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The patient's voice as a lever for change in health care strategies

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"The coach says that what matters is taking part," I heard a child say to his mother the other day at a bus stop. It sounded like consolation, a forced acceptance after defeat. It made me think about how little attention we pay to the meaning of what we say.

I have lived with a chronic illness since the age of four, and rarely have I been able to choose when to participate, although this is beginning to change. I have had to fight fire-breathing dragons, ill-tempered cyclopes and the fiercest storms at sea in order not to decide, but simply to participate. Participation is a right, not a special favour granted by someone. It is basic common sense.

Our families train us from birth to enable us to participate in society. We learn to speak through repetition, just as we learn mathematics –often with music to make the nine times table more digestible– or when we learn a language. When we start a new job, we are taught the terminology, duties, processes, organisational culture and facilities, with the aim of integrating us into the organisation.

In healthcare, however, experience tells me that things function differently. We come from a paternalistic concept of medicine, in which the person does what the doctor says –without question. It is cultural. Perhaps it stems from the classical conception of medicine in Greece and Rome. Etymologically, in Greece the term ho *pathón* referred to "the one who suffers", and in Rome *patī* meant "to suffer" or "to endure", combined with the suffix *–nte(m)* meaning "one who does".[1] Through this union of body and mind, a physical illness was believed to impair one's capacity to govern one's actions, and thus the doctor acted on one's behalf.

It was not until the mid-20th century that civil society began to organise itself, not only to provide social and health services –where the state failed to do so– but also to demand participation rights. Today, thanks to this collective effort and to a broader movement for participation, things are changing.

Patient organisations such as ALCER and the Platform of Patient Organisations (POP) have worked for many years on the concept of shared responsibility. We understand that the participation of people with chronic illness or persistent symptoms, through patient organisations[2], is a fundamental instrument for influencing health policy and institutional decision-making across all relevant sectors, with the aim of improving the health care and social support we receive.

We live in a society in which 22 million people —54% of Spain's adult population— live with a chronic condition.[3] This reality is exposing the seams of a health system designed for acute care, now transitioning towards a person-centred model. The system must adapt to this social reality.

Patients and their organisations have ceased to be passive subjects and have become active agents of their own health. This paradigm shift is essential for building a more effective health care system focused on the person, not merely the disease.

Patient organisations are calling for the transformation of the current health care system into a model centred on the needs of people with chronic conditions, requiring innovation in processes to make them more transversal, prevent gaps in care, enhance territorial cohesion and coordination, and provide multidisciplinary care that integrates both health and social services.

The need for patients to have a political agenda in the pursuit of better health care has become central to discussions about the future of the health system. It is crucial that patient organisations play an active role in shaping health policies from their inception, within a collaborative model of co-governance.

Participation must be based on equality, clearly defined objectives, objective indicators and outcome evaluation, as this directly improves patient safety and quality of care.

This new model requires the indispensable and irreplaceable participation of patients, who offer a unique experiential perspective on illness, complementing professional expertise of any specialty.

And you may wonder: how do patients begin to participate? There are two routes, both involving what we call "associative prescription".

First, map the resources in your health care centre's catchment area: patient associations, community groups, sports organisations and other local resources. Engage with them, identify simple collaborative initiatives —there is always somewhere to begin —and when treating a patient with a condition linked to a specific association, you will know where to refer them so they can find peers.

Second, embed structured information into nursing and medical consultations. Clear, complete, understandable, empathetic information, provided consistently over successive consultations, allows the person and their family or carers to understand the diagnosis, treatment options, benefits and risks, and the consequences of each decision. Through this process, patients move from receiving information to shared decision-making, becoming co-authors of their care. Associative prescription supports those experiences that require empathy from others who have walked the same path.

With education and support, patients can be actively involved in decisions affecting their health, becoming co-responsible for their illness, treatment and therapeutic adherence[4] not only during the ten hours spent in consultations each year, but throughout the remaining 8,750 hours.

But participation must extend beyond the micro level into the meso and macro levels.

POP has created participACCIÓN[5], a self-assessment tool for patient participation in these broader contexts: hospitals (meso) and institutions (macro), incorporating structured participation, strategy, planning, defined roles, continuity, task allocation, feedback and outcome evaluation.

We need a comprehensive and collaborative approach. The patient's voice provides first-hand information from the perspective of an expert user, offering non-clinical insights that add value to health care delivery. Value means care that, grounded in scientific evidence, empowers patients and families, advances shared decision-making, improves clinical outcomes and quality of life, and accounts for health care system costs[6].

Without delving deeply into the concept of value-based health care (VBHC), we approach its participatory dimension, which is rooted in addressing patients' individual needs and expectations –in essence, what truly matters to the patient. In other words, it involves reorienting the measurement of reported health outcomes towards what is expected from the patient's own perspective.

In a culture where quantitative indicators are measured more often than qualitative ones, and where, as we are seeing, the patient perspective is essential, we must actively seek their inclusion in decision-making. We count hospital beds and surgical procedures, but not the impact of disease on a person and their family, nor its effects on employment, social life or economic stability. We make limited use of PROMs (Patient-Reported Outcome Measures), which assess future expectations, and PREMs (Patient-Reported Experience Measures), which evaluate lived experiences — although these tools are gradually gaining prominence in addressing patients' unmet expectations.

I invite you to become familiar with CROBI[7] –an acronym for *chronicity and well-being*– a PROM created by patients with chronic conditions that measures biopsychological, emotional and occupational factors. These measures help us better understand the individual's situation and have proven to be highly sensitive to changes in the life of a person living with chronic disease. Understanding, for example, that what motivates an 85-year-old patient on haemodialysis to rise each morning is spending time with their grandchildren allows us to tailor treatment accordingly and helps the patient feel genuinely understood.

Many people with chronic conditions, in addition to health care needs, also have social, educational and occupational needs. These cannot be addressed in isolation without generating negative consequences for both the individual and the system –through duplication of services, inefficiencies, territorial inequities in access or fragmented systems that fail to communicate with one another. Those who experience and suffer these shortcomings most directly are the patients themselves.

Currently, the patient movement is working in the field of participation with numerous public institutions to advance societal progress. Together with the Spanish Ministry of Health, we are at the core of the new national strategy for chronic patient care. We are driving the forthcoming law on patient associations, aimed at structuring the participation of all those who form part of the National Health System, including patients. We actively contribute to the digital health strategy, participate in the review of Therapeutic Positioning Reports (IPT), sit on ethics and patient committees within hospitals and regional health authorities, and have formalised training collaboration agreements with AEMPS and ISCIII.

It is urgent to redirect efforts towards addressing the health and social needs of people living with chronic disease, as well as towards the prevention, diagnosis and treatment of chronic conditions –some of which have worsened due to gaps in health care coverage. This transformation will only be possible through the meaningful participation of patients and their organisations, if we truly wish to improve care, adapt to reality and build a health care system that is more efficient, effective, cohesive, equitable and sustainable.

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