Swiss Learning
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Giving patients a voice about cancer care: should Switzerland do more to collect patients' experiences of cancer care?

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List of acronyms and abbreviations

AHRQ	Agency for Healthcare Research and Quality
ANQ	National Association for Quality Improvement in Hospitals and Clinics
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CH-IQI	Swiss Inpatient Quality Indicators
CWF	Commonwealth Fund
FOPH	Federal Office for Public Health
NCPES	National Cancer Patient Experience Survey
NHS	National Health Service (Great Britain and Northern Ireland)
OECD	Organisation for Economic Co-operation and Development
PaRIS	Patient-Reported Indicators Survey
PREM	Patient-Reported Experience Measure
PROM	Patient-Reported Outcome Measure
UK	United Kingdom
US	United States

Policy Briefs and Stakeholder Dialogues of the Swiss Learning Health System

The Swiss Learning Health System (SLHS) was established as a nationwide project in 2017, involving academic partners across Switzerland. One of its overarching objectives is to bridge research, policy, and practice by providing an infrastructure that supports learning cycles. Learning cycles enable the continuous integration of evidence into policy and practice by:

- continuously identifying issues relevant to the health system,
- systemizing relevant evidence,
- presenting potential courses of action, and
- revising and reshaping responses.

Key features of learning cycles in the SLHS include the development of policy/evidence briefs that serve as a basis for stakeholder dialogues. Issues that are identified to be further pursued are monitored for potential implementation and eventually evaluated to inform new learning cycles and to support continuous learning within the system.

The **policy brief** describes the issue at stake by explaining the relevant contextual factors. It recommends a number of solutions to the issue (evidence-informed solutions when available), and for each possible solution/recommendation, it explains relevant aspects and potential barriers and facilitators to their implementation.

During a **stakeholder dialogue**, a group of stakeholders discusses the issue, recommendations, and barriers and facilitators presented in the policy brief, and works collaboratively towards a common understanding of the issue and the best course of action.

Box 1: Brief presentation of the stakeholder dialogue held on the policy brief "Giving patients a voice about cancer care: should Switzerland do more to collect patients' experiences of cancer care?"

In the course of this policy brief, various actors (stakeholders) from the French- and German-speaking parts of Switzerland were invited to participate in a virtual stakeholder dialogue (due to the COVID-19 sanitary crisis) held over Zoom on November 6, 2020. Stakeholders were either directly or indirectly involved in cancer care and/or quality assessment, with an interest in the collection and use of patients' experiences of care.

Eleven stakeholders representing patient associations, professional associations, educational institutions, quality associations, and hospitals, took part in the dialogue. Besides discussions in the plenum, participants were divided into two groups to facilitate in-depth discussions (each lasting about 20 to 30 minutes), discussing the two recommendations made in this policy brief and the facilitators and barriers to the implementation of the second recommendation. Results of the discussions are briefly indicated in boxes in the relevant sections of this policy brief.

Both the policy brief and the summary of stakeholder dialogue on "Giving patients a voice about cancer care: should Switzerland do more to collect patients' experiences of cancer care?" are available on the SLHS website: https://www.slhs.ch/en/learning-cycles.

Definitions of key concepts

Patient-centered care	Patient-centered care is defined as care delivered in a way that responds to patients' physical, emotional, social and cultural needs, where interactions with health professionals are compassionate and empowering, and where patients' values and preferences are taken into account (1, 2).
Patient-reported experience measures (PREMs)	PREMs are used to evaluate the quality of patient care according to the patients, measuring patients' experiences of the delivery of care, such as whether they understood the information provided, whether they received enough emotional support, and whether care was well coordinated between primary care doctor and specialist in their opinion (3, 4). PREMs usually focus on the eight dimensions of patient-centered care: respect for patients' values, preferences and needs; information, communication and education; physical comfort; emotional support; involvement of family and friends; coordination of care; continuity and transition between healthcare settings; and access to care (5).
Patient-reported outcome measures (PROMs)	PROMs are used to evaluate the impact of care on patients' health and well-being according to the patients, measuring patients' views on their health condition, such as symptoms (e.g. level of pain), functioning (e.g. level of mobility) and well-being (e.g. level of anxiety) (6, 7). PROMs can be used to evaluate the effectiveness of treatments in clinical trials or to evaluate patient progress in clinical care, for example.

Key Messages

Context

One of the three main objectives of a healthcare system is to improve the care and experience of care of people going through the system, by providing high-quality care responding to people’s needs (i.e. patient-centered care). This is important because it translates into more positive experiences of care, which in turn can translate into treatments working better and better health.

To evaluate patient-centeredness of care, data need to be collected directly from the patients, asking them about their experiences, such as:

- Whether their values and preferences were respected;
- Whether they received information about their treatment they could easily understand;
- Whether they received enough emotional support; and
- Whether their family and friends were involved in their care as much as wanted.

Cancer care

Cancer is one of the five most frequent non-communicable diseases in Switzerland. As four people out of ten are expected to have cancer during their life, most individuals will encounter cancer, either as a patient or as a caregiver to a family member or friend. Patient-centered care is especially important in cancer care, as cancer has a particular emotional, social and financial burden on patients and their families, in addition to the health burden.

In Switzerland, there is information on the safety and effectiveness of cancer care with the publication of survival rates for example. However, reports from patients themselves about cancer care are missing and needed to complete the assessment of the quality of cancer care and its patient-centeredness.

Recommendations

Recommendation 1: Develop a position statement on the importance and value of patients’ experiences of cancer care.
Recommendation 2: Collect patients’ experiences of cancer care at the national level, by implementing a national survey or by integrating data collection in cantonal cancer registries.

Implementation considerations for recommendation 2

The major facilitators for successful implementation and use of patients’ reports on experiences of care include:

- A patient-centered healthcare culture supported by management and politics;
- Awareness of the value of patients’ reports;
- Involvement of patients in all steps; and
- Sufficient financial resources.

Availability and cost of human resources to collect patients’ reports are also an important consideration, as well as privacy and ethical concerns and an adequate IT infrastructure.

Executive Summary

Background and context

One of the three main objectives of a healthcare system is to improve the care and experience of care of people going through the system, by providing high-quality care responding to people's needs, also called "patient-centered care". This means that:

- Care should be delivered in a way that responds to patients' physical, emotional, social and cultural needs;
- Interactions with health professionals should be compassionate and empowering; and
- Patients' values and preferences should be taken into account.

This is important because studies have found that patient-centered care translates into more positive experiences, which in turn can translate into treatments working better and better health.

To evaluate patient-centeredness of care, data need to be collected directly from the patients, asking them about their experiences. Among the different methods to collect patients' views, patient surveys are the most common, producing what we call patient-reported experiences of care measures (PREMs). PREMs differ from patient-reported outcome measures (PROMs) (see "Definitions of key concepts" on page 5).

Patients' reports on experiences of care have been increasingly collected worldwide, serving different purposes according to the organizational level:

- At the patient level, real-time (or rapid) patient feedback can help healthcare professionals address concerns and improve perceptions and processes of care immediately.
- At the institutional level, patients' reports on experiences of care can be used to:
  - Develop local quality improvement initiatives;
  - Compare providers or institutions (benchmarking); and
  - Inform the general public to support patient choice for providers or institutions.
- At the national level, patients' reports on experiences of care can be used for:
  - Performance measurement (overall quality of healthcare system);
  - Reimbursement decisions and payment models; and
  - Regulation and accreditation purposes.

Cancer care

Cancer is among the five most frequent non-communicable diseases in Switzerland. As four people out of ten are expected to have cancer during their life, most individuals will encounter cancer, either as a patient or as a caregiver to a family member or friend. While navigating through the healthcare system, people hope to receive high-quality care, responding to their needs. This is especially important in cancer care, as cancer has a particular emotional, social and financial burden on patients in addition to the health burden.

In Switzerland, there is information on elements of safety and effectiveness of cancer care with the publication of survival rates for example. However, reports from patients themselves are missing and needed to complete the assessment of the quality of cancer care and it patient-centeredness. This information is key to drive quality improvement initiatives at local, regional or national levels and achieve patient-centered cancer care.

Recommendations

Recommendation 1: Develop a position statement on the importance and value of patients' experiences of cancer care

Position statements are used to publically present an opinion of an organization, association or group of people about an issue. They can also be used to propose recommendations or guidance on a specific aspect of care. The development of a position statement on the importance and value of patients' experiences of cancer care is recommended, to provide guidance for future initiatives on patients' experiences of cancer care, but possibly also for other chronic conditions.

Recommendation 2: Collect patients' experiences of cancer care at the national level

Adopting a systematic approach to collecting, analyzing and reporting on patients' experiences of care is recommended. It will allow to gather the data necessary to evaluate patient-centeredness of cancer care and to inform quality improvement policy and practice. Two possible strategies for data collection were identified. The first strategy is to collect data from a sample of patients using postal or online questionnaires, at the country level through a national program. The second strategy is to integrate the collection of patients' experiences of care in clinical registries, although this has so far mainly be done for outcomes of care reported by patients (PROMs) rather than experiences of care reported by patients (PREMs).

