



# THE PATIENT'S PERSPECTIVE IN THE HEALTH CARE SYSTEM



NOVEMBER 2020

## Terms of reference

The aim of this document is to present a current and synthetic overview of integrating the patient's experience within health care institutions, what ways and how patient participation contributes to cultural change.

This report is the result of a joint production by members of Shared Patient Experience in November 2020.

## Bibliographical reference

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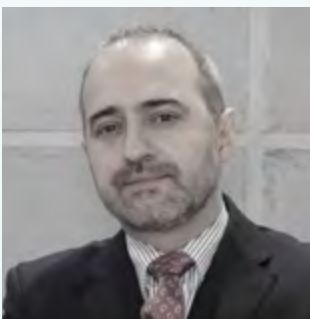
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## 1. INTRODUCTION : THE CONTEXT OF PATIENT PARTICIPATION

The participation of sick people and the people who take care of them represents a significant change in the care model. The paternalistic (even "authoritarian") model, centered on the illness and the authority of the professional, generated by the asymmetry of technical knowledge between patient and expert/professional, is evolving towards a more deliberative model, centered on the rights and duties of the patient<sup>1</sup>. Informing, consulting, involving, collaborating and empowering are increasingly complex and comprehensive levels of participation<sup>2</sup>.

The aim of this report is to present an updated and synthetic vision of the positioning of the Shared Patient eXperience Association in relation to patient participation in healthcare institutions. There are no standard criteria for approaching this participation. As a result, it is necessary to discuss representativeness, the types of patients who can actively

participate as well as the criteria and methodologies to be followed to assess the patients' point of view. It is very important to define the mode of participation (voluntary, with some kind of compensation or systematically paid) and the criteria for patient selection and renewal.

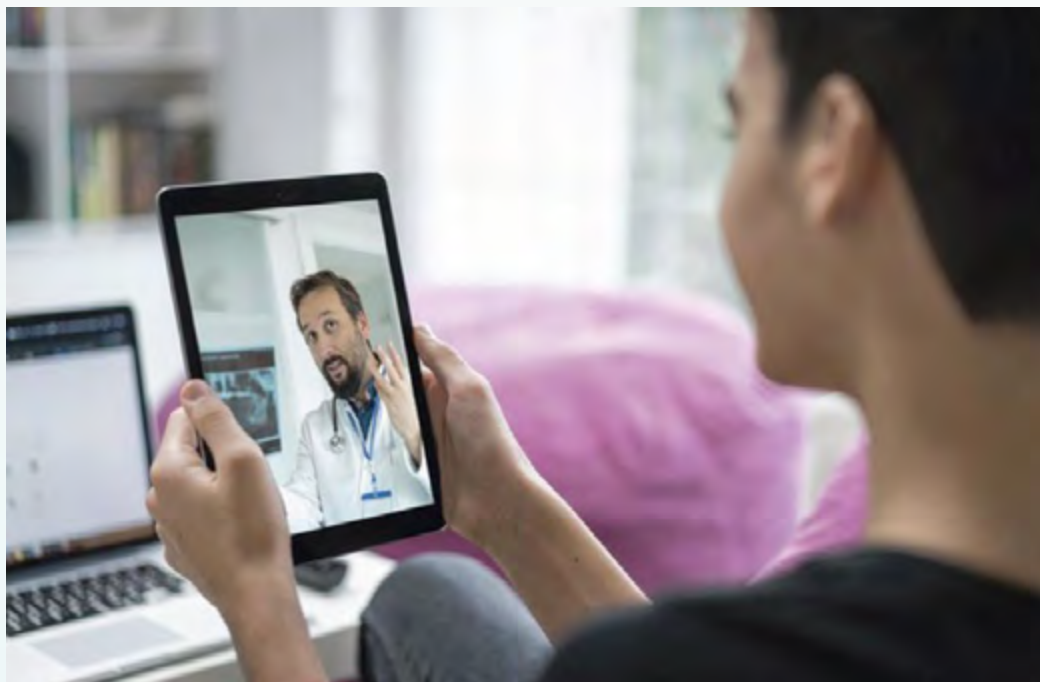
To understand better the importance of models of patient involvement in the health system, it is important to talk about the patient experience in its entirety. Participation is meaningless without an explicit focus on the patient experience.

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<sup>1</sup> Millaret M, Pons JMV. Participació de ciutadans i pacients en les polítiques de salut: conceptualització i experiències internacionals. Barcelona: Agència de Qualitat i Avaluació Sanitàries de Catalunya. Departament de Salut. Generalitat de Catalunya, February 2015.

**The patient experience covers the full range of interactions that patients have with the health care system. This includes the care received by both health programs and health professionals, from doctors' offices and from any care centre, as well as patients' interactions with the fields of health research and education<sup>3</sup>.**

This is a concept that has become increasingly important in recent years, especially in hospitals where there is a growing emphasis on placing the patient at the centre of processes and organization. Increasingly, the patient experience is seen as the "third pillar of quality"<sup>4</sup>.



