

Being a patient in Europe today: concerns about quality, access to care, reimbursement

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(IAPO)

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About IAPO

- Unique global alliance of almost 250 national, regional and international groups representing patients
- Crossing borders and diseases
- Vision: Patients throughout the world are at the centre of healthcare
- Membership spans over 65 countries and all world regions
- Representing an estimated 365 million patients



Capacity Building



Advocacy



Partnerships

IAPO's Mission

Our mission is to help build patient-centred healthcare in every country by:

1. **Realizing active partnerships with patients' organizations**, maximizing their impact through capacity building
2. **Advocating internationally** with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
3. **Building cross-sector alliances** and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives


What is patient-centred healthcare?

The essence of patient-centred healthcare is that the healthcare system is designed and delivered so that it can answer the needs of patients

Patient-Centred Healthcare Principles

- Respect and support for the individual patient, their wants, preferences, values, needs and rights
- Choice and empowerment
- Patient engagement in health policy
- Access and support
- Information that is accurate, relevant and comprehensive

* Principles defined in IAPO's Declaration on Patient-Centred Healthcare:
www.patientsorganizations.org/declaration



International Alliance of Patients' Organizations
A global voice for patients

Declaration on Patient-Centred Healthcare

Patient-centred healthcare is the way to a fair and cost-effective healthcare system

Health systems in all world regions are under pressure and cannot cope if they continue to focus on disease rather than patients; they require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage. Patient-centred healthcare may be the most cost-effective way to improve health outcomes for patients.

To us, the International Alliance of Patients' Organizations, the essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective. By promoting greater patient responsibility and optimal usage, patient-centred healthcare leads to improved health outcomes, quality of life and optimal value for healthcare investment.

Patients', families' and carers' priorities are different in every country and in every disease area, but from this diversity we have some common priorities. To achieve patient-centred healthcare we believe that healthcare must be based on the following Five Principles:

- 1. Respect**
Patients and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.
- 2. Choice and empowerment**
Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choice.
- 3. Patient involvement in health policy**
Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives. See IAPO's Policy Statement at: www.patientsorganizations.org/Involvement
- 4. Access and support**
Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that all patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.
- 5. Information**
Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture. See IAPO's Policy Statement at: www.patientsorganizations.org/HealthLiteracy

To achieve patient-centred healthcare at every level in every community, the International Alliance of Patients' Organizations is calling for the support and collaboration of policy-makers, health professionals, service providers and health-related industries to endorse these Five Principles and to make them the centre of their policies and practice. We call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

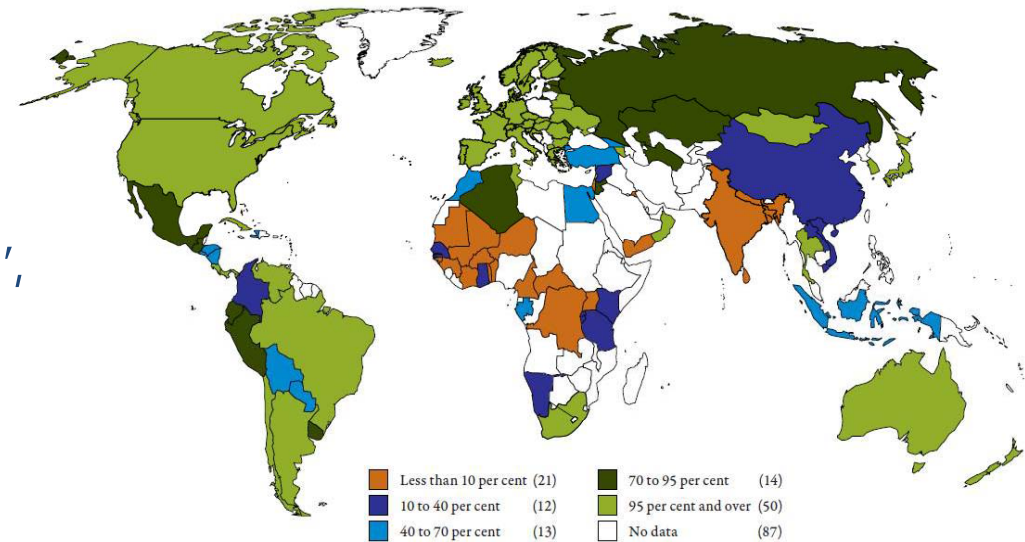
© 2016 IAPO. All rights reserved. This policy was adopted in February 2016 by IAPO following member consultation and agreement by the Governing Board. Further information about Patient-Centred Healthcare including evidence for its impact and benefit to its practice can be found in the IAPO publication *What is Patient-Centred Healthcare? A Review of Definitions and Principles* (IAPO, 2015) at: www.patientsorganizations.org/publications. Contact IAPO at: info@patientsorganizations.org

