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Responsiveness of cancer care in Switzerland through patients’ eyes: a study of patient-reported experiences of care (PREMs)

Arditi Chantal

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Faculté de biologie
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Centre universitaire de médecine générale et santé publique, Unisanté
Département d'Epidémiologie et Systèmes de Santé (DESS)
Secteur Services de Santé

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Thèse de doctorat ès sciences de la vie (PhD)

présentée à la

Faculté de biologie et de médecine
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par

Chantal ARDITI

Licence en sociologie avec mineure en géographie humaine de l'Université de Genève, Suisse
Master of Science in Health Studies and Gerontology, University of Waterloo, Canada

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Lausanne, le 23 janvier 2023

pour le Doyen
de la Faculté de biologie et de médecine

Prof. Solange Peters

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“I was completely under shock and had to return by car alone; the shock came from the brutal communication of the diagnosis” (Woman, 56, lung cancer)

“I rarely received the essential information spontaneously; [it was a] wrestling match to obtain answers to my questions” (Man, 66, lung cancer)

“We feel alone and not always heard. At each appointment with the oncologist, we repeat our side effects, they are recorded in the computer as if it were normal” (Woman, 51, breast cancer)

“After 6 months of sick leave and three surgical interventions my employer pushed me to leave” (Woman, 54, breast cancer)

“How to live a normal life with this relentless pain” (Man, 54, hematologic cancer)

“I want to take the opportunity to thank all of the hospital personnel (nurses, doctors, radiologist, auxiliary staff, etc.) for their good care, their tact, their capacity to listen and their kindness” (Woman, 61, lung cancer)

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Summary

Patients' perspectives on the care they receive have become central to health services research, as well as performance measurement and quality improvement. These perspectives, termed patient-reported experience measures (PREMs) when collected with patient experience surveys, are essential to evaluate responsiveness of care, one of the core dimensions of the quality of health services. As there were no information nor research on PREMs in cancer care in Switzerland, the objectives of this thesis were 1) to evaluate responsiveness of cancer care by collecting and analyzing PREMs with the Swiss CAncer Patient Experiences (SCAPE) study, 2) to study the added-value of free-text comments written at the end of the questionnaire, 3) to examine the association between experiences of care and type of cancer and patient characteristics, and 4) to develop policy recommendations for further actions related to the collection and use of cancer PREMs in a policy brief.

First, we observed from the 2755 participants of the cross-sectional SCAPE study diagnosed with one of the six most frequent cancers (breast, prostate, lung, colon, skin and blood) that overall rating of cancer care was fairly high, with an average score of 8.5 on a 0 (worst) to 10 (best) scale. While the rates of positive experiences of care were high for nurse consultations, diagnostic tests and inpatient care, they were lower for experiences related to communication, information and supportive care issues. Second, the computer-assisted textual analyses of the free-text comments showed that they provided additional understandings on the personal experience of living with cancer that complemented the quantitative information collected with PREMs. Third, we observed from multiple logistic regressions that experiences of care differed by type of cancer, without being systematically more positive (or negative) for one type of cancer. In addition, poor self-reported health, low health literacy, and financial hardship were three characteristics associated with lower overall rating of care and less positive experiences of care. Finally, we provided two recommendations in the policy brief, discussed and approved by eleven stakeholders during a dialogue: i) develop a position statement on the importance and value of patients' experiences of cancer care, and ii) collect patients' experiences of cancer care on a large scale by implementing a national survey.

The SCAPE study was the first investigation of patient-reported experiences of cancer care that went beyond institutional and monocentric surveys in Switzerland. It contributed to giving cancer patients a voice and allowed to evaluate whether current cancer care was responding to their needs. This thesis generated new knowledge about PREMs in cancer care and their determinants, while offering guidance for improvement initiatives in clinical care and guidance for policymakers. This work has also led to changes in clinical practice in participating hospitals and to further research on the responsiveness of cancer care, with the SCAPE-2 and SCAPE-CH surveys.

Résumé

Les points de vue des patient·e·s sur les soins qu'ils/elles reçoivent sont devenus un élément central de la recherche sur les services de santé, ainsi que de la mesure de leur performance et de l'amélioration de la qualité. Ces points de vue, appelés mesures d'expériences de soins rapportées par les patient·e·s (PREMs en anglais) lorsqu'ils sont recueillis au moyen d'enquêtes, sont essentiels pour évaluer si les soins répondent aux besoins des patient·e·s, l'une des dimensions fondamentales de la qualité des services de santé. En raison du manque d'information et de recherche sur les PREMs en oncologie en Suisse, les objectifs de cette thèse étaient 1) d'évaluer si les soins oncologiques répondent aux besoins des patient·e·s en collectant et analysant les PREMs recueillies avec l'enquête Swiss CAncer Patient Experiences (SCAPE), 2) d'étudier l'apport des commentaires libres notés à la fin du questionnaire, 3) d'examiner l'association entre les expériences de soins et le type de cancer et les caractéristiques des patient·e·s, et 4) de développer des recommandations d'actions liées à la collecte et l'utilisation des PREMs en oncologie dans une note d'orientation (policy brief en anglais).

Premièrement, nous avons observé à partir des 2755 participant·e·s à l'étude transversale SCAPE atteint·e·s d'un des six cancers les plus fréquents (sein, prostate, poumon, colon, peau et sang) que l'évaluation globale des soins contre le cancer était assez élevée, avec un score moyen de 8.5 sur une échelle de 0 (pire) à 10 (meilleur). Si les proportions d'expériences positives étaient élevées pour les consultations infirmières, les tests diagnostiques et les soins durant l'hospitalisation, elle étaient plus faibles pour les expériences liées aux questions de communication, d'information et de soins de support. Deuxièmement, l'analyse textuelle assistée par ordinateur des commentaires libres a montré que ces derniers apportaient une compréhension additionnelle sur l'expérience de la vie avec le cancer qui complétaient les informations quantitatives recueillies avec les PREMs. Troisièmement, les régressions logistiques multiples ont révélé que les expériences de soins différaient selon le type de cancer, sans être systématiquement plus positives (ou négatives) pour un type de cancer. En outre, un mauvais état de santé, une faible littératie en santé et une précarité financière étaient trois caractéristiques fréquemment associées à une moins bonne évaluation globale des soins et à des expériences spécifiques de soins moins positives. Enfin, nous avons émis deux recommandations dans la note d'orientation, discutées et approuvées par onze parties prenantes lors d'un dialogue : i) élaborer une prise de position sur l'importance et la valeur des expériences de soins des personnes atteintes de cancer, et ii) recueillir ces expériences de soins oncologiques à large échelle par le biais d'une enquête nationale.

L'étude SCAPE a été la première enquête sur les PREMs en oncologie à aller au-delà des enquêtes institutionnelles et monocentriques en Suisse. Elle a contribué à donner la parole aux patient·e·s atteint·e·s de cancer et d'évaluer si les soins actuels contre le cancer répondaient à leurs besoins. La thèse a généré de nouvelles connaissances sur les PREMs en oncologie et leurs déterminants, tout en suggérant des pistes d'amélioration des soins oncologiques et des conseils pour les décideur·se·s politiques. Ce travail a également conduit à des changements de pratique clinique dans les hôpitaux participants et à d'autres recherches sur les PREMs en oncologie, avec les enquête SCAPE-2 et SCAPE-CH.

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1 Introduction

Health services research is increasingly placing the patient at the center of research, highlighting the importance of considering their perspective and experiences when assessing health services (1, 2). Patients' point of view is especially essential when evaluating responsiveness (or patient centeredness) of care, one of the core dimensions of the quality of health services (2, 3). This has led to the development of patient-reported experiences of care measures (PREMs), which ask patients to evaluate specific experiences of care related to the key dimensions of patient-centered care (4-7).

Evaluating the responsiveness of care in oncology is of special interest for several reasons. First, cancer care represents a large portion of care delivered by health systems, as cancer prevalence and incidence have been increasing over the last decades, in addition to cancer becoming a long-term condition due to increased survivorship (8). Second, delivering care responding to patients' needs is particularly important in cancer care, as cancer carries an emotional, social and financial burden for patients and their families tied to the life threatening nature of the illness, in addition to the health burden (9).

This has led to the development of specific PREMs for cancer care, to account for the complex treatment pathways and to improve the interpretation of findings and prioritization of quality improvement initiatives. Countries like the United Kingdom (UK) and the United States of America (USA) have implemented systematic and wide-scaled measurement of cancer-specific PREMs (10, 11). In contrast, Switzerland is lagging behind in wide-scale and coordinated measurement of PREMs in cancer care, partly due to the late implementation of a national quality commission in Switzerland, founded in 2021.

There is thus a gap in measuring PREMS with a standardized instrument in routine cancer care in Switzerland, as well as a gap in Swiss research and policy to inform and promote the use of PREMs in cancer care. Thus, the project for this thesis was to collect and analyze data on experiences of cancer care reported by patients recruited from several cancer centers in the French-speaking region to evaluate the responsiveness of cancer care and guide future improvement initiatives, as well as to provide policy guidance for the future.

In this introductive section, the central concepts of this thesis, i.e. "responsiveness of care" and "patient experiences", are presented first, explaining why it matters to ask patients about their experiences and how patient experiences of care are measured. Then, after an overview of the current scientific evidence on patients' experiences of cancer care, the different uses of PREMs are presented to shed light on their policy implications. The section finishes with a presentation of the current situation and policy context in Switzerland.

1.1 Responsiveness of care

One of the main reason for collecting experiences of care reported by patients is that responsiveness of care, one of the core dimensions of the quality of care, is best evaluated by patients themselves, as they are thought to be the best judges to evaluate whether the care they received was responsive to their needs. The broader context of responsive care, as well as the concept of responsiveness, are briefly described below.

The primary purpose of the health system is to improve population health, by delivering preventive, promotive, curative and rehabilitative interventions through a combination of public health actions and health care facilities delivering health care (12). Within the health system, the health care delivery system is thus a key component, facing many challenges due to rising health costs, increase in non-communicable diseases and aging population, and future shortage of qualified health professionals, among many others. It has also been facing more scrutiny and accountability to ensure that the delivery system is performing well to reach the primary objective of improving population health, but also its other important objective of enhancing the quality of care and experience of care of people going through the health system (13, 14).

Robust indicators covering the spectrum of the performance of the system, at all levels and for all objectives, are thus needed to evaluate whether the health care delivery system is achieving its objectives. Traditional indicators of the impact of the system on achieving better health include life expectancy and mortality rates, for instance. While these indicators may demonstrate the physiological benefits of care, they only give a partial picture of the performance of the health care delivery system (15). Reports by patients themselves and their carers, also known as patient-reported measures, are necessary to evaluate how well the system is achieving better health and patient experience, according to the patients themselves (16, 17).

The framework developed by the Organisation for Economic Co-operation and Development (OECD) is widely used to guide the evaluation of health care delivery system performance and includes responsiveness / patient-centeredness as one of the six core dimensions of the quality of care, next to effectiveness, safety, accessibility, efficiency and equity (1, 2). Responsiveness (also called patient-centeredness or person-centeredness) 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 (3, 18). Key concepts in patient-centered care include dignity, respect, communication, information, collaboration, and involvement of patients and their loved ones. Patient-centered care also reflect the shift from offering "standardized" care to more "personalized" care, taking into account patient's age, culture, economic status, profession, place of living, and family situation in addition to the person's health condition when delivering care. In cancer care, responsive care also includes supportive care, defined as “the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement” (19).

1.1.1 Responsiveness of cancer care

Responsiveness of cancer care is of special interest for several reasons, the first one being the burden of cancer on the health system and population health with its impact on morbidity and mortality. Cancer is a leading cause of death in all countries around the world and is ranked second as the leading cause of disability-adjusted life-years loss. In Switzerland, cancer is among the five most frequent non-communicable diseases, with over 40’000 new cases diagnosed every year (8); it is also the first cause of premature mortality before the age of 70 (20). The most common cancer types diagnosed are breast, colorectal, prostate and lung cancers, which comprise about half of all cancer cases (21). For many affected people, cancer becomes a long-term condition due to more effective screening, diagnosis and treatments, leading to increased survivorship. In 2015, about 317’000 people were living with cancer in Switzerland.

These figures put pressure on the health care system, which is expected to provide high quality cancer care meeting the needs of each patient in an equitable and efficient manner. Cancer patients’ needs are not only health-related; previous reviews have identified a broad range of needs in people living with cancer, i.e. informational, spiritual, practical, emotional, psychological, social, physical, and functional needs (9, 22-24). Indeed, in addition to the effects of the disease and treatments on health, cancer can affect the social and professional life, often with financial consequences. It is therefore crucial that the health care delivery system responds comprehensively to all patients’ needs, not just those related to health.

In light of the specific impact of cancer on patients and their carers and its complex treatment pathways, studies have examined unmet needs in cancer care as well as experiences of care reported by cancer patients with specific instruments and dedicated measurement programs on experiences of cancer care. They have found that individuals affected by cancer continue to report various unmet needs, poor experiences and dissatisfaction, mostly with the informational and instrumental support provided (9, 22, 23, 25). For instance, patients often describe feeling overwhelmed with the nature of cancer information provided, not receiving adequate information to help navigate the cancer care system, and the paucity of emotional and social support (26).

1.2 The “patient experience”

The concept of “patient experience” can have different uses and meanings. It has been defined by the Beryl Institute as “the sum of all interactions, shaped by an organization’s culture that influence patient perceptions, across the continuum of care” (27). As such, the “patient experience” encompass both the way patients experience their illness or injury in their daily life, i.e. the emotional and physical lived experiences, and the way they experience the care received for their illness or injury when interacting with the system, i.e. experiences of care (28). In this thesis, we focus on the second aspect of the “patient experience”, i.e. experiences of care while interacting with the health care delivery system and ways to collect patients’ feedback on “what actually happened in the course of receiving care or treatment, both the objective facts and their subjective views of it on this aspect” (29) and use it to evaluate the responsiveness of care.

What defines an experience of care is important to establish, in order to measure this experience and set standard measurements. Although there is no universal operation definition or standard set of components of patient experiences of care (30), various conceptual frameworks of patient experiences have been developed to facilitate and standardize their measurement, mostly based on the principles of patient-centered care, as defined the previous section (6, 28). One of the first framework was developed in 1987 by the Picker Institute (31), with the establishment of the eight principles of patient-centered care, defined today as: 1) fast access to care and reliable care; 2) effective treatment by trusted professionals 3) continuity of care and smooth transitions; 4) involvement and support for family and carers; 5) clear information, communication and support for self-care; 6) involvement in decisions and respect for patients’ values and preferences; 7) emotional support, empathy and respect; 8) attention to physical and environmental needs, including pain management (32). These Picker Principles were used by the Agency for Healthcare Research and Quality (AHRQ) in the United States to launch the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys in 1995 and still running today throughout the country (4). They also guide all patient surveys conducted by the National Health Services (NHS) in the United Kingdom since 2002 (33). The Picker Principles are the guiding framework for this thesis as the instrument we used to evaluate responsiveness of cancer care was adapted from an NHS instrument.

Patient experiences of care are distinguished from satisfaction with care, which is defined as the extent to which health services fulfils patients’ expectations (34). Satisfaction ratings were shown to be influenced by patients’ expectations of and preferences for care, cultural norms as well as by variations in response tendencies amongst different patient groups, in addition to the care actually received, making them hard to interpret and to act on (6, 35, 36). Reports on experiences of care are considered to better reflect differences in care rather than differences in expectations, to be more actionable for quality improvement and to be less likely to get exceedingly positive responses compared to satisfaction ratings (7, 37, 38).

Listening to both “patient experiences” in terms of symptoms, function, emotional status, as well as their experiences with treatment and care received, is essential for both the empowerment of patients and their caregivers and their involvement in care as for evaluating the performance of the health system.

1.2.1 Why it matters

As said by Picker, there is not only a “moral case for listening to and acting on people’s views, but there is growing evidence that better experiences are associated with better patient outcomes and safer care” (39). Four reviews have investigated the association between patient experiences of care and a range of patient outcomes, two of which focused on cancer care. The first general review found that patient experiences of care were positively associated with clinical effectiveness and patient safety, supporting the case for their inclusion as one of the central pillars of quality in health care (40). The second general 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 health care utilization (41). The third review looking at the link between cancer patient experiences and cancer survival found that patients’ satisfaction, psychosocial support, and satisfaction with quality of life were the most common aspects associated with survival. However, negative and lack of association findings were also reported in the included studies. Authors cautioned about the methodological complexity of determining the relationship between cancer patient experience and subsequent survival (42). The last review investigating the associations between patient experiences measured with the CAHPS instrument for cancer care (see section 1.2.4) and clinical and quality outcomes in the USA also found inconsistencies between studies and concluded that ratings of patient experiences of care may influence clinical and quality outcomes of care (43). Two recent longitudinal studies in the USA (using the CAHPS-SEER database, see section 1.2.4) published after the last review found that excellent experience scores did not predict clinical outcomes, survival, nor health care utilization, among older cancer survivors (44, 45). General health status, cancer stage, and comorbidities were more predictive of survival.

Regardless of whether positive experience are associated with better outcomes, improving experiences of care as suggested by the triple and quadruple aim frameworks (13, 14) is an important objective of the health system on its own to ensure that delivered care is leading to positive experiences, with possibly better outcomes of care as well.

1.2.2 Methods to collect patients' experiences of care

There are several methods to collect patients' experiences of care, whether quantitative, qualitative or a combination of both (i.e. mixed methods) (30). Among the quantitative methods, surveys using questionnaires with closed-ended questions completed directly by patients themselves, given or sent to patients at a single or multiple points in time, are the most widely used method to collect patients' experiences, also in cancer care. The emphasis is on examining patterns and trends from large samples, with the possibility to compare them (6, 46). However, surveys have limitations, such as lack of depth – as questions and response options are predetermined – and issues of representativeness – as some patient groups are consistently underrepresented in survey data (e.g. patients who do not speak the survey language, with low (health) literacy, and in poorer health). Qualitative collection methods can overcome some of these issues, such as patient stories or interviews, to obtain an in-depth understanding of people's experiences and the way they explain, make sense or interpret these (46). Qualitative studies also have their shortcomings, such as the time and work required to analyze qualitative data and the difficulty in making comparisons. In response to these limitations, research designs with mixed methods can be conducted, combining elements of quantitative and qualitative methods within the same study (47). One of the approach is the convergent parallel design, where quantitative and qualitative data are collected and analyzed at the same time, then compared to discuss areas of convergence or divergence.

1.2.3 Patient-reported experience measures – PREMs

Patient-reported experience measures (PREMs), as well as patient-reported outcome measures (PROMs) under the umbrella term "patient-reported measures", are quantitative measures, collected with online and/or paper standardized surveys and defined as coming directly from the patient without interpretation by a physician or anyone else (48). When they are collected exclusively online, through an application or a web-based questionnaire, they are called ePREMs and ePROMs (or ePROs).

PREMs focus on measuring patients' experiences with the delivery of care, such as communication with nurses and doctors, physical and emotional support from health professionals, discharge organization, and coordination between primary care and specialist physicians, while PROMs focus on the health result of care received, such as patients' rating of their symptoms and their quality of life (6, 15, 49). PROMs are further classified into generic and condition-specific measures, while PREMs can be further divided into different types of experiences, including reports of subjective and objective experiences of care (related to the eight dimensions of patient-centered care), as well as observations of health care providers' behavior, as depicted in Figure 1. PREMs cover the range of interactions that patients have with the health care delivery system, including experiences with hospital care, general practice care and home-based care, as well as the transition between health services (e.g. from hospital to home-based care). They mostly focus on reports of what actually happened to patients during a hospital stay or a visit with a health professional (e.g. did you receive information about your treatment?) and evaluate the eight key domains of patient-centered care as defined in section 1.2. There are a wide variety of instruments measuring PREMs for different conditions, for different care services (e.g. physiotherapy, radiotherapy) and fur use in different settings (e.g. ambulatory hospital care, inpatient hospital care).

Figure 1 Proposed definition of patient-reported experience and outcome measures

Patient-Reported Experience Measure (PREM)	**Patient-Reported Outcome Measure (PROM)**
A measure of patients' perception of their experience of care focusing on the delivery and processes of care, to evaluate the quality and responsiveness of care according to patients. **PREMs** encompass the range of interactions that patients have with the health system and include measures of: • ***Subjective experiences of care*** (e.g. staff helped controlling pain while hospitalized); • ***Objective experiences of care*** (e.g. waiting time before appointment); and • ***Observations*** of health care providers' behavior (e.g. whether or not a patient was given discharge information). The measures of *subjective and objective experiences of care and observations* are often related to the eight Picker Principles 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 health care settings; and access to care.	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 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.

1.2.4 Cancer PREMs instruments

During the last 15 years, many surveys have been developed to assess patients' experiences with cancer care specifically. The instruments identified from our review of the published and grey literature cover most domains of patient-centered care and generally include an overall satisfaction rating. Although instruments need to be valid and reliable to be used for quality assessment of health care services (50), the validity and reliability of most instruments were not fully assessed, with information on responsiveness, an instrument's ability to detect changes overtime, lacking for the majority, according to three reviews on PREMs instruments in oncology (51-53). This finding was explained by one review by the lack of agreed definition of what the cancer patient experience really means and which elements are most important beyond the patient-centered care dimensions (51). Indeed, an ideal measure should contain the following key characteristics: (i) based on agreed definitions, (ii) specific and sensitive, (iii) valid and reliable, (iv) discriminant, (v) culturally appropriate, (vi) relating to clearly identifiable occurrences for the user, (vii) relevant and practical, (viii) permitting useful comparisons, and (ix) evidence-based (54, 55). While it is not possible to establish an ultimate "one size fits all questionnaire" for the cancer patient journey from the viewpoint of all cancer patients, identifying a range of measures of sound psychometric properties would provide a valuable foundation towards the valid evaluation of patient centered cancer care, as suggested by Saunders and colleagues (51). To date, however, there are no "gold standard" for assessing PREMs in cancer patients. We listed seven widely used instruments in Table 1 identified in our literature review and briefly describe two of those instruments in the following paragraphs.

The National Cancer Patient Experience Survey (NCPES) was implemented in the UK in 2010, the first country to implement a nation-wide specific survey for cancer care. The 2016 version of the instrument included 69 questions on experiences of care covering the eight dimensions of patient-centered care, following the Picker Principles. In addition to the public reporting of the yearly results, numerous studies have been published on the results, as well as on its reliability to compare hospitals scores (56), representativeness of survey participants (57-59) and the underlying structure of the instrument recently (60). However, its validity, discriminatory power and responsiveness to change have yet to be assessed.

Another widely used instrument to collect PREMs in cancer care is the CAHPS® Cancer Care Survey, developed between 2009 and 2016 by the Agency for Healthcare Research and Quality (AHRQ) in the United States and is inspired by the Picker Principles as well (10, 61). It covers six core dimensions, similarly to the NCPES. As in the UK, the results are publicly available on the agency website. Recently, the CAHPS results have been linked to the National Cancer Institute's Surveillance, Epidemiology, and End results (SEER) cancer registry and Medicare claims to explore relationships between cancer patient experiences, health care utilization, and subsequent patient outcomes (62, 63). The instrument was cognitively tested and the validity and reliability of dimensions were evaluated with psychometric analyses (61).

