Meeting Patients’ Needs

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1. About IAPO

- Unique global alliance of national, regional and international groups representing patients
- Established in 1999
- Crossing borders and diseases
- Vision: Patients throughout the world are at the centre of healthcare
- 200 member organizations
- Membership spans 50 countries and all world regions
- Representing an estimated 365 million patients
IAPO’s Mission

IAPO’s role is built around the understanding that patients’ voices are amplified and heard effectively when patients’ organizations are linked and connect resources to share best practices and practical strategies.

This role falls into three main areas following our mission to help build patient-centred healthcare 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
2. A Patient-Centred Approach?

The IAPO Declaration on Patient-Centred Healthcare outlines five principles:

- Respect and support for the individual patient, their wants, preferences, values, needs and rights
- Choice and empowerment
- Patient engagement in health policy
  (See www.patientsorganizations.org/involvement)
- Access and support
- Information that is accurate, relevant and comprehensive
  (See www.patientsorganizations.org/information)

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 1:

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

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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 further:

- 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
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.
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