

original paper

The PIEEX-Clínic model.

How participation, information, structured therapeutic education and patient experience come together in the real world.

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Abstract

The concept of value as a criterion for evaluating the quality of care is a paradigm shift. Value is closely linked to the person who receives the service. Thus, quality services, in addition to being safe and effective, must respond to people's needs. There is no single definition of person-centred care, but putting the person at the centre means progressively moving away from the paternalistic model of care to get as close as possible to a deliberative care model. There are several elements that are essential to build a person-centred care model. Information and therapeutic education are good examples. Both have their own methodologies and have obtained tangible results over the years. Information is the starting point and therapeutic education provides practical tools so that patients and caregivers can independently manage the disease.

For a few years now, there has been a growing interest in learning about patient experience, both to identify unmet needs and to assess the impact of the implementation of improvements in care services. All this is not applicable without a deliberative model that allows the active participation of all those involved. Information, education, patient experience and participation are facets of the same polyhedron. Each of these areas in the real world are closely related. The real world unfolds at the intersections of these domains with varying weight of each depending on context and clinical circumstances.

We define this intersection in the real world as the PIEEX-Clínic Model (Participation, Information, Education and Patient Experience). This conceptual framework aims to describe the process that has been followed at Hospital Clínic in order to improve quality through patient experience evaluation.

There is no proven roadmap. At Hospital Clínic, the starting point was the analysis of the quality of the information through a survey. From here, a therapeutic education methodology course was designed and, in parallel, work was done on the adaptation of tools for measuring patient experience. Based on the 2016-2020 Institutional Strategic Plan, the Patient Experience evaluation program was consolidated through the creation of the Patient Experience Forum (PEF) (living lab).

The PEF is a type of “test bed” where different points of view can be contrasted, different methodologies are used and improvements in care provision are explored.

Keywords: value, quality, therapeutic education, information, patient experience

Resumen

¿Por qué nos interesamos por la experiencia de “ser” paciente? El concepto de valor como criterio para evaluar la calidad asistencial ha significado un cambio de paradigma. De una manera inseparable, el valor va estrechamente ligado a la persona que recibe el servicio. Así, los servicios de calidad, además de ser seguros y efectivos, tienen que dar respuesta a las necesidades de las personas. No hay una definición única de atención centrada en la persona, pero poner la persona en el centro quiere decir alejarnos progresivamente del modelo paternalista de atención para acercarnos tanto como sea posible a un modelo deliberativo. Hay varios elementos que son imprescindibles para construir un modelo de atención centrada en la persona. La información y la educación terapéutica son un buen ejemplo. Tanto la información como la educación terapéutica tienen metodologías propias y resultados contrastados desde hace años. Informar es el punto de partida y la educación terapéutica ofrece herramientas prácticas para que pacientes y cuidadores puedan gestionar de manera autónoma la enfermedad.

Desde hace unos años ha aumentado el interés para conocer la experiencia de paciente, tanto para identificar necesidades no cubiertas como para evaluar el impacto de las mejoras que introducimos en los servicios asistenciales. Y todo esto no es aplicable sin un modelo deliberativo que permitan la participación activa de todos los implicados. Información, educación, experiencia de paciente y participación son facetas del mismo poliedro. Cada uno de estos ámbitos en el mundo real están íntimamente relacionados. El mundo real se desarrolla en las intersecciones de estos ámbitos con un peso variable de cada uno de ellos en función del contexto y de las circunstancias clínicas.

Esta intersección en el mundo real la definimos como el Modelo PIEEX-Clínic (Participación, Información, Educación y Experiencia de pacientes). Este marco conceptual quiere describir el proceso que se ha seguido en el Hospital Clínic para mirar de mejorar la calidad a través de la experiencia de pacientes.

No hay una hoja de ruta contrastada. En el Hospital Clínic el punto de partida fue el análisis de la calidad de la información a través de una encuesta. A partir de aquí se diseñó un curso de metodología de la educación terapéutica y, en paralelo se trabajó en la adaptación de instrumentos de medida de la experiencia de pacientes. A partir del Plan Estratégico 2016-2020 se consolidó el proyecto de evaluación de la experiencia de pacientes a través de la creación del Espacio de Intercambio de Experiencias (EIE) (living lab). El EIE es un tipo de «banco de pruebas» donde se puede contrastar puntos de vista diferentes, usar metodologías muy diversas y proponer mejoras en la prestación de servicios.

Palabras clave: valor, cualidad, educación terapéutica, información, experiencia de paciente.

Resum

El model PIEEX-Clínic. De quina manera s'integren la participació, la informació, l'educació terapèutica estructurada i l'experiència de pacients en el món real. El concepte de valor com a criteri per avaluar la qualitat assistencial ha significat un canvi de paradigma. D'una manera inseparable, el valor va estretament lligat a la persona que rep el servei. Així, els serveis de qualitat, a més de ser segurs i efectius, han de donar resposta a les necessitats de les persones. No hi ha una definició única d'atenció centrada en la persona però posar la persona en el centre vol dir allunyar-nos progressivament del model paternalista d'atenció per acostar-nos tant com sigui possible a un model deliberatiu. Hi ha una colla d'elements que són imprescindibles per bastir un model d'atenció centrada en la persona. La informació i l'educació terapèutica en són un bon exemple. Tant la informació com l'educació terapèutica tenen metodologies pròpies i resultats contrastats des de fa anys. Informar és el punt de partida i l'educació terapèutica ofereix eines pràctiques perquè pacients i cuidadors puguin gestionar autònomament la malaltia.