Option 1: Develop and implement a national program collecting patients' experiences of cancer care

This option proposes the development and implementation of a national cancer-specific program collecting patient's experiences of cancer care, with two options for the instrument (survey):

- Using the existing Swiss cancer-specific experiences of care survey, which has been implemented in French-speaking Switzerland in 2018, and is being scaled up to German-speaking Switzerland in 2021 (i.e. SCAPE survey); or
- Using the international generic survey collecting experiences of care developed by the OECD for patients with chronic conditions (i.e. Patient-Reported Indicators Survey (PaRIS) survey).

National programs collecting experiences of cancer care have been implemented in several countries, such as the National Cancer Patient Experience Survey in England and the CAHPS® Cancer Care Survey in the United States.

Option 2: Integrate the collection of patients' experiences of care in the cantonal cancer registries

This option proposes that the collection of experiences of care is integrated in the cantonal cancer registries. This new data would complement the clinical data currently being collected in the registries. The strict regulations and privacy protection in Switzerland would need to be carefully reviewed before the collection of patient-reported data could be integrated in the cancer registries.

The collection of PREMs through registries is an option that has been chosen in a few countries. For instance, Sweden has over a 100 national quality registries, around 40% of which collect patients' reports on experiences of care. A consortium in Australia is piloting the integration of patient-reported data, including experiences of care, in their Upper Gastrointestinal Cancer Registry.

Implementation considerations for recommendation 2

Many facilitators and barriers are reported in the literature for the implementation and use of patients' reports on experiences of care. A patient-centered healthcare culture supported by management and politics, awareness of the value of patients' reports, involvement of patients in all steps, and sufficient financial resources appear to be the major facilitators for successful implementation and use of patients' reports on experiences of care. Availability and cost of human resources to collect patients' reports are also an important consideration, as well as privacy and ethical concerns and an adequate IT infrastructure.

Implementing a wide-scale, coordinated, and useful measurement of patients' experiences at the national level is particularly challenging in Switzerland because of its federalism (26 healthcare systems), its complex public and private financing system, and the three main national languages.

Box 2: Brief summary of the stakeholder dialogue on the recommendations and implementation considerations

Recommendation 1: Develop a position statement on the importance and value of patients' experiences of cancer care

Stakeholders agreed on this recommendation, to push forward the importance of patients' reports on experiences of care in the political agenda, to clarify the concept of patients' experiences of care, and to shed light on stakeholders' interests. They suggested that some points should be clarified: the intended audience; the content and format (e.g. utility and necessity of patients' reports); the objective of the statement (call for action, not only providing information); and the leadership (lack of consensus on whom should take the lead).

Recommendation 2: Collect patients' experiences of cancer care at the national level

It was noted during the dialogue that the choice of instrument depends on the potential aims of data collection. While the Swiss cancer-specific survey could be more impactful to influence clinical care through improvement initiatives, the international survey could allow international comparisons of overall care. Both instruments could be used in parallel, or combined, by developing indicators in the Swiss survey complementing those from the international survey.

Regarding the integration of PREMs in cancer registries, there was disagreement between the stakeholders around the relative importance and benefits of integrating PREMs versus PROMs. While some argued that PROMs would make more sense and would add more benefit, others argued that both were useful and fulfilling different objectives. Stakeholders discussed several areas of uncertainty, such as difficulties in merging datasets, high workload for collecting data, issues of pseudo-anonymization, legal obligations and data protection.

Implementation considerations for recommendation 2

The stakeholders identified the following as the most important facilitators to the implementation of a national measure of cancer care experiences: having simple, disease-specific and meaningful questions, using a short questionnaire tailored to patients' literacy level, involving patients in the process, having electronic health solutions available, and having a clear objective of using results to implement change. On the other hand, the major barriers selected by the stakeholders were: concerns over confidentiality and security, financial barriers, difficulties in adopting a common standard and metric due to federalism, and legal issues.

Background and Context

This policy brief focuses on patients' experiences of cancer care and ways to collect these experiences to generate information to measure the performance of cancer care and drive quality improvement initiatives in oncology practice.

In this section, we present the general framework of this topic, the Swiss quality of care framework, followed by the definition of patients' experiences of care, the purpose and methods of their measurement, and the current situation of their measurement in Switzerland.

Patient-centered health system

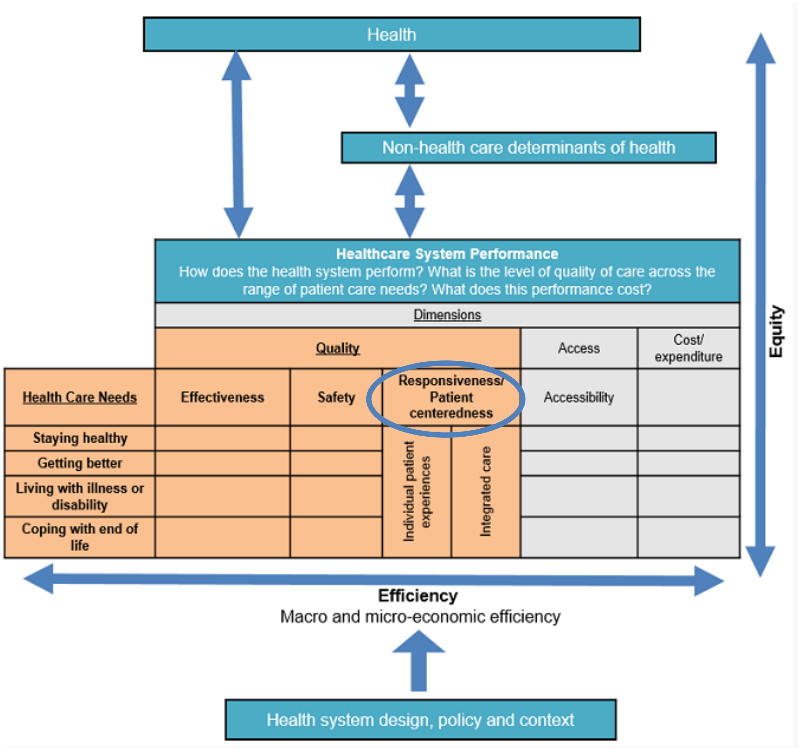
The health system has three main objectives according to the triple aim framework (8) and the World Health Organization' health system performance framework (9):

1. Improve people's well-being and their ability to play an active role in society (**better health**),
2. Improve the care and experience of care of people going through the healthcare system, i.e. responsiveness (**better care**), and
3. Reduce the per capita spending (**better value**).

In this brief, we focus on the "better care" objective of the health system, which aims to improve the quality of care and experiences of care, also reflected in the fifth objective of the new Swiss Health 2030 Health Policy Strategy of the Federal Council (10).

According to a framework developed by the Organisation for Economic Co-operation and Development (OECD), the quality of care provided within the health system is defined and measured through six core dimensions: effectiveness, safety, responsiveness / patient-centeredness, accessibility, efficiency and equity (11, 12) (see Figure 1).

Figure 1: OECD Framework for health system performance measurement



Among the dimensions we find patient-centeredness, defined as care delivered in a way that responds to patients' physical, emotional, social and cultural needs, where interactions with health professionals are compassionate and empowering, and where patients' values and preferences are taken into account (1, 2). To evaluate patient-centeredness of a health system, we need to collect data from patients on their experiences of care.

Quality of care framework in Switzerland

In Switzerland, the Confederation has set the target of ensuring that medical service delivery is safe, effective, efficient, patient-centered, timely and equitable, as defined by the OECD framework. In 2019, the section on strengthening quality and cost-effectiveness of the federal law on health insurance was partially revised and will come into effect in 2021. In this revision, the Federal Council has set up a Federal Commission for Quality (Commission for Quality Development), which is responsible for the implementation and achievement of the objectives of the quality system. Various players are responsible for quality assurance and promotion: the Confederation, the cantons, the care providers and the insurers. While the Confederation states the requirements for the approval of care providers, and in particular issues uniform planning criteria for hospitals and other establishments based on quality and cost-effectiveness, the cantons are responsible for evaluating the quality and cost-effectiveness of the hospitals in the course of their care planning.

Patient associations and organizations

Regarding patients' rights and participation, patient organizations and associations in Switzerland are not as well developed and organized as neighbor countries. This is especially the case for "general" patient and consumer organizations. Specific associations (e.g., cancer leagues) may have more resources, but globally, the actual participation is relatively limited.

Current quality indicators

Most efforts in Switzerland have focused on the collection of quality indicators pertaining to the effectiveness and safety dimensions in acute care hospitals. Indeed, the Federal Office for Public Health (FOPH) publishes annually quality indicators for acute care hospitals (CH-IQI), such as number of cases (e.g. number of patients treated for colorectal cancer) and mortality rates (e.g. mortality rates for patients with breast cancer who had had breast resection surgery).

