



PATIENT EMPOWERMENT AND CENTREDNESS



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Executive summary

There is a widespread consensus that empowering patients is good for healthcare systems. Empowerment is increasingly recognised as an essential element of future high-quality, patient-centred healthcare systems with regard to tackling the expanding burden of chronic diseases. Patients are expected to take more control over their illnesses or treatments where possible, and doctors are expected to encourage or 'empower' them to do so. But how do we translate this into reality at all levels (i.e. individual, organisational, and national)?

The Patient Empowerment and Centredness Committee call for the adoption of a Pan-European framework to ensure that patient empowerment is a top priority for Europe's healthcare systems and contributes to improved healthcare across Europe's national realities. Achieving patient-centredness is a key enabler in the process of creating sustainable and equitable systems for all.

A concrete action plan on health literacy and information to patients relating to all aspects of health is needed. Although empowerment is much more than education, the right information and resources are fundamental tools for enabling patients to become equal partners in the team managing their health.

The informed patient also needs a counterpart: the health professional who creates the right environment to enable patients' active participation in the decision-making process. There is clearly a need for targeted education of health professionals to build the skillset needed to effectively communicate with empowered patients, and to provide advice to less empowered patients on how they can take a more active part in the management of their condition.

This strategy should embed patient involvement at every level of the health system. This involves supporting the active participation of citizens with chronic diseases in their own care, but also in policy-making and in designing future care delivery systems.

I. INTRODUCTION

This Committee focuses on patient empowerment and centredness as it believes that approaching healthcare provision with a focus on creating patient-relevant outcomes is necessary, and is more likely to guarantee its sustainability and effectiveness.

It is time for patient empowerment and centredness to become part of the strategy for achieving quality healthcare systems. Patients are increasingly willing to learn about what is happening to them and to take an active role in the management of their own care. Consequently, healthcare professionals are dealing with more informed patients who want to have their say in the decision-making process that affects their health and treatment options.

Some health professionals or decision-makers may be reluctant to enter into patient-centred healthcare, wary that empowered patients will represent a burden rather than a solution.

Definitions

Empowerment can be seen as a multidimensional process that helps people gain control of their lives, increasing their capacity to act on issues that they themselves define as important (Luttrell, 2009).

The Patient Empowerment and Centredness Committee defines **empowered patients** as people who:

- have the necessary knowledge, skills, attitudes and self-awareness about their condition to understand their lifestyle and treatment options and make informed choices about their health;
- have the capacity to become 'co-managers' of their condition in partnership with healthcare professionals, with the aim of managing their condition when necessary and also to the extent they wish to do so, because choosing to not be empowered is also considered as a form of patient empowerment;
- have control over the management of their condition in their daily life;
- ideally, have the capacity to develop the self-confidence, self-esteem and coping skills needed to manage the physical, emotional and social impacts of their disease or condition in everyday life.

The Patient Empowerment and Centredness Committee defines a **patient-centred approach** as one that:

- places the outcomes, interests and overall experience of patients at the centre of the healthcare system;
- takes into account patients' medical needs, together with their social and psychological needs, as well as lifestyle preferences;
- requires healthcare professionals to have the knowledge, skills and attitudes to manage each patient's individual needs;
- gives the patients a place at the 'decision-making' table alongside healthcare professionals, health stakeholders and policy-makers.

Current research describes patient empowerment as a necessary process towards a patient-centred system that can improve patients' outcomes during their treatment (Robbins & Curro, 2013).

Scope

The Committee decided to limit the scope of the paper in order to avoid duplicating the work of other European Health Parliament Committees, while being mindful that patient empowerment and centredness are relevant across the entire spectrum of healthcare topics.

Challenges facing modern healthcare systems include the demographic shift, increasing costs of treatments, limited access to innovative care, intra-European differences and lifestyle trends. Empowerment and involvement of individuals should take place continuously, to allow people to make decisions concerning their lifestyle and treatment of their conditions or diseases.

This paper will focus on the situation for people diagnosed with a chronic condition, but without focusing on a specific illness, age group or gender (WHO, 2002), but concentrating on care delivery and the related patient experience in the post-diagnosis period.

