

Policy Statement

Patient Involvement



The rationale for patient involvement

Healthcare policy decisions, at whatever level they are made, will ultimately affect patients' lives. Therefore, patients have a moral and ethical right to play a meaningful role in developing healthcare policies. Engaging patients in health policy decision-making helps to ensure that policies reflect patient and caregiver needs, preferences and capabilities, making it an appropriate and cost-effective way to address the needs of the growing number of people with chronic conditions¹.

At present, the patients' voice is not valued enough in policy-making and practice. Patient involvement is often merely tokenism; its influence on policy-making can be restricted by practical and financial structures, differing knowledge bases, cultural barriers and personal attitudes. Patient involvement should not be dependent on the good will of individuals but institutionalised in policy frameworks in order to become the rule, rather than the exception.

A call to all involved in healthcare

More attention must be given to the views of the long-term users and beneficiaries of healthcare – the patients themselves – and to the organizations that can effectively represent them – the patients' organizations. Robust mechanisms must be created and enforced so that patient involvement is not just cursory, rather that patients play appropriate roles in decision-making processes with their views listened to and acted upon.

All stakeholders involved in healthcare must realize that the involvement of patients and patients' organizations in all health-related policy, systems and delivery decisions is essential to ensure that policies and practice properly address the needs of patients.

These stakeholders include:

- Patients and patients' organizations
- Carers and carers' organizations (including family members)
- Healthcare professionals, practitioners and students (e.g. physicians, nurses, pharmacists)
- Healthcare providers (e.g. hospitals, hospices, home care institutions)
- Governments (at local, national and regional levels)
- Third-party providers (e.g. social security, insurances)
- Healthcare-related services and industries (e.g. pharmaceutical, medical devices, biotechnological)
- Any intergovernmental, non-governmental, quasi-governmental and humanitarian organizations (e.g. WHO, Oxfam) when dealing with health-related issues

¹ There is growing evidence that patient-centred healthcare promotes greater patient responsibility and optimal usage which ultimately leads to improved health outcomes, quality of life and patient satisfaction (see references).

Policy Statement

Patient Involvement



Recommendations

1. Stakeholders should extensively review existing healthcare mechanisms and structures for patient involvement, working with patients and patients' representatives so that patient involvement is integrated into *all* decision-making processes, occurring from the start and on an ongoing basis.
2. Patient involvement initiatives should follow IAPO's guidelines (www.patientsorganizations.org/involvement) which incorporate the following:
 - Robust and transparent mechanisms to ensure that patient views are acted upon, not just recorded
 - Inclusion in initiation, design, implementation, communication and evaluation of initiatives
 - Practical, psychological, financial and educational support for participants
 - Varied methods to reach underrepresented groups and to gather a diversity of views
3. Patient involvement should occur whenever decisions are being discussed which will affect patients' healthcare or lives including, but not restricted to, the following areas:
 - Expert committees (e.g. ethics committees, reimbursement committees, governmental advisory committees, healthcare prioritisation and resource allocation committees)
 - Regulatory processes
 - Facilities design and development (e.g. hospital construction or refurbishment)
 - Education and training programmes design (e.g. for health professionals)
 - Research development (e.g. clinical trials design)
 - Care and treatment guidelines design
4. All patients' organizations should insist on involvement in all relevant health, economic, social and other policy-making where decisions will have an impact on patients' lives.

Related Publications and Selected References

IAPO Guidelines: Patient Involvement www.patientsorganizations.org/involvement

IAPO Policy Statement and Guidelines: Health Literacy www.patientsorganizations.org/healthliteracy

Department of Health (2004), *Patient and Public Involvement in Health: The Evidence for Policy Implementation*.

London: Department of Health Publications

Bauman A E, Fardy H J, Harris P G (2003), Getting it right: why bother with patient-centred care? *Medical Journal of Australia*, 179 (5), 253-256 (further references are available at www.patientsorganizations.org/involvement)

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

© 2005 IAPO. All rights reserved. This policy was adopted in May 2005 by IAPO following member consultation and agreement by the Governing Board.