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# Are patients shaping healthcare across Europe?

## What is patient involvement and what are its benefits?

Patient involvement is the input of patients in healthcare, not just as research participants and recipients of services, but as partners. Examples of this include the setting of research agendas, project proposal development and the production of clinical guidelines. Patient involvement also includes carers and the public where appropriate.

Eurobarometer's Qualitative Study on Patient Involvement [1], the report of which was published in May 2012, was commissioned by the health directorate of the European Commission (DG SANCO) to investigate the views of patients and healthcare professionals on patient involvement in healthcare. The study was conducted across 15 countries and, in each country, five healthcare professionals and 10 patients were interviewed.

The general findings from the study were that the term "patient involvement" was not well understood by either patients or professionals in most countries. However, patients with chronic conditions were more likely to understand the concept, as well as those who were younger and better educated. Both patients and professionals could see advantages to patient involvement in healthcare, essentially making patients more engaged and, therefore, responsible for their health and that of others. However, neither group could specifically list key benefits.

These findings reflect the current literature on the subject [2]. What patient involvement (which can also be termed patient empowerment or public and patient input (PPI)) means, what it comprises and what its advantages are, are not always clear. However, there is a growing sense that patient involvement in healthcare at both a personal and systemic level is positive and should be strived for [3].

Several countries are leading the way with patient involvement and making it a key part of their health strategies. In this issue of *Breathe*, an article from the UK looks at patient-reported experience measures (PREMS) and patient-reported outcome measures (PROMS), and how these can be effective in chronic obstructive pulmonary disease (COPD) care, treatment and management [4]. Although this is not strictly patient involvement, it shows how patient measures can provide a different perspective on the effectiveness of medical care and can give insight into the quality of medical care as experienced by the patient.

## What is the European Union doing to promote patient involvement?

The Innovative Medicines Initiative (IMI) is the world's largest public-private partnership in health research and development. It is a joint undertaking between the European Union and the European Federation of

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Pharmaceutical Industries and Associations (EFPIA). With its €2 million budget, it supports and promotes patient involvement in its projects. The European Lung Foundation (ELF) has recently taken part in an IMI Patient Focus Meeting looking at the challenges in many different disease areas from the patients' perspective. The event was engaging and lively, and brought about many exciting proposals for future research to be funded by IMI. The projects that are successfully funded by this initiative are also strongly encouraged to involve patients, from conception to completion – and this has already been successfully achieved in several in which ELF has been involved (including UBIOPRED ([www.ubiopred.eu](http://www.ubiopred.eu)) and PROactive ([www.proactivecopd.com](http://www.proactivecopd.com))).

As part of the European Commission Health Programme, there was a recent call for tender on patient empowerment. The aim of the call is to help understand the concept of patient empowerment – meaning a principle of patients making informed choices – as a prerequisite to exercising patient rights. It aims at identifying inherent advantages and barriers to empowering patients. Its final goal is to develop future European Union collaboration on the subject, which can only lead to further advances.

## Why do we feel it is important?

The European Respiratory Society (ERS) is very keen to support patient involvement in its work and values the perspective that patient input brings. At the recent ERS summit in Dublin, Ireland, on research gaps, patient needs and innovative solutions [5], three patients attended the summit to share their experiences of involvement in clinical trials and living with rare diseases. The session was a lively, interactive one, resulting

in much discussion and debate about the points raised.

In this issue of *Breathe*, there is a powerful example of how the ERS has involved patients in the work of the European COPD Audit [6], an ambitious and exciting attempt to assess the levels of care given to patients hospitalised due to exacerbations of COPD. That article outlines an event run in collaboration between ELF, ERS and the Österreichische Lungenunion during the ERS Annual Congress in Vienna, Austria in 2012 in order to garner the views of those people with living with COPD. Extensive insights were gathered from this group of patients and this information has been used in developing the next stage of the European COPD Audit.

There is also a new section in this edition of *Breathe* that looks at key respiratory issues from both the patient and healthcare professional perspective, illustrating how informative and important patients' experiences can be in supporting treatment and management in chronic conditions.

ELF will support more patients and carers to play a role in healthcare *via* an online programme that they can complete to gain essential skills to better understand research, guidelines and advocacy. This programme, the European Patient Ambassador Programme ([www.EPAPonline.eu](http://www.EPAPonline.eu)), has a final goal of bringing together an informed and empowered community of patients ready to represent themselves and others at a local, national and European level to further improve research and care.

I hope that *Breathe* readers will enjoy the insight this issue brings to the hot topic of patient involvement. If you want to know more about patient input and share this with your colleagues, the factsheet at the back of this issue aims to explain what patient involvement is and what it can do for you and your patients.

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## References

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