<sup>3</sup> Agency For Healthcare Research and Quality (AHRQ) <https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html>. Accessed on January 24, 2020.

<sup>4</sup> Doyle, C., Lennox, L., & Bell, D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;3:1-18.



One of the fundamental elements of the patient experience is participation. Patient participation is a necessary condition for using their experience to improve the health system (from the micro to the macro level). However, some elements need to be taken into consideration when talking about participation:

**1. The willingness to participate is part of a general social demand<sup>5</sup> and, at the same time, of a need to support those who have to make complex decisions.**

**2. Patient participation is not a sufficient condition to ensure that the experience that the patient can bring is used effectively.**

**3. The participatory process is not a substitute for decision-makers. Participation processes must combine deliberative logic with the exercise of authority<sup>6</sup>.**

**4. Beyond the strict scope of the patient experience, mechanisms for citizen participation around research or teaching must also be set up.**

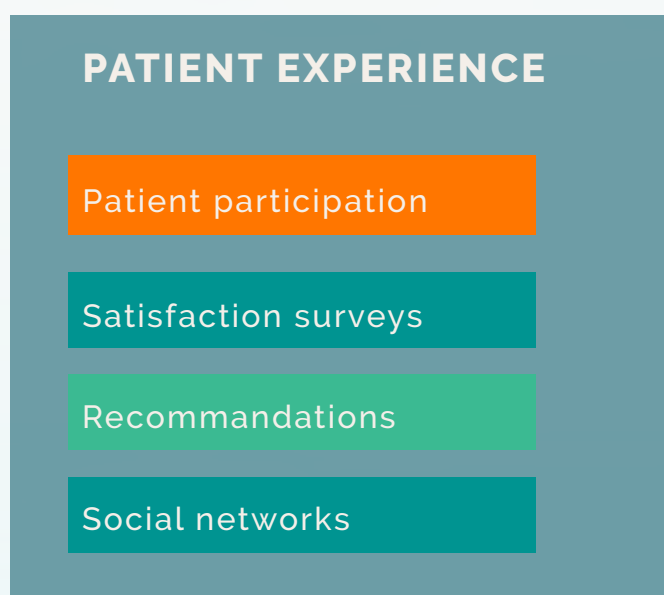


Figure 1: The patient's participation as an integral part of the patient experience (SPX, 2020)

<sup>5</sup> Gramberger M (editor). Citizens as Partners OECD Handbook on information, consultation and public participation in policy-making. OECD, 2001. <https://www.internationalbudget.org/wp-content/uploads/Citizens-as-Partners-OECD-Handbook.pdf> Accessed on February 6, 2020.

<sup>6</sup> Brugué-Torruella, Q. Políticas Públicas: Entre la deliberación y el ejercicio de autoridad. Cuadernos de Gobierno y Administración Pública, 2014;1:37-55



## 1.1 WHAT DO WE MEAN BY PATIENT PARTICIPATION?

The concept of “patient participation” has been described and defined by several authors in the scientific literature in recent years. However, there is no general agreement on what this concept exactly means, what elements it requires, nor in which cases its use is appropriate. For example, the four definitions below allow us to appreciate the differences of vision around patient participation:

1. One of the most widely accepted definitions is that of Angela Coulter, who emphasizes collaboration between patients and health care providers to “promote and support **the active participation** of the patient and the population in the health care system and enhance their influence on health care decisions, both individually and collectively”<sup>7</sup>.

2. The model of public participation developed by James Conway at the Institute for Healthcare Improvement is based on patient **involvement**: during the care experience, within the microsystem of the clinic or care unit, within the health care institution, and

within the society or community<sup>8</sup>.

3. For its part, the Center for Advancing Health sets the framework for **patient participation and involvement** by focusing on behavior, defining participation as “actions that people take for their health and to benefit from the health care they receive” and provides a list of participatory actions<sup>9</sup>.

4. Another definition of patient involvement in health is: “patients, families, health representatives and health professionals **working actively together** at different levels of the health system (care received, organizational design, public policy and governance development) to improve health and health care”<sup>10</sup>.

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8 Institute of Medicine. Engaging patients to improve science and value in a learning health system. Chapter 4 in: Institute of Medicine. Patients charting the course: citizen engagement in the learning health system: workshop summary. Washington (DC): National Academies Press; 2011. p. 103 – 10.

9 Center for Advancing Health. A new definition of patient engagement: what is engagement and why is it important? Washington (DC) : CFA ; 2010 <http://www.hret-hiin.org/resources/display/a-new-definition-of-patient-engagement-what-is-engagement-and-why-is-it-important> Accessed on February 6, 2020.

10 Kristin L. Carman, Palmo Dardess et. al. Health Affairs. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies <https://www.healthaffairs.org/doi/10.1377/hlthaff.2012.1133> Accessed on February 6, 2020.

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7 Coulter A. Engaging patients in healthcare. New York (NY): McGraw-Hill Education; 2011. p. 10.

