



# Measuring Health Outcomes and Experiences from a Patient's Perspective

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<i>Foreword</i>	Francesca Colombo	5
<i>Chapter Zero</i>	Once upon a time... the patient's voice heard Anabela Coelho, Tânia Gaspar	6
<i>Chapter One</i>	Measuring value in healthcare from a patient's perspective Tânia Gaspar, Fábio Botelho, Anabela Coelho	8
<i>Chapter Two</i>	From the patients' point of view: OECD's PaRIS initiative on hip and knee replacement, breast cancer, and mental health PROMs and PREMs Candan Kendir, Katherine de Bienassis, Eliana Barrenho, Niek Klazinga, Michael van den Berg, Frederico Guanais	20
<i>Chapter Three</i>	Mental health patient-reported experiences and outcomes: Denmark's experience Jan Mainz, Simone Witzel, Solvejg Kristensen, Klaudia Kristensen	28
<i>Chapter Four</i>	Implementing patient-reported measures (PROMs and PREMs) in a public psychiatric hospital Elisabetta Scanferla	33
<i>Chapter Five</i>	Mental health patient-reported experiences and outcomes: Portuguese findings Patrícia Frade, Catarina Jesus	39
<i>Chapter Six</i>	Patient-reported outcomes for breast cancer: the Basque experience Ane Fullaondo Zabala	41
<i>Chapter Seven</i>	Patient-reported outcomes for breast cancer: the Portuguese findings Cátia Ribeiro, Joaquim Abreu de Sousa, Salomé Monteiro, Patrícia Redondo, Ana Bastos, Armanda Nogueira	44



## Foreword

Francesca Colombo<sup>1</sup>

The primary objective of health systems is to improve people's health and well-being. Yet, health systems today face significant challenges, ranging from delivering high-quality care to tackling inequalities in health outcomes, getting rid of ineffective care and investing more in health systems' resilience. Faced with those challenges, the ability to assess whether health systems are successful in delivering good health outcomes and experiences for the people they serve is critical.

Health systems are awash with data. There are good measures of what providers can do and the resources this takes – think of the many administrative data about healthcare activities, costs, inputs, outcomes measuring mortality, and incidence and prevalence of diseases. Yet far too little is known about how healthcare impacts the lives of people. This makes it difficult to gain insight into the effectiveness of the healthcare and to assess how policy change contributes to improvement in health outcomes.

In January 2017, Health Ministers met at OECD and requested the development of a new generation of health statistics to measure and benchmark patient-reported experiences and outcomes of health care. The PaRIS (Patient Reported Indicator Surveys) initiative was launched as a response to this call.

Measuring patient-reported outcomes and experiences in a standardized, systematic and scientifically rigorous way supports efforts to answer questions like: to what extent is healthcare delivering comfort and quality of life? Does healthcare enable people to live free of pain and manage symptoms effectively? Does it improve their ability to function and live independently? Measuring to what extent the

care patients receive affects these and other meaningful outcomes provide key information about the success of policies seeking to address the many health systems challenges brought by demographic changes, the rising prevalence of chronic diseases and multimorbidity, as well as the emergence of better, but also more expensive, medical technologies. It supports policy change towards truly people-centered care.

PaRIS will help policymakers understand how health systems best meet people's needs and measure what matters to them. A new international survey is measuring outcomes and experiences reported by patients, focusing on people living with chronic conditions managed in primary care settings. The results of the first wave of this survey will be ready in 2024. Furthermore, work is underway to benchmark patient-reported outcomes and experiences for hip and knee replacements, breast cancer, and mental health. Health at a Glance reports initial results.

This e-book “Measuring Health Outcomes and Experiences from a Patient's Perspective” offers insights from national experiences under the PaRIS initiative, measuring patient outcomes and experiences in Denmark, France, Portugal and Spain. Such initiatives are a step in the right direction to build a truly people-centered view of health system performance and improve health and well-being for all.

Paris, 7 December 2022

Francesca Colombo  
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## Chapter Zero

# Once upon a time... the patient's voice heard

Anabela Coelho<sup>1,2,3,4</sup>, Tânia Gaspar<sup>4,5,6</sup>

Once upon a time... a group of health professionals concerned about the silenced voice of their patients, decided to start a project to evaluate health outcomes from the patient's perspective.

And so, our story begins in Portugal in 2019, led by me and Tânia Gaspar, and under the precious guidance of colleagues from the OECD, as promoters of international working groups to support the strategic decision of the OECD countries, within the scope of the OECD PaRIS (Patient Reported Indicator Surveys) project, in specific areas such as patient-reported outcomes in breast cancer, surgery for hip and knee replacement and mental health.

Portugal decided to collect data in all these dimensions of analysis, in an experimental way, and actively participate in all the OECD PaRIS working groups.

The first outcomes in 2022 could not be better; more than 20 Portuguese hospitals engaged in consensus meetings and decided to apply the instruments proposed by the OECD; the publication of two papers published in international journals; the organisation of an

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international conference, held on 1 April 2022, under the topic “Measuring value in Healthcare from a patient's perspective” with more than 700 participants around the world; and finally, the publication of this e-book that systematize some of the work carried out by us and by some of our European counterparts.

We hope these readings turn into enthusiasm and a willingness to change our health paradigm. Quality in health cannot be, exclusively, a clinical success, in terms of diagnosis or treatment effectiveness; it should necessarily involve the patients' voice and their reflection about how the clinical result fits into their own lives and how they value the medical/surgical success.

Therefore, almost 75 years after the presentation of the WHO definition of health, where it is clearly mentioned that “Health is a

state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”, we cannot continue to monitor the health status of our populations through indicators measuring the burden of disease (or its dimensions of disability, mortality, or morbidity) while completely ignoring the other side of the coin regarding the “physical, mental and social well-being” dimensions.

Once upon a time... a group of health professionals concerned about the silenced voice of their patients, sought to make it happen in their countries, regions, and hospitals and we hope these experiences, conclusions, and results could inspire you to do the same.

Lisboa, 7 November 2022  
Anabela Coelho and Tânia Gaspar







## Chapter One

# Measuring value in healthcare from a patients' perspective

Tânia Gaspar<sup>1-3</sup>, Fábio Botelho<sup>2</sup>,  
Anabela Coelho<sup>3-6</sup>

## Management, quality and performance of health systems

The quality of health services is one of the central objectives of health systems. The assessment of health systems and their performance includes indicators such as access, equity, quality, safety, and health service costs (Ashton, 2015). Seven pillars of health quality can be identified: 1) efficacy; 2) efficiency, 3) effectiveness; 4) adequacy/optimization; 5) conformity/acceptability; 6) legitimacy, and 7) equity. The assessment of the quality of health organizations, from a systemic perspective, should take into account various fundamental concepts, such as leadership, strategy, plans, patients, society, information and knowledge, people, processes, and results. The strategic management process with a view to quality and better health performance consists of six stages: 1) diagnosis or analysis of the influences of stakeholders, the strategic intention of the organisation, and analysis of the external and internal environments; 2) formulation or definition of the plan and strategic options; 3) implementation, of the strategy through the action plan; 4) control and monitoring of strategic performance through indicators; 5)

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feedback, that is, necessary changes and adaptations in the strategic trajectory; 6) learning, development of processes and practices that promote organizational learning in strategic management (OECD, 2017; 2020a; 2020b).

The World Health Organization (WHO, 2014) presents management functions in health services, such as policy and planning, financial management and planning, human resources management and planning, governance and evaluation, management and planning of service delivery, and information and performance management. For the quality management of health organisations, an account of quality assurance, accreditation, patient satisfaction and safety, waste management and monitoring and evaluation of service quality, risk management and organisational supervision climate and support should be taken. At the management level, health organisations need balance in four fields: 1) ensuring an adequate number of managers at all levels of the health system; 2) ensuring that managers have adequate skills; 3) creating a system of support and support of management; and 4) creating adequate conditions in the work environment. These four conditions are closely linked and should be strengthened as a whole. Solutions to understand and improve the quality, cost and accessibility to a health system that includes only one or two components of the system are not enough. The nature of the health system needs to be reformulated by

creating a value-based results competition, including healthcare professionals, health plans, patients and consumers, suppliers and the government. The literature argues that the reform should involve the transformation of strategies, organizational structure, financing approaches and evaluation of the practices of the various actors of the system (Ashton, 2015; Braithwaite et al., 2020; Porter, 2006). In this sense and according to the theory of systems, patient safety and the quality of health services are priority properties of the health system, and consequently, to improve the results of the health organisation, a systematic assessment of the entire system that contributes to these results should be carried out (Ukawa, Tanaka, Morishima, & Imanaka, 2015).

Like other systems, the health system is based on two sets of concepts: emergence and hierarchy; control and communication. The health system consists of different hierarchies, namely patients and the community, health organisations (hospitals, health centers, etc.), accreditation systems, and government. Bradley, Taylor and Cuellar (2015) identify eight fundamental competencies for strengthening health system management: 1) strategic thinking and problem-solving; 2) human resources management, 3) financial management, 4) operational management; 5) performance management; 6) governance and leadership; 7) political analysis and communication; 8) evaluation and involvement of the community and the patient (Table 1).



**Table 1. Management competencies that strengthen health systems (Bradley, Taylor & Cuellar, 2015)**

Competence	Description
Strategic thinking & problem-solving	Ability to set a goal (SMART*) and align resources to solve problems to achieve organizational goals.
Human Resource Management (HRM)	Recruitment and retention, education and training, compensation, labour relations, performance evaluation and leadership support.
Financial management	Budgeting with variable analysis, project accounting and capital evaluation.
Operational management	Patient registration, medical records, bed management, theatre management, care management, infection prevention, supplier management, information technology and patient process (admission, treatment, discharge)
Performance management and accountability	Logic model, process and outcome measurement, quality improvement and accountability systems.
Governance and leadership	Create enabling environments, develop governance activities, develop organisational and corporate culture, ensure succession planning.
Policy analysis and communication	Understand policy and regulatory environments, create compensation policy, conduct stakeholder engagement, and needs analysis.
Community and patient assessment and involvement	Epidemiology, research based on community participation, health education, understanding the patient, and having a patient-oriented service.

Note: \*SMART (Specific, Measurable, Assignable, Realistic, and Time-bound).

Human Resources Management in health organizations has three main objectives: 1) efficiency: achieved through, for example, subcontracting of services and professionals, performance-based contracts, 2) equity: by increasing financial protection mechanisms, identifying risk groups, and readapting services, and 3) quality and patient satisfaction: increasing acceptability and meeting patients' expectations. Some barriers can be identified in the quality of health services, related to budgets disproportionate to costs, lack of congruence between the values and indications of different stakeholders, high rates of absenteeism, and turnover of health professionals (Zurn, Poz, Stilwell, & Adams, 2004).

With the rapid development of information technology, the population is better informed

about their diseases and the possibilities of treatment linked to pharmaceutical and technological developments. Consequently, patients start to take a more active role, rather than just passive receptors of health services. A natural tendency is to expand the patient's ability to choose in the selection of health organization and physician, but also the expansion of the patient's rights and the facilitation of patient involvement in the prevention, treatment, monitoring, and development of services, emphasizing integrated and patient-centered care. Changing the role of the patient is one of the factors that affect the functioning of health services. Other factors are the aging of the population and changes in the composition of the population's health. An increasing number of older people not only mean that the provision

of health services increases but also affects the types of services performed (continued care, etc.). Similarly, lifestyle changes introduce new challenges in the health area, as is evident by obesity, and are now one of the main emerging challenges in developed countries (WHO, 2016). In the light of a systemic perspective, we will cover macro challenges at the political level, governance challenges related to human resources, patients and other factors relevant to the quality of health systems, so the government should address the population's health problems with quality, social justice and equity and should improve the sustainability of the system to prepare for the future, with very good professionals and adapted to health, economic, technological and social challenges. By making the population healthier and professionals more prepared the system becomes more resilient and more capable of facing challenges.

