

IAPO Policy Statement on Patient Information



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IAPO defines patient information as all forms of health information that relate to a patients' specific disease or condition, treatments, medication and health services.

Healthcare systems around the world are under increasing pressure from communicable and non-communicable diseases. The continuing rise in the incidence of chronic diseases in both developed and developing countries is placing a great strain on all health systems.

In order to cope with this increasing burden, health systems need to develop so that they are able to address the ongoing needs of patients and they increasingly require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage.

It is essential that patients are empowered with the information they need to make informed decisions about healthcare treatments and living with their condition. Without accurate, relevant and comprehensive information, patients lose control of the key choices that affect their lives. Therefore, there is a moral imperative to meet patients' information needs and by doing so protect their rights. In addition, it is not only at the personal level where information can empower but also at the healthcare system level. The voice of the patient must be strong in health-policy making if healthcare systems are to be patient-centred. An informed patient voice is a strong patient voice.

A call to all involved in healthcare

All stakeholders involved in communicating information to patients must involve patients and patients' organizations in all information-related policy and delivery decisions. This is essential to ensure that policies and practice address the information needs of patients whatever their disease area or geographical location.

IAPO calls on all stakeholders to ensure that patients and their representatives play a key role in the development and dissemination of patient information recognising that many patients are experts in their own condition.

When providing patient information, attention must be given to both the content of the information and how that content is communicated. This is to ensure that it is suitable to patients' individual conditions, language, age, understanding, ability and culture. Information must be accessible to all patients regardless of any physical barriers that may exist. IAPO recognises that quality principles provide a useful tool to judge the quality of information, but suggests that these are used in parallel with materials being reviewed by patients themselves.

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Recommendations

1. Stakeholders should extensively review their existing strategies and structures for communicating patient information. Existing and new mechanisms should be designed with patients and patient representatives taking a multi-stakeholder approach to ensure consistency, recognise best practice and to avoid mixed messages.
2. When considering how to communicate patient information, all stakeholders should understand the needs of patients and ensure that material is appropriate for their individual conditions, language, age, understanding, ability and culture and ensure that the needs of people at risk and minority populations are also met.
3. Alternative methods of communicating information should not be seen as a substitute for face-to-face/personal interaction between patients and healthcare professionals, but as a complement to give patients the opportunity to discuss concerns and request the information they need.
4. Where information is provided to support decision-making, providers must ensure that patients and carers understand fully the choices they can make and their implications.
5. Patient information must be produced to high quality standards and demonstrate that it is:
 - Patient-centred
 - Objective and unbiased
 - Comprehensive
 - Accurate
 - Reflect current thinking
 - Relevant
 - Transparent
6. All stakeholders should support the promotion of health literacy to ensure that patients have the basic tools to engage with and make the best use of information materials, and to promote public health.

IAPO is a unique alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world.

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