

Patient participation in improving services at Hospital Clínic (Barcelona)

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Abstract

The value of a service is the third pillar of healthcare quality, together with safety and effectiveness. The value of the service is defined by the patient not the provider. Patient participation is therefore essential in improving services to identify unmet needs. The PIEEX-Clínic model integrates information, therapeutic education to self-manage the disease, patient experience to identify the need and participation to co-design service improvement.



Healthcare quality improvement has been of interest to health professionals for more than 50 years. The structure, process and outcomes (Donabedian), effectiveness (Cochrane) and clinical safety (Institute of Medicine) are different aspects of the same issue. These strategies all have a common denominator: everything for the patient but without the patient. Definitions of quality are always from a technical viewpoint, without taking into account the service recipient.

Value

The idea of value represents a paradigm shift in the definition of healthcare service quality. Porter & Teisberg (2007) suggest that the main objective should be to increase value from the patient's perspective. Patients are interested in the entire healthcare process (not the sum of isolated procedures) and outcomes should be measured systematically. The value of a service is determined by the patient not the provider.

The concept of value changes the assessment criterion. A healthcare service must be safe and effective (it should produce a positive change for the patient). A document from the Health Quality and Assessment Agency of Catalonia (AQuAS) summarises the 12 areas in

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which patient experience can be important (Escarrabill et al., 2020). Information quality, participation in decision-making, time management, accessibility to professionals and respect are among the factors that contribute to shaping patient experience and, therefore, the value of the healthcare provision.

Aim

The redesign of services determines how we want to treat patients. The paternalistic model is replaced with a more deliberative model with patient participation. This will help identify unmet needs more precisely.

Patient experience assessment combines quantitative and qualitative research. Focus groups, interviews, shadowing and photovoice are combined with the design of patient experience indicators completed by patients themselves (Patient Reported

Experience Measurements, PREM) and with specific surveys.

In addition to specialised research there is also the information that all healthcare facilities have available: patient and family opinions through formal claims, acknowledgements and suggestions.

It is also very important to change how solutions are sought. The world of design has contributed very useful methodologies (design thinking) which avoid frequent errors such as seeking solutions before defining the problem properly. The change of approach can be expressed through five basic concepts:

- a) **Reciprocity:** the asymmetry between patient and professional must be mitigated. Suffering from a disease already implies an asymmetry between patient and professional. If the power of technical knowledge is added to this, the asymmetry becomes even bigger.
- b) **Iteration:** based on repetition, tests, trials and consolidation of what works well.
- c) **Prototype:** building solutions quickly which can be applied to the real world immediately. The prototype is based more on trial and error. The prototype is applied and, if it works well, is consolidated, whereas, if it does not work well, it is rejected.
- d) **Collaboration:** (also expressed under the umbrella term *co-design*) teams should consider everyone involved, especially patients.

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e) **Tokenism:** meaning symbolic participation of patients in improvement processes. A single patient cannot be included in a technical team of 10-12 professionals.

PIEEX-Clínic model

Hospital Clínic de Barcelona is a high-tech healthcare centre directly treating a population of over 500,000 inhabitants of Barcelona, and is the reference centre for more than two million people in Catalonia. It is a benchmark centre for patients throughout Spain for some healthcare processes. More than 40,000 patients are admitted each year with over 700,000 outpatient visits. It undertakes significant scientific activity and publishes an indexed scientific article every eight hours.

Ten years ago, the hospital management promoted improvement in care for patients with chronic diseases, initially by reviewing the information given to patients through a survey professionals answered. The survey also detected that the professionals required training in therapeutic education methodology to be able to provide patients with tools to manage their own chronic disease. Assessing patient experience helps identify needs and guide education. Patient participation completes this process to establish priorities and escalate solutions.

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The PIEEX-Clínic model (Escarrabill et al., 2021) is based on clear and useful high-quality information. This allows education programmes to be designed,



needs identified (patient experience) and participation promoted.¹

The first meeting on patient experience assessment was held in December 2014 and the project was consolidated when the hospital's 2016-2020 Strategic Plan identified patient participation and education as its first two key projects.

The hospital's living lab opened in 2019 with the name Experience Exchange Forum (Espai d'Intercanvi d'Experiències). The living lab is a free space and a testing ground which facilitates patient-professional interaction to identify service improvement opportunities. Since then, a combination of different methodologies has been used to analyse over 60 problems.

