Public involvement in a NIHR CLAHRC West research project:

Study title: Engaging patients meaningfully in self-harm research

Less than 10 per cent of service users who go to hospital emergency departments in Bristol following self-harm agree to take part in research. We don't know why this is. It may be because of ongoing distress, but could also be because research does not seem relevant or important to service users.

Every year in the UK, more than 200,000 people visit hospitals following self-harm, and people who self-harm are more likely to die by suicide. Research focused on this group is vital, to reduce distress and risk of suicide. But levels of participation in this kind of research are low.

The project

We worked with the Improving Care in Self-Harm Health Integration Team (STITCH HIT), part of Bristol Health Partners, on a project to engage patients meaningfully in self-harm research. The project aimed to:

- Find out how to improve the recruitment of service users to self-harm research studies, by identifying what helps and what stops service users from taking part
- Identify and start to develop research outcomes of importance to service users

The project team included researchers from Bristol and Exeter universities, CLAHRC West, health professionals who work in emergency departments with people who self-harm, and staff working in user-led organisations and self-help groups for people who self-harm. It was led by Kyla Thomas from Bristol University and Sabi Redwood from CLAHRC West.

This study is central to STITCH's ongoing work to transform understanding of self-harm across the health service, and improve treatment and support for self-harm patients. It also has the potential to influence a number of researchers who specialise in self-harm research.

What did we do?

The study began with an involvement phase, where service users were asked to advise the team on research aims. This phase of the project was led by Rosie Davies, the Research Fellow for Patient and Public Involvement with CLAHRC West.

Key partners on the steering group and in phase one of the study were staff with personal experience of self-harm, from two third sector organisations: Self Injury Self Help (SISH) in Bristol, which provides a self-injury support group, monthly wellbeing workshops and training, and Self Injury Support (SiS), a UK-wide charity providing support for women and girls, and training on self-harm. We developed detailed plans for the first phase with these partners, who also helped to facilitate involvement. Rosie is also a service-user researcher with personal experience of mental health problems, so the first part of the study drew strongly on service-user expertise.

The involvement opportunity was advertised widely. The flyer was given out to people attending two hospital emergency departments, and contacts were made through crisis services in Bristol. Information was sent out in the regional public involvement initiative People in Health West of England's newsletter, and via SISH and SiS emails and updates. A broad selection of mental health

services, Healthy Living Centres, and voluntary organisations were also contacted about the opportunity. It was important to use a wide range of contacts, as this group of people often do not engage in research.

These strategies resulted in 17 inquiries about contributing, and 12 people in total were involved, eight women and four men. People who got in touch were offered a variety of ways to contribute, including attending a discussion group, or contributing individually by email, telephone or face to face. Information about the project was sent to all those involved, including a written brief for those who did not attend discussion groups. Seven people took part in group discussions (four men and three women), five took part by email or in a one-to-one discussion (all women). A number of dates for discussion groups were offered, and everyone who contributed was given a £20 voucher as a thank you, plus travel expenses.

Of the 12 people who contributed, eight had attended an emergency department for self-harm. Four people identified more with self-harm as a coping strategy for emotional distress. Seven said their self-harm was both a coping strategy for emotional distress and also identified with self-harm with the intent to die. Only one identified suicide as the main intent for self-harm.

Information collected in the involvement phase was collated and analysed by Rosie with colleagues from SISH and SiS. The preliminary analysis was discussed with the project's steering group in April 2016. A report of the findings from the first phase has been produced, and a short summary of this report was sent to all those who were involved. We held a meeting to discuss the summary, providing another opportunity for feedback for those who contributed to the first phase. The planning and conduct of phase two will be based on the information collected in phase one, and the follow up involvement meeting with public contributors will help to refine and develop these plans.

What's next?
The next phase will explore what helps or prevents people from taking part in self-harm studies, to identify and develop research outcomes of importance to service users. The second part of the study will be a qualitative interview-based study, led by Sabi Redwood and Fiona Fox from CLAHRC West. The key partners with personal experience of self-harm are continuing to work with us to conduct phase two.

As well as generating information, phase one of this study has developed links with a group of service users who are willing and interested in contributing to future self-harm studies. This will help to increase the diversity of involvement over time. The project team has made particular efforts to include men's experiences. This first phase has shown the potential of involving service-user researchers more in self-harm studies, and if this is pursued we would be able to further develop involvement capacity and individual's skills.

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