In addition to patient participation, the concepts of **patient activation** and **patient- and family-centred care** are used. Although the concepts are related, they are not identical.

- **Patient activation** - involving the patient's knowledge, skills and self-confidence to manage his own health and health care - is one aspect of individual training to participate in his own health. Patient activation is considered as a precondition for being able to involve the patient and make him an actor in the processes of improving the unit, service, institution or health system<sup>11</sup>.

- **Patient- and family-centred care** is a broader term that expresses a vision of what health care should be: a partnership between professionals, patients and families (if appropriate) to ensure that decisions respect patients' needs, wishes and preferences and that patients have the education, information and support they need to make decisions and participate in their own recovery<sup>12</sup>.



11 Hibbard JH , Mahoney E . Toward a theory of patient and consumer activation. Patient Educ Couns . 2010 ; 78 ( 3 ) : 377 – 81

12 Institute of Medicine. Envisioning the national health care quality report. Washington (DC): National Academies Press; 2001.

Some authors<sup>13</sup> suggest going beyond the conceptual framework of “person-centered care” and refer to **Collaborative Health (CH)** to underline the intention to minimize the asymmetry between the professionals and the people under care. Thus, the basic elements for building collaborative health would be:

- **Sharing information (all), within the limits set by the person in care.**
- **Accepting flexibility in the way decisions are made.**
- **Replace the weight of technique (of the prescription) with trust.**

## **2. WHAT ARE THE DIFFERENT FORMS OF PARTICIPATION ?**

All the definitions and conceptual frameworks observed have in common the underlying idea that we want to highlight: **patient participation is a means to achieving a goal**, never an objective in itself. The general objective is to improve the health system in a broad sense, and the concrete goals are related to the environment (or the dimension) in which the patient

participates, as well as to his degree of participation.

This section deals with the forms of patient participation in the health system.

We found out that the different forms of patient participation can be classified, always with limits, around 4 dimensions, equivalent to fields of action classified from the most local to the most general.

As shown in the following graph, the 4 dimensions are:

- 1. Patients' participation in their own health**
- 2. Participation in the improvement of services and the organization of institutions**
- 3. Participation in the field of knowledge (research and teaching)**
- 4. Participation in the field of health policy design**

In turn, these different dimensions are divided into the following categories according to the degree of participation:

- **Consultation**
- **Collaboration**
- **Partnership and shared leadership**

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<sup>13</sup> Millenson ML. When “patient centred” is no longer enough: the challenge of collaborative health: an essay by Michael L Millenson. BMJ. 2017 Jul 5;358:j3048. doi: 10.1136/bmj.j3048.

LEVEL OF PARTICIPATION			
	Consultation	Collaboration	Partnership and shared leadership
OWN STATE OF HEALTH	The patient is informed about the diagnosis	The patient is asked what his preferences are in relation to the treatment	Treatment decisions are made according to patient preferences and medical judgement
ORGANIZATION DESIGN	The hospital asks patients for their opinions on their experience (e.g. with a questionnaire)	The hospital includes patients as assessors or members of assessor committees	Patients co-lead strategic committees (e.g. quality and safety improvement) within the hospital
KNOWLEDGE	Consulting patients in a concrete and concise way on an aspect of research	Patients express their views on research priorities	Systematic and equal collaboration during all phases of a study between patients and researchers
HEALTH POLICIES	The regulator conducts focus groups of patients to gather their opinions	Patients' recommendations on priorities are taken into account for funding decisions	Patients have equal representation on the decision-making committee that allocates resources to health programs
GOVERNANCE OF INSTITUTIONS	The hospital asks patients who are opinion leaders (e.g. via a questionnaire or interviews) to give their opinions on the subject	The hospital includes patients as assessors in a joint commission with the hospital management ("Advisory Commission")	The Patients' consultative commission plays an active role in decision making

Figure 2 Grade of patient involvement according to context (SPX, 2020)

Own design inspired by Kristin L.Carman Thomas A.Workman. 2016. Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement

Moreover, it should be noted that this scheme presented and widely used in the literature on patient participation can be useful for an institution (from a hospital or research center to a public regulatory organization) to position itself at one level or another of participation with the patient.

## 2.1 HOW DO PATIENTS PARTICIPATE IN THEIR OWN STATE OF HEALTH ?

This dimension of participation refers to the concept of patient activation described above and refers to the participation of the patient in his own state of health, i.e. in the health care received.

The literature of a few years ago on patient participation in the health care system focused largely on this dimension, which is understandable as the received care is the most obvious link between patient and provider of care<sup>14</sup>.

This dimension of participation refers to the relationship between the patient and the professional and strongly emphasizes the communication skills

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14 M. Maurer, P. Dardess, K.L. Carman, K. Frazier, L. Smeeding. Guide to Patient and Family Engagement: Environmental Scan Report. Agency for Healthcare Research and Quality: American Institutes for Research (2012).

of the patient and the team of health professionals: from the stage when the patient is informed of his diagnosis and understands it to the treatment decision process shared between the patient or his relatives and the professional health team.