The National Association for Quality Improvement in Hospitals and Clinics (ANQ) publishes satisfaction indicators for acute care hospitals and psychiatric and rehabilitation clinics, based on a 6-item questionnaire. Quality indicators are currently also being developed for the home nursing and home help organizations (SPITEX) and nursing homes. Another priority for the FOPH is to collect data and publish quality indicators for medical practices (outpatient medical care).

Definition of patients' reports on their health and experiences of care

Patients can report on their health – whether the treatment reduced their pain, for example, or if it helped them live more independently – but also on their experience of being treated – whether the treatment was properly explained, for example, or if they felt involved in decisions about their care.

The umbrella term "patient-reported measures" refers to both types of reports, that come directly from the patient without interpretation by a physician or anyone else (13) and are usually collected with standardized surveys. While patient-reported outcome measures (PROMs) assess the health result of care received, such as patients' rating of their symptoms and their quality of life, patient-reported experience measures (PREMs) assess patients' experiences with the delivery of care, such as communication with nurses and doctors and discharge coordination (see Box 3) (6, 14, 15).

Box 3: Definition of PROMs and PREMs

PROM: a measure of patients' perception of their health, symptoms, functioning, well-being and quality of life, to evaluate the impact of care on health and well-being according to patients. ***Generic PROMs*** are not specific to a particular disease or condition and are intended to	**PREM**: a measure of patients' perception of their experience of care focusing on the delivery of care, to evaluate the quality and patient-centeredness of care according to patients.

make comparisons between and within interventions, and across different diseases and sectors of care. Generic PROMs often focus on the person's health state, on the 'health-related quality of life (HRQoL)' or 'Quality of Life (QoL)' in general, but they can also focus on specific dimensions, such as physical functioning. ***Condition-specific PROMs*** measure health outcomes that are specific to a particular disease (e.g. diabetes), a set of conditions (e.g. cancer), a domain (e.g. pain), or an intervention (e.g. knee arthroplasty), for instance. Condition-specific PROMs are more sensitive to small, yet clinically significant, changes in specific patient populations than generic PROMs, but they do not allow comparisons across diseases or populations.	**PREMs** encompass the range of interactions that patients have with the health system relating to their: • **Satisfaction** (e.g. with information given by nurses and doctors); • **Subjective experiences** (e.g. control of pain); • **Objective experiences** (e.g. waiting time before appointment); and • **Observations** of healthcare providers' behavior (e.g. whether or not a patient was given discharge information).

Conceptual frameworks of patients' experiences of care

Various conceptual frameworks with dimensions of patient experiences have been developed (see Appendix I) to facilitate and standardize their measurement (16). They view patient experience as an indicator of quality of care, along with the other indicators such as clinical effectiveness, safety, equity and efficiency as shown in Figure 1, and have been used to implement performance monitoring systems in many countries, such as England with their NHS Patient Survey program.
Most frameworks incorporate the eight dimensions of patient-centered care (11):

1. Respect for patients' values, preferences and needs;
2. Information, communication and education;
3. Coordination of care;
4. Physical comfort;
5. Emotional support;
6. Involvement of family and friends;
7. continuity and transition between health care settings; and
8. Access to care.

Purpose of collecting patients' reports on experiences of care

Patients' experiences of care (PREMs) have been increasingly collected worldwide, in clinical, economic and health services research, as well as in general assessments of health services and health system performance. They have different purposes and uses at the three organizational levels (see Table 1 and Appendix II).

Table 1: Purpose and use of PREMs according to the organizational level

Level	Purpose of PREMs	Use of PREMs
Micro	In clinical practice: support patient-centered care	• Identify issues as they arise (e.g. coordination issues, social issues) • Improve communication (patient-provider, provider-provider)

	In research / clinical trials: evaluate effect of treatment / intervention on patients' experiences of care	• Compare treatments or interventions
Meso	Inform healthcare quality improvement initiatives	• Identify areas for quality improvement • Public reporting for informed provider choice • Comparing or benchmarking providers and organizations (e.g. practice variation, audits)
Macro	Monitor patient-centeredness of health system	Information for public health activities: • Prioritize patient groups, populations, etc. • Design public health initiatives • Monitor effects of policy initiatives • Generate new evidence
	Re-imbursement decisions Value-based reimbursement	• Assess relative effectiveness and/or cost-effectiveness of treatments/interventions • Assess patient issues associated with treatment
	Contracting services and payment models	• Pay-for-performance • Contracting decisions • Medical board certification • Value-based reimbursement

At the individual (micro) patient level, real-time (or rapid) patient feedback on their experiences of care, collected at the point-of-care through touch screens for instance, is not widespread but could potentially provide clinicians and other health care professionals with the opportunity to address concerns and improve perceptions and processes of care immediately (17, 18).

At the institutional (meso) level, aggregated PREMs are used to drive healthcare quality improvement initiatives. They are also used to assess and compare the performance of providers (benchmarking), to identify which quality issues remain insufficiently addressed in current practice, and to inform the general public to enable informed patient choice (public reporting) (4).

At the national (macro) level, PREMs are used for monitoring patient-centeredness of the health system, for reimbursement decisions, and for macro-level healthcare performance measurement. Many countries added PREMs to population health surveys to generate information at the population level that can help to prioritize, design and assess public health activities such as disease prevention, health promotion, measurement of health disparities and inequalities, and evaluation of interventions. The value of these measures at the population level increases when these data are linked to other surveillance data, such as clinical registries, billing and hospital discharge data.

PREMs can also be used at the macro level for contracting health care services, for payment models, such as pay for performance models (see Box 4) or value-based models, and for regulation and accreditation purposes, such as maintenance of medical board certification.

Box 4: The Pay for Performance (P4P) program in Belgium

Belgium introduced the "Pay for Performance" (P4P) program in 2018, which conditions the payment of care based on the quality of care, assessed by several structure, process and/or result indicators. The result indicator “patient experiences” account for 15 points out of a total of 100. In 2020, hospitals received 7.5 points if ≥80% patients are globally satisfied with their care and 7.5 points if ≥80% patients would recommend the hospital. For more information: https://www.health.belgium.be/fr/programme-pay-performance-p4p-pour-les-hopitaux-generaux-0

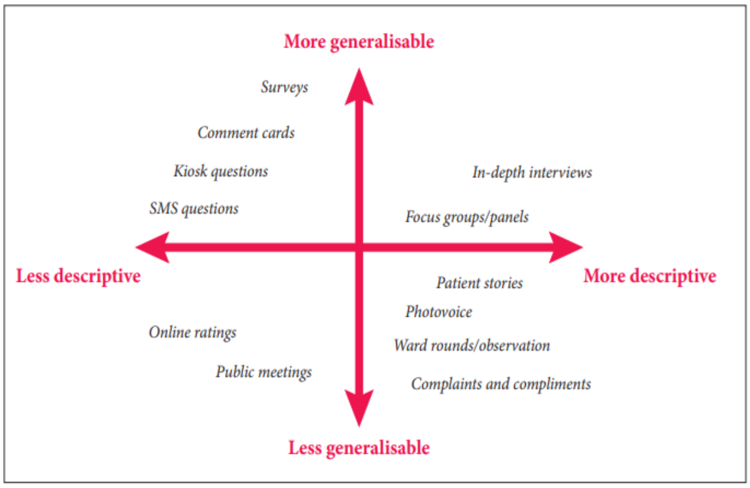
Methods of collecting patients' experiences of care

As seen above, measuring patients' experiences of care can serve different purposes at different levels; for each purpose, the typical data collection method, sample, instrument, frequency, and use may differ (see Appendix II for an overview according to the purpose).

We usually distinguish between quantitative and qualitative methods. Surveys using structured self-completed questionnaires, given or sent to patients at a single or multiple points in time, are the most common form of quantitative measures of patients' experience. Samples can be drawn based on the type of intervention received, type of illness / condition (e.g. multimorbidity), the geographic location, or type of care received (e.g. ambulatory or inpatient care). Data collection can be paper-based (e.g. paper surveys), electronic (e.g. touch screen at point-of-care), by phone (or text message) or face-to-face interviews. These surveys are designed to produce numerical data that can be analyzed statistically and used to describe and compare results from the sample population as a whole and specific subgroups. The emphasis is on examining patterns and trends from a large sample, providing large coverage and ability to compare, but often lacking depth because questions and response options are predetermined (4). An important and recurring issue with surveys is also that some patient groups are consistently underrepresented in the data: patients who do not speak the national language and with low (health) literacy.

Patients' experiences can also be collected through qualitative reports, such as patient stories, complaints and compliments, focus groups or interviews. The focus of these qualitative methods is on obtaining an in-depth understanding of people's experiences and the way they explain or interpret these. Qualitative data are usually reported using words, not numbers, and it is harder to use the evidence to make comparisons or generalizations (4).

Figure 2: Examples of methods used to measure patient experiences of healthcare services



Source: Da Silva 2013

Figure 2 presents different methods according to their descriptive and generalizable characteristics. Each method has its advantages and limitations (see Appendix III).

