

“What is Consumer Led Research” a consumer view

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My background

“Consumer Led Research”

- Dual stream cancer patient, active in pro-bono consumer representation in health service decision making, for the past 7 years.
- Engaged in cancer research for the past 6 years:
 - Representing consumer lived experience actively alongside researchers, and
 - A consumer voice on strategic governance and steering groups across the Melbourne Parkville precinct.
- The term appears to come from Mental Health over at least 20 years.
- Defined differently in many quarters – at the minimum, any consumer engagement/partnership/co-design is extremely welcome, to produce better research and patient outcomes.
- My current definition - **“research which includes consumers in active governance roles, potentially being active associate investigators, and active authors of the outcomes.”**

Examples of Consumer Led Research

- The Research Australia magazine INSPIRE Issue 21, September 2021–
“**The consumer’s role in Health & Medical Research**” is an excellent 72
page compendium of examples from across Australia. (freely available
online - https://issuu.com/researchaustralia/docs/inspire_issue_21).

- They summarise ...

“The myriad benefits of consulting with the consumer include greater accountability, improved quality and outcomes, decreased costs, more effective research translation and improved public confidence in research.”

A recent example

- The **CanEAT pathway** development and implementation.
 - Aim was **to reduce malnutrition** in all streams of cancer patients using trusted sources of nutrition information.
- An initiative of the Victorian government, with PMCC providing statewide leadership and project management. (Hat-tip to Jenelle Loeliger and her team.)
- Consumer involvement was at three levels
 - **Governance** – joining statewide representation from health services, GPs, and MU Implementation Scientists, were 2 consumers.
 - Focus groups and workshops providing valuable **advice** and feedback on the resources produced, (some 40 consumers), and
 - Patient and carer **questionnaires** for baseline and effectiveness evaluation.
- Stage 1 of the project developed the resources,
- Stage 2 was the implementation of the resources into clinical practice. This was effectively:
 - an Implementation Science intervention, using experience-based co-design (EBCD) methodology, and
 - Trialling acceptability of 47 new graphicly designed resources at 7 implementation sites in both health services and primary care.
- The 2 governance consumers in the project were active members of the statewide governance committee and actively involved and named in the project publication across many forums.

A forward looking definition

- ❑ **My view of the components of a great Consumer Led Research project can have the following key ingredients for success:**
 - ❑ A reasonable budget
 - ❑ Strong institutional commitment to enabling Consumer Led research
 - ❑ A consumer only governance structure
 - ❑ An education framework to empower the consumer governance
 - ❑ Consumers reviewing submissions from researchers and selecting an area of research
 - ❑ Consumers defining the research question and determining the approach
 - ❑ Consumers engaging Researchers to conduct the research
 - ❑ Consumers being accountable for the proposal, the conducting of the research, and the publication of results.
 - ❑ A reasonable time period, say 2-3 years, for a modest project.

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Thank You