

A series of five examples of public involvement in research developed by the NIHR Evaluation, Trials and Studies Coordinating Centre.

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## **Example 5: Outreach programmes for health improvement of Traveller communities: a synthesis of evidence**

### **About the research**

**Lead researcher:** Professor Susan M. Carr, Professor of Public Health Research, Faculty of Health & Life Sciences, Northumbria University, Fuse Associate Director.

**Funder:** National Institute for Health Research (NIHR) Public Health Research Programme.

**Project aims:** To assess whether outreach interventions for Travellers work and whether they are value for money, and importantly to find out how, why and in what circumstances outreach interventions may be effective.

**Type of research:** Systematic review of all published evidence.

**Duration:** Three years, June 2011 - July 2014.

### **Who we spoke to**

We interviewed Dr Monique Lhussier, Senior Lecturer in Public Health Research at Northumbria University, who spoke on behalf of the research team. Her comments are written in blue text below.

### **About the involvement**

#### **How were Traveller communities involved in the study?**

The Steering Group for the study included a member of the Traveller community, two staff members from Traveller organisations and a specialist outreach worker. They had an influence at all stages. Initially, the researchers also sought input from the wider Traveller community via a blog.

“We advertised the blog in Traveller organisations, posted regular updates and asked for comments, but that didn’t work. We hardly had anybody commenting. When you think about it, it’s hardly surprising. That’s what our research was telling us too – engaging these communities is not straightforward, and the way you do it is very important.” **Monique**

The research team found relying on the Traveller organisations a more effective means to develop links with other Travellers.

“Trust is a huge issue. We know that disengaged groups tend by and large to distrust any formal organisations, so going through the Traveller organisations was a good route in. They ran discussion groups for us. The staff regularly meet up with Travellers and on two or three occasions agreed to tag on our questions

to the end of their meeting, consulting them on the topic we wanted them to discuss.”

**Monique**

### **What difference did the involvement make?**

Very early on the research team realised the published evidence was limited in scope and often anecdotal in nature. They therefore did a lot of work to pull together the information from different sources to develop theories of what might explain why some outreach programmes work well and some don't. Involving members of the Traveller communities helped them to test out these theories to see whether they reflected people's actual experience. This helped to validate the findings and provided the team with a deeper understanding of the issues. It helped to reassure the researchers that their conclusions were reliable and meaningful.

“As the themes emerged, we explored them in more depth through the discussions with groups of Travellers, and then we went back to the literature. There was a lot of to-ing and fro-ing, consulting them and looking at the published evidence. This meant our theories were not only based on the literature, but also grounded in the accounts of people who had direct experience of outreach programmes. This greatly increased the validity of our findings.”

**Monique**

The partnership with the Traveller organisations has also led to further work to help put the findings into practice. The team are working on a decision-making tool for commissioners of outreach services. They are aware that the involvement of Traveller communities gives the findings more weight and credibility with this audience, since the conclusions are not just theoretical, but informed by Travellers' knowledge and experience.

“Our Traveller organisation partners are very enthusiastic about the report. Sometimes they are called to advise Clinical Commissioning Groups on how to approach Travellers and are looking forward to using our research to substantiate what they are saying. It helps them to reinforce their messages to decision-makers. As a researcher to be part of something like that is immensely gratifying – it's actually making a difference and helping people in that field.”

**Monique**

### **What helped the involvement to work well?**

The research team's experience of involvement mirrored the lessons that emerged from the research. The essential factors that helped the involvement work well was developing trust within the Traveller communities, adopting a flexible approach and showing willingness to meet people on their own terms.

“A member of our team went to an annual Traveller fair. On the back of that, they managed to arrange a conversation with Traveller community members. The participants said ‘If you hadn't come to the fair, there's no way we would have turned up here’. We were willing to come onto their turf and come out of the university to speak to them. That was a key step.” **Monique**

## Lessons learnt

“Don’t expect people to adapt to the system. The system may be alien to some people and they won’t adapt. That’s true for health services and for the research process. We sometimes assume that engagement will be easy – but why should it?”

When you’re working with disengaged groups, building trust through long-term relationships is essential. As researchers, we may not always have the time to do that, before we get asked to move on to the next project. Then it becomes absolutely invaluable to work with organisations who have established links.

We need to be sensitive about not ‘using’ people. This is especially important when working with disengaged groups who can feel over-researched – people consult them and then nothing happens. We must avoid using an approach that ticks our boxes but doesn’t do anything for them.” **Monique**

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## References:

[www.leedsgate.co.uk/2014/08/11/outreach-is-important-to-improving-gypsy-and-traveller-health-new-research-findings/](http://www.leedsgate.co.uk/2014/08/11/outreach-is-important-to-improving-gypsy-and-traveller-health-new-research-findings/)

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