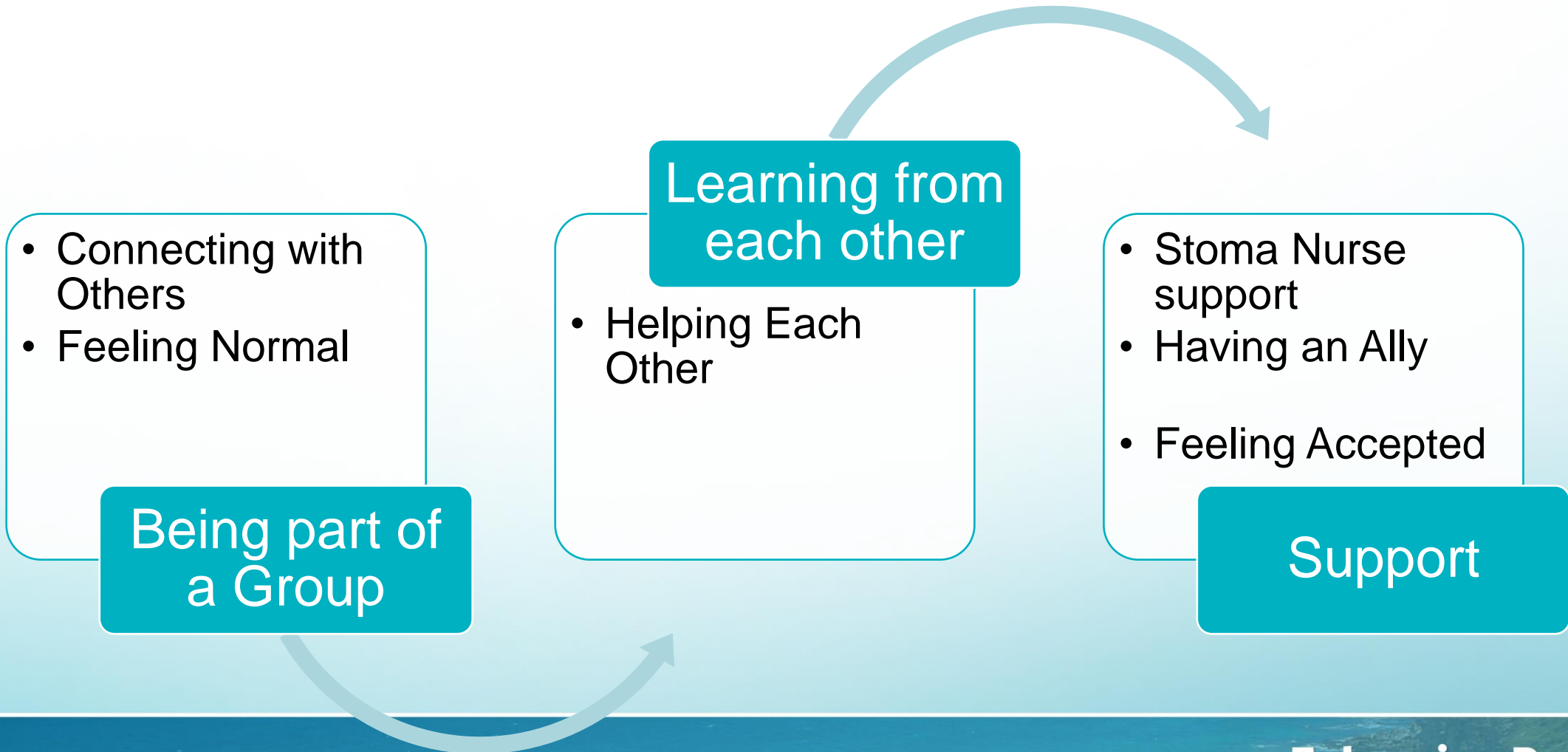
Analysis using Braun & Clarke (2006) 5 step thematic analysis