Table 1 Short description of widely used PREMs instruments for cancer care

Name and reference	Organisation	Country	# Q	Dimensions / sections
Ambulatory Oncology Patient Satisfaction Survey (AOPSS) (64)	National Research Corporation	Canada	~100	Emotional support; coordination and continuity of care; respect for patient preferences; physical comfort; information/education; and access to care; section for free comments
Consumer Assessment of Healthcare Providers and Systems (CAHPS) Cancer Care Survey (61)	Agency for Healthcare Research and Quality (AHRQ)	USA	56 +16	3 versions for radiation therapy, drug therapy, and cancer surgery. Six composite measures: Getting Timely Care; Supporting Patient Self-Management; Available to Provide Care and Information; Provider Communication; Care Coordination; and Courteous Office Staff); two single-item measures of family participation in care and interpreter services; and two global ratings of cancer care and the treatment team. Sixteen additional items form three supplemental composite measures: Shared Decision-Making, Keeping Patients Informed, and Access to Care.
Cancer Patient Experience Questionnaire (CPEQ) (54)	Norwegian Knowledge Centre for the Health Services	Norway	127	Doctor contact, nurse contact, information, organization, patient safety, next of kin, hospital standard
European cancer consumer quality index (ECCQI) (65)	The Netherlands Cancer Institute – BenchCan Europe	Netherlands	64	Accessibility; organization; hospitalization; safety; attitude of health professional, communication and information; own input; coordination; supervision and support; rounding off treatment
EORTC Satisfaction with cancer care (PATSATC33 & OUTPATSAT7) (66, 67)	European Organisation for Research and Treatment of Cancer (EORTC)	International	33 +7	Core questionnaire: rating of doctors, addressing technical skills, information exchange, and affective behavior; rating of nurses/radiotherapy technicians, addressing information provision and responsiveness and affective behavior; rating of services and care organization, including coordination and interaction with health care team. Outpatient module: continuity, convenience, transition
National Cancer Patient Experience Survey (NCPES) (2016 version) https://www.ncpes.co.uk/	National Health Services (NHS) England	UK	69	Before the diagnosis ; diagnostic tests; diagnosis; treatment decisions; clinical nurse specialist; support for people; operations; inpatient hospital care; outpatient hospital care; home care and support; care from the GP; overall care ; section for free comments
Patient Satisfaction and Quality of Life Cancer (PASQOC) (68)	German society for cancer	Germany	63	Physician-patient relationship; communication with physician; co-management and shared decision-making; nursing staff and other practice assistants; pain and pain management; handling of side effects; involvement of family and friends; Exchange with other patients; practice organization; further support in everyday life; practice environment; side effects (specific symptoms)

1.3 Research on patients' experiences of cancer care

Previous studies have been published on the patient-reported experiences of cancer care, mostly in the UK using the datasets collected with the NCPES (over 30 studies published e.g. (69-72)), in the USA using the CAHPS-SEER datasets (e.g. (73-76)), and countries in Europe, often using the EORTC instruments (e.g. (77-79)). There is also an increasing trend of studies from countries in other continents, such as Ethiopia (80) or India (81). Most studies were descriptive in nature (e.g. (68, 82-85) or reporting on the psychometric properties of the instruments (e.g.(54, 86-91)). Some studies also investigated the determinants of the experiences of cancer care (e.g. (92-96)), drivers of the experiences (e.g. (94, 97-102)) and inequalities in experiences of cancer care (e.g. (95, 103, 104)).

1.3.1 Determinants of patients' experiences of cancer care

An important aspect to examine in cancer care is whether experiences vary according to the type of cancer, to determine whether systematic differences of care exist and inform improvement interventions for specific cancers for instance. However, the current understanding how PREMS vary by organ (i.e. cancer diagnosis) is limited, as large national surveys with sufficient sample size for these analyses are relatively recent (103). We identified a few studies investigating the impact of cancer type on patient experiences, reporting mixed results (51, 69, 70, 94, 95, 105, 106).

Understanding how overall satisfaction and specific experiences of care vary among patients with different characteristics is also useful to help interpret results from patient surveys and to design targeted improvement intervention. Previous studies and a recent systematic review (107) have shown that cancer patients' experiences vary quite significantly by a wide array of patients' characteristics, sometimes in an inconsistent manner. Regarding socio-demographic characteristics, being from an ethnic minority group, having a more deprived socioeconomic status, being younger or very old, and being a woman were associated with poorer cancer care experience (72, 79, 92-96, 104, 108-111). Other frequent socio-demographic determinants of patient experiences reported in the literature were marital status (94, 108, 110), area of residence (26, 93, 112), education level (93, 94, 109), and level of social support (94, 108). Regarding health characteristics, poorer health status or quality of life was one of the most important determinants of reporting lower ratings and poorer experiences (79, 93, 94, 101, 109-111, 113, 114). Finally, studies looking at clinical characteristics of cancer have found that experiences varied by type of cancer and prognosis (72, 77, 79, 92, 94), treatments (79, 96) and time since diagnosis (110).

Some researchers advocate risk adjustment strategies on socio-demographic factors associated with experiences when comparing these experiences across populations and providers to ensure that differences can then be attributed to the health care delivered to the patient rather than the variation in patient characteristics and other factors of the populations and providers compared (i.e. case-mix differences). However, some research studies have found that adjusting patient experience scores for population characteristics (e.g. ethnicity, deprivation) makes only small differences to scores (11, 115, 116). It can however increase the acceptability of the results to health care providers (29). The argument against case-mix adjustment is that it may be a way of "institutionalizing sub-standard care by masking poor care provided to some patient subgroups" as asserted by Ahmed and colleagues (29). Some authors have thus advocated for reporting both adjusted and unadjusted data on patient experience (11, 116).

1.3.2 Patient experiences shared as free-text in cancer PREMs instruments

PREMs are collected with questionnaires including closed-ended questions producing quantitative data from a large sample of patients. These questionnaires usually also include one or more open-ended questions, eliciting general comments (e.g. "Is there anything else you would like to tell us about your cancer care services?" (117, 118)) or more specific comments (e.g. "Is there anything else you would like to tell us about your chemotherapy treatment?" (119)). While studies widely publish the results of the analyses of the quantitative data of closed-ended questions, studies more rarely publish the analyses of the qualitative data from the free-text comments, although more studies are publishing these types of results recently (e.g. (120, 121)). Manual thematic analysis of large amounts of text generated from open-ended questions remains time and resource intensive, leading to the underutilization of the additional insights of this type of data. However, information technology are now available to perform such analyses automatically (122-125), yielding comparable results to manual qualitative analysis (126). Exploiting the qualitative data is important as their analysis can provide deeper insights on patient experiences, on specific closed-ended questions (127) or subpopulations (128), identify issues not revealed in the closed-ended questions, guide the development of new survey questions and uncover issues with the survey or its methodology, and finally guide quality improvement initiatives (117-119, 127-133).

1.4 Use of cancer PREMs for quality improvement and other purposes

Another reason for collecting PREMs in cancer care stems from the various possible uses and policy implications for these measures, presented in this section. As stated earlier, PREMs are primarily used to measure patients' experiences while receiving care, to evaluate responsiveness of care and for research purposes. These measure can also be used for other purposes, presented below according to the three organizational (micro-meso-macro) levels and presented in Table 2 along with the preferred collection method, target population, frequency of measure, uses and type of reporting. We also present the current evidence on the effectiveness of using PREMs for their different purposes.

1.4.1 Use of PREMs to support patient-centered care, at the patient level

At the individual (micro) patient level, real-time (or rapid) patient feedback of their experiences of care, collected at the point-of-care through touch screens for instance, is not wide-spread yet, but could potentially provide clinicians and other health care professionals with the opportunity to address concerns and improve perceptions and processes of care immediately, as suggested by the few studies which have implemented real-time feedback of experiences in primary and hospital care (134-136). It can be a tool to directly support patient-centered care in the clinic or hospital by identify issues as they arise (e.g. coordination issues, social issues) and improve communication (patient-provider, provider-provider). No studies evaluating the use of cancer PREMs in clinical care were identified, but we found one project in Italy, called PATIENT VOICES, that is currently implementing a stepwise integration of ePROMs and ePREMS assessment into routine cancer care (137).

In contrast, PROMs have been used routinely in clinical cancer care for several years. Studies and a recent review have shown that systematic patient monitoring using PROMs improved patient-clinician communication, clinician awareness of symptoms, symptom management, patient satisfaction, quality of life, and even overall survival (138, 139).

1.4.2 Use of PREMs to compare care, improve care and inform the public, at the institutional level

At the institutional (meso) level, PREMs are collected and aggregated to assess and compare the performance of institutions or providers (benchmarking), to identify which quality issues remain insufficiently addressed in current practice to inform quality improvement initiatives, and to inform the general public to enable informed patient choice (public reporting) (46). Many examples of the use of cancer PREMs for benchmarking, quality improvement and publication reporting exist, as illustrated by the national programs in the UK and the USA detailed in section 1.2.4. The evidence on the effectiveness of using PREMs for improvement purposes is presented below.

Several systematic reviews have explored how patient experiences of care were collected, communicated and used to inform quality improvement (140-145). All 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 (140). The reviews also presented the most common barriers associated with data collection or use, including lack of time, resources and expertise in data analysis and quality improvement, and timeliness of data reporting. Surveys of patient experience on their own are thus not sufficient to change and improve practice (29, 145, 146), but collecting patient experience data is the initial and essential step to understanding challenges and opportunities in improving the quality of health care. Improving quality requires a strategy of implementing multiple interventions, sustained over time (29, 141).

Public reporting of quality of care measures, including patient experiences, intends to change behaviors of the consumer (patient) by allowing patients to make informed provider choice by helping them to identify high performing providers and behaviors of providers (health professionals) by encouraging improvements through increased competition and accountability (147-149). However, none of the three reviews on the topic found consistent evidence that the public release of performance data changed consumer behavior or improved care (147-149).

1.4.3 Use of PREMs to monitor the health system and for contracting services / payment models, at the national level

At the national (macro) level, PREMs can be used to monitor the health system, for reimbursement decisions, and for macro-level health care performance measurement and international comparisons. PREMs were added to population health surveys by the OECD, for instance, 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 (150). 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, as done in Sweden with their national quality registries (151). PREMs can also be used at the macro level for contracting health care services, for regulation and accreditation purposes, such as maintenance of medical board certification, and for payment models, such as pay for performance models or value-based models. The Pay-For-Performance (P4P) method, for instance, offers financial rewards to providers who exceed their performance on predetermined quality and cost measure, including PREMs (152). However, articles examining the effectiveness of P4P models incorporating PREMs specific for cancer care were not identified in the literature.

Table 2 Purposes and characteristics of PREMs by organizational level

Main 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 health care quality improvement initiatives and inform the public	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 (or sample) 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 / policymakers: • prioritize patient groups, populations, etc • Design public health initiatives • Monitor effects of policy initiatives • Generate new evidence	Scientific Public
Performance measurement of the system	National patient surveys (by phone, face-to-face, paper or electronic)	Representative population sample	Cross-sectional Longitudinal	For policymakers Make international comparisons	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

Source: adapted from (153)

1.5 Situation and policy context of cancer PREMs in Switzerland

Switzerland is lagging behind in wide-scale and coordinated measurement and reporting of patient-reported experiences in cancer care compared to other countries, whether for use in clinical practice, to evaluate responsiveness of care and performance of the health system, or for research purposes.

In research, studies focusing on patient-reported experiences of care are scarce, even more for studies in cancer care. A few monocentric studies have examined cancer patient experiences: for instance, Wangmo and colleagues conducted a qualitative study on communication and decision-making in pediatric oncology (154), while Brédart and colleagues conducted a quantitative study on supportive care needs, quality of life, and satisfaction with care in breast cancer patients (155).

At the clinical (micro) level, we are not aware of any initiatives collecting patient experiences at point of care for immediate provider feedback, in cancer care or in any other type of care.

At the institutional (meso) 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, leading to a wide range of instruments not allowing any comparisons. In regards to cancer care, no hospital was using a specific instrument for oncology, to the best of our knowledge.

At the national (macro) level, the National Association for Quality Improvement in Hospitals and Clinics (ANQ) is collecting PREMs with a short questionnaire for inpatient care, mandatory for all hospitals and clinics in Switzerland (156). While patients with cancer are included in the ANQ surveys, their results are not analyzed specifically and the instrument with six questions is not adapted to provide useable information for research purpose nor quality improvement. Switzerland also participates in various international surveys of patient experiences, such as the Commonwealth Fund (CWF) International Health Policy Survey and the OECD survey collecting PREMs in ambulatory care since 2006. In addition, Switzerland is participating in 2022 to the new international Patient-Reported Indicators Survey (PaRIS) of people living with chronic conditions (17), launched in 2017 with the OECD publication recommending to strengthen the international comparison of health system performance through patient-reported indicators (16). The aim of the survey is to provide insight in the quality and outcomes of primary care as perceived by people living with chronic conditions, with the collection of PREMs and PROMs (157).

In response to the lack of existing PREMs in cancer care in Switzerland, a new study aiming to collect experiences care reported by patients diagnosed with the most frequent types of cancers in several cancer centers in the French-speaking region of Switzerland was planned by Chantal Arditi, Isabelle

Peytremann-Bridevaux (principal investigator PI) and Manuela Eicher (co-PI), called the Swiss Cancer Patient Experience (SCAPE), in 2018. The study, funded by a grant for health services research in cancer care from the Swiss Cancer Research Foundation, with the support of the ACCENTUS Foundation (Marlies Engeler Fund) (Grant no HSR-4354-11-2017; CHF 226’000) began in the summer of 2018 and is one of the main research project of this thesis.

1.5.1 Consideration of PREMs in government policies

At the beginning of this thesis in 2018, the government had not formalized the consideration of PREMs in its policies, prompting us to provide policy guidance on the use of cancer PREMs in a policy brief, the second project of this thesis.

However, this has now changed. One of the federal government main aims is to improve the quality of health care, as defined in the fifth objective of the new Swiss Health 2030 Health Policy Strategy of the Federal Council (158) and in the new quality strategy and objectives from 2022 to 2024 (159). In order to achieve this, one of recommendations made in the national report in 2019 (160) was to “seek out the patient and carer voice” as an essential foundation for safe, high quality care. They further specified that this would include “routine monitoring of patient experience”, as well as involving patients in improvement initiatives and in the governance of the health care system. This was formally included in the new quality strategy published in 2022, under the objective of patient-centered care, by implementing and using the “insights from the patient reported experience measures (PREMs) in particular” (159).

2 Objectives

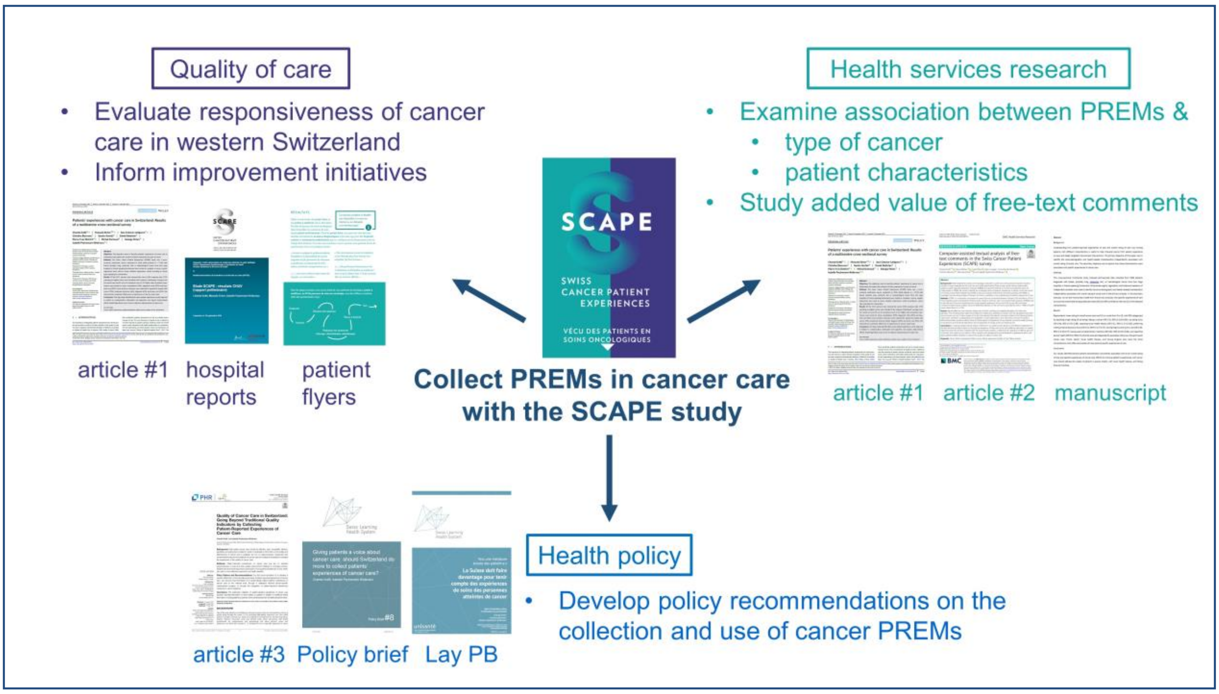
The overall aim of this thesis was to collect and analyze data on experiences of cancer care as reported by patients recruited from several cancer centers in the French-speaking region to evaluate responsiveness of cancer care, guide future improvement initiatives, and provide policy guidance for the future. The specific objectives were to:

1) Evaluate the responsiveness of cancer care by collecting and describing experiences with cancer care reported by individuals diagnosed with the six most frequent cancers in Switzerland *(Published article #1 in section 4.2)*;
2) Examine the association between experiences of care and type of cancer *(Published article #1 in section 4.2)*;
3) Study the added-value of free-text comments in patient surveys, by identifying the underlying themes of the free-text comments and comparing them with dimensions assessed in closed-ended questions (PREMs) *(published article #2 in section 4.3)*;
4) Model the association between patient characteristics and rating of overall care and experiences of care *(manuscript in section 4.4)*; and
5) Develop policy recommendations for further actions related to the collection and use of patient-reported experiences of cancer care to evaluate and improve responsiveness of cancer care *(published article #3 in section 4.5, policy brief in Appendix 4)*.

We used the data collected with the SCAPE study described in section 3.1 for objectives 1 to 4. For objective 5, we followed the framework of the Swiss Learning Health System, described in section 3.2.

The objectives and publications related to this thesis are presented in Figure 2 on the next page.

Figure 2 Outline of the objectives and publications of the thesis



3 Methodology

We describe in this section the methodology of the SCAPE study used to collect data for objectives 1 to 4, and the framework of the Swiss Learning Health System used for objective 5.

3.1 The methodology of the SCAPE study

3.1.1 Patient and Public Involvement (PPI)

Patient surveys represent unique opportunities for patients to evaluate whether care responds to their needs and expectations, as well as opportunities for patient and public involvement (PPI). PPI in research, defined as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”, is increasingly a requirement for public funding, as it serves the democratic principles of citizenship, accountability and transparency (161). Indeed people who are affected by research should have a right to be included in the research process. Patients can also offer different perspectives and their expertise of living with the researched disease. It also improves research quality and relevance (161). Recent reviews have shown that PPI is indeed increasingly used in health research (162), as well as in cancer research (163). INVOLVE further describes four approaches to involving patients that can often overlap: consultation, where you ask patients for their views to inform decision-making); collaboration, where there is an on-going partnership and where decisions about research are shared); co-production, where researchers, practitioners and patients work together, sharing power and responsibility from the start to the end of the project; and user-controlled research, where research is actively directed and managed by service users and organizations.

PPI was applied in most phases of the SCAPE study. A Patient Partner, Christine Bienvenu, was involved from the beginning of planning the SCAPE study, following three of the approaches described above (consultation, collaboration, and co-production). She was included as Patient Partner in the grant proposal and took part in the study steering committee. She participated in the translation, validation and pre-test of the questionnaire. She revised patient materials and answered patient email inquiries. She was included in the interpretation of the analyses of the free-text comments and was included as co-author for that paper. Finally, she led the dissemination of the lay summary of results sent to participants and communicated the study results on social media. Nine other patients were consulted to pre-test the questionnaire used in the SCAPE study, through cognitive debrief interviews.

3.1.2 Study design and population

It was a cross-sectional multicenter study of patient-reported experiences with cancer care.

The target population were adult patients (≥18 years old) with a diagnosis of breast, prostate, lung cancer, colorectal, melanoma, or hematological cancer (leukemia, lymphoma or myeloma), having received inpatient or outpatient care between January 1 and June 30, 2018 in one of the four participating hospitals in the French-speaking part of Switzerland. Another inclusion criteria was having a Swiss address. Eligible patients were identified through claims databases in two hospitals and through manual screening of patient records in two hospitals.

3.1.3 Data measures and data collection

Data were collected with the SCAPE questionnaire, a comprehensive cancer care survey containing 94 multiple-choice questions, divided into three main sections (see Appendix 3: SCAPE questionnaire).

The first section included 65 questions on experiences of care, based on the 2016 version of NHS Cancer Patient Experience Survey (NCPES) (164). The choice of instrument was made by a multiprofessional team led by Professor Eicher, who was mandated by one of the participating hospital wanting to implement a new PREMs instrument covering the cancer care trajectory. The team included representatives from the medical directorate and the interdisciplinary cancer centers, as well as experts in health services and nursing research. Seventeen criteria were pre-defined for the selection of the PREMs instrument: it had to be suitable for 1) adults, with 2) any type of cancer; it had to include questions on 3) inpatient and outpatient care, 4) coordination of care, 5) clinical nurse specialist, 6) information, 7) diagnosis, 8) treatment decisions, and 9) involvement of family and friends; other criteria were 10) cost, 11) psychometric validation, 12) time to complete, 13) length, 14) period evaluated, 15) summary score available, 16) time required for analysis, and 17) necessity of cultural adaptation. After a review of the published and grey literature to identify PREMs instruments for oncology, the team selected eight instruments for evaluation against the selection criteria. Although the NCPES had not undergone psychometric validation, it was selected through consensus by the team as it fulfilled most of the criteria. The first version of the NCPES in 2010 used questions from the previous Picker questionnaire with the addition of new questions developed specifically for cancer patients with input from cancer patients and advocates (165). Survey questions were subject to cognitive testing on samples of patients with different types of cancer in different English regions. The questions from the 2016 version were translated into French and culturally adapted following international guidelines (166, 167) by a multiprofessional team, including a patient and Chantal Arditi, Isabelle Peytremann-Bridevaux and Manuela Eicher. The section included 14 subsections on specific experiences of care at different points in the care pathway: diagnostic tests, communication about the cancer diagnosis, decision-making about the cancer treatment, hospital care as inpatient, home-based care and follow-up care. Seven of these subsections had filter questions, asking patients to answer only if they had had the targeted health care service (e.g. diagnostics tests, a hospitalization or an ambulatory visit) within the last 12 months. Most questions had a four- or five-point Likert-type scale response options (e.g. ‘yes, completely’, ‘yes, to some extent’, ‘no’, ‘not applicable’, ‘don’t know / can’t remember'); eight questions had binary response options (yes / no). The section ended with an overall rating of care item (i.e. "Overall, how would you rate your care?"), with a 0 (very poor) to 10 (very good) response scale.

The second section included 15 questions on cancer- and health-related characteristics, including a validated 7-item measure of quality of life (i.e. the functional assessment of cancer therapy (FACT-G7) for monitoring symptoms and concerns in oncology practice and research) (168) and two validated questions to detect depressive symptoms from the Primary Care Evaluation of Mental Disorders Procedure (PRIME-MD) (169). The third section included 14 questions on socio-demographic and economic characteristics. The questionnaire ended with one page for free-text comments.

The paper questionnaire was sent to patients' home (with the option of completing the survey online) between October 25 and November 8, 2018, with a reminder sent to non-respondents from two hospitals in January 2019. Questionnaires returned by the end of March 2019 were included in the analyses.

Further details of the SCAPE study can be found on the study website: www.scape-enquete.ch.

3.1.4 Data analyses

We computed the percentage of respondents reporting a positive experience for the 46 evaluative questions of the first section on experiences of care (i.e. questions asking patient to evaluate an aspect of care), following the methodology developed by the original NCPES team (170). After excluding the neutral (i.e. 'Don't know/can't remember') and not applicable answers from the calculation, the proportion of positive answers (i.e. 'yes, definitely') are calculated from the remaining sample. Thus, respondents who ticked 'yes, to some extent' and 'no' are considered as not reporting a positive experience.

We also performed item analyses, by computing for the rate of missing data (defined empirically as high if above 3%), the rate of respondents ticking the 'don't know/can't remember' (defined empirically as high if above 3%), and whether an evaluative question had a ceiling effect (defined empirically as present if more than 85% chose 'yes, definitely'). We also looked at the completion rates for the sections with filter questions (Q4, Q19, Q25, Q29, Q42, Q47, Q51).

For the analyses on the qualitative data, we used the IRaMuTeQ software that extracts frequent themes using an algorithm that separates the text into segments, which are then classified according to the co-occurrences of the words that compose these units using the Reinert method (171).

Other quantitative data analyses are described in each manuscript.