### **Health organisations and patient-related challenges**

Good governance positively affects the performance of the health organisation and is a necessary condition for sustained economic, social and human development. Hospitals are organisations with very complex management, which results from the diversity that involves government, administration, multidisciplinary professionals in interaction, patients, suppliers and others. Hospital organisations make intensive use of their resources (human resources, capital, technology, and knowledge) with the responsibility of providing direct health care, as well as in the promotion and protection of health. Hospital governance as the set processes and tools related to decision-making regarding the direction of institutional activity influences organisational behaviour and complex relationships between all stakeholders.

The principles of good governance of health systems are organized on three levels: 1) fundamental values, such as democracy, human rights, ethics, integrity, the public good, the rule of law and control of corruption; 2) strategic values,

such as the strategic vision of policies, participation, partnerships, consensus orientation, adequacy of organisation, regulation, transparency, equity and inclusion and production of information; and 3) values related to results, including effectiveness, efficiency, equity, quality of responses, sustainability, protection of financial and social risk, improvement in health, accountability/accountability for results (OPSS, 2018). At the level of hospitals and primary health care, there are great inequities in access to quality health in different regions and communities.

The citizen must be at the center of the system. The population that the SNS serves has been undergoing changes and can be characterised by an aged population with a low fertility rate. There is an increase in chronic non-communicable diseases, often preventable diseases such as diabetes, obesity, and some types of cancer disease, which in most cases result from the lifestyle and health behaviours of the population and increase morbidity and mortality and decrease quality of life. Citizens have new health needs, have greater access to information, are apparently better informed and are more demanding in care and decision-making. In this sense, it becomes a challenge to empower citizens, promote health literacy and prevent disease (Bleich, Ozaltin, & Murray, 2009). The NHS should contribute to promoting well-being, and improving positive social and working conditions for people's development and the economy. One aspect to improve is the quality and safety of the patient. In this context of ageing, continued care, for example, is a key response to providing short-term care to people with functional disabilities that greatly affects the elderly population. In Portugal, the National Integrated Care Network (RNCCI) should increase response capacity, in terms of the increase in vacancies and the recognition and support of informal caregivers (OPSS, 2018).

### **Quality management of health organizations: the cycle of value**

Global health systems are at increased costs and quality decrease/iniquity. Politicians try to outline

regulations, make patients better consumers, improve the information and technology system, combat fraud, reduce errors, etc., but none of these initiatives has had the necessary impact.

According to Porter (2010, 2014, 2017) Health Systems need a new strategy. This involves maximizing the value for patients, and consequently for the whole system, which will lead to better results at the lowest cost. The first step is to move from a system that is organized around health professionals and move to a system centered on the patient and their needs. The focus should not be on the volume and profitability of the services provided by health professionals, such as hospitalisations, procedures, complementary diagnostic tests, etc. but rather on the results that patients achieve. The fragmented health system today should be replaced by a highly specialized and centralised system. Instead of each health organization providing the full range of services, there should be specialised services for certain health conditions, and this will result in a high-value health provision.

Michel Porter (2010, 2014) calls this progressive strategy the Value Agenda, a process of restructuring the organisation, evaluating and financing of the provision of health services. The implementation of this new strategy is ultimately related to how health care is provided, so all health system stakeholder has a role to play, patients, managers, professionals, suppliers, insurers, etc. Some health organisations are already implementing this new strategy and there are improvements in results, efficiency and market growth. The value agenda can be characterised by several components: goal setting, integrated health systems, measurement of important outcomes for patients, measurement of care costs, funding for care cycles, a technological platform for patient information and improvement of the quality of health care. To determine the value, organisations must measure costs at the level of health condition, collecting all expenses incurred in treatment throughout the care cycle. This measurement lacks to understand and

identify the resources used to provide care to patients, such as professionals, equipment, and facilities, as well as the ability to store resources and the ability to bear care costs (e.g. technologies). Only after this measurement of care costs can you compare with the results achieved (Porter & Lee, 2013; Porter, & Teisberg, 2006).

Michel Porter (2014) suggests that the best way to measure costs is through time-driven activity-based costing (TDABC), the use of this method allows health organisations to reduce costs without negatively affecting outcomes (sometimes even increasing results), through greater capacity utilisation, more standardised processes, better articulation between the tasks and skills of professionals, centralization of services in an organization that carries greater cost-effectiveness, among others. If health organisations do not have information on costs per patient with a given condition, and how much these costs are related to outcomes, they do not have the basic information to improve processes and redefine care strategies. Health organisations and professionals are faced with arbitrary cuts rather than working together to increase the value of care to the needs of patients, a key objective of health organisations. In general, funding is carried out taking into account medical acts/treatments/examinations, etc. Funding is carried out by volume and not by increasing the value of care. The costs depend on the resources (human resources, facilities, examinations, procedures, materials, etc.) involved in the patient care process, namely the time dedicated to the patient for each of the resources. A funding model that assesses cost based on the patient should focus on the treatment cycle of a chronic disease e.g. (a one-year period), or in the case of primary health care, by accompanied patient/year. This funding model encourages teamwork and high-value health care. In this way, the organization knows what value it can count on, and everyone benefits from improving efficiency and maintaining or even increasing results. This financing model should include adjustments linked to the severity of certain conditions,



guarantees of care to avoid complications, stock management and mandatory reporting results (Porter, 2017; Porter, & Lee, 2013; Porter, & Teisberg, 2006).

The development of a technological platform for patient information as a tool for communication and monitoring of the patient, creator of value, as well as improving the quality of health services are powerful ways to reduce costs and improve value. Quality can be assessed by analysing health outcomes, namely disease prevention, early diagnosis, correct and rapid diagnostic cycle, appropriate treatment for a specific patient, less evasive treatment methods, fewer complications, fewer errors and repeated treatment, faster and more functional recovery without the need for long-term follow-up, fewer acute relapses and episodic, and slower disease progression. Better health is the goal, not more treatments. Better health has fewer costs than poor health. Quality assessment may include evaluation of processes, in particular by identifying the level at the hospital follows good practices in treatments in certain health conditions. In these cases, the higher the result, the higher the quality. However, often the evaluation of hospitals is based on the number of readmissions and deaths, for these measures, on the contrary, the higher the measure the worse results and quality. Many of these results are based on ineffective care in the treatment performed in the hospital and in the post-hospital period (Doyle, Graves, & Gruber, 2017; Duggan, Gruber, & Vabson 2015).

Promoting quality health care and creating value is the main objective of health systems. Creating value is the goal that must unite all elements of the system. Health systems are rapidly and constantly changing dynamic systems. The patient must be at the center of the system. Patient freedom of choice and patient value-based competition is key to health system reform in all countries. Improving value is the solution to reforming health systems, the opposite will be to increase costs for patients, restrict care and increase inequity, and reduce costs for healthcare professionals (Porter, 2013).

Michel Porter (2010, 2014, 2017) argues that a value-based healthcare delivery system should be created. This new system is based on six actions: 1) organising care in Integrated Practice Units (UPI) focused on patients' medical conditions, which reduces obstacles to the integration of care, and introduces standardised certification at the level of multidisciplinary teams, throughout the patient care cycle, and care management; 2) measuring results and costs for each patient, creating a national structure for recording and evaluating health outcomes for specific health conditions, linking funding to the reported results, and introducing accounting for standardised costs that measure the resources used per patient; 3) funding per patient care cycle, hospitals by health condition and primary health care per patient; 4) integrated health delivery in different health organisations/structures (partnership between organisations with lower volume levels with qualified centers with high volume and excellent and complex care); 5) increase high quality UPIs; 6) create and boost a technological information platform, in order to establish common language and procedures, facilitate the extraction of results, processes and costs and assess the quality of health systems. According to the author, a value-based healthcare delivery system can be applied to all health systems and in all countries, should involve all health system stakeholders (patients, managers, professionals, suppliers, health plans, etc.) and leads to improvements in results, efficiency and market increase.

### Results of health system management

The definition of objectives, goals, and results to be achieved by health organisations should include all their complexity and diversity. The evaluation of results in health systems at the global level is faced with several barriers, including coordination between organizations and health levels, ensuring patient safety, increasing costs, often with high levels of waste, and stagnation or decreased productivity and inconsistent scientific evidence (Kaplan et al., 2013). This last aspect is the importance of the need to invest and innovation and collaboration between organisations and the

research and development unit (Day-Duro, Lubitsh, & Smith, 2020).

If health organizations are only focused on health problems, this is clearly one of the determining factors for rising costs and can adversely affect the quality of care and care provided. If we redefine health in terms of patient-centered goals and their health experience, healthcare can focus more directly on meaningful outcomes, reducing the number of unnecessary tests and treatments for example. Greater emphasis would be placed on prevention, indispensable activities, early guidelines and personal growth and development. The role of patients in doctor-patient relationships would be more positive, strengthening therapeutic relationships. Reshaping health systems in terms of health-related objectives and not just disease and targeting the health system to help people achieve it can improve quality and reduce costs. The process could also make health care more humanized (Mold, 2017).

The results of health organisations should include indicators of financial economic performance and resource management, professional satisfaction and patient satisfaction, communication, and articulation between different levels of care and sectors, including social, education and justice (Ministry of Health, 2018).

The World Health Organization (WHO, 2016) stresses, at the level of health management, the lack of coordination between health services and organizations, between the ministry of health and other ministries and at various levels of government. The need for continuous process innovation and market competitiveness to maintain patient satisfaction and loyalty are growing concerns of health systems and a challenge in the management of organizations. Management requires autonomy to cope with the necessary adaptation in the management of the diversity of health professionals, patients, and socio-economic and cultural changes. Health, understood from an ecological perspective, considers the inner influence of social, cultural,

environmental, economic, and political factors, considering individual, interpersonal, organisational, and societal variables (Early, 2016).

The hierarchies that exist among health professionals are the greatest barriers to effective work among health teams. McMurtry (2007) argues that health professionals should have a more humanistic and holistic view of the patient, abandoning a purely biomedical perspective. This should be contemplated in the training of health professionals. Communication and teamwork between different professionals are other challenges that can bring more and better solutions in terms of health care. Different professionals must promote relationships, communication and adapt their contributions to each other. Members of multidisciplinary teams should unify as a team and identify as a team a global goal for the patient. Conditions necessary for effective teamwork can be identified, including respect for the individual contribution of each professional to the whole, considering that each professional area has its knowledge, skills and specialties that must be at the service and contribute to the whole and that members can learn from each other through good practices and their mistakes. A systemic approach requires greater inter-professional and inter-sectoral collaboration (Clarkson et al., 2018; Early, 2016).

Some changes must occur to achieve effective teamwork. However, changes must be made at various levels, for example, changes must occur at the individual level by professionals and managers (micro), and should be verified at the meso level, at the level of the health organisation by its values and principles. Changes at the micro and meso level can catalyse changes that must occur at the macro level, in the health system and in society. Another concern is the incidence of harm to patients. Patients may suffer a variety of damage in their interactions with the health system, especially in critical and complex environments (e.g. hospitals in times of flu epidemic) and in different health services/organisations (e.g. hospitals, health centres, palliative care, etc.). There are barriers to

addressing patient-centred care, including patient care, clearly explained information, treatment with respect and availability for their care and health concerns. The difficulties experienced by patients are not only explained by the attitude of professionals, nor by the resources available, one must take into account the management and culture of the health organization (Pham, Frick, & Pronovost, 2013).

