

## Section on International Organization Perspectives on Person-centered Medicine

# International Alliance of Patients' Organizations perspectives on person-centered medicine

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## Introduction

Non-communicable diseases or chronic conditions, such as cancer, diabetes and heart disease, are affecting the health and quality of life of an increasing number of patients around the world. The World Health Organization (WHO) estimated that in 2005 they caused an estimated 35 million deaths representing 60% of all deaths globally with 80% of deaths due to non-communicable diseases occurring in low and middle income countries [1]. This is placing an ever-increasing burden on health systems, originally designed to address acute medical conditions.

In order to cope with the continuing increase in the number of patients with chronic conditions, health systems need to develop so that they are able to address the ongoing needs of these people sometimes over many years or decades. In order to manage these conditions in an optimum way for both the individual and the health system a patient-centered approach is necessary because they require the long-term involvement of individual patients in their treatment so that they take their medicines correctly, self manage and make healthy lifestyle choices. Aspects of a patient-centered approach can be seen in the increase in self-management and patient education initiatives, resulting in a move to more collaborative care. This refocus and reorientation of health systems requires the commitment and involvement of all stakeholders.

This paper introduces the conceptual basis around definitions of patient-centered healthcare and outlines principles of patient-centered healthcare from the perspective of the International Alliance of Patients' Organizations (IAPO), a unique cross-disease alliance of 200 patients' organizations from around the world.

## What is patient-centered healthcare?

Patient-centered healthcare is a term that is commonly used but not always defined by those using it. As Stewart (2001) states, it is often understood by what it is not: *"technology centered, doctor centered, hospital centered, disease centered"*.

The traditional biomedical management model of healthcare encompassed 'paternalistic' treatment where the health professional decided the appropriate course of treatment, often without significant patient involvement in the decision. This situation has been changing as, over the years, many people have become more interested in health issues and in taking more responsibility for their personal healthcare.

The significance of patient-centered healthcare is that it moves the healthcare focus from the disease to the patient. It can, therefore, be a useful concept to ensure that the needs and preferences of patients are at the centre of all aspects of healthcare though this focus should not detract from equality in all relationships in healthcare.

## Principles of patient-centered healthcare

IAPO has undertaken extensive research and consultation on patient-centered healthcare and found that patients', families' and carers' priorities are different in every country and in every disease area, but from this diversity there

were some strong common priorities. The conclusion of this research was that the essence of patient-centered healthcare is that the health system is designed and delivered to meet the needs and preferences of patients.

To the International Alliance of Patients' Organizations (IAPO), patient-centered healthcare encompasses five fundamental principles which are outlined in the IAPO Declaration on Patient-Centered Healthcare [2]. This declaration is the 1st globally agreed declaration on patient-centered healthcare *developed and agreed by patients and patients' organizations themselves*. In addition, IAPO research with 1200 patient group members in 2006 found that patients' value a patient-centered approach to healthcare [3].

The five principles of patient-centered healthcare can be summarised as:

1. *Respect* – Patients, families and carers have a fundamental right to patient-centered 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.
3. *Patient involvement in health policy* – Patients and patients' organizations have a valuable role to play in 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.
4. *Access and support* – Access to safe, quality and appropriate services, treatments, preventive care and health promotion activities is needed with a commitment to equity so that all patients can access the appropriate treatments.
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.

These principles encompass many of the same values that are enshrined in international law and underpin many definitions of a patient-centered healthcare, based on human rights, participation and empowerment, and access and equity [4, 5].

The principles provide a basis which recognises that patients are individuals and have different needs and that the healthcare system can be responsive to this, encouraging patients to take responsibility for their health and healthcare whilst recognising and respecting the limits in people's ability or individual preferences. This is of particular importance for people that have a reduced capacity to make decisions about their health and healthcare for themselves, such as children, those with mental health conditions or degenerative conditions, such as Alzheimer's disease.

Patient-centered healthcare is about taking a holistic approach to health through addressing patients needs and recognizing what they consider to be important in their health and healthcare; recognizing the reductionist approach to health which focuses on the disease, the organs, the cells, the genes should not prevent the need to join all these elements up in the consideration of the whole person—body and mind.

## Benefits of patient-centered healthcare

There is growing evidence that designing health systems with the patient at the centre is an appropriate and cost-effective way to address the needs of people with chronic conditions. A number of research studies have concluded that there is a positive link between the practice of patient-centered healthcare in clinical settings and outcomes [e.g. 6–9]. Collectively studies indicate that the patient-centered approach can lead to a variety of positive outcomes including patient satisfaction, emotional health, symptom resolution, function, physiologic measures (i.e. blood pressure and blood sugar level), pain control, engagement and task orientation, reduction in anxiety, quality of life, doctor satisfaction and an increase in efficiency resulting in fewer diagnostic tests and unnecessary referrals. For example, elements of a patient-centered approach, such as effective communication, patient-tailored interventions, patient support and a holistic approach have been shown to be essential to encourage patients to adhere to their treatments [10].

## Gaining a clear picture of the situation: the need for further research

The research studies are encouraging but there is still much research to be done if there is to be a clear overall picture of how a patient-centered approach can improve health and quality of life supported by robust evidence base

for patient-centered healthcare. Often comparisons and conclusions are complicated by the different methodologies and varying definitions of patient-centered healthcare often used.

The costs and benefits of a healthy nation require measurement and consideration of social and economic outcomes of healthcare approaches in addition to health outcomes. Health is not just about the treatment of a condition but about social, physical and mental well-being. Patient-centered healthcare aims to bring the focus back to the whole person. It recognises that a person's quality of life does not solely depend on the impact of their disease on their health but also encompasses how the disease impacts on their participation in society, and their physical and mental wellbeing.

## **Conclusions: towards a patient-centered future**

It is necessary and right that healthcare focuses on the whole person rather than the disease. The involvement of all stakeholders is needed to reorient healthcare systems patient-centered healthcare and meaningful patient engagement must be central to efforts to refocus health systems on people and patients. IAPO welcomes and supports initiatives to reorient the healthcare system to bring patients to the centre of care.

Support for a patient-centered approach is growing globally and there is a unique opportunity to move from the rhetoric of patient-centered healthcare and its adhoc practice to widespread practice. There are many different starting points for patient-centered healthcare and patient involvement depending on national wealth, culture and attitudes. What is important is that throughout the world, people understand about patient-centered healthcare and patients and patients' organizations work in partnership with healthcare professionals, providers and policy-makers, helping to shape their health systems for the future.

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