Des de fa uns anys ha augmentat l'interès per conèixer l'experiència de pacient, tant per identificar necessitats no cobertes com per avaluar l'impacte de les millores que introduïm en els serveis assistencials. I tot això no és aplicable sense un model deliberatiu que permetin la participació activa de tots els implicats. Informació, educació, experiència de pacient i participació són facetes del mateix poliedre. Cadascun d'aquestes àmbits en el món real estan íntimament relacionats. El món real es desenvolupa en les interseccions d'aquests àmbits amb un pes variable de cadascun d'ells en funció del context i de les circumstàncies clíniques.

Aquesta intersecció en el món real la definim com el Model PIEEX-Clínic (Participació, informació, educació i experiència de pacients). Aquest marc conceptual vol descriure el procés que s'ha seguit a l'Hospital Clínic per mirar de millorar la qualitat a través de l'experiència de pacients.

No hi ha un full de ruta contrastat. A l'Hospital Clínic el punt de partida va ser l'anàlisi de la qualitat de la informació a través d'una enquesta. A partir d'aquí es va dissenyar un curs de metodologia de l'educació terapèutica i, en paral·lel es va treballar en l'adaptació d'instruments de mesura de l'experiència de pacients. A partir del Pla Estratègic 2016-2020 es va consolidar el projecte d'avaluació de l'experiència de pacients a través de la creació de l'Espai d'Intercanvi d'Experiències (EIE) (living lab). L'EIE és una mena de «banc de proves» on es pot contrastar punts de vista diferents, fer servir metodologies molt diverses i proposar millores en la prestació de serveis.

Paraules clau: valor, qualitat, educació terapèutica, informació, experiència de pacient

Introduction

In the real world, few projects are pursued without a map or some kind of model. Sometimes, however, the models are from separate disciplines and the most appropriate route is to merge the various fields of work through crosscutting,

interdisciplinary and holistic projects. Uncertain environments and interdisciplinary work are key elements for innovation in general¹ and, in particular, for innovation in service provision. And to accomplish this, it indeed proves harder to find maps in these cases. The opportunity to work on a map-less project should never be allowed to escape. This article aims to describe the path taken by the Hospital Clínic in its attempt to merge information, therapeutic education, patient experience and participation.

The point of departure

The journey begins in patient-centred care (PCC). It is hard not to embrace concepts like PCC. Even though PCC is difficult to define. PCC may be a sort of umbrella term or cover term used systematically to create a conceptual framework, but without the definition necessarily being shared. We use a lot of these terms: empowerment, empathy, humanisation, for example. None of these terms have negative connotations, but it remains unclear whether all their users share the same meaning. There are general concepts whose meaning is easier to quantify: proximity, amicability or respect, for example. They are also subjective, but they may be easier to share. In any case, Epstein points out that patient-centred care is an important conceptual change because it puts the person at the centre². There is more and more research that correlates clinical results with key elements of person-centred care, such as shared decision-making³. But, as Montori asserts⁴, it all begins with one key decision: how we wish to treat our patients. Putting the person at the centre means progressively distancing ourselves from the paternalistic care model and coming as close as we possibly can to a deliberative model. This transformation is especially transcendent when it addresses care for people with chronic illnesses. Chronic care operates in a context of great uncertainty. There are no totally good or totally bad solutions and the problems are recurring, which means the process never ends.

There may be three elements which make it possible to consolidate the concept of PCC: quality, value and personalisation.

Twenty years have passed since the publication of the Institute of Medicine's report "*Crossing the Quality Chasm: A New Health System for the 21st Century*"⁵. In this report, the six elements which define healthcare quality were established: safety, effectiveness, patient-centredness, timeliness, efficiency and equity. Doyle⁶ goes a bit further in the conceptual synthesis and calls patient experience the third pillar of quality, along with safety and effectiveness.

When it comes to quality, PCC seems a direct result of the rise of the conceptual framework of value (Porter)⁷ as a synthesis of a healthcare service's quality. A service is of quality if it adds value from the perspective of the one who receives it, not from who provides it.

It may also be thought that PCC, focused on individuals as people, guides care from an individual perspective. PCC leads rapidly to the idea of personalisation. Personalisation can be analysed in juxtaposition to the population viewpoint. In fact, the evidence is always based on population viewpoints. Perhaps there are steps in between, such as considering "groups of patients with common needs"⁸. Or imagining how populational evidence can be applied to a specific

person⁹. The dichotomy between “I” (personalisation) and “us” (population) has more than one solution. It is evident that “one size fits all doesn’t work”, but it isn’t easy to incorporate patient preferences into the handbooks of clinical practice¹⁰.