Health systems are complex and constantly changing and challenged. For example, new technologies enable more effective registration in health organisations and facilitate the complex information management process. However, for new technologies to be a positive contribution to quality, safety and costs, technological interventions need implementation, implementation and coordination. Otherwise, they can work negatively, making processes inefficient. Promoting unnecessary tasks, overloading professionals and leading to errors and safety issues for patients. Significant and sustainable improvements require a reconfiguration of the environment, systems and processes related to healthcare practice. The theory of systems applied to health organisations can have several implications, namely in terms of patient safety and disease prevention, improving coordination and communication among team members, managing the complexity of biomedical evidence, diagnoses and treatments and continuous improvement of care provided. Systems theory applied to health organisations can reduce problems in the planning, implementation and evaluation of care practices, and promote safety, quality and value. It allows an understanding of the factors that influence health outcomes, models of the relationship between factors and adapting processes and policies based on evidence, with the overall objective of producing better health at lower cost. It should be noted that, on the one hand, since the health system is not the only one that is related to improvements in health, it is essential to integrate all systems and subsystems that influence health. On the other hand, the optimization of only one component of the system does not necessarily imply the

optimization of the results of the whole system (Kaplan et al., 2013).

### Patient satisfaction

Patient satisfaction has been considered a key result in measuring the quality of health services and reforms in the health system have been developed to put the patient at the center (Perera, & Dabney, 2020).

The ageing of the patient population is a factor highlighted as a challenge for health organisations and professionals. Patients are more demanding in understanding and involvement in procedures. The type of funding and care provided does not explain much patient satisfaction (WHO, 2015). Satisfaction with the health system and health experience explains about 10% of the degree of patient satisfaction. Other factors that influence satisfaction are identified, including patient expectations, patient health status, patient mental health and personality (Zhang, Rohrer, & Farrell, 2007).

Patients today as health consumers expect from the health system what they expect from any other service, i.e. a high-quality service with added value, convenience, suitability and respect (Kash, Spaulding, Johnson, & Gamm, 2014; Kennedy, Caselli, & Berry, 2011). Sometimes patients bring unsuitable expectations, including exams, prescriptions and other clinically unnecessary services. Patients tend to be more satisfied if these expectations are met by health professionals. Health professionals adopt an assertive attitude and consultations with sufficient time to expose and reflect with patients their concerns, increasing patient satisfaction in addition to improving other outcomes (Otani, Chumbler, Judy, Herrmann, & Hurz, 2015). The relationship between the patient and the health professional is an important indicator of their satisfaction, particularly in terms of empathy, availability and sympathy (Griffith, 2015). The organisation, professionals and patients would benefit from the implementation of organisational measures to promote health literacy (Meggetto, Kent, Ward, & Keleher, 2020).

Patient satisfaction is related to the quality of care that is reflected in the maintenance or improvement of health and respect for the needs and values of patients. Patient-centered care is essential for quality for two reasons. On the one hand, it is intrinsically important because patients have the right to be treated with dignity and respect when they use health services. On the other hand, it is instrumentally important, since person-centered care is associated with better use of health services and health outcomes. Two categories of patient-centered quality of care measures should be considered: patient experience (interactions with the health system) and patient satisfaction (assessment of care provided in relation to their expectations) (Larson, Sharma, Bohren, & Tunçalp, 2019).

According to the study conducted by Gaspar (2020) patient satisfaction is an important objective of health organizations. Factors that contribute to patient satisfaction are identified, such as trust, communication and positive experience/connection to the professional and organization. They point out that patients may have different needs taking into account their illness, treatment phase, schooling, etc. Regarding the patient's satisfaction, this varies depending on the time of the disease/treatment in which it is made. To have a more accurate assessment should always be done at the same time or that aspect be commemorated. Patients' satisfaction is a fundamental objective. We are focused on patient satisfaction; the organisation and professionals should provide the patients with a positive experience. Trust in the technical competence of professionals is the most important factor for their satisfaction. Empathic communication and active listening on the part of professionals greatly influence patient satisfaction. In certain pathologies, particularly in oncologic disease, communication and the relationship of familiarity established with the patient and family is key to the perception of satisfaction. The patients do not only need technical skills, their experience and satisfaction are influenced by the feeling that he is the centre of attention. The most important variable for patients' satisfaction is trust, linking the link is

fundamental for the patients to be satisfied. It turns out that different patients have different needs, depending on age for example. Patients are very heterogeneous, and several factors influence their satisfaction, namely age, education, nationality, pathology, the frequency with which they use services, what they value most in services, such as care, waiting time, physical conditions, infrastructure, etc., health experience, etc., if they have insurance, and where they collect information on health-related issues. In general, patients consider having a positive health experience. The five areas that are associated with a less positive experience are related to waiting times and the involvement of patients in decisions, and also to the understanding of the information transmitted by the doctor. The vast majority of patients felt well attended, and comfortable in the care, reported that the professionals gave them the opportunity to clarify doubts and had no problems access in the consultations due to lack of transportation. There are no significant differences in gender, or age in relation to the patient's experience at the level of overall or in their dimensions, experience of general care and experience in access and economic and financial issues. The assessment of experience is influenced by the patient's health situation, patients with good and reasonable health report a more positive overall experience than patients with worse health (Gaspar, Domingos, & Matos, 2017).

In the study conducted by Coelho et al. (2022) on the value of satisfaction and well-being of patients with mental health problems, it was found that in general patients are satisfied with the experience, relationship with professionals and care outcomes. However, the study identifies factors that need improvement in promoting better patient satisfaction and health, notably in relation to care providers spending enough time with patients and care providers explaining things in a way that was easy to understand.

The OECD (2021) encourages countries to systematically adopt the monitoring of indicators

related to Patient-Reported Outcomes (PROM) and Patient Reported Experience (PREM) to assure that local institutions, regions, or countries can use information collected for strategic and analytical purposes, supporting macro decisions at the level of health policies, but also meso and micro-decisions at the level of quality and safety of healthcare provision and good clinical practices. Finally, harmonised data collection and reporting practices at the national level can be used for the purposes of international benchmarking (Coelho et al., 2022).

In conclusion, patient satisfaction should also be understood from a multidimensional

perspective. It is influenced by the relationship with the health professional, the general conditions of care and the health organization, as well as, with the patient's health condition, by their expectations, health literacy and socioeconomic and cultural factors (Otani, Chumblor, Judy, Herrmann, & Hurz, 2015). Patient satisfaction has been increasingly important in the quality of health services provided, as well as in reforms in the health system (Braithwaite et al., 2019). The paradigm of patient-centred care increases patient satisfaction and leads to better health outcomes (Gaspar, 2020; Larson et al., 2019; Porter, 2010, 2014, 2017; Perera, & Dabney, 2020).

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## Chapter Two

# Measuring value in healthcare from a patients' perspective

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## Introduction

Patient-reported measures are critical tools to improve quality of care and people-centredness of health systems. Standardised data on patient-reported measures can provide meaningful information on how health care, and its underlying policies, actually affect the lives of patients, while simultaneously allowing policymakers to explore areas for improvement and investment. Harmonising the process for collecting and reporting patient-reported measures on an international level is a tool for identifying opportunities to improve health systems structures and policies, as well as, fostering international learning and exchanges.

At the 2017 OECD Health Ministerial, international leaders in health care called on the OECD to lead further efforts to make health systems more people-centred. In response to this mandate, the OECD launched the Patient-reported Indicators Surveys (PaRIS) initiative in order to measure to what extent health systems are delivering meaningful patient outcomes.

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The OECD PaRIS initiative consists of two work pillars: 1) upscaling existing patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) data collections for hip and knee replacement, breast cancer, and mental health; and 2) developing a new international survey of PROMs and PREMs of people living with chronic conditions who are managed in primary care. This paper focuses on the former.

The OECD PaRIS condition- and procedure-specific working groups—hip and knee replacement, breast cancer, and mental health—were established to harmonise, and accelerate the uptake of existing patient-reported indicators, as well as advance new standards for patient-reported measures and maximise international comparable reporting. OECD co-leads the groups in collaboration with the Canadian Institute of Health Information (CIHI), Kronikune Institute of Health Services Research in the Basque Country (Spain), and officials from Denmark, respectively for the hip and knee, breast cancer, and mental health working groups. The co-leads assist the groups via technical support, and the OECD supports the coordination and activities of the working groups. The working groups consist of experts nominated by the Working Party for Health Care Quality and Outcomes (WP-HCQO)<sup>1</sup>, the governing body of work on Health Care Quality and Outcomes while the Health Committee<sup>2</sup> composed of official country delegates, and provides strategic direction to the overall work.

The working groups undertook data collection between 2020 and 2021 on PROMs for Hip and Knee and Breast Cancer working groups (second pilot data collection), and on PROMs and PREMs for the Mental Health working group (first pilot data collection). This chapter provides an overview of the results and provides directions for future discussions on PROMs and PREMs.



<sup>1</sup> Working Party for Health Care Quality and Outcomes (WP-HCQO) is composed of delegates from OECD member countries and overseeing the OECD's work regarding Health Care Quality and Outcomes.

<sup>2</sup> The OECD Health Committee is the governing body of the OECD composed of country officials and overseeing the overall work of the OECD Health Division.



## Methodology

Data from adult patients undergoing elective hip or knee replacement surgery with a principal diagnosis of osteoarthritis were collected to inform the work of the PaRIS Hip and Knee working group. Following the guidance provided by the OECD, countries/sites reported data for patients who completed, pre- and post-operatively, a condition-specific instrument

as applicable, among OHS, OKS, HOOS-PS and KOOS-PS and one generic instrument, either the EQ-5D or the SF-12 (SF-12v1 and SF-12v2) (see box below). Pre-operative measurement was done within eight weeks of surgery while post-operative measurement was either 5-8 months or 9-18 months after surgery. Data collection guidelines for Hip and Knee PROMs were published elsewhere (CIHI; OECD, 2019) (Kendir et al., 2022).

### OECD PaRIS Hip and Knee Replacement PROMs Condition/procedure-specific PROMs for Hip and Knee Replacement

**The Oxford Hip/Knee Score (OHS/OKS)** is a short 12-item patient-reported outcomes scale that assesses function and pain with patients undergoing hip replacement surgery. The scale ranges from 0 to 48 points with 0 being the worst outcome (severe arthritis) and 48 the best outcome (satisfactory joint function).

**The Hip disability and Osteoarthritis Outcome Score- Physical function Shortform (HOOS-PS)** is a 5-item questionnaire on the level of function in performing usual daily activities and higher-level activities. Items are coded from 0 to 4, none to extreme, respectively. The HOOS-PS questionnaire is scored by summing the raw response (range 0-20) and then converting the raw score to a true interval score (0-100).

**Knee injury and Osteoarthritis Outcome Score- Physical Function Shortform (KOOS-PS)** is a 7-item questionnaire on the level of function in performing usual daily activities and higher-level activities. Item responses are coded from 0 to 4, none to extreme, respectively. The questionnaire is scored by summing the raw response (range 0-28) and then converting the raw score to a true interval score (0-100).

### Generic PROMs

**12-item Short Survey (SF-12)** is a shortened version of SF-36 that covers eight domains: 1) limitations in physical activities because of health problems; 2) limitations in social activities because of physical or emotional problems; 3) limitations in usual role activities because of physical health problems; 4) bodily pain; 5) general mental health (psychological distress and well-being); 6) limitations in usual role activities because of emotional problems; 7) vitality (energy and fatigue); 8) general health perceptions. Two summary scores are reported from the SF-12 – a mental component score (MCS-12) and a physical component score (PCS-12). Summary scales are scored using norm-based methods.

