

Running a patient support network

What this involves

This is the development of a group of PPI Contributors who are patients with, their carers or interested members of the public in one given medical condition, illness or disease.

What are the benefits of running a patient support network?

- It may be easier to recruit to, as PPI Contributors will have a real connection to the issues concerned, even if it is a relative or friend who has the condition.
- It means that you can keep in regular contact with this group of PPI Contributors and provide them with updates about the research progress as well as seeking their input.
- It means that you have a ready group of people to disseminate your results to, who may also be willing to broadcast this further afield through their own networks.
- It could enable you to engage in more collaborations, as other researchers may be keen to partner with your PPI members
- It could enable you to provide very tailored learning & development opportunities for PPI Contributors.
- PPI Contributors can act as a peer support group to each other as they all have the same condition.
- This may also be a way of recruiting participants to trials.

When this might be a useful/appropriate approach:

- If you have a broad programme of work that has multiple projects within it. In such a case you would be able to use the same PPI Contributors on various projects as they would all have experience of the condition concerned.
- It could work well if you are collaborating with other organisations or departments on joint projects where you can pool your resources to support the register of members.
- This might be particularly appropriate if you work in a setting jointly with service provision colleagues who may be able to provide the PPI Contributors with advice or support in the relevant condition.

How can you run a patient support network?

As an example of some creative dissemination work the [South London Stroke Register](#) in July 2016, worked with photography students from Camberwell College of Arts to create an art exhibition inspired by their members. The art work was then displayed in Paul McPherson gallery in Greenwich and at community events.

What are the drawbacks of this approach?

It may limit the opportunities that arise for you to do research in other fields if too many of your resources are focused on supporting a large group with one condition

Resources:

- 'Transitions to palliative care for older people in acute hospitals' Health Services and Delivery Research Nov 2013 Christine Ingleton
- The Oxford Health Foundation Trust BRC has set up a Patients and Research group: <https://oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/>
As an offshoot of this work they plan to set up other condition specific groups such as Binvolved for bi-polar.
- [South London Stroke Register](#): Informing Innovation in Stroke Care'; Professor Charles Wolfe, Professor Anthony Rudd and Dr Christopher McKeivitt, Kings College London.
They have created a register of almost 5,000 stroke patients in the Register area, with each patient followed up at 3 months and annually after stroke, for life. From the register they have been able to form a [PPI Contributor group](#).
- [Keele University](#) has strong links with arthritis research and formed a Research User Group (RUG) initially around this condition, which has now grown to include other long-term health conditions. The RUG was set up in 2006. It has over 80 members involved in over 70 different projects.
- [Cancer Research UK](#) has created an Involvement Network. Part of their experience has been to recruit people from this network to become Cancer Campaigns Ambassadors and to volunteer for the charity in other ways.
- [Join Dementia Research](#): Example of how a campaign for involvement and participation focuses on one disease area and uses multiple media to promote the campaign.