In any case, it is possible to discuss PCC because theoretical content has been around for many years and practical tools are supported in relation to two basic elements: information and therapeutic education. Being intelligible and providing clear and accurate information is a key element in good clinical practice and, in addition, it is an obligation of respect for the people we care for. But informing is not enough¹¹. It means not telling patients what to do, but rather giving them the knowledge, skills, support and tools to consciously change their habits in relation to health. These strategies are not only feasible, but also have a demonstrated positive impact on results in health.

The associations between all these fields are proven through the development of the Hospital Clínic’s chronic care programme. Areas like education or information have their own methodologies but are quite difficult to view in isolation. The same happens when we start addressing patient experience or participation. The point of departure is precisely the reflection on links or relationships between these four areas:

- Information is where it all starts. Without quality information, it is hard to advance.
- Therapeutic education must give people with chronic illnesses the tools they need to manage their illness.
- Patient experience is essential to identifying unmet needs.
- Participation is key for giving everyone a voice and guaranteeing scalability.

Information

One key element of PCC is to ensure health literacy¹². In other words, it must be guaranteed that people are fully capable of facing health problems which are often quite complex or, at least, do not form part of the daily life of the people who suffer them. Information forms part of the foundation of PCC because without proper literacy, it will be quite difficult for the patient and caregiver to tackle the breadth of the clinical problem and actively participate in decision-making. The European Health Literacy Survey (HLS-EU)¹³ suggests that nearly half the European population has insufficient or problematic levels of literacy to face their health problems. But, in addition to increasing citizens’ skills to tackle health problems, the OECD remarks that it is essential to periodically take an interest in updating knowledge¹⁴.

In concerning ourselves with information, we started by considering the work done previously. One hardly ever begins from zero and it is very useful to keep antecedents in mind. In 2010, the Hospital Clínic turned its attention to the quality of therapeutic education programmes¹⁵. And using this benchmark, a survey was conducted in late 2013 to see the quality of the information and therapeutic education programmes¹⁶. The quality of the informational material was quite heterogeneous and the educational and self-care programmes were very diverse, with opportunities for improvement in design and assessment. Based

on this survey, criteria were proposed for unifying the materials and facilitating their access in a crosscutting way and promoting the training of healthcare professionals in educational programme methodology.

Therapeutic education

The conventional approach pursued until now is to “instruct” patients on the best way to effectuate the treatment, from the professionals’ perspective¹⁷. For over 20 years, the WHO has suggested that therapeutic education must serve to provide patients and caregivers with tools for managing illness (and preventing complications), reaching therapeutic agreements to facilitate adherence to treatment (with as little disruption as possible to people’s daily life) and attempting to achieve the highest possible quality of life. Diabetes is a paradigmatic example since, for years, we have been shown which road to follow. But even in this case there are still many opportunities for improvement. In the DAWN2 study¹⁸, they saw that more than half of all diabetes patients had not attended a therapeutic education programme. Many researchers have wondered what the reasons are, and Horigan et al¹⁹ suggest two: logistical problems for attending sessions and a failure to perceive the educational programme’s benefits.

A key element is the participation of patients and caregivers in the design and implementation of educational programmes. In Catalonia, the “expert patient” programme has been developed to promote information and self-care through peer learning²⁰. The *patient partenaire* concept is developed in Quebec based on this idea of cooperation between patients and professionals. The concepts of “*patient partenaire*” and “care partnership” are described as a cooperative relationship between the patient, the patient’s family and health professionals. One distinguishing factor in the case of the *patient partenaire* is the formal training proposals which, in addition to personal experience in handling the illness, qualify the patient to provide support to others.

Clearly, there are diverse forms of cooperation between patients well-versed in their own illnesses and medical professionals. However, under no circumstances should this cooperation serve to replace structured therapeutic education programmes or the functions of professionals. Therapeutic education is a responsibility of healthcare professionals. It is a responsibility of the entire care team, and the patient clearly plays a role in this care team²¹.

Patient experience

The task of improving quality is a polyhedron with different faces but which share the same goal. Structure, process and result (Donabedian), effectiveness (Cochrane) or clinical safety (Institute of Medicine) are faces of this polyhedron. They represent not substitutive strategies but rather complementary ones. In all these strategies the patient is present but without an active role: everything for the patient but without the patient.

In 1999, Angela Coulter²² wrote a relevant article demonstrating the paternalism of the healthcare system and calling for patient participation in healthcare improvement: “Partners work together to achieve common goals”. The cover of the BMJ is quite illustrative on what “partner” means: a couple dancing a tango, with a clear title “Embracing patient partnership”²³. The idea of considering the

patient’s perspective is more recent and is closely linked to a paradigm shift in the definition of quality. Michael Porter suggests that quality healthcare must increase value from the perspective of the service recipient: patient/caregiver²⁴. Defining value by the patient means the same thing as accepting that the goodness of a dish is defined by the diner, not the chef. Or that the beauty of a painting is defined by its observer and not the artist who has painted it.

