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**SANTÉ ET BIEN-ÊTRE**

ÉTUDES ET DOCUMENTS

Measuring patient  
experience through  
surveys: from concepts  
to best practices



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## FOREWORD

Like other regions in developed countries, Quebec faces many challenges relating to the organization and development of healthcare services. Whether stakeholders are seeking to continuously improve the quality of services or the overall performance of the healthcare system, the perspective of those most affected by the system—patients—is crucial. Despite the growing number of sources of data and their availability, population surveys remain the best tool to understand the healthcare system as seen by patients. As the need for information continues to grow, it is important to consider how we measure the experience of patients within the healthcare system, as well as the best practices associated with that measurement. This reflection will hopefully optimize the usefulness of the resulting data.

This document provides an overview of “patient experience” surveys in Quebec and elsewhere. Recently, this approach has been deemed one of the best ways to gather the information needed to improve the quality of care. We hope that this document will start discussions that can contribute to the development of a provincial patient experience measurement strategy that is thorough, effective, coordinated and useful for improving the quality of healthcare services.

Director General,



Stéphane Mercier

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## LIST OF ACRONYMS

AHRQ	Agency for Health Care Research Quality
AOPSS	Ambulatory oncology patient satisfaction survey
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CCHS	Canadian Community Health Survey
CIHI	Canadian Institute for Health Information
CISSS	<i>Centre intégré de santé et de services sociaux</i>
CIUSSS	<i>Centre intégré universitaire de santé et de services sociaux</i>
CPAC	Canadian Partnership Against Cancer
CPES-IC	Canadian Patient Experiences Survey — Inpatient Care
CPERS	Canadian Patient Experiences Reporting System
CQA	<i>Conseil québécois d'agrément</i>
CQC	Care Quality Commission
CQI	Consumer Quality Index
EQES	<i>Enquête québécoise sur l'expérience de soins</i>
EQLAV	<i>Enquête québécoise sur les limitations d'activités, les maladies chroniques et le vieillissement</i>
GMF	<i>Groupe de médecine de famille</i>
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
INSPQ	<i>Institut national de santé publique du Québec</i>
IOM	Institute of Medicine
ISQ	<i>Institut de la statistique du Québec</i>
MSSS	<i>Ministère de la Santé et des Services sociaux</i>
NHS	National Health Service
NRC	National Research Corporation
OECD	Organisation for Economic Co-Operation and Development
OPEQ	Outpatient Experiences Questionnaire
PEPC	Parent Experiences of Pediatric Care
PEQ	Patient Experiences Questionnaire
PPE	Picker Patient Experience

PREM	Patient-Reported Experience Measures
PROM	Patient-Reported Outcome Measures
P4P	Pay-for-Performance
QOF	Quality and Outcomes Framework
QUOTE	Quality of Care through the Patient's Eyes
WHO	World Health Organization



## KEY MESSAGES

- ▷ Patient experience measurement is recognized as one of the key components in evaluating healthcare quality.
- ▷ Patient experience surveys are preferable to standard satisfaction surveys.
- ▷ In Quebec, most local, regional and provincial patient experience surveys are conducted using customized tools that respond to a need for specific information, meaning that results cannot be compared over time or between different care providers.
- ▷ The questionnaires used to conduct surveys in healthcare settings, as well as the methodologies used to collect data, need to be standardized.
- ▷ Surveys should be repeated over time so that their data can contribute to continuous quality improvement processes and performance analyses in various sectors.
- ▷ Patient experience measurement strategies should include a system for declaring and compiling data from local surveys so that the performance of different healthcare facilities can be compared and provincial estimates can be produced.
- ▷ The numerous surveys conducted in Quebec by the ISQ on behalf of the MSSS have made it possible to develop expertise that can help to build a provincial patient experience measurement strategy that is thorough, effective, coordinated and useful for improving the quality of healthcare and related services.



# INTRODUCTION

The measurement of patient experience is increasingly being recognized as a key component of quality evaluations of healthcare services and, more generally, of performance analyses of healthcare systems. It is drawing more and more attention, reflecting the paradigm shift triggered, notably, by the Institute of Medicine's (IOM) 2001 *Crossing the Quality Chasm* report. This report recognized patient-centered care as one of the pillars of quality healthcare, alongside safety, effectiveness, accessibility, efficiency and equity (IOM, 2001).

The definition of “patient-centered care” varies, but broadly speaking it questions the traditional medical approach and considers the patient as an active participant in the care they receive (CMDC, 2014). Patients are the only ones who are present during every step of their journey through the healthcare system, giving them a unique perspective on services that respond to their needs and preferences (Fancott, 2012). Experts agree that patients are the best judges of the care they receive, and that their perspective can complement more conventional indicators obtained from clinical and administrative data, for example (Anhang Price et al., 2014; Haggerty et al., 2007).

Approximately 15 years ago, patient experience surveys have emerged as an interesting alternative to traditional satisfaction surveys, whose methodological validity was often questioned. Questions about patient experience are considered to have better discriminating power than questions about satisfaction, meaning that they have a greater ability to make comparisons between different clinical or organizational practices (Salisbury et al., 2010). Data on patient experience is therefore increasingly being used to guide continuous quality improvement efforts from an operational standpoint and evaluate performance from a strategic standpoint (Bélanger et al., 2013). Many countries regularly conduct this type of survey through national programs. The United Kingdom and United States are world leaders in this regard.

In Quebec, patient experience surveys gradually became common during the 2000s. At the provincial level, the Ministère de la Santé et des Services sociaux (MSSS) and the Institut de la statistique du Québec (ISQ) established a survey program in 2005 to document the use of services, as well as met and unmet needs and some aspects of patient experience. At the regional level, population surveys conducted in the Montréal and Montérégie areas in 2005 and 2010 documented some elements of patient experience for people using primary healthcare services (Agence des services de santé et des services sociaux de Montréal and INSPQ, 2012). Furthermore, patient experience measurements are becoming increasingly common in Quebec's healthcare facilities, particularly since 2013, when it became a requirement of Accreditation Canada. However, most local, regional and provincial patient experience surveys in Quebec are not integrated, systematic or conducted with standardized questionnaires. Instead, they use customized tools that respond to a need for specific information, meaning that results cannot be compared over time or between different care providers.

