

# The Global Patients Movement: The value of patient engagement and the need for collaboration

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Event name: Third Pacific  
Pharmaceutical Compliance Congress  
Date: 10-12 September 2013  
Location: Kuala Lumpur, Malaysia



International Alliance of  
Patients' Organizations

A global voice for patients

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# 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](http://www.patientsorganizations.org)

# I APO's Mission

Our mission is to help build patient-centred 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


# 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](http://www.patientsorganizations.org/declaration)



**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](http://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](http://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.

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# 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-centred 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

# Supporting collaborations

**Advocacy** – active in defining and promoting principles, guidelines and frameworks for patient engagement and partnerships including:

- World Health Organization Reform Process (2012 – current)
- 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

# IAPO's working with partners and stakeholders online toolkit

The screenshot shows the IAPO website homepage. At the top, there is a navigation bar with links for Feedback, Search, Contact Us, Languages, and Sitemap. Below this is a green banner with the text "A global voice for patients" and a small image of a person. A secondary navigation bar contains links for Home, About IAPO, News, Patient-Centred Healthcare, Membership, The Patients Exchange, and Global Patients Congress. The main content area features a large blue banner for the "5th Global Patients Congress" with the subtitle "Achieving Patient-Centred Healthcare: Indicators of Progress and Success" and the dates "17-19 March 2012 • Renaissance Hotel, London, UK". Below the banner is a welcome message: "Welcome to the website of the International Alliance of Patients' Organizations (IAPO)." followed by a paragraph describing IAPO's mission. To the right of the welcome message are social media buttons for Twitter and Facebook. Below the welcome message is a section titled "World Health Organization Sixty-fourth World Health Assembly - Geneva, Switzerland - 16-24 May 2011" with a link to the IAPO news page. At the bottom right, there is a purple box titled "PATIENTS' ORGANISATION TOOLKIT" with the text "Working with partners and stakeholders" and a right-pointing arrow. On the left side of the page, there is a sidebar with the IAPO logo, a search box, and a list of navigation links including Home, About IAPO, News, Membership, Events, Patient-Centred Healthcare, Global Directory, The Patients' Exchange, Global Congress, World Regions, Publications & Tools, Press, About this Website, Support, Contact Us, and Español. At the bottom left, there are login options and a copyright notice for 2009.

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International Alliance of Patients' Organizations

A global voice for patients

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5th Global Patients Congress  
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17-19 March 2012 • Renaissance Hotel, London, UK  
www.globalpatientscongress.org

Welcome to the website of the International Alliance of Patients' Organizations (IAPO).

IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world.

Our members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

World Health Organization Sixty-fourth World Health Assembly - Geneva, Switzerland - 16-24 May 2011  
[IAPO \[News\]](#) 5:38PM Wednesday 08 June 2011

IAPO attended the World Health Organization (WHO) Sixty-fourth World Health Assembly (WHA) in May in Geneva. The WHA is an important event for IAPO to highlight the issues and needs of patients to important

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PATIENTS' ORGANISATION TOOLKIT  
Working with partners and stakeholders

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# Patient Group – Industry Collaborations

## Benefits

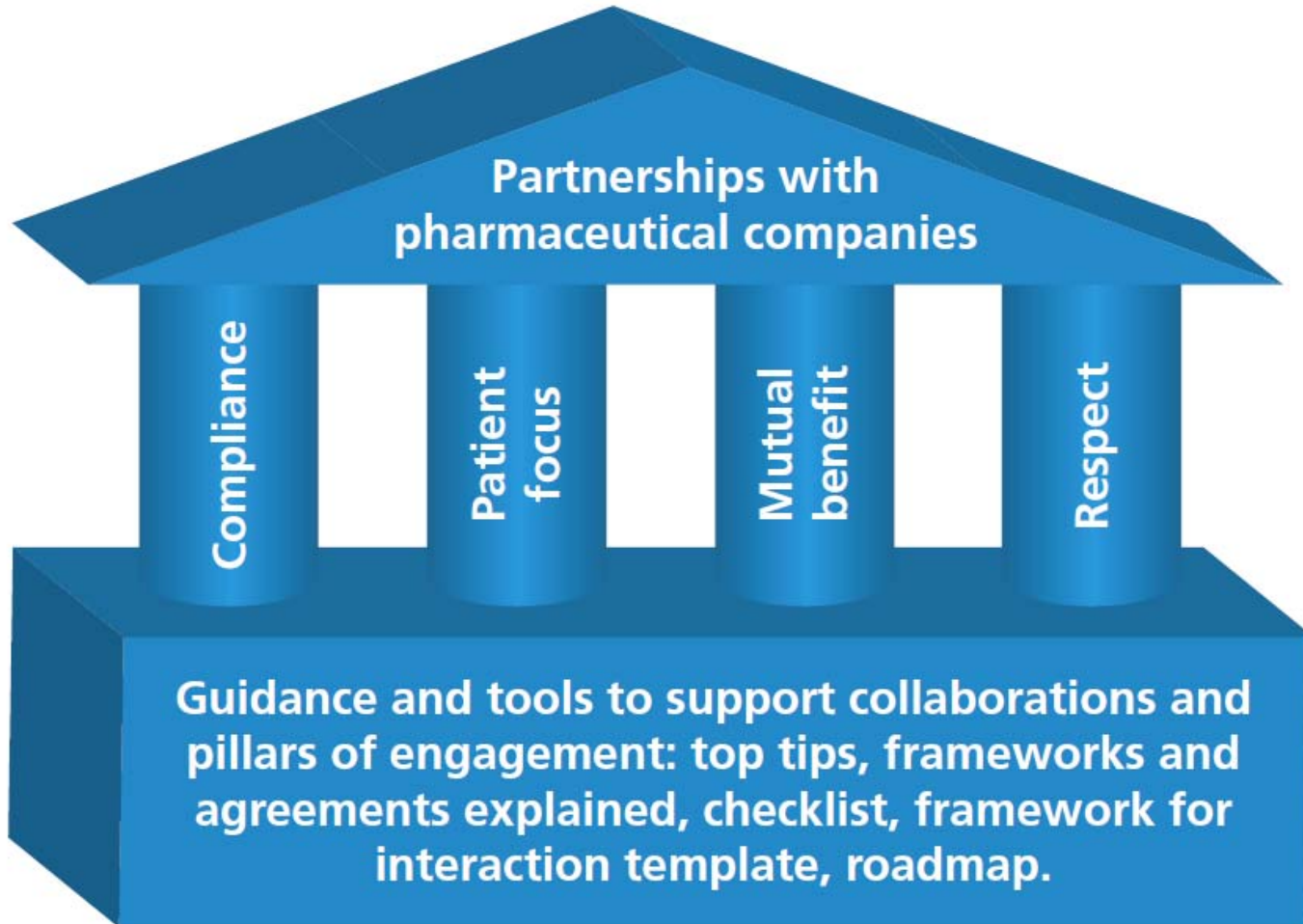
- ✓ Skills/expertise sharing
- ✓ Greater understanding of respective needs
- ✓ Access to information & data
- ✓ Funding, resources & in-kind support

## 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



# 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-centred healthcare we need an approach based on strong values of respect, partnership and equity – no patient-centred healthcare without cooperation of all stakeholders



## Contact us

Please visit our website to find out more:

[www.patientsorganizations.org](http://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:

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