Before 2013, nobody was talking about patient experience at the Hospital Clínic. By late 2016, it was no longer an unfamiliar conceptual framework and activities were being done to develop this line of work. Manary’s article²⁵ could serve as an initial landmark, or the definition of patient experience expressed by The Beryl Institute²⁶ at the Dallas congress,

The Beryl Institute defines patient experience as all interactions with healthcare mechanisms that influence the perception of the individuals served throughout the care continuum. Patient experiences go well beyond satisfaction.

Before formally incorporating the assessment of patient experience, some preliminary studies are conducted in relation to the experience of patients with home respiratory therapies²⁷ or the design of the Clínic website²⁸.

The work completed to assess the training programme for patients with insulin pumps helped consolidate a conceptual and methodological framework surrounding patient experience which can be summarised in this table 1 ²⁹ :

Tools	Understand	Explore	Experiment	Assess
Goals	Define the problem to study	Determine whether or not painful points can be generalised	Propose solutions	Assessment of solutions and global impact
Tasks	<ul style="list-style-type: none"> • Literature review • Professional perspective • Map of implicated parties • Journey map • Patient archetypes • Qualitative research & design thinking 	<ul style="list-style-type: none"> • Surveys • Complete the qualitative research • Design thinking 	<ul style="list-style-type: none"> • Prototypes • Iteration 	<ul style="list-style-type: none"> • PREMs • Global metrics • Surveys

Table 1: Conceptual and methodological framework surrounding patient experience.

The 2016-2020 Strategic Plan of the Hospital Clínic represented the consolidation of the assessment of patient experience.

Participation

The desire to participate forms part of a general social demand³⁰ and, at the same time, of a need to support people forced to make complex decisions. This general interest of the citizenry to participate could be translated in the medical



Figure 1: Focus group topics.

field with the sentence **“Nothing about me without me”**, a central argument of the document *Equity and excellence: Liberating the NHS*³¹.

There is a deliberative rationality which suggests that technical decisions are necessary, but insufficient, to provide a response to complex problems. This is why different points of view must be incorporated³². The potential benefits of participation can be manifested in the possibility of making more intelligent decisions and in facilitating the implementation of these decisions by promoting mutual trust. Participation should not be understood as “all or nothing”; rather, the participatory process can be described as a journey which includes a more formal phase (in which there is information, consultation) and a more mature phase in which a deliberative process takes its course and the direct influence on decision-making is seen³³.

Five large spheres of citizen/patient participation can be identified (Figura 1)³⁴:

Shared decision-making

Shared decision-making is a dialogue between the professional and patient to resolve uncertain situations, taking the context, scientific evidence and people’s preferences into account. Shared decision-making is a key element of person-centred care.

Service improvement

Co-creation is essential when solutions to complex problems must be addressed³⁵. Apart from being a more respectful approach, co-creating is a good way to facilitate the subsequent spread of innovation.

Governance

Shared decision-making, transparency and accountability are basic elements of a mature democratic society. People with responsibilities who have to make complex decisions must listen and explain the decisions they make. There aren’t many examples of governing medical institutions through patient participation, beyond advisory bodies.

Participation in research

Listening to society’s needs ought to be a common practice among research professionals. The participation of the citizenry in the establishment of research agendas and the assessment of research projects is considered more and more important. **Patient and public involvement (PPI)**³⁶ or the conceptual framework defined by **responsible research innovation (RRI)**³⁷, or the so-called **open innovation**³⁸, are examples of these approaches to citizen engagement in the establishment of research priorities or the assessment (oversight) of the methodologies used in research projects.

Health policy

The Health Department’s Patient Advisory Board³⁹ is an example of citizen participation in the design of health policy. The document “Framework of citizen participation in Health” describes the basis of participation⁴⁰.

The PIEEX model: the “academic” vision

Actions should serve to build a model. Models are the way to bring together diverse pieces of knowledge and multiple perspectives and to permit the scalability and reproducibility of the proposals.

The figure 2 summarises the characteristics of the elements comprising the PIEEX-Clínic model.

In essence, **information** is where it all starts. It forms part of the clinical relationship between the professional and the patient and, therefore, is an obligation. It relates closely to manners and communicative skills. The more complex the information is, the more necessary it is to offer written elements or quality links to transmit the intended message. Without adequate information it is impossible to advance. Without information, it is like making decisions randomly.

