



Patient information and health literacy

Patient information is one of the pillars of the IAPO Declaration of patient-centred healthcare. It represents a primary vehicle for patient advocates to better engage in and contribute to healthcare more effectively. For this to happen, however, it is crucial that patients play an active role in the information process.

Introduction

Having access to, and being able to rely on “accurate, relevant and comprehensive information” is one of the five principles of IAPO’s [Declaration on patient-centred healthcare](#). More specifically, high-quality information represents one of the necessary pre-conditions for patients to be able to make informed decisions and participate as equal partners in healthcare decision-making.

When information is of high-quality, patients can develop stronger awareness of the implications and risks that are associated with a potential choice. In this regard, the key challenge is to identify and understand what constitutes appropriate information and how to put that in practice.

Definition

According to IAPO’s [definition](#), patient information relates to all forms of disease or condition, treatments, medication and health services. Because each patient has unique values, perspectives, and preferences, patient information cannot be one-size-fits-all. The adequacy of information is indeed dependent on, and determined by the specific needs of those for whom information is meant. To “improve the quality and accessibility of health information for patients”, IAPO’s [guidelines](#) call attention on a number of aspects:

- **Credibility.** In an era in which the availability of information is no longer a problem, it becomes all the more crucial to use credible sources.
- **Clarity.** Every time information is provided to patients, it needs to be logical in structure and clearly communicate objectives and outcomes.
- **Patient engagement.** Patients are not mere recipients of information. When patients are appropriately engaged in information generation and dissemination, they can facilitate professionals and researchers’ understanding of patients’ needs.
- **Usability.** Language, wording, format and style need to be chosen and calibrated on the users’ individual needs and characteristics.
- **Communication.** Appropriate strategies, methods and channels must be used to ensure information is more accessible for patient organizations.

Policy landmarks and key projects

At global level, in the [Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development](#), the WHO states that health literacy “drives” equity by empowering patient communities and individual patients to engage in “collective health promotion”. Also, the WHO looks at health literacy as a strategic asset to make real advancement towards the achievement of multiple Sustainable Development Goals (SDGs) by 2030.

At the regional level, in Europe, European level, the landmark project in the field of patient information and health literacy is represented by the European Patients’ Academy (EUPATI). EUPATI is a multi-stakeholder, patient-led programme by the [Innovative Medicines Initiative](#). The project is led by the [European Patients’ Forum](#) and provides “education” and “training” to enable patients to better understand and “contribute” to medicines Research & Development. The word “contribute” is key. As mentioned earlier, information must go beyond knowledge advancement. Information can and must produce engagement. In this respect, the programme places a very strong emphasis on the usability of information and its practical implications, considering it to be a primary avenue to strengthen and increase patients’ engagement in R&D.

Finally, the specific aspect of how to best inform potential participants in medical research is fully addressed in the World Medical Association [Declaration of Helsinki](#), in which several ethical principles are listed for researchers to use when involving human participants.

Advocating for high-quality information

Identifying the basic criteria that healthcare stakeholders must observe to make the information process truly patient-centred is only the starting point. Equally important is that patients develop an awareness of the ways in which high-quality information can benefit and empower them.

- **Informing: The clue is in the name.** Whether it is intended for potential research study participants or patients considering different treatment options, information must aim to increase patients’ awareness of and familiarity with the procedures,

objectives, risks and benefits that a given healthcare process entails. The sole purpose of information cannot merely be to get the informed consent form signed. The gap between legal consent, informed consent, and patients’ best interest has recently been demonstrated by the UK Supreme Court in the [Montgomery v Lanarkshire Health Board](#) case.

- **Converting knowledge into engagement.** Information is the primary tool by which individual patients and patient advocates can increase their understanding of and knowledge about a wide range of issues affecting their own healthcare. But it is a tool, not an end in itself. Knowledge is most useful when it can be translated into meaningful engagement. In this respect, being adequately informed is only the first step of a longer path aimed at increasing the quality, impact, and effectiveness of patient engagement.
- **Critically assessing health evidence.** Patient advocates need to have the skills and tools to identify the most relevant and credible evidence when producing information. Whether communicating within the patient community, or making their case to policy-makers and prospective funders, it is crucial that advocates are confident in assessing and using the strongest sources when engaging in the generation of patient information.
- **A cross-stakeholder effort.** Generating high-quality information is a team effort and is the result of all stakeholders’ willingness to ensure patients are fully equipped with the information they need. However, no-one can know better than patients themselves what information they need. Patients are called on to actively engage in the production and dissemination of information.

How to move forward

Being able to evaluate the quality and credibility of information becomes all the more crucial today as information sources are continuing to increase. IAPO aims to engage with its members in the coming months with aim of seeing patients at the centre of information generation and exchange processes. In particular, IAPO members will play a leading role in:

- Updating IAPO’s guidelines on patient information to make sure they closely reflect the increasingly central role patients are called on to play in healthcare.
- Promoting and holding capacity building activities aimed at strengthening patients’ ability to critically assess the information they receive.