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Patient Rights to Actively Participate in Health Care

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"The people have a right and duty to participate individually and collectively in the planning and implementation of their healthcare." Alma Ata Declaration – Principle IV

In 1978, the Alma Ata Declaration (1) brought strong political commitment to a common vision to protect and promote the health of all people. The Declaration showed a clear mandate for people's engagement in both healthcare policy development and practice. Thirty-five years on, however, this is not the reality in many countries and contexts.

What is acknowledged is that health systems are under extreme pressure and cannot address the healthcare challenges of the 21st century, with the aging population and increase in the prevalence of chronic conditions, without undergoing significant changes.

A focus on the whole person

It is increasingly recognized that a core element of this change is that health systems need to realign to focus on the whole person. This is a shift away from the reductionist approach to healthcare which focuses on the disease or the technology or treatment. It is also a shift away from the paternalism and hierarchies in healthcare systems which disempower both health professionals and patients.

In the case of the individual, those that are educated and empowered are more likely to adhere to their treatments, make good healthy behaviour choices and self-manage. There is growing evidence that a person or patient-centred approach leads to enhanced patient experience which can lead to better outcomes, including reduced resource use (2).

The International College of Person Centered Medicine believes that person-centered medicine is dedicated to the promotion of health as a state of physical, mental, social and spiritual wellbeing as well as to the reduction of disease, and founded on mutual respect for the dignity and responsibility of each individual person.

We promote a medicine of the person (of the totality of the person's health, including its ill and positive aspects), for the person (promoting the fulfillment of the person's life project), by the person (with clinicians extending themselves as full human beings with high ethical aspirations), and with the person (working respectfully, in collaboration, and in an empowering manner) (3).

A role for all stakeholders

Along with this shift to bring people back to the centre of healthcare, shifting the focus of the field from disease to patient to person, it is also recognized that no one stakeholder can address these healthcare

challenges on their own. If we are going to truly provide all people with universal health coverage which means their having access to equitable, affordable, quality healthcare then we need to engage on an equal footing with all those involved in healthcare. We need a team effort and all healthcare stakeholders *must* be part of that team. Health professionals and policy-makers, of course, but also those that have traditionally been the passive recipients of healthcare - patients, families, carers and communities – must be more active partners on a personal individual level but also engaged in health policy-making at all levels.

A key element if we are to achieve person or patient-centred healthcare is therefore patient engagement. For healthcare systems to be designed to be able to meet individual and community needs the involvement of patients and those that represent patients – patients’ organizations is essential. This requires that patients are supported to be involved in their own healthcare and that patients and patients’ organizations are educated and empowered to contribute to decision-making processes. What is often not well recognised or understood is what patients and patients’ organizations can contribute and how they can be engaged in health policy decisions.

The International Alliance of Patients’ Organizations Declaration on Patient-Centred Healthcare states that, ‘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.’ (4)

Yet, whilst there are increasingly requirements to involve patients in health policy-making the influence of patient engagement is still often restricted by barriers such as differing knowledge bases, personal attitudes or inappropriate frameworks for engagement which prevent patient engagement leading to substantive change and positive outcomes.

Patients are often not at the centre of policy discussions and their contribution not always seen as integral to finding and implementing solutions to those health challenges we face globally.

Patients and patients’ organizations not only deliver significant levels of essential information, support and services to patients but they can contribute to healthcare policies based on:

- Their experience and knowledge of the issues patients and patient communities are facing
- Their ability to consult with and represent large numbers of patients views
- Their ability to access patients who can be involved in processes so that their individual or collective voices are heard

As the international community considers actions for the post 2015 development agenda which will follow from the Millennium Development Goals, and as the global healthcare community commits to making universal health coverage a reality for all, patients are in a better position than ever before to contribute. The time is right for every stakeholder to review and develop how they engage and work with individuals, patients, families, carers and patients’ organizations. Only then can the core of our

future healthcare environment be comprised of equal, respectful and constructive partnerships which value the expertise and opinions of all stakeholders and therefore achieve better health, well being and healthcare for all.

1. WHO. 1978. The Declaration of Alma Ata.
http://www.who.int/publications/almaata_declaration_en.pdf?ua=1
2. National Voices Prioritising person-centred care - the evidence.
<http://www.nationalvoices.org.uk/evidence>
3. ICPCM. 2011. BY-LAWS of the INTERNATIONAL COLLEGE OF PERSON-CENTERED MEDICINE.
<http://personcenteredmedicine.org/about-us.php>
4. IAPO. 2006. Declaration on Patient-Centred Healthcare
http://iapo.org.uk/sites/default/filesfiles/IAPO_declaration_English.pdf