II. CURRENT SITUATION

Citizens' right to healthcare is enshrined in the European Charter of Fundamental Rights (OJEC, 2000), as well as in international declarations (Nations) where empowerment is a core value. Healthcare provision is increasingly patient-centred, with the patient becoming an active subject rather than a mere recipient of healthcare.

In promoting patient empowerment, some countries have run multiple awareness-raising campaigns and even introduced laws on the matter. The French Act of 2 March 2002 called for a "health democracy" in which patients' rights and responsibilities are revisited, giving patients an opportunity to take control of their own health.

Since 2005, the European Commission has repeatedly invoked patients' rights in cooperation with health stakeholders. Some health and patient associations have also followed the path of patient empowerment through different Bills of Rights or Declarations (Laur, 2013).

The Committee has also built on some aspects of the EMPATHiE study report on "Empowering patients in the management of chronic diseases" published by the European Commission in March 2015 (EMPATHiE, 2015).

The Committee provides recommendations around three main enablers of patient centredness and empowerment: information to patients, patient involvement, and the relationship between healthcare professionals and patients.

Information to Patients

A key component of patient empowerment and centredness is patients' access to accurate and high-quality information about their disease and the treatment options available to them. This is commonly defined as health literacy, which entails "people's knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning healthcare [...] (EMPATHiE, 2015)."

Overall, health literate individuals tend to exhibit healthier behaviours that lead to a higher state of wellbeing, increased life expectancy, and lower chances of developing a chronic disease than people who are less health-literate (Sorensen, 2012).

The European Commission is promoting patient access adequate information about diseases and treatments, but so far mainly linked to transparency and research and innovation in relation to medicinal products, (see *Directive 2001/83/EC* and *Directive 2001/83/EC*). 'Information to patients' is included in legislation or recommendations, but is not the subject of separate treatment.

Today, a vast amount of health information is available online, but patients need to know where to find *reliable* information from *trustworthy* sources. The European Commission's recent paper on Digital Health Literacy focused on the use of the Internet to search for health-related information. The EU *eHealth Action Plan 2012-2020 – Innovative Healthcare for the 21st Century* also looks at how greater access to services and information and the use of social media for health can strengthen patient-centred care and empowerment.

The EU institutions have initiated non-legislative health measures that touch upon information to patients, notably the *2009 Council Recommendation on Patient Safety*, which states that patients should be informed and involved in the patient-safety process and have access to objective and understandable information about the risk of infections on the premises of a healthcare delivery organisation.

Between 2005 and 2008, the ministerial "*High Level Pharmaceutical Forum*" concluded that information to patients should be of higher quality and that existing partnerships and collaborations between various partners should be strengthened.

The latest legislation linked to information to patients is the *Cross-Border Health Directive on the application of patients' rights in cross-border healthcare (2011/24/EU)* that entered into force on 25 October 2013. This requires Member States to set up National Contact Points (NCPs) responsible for providing patients with information on their rights in cross-border healthcare provision. Unfortunately this has still not been implemented across all Member States, where it has, the information is not always complete or in line with patients' expectations or needs, suffering from non-functioning web links or contact only by telephone.

Other initiatives highlight the importance of informed patients. *Health information for patients and the general public* - a 2008/2009 review by the World Health Organization - evaluates evidence-based "encyclopaedia" for patients and the general public developed by the German Institute for Quality and Efficiency in Healthcare.

Patient - Healthcare Professional Relationship

The relationship between a healthcare professional and a patient is multi-faceted, going far beyond medical expertise about the disease. It is crucial in providing patients with a better healthcare experience. **Continuity of care, integration of care** and **shared decision-making** are three key aspects of this relationship.

Continuity of care encompasses the ability of a patient to form a therapeutic relationship with a doctor through a series of consultations, and the level of centralised coordination, collaboration and follow-up when the patient has contact with multiple care providers (Freeman, 2010).

