Co-designing for impact: A forensic dive into digital health research to develop a consumer and community involvement framework

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The University of Melbourne acknowledges the Traditional Owners of the unceded land on which we work, learn and live: the Wurundjeri Woi-wurrung and Bunurong peoples (Burnley, Fishermans Bend, Parkville, Southbank and Werribee campuses), the Yorta Yorta Nation (Dookie and Shepparton campuses), and the Dja Dja Wurrung people (Creswick campus).

The University also acknowledges and is grateful to the Traditional Owners, Elders and Knowledge Holders of all Indigenous nations and clans who have been instrumental in our reconciliation journey.

We recognise the unique place held by Aboriginal and Torres Strait Islander peoples as the original owners and custodians of the lands and waterways across the Australian continent, with histories of continuous connection dating back more than 60,000 years. We also acknowledge their enduring cultural practices of caring for Country.

We pay respect to Elders past, present and future, and acknowledge the importance of Indigenous knowledge in the Academy. As a community of researchers, teachers, professional staff and students we are privileged to work and learn every day with Indigenous colleagues and partners.

In making this Acknowledgment of Country we commit to respectful and responsible conduct towards all others according to the Traditional lores of this land, particularly at times of formal ceremony.

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THE UNIVERSITY OF MELBOURNE

POSTERA CRESCAM LAUDE

#1 in Australia
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Times Higher Education (THE) World University Rankings 2022

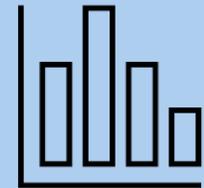**Strategic pillars and cross-cutting workstreams**

Education and Workforce Development	Digital Health Innovation	Health Informatics and Data Science

