Patients' Perspectives on Collaborations with Stakeholders

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Content of Presentation

- About IAPO
- Principles of patient-centered healthcare
- Patient-centered initiatives
- Patient Group – Industry Collaborations
- Conclusion
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

• www.patientsorganizations.org
IAPO’s Mission

Our mission is to help build patient-centered 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
Promoting patient-centered healthcare around the world

What is patient-centered healthcare?

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

Patient-centered 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-Centered Healthcare: www.patientsorganizations.org/declaration
Globalization and Healthcare

- Public health issues are global
- The health industry is increasingly multinational
- Healthcare policies are debated and developed internationally
- Progress in science, medicine and technology is international
- Other important stakeholders in healthcare are organized and influential internationally
The importance of a global patients movement

• The value of national perspectives to global policies

• National status of healthcare

• The relevance of patient-centered healthcare principles

• The value of working in a global context

• The value of sharing best practice

It is only through effective engagement by all stakeholders with IAPO that our work and the experiences of patients and patients’ organizations can be understood and acted upon.
Global Issues for Patients’ Organizations: IAPO’s Policy Priorities

- The massive issues of access to treatment and care
- Lack of meaningful patient involvement in health policy decision-making
- The need for an international concerted effort to address patient safety
- The need for quality health information and communication
The importance of collaboration

To address these global healthcare issues, we need the collaboration of all stakeholders, including patients.

Where should patient engagement take place?

- Individual level – involvement in own healthcare
  - E.g. Patient education and self management programmes
- Regional within a country – development of programmes
  - E.g. Family Health Teams in Ontario, Canada
- National
  - E.g. Patients Rights Law 2004, Cyprus
- International
  - E.g. patient representation with World Health Organization – IAPO is in official relations with WHO

Combining international, regional and national level advocacy

Patients for Patient Safety - WHO Patient Safety

- Ensuring and enabling patient involvement in strands of the Alliance at a global level
- Ensuring and enabling patient involvement at a regional and national level
Promoting patient-centered healthcare around the world

Supporting collaborations

**Advocacy** – active in defining and promoting principles, guidelines and frameworks for patient engagement and partnerships including:
- WHO Priority Medicines Reports (2004 and update 2013)
- European Medicines Agency Patients and Consumers Working Party
- IAPO Policy Statement and Guidelines on Patient Involvement
- Issues include: transparency, accountability, independence, conflict of interests etc

**Capacity Building** – supporting patients’ organizations and stakeholders we work with to develop effective long-term relationships through:
- Development of practical information, tips, tools and resources (e.g. online toolkit including template agreements etc)
- Provision of training (e.g. webinars, face to face workshops etc)

**Working together** – putting it into practice:
- Long term official partnerships with WHO, health professional organizations and industry based on principles of transparency and accountability
Promoting patient-centered healthcare around the world

IAPO’s working with partners and stakeholders online toolkit
Patient Group – Industry Collaborations

Benefits
✓ Skills/expertise sharing
✓ Greater understanding of respective needs
✓ Access to information & data
✓ Funding, resources & in-kind support

Challenges (and in some cases risks)
✓ Potential loss of independence (on both sides!)
✓ Differing expectations and aims
✓ Perceived threat to public image and credibility

Benefits and challenges are not exclusive to patient group-industry collaborations!
Patient Group – Industry Collaborations

Guidance and tools to support collaborations and pillars of engagement: top tips, frameworks and agreements explained, checklist, framework for interaction template, roadmap.

http://www.patientsorganizations.org/iapo_media/Toolkits/current/iapo_toolkit.html
Consensus Framework for Ethical Collaboration

- putting patients first;
- supporting ethical research and innovation;
- ensuring independence and ethical conduct; and
- promoting transparency and accountability.
Conclusions

• Patients and patient’s organizations can make a valuable contribution to redesigning and shaping healthcare systems to provide quality, safe and appropriate care

• Meaningful patient engagement must be central to efforts to refocus health systems on people and patients

• To achieve patient-centered healthcare we need an approach based on strong values of respect, partnership and equity – no patient-centered healthcare without cooperation of all stakeholders
Contact us

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