The ability to manage one’s own illness is crucial to achieving the expected effectiveness, especially in chronic processes. **Structured therapeutic education** is designed to offer tools for achieving self-care. Many methodologies can

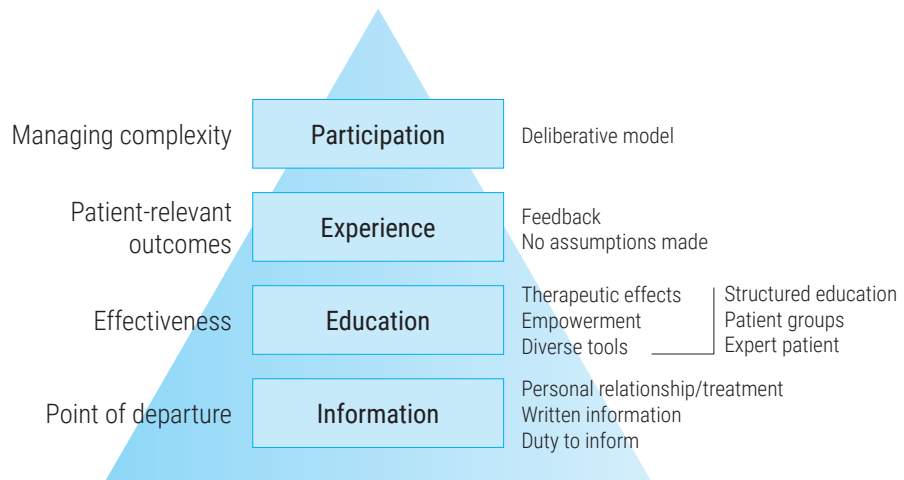


Figure 2. The key elements: PIEEX-Clínic model. M Jansà, J Vilardell, J Escarrabill.

be used and a number of actors may participate, but education must always be considered a responsibility of the healthcare professional. Most of the time, patients will have to make decisions by themselves. Not offering a therapeutic education programme is like offering a good car (a good treatment) to someone who doesn't have a driver's license.

One-size-fits-all doesn't work. The assessment of unmet needs can help us design educational programmes. **Patient experience** is nothing other than a way of getting feedback and not having to make assumptions. Healthcare must be geared toward needs. If you don't know where you have to go, it doesn't matter which path you take.

Finally, the challenge of implementation and scalability must be resolved. The management of complex problems requires taking the perspectives of everyone involved, in a very broad sense, into account. In the end, decisions must be made by the one with the responsibility, but **participation** (the real application of a deliberative model) allows the decision-maker to act in awareness of the impact their decisions may produce and to what point the decision will add value. The key elements are active listening, critical observation and systematic questioning.

The characteristics of the **PIEEX-Clinic model** are described in the table 2.

Characteristics of the PIEEX-Clinic model	
Interdisciplinarity	Interdisciplinary problem-solving, with the participation of medical and nonmedical professionals as well as patients and caregivers involved in the care-provision process.
Real world	Identifying successful activities in the spheres of information, education, patient experience and participation in the real world to learn and share.
Pragmatism	Designing practical materials for professionals and patients: <ul style="list-style-type: none"> - Normalised working procedures for professionals who must design materials. - Documents with information and recommendations for patients.
Networking	Creating professional networks (the community of practice educa2rs is spearheaded by the Hospital Clínic).
Assessment	Incorporating qualitative and quantitative methodologies to assess interventions. AQuAS has published a document to advance in the definition of patient-reported experience measurements (PREMs) as indicators for assessing patient experience ⁴⁰ .
Training	Course on Therapeutic Education Methodology (annual course since 2014) designed to spearhead structured therapeutic education programmes.
Patient	Working to systematically incorporate the patient's perspective from the projects' beginnings.
Accountability	This way of working implicitly entails the need to assess accountability in a systematic and intelligible way for all parties involved.

Table 2. Characteristics of the PIEEX-Clinic Model.

The PIEEX model: the real world

It is evident that the real world does not work like a pyramid and that the shift from one sphere to another is not described in stages. It is impossible to get everything from each sphere of information, education, patient experience or participation. In organisations, all these spheres are developed at variable paces. In the end, the best representation of the PIEEX-Clinic model is the figure 3.

The real world transpires in the areas of intersection, as the arrow shows. Every sphere has its own methodologies and meaning in itself. But when we approach

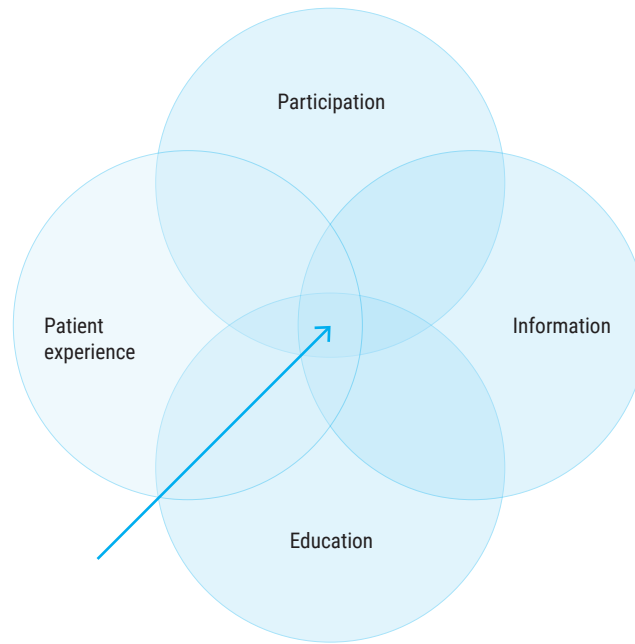


Figure 3. Representation of the PIEEX-Clinic model.

a healthcare problem with greater or lesser intensity we must speak about information, education, patient experience and participation.