**EQ-5D-5L/EQ-5D-3L** is a self-reported instrument on five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/ depression) in three or five severity levels from no problems to extreme problems. The visual analogue scale (VAS) records the patient's self-rated health on a vertical visual analogue scale, where the endpoints are labelled 'The best health you can imagine' and 'The worst health you can imagine'. More information can be found in the following document by clicking the following link: <https://www.oecd.org/health/health-systems/OECD-PaRIS-hip-knee-data-collection-guidelines-en-web.pdf>



Countries and sites reported data using the Breast-Q tool to measure and capture the outcome data for breast cancer care. OECD data collection guidelines focused on two modules of the tool – the post-operative Breast Conserving Therapy and Reconstruction modules, where the surgery was performed

within a specified 12-month period and the measurement was taken between 6-12 months after the surgery. Data collection guidelines and analysis of Breast Cancer PROMs were recently published in a technical report (Kronikgune; OECD, 2022) and reported in Health at a Glance 2021 (OECD, 2021).

### OECD PaRIS Breast Cancer PROMs

The **BREAST-Q Breast Satisfaction Module** is a patient-reported outcome measure designed to evaluate outcomes among women undergoing different types of breast surgery. Items cover breast appearance such as size, symmetry, softness, implant placement, and cleavage), and satisfaction with breasts in relation to how a bra fits and how the breasts look when clothed or unclothed. For reconstruction with an

implant, there are also items specific to implants such as rippling and postoperative issues such as scars. The responses of the patients are transformed into scores that range from 0-100. The scores are computed by adding the response items together and then converting the raw sum scale score to a score from 0-100. A higher score means greater satisfaction (Pusic et al., 2009).

WHO-5 and two OECD well-being core questions were used to measure PROMs for mental health. An adapted set of items from the OECD Guidelines on Patient Experiences

with Ambulatory Care were used to measure PREMs. Details of data collection guidelines were published elsewhere (Bienassis et al., 2022).

### OECD PaRIS Mental Health PROMs and PREMs

#### Mental Health PROMs

OECD Well-being Core Questions are two questions of patient-reported outcomes on satisfaction with life as a whole and the worthwhileness of life. Patients respond to a scale from 0 to 10 with 0 being not satisfied/worthwhile at all and 10 as completely satisfied/ worthwhile. A higher score means better well-being.

WHO-5 Score is a 5-item questionnaire on well-being such as feeling cheerful, feeling calm and relaxed, feeling active and vigorous, feeling fresh and rested in the mornings, feeling that daily life is filled with interesting things. The scale ranges from 0 to 5 with 0 being at no time and 5 at all the time. A higher score indicates better mental health and wellbeing.

#### Mental Health PREMs

In 2017 the OECD published an OECD-proposed Set of Questions on Patient Experiences with Ambulatory Care (Fujisawa and Klazinga, 2018). Based on Mapping the domains of interest from the working group, three items were recommended for inclusion. One additional item, not included in the OECD-Proposed Set of Questions on Patient Experiences with Ambulatory Care, on courtesy and respect, adapted from the Commonwealth Fund Questionnaire, was also recommended for inclusion. As of 2020, the item on respect and dignity has since been added to the HCQO bi-annual data collection as well.

**Results**

Results of the data collection have been reported in Health at a Glance 2021 (OECD, 2021[6]). Additional technical reports have been released for each working group, detailing further analyses and discussion (Bienassis et al., 2022; Kronikgune; OECD, 2022; Kendir et al., 2022 ). This section provides an overview of key results on PROMs and PREMs for the respective measurement areas.

Results from hip and knee working group,

adjusted for age, sex, and pre-operative score, show similar improvements as measured by PROMs for hip surgery across registries from 20.1 in the Netherlands to 23.9 in Ireland with the Oxford Hip Score<sup>3</sup> (Figure 1). The HOOS-PS<sup>4</sup> scale demonstrates a similar average change in score from 31.3 in Italy-Galeazzi to 35.1 in the Netherlands. Concerning knee surgery, Figure 2 shows slightly lower improvements between 16.1 in Australia and 20.5 in Finland-Coxa on the Oxford Knee Score.<sup>3</sup> KOOS-PS<sup>5</sup> also demonstrates an average of 18.5-23.0 improvement in score pre- and post-operative knee replacement surgery.

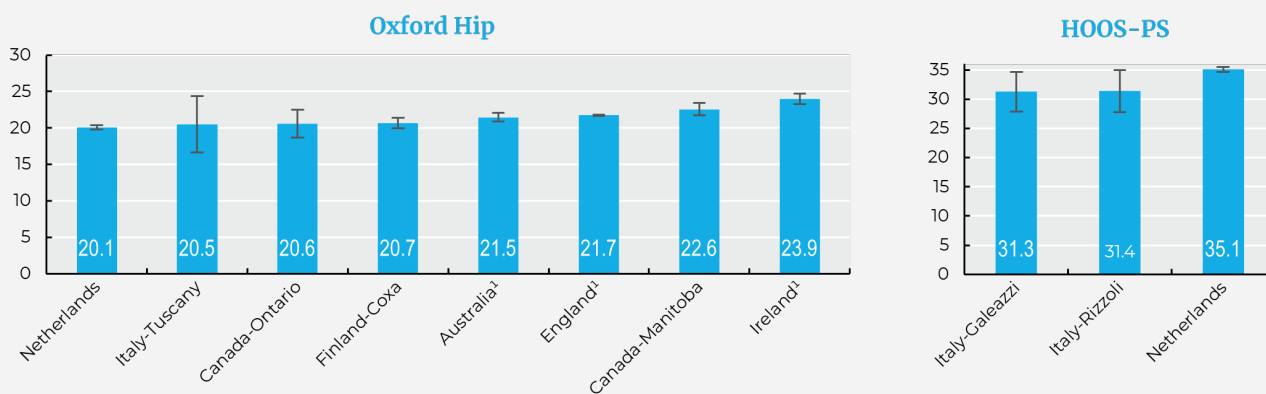


Figure 1. Adjusted mean change between pre- and post-operative Oxford Hip Score and HOOS-PS, 2014-20 (or nearest year).

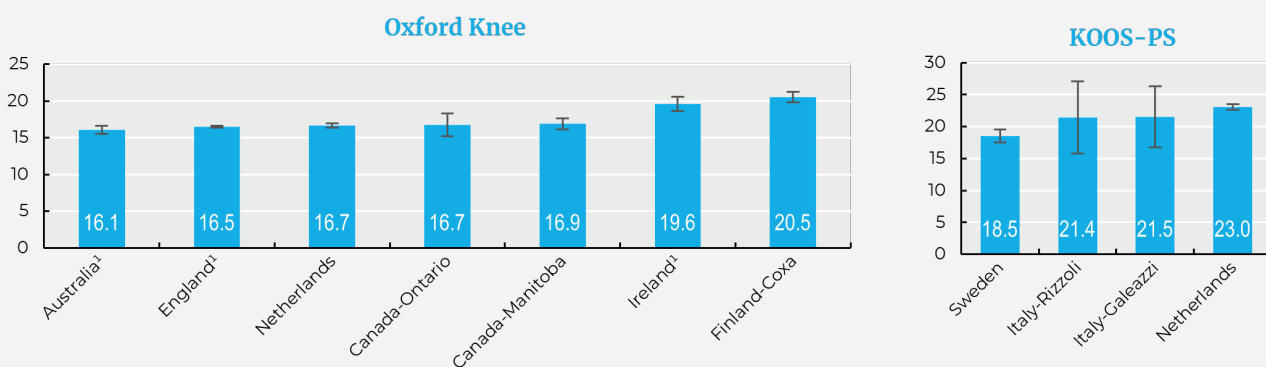


Figure 2. Adjusted mean change between pre- and post-operative Oxford Knee Score and KOOS-PS, 2014-20 (or nearest year).

Note: <sup>1</sup> post-operative collection at 6 months (all others at 12 months); Scales: Oxford 0-48; HOOS-PS 0-100. H lines show 95% confidence intervals.

<sup>3</sup> Oxford Hip/Knee Score: a short 12-item patient-reported outcomes scale that assess function and pain with patients undergoing hip replacement surgery.

<sup>4</sup> HOOS-PS: a 5-item questionnaire on level of function in performing usual daily activities and higher-level activities.

Fifteen sites from 11 countries submitted data to the OECD PaRIS Breast Cancer PROMs data collection in 2020-2021 and results from 10 sites were published in the Health at a Glance 2021 (Figure 3). Overall, patients following breast-

conserving therapy showed higher levels of satisfaction (74 points) than patients with reconstructive surgery (58 points). Outcomes were measured using the relevant postoperative breast satisfaction scales from the BREAST-Q tool<sup>6</sup>.

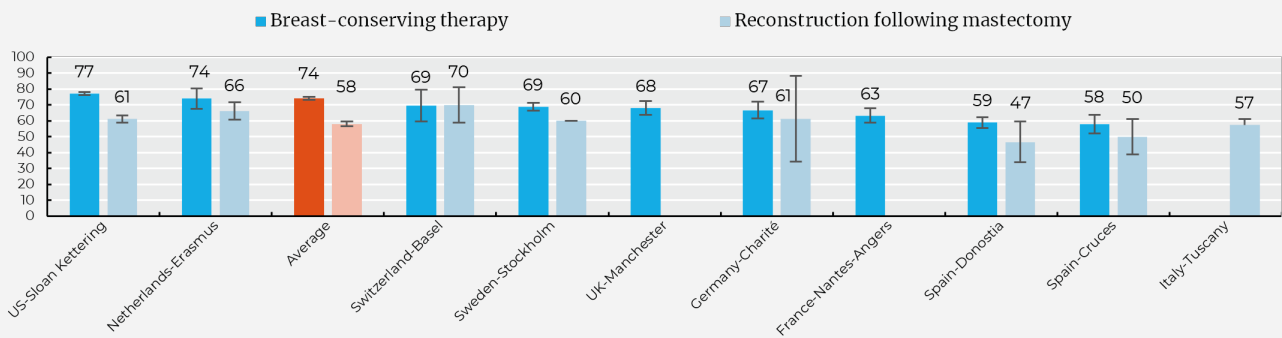


Figure 3. Self-reported breast satisfaction: Crude scores 6-12 months after surgery, 2020-21.

Note: H-lines show 95% confidence intervals. Weighted average based on site sample size was used to calculate crude average breast satisfaction. Data labels at the base of the histogram refer to the sample size at each site. Source: OECD PaRIS Breast Cancer PROMS Pilot Data Collection 2021.

The percentage of people with mental health conditions who reported being treated with courtesy and respect was slightly higher for community service users (87%) than for inpatient service users (85%) (Figure 4). Results from Portugal, Korea-Seoul, and Ireland show a better experience for inpatient service users as

compared to community service users whereas results from Australia (public and private) and New Zealand show higher rates of stratification among community health service users. Overall, rates are high, and on par with findings assessing the experience of patients receiving ambulatory care services.

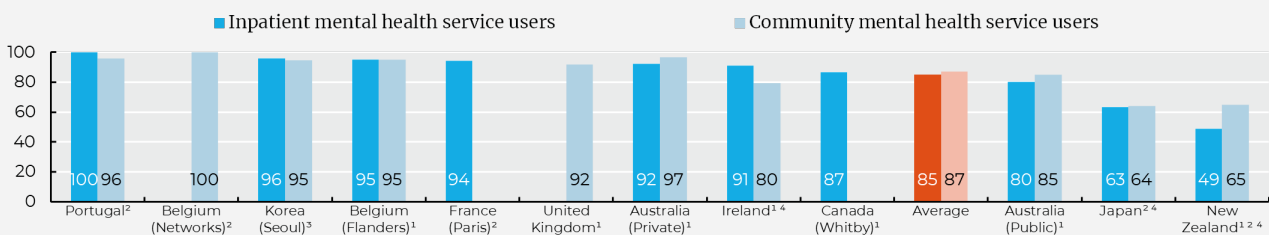


Figure 4. Share of inpatient and community mental health service users who reported to be treated with courtesy and respect by care providers, 2021 (or nearest year).