Making decisions in a shared manner would be a way of making participation effective. In a broader framework, it would be necessary to determine how the professional leaves sufficient space to understand and respect the patient's values and preferences. More and more professionals believe that the paternalistic model of clinical practice is completely inappropriate in most cases. In the deliberative model, the physician and patients discuss what values are most appropriate for the patient in each specific circumstance. Whatever the circumstances, the role of the physician is to persuade without forcing<sup>15</sup>.

Focusing attention only on the behavior of the patient and the health care provider ignores the fact that much of what happens in the care environment is affected by the policies, processes and culture of the provider's organization, as well as the

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15 Generalitat de Catalunya. Decisions compartides. <http://decisioncompartides.gencat.cat/ca/inici> Accessed on January 22, 2020.



public policies from govern regulators (and funders). Engaging patients and consumers in organizational design, at government levels and in public policy making can generate better systems to support patient participation in care. If we add the value of formalizing and operating such systems thanks to scientific evidence, better decisions will be made at all levels.

As a result, the current debate is widening to other dimensions such as the organizational design of health care institutions, health planning at the macro level and the field of knowledge.



## 2.2 HOW DO PATIENTS PARTICIPATE IN THE IMPROVEMENT OF SERVICES AND IN THE ORGANIZATIONAL DESIGN OF INSTITUTIONS?

In general, patient/citizen participation is considered for the co-design of services or regarding policies for evaluating service delivery. The value provided by a service is always defined by the user and not by the provider. Involving people in the redesign of the services they receive enables the services to be adjusted to real needs and is in turn a useful strategy to promote their implementation and evolutionary development. People's participation requires adequate tools and spaces to be effective.

The organizational design and improvement of services within health care institutions is one of the dimensions where the concept of patient participation has developed in recent years. As in the previous dimensions, the degree of participation can be classified into three levels.

### 1.Consultation:

Projects with a low degree of patient involvement in which patients are consulted on an ad hoc basis on specific aspects of their experience in

the institution. Some examples:

- Including patients in a hospital staff meeting to discuss their stay in the institution and highlight positive aspects, identify negative aspects, present ideas for change or improvement.
- Working with patients to develop or revise audio-visual or paper tools such as brochures for patients and families, informational videos or instructions.
- Consulting patients' councils on the type of communication strategies in order to improve quality.
- Systematically collecting patients' opinions through satisfaction surveys, mailboxes for complaints and suggestions, online questionnaires, etc.

## 2. Collaboration:

Participation of patients in continuous work teams, such as a patient and family committee.

- A patient and family committee is a formal group that meets regularly to encourage active collaboration between clinicians, hospital staff, patients and families in making policy and program decisions.
- Committees can identify opportunities to improve the patient and family experience, give advice on policies and good practices to support and encourage their participation, and make recommendations to better measure, quantify and evaluate.

Patient participation in committees assessing the quality of care processes provides a valuable complementary view.

## 3. Partnership:

The highest level of involvement of patients and relatives in a healthcare institution is one that not only includes patients as members of **strategic committees**, but also gives them a co-leadership position. An archetypal example is the quality and safety committees.

In these committees, patients can participate in the following tasks:

- Review and interpret the results of patient satisfaction questionnaires and other data related to hospital quality and safety and developing strategies for improvement.
- Participate in projects to improve the quality of care.
- Turn to nurses, medical staff and other staff who focus on improving communication, safety and quality during training sessions



## 2.3 HOW DO PATIENTS PARTICIPATE IN THE FIELD OF KNOWLEDGE (RESEARCH AND TEACHING)?

Several studies show that the accessibility and perceived usefulness of existing research to the patient is very limited<sup>16</sup>.

Solutions include:

- On the one hand, involve patients and the large public to ensure that the **research carried out is the most appropriate** and not only that which is developed according to the interests of sponsors (e.g. pharmaceutical companies) or the personal interests of professional researchers.
- On the other hand, to argue that patient and citizen participation is not only about making surveys more appropriate, but also about ensuring that **research is carried out properly**.

Patient and public input can help to ensure that researchers clearly explain what their study is about, that they communicate more sensitively with the public, but also that studies are carried out to make research more effective, and that the communication of the

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<sup>16</sup> Institute PCOR. Listening to Patients, Caregivers, and Clinicians: Meeting Stakeholder Needs for Comparative Effectiveness Research—A PCORI Survey. Washington DC2015.

results to citizens is improved<sup>17</sup>.

Patient participation in clinical research projects can also be classified into 3 levels according to the degree of involvement<sup>18</sup> :

1. The **consultation** can be very concrete and concise on a specific aspect, or it can be a consultation integrated into the research process.
2. In the case of **collaboration** in a research project, patients have even more control over the study, as they assume the role of collaborators or even co-producers.
3. The highest level of involvement is **patient-driven research**. In this case, patients and researchers systematically collaborate in all phases of the study, from defining the scope to disseminating their results, under the active guidance of patients or their representative organization.