¹ PIEEX is the Catalan acronym for "Participació, Informació, Educació i Experiència de pacients" (Participation, Information, Education and Patient Experience).

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Participation

The desire to participate is part of a general social demand and, at the same time, of professionals' need for support on making complex decisions. Citizens' general interest in participating could be translated to the healthcare field with the phrase "Nothing about me without me", one of the key arguments of the document Equity and excellence: Liberating the NHS (United Kingdom Government, 2010).

Deliberative rationality suggests that technical decisions are necessary, but not sufficient, to respond to complex problems. Different viewpoints should therefore be incorporated (Brugué, 2017). The participatory process can have different phases (Millaret and Pons, 2015).



Participation in the field of healthcare is no different to citizen participation in other areas. Five main spheres of citizen/patient participation can, however, be identified in the field of healthcare (Delbrassine et al., 2020):

1. **Shared decisions.** Shared decision-making is the dialogue between professional and patient to resolve situations of uncertainty bearing in mind the context, scientific evidence and individual values and preferences. Quality information, time for reflection and active listening by the professional are required for sharing decisions.
2. **Service improvement.** Service improvement should not be addressed without patient participation, especially when solutions have to be found for complex problems.
3. **Governance.** Individuals who have responsibilities and have to make complex decisions should listen and explain the decisions that they make. There are not many examples of healthcare institution governance based on patient participation, apart from consultative bodies.
4. **Participation in research.** It should be common practice for research professionals to listen to the needs of society. Patient and Public Involvement (PPI), the conceptual framework defined by Responsible Research Innovation (RRI), and Open Innovation (Bullinger et al., 2012) are examples of these approaches to citizen



involvement in establishing research priorities and assessing outcomes.

5. **Healthcare policies.** The Patient Advisory Council (Consell Consultiu de Pacients) of the Catalan Ministry of Health is an example of citizen participation in designing healthcare policies (see the 2017 *Marc de la participació ciutadana en salut* [*Framework for citizen participation in health*]).

Hospital Clínic has promoted patient participation in improving healthcare processes in various ways:

- a) **Information and Therapeutic Education Working Group** (GTIET in Catalan). A multidisciplinary group that assesses patient information proposals. Patients have participated actively since 2015.
- b) **Hospital Clínic Committee of Users and Patients (Comissió d'usuaris i pacients)** was created in 2017. It is formed by six patients and six hospital managers and meets on a quarterly basis. It is an advisory rather than a representative committee.
- c) Since 2018, patients have participated in the **training programme assessment committee** for patients who use continuous insulin infusion pumps.
- d) An increasing number of teams apply patient **accountability** in both healthcare and research. For example, the child and youth psychiatry service, and the liver cancer and liver



haemodynamics teams have held specific meetings with patients to apply this accountability.

- e) Active patient participation in **training programmes for professionals**.
- f) Patient participation in the process to **transform the physical space** of the hospital, for example with the new Pain Clinic and the systematic process of the outpatient appointments space.
- g) **Experience Exchange Week** (SIE in Catalan). A group of patients participated in designing the activities of the SIE held in March 2023. Seventeen activities were organised, with over 500 participants, 35% of which were patients.



Implementation

The success of patient experience assessment projects depends on five key factors:

- 1) **Management commitment.** The organisation's highest authority must systematically demonstrate their commitment and strategic plans must include patient experience as a core focus.
- 2) **Clinical leadership.** Patient experience is a new field related to other aspects of healthcare organisations (citizen assistance, quality, communication and social responsibility), but has its own domain in which all the institution's professionals must be involved, but with clear clinical leadership by frontline

healthcare professionals who establish the characteristics of the service.

- 3) **Multidisciplinary teams.** There are no patient experience specialists. Improvement proposals must come from multidisciplinary teams which include patients.
- 4) **Pragmatism.** The work of the teams that wish to improve patient experience should focus on identifying unmet needs. The Mayo Clinic's motto is very clear in this respect: Think Big, Start Small, Move Fast.
- 5) **Accountability.** Organisations need to perform systematic accountability exercises, either immediately with the people who have participated in improvement groups or more institutionally through various formats.

Patient participation in healthcare service improvement is a paradigm shift which profoundly transforms healthcare. Like all complex changes, it is an approach that requires patience, perseverance, the ability to solve immediate problems and, at the same time, a clear vision to build the healthcare models of the future. ■

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