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REPORT

Quality of care as perceived by patients – PROMs and PREMs indicators

Panorama of experiences in other countries and main lessons learned

This document is a translation of the original French document

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Description of the publication

Title	Quality of care as perceived by patients – PROMs and PREMs indicators Panorama of experiences in other countries and main lessons learned This document is a translation of the original French document
Work method	The report is supported by elements from the published literature and an expert review.
Objective (s)	To elucidate the theme of patient-reported quality indicators, by laying down the conceptual foundations based on scientific elements, and to foster a common vision of the subject. To promote the collection and appropriate use of patient-reported quality indicators, by raising awareness among the general public and informing healthcare professionals, care organisations and institutions.
Targets	Users, professionals, organisations and institutions
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Summary

Today, quality of care is assessed by both healthcare professionals and patients

Measuring quality of care is a prerequisite for defining actions to be implemented and demonstrating progress for the purposes of improving the service delivered to patients. This approach, which has long been used by professionals to self-assess their practices, is enriched by the complementary vision of patients.

Three types of measures are used to assess quality of care as perceived by patients, using different tools: Patient-Reported Outcome Measures (PROMs) for care outcomes, Patient-Reported Experience Measures (PREMs) for the care experience and patient satisfaction questionnaires to assess meeting of their expectations. Useful on an individual and collective level, patient-reported quality of care measures are increasingly employed in routine clinical practice, but they are still relatively little known, which justifies the publication of a series of clarifications on these new types of indicators by the HAS.

The growing number of initiatives in various countries demonstrates the benefits of these measures and the value of rolling them out more widely

Based on research published in the literature and numerous illustrations, this report describes the theoretical foundations and methodological approaches, accompanied by practical cases, as well as the challenges relative to quality of care that could be met by proficiency in the use of these solutions. In particular, the aim is to improve communication between patients and professionals, personalise care and more effectively monitor patients' health. Hence, a large number of countries have already adopted these types of measurement tools.

In a spirit of international comparison, the HAS examined the situation in 13 selected countries (England, Wales, USA, Canada, Australia, New Zealand, Sweden, the Netherlands, Norway, Germany, Denmark, Belgium and France). This panorama presents international experiences at various stages of progress in terms of their deployment, uses and results, with France in an intermediate position.

The use of patient-reported quality measures in routine clinical practice can significantly improve patient care

Various initiatives using patient-reported quality of care measures demonstrate improvements in terms of quality of care, especially in routine clinical practice, with a direct impact on patients. These improvements are facilitated by the standardisation of tools and the support of relays such as public disclosure or quality-based funding.

PROMs help patients to gain a clearer understanding of their disease/condition and their symptoms, to identify their most important symptoms and to communicate them more effectively. By providing patients and professionals with a shared vocabulary, PROMs facilitate communication.

PROMs help professionals discuss any care difficulties with patients. With the help of PROMs, professionals are able to identify more symptoms or at an earlier stage, implement more effective follow-up and propose more appropriate care, leading to very concrete and sometimes significant clinical impacts, such as prolonging the life of patients or improving their quality of life.

PREMs, which are based on the analysis of patients' experiences, help healthcare professionals and organisations improve on dimensions such as communication with patients, team responsiveness, pain management or, more generally, patient preferences. They also enable care teams to engage in approaches that improve the patient experience, such as coordination of care and teamwork.

The public disclosure of patient-reported quality measures and their potential use for the payment for care, such as bundled payment or pay for performance, provide incentives for healthcare providers to improve their results.

However, facilitating the use of these measures by professionals and patients requires information and support

Difficulties in overall perception - including confusion about the intrinsic objectives of each of these three tools - and technical obstacles can sometimes hinder the use of patient-reported quality measures in routine clinical practice, despite this being where they are most useful. Levers can be implemented to overcome these obstacles and facilitate their use.

For patients and professionals alike, it is important to communicate the benefits of these measures, particularly in terms of how they can meet their needs.

In order to help patients complete questionnaires, it is important to carefully choose questionnaires that are easy to read and understand, also proposing a variety of methods of administration and the possibility of assistance from a relative or a professional if necessary.

To help professionals adopt this method of collecting information from patients, it is necessary to define, by consensus, the instruments adapted to both their needs and those of patients, to offer them training tools and decision-making support and to make the results available to them in a format appropriate to patient care.

Aware of these issues, the HAS has decided to contribute to the promotion of these measures and is developing a first set of actions to better inform and support professionals and patients.

1. Introduction

1.1. Measuring quality of care to serve healthcare system players

Quality of care is crucially important for all healthcare system players. It is one of the five priority areas of the strategy for transforming the French health system, in which quality of care is presented as the "compass" that needs to guide health organisations (1).

> **Quality of care** is defined as "the degree to which healthcare services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge" (2)[1].

Box 1. Dimensions of quality of care

Care systems can make improvements to each of the six identified dimensions of quality of care (2):

effectiveness, providing care that is based on scientific knowledge and that is relevant to the health needs of individuals;

safety, providing care while avoiding any harm to the health of patients as far as possible;

timeliness/accessibility, providing the required care at the right time, within a reasonable period of time, delivered by services located at reasonable geographic distances;

patient-centeredness/responsiveness, providing care that is respectful, taking into account individual patient preferences and values;

efficiency, providing care making the best use of available resources;

equity, providing quality care for all, without any difference based on personal characteristics such as gender, ethnicity, geographic location and economic status.

In practice, quality care is "the right care, at the right time, in the right place, for the right patient, at the right cost" (4). To implement quality care, health professionals have several tools and methods at their disposal: on the one hand, good practice guidelines and, on the other, tools for evaluating the quality of care and monitoring its improvement, i.e. quality and safety indicators (see Box 2).

Box 2. Healthcare quality and safety indicators

Measuring the quality of care is a clear signal of its importance. In France, **healthcare quality and safety indicators** are valid, reliable measurement tools. They are based on priority objectives for public health and the organisation of care. For example, for care delivered within healthcare facilities, these indicators concern pain management and the prevention of healthcare-associated infections.

Quality of care is evaluated using three types of indicators: 1) **structural indicators**, assessing the level of equipment and staff qualifications, for example; 2) **process indicators**, assessing compliance of medical or care practices with medical knowledge and patient relationship rules; and 3) **outcome indicators**, assessing the consequences of care on the health of an individual or a population (5). These indicators are actioned to measure quality in various sectors, such as hospital care and primary care.

Care pathway quality indicators concerning both the community and healthcare facility settings have been developed as part of the healthcare system transformation strategy. Several chronic

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[1] This definition of quality of care, proposed by the USA's Institute of Medicine, is widely accepted internationally due to its flexibility and adaptability to different contexts (3).

condition care pathways are concerned, including the pathway for patients at risk of or with chronic obstructive pulmonary disease (COPD) [2]: this was the pilot pathway chosen to develop the method for the definition of care pathway quality indicators (6).

The data sources used to produce quality and safety indicators have gradually diversified: since 2008, indicators have been derived from care facility questionnaires and patient records; since 2016, medico-administrative databases[3] and patient questionnaires have also been used as sources.

Today, the HAS produces healthcare quality and safety indicators that enable inter-hospital comparison and public disclosure[4]. They may potentially be used in quality-based healthcare system regulation schemes.

Quality of care is assessed from two different perspectives: that of healthcare professionals and that of patients. Since each have their own perception of quality of care, these two perceptions are both singular and complementary. They can be measured using quality of care indicators. Quality of care indicators assessed by professionals have been being collected for longer (see Box 2). The more recent patient-reported quality of care indicators highlight aspects of care that are important to healthcare system users. The widespread implementation of patient-reported quality of care indicators is useful for all players because it enables:

- users to participate more actively in their care, to be better informed, to have a more balanced relationship with professionals and to judge the quality of care compared to their expectations;
- professionals to benefit from an aid to help improve their practices and an additional assessment of their practices;
- public authorities to have access to an additional tool for steering health policy.

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[2] The other care pathway quality indicators concern the pathways of patients with chronic kidney disease, stable coronary heart disease, stroke, obesity and breast cancer.

[3] Several medico-administrative databases exist, including, in particular, the *système nationale des données de santé* (SNDS - French National health data system), which will ultimately collate data from several databases, including the databases of the French national health insurance system (SNIIRAM), hospitals (PMSI) and medical causes of death (CépiDC).

[4] Healthcare quality and safety indicators are published on the Scope Santé website – https://www.scopesante.fr

PROMs are good tools to facilitate the participation of users in the personal or collective improvement of their care pathways.

They can also be a tool for health engagement, as developed by the HAS in its recommendation of July 2020: “Supporting and encouraging user engagement in the social, medico-social and health sectors[5]”.

The dynamics of engagement demand that patients do more than simply participate via the completion of a questionnaire. They require their involvement in the design of the collection tool, something that can easily be done in the context of the initiation of a specific PROM, for example. However, if the tool already exists, in order to be considered a tool for user engagement in accordance with the principles and values identified in the aforementioned recommendation, it would be appropriate for patients - through their associations or through an *ad hoc* group set up for such an approach, for example - to be involved in the implementation of this approach, its roll-out drive, the analysis of its results and any corrective measures envisaged.

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[5] https://www.has-sante.fr/jcms/p_3201812/fr/soutenir-et-encourager-l-engagement-des-usagers-dans-les-secteurs-social-medico-social-et-sanitaire

1.2. A gradual implementation of patient-reported quality measures

The measurement of patient-reported quality of care has been gaining momentum in numerous countries in the relatively recent past. Like other measures, it can be used to evaluate and improve the quality of routine care and to assess the performance of healthcare providers and organisations, but this requires routine and widespread measurement of patient-reported quality. This systematic measurement of quality as perceived by patients is already in place in some countries.

1.2.1. A comparison of reinforced quality of care at country level

Countries that spend a lot on their health system are facing increasing pressures. This is primarily due to the burden of chronic diseases and conditions, often lifestyle-related (e.g. smoking, alcohol, obesity) and population ageing (7). These countries are therefore seeking to control their health spending. Reforms focus on measuring and improving the quality of care, the aim being to deliver care that is safer, more effective and also more efficient (8).

Numerous quality of care indicators have been developed. They measure quality of care at different levels: at the clinical practice level (e.g. individual, group), at the health facility level, and at the geographic level (e.g. regions, countries). At a country level, the comparison used to be confined to aggregated measures rather than specific medical areas; for example, the health of countries' populations is compared on the basis of mortality rates. The desire of countries to compare themselves on the basis of more specific indicators relating to the quality of care led to the creation of the OECD Health Care Quality Indicators (HCQI) project (8).

After an initial phase during which the main concepts and dimensions of healthcare performance were defined (9), the HCQI project collected around 100 indicators, covering several topics (e.g. primary care, acute care, mental health, patient safety, patient experience). As the number of indicators increased and the methodology for collecting data for their calculation became more complex, one of the challenges for the HCQI project was to prioritise the choice of indicators; this choice focused on the indicators that were of most interest to decision-makers, i.e. indicators that had been shown to improve the quality and outcome of care (10).

1.2.2. Patient-reported quality measures introduced into international initiatives

In 2009, reforms aimed at making the use of resources more efficient or providing Value-Based Health Care (VBHC) were proposed in the USA. The objective was to improve results (11), in relation to health expenditure, focusing on access to care, patient preferences concerning their care and health outcomes, and the importance of involving patients in shared medical decision-making (12, 13). To do this, the first steps were to determine the health outcomes sought and then to measure them; a large proportion of the recommended outcomes were patient-reported outcomes; the VBHC approach was thus very closely linked to patient-reported outcomes (14). International initiatives have contributed to this approach, in particular the ICHOM (15) and the PaRIS project (16).

Created in 2012, the International Consortium for Health Outcomes Measurement (ICHOM) proposes to develop sets of disease-specific measures including valid outcome indicators for comparison. The measures are selected using a consensus-based approach by multidisciplinary working groups composed of international experts and patients. The measures recommended by the ICHOM are available for a list of diseases[6] (see Annexe 1). A collaborative process has been put in place between the ICHOM and the OECD for studies concerning patient-reported quality measures.

In 2017, the health ministers of OECD member states declared that it was important to re-orient health systems in order to improve knowledge and make care more people-centred[7]. Under the aegis of the OECD, the Patient-Reported Indicators Survey (PaRIS) initiative has also been tasked with developing comparative international indicators for patient-reported quality[8]. Guidelines have also been issued for the implementation of patient-reported quality indicators in countries (16). It should be noted that this willingness of countries to compare themselves in terms of care outcomes, and in particular patient-reported care outcomes, is reflected in the 2018 name change of the HCQI project, now called HCQO (Health Care Quality and Outcomes).

The OECD's PaRIS project is developing indicators in two areas:

1. in diseases and conditions for which countries already measure patient-reported quality, in order to accelerate the adoption of validated, standardised indicators that can be compared between different countries. Working groups were set up from 2018 to discuss measurement instruments and the definition of patient-reported care outcome indicators in three conditions: breast cancer, hip and knee replacements and mental health. The first comparative results were published in 2019 (7);
2. in primary care, where the objective is to develop an international survey focusing on measuring quality of care as perceived by patients being treated for one or more chronic diseases. This survey aims to improve knowledge in the field of primary care where standardised information between countries is still relatively unavailable (7).

The work being carried out as part of the ICHOM and the OECD's PaRIS initiative is providing more information about quality of care. It enables participating care providers[9] to compare themselves against others. In addition to the impetus to encourage measurement given by these projects, they are also driving the standardisation of the measures used[10]. They facilitate comparison, avoid fragmentation of effort and accelerate the adoption of patient-reported quality measures. Patient-reported quality measures are very important in all respects; their implementation requires the commitment of several players.

1.2.3. Patients, healthcare professionals and organisations involved in promoting the deployment of patient-reported quality measures

The evaluation of quality of care by patients has historically been carried out in the context of clinical research when new treatment strategies are tested. The impact of new treatment strategies on patients' health is assessed via different measures: 1) biological and physiological variables, 2) symptoms, 3) functioning, 4) patients' perceptions of their health and their quality of life (17) (see Box 3).

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[6] https://www.ichom.org/standard-sets/

[7] Ministerial statement on health reforms, during the meeting of the ministers of the 35 OECD member countries and their counterparts in other countries – January 2017. www.oecd.org/fr/sante/ministerielle/declaration-ministerielle-2017.pdf.

[8] https://www.oecd.org/health/paris/

[9] Care providers include healthcare facilities (including hospitals and primary care structures) and healthcare professionals.

[10] As part of the PaRIS project, working groups are organised by the OECD to develop outcome indicators for certain diseases or conditions. These groups include international experts and patient representatives. Guidelines concerning patient-reported outcome measures have been developed for hip and knee joint replacements. http://www.oecd.org/fr/sante/systemes-sante/OECD-PaRIS-hip-knee-data-collection-guidelines-fr-web.pdf

Box 3. The concepts of quality of life and health-related quality of life

The World Health Organisation defines **quality of life** as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (18).

Developed since the 1980s, **Health Related Quality of Life** (HRQoL) is a multidimensional concept encompassing the different assessable aspects of a patient’s life that can affect physical or mental health; this includes physical and mental health perceptions and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status (19).

In addition to measuring the patient's health, assessment of quality of care by patients also concerns their care experience. The care experience includes several dimensions. The dimensions studied particularly include those where improvements are expected, such as patients’ compliance with treatment and consideration of patient preferences (20). Other dimensions, such as information and coordination of care, are considered by patients as being dimensions of the care experience that could be improved upon (21). In France, the priority dimensions of the patient experience have been defined by professionals and patients: they concern the quality of chronic disease pathways, early diagnosis, announcement of the disease, patient involvement and long-term follow-up (1).

The evaluation of patient-reported outcomes, like the effectiveness and safety of care, is now well established in the context of clinical research. It shows benefits, particularly in the field of oncology (22), where recent clinical trials have demonstrated a link between the use of these measures in routine clinical practice and improved patient survival (23, 24). These studies demonstrating positive impacts support the interest of their widespread use in routine clinical practice.

To generalise the measurement of patient-reported quality, the involvement of all stakeholders is a prerequisite. The role of patients is important since this measurement is only possible with their participation. Similarly, the role of professionals is essential; these measures serve to give them additional information to improve care; they could even contribute to improving the satisfaction of professionals (25), but this will only be possible if professionals first have the intention, and then the means, to use these measures, which are often new for them. Finally, organisations are impacted, since the collection of these measures and their results may require adjustments to organisational processes and practices. The implementation of patient-reported quality measures in routine clinical practice - potentially beneficial on all levels - therefore requires collective participation.

The growing public interest in concepts such as quality of outcome and patient experience suggests that it is useful to explicitly define these concepts and to clarify their challenges (chapter 2). The measurement of care outcomes and patient experience quality is already implemented in clinical research and is used in routine clinical practice to improve the quality and safety of care, in particular in initiatives in other countries, which will be described in an international panorama, including France (chapter 3). The main impacts of the use of these measures on the quality of care will then be described, as well as the barriers and facilitators for their implementation in routine clinical practice (chapter 4).

2. Quality of care as perceived by patients: the different types of measures and their challenges

Measuring the quality of care as perceived by patients includes three different approaches: 1) measuring the care outcome, 2) measuring the care experience and 3) measuring satisfaction with care.

2.1. Patient-Reported Outcome Measures (PROMs)

The outcome as perceived by the patient is known as the **Patient-Reported Outcome** (PRO). This covers "any report of the status of a patient's health condition that comes directly from the patient, (without interpretation of the patient's response by a clinician or anyone else)" (26, 27). There are different types of patient-reported outcomes: symptoms experienced (e.g. pain, fatigue, anxiety), functioning (e.g. washing, getting dressed, walking) and quality of life (see Box 3). These patient-reported outcomes reflect patients' vision of their disease and their treatments (20, 28).

2.1.1. Measuring patient-reported health outcomes

Instruments used to measure patient-reported outcomes (PROs) are known as **Patient-Reported Outcome Measures** (PROMs). PROMs are questionnaires, accompanied by documentation specifying information such as methods of administration scoring, analysis and interpretation. PROMs can be used to obtain important information that is not collected using conventional clinical measurements.

PROMs can be administered in different ways: either via self-administered questionnaires by the patient; self-administration of the questionnaire is done on paper or on an electronic medium (e.g. computer, mobile phone, tablet); or during interviews (e.g. patients are questioned and their answers are entered by a professional during a face-to-face or telephone interview). If necessary, the patient's responses can be entered by a proxy such as a carer, relative or family member[11].

PROMs can be collected at different times, enabling changes in the patient's health to be detected. To use PROMs in clinical practice, it is necessary to: 1) collect PROMs on one or more occasions, 2) have their results available at the right time. For example, to assess the efficacy of a surgical procedure, the patient will be asked to respond to PROMs before and after the procedure; to monitor the health of a patient with a chronic disease, the patient will be asked to respond to a PROM several times during the course of the disease (31).

Numerous PROMs have been developed[12]; there are thousands of them and their numbers are increasing every day (32, 33). Depending on the type of population targeted by PROMs, these instruments are described as either generic or specific.

2.1.2. Generic PROMs

Generic PROMs are instruments measuring care outcome dimensions that are applicable in all clinical situations. They can therefore be administered to all patient populations. In practice, the most widely

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[11] Concerning possible differences according to the type of respondent, these are particularly observed in certain populations, such as the elderly and people with disabilities, whose proxies tend to report more limitations (29). Patient-reported and proxy-reported responses lead to similar results on average (30).

The [12] PROQOLID (Patient-Reported Outcome and Quality of Life Instruments Database) is a PROMs database. Mapi Research Trust. https://eprovide.mapi-trust.org/

used generic PROMs are PROMs measuring health-related quality of life. The 36-Item Short Form General Health Survey (SF-36) (34) and the EuroQol Group 5-Dimension Self-Reported Questionnaire (EQ-5D) (35) are instruments that have long been used; other instruments are more recent, such as the PROMIS-29 questionnaire derived from the Patient-Reported Outcomes Measurement Information System (see Table 1).

Table 1. Examples of generic PROMs

Questionnaire	**Short Form (SF)**		**EQ-5D**	**PROMIS**	
Questionnaire version	SF-36	SF-12	EQ-5D-3L, EQ-5D-5L	PROMIS-29	PROMIS-10 GH
Measured outcome	Health-related quality of life				
Number of items	36	12	6	29	10
Administration time (minutes)	10	2	8	10-15	2
Adaptive questionnaire (minutes)	-	-	-	2-3	-
French translation	Yes	Yes	Yes	Yes	Yes
Reading difficulty	Relatively easy	Relatively easy	Normal	Relatively easy	Relatively easy
Number of dimensions	8	8	5	7	5
Number of items: general health	6	1	1	-	1
Number of items: physical health – symptoms	2	1	1	8	2
Number of items: physical health – capacity	14	4	2	8	2
Number of items: mental health	12	5	1	8	2
Number of items: social health	2	1	1	4	2
Number of items: other	-	-	-	1	1
Licence fees	Applicable	Applicable	Applicable	Free	Free

SF-12: short version of the SF-36 questionnaire;
EQ-5D-3L and 5L: 3 and 5-level EQ-5D questionnaires;
PROMIS-10 GH: PROMIS-10 Global Health questionnaire

Source: adapted from Bryan *et al* (36)

Table 2. Example of questions from a generic PROM

The WHO-5 questionnaire (WHO well-being scale) is a short generic PROM that can be used in clinical practice as a screening tool for depression in adults (37).

Over the past 2 weeks…:	All of the time	Most of the time	More than half the time	Less than half the time	Some of the time	At no time
– I have felt cheerful and in good spirits	☐	☐	☐	☐	☐	☐
– I have felt calm and relaxed	☐	☐	☐	☐	☐	☐

– I have felt active and vigorous	☐	☐	☐	☐	☐	☐
– I woke up feeling fresh and rested	☐	☐	☐	☐	☐	☐
– My daily life has been filled with things that interest me	☐	☐	☐	☐	☐	☐

Source: WHO-5 questionnaire

Generic PROMs are used for making comparisons: between outcomes for the same individual, between outcomes for different patient and non-patient populations; over time and relative to reference data. The results of these comparisons need to be interpreted with caution, however, due to certain limitations (20):

- generic PROMs do not guarantee completely valid comparisons: comparisons are potentially biased because the psychometric characteristics of generic PROMs may vary depending on the groups analysed;
- generic PROMs may ignore some aspects that are important from the point of view of certain patient subgroups, generic PROMs contain questions that may seem irrelevant to them, possibly leading to missing or incorrect data;
- generic PROMs are not very sensitive for detecting specific problems; they therefore do not enable the evolution of outcomes to be precisely monitored;
- the most commonly used generic PROMs, such as the SF-36 and EQ-5D questionnaires, were designed as “fixed” questionnaires. The latter are themselves adaptations of pre-existing generic instruments; however, they no longer evolve to take into account new issues or those whose formulation changes over time.

In sum, generic PROMs have certain limitations that no longer encourage the development of this type of questionnaire. They are increasingly giving way to new tools, such as item banks. Item banks can have both generic and specific items, so they can be relevant to all patients.

2.1.3. Specific PROMs

Specific PROMs are instruments that measure outcomes that are important for particular target populations or particular outcome dimensions. These instruments focus either on a disease (e.g. depression, asthma, etc.), a group of patients (e.g. children, cancer patients, etc.), or an outcome dimension (e.g. pain, mobility, etc.).

Specific PROMs are sensitive instruments[13], i.e. they are able to precisely detect differences (e.g. detection of a difference in outcome between two treatment strategies, monitoring of outcome over time), which is one of the benefits of specific PROMs in terms of their use in clinical practice.

However, specific PROMs do not always enable comparisons to be made between the outcomes of patients with different diseases, since the specific PROMs used may differ from one disease to another (38). Where comparisons are possible, care should be taken to ensure that the following methodological conditions are met[14].

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[13] Specific PROMs are sensitive because they measure important dimensions of the outcome, hence the existence of different specific PROMs for different patient populations. Specific PROMs include questions that are relevant to the patients they target, and therefore improve the acceptability of the questions (e.g. by increasing response rates and minimising missing data). To determine important outcome dimensions, recommended questionnaire design methods include conducting interviews with patients, followed by statistical analyses to ensure that the identified dimensions are measured comprehensively and consistently in the questionnaires.

[14] New developments in scaling theory are in the process of being applied to enable this comparison; thus, comparison may become possible provided that the specific instruments used measure the outcome based on the same statistical model (20).

Table 3. Example of questions from a specific PROM

The KOOS-PS[15] questionnaire measures patients' knee function by asking them the degree of difficulty they have experienced when performing everyday activities.

The following questions concern what you are capable of doing.

For each of the following activities, please indicate the degree of difficulty you have experienced in the last eight days due to your knee problem.

	None	Mild	Moderate	Severe	Extreme
– Rising from bed	☐	☐	☐	☐	☐
– Putting on socks/stockings	☐	☐	☐	☐	☐
– Rising from sitting	☐	☐	☐	☐	☐
– Bending to floor to pick up an object	☐	☐	☐	☐	☐
– Twisting/pivoting on your injured knee	☐	☐	☐	☐	☐
– Kneeling	☐	☐	☐	☐	☐
– Squatting	☐	☐	☐	☐	☐

Source: KOOS-PS questionnaire

Complementarity of generic and specific PROMs

Generic PROMs and specific PROMs are complementary instruments that present respective advantages (see Table 4. A few characteristics of generic and specific PROMs). It is useful to administer them at the same time, as is usually the case in clinical research studies; this provides both a global and an accurate vision of the patient's perceived health; the combination of generic and specific PROMs is thus used to improve the quality of care (15, 39, 40).

Table 4. A few characteristics of generic and specific PROMs

	Generic PROMs	Specific PROMs
Population	– Applicable to all populations (patients and non-patients)	– Applicable to specific patient groups (e.g.: patients, care sectors)
Dimension	– General dimensions – Questions potentially not very relevant for certain patient groups	– Specific dimensions – Questions relevant for the patient groups concerned – Major clinical value
Comparison	– Comparisons possible between different patient groups (e.g.: patients, care sectors)	– Comparisons not always possible with other patient groups or with the general population
Sensitivity	– Not very sensitive for detecting specific problems	– Sensitive for detecting and monitoring specific problems

Source: adapted from the PROMs Background Document produced by the Canadian Institute for Health Information (CIHI) (31)

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[15] The KOOS-PS (Knee injury and Osteoarthritis Outcome Score – Physical Function Short Form) has 7 items, which are part of a subscale of the KOOS questionnaire, designed to assess difficulties experienced by patients during their activities due to their knees problem. http://www.koos.nu/koospsfrench.pdf

Combining generic and specific PROMs is useful to get a better understanding of the patient's perceived health. However, the administration of several questionnaires can be cumbersome for both patients and professionals. The process can be simplified thanks to new tools such as item banks.

PROMs item banks

An item bank is a catalogue of questions with, for each of them, a description of their content and other measurement characteristics, such as validity, reliability, item difficulty (41).

Item banks offer several advantages over traditional questionnaires, including greater reliability for comparison of outcomes and their ability to evolve (42):

- scores can be compared directly with each other, as all items are measured on the same scale, thus eliminating the problems of comparing scores between different questionnaires;
- scores can be compared over time, as the measurement scale (mean and standard deviation) remains stable over time, despite new versions or the addition of items;
- new measures (e.g. on specific dimensions or populations) can be easily constructed, based on items with known characteristics.

Item banks enable adaptive administration using electronic media (Computerized Adaptive Testing, CAT).

- The principle of CAT is to administer items selected on the basis of responses to previous items. For example, if a first question asking the patient to rate their degree of perceived difficulty in climbing stairs is answered with “extremely difficult”, then it assumes a low level of physical function. The next question, chosen automatically by the algorithm, will be more adapted, this time asking the patient to rate their difficulty for a simpler activity.
- The adaptive administration of items requires a small number of questions to obtain an accurate score. The administration of items (usually about ten) continues until a score is obtained with a predetermined level of precision. Compared to traditional questionnaires which can be lengthy, adaptive administration reduces the burden and completion time for patients (43).

Item banks can be adapted over time, provided there is continuous development to test and add new items. Development methods use measurement techniques such as the Rasch model and item response theory (IRT).

An example of an item bank: the PROMIS bank

- The Patient-Reported Outcomes Measurement Information System (PROMIS) is a large collection of item banks including generic and disease-specific measures that address different dimensions of health-related quality of life.
- PROMIS is being developed as part of a programme of the National Institute of Health (NIH), which creates item banks using modern development methods (e.g. IRT). The robust psychometric properties of PROMIS are an advantage for its use. The item banks included detail the functioning of PROMs in different populations. Several translations are available, including into French.
- In PROMIS, item banks can be used for different needs, employing appropriate instruments: short questionnaires to measure one dimension (Short Forms), adaptive questionnaires (CAT), questionnaires to measure several dimensions (Profiles).

