

Test case study

Title: Test Case Study 1

The project explored older people's experiences of transitions in care, what needs older people have during times of transition, and whether those needs are being met by local services. The project focused on four groups of older people whose needs are not well understood and/or whose needs might be expected to be more complex. One of those groups was older people from black and minority ethnic (BME) communities, and the research that explored the experiences of this group took place in Leicester. The project used a participatory research approach, involving developing and maintaining partnerships with older people as 'co-researchers' throughout the research process. In Leicester, eight people from Leicester's BME communities contributed to the project as co-researchers.

How you found people to involve: In each of the areas taking part in the project, the research lead formed a partnership with a local voluntary sector organisation that was working closely with the group that it wanted to involve. In Leicester, the partner organisation was the local branch of Age Concern, with the organisation's BME community development worker team playing a particularly important role in the partnership. Working through Age Concern's networks, information about the project and the opportunity to become a co-researcher was distributed to many local BME groups across the area. Given the responsibilities associated with the role, it was decided that people would have to submit an application and a short (informal) telephone interview was carried out. All co-researchers were CRB checked.

How you involved people: The research team had reviewed the literature on involving older people in research before getting underway with the project. From this they were aware that previous efforts of involve older people as co-

researchers had often been limited to participation in data collection, but had not extended to other aspects of the research project (such as research design or data analysis). With this in mind, they tried to design a project that could be co-produced at all stages. In Leicester, co-researchers were involved in:

- Identifying key issues to explore in the in-depth interviews, helping to ensure that the researched focused on the issues that mattered most to older people
- Developing interview tools, including a visual representation of the transition and interview prompt cards
- Reviewing data to identify the main themes and make sense of any complex issues emerging from the interviews
- Presenting the findings at feedback events
- Participating in 'All Sites Days' which brought together people from the different areas taking part in the project

What training and support did you offer?

A training programme was designed for co-researchers, which was delivered at various stages of the project. As well as the training days, the research lead met with the co-researchers as a group on other occasions as and when needed. The training programme was designed to fulfil three aims:

1. Supporting co-researchers to develop the knowledge and skills needed to fulfil their role.
2. Enabling relationships and trust (between co-researchers, and between co-researchers and the research lead) to develop.
3. Creating opportunities for co-researchers to shape the research process – see above for more details.

Early training sessions included role play activities to practice interview skills and the research team developed a DVD (with members of a service user and carer network at the

University of Birmingham) with good and bad interview scenarios to encourage discussion. Support was offered to co-researchers on an ongoing basis in many ways, including debriefs at the end of each interview. The involvement of the voluntary sector partner was also vital in this respect, as it gave co-researchers a source of support from somebody who was independent of the research team.

What difference did public involvement make?

The project's participatory approach was evaluated to explore what difference it made in terms of the research process and outcomes. The evaluation clearly demonstrated that both the academic researchers and co-researchers really enjoyed working together and learning from one another. The involvement of co-researchers in Leicester benefitted the project in many ways:

- They helped to ensure that the research focused on issues that matter to older people
- Their involvement in interviews often put people at ease and helped to elicit richer insights
- They played a vital role in approaching and recruiting people to take part in the research
- They carried out a number of interviews in their own community languages
- Their involvement in feedback activities was particularly beneficial: they 'gave voice' to the people who had shared their experiences by selecting and reading out quotes from interviews at feedback events.

What would you advise other researchers about involvement?

Learning from the project suggests that the following factors contribute to the success of co-research approaches:

- Recognise the value of peer support and take opportunities to develop this as part of the research process
- Always be open to the unexpected and to new ways of doing things

- Be open and flexible in your own boundaries, for example regarding self-disclosure
- Make sure that practical matters – like payment, transport, CRB checks – are properly thought out
- Allow enough time for regular communication and effective support
- Constantly work at building and maintaining relationships and trust
- Treat co-research as a learning process, and work together to try and solve problems and overcome challenges
- Keep co-researchers informed about what's happening, even if nothing's happening!