MEASURING IMPACT OF INVOLVEMENT IN RESEARCH: VIEWS OF SERVICE USERS

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Background

There Is increasing interest from researchers in evaluating public involvement by service users in health and social care research with debate about the feasibility of doing this. Discussion is led by researchers.

Objectives

This poster describes service users' views about whether evaluating impact of public involvement in research is feasible and helpful.

Methods

19 patients and carers were interviewed. All were members of the SUCCESS service users group supporting emergency, unscheduled and trauma research. Some had regular involvement in research studies about prehospital emergency care and chronic conditions management to reduce people's risk of using unscheduled services.

SUCCESS
Service Users with Chronic Conditions
Encouraging Sensible Solutions

The SUCCESS model supported service users to be involved in research about emergency care and chronic conditions management. All were members of a pool which researchers contacted to recruit patients and carers. Over seven years, members were involved in more than 200 research activities and projects including developing research proposals, managing funded research studies, preparing data collection tools, analysing data and disseminating findings. They worked with academics and partners from organisations managing and delivering health services.

Results

What involvement means to service users

Involving patients and carers in research gave value to experiential knowledge and placed this alongside clinical and academic knowledge.

> *I see it as a way of giving information to somebody who might give it to somebody who could appreciate it and maybe make some difference...all I can do is give my knowledge and experience and information*

> *If you don't include the patient in the scheme of things, something goes wrong because nobody understands somebody's body as you do*

What involvement means to research

Involving service users in research was seen as a radical approach because it challenged hierarchical relationships between academia and patients and carers.

> *(Academics) come down...(service users) come up ...and meet halfway*

> *You're taking another point of view on board...you don't want to be so tunnel visioned on what you're doing that you ignore the wider issues*

> *(Academics) taking a few moments to think what we are thinking*

Service users said that involving people in research changed research because it changed structures, relationships and, consequently, affected the results.

> *I think we've got a group of people who are starting to make some impact and starting to demonstrate an ability which is starting to be valued by the research community*

> *You've been dealing with people with chronic conditions and the way you see them must've changed your views*

Challenges of measuring involvement

Service users found it difficult to identify their impact on research. They questioned whether it was possible to measure the impact of their involvement. They recognised it was challenging to identify how their presence and their input ultimately affected decisions about the research. Involvement over the long timescales of research also made this difficult.

> *(My input) improved the reporting but whether it had any long term impact, I don't know*

> *In a very small way, it does help the meeting. Those questions wouldn't have been asked if we weren't there*

Because service users input was based on experiences and opinions, they found it difficult to know how much weight it carried.

> *A different perspective, that's the only thing I can give. If I'm doing engineering, its all absolutely cut and dried. This boils down to opinion and attitude*

They also doubted they could recognise impact on research studies, without insider knowledge of research.

> *I'm not awfully clued up about the difference, the ways of researching*

Conclusions

Service users believe involvement processes are key to ensuring that patient and carer views are included when designing and undertaking research, suggesting impact on research is a consequence of effective collaborations rather than an aim in its own right. This focus on process contrasts with academic emphasis on impact and needs to be considered when discussing whether and how to measure impact.

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