

# Putting Patients at the Centre of Healthcare

## Strategic Plan 2010–2014





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*“Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.”*

**Margaret Mead**

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## The Patient Voice

IAPO believes that the patient voice makes an essential and valuable contribution to healthcare debates and decision-making. This patient voice is one which captures and accurately represents the patient experience.

Patients' views and experiences can most effectively be shared in healthcare debates by patients themselves or by others designated by patients<sup>1</sup> to speak on behalf of patients.

*“The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare.”*

***Alma Ata Declaration – Principle IV (1978, WHO)***

<sup>1</sup> These may include patients' organization representatives, family members or carers.

## Introduction

The International Alliance of Patients' Organizations (IAPO) is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world. IAPO brings a global patient voice to healthcare decision-making based on the belief that patients' voices are amplified and heard effectively when patients' organizations are linked, can share best practices and practical strategies, and are connected with resources.

IAPO works within a global context on healthcare policy issues that cross geographical and disease boundaries such as access to health and health information, the quality and safety of healthcare and the engagement of patients in decisions that affect their lives.

IAPO was established in 1999 and now, through its membership of 200 organizations, represents an estimated 365 million patients. IAPO is in official relations with the World Health Organization (WHO) and has official partnerships with the International Council of Nurses (ICN), International Pharmaceutical Federation (FIP) and World Medical Association (WMA).

### Vision

IAPO's vision is that patients throughout the world are at the centre of healthcare.

For this vision to become a reality, patients must be empowered and engaged as equal partners in all decision-making processes affecting their health and healthcare needs or concerns. It is only by responding to patients' expressed needs and preferences that people will be enabled to lead healthier lives with improved quality of life and reduced health inequalities.

### Mission

IAPO helps build patient-centred healthcare worldwide by:

- Realizing active partnerships with patients' organizations, maximizing their impact through capacity building
- 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
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives



We are delighted to introduce our five-year Strategic Plan for the period 2010–2014. This strategy provides a strong framework for our work to enable the engagement of patients in *all* decisions that affect their health and quality of life. It is only with patient engagement at all levels of healthcare decision-making that healthcare systems can be designed and delivered to meet the needs of patients. IAPO is uniquely placed to deliver this strategy at the global level and aims to work equitably across all world regions.

This strategy provides a clear framework for our policy activities on a wide range of healthcare issues, as outlined on page 14. It also builds on the achievements of our 2006–2008 Strategic Plan,<sup>2</sup> during which time IAPO successfully defined patient-centred healthcare, brought together patient representatives globally on a number of shared agendas and assisted patients' organizations to advocate on healthcare issues affecting patients globally, regionally and nationally. This Strategic Plan should be considered together with the five-year overview, and annual plans which outline specific activities, targets and indicators.

<sup>2</sup> Annual reports for 2006–2008 are available online at: [www.patientsorganizations.org/development](http://www.patientsorganizations.org/development)

IAPO's strategic goal for the period 2010–2014:

*To strengthen the impact of the global patients' voice in decision-making processes globally.*

IAPO is committed to achieving this goal in order to lead to positive changes in healthcare design and delivery which ensure that the needs of patients globally are equitably and appropriately addressed, leading to beneficial health outcomes and improved quality of life.



### Strategic Objective 1: Engagement

Patients' organizations will be better engaged in influencing decision-making at an international level by:

- a) Strengthening IAPO's collaborations with the World Health Organization (WHO) and United Nations Economic and Social Council (UN ECOSOC)
- b) Facilitating the engagement of patient representatives in WHO activities and decision-making processes
- c) Proactively working with key international organizations to develop and implement appropriate and realistic frameworks for patient engagement
- d) Accurately representing and communicating the global patients' voice

#### Key outcomes and activities<sup>3</sup>

- 1) Increased awareness of the value of patient engagement within international decision-making processes:
  - IAPO will actively promote the role of patients in all types and phases of healthcare research and decision-making with a wide range of healthcare stakeholders
- 2) Improved frameworks for patient engagement in place within international organizations:
  - IAPO will collate a set of good practice models for engaging patients in decision-making processes
  - IAPO will encourage the development and use of appropriate models for patient engagement
  - IAPO will engage directly with relevant departments within international organizations to inform policies and procedures for engaging with patients and patients' organizations (e.g. health professional associations, regulators, United Nations agencies, industry etc)

<sup>3</sup> These outcomes and activities may address more than one part of the objective.

