

International Regulatory Convergence: Meeting Patients' Needs

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International Alliance of
Patients' Organizations

A global voice for patients

Content of Presentation

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2. Meeting Patient Needs: A Patient-Centred Approach?
3. Capturing the Patient Voice
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1. About IAPO

- Established in 1999
- Unique global alliance of over 200 national, regional and international groups representing patients
- Crossing borders and diseases



IAPO Chair, Durhane Wong-Rieger

Vision:

Patients throughout the world are at the centre of healthcare

IAPO's Mission

IAPO's mission is to help build patient-centred healthcare in worldwide 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



Capacity Building



Advocacy



Partnerships

IAPO Members



IAPO Members at the 5th Global Patients Congress, London, 2012

- Over 200 member organizations
- Spanning over 60 countries and all world regions
- Representing an estimated 365 million patients

International

- **Alzheimer's Disease International**
- Multiple Sclerosis International Federation
- World Hemophilia Federation

Regional

- European Organization for Rare Disorders (EURORDIS)
- Community Health and Information Network (CHAIN Uganda)

National

- **Alliance for Patients' Mutual Help Organizations (Hong Kong)**
- American Diabetes Association
- Argentine Cystic Fibrosis Association


2. 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



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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 choices.
- 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 assure 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 practices. We call upon all stakeholders to provide the necessary structure, 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: www.patientsorganizations.org/declaration or contact us for its impact and benefits to its practice can be found in the 2016 publication *What is Patient-Centred Healthcare? A New Paradigm and Principles* (IAPO, 2016) at: www.patientsorganizations.org/declaration. Contact IAPO at: info@patientsorganizations.org

The IAPO Declaration on Patient-Centred Healthcare

Principle 1:

**Respect and support for the individual patient, their
wants, preferences, values, needs and rights**

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

The IAPO Declaration on Patient-Centred Healthcare

Principle 2:

Choice and empowerment

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

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Principle 3:

Patient engagement in health policy

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

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Principle 4:

Access and support

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

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Principle 5:

**Information that is accurate, relevant and
comprehensive**

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

3. Capturing the Patient Voice

Value of the patient voice:

- Unique perspective
- Expert in own condition
- Unanticipated benefits/preferences

How to involve patients:

- Design of devices
 - Patients organizations' and individual patients
- Decision-making committees - Providers
- Research on what patients' value

4. Strengthening Patient Involvement in Decision Making

- Ensure a balance of representatives (general vs. experts in their own disease)
- Encourage participation and motivate
- Give support to enable involvement
- Provide information, education and training
- Monitor the involvement – ensure that it makes a difference

Collaboration

Accelerate international medical device regulatory convergence

Support innovation and timely access to safe and effective medical devices globally

Promote open discussion through the sharing of best practices among regulatory authorities responsible for medical device regulation

Facilitate frequent exchange of policy and regulatory information of common interest to regulatory authorities

Provide opportunities to identify commonalities and develop approaches to overcome them

Enhance communication, information sharing and scientific exchange among regulators and a broad range of stakeholders

Establish develop dialogue with relevant organizations

Best practice – transparency, accountability

Conclusions

- Key priorities for patients:
 - Respect
 - Choice
 - Involvement
 - Access and Safety
 - Information

Recommendation: Strengthen patient involvement in all processes to improve health outcomes and ensure needs are met.

Contact us



Please visit our website to find out more:
www.patientsorganizations.org

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