Reporting of patients' experiences of care

The reporting of patients' experiences of care is an important aspect that needs careful consideration when measuring experiences. Reporting can include instant alerts to healthcare professionals when using real-time feedback but also public reporting on website to inform consumers and inclusion of these measures in published quality reports.

The public reporting of patients' experiences of care is of special interest, as it is seen as an important mechanism for "holding providers to account for the quality of care ('voice') and for empowering patients to act as discerning consumers ('choice')" (19). However, a Cochrane review updated in 2018 concluded that the public release of performance data, including patient experiences of care data, leads to little or no difference in healthcare choices (made by either consumers or providers), or provider performance (20).

The communication of patients' experiences of care results to institutions for use to implement improvement initiatives is also an important area that needs to be addressed when implementing patient-reported experiences of care measurement programs. According to specialists in the UK, it was “discouraging to note that after more than ten years of gathering patient experience data in England, only a minority of hospital providers had taken effective action leading to demonstrable change” (19).

Review of the scientific literature

We searched the scientific literature for systematic reviews on the validity and reliability of instruments measuring patient experiences of care, their effectiveness to improve the quality of care and their impact on patient outcomes.

Validity and reliability of patient experience instruments and risk adjustment

Patient experience measures need to be valid and reliable to be used for quality assessment of healthcare services, in conjunction with other aspects, such as the clinical relevance of the instrument and the domains of patient-reported experience that the instrument covers (21). In a recent systematic review of 88 instruments measuring patient experiences in healthcare in general (21), the authors reported that seven of the 10 validity and reliability criteria were not undertaken in more than half of the instruments. Also, information on responsiveness, an instrument's ability to detect changes overtime, was lacking for over 90% of them.
The way patients evaluate their experiences can be influenced by their socio-demographic characteristics (age, sex, income level), expectations, preferences, personality, previous experiences, as well as their health status, for instance (22). Consequently, careful evaluation of risk adjustment strategies is required when patient experiences are compared across populations and providers.

Effectiveness of using reports of patients’ experiences to improve quality of care

We identified two systematic reviews exploring how patient experiences of care were collected, communicated and used to inform quality improvement (23, 24). Both reviews concluded there was limited evidence on the effectiveness of interventions informed by patient feedback for improvement of quality of care, as few have been tested in well-designed trials. In addition, one of these reviews showed that there was no single best way to collect or use patient experience data for quality improvement (23). It also showed that barriers associated with data collection or use included lack of time, resources and expertise in data analysis and quality improvement.

Link between patient experiences of care and patient outcomes

We identified three reviews that investigated the association between patient experiences of care and patient outcomes. The first review concluded that patient experiences were positively associated with clinical effectiveness and patient safety, and supported the case for the inclusion of patient experiences as one of the central pillars of quality in healthcare (25). The second review concluded that better patient care experiences were associated with higher levels of adherence to recommended prevention and treatment processes, better clinical outcomes, better patient safety within hospitals, and less healthcare utilization (26). In the third review looking at the link between patient experiences and cancer survival, patients’ satisfaction, psychosocial support, and satisfaction with quality of life were the most common aspects associated with survival. However, authors cautioned about the methodological complexity of determining the relationship between cancer patient experience and subsequent survival (27).

Collection of patients' experiences of care in Switzerland

At the patient level, we are not aware of any initiatives collecting patient experiences at point of care for immediate provider feedback.

At the institutional level, most private and public hospitals (regional, cantonal and university) conduct regular patient satisfaction surveys, among hospitalized (and ambulatory) patients using their own instruments for internal improvement purposes. The EQUAM foundation (www.equam.org) has developed quality indicators for doctors' practices, with the use of the EUROPEP questionnaire (23 questions) to measure patient experiences.

At the national level, the National Association for Quality Improvement in Hospitals and Clinics (ANQ) developed a short questionnaire collecting PREMs for inpatient care that is mandatory for all hospitals and clinics in Switzerland (see Box 5). There are also national cohort studies (e.g. Swiss Inflammatory Bowel Disease Cohort Study[1], Swiss Transplant Cohort Study[2]) and registries (e.g. Swiss Multiple Sclerosis Registry[3]) that collect PREMs.

Box 5: The National Association for Quality Improvement in Hospitals and Clinics (ANQ)

The ANQ is a non-profit association founded in 2009 regrouping hospitals, insurers and cantons, that coordinates and implements quality reviews in facilities providing inpatient acute care, rehabilitation and psychiatric care. Results are published on their website (www.anq.ch) and allow nationwide comparison between hospitals and clinics.

Their annual patient satisfaction survey collects **PREMs** with six questions relating to: quality of treatment, information and communication (i.e. opportunities to ask questions, ability to understand responses), explanations about medications, implication in decisions, length of hospitalization, and preparation of discharge.

Switzerland also participates in various international measures of patient experiences, such as the Commonwealth Fund (CWF) International Health Policy Survey and the OECD surveys.

The CWF's international program[4] conducts annual surveys of patients and clinicians in 11 high-income countries, including Switzerland. Themes covered by the survey are: accessibility (e.g. access and use of emergency departments, waiting times to see physicians; cost of care as barrier), continuity of care (e.g. gaps in care co-ordination), patient experience, perceptions of the health system, and health promotion and disease prevention.

The OECD, which has historically played a leading role in measuring health system performance, has been monitoring PREMs about ambulatory care in 19 countries, including Switzerland, since 2006. Results are published yearly in the Health at a Glance reports since 2013 (see Box 6 for the list of indicators). However, it recently recognized that data generated by health systems are too concentrated on health system inputs, activities and costs. There remained substantive gaps in what is known about the experience of patients and the outcomes of care, from the patient's point of view. In 2017, the OECD published recommendations to strengthen the international comparison of health system performance through patient-reported indicators and launched the Patient-Reported Indicators Survey (PaRIS) initiative[5].

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[1] http://www.ibdcohort.ch/

[2] https://www.stcs.ch/about/study-description

[3] https://www.multiplesklerose.ch/fr/le-registre-suisse-de-la-sep/

[4] https://www.commonwealthfund.org/series/international-health-policy-surveys

[5] http://www.oecd.org/health/paris

Box 6: List of OECD patient experience indicators

Consultation skipped due to costs
Medical tests, treatment or follow-up skipped due to costs
Prescribed medicines skipped due to costs
Waiting time of more than four weeks for getting an appointment with a specialist
Patients reporting having spent enough time with any doctor during the consultation
Patients reporting having spent enough time with their regular doctor during the consultation.
Patients reporting having received easy-to-understand explanations by their regular doctor
Patients reporting having had the opportunity to ask questions or raise concerns to any doctor
Patients reporting having had the opportunity to ask questions or raise concerns to their regular doctor
Patients reporting having been involved in decisions about care or treatment by any doctor

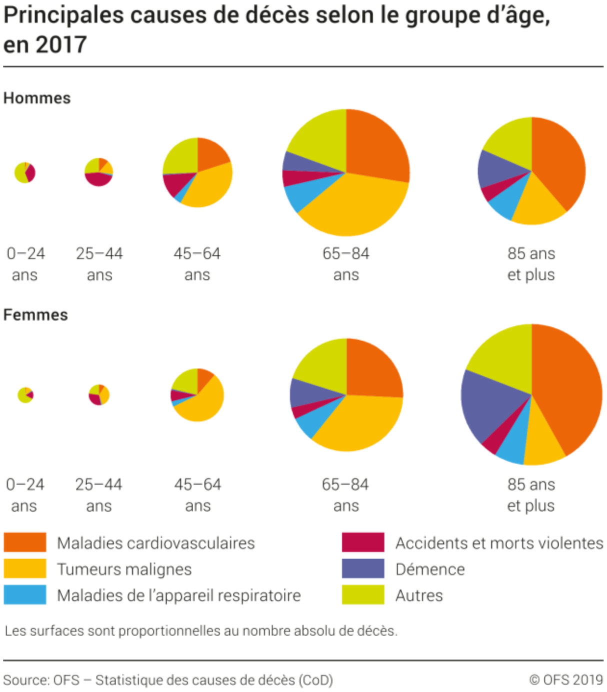
The Challenge

Cancer is among the five most frequent non-communicable diseases in Switzerland, with over 40’000 new cases diagnosed every year; it is also the first cause of premature mortality before the age of 70 (see Figure 3) (28).

As four people out of ten are expected to have cancer during their life, most individuals will encounter cancer, either as a patient or as a caregiver to a family member or friend, and navigate through the Swiss healthcare system.

At the institutional (meso) and national (macro) levels, collecting patients’ experiences of care is essential to evaluate the quality and safety of health services and, more specifically, to assess how well the health system is responding to patients’ needs (patient-centered care). This is especially important in cancer care, as cancer has a particular emotional, social and financial burden on patients in addition to the health burden.

Figure 3: Leading causes of death by age group, Switzerland



In Switzerland, we have information on elements of safety and effectiveness of cancer care with the publication of survival rates for instance. However, reports from patients themselves are missing and needed to complete the assessment of the quality of cancer care. Indeed, these reports are necessary to evaluate whether current cancer care responds to the patients’ needs.

