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NHS National Institute for Health Research

Example 9 : A multi-centre programme of clinical and public health research to guide health service priorities for preventing suicide in England

About the research

Lead researcher: Professor David Gunnell, School of Social and Community Medicine, University of Bristol, working with Professor Nav Kapur, University of Manchester and Professor Keith Hawton, University of Oxford.

Funder: National Institute for Health Research (NIHR) Programme Grants for Applied Research (PGfAR).

Project aim: To provide evidence to inform the National Suicide Prevention Strategy.

Type of research: Clinical and public health research.

Duration: Five years – started April 2012.

Who we spoke to

We interviewed the lead researcher Professor David Gunnell and Rosie Davies, a service user co-applicant on the Programme Grant. Their comments are in blue below.

About the involvement

How service users influenced the research question

This programme of work built on the findings from a previous programme grant, which had involved service users as co-investigators. As the first programme came to an end, the research team held a one-day meeting with all the potential end-users of the research including service users, the Medicines and Healthcare Products Regulatory Agency, the Samaritans, Madeleine Moon MP (Chair of the All-Party Parliamentary Group on Suicide and Self Harm Prevention), the Office for National Statistics, NHS managers and clinicians. This group discussed the priorities for the next grant and helped shape the research questions.

" The aim of the workshop was first to reflect on what we had learnt so far and then to brainstorm ideas for the next programme. We presented some of our ideas to open up the discussion. It was an extremely valuable meeting

which helped us cross off some possibilities from our list and add in others. " **David**

" One of the things the researchers wanted to look at was self-harm services. I suggested that they needed to include users of those services in that process so not just to look at hard outcomes, but also, for example, how relationships between users and staff influence the quality of care. " **Rosie**

Service user involvement prior to applying for funding

Rosie was one of the service users involved in the first programme grant and became a co-applicant on the new funding application. She helped write the section on patient and public involvement, and was involved in the same way as other members of the team in commenting and contributing to numerous iterations of the preliminary and full applications. She was paid for this work through funds from the first grant.

" Rosie had previously provided sound and grounded advice not only on the research itself, but also on maximising user involvement. She had been extensively involved in the previous programme and had contributed to the publications from that work as a co-author. It seemed a natural progression for her to become a co-applicant. This has given her responsibility for an element of the programme. Rosie's major contribution - she has many - is to advise on the service user involvement in the new programme. " **David**

Impact of the early involvement

Rosie's work on the funding application resulted in a step change in the **service user involvement** in the new programme. There are now more service user research advisors involved at all three project sites, and the role has broadened to include, for example, doing pilot interviews and providing feedback on draft topic guides, question wording and the interview process.

Rosie also helped to develop **policies and practice** around managing the risks of involving service users in this challenging area of research and ensuring people are properly supported.

" One stream of our work is around investigating lethal methods of suicide. Evidence shows that knowledge of effective methods will influence people's choice of method and the likelihood they will die from the attempt. So we wanted to ensure we didn't talk about this topic with potentially vulnerable people, including the service users we involved. We listened to Rosie's advice about how to manage that, as the last thing we want to do is increase people's risk or make their mental health worse. " **David**

" Some of the feedback we received on the preliminary application asked about our policies for managing participant distress. That led to discussions about the potential distress of the service users we involve. We then developed more explicit plans about how to provide support to me and the other service user members. " **Rosie**

Continuation of involvement following funding

Rosie has continued to be involved in the Programme and attends meetings of the research team. Her post is funded through the second grant. Her role has evolved into a more formal advisory role, overseeing a strategic approach to involvement and encouraging researchers to create further opportunities for involvement as the work unfolds.

Lessons learnt

> " There has been some caution about involvement in research. My experience has been generally positive. It's such an important dimension to the work we do – bringing new insights as to what is most relevant to people and to remind researchers that, at the end of the day, the purpose of research is to improve patient and population health. Without including service users there's a really important part of the jigsaw missing. " **David**

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