

# Patient and public involvement

As a patient or relative or carer, you have a unique perspective on the impact of a medical condition on life, work and family. This experience is invaluable to healthcare professionals, policy makers and researchers

Speaking up for yourself and others with your condition can make a huge difference to how healthcare is delivered in the future. This process is formally called “patient and public involvement” or PPI.

This factsheet explains what PPI is, what the benefits are for patients and healthcare professionals and how healthcare is changing as a result.

## What is it?

PPI is the active input of patients into healthcare decisions, not just as a participant in a research study to test a new treatment or as a person being treated by a doctor, but as equal partners.

Patient and public involvement can also be called patient and public input or engagement. Also, rather than using the term ‘patient and public’ some people use service-user or consumer.

There are different areas of healthcare in which PPI can be important. Two examples are guideline development and scientific research:

### *Guideline development*

Guidelines summarise the best available evidence, and advise healthcare professionals on the best way to treat and care for people with specific diseases and conditions.

Groups of professionals study the latest evidence to decide on what is currently known from trials about the best treatment for a condition. However, what they might not know is what patients want from their treatment, which treatments they prefer, how their condition affects their daily lives, how patients and carers think their care could be improved and the needs of different groups of patients (for example, in relation to their sex, age, or ethnic background).

Patients and carers can get involved by:

- Suggesting areas in which guidelines should be developed
- Being part of a guideline committee or guideline development group that oversees or develops a guideline
- Joining focus groups of patients set up to look at specific topics related to the guideline
- Responding to a survey as part of the research that is informing the development of a guideline
- Making sure that a guideline is worded sensitively
- Helping to develop easy-to-understand versions of a final guideline so people with a condition can understand what treatment they can expect
- Raising awareness of a guideline through patient networks and organisations



## Scientific research

Scientific research and clinical trials are carried out to test procedures, treatments, diagnostic tests and services to support patients or to understand more about how a disease develops.

As a patient or carer, you may be asked to take part in a trial as a participant. However, there are other ways in which you can use your unique perspective of a condition and your experience of various treatments and health services to help health research.

As a PPI representative, you can get involved in research by:

- Helping to identify important issues for research
- Contributing in the early stages of trial development to ensure studies directly address patients' concerns
- Providing feedback on the structure and design of a study to ensure it is relevant and ethical for other patients to be involved
- Providing advice to ensure successful patient recruitment and participation in a study
- Evaluating and commenting on the findings of the research and its impact for patients
- Raising awareness of the project's aims and results once completed

## Why get involved?

### For patients and carers

As an expert in your condition, you have daily experience of the impact it has on your life and the effect of different treatments. If patients or carers take a more active role in decisions around healthcare it can lead to:

- Development of healthcare systems that are more patient focussed, which could improve the management of a condition for all patients
- The ability for patients to manage a condition independently
- Better understanding of conditions and the impact of treatments
- Better explanations of research studies and communication of the results to the public
- The ability for carers to represent the people they support
- An increased awareness of a condition across the whole society

**Patient perspective:** Lina Buzermaniene is a Lithuanian patient representative in the EU project, U-BIOPRED. Her role is to input into the ethics board, supporting the scientific members of the project to help them consider factors that they may not have thought of from a patient perspective.

“I believe it is very important for patients to be involved in matters important to their health. One of the other patients in the project used the phrase, ‘nothing about us, without us’. This sums it up: patients should be involved in research because it directly affects the diagnosis and treatment of them and other patients in the future. Being involved in research projects gives patients the chance to learn about clinical trials and pass this information on to other patients. It was daunting to begin the project with no knowledge of clinical trials and how medical research works, but over time I gained in knowledge and confidence.

“Patient involvement is essential for transparency, dissemination and more fruitful discussions on how to use the outcomes of projects.”

Visit the U-BIOPRED website: [www.ubiopred.european-lung-foundation.org](http://www.ubiopred.european-lung-foundation.org)

### **For healthcare professionals**

PPI can also help healthcare professionals. Examples of possible benefits include:

- Greater insight into a condition and the experience of living with a condition
- Patients being happier with their treatments and more likely to adhere to them, which optimises the use of resources and help healthcare professionals to treat patients better
- More relevant research, making sure the outcomes are genuinely useful for patients
- Improving recruitment for research by adapting the design of research study to ensure it is patient friendly
- Improving dissemination of research findings *via* active patient organisations and patient networks



### **How is PPI developing across Europe?**

Healthcare systems across Europe have shown increased awareness and efforts to introduce PPI, although the extent to which it has been formally accepted varies considerably between countries.

Here are two examples of PPI in Europe.

#### **UK: A governmental case study**

In the UK, INVOLVE was established in 1996 to support active public involvement in the National Health Service, public health and social care research. It is one of the few government funded programmes of its kind in the world.

As a national advisory group, its role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

For more information see: [www.involve.org.uk](http://www.involve.org.uk)

#### **The Netherlands: A patient organisation case study**

The Lung Foundation Netherlands started to involve patients in research and health policy in 1997. In 2007, a dedicated advisory board was established consisting of patients with lung diseases. This board helps to develop standards of care, care guidelines, translations of these guidelines into simple language, establishing research priorities, development of criteria to evaluate research from the patients' perspective, evaluating research proposals and monitoring on-going research projects.

For more information see: [www.longfonds.nl](http://www.longfonds.nl)

## How can I learn more about PPI?

There are several organisations that are working to support patient involvement. Three examples are listed below. You can also contact your national patient organisation to find out more about how you can participate further in local activities.

### The European Patient Ambassador Programme

The European Lung Foundation together with the NIHR CLAHRC for Leeds, York and Bradford, with the help of patients, and professionals with expertise in key areas, have developed the European Patient Ambassador Programme. The online course is a self-learning programme giving patients and carers the essential skills needed to interact with healthcare professionals, policymakers, researchers and journalists.

[www.epaonline.eu](http://www.epaonline.eu)



### The European Patients' Academy on Therapeutic Innovation (EUPATI)

The EUPATI mission is to provide educational material, training courses and a public online library to educate patient representatives and the lay public about all processes involved in medicines development. It focuses specifically on clinical research and will allow patients and carers to learn the skills needed to input into clinical trials, drug safety and drug development.

[www.patientsacademy.eu](http://www.patientsacademy.eu)

### European Patient Forum

The European Patients' Forum is an umbrella organisation that works with patient groups in public health and health advocacy across Europe. Their mission is to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

[www.eu-patient.eu](http://www.eu-patient.eu)



The ELF was founded by the European Respiratory Society (ERS), with the aim of bringing together patients, the public and respiratory professionals to positively influence respiratory medicine. The ELF is dedicated to lung health throughout Europe, and draws together the leading European medical experts to provide patient information and raise public awareness about respiratory disease.



This material was compiled with the help of Pim de Boer, Principal Investigator on patient involvement and advisor on scientific affairs, Lung Foundation Netherlands and Lina Buzermaniene, a Patient Representative for the European Federation of Allergy and Airway Diseases Patients Association, (EFA) and member of the U-BIOPRED project Ethics Board.