Based on the literature presented in the previous section and experiences in other countries, this policy brief includes two recommendations to fill the knowledge gap:

Recommendation 1:	Develop a position statement on the importance and value of patients’ experiences of cancer care.
Recommendation 2:	Collect patients’ experiences of cancer care at the national level, by implementing a national survey or by integrating data collection in cantonal cancer registries.

Recommendation 1: Develop a position statement on the importance and value of patients' experiences of cancer care

Position statements are used to publically present an opinion of an organization, association or group of people about an issue. They can also be used to propose recommendations or guidance on a specific aspect of care. A position statement:

- Describes one side of an arguable viewpoint;
- Provides the background and rationale to support a particular viewpoint; and
- Makes the authors' stand on the viewpoint clear to the audience.

An example of a position statement on patients' reports on their health (PROMs) with a focus in oncology can be found in Appendix IV (29).
The development and publication of a position statement on the importance and value of patients' experiences of cancer care is recommended, to provide guidance for future initiatives on this topic. It could also promote similar developments for other chronic conditions in the future.

Box 7 Discussions on recommendation 1 during the dialogue

During the stakeholder dialogue (see p. 4), the stakeholders reached consensus and agreed on recommending the development of a position statement on the importance and value of patients' experiences of cancer care to:

- Push forward the importance of patients' experiences of care in the political agenda,
- Clarify the concept of patients' experiences (i.e. PREMs), and
- Shed light on stakeholders' interests.

They raised the following points that need to be clarified:

- The intended audience of the position statement;
- The content (e.g. utility and necessity of patients' experiences of care, role of patients) and format (i.e. keep it short and simple);
- The objective (call for action, not only providing information); and
- The leadership (lack of consensus on whom should take the lead: e.g. patient/consumer organizations vs professional organizations, Swiss Cancer League).

Recommendation 2: Collect patients' experiences on cancer care at the national level

Adopting a systematic approach to collecting, analyzing and reporting on patients' experiences of care is recommended. It will allow to gather the data necessary to evaluate patient-centeredness of cancer care and to inform quality improvement policy and practice. Three frequent strategies to collect patient-reported data at a regional or national level emerge from the literature and reports. The first strategy is to collect data using postal or online questionnaires, among a sample of patients. The second strategy is to integrate patient-reported data in clinical registries, although this has so far mainly be done for outcomes of care reported by patients (PROMs) rather than experiences of care reported by patients (PREMs). The third strategy is to collect online ratings and reviews, through social media or dedicated website. However, this strategy is very limited scientifically, as participation rate or other important factors cannot be estimated. In this brief, we will present two options, based on the first two strategies cited above.

Option 1: Develop and implement a national program collecting patients' experiences of cancer care

This option proposes to develop and implement a dedicated national cancer-specific measurement program collecting experiences of care, with two options for the instrument (survey): the Swiss cancer-specific survey or an international generic survey collecting outcomes and experiences of care from patients with chronic conditions (under development).

The Swiss cancer-specific survey

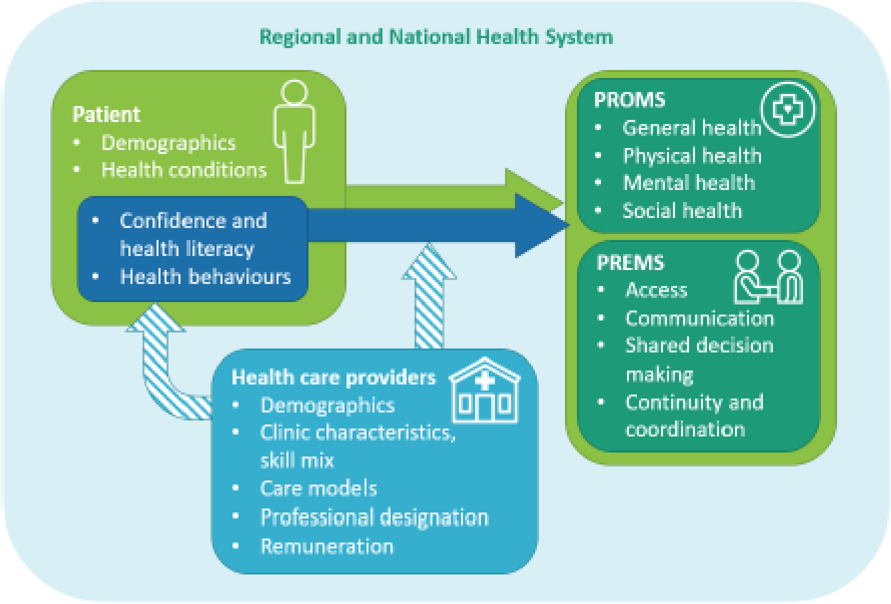
In 2018, the Swiss Cancer Patient Experience (SCAPE) study launched the first cross-sectional multicenter survey among patients diagnosed with the six most frequent cancers from four large cancer centers in French-speaking Switzerland (www.scape-enquete.ch). Data were collected with a self-administered questionnaire, including 94 questions on experiences of care as well as socio-demographic and clinical characteristics. The main study objective was to provide robust evidence on the perceived quality of cancer care. A follow-up study, SCAPE-2, has started in October 2020 and the survey will be carried out in 2021 among eight hospitals in French-speaking and German-speaking Switzerland.

The international Patient-Reported Indicators Survey (PaRIS) of the OECD

In 2017, the OECD published recommendations to strengthen the international comparison of health system performance through patient-reported indicators and launched the PaRIS initiative (30). It is divided into two work packages: the first aims to standardize the international monitoring of patient-reported indicators (including both PROMs and PREMs) in three areas of care: hip and knee replacements, breast cancer surgery and mental illness (31). The second package aims to develop new patient-reported indicators for patients with one or more chronic conditions who live in private homes and whose conditions are being managed in primary care or other ambulatory care settings. The development, field trial and implementation of the survey for patients with chronic conditions is expected to end in 2023, with the publication of the data.

Within the second package, the PREM section of the survey will cover important aspects of people-centered care which are common across health systems and conditions: accessibility, communication, shared decision-making, and continuity and coordination (31), as well as measures of health literacy and patient engagement and activation (see Figure 4). The PREM section of the survey could be implemented in patients affected by cancer.

Figure 4: PaRIS Survey Conceptual Framework



National measurement programs in other countries

A dedicated national measurement program on experiences of cancer care has been implemented in other countries, two examples of which are briefly presented below.

United Kingdom: the National Cancer Patient Experience Survey (NCPES)

The National Health Service (NHS) in England was the first health system to introduce the routine collection of patient-reported data at the system level. The routine collection of *PREMs*, through the NHS Patient Survey program managed by the Care Quality Commission, started in 2005 with the survey of adult inpatients from all NHS trusts across England. In 2010, it launched the National Cancer Patient Experience Survey (NCPES), which has been conducted annually since. It is managed by NHS England and NHS Improvement and run by Picker since 2019. It was designed to monitor national progress on cancer care, to drive local quality improvements, to assist commissioners and providers of cancer care and to inform the work of the various charities and stakeholder groups supporting cancer patients. The instrument includes 61 questions on experiences of care covering the eight dimensions of patient-centered care. Results are publicly available on the survey website: www.ncpes.co.uk.

United States of America: the CAHPS® Cancer Care Survey

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) is a program of the Agency for Healthcare Research and Quality (AHRQ). It was launched in 1995 in response to concerns about the lack of reliable information about the quality of health plans from the enrollees' perspective. Over time, the program expanded to address a range of health care services and settings to meet the various needs of health care consumers, purchasers, health plans, providers, and policymakers. The CAHPS® Cancer Care Survey was developed between 2009 and 2016. Its main purpose is to support the efforts of cancer centers, oncology practices, hospitals, and health systems to improve the patient-centeredness of cancer care, as well as to inform decisions made by providers, patients and their families, accrediting organizations, and payers. At first, a conceptual framework for understanding patient-centered cancer care was developed. Then, the survey development team created multiple survey questions to address different dimensions of cancer care. The final version has 27 core questions on getting timely care, communication, coordination, respect, support, continuity, involvement of family and friends, and overall ratings, and 7 supplemental questions on shared decision-making (32). All surveys are in the public domain and aggregated results are reported on their website: https://www.ahrq.gov/cahps/surveys-guidance/cancer.

Published recommendations for implementing a national program

Several organizations have published guidelines and principles for implementing a national PREMs programs. The OECD published seven key principles for establishing national systems of patient experience measurements in 2010 (see Appendix V) (33). The health department of the New South Wales government in Australia has also defined ten guiding principles within which patient-reported measures should operate (see Appendix VI) (34).

In brief, such guidelines recommend the following: the goals of measuring PREMs should be clear and explicit; the measures should be designed with input from patients, carers, clinicians, and decision makers; the measures should be valid, reliable and standardized, as well as culturally appropriate and patient-centered; the reporting method should be chosen with care; and the measurement systems should be consistent and sustainable.

