

Swiss Learning
Health System

Summary of the Stakeholder Dialogue on:

“Giving patients a voice about cancer care:
should Switzerland do more to collect
patients’ experiences of cancer care?”

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Keywords

PREMs, cancer care, patients' experiences, quality of care, patient-centeredness

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https://www.slhs.ch/images/learning-cycles/topics/2020-Arditi/PREMs_SD_final1.pdf

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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 discuss the issue, recommendations, and barriers and facilitators presented in the policy brief, and work collaboratively towards a common understanding of the issue and the best course of action.

Box 1 Brief presentation of the policy brief “Giving patients a voice about cancer care: should Switzerland do more to collect patients’ experiences of cancer care?”

The policy brief focuses on the lack of information on the quality of cancer care according to patients in Switzerland. So far, the quality of cancer care has been evaluated with measures pertaining to the safety and effectiveness of cancer care. Reports from patients’ themselves about cancer care are missing. Indeed, very little is known on whether cancer care is actually responding to patients’ needs, although this information is key to drive quality improvement initiatives at local, regional or national levels and achieve patient-centered cancer care.

The policy brief presents the background and context of patients’ experiences of care, including their definition, the purposes of their measurement, the methods of data collection, and a review of the scientific literature on the topic. Two recommendations are provided to overcome this lack of information, followed by a review of published facilitators and barriers to the implementation and use of patients’ reports on experiences of care.

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)	<p>PREMs are used to evaluate the quality of patient care according to the patients, measuring <u>patients' experiences of the delivery of care</u>, 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).</p> <p>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).</p>
Patient-reported outcome measures (PROMs)	<p>PROMs are used to evaluate the impact of care on patients' health and well-being according to the patients, measuring <u>patients' views on their health condition</u>, such as symptoms (e.g. level of pain), functioning (e.g. level of mobility) and well-being (e.g. level of anxiety) (6, 7).</p> <p>PROMs can be used to evaluate the effectiveness of treatments in clinical trials or to evaluate patient progress in clinical care, for example.</p>

Short description of the virtual stakeholder dialogue

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 to discuss the policy brief entitled “Giving patients a voice about cancer care: should Switzerland do more to collect patients’ experiences of cancer care?”. 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 that lasted about three hours. Participants were divided into two groups to facilitate in-depth discussions on the two recommendations made in the policy brief and the facilitators and barriers to the implementation of the second recommendation. After each group session (lasting about 20 to 30 minutes), reporters were asked to report back in the plenum, followed by discussions within the plenum.

Key points of the dialogue

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

Stakeholders agreed on recommending the development of a position statement:

- to push forward the importance of patients' experiences in the political agenda;
- to clarify the concept of patients' experiences on cancer care (i.e. PREMs); and
- to shed light on stakeholders' interests.

Points that need to be clarified for the position statement:

- the intended audience;
- the content (e.g. utility of PREMs, patients' role) and format (keep it short and simple);
- the objective (call for action, not only providing information); and
- the potential leaders in developing such a position statement (lack of consensus on whom should take the lead: patient/consumer organizations vs. professional organizations such as the Swiss Cancer League).

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

The choice of instrument for data collection depends on the potential aims:

- to influence clinical care through improvement initiatives, a Swiss cancer-specific survey could be more impactful;
- to evaluate overall care at the national level, an international generic survey could be a better option as it could 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.

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

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

Implementation considerations for recommendation 2

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

- at the patient level: having simple, disease-specific and meaningful questions, using a short questionnaire tailored to patients' literacy level, involving patients in the process;
- at the national level: having electronic health solutions available and having a clear objective of using results to implement change.

The most important barriers that were identified were:

- 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.

Comments on the policy brief

During the dialogue, stakeholders provided some suggestions on the policy brief, such as clarifying the concepts (PREMs, PROMs) and possibly avoiding those terms, and writing a “Citizen Brief” as the current brief was deemed too complex, technical and academic for lay readers.

Summary of group discussions

A summary of the discussions held during the stakeholder dialogue is presented below. Direct quotes from stakeholders are indicated in *“italic”*.

