

Engaging public and patient organisations with your findings

Why involve public and patient organisations?

Involving public and patient organisations can help you do the following.

- **Shape your communications approach:** they may bring important insights into how patients experience their care, or they may know about policy debates that are relevant to your area of study. This will help you ensure that your research communications are as relevant as possible, and could help you avoid some potential blind alleys.
- **Plan how you will engage patients, and identify relevant individuals or groups:** researchers that collaborate with patients aim to tap into their expertise and experiences to solve problems together. Some charities have extensive expertise in involving patients or carers in their work, and may be able to provide advice on the skills, techniques and resources required to identify and involve people with a range of physical and mental health needs.
- **Engage a wider audience with your findings:** if your research has the potential to throw up important questions or insights that are relevant to patients, you may need to plan how you will share your findings with public audiences. Public and patient organisations can help you understand patients' perspectives on the issue you are studying, and advise on how to go about communicating your findings to them. They may help you to anticipate their concerns or information needs.

If you have established a good relationship and demonstrated how your research can help public and patient organisations with their goals, they will be more likely to help you disseminate your findings through their established networks and channels. They may also be willing to actively champion your research if the findings have the potential to enhance care and knowledge for the people they represent.

Who to involve?

The organisations you might involve are entirely dependent on the nature and scope of your research, whether you are involving patients in the research process, and the extent to which your findings are likely to have broader relevance to patients. These organisations might include:

- the **Health Research Authority and local research ethics committees** (RECs), for research involving patients in the NHS. They should be able to provide advice on good practice for involving patients in research and help you determine when ethics approval will be necessary
- **patient involvement or public engagement staff** working in the NHS, universities and research institutes
- **national charities** that support people with specific health conditions, such as Macmillan Cancer Support, or which champion the needs of certain groups (eg Age UK or Mencap). In addition to providing services directly to patients, larger charities typically have well-established policy and communications functions. See the [Association of Medical Research Charities](#) for a list
- **small- to medium-sized patient groups or charities** working locally or regionally. Many are independent bodies, while others operate as part of a larger umbrella national charity or network. See [Patient UK's online tool](#) for identifying relevant support groups for patients
- **networks that bring people together** with a specific interest in how patients or the public are engaged and involved – for example, the [Patient Experience Network](#), the [Coalition for Collaborative Care, Involve](#) or the [National Co-ordinating Centre for Public Engagement](#) (NCCPE).

How to engage public and patient organisations

For some researchers, the first step is to invite representatives of public and patient organisations to engagement events involving a range of other stakeholders. Where a research project has a more formalised partnership in place with a public or patient organisation, there may be a requirement to involve them through a steering or advisory group.

As health problems may prohibit individual patients from taking on extended commitments, representatives of patient organisations and charities are often asked to champion their needs and experiences through roles on committees or advisory groups.

For such a group, operating effectively depends on:

- clearly defined roles, with a shared understanding of what is expected of external representatives
- clarity about which aspects of the work they can influence
- the skills and knowledge of the individuals involved and their ability to influence the communication of research findings appropriately.

Involving patients directly

If you are directly involving patients, carers and communities in helping to communicate your work, it will be important to assess whether you have the skills, resources and capacity within your team to listen to and build good two-way relationships. This might include providing training and support, and will almost certainly involve some financial resource – for example, expenses for travel and refreshments.

Charities like Macmillan Cancer Support often use trained patient advocates to work alongside patients and help them express their stories, priorities and needs.

“When involving patients, it’s the detail that counts. If you’re asking patients to speak up in meetings, you will need to provide them with appropriate training and support. If you’re asking them to travel to events, you will need to pay expenses up front.

Professor Jane Maher
Chief Medical Officer, Macmillan Cancer Support

Patients are often highly invested in the subject matter of their condition, treatment or care. The NCCPE has produced [an introductory guide](#) on anticipating the ethical and social issues that might be involved.

Communicating your findings with patients



The patient perspective is key. Their voice is a very effective communications tool.

Michael Nation

Development Director, Kidney Research UK

If you have involved patient and public-facing organisations from the outset of your research, listened to them and kept in touch with them, you may find you have established a pool of potential advocates that you can call upon to reach others. Patient advocates and stories can be a powerful means of bringing research insights to life for clinicians, commissioners and policymakers.

Resources

- How to involve people in your research: [a guide by Involve](#).
- Researchers' experiences of patient and public involvement: [a compilation via Healthtalk](#).
- Research Councils UK case study: Professor Irene Hardill's [account of her work](#) with voluntary sector organisations.
- Planning your public engagement: [a guide by the Wellcome Trust](#).
- Planning your public engagement: [a resource from the National Co-ordinating Centre for Public Engagement](#).