

Patient Engagement in Patient Safety

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About IAPO

- Unique global alliance of 207 national, regional and international groups representing patients
- Crossing borders and diseases
- Vision: Patients throughout the world are at the centre of healthcare
- Membership spans over 50 countries and all world regions
- Representing an estimated 365 million patients



Capacity Building



Advocacy



Partnerships

IAPO'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

IAPO's Membership

- Over 200 member organizations
- Membership spans over 50 countries and all world regions
- Representing an estimated 365 million patients

International

- Alzheimer's Disease International
- Multiple Sclerosis International Federation
- World Haemophilia Federation

Regional

- European Organization for Rare Disorders (EURORDIS)
- Community Health and Information Network CHAIN (Great Lakes Region of Africa)

National

- Alliance for Patients' Mutual Help Organizations (Hong Kong)
- American Diabetes Association
- Argentine Cystic Fibrosis Association

What is patient-centred healthcare?

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

A patient-centred approach to patient safety

- Access to **safe, quality** and **appropriate** services, treatments, preventive care and health promotion activities
- **Empowerment** of patients and patients' organizations through education, information and support
- **Patient engagement** - '...meaningful and supported engagement in all levels (of healthcare policy) and at all points of decision-making...' (from IAPO Declaration on Patient-Centred Healthcare)

What can patients and patient groups do?



Advocate – To raise political will to take action and implement appropriate patient safety strategies and partner with healthcare systems to develop solutions for patient safety.



Educate – and train patient groups to make an informed contribution to patient safety initiatives and patients be empowered to make a personal contribution to safety.



Raise awareness –of patient safety issues with the public and the media.

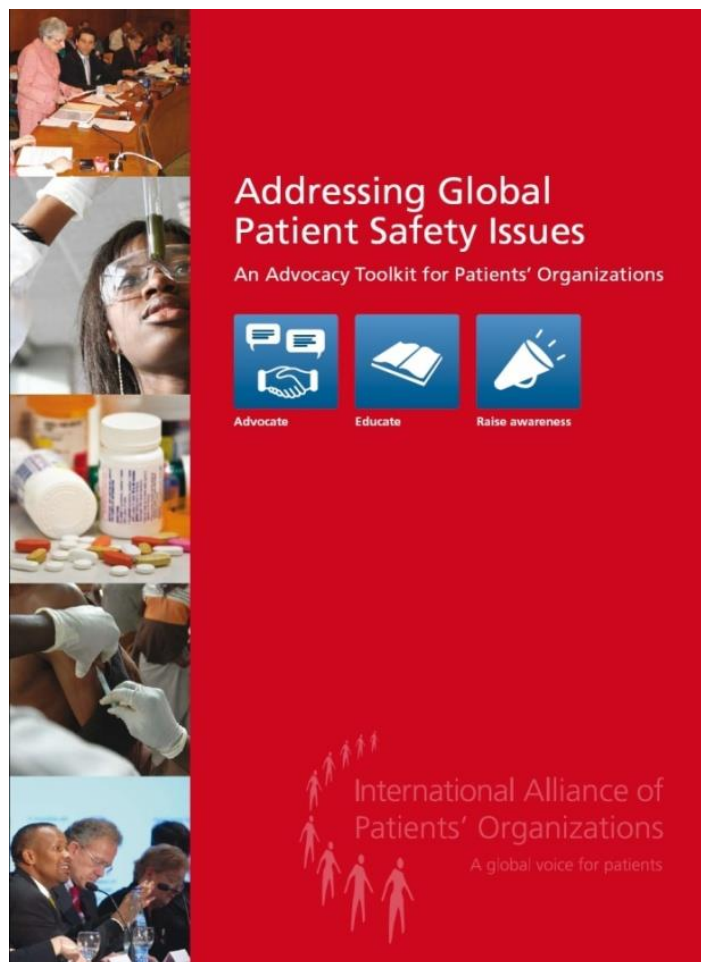
IAPO and Patients for Patient Safety (PFPS)

- IAPO is on the Steering Group for WHO's Patients for Patient Safety. PFPS has trained over 214 Patients for Patient Safety Champions worldwide in 51 Member States.
- Patients for Patient Safety (PFPS) emphasizes the central role patients can play in efforts to improve the quality and safety of health care around the world.
- PFPS works with a global network to support patient involvement in patient safety programmes, both within countries and in the global programmes of WHO Patient Safety.
- The purpose is to improve healthcare safety throughout the world by involving patients as partners.

IAPO and APPS

- IAPO works with its members in Africa and WHO on the African Partnerships for Patient Safety (APPS) programme.
- APPS is a WHO Patient Safety Programme building sustainable patient safety partnerships between hospitals in countries of the WHO African Region and hospitals in other regions.
- APPS works to strengthen health systems, assist in building local capacity and help reduce medical error and patient harm.
- The programme acts as a channel for patient safety improvements that can spread across countries, uniting patient safety efforts.

IAPO Advocacy Toolkit for Patients' Organizations



- In 2008, IAPO launched an advocacy toolkit for patient groups to inform and support them to advocate for improved patient safety.
- IAPO's Patient Safety Toolkit aims to equip patient advocates with an understanding of a range of important patient safety issues and provide a range of information and tools.
- Each section of the toolkit has an introduction explaining the issue and guiding the reader through the different materials available.

Lessons learnt

- To achieve improved quality and safety we need to work in partnerships with an approach based on strong values of respect, partnership and equity – no patient-centred healthcare without cooperation of all stakeholders including patient groups
- Educational initiatives to inform patients and the public about patient safety should be developed with the involvement of patients and patient groups
- Attention should be paid to the role of communication between healthcare professionals and patients – patients sometimes see things that busy health professionals do not and should feel comfortable communicating concerns they may have