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

The first recommendation presented in the policy brief was to develop and publish a position statement on the importance and value of patients' experiences of cancer care to provide guidance for future initiatives on patients' experiences of cancer care, but possibly also for other chronic conditions. Position statements are typically 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.

In parallel sessions, the groups discussed during 25 minutes the arguments in favor, against, and the feasibility of developing and publishing a position statement.

The arguments presented by the groups in favor of the position statement were the following:

1. It can help push forward the importance of patients' experiences and setting it up in the political agenda;
2. It can clarify what PREMs are and how useful they can be;
3. It can ensure that a safe environment and context is created for patients to share their experiences;
4. It can clarify the intentions of different stakeholders regarding the collection of patients' experiences of care.

The arguments against (or limitations) such a position statement were the following:

1. The collection of patients' experiences may lead to additional burden in an already overloaded healthcare system, as it requires time and resources that may not be available;
2. Patients might not be ready to share their experiences, if the environment does not make the patients feel safe to freely share;
3. In some areas of cancer care, such as breast cancers, patient experiences are already reported;
4. Some areas of uncertainty were raised by participants, such as the concept/definition of quality (“experienced quality” vs “objective quality”), the definition of PREMs, the availability of tools to collect PREM data, their validity, the distinction between quantitative and qualitative methods to collect patient experience, and patient experiences in their own words.

All participants agreed that it would be feasible to develop a position statement, signed by all (or most) participants of the dialogue. Participants underlined that there is a distinction between writing the position statement, which is *“easy”*, and implementing the position statement, which would be more difficult.

Discussion in the plenum

An important point that was raised during the discussion was the need to clarify the intended audience of the position statement. The audience should be clearly stated to avoid that the statement is considered *“just as an academic exercise”*. One stakeholder suggested the audience could be politicians, hospitals, the Swiss Academy for Quality in Medicine (SAQM) of the FMH

Swiss medical association, or the hospital association H+. While some participants agreed that the main audience should be the hospitals, others suggested that it could also be professional teams like the nurses, the doctors, as well as patients and communities.

The group also discussed the content and format of the position statement. Some participants suggested it should describe and explain the utility and necessity of reports on patients' experiences. It should also describe the patient role in the process of promoting PREMs. Some participants suggested the need for patients to be a "*strong voice*" in developing PREMs in the Swiss healthcare system. Regarding the format of the position statement, it should be short and simple, with a simple key message like "*listen to the patients*".

The group discussed the objective of the position statement, agreeing that the goal of the statement should go beyond providing information on patients' experiences of cancer care; it should be a "*call for action*".

When asked about who should take the lead, there was a lack of consensus. For patient representatives, it should be the patients themselves and patient organizations who take the lead, to ensure that the patient voice comes from the patients and ensure large adherence. Another participant suggested consumer organizations as well. Two major barriers to patients taking the lead were raised and agreed upon: 1) there is a lack of a strong patient association at the national level, each canton having their own organizations, and 2) patient and consumer organizations are not (financially) supported enough by the state to take on a stronger role. Another participant suggested that the Swiss Cancer League could be an important stakeholder in developing such a position statement. However, some participants disagreed about this suggestion, arguing that the cancer league lacks direct patient involvement: "*it is for the people, not with the people*". They added that professional organizations representing patients are not equivalent to patients representing themselves. A few organization representing patients were mentioned, such as the European Patients' Academy on Therapeutic Innovation (EUPATI), Organisation Suisse des Patients, Fédération Romande des Consommateurs (FRC).

At the end of the first session, there was an online anonymous poll on the first recommendation of the policy brief; all participants voted yes.

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

The second recommendation presented in the policy brief was to collect patients' experiences of cancer care at the national level, with two strategies for data collection. Each working group, in parallel sessions, discussed one strategy during 30 minutes, and were asked to agree on arguments in favor and against the strategy, and its feasibility.

Working group 1: Developing and implementing a national program collecting patients' experiences of cancer care

Participants discussed the option of developing and implementing a national cancer-specific program collecting experiences of care, with two options for the instrument (survey):

- Using the Swiss cancer-specific experiences of care survey, which has been implemented in French-speaking Switzerland, and is being scaled up to German-speaking Switzerland in 2021 (i.e. SCAPE survey), or
- Using the international generic survey collecting outcomes and experiences of care from patients with chronic conditions (i.e. PaRIS survey), under development.