Given that the expressions “patient experience” and “satisfaction” are often used interchangeably in literature, this document first aims to define and distinguish between the two concepts. Next, we will examine the usefulness of patient experience surveys, the ways in which patient experience is measured and how the surveys are used in Quebec, in Canada and elsewhere in the world. In conclusion, we will look back at the best practices for measuring patient experience: practices that optimize the use of survey data to improve quality and evaluate performance.



# 1

## WHAT IS “PATIENT EXPERIENCE”?

There is no single definition of “patient experience”, but the one sometimes used in Quebec is based on the Beryl Institute’s definition. It describes patient experience as the sum of all patient perceptions, interactions between an organization and its patients and the actual events experienced by patients throughout their trajectory of care. Measuring patient experience relies on both factual aspects of care episodes and patients’ perception of the quality of care and services they received (Bélanger et al., 2013). The patient experience approach is therefore based on an objective evaluation of services received and on a subjective evaluation of care, mostly based on personal judgment (Russell, 2013).

The survey questionnaire, which is the most common tool for evaluating patient experience, may therefore include declarative questions, which are designed to report facts, and evaluation questions, which are designed to document patients’ perceptions of the quality of the care they received. Declarative questions generally ask whether certain events occurred during a given visit, care episode or reference period. They may also gather information on wait times or frequency (see “Examples of patient experience questions” box). This type of question is currently used to determine whether the services received comply with clinical and administrative standards, or achieve certain targets. For example, they may refer to medical or professional practices, or the way in which services were provided from an accessibility, continuity or safety standpoint. Managers, researchers and other stakeholders who know the standards and frameworks that define quality service must therefore be involved in survey development, as they can transpose those elements into questions.

As for evaluation questions, they invite patients to evaluate the care or services they received, often through a rating system such as “very good, good, fair, poor, very poor” or “very strongly agree, strongly agree, agree, disagree, strongly disagree” (see “Examples of patient experience questions” box). That said, the difference between declarative and evaluation questions is not always as clear as it may seem. For example, some declarative questions contain evaluative elements in their wording (example 1) or answer format (example 2).

Example 1: Were you involved as much as you wanted to be in decisions about your care and treatment?

- Never
- Sometimes
- Often
- Always

Example 2: How much information did you receive about your condition or treatments?

- Not enough
- Enough
- Too much

## Examples of patient experience questions

### Declarative questions

**Example 1:** On average, how long does it take to receive an appointment with your physician?

- Less than 2 weeks
- 2 weeks to less than a month
- 1 month to less than 4 months
- 4 months or more

**Example 2:** Over the past 2 years, how often did you leave your doctor's office with unanswered questions?

- Never
- Rarely
- Sometimes
- Often
- Always

**Example 3:** During your treatment period, were you put in touch with healthcare professionals who could help ease your worries and anxieties?

- Yes
- No

### Evaluation questions

**Example 4:** How would you describe the wait time at your clinic before your appointment?

- Very poor
- Poor
- Fair
- Good
- Very good

**Example 5:** The services I receive at this location help me to manage my health problems.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

## 1.1 PATIENT EXPERIENCE SURVEYS: HOW THEY DIFFER FROM SATISFACTION SURVEYS

First of all, it is important to note that the terms “patient experience” and “satisfaction” are often used interchangeably in literature about the quality of healthcare services or performance of healthcare systems. Furthermore, evaluation questions found in patient experience surveys (see “Examples of patient experience questions” box) are often considered to be equivalent to questions about satisfaction. However, the latter traditionally require patients to specifically declare their level of satisfaction through answers such as “very satisfied, satisfied, mostly satisfied, mostly dissatisfied, very dissatisfied” (Drain and Clark, 2004; Lavela and Gallan, 2014).

This confusion is explained, at least in part, by the subjectivity shared by both types of questions. According to some authors, evaluation questions generally call on the cognitive processes used to evaluate past events and the way they occurred, while satisfaction questions relate to a patient’s feelings after a care episode (Lavela and Gallan, 2014; Wensing and Elwyn, 2002). Patient satisfaction with care or services is a subjective evaluation that depends on individual preferences, perceptions and expectations (ANAES, 1996; Coulter and Cleary, 2001). It is often considered to be the result of the perceived gap between a patient’s expectations of a service and the service they believe that they actually received (Risser, 1975).

The concept of “satisfaction” has long been controversial and subject to much debate. Critics cite subjectivity, the lack of consensus regarding a definition and the low discriminating power of the tools used to measure it as key issues (Kabengele et al., 2011). A review of 195 studies on patient satisfaction also showed that very few measurement tools used during the 1980s and 1990s were reliable and valid (Sitzia et al., 1999). Furthermore, it was noted that patients have a tendency to report higher levels of satisfaction, as they are reluctant to give negative responses (Risser, 1975; Rocheleau, 2013). Finally, research on satisfaction surveys has shown that high satisfaction is not always associated with a positive care experience (Jenkinson et al., 2002a) and that it may depend on factors other than the healthcare system itself (Bleich et al., 2009).

That said, some work has emphasized the relevance and validity of satisfaction-based tools when evaluating the quality of care and services. Rocheleau and Grenier, for example, suggested a model that can analyze differences between expectations and satisfaction to identify ways to improve quality of services (Rocheleau and Grenier, 2001). The *Enquête sur la satisfaction et les attentes des usagers à l’égard des services de santé et des services sociaux du Québec*, conducted in 2006–2007, drew inspiration from this model to measure user expectations, rank them in order of importance and analyze them against user satisfaction to strengthen the discriminating power of this type of tool (Rocheleau et al., 2008). This survey also showed that referring to a concrete consultation experience helps to reduce the subjectivity of satisfaction measurements (Neill et al., 2007).