Box 4. Example of chronic kidney disease and PROMIS-29

PROMIS-29 is one of the Profiles of the PROMIS system. This generic questionnaire assesses seven dimensions of health-related quality of life: physical function, anxiety, depression, fatigue, sleep disturbance, ability to participate in social roles and activities, and pain. Each dimension has 4 items; each item is evaluated on a 5-level scale; in addition, pain intensity is assessed on an 11-level scale.

PROMIS-29 is one of the PROMs recommended in chronic kidney disease

– In chronic kidney disease (CKD), the generic PROMIS-29 questionnaire is one of the measures for the follow-up and improvement of care recommended by the ICHOM (44). PROMIS-29 is a questionnaire validated in the specific population of kidney transplant recipients (45). This instrument is preferred to the specific PROMs that exist for chronic kidney disease, such as the specific KDQOL-36 (46) questionnaire, which is not recommended by the ICHOM due to the high number of items.
– In France, a national initiative aimed at bundled payment of CKD care envisages incorporating the use of PROMIS-29. Other generic PROMs, such as EQ-5D-5L and SF-12 are recommended by professional organisations (47).
– The use of different PROMs for chronic kidney disease may impede comparison of results between different patients. Nevertheless, in order to enable the comparison of results, scientific studies are seeking to validate the equivalence of results from one instrument to another. Research has shown, for example, that it is possible to match the results of the PROMIS-29 and EQ-5D-5L questionnaires (48).

Using measures such as PROMIS-29, in combination with clinical measures, makes it possible to assess the overall quality of care, including health-related quality of life, and can improve the management of dialysis patients.

– Dialysis outcomes are usually based on clinical measures, but the achievement of clinical goals is not always correlated with an improvement in patients' quality of life, as measured with PROMIS-29, for example. Clinical outcomes can thus be achieved without improving patient-reported outcomes, such as quality of life, hence the interest in the complementary use of measures such as PROMIS-29 to implement interventions aimed at improving patient-reported quality of dialysis care (49).
– The risk of falls in haemodialysis patients is associated with a deterioration in objective clinical measures such as patients' muscle strength. The risk of falls is also correlated with patients' psychosocial difficulties (e.g. depression, isolation), as demonstrated on subjective measures assessed by PROMIS-29. Using PROMIS-29 in this way can therefore show how other strategies for improving the quality of care of dialysis patients can be identified (50).

Box 5. Example of the use of PROMs in Covid-19

In the **management of Covid-19 illness**, the use of PROMs plays a central role according to some authors (51):

1. symptom reporting using PROMs can facilitate diagnosis of Covid-19; PROMs can help target individuals who need to be tested and can thereby trigger the “tests-track-isolate” strategy for new patients;
2. by enabling remote monitoring of patients, electronic PROMs can help identify those patients with severe symptoms who are in need of urgent care and those with mild-to-moderate symptoms who can continue to be managed at home.

– Remote monitoring of patients is illustrated by a French initiative at the Institut Gustave Roussy, where cancer patients whose PROMs results suggest Covid-19 infection are either referred to the hospital or tested at home. Patients with a positive Covid-19 test can enter a follow-up programme, after providing their consent, where they are initially assessed by a nurse and then followed up with regular collection of PROMs. PROMs results automatically generate alerts, enabling nurses to refer patients to the necessary care (52).
– Three months after the onset of Covid-19 symptoms, PROMs results from hospitalised patients, with or without pre-existing comorbidities, may demonstrate the persistence of symptoms, including dyspnoea and deterioration in quality of life. These results, which are consistent with previous results presented on other criteria, demonstrate the existence of persistent symptoms following Covid-19 (53).

2.2. *Patient-Reported Experience Measures* (PREMs)

Patient-reported experience can be defined in several ways. Different organisations have proposed their own definitions of patient experience. The US Agency for Health Research and Quality (AHRQ) proposes the following definition.

> **Patient experience** encompasses "the range of interactions that patients have with the healthcare system, including their care from doctors, nurses, and staff in hospitals, physician practices, and other healthcare facilities. As an integral component of healthcare quality, patient experience includes several aspects of healthcare delivery that patients value highly when they seek and receive care, such as getting timely appointments, easy access to information, and good communication with healthcare providers[16]".

Box 6. Patient experience

All patients want to be treated with respect, dignity and courtesy, and have their rights to information and privacy respected. Knowing that access to appropriate health services is available when needed, having physical and emotional support from competent healthcare professionals, being listened to and treated with empathy and understanding, and having coordinated care, delivered at the right time, are all elements of the expected patient experience.

Patient experience is a multidimensional concept; it therefore includes many aspects of care and its processes, such as appointment booking, cleanliness of premises, waiting times, information received and interactions with staff such as nurses and doctors.

Table 5. Patient experience dimensions

Institute of Medicine (IOM), USA	National Health Service (NHS), England	International Alliance of Patients' Organisations (IAPO)
– Respect for patient's values, preferences and needs	– Respect for patient's values, preferences and needs	– Respect
– Coordination and integration of care	– Coordination and integration of care	– Choice and empowerment
– Information, communication and education	– Information, communication and education	– Patient involvement in health policy
– Physical comfort	– Physical comfort	– Access and support
– Emotional support and alleviation of fear and anxiety	– Emotional support and alleviation of fear and anxiety	– Information
– Involvement of family and friends	– Involvement of family and friends	
	– Transition and continuity of care	
	– Access to care	

Source: adapted from NICE clinical guideline, 2012 (56)

Different dimensions of patient experience have been defined to facilitate measurement. These different dimensions have been formalised, on an international level or depending on context and priorities, by organisations such as academic institutions, research projects or user associations. Building on early work in this area (57), the dimensions of patient experience thus advocated are used in many countries, including England, to assess system performance (see. Table 5).

Patient experience dimensions are consensus-based. All the dimensions of the patient's experience make it possible to take into account the globality of the patient's interactions with the system; these dimensions are similar depending on the proposed models and, furthermore, are confirmed since the same ones are found in surveys of international experts (58).

Not all dimensions of patient experience are equally measured; patient information is a more important dimension than other dimensions, such as coordination and respect for patient preferences (59). Measuring patient experience remains useful, however, because when it is good, it is associated with higher levels of patient compliance with the recommended

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[16] This global definition of patient experience is similar to other definitions proposed by organisations such as the Beryl Institute (54). For the WHO, patient experience is a process indicator and reflects the interpersonal aspects of quality of care received. This indicator is broadly composed of three domains: effective communication; respect and dignity; and emotional support (55).

medical treatment and it improves clinical outcomes, as well as safety, by reducing complications and/or side effects (60, 61). Similarly, when patient information is good - the patient understands and accepts the need for treatment - compliance is improved. Improved patient experience also leads to better use of preventive services (e.g. screening for diabetes, high cholesterol, colorectal, breast and cervical cancers), as well as a positive impact on the use of primary and secondary care resources (e.g. reduced outpatient care, hospital admissions, readmissions) (61).

2.2.1. Measuring the patient-reported care experience

Numerous methods exist to assess the patient-reported experience; they all include the patient but differ in their approach. For example, some methods adopt a qualitative approach, such as individual patient interviews, narrative medicine, focus groups, analysis of administrative data, written complaints or free comments. Other methods adopt a quantitative approach, such as analysis of questionnaires, or a mixed approach (62).

Patient experience data can be used to improve the quality of care. This improvement of care via patient experience feedback can be classed into 4 categories: 1) care provider-initiated quantitative surveys, such as PREMs surveys in care facilities; 2) user-initiated qualitative feedback, such as complaints or social media comments; 3) hospital-initiated qualitative feedback, such as the patient tracer method; 4) other feedback, such as satisfaction scores (63).

Patient-Reported Experience Measures (PREMs) are instruments to measure the patient experience. These instruments, with their quantitative approach, are the most widely used method for assessing the experience as perceived by the patient. Like PROMs, PREMs are usually self-administered by the patient (64); the responses may also be entered by a proxy, such as the patient's carer, if necessary.

PREMs measure one or more dimensions of the patient experience (e.g. quality of information received, attention paid to patient pain, waiting times, relationships and interactions with care providers). PREMs are used more to measure quality of care at health organisation level, rather than clinical practice level.

Box 7. Examples of PREM questions

PREMs measure the patient experience using either an objective or a subjective approach, sometimes combining both by "drawing on both the factual elements of care episodes and patients' perceptions of the quality of care and services received" (65).

For example, by asking the patient how long they waited, and then asking them if they thought the wait was too long, both the length of the wait - objectively (e.g. on a time scale) - and the acceptability of the wait - which is a more subjective measure - are measured (66). The objective approach is more easily interpreted (see examples 1 to 3) and is therefore more likely to lead to improvement actions. Furthermore, subjective measures (see examples 4 and 5) generally give very positive responses (ceiling effect) resulting in fewer improvement actions (67).

Example 1: - Did you receive a patients' welcome booklet?

	☐ Yes	☐ No	☐ I don't remember

Example 2: Did the doctors or surgeons pay attention to what you said?

	☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

Example 3: Did you spontaneously receive (without asking) explanations on your health treatments, care, etc.?

	☐ Never	☐ Rarely	☐ Sometimes	☐ Often	☐ Always

Example 4: What do you think of the clarity of the answers given by the doctors or surgeons in the unit?

	☐ Poor	☐ Marginal	☐ Fair	☐ Good	☐ Excellent

Example 5: What do you think of the support provided by the nurses or healthcare assistants in charge of your care?

	☐ Poor	☐ Marginal	☐ Fair	☐ Good	☐ Excellent

Source: e-Satis + 48 h MCO questionnaire[17]

2.2.2. Generic and specific PREMs

Like PROMs, PREMs may be generic or specific. They are commonly used, on a national level, in some countries (69-71).

Generic PREMs are potentially relevant to all patients. They include questions that can be administered to all patients, regardless of their illness (e.g. did you feel worried or anxious during your hospital stay?). They may focus on particular departments, sectors of care (e.g. hospital admissions, emergency care, community care, home care, maternity care, psychiatric care, etc.).

Specific PREMs focus on patients' experience of particular diseases or conditions (e.g. diabetes, rheumatoid arthritis, asthma, mental health, cancer, etc.).

Patient experience dimensions are consensus-based (see Box 6). However, in practice they remain difficult to capture and therefore to collect. This difficulty may impact the reliability of some PREMs in terms of capturing the dimension(s) studied, thus measuring experience with a certain degree of variability (72). According to the experts, it is important to first clearly define the concepts and dimensions

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[17] The e-Satis + 48 h MCO (medicine, surgery, obstetrics) questionnaire is administered to patients hospitalised for at least 48 hours for medical, surgical and obstetrical care in a healthcare institution in France (68).

to be measured (73), since they may differ depending on the contexts; adaptations are then recommended (74).

The choice of PREMs is very important. It is crucial that PREMs measure experience dimensions that matter to patients and those that are associated with quality of care. The choice of PREMs is even more important when they are liable to be used for funding purposes (75, 76). Thus, PREMs with verified psychometric properties should be chosen to ensure their reliability and validity (77).

2.3. Measuring patient satisfaction

Patient satisfaction is a multidimensional concept, which is not very clearly defined and for which there is no scientific consensus as to its definition, or which dimensions should be included or considered important (78, 79)[18].

> **Satisfaction** is influenced by the patient's expectations and preferences; it reflects the degree of congruence between expectations of care and the perceived quality of the care provided (81).

Thus, in a situation where two patients receive exactly the same care leading to the same outcome, the two patients may have different expectations, and their satisfaction with the treatment and its outcome will therefore differ. Interpreting degrees of satisfaction is difficult because they depend on people's preferences, health status, characteristics and culture, in addition to the quality and outcome of care.

Patient satisfaction is measured by instruments such as patient self-administered questionnaires. Numerous instruments measuring satisfaction have been developed and used for different diseases and different sectors of care (see Table 6).

Table 6. Example of satisfaction questions

On my arrival at the hospital:	Better than expected	As expected	A little worse than expected	Quite a lot worse than expected	Very much worse than expected
– Administrative staff registered me quickly (short wait)	☐	☐	☐	☐	☐
– Administrative staff were helpful and kind	☐	☐	☐	☐	☐
– Concerning my care, the coordination between the different administrative departments was good	☐	☐	☐	☐	☐

Source: QSH-45 satisfaction questionnaire for hospital patients (82)

Satisfaction is associated with quality of care. Long a controversial issue, the relationship between satisfaction and quality of care has now been established, but it still needs to be clarified. This complex relationship is illustrated in the quality of surgical care (see Box 8).

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[18] Satisfaction dimensions can address all aspects of care. Overall, patient satisfaction concerns: quality and accessibility of care, availability of health services and structures, access to affordable care, patient information and participation. More specifically, satisfaction relates to elements such as quality of care, which includes the skills of caregivers, particularly for appropriate diagnostic and therapeutic care (80), appropriate information about the disease and its treatment, fair access to prevention, diagnosis and treatment (81).

Box 8. Satisfaction with surgical care

Studies based on robust data show that patient satisfaction with surgery is associated with better clinical outcomes. They refute some of the previous literature rejecting this positive correlation. They show, for example, that satisfaction scores are positively correlated with the quality of surgery, measured objectively by clinical outcome indicators such as occurrence of complications, recovery from complications and death (83-86).

Patient satisfaction is closely correlated with a response to patients' pre-operative expectations, particularly with respect to the degree of activity recovered, as in knee replacement surgery, for example. Patients with very high expectations, for example expecting to return to strenuous activity after surgery, or those experiencing post-operative complications and pain, are generally less satisfied with the outcome of the procedure (87, 88).

Patients' pre-operative expectations are not systematically correlated with PROMs after surgery. Some studies demonstrate a correlation between fulfilment of expectations and improved PROMs; others demonstrate fulfilment of expectations despite worse PROMs; and some studies find no link between pre-operative expectations and PROMs (88).

These results demonstrate the complex relationship between satisfaction and some quality of surgical care measures. Satisfaction encompasses more than just the quality of care (89). Furthermore, this relationship is not linear; the best degrees of satisfaction are not systematically associated with the best surgical quality outcomes; this may be due to satisfaction being more related to the patient's expectations and present health; it may also be due to the fact that the patient only remembers key periods rather than the entire care process. Finally, satisfaction remains difficult to capture because it is closely linked to patient characteristics – such as age, gender, ethnicity and socio-economic status, which are independent of the quality of care (90) – and because of its multiple dimensions and the different instruments used, which only imperfectly measure patient satisfaction (85).

Given the limitations of satisfaction measurement (see Box 9), some authors propose not measuring it. Others think, on the contrary, that it is still useful to measure satisfaction (91), while other experts recommend other measures, such as the measurement of patient experience, which is a more discriminating and relatively more objective measure of the quality of care. Indeed, satisfaction and experience are different concepts (see Box 10); there are advantages and limitations to measuring them both, making them measures that may be complementary (81, 92-96).

Box 9. Criticisms of patient satisfaction measurement

A first criticism is the lack of consensus with respect to the definition of satisfaction; this is explained by the multitude of research studies that have been undertaken on patient satisfaction, before the concept was clearly defined; several definitions specific to each discipline have been proposed, without any real consensus-based definition having emerged (80).

A second criticism is the subjectivity of satisfaction, since the patient's perception and values are assessed. However, on the contrary, this subjectivity can be seen as an advantage since it incorporates a psychological dimension into the patient’s assessment of their care.

The limitations of instruments measuring patient satisfaction notably include their low discriminatory power; this is illustrated by high satisfaction scores; these very positive scores (e.g. 75% to 90% of patients satisfied or very satisfied) do not identify problems relating to the quality of care.

Box 10. Distinction between the concepts of patient experience and patient satisfaction

Patient experience and patient satisfaction are often confused, but the two concepts are distinct. This stems from the similarity between satisfaction questions and “subjective” experience questions, which are sometimes seen as being equivalent (see Box 7).

Patient experience is different from satisfaction, as experience is considered to be less subjective. For example, a patient may be satisfied with their care despite a negative experience; the reverse is also possible (67). By asking the patient what happened during their care, the measurement of experience makes it possible to obtain a description of the facts.

Questions are considered to relate to satisfaction when a degree of satisfaction is specified in the response modalities (e.g.: very dissatisfied; dissatisfied; satisfied, very satisfied) (97). Hence, despite being similar because of their common approach, which is a subjective evaluation, the concepts of experience and satisfaction are actually quite distinct.

Although the measurement of satisfaction has limitations, it provides additional and useful information on the quality of care. When satisfaction is combined with other patient-reported quality information such as outcome and perceived experience of care, then together they provide a more complete picture of the quality of care. Overall, with a view to global assessment by the patient of the quality of care, satisfaction measures, PREMs and PROMs appear to be complementary and of joint interest.

2.4. Measuring patient-reported quality to improve the overall quality of care

Patient-reported quality measures such as PROMs, PREMs and satisfaction measures can be levers for improving the quality of care at different levels. Three levels of use (*micro-meso-macro*) of these measures are described in the literature (98-101):

1. the *micro* level concerns interactions in the clinical relationship between patients and healthcare professionals;
2. the *meso* level concerns the description of practices and outcomes at health care provider level (e.g. assessment of the level of health of patients in a healthcare facility);
3. the *macro* level concerns a description of the health of populations for epidemiological and health policy purposes.

Several potential benefits on the quality of care are envisaged depending on these three levels of use.

2.4.1. Completing the clinical picture and supporting good professional practice

In routine clinical practice, the patient's perspective provides additional information since it may differ from that of the healthcare professional.

Indeed, since the patient's health can be assessed by the professional on the one hand and by the patient on the other, there may be discrepancies between these two assessments. For example, when assessing adverse effects, healthcare professionals may either under-diagnose them or grade them on a lower severity scale than the level judged by the patient (102-105).

Similarly, there are differences between patients and healthcare professionals in terms of prioritising aspects of care (106), hence the importance of improving engagement, in particular by developing shared medical decision-making between professionals and patients (107, 108).

The improvement in the quality of care enabled by measurement of patient-reported quality may be due to its impact on care. Patient-reported quality is an outcome that, when taken into account by professionals, can influence their practices by generating actions such as the prescription of additional tests, referral of the patient to a specialist, adaptation of medical or drug treatments, delivery of information such as patient education, and adaptation of treatment goals to bring them into line with patients' needs and preferences (109).

Thus, measuring patient-reported quality may contribute to improving the quality of care on an individual level, via:

- a patient-centred approach through the implementation of personalised care, notably due to consideration of patients' concerns and needs (110, 111);
- improved diagnosis of diseases and their severity, more regular or systematic assessment of the effectiveness of care and monitoring of disease progression (112, 113);
- improved patient information, communication and shared medical decision-making (69, 114-117).

2.4.2. Participating in quality improvement processes

These measures are expected to provide information of interest to healthcare professionals and organisations. The expected benefits motivating their roll-out are as follows.

They are useful for healthcare professionals since they provide information on their practices or enable them to compare themselves with their peers. They can highlight variations in practices and outcomes, and help identify effective strategies at care provider level. All in all, they can be used to improve quality of care in the same way as with other comparison-based quality assessment instruments (118).

The improvement mechanisms envisaged are the same as those used in other types of assessment: the comparison of healthcare professionals and organisations, on the one hand, stimulates the ethos of professionals to want to improve intrinsically, and, on the other, encourages improvement in order to avoid the negative impacts of comparatively poorer outcomes, particularly in terms of reputation (119).

Although the comparison of outcomes is not, in itself, a means of directly identifying the causes of quality variations, it nonetheless provides an incentive to conduct internal assessments that are able to identify the causes of variation. Furthermore, healthcare organisations and professionals can learn from the best practices identified.

Thus, measuring patient-perceived quality helps to improve quality of care on a collective level, via:

- the transparency of outcomes, enabling comparison, highlighting variations and identifying best practices, all useful information for implementing actions designed to improve quality of care (98, 120);
- user choice, in favour of the care providers most likely to meet their expectations, with care providers aiming to improve their services (118).

2.4.3. Supporting quality-based regulation by public authorities

Finally, these measures are also envisaged as an information tool for steering health policy at different levels (national, regional, territorial, etc.) and as an aid to decision-making and impact measurement. They can thus be used to 1) monitor the health of populations, and 2) identify improvement actions to be implemented, including with respect to regulation (contractualisation, public disclosure, financial incentives) (38, 98, 121).

3. Panorama of international experiences

This quest for quality improvement is the main objective driving the implementation of patient-reported quality measure initiatives in different health systems around the world, these sometimes having been in place for several decades in some countries (see box 11).

Through a selection of 13 English-speaking and European countries with advanced healthcare systems, different methods of collection and uses of patient-reported quality measures are presented (see table 7):

– seven European countries: Sweden, Netherlands, Norway, Germany, Denmark, Belgium, France;

– six English-speaking countries: England, Wales, USA, Canada, Australia, New Zealand.

These countries were chosen (see Box 11) because they report both PROMs and PREMs (details in Tables 9 and 10 of **Annexe 2**) with sufficient information concerning the collection level and habitual uses of quality measures to be able to list them (see Boxes 12 and 13) in an overall table (see table 7).

The impacts of use of PREMs and PROMs are detailed in part 4.

Box 11. History of research relative to the collection of the patient perspective

The earliest work relating to the collection of patients' perspectives dates back to the 1970s (Sweden, England, the Netherlands and the USA) and was based on registries in which patient-reported quality measures were recorded. This is the case for Sweden, for example.

Routine use of these measures became more widespread from the mid-1990s onwards in English-speaking countries (England, Wales, USA, Canada, Australia, New Zealand) and Northern European countries (Sweden, Norway, Denmark), followed in the 2000s by other European countries (Germany, Belgium, France).

Most OECD countries have at least one national data collection of PREMs (Korea, Hungary, Israel, Singapore, Czech Republic, Ireland, Finland, Italy, Spain, Portugal, etc.) and more and more countries are starting to set up compendia of PROMs (Ireland, Finland, Israel, etc.), but national initiatives remain more limited than for PREMs.

In this report, only the most advanced initiatives are presented. They concern either countries that are leaders in the collection of PROMs and PREMs (national collection system or collection in national registries), or countries in which a national/regional collection system is in the process of being developed.

Table 7. Levels of collection and use of PROMs and PREMs in the 13 selected countries

Country			PROMs							PREMs						
	Size		Collection level			Use				Collection level			Use			
	Pop (M)	Beds/10^3 Inhab.	N	R	L	C/B	AC	PD	PP	N	R	L	C/B	AC	PD	PP
Sweden (7, 16, 70, 71, 122-127)	10	2.1	📍		📍	✔	✗	✔	✔	📍		📍	✔	✗	✔	✔
Netherlands (7, 16, 65, 69-71, 122, 126-130)	17	3.1	📍		📍	✔	✗	✔	✔	📍			✔	✗	✔	✔
Norway (16, 65, 70, 71, 131, 132)	5	3.5	📍		📍	✗	✗	✗	✓	📍			✔	✗	✔	✔
Germany (16, 70, 71, 122, 127, 130, 133-135)	83	8			📍	✗	✗	✗	✔	📍	📍		✔	✗	✔	✗
Denmark (16, 70, 136-141)	5.6	2.6			📍	✗	✗	✗	✓	📍			✔	✔	✔	✗
Belgium (16, 69, 70, 142)	11.4	5.6	📍	📍	📍	✔	✗	✗	✔	📍	📍		✔	✗	✔	✔
France (16, 68, 70, 71, 143, 144)	70	6			📍	✔	✗	✗	✗	📍			✔	✔	✔	✔
England (7, 16, 65, 70, 71, 126, 127, 130, 135, 145-153)	66	2.5	📍			✔	✗	✔	✗	📍			✔	✗	✔	✔
Wales (16, 70, 152, 154)	3	4.4	📍			✔	✗	✗	✗	📍			✔	✗	✗	✗
USA (14, 16, 65, 71, 122, 126, 127, 155-165)	327	2.8	📍	📍	📍	✔	✗	✔	✔	📍			✔	✗	✔	✔
Canada (16, 31, 65, 70, 71, 126, 130, 166-168)	37.6	2.5		📍	📍	✔	✗	✗	✗		📍	📍	✔	✔	✔	✔
Australia (7, 16, 70, 71, 122)	36.5	3.8	📍		📍	✔	✗	✗	✓	📍	📍	📍	✔	✔	✔	✓
New Zealand (16, 70, 71, 122, 169, 170)	4.8	2.6	📍		📍	✔	✗	✗	✗	📍	📍		✗	✗	✔	✔

Key

Use

- C/B: comparison and/or benchmarking
- AC: accreditation of care structures (certification in France)[19]
- PD: public disclosure of results
- PP: pay for performance

Use situation

✓ : done

⊗ : not done

🕓: not done currently but scheduled

Comparison/benchmarking

✓ : comparison+/- benchmarking

⊗: neither comparison, nor benchmarking

Collection level

- N: national
- R: regional (or provincial)
- L: local

Collection situation

📍 : done

Size

- Pop. (M): population in the country
- Beds/10^3 inhab: average number of beds per 1,000 inhabitants

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[19] See definition of accreditation in **Annexe 2**.

Box 12. Method used to analyse the countries selected

The choice of countries was based on the accessibility of information in scientific article databases, such as PubMed, and the grey literature; availability in English or French; and how long patient-reported quality measures have been used.

For each country, the PROMs and PREMs collection levels were specified since they varied from one country to another. These indicate the degree to which these measures are coordinated. Three levels were identified:

- national (country or federation);
- regional (region, state or province, territories, defined administrative areas);
- local.

The national level refers either to a national mechanism for coordinating the collection of validated PROMs and/or PREMs, or to the collection of PROMs/PREMs in at least one national registry.

The regional level refers to at least one regional mechanism for coordinating the collection of validated PROMs and/or PREMs, or to the collection of PROMs/PREMs in at least one regional registry. It can also concern a mechanism for coordinating the collection of PROMs in health territories (specific administrative division within a region).

The local level refers to the collection of PROMs/PREMs developed, validated and collected locally, in a hospital or a group of hospitals; to be distinguished from the local deployment of PROMs/PREMs that are part of a national initiative (e.g.: CMS). Only local initiatives found in the literature are reported in Table 7.

The uses of patient-reported quality measures investigated in each country are as follows:

- comparison with or without a benchmarking approach[20];
- accreditation of care structures (certification of healthcare facilities in France);
- public disclosure;
- pay for performance.

PROMs and PREMs uses are described in detail in the introduction to **Annexe 2**. In principle, they concern all care providers: healthcare facilities/hospitals and/or primary care structures in the community setting.

Additional information on the size and health capacity of countries is presented to support the comparison of countries and to estimate the level of difficulty in terms of organising the collection of measures: the country's population[21] and the number of hospital beds per 1,000 inhabitants[22].

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[20] A benchmarking approach is an ongoing effort to measure the results of care providers, compare them with other care providers, learn how these results are achieved and apply the lessons learned in order to improve.

[21] Different data sources: Eurostat in Europe, Office for National Statistics (ONS) in the UK, the World Bank, the Census Bureau in the USA, INSEE in France.

[22] OECD data for 2019 or the most recent year available. Link: https://data.oecd.org/fr/healtheqt/lits-d-hopitaux.htm

3.1. PROMs and PREMs collection initiatives

3.1.1. PROMs

Regarding patient-reported outcome measures (PROMs), the majority of countries have structured national initiatives (9 countries/13), sometimes accompanied by local initiatives (5 countries/13: Sweden, Netherlands, Norway, Australia, New Zealand), or even local and regional initiatives (2 countries/13: Belgium and USA).

Canada has initiatives in place at regional and local levels.

Germany and Denmark do not report initiatives at national and regional levels, allowing local development to take place. In Denmark, the National Health Data Authority has set up a working programme to establish a national routine PROM collection system in the near future.

In France, in addition to local initiatives and a regional initiative in the Aquitaine region[23], a reflection process is ongoing to develop a regional - or even national - mechanism, particularly in the context of the experimentations being conducted under Article 51 of the French Social Security Financing Act for 2018 (LFSS 2018)[24] (see box 13) or as part of research projects (see table 9, **Annexe 2**).