Below are provided the arguments mentioned in favor of these two survey options:

Arguments in favor of the Swiss cancer-specific survey	Arguments in favor of the international survey
<ul style="list-style-type: none"> • Takes into account the Swiss care situation; easier to implement. • Provides fine-grained image of patient care that allows immediate (micro-, meso-) quality improvement initiatives. • Provides feedback to patients, which was appreciated by patients. 	<ul style="list-style-type: none"> • Needs of cancer patients are similar to those of other countries. • Adhering to international standards, offering the possibility to participate in international trials using the same measure. • Includes assessment of health literacy and patient engagement.

Below are provided the arguments mentioned against the two survey options:

Arguments against the Swiss cancer-specific survey	Arguments against the international survey
<ul style="list-style-type: none"> • May not have a sufficient impact at the macro level (too specific, i.e. "only" for cancer) • Requires a lot of work to evaluate & translate (in German, Italian, English, other languages). • Complex reporting requiring considerable resources. • The Swiss cantonal system may not allow a direct comparison between healthcare systems in different cantons. 	<ul style="list-style-type: none"> • May not have a sufficient impact on patient care at the meso level (i.e. too generic and not informative enough). • Cancer care processes in other countries may differ from those in Switzerland (although these differences are probably small). • Focusses on chronic conditions, not specifically cancer (i.e. too generic); cancer differs from other conditions, such as hip & knee replacement, regarding emotional experiences for instance.

In terms of feasibility, the group discussed the need to guarantee the sustainability of the Swiss cancer-specific survey in terms of financial resources and credibility, which could be attained through its affiliation to a recognized national body/organization. The international survey would require time for its adaptation to the Swiss context, which may be difficult, due notably to the "Röstigraben" and the Swiss organization of healthcare services at the cantonal

level. In addition, the group noted that questions on experiences with some medical professions were not included in the questionnaire, and psychosocial patient support was not covered at all, impacting its acceptability.

When asked which option was preferred, stakeholders replied that the choice of instrument would depend on the potential aims of data collection. If the aim is to have an impact on clinical care, then the Swiss cancer-specific survey could be a better choice; if the aim 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. Both surveys could be used in parallel, or combined, by developing indicators in the Swiss survey complementing those measured in the international survey.

Working group 2: Integrating the collection of patients' experiences of cancer care in the cantonal cancer registries

Participants discussed the option of integrating the collection of patients' reports in the cantonal cancer registries. During the working session, the group took some time first to clarify for all participants how the cancer registries work under the new law (not one national registry, but several cantonal registries) and what the new law on the registration of oncological diseases is. One participant explained that under the new law, registries are only allowed to collect data if there is a date when patients have been informed and have agreed to data collection. Each canton has to have and maintain a cantonal registry; it is now compulsory and no longer voluntary.

One important aspect the group discussed was to consider both PREMs and PROMs in cancer registries; for some participants, the addition of PROMs in the registries would make more sense and add more benefit. One example of PROMs to include in the registries was information on side-effects of treatments, according to patients. According to the group, measuring PREMs alone are "*not important enough to justify such a large project*", they need to be combined with PROMs.

The group also mentioned some areas of uncertainty, such as the sensitivity and validity of experience measures, and discussed the possible difficulties in merging datasets as well as in data collection. They also discussed the opportunities offered by smartphone applications to collect the data, although results could be biased due the limited use of smartphones among older patients.

In terms of feasibility and implementation, the group underlined the high workload of gathering this type of data and the issues of pseudo-anonymization, legal obligations and data protection. However, one participant said these issues are not "*insurmountable*". They suggested that a pilot study could be done in one or several cantons with a limited number of measures, in a project similar to ANQ measurement.

Discussion in the plenum

There was some disagreement on the relative importance and benefits of integrating PREMs versus PROMs in cancer registries. While some argued that PROMs would be more useful in the registries, others argued that PREMs are just as useful. One participant explained that the objectives of measuring PREMs versus PROMs are quite different: while PREMs are measured to improve the quality of care throughout the cancer trajectory, PROMs are measured to evaluate the efficacy of treatments in clinical trials or clinical care. Many hospitals measure both but by different units and in an unstructured way. One participant also raised the challenges around the use of the collected data, such as how to use the data to implement change.