Note: <sup>1</sup> Information mapped from existing survey program. <sup>2</sup> Sample size between 500-100. <sup>3</sup> Sample size smaller than 100. <sup>4</sup> Web-based survey. Source: PaRIS Mental Health Pilot Data Collection 2020-2021.

<sup>5</sup> KOOS-PS: a 7-item questionnaire on level of function in performing usual daily activities and higher-level activities.

<sup>6</sup> BREAST-Q Breast Satisfaction module covers breast appearance such as size, symmetry, softness, implant

placement, cleavage), and satisfaction with breasts in relation to how a bra fits and how the breasts look when clothed or unclothed. The scores are computed by adding the response items together and then converting the raw sum scale score to a score from 0-100. A higher score means greater satisfaction.

## Discussion and Conclusion

OECD PaRIS condition-specific working groups have brought together policymakers and other stakeholders, including clinicians and patients, to discuss the patients' perspective on health care delivery. Working group participants have had the opportunity to learn from each other while exchanging methodological points, as well as materials, such as translated tools, resources, and implementation guidance. Together, the working groups have resulted in initially defined international standards for reporting PROMs and PREMs for these specific procedures and conditions.

Efforts of the working groups have also highlighted challenges in the measurement and implementation of PROMs and PREMs. Strong institutional and policy support is an important facilitator for the increased adoption of patient-reported metrics, as is the engagement of patients and providers in discussions on the selection and use of the measures for clinical improvement. Insufficient data infrastructure, data governance and integration challenges, and methodological issues (such as variations in caseloads) were highlighted as the main challenges for data collection and reporting. PROMs and PREMs are critical tools for improving the quality of care and making health systems more people-centred. Lessons learnt from the OECD PaRIS condition-specific working groups show that although data reflecting the patients' perspective still requires considerable advancement, countries are making progress on their way toward more people-centred health systems.

Accelerating the uptake of PROMs and PREMs at the national level will be possible with targeted investments in strengthening data infrastructure, improving data governance, and enabling digital health.

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### Chapter Three

## Mental health patient-reported experiences and outcomes: Denmark's experience

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### Introduction

Quality improvement and patient safety have been important topics on the agenda in the Danish health care system for over 20 years (Mainz et al., 2015; OECD, 2013). This agenda has among other focus on the unique voice of patients, their experiences, and outcomes in quality improvement since patients can make a valuable contribution to setting the standards by which care should be evaluated (Mainz et al., 2022). Patients are in a unique position to contribute to the quality of health care since they are the only ones who experience the whole episode of care. It is the patient who should define what is desirable and undesirable and report what is accessible, convenient, comfortable and timely. Also, it is them who should inform to what extent they have been listened to, informed, involved in decision making and treated with respect (Mainz et al., 2022).

Consequently, assessing patient experiences, satisfaction, (patient-reported experience measures (PREMs)) and outcomes (patient-reported outcomes measures (PROMs)) has become an essential component in the quality

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improvement enterprise in Denmark. While PREMs capture patients' experience of health service delivery, PROMs provide patients' perspectives on their own health status and how it may have changed over the course of treatment (Mainz et al., 2022).

### Patient-reported experience measures (PREM): the Danish National Survey of Patient Experiences (the Danish PREM)

The Danish National Survey of Patient Experiences was implemented in Denmark in 2000 on the somatic health area and has since grown to include the area of psychiatry, maternity/childbirth, and emergency care. The Danish PREM is conducted on the behalf of the five regions in Denmark and the Ministry of Health. The main objective is to identify varieties inpatient experiences within specific topics through comparison across regions and hospital wards, to provide inputs for the quality improvement work and to follow the development in patient experiences. This is done by collecting data from patients, benchmarking results among comparable units and systematically monitoring the development of experience over time (OECD, 2013).

Approximately 260.000 questionnaires are distributed every year, and the overall response rate is between 33-68% (DEFACTUM, 2022). To ensure easy access to data, the results from the survey are published in the main site of health in Denmark (sundhed.dk). Sundhed.dk, is the official portal for public Danish healthcare services. It enables patients and healthcare

professionals to find information and communicate. In a secure part of the website, the patient has access to data on personal health, appointment information, prescription renewals, information regarding waiting time and patient networks (OECD, 2013).

#### The Danish PREM Psychiatry

The Danish PREM Psychiatry was implemented in 2005 and was developed in collaboration with healthcare providers and patients. It includes answers from adult inpatients and outpatients as well as their relatives, children, adolescents and their parents, and patients admitted to specialised forensic psychiatric wards in hospital psychiatry. The survey has until 2022 consisted of 25 and 35 questions, as each region had the possibility of a local selection of additional questions. The regular questions touched on the following themes:

- The reception (inpatients only)
- Staff
- The treatment
- Patient/relative experienced errors
- Patient and relative involvement
- Coercion during hospitalisation
- Coherence and collaboration (adult patients and all relatives only)
- The discharge from the bed section (only adult inpatients and their relatives and relatives of inpatients in children and adolescent psychiatry)
- Overall impression

Two examples of questions from the survey are shown in Table 1.

Table 1. Examples of questions from The Danish National Survey of Patient Experiences (LUP)

#### Patients

Item 1: Did you get better due to the hospitalisation (inpatients) / treatment in the hospital department (outpatients)?

Item 2: All things considered, are you satisfied with the hospitalisation (inpatients) / hospital contact (outpatients)?

In 2021 more than 8000 patients returned the survey, and 81 % answered that they are satisfied or very satisfied with the treatment they have received in the hospital psychiatry. The results in Figure 1 shows satisfaction of patients across inpatient, outpatient and forensic patients in the five Danish regions.

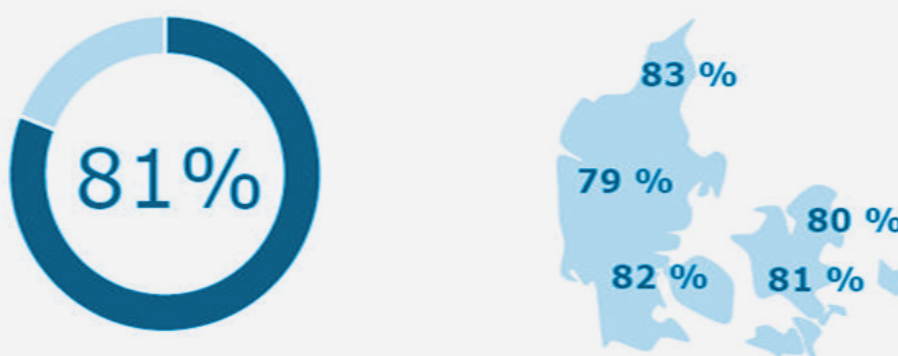


Figure 1. Overall satisfaction among psychiatric patients and regional differences in satisfaction.

Additionally, more than 2000 relatives have returned the survey in 2021. Figure 2 shows the results of their satisfaction which in general is lower than patients.



Figure 2. Overall satisfaction of relatives and regional differences in satisfaction of relatives.

Healthcare staff has been responsible for personally handing out the survey since 2005 but from 2022 the questionnaires will be sent digitally to adult patients and there will be a continuous data collection monthly over the year which will enhance the possibility of using the data for quality improvement on a regional/hospital, ward or section level (DEFACTUM, 2022).

#### Patient-reported outcome measures (PROM)

PROMs provide the service users' perspective on or their own health status and how it may have changed over the course of treatment without the interpretation of healthcare professionals (e.g. symptom burden, side effects, psychological well-being and social functioning) (Bienassis et al., 2022).

PROMs are a relatively new concept in the Danish setting, but they are currently already being used in 10 different clinical areas.

### PROM in psychiatry: PRO-Psychiatry

In Denmark PROMs for patients in hospital-based psychiatry were developed in an iterative co-development process involving patients and relatives together with clinicians (Kristensen et al., 2019).

The process led to the selection of a set of 20 PRO items and a national measurement concept, PRO-Psychiatry. The concept contains questions in the category of general health, symptoms, side effects, well-being and social function with inspiration from SF-36 (36-Item Short Form Health Survey), WHO-5 (WHO's Well-being Index) and WSAS (Work and Social Adjustment Scale).

The initiative is the first of its kind in Danish mental healthcare and was established in 2016 as a provisional research and quality improvement initiative (Kristensen et al., 2019). PRO-Psychiatry was clinically tested, and PROMs were validated after the development phase. Currently, the initiative is in the final stage of national implementation (Kristensen et al., 2022).

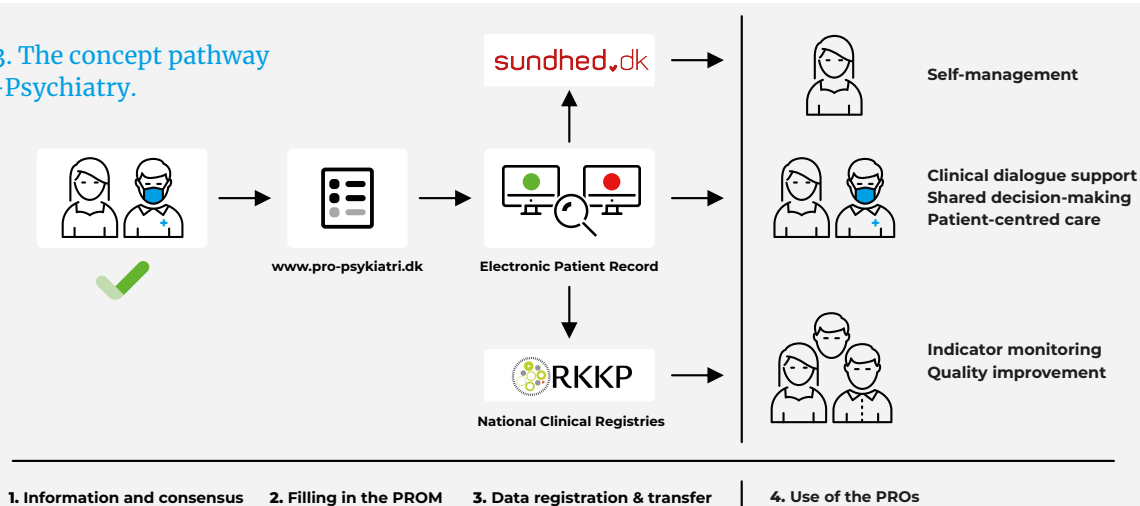
Figure 3 illustrates the concept pathway of

PRO-Psychiatry. Patients are foremost asked to participate and to fill out the PROM digitally. The results then go to the public website (Sundhed.dk) which is the public main point of contact where all patients have a private profile. From there, patients can use their results for self-management or the results can be used in the clinical dialogue between patients and health professionals, which supports shared decision-making and underscores opportunities for care or quality improvement. Furthermore, data on a summarized level can be used in the quality improvement enterprise as part of the National Clinical Registries in Denmark.

### Perceptive

In Denmark, the measurement of value in healthcare is an area under development. It is regarded old-fashioned to involve or include patients. Patients should be part of co-creation processes in the development of measurement tools. Further development of PREMs and PROMs should therefore be either in co-development or co-design, where patients, relatives and healthcare providers serve as equal partners (Mainz et al., 2022). Co-creation should determine the content of the measures, how they should be implemented, and used and how results should be communicated to both service users and clinicians to improve care quality and delivery.

Figure 3. The concept pathway of PRO-Psychiatry.