A large body of research suggests that continuity is a determinant of positive patient experience, better patient outcomes and lower costs for the healthcare system (Freeman, 2010); (Ovretci, 2012) (The King's Fund, 2010); (J R Soc Med., 2003). Some non-harmonised practices in Member States are successful examples of driving continuity of care. In the **Netherlands** and **Denmark**, nurses and general practitioners are responsible for managing and coordinating multidisciplinary teams providing care to chronic patients; healthcare strategies in **Sweden** and **Finland** have re-defined the role of Advanced Nurse Practitioners, who are effectively assuming many of the responsibilities of physicians, offering increased access to primary care, earlier intervention possibilities and a better-coordinated flow of healthcare (Federation, 2010). In **Germany** and **Ireland** there is a focus on early diagnosis of chronic diseases and on post-hospitalisation remote monitoring through a general practitioner or specific agencies (ESG, 2015).

Integration of care provides a **holistic perspective** of the relationship between patients and healthcare professionals, based on the needs of each individual. It avoids duplication and gaps in service delivery and eliminates confusion among patients receiving care from several healthcare practitioners – as is often the case for people living with chronic diseases with complex needs and receiving social-service and community-care support.

Supporting **self-management** can also help make care more efficient and optimise the relationship between healthcare providers and patients.

Shared decision-making means allowing patients and healthcare professionals to **make healthcare decisions together**, more in line with patients' preferences and values. Shared decision-making increases patient engagement and knowledge, diminishes anxiety related to the care process, improves health outcomes, and reduces unwarranted variations in care (ESG, 2015). **Different models** of the patient-healthcare professional relationship have been identified. Working in partnership and dialogue provides the most added value. With an increasing experience level of the patient, shared decision-making helps align the doctor's interest in treatment and the patient's preferences and expectations (Bieber, et al., 2006).

This model may need to be revisited to include a team-based approach, reflecting the way the patient is connected to other professionals in the health and social sectors.

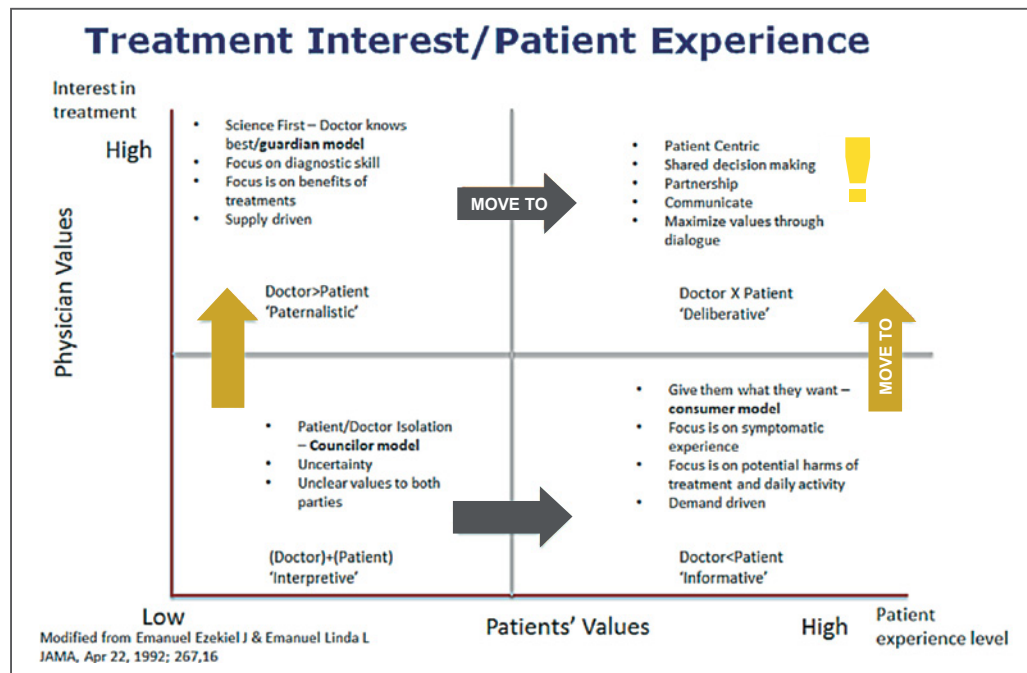


Figure 1 Physician-Patient Relationship Models

Patient Involvement

The concept of patient empowerment is often equated with patient involvement, but although closely interrelated, these two concepts are not exactly the same (Holmström, 2010) (EPF, 2012).