3.1.5 Ethics approval

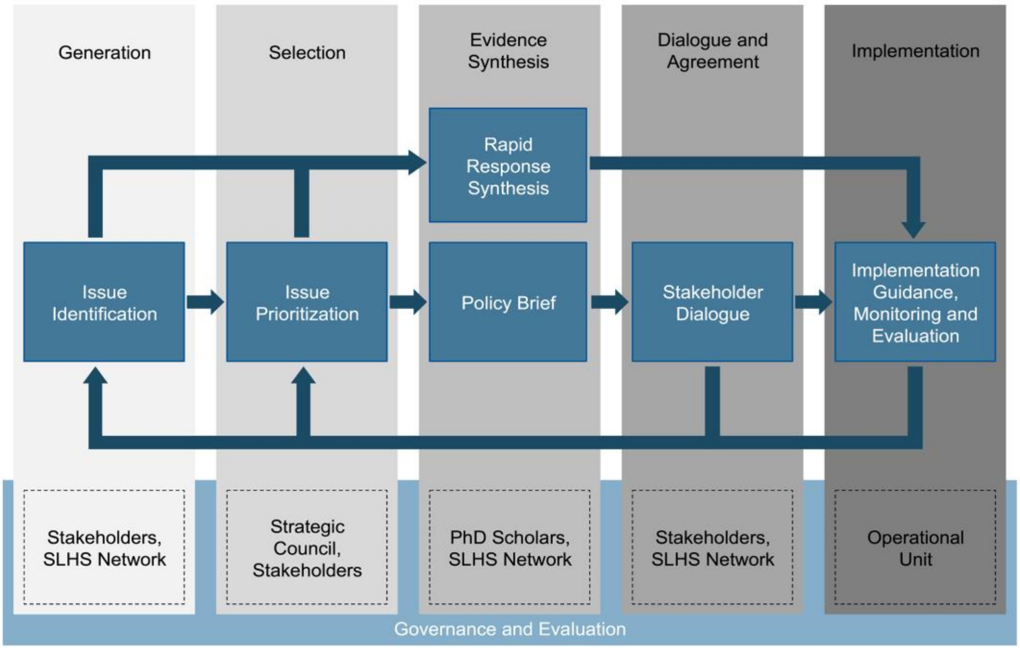
The study was approved on October 8, 2018 by the Commission cantonale d'éthique de la recherche sur l'être humain (CER-VD) (authorization number 2018–01345), member of the association of Swiss Ethics Committees on research involving humans (swissethics).

The study participants provided informed consent by returning the completed questionnaire.

3.2 The framework of the Swiss Learning Health System

The Swiss Learning Health System (SLHS), created in 2017, developed a framework to bridge research, policy, and practice by providing an infrastructure that supports learning cycles (172). Key features of learning cycles in the SLHS include the development of policy briefs that serve as a basis for stakeholder dialogues (see Figure 3). The objective of the policy brief is to describe the issue at stake and explain the relevant contextual factors. It then recommends a number of solutions to the issue (evidence-informed solutions when available), and for each possible solution/recommendation, it presents potential barriers and facilitators to their implementation. During a stakeholder dialogue, a group of stakeholders, ideally representing patients, providers, insurers, researchers and policymakers, discuss the issue, recommendations, and barriers and facilitators presented in the policy brief, and work in a collaborative manner towards a shared understanding of the issue and the best course of action.

Figure 3 Bridging mechanisms in the Swiss Learning Health System (SLHS) - the SLHS cycle



Source: (172)

3.2.1 Policy brief

We followed the guidance from the SLHS, based on the SURE collaboration guides (173) as well as the SUPPORT Tools for evidence-informed health policymaking (174), to write the policy brief on the topic of measuring PREMs in oncology, which needed to include the following elements:

1. Description of the underlying problems (lack of information on PREMs in oncology) and what is known about them, referring to systematic reviews if available (description of PREMS and their purposes, review of the available evidence on their effectiveness)
2. Policy and program options to implement PREMs in oncology, with the description of options followed in other countries
3. Review of the barriers and facilitators to implement PREMs in oncology, according to different levels (patient (micro), provider and institution (meso) and national health system (macro))

As the target audience is policymakers, the SLHS recommended a graded entry-format (1:3:25) for the policy brief, written in non-scientific terms, to allow policymakers to quickly evaluate the importance of the issue and whether it overlaps with their own key issues: one page of take-home messages, three-page executive summary, and 25 pages of report.

To prepare the brief, we searched for reviews, systematic reviews, grey and peer-reviewed literature on our topic in the following databases:

- Health systems evidence (https://www.healthsystemsevidence.org/), a repository of syntheses of research evidence about governance, financial and delivery arrangements within health systems, and about implementation strategies that can support change in health systems, using the following free key words combined with cancer: patient experience; patient-reported experience; patient perspective; patient satisfaction; patient-reported measures; quality monitoring using patient-reported measures; public reporting of patient-reported measures; quality improvement; quality indicators; patient-centered care
- PubMed (https://pubmed.ncbi.nlm.nih.gov/), using the key worde above and the following MeSH terms combined with neoplasms: Quality of Health Care*/standards; Delivery of Health Care/standards; Quality Improvement; Patient Outcome Assessment*; Self Report; Patient Satisfaction; Surveys and Questionnaires* ; Health Care Sector/statistics & numerical data*; Outcome Assessment (Health Care)*; Patient centered care; Review [pt] ; Systematic review [pt]

We also used the google search engine to identify reports on the topic of measuring PREMs in oncology. We checked reference lists of all relevant reports and studies to identify further relevant material.

3.2.2 Stakeholder dialogue

According to the SLHS framework, a stakeholder dialogue is defined as a structured interaction where stakeholders are brought together for the purpose of defining a common ground and to identify areas of agreement and disagreement on how to solve problems in the Swiss health care system (172). The dialogue takes the form of a deliberation where stakeholders work together to develop solutions that are acceptable to all parties (172). Thus, all stakeholders are invited to express their views - and the reasons behind them - in a constructive environment that facilitates mutual sharing and understanding of each other positions.

A list of stakeholders either directly or indirectly involved in cancer care and/or quality assessment (e.g. representatives of patient and professional associations, quality associations, quality of care) was made and invited to participate to the dialogue. A few weeks before the dialogue, the draft of the policy brief was sent to the stakeholders who agreed to participate. On the day of the dialogue, participants received a basic introduction to the format of the dialogue, with a specification of different stages and related tasks. They were then guided by the moderator, Sarah Mantwill from the SLHS, to assure participations from all the parties, and to ensure the incorporation of different opinions, arguments and preferences. 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.

4 Results

4.1 Feasibility of the SCAPE study

We provide here some results pertaining to the feasibility of the SCAPE study, defined as the extent to which the study could be carried out as planned and was completed by patients. Feasibility measures were operationalized as: the number of contacted hospitals that accepted to recruit patients, the number of postal returns, patient participation rates (paper and online; before and after the reminder), the completion rates of the different sections of the questionnaire, and rates of missing data.

Participating hospitals

Of the initial eight hospitals invited to participate to the SCAPE study, four hospitals (two university hospitals and two regional hospitals) accepted; one hospital declined participation due to lack of time and resources, one withdrew participation before patient recruitment due to organizational issues, and the last two hospitals never replied.

Mailing return rates and hotline calls

Of the 7145 envelopes sent, 134 were returned by post because of an error in the address (1.9%), the percentage ranging between 1.2% and 3.9% across the hospitals. A little over 1000 patients (14.7%) sent the coupon back or called the hotline to decline participation for various reasons (e.g. patient had died, patient was diagnosed with an ineligible cancer, patient was unable to respond due to dementia, patient did not speak French). We had about 190 calls on the central hotline, in addition to about 25 calls made to each hospitals and 20 emails to the study team.

Impact of reminders on response rate and characteristics of respondents responding after the reminder

A unique identification number to track responses allowed us to send a paper reminder letter (with a questionnaire and a return envelope) to non-responders three months after the initial mailing for two hospitals. Reminders could not be sent in the other two hospitals as local leaders did not wish to send them. For the two hospitals with reminders, the response rate went from 37.6% (n=1748, week 13, January 2019) before the reminder to 48.8% (n=2304, week 23, end of March 2019) after the reminder, increasing by 11.2 percentage points. The overall response rate was 44%.

The respondents who sent the questionnaire after the reminder were more likely to not speak French as a principal language, to have primary-level education, be on disability or sick leave, and have a precarious financial situation compared to respondents who replied before the reminder, among respondents from the two hospitals that sent reminders. They also differed on three health-related characteristics, reporting more often depressive symptoms (46.3% vs 35.8%) and reporting lower mean scores on overall health (50.2 vs 52.9) and quality of life (18.5 vs 19.2).

There were no systematic differences regarding their evaluation of experiences of care, although their overall rating of care was significantly lower in bivariate analyses (8.2 for reminder respondents vs 8.5 for first respondents).

Rate of online survey completion, characteristics and reported experiences of online respondents

The survey was completed online by 225 (7.2%) patients.

The sociodemographic profile of respondents who replied online differed significantly in bivariate analyses from the paper-based respondents on several characteristics: they were more likely men, younger, more educated, and professionally active.

Regarding experiences of care, online respondents were significantly less likely to report positive experiences for 15 questions (out of 46) in bivariate analyses, including the overall rating of care: 8.3 for online vs 8.6 for paper respondents.

Rates of missing data, 'don't know/can't remember' answers, and presence of ceiling effect

In the first section of the questionnaire relating to experiences of care, the percentage of missing data varied between 0.2% and 5.6%, with a rate above 3% for 9 questions. The highest percentages of missing data were found for the filter questions. In sections 2 (cancer and health-related characteristics) and 3 (socio-demographic characteristics), missing data varied between 1.3% (type of treatment received) and 5.1% (use of complementary and alternative medicine) and between 0.6% (sex) and 2.5% (age), respectively. Three questions in section 2 had a rate above 3%.

Regarding the rate of 'don't know/can't remember' in the first section, it ranged from 0.1% to 10.4% (Q10 told they could bring family or friend at diagnosis). The rate was above 3% for 12 questions out of 31 questions with that response option. The other sections had only four questions with that option, with 8% choosing it for Q68 (presence of metastasis at diagnosis). Rate was lower than 3% in the other three questions.

Ceiling effect was present for two questions: Q6 on waiting times before diagnostic test and Q38 on being treated with respect and dignity during inpatient stay.

Completion rates of sections with filters

The percentage of patients who said yes to the seven filter questions and completed the related sections ranged from a high 79.5% for a diagnostic test within the last 12 months to a low 28.0% and 27.1% for chemotherapy and radiotherapy within the last 12 months, respectively; 52.9% of respondents answered about an ambulatory visit, 39.4% about a hospitalization, 38.0% about an operation within the last 12 months, and 43.1% of respondents said they had a consultation with a clinical nurse specialist.

4.2 Patient-reported experiences of cancer care in Switzerland and variation by type of cancer *(article #1)*

Title of the manuscript published in the peer-reviewed European Journal of Cancer Care: "Patients' experiences with cancer care in Switzerland: results of a multicenter cross-sectional survey"

The manuscript presents the main results of the SCAPE study relating to respondents' characteristics and the experiences of care as reported by patients in French-speaking Switzerland. Respondents rated overall cancer care at 8.5 on a scale from 0 (worst) to 10 (best). Areas of cancer care with the highest rates of positive experiences were nurse consultations, diagnostic tests and inpatient care (e.g. confidence and trust in doctors, treated with respect and dignity, enough nurses). On the other hand, areas of cancer care the lowest rates of positive experiences were related to communication, information and supportive care issues (e.g. receiving written information at diagnosis, advice and support short- and long-term side effects, information about social and financial support). The analyses of the variation of experiences of care by cancer type showed that experiences of care differed by type of cancer, without being systematically more positive (or negative) for one type of cancer.

Chantal Arditi conceptualized and acquired the funding support for the SCAPE study with Isabelle Peytremann Bridevaux and Manuela Eicher; she managed the research planning and execution; she conducted the data acquisition under the supervision of Manuela Eicher and Isabelle Peytremann Bridevaux; she conducted all analyses and wrote the initial draft.

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ORIGINAL ARTICLE

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Patients' experiences with cancer care in Switzerland: Results of a multicentre cross-sectional survey

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Abstract

Objectives: The objectives were to describe patients' experiences of cancer care in Switzerland and explore the variation of these experiences by type of cancer.

Methods: The Swiss Cancer Patient Experiences (SCAPE) study was a cross-sectional, multicentre survey conducted in 2018. Adult patients ($n = 7145$) with breast, prostate, lung, colorectal, skin or haematological cancer from four large hospitals in French-speaking Switzerland were invited to complete a survey. Logistic regressions were used to assess whether experiences varied according to cancer type, adjusting for confounders.

Results: Of the 3121 persons who returned the survey (44% response rate), 2755 reporting an eligible cancer were included in the analyses. Participants' average score for overall care was 8.5 out of a maximum score of 10. Higher rates of positive experiences were found for nurse consultations (94%), diagnostic tests (85%) and inpatient care (82%). Lower positive responses were reported for support for people with cancer (70%), treatment decisions (66%), diagnosis (65%) and home care (55%). We observed non-systematic differences in experiences of care by cancer type.

Conclusions: This large study identified that cancer patient experiences can be improved in relation to communication, information and supportive care aspects. Improvement efforts should target these areas of care to enhance responsiveness of cancer care.

KEYWORDS
cancer, patient experiences, patient satisfaction, patient survey, quality of care, Switzerland

1 | INTRODUCTION

The importance of integrating patients' perspectives into clinical practice and research as well as into the evaluation of the quality of care has been recognised internationally (Institute of Medicine Committee on Quality of Health Care in America, 2001; Kelley & Hurst, 2006). More specifically, patients' perspectives are key to evaluate responsiveness of care. This core dimension of quality of care is defined as care that responds to people's physical, emotional, social and cultural needs, where interactions with health professionals are compassionate and empowering, and where people's values and preferences are taken into account ("What Is Patient-Centered Care?", 2017; The

Health Foundation, 2016). Collecting patients' experiences of care through surveys using self-reported questionnaires is a widely used method to evaluate responsiveness of care on a large scale (Cleary, 2016; McKenna, 2011; Snyder et al., 2013). These surveys ask patients to rate their experience and satisfaction with health services, including experiences during hospital care, general practice care and home-based care. While earlier studies focused on patient satisfaction, more recent studies questioned its frequent ceiling effects and limited responsiveness. Consequently, studies shifted their focus on the underlying components of satisfaction, i.e. expectations and experiences, by collecting reports of what actually happened to patients during a hospital stay or medical consultation (Sixma et al., 1998). These reports, called patient-reported experience measures (PREMs), are also more actionable to drive interventions to improve responsiveness of care (Coulter et al., 2020).

In cancer care, evaluating responsiveness of care is especially relevant, as cancer carries an emotional, social and financial burden on patients and their carers in addition to the health burden and impact on quality of life. The use of cancer-specific PREMs are encouraged to account for the complex treatment pathways and to improve the interpretation of findings and prioritisation of quality improvement initiatives (Abel et al., 2014). Several countries have thus established wide-scaled measurement of cancer-specific PREMs to systematically examine cancer patient experiences. Such initiatives include the CAHPS Cancer Care survey in the United States (Agency for Healthcare Research and Quality, 2017), the NHS Cancer Patient Experience Survey in the UK (Abel et al., 2014), and the European Cancer Consumer Quality Index survey in six European countries (Wind et al., 2016). To date, similar standardised initiatives do not exist in Switzerland. Despite the efforts of the Swiss National Association for quality development in hospitals and clinics (ANQ) to collect PREMs using a 6-item generic questionnaire (Groupe qualité interdisciplinaire Satisfaction des patients [QA PatZu], 2017), no large-scale, comprehensive or systematic collection of cancer-specific PREMs has been established in Switzerland to date. This lack of standardised experience surveys might partly be related to the late implementation of a national quality commission in Switzerland, founded in 2021 only. There is thus a gap in measuring PREMS with a standardised instrument in routine cancer care in Switzerland, as well as a gap in Swiss research to inform and promote the use of PREMs in cancer care. To our knowledge, only a few studies focusing on cancer experiences in Switzerland have been published in the last 10 years, one of which was a single site qualitative study in paediatric oncology (Wangmo et al., 2016) and another one including breast cancer patients only (Brédart et al., 2013).

The assessment of experience variations according to cancer type is relevant to determine whether systematic differences of care exist. Such analyses can inform the development of more targeted interventions within organ-specific cancer centres for instance. However, the current understanding of the variation of PREMS by organ (i.e. cancer diagnosis) is still limited, as large national surveys with sufficient patients diagnosed with different cancers enabling such analyses are relatively recent, with few studies investigating the impact of type of cancer on patient experiences (Saunders et al., 2015). Previous studies have reported mixed results, with better experiences reported in general for breast cancer and skin cancer and worse experiences for prostate and colorectal cancers (Bone et al., 2014; Clucas, 2016; El Turabi et al., 2013; Heerdegen et al., 2017; Pham, Abel, et al., 2019; C. Saunders et al., 2016; Sherlaw-Johnson et al., 2008). The observed differences could be explained by clinical features of different cancers, such as the diagnostic processes, the treatment burden and the prognosis, as suggested by Saunders and colleagues (Saunders et al., 2015).

The primary objective of the Swiss Cancer Patient Experiences (SCAPE) study was thus to describe the experience of care of patients with cancer treated in large hospitals in the French-speaking region of Switzerland. The secondary objective was to explore the variation of experiences of care by type of cancer, adjusting for confounders.

2 | METHODS

2.1 | Study design and population

The SCAPE study was an observational cross-sectional multicentre survey of patients diagnosed with cancer in four large hospitals in the French-speaking region of Switzerland. [Correction added on 6 October, after first online publication: The name of the study in this section was corrected in this version.] The patient inclusion criteria were predefined as all adult Swiss residents (≥18 years) with a confirmed diagnosis of one of the six most frequent cancers in Switzerland (i.e. breast, prostate, lung, colorectal, skin or haematological cancer [leukaemia, lymphoma and myeloma]) and who had had at least one hospitalisation or outpatient visit in an oncology unit at the recruiting hospital between 1 January 2018 and 30 June 2018. The diagnostic inclusion criteria was limited to six cancer types with high prevalence in Switzerland, based on the estimations of minimum sample size for the planned analyses by cancer types and the feasibility of the study. Patient selection procedure was performed by the local hospital teams, through manual review of patient lists in two hospitals and through data inquiries in electronic databases (including diagnostic codes) in the other two hospitals.

2.2 | Data collection

All data were collected using a paper and pencil or electronic self-administered questionnaire. The paper questionnaire (with the option of completing the survey online) was sent out by each hospital to patients' home end of October 2018. A reminder was sent to non-respondents in January 2019. Individuals who returned the questionnaire by the end of March 2019 and reported at least one of the eligible cancers were included in the analyses.

2.3 | Measures

The questionnaire was structured into three sections (Section 1: experiences of care; Section 2: cancer and health characteristics; Section 3:

socio-demographic and economic characteristics) and space was provided at the end for free-text comments. The analyses of the free-text comments have been reported elsewhere (Arditi et al., 2020).

Section 1 on experiences of care included 46 evaluative questions on experiences of care (i.e. questions asking patient to evaluate an aspect of care), based on the 2016 version of the NHS Cancer Patients Experience Survey (CPES), originally developed in the UK (NHS England, 2021). With their approval, questions were translated into French and culturally adapted following international guidelines (Cull et al., 2002; Wild et al., 2005). The section included 14 subsections related to patient experiences throughout the care pathway, spanning from cancer diagnosis to follow-up care in the community (e.g. diagnostic tests; communication about the cancer diagnosis; decision-making about the cancer treatment and hospital care as inpatient). Seven of these subsections had filter questions, asking patients to answer only if they had had the targeted healthcare service (e.g. diagnostics tests, a hospitalisation or an ambulatory visit) within the last 12 months. Most questions had a 4- or 5-point Likert-type scale response options (e.g. *yes, completely*; *yes, to some extent*; *no*; *not applicable*; and *don't know/can't remember*); eight questions had binary response options (yes/no). The section ended with an overall satisfaction item (0 to 10 rating scale).

Section 2 on cancer and health characteristics included 15 questions on cancer diagnosis and treatments, other health conditions (list of 12 chronic conditions), overall health status (excellent, very good, good, poor, bad), quality of life (FACT-G7) (Yanez et al., 2013), two questions on depression symptoms (Whooley et al., 1997), and psycho-social characteristics (e.g. health literacy). Self-reports of cancer diagnosis and treatments were used as they have been extensively used in epidemiological and clinical studies and shown to be valid and sensitive (Kool et al., 2017; Navarro et al., 2006).

Section 3 on socio-demographic and economic characteristics included 12 questions, such as age, sex, principal language (French, other), living status (alone/couple, with/without children, other), education, professional occupation, and financial hardship.

2.4 | Data analyses

For the descriptive analyses, the percentage of patients reporting a positive experience (dichotomous variable) was computed for the 46 evaluative questions, according to the methodology developed by the original CPES team (NHS England, 2021). After excluding the neutral (i.e. 'Don't know/can't remember') and not applicable answers from the calculation, the proportion of positive experience answers (i.e. 'yes, definitely') was calculated from the remaining sample for the 46 evaluative questions. The percentages of positive experiences were colour-coded by 10% segments to visually assess levels of positive experiences in Table 2. The proportion of positive experiences (i.e. the proportion of 'yes, definitely' for patients who answered more than 50% of the questions in the subsection) was also averaged across patients for each of the 14 subsections of the questionnaire.

The percentage of positive experience was compared across types of cancer, using Pearson's chi-square test (or Fisher's test if the number of events in a category was under five). Univariate logistic regressions were used to calculate unadjusted odds ratios (OR) and 95% confidence intervals (CI) of reporting a positive experience by type of cancer for each evaluative question ($n = 46$) and overall satisfaction. This was followed by multiple logistic regressions to evaluate the associations between type of cancer and positive experiences of care, adjusting for five major confounders for patient satisfaction reported in previous studies (Abel et al., 2014; Hargraves et al., 2001) (age, sex, health status, education and financial hardship) and for the recruiting hospital. For each logistic regression, a likelihood ratio test was performed to estimate the *p*-value associated with the main independent variable of interest, that is, type of cancer. Patients reporting more than one eligible cancer ($n = 128$) were excluded from the analyses by type of cancer as they could not be assigned to one cancer group.

The intraclass correlation coefficients obtained from mixed-models with a random effect for each hospital were calculated for all evaluative questions. As they were all below 0.01, the effect of clustering by hospital was considered to be negligible and thus multilevel modelling not necessary. All *p*-values were corrected for multiple testing using the False Discovery Rate method (Benjamini & Hochberg, 1995). Complete case analysis was performed; all statistical analyses were conducted with Stata 16.1.

2.5 | Patient involvement

A Patient Partner, co-author of this paper, was involved in the research process. She took part in the study steering committee and participated in pre-testing the questionnaire, writing the patient materials sent with the questionnaire, answering patient inquiries by email during the recruitment phase, analysing the open comments, preparing and writing the lay summary of results sent to participating patients, communicating the results on social media, and disseminating the study to the scientific community.

3 | RESULTS

3.1 | Participants' characteristics

Among the 7145 individuals invited to participate in the survey, 3121 completed the survey (225 completed it online [7.2%]), resulting in a 43.7% participation rate. Participants who reported a non-eligible cancer diagnosis were excluded from the analyses ($n = 366$), leading to 2755 participants (344, 372, 498 and 1541 in each hospital) included in the descriptive analyses. The number of respondents included in the calculated percentage of positive experiences for each evaluative question of the first section of the questionnaire (Q1 to Q46) varied between 626 for Q33 (22.7% of sample) and 2729 for Q7 (99.1% of sample), with a median of 1500 respondents (54.4% of sample) (see Table 2).

