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What researchers think of involving consumers in health research

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Does it take one to know one?

Doing consumer-focused health research

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Background

Health service users' involvement in research has traditionally been as 'object', with little consultation about how research problems are defined and prioritised. In a period of ever decreasing research resources, there is increasing pressure to conduct research that has genuine translational value.

Consumer involvement in research is evolving towards a more meaningful space, beyond one in which they are mere objects of enquiry, to one where they are actively included in all aspects of the research process and its translation. However, their inclusion continues to be challenged in some sectors of the health research community. This is particularly so for mental health research, but is apparent across research with health service users populations more broadly.

Objectives

This study seeks to investigate the range of issues and arguments for greater involvement of health consumers in the planning, conduct, evaluation and translation of research. To do this, a brief survey of health researchers is being conducted.

The survey includes the following questions:

- 1) What are your perceptions of what is meant by service user involvement in research?
- 2) Do you believe that one needs to have direct experience of an issue to do effective research about that issue?
- 3) To what extent do you involve service users within your research projects?

Assumptions

By actively including health service users in the research process, translation to practice will be more authentic and effective and recruitment rates will improve. Such research can investigate the difficult issues that confront the health sector, with honesty and greater potential trust arising from collaboration between researchers, service providers and service users. Failure to genuinely include service users in research can lead to the perpetuation of rhetoric-laden, token outcomes. This wastes valuable research resources, hinders effective translation, and stifles efforts to improve delivery of care.

Prof Til Wykes, King's College London:

'A third of clinical trials fail to reach their recruitment target.'

'Studies that included collaboration with patients in designing or running the trial, initiated by researchers, were 1.63 times more likely to recruit to target than those that only "consulted" patients...Studies created through the highest level of patient involvement...were 4.12 times more likely to recruit the requisite number.'

Kofi Annan

No man's knowledge here can go beyond his experience.

John Locke

The knowledge of the world is only to be acquired in the world, and not in a closet.

Philip Dormer Stanhope

You have to live to really know things.

Dan Simmons, Hyperion

Those who see things grow from the beginning will have the best view of them.

Aristotle

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