There was also some discussion between specific versus generic measures, the distinction between PREMs and PROMs, which was not that clear for some participants, the difference between clinician-reported and patient-reported measures, and the distinction between anonymization and pseudo-anonymization.

There was another online anonymous poll on the three options for collecting patients' experiences of cancer care at the national level (Swiss survey, international survey, cancer registries), presented in the second recommendation of the policy brief. Before the vote, one participant remarked that the first two options were about the method of collecting the data, while the third option was about "where you store the data". The Swiss survey collected 7 votes, the international survey collected 1 vote and cancer registries collected 1 vote.

Discussion 3: Implementation considerations for recommendation 2

A long list of barriers and facilitators reported in the literature to the implementation and use of patients' experiences of cancer care at the patient (micro), institution (meso) and national (macro) levels was presented in the policy brief. Each working group, in parallel sessions, had 20 minutes to discuss and select the three main facilitators and the three main barriers.

Below are presented the main facilitators and barriers selected by the working groups:

Facilitators	Barriers
<p><u>Patient level</u></p> <ul style="list-style-type: none"> • Disease-specific and meaningful questions • Simple questions and scales (e.g. scale with verbal descriptors) • Parsimonious (length of questionnaire) • Patient involvement (e.g. involving patients in designing the questionnaire) • Adequate health literacy level of questionnaire <p><u>Institution level</u></p> <ul style="list-style-type: none"> • Communication: facilitation of reporting process and providing feedback to patient <p><u>National level</u></p> <ul style="list-style-type: none"> • Availability of electronic health solutions • Clear objective of using results to implement change (i.e. information collected should be used to implement improvement measures in patient care) • Continuity plan (i.e. measures are done on the long term) 	<p><u>Patient level</u></p> <ul style="list-style-type: none"> • Concerns over confidentiality and security <p><u>Institution level</u></p> <ul style="list-style-type: none"> • Lack of acceptance (financial, administrative) <p><u>National level</u></p> <ul style="list-style-type: none"> • Financial barriers (<i>major barrier</i>) • National level (<i>as a whole</i>): adopting a common standard and metric will be difficult due to federalist organization of the healthcare system • Issues around the legal basis for data collection.

The most important facilitators were mainly identified at the patient level (design of the questionnaire), while the most important barriers were mainly identified at the national level (financial barriers and federalist organization).

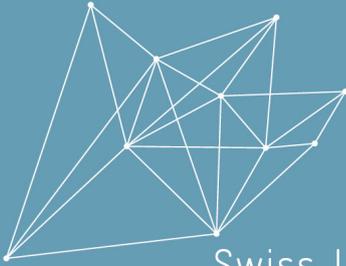
Comments on the policy brief

At the end of the dialogue, the participants had the opportunity to share their remarks on the policy brief.

A first comment concerned the understanding of PREMs and PROMs; these concepts were hard to grasp for some participants, and would require better explanation in the brief. Another participant suggested that there are a lot of overlap between PREMs and PROMS and questioned the focus of the brief on PREMs only.

Another comment concerned the complexity of the brief and the language used, which was deemed too academic for some participants. It was suggested to simplify the brief to make it more accessible and to avoid making people feel excluded because they cannot understand the content. One solution that was discussed was to write a “Citizen Brief”, in addition to the “Policy Brief”. This Citizen Brief would be shorter and aimed at patients and citizens. One participant also added that a shorter and simpler brief would also be useful for policymakers. One participant suggested to write a simple and short version of the brief, presented as a leaflet.

Other suggestions included: shortening the list of facilitators and barriers, discarding the terms “PREMs” and “PROMS”, starting with why PREMs are important, focusing less on technicalities and more on its impact on reducing health costs, focusing less on the treatment phase of cancer and more on the “after treatment” phase, and getting endorsed by an association or interest group, such as Oncosuisse, the Swiss Cancer League, or Onkologiepflege Schweiz.



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