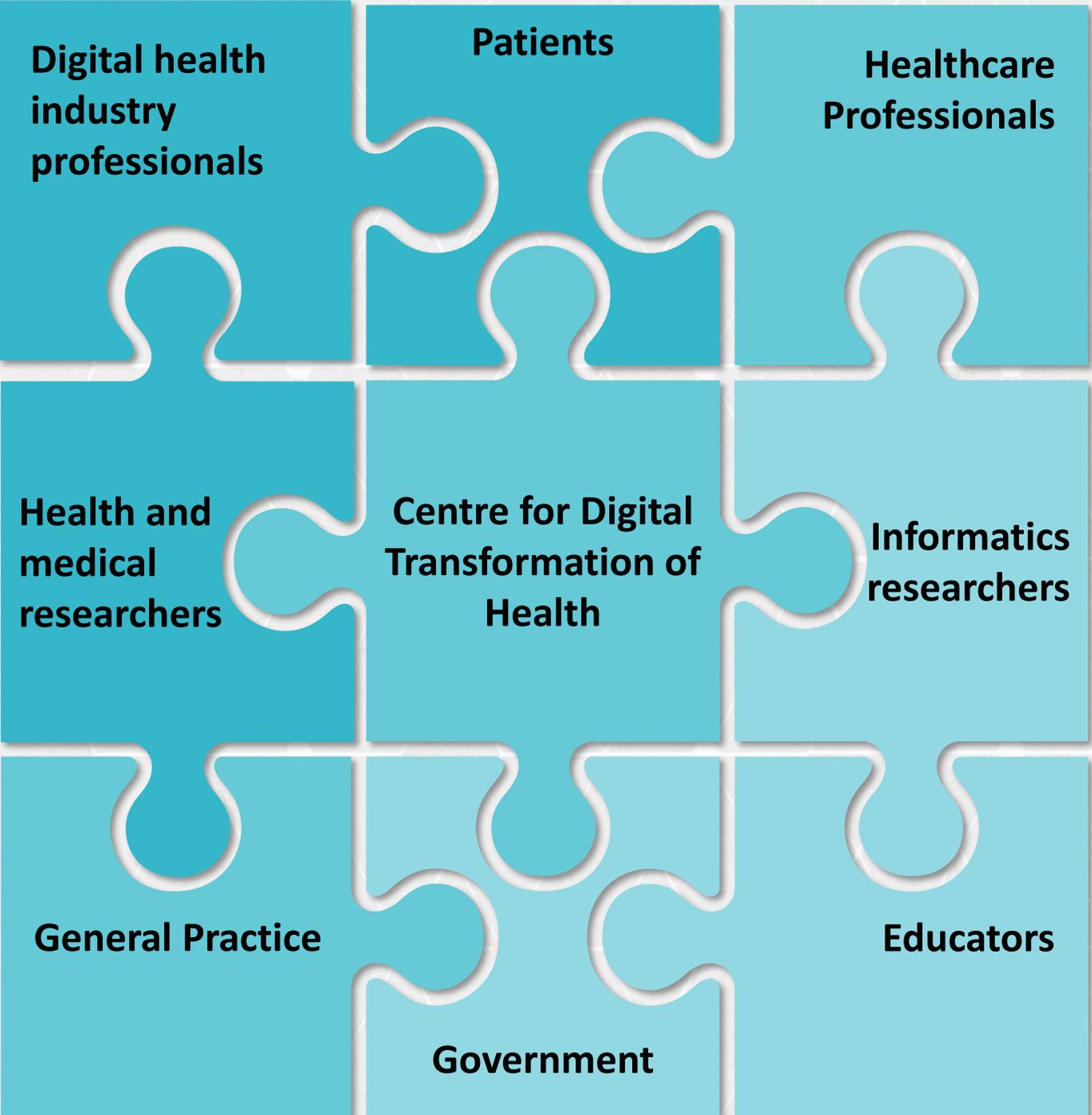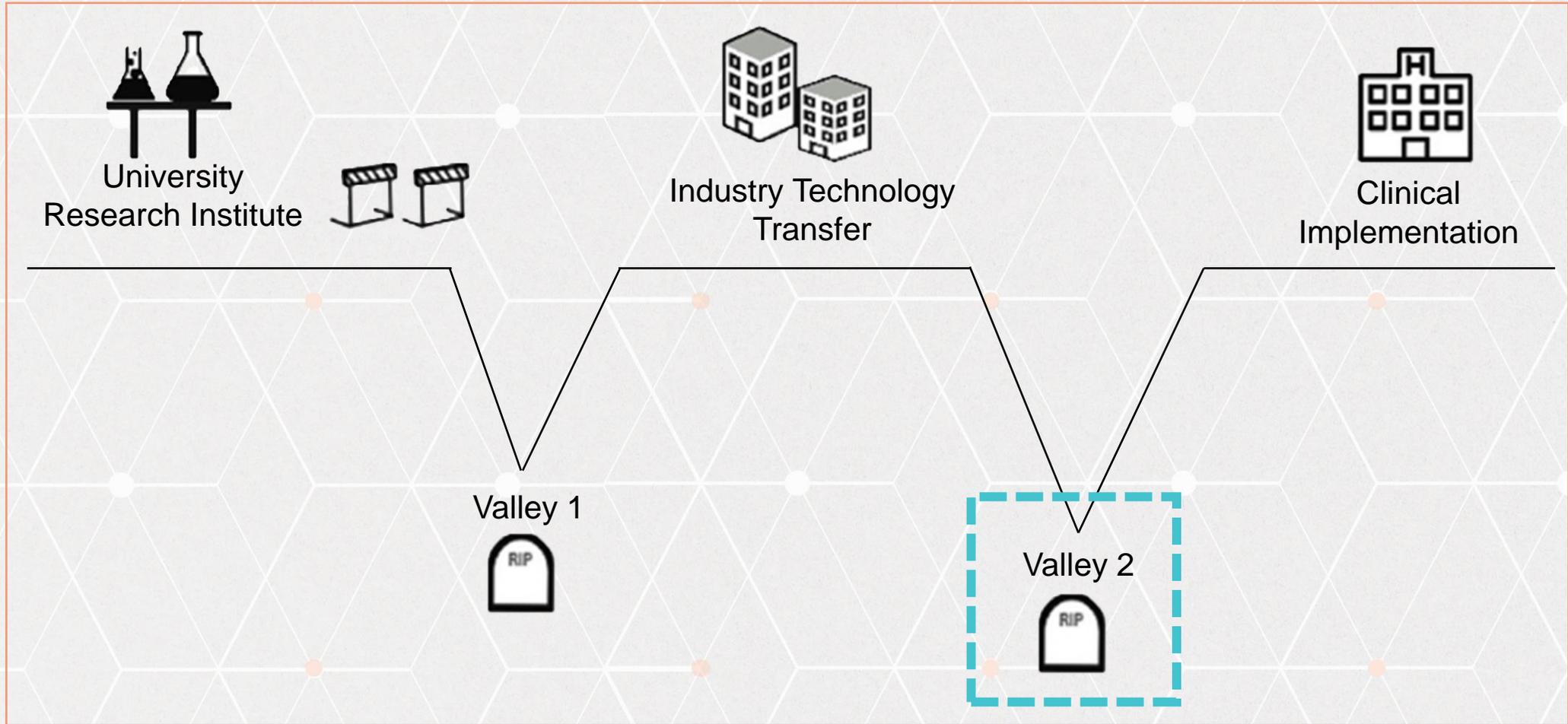Collective Impact Incubator