Participants' mean age was 63.9 (standard deviation [SD] 12.8) and 61% of respondents were women. Eighty-one percent of respondents reported a first cancer, the most common cancers being breast

TABLE 1 Respondents' sociodemographic and clinical characteristics

	N (%) or mean (SD)
Sex	
Women	1670 (61.0%)
Men	1068 (39.0%)
Age	
mean (SD)	63.9 (12.8)
18–34	61 (2.3%)
35–44	145 (5.4%)
45–54	390 (14.5%)
55–64	680 (25.3%)
65–74	861 (32.0%)
75–84	470 (17.5%)
85+	80 (3.0%)
Education	
Primary	429 (16.0%)
Secondary	1347 (50.2%)
Tertiary	909 (33.8%)
Professional status	
Active	737 (27.1%)
Disability or sick leave	293 (10.8%)
Retired	1431 (52.7%)
Other	254 (9.4%)
Principal language	
French	2634 (86.4%)
Other	373 (13.6%)
Had trouble paying household bills in past 12 months	
Yes	569 (21.0%)
No	2138 (79.0%)
Type of diagnosis	
First cancer	2168 (80.5%)
Recurrence	275 (10.2%)
2nd or 3rd cancer	249 (9.3%)
Time since first treatment	
<1 year	741 (27.7%)
1–5 years	1281 (47.8%)
>5 years	656 (24.5%)
Treatment(s) received	
Surgery	1669 (61.1%)
Chemotherapy	1573 (57.9%)
Radiotherapy	1426 (52.5%)
Hormonotherapy	759 (27.9%)
Immunotherapy	354 (13.0%)
Other therapy (target, transplant)	242 (8.9%)
None	40 (1.5%)
Co-morbidities	
≥1 chronic disease other than cancer	1582 (59.2%)
None	1090 (40.8%)

TABLE 1 (Continued)

	N (%) or mean (SD)
Overall health status (0–100 excellent)	
mean (SD)	52.6 (20.6)
Excellent/very good	674 (25.0%)
Good	1563 (57.9%)
Poor/bad	462 (17.2%)
Depressive symptoms in past month	
Yes	999 (36.8%)
No	1715 (63.2%)
Quality of life (FACT-G7 0–28 excellent)	
mean (SD)	19.2 (4.4)

[Correction added on 6 October, after first online publication: In Table 1, right column of ‘Quality of life (FACT-G7 0–28 excellent)’, the number “19” has been removed from this version.]

cancer (40.1%) followed by haematologic cancer (15.9%), lung cancer (15.0%) and colorectal cancer (10.5%). About half (47.8%) were first treated between 1 and 5 years before completing the survey. Details of participants' sociodemographic and clinical characteristics are presented in Table 1.

3.2 | Overall satisfaction and experiences of care: Global results

The overall satisfaction (Q47) was rated at a mean 8.5 (SD 1.4). The percentage of patients reporting positive experiences ranged from 36.5% (Q45) to 96.1% (Q15) (see Table 2). Over 80% of respondents reported positive experiences with timely access to specialist care (Q1), timely access to and information about diagnostic tests (Q2, Q3 and Q4), explanations about different treatments (Q9), communication with specialist nurses (Q14 and Q15), most aspects of hospital care as inpatient (Q18, Q19, Q20, Q22, Q25, Q26 and Q28), availability of documents during ambulatory care (Q30), information before the radiotherapy (Q32), GP receiving enough information (Q42) and administration of care (Q46). However, less than 60% of respondents reported positive experiences in relation to being told they could bring someone at diagnosis (Q5), receiving written information at diagnosis (Q8), being offered practical advice and support for side effects (Q11) and information about long-term side effects (Q12), information for family to help at home (Q36), about social support during and after treatment (Q37 and Q38) and financial support (Q41), and receiving a care plan (Q45). The results are graphically summarised using radars presenting the average positive experience score by subsection of the questionnaire (see overall line in Figure 1).

3.3 | Overall satisfaction and experiences of care: By type of cancer

Overall satisfaction (Q47) varied according to cancer, with patients reporting skin cancer rating their overall care the highest and patients reporting breast cancer the lowest (see Table 2). When adjusting for patients' characteristics and the hospital, individuals with prostate cancer were the least likely to being satisfied overall (see Table 3).

Experiences of care varied significantly by type of cancer for 11 evaluative questions, without being systematically more positive (or negative) in all areas of care for one type of cancer (see Table 3 and Figure 1; the details of the 95% CI of unadjusted and adjusted ORs are provided in Table S1). Results showed that patients reporting colorectal cancer were the least likely to report positive experiences for waiting time before diagnostic test (Q3), information on long-term side effects (Q12), hospital care as inpatient (Q23, Q26 and Q27), and radiotherapy (Q35 and Q36). Individuals with breast and lung cancers were the most likely to report positive experiences of care for at least a quarter of the evaluative questions: especially in the subsections ‘support for people with cancer’ and ‘inpatient care’ for breast cancer and in the subsections ‘finding out what was wrong’ and ‘deciding the best treatment’ for lung cancer. On the contrary, the latter two subsections were the least likely to be reported as positive by individuals reporting haematologic cancer. Finally, individuals with prostate and skin cancers were the least likely to report positive experiences for ‘support for people with cancer’, while individuals with prostate cancer were also the least likely to report positive experiences for ‘home care and support’.

4 | DISCUSSION

This was the first large-scale measure of patient-reported experiences of cancer care in Switzerland using a validated questionnaire adapted to the Swiss context. Overall, experience with cancer care was rated rather highly. In particular, our results identified which areas of care were patient-centred, with over 80% of respondents reporting positive experiences with nurse consultations, diagnostic tests and inpatient care (e.g. confidence and trust in doctors; treated with respect and dignity and enough nurses). On the other hand, results showed where patient-centredness was suboptimal, with less than 60% of patients reporting positive experiences in relation to communication, information and supportive care issues, such as receiving written

TABLE 2 Percentage of positive experience by evaluative question, overall and by type of cancer

Percentage of positive experience	n	All Cancers	Colorectal (*n* = 289)	Breast (*n* = 1105)	Prostate (*n* = 237)	Lung (*n* = 414)	Haematologic (*n* = 438)	Skin (*n* = 144)	*p*-value
Before seeing a specialist									
Q1. Seen as soon as necessary	2545	84.4	81.2	86.7	82.6	83.3	84.5	87.2	
Diagnostic tests									
Q2. Had all the information needed beforehand	2162	83.3	84.0	86.7	80.7	89.6	72.1	89.8	
Q3. Waiting time before the test thought to be right	2148	89.9	85.1	90.8	86.3	90.5	92.8	95.0	*
Q4. Test results explained in an understandable way	2151	80.9	82.0	81.4	78.5	83.3	77.1	79.2	
Finding out what was wrong									
Q5. Told they could bring family or friend beforehand	2435	48.9	46.3	46.9	45.9	55.1	52.9	39.2	*
Q6. Told they had cancer in a sensitive manner	2666	77.5	78.6	77.6	77.1	79.6	74.3	81.0	
Q7. Understood explanations of what was wrong	2729	74.2	74.9	74.9	78.2	79.6	64.4	75.4	**
Q8. Received written information about cancer that was easy to understand	1695	49.9	57.1	46.3	65.1	52.2	40.7	49.4	**
Deciding the best treatment									
Q9. Different types of treatment explained beforehand	2416	81.0	78.0	80.9	81.2	84.4	77.6	81.5	
Q10. Possible side-effects explained in an understandable way	2634	68.4	67.7	68.8	68.1	72.3	64.2	65.7	
Q11. Offered practical advice and support in dealing with side-effects	2280	57.7	58.6	59.7	52.1	63.4	54.1	42.4	**
Q12. Told about possible side-effects occurring in the future	2442	49.9	43.1	46.8	62.0	54.8	48.7	53.3	**
Q13. Involved as much as wanted to be in care decisions	2654	71.0	72.2	68.5	75.6	76.5	67.4	76.8	*
Consultation with specialist nurse									
Q14. Easy to contact nurse	1100	92.6	90.1	92.8	95.7	92.7	89.0	100.0	
Q15. Received understandable answers to important questions	1096	96.1	97.1	96.6	97.1	94.9	93.6	87.5	
Operations									
Q16. Had all the information needed beforehand	1045	85.0	82.8	82.2	92.2	90.4	84.0	88.0	
Q17. Operation results explained in an understandable way	1011	73.8	75.2	67.9	73.7	78.8	82.8	82.2	*

TABLE 2 (Continued)

Percentage of positive experience	n	All Cancers	Colorectal (*n* = 289)	Breast (*n* = 1105)	Prostate (*n* = 237)	Lung (*n* = 414)	Haematologic (*n* = 438)	Skin (*n* = 144)	*p*-value
Hospital care as inpatient									
Q18. Doctors and nurses did not talk in front of patient as if they were not there	1077	84.7	77.6	91.3	86.1	77.7	84.7	81.0	**
Q19. Confidence and trust in all ward doctors	1080	82.6	84.3	83.8	86.4	76.5	82.8	87.3	
Q20. Patient's family had opportunity to talk to doctor	789	81.9	82.5	81.3	83.3	78.1	83.2	86.1	
Q21. Confidence and trust in all ward nurses	1082	77.8	76.5	77.3	84.0	73.3	81.5	81.0	
Q22. Always or nearly always enough nurses on duty	1074	87.3	84.8	88.6	90.1	81.9	92.9	83.9	
Q23. Always given enough privacy when discussing condition or treatment	1077	77.9	73.2	77.5	84.0	73.5	83.4	80.7	
Q24. Found someone on hospital staff to talk to about worries and fears	786	57.3	52.2	58.8	60.4	52.6	67.7	44.4	
Q25. Hospital staff did everything they could to help control pain	1011	84.5	82.8	83.8	84.9	83.0	88.4	89.5	
Q26. Always treated with respect and dignity by staff	1081	91.3	88.9	91.8	93.8	87.6	92.4	93.7	
Q27. Received written information about what they should (not) do post discharge	684	71.1	65.7	73.6	74.5	61.2	75.5	75.0	
Q28. Told by staff who to contact if worried post discharge	815	90.6	89.1	88.5	90.6	90.6	92.7	95.7	
Hospital care as day patient/outpatient									
Q29. Find someone on hospital staff to talk to about worries and fears	1156	70.9	69.1	69.8	71.3	74.0	78.0	58.6	
Q30. Doctor had the right notes and documents available	1293	85.7	86.7	80.5	84.9	92.2	88.8	86.1	**
Q31. Time spent in waiting room correct/quite correct	1444	78.8	80.6	78.9	86.5	76.6	85.4	62.5	**
Radiotherapy									
Q32. Had all the information needed beforehand	737	85.6	80.3	86.5	83.8	87.1	85.1	86.4	
Q33. Results explained in an understandable way	626	67.9	60.0	67.8	60.7	69.7	73.8	66.7	
Chemotherapy									
Q34. Had all the information needed beforehand	762	79.5	81.3	79.2	92.0	75.3	79.5	85.7	
Q35. Results explained in an understandable way	689	74.3	73.6	72.0	81.0	72.7	77.9	66.7	

(Continues)

TABLE 2 (Continued)

Percentage of positive experience	n	All Cancers	Colorectal (*n* = 289)	Breast (*n* = 1105)	Prostate (*n* = 237)	Lung (*n* = 414)	Haematologic (*n* = 438)	Skin (*n* = 144)	p-value
Home care and support									
Q36. Family given all information needed to help care at home	1914	57.5	64.8	51.2	57.5	60.5	60.9	62.8	*
Q37. Given enough care from health or social services during treatment	1767	58.0	66.5	58.1	52.7	51.7	57.0	64.1	
Q38. Given enough care from health or social services after treatment	1161	48.6	45.7	48.6	43.1	47.7	49.7	46.9	
Support for people with cancer									
Q39. Hospital staff gave information about support groups	1752	79.7	77.8	86.0	64.6	72.2	78.3	56.9	*
Q40. Hospital staff discussed or gave information on impact of cancer on daily activities	1556	76.2	76.0	77.0	76.3	75.9	78.7	59.4	
Q41. Hospital staff gave information on getting financial help or benefits	1304	48.6	38.2	55.4	38.4	38.8	52.5	33.3	*
Care from GP									
Q42. GP given enough information about patient's condition and treatment	2351	86.7	91.1	83.2	89.2	88.2	89.0	83.3	**
Q43. GP and staff did everything they could to support patient	1935	73.1	76.5	68.5	72.2	76.7	75.2	77.1	
Overall care									
Q44. People treating and caring for you worked well together	2655	62.0	68.0	55.7	69.5	64.3	65.0	62.2	*
Q45. Received a care plan	2096	36.5	41.1	37.3	37.8	34.7	34.4	27.7	
Q46. Administration of care rated as very good or good	2696	89.9	92.2	88.8	89.7	91.8	89.6	92.8	
Q47. Overall rating of care = 10/9/8	2696	83.0	84.3	79.7	85.2	85.7	84.5	89.9	*
Overall rating of care, mean (SD)	2696	8.54 (1.4)	8.60 (1.3)	8.40 (1.5)	8.53 (1.6)	8.63 (1.3)	8.63 (1.3)	8.75 (1.2)	##

Note: Pearson's χ^2 (or Fisher's) test $^{*}p < 0.05$; $^{**}p < 0.01$; one-way ANOVA test $^{\#\#}p < 0.01$; all *p*-values corrected for multiple testing.
Colour-shading of the percentages of positive experiences:

100.0-90.0%	89.9-80.0%	79.9-70.0%	69.9-60.0%	59.9-50.0%	49.9-0.0%

information at diagnosis, advice and support short- and long-term side effects, as well as information about social and financial support. We also found that experiences of care varied according to the type of cancer, without being systematically more positive (or negative) in all areas of care for one type of cancer.

Experiences around the communication of cancer diagnosis, especially regarding the receipt of written information and the involvement of family or friends, were poorly rated by study participants. This was particularly the case in respondents with haematologic cancers, similarly to the findings of a recent systematic review covering mainly studies from Australia, the United States and Canada where a high prevalence of unmet informational needs was found in this population (Tsatsou et al., 2020). Communication around the cancer diagnosis is a key moment in the patient journey, which requires

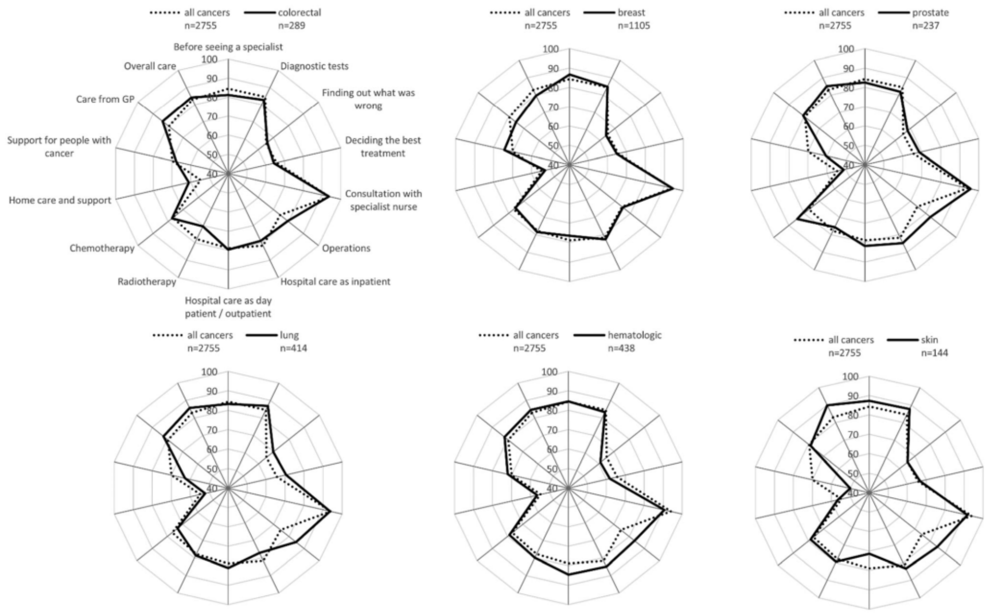

FIGURE 1 Positive experience score in the 14 subsections, overall and by type of cancer. Legend: all cancers: all respondents; colorectal: respondents reporting colorectal cancer; breast: respondents reporting breast cancer; prostate: respondents reporting prostate cancer; lung: respondents reporting lung cancer; haematologic: respondents reporting haematologic cancer; skin: respondents reporting skin cancer. Positive experience scores were calculated as the proportion of positive experiences in the questions of the subsection averaged across patients.

healthcare professionals to be responsive to each patient's individual needs making it a difficult exercise. Tailored information for each patient and his/her relatives remains a challenge to date, despite its important impact on quality of life, anxiety and depression (Husson et al., 2011). Cancer-specific information brochures intended for patients and published by the Swiss cancer league are available in the three national languages. However, our results suggest that these brochures might not be sufficient to ensure responsive care during the diagnostic phase; more tailored approaches are required to meet patients' needs.

Less positive experiences also concerned information and support on side effects during and after the treatment, especially for individuals diagnosed with colorectal and haematologic cancers. This is a frequently reported problem area in cancer care, as shown in studies in Germany in outpatient settings for instance (Kleeberg et al., 2008; Liekweg et al., 2005). The need for interventions to facilitate self-management of symptoms has been previously highlighted (Howell et al., 2021) and programmes are currently being implemented in Switzerland (Bana et al., 2020). To improve the management of symptoms and side effects, these programmes should be further developed, implemented and evaluated.

Within our surveyed population, we observed that experiences of care varied among patients with different cancer diagnoses, although not consistently: better experiences were reported for different types of cancer at different times in the care pathway. As our analyses were adjusted for the main socio-demographic drivers of patient satisfaction (age, sex, health status, education and financial hardship), explanations for these patterns may be related to disease-specific factors, such as treatment burden and prognosis as suggested in previous studies, where patients with poor prognosis tend to report worse experiences of care for instance (Ayanian et al., 2010; Saunders et al., 2015). This finding suggests that improvement strategies should be tailored by type of cancer and care trajectory. These strategies should include the provision of information more easily understandable as well as emotional support for patients with diagnoses at higher risk of poorer experience. In our study, inpatient care for individuals with colorectal and lung cancer was consistently rated the lowest, suggesting that inpatient care for these patients would benefit the most from more patient-centred care responding to their specific needs. Lower ratings among colorectal patients were also often reported in previous studies (Bone et al., 2014; Clucas, 2016; Engel et al., 2018; Heerdegen et al., 2017; Sherlaw-Johnson et al., 2008). On the other hand, patients with breast cancer tended to report more often higher levels of positive experiences, as reported in most studies (Clucas, 2016; Davidson & Mills, 2005; Heerdegen et al., 2017; Pham, Gomez-Cano, et al., 2019; Saunders et al., 2015; Sherlaw-Johnson et al., 2008), though some also reported the contrary (Arraras et al., 2013; Liekweg et al., 2005). These conflicting findings may be

TABLE 3 Adjusted odds ratios (OR) of reporting a positive experience, by type of cancer

Adjusted OR of reporting a positive experience	*n*	Colorectal (*n* = 289)	Breast (*n* = 1105)	Prostate (*n* = 237)	Lung (*n* = 414)	Haematologic (*n* = 438)	Skin (*n* = 144)	*p*-value
Before seeing specialist								
Q1. Seen as soon as necessary	2285	Ref	2.00	0.90	1.27	1.45	1.57	
Diagnostic tests								
Q2. Had all the information needed beforehand	1938	Ref	1.13	0.93	2.24	0.87	1.84	
Q3. Waiting time before the test thought to be right	1926	Ref	1.87	1.08	1.88	2.15	2.91	*
Q4. Test results explained in an understandable way	1926	Ref	1.04	0.83	1.21	0.67	0.72	
Finding out what was wrong								
Q5. Told they could bring family or friend beforehand	2160	Ref	1.02	1.04	1.42	1.28	0.75	
Q6. Told they had cancer in a sensitive manner	2381	Ref	1.32	0.75	1.22	0.88	1.19	
Q7. Understood explanations of what was wrong	2431	Ref	1.30	0.99	1.56	0.64	1.06	**
Q8. Received written information about cancer that was easy to understand	1494	Ref	1.04	0.94	0.99	0.53	0.79	*
Deciding the best treatment								
Q9. Different types of treatment explained beforehand	2139	Ref	1.20	1.38	1.73	1.00	2.03	
Q10. Possible side-effects explained in an understandable way	2347	Ref	1.19	1.06	1.57	0.92	1.06	
Q11. Offered practical advice and support in dealing with side-effects	2032	Ref	1.13	0.76	1.46	0.84	0.60	**
Q12. Told about possible side-effects occurring in the future	2177	Ref	1.41	2.29	1.76	1.30	1.77	*
Q13. Involved as much as wanted to be in care decisions	2368	Ref	0.95	1.08	1.60	0.89	1.27	*
Operations								
Q16. Had all the information needed beforehand	929	Ref	1.09	2.55	2.34	1.16	1.89	
Q17. Operation results explained in an understandable way	898	Ref	0.75	0.96	1.50	1.85	1.65	
Hospital care as inpatient								
Q18. Doctors and nurses did not talk in front of patient as if they were not there	949	Ref	2.58	1.53	1.19	1.60	0.94	
Q19. Confidence and trust in all ward doctors	951	Ref	1.57	0.82	0.68	0.89	1.33	
Q20. Patient's family had opportunity to talk to doctor	693	Ref	1.04	1.04	0.91	1.27	1.60	
Q21. Confidence and trust in all ward nurses	952	Ref	1.78	1.36	0.92	1.75	1.92	
Q22. Always or nearly always enough nurses on duty	905	Ref	1.70	1.09	0.96	2.39	0.93	
Q23. Always given enough privacy when discussing condition or treatment	948	Ref	1.88	1.46	1.20	2.44	1.48	

TABLE 3 (Continued)

Adjusted OR of reporting a positive experience	*n*	Colorectal (*n* = 289)	Breast (*n* = 1105)	Prostate (*n* = 237)	Lung (*n* = 414)	Haematologic (*n* = 438)	Skin (*n* = 144)	*p*-value
Q24. Found someone on hospital staff to talk to about worries and fears	690	Ref	1.27	1.23	1.17	2.18	0.84	
Q25. Hospital staff did everything they could to help control pain	885	Ref	1.41	0.85	1.23	1.75	1.81	
Q26. Always treated with respect and dignity by staff	911	Ref	2.37	1.36	1.16	2.14	2.10	
Q27. Received written information about what they should (not) do post discharge	601	Ref	2.56	1.10	1.04	1.83	1.65	
Q28. Told by staff who to contact if worried post discharge	793	Ref	0.93	1.43	1.49	2.05	2.38	
Hospital care as day patient/ outpatient								
Q29. Find someone on hospital staff to talk to about worries and fears	1022	Ref	1.01	1.19	1.79	1.76	0.85	
Q30. Doctor had the right notes and documents available	1157	Ref	0.76	0.92	2.48	1.40	1.29	*
Q31. Time spent in waiting room correct/quite correct	1287	Ref	1.05	1.29	0.99	1.64	0.47	*
Radiotherapy								
Q32. Had all the information needed beforehand	638	Ref	1.65	1.12	2.52	1.50	1.96	
Q33. Results explained in an understandable way	548	Ref	1.37	1.15	2.03	2.35	1.41	
Chemotherapy								
Q34. Had all the information needed beforehand	679	Ref	1.46	2.46	0.83	0.82	1.18	
Q35. Results explained in an understandable way	614	Ref	1.14	1.61	1.04	1.29	0.68	
Home care and support								
Q36. Family given all information needed to help care at home	1711	Ref	0.70	0.70	0.91	0.89	0.91	
Q37. Given enough care from health or social services during treatment	1561	Ref	0.81	0.54	0.60	0.76	0.92	
Q38. Given enough care from health or social services after treatment	1027	Ref	1.66	0.74	1.39	1.38	1.34	
Support for people with cancer								
Q39. Hospital staff gave information about support groups	1554	Ref	2.62	0.44	0.97	1.10	0.46	*
Q40. Hospital staff discussed or gave information on impact of cancer on daily activities	1390	Ref	1.56	0.91	1.33	1.28	0.47	*
Q41. Hospital staff gave information on getting financial help or benefits	1142	Ref	2.24	0.91	1.22	1.79	0.82	*
Care from GP								
Q42. GP given enough information about patient's condition and treatment	2094	Ref	0.76	0.60	1.07	1.07	0.72	
Q43. GP and staff did everything they could to support patient	1706	Ref	0.82	0.88	1.42	1.13	1.07	

(Continues)

TABLE 3 (Continued)

Adjusted OR of reporting a positive experience	*n*	Colorectal (*n* = 289)	Breast (*n* = 1105)	Prostate (*n* = 237)	Lung (*n* = 414)	Haematologic (*n* = 438)	Skin (*n* = 144)	*p*-value
Overall care								
Q44. People treating and caring for you worked well together	2367	Ref	0.82	0.92	0.98	1.01	0.88	
Q45. Received a care plan	1881	Ref	1.05	0.74	0.72	0.71	0.53	
Q46. Administration of care rated as very good or good	2410	Ref	0.98	0.52	1.14	0.70	1.11	
Q47. Overall rating of care = 10/9/8	2406	Ref	0.97	0.77	1.36	0.98	1.58	

Note: Adjusted for sex, age, education level, health status, financial hardship, and hospital. There were not enough individuals in the dichotomous response categories in the 'consultation with specialist nurse' section to perform adjusted analyses. ref: reference category; all *p*-values corrected for multiple testing $*p < 0.05$; $**p < 0.01$.