It is very difficult to say which route is best for consolidating an integrative project like the one proposed. In practice, the PIEEX-Clinic project's procedure could be summarised like this:

- a. First, analyse what kind of information is offered to patients (and caregivers) by the organisation. Information isn't everything, but as has been reiterated in this text, information is where it starts.
- b. Information analysis can be used to detect fundamental unmet needs. In general, it always tends to be necessary to establish mechanisms for improving the quality of the information and providing methodological support to professionals to offer these tools to patients and caregivers. In the case of the Hospital Clínic, the Infoteca and the Therapeutic Education Methodology course are the practical examples of the response to the detected needs.
- c. It is essential to acquire tools for identifying needs and specifically assessing the impact of the actions on patient experience. The teams must understand why they have to take an interest in their patients' experience⁴². Fundamentally, there are three reasons. Taking an interest in patient experience means thinking about how we want to treat people. Secondly, caring about patient experience is not an exercise of good intentions: there are measurements and methods for approaching this entire sphere. And, finally, there is more and more evidence to show that improving patient experience makes it possible to obtain better clinical results⁴³.
- d. One important decision is how organisations choose to assess patient experience. The assessment of patient experience has many links to

other mechanisms of healthcare systems directly associated with patients, caregivers or the citizenry in general. Thus, the areas of Attention to the Citizenry or Quality Policy (especially with regard to clinical safety) overlap patient experience quite a bit. There is no general recommendation on the position patient experience ought to occupy in organisations. Nonetheless, if one shares the idea of value as a parameter for assessing the quality of health services, it is evident that the perspective of the service recipient is a nuclear element in organisational dynamics. In diverse ways, the assessment of patient experience must represent a direct concern of the healthcare organisation's leadership.

- e. The assessment of patient experience must be focused on action and, therefore, is indistinguishable from the assessment of results. Patient experience must be assessed by transdisciplinary teams, but the clinical perspective is crucial.
- f. The participation of all parties involved is an indispensable element both for ideological reasons (it matters to the service recipient) and practical reasons. Participation allows unmet needs to be identified more precisely and, in addition, facilitates diffusion and scalability.

The dimensions comprising the assessment of patient experience are summarised in the figure 4.

The column of the activities surrounding patient experience is materialised as improving services, training and promoting shared decision-making. The foundation is assessment and research. There are four elements which complement these activities: communication, strategies for improving participation, the acquisition of diverse methodologies, and skills and knowledge for using and assessing measuring instruments like surveys.

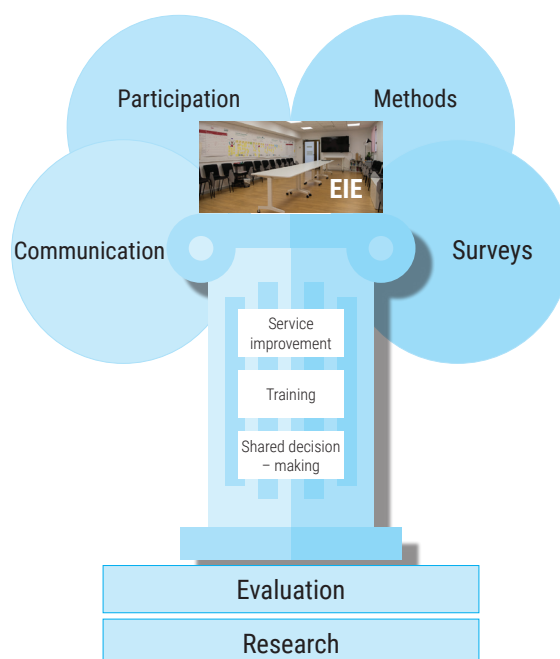


Figure 4. Dimensions comprising the assessment of Patient Experience.

Results

The collective work of these past six years has been materialised in some tangible results.

The table 3 shows a chronology of the implementation process.

Cronologia del procés d'implementació	
Data	Activitat
10.2013	Presentation of the Chronic Care programme
05.2014	First meeting of the Information and Therapeutic Education Working Group (GTIET)
05.2014	Presentation of the inventory of informational and therapeutic education activities at the Hospital Clínic
10.2014	1st Therapeutic Education Methodology course. The course's 8th edition will be run in 2022.
12.2014	1st patient experience seminar
2015-2021	Regular publication of the online newsletter Educa2rs to share ideas and activities with the community of practice promoted by the Therapeutic Education Methodology course.
05.2015	Presentation of the policy on information and therapeutic education to the Executive Committee
06.2015	Presentation of the inventory of informational and educational activities in Primary Care
09.2015	1st XPA – Patient Experience Congress, Barcelona
2015	Standard operating procedure (SOP) and staff: <ul style="list-style-type: none"> • Creation of materials. • Planning of a structured therapeutic education programme. • Therapeutic Education on safety in the hospitalised patient before release.
2016	SOP: Hospital registry of informational materials
2015-17	Development of the INFOTECA
2017	2016-2020 Strategic Plan
07.2017	Presentation of the PIEEX-Clínic model
09.2017	First meeting of the Hospital Clínic Patient and User Participation Commission
11.2018	Hospital Clínic – AquAS working group for designing patient-reported experience measures (PREMs) with the participation of patients.
11.2019	Official inauguration of the Patient Experience Forum (EIE).