Backbone

Overcome the second 'valley of death'

Vision CDTH is known as a place where **consumers** have a say in the future of digital health, including how to access, understand and use their data.

Purpose To guide researchers to **actively involve** consumers and community members in all aspects of digital health and health informatics research.

Agenda

Why partner with consumers?

Research Aims

Methodology

Results

Discussion and Conclusion

Why partner with consumers?

- **NHMRC's Statement on consumer and community involvement in health and medical research[1]**
- **National Safety and Quality Health Service Standard[2]**
- **National Institute of Health & Care Research[3]**
- **MRFF's Australian Medical Research and Innovation Priorities 2022-2024[4]**
- **Case Study, Fostering African-American improvement in total health (FAITH!)[5]**

NHMRC

STATEMENT ON CONSUMER AND COMMUNITY INVOLVEMENT IN HEALTH AND MEDICAL RESEARCH

September 2016

WORKING TO BUILD A HEALTHY AUSTRALIA

CHF

NSQHS STANDARDS

NIHR | National Institute for Health and Care Research

Australian Medical Research and Innovation Priorities 2022–2024, MRFF

Case Study: Brewer et al: Fostering African-American improvement in total health (FAITH!)

Research Aims

- Digital health technologies (DHTs) hold great promise for improving patient care but require co-design with end users for success.

- Co-design is the key to delivering person-centred care as it allows **consumer and community involvement (CCI)** in the development of health digital solutions [6].

- Co-design and CCI is widely used in research, but seldom described or evaluated in detail, requiring better description and reporting [7].

- Rapid ethnography (RE) is a way to explore consumer, health service staff, and academic partnerships in research that can produce frameworks and evaluation [8]

- RE is increasingly being used in digital health and human computer internation research [9]

AIM: To codesign a framework for consumer and community involvement within a digital health research centre, aimed at strengthening our capacity to measure and assess CCI impact and excellence.

Methodology

Narrative literature review

Focus Group with CDTH Staff

2 x exploratory focus groups with CDTH staff at all levels

Workshop with Consumers

3-hour workshop with consumers interested in digital health

Consumer-led staff Interviews

45-minute interviews with research staff engaged in CCI

Consumer Community Involvement Framework

Consumer and researcher work together to iteratively synthesis results

Stages of research [8,9,10]

1. **Focus and scope:** Area of exploration was clearly defined as the operationalisation of CCI in a digital health research Centre, avoiding an open-ended, exploratory approach used in traditional ethnography.

2. **Key informants and positionality:** Researcher and consumer stakeholders were included, and positionality was examined and critical to illicit ideas on operationalisation of CCI, data analysis and synthesis

3. **Rich data points using multiple observers:** Several intensive qualitative data collection methods were combined to provide a rich insights and triangulation of concepts

4. **Collaborative qualitative data analysis:** Collaborative and electronic data analysis methods combined to makes sense of the data