Box 13. PROMs collection initiatives in France

- The AP-HP's ComPaRe[25] public research platform enables patients with chronic diseases to voluntarily participate in research projects by completing online PROMs questionnaires.
- Patient associations such as Renaloo and its *Moi Patient*[26] ("Me Patient") platform propose PROM-type questionnaires.
- Within the framework of the bundled payments allocated for the care of chronic kidney disease patients, the PROMIS-29 questionnaire will be administered[27].
- As part of the national innovative organisations experimentations (article 51 of the LFSS 2018) for payment per surgical care episode[28] for three surgical procedures (hip replacement surgery, knee replacement surgery, colectomy for bowel cancer), healthcare professionals will be able to implement an approach for administering and using PROMs questionnaires, using tools that already exist[29].

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[23] Implementation of a PROMs collection initiative in HIV patients, as part of a project led by the ANRS, in 2018, in 13 Aquitaine hospitals.

[24] These experiments are as follows: Care episodes (EDS), incentives for shared care (IPEP), bundled payment in community healthcare professional teams (PEPS), bundled payments allocated to hospitals (chronic kidney disease) and PROMIS-29).

[25] ComPaRe research project website: https://compare.aphp.fr/

[26] *Moi Patient* platform website: https://www.moipatient.fr/

[27] Order of 27 December 2019 amending the order of 25 September 2019 relating to the bundled payments allocated to healthcare facilities for the care of chronic kidney disease patients, pursuant to Article L. 162-22-6-2 of the French Social Security Code. Link: https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000039699438?r=bYoZwNi5FZ

[28] Link to the presentation sheet of the payment per surgical care episode project: https://solidarites-sante.gouv.fr/IMG/pdf/20191011_eds_fiche_faq_vf.pdf

[29] User guide for patient questionnaires to measure care outcomes in the context of the "Care episode" trial - About 3 care episodes: elective total hip replacement; elective total knee replacement; colectomy for cancer. Link: https://www.has-sante.fr/upload/docs/application/pdf/2019-10/iqss_2019_aide_utilisation_proms_eds.pdf

- As part of the ICHOM project[30] (126, 171), some French healthcare facilities are participating in comparative analysis initiatives for several diseases or conditions: colorectal cancer[31]; breast and lung cancer[32]; cataract[33].

3.1.2. PREMs

Regarding patient-reported experience measures (PREMs), the majority of countries analysed have structured national initiatives (12 countries/13), sometimes accompanied by a local initiative (1 country/13: Sweden), or a regional initiative (3 countries/13: Belgium, Germany, New Zealand), or local and regional initiatives (1 country/13: Australia).

France has had a national system for measuring hospital patient satisfaction and experience (e-Satis) since 2016 (see box 14). In addition, a national system for collecting PREMs is currently being tested in the context of Article 51 of the 2018 French Social Security Financing Act (LFSS) (see box 15).

In Belgium, data collection is coordinated in the Flemish and Walloon regions, but there is national centralisation of PREMs data, in the Health Information Survey (HIS) (see table 10, **Annexe 2**).

Australia and New Zealand report national and regional initiatives; Australia also has local initiatives.

Canada and Germany report regional initiatives. Germany is planning to implement a national voluntary PREMs collection scheme (Patient Experience Questionnaire (PEQ)), following the creation of the Institute for Quality Assurance and Transparency in Health Care (IQTIG) in 2016 to coordinate quality management throughout the German healthcare system. The routine collection of PEQs is based on the voluntary participation of healthcare facilities. Data collection is coordinated at a regional level (see table 10, **Annexe 2**).

Canada also reports local initiatives.

Box 14. : The French national e-Satis system

The e-Satis system enables the collection of patient satisfaction and experience on a national level for hospital patients. This measurement is standardised through the use of validated patient questionnaires, common operational procedures for the hospitals involved and the patient respondents, and continuous assessment throughout the year. It is deployed across the country in three sectors: 1) in medicine-surgery-obstetrics for patients hospitalised for more than 48 hours, since 2016 (*e-Satis +48h MCO* survey[34]); 2) in outpatient surgery (*e-Satis chirurgie ambulatoire* survey[35]), since 2018; 3) in follow-on care and rehabilitation, since October 2020. Further work is underway for home hospital patients and mental health inpatients.

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[30] Link to ICHOM project: https://www.ichom.org/

[31] ICHOM - colorectal cancer: *IHU de Strasbourg*.

[32] ICHOM - breast and lung cancer: *Institut de cancérologie de l'Ouest* (Nantes), *Centre Léon Bérard* (Lyon), *Hôpital européen George Pompidou* (AP-HP).

[33] ICHOM – cataract (Catquest): the Value-Based Health Care Consortium (VBHC) France - an association tasked with accelerating the creation of standardised registries, evaluating care outcomes - has launched a trial to collect ICHOM indicators for cataracts (Catquest 9-SF) and has brought together around 40 ophthalmologists from 3 healthcare facilities: *Polyclinique Atlantique* (Nantes), *clinique François Chénieux* (Limoges), *CHU de Nantes*.

[34] Link: https://www.has-sante.fr/jcms/c_2030354

[35] Link: https://www.has-sante.fr/jcms/c_2844894

The results, enabling comparison and ranking, are made available to healthcare facilities. They are made public by the HAS. They are also used in a quality-based funding mechanism: the financial incentive programme to improve healthcare quality (IFAQ)[36].

Box 15. PREMs collection initiatives in France

- As part of the national innovative organisations experimentations (article 51 of LFSS 2018):
  - payment per surgical care episode[26] (article 51 of LFSS 2018), for three surgical procedures (hip replacement surgery, knee replacement surgery, colectomy for bowel cancer).
  - incentives for shared care (IPEP)[37], with financial incentives for health professional groups, to promote care coordination;
  - bundled payment in community healthcare professional teams (PEPS)[38].
- Patient associations such as Renaloo and its *Moi Patient*[27] platform propose PREM-type questionnaires.
- In the context of clinical research, such as the AP-HP's ComPaRe[26] public research platform, patients with chronic diseases voluntarily participate in research projects by completing online PREMs questionnaires.

3.2. The different uses of PROMs and PREMs in the 13 countries studied

3.2.1. PROMs and PREMs are often used for comparison, with or without benchmarking

Ten countries report the use of PROMs to compare their care providers.

This is the case of England, which compares the results of PROMs between National Health Service (NHS) care structures and carries out benchmarking in order to identify the strengths and weaknesses of care services and improve their quality. Wales also conducts outcome comparisons and benchmarking between healthcare facilities that supply their data to English providers (NHS databases or NHS registries (e.g. National Joint Registry).

In the USA, PROMs results are used in Centers for Medicare & Medicaid Services (CMS) programmes to perform inter-hospital comparisons and benchmarking analyses in models that can be adapted to national, regional or local levels. For example, in the AJRR Model, PROMs data collected for total hip replacement (THR) and total knee replacement (TKR) procedures is used for inter-hospital comparisons, and for benchmarking on a national, regional or local level or as a function of patient risk profile. Analyses are carried out to understand variations in quality of care and complications after THP or TKR.

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[36] Link: https://solidarites-sante.gouv.fr/professionnels/gerer-un-etablissement-de-sante-medico-social/qualite-dans-les-etablissements-de-sante-sociaux-et-medico-sociaux/article/incitation-financiere-a-l-amelioration-de-la-qualite-ifaq

[37] Link: https://solidarites-sante.gouv.fr/systeme-de-sante-et-medico-social/parcours-des-patients-et-des-usagers/article-51-lfss-2018-innovations-organisationnelles-pour-la-transformation-du/article/experimentation-d-une-incitation-a-une-prise-en-charge-partagee-ipep

[38] In the PEPS project, the same PREMs questionnaire is used for the IPEP project. This is a developed and validated questionnaire.

In Sweden, outcome comparisons and benchmarking are carried out in more than 100 national clinical registries in which PROMs are collected.

In the Netherlands, private insurance companies and patient organisations can use PROMs data published on an open-access basis by the Dutch Institute for Clinical Reporting to make comparisons and produce rankings of hospitals. An initiative was launched in 2010 in the field of mental health (Routine Outcome Monitoring), to perform benchmarking between care providers.

Australia also performs benchmarking of mental health facilities.

Australia and New Zealand conduct outcome comparisons and benchmarking between follow-on care and rehabilitation structures.

In Canada, comparisons of outcomes and benchmarking are conducted between providers within and between certain provinces. Structuring on a national level is expected.

Belgium and France run some initiatives for comparing outcomes and benchmarking between healthcare facilities.

In addition to national initiatives, international projects such as the ICHOM project offer standardised sets of PROMs that enable healthcare facilities in different countries, such as Belgium, the Netherlands, France, Sweden, England, Wales, the USA, Canada and Australia, to assess their clinical practices and compare themselves with each other.

Twelve countries report using PREMs to compare their care providers.

The Netherlands and Norway have a ranking system to compare the performance of each hospital against an expected national level. In the Netherlands, this takes the form of a star rating system, which shows the performance of a hospital in relation to the national average (one star: below the national average; two stars: at the national average; three stars: above the national average). In Norway, the results of each hospital are compared against a national level, using a traffic light system (colours).

In France, the results of the e-Satis indicators are used for national comparison and ranking of healthcare facilities. The ranking methodology is described in the appendices (see table 10, **Annexe 2**).

In Sweden, Germany, England and Denmark, comparisons of PREM results are made between hospitals, but also between private practices and/or primary care facilities.

Wales participates in comparisons and benchmarking analyses of NHS databases or shared registries with England (e.g. National Pain Audit, National Joint Registry).

In the United States, the CMS publishes the results of the Consumer Assessment of Healthcare Provider and Systems (CAHPS) survey in “Hospital Compare”, four times per year. Inter-hospital comparisons are made at national, regional and local levels, with standardised formats for the presentation of results. Benchmarking is also carried out against the CAHPS national database and automated reports, as well as customised analyses, can be downloaded online by the public.

In Canada and Belgium, PREMs are used to benchmark within regions[39]. In Canada, comparisons of results are also made between regions that coordinate centralised surveys. To date, no national structuring has been reported, but work is underway to harmonise the analysis of results on a national level.

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[39] In Canada, regions include territories.

In Australia, there are patient experience comparisons between primary care networks[40].

Furthermore, no initiatives using PROMs and PREMs to compare healthcare professionals with each other were found.

3.2.2. Their use in accreditation mechanisms is rare

No countries report the use of PROMs results in accreditation mechanisms for hospitals or primary care structures, whereas four countries use PREMs results in these mechanisms.

These may be mandatory national compendia of PREMs:

- In France, the results of the national e-Satis system are used in the accreditation of healthcare facilities to guarantee healthcare professional engagement in any actions to be taken.
- In Denmark, the results of national patient experience surveys in psychiatric and acute care facilities are taken into account in the accreditation of healthcare facilities, along with the results of satisfaction surveys among the relatives of psychiatric facility inpatients.
- In Australia, feedback from the results of national surveys measuring patient experience in hospitals and primary care settings is mandatory as part of the accreditation of these facilities.

There may also be mandatory regional collection of PREMs: this is the case in some Canadian provinces, where the results of patient experience surveys in acute care facilities are used in accreditation. The results of surveys conducted in 2015 in long-term care facilities were also used for accreditation purposes. Eventually, there will be a requirement to include survey results in all care sectors (long-term, home, primary, mental health) in the Canadian accreditation system.

3.2.3. Public disclosure of outcomes is not systematic

12 out of 13 countries publish PREMs results and 4 out of 13 countries (Sweden, UK, Netherlands, USA) publish PROMs results.

Public disclosure[26] of **PREMs results** takes a variety of formats.

- **Results presented nationally:**
  - for each hospital: USA (HCAHPS results in Hospital Compare[41]), England (NHS and Care Quality Commission (CQC) [45] websites), Sweden (reports available on the websites of each national quality registry (NQR) by disease/procedure[45]), Denmark[45] (two websites publishing the results for somatic and outpatient care[45]; one website publishing the results of patient satisfaction surveys in the primary care setting), Norway and the Netherlands[45], France[45] (results of the e-Satis survey published by the HAS).
  - for each primary care structure: Sweden (two sites publishing results from primary care units in all counties and reports from surveys conducted by different organisations), England (NHS website[45]), USA (CAHPS results in Hospital Compare[45]).

In Canada, public disclosure of results by healthcare facility is scheduled for 2022.

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[40] In Australia, there are six major provinces divided into 31 geographic areas, where primary care networks are structured.

[41] Inter-hospital comparisons and rankings.

- **Results presented on a regional level:**
    - for each hospital: Germany (two *Bertelsmann Stiffung* websites publishing the results of hospitals on a voluntary basis), Belgium (*"zorgkwaliteit"* website for the Flemish region).

- **Aggregated results reports:**
    - **on a national level:**
        - concerning all hospitals: Sweden (Swedish Association of Local Authorities and Regions website), England (NHS and CQC websites), Australia (Australian Institute of Health and Welfare (AIHW)), New Zealand (Health Quality & Safety Commission New Zealand (HQSCNZ)), France (HAS website).
        - concerning all primary care structures: England (NHS and CQC websites), Australia (Australian Bureau of Statistics (ABS) and AIHW).

    - **on a regional level:**
        - concerning all hospitals: Germany (Robert Koch Institute reports, health insurance funds, scientific institutes, health insurance system physicians' associations, private organisations, etc.), USA (the IHA's Value Based Pay for Performance county quality reports), Canada (results of the CPES-IC survey conducted in 5 provinces on the ICIS-CIHI website), Australia (ABS and AIHW reports); New Zealand (HQSCNZ reports[42]).
        - concerning all primary care structures: in Australia (ABS and AIHW reports).

- Patient comments/verbatims published on specific websites: in the Netherlands (patient comments on care providers and physicians) and in Sweden (surveys on patient habits).

In France, the results of the e-Satis system are made public for each hospital by the HAS. As the surveys also collect comments (verbatims) from patients, a national analysis is envisaged.

For each country, the detailed format of the published results (national, regional level) is presented in table 10, in **Annexe 2**.

Similarly, public disclosure of **PROMs results** takes a variety of formats.

- **Results presented nationally:**
    - for each hospital: Sweden (reports available on the website of each national quality registry (NQR) by disease/procedure), Netherlands (ranking of hospitals by private insurance companies and patient organisations, based on raw data from the Dutch Institute for Clinical Reporting), England (NHS Digital and NHS websites[43]), USA (Hospital Compare[48]).
    - for each primary care structure: England (NHS website[48]).

- **Aggregated results reports:**
    - **on a national level:**
        - concerning all hospitals:
            - England: annual reports on NHS Digital, survey results on the NHS website.

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[42] It is possible to select the results for a health district and compare them with the national average, using a drop-down menu.

[43] Individual results detailed by hospital, inter-hospital comparison, visualisation of outliers.

        - USA: reports from hospital networks of the WSC national databases (e.g. FORCE-TJR aggregated annual results report; AJRR Model national benchmarking analyses, etc.).
- **on a regional level:**
    - in the USA:
        - the Minnesota Community Measurement publishes annual reports on indicator results, including PROMs – for all medical groups[44] and for all healthcare facilities.
        - the AJRR Model publishes benchmarking analyses by region (e.g. California).

For each country, the detailed format of the published results (national, regional level) is presented in table 9, in **Annexe 2**.

3.2.4. Pay for performance schemes use these measures

More than a third of the countries analysed (5/13) use PROMs results in pay-for-performance models.

In some countries, these are mandatory national models, in which the diseases vary depending on the initiatives:

In Sweden and the Netherlands, pay-for-performance schemes are linked to the achievement of quality improvement targets.

- In Sweden, the Ortho-Choice programme offers a bundled payment model with a package that includes all **treatment phases** for a total hip or knee replacement, including diagnosis, surgery, all post-operative care (the prosthesis and patient follow-up) and a **care guarantee** for complications within two years of surgery. Hospitals are rewarded to the tune of 3.2% of the bundled payment if quality improvement targets are met, based on indicator results, including PROMs, collected in clinical registries.
- In the Netherlands, the Dutch Institute for Clinical Reporting, which coordinates the collection of indicators in hospitals, has decided to link payments for diagnosis-related groups (DRGs) to the achievement of indicator results, including outcome indicators such as PROMs (e.g. ICHOM) collected in clinical registries. When a registry is operational, the costs related to the collection of indicators are integrated into the financing of DRGs and the fixed and prospective payments for patient care, depending on the diagnosis. If care providers do not measure these indicators correctly, they also risk losing the funding linked to collection of the data.

In Sweden, there is also a national platform for monitoring reimbursements (SVEUS) with the aim of improving quality of care and reducing healthcare spending. Performance is monitored through the analysis of a number of process and outcome indicators, including PROMs. Some countries are considering adopting this system, including Norway and Denmark.

In Belgium, PROMs results are used in the reimbursement decisions taken by the National Institute for Health and Disability Insurance. For the time being, this approach is limited to PROMs used in the context of clinical trials, but it could be extended to routine use, especially for procedures that are already reimbursed.

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[44] Physician partnerships in charge of a medical practice.

In the USA, the healthcare system is financed by numerous health programmes or plans, commercial programmes or private insurance. This includes CMS-led health programmes that use pay-for-performance models to leverage care providers in order to improve quality of care. For example, the Comprehensive Joint Replacement Care (CJR) Model is a health programme that links hospital payments to a composite score taking into account three measures, including PROMs (see table 9, **Annexe 2**) for a care episode linked to THR or TKR. The model takes into account PROMs results published in Hospital Compare for the hospitals concerned.

In Australia, trials are scheduled to integrate PROMs into pay-for-performance models.

For each country, the detailed description of the pay-for-performance models is presented in table 9, in **Annexe 2**.

More than two thirds of the countries analysed (9/13) use PREMs results in pay-for-performance models.

The results of PREMs are integrated into pay-for-performance programmes for institutional care in seven countries (Norway, Netherlands, Belgium, France, England, USA, Canada) or primary care centres in four countries (Sweden, USA, England, New Zealand).

The types of care included in these programmes vary depending on the initiatives (e.g. in the USA, acute care, home care, dialysis, etc.; in Denmark, psychiatric care; in Canada, cancer care, etc.).

In the United States, there are several pay-for-performance programmes. In the CJR Model, cited above, the composite score takes into account the results of PREMs from the Consumer Assessment of Healthcare Provider and Systems (CAHPS), for a care episode related to a THR or a TKR (see table 10, **Annexe 2**).

In France, the results of the e-Satis system in acute care have been integrated into the financial incentive model for quality improvement (IFAQ)[45] since 2016. In parallel, the experimentations conducted in the context of article 51 of the French Social Security Financing Act, dating from 2018, envisage funding adjustments based on PREMs results.

In Australia, trials are scheduled to integrate PREMs into pay-for-performance models.

For each country, the detailed description of the pay-for-performance models is presented in table 10, in **Annexe 2**.

This international panorama sheds light on patient-reported quality measure initiatives and their uses in different health systems, in order to improve quality of care. PROMs are less often used than PREMs in comparison and benchmarking or pay-for-performance initiatives; and the results of PROMs are never used in healthcare structure accreditation initiatives, in contrast with PREMs results.

France is revealed as being one of the most advanced countries in terms of the collection (national level) and use of PREMs (comparison/benchmarking, certification of healthcare facilities, public disclosure and pay for performance). It is less advanced when it comes to the collection of PROMs, but PROMs collection initiatives - such as the ComPaRe project, the *Moi Patient* platform (Renaloo), the care episode project in the context of article 51 (financing reform), the ICHOM project - are being

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[45] IFAQ link: https://solidarites-sante.gouv.fr/professionnels/gerer-un-etablissement-de-sante-medico-social/qualite-dans-les-etablissements-de-sante-sociaux-et-medico-sociaux/article/incitation-financiere-a-l-amelioration-de-la-qualite-ifaq

developed. A regional initiative to collect PROMs in HIV patients was set up in Aquitaine (13 hospitals) in 2018 as part of a project led by the ANRS.

The longstanding nature of the many initiatives enables us to identify the strengths and weaknesses of the measures carried out and of their uses (see section **4**).

4. Main lessons learned

There is now a certain amount of experience with the use of patient-reported quality measures such as PROMs and PREMs in the pioneering countries. The literature includes several studies describing the impacts of the use of PROMs and PREMs enabling lessons to be learned.

The lessons presented in this section are the main impacts of the use of PROMs and PREMs on quality of care, which began to be identified more than a decade ago (120, 172) and have been summarised in recent work consolidating knowledge of these impacts (69). Next, impacts on the results of patient-reported quality measures via the use of PROMs and PREMs, health system regulation mechanisms and the public disclosure of quality of care results and care funding are presented. Finally, the main barriers to the implementation of PROMs and PREMs in routine clinical practice are presented, as well as facilitators that may aid their implementation.

4.1. Impacts of patient-reported quality measures in routine clinical practice

Measuring patient-reported quality with PROMs and PREMs and using these in routine clinical practice are actions liable to have an impact on the quality of care. These impacts occur 1) on an individual level, i.e. directly for professionals and patients, and 2) at a collective level, e.g. at the level of a group of patients, a physician, a team, a pathway or an organisation, where patient-reported quality measures can also be used for quality improvement purposes (118, 173, 174).

4.1.1. Main positive impacts of PROMs

PROMs are used for a variety of purposes (see chapter 3) but they are most often used directly at the individual level as an aid to professional practice for the direct benefit of patients. Patients usually complete PROMs at one or more times, depending on the objectives and contexts. The idea is to evaluate and/or monitor care outcomes using indicators, including PROMs, to enable adaptation of care. PROMs results are interpreted by professionals who can use them to discuss with patients and improve clinical care.

4.1.1.1. Impacts on the clinical care of patients

Improved communication

PROMs help focus professional and patient attention on symptoms

PROMs help professionals gain a better understanding of the symptoms experienced by patients, their clinical view being supplemented by the patients' perspective. This enables professionals to engage with patients more effectively and, where necessary, to initiate care and treatment aimed, for example, at alleviating symptoms reported by patients in this way (175, 176).

PROMs help patients gain a better perception of their symptoms, through the analysis of their experiences. Thanks to PROMs, patients have a better understanding of how the disease affects their lives, they identify the symptoms that seem most important to them and they are able to express them better. PROMs also facilitate communication by linking the perceptions and understanding of symptoms by professionals and patients (175, 176).

PROMs help encourage discussion and guide consultation

Sometimes patients refrain from talking about their health problems for fear of bothering professionals. PROMs help to remove this inhibition for some patients and also help professionals to engage discussions based on the importance of the symptoms, to ensure they go through all potential problems. Patients are willing to discuss PROMs results with professionals. This discussion is more likely to take place when there is a relationship of trust between professionals and patients (175-181).

PROMs help patients in several ways during discussions with professionals. They help patients to remember points to be covered, to organise their train of thought, and to describe their symptoms more easily using PROMs terms; PROMs therefore enable patients to increase their capacity to engage in their own care (176, 179, 180).

By listing symptoms reported by patients, PROMs help professionals identify important issues for discussion. They make it possible to have more effective consultations, primarily by encouraging the discussion of complicated problems. PROMs enable professionals to more effectively monitor patients' symptoms (176, 179, 180).

PROMs facilitate communication between professionals

PROMs facilitate the communication of patient information between healthcare professionals by standardising patient follow-up information (176, 180).

Improved identification of health problems and follow-up of patients

PROMs help to identify health problems that may not be spontaneously addressed by patients and to personalise the clinical management of patients

The use of PROMs makes it possible to identify more symptoms or at an earlier stage (103, 179, 180, 182, 183).

The use of PROMs can lead to changes in clinical care, including changes in drug prescriptions, referrals to other healthcare professionals, advice to improve quality of life (183).

For example, in the management of cancer patients, clinical decisions made as a result of the use of PROMs may include referral to a psychologist for support or prescription of medication for pain relief (176, 179).

PROMs improve patient health monitoring

The use of PROMs enables better follow-up of cancer patients treated with outpatient chemotherapy, since PROMs incorporate questions relating to the monitoring of symptoms, side effects and toxicity; follow-up is further improved when the use of PROMs is implemented in real time (182).

4.1.1.2. Impacts on care outcomes

PROMs sometimes significantly improve patients' health outcomes but this positive impact, where found, remains heterogeneous and modest overall

The use of PROMs reduces the presence and intensity of physical symptoms, such as pain or fatigue (176, 180, 183). This impact is shown particularly in frail patients with active disease, such as cancer patients and palliative care patients (182, 184). For these patients, an improvement is shown for emotional and psychological quality of life (183). The use of PROMs in routine paediatric clinical care also demonstrates a positive impact on health-related quality of life (185).

PROMs have a greater impact when they are integrated into patient follow-up

For the care of cancer patients, recent studies demonstrate interesting results relative to the use of PROMs for remote monitoring: PROMs are completed online by patients. This use leads to improved patient survival (23, 24). This important result may be due to early detection of adverse events, through remote monitoring of regularly reported symptoms, enabling rapid treatment where necessary.

- Improved patient survival, improved quality of life, reduced symptom severity and reduced emergency hospitalisations are demonstrated in a US randomised clinical trial testing electronic symptom monitoring of patients treated with chemotherapy for metastatic solid tumours (23).
- Improved patient survival is also demonstrated in a multicentre randomised trial in France testing remote symptom monitoring in patients with advanced lung cancer (24, 186). It is also demonstrated the cost effectiveness and cost utility of web-based monitoring via PROMs, based on widely accepted thresholds (187).
- Improved survival is demonstrated for cancer outpatients when PROMs are used in a study in Canada that retrospectively compared two comparable patient populations that differed in whether or not they had responded at least once to the Edmonton Symptom Assessment System (ESAS) (188).
- The use of PROMs in routine clinical practice also demonstrates indirectly positive impacts for patients by reducing the need for care: in particular, a reduction in emergency department visits, and a reduction in consultations for psychosocial and palliative care were demonstrated in a real-world study in three regional cancer treatment centres in Canada trialling the use of PROMs by clinicians (189).

PROMs can help improve patients' health in certain conditions

For psychiatric and mental health care, the PROMs results of monitored patients are predictive of psychiatric re-hospitalisation, suggesting the value of using PROMs to avoid readmission to hospital (190).

For the primary care of patients with depression or anxiety, the use of PROMs in routine clinical practice, however, does not demonstrate any positive impact on patient health outcomes. For the authors, this use could nonetheless be beneficial for certain patient populations, such as patients who find it difficult to spontaneously communicate their symptoms or articulate how they are feeling when asked in an open-ended manner, and patients who are unsure can thus realise how many symptoms they have and the need for the proposed treatment (191).

Simply having the information to identify or monitor a patient with depression, for example, is not enough to improve the outcome of complex care; but it can help inform an overall action strategy (shared medical decision-making, patient education, care pathway, etc.) (182).

The need for a comprehensive management strategy that integrates the use of PROMs into routine clinical practice is illustrated in psychiatry, where PROMs results are significantly better when PROMs data is both fed back to and discussed by professionals and patients, compared to the situation where PROMs results are neither fed back nor discussed. This suggests the value of feedback and discussion of PROMs results between professionals and patients (192, 193).

Summary of the impacts of the use of PROMs in routine clinical practice

The use of PROMs in routine clinical practice demonstrates positive impacts on the quality of care and health of patients. A major impact is the improved survival of patients. This key result is demonstrated in the follow-up of cancer patients, when PROMs are used in remote monitoring, enabling the rapid identification of situations requiring adapted care.

The positive impact on patient health of the use of PROMs in routine clinical practice can also be seen by the demonstration of benefits in other fields and diseases. However, these have been less clearly demonstrated to date, for reasons including greater difficulty in showing visible health benefits to patients, methodological limitations in some studies and a still limited knowledge of how PROMs work.

Improved communication between professionals and patients is another clearly demonstrated positive impact of the use of PROMs by professionals in routine clinical practice. Better communication through the use of PROMs is very often demonstrated in various contexts. Better communication helps both professionals and patients. It makes consultations more efficient, professionals better informed and patients more able to make decisions and take action.

Table 8. Summary of the impacts of the use of PROMs

Impacts of PROMs	Evidence of the impact of PROMs
Impacts on the clinical care of patients	
– Communication (patient-professionals, professionals-professionals)	+++
– Management of symptoms (diagnosis, follow-up, etc.)	++
– Clinical actions generated (treatment modification, referral to other health professionals, etc.)	+
Impacts on care outcomes	
– Physical symptoms (reduced severity, reduced prevalence, etc.)	+
– Psychological symptoms (reduced anxiety, etc.)	+
– Patients' quality of life	+
– Patient satisfaction	+++
Impacts on healthcare system performance and regulation	
– Public disclosure (transparency), external evaluation, quality-based payment (spending control), population-based monitoring	+

Interpretation of table: +: positive impact sometimes demonstrated; + + + +: positive impact very often demonstrated
Source: adapted from Chen *et al* (182)

4.1.2. Main positive impacts of PREMs

PREMs are used for different purposes (see chapter 3). They are generally used in large-scale surveys designed by organisations external to the healthcare team liable to use the data (64). The idea is to evaluate the quality of the organisations over time and to improve clinical care.