In order to overcome the issues inherent to joint analyses of satisfaction and expectations, as well as to the interpretation of the resulting data, patient experience surveys have gradually emerged as an alternative to traditional satisfaction surveys. For the past decade, most surveys to determine the population’s perception of healthcare services have been based on patient experience measurements. Nevertheless, the subjective nature of evaluation questions about patient experience is seen by some as a weakness, similar to the subjective nature of satisfaction questions. According to these authors, declarative questions are more objective and therefore more useful for improving the quality of services (Salisbury et al., 2010).

For others, subjectivity is seen as an asset, as it incorporates the psychological aspect of patients' evaluation of care (Haggerty, 2010; Kabengele et al., 2011). Proponents of the evaluation approach maintain that it takes into account many aspects of care not easily measured by the declarative approach, such as the staff's empathy and compassion or the quality of information and explanations. Proponents also note that declarative questions focus primarily on problems from the healthcare facility's point of view regardless of their importance to patients (Drain and Clark, 2004).

While patient experience surveys currently tend to favour declarative questions (Drain and Clark, 2004), doubts about the usefulness of evaluation questions are generally founded on questions about the overall care experience, rather than those about specific aspects of care. Indeed, it has been shown that results based on evaluation questions about overall appreciation of services provide a limited, optimistic view of care experiences (Jenkinson et al., 2002a).



# 2

## WHY MEASURE PATIENT EXPERIENCE?

Patient experience can be approached in different ways; the aspects to be measured determine the measurement tools. Generally, patient experience is measured to evaluate the quality of services, the performance of care providers or healthcare systems or the achievement of results. These approaches are not contradictory, but they are not quite complementary, either (Cantin and Rocheleau, 2006; Reeves and Seccombe, 2008). That said, they do share the same goal: to improve the quality of services provided to patients, and therefore their care experience.

### 2.1 TO EVALUATE THE QUALITY OF HEALTHCARE SERVICES

Although definitions of quality of healthcare services are numerous, most consider patient experience to be one of its key components. (Russell, 2013). Quality of healthcare services is defined not only by the technical aspects of medical procedures, but also by the way care is provided (Rocheleau, 2013). Certainly, patients are the best judges of some aspects of quality. This point of view is the cornerstone of patient-centered healthcare systems, unlike healthcare systems that simply focus on treating illnesses. Patient perspective therefore provides a complementary view of the quality of service, which can be used alongside more conventional indicators drawn from sources such as clinical and administrative data.

When evaluating the quality of healthcare services, variations in patient experience between different services are examined, which allows their strengths and weaknesses to be identified. The measurement tool used must therefore be exhaustive; it must document all aspects of patient experience about which respondents can or may wish to describe (Rocheleau, 2013). Otherwise, a survey could skew the truth by displaying positive results when in fact, patients had a negative experience with other unmeasured aspects.

### 2.2 TO EVALUATE PERFORMANCE

Measuring patient experience to evaluate performance is primarily intended to allow comparisons between care providers or healthcare systems (benchmarking), using a limited number of indicators with common features that can be compared. This approach focuses on variations in patient experience between different establishments, allowing them to be ranked by the indicators being studied. It also allows performance changes to be monitored over time. Measurement tools must therefore be able to reproduce the same evaluation in multiple locations and at different times (reliability) and be accurate enough to detect differences, no matter how small, between the groups being compared (sensitivity) (Cantin and Rocheleau, 2006).

The United Kingdom and United States have the longest record of measuring patient experience to analyze performance. They use standardized questionnaires and data collection methods to compare healthcare facilities. The results of some of these surveys are used in Pay-for-Performance (P4P) programs, which offer financial incentives to care providers who meet certain performance criteria. Results are also released publicly to guide patients in their choice of care providers (Kalucy et al., 2009).

## 2.3 TO EVALUATE ANTICIPATED RESULTS

Patient experience measurements can also be used to evaluate whether certain results have been achieved. In these cases, patient experience is seen as a product of the provision of services. It is assumed that if a service is provided properly, users will report a positive care experience (Cantin and Rocheleau, 2006). This approach is similar to the approach used to evaluate health improvement outcomes, which include measurements such as symptoms, health problems and activity limitations. Patient experience measurement may therefore be used as part of a program evaluation to study how certain clinical practices or organizational processes affect the care experience.

## 2.4 TO IMPROVE PATIENTS' EXPERIENCE

Information about patient experience can be used in different ways: to improve specific interventions, change professional practices or even influence the development of public policies (Russell, 2013). That said, the end goal is always to use this information to improve the experience of the patients themselves. A number of studies have found that a positive care experience is correlated with greater adherence to treatment and prevention recommendations, better clinical results, improved patient safety and less use of services (Anhang Price et al., 2014; Doyle et al., 2013).

A growing body of work is showing that data from patient experience surveys can truly improve patient experience (Anhang Price et al., 2014; Reeves and Seccombe, 2008). However, organizations appear to be focusing more on collecting information than on finding ways to use that information to improve their services (Russell, 2013). Many studies have shown that managers and clinicians therefore have difficulty using data to identify changes that could improve service quality (Baker, 2014). The effectiveness of patient experience measurements as a service quality improvement tool depends on many factors, including organizational culture and the mechanisms used to translate the data into better care (Patwardhan and Spencer, 2012). A review of studies about this issue shows that healthcare organizations often lack the time, resources and expertise to interpret results. This is one of the main roadblocks to using information about patient experience (Gleeson et al., 2016). Additionally, the overly general nature of the surveys, as well as the fact that they are rarely repeated, are frequently considered to prevent data from being used properly.