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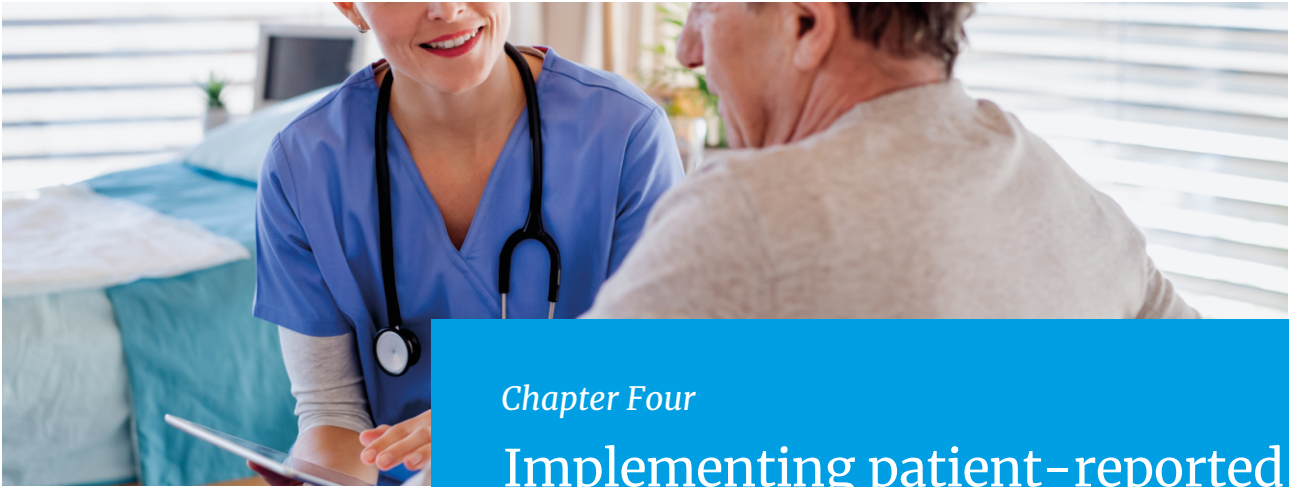
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## Chapter Four

# Implementing patient-reported measures (PROMs and PREMs) in a public psychiatric hospital

Elisabetta Scanferla<sup>1,2</sup> and Philip Gorwood<sup>1</sup>

*This presentation reports on the results of a pilot study on the implementation of patient-reported outcome and experience measures (PROMs and PREMs) at the “GHU Paris Psychiatrie et Neurosciences”, the leading player in care for mental and brain diseases in the Paris area (2 million inhabitants).*

### Why implementing patient-reported measures in a psychiatric hospital?

The GHU Paris, a university hospital group, is a public hospital and one of the largest psychiatric hospitals in Europe. It includes more than 100 care facilities, 1300 hospital beds; 50 inpatient mental health structures and almost 30 community care facilities. It has 5600 employees and among them, 600 medical doctors. The GHU Paris is an integral part of the public health care system for the city of Paris and is therefore organised into care 'sectors'. A 'sector' is a specific geographic and demographic division of areas. Its goal is to dedicate the same medical and social team for diagnosis, ongoing treatment, hospitalization care and post-cure for the patient. The key element of a sector is the “Medico-psychological Center (CMP)”, a community-based care setting, which gathers psychiatrists, psychologists, nurses and other mental health care workers. The team coordinates the patient's care and a whole care network within the hospital and outside the hospital, aiming at optimising the patient care pathway.

GHU Paris has a strong institutional commitment to the development of patient-reported measures

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within the hospital group as an essential dimension of the hospital's value-based health care (VBHC) approach, which drives the strategy. The GHU Paris Strategic Plan 2021-2025 states: "GHU Paris will commit to a more systematic use (...) of quality measurement tools by adopting indicators that reflect the patient's perspective".

The value-based healthcare (VBHC) model grounds the improvement of quality and performance of care on 'value' for patients, incorporating patient-centered outcomes and preferences into the definitions and metrics of value and costs (1-2). It promotes the development of person-oriented health services where quality of that care and therapeutic strategies performance reflect patients' "voice", patient goals and preferences rather than clinician-identified ones (3-7).

In this context, increasingly emphasising patient-centred care, patient-reported outcome and experience measures (PROMs and PREMs) that assess an individual's overall sense of health and well-being appear to be crucial in particular for populations suffering from chronic diseases such as those who suffer from mental health disorders who often need acute hospital care (9-10). Patient-reported indicators may provide essential information leading to improved care, in particular in situations where patients' health status cannot be improved or maximised.

As real-world data is missing in this field, we decided to conduct an exploratory study using the PROMs and PREMs recommended by the PaRIS mental health Working Group led by the Organization for Economic Co-operation and Development (OECD) that is currently developing a set of patient-reported data collection standards in order to facilitate international comparisons in mental health care (5,8). Data collected as part of our study were included in the first pilot data collection using this set of indicators launched by the OECD PaRIS Working Group in 2020.

The main objectives of our study were to explore the change in patients' reported overall well-being and clinical outcome (PROMs) between admission

and discharge, as well as the quality of patients' experience of care measured at discharge.

### Material and methods

#### *Participants*

The study employed data collected in routine care of patients admitted to a university group hospital. Consecutively hospitalized patients in two departments of the GHU Paris, between 31 January 2021 and 30 June 2021, were assessed for eligibility. The first department was a 'sector', providing general psychiatric care to the residents of a given area of Paris. The second department was a university department specialised in mood disorders and eating disorder. Inclusion criteria were: all inpatients, 18 and over, who were admitted to hospital with a principal diagnosis code of mental health and behavioural disorders and whose hospital stay length was at least 15 days. Exclusion criteria were: non-French-speaking, suffering from a major neurological disorder, being hospitalised for less than 15 days.

#### *Instruments*

Participants completed self-administered questionnaires assessing: the specific symptoms of the disorder for which they were hospitalized (disease-specific PROMs), subjective well-being (generic PROMs) and experience of care (PREMs). Patients suffering from psychotic disorders and Alcohol Use disorders (AUD) did not fill-in the disease-specific PROMs questionnaires.

To measure the evolution of participants' subjective well-being we used the PROMs recommended by the PaRIS Mental Health Working Group (OECD). They explore in particular in the domain of well-being, identified as a priority in the PROMs area (8). The standard set consisted of the following: a) The OECD Assessment of Subjective Well-being Core Items Coverage (two items), evaluating satisfaction in life and feel that the things in life are worthwhile; b) The World health organization well-being index (WHO-5) (five items/composite measure) that covers important aspects of subjective well-being of the respondents (cheerfulness, calmness, activity, rest, interest).

The experience of care was measured using PREMs recommended by the OECD PaRIS Mental Health Working Group. These were adapted from the OECD-Proposed Set of Questions on Patient Experiences with Ambulatory Care and Commonwealth Fund Items (four items) and explore the following dimensions: 1) Be treated with courtesy and respect; 2) Time spent with the clinician; 3) Clarity of the explanations, 4) Shared decision making.

To measure symptoms outcomes reported by patients, we used disease-specific questionnaires, based on the disease that caused the admission to the hospital: the Hospital Anxiety and Depression Scale (HADS), a self-assessment scale measuring anxiety and depression; the Eating Disorder Inventory-2 (EDI-2), a self-rating inventory designed for the exploration of attitudinal and behavioural dimensions relevant to eating disorders; the Beck Hopelessness Scale (BHS), a self-report inventory designed to measure three major aspects of hopelessness and negative attitudes about the future, used as an indicator of suicidal risk in depressed people who have made suicide attempts; the Beck Scale for Suicide Ideation (BSS), a self-report instrument designed to assess the severity of a patient's suicidal ideation and helps identify individuals at risk.

Patients were invited to complete the questionnaires at admission (day of admission + 48h) (T0) and discharge or following discharge (+ 48h) (T1). At T0, they completed the two PROMs questionnaires (the first one, generic, and the second one, disease-specific). At T1, they completed the same two PROMs questionnaires, plus a PREMs one.

### Preliminary results

311 were enrolled in the study. 52 failed to attend assessment at discharge, 11 were excluded because the length of their stay finally didn't meet the inclusion criteria. A total of 248 participants were included in the final sample (drop-out rate, 20.2%).

76 (30.6 %) of the participants suffered from eating disorders, 72 (29.0 %) from psychotic disorders, 46 (18.5 %) from mood disorders, 44 (17.8 %), were hospitalised for suicidal crises, 10 (4.0 %) suffered from alcohol use disorders (AUD). The mean age on enrolment was 37 (SD=14.1 range: 18-85), 72.9% (n=184) were female. The mean length of hospitalisation was 45.6 days (SD=32.5, range: 14-222). 184 were hospitalised in the university department and 64 patients in the 'Sector' department. The profile of the patients varied considerably across disorders.

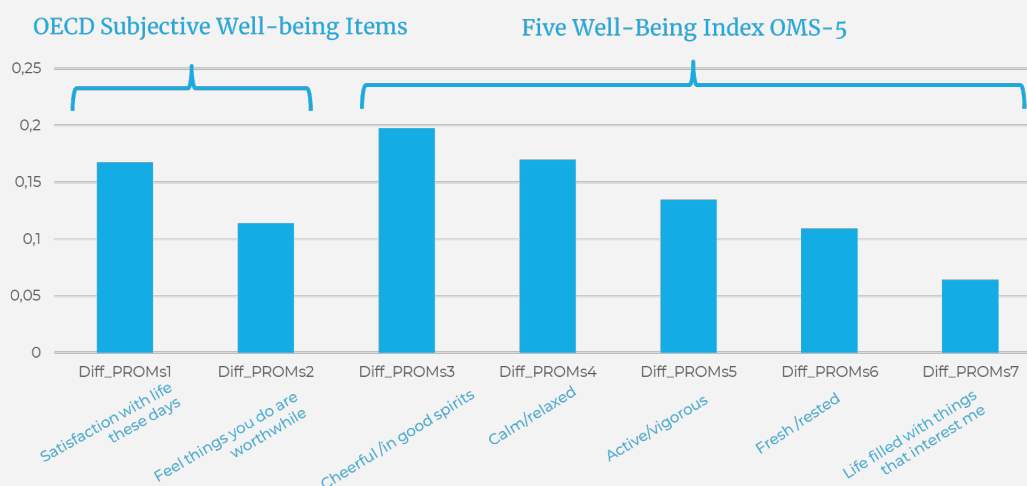


Figure 1. Subjective wellbeing observed improvements (%).

**Change in subjective well-being**

The subjective well-being significantly improved at discharge. This is reflected in the results of each specific patient-reported outcomes on well-being explored, namely the OECD Well-Being Core Set (two items) “life satisfaction” and “feeling that things in life are worthwhile”, as well as in the score of the WHO-5 Well-Being Index (Figure 1). Based on these results, we aimed at identifying whether any patients' sociodemographic characteristics or diagnosis was associated with higher subjective well-being at discharge and found that there was a significant effect of the type of disorder. Furthermore, improvement in well-being at discharge was significantly higher for patients suffering from mood disorders than for those suffering from eating or psychotic disorders.

**Change in patient-reported clinical outcome**

As for the patient-reported measures of well-being, across mental disorders, disease specific PROMs scores significantly improved at discharge reflecting that most patients reported an improvement in symptoms. Results also showed lower scores for patients suffering from eating or psychotic disorders.

**Patient-reported experience of care (PREMs)**

Most patients reported a satisfying experience of their hospital stay for the four items rated. The items “Respect and dignity” and “Clarity of explanations” obtained a higher score than the items “Time spent with the clinician” and “Shared decision making”. About 28% of the participants reported an 'extremely satisfying' experience for all the items.

