

Involving Health Consumers in Health and Medical Research

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www.hcnsw.org.au

Research Partnerships in Western Sydney

WentWest

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Health Consumers NSW

is the state wide, independent, member based charity that provides a voice for people using the health system (health consumers) to shape health policy, services, and health and medical research in NSW.



Nothing about us without us!

Definition

Consumer engagement [*involvement*] is the active public involvement in research priority setting, question development, methodological choice and translational inquiry.

Anderst et.al. (2020)

Benefits of Involving Consumers in Research

To the public

- Relevance to community
- Public awareness
- More effective translation of research

*Nothing about us
without us*

To researchers and research institutions

- Ensures research priorities met public expectations
- Public confidence / ownership of results
- Increased participation

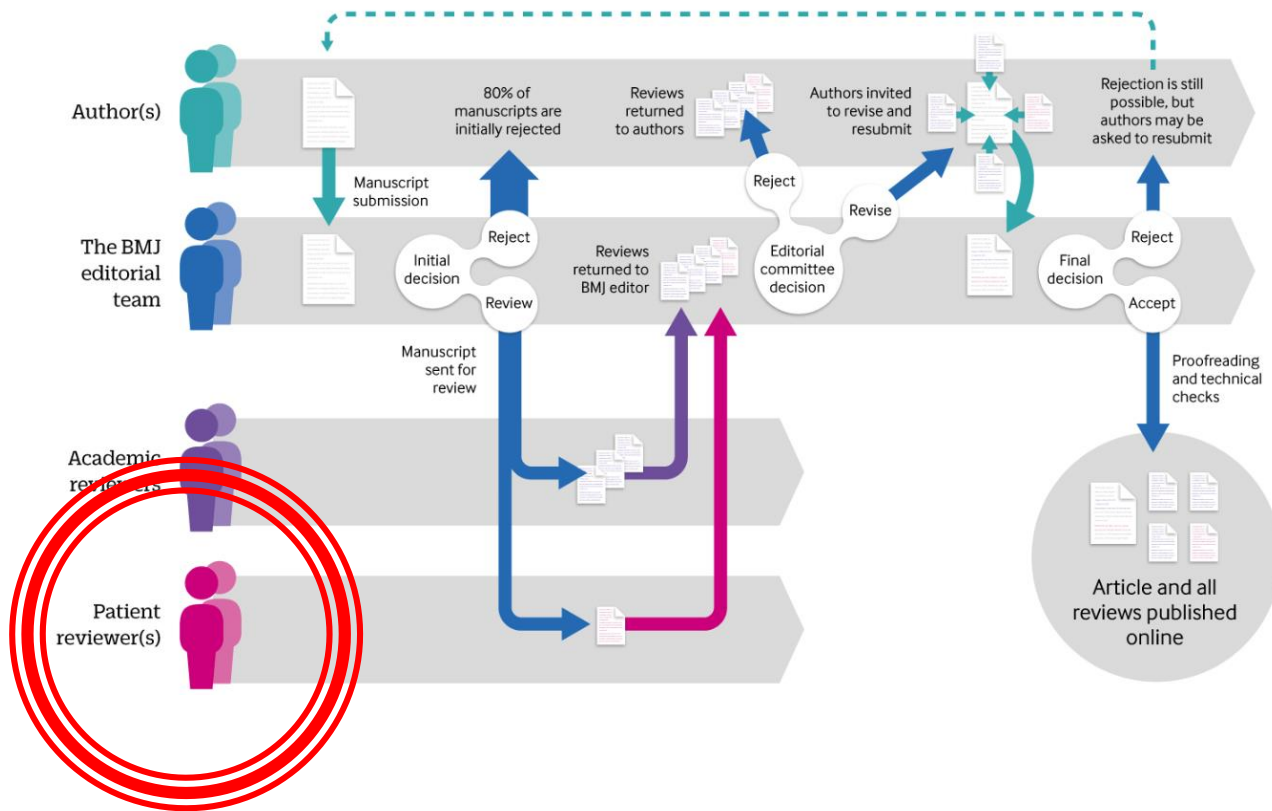
R4Me, HCNSW (2017)
Howe (2018)

Why Involve Consumers in research?

- Benefits / evidence
- NHMRC – funders
- Journals – BMJ
- Growing consumer expectations



Outline of **thebmj** review process



BMJ website

Patient
reviewer(s)



Guidance for BMJ Patient and Public Reviewers

Patient and public review at *The BMJ*

If you're a patient living with disease or have experienced a significant illness or medical condition, a carer of a patient, a patient advocate acting on behalf of a patient group, or you play a leading part in advocating for patient participation and partnership in healthcare we'd like to invite you to take part in a unique initiative. *The BMJ* has committed to improving the relevance and patient centredness of its research, education, analysis, and editorial articles by asking patients to comment on them. We need your help to make these changes.

If you already review for *The BMJ* as a researcher or clinician, but you are also interested in reviewing as a patient, carer, or patient advocate, you can do this too.

BMJ
website

Involving Health Consumers in Research

Published 2017

Partnership with



What impacts on Consumer Involvement?

- 1. The type of research**
- 2. Consumer Availability**
- 3. Funding Consumer Involvement**
- 4. Finding the 'right' consumer**
- 5. Consumer training and support**
- 6. Researcher Beliefs and Culture**
- 7. Researcher Training**
- 8. Clarity around roles and expectations**
- 9. Language**

Key themes from consumers

- Being Valued and Listened to
- Support and Training for Consumers
- Training of researchers
- Being involved throughout the research cycle
- Involvement at all levels of research / across all levels of engagement
- Improved Communication - Researchers & Consumers
- Use of technology

What can consumers do?

- Be more involved in the ethical review of projects
- Better understand consumer experience of clinical trials
- Create standing consumer panels
- Develop a guiding set of principles of around engaging consumers research
- Create a consumer involvement logo or tick

Partnership with SHP



- Advanced Health Research and Translation Centre
- Translating research into evidence-based healthcare
- Sydney, Northern Sydney and Western Sydney LHDs; the Sydney Children's Hospital Network (at Westmead), the University of Sydney and ten affiliated medical research institutes

Project

Project with HCNSW

- Mapping consumer and community involvement in SHP
- Identifying best way SHP and HCNSW can add value
- Will develop training (for consumers and researchers)
- Identify additional resources / structures

We want to hear from you!

We want to hear from people in Western Sydney about consumer involvement in research.

Open to both consumers and researchers.

www.surveymonkey.com/r/involvinghealthconsumersinresearch

*survey closes **Friday 11 September***

References

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