Framework for Consumer and Community Engagement for the South Australian Health and Medical Research Institute

Introduction

This Framework for Consumer and Community Engagement for the South Australian Health and Medical Research Institute (SAHMRI) has been developed by the Health Consumers Alliance of SA (HCA). The Framework has been developed in partnership with SAHMRI, health consumers, and staff researchers as members of a Partnership Reference Group.

Examples of strategies for the engagement of consumers in health and medical research were identified in Australia, Europe and North America. Evidence on the effectiveness of consumer engagement strategies in health and medical research is limited and this may present an opportunity for SAHMRI. Among the key stakeholders involved in the project there is broad agreement about the importance of consumer and community engagement in health and medical research. The opportunity and need to build the evidence base in this area was also noted.

Conclusions from the literature

Benefits and challenges of consumer participation in research

There is evidence about the contribution that consumers make to research projects. That evidence highlights both benefits and challenges from the perspective of both parties:

Benefits for researchers

Benefits identified for researchers (and the research process) include: enhanced scientific and ethical standards; improved research outcomes and translation of research; enhanced legitimacy and authority to the research; assistance with sensitive issues; a fresh/independent perspective; strengthening of communication with consumers and the community; and an increase in work satisfaction among researchers engaging with consumers.

Benefits for consumers

In addition to the above benefits for consumers in general, benefits identified for individual consumers engaged in research include: acquisition of new skills and knowledge; personal development; support and friendship; enjoyment and satisfaction; increased research literacy; and (sometimes) financial gain.

Challenges for researchers

Challenges for researchers include: concerns about pressure to diverge from scientific methods therefore raising ethical dilemmas; new relationship dynamics; time and cost; lack of training in how to engage consumers; and limited knowledge of and skills in working with consumers.
Challenges for consumers

Challenges for consumers include: tokenism; unfamiliar research language and jargon; power imbalance and conflict; emotional burden; work overload; personal exposure through the media; and frustrations at the limitations of participation.

Building consumer engagement competence

There are some critical factors required to build consumer engagement competence in a research organisation. These factors have been shown to contribute to success in consumer engagement in health and medical research.

Governance

Appropriate structures within a research organisation are required to facilitate the engagement of consumers in health and medical research. A research organisation needs to have policies that encourage and support researchers to engage consumers in their research. Resources and funding are required to encourage and support consumer participation.

Infrastructure

A range of infrastructure is necessary to support consumer engagement including registers of people interested in advising or contributing to research projects; and quality information materials that explain the roles that consumers can play in the organisation, how their participation is supported, and how their contribution to health and medical research can make a difference.

Capacity

Activities that build the capacity and skills of both researchers and consumers are vital to the success of any approach to consumer engagement. This includes training for both researchers and consumers on how to work together. The literature suggests that partnerships are likely to work best when all parties are clear about their intentions, assumptions and limitations from the start.

Advocacy

Consumer-researcher collaborations require planning and perseverance and these partnerships are reliant on a level of human interaction between people who are not necessarily like-minded.

Persistence is required for consumer engagement to be sustained, accepted, and integrated as a natural part of the life of a research organisation. Advocacy from consumers and from researchers is essential to maintain the effort and build organisational culture, both from within the Institute and from outside.
A Consumer and Community Engagement Framework for SAHMRI

For an engagement framework to be successful, advocacy and agenda setting from the leaders of an organisation is required. This is very evident in SAHMRI by the championing of consumer and community engagement by the Executive Director and Research Executive; by the funding of this project by the Institute; and by the striking unanimity of support for consumer engagement expressed by the Research Theme Leaders in their interviews.

Following synthesis of the literature review, interviews and workshop recommendations a Consumer and Community Engagement Framework for SAHMRI has been constructed and is composed of four organisational domains adapted from Saunders and Girgis (2011). The Framework is encircled by the IAP2 Levels of Participation, identifying the different levels of engagement that may be utilised. Finally, the three phases of health and medical research identified by Shippee et al are presented, connecting the Framework to the Phases and Stages of Research. A diagram summarising the Framework is provided in the figure below.

Framework Domains and Elements
References


Johnson A. What strategies for consumer engagement in health and medical research have been effective for consumers and researchers? A review of the literature. Health Consumers Alliance of South Australia. 2013.


Saunders C and Girgis A. Enriching health research through consumer involvement – learning through atypical exemplars in Health Promotion Journal of Australia 2011: 22(3).


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Consumers at the centre of health in South Australia