International Regulatory Convergence: Meeting Patients’ Needs

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2. Meeting Patient Needs: A Patient-Centred Approach?
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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

**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
Promoting patient-centred healthcare around the world

IAPO Members

• 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

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

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Principle 3:

Patient engagement in health policy

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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

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www.patientsorganizations.org

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