# 3

## USING THE SURVEY QUESTIONNAIRE TO MEASURE PATIENT EXPERIENCE

Patient experience studies can be either qualitative or quantitative. The survey-based quantitative approach is by far the most common. It provides larger sample sizes, allowing for statistical tests to study the relationship between variables and compare groups of individuals. Patient experience measures from survey questionnaires are also called “patient-reported experience measures” (PREM). They explore both the practical aspects of care, such as wait times and accessibility, and the relational aspects, like communication or emotional support.

As with any measurement tool, the qualities of the questionnaire must be known before starting a study. This requires qualitative and quantitative evaluations. The qualitative evaluation of a questionnaire is generally performed while the questions are being designed. The process involves submitting the questionnaire to the judgment of experts (managers, researchers, patients, stakeholders) and doing a preliminary test in a representative sample group. This step ensures that the items in the questionnaire fully reflect every aspect of the phenomenon being studied (validity of content) and that the questions are clear and easy to understand (intelligibility). Quantitative evaluation, on the other hand, involves analyzing the metrological properties of the questionnaire through statistical analysis. Doing so ensures that the questionnaire will provide reproducible results in similar situations (reliability), be able to detect even minimal changes in the phenomenon being studied (sensitivity) and effectively measure the theoretical model on which it relies (construct validity).

Many questionnaires have been developed to meet specific information needs in a given sector, but these cannot be compared to other tools. Other questionnaires use a standardized structure and content, with the intent of comparing the performance of care providers or healthcare systems. Standardized questionnaires are generally based on patient-centred care models, and their quality has been proven (Soubeiga et al., 2013).

## 3.1 DIMENSIONS OF THE PATIENT EXPERIENCE

There are many “patient-centred care” models that describe the various dimensions of the patient experience. The two most common models were developed by the Institute of Medicine (IOM) and the Picker Institute. Both were based on the work of Gerteis et al., financed by a joint program between the Commonwealth Fund and the Picker Institute called the Picker/Commonwealth Patient-Centred Care Program (Gerteis et al., 1993). Their work described seven dimensions of the patient experience, drawn from studies that included discussion groups composed of patients and hospital staff. These dimensions are:

1. Respect for patients’ values, preferences and needs
2. Coordination and integration of care
3. Information, communication and education
4. Physical comfort
5. Emotional support
6. Involvement of family and friends
7. Continuity and transition of care

The IOM uses the same dimensions as Gerteis et al., except that dimensions 6 and 7 are combined. Picker also uses these dimensions, but has added an eighth: access to care. The United Kingdom’s National Health Service (NHS) published a patient experience framework in 2012. It included nine measurable dimensions, drawn from the IOM and Picker Institute models; the ninth dimension is “general appreciation of the facility”. This framework is used in all areas of healthcare, both acute and long-term, and applies to all conditions (Soubeiga et al., 2013).

## 3.2 TYPES OF QUESTIONNAIRE MEASUREMENTS

### 3.2.1 Composite scores

Generally, the dimensions of patient experience cannot be studied using a single item. Surveys therefore include multiple items that cover the same theoretical concept, meaning that composite scores are needed to summarize the information. The easiest way to calculate a composite score is to add all patient responses to questions about a single dimension. Another common method used with Picker-type questionnaires is to transpose answers from items related to one dimension into positive or negative categories, then calculate the percentage of people who gave positive or negative answers to those items. This is known as a problem/positive score (Dubé-Linteau, 2014).

The suggested structure of questionnaires used to analyze the dimensions of patient experience must be confirmed by the data. This construct validity is normally evaluated by checking whether the scores for each dimension are correlated with other measurements of the same phenomenon (external construct validity) and by performing exploratory or confirmatory factor analyses (internal construct validity). This type of measurement is often used as an indicator to compare the performance of different care providers or healthcare systems, or to compare the impact of different programs or practices on the quality of healthcare services, as perceived by patients.

These scores are useful for managers, political decision-makers, analysts and planners, as they are summary measurements of quality of care that can be applied to a set of processes (Aucoin, 2006).

### 3.2.2 Single items

The analysis of single items, or individual questions in a questionnaire, is particularly useful for managers and clinicians who wish to use the data to improve the delivery of services. This type of measurement is often used for continuous quality improvement, as it can identify particular aspects of care that received poorer evaluations and therefore need improvement.

The answer format for evaluation items may cause biases that need to be accounted for when analyzing and interpreting results. It is known that patients tend to give positive responses to this type of question. Therefore, some authors have found it useful to combine all answers except the most positive during their analysis in order to avoid compromising precision and sensitivity (Haggerty, 2010; Rocheleau, 2013).

## 3.3 METHODOLOGICAL AND ANALYTICAL CONSIDERATIONS IN QUESTIONNAIRE DEVELOPMENT

### 3.3.1 Patient characteristics

Patient experience, as measured by surveys, is associated with a complex mix of organizational and human factors. It has been shown to be influenced by age, sex, ethnicity, level of education, overall health, expectations, social status, time since episode of care and previous experience (Kalucy et al., 2009; Russel, 2013). According to Salisbury et al. (2010), this raises the question: does the measurement of patient experience reflect differences in the quality of practice or variations between the patients themselves? Some authors (Damman et al., 2011) believe that data needs to be adjusted for patient characteristics, in order to isolate the information that reflects professional and organizational practices so that patient experience can be effectively compared between care providers or healthcare systems. This type of adjustment is sometimes used for hospital surveys, but its relevance for surveys of primary healthcare providers continues to be the subject of debate (Salisbury et al., 2010). That said, to test the validity of this type of adjustment within a survey, it is important to include questions about social, demographic and health characteristics (number of chronic diseases, disabilities, perception of health status, etc.).