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<sup>17</sup> Kristin L. Carman, Thomas A. Workman. Elsevier. Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement. 2017.

<sup>18</sup> Centre Fédéral d'Expertise des Soins de Santé (KCE). 2019 ; Report 320Bs Position du KCE concernant el implication des patients dans les projets de recherche en politique des soins de santé.



In the field of health, a movement promotes citizen participation in the definition of research priorities. **Patient and Public Involvement (PPI)**<sup>19</sup> is an example of such approaches to involve citizens in setting research priorities or evaluating (monitoring) the methodologies that are used in research projects. The current opinion under the aegis of **Open Science**<sup>20</sup> is also moving in this direction of information sharing

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19 Patient and public involvement in research. <https://healthtalk.org/patient-and-public-involvement-research/what-is-patient-and-public-involvement-ppi-in-research-why-does-it-matter>. Accessed on January 22, 2020.

20 Mehler, D. and Weiner, K. 2018 Open science: Sharing is caring, but is privacy theft? <https://blogs.plos.org/neuro/2018/01/31/open-science-sharing-is-caring-but-is-privacy-theft-by-david-mehler-and-kevin-weiner/>. Accessed on January 22, 2020.

between scientists and citizens.

Some representative examples are **the InSPIRES**<sup>21</sup> project which includes these perspectives of opening up research processes to civil society, and **the SARIS**<sup>22</sup> (System for the Evaluation of Research and Innovation in Health) which includes the participation of stakeholders (patients and civil society) as an obligation for the proper evaluation of studies.

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21 Inspire Project <http://inspiresproject.com/>. Accessed on January 22, 2020.

22 AQUAS (Agència de Qualitat i Avaluació Sanitàries de Catalunya. SARIS <http://aquas.gencat.cat/ca/ambits/recerca-salut/saris/>. Accessed on January 29, 2020.

To a lesser degree, patient participation in medical health education is also developing in various universities around the world, such as the University of Montreal, where since 2010 a new relational model based on association has been developed between patients and healthcare professionals. This collaborative model is based on the recognition of patients' experience (and knowledge) and its complementarity with the healthcare professional's scientific knowledge. This association is part of an ongoing involvement with the patient and may be applied to the fields of health, professional training, education and research.

Another notable example is the Université Libre de Bruxelles (ULB). According to the ULB's University Certificate in Partnership with Patients Program, the first university certificate in the world in this field, there are 3 main types of patients according to collaboration: the patient involved in his care, the patient involved in improving the health system, and finally the patient involved in the health system through teaching<sup>23</sup>.

## 2.4. HOW DO PATIENTS PARTICIPATE IN THE DESIGN OF HEALTH POLICIES?

At the level of public policy design, participation focuses on the development, implementation and evaluation of health policies and programs at national, regional and local levels. Patient engagement in public policy, often described as "citizen" or "public" engagements, helps to ensure that the health system is oriented and responsive to the perspectives of patients and citizens.

Patients work with community representatives and decision-makers - for example, government officials, health planners and health care providers - to solve health and social problems, shape health policies and set priorities for resource use.

At the highest level of patient involvement in the design of health policies, patients or their representatives should set priorities and make policy and program decisions at the same level as technicians.

However, it is still exceptional for patients to have significant power and

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<sup>23</sup> Université Libre de Bruxelles (ULB) <https://www.ulb.be/fr/programme/fc-613> Accessed on January 24, 2020.

influence in this dimension<sup>24</sup>.

### HEALTH INFORMATION TECHNOLOGY POLICY COMMITTEE

An example of progress towards this higher level of collaboration is the Health Policy Technology Policy Committee established by the American Recovery and Reinvestment Act of 2009. This federal advisory committee reserves three of its twenty seats for user representatives to make recommendations on policies that promote the adoption and "meaningful use" of health information technology, including its use to promote engagement with patients and their families<sup>25</sup>.

### 3. IS THE PATIENT'S POINT OF VIEW HOMOGENEOUS?

For us, the patients' perspective is not homogeneous, because each patient has his own experience of health and this implies a different view of the health system (at different levels) which also influences the way in which he participates in it. In this sense, it was necessary to analyze the different typologies of patients cited in the literature and their adequacy for each dimension described above.

#### « Witness » patient

- This type of patient explains his experience as a patient of a certain health institution or disease. He is not involved at any other level of participation other than explaining his case and experience.
- He is at the levels of consultation of the above scale of participation and within the dimensions of organizational design and health policies.

#### « Sick » health professional<sup>26</sup>

- This is a different type of patient because, being a health professional, he has a different capacity for observation than a non-care patient. He has great credibility in front of

<sup>24</sup> Kristin L. Carman, Palmo Dardess et. al. Health Affairs. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies <https://www.healthaffairs.org/doi/10.1377/hlthaff.2012.1133> Accessed on January 24,2020

<sup>25</sup> Health Information Technology Advisory Committee (HITAC). <https://www.healthit.gov/hitac/committees/health-information-technology-advisory-committee-hitac> Accessed on February 6, 2020

<sup>26</sup> Hospital Clínic de Barcelona. Nou setmanes i mitja. Experiència d'un metge malalt. 2016 <https://www.youtube.com/watch?v=hNShUqQiyYM>. Accessed on January 20, 2020

other health professionals.