4.1.2.1. Impacts on teams and healthcare organisations

PREMs can help identify areas for improvement, but their use by healthcare teams still needs to be developed

Care teams are provided feedback from PREMs in various ways, depending on the type of data collected and the survey methods: they enable care teams to identify areas for improvement and to assess the impact of changes.

The impact of PREMs on improving quality of care is often analysed qualitatively; it is therefore difficult to interpret and reach any conclusions with respect to the impact of PREMs (64). PREMs results are generally not specific enough or do not enable targeting of certain areas of interest to healthcare teams in order to inform them sufficiently about the quality of the service provided to the patient (194). Care teams generally find patients' comments more interesting than quantitative data, although analysis of these comments is more difficult (64).

The collection and availability of PREMs alone is not enough to improve care. PREMs results should be discussed by health professionals in order to implement improvement actions (194, 195). Healthcare professionals are generally in favour of measuring patient experience; however, this does not guarantee that feedback will lead to action; indeed, only a minority of healthcare providers take the opportunity to use PREMs to implement actions to improve the quality of care (196, 197).

PREMs enable healthcare organisations to improve progressively, especially when they are committed to a long-term approach

The impact of PREMs is greater when the improvement actions implemented involve small incremental changes, as in all quality improvement processes (64).

The improvement actions implemented tend to be concentrated on care organisations with low scores or on areas already identified as being problematic. The improvement actions most often concern the admission process and the production of information documents for patients (64).

Implementing improvement actions requires sufficient resources, in terms of knowledge, time and staff, as well as PREMs data of sufficient quality and that is interpreted and monitored over time (198).

To remain relevant, PREMs surveys must be able to evolve to meet the needs and expectations of healthcare professionals and health system users (199).

Nevertheless, it should be noted that PREMs appear to have little correlation with the level of commitment of healthcare facilities to the inclusion of patient experience in the assessment of the quality of care, or to the level of maturity of the healthcare facilities in terms of quality management (200).

4.1.2.2. Impacts on patient experience

Patient experience can be improved with the implementation of actions identified by PREMs. Improving important dimensions for patients, such as communication and care coordination, promotes a better experience of care.

Coordination improves the experience of hospital care

Coordination of care improves the experience of patients. Healthcare facilities that have put in place actions to promote coordination have better PREMs results than facilities where there are no such actions. It is also suggested that coordination actions that improve patient experience are those actions that involve interaction with patients. For example, at patient discharge, the involvement of discharge coordinators, the supply of a discharge letter and calling patients 48 hours after discharge are actions that improve patient experience (201).

Communication improves the experience of care in emergency departments

Communication improves patient experience: communication between professionals and patients is the action most often found to improve patient experience in emergency departments. Other aspects impacting on patients' experience in emergency departments include patients' perceived waiting times and professionals' empathy and compassion towards patients (202).

It is suggested that communication, empathy and compassion from professionals make patients more understanding of other aspects that are more difficult to improve, such as waiting times. Conversely, a patient who feels ignored or disregarded, for example, will not perceive their wait in the emergency department as a good experience, even though it may objectively be a short one; the same goes for spacious and clean premises. Communication and empathy are thus the actions that have the greatest impact on patients' experience in the emergency department (202).

Teamwork improves the experience of cancer patients

Teamwork improves the experience of patients. Teamwork brings professionals together around common goals and the quest for solutions in order to improve patient care by collaborating with other players within the hospital and with sectors outside the hospital. Teamwork in cancer care has been shown to improve patient experience dimensions, such as access to care and communication (203).

Teamwork of professionals impacts the experience by improving patients' perception of how easy it is to contact a professional, whenever the need arises, at any time of the day or week. Teamwork improves the patient experience through better communication between professionals and patients, through listening to patients and through shared medical decision-making (203).

4.1.3. Barriers and facilitators

Barriers related to the use of patient questionnaires have also been identified in the literature. The difficulties are similar for both types of questionnaires, PROMs and PREMs, and the barriers are also similar for the different patient populations and fields of care where these questionnaires have been used. The facilitators described in the literature depend on the use contexts (204-207).

The barriers related to the use of questionnaires on an individual level can be divided into two types: 1) technical barriers, related to the practical use of the questionnaires; 2) perceptual barriers, related to what patients and professionals think of the questionnaires.

4.1.3.1. Barriers and facilitators related to use of questionnaires

Difficulties obtaining complete questionnaires

Patients may have difficulty completing the questionnaires for various reasons. These difficulties can lead to low response rates or low degrees of completion of questionnaires. For example, using methods such as online surveys only, patient response rates to PROMs are relatively low in routine clinical practice, demonstrating the need for organisations wishing to collect them to give early consideration to this aspect for successful implementation (208, 209)

The questionnaires sometimes take a long time to complete. They are difficult for some patients to read and understand; yet there are guidelines and rules for designing questionnaires that are accessible to all (210, 211). Some patients may have difficulty remembering their past health or may not feel well enough to complete the questionnaire, especially patients who are frail due to their illness and treatment. Some patients may not be able to answer the questionnaires due to a technological barrier, especially patients who are not comfortable with computers and where the interface is not easy to use (212).

Some patients do not answer questionnaires because they may feel anxious about doing so because it makes them think about their illness and symptoms. Conversely, some patients do not think it is useful to complete the questionnaire when they feel it is not appropriate, for example when they do not feel sick. Similarly, patients who do not feel concerned by the questionnaires do not take the time to respond (213).

Maintaining long-term patient compliance for completion of disease monitoring questionnaires, while avoiding problems related to missing data, can be difficult since patient engagement tends to decline over time (214).

Facilitators to help patients complete questionnaires

Use questionnaires that are easy to read and understand

- Choose questionnaires that are simple for patients (e.g. questionnaires that have been verified as being easy to understand by patients; questionnaires designed with patients) and, ideally, metrologically validated tools recommended by professionals and patients.

Help patients to respond

- Allow patients to respond on site (e.g. on an electronic tablet in the waiting room before the consultation) and/or at home (e.g. online survey before and between visits).
- Suggest that patients fill in the questionnaire with someone in their entourage (family member, friend, carer, etc.), or with the help of a professional.

Provide patients with an easy-to-use interface

Difficulties encountered by professionals with respect to adoption of questionnaires

Difficulties finding the time

To use PROMs, clinicians must invest time: consulting PROMs data, interpreting it, discussing the results with patients, following up with useful actions. Each of these steps takes time.

There are differing views on the benefit of PROMs compared to the time spent on them: some professionals consider that PROMs are difficult to use in routine clinical practice due to a lack of time (173, 212). Others see PROMs as time-saving or time-efficient: they avoid the need for clinicians to ask patients questions that PROMs already address and enable them to focus on the problems identified.

In fact, there does not seem to be any difference in terms of time between consultations using or not using PROMs. In addition, it may be possible to postpone consultation appointments and reschedule them for a later date when patients do not report any problems between visits, thus saving time slots for patients who need them most (179, 192, 215).

Difficulties acting on the questionnaires

Professionals do not immediately have the knowledge or adequate tools to interpret the data from the questionnaires and to modify their practices; the implementation of training programmes for clinicians can remedy these shortcomings (216).

Facilitators to help professionals use the questionnaires

Propose training tools for professionals

- Provide training that covers the whole process of using the questionnaires (administration, analysis, interpretation of data and management of identified problems).
- Offer flexible training arrangements: e.g. short, à la carte, group or individual, distance learning, which can be included as part of ongoing staff development (e.g. case study videos).

Provide professionals with decision-making aids

- Provide professionals with detailed and summarised results, accompanied by aids for interpreting the results and clinical decision-making aids (e.g. calculation of scores in real time, score monitoring, easy-to-interpret graphs, recommendations, decision trees, practical guide sheets).

Involve professionals and help them choose tools

- Provide professionals with a choice of validated, relevant and useful tools for their needs (e.g. list of validated PROMs, user guide, etc.).

Provide professionals with an easy-to-use interface

Barriers to integration of questionnaires within healthcare organisations

Integrating questionnaires into practices requires investment on the part of professionals and organisations. This integration can be an additional constraint, especially if the use of questionnaires requires organisational arrangements that are too complex, difficult to put into practice or do not correspond to needs.

It is therefore a question of integrating the questionnaires into routine clinical practice, taking into account what already exists and allowing for flexibility. For example, proposing questionnaires in line with consultations and allowing flexibility in their use by professionals can facilitate implementation (205).

In some cases, once problems are identified by questionnaires, particularly health problems identified by PROMs, it is not always possible to treat patients immediately due to the unavailability of services or healthcare professionals to whom patients could be referred; this may also raise liability issues (212).

Facilitators for the integration of questionnaires into practices

Define use objectives, the populations concerned and methods

- Define the objectives of the measure, which, broadly speaking, are: 1) individual patient care, 2) improvement of quality of care in organisations, 3) quality-based payment, 4) clinical research. These objectives are not exclusive; a care organisation may target one or more of these objectives.
- Define the target populations since these will impact the choice of methods, such as the frequency and duration of collection.

- Define questionnaire collection times, which are generally either at regular intervals or coinciding with visit times.

Provide resources facilitating the use of questionnaires

- Have information systems in place enabling the creation of an electronic database of collected questionnaires and generation of automatic functionalities (e.g. online platform, data visualisation tools, alerts if PROMs results exceed a certain threshold).
- Identify people in charge of implementing the questionnaires; support a data collection culture at governance level, support long-term investment and have a clear strategy for the use of questionnaires (e.g. define the objectives of data collection, integrate the use of PROMs into consultations, set up dedicated times to discuss the results in teams).
- Refer to dedicated services and available healthcare professionals (such as a coordinating nurse), who are part of a care network, for example, to receive and manage patients as soon as particular problems are identified.

Adapt the use of questionnaires to needs and the context

- Propose simple and flexible implementation methods (collection time, administration methods, etc.) that are adapted to the needs of professionals.
- Present results that are relevant to professionals (e.g. PREMs results are relevant to a professional, a team, a care service, etc.) and report the results on a regular basis to enable improvement.
- Involve professionals in the choice and implementation of tools.

4.1.3.2. Barriers and facilitators related to the perception of questionnaires

Patients and professionals may not perceive the value of questionnaires for a variety of reasons.

Barriers related to what patients think about questionnaires

The vast majority of patients are in favour of completion of questionnaires, especially PROMs; for example, cancer patients are willing to fill in a questionnaire for each consultation and almost all of them see the benefits of electronic administration (179).

However, some patients may have doubts about the pertinence and value of questionnaires to their care; this is particularly the case when they feel that some of the questions are not relevant to them and when they do not see the point of filling in questionnaires due to a lack of explanation (212).

Furthermore, patients who are initially in favour of a questionnaire collection process may later lose interest, particularly if they find that professionals do not take the time to discuss the results with them or if there is no coordination between professionals, asking patients the same questions again; all of this may lead to patients refusing to take part in further PROM collection (217).

Facilitators to promote patients' understanding and acceptance of questionnaires

Communicate the value and discuss questionnaire results with patients

- Inform patients and explain the value of questionnaires to them.
- Discuss questionnaire results with patients, in order to maintain their long-term commitment.

Choose questionnaires that correspond to patients' expectations

- Select questionnaires that are relevant to patients, for example questionnaires that have been designed with patients, and that are easy to read and understand.
- Propose different administration methods and the possibility of help from a relative or professional.

Barriers related to what professionals think about questionnaires

Professionals have differing views on the value of using questionnaires such as PROMs, which may be considered either good and useful or, conversely, useless or even harmful to their relationship with patients.

On the one hand, professionals who support the use of PROMs see them as a tool that complements their clinical judgment. Thus, PROMs are seen as having the potential to improve the care process by supporting better communication, promoting patient education, shared medical decision-making, diagnosis of health problems, monitoring of the disease and response to treatment, and aiding better planning of care.

On the other hand, some professionals doubt that PROMs can help them and consider that these questionnaires are of no interest since they do not provide any new information. Furthermore, PROMs may be perceived as intrusive, in relation to patients' privacy and the patient-professional relationship, since the questionnaires may focus the discussion on certain issues only and thus prevent discussion of other potentially more important issues (173).

Facilitators to promote professionals' understanding and acceptance of questionnaires

Communicate the value of the questionnaires to professionals

- Inform professionals about the value of PROMs as an aid to clinical practice and PREMs as an aid to improving the organisation of care.
- Raise awareness of the use of questionnaires and encourage professionals to discuss the results with their patients.

Choose questionnaires that correspond to professionals' expectations

- Select questionnaires that are validated and relevant for professionals (e.g. combination of a generic PROM and a PROM specific to the professional's field of interest), with acceptable costs, that can be easily integrated into routine clinical practice (reasonable number of items, several possible methods of administration) and also used by other organisations (comparison of results).

4.2. Impacts of regulation mechanisms incorporating patient-reported quality measures on quality improvement

The regulatory mechanisms put in place in health systems are progressively including PROMs and PREMs; these mechanisms thus differ in their age and in the objectives sought (see chapter 3).

The impacts of these mechanisms on PROMs and PREMs results are less well documented than those relative to use in routine clinical practice.

In addition, the impacts described relate more to certain regulatory mechanisms. For example, in the accreditation of healthcare providers (certification in France), where PROMs and PREMs are still little used, the impacts of this mechanism are rarely described. Conversely, the impacts of public dissemination and funding models incorporating PROMs and/or PREMs are more often described in relation to recent quality-based payment initiatives (218-220).

4.2.1. Impacts of public disclosure of outcomes

It is becoming increasingly common for the results of indicators of the quality of care delivered by healthcare providers to be published in health systems. This public disclosure is a facilitator for the improvement of quality of care. Public disclosure is expected to improve the quality of care by encouraging healthcare providers to implement actions on the basis of three mechanisms: 1) patient choice, comparing and selecting care providers based on the quality of care; 2) identification by care providers of quality domains to be improved upon; 3) the reputation of care providers (221, 222).

Public disclosure encourages care providers to improve quality of care

In general, the impact of public disclosure on user choice and patient health outcomes is either not demonstrated or exists but with a low level of evidence (223). Although this impact seems limited, public disclosure nevertheless provides a strong incentive for healthcare providers to implement actions to improve the quality of care (224).

More specifically, the public disclosure of PREMs data provides an incentive for healthcare institutions to improve, which in turn leads to better PREMs results. All dimensions of the patient experience are improved (nursing communication, team responsiveness, pain management, communication about medication, hospital environment, discharge), except for communication with physicians. And as with any quality improvement initiative, improvements in patient-reported experience outcomes are greatest in facilities with initially lower scores (225-228).

Comparative analysis is a lever for improvement

Comparative analysis encourages practitioners to improve in order to be as good as or better than their peers and to learn from best practice, especially when it is data where practitioners have been involved in the processes of selecting and defining indicator methods (229, 230).

4.2.2. Impacts of healthcare funding arrangements

Innovative models complementing fee-for-service payment are used to finance healthcare spending. In these models, quality measures including those based on patient perception are used to assess the quality of care. In general, these new models aim to make economic savings and are also designed to provide incentives for professionals and organisations to improve the quality of care. Initial evaluations show that these objectives are being met. Trialled payment models demonstrate a reduction in care spending that is sometimes significant, at the same time improving the quality of care or at least maintaining it at a comparable level.

Impacts of the payment models of the Centers for Medicare & Medicaid Services (CMS), USA

In 2015, the majority of Medicare fee-for-service payments already had a link to quality of care. A first objective was to extend the proportion of fee-for-service payments tied to quality and a second objective was to increase the proportion of care funded through new payment models (231). Examples of these new payment models include bundled payments, Accountable Care Organizations (ACOs), advanced primary care medical homes and pay for performance.

Since 2013, CMS are funded by a pay-for-performance mechanism for a share of spending on acute hospital care. This pay-for-performance mechanism is dependent on outcomes, including patient-reported experience outcomes, adopting the Value-Based Health Care (VBHC) approach rewarding quality of care.

Hospital pay-for-performance model

Example 1: the HVBP pay-for-performance model

The Hospital Value-Based Purchasing (HVBP) initiative is a CMS programme aimed at improving the performance of hospitals and the experience of hospitalised patients. Pay for performance based on outcomes, including Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) PREMs, encourage hospitals to implement strategies designed to improve patient experience. Hospitals are remunerated according to their position in the overall hospital ranking, or according to their progress, based on indicators including PREMs (there is also an incentive mechanism for maintaining performance scores above the national median) (232).

The HVBP programme accounts for almost 2% of the funding of CMS hospitals and, since 2015, the weight of the hospitals' PREMs score in the overall performance score is 25%. Even before the introduction of the HVBP initiative, PREMs outcomes were improving, and there is no evidence that the introduction of HVBP has accelerated the improvement of the inpatient experience; if anything the pace has slowed. When the PREMs results of hospitals participating in the HVBP initiative are compared with non-participating hospitals, the only difference in favour of HVBP hospitals concerns the cleanliness of the hospital environment (232).

Several reasons are put forward to explain the slowdown in the improvement of PREMs and the low impact of the HVBP programme, compared to the earlier simple measure of publicly reporting PREMs results, which had led to significant progress. First of all, the financial incentive may have been too modest to encourage hospitals to act. Secondly, there may be a “ceiling effect” for patient experience. Finally, a third explanation is that the PREMs results may strongly depend on aspects that cannot be modified by hospitals, such as their activities (e.g. intensive care, teaching, etc.) or the type of populations the hospitals serve. Thus, to enable improvements in the quality of care, the authors suggest that the model needs to evolve, towards greater simplification and stronger financial incentives (232, 233).

> ***The HVBP initiative does not demonstrate any improvement in patient experience***

Bundled payment models for hospital care episodes and outpatient care episodes

A bundled payment or care episode-based payment model makes it possible to link all the payments of the different care providers during a care episode. Outside a care episode, providers are separated and seek to increase their respective care volumes. Care episode-based payment reduces this incentive to increase volumes and instead provides an incentive to improve the efficiency, coordination and quality of care.

The CMS Innovation Center has designed three care episode-based payment models: the Bundled Payments for Care Improvement (BPCI) model, the Comprehensive Care for Joint Replacement (CJR) model, and the Oncology Care Model (OCM). These models share a common principle: the responsibility for most care during an episode rests with a single provider.

Example 2: the BPCI initiative for care episode-based payment following hospitalisation

The Bundled Payments for Care Improvement (BPCI) initiative is a CMS programme for the bundled payment of 48 care episodes, triggered following hospitalisation for certain types of medical or surgical care. The BPCI initiative includes four episode-based payment models, including hospitalisation, any re-hospitalisations and follow-on care depending on the model chosen by the care providers.

It is shown, for example, that in the model including inpatient and follow-on care (2 ACH model), there is a reduction in care consumption. The hospital stays of the patients included in this model are shorter than the stays funded via the traditional fee-for-service payment system. This cost reduction is achieved while maintaining patients' perceived quality of care, since SF-36 PROMs scores are stable. Similarly, although very slightly lower, the results for PREMs and patient satisfaction remain high (234).

Example 3: the CJR initiative for care episode-based payment for hip and knee replacement surgeries

The Comprehensive Care for Joint Replacement (CJR) initiative is a CMS programme for the bundled payment of care episodes for hip replacement (THR) and knee replacement (TKR) surgeries. Participating providers are responsible for the quality and cost of care episodes. The CJR model encourages care providers to coordinate with each other and avoid unnecessary spending during the care episode. At the end of the year, if the total actual spending for an episode of care is below a predetermined expenditure, then the provider will receive a share of the savings (235).

The impact on spending of the CJR model is demonstrated. Savings are made, in particular by reducing spending on follow-on care. While reducing expenditure, the CJR model does not affect the quality of care. Following THR or TKR performed within or outside the CJR model, the medical or surgical complication rates are comparable (236). Similarly, the quality of care reported by patients is similar whether the payment is bundled or fee-for-service. PROMs results for THR and TKR evaluated by HOOS, KOOS and PROMIS-PH questionnaires do not differ from one payment type to another (235).

> ***The BPCI and CJR initiatives demonstrate a reduction in healthcare spending, while maintaining the same levels of patient-reported quality***

Example 4: the OCM initiative for care episode-based payment in cancer

The Oncology Care Model (OCM) initiative is a CMS programme for incentive payment for the first six months of medical care for cancer patients. Healthcare providers receive monthly remuneration for care coordination on a per capita basis, while continuing to bill for all care provided on a fee-for-service basis. At the end of the episode, if the total cost of care billed is less than a risk-adjusted benchmark amount, and if quality goals are met, the health provider will receive a performance-based payment (237).

According to the results of the evaluation of the OCM model, the total cost of care episodes is only slightly higher, but, overall, the OCM model is in deficit; PREMs results remain at very high levels. The OCM model prioritises issues such as access to care, coordination of care and shared medical decision-making, which can reduce emergency care and hospitalisations. On these aspects, the results of the OCM model evaluation do not demonstrate any impact (238).

> ***The OCM initiative does not demonstrate any reduction in care spending or impact on patient experience***

Quality-based payment models for dialysis care

Since 2011, CMS dialysis centres have received bundled payment to deliver dialysis care, including medicines and complementary examinations. This bundled payment is linked to quality of care measures. Since 2012, the QIP programme has complemented the bundled payment model, for the first time introducing a mandatory federal pay-for-performance programme, with the aim of ensuring that the quality of care remains high. Since 2015, in order to improve transparency and inform users, the performance scores and ranking of dialysis centres on a one to five-star scale have been publicly reported (239).

Example 5: the ESRD QIP initiative for dialysis centres

The End-Stage Renal Disease Quality Incentive Program (ESRD QIP) initiative is a CMS programme for the performance-based payment of dialysis centres. A penalty system applies to the quality-based payment part, which represents up to 2% of the total payments received by a dialysis centre. The application of the penalty reducing payments is determined by the attainment or otherwise of prespecified performance thresholds. In actual fact, the majority of facilities receive no penalty, and only a minority have received a full 2% penalty (239).

The ESRD QIP model is adaptive. The model's benchmarks evolve in line with improvements in national performance rates. New indicators are incorporated as the ESRD QIP model is revised. Patient-reported quality measures, which were initially absent, have subsequently been incorporated into the model. For example PROMs assessing pain and symptoms of depression in patients were introduced after it was realised that these issues were given inadequate consideration (239).

Several PROMs measuring health-related quality of life, such as the Kidney Disease Quality of Life (KDQOL-36), SF-12 and PROMIS, have been recommended for inclusion in the ESRD programme. The choice and implementation of PROMs is left to the discretion of teams and dialysis centres. Similarly, several PROMs measuring pain or depression symptoms, including the Patient Health Questionnaire (PHQ-9) have been recommended for inclusion in the ESRD QIP model.

The specific In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) PREM has been included in the ESRD QIP model since 2016. Dialysis centres receiving fewer than 30 patients per year are exempted from administering the PREM to their patients; these centres therefore do not obtain a PREMs score. The PREMs results identified the patient characteristics and dialysis centre statuses with lower scores. These differences in PREMs results can guide choices in order to guarantee equitable access to and experience of care (240).

> ***The free choice of measures or the absence of collection of patient-reported quality complicate the evaluation of the impact of the ESRD QIP programme***

Example 6: the ESCO pay-for-performance initiative for dialysis care

The ESRD Seamless Care Organizations (ESCO) initiative is a CMS programme aimed at reducing dialysis care spending, reducing hospitalisations and improving the health outcomes of patients treated in these organisations. ESCOs are rewarded or penalised on the basis of clinical outcomes, quality indicators and spending. ESCOs cover all costs related to care, including hospitalisation, but exclude costs related to drugs and transplants. ESCOs receive financial incentives to meet minimum quality targets in order to receive their share in any financial savings made; if these targets are not met, their share of these potential savings is reduced (241).

In the ESCO model, for PREMs, the ICH-CAHPS score is heavily weighted against other quality measures, demonstrating the importance of taking into account patient experience; for PROMs, the KDQOL-36 is administered to all patients included in the ESCOs. The impact of the model on PROMs results shows that patients treated with ESCOs have fewer symptoms and better physical function than patients treated outside ESCOs, but this difference in outcomes in favour of the ESCO model is small and this improvement may not be clinically significant for patients (241).

> ***The ESCO initiative demonstrates improved health outcomes for patients***

Per capita payment model for patients with chronic diseases

Example 7: the ACO per capita payment initiative for patients with chronic diseases

The Accountable Care Organizations (ACO) initiative is a CMS programme intended to coordinate care within patients' care pathways. ACOs are grouped care providers, often including physicians and healthcare facilities, who are jointly responsible for the quality and costs of their patients' care. ACOs are remunerated on a per capita basis through a global payment and are interested in the financial results. For ACOs whose spending is below the fixed threshold, a share of the savings made is paid to them, and conversely, for those with expenses exceeding the threshold, a share of the excess must be reimbursed (242).

The ACO model may lead care providers not to offer their patients certain services that may appear to be important to them. It is therefore important for ACOs to maintain, if not improve, the experience of their patients, otherwise their patients might seek care elsewhere, which would reduce the value of the model. This challenge explains the significant weighting in the model of the PREMs score, representing 25% of the overall quality score (242). ACOs therefore develop strategies to engage patients, improve quality of care and reduce costs. Due to epidemiological factors, lifestyles and associated health care costs, the success of the model depends on the ability of ACOs to improve the engagement of patients in their primary care, particularly those with chronic diseases such as diabetes, cardiovascular disease and mental health problems (243).

Strategies to improve patient engagement are implemented by the majority of ACOs. The results demonstrate the need for professionals to emphasise aspects such as shared medical decision-making and the involvement of patients in the development of care plans, as well as the benefits to professionals of being involved in the governance of ACOs and in actions to improve the quality of care. Furthermore, the results show that ACO professionals are more involved in the coordination of hospital care, in particular thanks to better communication between non-hospital professionals and hospital professionals at the time of patient admission and discharge. Collaboration between professionals, facilitated by being in the same place and/or by the presence of care coordinators, promotes the quality of care by freeing up time for professionals (244).

The impact of ACOs on patient engagement demonstrates an improvement in PROMs results. PHQ-4 (4-items Patient Health Questionnaire) and PROMIS items PROMs, measuring patients' physical, emotional and social functions, are improved when there is a patient-centred culture within ACOs (245). The impact of ACOs on PREMs results, measured via the Consumer Assessment of Healthcare Providers and Systems (CAHPS), demonstrate that the patient experience within ACOs is substantially improved, particularly as concerns access to care and organisation of care dimensions (242).

> ***The ACO initiative demonstrates the implementation of organisational strategies that improve the patient experience***

Impacts of payment models in the Stockholm region, Sweden

Example 1: the OrthoChoice initiative for care episode-based payment in orthopaedic surgery

The OrthoChoice initiative is a programme in the Stockholm region of Sweden that aims to improve access to hip (THR) and knee (TKR) replacement surgery for eligible patients by allowing them to choose where to undergo surgery from among pre-approved providers. The approval of healthcare providers is subject to several criteria, including the declaration of quality of care measures and a volume of at least 50 surgeries per year per surgeon. Care providers are remunerated per care episode via bundled payment (246).

In order to reconcile facilitated access to surgery with the risks of inducing wider and more premature surgical indications than would be medically required, financial penalties are scheduled to prevent patients' pathways from being initiated outside the primary care setting. Healthcare providers are responsible for the risk of surgery-related complications occurring up to two years after the operation; or up to five years afterwards in the case of antibiotic-treated surgical site infections occurring in the first two years. The share of performance-based payment is 3.2%. This is received by care providers if they reach predetermined quality targets (246).

The impact of the OrthoChoice model on PROMs is neutral. No difference was demonstrated for patients' health-related quality of life (EQ-5D) or pain (visual analogue scale). In a comparison between care providers based on changes in their activity, it was demonstrated that PREMs results were better for providers who increased their activity. Expenditure was reduced by up to 20% per care episode. In the Stockholm region, total spending relating to hip and knee replacement surgeries fell by 3% despite an increase in procedure volume of around 20% (246).