The Committee defines patient empowerment as a necessary process on the road to patient involvement to achieve a patient-centred healthcare system. Published models of patient empowerment have stated the need for patient involvement and participation (EPF, 2012).

Patient involvement is based on the premise that patients are in a position to have specific expertise derived from living with a disease or condition, and this represents a valuable source of knowledge:

- At individual level, patients, their families and caregivers take part in decisions about to their healthcare (e.g. through shared decision-making or self-management);
- Patients or their representatives participate at provider-level (e.g. in hospitals) using their specific experiences with learning and educational tools in order to design better services;
- At the highest (or policy) level, through their representative organisations, patients can offer guidance to decision-makers on quality care that is also cost-effective, and can therefore contribute to the debate for re-shaping healthcare systems.

Not all patients choose to become involved at all levels. Research has shown a positive trend in involvement in the last decade, when less than 50% wished to be involved in decision-making, (Elwyn, et al., 2003) (Schneider, 1998) (Benbassat & Pilpel, 1998) (Guadagnoli, 1998)). The desire for involvement varies between social groups., Younger and better-educated people are more likely to want to play an active role. However, many older people and people from disadvantaged groups also want to play an active role in decisions about their care, and clinicians should encourage people to participate. Making this choice itself can already be a form of patient empowerment (Coulter & Collins, 2011).

The **main barriers** for implementing patient involvement can be summarized as follows (Qual, 2012):

- Communication is key but the time needed to communicate effectively can be an issue;
- Resourcing and asset requirements for achieving patient involvement;
- General lack of recognition by healthcare professionals of patients' expertise and ability to contribute;
- Power imbalances and attitudes between qualified professionals and the (perceived) lack of scientific/medical knowledge among patients.

Over the years, patient groups have been giving individual patients a stronger voice. They are also involved in disease education for patients and healthcare professionals by providing helplines, emotional support, information, access to treatment and generally fighting for patients' rights. And they conduct advocacy discussions about the healthcare system.

The European Medicines Agency (EMA) is committed to working closely with patients and other stakeholders. It involves them in many areas of its work (Human Scientific Committees, Patients' and Consumers' Working Party), a practice which is now well established under the "EMA Framework for interaction with patients and consumer organisations".

Patients' organisations and pharmaceutical companies also work together in discussions over EU policies where they have a common agenda. The European Federation of Pharmaceutical Industries and Associations engages in dialogues known as 'Patients-MedTech', which are examples of some of the constructive exchange platforms that have been set up. Their aim is to foster transparent and ethical exchanges of information and to help patients to speak with an independent voice.

III. TOOLBOX OF SOLUTIONS FOR PATIENT EMPOWERMENT AND PATIENT CENTREDNESS

ENSURING THAT THE FUNDAMENTAL PRINCIPLES OF PATIENT EMPOWERMENT AND CENTREDNESS ARE EMBEDDED INTO AN EU FRAMEWORK

- The Committee acknowledges that there is currently **no EU strategy on patient empowerment and centredness**, despite the recognised benefits patient-centered health systems provide (IAPO, 2015). The Committee calls upon decision-makers **to adopt a European framework** to ensure that patient empowerment becomes a reality and contributes to improved healthcare across Europe's national systems. This will guarantee that patient-centredness becomes a principle guiding policy-makers when creating sustainable and equitable systems for all.
- The Committee urges the European institutions to play a coordination role and look into how gaps in healthcare provision across EU Member States can be bridged. The Committee endorses the **recommendation for EU-level cooperation** on patient empowerment made by the **EMPATHIE research project** of the European Commission in 2015. The EU institutions should play a coordination role in fostering national initiatives on patient empowerment and centredness in accordance with the subsidiarity principle.
- The Committee further recommends that the EU institutions ensure that Member States comply with the basic principles of patient empowerment and centredness.

