

## Working with community groups

### What this involves

Rather than recruiting people for your project you could work with an existing organisation or peer support group, relevant to the condition that you are researching.

### What are the benefits of working with an existing group?

- It gives you ready access to people who already have an interest in your topic and who on some level have committed to engage with it.
- It enables you to potentially recruit some PPI Contributors from within the group to work with you more closely if they appear keen.
- It means that you can work with the group at various points in the project and that you can use their skills and networks to help disseminate your results. In situations where the group is part of a larger charity this will include the option to use the organisation's own media resources.
- It may mean that you are able to reach people who are seldom heard otherwise

### When this might be a useful/appropriate approach:

- It could be helpful if you feel that the sort of PPI Contributor you need may be difficult to recruit because of their personal circumstances (e.g. the very old), the nature of the condition (women who have been victims of FGM) or because the ideal candidates are unlikely to respond to a University advert (e.g. those who do not have English as a first language).
- By working with staff in a voluntary sector organisation you will also be able to gather a wide range of opinions in the sense that they can represent many of their clients.

### How can you work with a community group?

- You can work with an existing group at any point in the research cycle.
- You can also work with a community group outside of the research cycle, offering support to them from your own expertise so that the relationship grows in a mutually beneficial way.

These sorts of links may be particularly appropriate if you specialise in a narrow field and are able to develop close contact with a relevant group.

## What are the drawbacks of this approach?

- The group is meeting for its own purposes and your research may not be high on their agenda.
- Knowledge levels and understanding of how research works will be lower than with established PPI Contributors, which may occasionally be an issue in terms of time spent explaining things.
- If you work with a voluntary sector group to develop a dissemination plan you may lose some control of the message.

## Directories of community groups

Contact a Family – for families with disabled children [www.cafamily.org.uk/medical-information/conditions](http://www.cafamily.org.uk/medical-information/conditions)

Patient - trusted medical information and support – NHS Choices

[www.patient.co.uk/directory](http://www.patient.co.uk/directory)

Self-Help UK – the guide to patient support and self help [www.self-help.org.uk/directory](http://www.self-help.org.uk/directory)

Shaping our Lives - National network of service users and disabled people

[www.shapingourlives.org.uk/list-of-members](http://www.shapingourlives.org.uk/list-of-members)

Rare Disease UK – the national alliance for people with rare diseases and all who support them

<http://www.geneticalliance.org.uk/find-support/>

McPin Foundation – transforming mental health research <http://mcpin.org/resources/service-user-and-carer-groups/>

Coach – County of Oxfordshire advice on care & health set up by GP Federation

<http://directory.my-coach.org.uk/#/search/list>

## Case study:

James Sheppard (NDPCHS) needed PPI from people over 80 so he went to his gran's day care to get it: [www.clahrc-oxford.nihr.ac.uk/i-r/attending-an-existing-group-to-do-PPI](http://www.clahrc-oxford.nihr.ac.uk/i-r/attending-an-existing-group-to-do-PPI)