> ***The OrthoChoice initiative demonstrates a reduction in health spending and an improvement in patient experience***

Example 2: Stockholm VBRP initiative for care episode-based payment in spinal surgery

The Stockholm Value-Based Reimbursement Program (STHLM-VBRP) is a programme in the Stockholm region of Sweden that combines both a bundled payment model and a pay-for-performance model for spinal surgery care episodes, such as herniated disc and lumbar spinal stenosis surgery. The bundled payment is intended to cover all the care for the episode, including any complications for a period of one year. In addition to bundled payment, the performance-based payment is prospective and is adjusted on the basis of the PROMs score, obtained by a general assessment question asking the patient how their back or leg pain is currently compared to before the operation. The prospective performance-based payment is calculated based on national benchmark results. At the end of the care episode, it is adjusted based on the PROM results: if the PROMs results are better than expected, the performance-based payment is increased, and conversely a reimbursement will be requested in the event of worse than expected results (247).

The impact of the STHLM-VBRP programme is neutral on patient-reported quality of care. The PROMs results (general pain assessment, EQ-5D-3L, Oswestry Disability Index) are compared over time. Between before and after the introduction of the STHLM-VBRP, it is demonstrated that the PROMs results show the same trend over the two periods (247).

> ***The STHLM-VBRP initiative does not demonstrate any improvement of patient health outcomes***

Summary of impacts of healthcare funding arrangements

The initiatives described integrating patient-reported quality into care payment models demonstrate positive impacts on improving the quality of care, reducing health spending, or both, depending on the case. Although these are only a selection of initiatives, their positive results illustrate the value of quality-based financial regulation. These results are obviously limited to the specific contexts in which these initiatives have been introduced and therefore cannot be automatically generalised. However, it is interesting to note that some models have had their results replicated in different contexts, such as the reduction in spending in care episode-based payment for hip and knee surgery in the USA and Sweden. When the different initiatives do not demonstrate positive results in terms of quality improvement, their results remain at least neutral in this respect. And without prejudging the impact, these initiatives also show that quality-based financial regulation provides an incentive to improve targeted areas, such as patient experience. Professionals are adapting by implementing changes in their practices and organisations. The example of the USA, where numerous initiatives have been introduced, is instructive in that it demonstrates that the expected results are not always achieved or that successes can then be replicated. This demonstrates the value of proceeding by means of trials, in which the various models could be improved along the way in an incremental manner. It is also interesting to note that one of the levers for facilitating the evaluation and comparison of outcomes is the standardisation of the measures used, made possible by the coordination of initiatives.

4.3. Levers to promote the widespread use of patient-reported quality measures

Countries that have succeeded in introducing and widely using PROMs and PREMs either have medical registries in which these measures can be collected, or have strong incentives, including financial incentives, or even an obligation to collect them (see chapter 3. Panorama of international experiences). However, these provisions alone do not always ensure that the use of PROMs and PREMs is properly implemented to achieve the hoped-for improvement in quality of care.

At routine clinical care level, the use of PROMs and PREMs by professionals could become an established practice provided that professionals perceive the value of these instruments in the management of patients and that professionals are helped by having the tools to facilitate their use.

At the level of regulation through quality of care, mechanisms such as public reporting or benchmarking of outcomes can be facilitators for improvement, provided that common instruments are used to allow comparison of outcomes.

To reconcile these two levels of use, it is necessary to involve professionals and patients in the choice and definition of the methods of use of these instruments, so that they are relevant and adapted to their needs. Once the instruments have been agreed, the next step is to implement a broad roll-out that multiplies the beneficial impacts of patient-reported quality measurement.

The deployment of patient-reported quality measurement initiatives that do not use the same PROMs and PREMs complicates comparisons that are nonetheless useful for improving the quality of care. A coordinated approach thus contributes to the choice of standardised measures enabling comparisons and the use of the results in quality improvement mechanisms.

Initiatives such as ICHOM and the OECD provide guidance on the choice of these measures for healthcare providers interested in comparing themselves internationally. Some countries are adopting this nationally coordinated approach to measuring patient-reported quality; the example of Wales shows that this type of harmonisation is possible and useful with the initial results.

Example of a standardised approach to the national use of PROMs and PREMs in Wales, UK

The All Wales PROMs, PREMs and Effectiveness Programme (PPEP) initiative is a programme in Wales, UK to develop a platform for the electronic collection of PROMs and PREMs for all secondary care patients. Ultimately, the idea is to propose the completion of PROMs to all patients receiving secondary care before and after treatment, as well as PREMs after their care experience. Within NHS Wales, the collection of PROMs and PREMs has existed for several years but has been conducted via local initiatives without a systematic and fully coordinated approach, which has now been made possible by the implementation of the PPEP programme.

National coordination on the joint choice and use of PROMs and PREMs agreed with professionals and patients

To facilitate the benchmarking of care organisation outcomes and learning from best practice, the PROMs and PREMs used in the PPEP programme are common at national level. The selection process for PROMs and PREMs instruments, supported by the Welsh Government, involves professionals and patients (248).

For the generic PROMs, the instruments chosen are the EQ-5D-5L and the Work Productivity and Activity Index (WPAI), which enable comparisons between diseases, medico-economic analyses and the identification of the impact on productivity and work activity limitations respectively.

Regarding specific PROMs, it is envisaged that common instruments will be used on national level for each disease or treatment. For each field concerned, professionals are consulted and their agreement sought. The Welsh Government determines the fields where the collection of PROMs and PREMs is prioritised. The government order is thus to focus first on orthopaedic and cataract surgery, heart failure and lung cancer. In total, professionals have so far agreed on more than 30 PROMs for different diseases (248).

For PREMs, working groups with patients have led to the definition of nine common patient experience questions to be used universally. Other questions can be added to these nine experience questions, to make them more relevant to different diseases and specific local needs. In addition, qualitative analysis of patients' experiences at a national level is also a long-term objective (249).

The relevance of the national implementation of patient-reported quality measures demonstrated by the early results of the programme's impact

In practice, patients receive their PROMs results, which are also automatically integrated into the patient's electronic health record and can therefore be used by the care team for follow-up and during consultations to improve communication and shared medical decision-making.

The impact of the use of PROMs and PREMs through the PPEP programme demonstrates an improvement in the relevance and outcome of care. Initial results suggest that: 1) the number of orthopaedic consultations considered to be of little relevance has decreased by about 70%; 2) the results of PROMs collected six months after surgery, determining the need for a hospital visit or not, seem to indicate that fewer patients need to come for a consultation (248).

5. Conclusion

Measuring patient-reported quality is essential to improve quality of care. PROMs and PREMS questionnaires are instruments that measure patient-reported health outcomes and patients' experience of care in a quantitative, accurate and comparative manner. Useful for both patients and professionals, these measures are still not widely used in routine clinical practice, but the number of initiatives implementing them is steadily increasing.

Initiatives outside France are heterogeneous; they differ in terms of the objectives pursued, the approaches adopted, whether they are mandatory or not, the scales of deployment, the instruments used, the methods of administration, the uses and the results obtained. These differences make it difficult to assess the impact of PROMs and PREMs on quality of care. However, the benefits so far demonstrated in terms of quality and costs across different populations and different areas of care suggest the value of continuing the measurement of patient-reported quality. This requires choosing useful, relevant and standardised measures, based on existing recommendations, and supporting their roll-out so they can benefit as many patients as possible.

One difficulty lies in the practical implementation of these measures, especially PROMs, but levers, such as technology, exist to facilitate their use in routine clinical practice, the first place where such use is desired and has been shown to improve quality of care.

6. Work in the pipeline at the HAS

In France, progress to be continued and ambitions to be realised

With regard to PREMs, there is now widespread measurement of hospital patient experience and satisfaction in France, and this is continuing to be extended in order to reach more patients and to be promoted within various mechanisms designed to improve quality of care. Hence France is one of the most advanced countries when it comes to measuring patient experience, this having been implemented on a national level for a number of years already. This contrasts with national progress concerning the implementation of PROMs, with France currently lagging behind some other countries making very active use of PROMs.

There is already a clear ambition to make progress in terms of the use of these two measures. This is illustrated by voluntary and dedicated local initiatives on the one hand and initiatives within the framework of national and regional trials, led by the Ministry of Health and the national health insurance system, on the other, which could be generalised in the coming years. The acceleration of digital health care and the forthcoming implementation of the *Mon Espace Santé*[46] ("My Health Space") platform should also make it possible to address the challenges and expectations of patients and professionals, in which the HAS is closely involved to fulfil its mission of improving the quality of care for all.

The HAS is continuing its actions and reinforcing its support for patient-reported quality measurement

Prospective actions for PROMs

Identify French initiatives using PROMs

In France, there are both international (ICHOM, PaRIS OCDE) and national (IPEP, PEPS, EDS) ongoing PROMs initiatives. Other initiatives exist, either local or regional, but there is no centralised information on their number and characteristics. Before considering any large-scale roll-out, a first step is to have an overview of the PROMs situation in France, which could potentially help guide such a roll-out.

The HAS therefore plans to conduct a national survey in order to identify and describe French initiatives collecting and using PROMs by healthcare professionals and organisations.

Support projects using PROMs

It is often difficult to use PROMs in routine clinical practice. These difficulties are either common or context-dependent. It is important to identify barriers to their use, as well as facilitators that can be used by the players involved to encourage their routine implementation.

The HAS thus intends to support initiatives in the community setting or in hospitals. Its main objective is to learn from initiatives already launched locally or regionally to improve the quality and safety of care. Feedback from professionals concerning their use of PROMs will make it possible to assess the feasibility of a national roll-out.

Produce guides to assist in the use of PROMs

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[46] https://esante.gouv.fr/mon-espace-sante

Numerous PROM questionnaires exist already. One of the objectives of the HAS is to make available practical guides to help those who want to understand and deploy PROMs locally. The first three guides have already been published. One explains the theoretical concepts and operational criteria. The other two have a specific context: one presents what exists for total hip replacement, knee replacement and colorectal cancer; the other is part of the work on pathways for patients with chronic obstructive pulmonary disease. Other guides are already planned.

Use PROMs to assess health products

The HAS recommends the integration of PROMs to assess health products in routine clinical practice, in the context of early-access programmes[47] or real-world studies[48].

Prospective actions for PREMs

Extend the national e-Satis patient experience and satisfaction measurement system

In France, the use of PREMs is well established in healthcare facilities, thanks to the HAS's national e-Satis system, which has been gradually rolled out. Since 2016, the e-Satis system has concerned patients hospitalised in medical, surgical and obstetrical departments (*e-Satis + 48 h MCO*); since 2018, surgical outpatients (*e-Satis CA*); since 2020, patients hospitalised for follow-on care and rehabilitation (*e-Satis SSR*).

The HAS is continuing to extend the measurement of patient experience and satisfaction, developing PREMs questionnaires for patients hospitalised at home (HAH) and for patients receiving care in psychiatric facilities.

Complement the measurement of experience and satisfaction with analysis of patient feedback

Within the framework of the HAS e-Satis system, the questionnaires contain closed questions on patient experience and satisfaction, the answers to which are analysed by the HAS, with constant feedback to healthcare facilities. At the end of the questionnaires, patients can also give free comments, which, to date, have been kept and used by the health facilities only.

The HAS plans to conduct a descriptive and qualitative analysis of the information contained in the patients' comments on a national level. This analysis will first of all provide professionals, patients and facilities with information about what is important to patients. It is envisaged that this work will subsequently be continued, helping health facilities exploit patient feedback.

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[47] https://www.has-sante.fr/upload/docs/application/pdf/2021-06/acces_precoces_-_doctrine.pdf

[48] https://www.has-sante.fr/upload/docs/application/pdf/2021-06/guide_etude_en_vie_reelle_medicaments__dm.pdf

Table of appendices

Annexe 1. Examples of PROMs recommended by the ICHOM

Disease or population	Population concerned	Recommended PROMs
Primary care and prevention		
– General adult population (article pending publication)	Over 18 years of age	PROMIS-10
		WHO Disability Assessment Schedule 2.0 (WHO-DAS-12)
		WHO (Five) Wellbeing Index (WHO-5)
– General paediatric population (250)	Aged 6 to 12 years	PROMIS Parent Proxy Scale v1.0 – Global Health 7+2
		PROMIS Parent Proxy Short Form v1.0 – Cognitive Function 7a
	Aged 13 to 17 years	PROMIS Paediatric Scale v1.0 – Global Health 7+2
		NIH Toolbox Self-Efficacy CAT Ages 13-17 v2.0
	Aged 18 to 24 years	Assessment of Quality of Life (AQoL) – 8D
		PROMIS Short Form v1.0 – Sleep Disturbance – 4a
		PROMIS Pool v2.0 – Sexual Function and Satisfaction: Screeners
		PROMIS Short Form v2.0 – Cognitive Function 4a
– General geriatric population (251)	All patients	SF-36
		University of California, Los Angeles – 3 Item Scale
		Adult Social Care Outcomes Toolkit
		Zarit Burden Interview (carer responses)
Cardiovascular and circulatory diseases		
– Hypertension (252)	All patients	EQ-5D-3L SF-12 VR-12 PROMIS-10
	Men	PROMIS (one single item on erectile function)

Disease or population	Population concerned	Recommended PROMs		
– Heart failure (253)	All patients	PROMIS Physical Function Short Form 4a		
		Kansas City Cardiomyopathy Questionnaire-Short Version (KCCQ-12)		
		Patient Health Questionnaire (PHQ-2)		
– Atrial fibrillation (254)	All patients	PROMIS-10		
– Stroke (255)	All patients	PROMIS-10		
		Simplified modified Rankin Scale Questionnaire		
Hormonal and metabolic disorders				
– Diabetes (256)	All patients	WHO-5 Well-Being Index		
		Problem Areas in Diabetes Questionnaire (PAID)		
		Patient Health Questionnaire (PHQ-9)		
– Chronic kidney disease (44)	All patients	PROMIS-29 + PROMIS Global Health	RAND-36	SF-36
Musculoskeletal disorders				
– Osteoarthritis of the hip or knee (257)	All patients	EQ-5D-3L + EQ-VAS		
		Veterans RAND 12 (VR-12)		
	Patients affected primarily by osteoarthritis of the hip	Hip Disability and Osteoarthritis Outcome Score – Physical Function Shortform (HOOS-PS)		
	Patients affected primarily by osteoarthritis of the knee	Knee Injury and Osteoarthritis Outcome Score – Physical Function Shortform (KOOS-PS)		
Vision disorders				
– Cataract (258)	All patients	Catquest-9SF		

Disease or population	Population concerned	Recommended PROMs
– Age-related macular degeneration (259)	All patients	Brief Impact of Vision Impairment Profile (B-IVI)
Malignant diseases		
– Cancer of the colon and rectum (260)	All patients	EORTC QLQ-C30 EORTC QLQ-CR29
	Patients treated by surgery and/or radiotherapy	EORTC QLQ-CR29 MSKCC Bowel Function – Dietary Subscale
	Patients treated by systemic chemotherapy	EORTC QLQ-LMC21 (one single item)
– Breast cancer (261)	All patients	EORTC QLQ-C30 EORTC QLQ-BR23
	Patients treated by surgery and/or radiotherapy	BREAST-Q Patient Reported Outcomes Instrument (BREAST-Q)
	Patients treated by systemic chemotherapy	EORTC QLQ-LMC21 (one single item) Functional Assessment of Cancer Therapy Endocrine Subscale (FACT-ES) (one single item)
– Lung cancer (262)	All patients	EORTC QLQ-C30 EORTC QLQ-LC13
Mental health		
– Depression and anxiety (263)	All patients	Patient Health Questionnaire (PHQ-9) Generalized Anxiety Disorder (GAD-7) World Health Organization Disability Assessment Schedule 2.0 (WHO-DAS 2.0)

Disease or population	Population concerned	Recommended PROMs	
		Medical Outcomes Study: Social Support Survey (MOS-SSS)	
	Patients with social phobia	Social Phobia Inventory (SPIN)	
	Patients with agoraphobia	Mobility Inventory for Agoraphobia (MIA)	
	Patients with post-traumatic stress disorder	Impact of Event Scale – Revised for Post-traumatic Stress Disorder (IES-R)	
	Patients with panic disorder	Panic Disorder Severity Scale (PDSS-SR)	
	Patients with obsessive-compulsive disorder	Obsessive-Compulsive Inventory (OCI-R)	
– Anxiety, depression, obsessive-compulsive disorder and post-traumatic stress disorder in children and adolescents (264)	Children and adolescents	Revised Children’s Anxiety and Depression Scale – 25-item version (RCADS-25)	
		KIDSCREEN-10 Index (KIDSCREEN10)	
		Children’s Anxiety Life Interference Scale (CALIS)	CALIS – Parent-report Scale
		Children’s Global Assessment Scale (CGAS)	
	Patients with post-traumatic stress disorder	Children’s Revised Impact of Events Scale – 8-item version (CRIES-8)	CRIES parent-report 13 items (CRIES-13)
	Patients with obsessive-compulsive disorder	Obsessive Compulsive Inventory – Child Version (OCI-CV)	
	Patients over the age of 10	Columbia Suicide Severity Risk Scale (C-SSRS)	
– Personality disorders (article pending publication)	All patients	Level of Personality Functioning Scale – Brief Form (LPFS-BF)	
		Recovering Quality of Life – 10-item version (ReQoL10)	
		Difficulties in Emotion Regulation Scale – 16-item version (DERS-16)	
		Columbia Suicide Severity Rating Scale – Screener/Recent – Self-report (C-SSRS)	
		Modified Overt Aggression Scale (MOAS)	
		WHO Disability Assessment Schedule 2.0 – 12-item version (WHO-DAS-12)	

Disease or population	Population concerned	Recommended PROMs
		PROMIS Short Form v2.0 – Social Isolation 4a
	Children and adolescents	KIDSCREEN-10 Index (KIDSCREEN10)
– Psychotic disorders (265)	All patients	Patient Health Questionnaire 9-item (PHQ-9)
		Modified Colorado Symptom Index (MCSI)
		Recovering Quality of Life – 20-item version (ReQoL20)
		PROMIS Short Form v1.0 – Sleep Disturbance 4a (PROMIS-Sleep)
		WHO Disability Assessment Schedule 2.0 – 12-item version (WHO-DAS-12)
		Patient Health Questionnaire 15-item (PHQ-15)
	Patients treated with antipsychotic drugs	Glasgow Antipsychotic Side-Effect Scale (GASS)
	Patients with type I bipolar disorder	Altman Self-Rating Mania Scale (ASRM)
	Children and adolescents	KIDSCREEN-10 Index (KIDSCREEN10)
Respiratory diseases		
– Covid-19 (article pending publication)	All patients	PROMIS Global Health
		PROMIS Short Form v2.0 – Social Isolation 4a
		Influenza Patient-Reported Outcome (FLU-PRO)
Neurological diseases		
– Parkinson's disease (266)	All patients	Movement Disorder Society (MDS-UPDRS)
		International Parkinson's and Movement Disorders Society (IPMDS) Non-Motor Symptoms Questionnaire (NMSQ)
		Parkinson's Disease Quality of Life Questionnaire (PDQ-8)
– Dementia (267) including Alzheimer's disease, vascular	All patients	Quality of Life in Alzheimer's Disease (QOL-AD)
		Quality of Wellbeing Scale-Self Administered (QWB-SA)

Disease or population	Population concerned	Recommended PROMs	
dementia, Lewy body dementia and frontotemporal dementia	Caregivers	EQ-5D-5L	Veterans RAND 12 (VR-12)
	All patients	Neuropsychiatric Inventory (NPI)	
		Clinical Dementia Rating (CDR)	
		Bristol Activity Daily Living Scale (BADLS)	
		Montreal Cognitive Assessment (MoCA)	

Annexe 2. Detailed tables of initiatives using PROMs and PREMs in 13 countries

Annex 2 refers to tables 9 and 10, which are detailed tables of initiatives measuring and using PROMs and PREMs in 7 European countries and 6 English-speaking countries. These tables contain more detailed information than that in table 7 in part 3.

1. Organisation and collection level

For each country, the following are indicated:

- the name(s) of the organisation(s) tasked with collecting PROMs and/or PREMs;
- the level of coordination of PROMs and/or PREMs collection:
  - national (country or federation);
  - regional (region, state or province, territories, defined administrative areas);
  - local.

The **national level** refers either to a national mechanism for coordinating the collection of validated PROMs and/or PREMs, or to the collection of PROMs/PREMs in at least one national registry.

The **regional level** refers to at least one regional mechanism for coordinating the collection of validated PROMs and/or PREMs, or to the collection of PROMs/PREMs in at least one regional registry. It can also concern a mechanism for coordinating the collection of PROMs in health territories within a region.

The **local level** refers to the collection of PROMs/PREMs developed, validated and collected locally, in a facility or a group of facilities; to be distinguished from the local deployment of PROMs/PREMs that are part of a national initiative (e.g.: CMS). Only local initiatives found in the literature are reported in tables 8 and 9.

2. The list of the main PROMs collected by care providers[49] (table 9)

- **Generic:** health status assessment questionnaires (SF-36, SF-12, EQ-5D);
- **Specific:**
  - by disease (e.g. QLQ-C30 for cancers);
  - by surgical procedure (e.g. Oxford Hip Score (OHS) for hip replacements).

3. The list of the main PREMs collected by care providers (table 10)

Different types of PREMs questionnaires are found:

- **standardised** and adapted to different types of care (e.g. Consumer Quality Index (CQI) in the Netherlands, CAHPS in the USA (outpatient, primary, hospital, nursing care, dialysis centres), etc.);
- **by type of care:**
  - general medicine (e.g. Denmark);
  - hospital care (e.g. England, Australia);
  - outpatient care (e.g. Denmark, New Zealand);
  - mental health (e.g.: Denmark);
  - primary care (e.g. England, Australia, New Zealand, etc.).

- **by disease:**
  - cancer (e.g. Canadian Partnership Against Cancer in Canada);

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[49] Health facilities/hospitals and/or primary care structures.

- psychiatry (e.g. Denmark);
- rheumatoid arthritis (e.g. England, Wales);
- depression (e.g. USA).

4. The administration methods and formats used

Questionnaires may be administered:

- during a face-to-face interview;
- by telephone (PDA/smartphone);
- by interactive voice response system (IVR);
- self-administered by the patient (paper (Pdf), online, or received by post).

Questionnaires may be administered in the following formats:

- paper/pen (Pdf);
- online questionnaire (PC/laptop/tablet);
- telephone (PDA/smartphone);
- interactive voice server (IVS).

5. The websites for public disclosure of PROMs/PREMs results and method(s) of presentation of results

Public disclosure corresponds to providing public access to quality of care indicator results. These indicators may include patient-reported quality measures.

This public disclosure may correspond to various formats for the presentation of results:

- **care structure results:**
  - hospital;
  - primary care structure (private practice, health centre, healthcare network);
- **Aggregated results:** national, regional, by provinces, hospital networks (for a given care), insurance schemes, healthcare programmes, associations, etc. ;
- **comparative results:**
  - comparison/benchmarking: star-rating system relative to a mean or a performance target;
  - funnel plots: visual representation of statistical data in a scatter plot showing facilities that are outliers [50];
- **comments/verbatims:** summary of patient comments.

6. The objectives of use of PROMs and PREMs results

- **Comparison/benchmarking**
  - **Comparison** of the results of care providers and a description of results may be performed using a cross-sectional or longitudinal analysis.
    - **Cross-sectional comparison**

Comparisons may be described at the same time, based on the geography of care providers (care providers from the same local area, region (state, province) or an inter-regional, national (country or

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[50] Tendency for a facility to have a higher or lower than expected mortality rate, for example.

federation) or even international comparison). Comparisons may concern care providers from a specific care sector (e.g. community care, hospital care, mental health, cancer, etc.).

Comparisons are presented in the form of care provider rankings. The benchmark may be a national mean or an expected target objective, for example.

- **Longitudinal comparison**

This is the monitoring of the results of healthcare providers over time, enabling comparisons with themselves.

A benchmarking approach is an ongoing effort to measure the results of care providers, compare them with other care providers, learn how these results are achieved and apply the lessons learned in order to improve (268); hence benchmarking encompasses the following actions:

- regular comparison of outcomes with those of the best care providers;
- identification of causes of differences between care providers;
- the search for new approaches to implement quality improvement strategies;
- the monitoring of indicator results.

– Accreditation of healthcare structures

In the majority of countries, healthcare structure accreditation is a system for assessing the quality of healthcare activities for both hospitals and primary care structures. The level of assessment chosen depends on the organisation of the country analysed.

In France, the term **"accreditation"** corresponds to the accreditation of physicians and medical teams for certain so-called risk activities. It is a voluntary risk management approach that constitutes a method of continuous professional development. https://www.has-sante.fr/jcms/c_428381/fr/accreditation-des-medecins-et-equipes-medicales

For the assessment of healthcare facilities/hospitals, since 2007, the term used has been **"certification"** (initially called "accreditation" in 1999), which is a mandatory external assessment procedure by appointed professionals.

– Pay for performance

Pay for performance means taking into account the outcomes of healthcare providers in order to finance them. Pay for performance models are based on the results of indicators, including patient-reported quality indicators. The models observed consist of a contract between an insurer and a chosen care provider based on the attainment of objectives in terms of improving quality of care (130).

Table 9. Summary of initiatives measuring and using PROMs in 7 European countries and 6 English-speaking countries

Country	Organisation and collection level (national, regional/provincial, local)	PROMs collected		Method of collection and data sources used	Website(s) for public disclosure/method of presentation of results	Uses: comparison and/or benchmarking, accreditation, pay for performance
				European countries		
Sweden	• **National initiative:** leading country in the routine collection and use of PROMs in national clinical registries by specialisation/disease since 1975. • There are around **108 national quality registries** (National Quality Registry (NQR)) 96 of which include PROMs and PREMs: – **cataract:** Cataract Registry; – **rheumatology:** National Quality Registry for Rheumatic Diseases; – **hip arthroplasty:** Swedish Hip Arthroplasty Register (orthopaedic units/voluntary participation of patients); – **spine:** Swedish Rheumatology Quality Registry; – **intensive care:** National Quality Registry for Intensive Care, etc.	**Generic PROMs in 50% of registries:** – **EQ-5D-5L/EQ-5D-VAS:** hip arthroplasty; stroke; pain. – **SF-36/RAND-36.**	**Specific PROMs** collected in more than 50% of national clinical registries: – cataract: Catquest-9SF; – hip arthroplasty; – stroke; – rheumatology: – surgeries; – chronic diseases; – psychiatric disorders; – cancers; – etc. ⇒ More than 100 registries covering these different diseases and hospitalisation reasons.	**Collection of PROMs in registries:** **e.g.** hip arthroplasty – self-administered patient questionnaires before surgery (1 year before) and repeated at fixed time intervals after surgery (1 year, 6 and 10 years); – sent by post (paper questionnaire) or electronic collection (tablet). Healthcare facilities organise the collection of PROMs and send data to web applications. ⇒ 96 out of 108 registries include PROMs or PREMs.	• **For each NQR registry**, the results of PROMs are published in the form of an annual report, specific to each disease, on a website: ⇒ standardised formats for the presentation of results: hospital average compared to an expected target value and the national average – **e.g.** pain following a hip joint replacement in the Swedish Hip Arthroplasty Register. **The same is true for generic PROMs:**	• **Comparison and benchmarking:** more than 100 registries compare the costs and results of treatments, for numerous diseases (dementia and mental disorders). ⇒ Computer tools adapted to disease follow-up and patient involvement. • **Financing of registries:** in their annual applications for registry funding, hospitals must indicate what their PROMs and PREMs results are and how they can be used to improve quality of care[52]. There is also a consideration of results compiled at regional level, by dedicated expert groups. The registries are funded by the state (70%) and the regions (30%). • **Pay for performance:**

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[52] The obligation to indicate the results of PREMs and PROMs and how they are used dates back to 2014.

	• **Management of each registry by experts**[51]: – **50%** of national registries use generic PROMs (EQ-5D/SF-36) and more than half of them include specific PROMs; – **20%** of national registries include patient-reported data to improve quality of care on a local level: i) improve shared medical decision-making at clinical meetings; ii) inform/involve patients in their care plans; iii) improve the precision of surgical indications and the follow-up of post-discharge complications. • **International initiative:** participation in the ICHOM project. • Launch of a project to monitor the quality of care in the management of psychotherapy in adult patients. • Participation in the collection of PROMs for the OECD panorama (hip arthroplasty, breast cancer/breast surgery, mental health).				– **e.g.** pain management: outcomes of a hospital compared to expected outcomes and the national average for hospital outcomes.	– **OrthoChoice (Stockholm – 2009):** a bundled payment model with a package that includes all care services for all treatment phases for a total hip or knee replacement [53] AND guarantees care for complications for 2 years after surgery. ⇒ Rewarded to the tune of 3.2% of the bundled payment if quality improvement targets are met (EQ-5D and VAS). This is a financial compensation for performance measurement. – **Stockholm-VRBP:** pay-for-performance model combines with a bundled payment model for spinal, herniated disc and lumbar spinal stenosis surgery care episodes. ⇒ The bundled payment covers all care episodes and all complications for a period of one year. ⇒ Prospective performance-based payment adjusted on the basis of PROMs results: leg and back pain is compared before and after surgery. Payment is adjusted based on PROMs results: if the

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[51] Patients can participate in the management of certain registries.