# Jenny

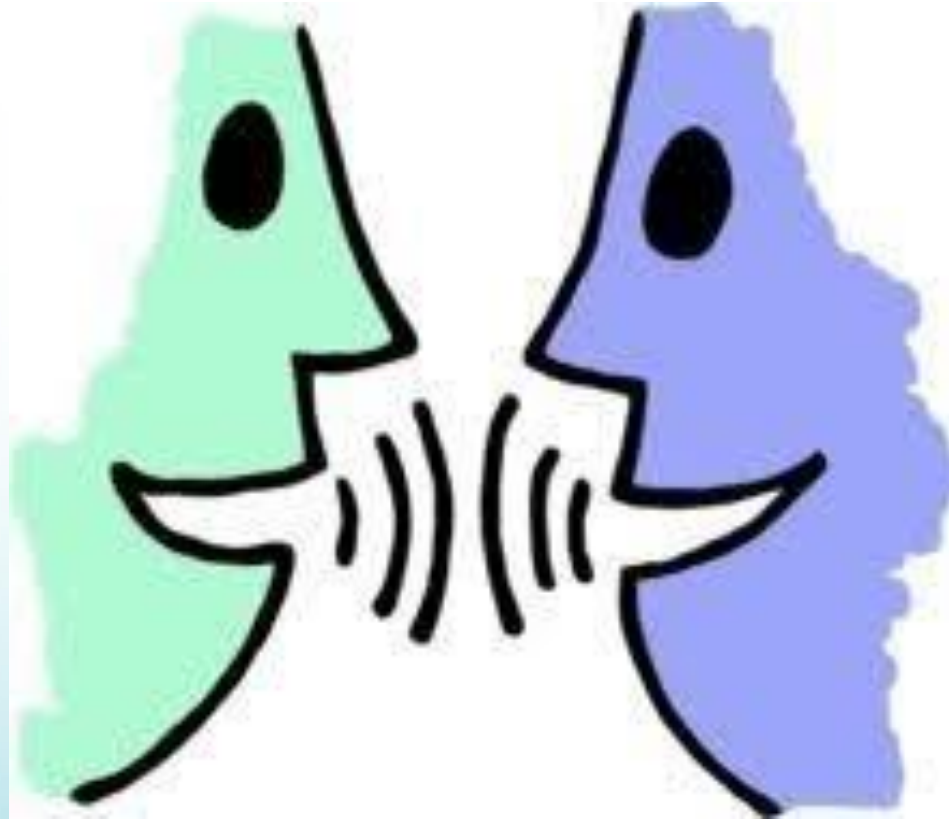


# Review preliminary analysis of focus groups & invitation to conduct patient interview study





# Ian

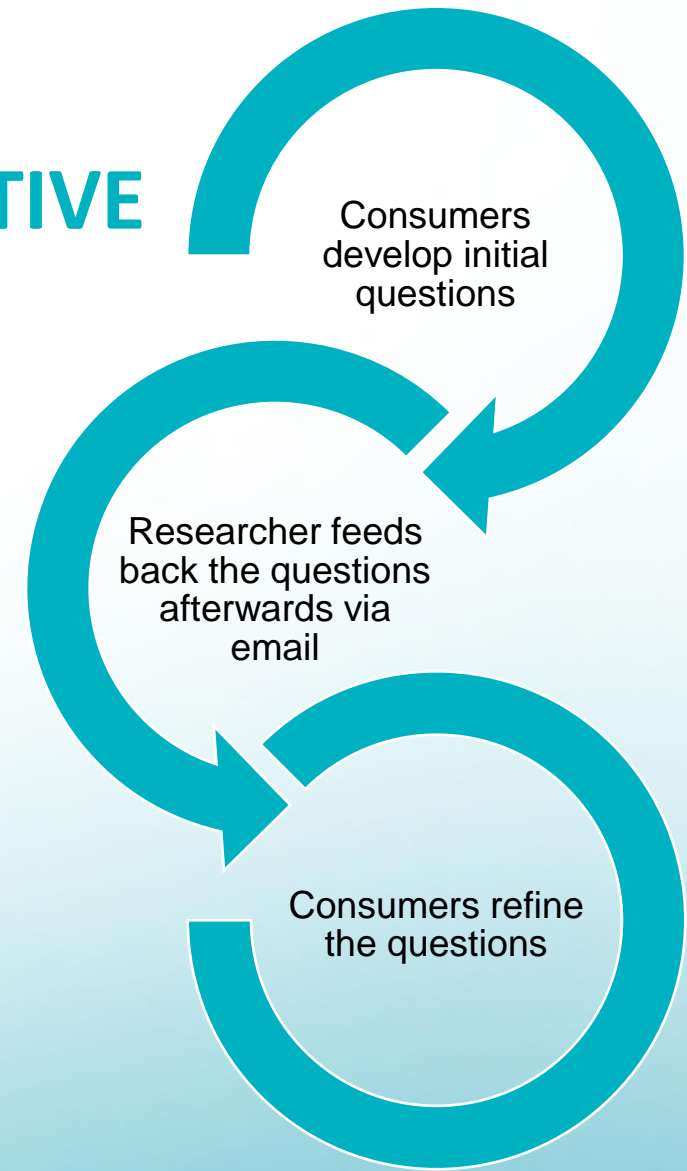


# Review of preliminary analysis, co-design of patient interview study- RESEARCHER PERSPECTIVE

Confirmation of themes- reassuring!!

No hesitation when asked if they wanted to participate in patient interview study

Researching WITH consumers- felt like 'we are in this together'



## What is it like for Karen to be included.....

‘Being asked to participate in research as a consumer makes me feel like my input is valued and will be listened to and evaluated, and that I am not just another number as a consumer. Thus, I am not just a consumer, I have some input into what will be offered and available in the future’.

‘It feels really good to be part of a research study as an ostomate because this field has changed so much in recent times and is clearly continually evolving, so if the people "at the coal-face" can have some input, this will hopefully be valuable for future ostomates. Nobody really knows what it feels like to be an ostomate unless they are one, so if we have input into our treatments, this can only help other Ostomates’.

‘I appreciated being able to participate in the Zoom meeting and ongoing study. It was a good exercise, well-organized and hopefully of value’.

# Next phase - conduct patient interview study together

- Ethics
- Consumer training
  - discuss- the role of the consumer
  - learn- about the research study
  - explore- conflict of interest, confidentiality, distress
  - practice- conducting interviews
- Recruitment
- Conduct interviews
- Debrief
- Ongoing consumer engagement with data analysis



Conducting patient  
interviews with consumers

# What I might have done different

If it wasn't for the contribution of consumers, I would have done the interviews at the 2 week follow-up

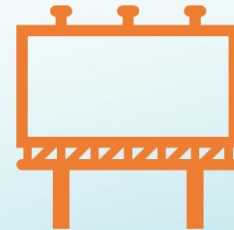
I would have done the interviews in clinic

My questions may not have been as in-depth



# Impact of this innovation

- Strengthen the Illawarra ostomy information group
- Identify strategies to attract the non-attenders
- Enable planning based on findings from the study in relation to psychological support and peer support
- To support development of other services



Codesign with  
consumers

# Lessons learned

It's not all about me- it's all about us

Enriches the experience of conducting research

Consumers will think of things I would not have considered based on their lived experience

Capture the complexity of reality

# Transforming Our Future Through Person-Centred Practices

Always engage consumers- from the start

**We** is better than **me** for all of **US!**



**Thank you  
Jenny and  
Ian**



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