Colour ranking: ranking from dark blue indicating 1st rank and highest OR (most likely to report positive experience) to dark red indicating 6th rank and lowest OR (least likely to report positive experience).

1st rank = highest OR	**2nd rank**	**3rd rand**	**4th rank**	**5th rank**	**6th rank = lowest OR**

due to how care is organised and delivered. Breast cancer centres were among the first centres to be implemented in Switzerland, aiming at delivering comprehensive and coordinated cancer care. Breast cancer is also among the most researched type of cancer, receiving considerable amount of funding for improvement initiatives and support programmes as well as for the development and regular update of comprehensive evidence-based practice guidelines, all contributing to better care provided to women with breast cancer (Biganzoli et al., 2021; Carter & Nguyen, 2012). Implementation of cancer centres for other types of cancer, such as prostate and lung cancers, is more recent. This temporal lag and difference in availability of clinical practice guidelines might explain the difference regarding patient experience and warrants further investigation.

Our study adds useful information to the growing literature on patient experiences with cancer care reported in other countries such as the UK (Abel et al., 2014; Saunders et al., 2015), Denmark (Heerdegen et al., 2017; Sandager et al., 2015), Spain (Arraras et al., 2013), Canada (Coronado et al., 2017; Tremblay et al., 2015) and the United States (Ayanian et al., 2010; Lis et al., 2009), as well as on their use and usefulness to evaluate the quality of care delivery. Although our data reflect experiences with cancer care reported by patients treated within the Swiss healthcare system, they are quite similar to the results from cancer surveys conducted in other countries with different instruments. Indeed, issues related to communication and information, supportive care, or social and financial support, are often reported in patient experiences surveys as well as surveys on unmet needs (Harrison et al., 2009; Moghaddam et al., 2016). We can also compare our results to those published in England with the same instrument, despite differences in eligibility criteria (Gomez-Cano et al., 2020). While the mean rating of overall care (8.5) was slightly lower in our study compared with the mean rating reported in the yearly reports for the CPES national results [between 8.7 in 2015 and 8.8 in 2019 (NHS England, 2020)], the percentage of positive experiences followed a similar pattern in Switzerland and England, with the lowest scores reported in the 'home care and support' subsection. Rates differed notably for a few key questions when comparing results for 2018 in both countries: the rate of respondents reporting receiving written information at diagnosis, advice and support for side effects, and information on financial help was lower in our respondents (50% vs. 74%; 58% vs. 67%; and 49% vs. 60%, respectively). On the other hand, the percentage of patients reporting enough nurses on duty and support from GP was higher in Switzerland (87% vs. 67% and 73% vs. 59%, respectively). The interpretation of this international comparison is limited by many factors, but it allows us to put results in perspective and possibly investigate further reasons for the observed differences.

Our study had several strengths: It evaluated patient-reported experiences across the whole cancer care pathway using a cancer-specific validated questionnaire, evaluating key aspects of patient-centred cancer care in addition to overall satisfaction, in a relatively large sample of patients from university and regional hospitals. In addition, the variance observed in the participants' responses and limited number of items with a ceiling effect (>90%) can be interpreted as a methodological advantage of this experience survey in comparison to traditional satisfaction surveys. However, the results of our study should be interpreted with caution considering the following inherent limitations to survey data. Results reflect experiences of care from patients who responded to the survey. Indeed, previous studies have shown that survey respondents tend to be younger and of higher socio-economic background (Abel et al., 2016; Alessy et al., 2019; Nartey et al., 2020) compared with non-respondents, impacting representativeness of survey results and levels of reported satisfaction. In addition, surveys in cancer are surveys of survivors by design, excluding patients with short survivals (Lyratzopoulos et al., 2012; Nartey et al., 2020). Reaching patients who tend to not respond to surveys can be achieved through different methods, such as qualitative interviews. Regarding cancer representativeness, compared with the distribution of incident cases available from the Federal Office of Statistics for the French- and Italian-speaking region of Switzerland (Federal Statistical Office [FSO], 2020), individuals reporting breast cancer were overrepresented in our sample, while individuals reporting prostate cancer were underrepresented. Finally, the eligibility criteria regarding the type of cancer was restricted to the six most frequent types for statistical and feasibility reasons, limiting the generalisation to other types of cancer. Based on the results of this study, a follow-up study was launched in 2021 among patients with any types of cancer to overcome this limitation.

5 | CONCLUSION

The consideration of patient experience is both important and necessary to evaluate and improve the responsiveness and quality of healthcare services, aiming to meet both the clinical and social needs of each individual patient. Our study demonstrates the feasibility of conducting a wide-scaled study of patient experiences in the Swiss cancer care setting and provides an overview of the responsiveness of cancer care according to a large sample of cancer patients in French-speaking Switzerland. Such information helps inform and guide future research and improvement initiatives at the hospital level, particularly targeting patients with specific cancers at higher risk of a less positive experience. The successful implementation of the survey also gave the impulse for a larger experience survey in Switzerland, encompassing hospitals in both the French- and German-speaking regions of Switzerland.

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CONFLICTS OF INTEREST

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DATA AVAILABILITY STATEMENT

Data are available from the corresponding author upon reasonable request or from Data@Unisanté, the institutional data repository under DDI Document ID 10.16909-DATASET-20.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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Supplemental table. Unadjusted and adjusted ORs of reporting a positive experience with 95% CI, by cancer and by question

Likelihood of a positive experience	**CRC**	**breast**	**breast**	**prostate**	**prostate**	**lung**	**lung**	**hemato**	**hemato**	**skin**	**skin**
		unadj	**adj**	**unadj**	**adj**	**unadj**	**adj**	**unadj**	**adj**	**unadj**	**adj**
Before seeing a specialist											
Seen as soon as necessary	ref	1.50 1.05-2.15	2.00 1.31-3.05	1.10 0.69-1.74	0.90 0.54-1.51	1.15 0.77-1.74	1.27 0.82-1.95	1.26 0.84-1.90	1.45 0.94-2.24	1.58 0.88-2.83	1.57 0.85-2.88
Diagnostic tests											
Had all the information needed beforehand	ref	1.05 0.71-1.53	1.13 0.71-1.77	0.97 0.58-1.61	0.93 0.53-1.63	1.64 1.02-2.63	2.24 1.34-3.75	0.88 0.57-1.38	0.87 0.55-1.39	1.85 0.95-3.62	1.84 0.91-3.70
Waiting time before the test thought to be right	ref	1.72 1.12-2.66	1.87 1.09-3.22	1.10 0.63-1.92	1.08 0.28-2.02	1.65 0.98-2.78	1.88 1.08-3.26	2.25 1.26-4.02	2.15 1.17-3.93	3.35 1.36-8.23	2.91 1.17-7.27
Test results explained in an understandable way	ref	0.96 0.66-1.41	1.04 0.67-1.63	0.80 0.49-1.31	0.83 0.48-1.45	1.10 0.70-1.71	1.21 0.75-1.94	0.74 0.48-1.15	0.67 0.42-1.06	0.84 0.48-1.46	0.72 0.40-1.29
Finding out what was wrong											
Told they could bring family or friend beforehand	ref	1.02 0.78-1.35	1.02 0.74-1.42	0.98 0.68-1.42	1.04 0.70-1.56	1.42 1.03-1.96	1.42 1.02-1.99	1.30 0.95-1.79	1.28 0.92-1.79	0.75 0.48-1.16	0.75 0.47-1.19
Told they had cancer in a sensitive manner	ref	0.94 0.69-1.29	1.32 0.91-1.92	0.91 0.60-1.39	0.75 0.47-1.19	1.06 0.73-1.54	1.22 0.82-1.80	0.79 0.55-1.13	0.88 0.60-1.29	1.13 0.70-1.94	1.19 0.70-2.02
Understood explanations of what was wrong	ref	1.00 0.74-1.35	1.30 0.91-1.85	1.20 0.79-1.81	0.99 0.63-1.54	1.30 0.91-1.87	1.56 1.07-2.28	0.61 0.44-0.85	0.64 0.48-0.93	1.02 0.64-1.63	1.06 0.65-1.73
Received written information about cancer that was easy to understand	ref	0.65 0.46-0.91	1.04 0.68-1.58	1.40 0.89-2.22	0.94 0.57-1.56	0.82 0.55-1.23	0.99 0.64-1.54	0.52 0.35-0.77	0.53 0.34-0.81	0.73 0.43-1.26	0.79 0.44-1.40
Deciding the best treatment											
Different types of treatment explained beforehand	ref	1.19 0.85-1.67	1.20 0.79-1.81	1.22 0.78-1.91	1.38 0.83-2.28	1.53 1.01-2.31	1.73 1.10-2.69	0.98 0.66-1.44	1.00 0.66-1.51	2.07 1.12-3.83	2.03 1.08-3.84
Possible side-effects explained in an understandable way	ref	1.05 0.79-1.40	1.19 0.84-1.67	1.02 0.70-1.49	1.06 0.70-1.60	1.25 0.89-1.75	1.57 1.10-2.25	0.86 0.62-1.18	0.92 0.65-1.30	0.91 0.59-1.42	1.06 0.66-1.70
Offered practical advice and support in dealing with side-effects	ref	1.05 0.79-1.40	1.13 0.79-1.61	0.77 0.52-1.13	0.76 0.50-1.17	1.22 0.87-1.73	1.46 1.01-2.12	0.83 0.60-1.16	0.84 0.58-1.19	0.52 0.32-0.84	0.60 0.36-1.00
Told about possible side-effects occurring in the future	ref	1.16 0.88-1.53	1.41 1.01-1.97	2.15 1.49-3.10	2.29 1.52-3.44	1.60 1.15-2.21	1.76 1.25-2.49	1.25 0.91-1.72	1.30 0.92-1.82	1.51 0.97-2.33	1.77 1.11-2.81
Involved as much as wanted to be in care decisions	ref	0.84 0.62-1.12	0.95 0.67-1.35	1.20 0.80-1.78	1.08 0.70-1.68	1.25 0.88-1.78	1.60 1.10-2.33	0.80 0.57-1.11	0.89 0.62-1.27	1.28 0.79-2.05	1.27 0.77-2.09
Operations											
Had all the information needed beforehand	ref	0.96 0.59-1.58	1.09 0.59-1.99	2.46 0.97-6.26	2.55 0.94-6.94	1.95 1.00-3.80	2.34 1.16-4.71	1.09 0.55-2.16	1.16 0.57-2.38	1.53 0.68-3.44	1.89 0.76-4.71
Operation results explained in an understandable way	ref	0.70 0.45-1.08	0.75 0.44-1.27	0.92 0.49-1.74	0.96 0.47-1.94	1.23 0.72-2.08	1.50 0.86-2.61	1.59 0.81-3.10	1.85 0.91-3.77	1.52 0.75-3.09	1.65 0.78-3.50
Hospital care as inpatient											
Doctors and nurses did not talk in front of patient as if they were not there	ref	3.01 1.79-5.08	2.58 1.38-4.83	1.78 0.85-3.74	1.53 0.68-3.41	1.00 0.60-1.68	1.19 0.68-2.08	1.60 0.90-2.85	1.60 0.86-2.96	1.22 0.59-2.56	0.94 0.43-2.05
Confidence and trust in all ward doctors	ref	0.96 0.58-1.61	1.57 0.87-2.83	1.18 0.55-2.56	0.82 0.36-1.90	0.61 0.35-1.06	0.68 0.38-1.22	0.90 0.49-1.63	0.89 0.48-1.68	1.28 0.54-3.02	1.33 0.53-3.36

Supplemental table for Arditi C, Eicher M, Colomer-Lahiguera S, Bienvenu C, Anchisi S, Betticher D, Dietrich PY, Duchosal M, Peters S, Peytremann-Bridevaux I. Patients' experiences with cancer care in Switzerland: results of a multicenter cross-sectional survey. Eur J Cancer Care. 2022; e13705. doi: 10.1111/ecc.13705

Likelihood of a positive experience	**CRC**	**breast**	**breast**	**prostate**	**prostate**	**lung**	**lung**	**hemato**	**hemato**	**skin**	**skin**
		unadj	**adj**	**unadj**	**adj**	**unadj**	**adj**	**unadj**	**adj**	**unadj**	**adj**
Patient's family had opportunity to talk to doctor	ref	0.92 0.52-1.62	1.04 0.53-2.03	1.06 0.45-2.48	1.04 0.41-2.67	0.75 0.41-1.38	0.91 0.48-1.73	1.05 0.55-1.99	1.27 0.65-2.50	1.30 0.49-3.47	1.60 0.58-4.42
Confidence and trust in all ward nurses	ref	1.04 0.67-1.63	1.78 1.04-3.06	1.61 0.80-3.24	1.36 0.62-2.95	0.85 0.51-1.39	0.92 0.54-1.58	1.36 0.78-2.35	1.75 0.96-3.19	1.31 0.63-2.72	1.92 0.84-4.42
Always or nearly always enough nurses on duty	ref	1.40 0.81-2.42	1.70 0.88-3.27	1.64 0.70-3.85	1.09 0.43-2.76	0.81 0.45-1.46	0.96 0.51-1.79	2.35 1.10-5.01	2.39 1.07-5.34	0.93 0.42-2.10	0.93 0.39-2.22
Always given enough privacy when discussing condition or treatment	ref	1.26 0.82-1.94	1.88 1.11-3.18	1.91 0.96-3.83	1.46 0.69-3.09	1.01 0.62-1.65	1.20 0.71-2.04	1.84 1.06-3.20	2.44 1.33-4.49	1.53 0.74-3.15	1.48 0.69-3.17
Found someone on hospital staff to talk to about worries and fears	ref	1.31 0.84-2.02	1.27 0.75-2.16	1.40 0.70-2.77	1.23 0.58-2.63	1.02 0.62-1.68	1.17 0.69-2.00	1.92 1.13-3.26	2.18 1.23-3.84	0.73 0.34-1.56	0.84 0.37-1.88
Hospital staff did everything they could to help control pain	ref	1.07 0.64-1.80	1.41 0.76-2.61	1.17 0.54-2.54	0.85 0.39-1.98	1.02 0.57-1.84	1.23 0.66-2.30	1.59 0.82-3.10	1.75 0.86-3.54	1.77 0.69-4.58	1.81 0.68-4.83
Always treated with respect and dignity by staff	ref	1.40 0.75-2.61	2.37 1.15-4.89	1.90 0.67-5.35	1.36 0.44-4.17	0.89 0.45-1.74	1.16 0.56-2.39	1.52 0.70-3.30	2.14 0.93-4.89	1.84 0.59-5.71	2.10 0.65-6.74
Received written information about what they should (not) do post discharge, easy to understand	ref	1.46 0.89-2.41	2.56 1.37-4.80	1.53 0.72-3.25	1.10 0.49-2.50	0.83 0.46-1.48	1.04 0.56-1.94	1.61 0.88-2.95	1.83 0.95-3.54	1.57 0.64-3.86	1.65 0.64-4.25
Told by staff who to contact if worried post discharge	ref	0.94 0.48-1.83	0.93 0.41-2.11	1.19 0.43-3.28	1.43 0.47-4.30	1.18 0.53-2.62	1.49 0.64-3.49	1.55 0.65-3.67	2.05 0.79-5.32	2.70 0.58-12.46	2.38 0.50-11.33
Hospital care as day patient / outpatient											
Find someone on hospital staff to talk to about worries and fears	ref	1.03 0.67-1.59	1.01 0.60-1.71	1.11 0.64-1.94	1.19 0.64-2.23	1.27 0.77-2.09	1.79 1.04-3.05	1.59 0.94-2.68	1.76 1.00-3.08	0.64 0.33-1.21	0.85 0.42-1.71
Doctor had the right notes and documents available	ref	0.63 0.37-1.07	0.76 0.41-1.44	0.86 0.44-1.68	0.92 0.43-1.95	1.82 0.92-3.60	2.48 1.21-5.06	1.22 0.65-2.32	1.40 0.71-2.76	0.95 0.43-2.10	1.29 0.56-2.98
Time spent in waiting room correct/quite correct	ref	0.90 0.58-1.40	1.05 0.62-1.77	1.54 0.83-2.88	1.29 0.66-2.53	0.79 0.48-1.29	0.99 0.59-1.68	1.40 0.82-2.42	1.64 0.92-2.93	0.40 0.22-0.72	0.47 0.25-0.87
Radiotherapy											
Had all the information needed beforehand	ref	1.57 0.77-3.19	1.65 0.6-3.93	1.26 0.53-3.00	1.12 0.41-3.00	1.65 0.75-3.65	2.52 1.05-6.03	1.40 0.56-3.51	1.50 0.55-4.09	1.55 0.39-6.11	1.96 0.46-8.36
Results explained in an understandable way	ref	1.40 0.77-2.56	1.37 0.66-2.85	1.03 0.49-2.16	1.15 0.49-2.67	1.53 0.80-2.95	2.03 1.00-4.10	1.88 0.86-4.11	2.35 1.01-5.47	1.33 0.44-4.08	1.41 0.43-4.64
Chemotherapy											
Had all the information needed beforehand	ref	0.87 0.51-1.50	1.46 0.77-2.76	2.65 0.59-11.94	2.46 0.51-11.91	0.70 0.40-1.22	0.83 0.45-1.53	0.89 0.51-1.57	0.82 0.45-1.52	1.38 0.16-11.96	1.18 0.12-11.19
Results explained in an understandable way	ref	0.92 0.55-1.54	1.14 0.63-2.07	1.52 0.48-4.86	1.61 0.48-5.43	0.96 0.56-1.63	1.04 0.59-1.83	1.27 0.74-2.18	1.29 0.72-2.29	0.72 0.13-4.10	0.68 0.12-4.03
Home care and support											
Family given all information needed to help care at home	ref	0.57 0.42-0.79	0.70 0.48-1.01	0.74 0.48-1.14	0.70 0.44-1.12	0.83 0.58-1.20	0.91 0.62-1.34	0.85 0.59-1.21	0.89 0.61-1.30	0.92 0.55-1.55	0.91 0.53-1.55
Given enough care from health or social services during treatment	ref	0.70 0.50-0.97	0.81 0.55-1.19	0.56 0.35-0.90	0.54 0.33-0.91	0.54 0.37-0.79	0.60 0.40-0.90	0.67 0.46-0.98	0.76 0.51-1.14	0.90 0.52-1.56	0.92 0.52-1.62

Supplemental table for Arditi C, Eicher M, Colomer-Lahiguera S, Bienvenu C, Anchisi S, Betticher D, Dietrich PY, Duchosal M, Peters S, Peytremann-Bridevaux I. Patients' experiences with cancer care in Switzerland: results of a multicenter cross-sectional survey. Eur J Cancer Care. 2022; e13705. doi: 10.1111/ecc.13705

Likelihood of a positive experience	CRC	breast	breast	prostate	prostate	lung	lung	hemato	hemato	skin	skin
		unadj	adj	unadj	adj	unadj	adj	unadj	adj	unadj	adj
Given enough care from health or social services after treatment	ref	1.12 0.74-1.71	1.66 1.00-2.74	0.90 0.49-1.64	0.74 0.39-1.46	1.08 0.67-1.76	1.39 0.82-2.34	1.17 0.73-1.90	1.38 0.82-2.32	1.05 0.53-2.07	1.34 0.65-2.74
Support for people with cancer											
Hospital staff gave information about support groups	ref	1.76 1.15-2.70	2.62 1.61-4.28	0.52 0.30-0.90	0.44 0.24-0.82	0.74 0.46-1.19	0.97 0.59-1.62	1.03 0.64-1.67	1.10 0.66-1.83	0.38 0.20-0.72	0.46 0.23-0.91
Hospital staff discussed or gave information on impact of cancer on daily activities	ref	1.06 0.69-1.61	1.56 0.94-2.60	1.01 0.57-1.79	0.91 0.47-1.75	1.00 0.61-1.63	1.33 0.77-2.29	1.17 0.72-1.90	1.28 0.75-2.19	0.46 0.25-0.86	0.47 0.24-0.93
Hospital staff gave information on getting financial help or benefits	ref	2.01 1.32-3.05	2.24 1.36-3.71	1.01 0.55-1.85	0.91 0.46-1.80	1.03 0.63-1.66	1.22 0.73-2.05	1.79 1.12-2.85	1.79 1.08-2.96	0.81 0.39-1.68	0.82 0.37-1.79
Care from GP											
GP given enough information about patient's condition and treatment	ref	0.48 0.30-0.77	0.76 0.44-1.29	0.81 0.43-1.49	0.60 0.30-1.19	0.73 0.43-1.25	1.07 0.61-1.89	0.79 0.46-1.35	1.07 0.60-1.91	0.49 0.26-0.92	0.72 0.36-1.41
GP and staff did everything they could to support patient	ref	0.67 0.47-0.95	0.82 0.54-1.24	0.80 0.51-1.26	0.88 0.52-1.46	1.01 0.68-1.52	1.42 0.92-2.19	0.93 0.62-1.40	1.13 0.73-1.73	1.03 0.59-1.83	1.07 0.59-1.93
Overall care											
People treating and caring for you worked well together	ref	0.59 0.45-0.78	0.82 0.59-1.14	1.07 0.74-1.57	0.92 0.61-1.40	0.85 0.62-1.17	0.98 0.69-1.38	0.88 0.64-1.21	1.01 0.72-1.42	0.78 0.51-1.19	0.88 0.56-1.40
Received a care plan	ref	0.85 0.63-1.15	1.05 0.73-1.52	0.87 0.59-1.30	0.74 0.48-1.14	0.76 0.54-1.08	0.72 0.50-1.01	0.75 0.53-1.06	0.71 0.49-1.02	0.55 0.34-0.90	0.53 0.32-0.89
Administration of care rated as very good or good	ref	0.67 0.42-1.07	0.98 0.57-1.70	0.74 0.40-1.35	0.52 0.26-1.04	0.94 0.54-1.65	1.14 0.63-2.07	0.72 0.43-1.24	0.70 0.40-1.24	1.08 0.50-2.35	1.11 0.49-2.54
Overall rating of care 8-9-10	ref	0.73 0.51-1.04	0.97 0.64-1.49	1.07 0.66-1.74	0.77 0.45-1.32	1.11 0.73-1.70	1.36 0.86-2.15	1.01 0.67-1.53	0.98 0.63-1.53	1.64 0.87-3.12	1.58 0.80-3.12

Supplemental table for Arditi C, Eicher M, Colomer-Lahiguera S, Bienvenu C, Anchisi S, Betticher D, Dietrich PY, Duchosal M, Peters S, Peytremann-Bridevaux I. Patients' experiences with cancer care in Switzerland: results of a multicenter cross-sectional survey. Eur J Cancer Care. 2022; e13705. doi: 10.1111/ecc.13705

4.3 Comparisons of themes of free-text comments and PREMs results *(article #2)*

Title of the manuscript published in the peer-reviewed journal BMC Health Services Research: "Computer-assisted textual analysis of free-text comments in the Swiss Cancer Patient Experiences (SCAPE) survey"

The manuscript presents the computer-assisted textual analysis of the free-text comments written at the end of the questionnaire by one third of the respondents to identify the underlying themes of patients' experiences shared in their own words and compare these themes with patient-centered care dimensions assessed in closed-ended questions of the questionnaire. Five main thematic classes were identified and labelled as follows: 'cancer care pathways', 'breast cancer care pathways, 'medical care', 'gratitude and praise', and 'cancer and me'. A new analysis of the last class identified five subthemes: 'initial shock', 'loneliness', 'understanding and acceptance', 'cancer repercussions', and 'information and communication'. Our analyses showed that while closed-ended questions related primarily to factual aspects of experiences of care, free-text comments related predominantly to the personal and emotional experiences and consequences of having cancer and receiving care.

Chantal Arditi conceptualized the analysis with Isabelle Peytremann Bridevaux and Manuela Eicher; she formatted and coded the free-text comments with Diana Walther; she supervised the analysis and interpretation of the free-text data; she wrote the initial draft with Diana Walther.