Box 8 Discussions on recommendation 2 option 1 during the dialogue

It was noted during the dialogue that the choice of instrument depends on the potential aims of data collection:

- If it is to have an impact on clinical care, then the Swiss cancer-specific survey could be a better choice;
- If it is to evaluate overall care at the national level, then the international generic survey could be a better option as it would also allow international comparisons.

Combining both options was suggested, with the possibility of developing indicators in the Swiss survey complementing those measured in the international survey.

Option 2: Integrate the collection of patients' experiences of care in the cantonal cancer registries

This option proposes that the collection of a minimum dataset of patent reports on experiences of care is integrated in the cantonal cancer registries.

Cancer registries in Switzerland

The new federal law on the registration of oncological diseases (LeMO in French, KRG in German), introduced on January 1, 2020, requires doctors, laboratories, hospitals and health institutions to report data relating to diagnosed cancers to cantonal registries or to the childhood cancer registry. The law also obliges all cantons to finance and maintain these registries. The aim is that data recorded should be complete, exhaustive, and harmonized throughout Switzerland and internationally comparable in order to enable uniform evaluations throughout Switzerland. The Federal Office of Public Health (FOPH) will carry out annual cancer monitoring and publish a report every five years. The new law also gives patients the right to be informed and to object. In addition, they have the right to support and access their data.

The basic data collected for all cancers are clinical data on the type and stage of the disease and the first treatment. Additional data for three frequent cancers (breast, prostate and colorectal) will be collected to establish the influence of predispositions as well as pre-existing and concomitant diseases on the evolution of the disease, the time of remission, and the duration of survival. The law also anticipates that additional data concerning early detection measures may be reported to the tumor registry, such as fecal occult blood tests, colonoscopies, mammograms, prostate antigen tests or prostate palpations.

This new law is currently being implemented; regulations and privacy protection are very strict and would need to be carefully reviewed to integrated patient-reported data as well.

Collection of patient experiences through registries in other countries

The collection of patient experiences through registries is an option that has been chosen in a few countries, two examples of which are briefly presented below.

Sweden

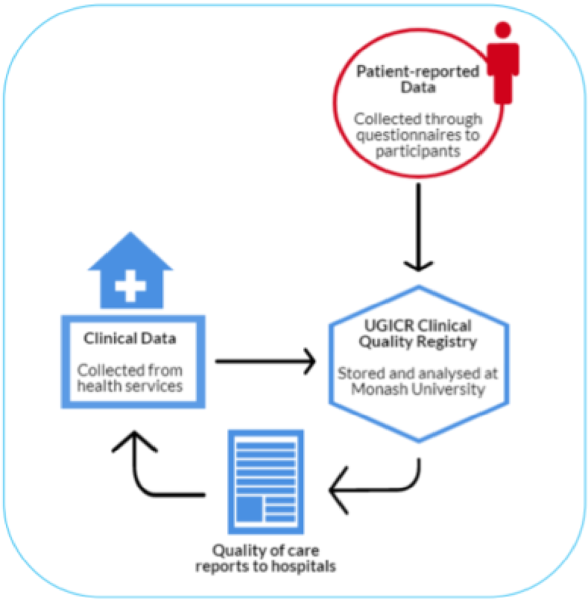
Sweden has set up over a 100 national quality registries, around 40% of which collect a patient experience measure (35). These government-administered quality registries collect information on individual patients' problems, interventions, and outcomes of interventions in a way that allows the medical and personal data to be compiled for all patients and analyzed at the unit level (36). Whereas the purpose is to develop and ensure the quality of care, these registries are also used for certain other purposes, such as clinical research and public quality reporting.

For example, the National Quality Registry for Breast Cancer, started in 2008, contains data on: diagnoses, intervention(s), PROMs or other patient-reported health effects, and follow-up data (including patient satisfaction) 12 months or later after the case is registered in the registry. Its aim is to monitor the continuum of care from diagnosis to any recurrence and death in an objective and standardized manner, to enable the identification of regional differences, to assess quality targets based on the Swedish Board of Health and Welfare's national guidelines for breast cancer, and to facilitate research and developments in breast cancer. For more information: https://www.cancercentrum.se/samverkan/cancerdiagnoser/brost/kvalitetsregister/ (in Swedish).

Australia

The Monash Partners Comprehensive Cancer Consortium (MPCCC) in Australia is currently piloting the collection of PROMs and PREMs data from pancreatic cancer patients at regular intervals over the course of their treatment, using an online PROMs and PREMs questionnaire that is sent to patients via text or email. The project team will integrate the patient-reported data within the Upper Gastrointestinal Cancer Registry. Data will also form part of each participating hospital's quality of care reports, to inform improvements in quality of care for future patient (see Figure 5).

Figure 5: MPCCC data collection framework



Recommendations for setting up a registry with patient-reported data

The 2020 updated AHRQ publication, "Registries for Evaluating Patient Outcomes: A User's Guide" is a reference handbook with practical information on the design, operation, and analysis of patient registries and inclusion of patient-reported outcomes; it could be adapted to patient-reported experiences of care[6].

Box 9: Discussions on recommendation 2 option 2 during the dialogue

Regarding the integration of PREMs in cancer registries, there was disagreement between the stakeholders around the relative importance and benefits of integrating PREMs versus PROMs. While some argued that PROMs would make more sense and would add more benefit, others argued that both were useful and fulfilling different objectives.

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[6] https://effectivehealthcare.ahrq.gov/products/registries-guide-4th-edition/users-guide

Stakeholders discussed and mentioned several areas of uncertainty around the integration of PREMs in the cancer registries: e.g. difficulties in merging datasets, high workload for gathering data, and issues of pseudo-anonymization, legal obligations and data protection.

Implementation considerations for recommendation 2

There are many barriers and facilitators reported in the literature for the implementation and use of patient's experiences of care at the patient (micro), institution (meso) and national (macro) levels. They are summarized in Table 2 according to the organizational level (23, 37-42).

Table 2: Barriers and facilitators for the implementation and use of PREMs

Barriers	**Facilitators**
Patient (micro) level	
Questionnaire related • Length and complexity of the questionnaire • Lack of availability of translated and culturally meaningful versions • Questions not relevant to patients' issues • Compliance issues in completing the questionnaire • Literacy issues	**Questionnaire related** • Parsimonious questionnaires • Disease-specific and meaningful questions • Simple questions and scales (e.g. scale with verbal descriptors) • Translations available • Involving patients in designing the questionnaire
Privacy concerns • Over confidentiality of answers • Over potential identification	
Technology (electronic questionnaire) • Comfort level with technology & the internet (if electronic) • Technical problems during completion • Concerns over confidentiality and security	**Technology (electronic questionnaire)** • IT support available
Patient health condition & abilities • Too ill to answer (response bias) • Disability (e.g. sight, hands)	
Provider and institutional (meso) level	
Data collection and use • Lack of understanding the interpretation of the aggregated results • Poor specificity of results • Poor perceived reliability and validity of the measure • Administrative burden • Response and selection bias	**Data collection and use** • High response rate (representativeness) • Repeated measures over time • Providing training on the use and interpretation of aggregated PREMs • Disseminating positive survey findings to boost morale
Organization and logistics • Not enough staff • For electronic surveys: lack of patient emails	**Organization** • Working culture supportive of improvement, change and patient views • Dedicated meeting time to present results • Patient-centered work culture

Barriers	Facilitators
• No integration of electronic results into electronic health records **Providers' beliefs & attitudes** • Fear of change • Feeling of being assessed and criticized according to aggregated results • Lack of understanding the added value of aggregated results • Fear of increased workload	• Leadership by senior member or having a coordinator in charge • Involving providers in the implementation process • Fully integrated electronic data
Communication • Long delay between PREMs measurement and reporting • Technical problems when communicating the results	**Communication** • Providing timely feedback • Providing results in an easily accessible format • Aggregated measure issues relevant to clinical management
Financial • Not enough financial resources to implement program • High cost of collecting PREMs by paper mailings • Lack of time and knowledge to ensure scientific validation of the questionnaires or financial means to outsources the scientific validation	**Financial** • Financial incentives
National health system (macro) level	
• Tension among stakeholders regarding the use of data for different purposes • Conflicting or competing priorities (nationally, regionally, within organizations) • Lack of national and conceptual framework including patient-reported experiences of care • Lack of risk- and case-mix-adjustment strategies • Lack of effective reporting strategies • Lack of interoperability between systems • Complexity of integrated data collection • Privacy legislation	• Adopting a common standard and metric • Acceptability of usefulness of measures • Including the results in the performance management system and financial targets • Central coordination • Gradual implementation • Support from e-health • Legal basis
Financial • Costs of developing a national program, providing training, implementing program, analyzing data, communicating data	

Among the many facilitators for the implementation and use of patients' experiences of care reported above, several facilitators appear to be more important than others according to a recent report from Belgium (38): a patient-centered healthcare culture supported by management and politics, awareness of the potential value of PREMs from the providers, involvement of patients in all steps, and sufficient resources appear to be the major facilitators for successful PREMs implementation. Availability and cost of human resources to collect PREMs data are also an important consideration for the implementation of PREMs, as well as consideration of privacy and ethical concerns. Moreover, an adequate IT infrastructure is needed to manage all the data, as well as the availability of people for the management and analysis of the data.