- 3) Patient-centred policies developed on targeted healthcare issues at an international, regional and national level:
- On an annual basis, IAPO will identify priority policy issues, develop patient-centred policy positions and promote them at an international, regional and national level
  - IAPO will strengthen the evidence base for patient-centred healthcare
  - IAPO will ensure the high-level engagement of patient advocates in relevant international research and decision-making processes through coordinating and supporting their engagement

## Strategic Objective 2: Voice

The global patients' voice will be strengthened; ensuring it accurately reflects the diverse needs and experiences of patients globally and is well communicated by:

- a) Developing the capacity of patients' organizations globally
- b) Supporting the development of active and empowered networks of patients' organizations (within world regions and globally)
- c) Enabling patients globally to develop and communicate a strong unified voice on shared agendas

### Key outcomes and activities<sup>4</sup>

- 1) Stronger partnerships and networks between patients' organizations:
  - IAPO will promote the relevance and role of partnerships between patients' organizations
  - IAPO will develop and promote a strong framework including guidelines and tools for effective partnerships and networks between patients' organizations
  - IAPO will provide opportunities for patients' organizations to network and develop shared understandings and approaches to promoting patient-centred healthcare on an international and/or regional level
- 2) Patients' organizations are more empowered to work collaboratively on patient-centred healthcare:
  - IAPO will promote and support joint working between members towards patient-centred healthcare through its exchange programme
  - IAPO will ensure its frameworks for partnerships and networks provide practical support and promote collaborative approaches to patient-centred healthcare

<sup>4</sup> These outcomes and activities may address more than one part of the objective.

- 3) Unified patients' perspectives are voiced on shared agendas (within world regions and globally):
- IAPO will maximize opportunities for members to work towards unified patients' perspectives
  - IAPO will ensure its policy interventions articulate clear positions which are informed by comprehensive consultation processes with patients
  - IAPO will establish and support remote (e-technology) groups of members to discuss and promote patient-centred solutions to relevant healthcare challenges (policy and/or regionally focused)

### Strategic Objective 3: Member-led<sup>5</sup>

Increased participation of IAPO member patient representatives in all aspects of IAPO's work, ensuring that the voice of patients globally will be integral to IAPO's work by:

- a) Providing increased opportunities for IAPO's members to participate actively in and shape IAPO's work
- b) Building the capacity of IAPO's members to participate actively in and shape IAPO's work

#### Key outcomes and activities<sup>6</sup>

- 1) IAPO members consider that IAPO is member-led and accurately represents their views:
  - IAPO will ensure integrity and consistency in the way that its members inform and drive the agenda of the organization
- 2) More members engaged in shaping and delivering a wider range of IAPO's work:
  - IAPO will ensure that all new members develop an understanding of their role participating in IAPO's governance and work within six months of becoming a member
  - IAPO will provide members with training at the Global Patients Congress and other events to promote greater meaningful engagement in IAPO's decision-making
  - IAPO will develop a clear framework for increased and regular opportunities for members to participate in IAPO's work

<sup>5</sup> IAPO's members are patient-led organizations and, as such, IAPO is itself patient-led.

<sup>6</sup> These outcomes and activities may address more than one part of the objective.



### Strategic Objective 4: Sustainability

IAPO's capacity and sustainability as an organization will be developed in the most appropriate ways to ensure that IAPO can achieve its vision by:

- a) Sustaining and diversifying the funding base of the organization
- b) Ensuring an approach to human resources, organizational management and administration that promotes good governance and positive organizational development

#### Key outcomes and activities<sup>7</sup>

- 1) Improved security and diversity of funding base:
  - IAPO will actively promote longer-term commitments from existing donors
  - IAPO will actively seek to diversify its funding base
- 2) Increased integrity of management and governance structures:
  - IAPO will continue to audit, review and develop management and governance policies and procedures that promote our values throughout our operations

IAPO has seven values which underpin the way we work: *Accessibility, Accountability, Commitment to Diversity, Inclusiveness, Independence, Representation, and Transparency*. These inform our professional relationships with members, partners and other stakeholders, and are available on our website at: [www.patientsorganizations.org/values](http://www.patientsorganizations.org/values). In addition to these values, four operational approaches have been identified as fundamental to the success and sustainability of this strategy:

**1) Mainstreaming<sup>8</sup> patients:** In working to support our patient-led member organizations, it is vital that IAPO ensures a consistent and considered approach to working with and for patients. By working to mainstream patients throughout our work over this strategic period, IAPO aims to develop and model an approach that maximizes the inclusion of patients in all that we do, ensuring we are truly patient-led, and represent the patient voice.

**2) Working in collaborative partnerships:** IAPO has a firm commitment to our approach to partnership, believing that the strongest and most effective partnerships are open and equal. The goal of patient-centred healthcare requires individuals, groups and organizations with different constituencies and opinions to work together collaboratively and respectfully. Effective implementation of this approach to partnership will be central to the sustainability and reach of our outcomes during this strategic period.

**3) Evidence-based:** IAPO is committed to strengthening the evidence-base for patient-centred healthcare, in particular through promoting the development and use of the patient experience.

**4) Impact-focused:** During this strategic period, IAPO is committed to maximising the impact of our work. This will be achieved through the regular and consistent measurement of our effectiveness, and by remaining focused on achieving our key strategic priorities.

<sup>7</sup> These outcomes and activities may address more than one part of the objective.

<sup>8</sup> Mainstreaming is widely understood to mean the systematic and meaningful inclusion or consideration of a group of people, in this case patients, in all aspects of the systems, policies, methodologies and work of an organization.



The healthcare policy issues that IAPO addresses are informed by our global context. The prioritization of these policy issues is based on regular consultation with our members and partners. These issues are those that patients and patients' organizations face throughout the world.

