

Establishing the Consensus Framework for Ethical Collaboration: Patients, HCPs and Industry

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International Alliance of
Patients' Organizations

A global voice for patients

About IAPO

- Established in 1999
- Unique global alliance of national, regional and international groups representing patients
- Crossing borders and diseases



IAPO Chair, Kin-ping Tsang

Vision:

Patients throughout the world are at the centre of healthcare

IAPO Members



IAPO Members at the 6th Global Patients Congress, Ascot, UK, 2014

- Over 230 member organizations
- Spanning over 60 countries and all world regions
- Representing an estimated 365 million patients
- Members are at the core of IAPO's work and the impact of what we do is created by the diversity and breadth of our alliance.

IAPO's Mission

IAPO's mission is to help build patient-centred healthcare in 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



Capacity Building



Advocacy



Partnerships

Development of the framework

- recognition that **collaboration is essential**
- mutual interest in relationships based on **ethical and responsible decision-making**
- best **meet patients' needs**
- opportunity to **consolidate progress** made in ethical collaboration
- partners have been meeting twice a year since 2011
- identified that respective codes and principles contain **common fundamental values**

Our roles and responsibilities

Ensuring patients receive the most appropriate care

- patients must be **informed** and **empowered** to, along with their caregivers, **decide on the most appropriate treatment** options for their individual health needs and to **participate responsibly in use of health resources and managing their own health**
- healthcare professionals must ensure that the **treatment options they offer to patients are appropriate**
- the pharmaceutical industry has a duty to provide **accurate, fair, and scientifically grounded information** for their products, so that the responsible use of medicines can be facilitated



Consensus Framework for Ethical Collaboration between Patients' Organisations, Healthcare Professionals and the Pharmaceutical Industry

A Consensus Framework established for ethical collaboration between patients' organisations, healthcare professionals and the pharmaceutical industry, in support of high quality patient care. This Consensus Framework and the accompanying resources are intended to serve as a toolkit for those associations, groups and alliances who wish to develop their own policies. It neither aims to be comprehensive nor does it constitute a single common policy of the organisations involved. The individual policies of the participating organisations set out each organisation's detailed commitments and offer more diverse and in depth information and guidance.

Four overarching principles:

- Put patients first
- Support ethical research and innovation
- Ensure independence and ethical conduct
- Promote transparency and accountability

Launch of the framework



20 January 2014, Geneva Switzerland

Putting patients first!

An empowered activated patient:

- Understands their health condition and its effect on their body
- Feels able to participate in decision-making with their healthcare professionals
- Feels able to make informed choices about treatment
- Understands the need to make necessary changes to their lifestyle for managing their condition
- Is able to challenge and ask questions of the healthcare professionals providing their care
- Takes responsibility for their health and actively seeks care only when necessary
- Actively seeks out, evaluates and makes use of information

As outlined by the European Network for Patient Empowerment (ENOPE):

www.enope.eu/

The rationale for patient engagement

- Health systems need to reorient to focus on the whole person not the disease
- Patients and families are there throughout the patient journey
- Patient groups can represent the views of communities of patients



Principles of patient engagement

- Robust and transparent mechanisms to ensure that patient views are acted upon, not just recorded
- Involvement in all stages - initiation, design, implementation, communication and evaluation
- Provision of necessary support which may include practical, psychological, financial and/or educational support
- Use of varied methods to reach underrepresented groups and to gather a diversity of views and input
- Provide information, education and training for both parties on how to collaborate

See IAPO's Policy Statement and Guidelines on Patient Involvement

www.patientsorganizations.org/involvement

What's next?

- Model for joint initiatives between patients' organizations, healthcare professionals and pharmaceutical industry associations on the national level
- Complement existing national and regional codes and guidelines
- Living document open to comment and endorsement
- Build on framework by sharing tools, promoting dialogue with a broader stakeholder network, deciding on next steps

Tools and resources for effective engagement



IAPO's working with partners and stakeholders toolkit



working with partners and stakeholders

Welcome

Collaborating with stakeholders

Working with pharmaceutical companies

Key patients' organisation activities

'How to...' guides

Other tools and resources

Foreword from IAPO

IAPO involvement

Novo Nordisk involvement

Pope Woodhead involvement

Welcome

Patients' organisations are important patient advocates that truly understand patients' needs. While there are other stakeholders who, like patients' organisations, want to improve the health and quality of life of patients, they are not fully aware of patients' needs or how best to address them. Therefore, establishing partnerships between patients' organisations and other stakeholders can help provide real benefits to patients, their families and carers.

This toolkit has been designed specifically to support patients' organisations develop effective relationships with key stakeholders. It contains information and tools to help understand and overcome challenges that they sometimes experience when working with external parties.

The design and content of the toolkit has been developed by an independent third party (Pope Woodhead and Associates Ltd; see [Pope Woodhead involvement](#)) in consultation with the International Alliance of Patients' Organizations (IAPO; see [IAPO involvement](#)). The case studies were provided by IAPO member organisations. Novo Nordisk, a pharmaceutical company, provided project funding (see [Novo Nordisk involvement](#)).

Useful links

[How to use the toolkit](#)

[Site map](#)



[Print-friendly text \[PDF\]](#)

[How to use the toolkit](#)

[Site map](#)

[Acknowledgements](#)

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Thank you!



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www.patientsorganizations.org

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