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BMC Health Services Research

RESEARCH ARTICLE **Open Access**

Computer-assisted textual analysis of free-text comments in the Swiss Cancer Patient Experiences (SCAPE) survey

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Abstract

Background: Patient experience surveys are increasingly conducted in cancer care as they provide important results to consider in future development of cancer care and health policymaking. These surveys usually include closed-ended questions (patient-reported experience measures (PREMs)) and space for free-text comments, but published results are mostly based on PREMs. We aimed to identify the underlying themes of patients' experiences as shared in their own words in the Swiss Cancer Patient Experiences (SCAPE) survey and compare these themes with those assessed with PREMs to investigate how the textual analysis of free-text comments contributes to the understanding of patients' experiences of care.

Methods: SCAPE is a multicenter cross-sectional survey that was conducted between October 2018 and March 2019 in French-speaking parts of Switzerland. Patients were invited to rate their care in 65 closed-ended questions (PREMs) and to add free-text comments regarding their cancer-related experiences at the end of the survey. We conducted computer-assisted textual analysis using the IRaMuTeQ software on the comments provided by 31% ($n = 844$) of SCAPE survey respondents ($n = 2755$).

Results: We identified five main thematic classes, two of which consisting of a detailed description of 'cancer care pathways'. The remaining three classes were related to 'medical care', 'gratitude and praise', and the way patients lived with cancer ('cancer and me'). Further analysis of this last class showed that patients' comments related to the following themes: 'initial shock', 'loneliness', 'understanding and acceptance', 'cancer repercussions', and 'information and communication'. While closed-ended questions related mainly to factual aspects of experiences of care, free-text comments related primarily to the personal and emotional experiences and consequences of having cancer and receiving care.

Conclusions: A computer-assisted textual analysis of free-text in our patient survey allowed a time-efficient classification of free-text data that provided insights on the personal experience of living with cancer and additional information on patient experiences that had not been collected with the closed-ended questions, underlining the importance of offering space for comments. Such results can be useful to inform questionnaire development, provide feedback to professional teams, and guide patient-centered initiatives to improve the quality and safety of cancer care.

Keywords: Cancer, Patient perspectives, Patient survey, Patient experiences, Quality of care, Textual analysis

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Background

Health care research is becoming increasingly patient-centered, highlighting the importance of considering patients' perspectives and experiences when evaluating the quality of care [1]. This has led to the development of patient-reported measures — reports that come directly from the patient about their health condition and experiences [2] — which provide the basis for a more holistic interpretation and assessment of care than traditional clinical outcome measures alone [3]. Patient-reported experience measures (PREMs) assess patients' view on the delivery of care, such as communication with health care professionals and coordination of care [4, 5]. In contrast to satisfaction measures, experience measures focus on the underlying components of satisfaction by collecting information on what actually happened to patients during a hospital stay or a medical consultation [6]. In cancer care, specific experience measures have been advocated to account for the complex treatment pathways involved. Examples of cancer PREMs include those collected with the UK National Cancer Patient Experience Survey (CPES) and the US Consumer Assessment of Healthcare Providers and Systems (CAHPS) Cancer Care Survey [7, 8]. PREMs are usually collected through cross-sectional surveys using questionnaires with closed-ended questions producing quantitative data from a large sample of patients that can be used as indicators for the quality of health services. Questionnaires usually also include one or more open-ended questions, eliciting general comments (e.g. "Is there anything else you would like to tell us about your cancer care services?" [9, 10]) or more specific comments (e.g. "is there anything else you would like to tell us about your chemotherapy treatment?" [11]).

While quantitative results of closed-ended survey questions are widely published, analysis of free-text responses to open-ended questions or free-text sections are rarely performed and published. Indeed, manual thematic analysis of large amounts of text generated from open-ended questions remains time and resource intensive; therefore, the additional insights within this type of data often remain underutilized. However, such analyses can now be more easily performed thanks to information technology opportunities [12–15], yielding comparable results as manual qualitative analysis [16]. The analysis of free-text comments can serve various purposes: provide deeper insights on patient experiences, on specific closed-ended questions [17] or on subpopulations [18], identify issues that closed-ended questions might not reveal, guide the development of new survey questions and uncover issues with the survey or its methodology, and guide quality improvement initiatives [9–11, 17–23].

The aim of this study was to identify the underlying themes of patients' experiences shared in their own words at the end of a cancer survey, using computer-assisted textual analysis, and to compare these themes with patient-centered care dimensions assessed in closed-ended questions (PREMs) to investigate how the textual analysis of free-text comments contributes to the understanding of patients' experiences of care.

Methods

Study design

Textual analysis of free-text data collected between October 2018 and March 2019 in the multicenter cross-sectional Swiss Cancer Patient Experiences (SCAPE) survey.

Population and setting

Patients aged 18 or older having received stationary or ambulatory care between January 1, 2018 and June 30, 2018 for breast, prostate, lung, colorectal, hematologic cancers (leukemia, lymphoma or myeloma) or melanoma, were eligible for inclusion in the SCAPE survey. The latter was conducted in four Swiss hospitals: the Lausanne university hospital, the Geneva university hospitals, and the cantonal hospitals of Fribourg and Valais.

Measures

The SCAPE questionnaire, a comprehensive cancer care survey, was based on a French translation of the UK CPES [8] adapted to the Swiss context. It included 64 questions with a four- or five-point Likert-type scale response options on experiences of cancer care along the care pathway, from pre-diagnostic care to home care. The questions assessed the eight core dimensions of patient-centered care: information and education, coordination and integration of care, physical comfort, emotional support, respect for patients' preferences, involvement of family and friends, continuity and transition, and access to care [24]. The questionnaire also included an overall rating of satisfaction with care (0 to 10 scale) and questions regarding demographic and socioeconomic characteristics as well as clinical and health status (age, sex, cancer type etc.). This amounted to a total of 94 multiple-choice questions and a final section for free-text comments ("If you wish to share cancer related experiences not covered in this questionnaire or if you have suggestions for improving cancer care, please share them on the following page"). Paper questionnaires were sent to the participants' home address in October 2018; those returned by the end of March 2019 were considered for analysis.

Textual analysis

To analyze the free-text comments, we performed a computer-assisted textual analysis using the IRaMuTeQ software (version 0.7 alpha 2, 2008–2014 Pierre Ratinaud). This is a tool particularly recommended for the analysis of large amounts of text [12]. Using the Reinert method [25], the software extracts recurrent themes using an algorithm that splits the text into segments which are then classified according to the co-occurrences of the words that compose these units. This classification results in a number of classes that are associated with typical vocabulary and typical extracts. The strength of association between the vocabulary and the classes is determined by Chi-square tests. Then, the researcher analyses the typical vocabulary and extracts for each class, and returns to the free-text comments to label and interpret the classes (first stage analysis). A repetition of the analysis can be performed on one or more of the classes, using the same method as described above (second stage analysis); the latter is typically done when one class contains a large amount and wide variety of vocabulary and themes. In addition to these analyses, the strength of association between modalities of latent variables (not used to build the classification variables) and the identified classes is determined with Chi-square tests, indicating if text included in the classes are specific to a modality of the latent variable. We included the following latent variables: age, sex, cancer type, overall satisfaction with care (approximate quartiles of a 0 to 10 scale: ≤7; 8; 9; 10), and the overall nature of each participant's response (positive; negative; mixed; neutral), as coded by a researcher; unclear cases were discussed with one to two other researchers to reach consensus. All comments were considered for analysis except technical remarks concerning the survey.

Data interpretation

Data interpretation was performed by three researchers who proceeded as follows: 1) they read all the comments while formatting the corpus to become familiar with the data; 2) once the software had classified the text into classes, they looked at the typical words and extracts associated within each class to make a preliminary thematic interpretation; 3) they went back to the original text in order to recontextualize the typical extracts and limit over-interpretation; 4) they discussed their thematic interpretation and labeling of classes with the multidisciplinary research team (i.e. researchers with backgrounds in nursing science, medical science, public health, and social science, and a cancer survivor who had taken part in the survey); and 5) they matched the thematic classes identified with the textual analysis to questions and dimensions of patient-centered care assessed in the closed-ended questions.

Results

Respondents' characteristics

Of the 7145 individuals invited to participate in the survey, 3121 (43.7%) completed and returned the questionnaire. Of these, 2755 (88.3%) reported having either breast, prostate, lung, colorectal, hematologic cancers or melanoma and about a third wrote a comment at the end of the questionnaire (comment rate: 30.6%) and were included in the textual analysis (Fig. 1). As the ethics committee did not allow access to non-respondents' personal data, comparisons between respondents and non-respondents were not possible. Mean age of those commenting was 62.1 years, 66.2% were women and 33.9% had completed tertiary education (Table 1). Participants who left a comment ($n = 844$) were more likely to be female, speak French, be more educated, and have breast cancer than those who did not leave a comment ($n = 1912$) (Table 1).

Characteristics and analysis of comments

The 844 comments, ranging from one sentence to several pages of text, contained a total of 70′757 words; 28.0% of the comments were predominantly positive, 35.3% predominantly negative, 15.6% were an even mix of positive and negative statements and 21.1% were predominantly neutral. The software analysis allowed the classification of 95.2% of the text segments and identified five thematic classes. These classes were labelled by the research team as follows (percent of the text segments classified within each group indicated in parenthesis): 'cancer care pathways' (18.9%), 'breast cancer care pathways' (13.5%), 'medical care' (22.5%), 'gratitude and praise' (15.2%), and 'cancer and me' (29.9%). The structure of the classification is provided in a dendrogram showing the hierarchical clustering of the classes (Fig. 2), and details of the classes with typical words and extracts are provided in Table 2.

'Cancer care pathways'

> *Patient quotes (gender, age, type of cancer): "Lumpectomy, excision of the sentinel lymph node, 25 radiotherapy sessions at the [name of clinic], hormonotherapy" (Woman, 67, breast cancer); "Relapse in July 2016" (Woman, 71, hematologic cancer); "Currently, hormonotherapy and regular checkups" (Woman, 61, breast cancer).*

In this class, respondents recounted their cancer journey from diagnosis to treatment and follow up, mainly in a descriptive and neutral manner. Type and spread of cancer were often described, with details regarding cancer location, presence of cancer cells in lymph nodes as well as metastases. Respondents listed the examinations performed and types of treatment received. The course of disease, including remission and relapse, was also mentioned along with the frequency of follow-up appointments. Respondents often explained the timing and sequence of events. This class was overrepresented in those aged ≥65 yrs., in men, in those having left a neutral comment, with in those with overall satisfaction of 8/10, and respondents with prostate, lung and hematologic cancers.

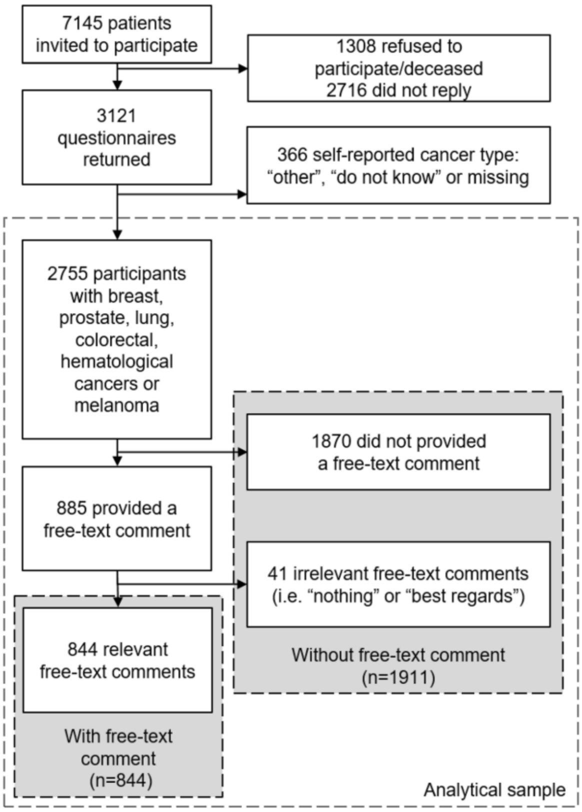

Fig. 1 Flowchart of the SCAPE study

'Breast cancer care pathways'

> *Patient quotes: "It was during the mammography exam at the screening center in August 2017 that they discovered a 3 cm tumor" (Woman, 70, breast cancer); "12 lymph nodes are affected" (Woman, 49, breast cancer); "Checkups every 6 months"* (Woman, 66, *breast cancer*).

This class focused on breast cancer and was closely linked to the previous one. It included detailed descriptions of cancer care pathways, including technical terms, and specifications about the course of disease with temporal indications (diagnosis, treatment, follow-up, remission/relapse etc.). As in the previous class, respondents mentioned the examinations performed (mammography, echography, biopsy), details about the cancer location, size, type and spread, and the treatment received (mainly surgery). Again, the tone was rather neutral and descriptive. In addition, respondents in this class reported the reason for which they first sought medical care, such as a screening test or because they had noticed a lump in their breast. This class was overrepresented in respondents with breast cancer, in those aged ≥75 yrs., in those having left neutral comments, and with an overall satisfaction of 10/10.

'Medical care'

> *Patient quotes: "The personnel were all stressed, including the doctors" (Man, 67, hematologic cancer); "Junior doctors change too often and don't know our situation" (Woman, 55, breast cancer); "It took 26 phone calls to the [name of hospital] to get an appointment" (Woman, 72, breast cancer); "despite our requests, the records and test results do not always follow and the documents I receive are sometimes*

Table 1 SCAPE respondents' characteristics, according to having left (or not) a free-text comment

Variable	With a free-text comment ($n = 844$) %	Without a free-text comment ($n = 1911$) %	Chi-squared p-value or Hedges' g for means
Women	66.2	58.7	< 0.01
Age (mean)	62.1	64.7	0.20
French as principal language	90.2	83.9	< 0.01
Education			< 0.01
Primary	9.3	19.0	
Secondary	46.9	51.6	
Tertiary	43.8	29.4	
Overall satisfaction (0 to 10)			< 0.01
≤ 7	20.9	15.1	
8	24.5	27.2	
9	26.7	29.0	
10	28.0	28.7	
mean	8.4	8.6	0.13
Cancer type			< 0.01
Breast	44.9	38.0	
Prostate	7.1	9.3	
Lung	11.6	16.5	
Colorectal	9.7	10.8	
Hematologic	16.7	15.5	
Melanoma	5.2	5.2	
Several	4.7	4.6	
Hospital			0.34
Hospital 1	58.3	54.9	
Hospital 2	11.3	13.0	
Hospital 3	13.4	13.6	
Hospital 4	17.1	18.5	

> *not up to date with the latest decision taken by the doctor" (Woman, 64, lung cancer).*

In this class, respondents related their experiences concerning cancer care, especially in regards to physicians. The majority of text in this class was negative. The frequent changes in staff at the junior physician level were often mentioned and described as problematic from the patient's perspective. Staff were described as not being aware of the patients' medical record, looking tired or overwhelmed and lacking time and supervision. The absence of senior physicians in direct patient care was also reported. Furthermore, respondents described poor organization and coordination of care including problems concerning their medical records, appointments and inter-professional communication. This class was overrepresented in women, in those having left predominantly negative or mixed comments, and in those with overall satisfaction of ≤7/10.

'Gratitude and praise'

> *Patient quotes: "I'll take this opportunity to thank all of the hospital personnel (nurses, doctors, radiologist, auxiliary staff, etc.) for their good care, their tact, their capacity to listen and their kindness" (Woman, 61, lung cancer); "The whole team saved my life, thank you from the bottom of my heart" (Man, 68, colorectal cancer).*

In this class, respondents expressed their gratitude and praise towards hospital staff as a whole or more specifically to professional groups or individuals including physicians, nurses, caregivers, therapists, technicians, social workers, receptionists and cleaning personnel. Respondents thanked health care professionals for the care provided, their competence, professionalism, kindness, empathy, benevolence, support and respect. The quality of care was highlighted both in terms of human relations as well as medical and

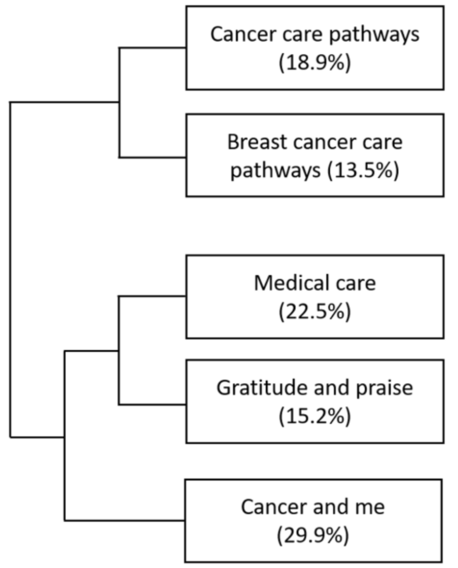

Fig. 2 Hierarchical clustering dendrogram. (Dendrogram generated by IRaMuTeQ; percent of the text segments classified within each class indicated in parenthesis)

technical expertise. Moreover, a few respondents mentioned the resulting effects including life-saving, reinforcing peace of mind, courage and trust. Those having left positive comments, those with an overall satisfaction of 10/10 and respondents with colorectal cancer were overrepresented in this class.

'Cancer and me'

As the 'cancer and me' class included a large amount of text (29.9%), we repeated the analyses on this class separately in order to have a more detailed understanding of its content. The secondary analysis of this class resulted in five subclasses, labelled as follows (percent of text segments classified within each group indicated in parenthesis): 'initial shock' (3.6%), 'loneliness' (6.0%), 'understanding and acceptance' (5.0%), 'broad impacts of cancer' (6.2%), and 'information needs' (9.1%). The structure of the 'cancer and me' sub-classification is provided in a dendrogram showing the hierarchical clustering of the subclasses (Fig. 3).

'Initial shock' *Patient quotes: "I was completely under shock and had to return by car alone; the shock came from the brutal communication of the diagnosis" (Woman, 56, lung cancer); "There is no good way to announce cancer, once the word is said it's a real tsunami" (Woman, 61, breast cancer); "At the time of the cancer diagnosis, under shock, we don't retain anything, the need for information comes later" (Woman, 52, colorectal cancer).*

In this class, respondents reported negative experiences regarding the manner and circumstances in which they were told about the cancer diagnosis or the treatment needed, resulting in a state of shock. Respondents' criticism included being told the diagnosis in a brusque manner, without empathy, over the phone, in a shared hospital room with little privacy, or when alone without the presence of a friend or family member. The sense of shock was also reported by patients who reported being told in a tactful manner, resulting in difficulty in retaining information and in making decisions at the time. Suggestions for improvement included receiving written information on the disease, disease course and treatment after receiving the news, in a follow-up appointment. This class was overrepresented in respondents having left negative comments.

'Loneliness' *Patient quotes: "I struggle alone to pull through" (Woman, 54, breast cancer); "We feel alone and not always heard. At each appointment with the oncologist we repeat our side effects, they are recorded in the computer as if it were normal" (Woman, 51, breast cancer); "And then comes the hormonotherapy, no more information, just a prescription and 'we'll see each other in 3 months' … we discover the side effects alone, they can be very difficult. We just know that it will be for a long time, a very long time." (Woman, 53, breast cancer); "I felt alone, abandoned by the doctors, lost after the treatment" (Woman, 42, breast cancer).*

In this class, respondents described the loneliness felt during treatment, either lacking support from medical personnel or from friends and family. Loneliness was also expressed regarding the side effects of treatment, especially when met with a lack of understanding or solutions from medical staff. Respondents expressed how they had to deal with these side effects "alone", turning for example to alternative medicines. Another recurrent theme was the loneliness felt at the end of treatment, when respondents felt "abandoned" and having to deal by themselves with the difficulties of returning to work or with the incapacity to work, resulting in financial difficulties for some respondents. This class was overrepresented in respondents with an overall satisfaction of 9/10, those having left positive comments and with prostate cancer.

'Understanding and acceptance' *Patient quotes: "I wanted to function like before my illness, everyone was pushing me, they didn't understand, didn't accept that I'm unable to" (Woman, age unknown, breast cancer); "The empathy, interest, understanding, asking for news and the messages of support from family, friends, work colleagues and acquaintances are very important in order to accept*

Table 2 Computer-assisted textual analysis, summary results

Class	Typical words	Typical excerpt	Associated modality ($p < 0.05$)
Cancer care pathways	Prostate, lung, leukemia, lymphoma, nodule, CT, to detect, operation, chemotherapy, radiotherapy, immunotherapy, months of the year, weeks, sessions	"My colon and liver cancer were discovered in July, operated in August, followed by chemotherapy from September to February"	Age ≥ 65 Men Prostate, lung and hematologic cancers Neutral comments Overall satisfaction 8/10
Breast cancer care pathways	Breast, tumor, cancer, malignant, metastasis, lymph nodes, gynecologist, screening, radiography mammography, echography, biopsy, to show/reveal, operate rate, removal	"hormone dependent breast cancer on the left side, discovered at a screening mammography […] lumpectomy followed by radiotherapy in January"	Age ≥ 75 Breast cancer Neutral comments Overall satisfaction 10/10
Medical care	Doctor (junior and senior doctors, oncologist, surgeons), medical department, patient, case, appointment, medical care, medical record, communication, organization, decisions, change, improve, follow, remind	"The post-operative care for the regular checkups is badly organized, the doctors change too often»	Women Negative and mixed comments Overall satisfaction ≤7/10
Gratitude and praise	Personnel, team, caregiver, nurse, oncology, thanks, gratitude, kindness, care, listening, competence, empathy, availability, quality, humanity, caring, extraordinary	"I'll take this opportunity to thank all of the hospital personnel (nurses, doctors, radiologist, auxiliary staff, etc.) for their good care, their tact, their capacity to listen and their kindness"	Colorectal cancer Positive comments Overall satisfaction 10/10
Cancer and me	disease, side effects, pain, hormonotherapy, insurance, finances, information, understand, life, activity, psychologically, entourage, to help, think, feel, talk, face, live, search, find, suggest	"The disease destroyed my marriage and my family but especially the lack of support and psychological help in view of the situation that we had to face, we didn't have enough information on the treatments, the side effects and financial help etc."	Age < 65 yrs. Women Breast cancer Negative comments Overall satisfaction 8/10

the disease and always useful for the morale" (Man, 54, melanoma).

Elements concerning the patients' understanding and acceptance of the disease and its treatment were expressed in this class. On the one hand, the lack of information and poor communication with medical staff or the lack of opportunities to share experiences with fellow patients created barriers to understanding and acceptance of the disease. On the other hand, adequate information from staff or external sources (e.g. websites, books) facilitated understanding and acceptance. "Understanding" from others was also expressed as either present and of great importance to patients, or as absent. Lack of understanding, be it from medical staff, loved ones, employers, colleagues or insurance companies, was a source of suffering for some patients. This class was overrepresented in respondents with hematologic cancer and in those with an overall satisfaction of 10/10.

'Cancer repercussions' *Patient quotes: "How to live a normal life with this relentless pain" (Man, 54, hematologic cancer); "The disease destroyed my marriage and my family" (Woman, 35, breast cancer); "After 6 months of sick leave and three surgical interventions my employer pushed me to leave" (Woman, 54, breast cancer).*

In this class, the respondents' discourse focused on the period during which the treatment took place and the way in which the disease and its treatment disrupted their quality of life as it affected their physical and emotional health. They described the negative impacts on different aspects of their life including friends, family, work and leisure. For example, respondents reported the difficulties they had to reconcile their professional life with care (e.g. amount of appointments, work interruptions). Respondents also mentioned adverse effects of treatments, such as pain or insomnia, as well as financial issues linked with treatment costs and their inability to work. From within this turmoil, respondents related their aspirations to be able to lead once again – a "normal life". No category of respondents was overrepresented in this class.