- On the other hand, he has limitations: for example, a professional who has been treated in the institution where he works may have received special attention from colleagues and thus have a biased view of the patient's experience in the institution.
- He can be located in the medium and high levels of participation (Collaboration and Partnership).

### **Patient expert**

- A person who lives or has lived with one (or more) disease(s) enough to be able to help peers manage it from different perspectives and even train other patients. There is currently a debate about the institutionalization of this patient profile through regulated and certified training (e.g. through the patient's school or university).
- From the research point of view, these are experienced patients who are familiar with scientific research, either because of their training or because they have already frequently participated in research projects as patients.

### **Patient collaborator**

- A patient who has a collaborative attitude and offers constructive criticism and whose participation is requested on an ad hoc basis.

### **Patient educator (Montreal model)**

- Also called "patient partner".
- Patient who offers his experience and knowledge to health professionals or students through the regulated training of health professionals.
- They may also be patients who are experienced in the world of training and who take on the role of training other patients to participate.
- He is normally associated with the knowledge dimension and the highest levels of involvement.
- In many cases, formal recognition of this activity is required. This recognition is associated with a request for status within the organization and economic compensation (salary).



### Patient volunteer

- Patient who is dedicated to accompanying and supporting other patients in a health establishment. Usually the volunteer patient has been treated in the same institution. His field of action is defined and he is part of a team with other volunteers and is supervised by the institution.
- Usually at level 2 of involvement (collaboration) because they have regular participation without being part of a professional team.

### Patient representative

- Also called patient activist.
- A person who represents the collective of patients in a health care institution regardless of his medical problems.
- Participates in high levels of involvement and generally in the dimensions of organizational design and service improvements.

### Patient representative in health policy bodies

- This type of patient differs only in the dimension in which he is situated: health policies and governance. He is specialized in this type of activity, but can participate in any level of involvement.

We can also note that **patients' relatives speak on their behalf** when they cannot do so themselves. In this case, this is not a differentiated patient typology as it may be one of the above, but in the mouth of a relative/caregiver.

This is not to be confused with the possibility of involving caregivers and families in research related to their specific role as experts in the caring function. In this case, they do not speak on behalf of the patient but on their own behalf.

We must keep in mind that these typologies are not incompatible with each other, and that the same patient may have different roles.

In addition, we want to separate another typology of actors, which are **patient associations** (or **patient advocacy**). Although they play the role of patient advocates, they present problems of representativeness, mainly for two reasons:

1. They do not always represent a significant number of patients with the same disease.
2. On the same territory, there may be several patients' associations interested in the same care problem.

## 4. WHO REPRESENTS THE PATIENTS?

The answer to this question is very difficult. Depending on the perspective adopted, representativeness may vary. From the point of view of health service planning, patient associations could offer a view from the patient's point of view (even if this would have obvious biases).

From the point of view of planning and improving the services of a health centre, patients' associations provide an incomplete vision and do not guarantee the presence of all the visions of the people welcomed.

The willingness to participate is part of a general social demand<sup>27</sup> and, at the same time, a need for support from those who have to make complex decisions.

In some ways, in the health field this general interest of citizens to participate could be translated into the phrase **“Nothing about me without me”**, which is one of the key titles in the document *Equity and excellence: Liberating the*

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27 Gramberger M. (editor). Citizens as Partners OECD Handbook on information, consultation and public participation in policy-making. OECD, 2001. <https://www.internationalbudget.org/wp-content/uploads/Citizens-as-Partners-OECD-Handbook.pdf> Accessed on January 22, 2020.

*NHS*<sup>28</sup>. A deliberative logic suggests that technical decisions are necessary but not sufficient to respond to complex problems. For this reason, it is essential to integrate different points of view<sup>29</sup>.

The potential benefits of participation can be the possibility of making smarter decisions and facilitating the implementation of these decisions through the promotion of mutual trust.

These criteria are important when identifying the patients/citizens who will be part of the participatory process. Given the difficulty of identifying who represents patients, we can adopt pragmatic criteria.

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28 Equity and excellence: Liberating the NHS. London. Department of Health. UK. 2010.

29 Brugué Torruella, Joaquim Guia per dissenyar i executar processos participatius en l'àmbit municipal. Barcelona, Departament d'Afers i Relacions Institucionals i Exteriors i Transparència. Febrer de 2017. <http://governobert.gencat.cat/ca/participacio-ciudadana/difusio-i-recerca/guies-breus-de-participacio-ciudadana/guia-per-dissenyar-i-executar-processos-participatius-en-lambit-municipal/> Accessed on January 22, 2020.



