

What is the institutional role for patients in healthcare organisations?

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International Alliance of
Patients' Organizations

A global voice for patients

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About IAPO

- Unique global alliance of over 240 national, regional and international groups representing patients
- Crossing borders and diseases
- Membership spans over 65 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:

- Partnerships with and supporting patients' organizations
- Bringing a strong patient voice to international health policy decision-making
- Building cross-sector alliances and working collaboratively with others

The problem

Healthcare systems are under threat

1. The global economic crisis and cuts across healthcare
2. The aging population
3. The increase in non-communicable diseases : 38 million deaths every year.

These present a growing economic, social and personal challenge for individuals, communities and countries.

The solution

Patient-centred care institutional patient involvement

- Re-focus and place patients in the centre of healthcare
- Strengthen institutional and personal patient involvement at every level.
- WHO, Alma Ata Declaration, Principle IV, 1978:


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

What is patient-centred healthcare?

A healthcare system which is designed and delivered so that it can answer the needs of patients

Patient-Centred Healthcare Principles

1. Respect and support for the individual patient, their wants, preferences, values, needs and rights
2. Choice and empowerment
3. Patient engagement in health policy
4. Access and support
5. Information that is accurate, relevant and comprehensive



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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
- 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 ensure 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

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 basis of their policies and practices. We call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

© 2006 IAPO. All rights reserved. This policy was adopted in February 2006 by IAPO following member consultation and agreement by the Governing Board. Further information about Patient-Centred Healthcare including evidence for its impact and how it can be best in the WHO guideline What is Patient-Centred Healthcare? A Review of Definitions and Principles (IPO, 2008) at: www.patientsorganizations.org/whoweb Contact IAPO at: info@patientsorganizations.org

Why patient-centred healthcare?

Many benefits including:

- Patient quality of life
- Improved physiological measures
- Increased efficiency in use of healthcare services

Where should patient-centred healthcare take place?

- Individual level, e.g. self management
- Institutional level, e.g. systematic feedback, patients on boards and committees
- National level, e.g. governments encouraging patient involvement in health policy

How can patient-centred healthcare happen?

1. A shift in mindset

“The essence of care is to centre on the patient. This is a shift from traditional, provider focused practice, and it requires the workforce to develop communication skills that empower patients through seeing health from the patient’s perspective, and motivating and training patients in health-related self management.”

Preparing a Health Care Workforce for the 21st Century: The Challenge of Chronic Conditions (WHO 2005)

How can patient-centred healthcare happen?

2. Practical details

- Mechanisms which ensure that patient views are acted upon
- Involvement at all stages from initiation
- Practical and educational support and training
- Reach underrepresented groups

IAPO's Guidelines on Patient Involvement available at:
<http://iapo.org.uk/patient-involvement>

How can patient-centred healthcare happen?

IAPO's Guidelines for Patient Engagement

1. Identify issue and set out the objectives
2. Identify appropriate patient representatives
3. Encourage participation and motivate
4. Determine appropriate methods of involvement
5. Give support to enable involvement
6. Provide information, education and training
7. Monitor the involvement – ensure that it makes a difference
8. Evaluate the project
9. Recognize involvement
10. Reassess internal frameworks
11. Educate staff

<http://iapo.org.uk/patient-involvement>

Example 1: Institutional Patient Involvement in Hong Kong

- Hong Kong Alliance of Patients' Organizations
- Patient Ambassador training
- Improving patient experience

Example 2: Institutional Patient Involvement in South Africa

- South African Depression and Anxiety Group (SADAG) and Helen Joseph Hospital, Johannesburg
- Reminder and Support Adherence Programme
- Medical adherence rate rose from 15.8% to 88.6%

<http://iapo.org.uk/patient-engagement-hospitals>

Conclusions

- Re-think and restore patients to the centre of healthcare
- Strengthen personal and institutional patient involvement at every level
- Review methods of patient involvement and check against these guidelines.