[53] The package of care services includes diagnosis, surgery, all post-operative care, all prosthetic joint care and patient follow-up.

						outcomes are better than expected, the performance-based payment is increased, and if they are worse than expected a reimbursement will be requested. – **SVEUS =** collaborative payment trial tested between 2013 and 2015[54]. ⇒ National platform for monitoring reimbursements: objective of improving quality of care and reducing spending. ⇒ Healthcare system performance measure results are taken into account: process indicators, outcomes (PROMs, etc.); ⇒ Norway, Denmark, the UK and the Netherlands will soon use this model.
Netherlands	• **National initiative:** leading country in the routine collection and use of PROMs in national clinical registries by specialisation and disease since the 1970s. – **2009:** creation of the Dutch Surgical Colorectal Audit (DSCA), of the of the Association of Surgeons of the Netherlands.	**Generic PROM:** EQ-5D. – An EQ-5D collection test was routinely performed in the national traumatology registry.	**Specific PROMs:** **Routine collection:** – **THR:** HOOS, OHS; – **TKR:** KOOS, OKS; – **dermatology:** *Skindex for skin disease, Dermatology Life Quality Index.*	Collection of PROMs in national or local clinical registries: – questionnaires are sent online or by post, and integrated into national registries, to be administered at specific times during a treatment.	– The DICA publishes all the PROMs data collected in registries, in the form of Excel files, containing the raw data, as **open data** on the following link: www.zorginzicht.nl ⇒ The DICA is against the ranking of	• **Benchmarking:** – **ROM:** initiative launched in 2010, to use PROMs in mental health facilities (diagnosis, monitoring of symptoms and treatment progress) and to enable quality benchmarking between care providers. • **Comparison:**

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[54] This platform has been tested for the following conditions: osteoarthritis, spine, hip, knee and bariatric surgery, obstetrics, myocardial infarction, diabetes, osteoporosis, breast cancer.

– **2011:** creation of the Dutch Institute for Clinical Reporting (DICA) responsible for the development and collection of indicators in hospitals. ⇒ Setting up of national clinical registries (diseases, oncology - breast, colorectal, surgery) in charge of collecting process indicators, outcomes and hospital organisation data. At present, the DICA manages more than **23 national clinical registries** (**e.g.** Dutch Surgical Spine Registry). – **2011-2012:** the DICA implements the routine collection of PROMs in national clinical registries. ⇒ The first PROMs related to mental health: Routine Outcome Monitoring (ROM) project. At present, the majority of registries incorporate PROMs. **Other bodies:** – Netherlands Institute for Health Services Research (NIVEL): research institute responsible for the development of PROMs. – Consensus-based standards for the Selection of health Measurement Instruments (COSMIN): research group		**Voluntary approaches:** – **lung cancer:** EORTC QLQ-C30 & LC1; – **prostate cancer:** EORTC-QLQ-PR25; SHIM; ICIQ; IPSS; EPIC; – **THR:** Harris Hip Score (HHS); – **TKR:** WOMAC[55]; Knee Society Score (KSS); – **spine surgery:** *Neck Disability; Oswestry Disability Index*; – **Stroke:** PROMIS-10 Global.		hospitals and the published raw data is difficult for patients to interpret. – Rankings produced by private insurance companies and patient organisations, based on this raw data, are published on their respective websites. ***Last accessed:*** 12/11/2020.	– private insurers, patient associations, etc. can freely use data published as open data to produce and analyse their own results and produce their own hospital rankings. • **Pay for performance:** – The DICA, in partnership with the ICHOM, has decided to link payments for diagnosis-related groups (DRGs) to indicator results and to incorporate all outcome indicators (including ICHOM-type PROMs) in clinical registries. ⇒ When a registry is operational, the costs related to the collection of indicators are integrated into the financing of DRGs and the fixed and prospective payments for patient care, depending on the diagnosis. ⇒ If care providers do not measure these indicators correctly, they risk losing the reimbursements related to collection of the data. – Mental health services are obliged to introduce PROMs into their clinical practice

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[55] Western Ontario and McMaster Universities Osteoarthritis Index.

	that proposes a manual of guidelines to assess existing PROMs. • **Local initiative:** routine collection of PROMs on total hip replacement (Harris Hip Score (HHS)/Oxford Hip Score (OHS)), knee replacement (WOMAC; Knee Society Score (KSS)) in the orthopaedic registry of Radboudumc university hospital (1993). • **International initiative:** participation in the ICHOM project. • **Participation in the collection of PROMs for the OECD panorama** (hip arthroplasty, breast cancer/breast surgery, mental health).					even if services are free to choose them from a set of proposed measures. ⇒ The incentive to comply with collection is strong: mental health services face sanctions if they do not achieve the desired response rates. ⇒ The objective of insurance companies is to use the database results to compare mental health services and sign contracts with the most cost-effective services.
Norway	• There are **19 national registries**, some of which include PROMs**:** – **Centre for Rehabilitation in Rheumatology:** PROMs on low back pain (collaboration with the ICHOM project). • **Local initiatives:** numerous research and experimental projects to introduce the routine collection of PROMs in other disciplines. – **QUASER project:** multi-level analysis (national, hospital, department) of quality of care policies and practices through longitudinal case studies in 10 hospitals in 5 European	**Generic PROMs:** – SF-36; – EQ-5D.	**Specific PROMs:** – low back pain: ICHOM; – anxiety; – depression; – pain.	**Collection of PROMs in registries:** – routine collection in national registries; – local initiatives.	No public disclosure site found.	• **QUASER project:** prescriptive system with health plans, increased self-regulation by operators on quality and safety of care. • Norway will soon use the SVEUS model for monitoring healthcare reimbursements.

	countries (Norway, UK, Portugal, Sweden, Netherlands): conduct of semi-structured interviews. – Desire to set up a national mental health registry, incorporating indicators, including PROMs. • A national survey was conducted by the Norwegian Institute of Public Health, between September 2018 and August 2020 on patient experience following treatment in rehabilitation facilities (private and public). The questionnaire included both PREMs and PROMs (results not yet available).					
Germany	*A healthcare system shared between the federal government and 16 states, and a health insurance system managed either by public (government) funds or by private (non-government) for-profit funds.* • No national system for the collection of PROMs/local initiatives.	**Generic PROMs:** information not found.	**Specific PROMs:** – adverse events after cancer treatment: PRO-CTCAE; – long-term survival following allogenic stem cell transplant: PROVIVO; – prostate cancer; – migraine; – EORTC QLQC30.	Information not found.	No public disclosure site found.	**Local initiatives:** • **Improvement of quality of care:** the Martini clinic performs 2,000 prostate cancer operations per year and organises the collection of survival data, as well as data on symptoms (incontinence/sexual function) and quality of life after each operation (annual collection of PROMs after initial recovery). It performs better than other clinics for prostate cancer care indicators. • **Bundled payment system:** in the 2000s, the West German Headache Centre adopted a bundled payment

					system using the results of PROMs to measure the quality of migraine care, looking at the **number of days off work saved** after a change in management AND **the evolution in spending on medication** in the community medicine setting. ⇒ A patient-centred approach was put in place by the centre's manager, through a care contract with KKH Insurance, which was later extended to the majority of insurance companies. Instead of a medical follow-up in the community setting, 3 strategies were proposed to each patient, after consultation with a neurologist, a psychologist and a physiotherapist[56]. ⇒ Data on the number of days off work saved was reported in the PROMs questionnaires. ⇒ The centre demonstrated better care outcomes in terms of reduction in days off work per patient[57] and costs related to drug treatment.

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[56] Proposed strategies: (i) follow-up by a network of specialised neurologists; (ii) patient education programme; (iii) hospitalisation.

[57] The percentage of patients with 6 days off work per month decreased from 58% to 11% after the implementation of the programme.

Denmark	*Country divided into 5 regions since 2007, following the merger of 5 counties.* – No national or regional system for the collection of PROMs/local initiatives. – At this stage, there are local initiatives or research projects. – Creation of an expert group in 2016, to assess the benefits, needs and barriers for the implementation of routine national collection of PROMs. – The National Danish PRO Secretariat and National PRO Working Group is responsible for the standardisation of the questionnaires that will be used on a national level. – The National Health Data Authority has set up a working programme to establish a national routine PROMs collection system. It concerns information systems, the development method for PROMs and the clinical fields of application. • **Projects / studies conducted:** – National Clinical Indicator Programs for Adult Patients Diagnosed with Depression and Schizophrenia: work in	**Generic PROMs:** information not found.	**Specific PROMs (ongoing projects):** • **Priority fields:** – osteoarthritis of the hip /(HAQ-DI); – apoplexy; – mental health: anxiety/depression, schizophrenia (national project in progress). • **Other fields:** – epilepsy; – prostate cancer: EPIC-26; – breast cancer (chemotherapy); – lung cancer; – myeloma; – general medicine: depression/blood pressure problems; – herniated disc/low back; – psoriasis; – THR; – EORTC Short Form; – obesity surgery (BODY Q); – stoma; – menopause; – medicinal treatment of thyroid problems; – dermatology: psoriasis (PASI, DLQI).	**Collection of PROMs in registries:** psychiatry/mental health, cancer, etc.	**To date, no public disclosure site:** the national system for collection and public disclosure is in the process of being developed.	• **Improvement of quality of care/local initiatives:** – **general medicine** get patients more involved in their care (depression/blood pressure); – **outpatient care:** epilepsy, cancer (prostate and breast). • **Improvement of quality of care/regional initiative:** – **mental health:** PROMs used to improve decision-making on a regional level. • Denmark will soon use the SVEUS model for monitoring healthcare reimbursements.

	progress to set up the national collection of mental health PROMs in 2 registries on depression/schizophrenia. Ultimately, national collection will be mandatory. – Routine Outcome Monitoring (ROM): implementation of a programme for the collection of mental health PROMs in 2000 (Copenhagen). – Collection of PROMs following prostate cancer surgery in the Danish Prostate Cancer Registry, for a period of 5 years (2010 – 2016), to study the evolution of patients' symptoms. – Collection of PROMs on psoriasis in the Danish National Registry for 5 years.					
Belgium	PROMs less frequently measured than PREMs in Belgium. • **National (federal) system for the collection of PROMs,** in the context of the Health Information Survey (HIS), deployed in the in the Flemish and Walloon regions. • **Local PROMs collection initiatives:** – healthcare facilities: detection of symptoms for patient follow-up/improvement of doctor-patient communication;	**Generic PROMs:** – PROMIS; – EQ-5D; – SF-36; – SCL-90, etc.	**Specific PROMs:** ▪ **TKR:** – KOOS; – EORTC BR23; – EORTC CR29; – EORTC QLQ C30; – EORTC QLQ 30 Short Form / four-item scale (EF4); – POKIS; – REPOS. ▪ **Cancer:** EORTC QLQ-C30; EORTC BR23 (breast cancer).	**Different collection methods:** paper, internet, tablet. – **Patient level:** PROMs are integrated into the electronic health record (EHR) and other databases, such as clinical registries, to measure the impact of treatments on a larger scale. – **National level:** centralisation of collection of PROMs data from	• There are results presented in the form of reports, summaries, or feedback to hospitals, but no public disclosure site was found for the publication of results by hospital, or region. Feedback needs to be standardised. • Outcomes directly calculated in the HIS and reported back in	• Inter-hospital comparison and benchmarking: a few initiatives. • Lack of standardisation in the use of PROMs, making benchmarking difficult. • **Repeated measures:** chronic diseases and complex procedures (ICHOM). • **Pay for performance:** – PROMs data could be used in **reimbursement decisions** taken by solidarity funds or the National

	– other institutions: research organisations and structures. • **International initiative:** participation in the ICHOM project.		▪ **Diabetes:** Diabetic foot ulceration. ▪ Pain. **Flemish region:** PROMs are part of the Flemish indicator project, VIP, which is responsible for the development of process and outcome indicators (PREMs and PROMs). It includes several platforms for collecting indicators (including the VIP platform). **E.g.** Flemish version of the Juvenile Arthritis Multidimensional Assessment Report. **French/Walloon region:** use of PROMs in the*Attentes et satisfaction des Patients et de leur entourage* (ASPE) coordinated by Be Service Minded (BSM) since 2005.	hospitals on a voluntary basis, within the Health Information Survey (HIS), which is a national survey database.	aggregated form to volunteer hospitals.	Institute for Health and Disability Insurance (RIZIV-INAMI). ⇒ For the time being, this approach is limited to PROMs used in the context of clinical trials, but it could be extended to routine use, to assess new treatments or reassess treatments that are already reimbursed.
France	**No national or regional system for the routine collection of PROMs.** • **National initiatives launched to date[58]:**	**Generic PROMs:** – EQ-5D; – SF-36; – SF-12; – PROMIS.	**Specific PROMs:** – chronic kidney disease; – breast cancer; – colectomy for colorectal cancer;	**Collection of data specific to local initiatives of facilities.** **Specific information systems** for research projects,	No public disclosure of outcomes. Variable results depending on the initiatives (local,	**Comparison and benchmarking:** local initiatives.

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[58] See box 9, page 39.

	– The AP-HP's ComPaRe research platform enables patients with chronic diseases to participate in research projects by collecting PROMs; – the Renaloo association proposes the *Moi Patient* PROMs collection platform for patients with diseases; – bundled payments allocated for chronic kidney disease patients (PROMIS-29); – **article 51 of the LFSS 2018:** national innovative organisations trials for payment per surgical care episode for three surgical procedures (hip replacement surgery, knee replacement surgery, colectomy for bowel cancer), healthcare professionals will be able to implement an approach for administering and using PROMs that already exist. • **Regional initiative:** collection of PROMs for HIV patients, tested from December 2017 to May 2018, as part of an ANRS study concerning a cohort of 13 hospitals, in the Aquitaine region. • **International initiative:** participation in the ICHOM project: – facilities are participating in benchmarking initiatives for		– lung cancer; – THR/TKR; – HIV: WHOQOL-HIV; BREF; – mental health; – cataract.	bundles and innovative trials. ⇒ For the Aquitaine initiative, an information system was created for the collection of PROMs relating to HIV.	regional)/survey in progress. – **ANRS Co3 cohort:** the information system will enable PROMs results to be reported in a format accessible to all clinicians. It will be used for future research in HIV patients.	

	several diseases or conditions: colorectal cancer; breast and lung cancer; cataract. • **Participation in the OECD panorama:** collection of PROMs for hip arthroplasty, breast cancer/breast surgery.					

Table 9. Summary of initiatives measuring and using PROMs in 7 European countries and 6 English-speaking countries

Country	Organisation and collection level (national, regional/provincial, local)	PROMs collected		Method of collection and data sources used	Website(s) for public disclosure/method of presentation of results	Uses: comparison and/or benchmarking, accreditation, pay for performance
English-speaking countries						

England	• **National system for the routine collection of PROMs** in all National Health Service (NHS) structures, coordinated by the Department of Health, supported by NHS Digital.
	⇒ A small number of Welsh patients were included in the data analyses, where these were carried out by English providers.
	• **Collection of PROMs in national registries:** National Joint Registry (NJR).
	• **International initiative:** participation in the ICHOM project.
	• **Participation in the collection of PROMs for the OECD panorama** (hip
		Generic PROMs/mandatory national collection:
		– EQ-5D;
		– EQ-VAS.
		⇒ Used for 4 procedures (specific PROMs) appended.
			Specific PROMs/mandatory national collection:
			– total hip replacement (THR): Oxford Hip Score (OHS);
			– total knee replacement (TKR): Oxford Knee Score (OKS);
			– varicose vein surgery: Aberdeen Varicose Vein Questionnaire (AVVQ);
			– inguinal hernia.
			Link: https://digital.nhs.uk/data-and-information/areas-of-interest/hospital-care/quality-accounts/domain-3-helping-people-to-recover-from-episodes-of-ill-
				Questionnaires sent by post to patients' homes:
				– **preoperatively** (18 weeks **before the procedure:** secure link to the Hospital Episodes Statistics (HES) administrative database;
				– **postoperatively**(3 to 6 months after the procedure): digitised and linked to the preoperative questionnaires, by the PROM serial number (identical for the 2 questionnaires), in the HES system.
				⇒ Questioning of patients about difficulties moving around, their ability to carry out usual activities, possibility of returning to work, assessment of pain, etc.
					NHS Digital[61]:
					– aggregated annual performance reports for all NHS hospitals;
					– results tables for download:
					  – *funnel plots and visualisation of outliers*[62];
					  – hospital comparison tool available: position on funnel plots and detailed funnel results.
					  – individual results detailed per hospital (score, mean, confidence interval).
					Link: https://digital.nhs.uk/data-and-information/publications/statistical/patient-reported-outcome-measures-proms
					Last accessed: 19/01/2021.
						• **Comparison** between NHS hospitals.
						• **Benchmarking** to study variations in practices and improve them, to conduct follow-up analyses of PROMs results over time (NHS hospitals and National Joint Registry).
						Link to NJR 2020 report: https://reports.njrcentre.org.uk/Portals/0/PDFdownloads/NJR%2017th%20Annual%20Report%202020.pdf
						• **Gradual decline in pay for performance,** since the trials implemented by the NHS Quality and Outcome Framework in 2004, particularly in primary care.

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[61] **Former NHS Digital website:** Health Social Care Information.

[62] These are hospitals whose results are above or below the national average. Hospitals identified as "outliers" should check the accuracy of the data on which the analyses are based (confidence intervals and data quality). It is their responsibility to implement quality improvement strategies.

	arthroplasty, breast cancer/breast surgery, mental health). • **Other initiatives:** – **Local/voluntary:** collection of PROMs on pain in specialist clinics (England and Wales), between 2011 and 2013, in a national database as part of the National Pain Audit, led by the Health Quality Improvement Partnership[59]. ⇒ Objective: collect PROMs on a national level, in all clinics (England/Wales). – **Research programme in progress:** trialling the collection of PROMs for long-term mental health patients, coronary revascularisation and cancer care. – Trialling a PROMs collection system in cancer treatment (ePOCS). ⇒ **Objective:** link data in cancer registries, in order to		health-or-following-injury ***Last accessed:*** 30/10/2020. Other PROMs[60] usable in NHS structures: – chronic kidney disease; – heart failure; – asthma; – epilepsy; – stroke; – paediatrics; – chronic obstructive pulmonary disease (COPD); – diabetes; – cancer: colorectal, lung, prostate, breast; – surgery: heart, carpal tunnel, prostate, gynaecology, cosmetic; – cholecystectomy; – mental health: depression, anxiety, severe mental health disorders(Improving Access to Psychological Therapies); – pain.	The **National Joint Registry** collects information on total hip, knee, ankle, elbow or shoulder replacements (arthroplasty) in all participating hospitals in England and Wales, etc.	**NHS website:** – survey results accessible in public NHS databases, after retrieving data from HES databases; – possibility for patients to choose a hospital, a healthcare professional (general medicine, primary care) on the basis of indicator results. **Link:** https://www.nhs.uk/about-us/nhs-website-datasets/ ***Last accessed:*** 05/11/2020. The **National Joint Registry** produces results reports, including PROMs results in particular. **Link:** https://www.njrcentre.org.uk/njrcentre/Reports-Publications-and-Minutes ***Last accessed: 19/01/2021.***	

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[59] Independent organisation created in 2008, directed by the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. It is responsible for promoting quality and measuring the impact of clinical audits on improving the quality of care.

[60] These PROMs questionnaires are not part of the mandatory national system and are not routinely collected. They can be used by health facilities that wish to do so.

	ultimately inform care planning and information sharing (symptom/psychosocial difficulties) or for use in research and epidemiology on a national level. – Collection of PROMs for the OECD panorama (hip arthroplasty, breast cancer/breast surgery).		**Find out more:** https://phi.uhce.ox.ac.uk/newpubs.php ***Last accessed:*** 12/11/2020. **NJR:** OHS, OKS.			
Wales	• ***National initiative:*** – **Patient-Reported Outcome Measures (PROMs), patient-reported experience measure (PREMs) and Effectiveness Programme (PPEP):** initiative put in place in 2016, with a national platform for the collection of PROMs and PREMs, for patients receiving secondary care. • ***There are proposed tools for the collection of PROMs:*** *orthopaedic surgery, tonsillectomy, paediatrics, lung cancer, asthma, and cataract.* • ***Voluntary process:*** *collection of PROMs on pain in specialist pain clinics in collaboration with England*	• ***PPEP:*** *new national system for the collection of PROMs (33 questions):* – ***EQ-5D:*** 5 questions; – ***EQ-VAS:*** *1 question;* – ***Work Productivity and Activity Impairment (WAPI):*** *16 questions to measure the health-related work productivity of the working population;* – ***About You:*** *questions about factors that can affect health outcomes (e.g. comorbidities).* **WAPI website:** http://www.reillyassociates.net/WPAI_General.html ***Last accessed:*** *12/11/2020.*	• **PPEP:** Specific PROMs: – orthopaedic surgery; OHS, OKS; – tonsillectomy (paediatrics) ; – lung cancer; – asthma; – heart failure; – cataract.	• **National platform for the collection of PROMs and PREMs set up in 2015:** *NHS Wales Informatics Service* (NWIS). – Collection in paper or electronic format. ⇒ Use for the collection of PROMs at home (copy integrated into the patient's file) or in hospital (questionnaire accessible by each professional in a dedicated portal). ⇒ The data is stored in a national database (National Data Warehouse). **Link:** Home | Patient Reported Outcome Measures (nhs.wales) ***Last accessed:*** *16/03/2021.* • Participation in the collection of information on total hip, knee, ankle, elbow or shoulder	• No website found/ information not available.	• **Comparison and benchmarking:** participation in analyses carried out in databases or registries shared with England: – National Pain Audit; – National Joint Registry. **Link:** https://reports.njrcentre.org.uk/Portals/0/PDF-downloads/NJR%2017th%20Annual%20Report%202020.pdf ***Last accessed:*** 16/03/2021.

	between 2011 and 2013 (see above). • ***International initiative:*** *participation in the ICHOM project.* – *Use of tools in Parkinson's disease, low back pain and cataract.*			replacements (including PROMs) in the National Joint Registry. **Link:** https://www.njrcentre.org.uk/njrcentre/News-and-Events/NJR-responds-to-NHS-Englands-PROMs-consultation ***Last accessed:*** *20/01/2021.*		
USA	• **National initiatives:** ***Health programmes led by the CMS:*** – **American Joint Replacement Registry (AJRR):** national registry created in 2009, with the American Academy of Orthopedic Surgeons, ensuring the collection of data relating to THR/TKR[63]. It represents 32% of total hip/knee replacements performed in the USA. – **Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement**	**Generic PROMs:** – SF-36; – SF-12; – VR-12; – PROMIS Global Health, etc.	**Specific PROMs:** *Asthma:* – Optimal Asthma Control; – Patient Health Questionnaire 2 (PHQ-2); – PROMIS-Global (VR-12). *Depression:* – **PHQ-2:** Depression Remission at 6/12 months; – **Depression Response** at 6 months/12 months-Progress Towards Remission. *Other mental health disorders:* variation in	**Standardised surveys:** electronic data collection (Electronic Health Record) in real time: - PROMs completed by the patient and/or caregiver, depending on the disease, patient situation and state of health. - PROMs collected in different ways: 1) medical visit (e.g. tablet or paper/in the waiting room); 2) home (e.g. tablet or paper (postal follow-up, 3) online portal; 4) phone call/text message. **e.g.** – **PROMIS:** computer format (Computer Adaptive Testing), with administration of questions adapted to the	*Variation in the level of publication of results depending on the CMS programme*[66]*.* ♦ ***Health programmes:*** **THR/TKR:** – **AJRR Model:** publication of results by hospital, reports specific to the patients managed at a site, benchmarks (country, state, region, or patient risk profile level) and summary results for each PRO-PM. Link: https://www.aaos.org/registries/publications/ajrr-annual-report/ ***Last accessed:*** *04/04/2021*	• **Inter-hospital comparison.** • **Benchmarking:** national, by state, regional, local or by patient risk profile: **THR/TKR:** – **AJRR:** PROMs data used to compare hospitals and conduct benchmarking analyses. ⇒ Analyses of variations in quality of care and complications after THR/TKR: publication of outcomes for each hospital and benchmarks for each PROM (see public disclosure). – **FORCE-TJR:** incentive linked to 1 composite score of

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[63] Data collected: practices, comorbidities, average hospital stays.

[66] In this column, only programmes for which publicly disclosed reports exist are indicated. There may be internal publication within health programmes: that is the case for the IHA/PBGH ACO Measure Set, which conducts private publication of a report on the outcomes of all medical groups (quality measures, including PROMs on depression). The AHIP/CMS does not publish its results either.

	(FORCE-TJR): programme for bundled payment of care episodes, for THR/TKR. This is the first national cohort with risk-adjusted outcomes after THR/TKR: 790 hospitals, 250 surgeons, > 30,000 patients in 28 US states. – **Comprehensive Care for Joint Replacement (CJR):** programme concerning the bundled payment of care episodes, including THR/TKR (April 2016 – December 2020). It is mandatory for around 500 hospitals covering 67 geographic zones. – **Bundled Payments for Care Improvement (BPCI):** programme for the bundled payment of 48 care episodes. – **End-Stage Renal Disease Quality Incentive Program (ESRD QIP):** financial incentive programme to promote the quality of care in kidney dialysis centres (In-Center Hemodialysis (ICH)). The system is adaptive and the proposed indicators vary		initiatives dependent on the US healthcare system and the strategies put in place at state level. *Cardiovascular diseases:* – Seattle Angina questionnaire; – Kansas City Cardiomyopathy questionnaire; – Rose Dyspnea Scale. *Orthopaedic surgery:* **THR:** HOOS; **TKR:** KOOS; **Arthritis:** WOMAC. ⇒ **AJRR Model et CJR Model:** collection of VR12 and/or PROMIS and HOOS/KOOS.	patient's capacities or symptoms. – **AJRR:** implementation of an infrastructure for the collection of PROMs. • The NQF approves the use of PROMs for public disclosure and pay for performance. ⇒ Provision of a methodological report on PROMs for performance management. **Link:** http://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx	– **FORCE-TJR:** ⇒ Aggregated annual reports: risk-adjusted outcomes compared to the national average. **Link:** https://force-tjr.org/force-qi/analysis-benchmarking/ – **CJR Model:** ⇒ Consideration of results published in Hospital Compare (KOOS/HOOS): https://data.medicare.gov/d/tgkv-mgxg/vizualization ♦ ***Commercial programme:*** – Minnesota Community Measurement publishes annual indicator result reports (PROMs) at medical group level. – **2018 results:** https://www.leg.state.mn.us/docs/2019/mandated/190469.pdf	3 measures (PROMs, absence of complications, implant longevity) for one care episode (THR/TKR). ***DEPRESSION:*** – **IHA/PBGH ACO Measure Set:** measures integrated into the IHA-PBGH Commercial ACO Measurement & Benchmarking Initiative. ⇒ Since 2018, approximately **30 indicators** (including PROMs) have been proposed in the set. The aim is to harmonise efforts to measure and improve quality of care, the efficiency of structures and to understand the outcomes by hospital. **Link:** https://www.pbgh.org/wp-content/uploads/2020/12/iha-pbgh_commercial_aco_measurement_benchmarking_initiative_2017.pdf • **Pay for performance:**

	from year to year, leading to payment reductions in the year following measurement if targets are not met. ***Health plans:*** – ***America's Health Insurance Plans (AHIP) CMS Core Quality Measures Collaborative (CQMC):*** national association providing services that improve the health and financial security of consumers, families, businesses, communities and the nation. It is in partnership with the National Quality Forum, which develops quality measures. ***Regional health programmes:*** – ***Minnesota Community Measurement:*** commercial programme[64] that helps share information to improve health outcomes for the people of Minnesota.					– **THR/TKR:** CJR Model (2016-20) = payment model tested for care episodes related to THR/TKR, from admission until 90 days after discharge. Funding of a care episode is linked to a composite score of 3 measures: 1) CAHPS; 2) complication/readmission rates up to 90 days after discharge; 3) PROMs (VR12/PROMIS and HOOS/KOOS) and variables on the risk for a care episode. ⇒ 10% of the score takes into account the collection and publication of PROMs results in Hospital Compare. Hospitals not submitting PROMs results cannot achieve a maximum quality score above 90%. **Link:** https://innovation.cms.gov/innovation-models/cjr – **DEPRESSION:** ***1.* AHIP/CMS CQMC:** obtain a consensus on the choice of measures, harmonise their use between payers (public/private). ⇒ **Objective:** leverage care providers, using the results of

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[64] The programme includes medical groups, clinics, physicians, hospitals, health plans, employers, user representatives and quality improvement organisations.