Table 3. Chronology of the implementation process.

Information and therapeutic education working group (GTIET)

The GTIET was created in 2014 with a crosscutting and interdisciplinary vision as a result of the needs detected through the inventory of informational and therapeutic education resources⁴⁴. The GTIET initially served to support the professionals who have to create information for patients and, at the same time, promote the therapeutic education methodology course. Healthcare professionals, communication experts and technologists participate in the group. The GTIET receives material proposals from all healthcare professionals, revises them and facilitates the most appropriate design. Patients have participated in the GTIET's development.

An INFOTECA was designed in the framework of the GTIET (2015-17). It con-

sists of a document manager used to gather all the validated material and make it digitally accessible to all healthcare professionals.

During the Hospital Clínic's 2016-2020 Strategic Plan, the members of the GTIET were incorporated into the working group of Transversal Project 2: Information and Therapeutic Education for the Patient, Family Member or Caregiver. Different working subgroups were formed:

- a. Infoteca, collaborating with the previously mentioned tasks.
- b. On-site and online therapeutic education programmes, which, it was determined, must be assessed in terms of: clinical results, patient-reported results (PROMs) and patient experience (PREMs). In order to facilitate the assessment of the PROMs, the QUEST-CLINIC, a digital manager of validated digital questionnaires, was created to make the questionnaires individually accessible, by any patients who require it, through the "My Clínic" patient website.
- c. Hospital-Primary Care educational coordination to encourage better care continuity for patients who have been hospitalised and released with an appointment scheduled with the Primary Care doctor and/or nurse as needed. As a pilot, it is being developed in the subgroup of patients with diabetes and cardiovascular risk.

Therapeutic education methodology

The result of all the work in the therapeutic education field is summarised in this publication from Bertran et al⁴⁵ on the therapeutic education programme design methodology. The key elements are summarised in the table 4.

Elements of a therapeutic education programme (adapted from Bertran et al)	
-	Defining the health problem
-	Situation analysis <ul style="list-style-type: none"> - Identifying unmet needs
-	Structuring the programme <ul style="list-style-type: none"> - Human resources - Material resources
-	Goals <ul style="list-style-type: none"> - Health - Behaviour - Educational
-	Methodology <ul style="list-style-type: none"> - Format: online, on-site or hybrid
-	Application <ul style="list-style-type: none"> - Circuit of the patient and caregiver following the programme
-	Assessment <ul style="list-style-type: none"> - Indicators
-	Communication of results and diffusion

Table 4. Elements of a therapeutic education program.

Hospital Clínic Patient and User Participation Commission

The Hospital Clínic Patient and User Participation Commission was created by a Governing Board decision in January 2017 for three main reasons:

1. The person (patient and professional) is the key element of the Strategic Plan and, therefore, patient participation is nothing other than the consequence of this priority⁴⁶.
2. Social changes largely related to the digital transformation. These changes mean that public institutions, in addition to the results expected of them (services, prioritisation, decisions...), can also be converted into platforms of citizen participation⁴⁷.
3. The willingness of the Hospital Clínic General Management to put patient participation into practice and demonstrate to what extent the perspective of the individuals treated at the Hospital Clínic is valued⁴⁸.

Right from the start, it was quite clear that the commission was not representative and that its basic functions were:

- Create model of participation
- Identify unmet needs
- Accountability
- Example for the organisation
- Document revision and opinion about projects.

After determining the patient selection criteria, patients who fulfilled the criteria expressed in the following table were invited to form part of the Commission.

Característiques	Descripció
Pacient	Only Hospital Clínic patients (or people who care for or have cared for Hospital Clínic patients) may form part of the Commission.
Personal competence	All members of the Commission must have recognised professional competence.
Diversity of opinions	The Commission's composition must guarantee the diversity of opinions.
Gender awareness	The Commission's composition must guarantee that reality will be represented, taking gender into account.
Candour	The Commission's composition must guarantee enough candour to express ideas with sincerity and clarity
Independence	The individuals who belong to the Commission must be independent and with no conflicts of interest to express their opinions.
Collaborative attitude	The people who form part of the Commission must be willing to participate in collaborative tasks associated with the Hospital Clínic.

Table 5. Patient selection criteria to participate in the Patient and User Participation Committee of the Hospital Clínic.

Assessment tools

One of the challenges of assessing patient experience is having tools to objectify the situation and the interventions' impact. Apart from generic metrics (PLAENSA or Net Promoter Score), specific tools have been designed.

- Picker survey. The translation into Catalan and Spanish, and the process of validating the Picker survey, has been completed⁴⁹.
- In collaboration with AQUAS, the basic elements for defining patient-reported experience measurements (PREMs)⁵⁰ have been described.
- The tool XPA-Q is designed with OnSanity. This tool is based on elements

from the Picker survey and the instrument for assessing the experience of patients with chronic obstructive pulmonary disease -COPD- (PREM-C9)⁵¹. This tool makes it possible to contrast professional and patient perspectives on the same questions.