'Information and communication' *Patient quotes: "I rarely received the essential information spontaneously; [it was a] wrestling match to obtain answers to my questions" (Man, 66, lung cancer); "It's necessary to improve information to patients about side effects, which are sometimes harder than the cancer itself" (Man, 60, colorectal cancer); "Nurses are more open than the doctors to talking about benefits of homeopathy, osteopathy and hypnosis. It's a complementarity that helped me a lot because I decided to do something that made me feel good rather than to "suffer" under the prescribed treatments" (Woman, 55, breast cancer).*

This class includes comments on the information and communication around cancer. Respondents expressed difficulties obtaining information on the disease, the treatment, the side effects, their results and medical reports, as well as on the range of programs and help available to

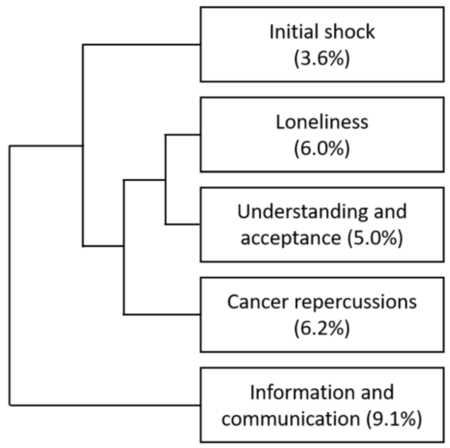

Fig. 3 Hierarchical clustering dendrogram of the 'cancer and me' class. (Dendrogram generated by IRaMuTeQ; percent of the text segments classified within each class indicated in parenthesis)

patients. Shortcomings included the content, the amount (too much/too little), the form (oral/written) as well as the timing (too early/too late) of the information delivered. Respondents also provided suggestions to improve communication; for example, they proposed that information could be communicated orally and in written form using clear simple language. A particularly frequent theme in this class was the lack of information on side effects and sequelae, the lack of understanding, compassion and help for side effects from medical professionals and the desire for more information on complementary therapies. Medical professionals, especially physicians, were described as being closed to complementary therapies, though they featured regularly as a means by which patients coped with the side effects. No category of respondents was overrepresented in this class.

Comparisons with patient-centered dimensions from closed-ended questions

Comparisons between the thematic classes from the textual analysis of free-text comments and the patient-centered care dimensions assessed in the closed-ended questions are presented in Table 3. In general, the themes that emerged from free-text comments were related to the patient-centered care dimensions and other components assessed in closed-ended questions, but went beyond the evaluation of whether an episode of patient-centered care happened or not. Indeed, the thematic classes provided more details on specific episodes of both positive and negative experiences of care and on qualities of healthcare professionals not fully assessed by the closed-ended question. While most closed-ended questions related to experiences of care within the last 12 months, free-text comments included experiences that happened during a larger period. In addition, the content of the thematic classes also related to the personal experience of receiving the diagnosis and living with cancer, as well as the impacts of poor experiences of cancer care. These aspects were not directly evaluated by PREMs.

Discussion

This computer-assisted textual analysis of free-text comments provided by patients with cancer in response to an invitation to share cancer-related experiences and suggestions for improving care at the end of the SCAPE questionnaire (31% comment rate) allowed us to identify five main thematic classes: 'cancer care pathways', 'breast cancer care pathways', 'medical care', 'gratitude and praise', and finally 'cancer and me'. This latter class was further divided into five subclasses: 'initial shock', 'loneliness', 'understanding and acceptance', 'cancer repercussions', and 'information and communication'. Apart from the first two classes, the thematic classes of the free-text comments related more to the personal and emotional experience and consequence of having cancer and receiving care, while the dimensions of the closed-ended questions assessed mainly the factual aspects of people's experience of patient-centered care.

We also observed a sharp contrast within the free-text comments between the factual descriptions of medical history and care pathways, grouped in the 'cancer care pathways' and 'breast cancer care pathways' themes and the more personal aspects of living with cancer, especially present in the 'cancer and me' class. The described care pathways encompassed diagnosis to treatment through to remission or relapse, framed by key examinations, interventions, treatments and results. On the other hand, personal elements included emotional and social aspects related to cancer and care, such as coping with cancer and its treatments and the interactions with health care providers. This distinction in the free-text comments may reflect the way patients and health professionals interact. Their interaction has been described as being structured by two distinctive needs: professionals' needs of 'knowing and understanding' and patients' needs of 'feeling known and understood' [26]. In our results, the former would be expressed in the neutral description of the care pathways whereas the latter would be expressed through the more personal and embodied experiences. The 'cancer and me' class is a typical example of the participants' need of 'feeling known and understood' with particularly rich illustrations of the vast array of challenges faced by respondents. Confronted with cancer, patients have to absorb the initial shock of diagnosis, deal with feelings of loneliness, seek adequate information, understand and accept the disease, and manage the

Table 3 Comparisons and contributions of thematic classes to patient-centered care dimensions

Thematic classes of free-text comments	**Patient-centered care dimensions of closed-ended questions** ***Exemples of questions***	**Contributions of thematic analysis of free-text comments to closed-ended questions**
Cancer care pathways and breast cancer care pathways	Clinical information *What is your principal cancer diagnosis?* *How long has it been since you were first treated for this cancer?* *What type(s) of treatment have you received?*	Thematic analysis added details on the temporal course of cancer diagnosis, care and clinical pathways. Note: the questions related to clinical information were not part of the patient-centered care dimensions assessed by the closed-ended questions.
Medical care	Coordination and integration of care *Did the different people treating and caring for you work well together to give you the best possible care?* *In your opinion, were there enough nurses on duty to care for you in hospital?*	Thematic analysis added details on specific issues related to coordination between different healthcare professionals and integration of services: e.g. negative comments on individual physicians and specific episodes, comments on aspects such as 'staff changes' or 'doctor looking tired or overwhelmed' not evaluated by closed-ended questions.
Gratitude and praise	Emotional support *Did you trust the doctors/nurses treating you?* *During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?*	Thematic analysis added detailed descriptions of and reasons for the positive aspects of care and relationships with a wide variety of actors (e.g. doctor, nurse, therapist, social worker, receptionist, cleaning personnel): specific thanks, gratitude, and qualities (e.g. kind, caring, competent, empathic, attentive, available, extraordinary, dedicated, excellent).
Cancer and me: initial shock	Respect for patients' preferences *How do you feel about the way you were told you had cancer? [done sensitively?]* Information and education *Did you understand the explanations about what was wrong with you?*	Thematic analysis added description of the impact of learning they had cancer (e.g. shock), which was not assessed in closed-ended questions. Patients' needs and suggestions to improve the delivery of the diagnosis and other important medical information were also a valuable contribution obtained from thematic analysis.
Cancer and me: loneliness	Emotional support *During your hospital visit/while you were being treated as an outpatient, did you find someone on the hospital staff to talk to about your worries and fears?* Continuity and transition *Did hospital staff give you information about support or self-help groups for people with cancer?* *During/after your cancer treatment, did you receive enough care and support from health/social services?*	Thematic analysis added description of the impact of poor experiences of care regarding emotional support and continuity of care. This included: patients' feelings of loneliness during and after treatment (e.g. while managing side effects, accessing complementary medicine, or resuming a professional activity after treatments); and patient's needs and suggestions on how to alleviate loneliness (e.g. help & support with administration & finances).
Cancer and me: understanding and acceptance	Information and education *Did you understand the explanations about what was wrong with you?* *Were the results of the diagnostic test explained in a comprehensible manner?* Involvement of family and friends *When you were first told that you had cancer, had you been told you could bring a family member or friend with you?*	Thematic analysis added information on support (or lack thereof) from families, friends or support groups in accepting the disease, and on the negative impact of lack of understanding from medical staff, employers, and insurance companies.
Cancer and me: cancer repercussions	Health-related quality of life *I have a lack of energy; I am able to enjoy life; I worry that condition will get worse; I have nausea; I am content with the quality of life right now; I am sleeping well; I have pain ['not at all' to 'very much']* Continuity and transition *Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities?* *Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?* Physical comfort *Do you think the hospital did everything they could to help control you pain?*	Thematic analysis added detailed descriptions of how cancer affected patients' (and their families') quality of life, including physical and emotional health, family, social and professional life, financial impact, and fears, as well as reports on how difficult it is to have a "normal life" after cancer treatment. Note: the seven questions on health-related quality of life were not part of the patient-centered care dimensions assessed by the closed-ended questions; they were from the rapid version of the functional assessment of cancer therapy-general (FACT-G7) instrument.
Cancer and me: information and	Information and education *Were the possible side effects of treatment(s)*	Thematic analysis added information on patients' needs and suggestions for: better access to and explanation regarding medical information

Table 3 Comparisons and contributions of thematic classes to patient-centered care dimensions *(Continued)*

Thematic classes of free-text comments	**Patient-centered care dimensions of closed-ended questions** ***Exemples of questions***	**Contributions of thematic analysis of free-text comments to closed-ended questions**
communication	*explained in a comprehensible manner?* Continuity and transition *Were you offered practical advice and support in dealing with the side effects of your treatment(s)?* Coordination and integration of care *Did the different people treating and caring for you work well together to give you the best possible care?* Complementary medicine *Have you used any complementary medicine?*	(including side-effects); better communication between healthcare professionals; and better recognition and integration of complementary medicine by doctors

repercussions of cancer on their lives. This class included comments related to how cancer and cancer symptoms had an impact on the person, on *self*, on the emotional experiences of living and coping with cancer, aligning with experiences reported in previous meta-analyses on living with cancer and symptom experiences [27, 28]. Compared with the closed-ended questions on emotional support, the ‘cancer and me’ class went beyond positive or negative experiences to encompass descriptions of living with cancer.

The challenges patients face when confronted with cancer and cancer symptoms, as well as the discontinuity of care brought about by the frequent changes at the junior physician level along with the faulty inter-professional communication expressed in the ‘medical care’ theme, illustrates the need for ongoing and better care coordination and multifaceted support. This theme is a recurrent theme reported in other similar studies on the analysis of free-text comments, highlighting the importance of this aspect to individuals with cancer [9, 11, 19, 21]. The importance of this theme for patient-centered care is also reflected in the questionnaire as the ‘coordination and integration of care’ dimension was assessed in six closed-ended questions. Recent systematic reviews have shown that cancer care coordination interventions, such as increased communication across multidisciplinary teams, patient navigation, home telehealth, self-management education and nurse case management, have the potential to improve a range of cancer related outcomes, including measures of patient experience with care, and quality of life [29–32]. It may be beneficial to further develop such interventions.

In all classes, except the two classes about care pathways, participants expressed positive and negative statements when describing their care experiences, which may further guide quality improvement initiatives. Negative comments identify aspects that need change while positive comments help staff identify how they are valued and what they are doing well, providing motivation to continue [33]. The negative feedbacks and suggestions provided by the study respondents mostly concerned the four following areas: 1) the frequent staff changes at the junior physician level; 2) communication issues, with particular emphasis on the lack of information (oral and written) on side-effects and complementary therapies; 3) the manner and circumstances in which the cancer diagnosis and treatment were communicated; and 4) the lack of support from health care professionals throughout the treatment process, with particular shortcomings in regards to side effects and end of treatment. The first two areas of care, i.e. ‘staff changes’ and ‘communication about complementary therapies’, were not specifically assessed with closed-ended questions, thus providing useful information for questionnaire improvement. On the other hand, the survey contained several closed-ended questions on the communication of diagnosis as well as information and support about side-effects. Quantitative results of these questions also showed more negative experiences compared to questions on other dimensions. Thus, these latter themes from free-text comments consolidated the quantitative findings and provided in-depths illustrations of these issues and concerns around communication and support, which have also been reported in other studies [19, 21].

Concerning positive feedback, an entire class was dedicated to expressing ‘gratitude and praise’ toward health care professionals for their medical/technical expertise and the quality of human relations. If respondents felt the need to express gratitude and difficulties in this questionnaire, it maybe that they did not have sufficient opportunities to do so during care and in the section of the questionnaire with closed-ended questions. Previous studies have also reported frequent positive feedback in free-text comments, ranging from one third of comments related to appreciation and gratitude [9] to two thirds of comments being positive [19]. These comments have been very useful when communicating the results to the participating hospitals in our study, and could also be used to inform a “safety II culture” approach, which builds on ‘things that go right’ instead of focusing primarily on critical incidents and adverse events [34].

The use of a computer-assisted textual analysis method represents the main strength of this study, having allowed comprehensive analysis of all free-text comments within a large survey sample in a time-efficient way. It resulted in the identification of important themes for individuals with cancer, some of which have been reported in other studies using different approaches, both inductive and deductive and manual or computer-based methods [9, 11, 19, 21]. The results of this study need nevertheless to be interpreted taking into consideration the following limitations. First, our results reflect experiences of patients who transited within one of the four hospitals involved in recruitment. However, this includes both university and non-university hospitals covering a wide range of French-speaking Switzerland. Secondly, since the questionnaire was only available in French, patients not speaking the language well would not have been able to express their experiences fully and may experience care differently [35]. Thirdly, free-text comments were written by a third of the respondents, who were more likely to be female, speak French, be more educated, and have breast or lung cancer. This may bias results, though mean age and overall satisfaction with care between those having left and those not having left a comment were similar. Finally, a frequent criticism made about computer-assisted text analyses is that the results are not sensitive to the context because the text is fragmented into analytic units. The impact of this criticism has however been limited, as the researchers frequently returned to the original text to consider the context and validated their interpretation with a patient representative.

Conclusions

In cancer patient experience surveys, providing space for free-text allows respondents to express themselves in their own words and to report in more details about their personal experiences of living with cancer, contributing to the better understanding of their experiences and going beyond the standardized evaluation of patient-centered care. Indeed, the analysis of free-text comments sheds light on important themes and aspects of care that patients choose to report freely and that closed-ended questions may not reveal, providing complementary insights. It also underlines the importance of offering space for comments and highlights the diversity of cancer patients' journeys and experiences, encompassing aspects outside of health care. Such results are particularly useful to inform questionnaire development, provide feedback to hospitals and healthcare teams, and guide quality and safety of care initiatives aiming at enhancing the patient-centeredness of care and improving the cancer care experience overall.

Abbreviations

CPES: Cancer Patient Experience Survey; CAHPS: Consumer Assessment of Healthcare Providers and Systems; IRaMuTeQ: Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires; PREM: Patient-reported experience measure; SCAPE: Swiss Cancer Patient Experiences

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Authors' contributions

CA, ME, and IPB conceptualized and acquired the funding support for the SCAPE study. CB and ACG took part in the SCAPE study steering committee. CA managed the research planning and execution and conducted the data acquisition under the supervision of ME and IPB. DW, IG and SL analyzed and interpreted the free-text data under the supervision of CA, ME and IPB. CB interpreted the free-text data and selected the relevant patient citations with DW. DW and CA wrote the initial draft, which was then revised by ME, IPB, IG, SL and ACG. All authors read and approved the final manuscript.

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Availability of data and materials

The French version of the survey is available upon request. The data that support the findings of this study are available on request from the corresponding author [CA]. The free-text data are not publicly available due to them containing information that could compromise research participant privacy.

Ethics approval and consent to participate

The study was approved by the Commission cantonale d'éthique de la recherche sur l'être humain (CER-VD) (authorization number 2018–01345), member of the association of Swiss Ethics Committees on research involving humans (swissethics). The study participants provided written informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

4.4 Determinants of overall rating and experiences of cancer care *(manuscript)*

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Chantal Arditi conceptualized the analysis with Isabelle Peytremann-Bridevaux and Manuela Eicher; she supervised the analysis done by Julien Junod and interpreted the data; she wrote the initial draft.

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Key words: Cancer, patient survey, patient experiences, patient satisfaction, quality of care, Switzerland

Abstract: 339
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Abstract

Background

Understanding how patient-reported experiences of care and overall rating of care vary among patients with different characteristics is useful to help interpret results from patient experience surveys and design targeted improvement interventions. The primary objective of this paper was to identify the socio-demographic and health-related characteristics independently associated with overall rating of cancer care. The secondary objective was to explore how these characteristics were associated with specific experiences of cancer care.

Methods

This cross-sectional multicenter study analyzed self-reported data collected from 2696 patients diagnosed with breast, prostate, lung, colorectal, skin, or hematological cancer from four large hospitals in French-speaking Switzerland. Multivariate logistic regressions with backward selection of independent variables were used to identify the socio-demographic and health-related characteristics independently associated with overall rating of cancer care in the primary analyses. In the secondary analyses, we ran the multivariate model from the primary analyses with specific experiences of care as outcomes to estimate the adjusted odds ratios (OR) and 95% confidence intervals (CI) of the selected characteristics.

Results

Respondents' mean rating of overall cancer care was 8.5 on a scale from 0 to 10, with 83% categorized as reporting a high rating (8-10 rating). Being a woman (OR 0.70, 95% CI 0.55-0.89), not being Swiss (OR 0.68, 95% CI 0.51-0.89), reporting lower health literacy (OR 0.51, 95% CI 0.41-0.65), preferring making medical decisions alone (OR 0.52, 95% CI 0.37-0.73), having forgone care due to cost (OR 0.58, 95% CI 0.44-0.77), having used complementary medicine (OR 0.64, 95% CI 0.51-0.82), and reporting poorer health (OR 0.32, 95% CI 0.22-0.46) were all independently associated with a low rating of overall cancer care. Poorer health, lower health literacy, and having forgone care were the three characteristics most often associated with less positive specific experiences of care.

Conclusions

Our results identified several patient characteristics consistently associated with lower overall rating of care and specific experiences of cancer care. Efforts to improve patient's experiences with cancer care should address the needs of patients in poorer health, with lower health literacy, and facing financial hardship.

Introduction

Patients-reported experience measures (PREMs) are now widely recognized as one of the important quality indicators of cancer care, along other indicators such as clinical and mortality outcomes. These PREMs are typically collected with online and/or paper patient surveys, asking patients to report on their experiences while receiving cancer care and interacting with health professionals. Cancer PREMs surveys usually include a number of items asking about specific experiences of care along the cancer care continuum, spanning from detection and diagnosis to follow-up care, and often end with an overall rating of care, used as an aggregated measure of overall experience (1, 2). Understanding how overall rating and specific experiences of care vary among patients with different characteristics is useful to help interpret results from patient surveys and to design targeted improvement intervention. Previous studies and a recent systematic review (3) have shown that cancer patients' experiences vary quite significantly by a wide array of patients' characteristics, sometimes in an inconsistent manner. Regarding socio-demographic characteristics, older age was reported to be either positively (4-8), negatively (9) or not related to positive ratings of care (10, 11). Being married was associated with lower ratings in one study (11) while being single was associated with lower ratings in another study (12). There was more consensus around women tending to report less positively (4, 6-8, 11, 13, 14), as patients from ethnic minorities (7, 8, 11, 14, 15) and lower income (11, 13, 15). Other frequent socio-demographic determinants of patient experiences reported in the literature were area of residence (5, 13, 16), education level (5, 6, 10), and level of social support (6, 11). Regarding health characteristics, poorer health status or quality of life was one of the most important determinants of reporting lower ratings and poorer experiences (5, 6, 9, 10, 12, 15, 17-19). Finally, studies looking at clinical characteristics of cancer have found that experiences varied by type of cancer and prognosis (4, 6, 9, 13, 16), treatments (8, 9) and time since diagnosis (12). To date, there were no studies in Switzerland examining the interplay between patient-related characteristics and overall rating of cancer care and specific experiences of care. As the Swiss health care system differs from the UK and the USA systems where most previous research was done, one might expect different determinants than in other countries. In addition, we did not find studies examining health literacy as a determinant of patient experiences, despite low literacy being a predictor of inadequate use of health care services and poor health outcomes (25, 26). Our primary objective was to identify the socio-economic and health-related characteristics independently associated with the overall rating of cancer care in Switzerland. The secondary objective was to explore how these characteristics were associated with specific experiences of care.

Methods

Study design and population

We used data collected for the Swiss Cancer Patient Experiences (SCAPE) study, an observational cross-sectional multicenter survey of patients diagnosed with cancer in four large hospitals in the French-speaking region of Switzerland (20). Patient eligibility criteria were adult Swiss residents (> 18 years) with a confirmed diagnosis of breast, prostate, lung, colorectal, skin, or hematological cancer (leukemia, lymphoma, myeloma); who were hospitalized or had an outpatient visit in an oncology unit at the recruiting hospital; between January 1, 2018 and June 30, 2018. Data were collected with a questionnaire mailed to eligible patients in October 2018. Patients could complete and return the survey questionnaire by post or complete it online. Non-respondents received a reminder in January 2019. We included in the analyses individuals reporting an eligible cancer who returned the questionnaire by the end of March 2019.

Overall rating of cancer care (primary outcome of interest)

Overall rating of cancer care was measured with the following question, at the end of the first section of the self-administered questionnaire about experiences of care: ‘How would you rate your overall cancer care?’, with a 0 (worst) to 10 (best) rating scale. We dichotomized answers as ‘high’ if rating was between 8 and 10 and ‘low’ if below 8. We excluded from the analyses patients who did not answer the question (n=59).

Specific experiences of care (secondary outcomes of interest)

Outcomes of interest for the secondary objective comprised the ‘core’ experiences of care from seven subsections of the first section questionnaire, including 21 questions asking patients to evaluate: 1) waiting time before seeing a specialist (before_wait); 2) the diagnosis process (told they could be accompanied (dx_accompanied), told in a sensitive manner (dx_tactful), understood explanations (dx_explanation), received written information (dx_information)); 3) treatment decision making (treatment options were explained (ttt_opt), side-effects were explained (ttt_sidefx_expl), offered support for dealing with side effects (ttt_sidefx_support), told about long-term side effects (ttt_sidefx_future), involved in treatment decisions (ttt_involve); 4) support for people with cancer (received information on support groups (info_support_gp), on impact of cancer on daily activities (info_impact), on getting financial help (info_support_fin); 5) home care (information to help care at home (home_info), care from health or social services during (home_service_during) or after (home_serv_after) treatment; 6) care from the general practitioner (GP) (GP receiving information (gp_info), GP support (gp_support) and 7) overall aspects of care (professionals working well together (overall_collab), receiving a care plan (overall_careplan) and administration of care (overall_admin). A second set of ‘optional’ experiences of care from three subsections of the questionnaire preceded by a filter question asking patients to answer only if they had had the targeted health care service within the last 12 months comprised 17 questions on: 1) diagnostic tests (received information before (dx_test_info), waiting time before (dx_test_wait), received explanations after (dx_test_explanation); 2) inpatient hospital care (staff talking while ignoring patient (hosp_ignor), trust in doctors (hosp_trust_dr), opportunity for family to talk to doctors (hosp_fam_involve), trust in nurses (hosp_trust_nurse), enough nurses (hosp_enough_nurse), enough privacy (hosp_privacy), found someone to talk about worries (hosp_worries), received help with pain (hosp_pain), treated with respect (hosp_respect), received information about post discharge (hosp_post_info), told whom to contact if worried (hosp_post_contact); and 3) outpatient hospital care (found someone to talk about worries (ambu_worries), doctors had documents available (ambu_documents), waiting time (ambu_wait)). These core and optional experiences were dichotomized as the percentage of patients reporting a positive experience (e.g. ‘yes, completely’) after excluding the neutral (i.e. ‘Don't know/can't remember’) and not applicable answers.

Patient characteristics (explanatory variables)

Socio-demographic explanatory variables available were sex, age, marital status (single, married/partnership, divorced/separated, widowed), education (primary, secondary, tertiary), professional activity status (active, on disability or sick leave, retired), principal language (French, other), nationality (Swiss, non-Swiss), financial hardship (trouble paying household bills in past 12 months, forwent care due to costs in past 12 months), health literacy (frequency of having difficulty understating written medical information, a single screening question shown to have good sensitivity and specificity to detect people with health literacy limitations (21)) and medical decision making preference (with doctor, alone, doctor alone). Cancer and health-related explanatory variables were cancer diagnosis and treatments, use of complementary medicine, any comorbidity (list of 12 chronic conditions), overall health status, validated screening question of depressive symptoms (22), and a previously validated measure of health-related quality of life Functional Assessment of Cancer Therapy - General 7 item version (FACT-G7) (23). Further details on the questionnaire can be found in the previous publication on the analyses of the variation of reported experiences of care by type of cancer (20).

Data analyses

For the primary analyses, we first ran descriptive analyses on patient characteristics (i.e. socio-demographic, health-related) and the overall rating of cancer care. We then performed univariate logistic regressions to identify explanatory variables associated with reporting a high rating of cancer care. To build a final multivariate model of factors independently associated with a high rating of cancer care, we started with all the variables associated with the outcome variable with a P-value of 0.15 or lower in the univariate logistic regressions. We then followed the 'purposeful selection' process suggested by Hosmer and colleagues (24) for the selection of explanatory variables. It corresponds to a backwards stepwise construction, in which one monitors the influence variables may exercise on each other. We used graphical representations to assess the influence of single or groups of observations on the model (leverage points) and to check whether subgroups (e.g. hospitals) were appropriately fitted by the model (25). We used the likelihood ratio as goodness-of-fit measure. We reported unadjusted and adjusted odds ratio (OR) and 95% confidence intervals (CI) for the explanatory variables.