Implementing a wide-scale, coordinated, and useful measurement of patient-reported experiences of cancer care would be particularly challenging in Switzerland because of three additional country-specific factors: Swiss federalism with the 26 cantons and 26 slightly different healthcare systems, the fragmented, complex, and mixed-financed healthcare system, and the three main national languages.

Box 10 Selection of the most important facilitators and barriers during the stakeholder dialogue

Stakeholders identified the following as the most important facilitators to the implementation of a national measure of cancer care experiences:

- At the patient level: simple and short questionnaire, disease-specific and meaningful questions, developed with patients and taking into account different levels of health literacy
- At the national level: availability of electronic health solution, clear objective of using results to implement change

The most important barriers to the implementation of a national measure of cancer care experiences identified by the stakeholders were the following:

- At the patient level: concerns over confidentiality and security of personal information
- At the national level: financial barriers (major barrier), difficulties in adopting a common standard and metric due to federalist organization of the healthcare system, issues around the legal basis for data collection.

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Appendix I Dimensions of patient experiences

Through the patient's eyes & Crossing the quality chasm (11)	Picker Principles of patient centered care 1987 Link	NHS Patient experience Framework 2011 Link	International alliance patients' organisations 2006 Link	The Warwick patient experience framework 2014 (43)	New Zealand Health and Quality Commission Patient experience domains 2013 Link
Respect for patients' views, preferences and expressed needs	Respect for patients preferences	Respect for patient-centred values, preferences, and expressed needs	Respect	Lived experience	Physical and emotional needs: treating patients, consumers, carers and families with dignity and respect and providing the necessary physical and emotional support
Coordination and integration of care	Coordination and integration of care	Coordination and integration of care			Coordination: coordination, integration and transition of care between clinical, ancillary and support services across different provider settings
Information, communication and education	Information and education	Information, communication, and education	Information	Information Communication	Communication: communicating and sharing information with patients, consumers, carers and families
Physical comfort	Physical comfort	Physical comfort			
Emotional support and alleviation of fear and anxiety	Emotional support	Emotional support		Support	
Involvement of family and friends	Involvement of family and friends	Welcoming the involvement of family and friends			
Transition and continuity	Continuity and transition	Transition and continuity		Continuity of care and relationships	
	Access to care	Access to care	Access and support		
			Choice and empowerment Patient involvement in health policy	Patient as active participant Responsiveness of services— an individualized approach	Partnership: encouraging and supporting participation and collaboration in decision making by patients, consumers, carers and families

Appendix II Purpose and characteristics of PREMs

Purpose	Data collection method	Target population	Frequency	Use	Reporting
Micro level					
In clinical practice: support patient-centered care In research / clinical trials: evaluate effect of treatment / intervention on patients' experiences of care	Individual patient data (e.g. checklists before/after seeing the doctor) Paper or electronic	All patients from the target group	Pre and/or post intervention (e.g. elective surgery, clinical trial) Longitudinal (chronic care)	Identify issues as they arise (e.g. coordination issues, social issues) Improve communication (patient-provider, provider-provider) Compare treatments or interventions	Internal Scientific
Meso level					
Inform healthcare quality improvement initiatives	Paper or electronic surveys aggregated at the level of the provider or organization (for benchmarking and public reporting) or at the patient group level	All patients receiving a particular service or a sample	Cross-sectional Longitudinal	Identify areas for quality improvement Public reporting to allow informed provider choice Comparing or benchmarking providers and organizations (e.g. practice variation, audits)	Internal Scientific Public
Macro level					
Monitor patient-centeredness of health system	National patient surveys (by phone, face-to-face, paper or electronic)	Representative population sample Census	Cross-sectional Longitudinal	Information for public health activities: • Prioritize patient groups, populations, etc. • Design public health initiatives • Monitor effects of policy initiatives • Generate new evidence	Scientific Public
Re-imbursement decisions Value-based reimbursement	Paper or electronic surveys	Patients receiving treatment/intervention	Post intervention	Assess relative effectiveness and/or cost-effectiveness of treatments/interventions Assess patient issues associated with treatment	Internal
Contracting services and payment models	Paper or electronic surveys	All patients from target group or sample	Post intervention Cross-sectional Longitudinal	Pay-for-performance Contracting decisions Medical board certification Value-based reimbursement	Internal Public

(adapted from: Desomer 2018)

Appendix III Strengths and limitations of data collection methods

Data collection method	Strengths	Limitations
Quantitative		
Postal paper survey	• Can reach large numbers • Less intrusive than other methods • No interviewer bias • Can be long and detailed • Can collect demographic data • Possible to achieve high response rates if reminders are sent • Relatively cheap	• Not suitable for those with very low literacy • Not suitable for non-native speakers • Requires careful administration • Data entry (manual/scanned) takes time • Requires expertise in use of statistical package for analysis
Online survey	• User-friendly design – questions can be tailored and ‘skips’ avoided leading to better item completeness • Reminders are easy to send • Data entry is automatic allowing for rapid turnaround of results	• Requires list of email addresses or invitation to go to a website • Not suitable for people who do not have internet access • Questionnaire needs to be brief
Face-to-face survey	• Suitable for low literacy groups • Can include more detailed/complex questions • Can collect demographic data	• Training required for interviewers • Similar problems as for postal surveys re other languages, data entry and analysis • Time-consuming and expensive
Qualitative		
Focus groups	• Rich source of data on experiences and their impact on patients • Groups often ‘spark’ off each other to produce less predictable responses	• Moderators need training • Influences by dominant individuals • Transcribing and data analysis is time-consuming
Patient diaries	• Can be used to gather continuous feedback on patient journey • Allows for unstructured feedback	• Places a considerable burden on patients to record relevant information • Can produce voluminous data difficult to analyze • Not suitable for those with low literacy

Appendix IV Example of a position statement

Ahmed, S., et al. (2020). "A catalyst for transforming health systems and person-centred care: Canadian national position statement on patient-reported outcomes." Curr Oncol 27(2): 90-99.

Overarching patient-reported outcomes (PROs) Position Statements

- Dedicated resources (including human, financial, health systems) should be invested to integrate PROs into clinical care, given their demonstrated value and benefits.
- A Canadian national PROs body consisting of PROs experts is needed to guide expert direction in all areas of health care, policy, and research.
- This PROs body would provide direction to national and regional authorities (…).
- Responsibilities would include establishing Canadian PROs standards to guide global clinical trials and the appropriate selection of PROMs and interpretation of PROs data for action and decision-making.
- The application of PROs must incorporate specific tools and strategies as needed to address equity, diversity, and inclusion. The tools and strategies have to be meaningful, accessible, and useable by all patients, including patients who are affected by differences in ability, language, culture, gender, sex, sexual orientation, socioeconomic status, or place of residence. They have to address the unique needs of diverse and underrepresented groups including Indigenous, Inuit, and Métis individuals.

Appendix V Principles for establishing national systems of patient experience measurements (OECD)

Principle 1. Patient measurement should be patient-based

Patient experience survey instruments should be formulated with the input of patients themselves. This can be done through focus groups or interviews of representative patient groups. Doing so will ensure that issues included in the survey are relevant and important. It is also useful to assess the relative importance of the priority areas that have been identified. Items included in the survey should reflect “demand” side characteristics rather than need “need” side characteristics. Finally, for the measured results to be taken seriously it is important that the institution(s) in charge of the work have public credibility.

Principle 2. The goals of patient measurement should be clear

Patient measures can be used for a variety of goals. Some systems are set up for “external” reasons such as the provision of consumer information to increase patient choice, accountability towards the general public on performance or as information used by financiers in pay-for-performance schemes. Other initiatives have more “internal” goals such as quality improvement by the providers. Although specific measures can be used for various goals, it is important to be explicit about the goals before developing the measurements. For example, if the goal is quality improvement, the instrument should deal with the actionable aspects of the care delivery process. By doing so the results will be tailored in such a way so as to enable health care providers to learn lessons and improve. When the goal is to facilitate choice, the measures should be able to show meaningful differences between health care providers.

Principle 3. Patient measurement tools should undergo cognitive testing and the psychometric properties should be known

Like all indicators, patient measurement tools such as surveys should meet the basic scientific criteria of validity. Documentation should exist on the testing of the tools, including the results of cognitive testing (e.g. assuring correct and consistent interpretation of the questions) and the psychometric properties (e.g. assuring that the items used in the questionnaire actually measure the constructs they pertain to measure). Changes in questionnaires should be documented and when necessary re-tested.

Principle 4. The actual measurement and analyses of patient experiences should be standardized

The methodology of patient experience measurement does not only apply to the development of measurement tools but also to the actual measurement (e.g. via mail survey, telephone survey, structured interview), the analyses of data and the reporting. To ensure reliability, the data collection methods and analyses must be standardised and reproducible. Several countries working with systematic measurement of patient experiences have introduced accreditation procedures for the various agencies/vendors who conduct surveys.

