# International Regulatory Convergence: Meeting Patients' Needs

Jo Groves
Chief Executive Officer

IMDRF-3 Stakeholder Forum 20 March 2013 Nice, France



## **Content of Presentation**

- 1. A short introduction to the International Alliance of Patients' Organizations (IAPO)
- 2. Meeting Patient Needs: A Patient-Centred Approach?
- 3. Capturing the Patient Voice
- 4. Strengthening Patient Involvement in Decision-Making
- 5. Conclusions

## 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:

- 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

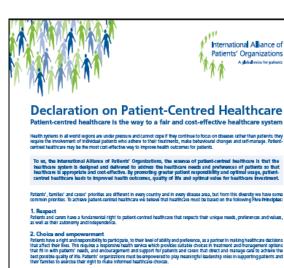
## 2. What is patient-centred healthcare?

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



issues which impact on their approach to healthcare choices and management.

Falsets and palaeths' organizations disease to this this regionability of healthcare policy-maining through manning und supported organization and palaeths' organizations disease to decision-markets, to ensure that they are designed with the palaete at the confer. This school for the restricted to healthcare policy but include, for example, social policy that will ultimately impact on parliamit lives. See MADD Febry Schoolmant at it were parliamitoring maintainess upper physiological manning and palaeths.

services, treatments, preventive care and health promotion activities. Provision should be made to ensure that all patients can access memory services, requires to advise the best possible quality of this, healthcale must apport published "emblornal requirements, and consider non-health factors such as education, employment and farmily

3. despending of the competency of the control o

To achieve patient-centred healthcare at every level in every community, the International Alliance of Potismb Organizations is calling for the support and collaboration of policy-makers, health professionals, sevice provides an haitm-netized inclusives to endors the sea Fee Principles and for main term the centre of their poticisis and practice Was call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principle continual in the Decaration are uplished by all.

information shout Patient-Centred-Hastiticare including endance for its impact and barriers to its practice can be found in the IAMO publication What is Added-Hastiticars?: A Assist of Defetition and Ricopies (IAMO, 2005) at researce prior to organizations organization organization.

Principle 1:

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

Principle 2:

#### **Choice and empowerment**

Principle 3:

Patient engagement in health policy

Principle 4:

**Access and support** 

Principle 5:

## Information that is accurate, relevant and comprehensive

## 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

If you would like to receive our **free** monthly email newsletter and details of other publications, please send your details to us:

#### International Alliance of Patients' Organizations

49-51 East Road London N1 6AH United Kingdom

Tel: +44 20 7250 8280 Fax: +44 20 7250 8285

Email: <u>info@patientsorganizations.org</u>
Website: <u>www.patientsorganizations.org</u>