DEVELOP A QUALITY CARE STANDARD FRAMEWORK AND INDICATORS ON PATIENT EMPOWERMENT AND CENTREDNESS TO ASSESS THE STATUS AT NATIONAL LEVEL

- The Committee draws attention to the fact that measuring patient empowerment and patient-centredness is possible only if common standards are developed, such as ISO or QISMET (QISMET, 2015). A recent European report discussed the importance of measuring, evaluating and comparing the quality of health care systems at EU level to promote accountability, to inform effective policy development, and to help health care providers learning from each other. It said the proposed common understanding of such quality statements should take into account the following dimensions: safety, clinical outcomes and patient involvement (European Commission, 9 October 2014).
- As such standards need to be created by a panel of experts within a technical committee, the Committee further suggests working with the Directorate-General for Health and Consumers or the Scientific Committee on Emerging and Newly Identified Health Risks on developing a common measurement across the Member States for its institutions delivering health care. The Committee recommends a two-fold standard for patients and health professionals, outlining rights and responsibilities at national level. Also suggested is the development of the Health Systems Performance Assessment (HSPA) that includes quality of care and patient safety, and a common and comprehensive set of indicators as a basis for measurement (European Commission, 9 October 2014).

Information to Patients

DEVELOPMENT OF AN EU ACTION PLAN ON HEALTH LITERACY AND INFORMATION TO PATIENTS THAT COMPRISES INCENTIVES AND A FRAMEWORK TO ADOPT NATIONAL HEALTH INFORMATION PLAN

- The Committee suggests, when adopting an EU strategy on patient empowerment and centredness, the inclusion of **an action plan on health literacy and high quality information** for all citizens, spanning many aspects of care-provision.
- The Committee requests **social and economic incentives** to boost health literacy with the support of patient organisations. The European Health Literacy Survey (HLS-EU) found that 11.83% of respondents had inadequate health literacy and that on average nearly every second person participating in the survey had limited health literacy. Moreover, good health literacy also has the potential to provide financial benefits to healthcare systems. A Canadian study showed that 3-5% of healthcare spending arises from limited healthcare literacy; this money could be spent on empowering and informing patients (WHO, Health Literacy: The Solid Facts, 2013).
- The Committee calls upon the EU institutions to encourage Member States to adopt a **national health information action plan** to provide information about health, prevention, empowerment and patient-centredness. This could be done through:
 - National public health campaigns and seminars, workshops and training sessions, starting with schools. When diagnosed with a chronic disease, patients only see their doctor once in a while and need to self-manage the rest of the time without having ever been given adequate advice. These patients might feel less discriminated against or intimidated by their condition if the public in general were more aware of the challenges that their conditions pose.
 - A broader information network, website, or platform could be launched where patients could access all kinds of relevant health information (e.g. about different diseases and different treatment options).
- The Committee encourages EU institutions to **widen the scope** of legislative and non-legislative measures related to information to patients so that they cover a wider range than merely information about medicines or patients' rights.
- The Committee suggests that the European Commission should play **a coordination role** after legislation is adopted and implemented at national level to ensure that patients and the public at large are aware of changes to their rights. In 2013-2015, the European Patients' Forum (EPF) organised a series of regional conferences in collaboration with the European Commission to encourage national patients' groups to make full use of the opportunities afforded to them by the Cross-Border Healthcare Directive. The outcome of these conferences will feed into the European Commission's report and a major event has been scheduled for July 2015.

Patient - Healthcare Professional Relationship

GENERAL RECOMMENDATIONS

- The Committee **calls for** the creation of **a framework including qualitative and quantitative criteria for measuring** different aspects of an improved patient-healthcare professional relationship, taking into account the patient perspective, in order to define steps to be taken by healthcare providers.
- The Committee calls upon the European institutions to set up a system for **providing training** to healthcare professionals, based on an approach encompassing patient empowerment and centredness. These aspects should be included in **Continuous Professional Development**, to ensure consistent communication so that the workforce is capable of addressing these issues adequately. This training should equip healthcare professionals with the tools and techniques needed (e.g. motivational interviews) to communicate effectively with empowered patients.