Patient-reported outcome measures (PROMs) are standardized, validated instruments that measure patients' perceptions of their health status, their functional abilities and their health-related quality of life (Coulter et al., 2009; CIHI, 2015a). They can be used to measure patients' general health in patient experience surveys.

### 3.3.2 Type of health conditions

Many patient experience studies focus on people with specific condition, such as diabetes, asthma, heart disease, mental illness and cancer. The implied hypothesis behind these surveys is that patient experience depends, at least in part, on the nature of services required by a particular health problem. Nevertheless, some authors believe that patient experience surveys should not address specific patient groups or even specific areas of the healthcare system (Robert et al., 2011). They believe that a generic patient experience model, such as the IOM or Picker model, can be applied to all health conditions and treatments.

### 3.3.3 Timing and reference period

In many patient experience surveys, the patient is surveyed either immediately after an appointment (in “real time”) or some time later. For example, the American Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) questionnaire is administered within 42 days of the patient’s release from hospital (Lavela and Gallan, 2014). Meanwhile, population-wide surveys often require patients to take all of the services they received within the previous year into consideration. This can lead to significant recall biases (Manary et al., 2013). Studies on the effects of delays between a medical appointment and the time the patient fills out a questionnaire have produced contradictory results (Lavela and Gallan, 2014). That said, most did find that patients are more likely to evaluate their experience less favorably if they fill out the questionnaire a long time after an appointment.

Some authors argue that patient feedback collected shortly after a care experience is more useful to organizations in terms of service improvement (Brown et al., 2009). However, other authors claim that surveys conducted in real time generally focus on “snapshots” within a care experience and do not reflect the larger context in which they occur (Robert et al., 2011; Russell, 2013). In the same vein, a longer time frame can be useful when documenting certain aspects of patient-centered care, such as the relational continuity with the physician or the experience of patients with chronic diseases; the latter, by definition, require care over several years (Hudon et al., 2011).

### 3.3.4 Geographic scope

Patient experience surveys can be conducted on the level of healthcare facilities or units of care. They may also have a wider geographic scope, covering a regional, provincial, national or even international area. According to some authors, conducting surveys in different healthcare settings can increase the use of the data by staff, motivate them to improve results and encourage better patient-staff dialogue (Robert et al., 2011). Generally, this type of initiative focuses mainly on a patient’s experience within a particular unit of care, rather than their progression through the continuum of care and services. That said, some standardized surveys are starting to focus on patients’ journeys through the healthcare system, rather than their experiences in a specific sector (Russell, 2013). These surveys thus measure the coordination and continuity of services in various healthcare settings, which, according to some, represent dimensions that must be measured in part through the patient’s point of view (Burgers et al., 2010; Reid et al., 2002).

### 3.3.5 Multi-level data structure

Patient experience surveys tend to use a hierarchical or multi-level structure. For example, patients can be “clustered” by doctor, then the doctors themselves can be “clustered” by healthcare facility (hospital, clinic, etc.). According to some authors (Salisbury et al., 2010), analyses of this type of data should be based on multi-level modelling approaches, which account for this “natural clustering” of data and explore sources of variation at each level. Multi-level modelling requires data about patient experience as well as data about the “clusters” involved, such as physicians or healthcare facilities.

# 4

## PATIENT EXPERIENCE IN QUEBEC

### 4.1 SURVEYS IN HEALTHCARE FACILITIES

In Quebec, patient experience is increasingly being measured in healthcare facilities, particularly since it became a requirement by Accreditation Canada<sup>1</sup> (Ebnoether and Soubeiga, 2013). Since 2013, organizations that offer acute care and that are seeking accreditation are required to conduct a patient experience survey and provide the results, using a tool and an approach that meet the program's requirements. In 2018, all organizations that provide services directly to users will be required to evaluate user experience. To do so, these organizations may use a questionnaire revised or created by Accreditation Canada, their own questionnaire or one created by another organization. Survey tools must be able to document the following four dimensions of patient experience: respecting client values, expressed needs and preferences; sharing information, communication and education; coordinating and integrating services across boundaries; and enhancing quality of life in the care environment and in activities of daily living (Accreditation Canada, 2016).

Accreditation Canada has developed tools to evaluate user experience for the acute care and mental health care sectors (Accreditation Canada, 2016). The survey on acute care is largely based on the standardized American Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) questionnaire, which is a worldwide reference for measuring patient experience. It contains 34 questions, 22 of which are from HCAHPS. The additional questions cover the transition and continuity of care, whether the patient's cultural values (and those of their family) were taken into account, the involvement of the patient and their family in healthcare decisions, the level of emotional support provided to patients and their families and, finally, the patient's demographics. Because this Accreditation Canada survey is a "general-purpose" standardized tool, it can be used to document the care experience throughout a facility.

Depending on the organization's mission, services and types of patients, it may also be necessary to complement these general surveys with more specific ones in order to more easily identify avenues for improvement (Soubeiga et al., 2013). To do so, most healthcare facilities rely on customized or "in-house" tools to perform evaluations that reflect their internal projects and improvement priorities (Ebnoether and Soubeiga, 2013). For example, the CHU Sainte-Justine's Patient Experience Office has become an expert in designing tools for client programs. It has worked with patients, stakeholders and the local complaints commission to develop in-house questionnaires for the emergency, mental health, and neonatology departments, medical imaging, pediatric endoscopy service, outpatient clinics, day surgery and inpatient care units, (Lavallée et al., 2013). Unlike standardized questionnaires, in-house tools are not always tested for validity and reliability, and do not allow for comparisons between facilities (Bélangier et al., 2013).

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1 Since December 19, 2005, all public and private establishments, no matter what their mission or number of facilities, must, without exception, receive accreditation from a recognized organization such as the Conseil québécois d'agrément (CQA) or Accreditation Canada (AC) (MSSS, 2012).