5. **Synthesis performed by researcher and consumer:** The framework developed abductively and iteratively, co-designed by a consumer and researcher to agreement.
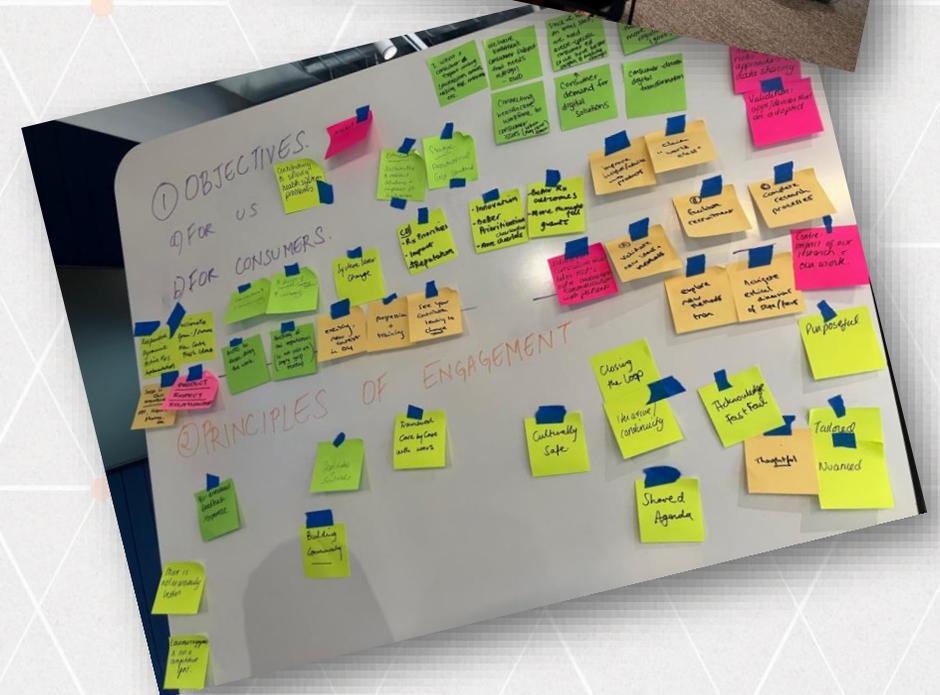
Results

Study 1: Focus groups with staff

Aims of the focus group:

1. Explore recognised benefits of consumer engagement for both researchers and consumers

2. Develop a set of principles to underpin all work across the Centre

3. Describe consumer roles and associated remuneration fees

4. Explore Consumer Engagement Manager role and the role's responsibilities

Benefits for researchers:

- Enhanced local knowledge and consumer centredness
- Support for industry transformation
- Leadership in best practice engagement

Benefits for consumers:

- Sharing their voice and lived experience
- Learning new skills, capabilities, part of a community
- Contributing to digital health
- Working on new projects
- Working with people who respect equity, diversity, and inclusion
- Growing and improving the University's reputation for excellence in CCI

Framework Version 1

Consumer Engagement Manager responsible for Resources and Systems of Evaluation

People: A Diverse Consumer Engagement Network

Roles: Fast Feedback Panel, Lived Experience, Experts in the Patients Perspective, Team Member

Benefits: knowledge exchange, consumer centredness, industry transformation, best-practice

Values: Deliberate and Purposeful, Empowering and Safe, Tailored, Reciprocal and Responsive