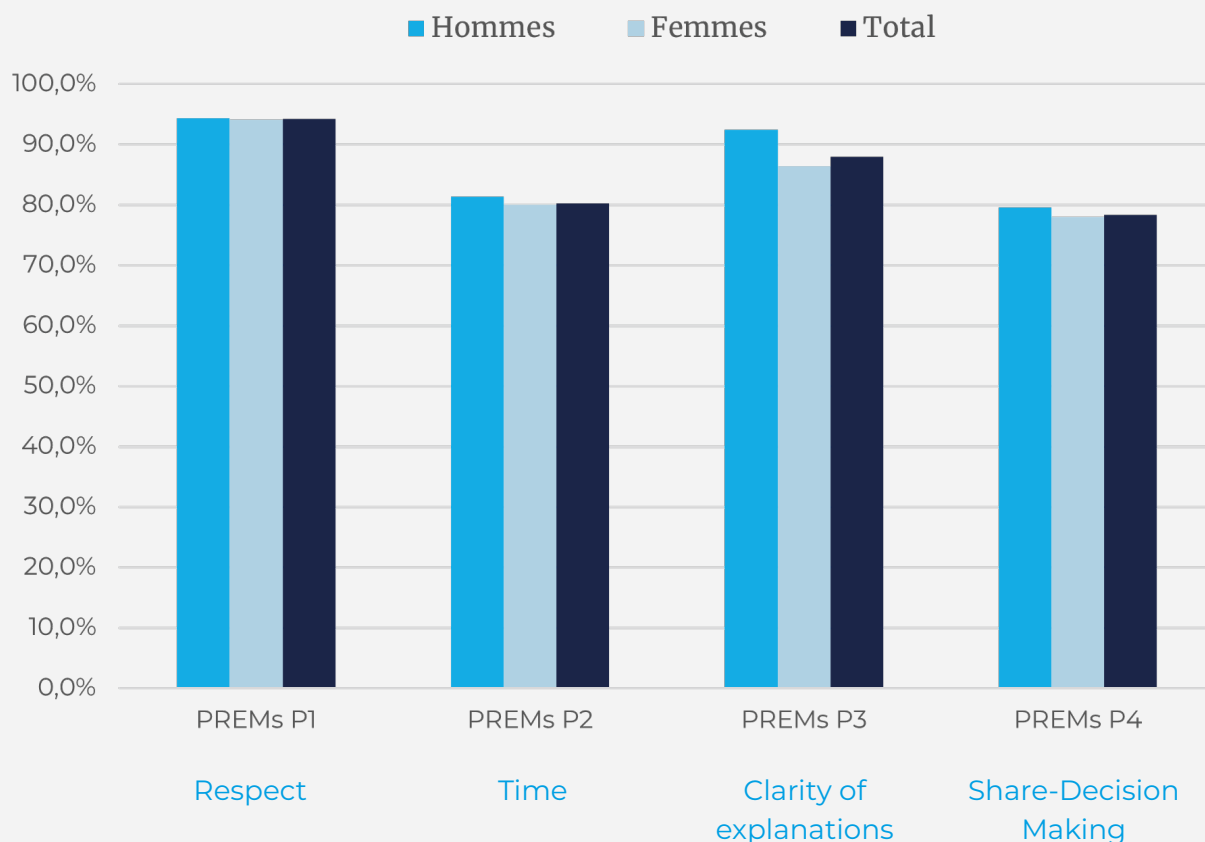


Figure 2. Positive patient-reported experience of care (%).

*Relation between subjective well-being, clinical outcomes and patient experience of care*

Overall, there was a significant association between patient-reported clinical outcomes and change in subjective well-being. The strength of the correlation varied according to the disorder that led the patient to be admitted to hospital.

Concerning the relationship between changes in the subjective well-being, outcome measures and patient-reported experience measures, analysis highlighted a significant correlation between these three measures, but the strength of the correlation was weak, thus emphasizing that patient-reported experience scores explained only a small part (5%) of the improvement in clinical and subjective wellbeing scores. Of note also is the fact that even those patients who reported a lower clinical outcome still showed quite a high level of satisfaction with their experience of care.

**Lessons learnt and future steps**

The main barriers encountered during our study were as follows: in the first place, the difficulty in obtaining responses to questionnaires from the most severe or cognitively impaired patients; secondly, the value of collecting patient-reported measures seemed not fully understood by clinicians: some of them expressed concerns about the relevance of patient-reported measures and the additional workload generated by data collection. Thirdly, at an organisational level, the burden and cost related to the collection of data, and in particular the cost of dedicated staff.

Altogether, the main results of our study, one of the first on patient-reported measures implementation in a French psychiatric hospital,

are that the indicators of subjective well-being, clinical outcomes (PROMs), and the measures of the experience of care (PREMS) are relatively independent and should therefore be measured separately. These new indicators are crucial as they provide novel and valuable insights that help to improve patient-clinician dialogue and share-decision making, and then optimize the quality of mental health care, also in hospital settings.

However, these initial results require further studies to examine, on the one hand, the relevance of patient-reported outcome and experience measures in different mental health settings, including childcare units and out-patient community care (Medico-psychological Centers) as well as the evolution of results over the long terms, and, on the other hand, to explore the impact of the integration of PROMs and PREMS into daily clinical practice.

These next steps in the development of the use of PROMs and PREMS in psychiatric settings may benefit from the recommendations on this topic proposed by the guidelines already available, such as the “Roadmap for Implementing Value-Based Healthcare in European University Hospitals”, recently published by the European University Hospital Alliance (11).

Finally, on a broader perspective, our study helped to confirm that there is an urgent need to (re)think psychiatric standard care by better listening to the patients' voice and involving them in clinical decisions. However, while the interest in this game-changing path is growing, there is still a long way to go in many mental health care systems at local, national and European levels (12).



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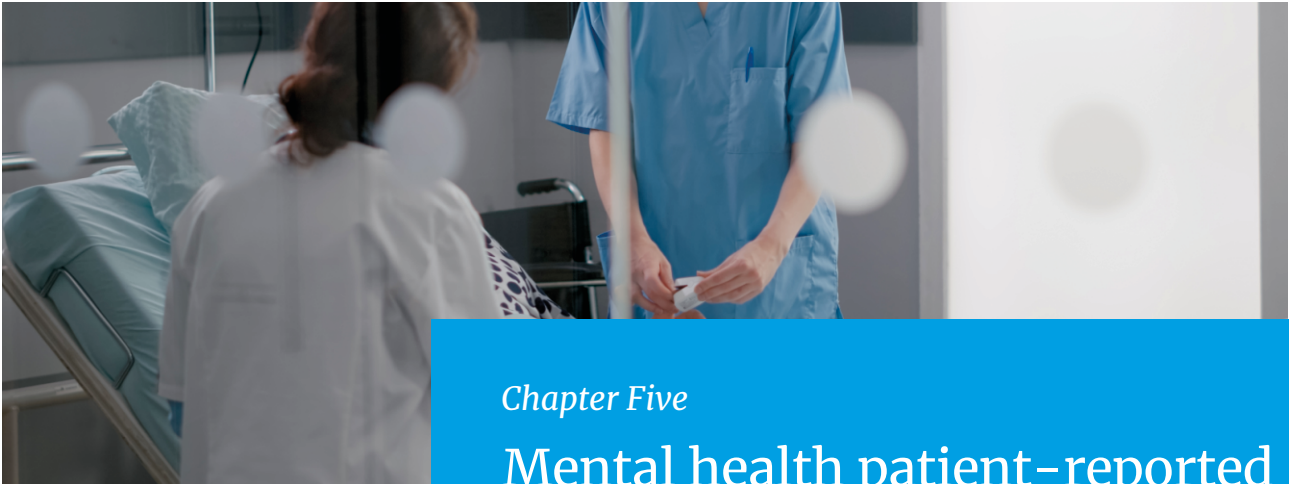
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## Chapter Five

# Mental health patient-reported experiences and outcomes: the Portuguese findings

Patrícia Frade<sup>1,2</sup>, Catarina Jesus<sup>2</sup>

## Introduction

The Centro Hospitalar do Oeste (CHO) is located in the west coast of Portugal and the covered area contains around 300 000 inhabitants. The CHO Psychiatry Department is constituted of the Centre of Integrated Responsibility (CRI), the Child and Adolescent Psychiatry Unit and two Psychology Units.

CRI is an intermediate management unit, with more autonomy and more responsibility, allowing for increased efficiency, as well as to quality and safety improvement. The cornerstones of Clinical Governance at CRI are the patients, the professionals and the organization. They allow the development of innovative work methods.

The service quality depends on agility, responsiveness and leanness, and is assessed through the outcomes, the process and patient satisfaction. Based on this knowledge, the questionnaires were applied to the patients to assess the PREMs and the PROMs.

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### Main Contents

The objective was to have patients answering to the questionnaire, the process was adapted to the patients' skills and each team member's role was defined, in order to support the process.

The process is represented in Figure 1.

The PREM and PROMs are very important for us, to evaluate and detect what we have to change in order to improve, they are part of a continuous improvement process.

Involvement of the patient in decision making by continuing to collect PROM and PREM information, increases the recognition of patients as providers of value and making decisions about their treatment after listening to their opinions in order to meet their needs.

Regarding the time spent – we know that the indicator “the number of consultations” reduces

the time spent in each consultation, but if we change the indicator to “per patient treated” there is no longer the focus on time but more on the patient.

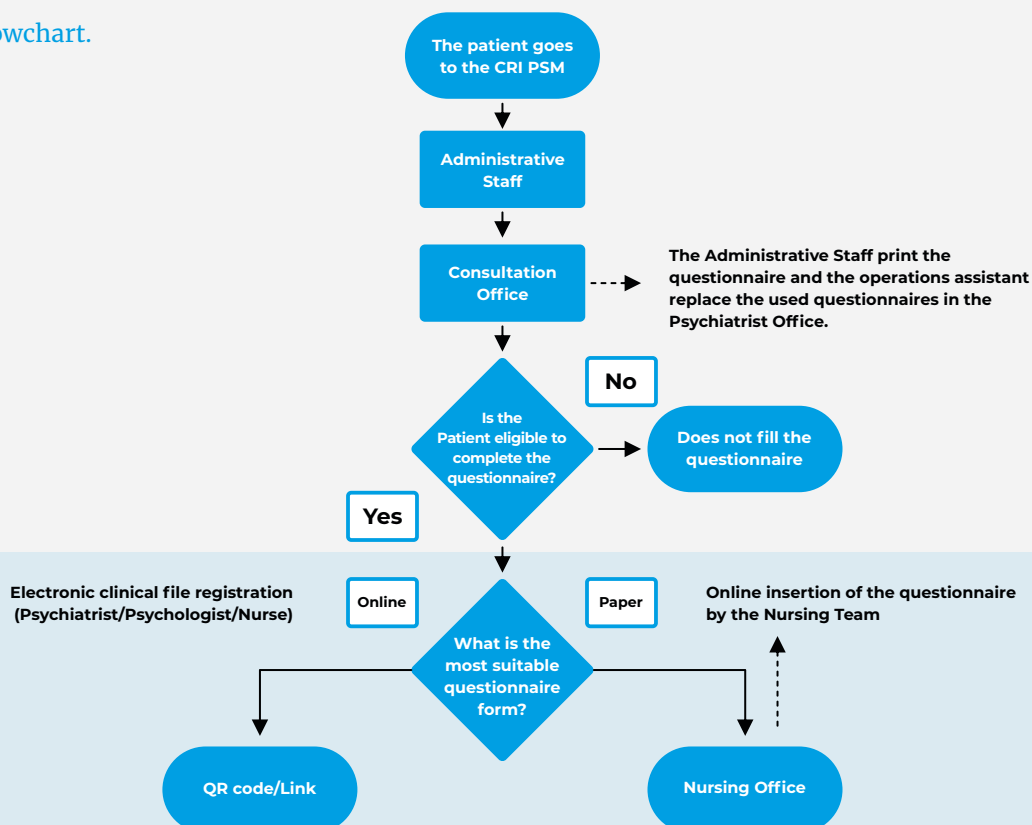
### Conclusion

In general, patients were very satisfied with the treatment given at CRI, they valued the way they were treated and the explanation given about the treatment process. 20% were not totally satisfied, with regard to the involvement in the decision-making and the amount of time spent with them.