## 4.2 PROVINCIAL SURVEYS

In 2005, the MSSS implemented the *Plan ministériel d'enquêtes sociales et de santé* to, among other things, optimize its ability to respond to the need for information about the health of the population and the organization and performance of services. It is in this context that the ISQ and the MSSS developed a survey program to document the care experience, evaluate the quality of services and measure met and unmet healthcare needs. Additionally, two surveys that included patient experience questions were conducted in 2010–2011: the *Enquête québécoise sur l'expérience de soins* (EQES) and the *Enquête québécoise sur les limitations d'activités, les maladies chroniques et le vieillissement* (EQLAV). The ISQ conducted further studies on behalf of the MSSS as part of program evaluations, notably the *Enquête québécoise sur la qualité des services de lutte contre le cancer* (2008 and 2013 cycles), the *Enquête québécoise sur le dépistage prénatal de la trisomie 21* (2015) and the *Enquête sur l'expérience de soins des usagers des groupes de médecine de famille* (GMF) (2017). Aside from the 2013 cancer survey, which included a standardized tool (the Ambulatory Oncology Patient Satisfaction Survey, or AOPSS), the questionnaires used for these surveys were custom-built to respond to specific needs for information. Note that these were conducted on an ad hoc basis rather than recurrently.

Furthermore, it is worth noting that Quebec participated in the Commonwealth Fund's International Health Policy Survey. Between 2008 and 2016, the Commissaire à la santé et au bien-être financed oversampling of Quebec's population. This survey, intended to document adults' perception of the healthcare system and their experience with healthcare and related services, was conducted in 11 countries, including Canada, Australia, New Zealand, the United Kingdom and the United States. Data from Quebec's population was compared to those obtained from other countries (CSBE, 2017). Note that the response rates<sup>2</sup> for the Commonwealth Fund surveys, particularly in Canada, were not high enough to infer results for target populations.

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2 The response rate for the 2016 survey was 25.1% in Quebec and 21.4% in all of Canada.



# 5

## PATIENT EXPERIENCE ELSEWHERE IN CANADA

In Canada, the tools and methods used to collect data on patient experience vary not only from one province or territory to the next, but from one establishment to the next as well. There is currently no mandatory reporting system for standardized data about patient experience, and comparisons between provinces are not yet possible. That said, many patient experience surveys have been conducted in healthcare establishments, particularly those that are seeking accreditation from Accreditation Canada. The results of these studies are for the exclusive use of the care provider and are not compiled on a regional, provincial or national level.

With that in mind, the Canadian Institute for Health Information (CIHI) worked with provinces, territories and national experts to create a standardized measurement tool, the Canadian Patient Experiences Survey — Inpatient Care (CPES-IC). This questionnaire aims to evaluate quality of care from the point of view of acute care inpatients across the country. It is on Accreditation Canada's list of approved tools. Alberta and Manitoba were the first to use this tool, starting in 2014. The CIHI also implemented the first national patient experience reporting system (the Canadian Patient Experiences Reporting System, or CPERS), with which provinces, territories and hospitals are encouraged to submit their survey data. The CPERS has been accepting data since 2015 (CIHI, 2015b).

As for primary healthcare services, the CIHI has also established a series of national surveys on the subject—including one patient survey—in collaboration with researchers and experts. The patient survey asks patients about their healthcare experience, including prevention, interactions with every member of the care team, interpersonal dynamics, coordination of care and self-management. The series of surveys was designed to help primary healthcare providers produce useful, relevant and comparable information.

Other Canadian surveys also include questions regarding the use of healthcare services and the patient experience. This is the case for the *Canadian Community Health Survey* (CCHS), which has been conducted by Statistics Canada since 1991. This biennial survey produces representative data on a provincial and regional scale. Statistics Canada also conducted a Health Services Access Survey in 2001; since 2003, this survey has been part of the CCHS. The organization has also conducted national surveys that contain questions about certain aspects of the patient experience for people who use specific healthcare services. These surveys include the *Maternity Experiences Survey* (2006), the *Canadian Survey of Experiences with Primary Health Care* (2008), the *Residential Care Facilities Survey* (1996–2011) and the *Long-term Care Facilities Survey* (2012–2014).

Additionally, the Canadian Partnership Against Cancer (CPAC) compiled the results of the National Research Corporation (NRC) and Picker Canada's Ambulatory Oncology Patient Satisfaction Survey (AOPSS) in its 2012 and 2014 performance reports on the cancer care system. In 2017, the CPAC also conducted the pan-Canadian *Cancer Transition Survey* in partnership with all provinces including the MSSS and ISQ.

Finally, it is worth noting that Ontario was the first province to develop a patient experience measurement strategy (Health Quality Ontario, 2016). Their strategy aims to improve coordination of the numerous attempts to measure patient experience, allowing the province to establish mechanisms to produce reliable data that can be used to improve Ontarians' healthcare experience. In particular, the strategy recommends improving the standards and best practices for measuring patient experience in healthcare facilities, building a common set of questions about continuity of care, creating a standardized questionnaire to measure the experience of patients who regularly visit multiple healthcare facilities and establishing a coordinated provincial system for reporting patient experience data.

# 6

## PATIENT EXPERIENCE IN OTHER COUNTRIES

### 6.1 NATIONAL STRATEGIES

National strategies to document patient experience within healthcare systems are relatively new. The United Kingdom and United States are world leaders in the integration of these system-wide strategies. Other countries, such as Norway and the Netherlands, also use standardized patient experience surveys in various healthcare sectors.

