

Working with patient advocates

What this involves

Recruiting PPI Contributors specifically because of their networking and advocating capacity, either in existence or their commitment to developing such a role.

A patient advocate is someone who promotes health research from a patient point of view. They could be a patient, service user, carer or lay person who is enthusiastic about health research and willing to communicate that to other patients and public as well as healthcare professionals. They often have a more prominent presence on social media than clinicians and researchers, are committed to using it as a medium and can be relied upon to post regularly.

What are the benefits of working with patient advocates?

Patient Advocates are very good at spreading the word about their disease and advances being made, which could improve the visibility of your work or recruitment rates.

Advocates can become campaigners to drive for research results to become part of practice in the NHS.

In the David Supple et al project highlighted below this was said “Patients are very much a part of this U-BIOPRED virtual network and have, in fact, aided its cohesion as they transcend work package boundaries and give a much-needed overview of the project as a whole.”

When this might be a useful/appropriate approach:

- in situations where broadly disseminating the results of your research is important
- if you feel that your project would be better able to recruit if it had strong patient peer endorsement
- If you want to make strong links with the community who have the condition that you are studying, in part to help you in recruiting other PPI Contributors or participants.
- If you need to explain difficult research outcomes or help to manage public expectations around research results.

How can you work with patient advocates?

- You Approach known bloggers, social media personalities, or leading advocates in your area.
- Alternatively, phrase advertisements for your voluntary role in such a way that it is clear you want the successful person to develop a Patient Advocate role, and what support you will be able to offer them. This might include, for example, training in effective use of Twitter.
- If you want good public speakers to share the platform with you at professional conferences

What are the drawbacks of this approach?

- You may lose control over some of the messages about your work that are disseminated.
- You will, at the very least, have to put time into co-ordinating with the Patient Advocate to ensure that their message is as accurate as possible.

Resources:

- 'From tokenism to meaningful engagement: best practices in patient involvement in an EU project' by David Supple et al in Research Involvement and Engagement 25 June 2015
- www.nihr.ac.uk/patients-and-public/how-to-join-in/patient-research-ambassadors/ambassador-stories/