## 4.1. WHAT ARE THE MOST COMMON SELECTION METHODS?

Three main selection methods can be described:

**a) Random selection.** Faced with a specific question, patients who can answer this question are selected at random (those suffering from a terminal illness or who have used specific services, for example). The method of random selection can be made more sophisticated in a number of ways, but it is usually very useful to have a global view of a problem.

**b) Known patients (collaborators).** The collaboration of patients who are closely linked to a team or department is requested. This is easy, but can result in significant bias by limiting criticism of the service with which there is a close relationship.

**c) Patients who spontaneously offer to participate.** Some institutions open their doors to patients and their relatives who spontaneously offer to participate, such as the “Patient-Family Partner Program” at Virginia Mason Hospital in Seattle<sup>30</sup>.

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<sup>30</sup> Virginia Mason Institute <https://www.virginiamasoninstitute.org/quality-and-safety/patient-experience/patient-family-partner-program/>. Accessed on February 5, 2020.

Definition of typologies. Because of the difficulties in selecting patient representatives, the strategy for defining typologies can be based on a definition of the “characteristic person” of the problem to be studied.

In working meetings with patients and professionals, it is very important to take into account both the **proportion** between them and **the role attributed to each**. Placing a patient in a meeting with different professionals without giving him a particular role can have a purely decorative sense (tokenism)<sup>31</sup>.

In each of the three situations, it is useful to take into account the elements that can facilitate the selection. The basic criteria are as follows:

- **Diversity**

It is essential that the group includes a diversity of patients with the same clinical problem. Here diversity is understood from the point of view of the disease: there must be patients at different stages of the disease, with more or less complex treatments, different ages, etc.

- **Plurality**

Where the issue may contain elements

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<sup>31</sup> Hahn, D. L., Hoffmann, A. E., Felzien, M., LeMaster, J. W., Xu, J., & Fagnan, L. J. Tokenism in patient engagement. *Family practice*, 2017;34:290-295.

that highly depend on people's values, the plurality of values must be taken into account.

#### •Inclusion

In order to have all the perspectives, we have to think about inclusion. The invitation to participate must reach all candidates. In addition it is necessary to consider whether participants need prior support to participate (information on the health system, mechanisms to overcome language barriers,...).

#### •Stigmatisation

Stigmatisation should be avoided. Sometimes it is assumed that the patient will not understand the problem or will have difficulties in communicating. Sometimes a simple question solves many difficult issues.

#### •Gender bias

Gender bias, which sometimes may appear unsuspected, must be avoided<sup>32</sup>.

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<sup>32</sup> The Guardian. The five: medical biases against women. 29th July 2019. There are gender biases in the approach to heart failure, Alzheimer's disease or endometriosis. Also in clinical trials. But in this article in The Guardian, it is revealed that even dolls for cardiopulmonary resuscitation have a male form (and the problem is serious when we see that more men are resuscitated than women). <https://www.theguardian.com/science/2019/jul/28/medical-bias-against-women-drug-trials-cpr-medicine-gender-inequalities> Accessed on January 20, 2020.

#### •Taking the caregiver into account

Especially in the case of chronic illnesses, the caregiver has an interesting view of the care process.

### 4.2 HOW PARTICIPATION AND AUTHORITY ARE LINKED?

Promoting participatory processes should not be used to exonerate those in charge of making decisions from their responsibilities. Precisely because they are complex decisions, whoever is responsible for them must listen to all those involved before deciding<sup>33</sup>.

A key element in deliberative logic is to have to report. Whoever has the responsibility to decide must listen, make the decision they feel is most appropriate and then clearly show the reasons why they made the decision.

Therefore it is important to remember that, contrary to popular belief, a participatory process does not imply a decision taken by the assembly.

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<sup>33</sup> Brugué-Torruella, Q. Políticas Públicas: Entre la deliberación y el ejercicio de autoridad. Cuadernos de Gobierno y Administración Pública, 2014;1:37-55.

### 4.3 HOW OFTEN SHOULD THERE BE A RENEWAL OF PARTICIPANTS?

Depending on the typology of the patients, and above all their degree of involvement, it is necessary to have continuous participation of the same people (for example, in committees or working groups).

In these cases, it is important to establish criteria for the renewal of people who contribute their point of view as patients. These criteria must allow to find a balance between necessary training, knowledge and objectivity.

#### Training:

In most cases it will be necessary to inform and train patients according to the group in which they are going to participate (e.g. regarding the working methodologies used by the group, what is important for the institution, the professionals involved, etc.). To benefit from such training, it is advisable that one or more of the same person(s) participate(s) assiduously in the same working group.

#### Knowledge:

It is therefore necessary to take into account the "amortization" of the knowledge provided to the patient

during the training. His learning curve must be taken into account.

#### Objectivity:

The third factor to be considered is when a patient participates for a long time in the same institution, he ends up losing a part of his objectivity and independence, but also his critical mind.

Because of these reasons, it is important to find a balance regarding the renewal of participants.

