

Involving service users as co-learners in research about quality improvement, interprofessional education and back pain - the service user perspective

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Background

The personal experience of service users who are involved in research is rarely reported in study findings. We describe an exploration of service user involvement that builds on a larger study evaluating an interprofessional educational initiative. Primary health care teams worked alongside service users to learn about the clinical management of back pain, quality improvement and implementation.

A gap in the evidence

What is it like for those who get involved?
What is the service user perspective?
What can we learn about their experience of being involved in research?
Could our learning about the experience be relevant to future involvement activities?

Methods

Semi structured interviews with service users were undertaken and analysed thematically and integrated with data from the larger study.

The patient experience



Support for service users contributes to a positive experience. This includes provision of information including web-based support, making time and peer support.



Creating the right environment, agreement of ground rules and stating clear aims for involvement are all important factors influencing the service user experience.



Commencing involvement early, communication about possible expectations, and showing respect are important for the service user experience.



Experiences are different and not everyone benefits and this should be communicated at the recruitment stage

We learnt that

Involving service users in research can lead to attitudinal and behavioural change in relation to the value of service user involvement in clinical practice.

Important features included: renewed understanding, the importance of time to listen, and the gains from “being on the other side.”

Themes



We suggest that

We need to be prepared to embrace and utilise the wealth of knowledge and experience held by service users and encourage them to take the lead in influencing change.

It is important that we know about what is important to service users and how they feel.