IAPO's work through capacity building and the promotion of patient engagement strengthens healthcare systems and has a wider impact on mainstream global health concerns such as the health-related goals outlined in the Millennium Development Goals.

IAPO works on a diverse range of specific healthcare policy issues. These may be specific long-term issues of concern to patients or emerging issues. From 2010–2014, IAPO will focus on a wide range of broad and more focused issues such as those listed below. Some of these are new areas for IAPO and others are key issues we have been working on for some time and possess expertise in. They fall broadly into four areas:

- 1) Meaningful patient engagement in healthcare policy decision-making
- 2) Access to health, treatment and care
- 3) Access to good quality health information which is communicated effectively
- 4) Access to safe and quality healthcare services

Specific issues will include, but will not be limited to:

- Biosimilar medicines
- Chronic disease prevention and management
- Clinical trials
- Counterfeit medicines
- Health financing
- Health literacy
- Health technology assessment
- Patient-health professional communications
- Patient information
- Patient safety
- Pharmacovigilance

This strategy was informed by a thorough and consultative review and planning process in 2008 and 2009. IAPO's members, governing board and staff were the internal stakeholders developing and shaping the strategic direction. The strategy was framed by consultation and discussion with invited external stakeholders including policy makers, healthcare professionals, academics and industry representatives. This strategy was shared with all IAPO's Full and Associate members, partners and other key international stakeholders in global healthcare for review and comment prior to its being finalized in February 2010.

We would like to thank all those that took the time to provide their knowledge and thoughtful input which contributed to the development of the plan.

**Members:** Members were consulted on what they valued most in the previous strategic plan and would most like to see in the coming years. Members also reviewed the strategy prior to finalization.

**Governing Board:** The elected Governing Board were instrumental in informing the direction and content of the strategy through a range of scanning exercises, facilitated group work and individual interviews.

**Staff:** IAPO staff undertook environmental analyses and contributed their experience and ideas during the development process.

**External Experts:** In-depth interviews were held with a range of experts to explore the current policy trends and healthcare environment and its likely development in the coming years.

**Other Stakeholders:** Through formal and informal meetings and via an email consultation, a range of other stakeholders have been given the opportunity to discuss and share their thoughts on IAPO's role and relevance in the current healthcare environment.

**Methods:** Literature review, online survey, interviews, pair work, group work and environmental analyses (e.g. SWOT, PEST etc).

# Operating Environment

IAPO undertook an external analysis of the environmental factors and global trends that may impact IAPO's work in the next five years. Three main trends were highlighted: the global economy; health demographics; and globalization.

## Global Economy


The impact of the global economic situation raised differing views from those consulted. Cutbacks or freezes in health budgets are leading to a change in focus in the appraisal of healthcare technologies which will likely affect which services and treatments patients can access. Multiple actors within the international community have a role in this economic downturn to maintain and improve health funding levels nationally and internationally. In addition, the current economic climate is also likely to impact the level and type of income available to patients' organizations globally.

## Health Demographics

A number of health demographics within the global population will impact healthcare systems in the coming years. The aging population combined with an increase in people that have one or more chronic conditions<sup>9</sup> will require the health system to change and adapt. This issue is further compounded by an aging healthcare workforce. Population mobility and migration will likely continue to increase, possibly bringing associated risks related to communicable diseases and potential global health epidemics.

The effect of a person's lifestyle on her/his health and the social determinants of health were raised with relation to the need to focus on prevention, lifestyle changes, environmental factors and health inequities to reduce the increase in chronic conditions. This is in addition to addressing conditions that are due to an individual's own personal characteristics such as genetics.

<sup>9</sup> Noncommunicable diseases cause 38 million deaths annually and together with injuries are responsible for 70% of all global deaths, with 80% of these deaths occurring in low- and middle-income countries. WHO estimates that, globally, deaths from noncommunicable diseases are forecast to increase by 17% over the next ten years, with the greatest increase projected in the African region (27%), followed by the Eastern Mediterranean region (25%) (WHO, 2009).



An effect of these health demographics is that it is becoming increasingly important that patients are empowered and play an increasing role in self management.

## Globalization (Human and Technological)

**Human:** There are many ways in which globalization is impacting on the human aspects of healthcare and health systems. These include the global healthcare worker crisis in many countries that have a lack of healthcare professionals, in part caused by the migration of health professionals to other countries. The mobility of healthcare staff is mirrored to an extent in flows of patients between and across borders in search of affordable and appropriate healthcare. Both trends are creating shifts in healthcare needs and resources, and impacting the availability and quality of care for patients.

**Technological:** There was strong consensus that the development of information and communication technologies (ICTs) and health information technologies (HITs) could be very important internationally. This could have a significant impact on health, such as improving the efficiency of the organizing and monitoring of patients' health and improving information flows between health professionals, leading to better continuity of care. In addition, they could have a significant impact in enabling patients to access information and resources to help them to manage their own health wherever they are in the world. The implementation of new technologies requires that systems are developed to appropriately address the ethical issues they raise, such as ensuring the privacy and confidentiality of personal data.



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Patients' Organizations

A global voice for patients

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