



Empowered patients in research: moving beyond participation

Empowered patients are those considered to be true partners in their own healthcare, with a sense of control over their healthcare decisions. An empowered patient is a patient who is in a position to shape the research process and choose how to be involved in it. In this briefing, IAPO discusses what it means for patients to be considered empowered actors in research, why this is important, and ways in which patients can achieve this.

Introduction

Patient empowerment is one of the key principles outlined in IAPO's [Declaration on patient-centred healthcare](#) and is an important determinant of a patient's ability to meaningfully participate in research. Simply being involved in research suggests a patient is empowered to do so, since they are taking control of their decisions relating to their health. However, further to this, there is also a need for patients to be empowered and knowledgeable whilst taking part in this research.

Research that truly translates into real-world benefits hinges on an understanding of the needs of patients. Therefore, being empowered in research not only means being involved in research as a participant, but becoming a co-partner in the research process. For example, patient input can shape the way in which research is reported after the study, like communicating how patient input was used and what it helped to achieve. In this way, patient empowerment in research creates a more patient-centred process and outcome.

In this policy briefing, IAPO further develops the idea of patient empowerment, the theme of [Patient Solidarity Day 2017](#), this time focusing on patients being empowered before, during and after research studies, and the ways in which patients can be best equipped to do so.

Definition

The concept of patient empowerment was outlined in last month's policy briefing, where empowered patients are described as partners in their healthcare decisions, rather than participants. This concept is significant when discussing patient involvement in research, where patients should not just be seen as a source of data. Patient empowerment in research means being informed of what research they can take part in, being involved in decision-making regarding the research process, and knowing their rights and responsibilities when taking part in research.

Key resources

There are now multiple resources that enable patients to empower themselves in research participation. One example is [INVOLVE](#), a UK-based scheme funded by the National Institute for Health Research (NIHR) which aims to support public involvement in research. INVOLVE provides resources for researchers and patients, including a research project database to help public find research projects that could be relevant to them.

Similarly, on a European level, The European Patients' Academy ([EUPATI](#)) aims to train patients to become experts on medicines development and clinical research, and improve health literacy in topics surrounding patient participation in research. The European Lung Foundation also runs a programme ([EPAP](#)) that provides patients and carers, regardless of condition, with the skills and information that is vital to become a good representative for patients. One module on the EPAP programme teaches the basics of clinical research and ways patients can get involved.

Advocating for patient empowerment

It is crucial that patients are empowered and engaged in *all* stages of research. Researchers increasingly use patient input when the research study is being designed in order to achieve more relevant results. By identifying and tailoring research priorities based on what is important to patients, the findings will be more valuable. During research too, patients being involved in the wording of research tools such as questionnaires ensure they are easily understood by patients without a scientific background. At the end of research studies, empowering patients could mean developing appropriate tools for post-research dissemination and communication.

[Domecq et al \(2014\)](#) found that patient input was beneficial during dissemination of results, by making the outputs easier to understand, and more appropriate for patients. Also, keeping patients informed on the outcomes and progress of the research, and how patients contributed to this outcome, is vital for meaningful involvement of patients that goes beyond just participation.

- **Know expertise:** Patients should know that they

themselves already hold valuable information to researchers, and not simply by collection of their data. Whether it is knowledge about their own condition, or what research will make the most difference to those living with the condition, patients bring the real-world perspective to research discussions. Advocacy efforts should also be oriented towards other key stakeholders, and they too must recognise the value patients can add.

- **Know rights:** Patients should know what their lawful right is in taking part in research. For example, gaining full, comprehensive understanding of the goals or risks of a research study through a high-quality informed consent process.
- **Know the process/network:** Patients being empowered in the study process means a greater understanding of the overarching goals and outcomes of taking part in a study, the structure of the research, and how these aspects are decided upon. For this, patients can seek out points of contact within the research study, and inform themselves upon the research process through information platforms such as [EUPATI](#), [EPAP](#) or [INVOLVE](#).
- **Know support:** Patient advocacy groups in research can provide support to patients thinking of taking part in research. For example, the [Research Advocacy Network](#) in the US aims to develop a network of advocates and researchers that promote patient involvement in cancer research.
- **Know opportunity:** Firstly, knowing that the opportunity exists to take part in clinical research, and secondly identifying research participation as an area that is important in making healthcare more patient-friendly.

How to move forward

It is recognised that patients have a key role to play in the shaping of research studies. However, for this to happen in a satisfactory way, there needs to be willingness by industry and other research stakeholders to involve and engage with patients, and create appropriate conditions to make patient involvement in research feasible. This willingness can only be in place if the value that patient involvement can bring to the research process is properly acknowledged. Involving patients in research is more than “the right thing to do”. Patients want their involvement to be meaningful and not tokenistic. Therefore, researchers need to have an understanding of what defines patient empowerment to patients within the research process, and be able to involve patients in a way that allows them to become co-shapers of the process, not simply “data suppliers”.