#### 6.1.1 United Kingdom

The United Kingdom's processes to improve the quality of healthcare services rely heavily on data from patient experience surveys. Large national surveys are conducted annually through the National Health Service's (NHS) Patient Survey Programme. This program is integrated at all levels of the healthcare system and supervised by the Care Quality Commission (CQC), England's healthcare regulator, which works closely with the Picker Institute Europe. All regional NHS organizations responsible for planning, organizing and providing healthcare services are involved in the NHS Patient Survey Programme and are required to conduct surveys, the results of which are compiled by the CQC to produce national estimates. The first of these surveys (the GP Patient Survey) was conducted in 1998 and concerned general practitioners. Other national surveys of emergency, obstetric, mental health, primary care and acute inpatient care have also been conducted. All surveys are based on the Picker Institute's principles and are standardized, meaning they use standard questions and methods. They allow the CQC to compare different healthcare facilities, monitor changes in patient experience and detect differences between patient groups (INSERM, 2011). The survey results are released publicly, allowing patients to make informed decisions about their healthcare providers. The results are also used by care providers to improve the quality of services; they are also used by the Quality and Outcomes Framework (QOF), which is an incentive program for general practitioners (CQC, 2016). In addition to conducting nation-wide surveys, the NHS provides its regional organizations with standardized questionnaires that allow them to perform local surveys that are comparable to the national program. These organizations are also invited to consult ongoing national surveys to avoid unnecessary duplication of effort (NHS, website consulted March 3, 2017).

### 6.1.2 United States

In the United States, patient experience surveys are mainly conducted through the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program. This program was established in 1995 by the Agency for Healthcare Research and Quality (AHRQ), which is the government agency responsible for healthcare quality and research in the United States. CAHPS surveys were initially designed to evaluate patients' experiences as they related to their insurance plan. However, the program has since released other surveys that cover a wide range of services, including those received at the hospital, in primary healthcare clinics, retirement homes, oncology, surgery, etc. The Hospital CAHPS (HCAHPS) is the first standardized national survey designed to produce comparable data about the experience of hospitalized patients across the country. The vast majority of hospitals participate in this survey, and the data is released publicly in order to encourage hospitals to improve the quality of their services and support the public in choosing a hospital. Since 2007, the survey results have also been used in performance incentive programs for hospitals (Kalucy et al., 2009).

### 6.1.3 The Netherlands

In 2006, the Dutch Ministry of Health implemented the Consumer Quality Index (CQI), which is a standardized survey questionnaire that measures patient experience. This tool was developed by combining the US CAHPS questionnaire and the Dutch QUOTE (Quality of Care through the Patient's Eyes) tool. The CQI covers topics such as caregiver skills, information given to the patient and the accessibility of facilities. Since the CQI was developed, many similar surveys have been developed for specific services (cataract surgery, hip and knee arthroplasty, general medicine, physiotherapy, oncology, emergency medicine, hospitalizations, etc.) and health conditions (diabetes, breast cancer, disabilities, etc.) (Delnoij et al., 2010; INSERM, 2011).

### 6.1.4 Norway

Norway has also been conducting national patient experience surveys since 1995, using the standardized Patient Experiences Questionnaire (PEQ) and its derivatives: the Outpatient Experiences Questionnaire (OPEQ), Parent Experiences of Pediatric Care (PEPC) and the Rehabilitation Patient Experiences Questionnaire (Re-PEQ). The PEQ consists of 35 questions, which cover topics such as communication, caregiver skills, pain management, the quality of medical equipment and overall assessment of care. It was initially developed to analyze the experience of hospitalized patients; its validity and reliability have both been studied (INSERM, 2011; Pettersen et al., 2004).

## 6.2 INTERNATIONAL COMPARISONS

Some organizations have conducted international patient experience surveys to compare results between countries. In particular, the Picker Institute Europe, the Commonwealth Fund, the World Health Organization (WHO) and the Organization for Economic Co-operation and Development (OECD) have all conducted surveys. While these surveys have been able to determine many differences between countries, it is unclear whether those variations are due to cultural differences or actual variations in quality (INSERM, 2011).

### 6.2.1 Picker Institute Europe

The Picker Institute Europe was founded in 1986. It is the result of the Patient-Centred Care Program, which was created by the James Picker Foundation and the Commonwealth Fund of New York. Its mission is to develop standardized survey questionnaires and conduct national surveys in Europe. The Picker Patient Experience (PPE) survey includes 40 questions about the seven dimensions of patient experience identified in the work of Gerteis et al. (see section 3.1 Dimensions of the Patient Experience). It also includes a question about overall assessment of care and a question about whether the patient would recommend the hospital they visited to their family or friends.

A shortened version of the questionnaire, the PPE-15, is also available. It includes 15 questions and its validity and reliability have been demonstrated. The PPE-15 is one of the questionnaires used by the NHS to perform national surveys in England. It was also used in surveys of hospitalized patients in five different countries (the United Kingdom, Germany, Sweden, Switzerland and the United States) between 1998 and 2000 (Jenkinson et al., 2002b). Because the selected samples were not representative of the population of each country, some authors have expressed reservations about the ability to use data from the surveys for international comparisons (Coulter and Cleary, 2001).

### 6.2.2 Commonwealth Fund

The Commonwealth Fund is a private US organization that conducts an annual International Health Policy Survey in 11 countries, alternating between patients and physicians. The 2016 questionnaire marked the 19th edition of the survey. The International Health Policy Survey is used to evaluate and compare the healthcare systems of different countries. The “patient experience” component covers primary and outpatient care, as well as perceptions of the healthcare system. Since 2008, Quebec has helped to design and finance the Commonwealth Fund survey through the Commissaire à la santé et au bien-être (CSBE, 2017). Originally, this survey was developed with the help of experts who worked on the PPE survey. It therefore closely aligns with its dimensions (Kalucy et al., 2009). The International Health Policy Survey mainly consists of general questions that do not specify particular features of the provision of care, allowing for comparisons between countries.