Consumer Engagement Research & Leadership Activities

Consumer Engagement Excellence

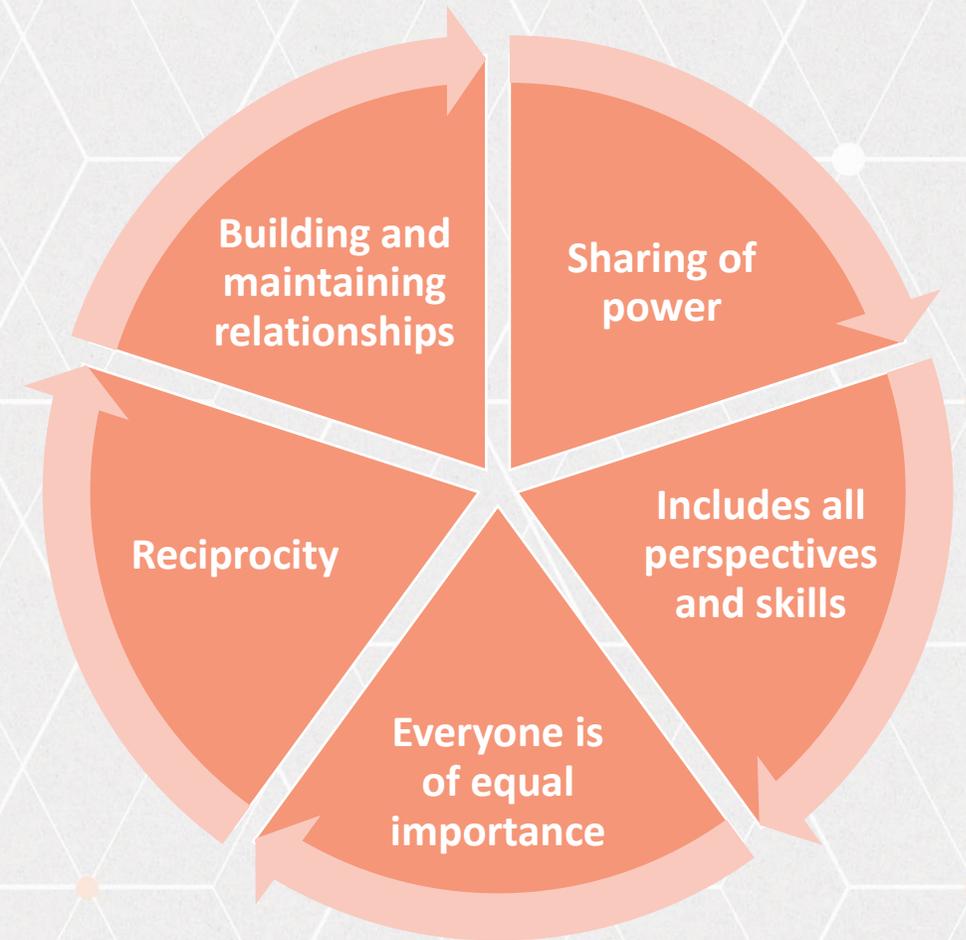**Study 2: Workshop with consumers**

Aims of the workshop:

1. Explore and co-design consumer engagement framework developed by researchers

2. Review and confirm the set of principles to underpin all work across the Centre

3. Confirm and contribute to consumer roles and associated remuneration fees

4. Describe Consumer Engagement Manager role and its responsibilities

Principles of CCI and co-producing research

- **Deliberate and purposeful**

- **Empowering and safe**

- **Tailored**

- **Reciprocal and responsive**

CDTH Centre Workshops, 2023

Building and maintaining relationships

Sharing of power

Includes all perspectives and skills

Everyone is of equal importance

Reciprocity
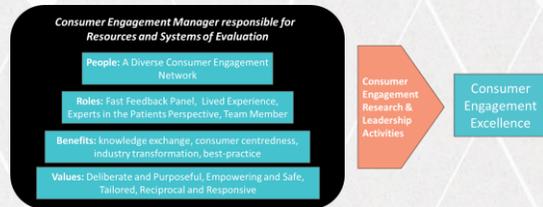
NIHR, Guidance on co-producing a research project, April 2021, https://www.learningforinvolvement.org.uk/content/resource/nihr²-guidance-on-co-producing-a-research-project/

Summary of Questions

Q1. We've provided you with the Consumer Engagement Framework. What stands out to you?

Q2. Values identified by the Centre and the principles of the NIHR. Which do you prefer and why?

Q3. Is there anything else you would like to share about the framework?
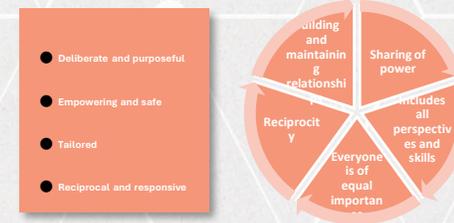
Q4. What would stop us from using this framework? What will help us make the framework a reality?

Summary of Questions

Q1. We've provided you with the Consumer Engagement Framework. What stands out to you?

1. Clarifying what constitutes the framework, importance of concrete actions to implement principles
2. Role clarity and the crucial role of the Consumer Engagement manager

Q2. Values identified by the Centre and the principles of the NIHR. Which do you prefer and why?

1. Necessity for diverse representation, especially from priority populations
2. Maintaining relationships between consumers and researchers

Q3. Is there anything else you would like to share about the framework?

1. Clarity on timeframe for implementation and actions
2. Clear and accessible language so framework is understandable, increasing engagement

Q4. What would stop us from using this framework? What will help us make the framework a reality?