Access to healthcare and universal health coverage

- Access is the number one key issue identified by our members.
- Universal health coverage is a priority area for the World Health Organization (WHO) and Member States.
- The patient perspective is key – as the recipient of healthcare services so should have a say in how universal health coverage (UHC) is defined.
- Equity and quality are key considerations when discussing improved access to healthcare.

UHC Information Paper

- **'IAPO Information Paper: Universal health coverage'**, provides an introduction to universal health coverage



- **'Country examples towards universal health coverage'**, examples from six countries; Mexico, Rwanda, Japan, Ghana, Thailand, and Chile, expanding healthcare coverage

Core requirements in access to healthcare and universal health coverage

1. Patient-centred
2. Accessible
3. Equitable
4. Quality
5. Empowerment
6. Value
7. Collaboration
8. Accountability

Access to healthcare for interstitial cystitis patients – a case study

- Interstitial Cystitis Patients (ICP) association – represent patients with interstitial cystitis and painful bladder syndrome
- Interstitial cystitis, or bladder pain syndrome is a chronic inflammatory condition affecting the bladder characterised by urinary urgency, urinary frequency, waking at night to urinate
- Those with interstitial cystitis may have symptoms that overlap with other urinary bladder disorders such as: urinary tract infection, overactive bladder, urethritis, urethral syndrome, and prostatitis
- IC/BPS can result in a quality of life comparable to that of a patient with rheumatoid arthritis, chronic cancer pain, or a patient on kidney dialysis

Reimbursement of bladder instillations

- In July 2013, the health system issued advice to insurers to cease reimbursement under the basic insurance package of bladder instillations containing two specific substances.
- This applied to pathologies such as interstitial cystitis, radiation cystitis, overactive bladder, amongst others, affecting over 20,000 patients in the Netherlands

Opposing the decision– a multi-stakeholder response

- The ICP worked with other organizations including the patients' organizations, urologists, physiotherapists, psychologists and suppliers opposing the decision
- Set up a multi-stakeholder Task Force to coordinate action
- Wrote letters and met with the Ministry of Health and health insurers
- Generated media coverage
- Initiated legal battle – have won initial case, but legal issues are likely to continue

Lessons learnt

- The publication of the new guidelines were issued without consultation with other stakeholders
- Patients need to be involved in discussions and decisions on medical products effectiveness
- In this case, patients valued the effectiveness much more highly than the evidence used to make the decision suggested.
- Governments should ensure patient involvement and factor time in for consultation time to ensure issues like this do not surface

Summing up

- Patients need to need to define what is meant by quality in healthcare and bring their perspective to debates on access to healthcare and universal health coverage
- Patient involvement in decisions on access to healthcare
- IAPO is developing a set of patient-centred principles for universal health coverage which once finalised, will form the core part of our advocacy on access to healthcare
- Role of the media for patients organizations very variable and open for debate: Short-term flashpoint or longer-term policy and strategic focus? Highlighting patient concerns? Increasing knowledge and understanding?



Questions or comments?

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www.iapo.org.uk

info@iapo.org.uk

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