	– **IHA's Value Based Pay for Performance (VBP4P) program:** non-governmental performance measurement and financial incentive programme. The following are targeted: prevention indicators, process, relevance, patient experience, outcomes, cost-effectiveness analyses. – **Integrated Healthcare Association (IHA) and Pacific Business Group on Health (PBGH) ACO Measure Set:** private insurer responsible for implementing cost and quality measures in Accountable Care Organizations (ACO) to address the needs of purchasers, health plans, care providers and to improve the quality of care. In California, there is a contract with 10 health plans and 200 physician organisations. • **International initiatives:** – **ICHOM:** non-profit organisation responsible for					PROMs in P4P, to improve the quality of care. ***Link:*** https://www.ahip.org/wp-content/uploads/2018/03/Core-Quality-Measures-Collaborative-Research-Findings_Executive-Summary.pdf ***2.*** **IHA's Value Based Pay for Performance (VBP4P) program:** the financial incentive is linked to 1 composite score of 3 types of indicators: 1) clinical practices (60%), 2) patient experience (30%), 3) information systems (IS)/health technologies (HT) (10%). It could incorporate PROMs, such as PROMIS, and target themes such as anxiety, depression, pain and physical function. **DIALYSIS:** – **ESRD QIP:** the programme links quality indicators to a payment. The indicators included vary from one year to another: process, safety, co-ordination of care, outcomes (including PROMs) and PREMs (see table 8). ⇒ A penalty system applies to the quality-based payment part, which represents up to 2% of

	the development of PROMs. – **PROMIS:** five-year research programme of the National Institute of Health (2004), tasked with developing, validating and standardising a bank of items to measure PROMs[65].					the total payments received by a centre. The application of the penalty[67] reducing payments is determined by the attainment or otherwise of prespecified performance thresholds. – **ESRD Seamless Care Organizations (ESCO):** another programme to reduce dialysis spending and hospital admissions and improve health outcomes for treated patients [68]. ⇒ A quality score is calculated by weighting different quality measures (process, safety, outcomes (including PROMs), patient experience). • **Last accessed:** 08/03/2021.
Canada	*6 regions grouping together 10 provinces and 3 territories (regional level), themselves including census divisions (local level).* **• Regional and local PROMs collection initiatives.** - The collection and use policy varies depending on the province. It was noted	**4 generic PROMs** selected for all regions of Canada (CIHI incentive report – 2015): – VR-12; – SF 36 (adapted from the American VR-12); – EQ-5D (3L and 5L); – Health Utilities Index (HUI); – PROMIS-10 Global Health.	**Specific PROMs:** – arthritis: Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC); – TKR: OKS, KOOS; – THR: OHS, HOOS; ⇒ OKS and OHS are the most widely used PROMs	**• various collection methods:** paper, telephone, online, registries. ⇒ Variation of choice as a function of provinces. **• Collection of PROMs in registries:** - Alberta Hip and Knee Registry; - Alberta Hip and Lung Transplant collection;	**• No public disclosure of outcomes per hospital or in the form of aggregated reports.**	**• Inter-hospital comparison and benchmarking:** within a region or between regions; – Difficulty conducting benchmarking between institutions and regions; ⇒ This can be explained by a lack of funding, competing priorities and a lack of coordination between provinces.

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[65] PROMs are calculated for populations, chronic conditions, physical health, and mental health. A platform enables data collection, storage and searches.

[67] Only a minority of dialysis centres are concerned by the maximum 2% penalty.

[68] In this programme, the organisations set up correspond to a grouping of dialysis centres, nephrologists and other health professionals.

that there is a lack of standardisation of the PROMs collected between provinces (see CIHI incentive report 2015). Often, regional surveys are conducted, such as the Canadian Community Health Surveys. **Advanced provinces:** – **Alberta:** collection of PROMs for a number of years for population surveys (THR/TKR, transplantation[69]); – **British Columbia:** routine collection of EQ-5D (2016), VR12 (2015) in acute care (cancer, THR/TKR) and ongoing work to adapt VR12 in long-term care. ⇒ **Forecast:** expansion of routine collection of PROMs and regular use for cardiovascular disease, COPD and other chronic diseases. ⇒ Some provinces have implemented the collection of PROMs in pain and symptom management in oncology/palliative care (e.g. Ontario).	The experts recommend the use of **VR-12 and EQ-5D**, which are more suitable for periodic collections, with a view to standardised national implementation in Canada. See CIHI incentive report (2015). **Link:** https://www.cihi.ca/sites/default/files/document/visioning-day-paper-en-web.pdf ***Last accessed:*** *02/06/2020.*	in Canada, in front of KOOS and HOOS.	- British Columbia PEAK project; - Knee arthroplasty; - British Columbia Spinal Cord Injury Registry; - Manitoba-Winnipeg Joint Replacement Group/Saskatchewan joint replacement and spinal surgery; - Rick Hansen Spinal Cord Registry; - Statistics Canada Community Health Survey; - Ontario Electronic Rheumatology Collection; - Ontario Initiatives Research Program. • The CIHI has developed a methodological guide for the collection of PROMs on THR and TKR (OHS and OKS): https://www.cihi.ca/sites/default/files/document/proms-data-collections-manual-2019-en-web.pdf ***Last accessed:*** *02/11/2020.* • Statistics Canada collects indicators on the Canadian population or outcomes – including PROMs – in the Canadian		– The experts stress the need to coordinate a national approach to compare regions with one another, with respect to the national and international level.

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[69] the Edmonton Heart and Lung Transplant Clinic Project includes PROMs on transplantation, including the Health Utilities Index (HUI), to measure the pre- and postoperative satisfaction of patients on a transplant list.

	⇒ **Drive to standardise the collection of PROMs nationally:** – the CIHI report calls for national coordination of all initiatives and standardisation of the PROMs collected; – 2019: a committee formulated recommendations to harmonise the collection of PROMs (national, regional, local levels). ⇒ **Participation in the collection of PROMs for the OECD panorama:** hip replacement, breast cancer/breast surgery, mental health (Alberta and Manitoba). • **International initiative:** participation in the ICHOM project.			Community Health Surveys (CCHS), using the Health Utilities Index (HUI), a tool designed for the collection of PROMs in Canada (e.g. SF-36). This module is optional and cannot be used by all provinces/territories (sampling and cost limitations). • Routine **national** collection of PROMs and regular use is envisaged: – **chronic diseases:** renal failure, congestive heart failure, mental health care, COPD, cancer treatments. – **elective surgery:** THR/TKR, cataract, angioplasty, coronary artery bypass surgery, major surgery.		
Australia	*6 large provinces divided into 31 primary care zones.* • Initiatives for the collection of PROMs in certain national registries. ⇒ At this stage, no routine national collection in all registries. ⇒ The Australian Commission on Safety and	**Generic PROMs:** – EQ-5D; – SF-36; – PROMIS; – WHOQOL; – pain: BPI, MPQ, WHYMPI, etc.; – mental health: BSI, HADS; – chronic diseases: FACIT, etc. **Find out more:**	**Specific PROMs:** – prostate cancer; – thyroid cancer; – mental health; – palliative care; – rehabilitation; – cardiovascular diseases: – respiratory diseases: – neurological diseases; – endocrine diseases: – gastrointestinal diseases;	**Collection of PROMs in national registries or databases:** – Prostate Cancer Outcomes Registry (PCOR-ANZ); – South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC); – Australian Mental Health Outcomes and Classification Network (AMHOCN); – Palliative Care Outcomes Collaboration (PCOC);	Reflection in progress on the method of dissemination/reporting of the results.	• **National benchmarking:** mental health, palliative care, follow-on care and rehabilitation: – **e.g.** The aim of the PCOC is to improve patient outcomes, including pain and symptom control, by comparing/benchmarking against the outcomes of specialist palliative care pain management services. The Electronic Persistent Pain Outcomes

	Quality in Health Care (ACSQHC) has developed a strategy to implement the routine national collection of PROMs, to improve hospital quality and ensure patients' voices are heard. • **Local initiatives:** collection of PROMs in certain hospitals or certain departments/units. • **International initiative:** participation in the ICHOM project. • **Collection of PROMs for the OECD panorama** (hip arthroplasty, breast cancer/breast surgery, mental health).	– https://www.safetyandquality.gov.au/list-generic-proms ***Last accessed:*** *04/11/2020.*	– kidney and urinary diseases; – oral and dental disorders, etc. **Find out more:** https://www.safetyandquality.gov.au/condition-specific-proms ***Last accessed:*** *04/11/2020.*	– Australasian Rehabilitation Outcomes Centre (AROC), etc. **Ongoing work:** setting up of a national programme to collect PROMs: – choice of collection tools; – target the needs of clinicians/services; – method of reporting results (clinicians/departments); – transfer of knowledge to disseminate results; – change of clinical practices, funding mechanisms, research programmes/policies that can incorporate PROMs. ⇒ **Palliative care:** Palliative Care Outcomes Collaboration (PCOC) is a national benchmarking programme proposing the collection of 4 types of data in [70] voluntary hospitals, including PROMs on pain in the Electronic Persistent POC (ePPOC).		Collaboration (ePPOC) is an information system that makes it possible to perform these analyses. • Trials envisaged to integrate PROMs into pay-for-performance models, in particular bundled models, including PROMs, outcome indicators, and survival or cost data.

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[70] The following data are collected by the PCOC information system:
1) provide clinicians with a systematic approach to assess individual patient experience;
2) include routine collection of PROMs on symptom-related distress;
3) define a common clinical language to enable palliative care providers to communicate with each other;
4) facilitate the routine collection of data on palliative care on a national scale, for reporting and comparative analysis, and ultimately to improve care.
To access detailed outcome reports (including PROMs), it is necessary to log in with a password: https://www.uow.edu.au/ahsri/pcoc/reports/

				⇒ **Oncology:** ongoing research to use more PROMs (based on the literature and ICHOM). National working group set up (strategic partners with ICHOM).		
New Zealand	• **National initiatives for the collection of PROMs in national registries:** – Patient Cancer Outcomes Registry ANZ; – Prostate Cancer Outcomes Registry: collaboration with Australia to collect PROMs on prostate cancer; – New Zealand total joint arthroplasty (TJA) registry: ⇒ hip and knee replacement: NHS PROMs adapted to New Zealand (OHS and OKS). • **Local uses of PROMs:** mental health, cataract (Catquest).	Information not found.	**Specific PROMs:** – **cataract:** ▪ measuring the impact of the operation on lifestyles and activities of daily living; – ophthalmology: Catquest-9SF. – THR: adapted OHS; – TKR: adapted OKS; – general surgery: Otago Condition Specific Questionnaire; – mental health; – cancer; – follow-on care and rehabilitation.	**Data collected in registries:** – **national:** – THR (OHS)/TKR (OKS), – **oncology:** Patient Cancer Outcomes Registry ANZ, – **arthroplasty (hip/knee):** New Zealand Joint Registry. – Healthcare providers can hold their administration accountable for the results of their patients' PROMs; – drive to introduce national data reporting in mental health[71]: outpatient addiction treatment. ⇒ **Objective:** study the progress observed after treatment of patients with alcohol dependency or other addictions: lifestyle, well-being, satisfaction, recovery (such as the Australian AMHOCN registry).	No website found/ information not available.	• **Inter-hospital comparison** for certain diseases or treatments; – **e.g.** Otago Condition Specific Questionnaire (in surgery). • **Benchmarking:** follow-on care and rehabilitation services carry out benchmarking analyses, sharing PROMs data with the Australian Rehabilitation Outcomes Centre.

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[71] Request by the Ministry of Health in 2015

Table 10. Summary of initiatives measuring and using PREMs in 7 European countries and 6 English-speaking countries

Country	Organisation and collection level (national, regional/provincial, local)	PREMs collected	Method of collection and data sources used	Website(s) for public disclosure/method of presentation of results	Uses: comparison and/or benchmarking, accreditation and/or pay for performance
Sweden	• Leading country for the collection of PREMs in national clinical registries by speciality and disease since the early 1970s. • Inclusion of PREMs in around 40% of national registries. Participation in the collection of PREMs data for the OECD panorama (mental health).	Information not available.	Collection of PREMs in 40% of national registries. ⇒ 96 out of 108 national registries include PROMs or PREMs.	• **For each NQR registry**, PREMs results are published in the form of an annual report, specific to each disease, on a website: patient satisfaction results are indicated. ⇒ Standardised formats for the presentation of results: hospital average compared to the expected target value and the national average. • Results per primary care unit, for all counties of Sweden, available on the following websites[72]: - https://www.1177.se/ - https://www.indikator.org/ **Last accessed:** 16/11/2020. • The Swedish Association of Local Authorities and Regions presents national patient experience data on a specific website. This data is compared with data from units or hospitals in different counties. ⇒ Decision-making aid to help the public choose primary healthcare.	• **Comparison of outcomes:** – between primary care units (all counties); – between hospitals or units (all counties). • **Funding of registries:** national registries must indicate in their annual funding applications how PROMs and PREMs are used to improve quality of care (since 2014). • **Pay for performance:** remuneration of primary care providers according to PREMs results (taking into account waiting times, preventive care, prescriptions for generic medicines, etc.)

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[72] Information not available in English.

				Website *(information not available in English)***:** https://skr.se/tjanster/englishpages.411.html **Last accessed:** 16/11/2020. • Results of telephone surveys assessing citizens' habits, knowledge and expectations of the Swedish healthcare system. **Website:** www.vardbarometern.se **Last accessed:** 16/11/2020.	
Netherlands	• The Ministry of Health introduced a standardised patient experience questionnaire in 2006: the Consumer Quality Index (CQI), to accelerate the public reporting of information on quality of care. This is an adaptation of the CAHPS. • Government funding. • National collection of PREMs in clinical registries since the creation of the CQI in 2006. • Participation in the collection of PREMs data for the OECD panorama (mental health).	**CQI:** standardised PREMs questionnaire, covering topics such as the competence of the nursing staff, information given to patients, or the accessibility of the premises (adaptation of the CAHPS and of a Dutch patient experience measure (Quality of Care through the Patient's Eyes (QUOTE)). ⇒ Questionnaire accompanied by a rigorous scientific methodology for conducting surveys (data collection/analysis). ⇒ Variation in PREMs used depending on diseases, departments and treatments. **Sectors:**	Collection of PREMs in national clinical registries. – Questionnaires are sent online or by post, and integrated into national registries, to be administered at specific times during a treatment.	• CQI outcomes by healthcare facility, on the following website *(information not available in English)*: http://www.kiesbeter.nl ***Last accessed:** 05/11/2020.* – Standardised formats for the presentation of results: star rating system demonstrating the performance in relation to the national average (open data): *: value below average; **: value equal to the average; ***: value above average. – Bar charts describing the frequencies of positive and negative patient experiences. • Patient comments on care providers and doctors:	• **Inter-hospital comparison:** system for ranking hospitals against the national value (CQI). • **Pay for performance:** use of PREMs results to inform healthcare funding agencies on the basis of selective contracts.

		– cataract surgery; – hip and knee replacement; – general medicine; – physiotherapy; – cancer; – emergency care; – hospitalisations; – asthma; – heart failure; – retirement home. **Specific conditions:** – diabetes; – breast cancer; – disability.		– https://www.zorgkaartnederland.nl/ – https://www.zorginzicht.nl/ontwikkeltools/prom-toolbox/prom-cycle-summary-in-english ***Last accessed:*** *16/11/2020.* • Website on shared medical decision-making support: https://patientplus.info/en ⇒ accessible reports. ***Last accessed:*** *16/11/2020.*	
Norway	• Expertise in patient experience and PREMs measurement and research. • Funding by the Norwegian Knowledge Centre for the Health Services (created in 2004): responsible for measuring quality and patient experience. • National online indicator collection system since 1995 with several questionnaires (see below). • A national survey was conducted by the Norwegian Institute of Public Health, between September 2018 and August 2020 on patient experience following treatment in private or public rehabilitation facilities. The	**National online survey:** standardised patient questionnaire entitled Patient Experiences Questionnaire (PEQ). ⇒ 35 questions on the following topics: – communication; – competence of the nursing staff; – pain management; – medical equipment quality; – overall assessment of services received. **Derived questionnaires:** – Outpatient Experiences Questionnaire (OPEQ);	National system for the routine collection of indicators. National patient experience survey conducted every year: Patient Experience Survey.	• Results by hospital, on the following website *(information not available in English)*: https://helsenorge.no/other-languages/english – comparison of the results of each hospital compared against a national level: traffic light system (colours); – indication of the statistical profile and the performance score: hospital managers or healthcare professionals can quickly understand their hospital's performance compared to that of other hospitals. ***Last accessed:*** 16/11/2020.	• **Inter-hospital comparison:** comparison of the performance of each hospital compared to that of other hospitals (see column 4). • Pay for performance, based on comparison of patient experience between hospitals.

	questionnaire included both PREMs and PROMs (results not yet available).	– Parent Experiences of Pediatric Care (PEPC); – Rehabilitation Patient Experiences Questionnaire (Re-PEQ). **Other surveys/diseases (adult or child):** – mental health care (hospitalisation/outpatient); – oncology (hospitalisation).			
Germany	A healthcare system shared between the federal government and 16 states, and a health insurance system managed either by public ("legal health insurance") funds or by private ("private health insurance") for-profit funds. There are numerous health insurance funds corresponding to different professions across the whole country. · National system for routine collection of PREMs based on the voluntary participation of hospitals. · Patient experience surveys are coordinated at regional level (based on the voluntary participation of hospitals). · Since it was created in 2016, the Institute for Quality Assurance and Transparency in Health Care (IQTIG) has sought to	**PREMs in outpatient and hospital care:** – oncology: tool including PROMs and PREMs translated from Danish into German (Danish National Cancer Patient Questionnaire), sent to all cancer patients at all the oncology sites concerned and covering the entire care pathway; – neonatal care: Prematurity Risk Evaluation Measure; – cancer: Cancer Registry; – arthroplasty: German Joint Replacement Register; – multiple sclerosis, etc.	**Three health insurance funds** (Barmer, AOK, KKH) have proposed a standardised satisfaction and patient experience questionnaire to their beneficiaries since 2011: the Patients' Experience Questionnaire (PEQ). ⇒ PEQ collected from healthcare facilities on a voluntary basis. **Find out more:** https://www.weisse-liste.de/de/service/ueber-krankenhaussuche/versichertenbefragung/downloads/ ***Last accessed:*** 16/11/2020. – The Robert Koch Institute organises a patient	• Public disclosure of results on patient experience and/or satisfaction within different organisations: Robert Koch Institute, health insurance funds, scientific institutes, health insurance physicians' associations (Association of Statutory Health Insurance Physicians), private organisations, etc. • **PEQ:** the results (AOK, Barmer and KKH health insurance funds) of surveys of hospitals are centralised by the Bertelsmann Stiftung Foundation, which then publishes them on the following websites[74]:	• Comparison and benchmarking between hospitals and private practices in publicly disclosed survey reports (including PEQ).

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[74] The two sites correspond to groups of different funds.

	monitor the quality and safety of care on a national level and obtain exhaustive data. · Surveys on the satisfaction of outpatients and inpatients are carried out twice a year by some health insurance funds, in cooperation with the Bertelsmann Stiftung Foundation[73], and healthcare professionals from the National Association of Statutory Health Insurance Physicians. · ***Robert Koch Institute***: organisation in charge of the national collection of patient experience data since 2009, carried out on a non-regular basis.	**Standardised satisfaction and patient experience questionnaire since 2011:** Patients‘ Experience Questionnaire (PEQ): – **15 questions:** medical care in hospital, nursing care, the hospital stay, overall assessment of the stay.	experience and health survey every 2/3 years: German Health Interview and Examination Survey for Adults.	– https://www.weisse-liste.de/de/krankenhaus/krankenhaussuche/ – https://weisse-liste.krankenhaus.aok.de/ ⇒ It is possible to choose a hospital and access its individual outcomes. • The Bertelsmann Stiftung Foundation also publishes its own outcomes in the following report: https://www.bertelsmann-stiftung.de/fileadmin/files/BSt/Publikationen/GrauePublikationen/VV_SG_KhQualitaet-aus-PatSicht_en.pdf ***Last accessed:*** 16/11/2020.	
Denmark	*Country divided into 5 regions (since 2007), following the merger of 5 counties.* • **National system for the collection of PREMs and patient satisfaction** • **Center for Experience and Evaluation:** patient experience research centre. This centre collaborates with Public Health and Quality Improvement, to conduct evaluations, surveys/studies,	**National patient experience surveys:** – ***Hospital and outpatient somatic care:*** National Danish Survey of Patient Experiences: national patient experience survey (1 part on hospital care and 1 part on outpatient care) created in 2000;	**National surveys:** – Hospital and outpatient somatic care: National Danish Survey of Patient Experiences; ⇒ LUP questionnaire: https://patientoplevelser.dk/files/dokumenter/artikel/q_uk_lup10.pdf	**Hospital and outpatient somatic care:** National Danish Survey of Patient Experiences*:* -https://patientoplevelser.dk/ - https://www.sundhed.dk/ – Standardised formats for the presentation of PREMs results. – National, regional results, by hospital, by care unit.	• **Comparison/benchmarking:** – use of the results of the national patient experience survey in somatic and psychiatric care facilities: benchmarking analyses and inter-hospital comparisons (outcomes reported by unit and by care department); – use of the results of the national primary care survey

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[73] Independent private foundation created in 1977. It supports and finances projects to measure quality of care and provides training for healthcare professionals. It has developed health outcomes portals, which help users find a physician, hospital, retirement home or nursing services (*weisse-list*).

	research projects on patients' experiences in the Danish healthcare system.	– **since 2009:** annual collection in healthcare structures (funded by 5 regions). – ***General medicine:*** Danish Patients Evaluate General Practice Survey: national primary care survey; PREMs results are reported by practice, by region and by physician. – ***National survey on patient satisfaction in primary care*** led by Danish Patients Evaluate Practice (DANPEP) since 2001: collection of questions about the quality of primary care, including the patient's experience of the care pathway, and the degree of involvement in decisions about care coordination. – National survey on the satisfaction of relatives of patients hospitalised in psychiatric facilities. – **Other national surveys:**	⇒ **23 questions targeting the following fields:** clinical services, patient safety, continuity of patients and staff, co-involvement and communication, information, conduct of treatment, discharge, cooperation between sectors, etc. – Questionnaires sent by post to patients' homes a few months after their discharge or hospital visit. – Manual collection or online entry. – Collection period defined to obtain sufficient questionnaires. ***Last accessed:*** *17/11/2020.* – **National survey on patient satisfaction in primary care led by DANPEP:** adaptation of the EUROPEP survey to assess general medicine practices. ⇒ **23 questions targeting the following fields:** relationship with the physician, quality of medical care, information and support, organisation of services and accessibility of care, involvement of the patient in decisions and coordination of care.	***For more information:*** https://patientoplevelser.dk/files/dokumenter/artikel/lup_pixi_uk.pdf ***Last accessed:*** *17/11/2020.* – Danish Patients Evaluate General Practice Survey: PREMs results by practice, by region and by primary care structure. – Website not found. – Danish Patients Evaluate Practice *(DANPEP):* – Website not found. – *National survey on the satisfaction of relatives of patients hospitalised in psychiatric facilities.* – Website not found. – *National survey on patient experience in acute and psychiatric facilities:* publication of results by unit and by care department. – Website not found.	(Danish Patients Evaluate General Practice Survey). • **Accreditation of hospitals:** – use of the results of the national satisfaction survey of relatives (family members), for care in psychiatry; – use of national surveys on patient experience in acute and psychiatric care facilities.

		– Acute care: emergency and maternity care; – psychiatric outpatient and hospital care (adults/children). ⇒ Collection every 3 years.			
Belgium	National system for the collection of PREMs as part of the Health Information Survey (HIS), relative to the general population. • **2 major PREMs collection initiatives:** - Flemish region: Flemish indicators project, the *Vlaamse Patiëntenpeiling* (VIP); - French region: *Attentes et satisfaction des patients et de leur Entourage* (ASPE) project run by the independent consultancy, Be Service Minded (BSM) Management. ***Centrum Klantervaring Zorg* (CKZ):** centre for patient experience analysis. • Participation in the collection of PREMs data for the OECD panorama.	**Flemish region:** – PREMs are part of the Flemish indicator project, VIP, which is responsible for the development of process and outcome indicators (including PREMs and PROMs). It includes several platforms for collecting indicators (including the VIP platform). – 60 other PREMs are collected (use of validated questionnaires, including a questionnaire adapted from the HCAHPS for acute care facilities). – HCAHPS validated in the field of paediatrics in the Flemish region. **French/Walloon region:** - **ASPE project coordinated by BSM since 2005:** Generic and specific PREMs.	**Flemish region:** National online collection in the *Vlaamse Patiënten Peiling*, a collection module put in place in 2013 in the Health Information Survey (HIS). ⇒ This tool is used for the collection of most of the PREMs questionnaires in hospitals, on a voluntary basis. ⇒ Data collection is coordinated by the Flemish healthcare agency (*Vlaams Agentschap Zorg en Gezondheid*). **French/Walloon region:** - ASPE project coordinated by BSM; - project led by the Platform to improve the quality and safety of patient care (PAQS). **National coordination:** PREMs data included in the Health Information Survey (HIS), a national survey database.	**Flemish region:** Public disclosure of the results of a series of VIP indicators, including PREMs: https://www.zorgkwaliteit.be/ – possibility of comparing any hospital with a choice of another 2 hospitals; – availability of results based on the voluntary participation of hospitals. ⇒ Each hospital also receives detailed aggregated results, in which the names of the other hospitals are hidden. ⇒ Standardised formats to present results. ***Last accessed:** 16/11/2020.* **French/Walloon region:** – No public disclosure of outcomes.	• **Inter-hospital comparison;** • **Benchmarking:** – *Flemish region:* VIP provides feedback and benchmarking reports to care providers and institutions; – *French region:* benchmarking analyses conducted by the BSM every year or every 2 years in specific fields (some ASPE project questionnaires). The hospitals receive detailed individual results and anonymised aggregated results. ⇒ The lack of standardisation in the use of PREMs in hospitals makes benchmarking difficult in the hospital sector. • **PREMs integrated into the set of indicators of the pay for performance programme since 2018.** ***Indicators proposed in 2019:***

		– PREMs collected on the platform to improve the quality and safety of patient care (PAQS). – Assistance in the choice of questionnaires, methodological tools, statistical analyses, benchmarking between hospitals. **Objective:** harmonise the collection tools for the whole of Belgium.			– 1 process indicator: proportion of general hospitals measuring PREMs after a bed C or D stay). – 6 outcome indicators: questions sent to patients.
France	**HAS:** – **Measurement of patient experience and satisfaction** (e-Satis +48h MCO, e-Satis chirurgie ambulatoire, and e-Satis SSR). ⇒ Mandatory national collection system (e-Satis). – **National experimentations (art. 51 – LFSS 2018):** – **payment per surgical care episode** (EDS) for three surgical procedures (hip replacement surgery, knee replacement surgery, colectomy for bowel cancer); – **incentives for shared care** (IPEP), with the involvement of groups of health professionals, to promote care coordination; – **bundled payment:** community healthcare professional teams (PEPS).	– **e-Satis system:** complete, reliable questionnaires, metrologically validated by the HAS. – Questions on patient experience and satisfaction.	**e-Satis national data collection platform:** https://cas.atih.sante.fr/cas/login?service=https%3A%2F%2Fe-satis.atih.sante.fr%2F – collection of patients' comments at the end of questionnaires. ***Last accessed:*** *16/11/2020.* – Collection methods common to all French hospitals. – Continuous assessment of the patients concerned: – results reported in the form of a score out of 100 and continuously detailed by the hospital;	**Scope santé:** https://www.scopesante.fr/#/ – **e-Satis** results by healthcare facility: score and ranking from A to D. – Dynamic regional mapping: "regional focus" part. ⇒ Classes are defined by an **"ascending hierarchical classification"** method, which makes it possible to create homogeneous score classes; – class A corresponds to the best class, in terms of satisfaction; – class D corresponds to the least good class (hospitals not responding to the collection). A descriptive and qualitative analysis of the comments collected by patients at the end of the questionnaire	**e-Satis system:** – inter-hospital comparison; – incorporation of e-Satis results in health facility certification results; – integration in the IFAQ financial incentive to improve quality. See order of 18/06/2019