1. Funding sustainability of consumer involvement and those leading engagement
2. Good leadership, authentic and transparent communication
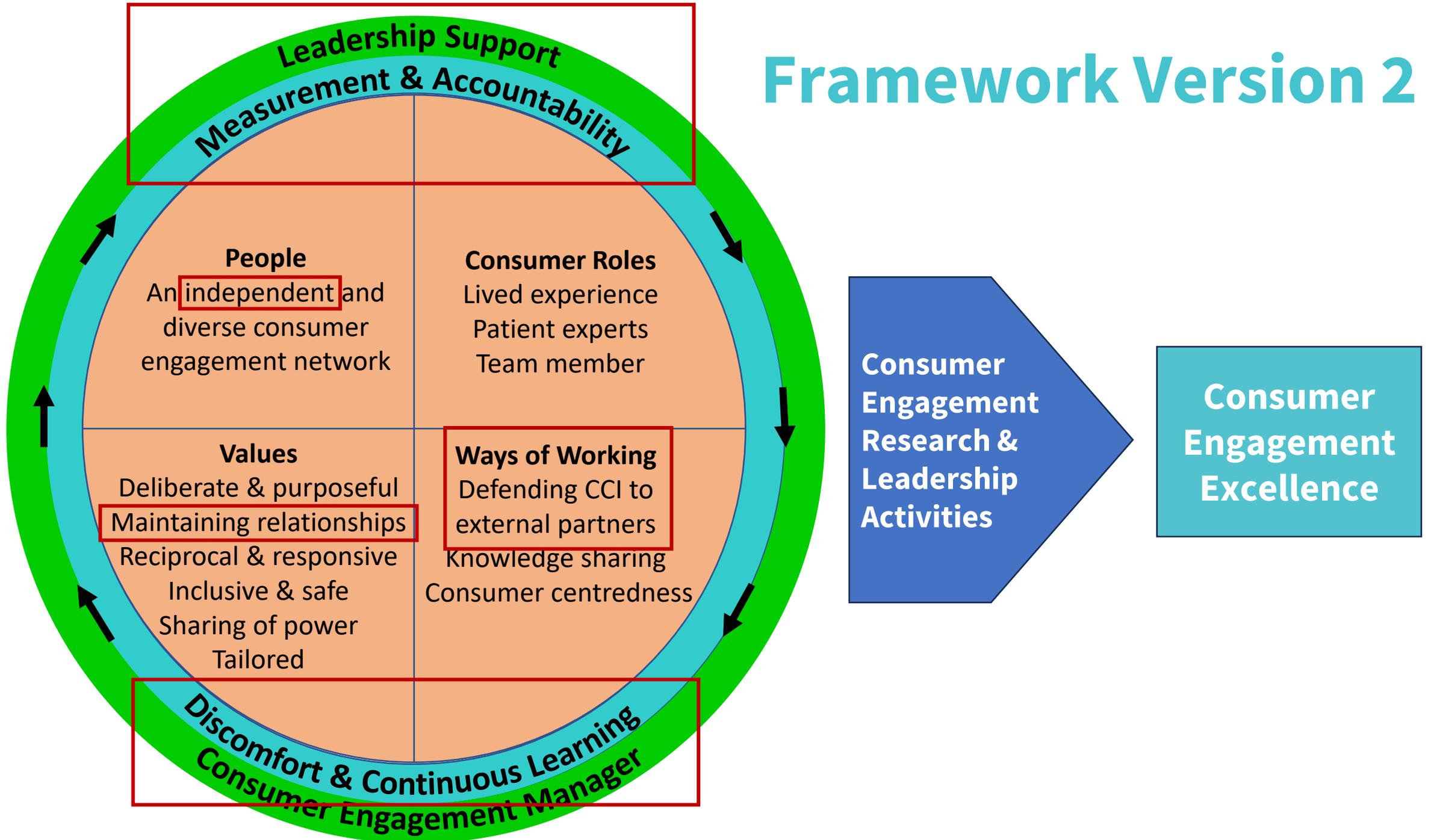
Study 3: Interviews with researchers

Aims of the interviews:

1. Explore researcher experiences of consumer involvement in digital health research

2. Review and confirm the set of principles to underpin all work across the Centre

3. Confirm and contribute to consumer roles and associated remuneration fees

4. Explore if consumer framework is a useful guide for research activities

Framework Version 2

Leadership Support
Measurement & Accountability

People
An independent and diverse consumer engagement network

Consumer Roles
Lived experience
Patient experts
Team member

Values
Deliberate & purposeful
Maintaining relationships
Reciprocal & responsive
Inclusive & safe
Sharing of power
Tailored

Ways of Working
Defending CCI to external partners
Knowledge sharing
Consumer centredness

Discomfort & Continuous Learning
Consumer Engagement Manager

Consumer Engagement Research & Leadership Activities

Consumer Engagement Excellence

Discussion & questions

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