In the future, the patient will truly be at the centre and the various stakeholders will articulate with each other better in order to respond to the patient's needs.

Our team was the secret: the way we communicate, how we get involved in our work and work as a team. We believe that our multidisciplinary work makes a difference.

Figure 1. Flowchart.





*Chapter Six*

## Patient-reported outcomes for breast cancer: the Basque experience

### **Ane Fullaondo Zabala**

*Scientific coordinator of Kronikgune Institute  
Basque Country, Spain*

### **Introduction**

The VOICE Community was created in 2018 by organizations originally participating in the All.Can initiative launched by International Consortium for health Outcome Measurements (ICHOM). Value based healthcare paradigm is a core strategic working area for all VOICE organisations which is reflected in their significant and valuable engagement and commitment to the Community. Thirteen European hospitals form the VOICE Community, and those involved in breast cancer are Cruces University Hospital, Donostia University Hospital, 12 Octubre University hospital, Hospital Juan Ramón Jiménez, Institut de Cancerologie de l'Ouest, Istituto Scientifico Romagnolo per lo Studio e la Cura dei Tumori. The VOICE study combines an implementation research component and effectiveness, using quantitative and qualitative methods for data collection and analysis.

The main objectives of VOICE are:

- Benchmark health outcomes to improve care delivery.
- Measure patient-reported health outcomes in routine clinical practice on a systematic and long-term basis.
- Include patients' perspectives in clinical decision-making.
- Share best practices among organisations.
- Boost knowledge generation and best practice exchange.

### Main contents

The 'value' definition considered in the VOICE Community is the most optimal situation refers to increasing health outcomes while reducing costs. To measure patient health outcomes, the variables included are those in the renowned ICHOM standard sets for breast cancer. The dimensions to be explored are: depression, pain, fatigue, body image, arm and breast symptoms, vasomotor symptoms, neuropathy, arthralgia, sexual dysfunction, health-related quality of life, survival, recurrence-free survival, reoperation due to positive margins and acute complications.

The intervention in VOICE consisted of four main stages:

- **Stage 1. Value identification and description of current care processes:** at this stage needs were detected from two perspectives: On the one hand, feedback from patients with breast cancer was collected to get to know their experience and understand their needs and expectations. On the other, current healthcare processes were mapped with the collaboration of a multidisciplinary team made up of representatives from professional groups involved in breast cancer care and treatment. In addition, professionals analyzed the battery of questionnaires proposed in the ICHOM standard set and considered the need for any additional questionnaire or variable to

be added. All tools needed for the intervention (patient surveys in digital and/or paper format) and clinical forms were developed. The methodology for cost analysis was set up as well.

- **Stage 2. Intervention implementation:** at this stage patients were recruited (700 patients) according to the eligibility criteria by the corresponding professionals. Those patients invited to take part in the study and accepted had to sign the informed consent form. Once admitted to the study, the patient's illness treatment was applied according to the existing healthcare pathway and patient information was collected at different time points. The information collected comes from surveys completed by the patient and from clinical information registered by the professionals.
- **Stage 3. Assessment of outcomes and continued benchmarking:** once the intervention was implemented, quantitative data collected by professionals and patients and costs were analyzed at both the local level and the community level (benchmarking). For the analytical phase, groups of similar patients (patient archetypes) were identified based on clinical information using Hierarchical Clustering on Principal Components method. This approach allows for comparing patients' outcomes and perceptions between individuals with a similar profiles. Forty-three indicators were agreed upon among all clinicians of the participating organizations: health outcomes (17) including PROMs, survival, recurrence and complications related, process (8), economic (11), and adjustment-risk (7). Regarding the breast cancer PROMs, 13 dimensions were defined: overall well-being, asthenia/pain, emotional functioning, cognitive functioning, labour, and economic impact, social functioning, sexual functioning, body image, satisfaction with breasts, arm and breast symptoms, adverse effects, vaginal symptoms and quality of life.



- **Stage 4. Model construction:** based on the existing process mapping and after reflecting on areas of improvement that can be tackled during the project (root cause analysis), the multidisciplinary team will design the new care pathway. In addition, during this phase, professionals will be trained in those tasks allocated according to the new care process.
- The ICHOM standard sets have been used without any modification ensuring the comparability between VOICE hospitals and others. The potential addition of other variables has been proposed in the Community as well as extending the inclusion criteria established by ICHOM.
- Incorporating the perception of patients in the clinical processes increased the awareness of patients with regard to their health and the patient-professional relationship became tighter.

## Conclusion

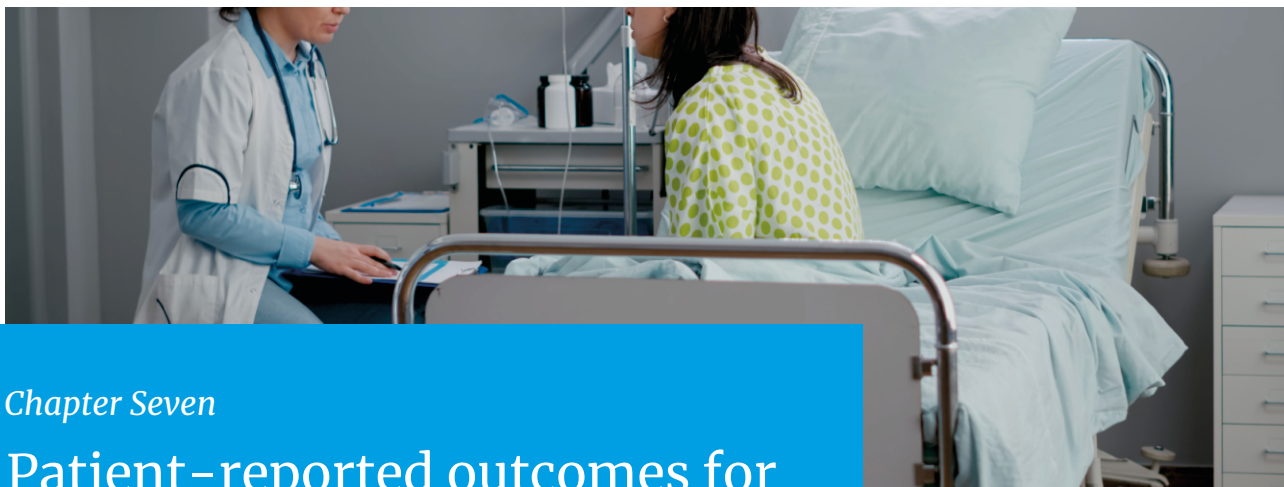
Value-based healthcare is a strategic field of the organizations involved in VOICE. All of them present considerable commitment to continue with the initiative. In fact, some of them continue recruiting and monitoring patients and collecting the variables included in the ICHOM standard sets (both clinical and PROMs). Extending the inclusion criteria to metastatic patients is under study as well.

The VOICE Community stimulates patient value improvement through:

- Implementation of innovation and quality methodologies (care process mapping, patient journey map, etc.) in the participating hospitals increased their capacity for care transformation.
- Creation of multidisciplinary teams and collaborative work helped the successful implementation of the intervention in each hospital.

- Analyzing in detail the care processes considering patients' views enabled the optimization of care activities.
- Learning exchange among the VOICE hospitals allows improvement in hospitals' performance in a broader sense.
- The existence of the VOICE Community is key to placing value-based healthcare as a priority in health organizations and policies.

The ambition of the VOICE Community is to create a strong network of healthcare organisations over Europe for VBHC breast cancer and connect with technological partners that are innovative and well-established in the health field. As a Community, we are exploring opportunities to move forward and implement a more sophisticated intervention, not only collecting PROMs but also using real-world data for example. Future studies will help the Community provide personalized medicine.



## Chapter Seven

# Patient-reported outcomes for breast cancer: Portuguese findings

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The Portuguese Institute of Oncology in Oporto (IPO Porto) is a Portuguese public hospital, specialising in cancer treatment, with about 350 inpatient beds and 2,000 healthcare professionals. Every year around 40,000 patients are treated, 10,000 of whom are new patients.

Since 2016, IPO Porto is a national reference centre for six pathologies and now integrates the European reference network.

In 2007 IPO Porto was organized into 11 integrated pathology units (IPUs): Breast clinic, Skin and Soft Tissue Clinic, Digestive System clinic, Urology clinic, Gynecology clinic, Hematology clinic, Head and neck clinic, Ling clinic, Endocrine System clinic, Central Nervous System clinic and Pediatrics clinic. Each IPU is composed of clinical and non-clinical personnel who provide the 'full cycle of care' for a patient with a given medical condition. We believe value is added by centralizing patient care into large units that provide high volume services.

Last year alone, 1,745 new patients were admitted at the Breast unit. Almost 12,000 patients were in the various phases of treatment. 3,600 multidisciplinary appointments were

performed. Surgical treatment was carried out in 1,070 patients and 3,600 had systemic treatment, in a total of 25,800 treatment sessions.

Admittance for a breast cancer patient at our unit is done by referral by a general practitioner or by the Portuguese national breast cancer screening program. After a maximum of 4 days from a referral, the patient has the first medical consultation. In a maximum of 12 days, after diagnostic testing, a multidisciplinary team meeting is performed in which the treatment is decided. Finally, in a maximum of 21 days, the first treatment is done. This process takes a maximum of 45 days, which is in line with our NHS guidelines.

Our clinical decision pathway follows the ESMO and St. Gallen Guidelines for breast cancer. Regarding each stage of the disease, the patient is allocated to a standardized treatment plan, in order to achieve the best clinical outcomes.

Patients are encouraged to enrol in clinical trials whenever possible, this allows cutting-edge clinical research with innovative drugs or treatment plans.

Nowadays, the patient's perspective is highly relevant to improve the quality and effectiveness of health care. One of the key challenges to achieving this is the limited measurement of what matters most to patients. So, the introduction of Patient Reported Outcomes – PROMs – is one strategy to ensure that patients' perspectives are incorporated into delivering better healthcare services.

Since October 2020, IPO Porto has had a Quality Of Life (QOL) office in which patients are invited to answer a QOL questionnaire with user-friendly software. There is support from a nursing professional as a quality monitor. Data treatment has specific software to collect large-scale data and create automatic reports.

The Breast Q is a questionnaire that evaluates the patients' experience who underwent breast surgery, promoting the value of PROMs.

Inclusion criteria for Breast Q application are aged 15 years or older, who underwent breast conserving surgery (BCS) or mastectomy with reconstruction (MT). After the informed consent is signed, the questionnaire is applied by a trained nurse on the same day the patient has a medical appointment up to 1 year after surgery.

The questionnaire is afterwards submitted online by the data manager of the Outcomes Research Lab at IPO to the national team that processes the data and makes the reports. From May 2021 to February 2022, 165 patients were included at IPO Porto. 137 patients with BCS and 28 MT patients. Most BCS patients were older. The majority of the reconstructions were made with breast implants. The BCS group reported a higher degree of satisfaction regarding breast symmetry compared to the MT group. Both groups were satisfied regarding surgical outcomes and QOL. Both groups were satisfied with global health and reported good overall QOL.

In recent years, there has been a shift away from the conventional models of care delivery to a patient-centred approach which places the individual receiving care at the center of the healthcare ecosystem.

Thus, PROMs evaluation provides various benefits:

- Enable the identification of areas for the QOL improvement;
- Allow clinicians to gain insights from the perspectives of patients into how aspects of their health and the impact of disease and treatment are perceived to be having on their lifestyle and QOL;
- Improve communication between professionals and patients, and consequently the provision of better care;
- Comparing providers and organizations or benchmarking them to identify poor performers and learn from good performers;
- Improvement in the quality of services provided, with significant repercussions on the optimisation and consistency of the oncological disease treatment process.





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