	– **Other mechanisms for the collection of PREMs questionnaires:** – **Renaloo patient association:** the MoiPatient platform proposes PREMs-type questionnaires; – **clinical research:** the AP-HP's ComPaRe public research platform, in which patients with chronic diseases voluntarily participate in research projects by completing online PREMs questionnaires.			is planned in the near future, and it is intended to produce a national report. **Calculation methods and classification methodology available on the following link:** https://www.has-sante.fr/upload/docs/application/pdf/2017-02/modalites_calculs_esatis48hmco_vf.pdf ***Last accessed:*** *16/11/2020.*	

Table 10. Summary of initiatives measuring and using PREMs in 7 European countries and 6 English-speaking countries

Country	Organisation and collection level (national, regional/provincial, local)	PREMs collected	Method of collection and data sources used	Website(s) for public disclosure/method of presentation of results	Uses: comparison and/or benchmarking, accreditation, pay for performance
			English-speaking countries		
England	• National patient experience measurement policy for more than 20 years. • The NHS national patient experience measurement surveys ***(NHS Patient Survey Programme)*** have been coordinated since 2009 by the **Care Quality Commission (CQC),** an independent healthcare regulation organisation that works closely with the Picker Institute Europe[75], using a standardised collection methodology: – The CQC assesses the quality of hospital (inpatient and outpatient) and community care, dental care, ambulance services, psychiatric services, retirement homes and home care. – It runs annual surveys on patient experience and quality of care for the following services: emergency care, community care, adult inpatient care, quality of emergency calls, maternity care, child and adolescent care, mental health.	• **National PREMs collection system (NHS):** NHS Patient Survey Programme; – management of patient experience surveys by the CQC; – the following types of care: primary care, short-term hospitalisation, emergency, maternity, mental health, outpatient care, ambulance services, child and adolescent care. ⇒**Questions on satisfaction cover the following themes:** listening to patients, respecting their values, explanations of treatments provided by medical teams, waiting time in healthcare services, organisation of healthcare services or other questions about care. · **Other standardised NHS questionnaires:**	• **National patient experience measurement system:** – **NHS Patient Experience Survey:** surveys accessible on the NHS website. **Link:** https://nhssurveys.org/surveys/ ***Last accessed:*** 23/11/2020. • **Other standardised NHS questionnaires:** – **National Clinical Audit Programme:** surveys accessible on the HQIP website. **Link:** https://www.hqip.org.uk/a-z-of-nca/#.X7upamSWzmI ***Last accessed:*** 23/11/2020.	• **NHS website:** results of national surveys (CQC) for each type of care. **Overall results:** – Patient experience scores by dimension and overall scores (out of 100); – benchmarking analyses: distribution curves of overall scores by hospital. **Link:** https://www.england.nhs.uk/statistics/statistical-work-areas/pat-exp/ **Report example (patients hospitalised in 2018):** https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2019/06/Bulletin_2018_IP_FINAL.pdf ***Last accessed:*** *23/11/2020.* ⇒Uploading of NHS structure	• **Comparison** of results between hospitals and primary care structures. • **Benchmarking** in outcome reports by NHS hospital or primary care structure depending on the type of care; distribution of overall hospital scores. • **Pay for performance:** – **NHS Outcomes framework (2012/13):** taking into account the results of PREMs in primary care (respect for patient values, preferences, coordination of care, emotional aspects, involvement of carers). – **Commissioning for Quality and Innovation Payment Framework:** pay for performance

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[75] Institute tasked with developing standardised patient experience questionnaires and conducting national surveys in Europe. The Picker Patient Experience (PPE) questionnaire includes 40 questions relating to 7 patient experience dimensions, as well as a question concerning the overall assessment of the services received and one question to know whether patients would recommend the hospital where they received their care to family or friends. A short 15-question version exists, the validity of which has not been demonstrated. This questionnaire has been used in surveys conducted in several countries (England, Germany, Sweden, Switzerland and USA, etc.) but has not been the subject of international comparisons. Other countries have also used and adapted it.

⇒ Questions asked to patients on the following topics: listening, respect, explanation of treatments given to patients by medical teams, waiting times in departments, good organisation of care services, etc. • Since 2011, the **Commissioning for Quality and Innovation payment framework (CQUIN)** has taken into account the results of the PREMs developed by the CQC, to reward patient-centred care in hospital (behavioural and relationship aspects with clinicians). • Participation in the collection of PREMs data for the OECD panorama (mental health).	– **National Clinical Audit Programme:** clinical audits which are part of the national NHS programme and enable regional bodies to organise local surveys. ⇒ **Diseases/conditions concerned:** falls and fractures, heart disease, heart surgery, diabetes (adults and children), asthma, breast cancer, end of life, dementia, psychosis, rheumatoid arthritis, laparotomy, epilepsy, gastrointestinal, lung and prostate cancer, maternity/perinatal care, vascular disease, intensive care, stroke. • **Other survey:** – **Friends and Family Test (FFT):** a new national survey created by the NHS, based on a marketing concept, to assess whether a care facility can be recommended to friends or family. Concerns most of the abovementioned care. ⇒ Possibility of leaving comments.	– **Friends and Family Test (FFT):** survey accessible on the NHS website. **Link:** https://www.nhs.uk/using-the-nhs/about-the-nhs/friends-and-family-test-fft/ ***Last accessed:*** *23/11/2020.*	results via a tool (Diagnostic Tool): **Link:** https://www.england.nhs.uk/statistics/statistical-work-areas/pat-exp/sup-info/ ***Last accessed:*** *23/11/2020.* • **CQC website:** other annual outcome reports, for each type of care. ⇒ Satisfaction questionnaire analyses and use of Picker Institute Europe sampling methods. ⇒ For each type of care, the following are found: – a report on the overall satisfaction results; – benchmarking analyses by hospital. **Link:** https://www.cqc.org.uk/publications/surveys/surveys ***Last accessed:*** 23/11/2020. • **Other surveys:** Cancer Patient Experience Survey: – patient experience scores by dimension and overall scores (out of 100); – benchmarking: distribution of overall scores by hospital.	model used for the different types of CQC care, taking into account the results of structural, process and outcome indicators (including PREMs). ⇒ *Model 2010/2012:* 5 PREMs were taken into account in the CQC hospital survey. An aggregated score was calculated from the scores of the 5 PREMs, and used for performance-based payment of each facility, taking into account 1 to 2% of the overall income. ⇒ *Model 2017-2019:* 3 mental health patient experience indicators and one acute care patient experience indicator were considered from a set of 13 indicators. The financial incentive was 2.5% of overall income, of which 1.5% took into account the results of quality indicators (clinical and organisational practice). **Link:** https://www.england.nhs.uk/nhs-standard-contract/cquin/cquin-17-19/

				Link: https://www.ncpes.co.uk/2019-national-level-results/ FFT: https://www.nhs.uk/using-the-nhs/about-the-nhs/friends-and-family-test-fft/ ⇒ Overall score published on the NHS website. ***Last accessed:*** *23/11/2020.*	
Wales	• **National initiative:** – **Patient-Reported Outcome Measures (PROMs), Patient-Reported Experience Measure (PREMs) and Effectiveness Programme (PPEP):** initiative put in place in 2016, with a national platform for the collection of PROMs and PREMs, for patients receiving primary or secondary care. • **Other national surveys:** – Introduction of a national survey in 2012 on local health services. – A patient experience survey in the field of oncology includes questions proposed by the OECD. – Collection of a PREM on rheumatoid arthritis in 2015 (National Clinical Audit in England and Wales).	• **National patient experience survey:** Patient Experience Survey*:* – set of 7 questions. ⇒ Some of the questions proposed by the OECD are included, particularly in the field of oncology. • **National Clinical Audit in England and Wales:** PREMs on rheumatoid arthritis (2015). • Collection of PREMs to measure patient experience in chronic diseases. – **E.g.** Parkinson's disease, low back pain.	• Collection in paper/electronic format. – **National online collection platform (2015):** NHS Wales Informatics Service (NWIS). ⇒ Application usable at home or in hospital.	• No website found/ information not available.	• **Benchmarking:** the inclusion of PREMs in the platform enables the identification of areas of excellence or those requiring improvements in care, via a more in-depth survey. • **Comparison:** the inclusion of PREMs in the platform makes it possible to compare patient experience in Welsh hospitals. **Link:** http://www.wales.nhs.uk/nhswalesaboutus ***Last accessed:*** *23/11/2020.*
USA	• **National PREMs collection system:** Consumer Assessment of Healthcare Provider and Systems (CAHPS): initiative created in 1995 by the AHRQ, responsible for measuring patient	**Collection of PREMs as part of the CAHPS programme:** – hospital care (HCAPHS): hospitalisation (adults/paediatrics), surgery (hospitalisation), outpatient	**Standardised CAHPS questionnaires:** https://hcahpsonline.org/home.aspx	• The CMS publishes the results of CAHPS national surveys in Hospital Compare, 4 times per year.	• **Comparison and benchmarking:** online reports, personalised analyses, use of data for research.

experience in outpatient, primary, hospital or nursing care or in dialysis centres. – Continuous collection of PREMs by care structures (healthcare facilities); – Data stored in the CAHPS national database. • **Local initiatives:** in some healthcare facilities. – **E.g.** the Cleveland Clinic a implementation of a patient experience programme, with measures and improvement action plans. **Link:** https://experiencepatient.fr/lexperience-patient-made-in-usa ***Last accessed:*** *08/12/2020.* • There are numerous CMS programmes (see table 9) – **Hospital Value-Based Purchasing (HVBP):** programme to ensure better quality of care and enhance the patient experience.	surgery and care, follow-on care and rehabilitation; – care providers (CAHPS): home care, retirement homes, in-centre haemodialysis, dental care, community care. **A certain number of care sectors are targeted:** mental health, oncology, etc. **CAHPS questionnaire =** 32 questions applied to a sample of patients in various care sectors: – Hospital CAHPS (HCAHPS); – Home Health CAHPS; – Home and Community-Based Services Survey CAHPS (HCBS CAHPS); – Fee-for-Service CAHPS; – Medicare Advantage and Prescription Drug Plan CAHPS; – In-Center Hemodialysis CAHPS; – Nationwide Adult Medicaid CAHPS; – Hospice; – CAHPS® Survey for Accountable Care Organizations Participating in Medicare Initiatives; – Outpatient and Ambulatory Surgery CAHPS;	**Different methods of administration:** email, telephone, email followed by telephone, interactive voice server.	– National results, or by state (downloadable versions). – Inter-hospital (or inter-structure) comparisons. ⇒ Standardisation of presentation formats. **Link:** https://data.medicare.gov/browse?q=Patient%20survey%20(HCAHPS)%20-%20Hospital&sortBy=relevance ***Last accessed:*** 08/12/2020. • **Integrated Healthcare Association (IHA)'s Value Based Pay for Performance (VBP4P) program:** public disclosure of results every year. ⇒ A quality report compares the performance of physician organisations by county, showing overall performance and individual clinical quality scores, patient experience and total cost of care measures. **Link:** https://www.iha.org/our-work/accountability/value-based-p4p/results-public-reporting	• **Pay for performance:** **1. Inpatient Prospective Payment System (IPPS):** the hospitals in this programme not publishing their results in Hospital Compare may have their funding reduced by 2%. **2.** *Hospital Value-Based Purchasing*[76] **(HVBP):** remuneration based on a 2% reduction in the Medicare hospital base payment, and depending on the severity of diagnoses of hospitals participating in the one-year period. The total amount of savings (expenditure reduction) is redistributed based on the total hospital performance scores achieved over a one-year period[77]. ⇒ The remuneration of the hospitals is based on their position in the general ranking or on the improvement of the results of the quality of care measures (including PREMs), and on an additional incentive to maintain

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[76] Hospitals affiliated to the Medicare programme.

[77] The hospitals are paid based on their performance for quality measures and the use of resources. A performance score is calculated based on several types of indicators: 1) Mortality and complications; 2) Healthcare-associated infections; 3) Patient safety; 4) Patient experience; 5) Efficacy and cost reduction. For each indicator, there are two measures: one for success and one for improvement. For more information: *Hospital Value-Based Purchasing | CMS*

		– CAHPS for Merit-based Incentive Payment System (MIPS); – Emergency Department CAHPS. **Link:** https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS ***Last accessed:*** *08/12/2020.*		***Last accessed:*** *18/11/2020.*	scores above the national median (see **2.4**). **3. IHA's** VBP4P program**:** incentive related to 1 composite score of 3 types of indicators: 1) clinical practices (60%), 2) patient experience (30%), 3) information systems (IS)/health technologies (HT) (10%). **4. CJR Model:** payment for a care episode (THR/TKR) linked to a composite score including the results of CAHPS indicators (see table 9). **5. ESRD QIP:**. ⇒ The indicators used (see table 9) include CAHPS PREMs (ICH-CAHPS). ⇒ A penalty system applies to the quality-based payment part, which represents up to 2% of the total payments received by a centre. Application of the penalty[78] reduces payments. **6. ESRD Seamless Care Organizations (ESCO):** see table 9. ⇒ The quality score calculated includes patient experience measures (CAHPS).

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[78] Only a minority of dialysis centres are concerned by the application of a maximum 2% penalty.

					Last accessed: *04/03/2020.*
Canada	*6 regions grouping together 10 provinces and 3 territories (regional level), themselves including census divisions (local level).* • **Lack of standardisation of collection on a national level:** uneven collection between and within provinces (regions). – **Some provinces:** longitudinal surveys conducted: – either at province level; – or in selected care sectors, in one or more provinces: acute care, emergencies, rehabilitation, long-term care, mental health, cancer, community care, primary care. ⇒ Centralised coordination, facilitating comparisons between provinces, regions and peer groups. – **Other provinces:** surveys at territory level (within a province) or in certain hospitals of a region.	• **Cross-sectional surveys or by care sector (acute care, cancer, geriatrics, etc.).** **CIHI:** Canadian Patient Experience Survey-Inpatient Care (CPES-IC), comparable to the CAHPS-IC Survey, developed with accreditation experts. **It includes 48 questions:** – 22 from the CAHPS-IC Survey; – 19 linked to the Canadian context (discharges, transfers, etc.); – 7 on demographics. **Cancer:** the most advanced sector. – Ambulatory Oncology Patient Satisfaction Survey*:* satisfaction survey in patients receiving outpatient oncology care developed by the National Research Corporation Canada and implemented in 8 provinces[79] between 2003 and 2016.	• Diversity of survey tools between provinces and care sectors. Lack of standardisation of surveys between different provinces and differences in data collection methodologies. – **CPES-IC survey:** https://www.cihi.ca/sites/default/files/document/patient_expsurvey_inpatient_fr.pdf – **Different methods of administration:** email, telephone, postal. See procedure manual: https://www.cihi.ca/sites/default/files/document/cpes-ic-procedure-manual-2019-fr-web.pdf ⇒ Survey tested in 5 provinces: Manitoba and Alberta (2014), New Brunswick (2015), Ontario and British Columbia (2016). ⇒ There is an ***ad hoc* information system for the**	• **Lack of standardisation of formats for the presentation of results:** province, region, or hospital/unit level. In some provinces, jurisdictions require that global results be supplied for the province. – The results of the **CPES-IC** survey conducted in 5 provinces can be accessed on the ICIS website. **Link:** https://www.cihi.ca/fr/experience-des-patients/experience-des-patients-dans-les-hopitaux-canadiens **Last accessed:** 03/11/2020. ⇒ By 2021, the CIHI will produce detailed public reports by province, with the results of 5 survey questions: 1) communication with nurses; 2) doctors; 3) participation in decision-making; 4) discharge management; 5) overall hospitalisation experience.	• **Comparisons between provinces** (see results of the survey in 5 regions), territories and peer groups in territories that coordinate centralised surveys. • **Difficulties conducting comparisons and benchmarking between regions:** work ongoing to harmonise analyses on a national level. • **Accreditation of hospitals:** – **CPES-IC survey:** patient experience measures are used in the accreditation of acute care healthcare facilities in some provinces (Prince Edward Island, Nova Scotia, Ontario). ⇒ The results of a patient experience survey should normally be included in each accreditation cycle

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[79] Eight provinces: Alberta, Manitoba, Nova Scotia, Ontario, Saskatchewan, British Columbia, Newfoundland and Labrador and Prince Edward Island.

	⇒ The survey focuses on 2 phases of **cancer care:** i) detection/diagnosis then ii) treatment. Patients are asked about their experience for six dimensions: access to care, coordination and continuity of care, emotional support, information, communication and patient education, physical comfort, respect for patient preferences. ⇒ Questions targeting the following topics: diagnosis, treatment planning, tests, surgery, chemotherapy, radiotherapy, symptom management, care delivery and general patient perceptions. – In 2016, the **Canadian Partnership Against Cancer** on the experience of cancer patients in transition from a cancer care system to a broader care system in 10 provinces across the country. – In 2015, the **Regional Geriatric Programs of Ontario** launched a survey entitled https://www.rgptoronto.ca/wp-content/uploads/2019/04/RGP-Webinar-SGS-Patient-Experience-Survey-Development-March-29-2019.pdf 16 questions concerning 6 topics: i) access to care; ii) communication with doctors; iii) trust; iv) patient feedback on the impact of care; v) exhaustiveness of care; vi) continuity and coordination of care.	collection of data and reporting of results**:** Canadian Patient Experiences Reporting System. ***Last accessed:*** *05/11/2020.*	⇒ The results by hospital will soon be published on the CIHI website: http://yourhealthsystem.cihi.ca/hsp/indepth?lang=fr#/) ***Last accessed:*** 03/11/2020. **For more information:** https://www.cihi.ca/fr/experience-des-patients/donnees-canadiennes-sur-lexperience-des-patients-diffusion-publique-a ***Last accessed:*** 03/11/2020. • The ICIS is also working on the public disclosure of the results of 5 patient experience indicators, by hospital in the Web tool Your health system: in depth. ⇒ The online results will allow comparisons to be made at national, provincial and hospital levels. ***Last accessed:*** *03/11/2020.* • It is possible to access tools, reports, surveys or other patient experience documents using the following link: https://www.cihi.ca/fr/acceder-aux-donnees-et-aux-rapports ***Last accessed:*** *03/11/2020.*	(every 4 years), in provinces with this requirement. ⇒ The requirement to include experience surveys in the Canadian accreditation system is gradually being extended to all care sectors: long-term, home, primary, mental health, etc. **Links:** – https://www.cihi.ca/sites/default/files/document/visioning-day-paper-en-web.pdf – https://www.oecd-ilibrary.org/fr/social-issues-migration-health/measuring-patient-experiences-prems_893a07d2-en ***Last accessed:*** 03/11/2020. • In some provinces, **hospital funding** is linked to PREMs results.

		⇒ Questionnaire developed between 2015 and 2018, tested at the end of 2018 (in the process of being finalised/soon to be rolled out). – Participation in the **Commonwealth Fund International Health Policy surveys**, concerning 11 countries.			
Australia	*6 large provinces divided into 31 primary care zones.* • Centralisation of patient experience measures at national level in the **Australian Bureau of Statistics** (ABS), responsible for collecting, processing and publishing the results of national patient experience surveys, in liaison with the Australian Institute of Health and Welfare (AIHW). • **National** system for the measurement of patient experience in hospitals and in primary care (community). •**Regional** initiatives for the measurement of patient experience in hospitals and in primary care. – Numerous provinces collect data on the common questions defined by the Patient Experience Information Development Working Group (PEIDWG), a non-mandatory, national questionnaire, seen as a benchmark for measuring patient experience in hospitals. Ultimately,	**Collection of PREMs on primary or hospital care. Several standardised questionnaires.** ***Primary care:*** – Patient Experience Survey (PEx): patient experience survey for hospital care. ⇒ **Several modules:** general medicine, specialised, dental, chronic diseases, imaging, emergencies, hospital admission, other healthcare professionals, private insurance, etc. ***Hospital care:*** – ***Patient Experience Information Development Working Group (PEIDWG)****:* 18 questions measuring patient experience in the form of a retroactive feedback system. – overall satisfaction (1 question);	**Different methods of administration:** online, paper, telephone, tablet). ***Primary care:*** – *Patient Experience Survey* (PEx)). **Link:** https://www.abs.gov.au/statistics/health/health-services/patient-experiences-australia-summary-findings/latest-release#survey-material ***Last accessed:*** 19/11/2020. – *Hospital care:* *PEIDWG questionnaire*: **Link:** https://www.safetyandquality.gov.au/sites/default/files/migrated/National-set-of-core-common-patient-experience-questions-%E2%80%93-for-	• No site for public disclosure by healthcare facility found. • **Publication of national results:** aggregated survey reports. • **National reports:** *Primary care:* – *Patient Experiences in Australia: Summary of Findings* *:* experience with general practitioners, specialists, dental care, admissions (hospital and emergency), coordination of care, other healthcare professionals. *Use of the PEx.* – *Coordination of health care: experiences of information sharing between providers for patients aged 45 and over 2016*: continuity of care and information sharing between healthcare	• Comparison of patient experience with respect to information from their primary care physicians on their follow-up needs after hospitalisation, a visit to the emergency department, etc. between primary care networks (see 2016 survey among patients aged 45 or over attached). • **Accreditation of healthcare facilities:** – Measurement of patient experience mandatory in the accreditation of hospitals and primary care structures: consideration of feedback from the results of the Accreditation and Improvement Survey, which collects comments from patients having received hospital and primary care (accreditation standards).

national collection is scheduled. There are also other questionnaires used in national surveys. •**Local initiatives** for the measurement of patient experience in hospitals and in primary care. – To date, many local initiatives use various collection tools and methodologies, without a national approach. Hospitals are increasingly using the common questions defined by the PEIDWG (see attached description). – Local initiatives use the Patient Experience Survey (see below*)* to model health personnel planning. • Participation in the collection of PREMs data for the OECD panorama (mental health).	– patient experience (12 questions); – 5 general questions; – 7 questions from the Picker Institute. – **South Australian Consumer Experience Surveillance System** *(*SACESS*)* survey: hospital telephone survey. ⇒ **5 areas:** – general questions (Picker Institute); – composite patient experience indicator: involvement in decision-making relative to care and treatments; – other questions: hospital environment, healthcare consumer feedback, patient rights and engagement, open disclosure, emergencies, staff, hand hygiene; – questions defined by the *PEIDWG* (see above); – questions on overall satisfaction. ***Last accessed:*** 18/11/2020. – **Australian Hospital Patient Experience Question Set**	overnight-admitted-patients-Pen-and-Paper.pdf ***Last accessed:*** 19/11/2020. – Australian Hospital Patient Experience Question Set (AHPEQS). **Links:** – https://www.surveymonkey.com/r/ahpeqs – https://www.safetyandquality.gov.au/sites/default/files/2019-09/australian_hospital_patient_experience_question_set_ahpeqs_technical_specifications_august_2019.pdf – The collection of data is voluntary but is encouraged as it relates to quality and safety of care measures. – Some regions use other patient experience surveys. ***Last accessed:*** 19/11/2020.	professionals[80] (national results and by health territory). ⇒ Use of the *2016 Survey of Health Care*: specific survey conducted in 2016. ***Last accessed:*** *23/11/2020.* *Hospital care:* – **AHPEQS:** results available soon. – **SACESS Survey** 2018 results ***Last accessed:*** 18/11/2020. *Primary and hospital care:* – *Australia’s health snapshots 2020 - Australian Institute of Health and Welfare*: experience with general practitioners, specialists and coordination of care. ⇒ Overall compilation of results for hospital and community care. Coordination by the AIHW. ***Last accessed:*** *23/11/2020.* • **Regional reports:** – *Primary care:* *Patient Experience in Australia by small geographic areas in 2017-18*: assessment of the health and quality of care of	• Experimentations **envisaged** to integrate PREMs into pay-for-performance models.

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[80] Information sharing between healthcare professionals: general practitioners and specialists, and between general practitioners and hospital professionals (including emergency departments).

		(AHPEQS) survey: new survey with 12 questions on patient experience of treatment, the most important care, pain management.		patients in 31 primary care areas. ⇒ *Use of the PEx.* ***Last accessed:*** 03/11/2020. • **Regional or local results:** – *Hospital care:* **PEIDWG questionnaire**: publication of results at regional level, by hospital or department/unit (most regions are involved in the collection). ⇒ No reports available.	
New Zealand	There are 6 states and 10 territories. There are 20 health districts (District Health Boards (DHB)). • National patient experience measurement system since 2011 (care pathway). • **2 surveys** led by the Health Quality and Safety Commission every quarter: – Hospital patient experience survey launched in 2014 (National Inpatient Experience Survey). – Primary care survey launched in 2016 (Integrated Performance and Incentive Framework).	• PREMs for hospitalised patients. • PREMs for patients treated in the primary care setting.	**National initiatives:** performance of patient experience surveys every 3 months for community and hospital care: – **Experience of hospitalised patients:** surveys conducted in the DHBs since 2014. ⇒ Methodology via the following link: https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/1658/ – **Experience of patients treated in the primary care setting:** surveys conducted in private practices since 2015/2016.	• No site for public disclosure by healthcare facility found. • **Results for inpatient experience in 4 main areas (score out of 10 per quarter):** communication, partnership, coordination and physical and emotional needs. – **National:** https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/adult-inpatient-experience/survey-results/ – **By district (DHB):** https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/3936/	**Integration of PREMs in primary care quality regulation mechanisms:** Integrated Performance and Incentive Framework.

		– Methodology via the following link: https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/adult-primary-care-experience/survey-information-and-methodology/ – **Experience of patients with Covid 19:** https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/covid-19-patient-experience-survey/	⇒ **Graphs:** comparison of the results of each DHB with respect to a national level: traffic light system (colours). • **Results by district for the experience of patients treated in the primary care setting:** https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/patient-experience/adult-primary-care-experience/survey-results/ ⇒ Graphs: comparison of the results of each DHB with respect to a national level (traffic light system). ***Last accessed:*** 03/11/2020.

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Abbreviations and acronyms

AHRQ	*Agency for Health Research and Quality*
AIHW	*Australian Institute of Health and Welfare*
COPD	*Chronic obstructive pulmonary disease*
CAHPS	*Consumer Assessment of Healthcare Provider and Systems*
CAT	*Computerised Adaptive Testing,*
CIHI	*Canadian Institute for Health Information*
CMS	*Centers for Medicare & Medicaid Services*
CQC	*Care Quality Commission*
DICA	*Dutch Institute for Clinical Auditing*
EDS	*Épisodes de soins (Care episode)*
EQ-5D	*EuroQol Group 5-Dimension Self-Reported Questionnaire*
e-Satis	*National system for the measurement of patient experience and satisfaction*
HAS	*Haute Autorité de santé (French National Authority for Health)*
HCQI	*Health Care Quality Indicators*
HCQO	*Health Care Quality and Outcomes*
HRQoL	*Health Related Quality of Life*
IAPO	*International Alliance of Patients' Organisations*
ICHOM	*International Consortium for Health Outcomes Measurement*
IOM	*Institut Of Medicine*
IPEP	*Incitation à la prise en charge partagée (incentive for shared care)*
IQTIG	*Institute for Quality Assurance and Transparency in Health Care*
IRT	*Item Response Theory*
KCE	*Belgian Health Care Knowledge Centre*
CKD	*Chronic kidney disease*
NHS	*National Health Service*
NIH	*National Institutes of Health*
NQR	*Swedish National Quality Register programme*
OECD	*Organisation for Economic Cooperation and Development*
P4P	*Pay for Performance*
PaRIS	*Patient-Reported Indicators Survey*

PEPS	*Paiement forfaitaire en équipe de professionnels de santé en ville (bundled payment in community healthcare professional teams)*
PREMs	*Patient-Reported Experience Measures*
PROMs	*Patient-Reported Outcomes Measures*
PROMIS	*Patient-Reported Outcomes Measurement Information System*
TKR	*Total knee replacement*
THR	*Total hip replacement*
SF-36	*36-Item Short Form General Health Survey*
SVEUS	*National collaboration for value-based reimbursement and monitoring of health care in Sweden*
VBHC	*Value-Based Health Care*

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