## 5. HOW IS THE LINK BETWEEN THE PATIENT AND THE INSTITUTION AT THE LEGAL-ADMINISTRATIVE LEVEL?

The consulted literature does not provide in-depth details on best practices to follow regarding administrative and legal aspects, such as the working regime of these patients, whether they should be compensated, whether they are part of the hospital's teams, etc.

Our opinion is that it is necessary to establish a gradation regarding the relationship between the patient (worker) and the institution in which he participates, according to his involvement and role in it.

To this end, we can identify four models of relationships:

1. Consultation
2. Occasional advice
3. Systematic advice
4. Integration into the workforce

## 5.1 CONSULTATION

This is the most common form of participation at present. The participation of patients who have used a care device, or who use it regularly, is required. The patient is presumed to participate in an altruistic way, without receiving anything in return.

The aim of this type of participation is to obtain feedback from patients who live in the real world, without too many biases linked to knowledge of the system or a relationship with the institution. The "naïve" opinion of the patient is very useful in the reorganisation of health care services<sup>34</sup> but also in the formalization of clinical practice guidelines<sup>35</sup>.

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34 Bolz-Johnson M, Meek J, Hoogerbrugge N. "Patient Journeys": improving care by patient involvement. *Eur J Hum Genet.* 2019 Dec 4. doi: 10.1038/s41431-019-0555-6.

35 Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Recommendations for patient engagement in guideline development panels: a qualitative focus group study of guideline-naïve patients. *PLoS ONE* 2017;12: e0174329.

## 5.2 OCCASIONAL ADVICE

In some cases, in addition to experience as a patient, special skills are required to participate in working groups. The boundaries between "consultation" and "advice" are indeed very blurred. In some countries, these consultants are not paid but participants receive financial compensation to cover their travel expenses.

In this case, patients participating in specific consultations are at the disposal of the establishment when certain circumstances appear.

## 5.3 SYSTEMATIC ADVICE

When the advice is systematic (i.e. with periodic meetings), it is necessary to compensate for the time spent with fixed allowances (in addition to covering travel expenses).

## 5.4 INTEGRATION INTO THE WORKFORCE

Patients can be integrated into health institutions in different ways:

1. Integration in committees
2. Patient partner
3. Patient director

### 5.4.1 Committee membership

In the first case, the patients in the committees have the same functions as the rest of the committee and carry out the assigned activities (training, monitoring of activities, etc.). An example of a patient committee in many hospitals is the bioethics committee. However, although this is a relatively widespread practice, the desired function is not filled if the included patient is a professional from the same institution, because bias occurs and the principle of objectivity as well as the patient's critical thinking are lost.

### 5.4.2 Patient partner

The concept of patient partner was developed in Quebec from the idea of cooperation between patients and professionals<sup>36</sup>.

The concepts of "patient partners" and "care partners" are described as a cooperative relationship between the patient, his family and the health care professionals. A "patient partner" is a person who little by little is being trained throughout his care process to make health care decisions in a free and appropriate manner.

<sup>36</sup> Psychomédia. "Les patients partenaires" <http://www.psychomedia.qc.ca/sante/2019-05-21/patients-partenaires> Consulted on January 24, 2020.

Although he acknowledges the experience of health professionals, he focuses his concerns on his long-term needs and well-being. Around the patient partner emerges a very concrete discourse on the need for training and, inevitably, the need to integrate this highly specialized and prepared patient into the hospital staff. In the context of therapeutic patient education, the role of the patient partner is very emphasized, particularly in France and recently in Switzerland<sup>37</sup>.

### 5.4.3 Patient director

In the United Kingdom (Sussex)<sup>38</sup>, the experience of the "Patient director" has been tested with an executive role comparable to that of "Clinical director" or "Director of operations". The functions of the "Patient director" aim to ensure that systems, processes and culture focus on what is important to the people who use the services.

<sup>37</sup> Hôpitaux Universitaires Genève. 2019. Patients Partenaires. <https://www.hug-ge.ch/patients-partenaires> Consulted on January 24, 2020

<sup>38</sup> Patient leadership for real - The Sussex model for patient partnership 2018 <https://www.hsj.co.uk/patient-and-public-involvement/patient-leadership-for-real-the-sussex-model-for-patient-partnership/7022549>. Consulted on January 20, 2020.

## 6. CONCLUSION

The concept of patient experience (PX) has become increasingly important in the healthcare system in recent years. One of the fundamental elements of the Patient eXperience is the active participation of the patient and/or his/her family member in order to improve the health care system.

Patient participation is one of the essential conditions to guarantee the Patient eXperience, but it is not sufficient on its own to change the organisational culture of an institution.

Depending on each the experience lived by every patient concerning their own health, their point of view will be different, leading to different types of patients.

The method of selection and the representativeness of patients will vary according to the objective and the roles they are expected to play.

Concerning the administrative and legal aspects, it is important that the patient, the professionals and the institution define working and operating methodologies to be integrated by all parties.

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