Principle 5. The reporting method of findings of patient experiences measurement should be chosen with care

In presenting the results of patient experience measurement, there is always a tension between presenting a clear and easy-to-understand message and the methodological limitations of drawing certain conclusions. There is a good deal of literature is available on the reporting of patient experience information, and this body of knowledge should be taken into account when choosing a particular reporting format.

Principle 6. International comparability of measurement of patient experiences should be enhanced

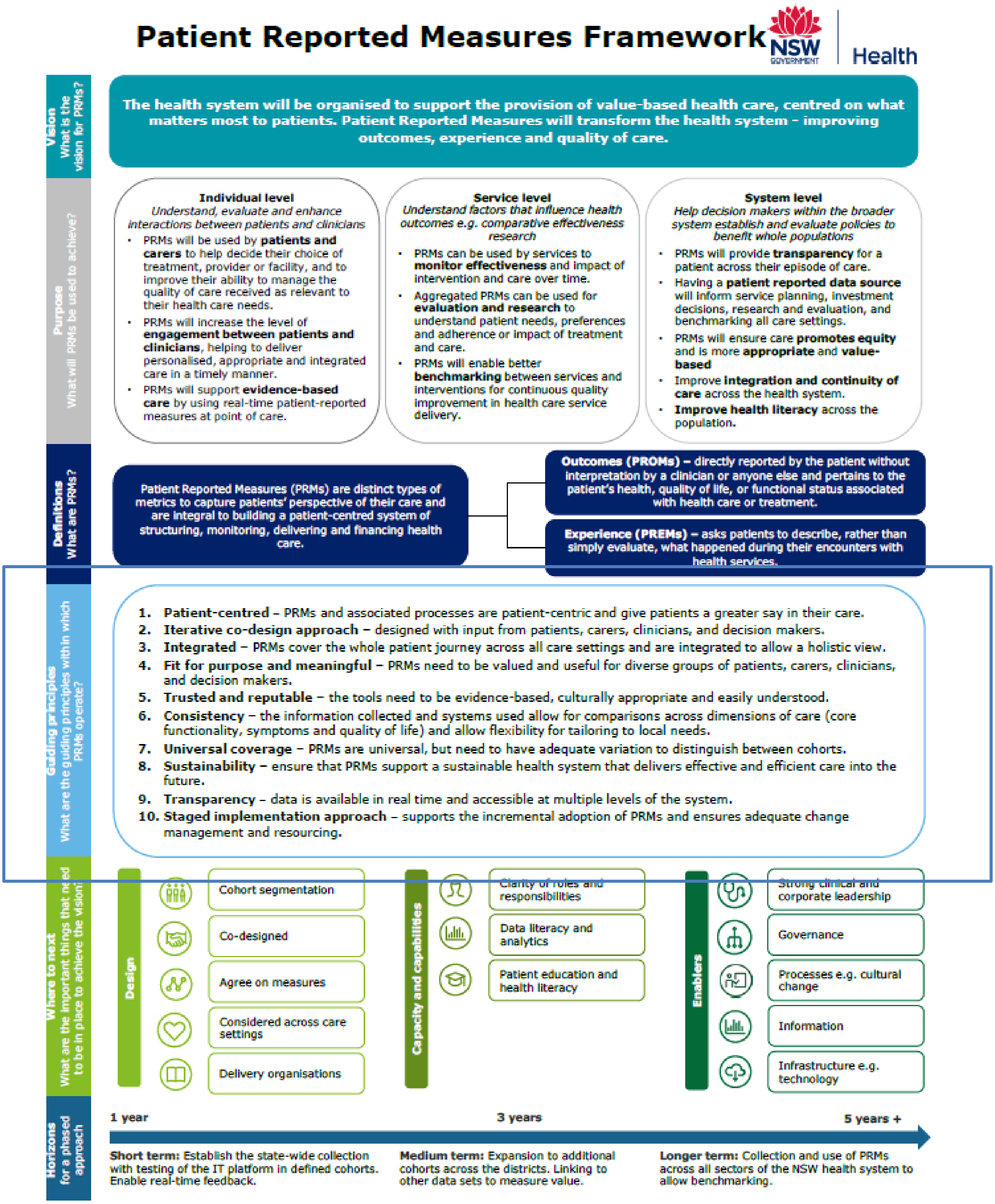
Methodological efforts by countries to develop and use systematic ways of measuring patient experience information are diverse and plentiful. Experience indicates that countries are keen to copy and adjust questions and questionnaires applied elsewhere. Given the OECDs work in this field and its position as a central broker of quality improvement initiatives, it is ideally placed to facilitate shared learning of national experiences in this regard. To this end, the HCQI Project will continue to act as a repository and disseminating centre for patient experience expertise.

Principle 7. National systems for the measurement of patient experiences should be sustainable

A national system for the measurement of patient experience should monitor trends longitudinally. This requires long term health system commitment and resourcing. Therefore, sustainability of the organizational and research and development infrastructure is an important condition for its success.

Reference: (33)

Appendix VI Guiding principles of the patient reported measures framework in Australia



Patient Reported Measures Framework

NSW GOVERNMENT | Health

Vision
What is the vision for PRMs?

The health system will be organised to support the provision of value-based health care, centred on what matters most to patients. Patient Reported Measures will transform the health system - improving outcomes, experience and quality of care.

Purpose
What will PRMs be used to achieve?

Individual level
Understand, evaluate and enhance interactions between patients and clinicians

- PRMs will be used by **patients and carers** to help decide their choice of treatment, provider or facility, and to improve their ability to manage the quality of care received as relevant to their health care needs.
- PRMs will increase the level of **engagement between patients and clinicians**, helping to deliver personalised, appropriate and integrated care in a timely manner.
- PRMs will support **evidence-based care** by using real-time patient-reported measures at point of care.

Service level
Understand factors that influence health outcomes e.g. comparative effectiveness research

- PRMs can be used by services to **monitor effectiveness** and impact of intervention and care over time.
- Aggregated PRMs can be used for **evaluation and research** to understand patient needs, preferences and adherence or impact of treatment and care.
- PRMs will enable better **benchmarking** between services and interventions for continuous quality improvement in health care service delivery.

System level
Help decision makers within the broader system establish and evaluate policies to benefit whole populations

- PRMs will provide **transparency** for a patient across their episode of care.
- Having a **patient reported data source** will inform service planning, investment decisions, research and evaluation, and benchmarking all care settings.
- PRMs will ensure care **promotes equity** and is more **appropriate** and **value-based**
- Improve **integration and continuity of care** across the health system.
- **Improve health literacy** across the population.

Definitions
What are PRMs?

Patient Reported Measures (PRMs) are distinct types of metrics to capture patients' perspective of their care and are integral to building a patient-centred system of structuring, monitoring, delivering and financing health care.

Outcomes (PROMs) – directly reported by the patient without interpretation by a clinician or anyone else and pertains to the patient's health, quality of life, or functional status associated with health care or treatment.

Experience (PREMs) – asks patients to describe, rather than simply evaluate, what happened during their encounters with health services.

Guiding principles
What are the guiding principles within which PRMs operate?

1. **Patient-centred** – PRMs and associated processes are patient-centric and give patients a greater say in their care.
2. **Iterative co-design approach** – designed with input from patients, carers, clinicians, and decision makers.
3. **Integrated** – PRMs cover the whole patient journey across all care settings and are integrated to allow a holistic view.
4. **Fit for purpose and meaningful** – PRMs need to be valued and useful for diverse groups of patients, carers, clinicians, and decision makers.
5. **Trusted and reputable** – the tools need to be evidence-based, culturally appropriate and easily understood.
6. **Consistency** – the information collected and systems used allow for comparisons across dimensions of care (core functionality, symptoms and quality of life) and allow flexibility for tailoring to local needs.
7. **Universal coverage** – PRMs are universal, but need to have adequate variation to distinguish between cohorts.
8. **Sustainability** – ensure that PRMs support a sustainable health system that delivers effective and efficient care into the future.
9. **Transparency** – data is available in real time and accessible at multiple levels of the system.
10. **Staged implementation approach** – supports the incremental adoption of PRMs and ensures adequate change management and resourcing.

Where to next
What are the important things that need to be in place to achieve the vision?

Design
- Cohort segmentation
- Co-designed
- Agree on measures
- Considered across care settings
- Delivery organisations

Capacity and capabilities
- Clarity of roles and responsibilities
- Data literacy and analytics
- Patient education and health literacy

Enablers
- Strong clinical and corporate leadership
- Governance
- Processes e.g. cultural change
- Information
- Infrastructure e.g. technology

Horizons
for a phased approach

1 year | 3 years | 5 years +

Short term: Establish the state-wide collection with testing of the IT platform in defined cohorts. Enable real-time feedback.

Medium term: Expansion to additional cohorts across the districts. Linking to other data sets to measure value.

Longer term: Collection and use of PRMs across all sectors of the NSW health system to allow benchmarking.

Swiss Learning
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