CONTINUITY OF CARE AND SELF-MANAGEMENT

- The Committee acknowledges that despite positive developments in continuity of care in many Member States, there is still a **need for specific actionable information** regarding the **implications** for, and **expectations** from, **patients and healthcare professionals** in co-promoting and improving continuity of care.
- The Committee calls on the EU institutions to support **access to quality and evidence-based programmes** so that citizens can develop the confidence, knowledge and skills to actively manage their health. Although different conditions require different approaches, supporting **self-management** can alleviate the pressure on health and social services caused by workforce shortages, rising demand for services, demographic change and budgetary constraints.

INTEGRATED CARE

- The Committee **recommends support for local initiatives** that can help identify the most effective interventions for developing patient centredness in an integrated health delivery model. Since there **cannot be a single definitive model of integrated care** applicable to all national healthcare systems, more evidence is needed of what does and does not work well in each system. National healthcare systems should collect data from healthcare providers to identify where integrated care and better relationships with patients have the most impact in improving outcomes, and what barriers, either institutional or structural, discourage change. **Providing administrative guidance, tools and incentives** for further expansion can help countries and regions lagging behind to develop working solutions based on local needs.

SHARED DECISION-MAKING

- The Committee **recommends leveraging currently available tools for shared decision-making** in **establishing** an EU framework. Establishing and reporting principles of shared decision-making, can help healthcare systems at national level evaluate the quality of treatment provided.
- The Committee further proposes the implementation of **training programs for healthcare professionals and patients in the principles of shared decision-making**. These could increase the efficiency and effectiveness of interactions between patients, their families and healthcare professionals.

Patient Involvement

- The Committee urges the European institutions to enhance awareness of the patient's contribution. There are still power imbalances in the attitudes relating to qualified professionals and those sitting opposite them. Such differences in attitudes could be overcome with specific coaching of secondary support (e.g. nurse, home caregiver). The skills acquired could be translated into validated certified programs, supporting patients in achieving a balance when communicating with healthcare professionals or researchers. Using a disease-specific questionnaire during a coaching session (online when available), the patient would be better able to express the wish to be involved. This information would be valuable for the healthcare provider in reviewing and evaluating current treatment success, willingness to self-manage, and even negative experiences.
- The Committee recommends further exploration of **existing tools and principles** such as **OPTION** (Observing Patient Involvement) to support higher levels of patient involvement in decision-making and coaching, as these have experienced barriers to implementation in today's healthcare systems.

PATIENT INVOLVEMENT IN REGULATORY MATTERS

- The Committee calls on EU decision-makers to create a framework for a regulatory process that ensures patients are involved in healthcare research and policy-making. Initiatives in place already (IMI, EUPATI) represent steps towards European patient involvement, but harmonisation is still missing.
- There is no adequate structure where patients' experiences can be exchanged between countries. To remedy this, the Committee recommends involving patients in ethics committees on a constant basis, to provide a common framework for interaction.
- The Committee also emphasises that patient organisations representing individual patients require assets and means to function. Sustainable financial viability (not depending on year-on-year financial support) would reinforce the credibility and independence of patients' coalitions.

IV. CONCLUSIONS

Patient empowerment and centredness are necessary on all levels to build high quality and sustainable European healthcare systems.

Achieving high levels of patient empowerment and centredness requires a complete shift in mindset over healthcare design and delivery. It also challenges European healthcare systems, requiring specific strategies, including embedding meaningful patient involvement in every level of every healthcare system. The Committee recognises that this will be no easy task.

However, change is needed, as empowered patients have proved to be an enduring force that can have an ever higher impact on healthcare systems. Patients can take more responsibility for their care by collaborating with healthcare professionals, adopting preventive measures, seeking earlier diagnoses, and adhering to treatment. These actions will bear fruit in the long run.

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DISCLAIMER

The views and opinion expressed in this article reflect the perspective of the European Health Parliament Committee on Patient Empowerment and Centredness collectively. It does not reflect the views of the individual members in the committee, nor the views of their respective employers or other organizations they may be affiliated with.

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