Infoteca

The training activity inventory was used to create a repository of all the materials available, with an eye toward ensuring the quality of the products being offered to patients and caregivers. The INFOTECA was presented in November 2018. The INFOTECA has these functions:

- Material registry
- Material editing -in their phases of style correction, monitoring the level of language, addition of illustrations and graphics.
- Updates.
- Guarantee of accessibility

At this time, there are over 120 materials registered.

Currently, professionals may access the materials through the hospital intranet and the patient's clinical history. The circuit is being developed for the patient to have their own individual Infoteca through the "my clinic" patient website.

Therapeutic Education Methodology course

The therapeutic education methodology course is a response to the needs expressed by professionals. The aim of the course is to transversally promote and improve the quality of information and therapeutic education. The course is imparted to a small group of healthcare professionals (14 to 16 people) to complete a hybrid, theoretical and practical course of 35 hours, during a period of 6 to 8 weeks. After the theoretical training, participants must complete an improvement project associated with therapeutic education in their area of work which includes material for patients, a plan for implementation and assessment and recommendations of quality websites.

As of 2021, this course has been imparted to over 70 professionals, mainly from the hospital but also from primary care centres in the hospital's referral area, as well as from the hospitals which use the Hospital Clínic as a tertiary referral centre (Aliança de la C-17). Most of them have presented improvement proposals on issues related to therapeutic education and support materials depending on the patient subgroups of the respective services where they work.

Living Lab

The approach of using peer interaction to "coproduce" services has been associated with certain frames of reference and exchange spaces frequently identified with the Living Lab movement. This movement emerged in the USA in the 90s and spread to Europe with the creation of the European Network of Living Labs in 2006 ⁵².

The Living Lab is an innovative and open research method which aims to develop new products or services or identify new lines of research. This approach is

based on the concept of co-creation with end users in real conditions and the participation of all implicated members of the healthcare ecosystem^{53,54}.

There are European experiences which promote these spaces for sharing experiences and which are identified with the generic name of living lab.

- The **Copenhagen Living Lab**⁵⁵ investigates how person-centred innovation can increment the value and precision of creation. There is a need to find solutions which raise quality and lower costs. This approach has led emphasis to be placed on the People Value Canvas⁵⁶, a tool which allows designers and stakeholders to interact.
- The **Knowle West Media Centre**⁵⁷ is a member institution of the European Network of Living Labs (ENoLL)⁵⁸. Like all living labs, it offers “an environment for conducting tests in the real world” – a place where citizens, designers, professionals, managers and organisations from the public sector can work together to co-create ideas, tools or technologies which respond to local challenges and explore and innovate new possibilities.
- **Waag**⁵⁹ is a non-profit institution which “operates at the intersection of science, technology and the arts, focusing on technology as an instrument of social change, guided by the values of fairness, openness and inclusivity”. The “Chamber of Commons” idea (sharing tools to mitigate vulnerable situations)⁶⁰, as well as gamification, plays an important role⁶¹.

The living lab at the Hospital Clínic (there, known as an Patient Experience Forum -EIE) is an evidence bank. The EIE is the physical framework for putting participation into practice and testing if it is done in the most suitable manner. The EIE is an innovative space for:

- Formulating and answering questions.
- Identifying unmet needs of patients and the people who care for them.
- Testing prototypes of possible solutions to problems.
- Testing educational proposals in the real world (with external observers who can improve the formats).

The EIE will not perform (or will perform very few) routine activities. The aim is to answer a question or test a solution and, after a reasonable trial period, scale it to the real world. The routine application of a solution must always be done in the context where the care process occurs.

The EIE stems from a physical space in the hospital, but the content it generates, through a platform, must be accessible online (network of friends of the Clínic/volunteers, collaborators...) and must be linkable to other similar initiatives or other areas of the Hospital. Through the physical space and the website, professionals connect to the academic realm and, in the future, this must become a distributed network of knowledge on patient experience.

The elements which must distinguish the EIE's way of working to achieve its goals are summarised in the table 6.

Element	Description
Co-creation	<ul style="list-style-type: none"> - With people and for people - Let patients help - Reciprocity - Equalisation: connections between human beings
Real life	<ul style="list-style-type: none"> - Interest in how people experience illness - Context counts - Systemic vision
“Safe space”	<ul style="list-style-type: none"> - No limits on the type of “conversation” used to express ideas, emotions or fears - A space of trust, with no prior assumptions - An incubator of new ideas through prototypes
Education	<ul style="list-style-type: none"> - Different ways of establishing “conversations” to make decisions - Inviting patients to participate actively - Shared responsibilities
Results	<ul style="list-style-type: none"> - Patient experience counts when making decisions - Sharing the definition of value, from the perspective of patients - Pursuing “right care” to prevent waste - Deliberation for prioritisation - Social impact

Table 6. Elements defining the work methodology of the Patient Experience Forum.

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