
Example 10: Health care innovations from policy to practice: A case study of rapid HIV testing in General Practice.

About the research

Lead researcher: Heather McMullen, Centre for Primary Care and Public Health Barts and The London School of Medicine & Dentistry.

Funder: National Institute for Health Research (NIHR) Trainees Coordinating Centre - Doctoral Research Fellowship.

Project aim: To examine health innovations from policy to practice in terms of the ways they get picked up and dispersed across primary care settings - using rapid HIV testing as a case study. A second aim is to explore how national guidance is put into practice.

Type of research: Qualitative research.

Duration: Started January 2013 – three years duration.

Who we spoke to

We interviewed the Ph.D. student who is carrying out this research, Heather McMullen. Her comments are in blue below.

About the involvement

Background

Heather worked as a trial manager and co-ordinator on a large study that explored whether rapid HIV testing in primary care led to earlier and greater detection of HIV. In the trial, the test was offered to some of the patients undergoing a new patient health check at their GP surgery.

The idea for this Ph.D. project came out of the work that she did on the trial:

“I was going into the GP practices to train them in rapid HIV testingThis led to a lot of questions about why some practices were able to pick up the intervention and roll it out to good effect and why some practices weren't.” Heather

For Heather, it was also important to explore the patients' experience of rapid HIV testing in more depth than had been explored in the clinical trial.

“ I was passionate about interviewing patients as part of my study as that was something that was missing. We had looked at providers’ experiences of delivering the tests, but not at the patients’ experience of being diagnosed within a minute. All the research was designed around the patients, but we hadn’t heard from them – not in the write-ups. I wondered what would happen if the trials showed it’s really significant in terms of public health outcomes, and the qualitative studies showed that health professionals found it acceptable and feasible, but the patients found it hugely traumatising? ” Heather

Patient / carer involvement prior to applying for funding

Prior to submitting her application Heather consulted senior academics, representatives of community and patient organisations and also individual patients - about a dozen in total.

“ I consulted patients and their representatives because I wanted to know that the work I was going to do would be useful. I had academics telling me that it would be, but I wanted policy people and patients to tell me that too. I also knew I had to do it, as a huge part of the application asks you how your study is connected to the people it is meant to help. Finally, I wanted to make sure that patients were involved in my project design, because as I was going to be speaking to patients, I wanted to make sure I got those questions right. ” Heather

The patients and organisation representatives were sent a copy of the research proposal and invited to comment by email or by meeting face-to-face. Heather selected local community organisations who were working in the same area of London as well as HIV charities working with more commonly affected groups, including Africans and men who have sex with men.

“ It was easy for me to get access to the right people and fairly quickly because I already had key people on board for the trial and I already knew which organisations had good reputations. I also knew some patients personally, as I had involved them in the training I provided to the GP practices. I had found the patients through the local HIV liaison nurse and local organisations... It was part of my job to talk to everyone involved in the trial, so I could do this consultation alongside other work, which meant the costs weren’t an issue for me either. ” Heather

The patients who met with Heather received a £10 gift voucher as a thank-you and also had their travel expenses paid. It is unlikely some of the patients would have been able to attend a meeting if they had had to pay for their own travel.

Impact of the early involvement

The involvement helped to increase Heather’s **confidence in the relevance and importance** of the research.

“ It helped me nuance some of the perspectives and some of the reasons why the study is important. It also gave me confidence - which isn't easy to measure - but I think it comes through when you're putting in an application and certainly helped me during the interview with the funders. Knowing that you believe in your project and so does your community - that comes through in those moments. ” Heather

It also helped to improve the **accessibility and acceptability** of the language used in the written information about the project.

“ How you phrase things is particularly important in HIV – for example you might not use the term ‘gay men’ and use the term ‘men who have sex with men’ instead. I hadn't written that in my application – but those are the types of things that can be pointed out when working with a community – or they can tell you if you get too medical in your language – it's invaluable to have that kind of feedback. ” Heather

Continuation of involvement following funding

The patients and organisation representatives who were consulted about the application have since joined the study steering committee and will be involved in the rest of the project.

Lessons learnt

“When you talk with patients and their representatives, you have to be prepared for the offshoot conversations. People will ask all sorts of questions. I was mostly equipped to answer those questions because of my experience in the trial. When they asked me questions about things I wasn't sure about, for example, access to care by illegal immigrants, I was able to refer them to the specialist clinic. I knew who else to talk to and where to get the information.

There is a difference between activists and lay patients. There isn't a universal patient experience. This is very true in HIV because of its political history. I find the activists know loads about it, are already involved in policy decisions and give you one version of the patient perspective. Their experience is different because of the world they're part of – they are usually comfortable with their HIV status as its part of their job. But with other patients, you may be one of the very few people that know they are HIV positive. It makes sense to go to patient organisations – because that's an easy point of access – but you need to be aware that you may be accessing a certain realm of experience. It's particularly highlighted in the HIV field – it might not be the same say for asthma patients... I'm not sure. ” Heather

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