### 6.2.3 World Health Organization

In 2000 and 2001, the WHO conducted the WHO *Multi-Country Survey Study* in 61 countries. One of its sections analyzed healthcare systems' reactivity, or their ability to respond to the population's needs and expectations (WHO, 2001). Two versions of the survey questionnaire were released: a short version with 78 questions, and a longer version with 142 questions. The survey included eight aspects of patient experience: autonomy, choice, communication, confidentiality, dignity, prompt attention, environment quality and social support (Bleich et al., 2009).

### 6.2.4 Organisation for Economic Co-operation and Development

In 2010, the OECD developed a patient experience survey with the help of international experts and the participation of the WHO, the Commonwealth Fund and the Dutch Centre for Consumer Experiences in Health Care. The survey primarily analyzed access to care, communication (time taken, exchange of information and answers to questions) and patient involvement in decision-making. It was tested through the Commonwealth Fund's 2010 *Health Policy Survey* in 11 countries, such as Australia, Canada, France, Germany, England and the United States (Schoen et al., 2010).



# CONCLUSION

## *Using patient experience to evaluate quality*

Patient experience is increasingly being recognized as a pillar of healthcare quality. This is supported by a number of studies that have found that a positive care experience is correlated with greater adherence to the treatment plan, better clinical outcomes, improved patient safety and less use of services (Anhang Price et al., 2014; Doyle et al., 2013). Other works have shown that using data from patient experience surveys can measurably improve patient experience by increasing support for clinicians and encouraging a patient-centered organizational culture (Anhang Price et al., 2014; Gleeson et al., 2016; Reeves and Seccombe, 2008). These findings suggest that patient experience surveys can be useful for evaluating the quality of service as long as the measurement tools are validated, they obtained acceptable response rate and adjustments are made to allow inference for the target population (Ahmed et al., 2014; Anhang Price et al., 2014).

## *Patient experience in Quebec*

To date, most regional and provincial patient experience surveys in Quebec have not used standardized questionnaires. Instead, they have used customized questionnaires to respond to specific information needs. Furthermore, surveys in Quebec are not necessarily conducted on a recurring basis. As for local surveys, some healthcare facilities that offer short-term hospital care use the standardized Accreditation Canada survey. However, these results are not compiled in a way that allows estimates to be produced for the entire province. Finally, many healthcare facilities use in-house surveys to document patient experience in other areas. Plenty of work needs to be done to develop valid, reliable tools for measuring patient experience, coordinate their use and identify ways to use the resulting data to improve the quality of healthcare and related services.

## *Best practices for measuring patient experiences*

This study brought to light some best practices for measuring patient experience. Quebec would do well to take note of these practices. Some countries have established national strategies to coordinate all efforts to measure patient experience, allowing them to produce compelling data on which decisions can be based. For example, in the United Kingdom, all healthcare establishments are required to conduct patient experience surveys in each of their sectors. The questionnaires and data collection methodologies (sampling and collection mode) are standardized. Furthermore, the results of local surveys are compiled to produce national estimates. This method makes it possible to compare healthcare facilities, track progress over time, avoid unnecessary duplication of effort and reduce variations in data quality from one facility to the next.

Local teams' key involvement in the implementation of surveys in healthcare settings can encourage the use of the data by staff, motivating them to improve their patients' experience. The questionnaires used in these surveys should be delivered as quickly as possible after a care episode in order to reduce memory biases (Brown et al., 2009) and allow faster feedback on results. Furthermore, these surveys should be repeated over time so that they can contribute to the continuous quality improvement processes and performance analyses of various sectors.

Countries that have developed national patient experience measurement strategies have implemented survey programs with standardized questionnaires for specific areas of activity (primary care, emergency and inpatient services, maternity, neonatology, pediatric care, psychiatry, surgery, outpatient clinics, medical imaging, long-term care, home care, end-of-life care, etc.). These questionnaires allow facilities that offer similar services to be compared. That said, their use does not prevent the addition of extra sections that are specific to certain patient programs or units of care.

In order to cover all patients, a survey program should also be able to document the experience of patients who regularly visit multiple care settings. For that reason, Ontario's patient experience measurement strategy suggests developing a common set of questions on the continuity of services from one care setting to another that can be integrated into existing tools. It also recommends developing a standardized provincial questionnaire for patients who have complex healthcare needs and regularly visit multiple care settings.

Generally, survey questionnaires should be designed to document the dimensions of patient experience and allow composite scores to be calculated. Performing a dimensional analysis in addition to an item analysis may prove particularly useful for evaluating the performance of care providers and studying the impact of specific clinical practices or organizational processes on patient experience. The questionnaire design process should include a rigorous quality evaluation from a qualitative (judgment of experts and patients, pretesting) and quantitative (reliability, validity and sensitivity) point of view.

Furthermore, as with any other phenomenon, simply measuring patient experience is not enough to ensure an improvement in quality. The resulting information must be incorporated into a system that is specifically designed to support its use (Kalucy et al., 2009). Studies performed in several countries have shown that managers and clinicians often struggle to link patient experience data to concrete transformations that could lead to an improved care experience (Baker, 2014).

Conducting a survey involves many steps that follow a standard procedure: defining objectives, selecting a survey frame, selecting samples, designing a questionnaire and collecting, processing and analyzing data. With patient experience surveys, it is important that the questionnaires thoroughly document respondents' concerns and all aspects that patients may describe, in order to provide an accurate portrait of the quality of healthcare services. Otherwise, a survey could skew the truth by displaying positive results and passing over negative experiences related to aspects that were not measured (Rocheleau, 2013). This type of survey therefore requires the cooperation not only of survey specialists, stakeholders, clinical experts and researchers, but also patients. Many Quebec initiatives, including the surveys conducted by the ISQ on behalf of the MSSS in recent years, have made it possible to build solid expertise adapted to the unique features of Quebec's health and social services system. This expertise could be used to develop a provincial patient experience measurement strategy that is thorough, effective, coordinated and useful for improving the quality of healthcare and related services.



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