

# PATIENT EMPOWERMENT: THE ROAD IS STILL LONG

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*Non quia difficilia sunt non audemus,  
sed quia non audemus difficilia sunt*

LUCIUS ANNAEUS SENECA

Patients are no longer passive recipients of care, but increasingly active participants in promoting their health. Patient-centred models of care have demonstrated improved quality of care and potential long-term cost efficiencies. However, patients with chronic conditions struggle to get the support and tools they need to become equal partners in their care and are often referred to as the most underutilized resource in the healthcare system.

In the literature, the inconsistent and imprecise use of terms such as ‘patient involvement’, ‘patient activation’, ‘patient enablement’, ‘patient engagement’ and ‘patient empowerment’ to describe the active behaviour of patients/individuals in their healthcare leads to multiple problems in research, such as poor understanding, difficult communication, lack of standard conceptual measures, deficiencies in theory building and difficulties in testing.

Patient engagement is the most immediate and intuitive term and stands for a type of relationship between patients and health care providers in which both parties work together to “promote and support the active involvement of patients and the public in health and health care and to increase their influence on health care decisions, both individually and collectively”<sup>1</sup>.

Patient engagement is the most restrictive term and stands for a strategy adopted and implemented by pharmaceutical and medical device companies to improve patient compliance and adherence to treatment protocols during clinical trials and care processes. Engagement implies that someone is involving them, and in this case it’s the providers<sup>2</sup>.

The move from involvement to engagement, a kind of final stage on some conceptual maps, means that providers no longer give patients their information and allow them to control the outcome, but that providers now actively work to involve patients in their healthcare. The focus has shifted from a patient-driven process to a provider-driven process. Patient and family engagement offers a promising pathway to higher quality healthcare, more efficient care and improved population health<sup>3</sup>.

Patient empowerment is a very complex, superordinate and inclusive concept in relation to other terms used in the language of health care, which: is situated at different levels (micro and macro); can be approached from different perspectives (the patient, the provider or the health care system); leads to different interpretations (a theory, a process, an intervention, an outcome, a paradigm); and appears in different domains (health and wellness) and disciplines (medicine, psychology, nursing, sociology)<sup>4</sup>.

Healthcare organisations that are able to prioritise this peer-to-peer collaboration not only build trust, but also improve the outcomes of care processes. In this sense, three main measurable and transformative benefits of patient empowerment can be recognized.

1. **Better Provider-Patient Relationships**  
Open communication and shared decision-making build trust and rapport between empowered patients and providers, leading to more personalised and effective care. Patients are also more satisfied when they are involved in their own care decisions.
2. **Improved Health Outcomes**  
Engaged patients are more proactive in managing their own health, leading to better disease management. For example, patients who are actively involved in their care are more likely to adhere to medication regimens and lifestyle recommendations.
3. **Cost Savings and Operational Efficiency**  
Engaged patients are less likely to request emergency procedures, miss appointments and go against treatment indications. In addition, adjustments based on feedback are more acceptable and ultimately save time and money.

The full realisation of patient/family empowerment is increasingly an unavoidable necessity for patients with complex chronic diseases, especially those with minor illnesses. For this population, empowerment is a complex and individualised process that requires a systemic view and a multidisciplinary approach to the care pathway of the person with chronic disease and cannot be reduced to an “on-off” state.

To promote the empowerment of the child with chronic illness and his or her family, it is necessary to:

- *Raise awareness and train health professionals and the care team, starting with university curricula.*
- *Consider the family and informal network of the person with a chronic illness as the backbone of the engagement promotion system.*
- *Recognise the crucial role of associations of people with chronic conditions, family members and volunteers (third sector) as preferred interlocutors.*
- *Accept the key role of new technologies in the involvement of the person with chronic illness, always keeping in mind that they cannot replace the doctor-patient relationship, which is the basis of therapeutic-caregiving activities.*
- *Consider the realisation of involvement in health care as a function of social and cultural awareness of its importance and relevance. (A scientific society for the study of hereditary metabolic diseases, such as ours, cannot shirk this duty!).*

## SOME FINAL THOUGHTS

Many patients and clinicians still operate in an older paradigm of a paternalistic system of clinicians and policy-makers (too often interdependent).

Examples from different countries show where empowerment is taking place and achieving results, but engagement is not a quick fix.

Efforts need to be made to raise awareness of the benefits of patient empowerment, and to encourage and support increasing patient responsibility and leadership.

We must prevent the federative aggregation of patient organisations from dissipating the participatory potential of individual entities and becoming yet another political intermediary.

To move forward: health care organisations and policy makers need to embrace new norms and make substantial changes in their culture, processes and structure; health care organisations and policy makers cannot make changes in isolation; the path to true patient empowerment involves working in partnership with patients and families.

Pharmaceutical companies can effectively contribute to the development of the patient empowerment approach, not only because of their direct interest in conducting clinical trials, but also because of their autonomy in implementing patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs).

Scientific societies need to promote the culture of patient empowerment (Nurses Working Group) and take this element into account when developing guidelines and recommendations.

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**ETHICS APPROVAL AND INFORMED CONSENT:**

Not required due to the nature of the study.

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