For the secondary analyses, we ran the selected multivariate model from the primary analyses with the core and optional experiences of care as outcomes to estimate the adjusted OR and 95% CI of the selected characteristics, presented in forest plots for each characteristic.

We estimated the intraclass correlation coefficients of mixed-models with a random effect for each hospital. As they were all below 0.01, the effect of hospital clustering was negligible and multilevel modelling not necessary. Missing data were not computed; all statistical analyses were conducted with Stata 16.1.

Patient involvement

A Patient Partner took part in the study steering committee. She was also involved in pre-testing the questionnaire, writing the patient materials, answering patients' email inquiries, analyzing the free-text comments, preparing and writing the lay results for patients, and disseminating the study and results on social media and to the scientific community.

Results

Participants' characteristics

Of the 7145 patients invited to complete the survey, 3121 returned the questionnaire (44% participation rate). Of these, 2696 participants reported an eligible cancer and answered the question on the overall rating of care. Table 1 provides a descriptive overview of respondents' characteristics. Their mean age was 63.8 and 61% were women. A third reported tertiary-level education, while a fifth reporting trouble paying household bills in the previous year. Eighty-one percent of respondents reported a first cancer and 28% initiated their treatment within the previous year. The most frequently reported cancer was breast cancer (40%), followed by hematologic cancers (16%), lung cancer (15%), colorectal cancer (10%), prostate cancer (9%) and skin cancer (5%). A quarter reported excellent or very good health and mean quality of life was 19.3 on a scale from 0 to 28 (highest quality of life).

Overall rating of care and patient characteristics

Overall cancer care was rated at a mean 8.5 (standard deviation 1.4), with 83% of respondents categorized as reporting a high rating (8-10 ratings) (see Figure 1).

The associations between patient characteristics and a high rating of overall care are shown in Table 1. Of the 21 patient characteristics under consideration, 17 were associated with overall rating of care in univariate analyses and seven remained in the final multivariate model (likelihood ratio 171.46; p-value <0.001; pseudo R2 0.08 indicating good fit). Being a woman (OR 0.70, 95% CI 0.55-0.89), not being Swiss (OR 0.68, 95% CI 0.51-0.89), reporting low health literacy (OR 0.51, 95% CI 0.41-0.65), preferring making medical decisions alone (OR 0.52, 95% CI 0.37-0.73), having forgone care due to cost (OR 0.58, 95% CI 0.44-0.77), having used complementary medicine (OR 0.64, 95% CI 0.51-0.82), and reporting poorer health (OR 0.32, 95% CI 0.22-0.46) were all independently associated with a lower likelihood of reporting a high rating of cancer care.

When examining how these seven factors were associated with the 21 core experiences of care (see Figure 2) and the 17 optional experiences of care (see Figure 3), three factors were consistently associated with poorer experiences of care: reporting poorer health, having forgone care, and reporting low health literacy. Having used complementary medicine was associated with reporting less positive experiences for about half of the questions, while being a woman predicted less positive experiences for six specific experiences and more positive experiences for three experiences. Respondents without the Swiss nationality tended to be more likely to report a positive experience, in contrast to their overall rating of care. Decision making preference was not strongly associated with core and optional experiences.

Discussion

While rating of overall cancer care was fairly high, it did vary quite substantially across seven patient characteristics: sex, nationality, health literacy, medical decision making preference, financial hardship, health status and use of complementary medicine. Age, education, and marital status were not independent factors, neither were any cancer-related characteristics (e.g. type of cancer, time since diagnosis, treatments received). The variation of experiences of care followed a similar pattern for three of the determinants of overall cancer care (health literacy, financial hardship, health status). Use of complementary medicine tended to also predict less positive experiences of care, while not being Swiss tended to predict more positive experiences of care in contrast to the overall rating.

The most important determinant was self-reported health status, where individuals with poor health status were systematically less likely to report a high rating of overall cancer care and positive experiences of care. This finding concurs with those from previous studies (5, 6, 9, 10, 12, 15, 17-19).

Although our cross-sectional design does not allow to infer the direction of the relationship, other authors have suggested that health status may influence rating of care (17, 18). One of their explanation is that individuals in poorer health may rate their care more poorly as care is not helping them to improve their health, leading them to have a more negative attitude towards medical care. In a longitudinal study of cancer patients, authors were able to show that a deterioration in global health was linked to a decrease in satisfaction in general, and with doctors in particular (9). Patients with deteriorating or poor health would have more expectations from care and doctors, which are not fulfilled. Identifying these patients early and providing them with comprehensive support for their health needs could improve their experiences of care, as could discussing their health-related issues. Indeed, one study showed that routine and repeated measurements of quality of life lead to increased discussion of health-related issues, resulting in clinically meaningful improvement in patient well-being (26).

Health literacy was another important determinant in our study, as respondents with low health literacy consistently reported lower experiences of care, especially for experiences related to information and explanation around cancer and cancer treatment and related to support. More frequent problems with care reported by patients with low health literacy indicate that having difficulties in understanding medical information may be an important contributor to disparities in care. This evidence adds to the existing evidence that low levels of health literacy in patients are associated with poor health outcomes and inadequate use of health care services (27, 28). Health literacy is a particularly important issue for cancer patients who must navigate a complex and fragmented health care system (27). Limited health literacy was shown to hamper patients' ability to understand the risks and benefits of cancer treatment (29), which can explain the poor experiences of care reported in our study. Clinicians should pay special attention to providing effective communication and information, to ensure that people with low health literacy have an equal chance to receive the care and support as people with higher health literacy.

Forgoing care due to cost, a proxy of financial hardship, was a strong determinant of lower rating of care and lower experiences of care. The percentage of patients indicating they forwent care in the last 12 months due to costs was quite high at 13%, a worrying rate in a population of patients who are expected to require regular care and/or follow-ups. The rate was similar to the rate found in a Swiss population-based survey from 2010 and a diabetic population in 2017 (30, 31). Although Switzerland has universal health insurance coverage, out-of-pocket expenditures is the highest among the OECD countries (32), in addition to high health insurance premiums. As these deductible and premiums are independent of income, people with lower incomes pay proportionately more than people with high incomes, which can lead to forgoing care due to costs. Our finding suggest that cancer care in

Switzerland is affected by the cost burden put on patients, who reported poor experiences with the current unequitable health system. As forgoing care may lead to worse health status and worse cancer outcomes, health professionals should be aware of this issue and pay attention to patients who might be in this situation, providing them with information on available support.

Complementary and alternative medicine is often used by individuals with cancer to alleviate symptoms, cope with side-effects, and improve physical and emotional well-being (33, 34). In our sample, 30% of respondents reported having used complementary medicine, similar to the rate reported in the Swiss general population (35). They were also more likely to report lower overall rating of care and less positive experiences of care. One hypothesis for this association is provided by previous studies suggesting that patients who were dissatisfied with their medical care were more likely to use complementary medicine (36, 37). Although the causality cannot be determined from our cross-sectional design, the use of complementary medicine may reflect dissatisfaction and possibly distrust with conventional cancer care, as users were more likely to report poor experiences during the diagnostic process and regarding the handling of treatment side effects. The process of integrating complementary medicine in oncology centers is still beginning in Switzerland, through integrative medicine approaches. Future studies could evaluate whether this negative association between use of complementary medicine and reporting poorer experiences of care reverses in cancer centers offering complementary medicine on site.

In contrast to previous studies, age and education were not independent factors associated with overall rating of care, nor were marital status and living status, our proxies for family support. In addition, none of the cancer-related characteristics (e.g. type of cancer, time since diagnosis, treatments received) were associated with overall cancer care, suggesting that the overall rating of cancer is not determined by the specific cancer trajectory but rather personal characteristics.

The strength of our study reside in the examination of a wide array of potential factors associated with overall rating of care, in a fairly large sample of patients with cancer recruited from four cancer centers in a large region of Switzerland. This was also the first study to assess determinants of patient experiences with cancer care in the French-speaking region of Switzerland. Interpretation of our findings are however limited by several factors. Availability of data was limited to what was collected in the survey. In addition, all data were self-reported, leading to limited information on the specificities of cancer (lack of information on stage at diagnosis for instance) that might be associated with overall rating of care. The cross-sectional nature of the study also prevents drawing conclusions on causality between associated factors and overall rating of care.

Nevertheless, the patient-related factors associated with ratings of care identified in this study are important information for health professionals. Indeed, patient with those characteristics appear to require additional attention or even specific interventions to ensure that delivery of care is responding to their specific needs and improve their experiences of care. Among these patients groups, those with lower health literacy could benefit from tailored information to ensure that cancer care is explained in a comprehensible way. Patients reporting financial hardship are another group that could benefit from special support to ensure they can obtain the care they need regardless of their ability to pay. The identified determinants are also important information at a policy level and when comparing performance of cancer centers. Indeed, the distribution of the identified patient-related characteristics among patients cared for in cancer centers can have an impact on their global results in patient surveys. Cancer centers serving patients from lower socioeconomic background and with poorer health can advocate for more means to improve the responsiveness of their care.

Conclusions

Identifying patient-related determinants of patient experiences is useful and valuable to plan efforts for improving patients' experiences of care and better understand the variability of experiences of care. Cancer care should ensure the provision of care meeting all of patients' needs, including those in poorer health, with lower health literacy, and facing financial hardship.

Declarations

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Ethics approval and consent to participate: The study was approved by the Ethics Committee on research involving humans of Canton of Vaud (authorization number 2018-01345) in Switzerland. The study participants provided informed consent.

Consent for publication: Not applicable

Availability of data and materials: Data and survey materials are available from the corresponding author upon reasonable request or from Data@Unisanté, the institutional data repository under DDI Document ID 10.16909-DATASET-20.

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Figure 1: Frequency (%) of ratings of overall cancer care

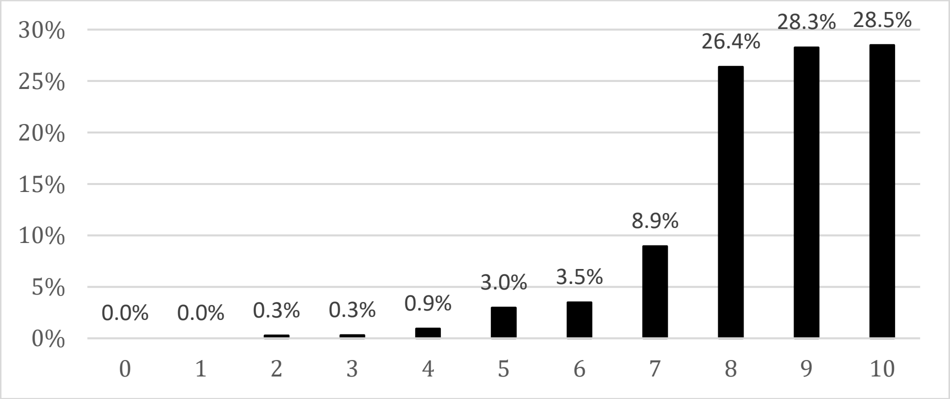


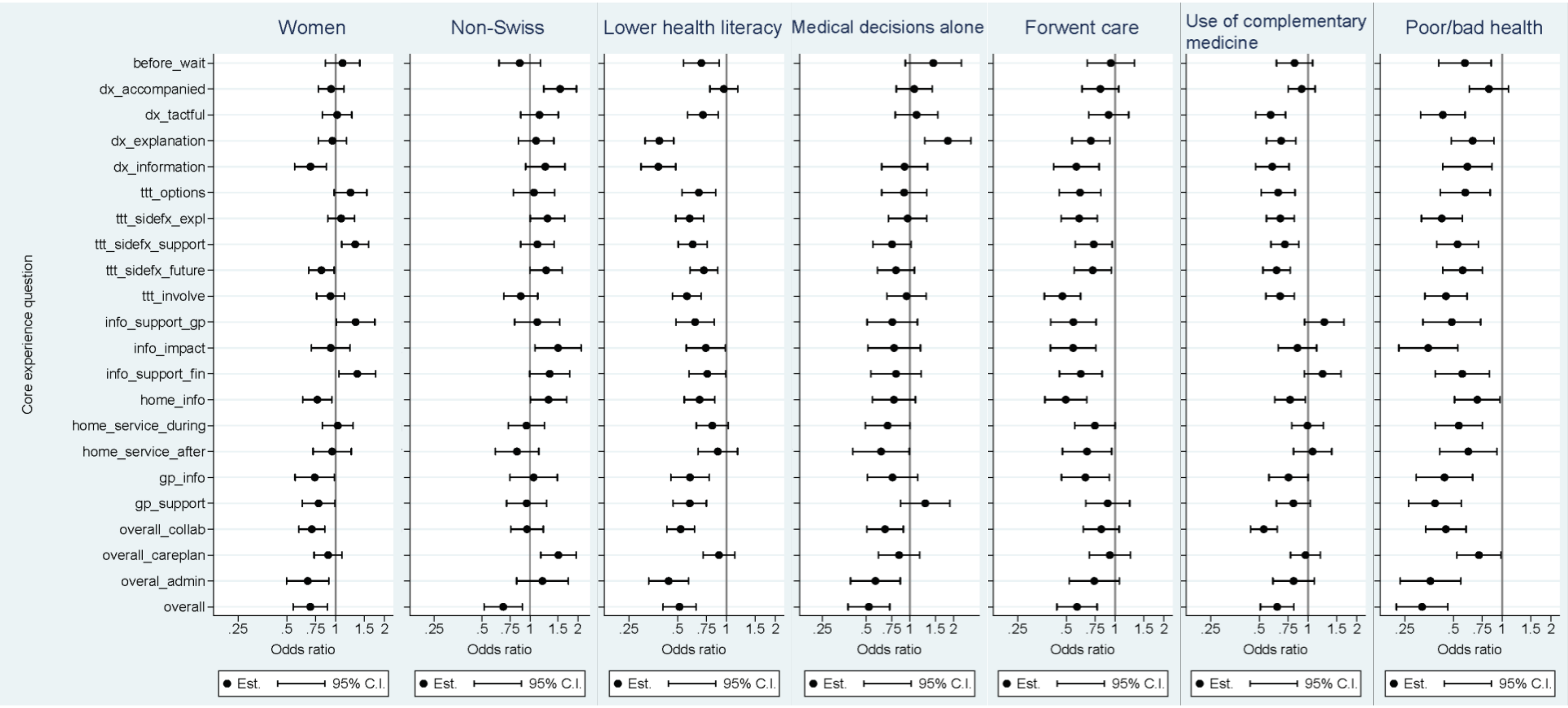
Table 1: Crude and adjusted odds ratios of a high rating of overall cancer care by socio-demographic and health-related characteristics

Variable	N (%)	High rating of overall cancer care n (%)	Crude OR (95% CI)	Adjusted OR (95% CI)
Socio-demographic characteristics				
Sex				
Men	1046 (39.0)	906 (86.6)	1	1
Women	1634 (61.0)	1321 (80.4)	0.65 (0.52-0.81)	0.70 (0.55-0.89)
Age				-
18-54	591 (22.5)	464 (78.5)	1	
55-64	668 (25.4)	549 (82.2)	1.26 (0.96-1.67)	
65-74	848 (32.2)	722 (85.1)	1.57 (1.19-2.06)	
75+	524 (19.9)	452 (86.3)	1.72 (1.25-2.36)	
Marital status				-
Married/partnership	1598 (59.8)	1358 (85.0)	1	
Separated/divorced	510 (19.1)	413 (81.0)	0.75 (0.58-0.98)	
Single	274 (10.3)	213 (77.7)	0.62 (0.45-0.85)	
Widowed	289 (10.8)	238 (82.4)	0.82 (0.59-1.15)	
Living situation				
Living with adult partner	1770 (66.2)	1499 (84.7)	1	
Living without adult partner	767 (28.7)	617 (80.4)	0.74 (0.60-0.93)	
Other living arrangements	138 (5.2)	109 (79.0)	0.68 (0.44-1.04)	
Education				-
Primary	418 (15.9)	338 (80.9)	1	
Secondary	1314 (50.0)	1107 (84.2)	1.27 (0.95-1.68)	
Tertiary	898 (34.1)	746 (83.1)	1.16 (0.86-1.57)	
Professional activity status				-
Active	729 (27.4)	603 (82.7)	1	
Disability or sick leave	287 (10.8)	225 (78.4)	0.76 (0.54-1.07)	
Retired	1395 (52.5)	1196 (85.7)	1.26 (0.98-1.60)	
Other	248 (9.3)	191 (77.0)	0.49 (0.61-1.00)	
Principal language				-
French	2312 (86.3)	1938 (83.8)	1	
Other	288 (13.7)	288 (78.5)	0.70 (0.54-0.92)	
Nationality				
Swiss	2230 (83.3)	1882 (84.4)	1	1
Non-Swiss	446 (16.7)	341 (76.5)	0.60 (0.47-0.77)	0.68 (0.51-0.89)
Health literacy (difficulty understanding written medical information)				
High (never/occasionally)	1905 (72.3)	1651 (86.7)	1	1
Low (sometimes/often/always)	731 (27.7)	540 (73.9)	0.43 (0.35-0.54)	0.51 (0.41-0.65)
Preference for making medical decisions				
With doctor	2239 (84.3)	1882 (84.1)	1	1
Alone	249 (9.4)	182 (73.1)	0.52 (0.38-0.70)	0.52 (0.37-0.73)
Doctor	169 (6.4)	136 (86.4)	1.20 (0.76-1.90)	1.38 (0.83-2.28)

Variable	N (%)	High rating of overall cancer care n (%)	Crude OR (95% CI)	Adjusted OR (95% CI)
Had trouble paying household bills				-
No	2091 (78.9)	1787 (85.5)	1	
Yes	559 (21.1)	423 (75.7)	0.53 (0.42-0.66)	
Forwent care due to costs				
No	2294 (86.6)	1955 (85.2)	1	1
Yes	354 (13.4)	252 (71.2)	0.43 (0.33-0.55)	0.58 (0.44-0.77)
Health-related characteristics				
Type of cancer				-
Breast	1084 (40.2)	864 (79.7)	1	
Hematological	432 (16.0)	365 (84.5)	1.39 (1.03-1.87)	
Lung	405 (15.0)	347 (85.7)	1.52 (1.11-2.09)	
Colorectal	281 (10.4)	237 (84.3)	1.37 (0.96-1.95)	
Prostate	230 (8.5)	196 (85.2)	1.47 (0.99-2.17)	
Melanoma	138 (5.1)	124 (89.9)	2.26 (1.27-4.00)	
Several	126 (4.7)	108 (85.7)	1.53 (0.91-2.57)	
Type of diagnosis				-
First cancer	2127 (80.5)	17583 (82.7)	1	
Recurrence	271 (10.3)	229 (84.5)	1.14 (0.81-1.62)	
2nd or 3rd cancer	243 (9.2)	206 (84.8)	1.17 (0.81-1.69)	
Time since first treatment				-
<1 year	729 (27.7)	610 (83.7)	1	
1-5 years	1260 (47.9)	1045 (82.9)	0.95 (0.74-1.21)	
>5 years	640 (24.3)	528 (82.5)	0.92 (0.69-1.22)	
Treatment(s) received				-
Surgery	1626 (28.6)	1346 (82.8)	0.94 (0.77-1.16)	
Chemotherapy	1550 (27.3)	1299 (83.8)	1.13 (0.92-1.38)	
Radiotherapy	1400 (24.7)	1146 (81.9)	0.83 (0.68-1.02)	
Hormonotherapy	748 (13.2)	604 (80.7)	0.80 (0.64-0.99)	
Immunotherapy	352 (6.2)	297 (83.1)	1.11 (0.82-1.52)	
Use of complementary medicine				
No	1782 (69.4)	1520 (85.3)	1	1
Yes	785 (30.6)	612 (78.0)	0.61 (0.49-0.76)	0.64 (0.51-0.82)
Chronic comorbidities				-
None	1067 (40.7)	912 (85.5)	1	
≥1 other than cancer	1553 (59.3)	1268 (81.6)	0.76 (0.61-0.94)	
Overall health status				
Excellent / Very good	660 (25.0)	601 (91.1)	1	1
Good	1532 (57.9)	1272 (83.0)	0.48 (0.36-0.65)	0.57 (0.41-0.77)
Poor/bad	453 (17.1)	324 (71.5)	0.25 (0.18-0.35)	0.32 (0.22-0.46)
Depressive symptoms				-
No	1678 (63.1)	1455 (86.7)	1	
Yes	980 (36.9)	753 (76.8)	0.51 (0.41-0.62)	
Quality of life (0-28 highest)				-
23-28	653 (24.7)	591 (90.5)	1	
20-22	700 (26.5)	605 (86.4)	0.67 (0.48-0.94)	
17-19	592 (22.4)	481 (81.3)	0.45 (0.33-0.63)	
0-16	701 (26.5)	517 (73.8)	0.29 (0.22-0.40)	

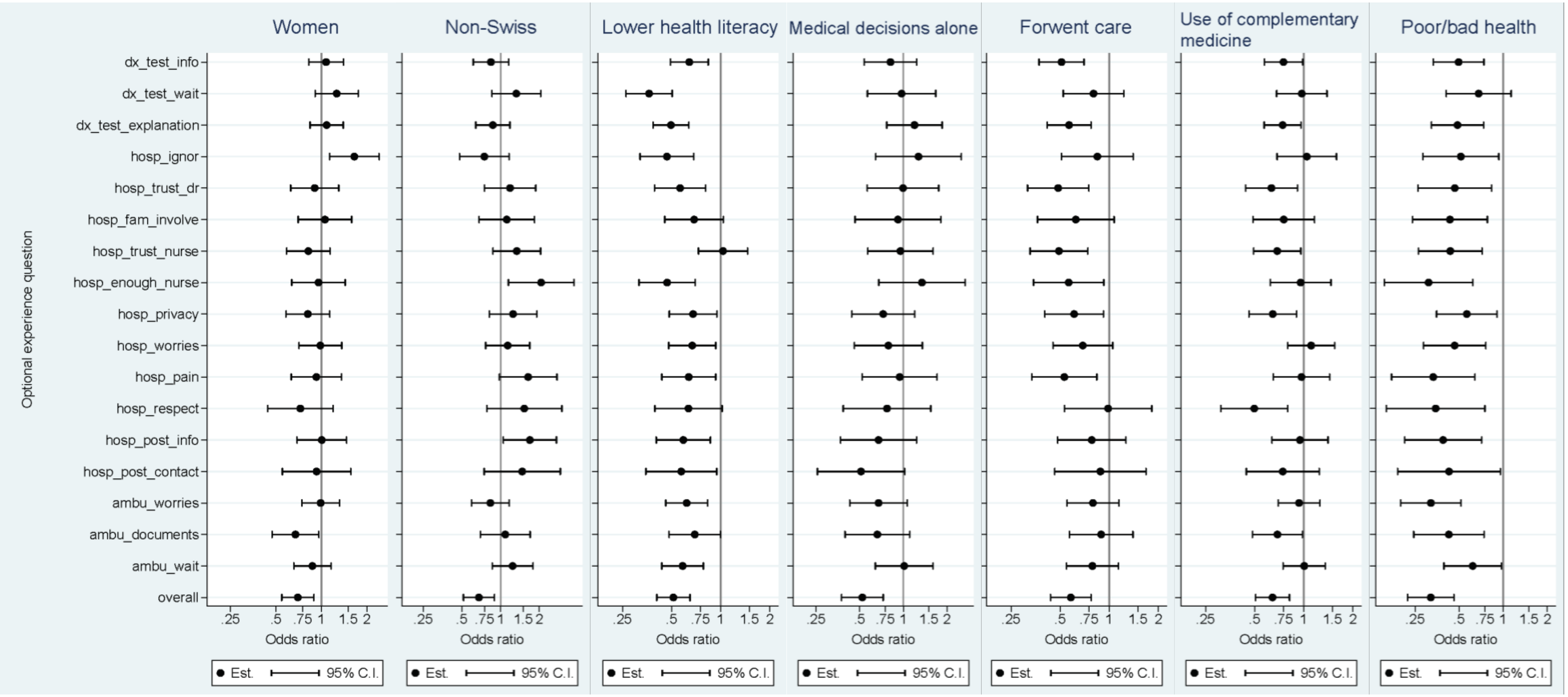
Adjusted odds ratios from the multivariate model with the 7 factors

Figure 2: Adjusted odds ratio and 95% confidence intervals of the seven patient characteristics for the 21 core experiences of care



before_wait: waiting time before seeing a specialist; dx_accompanied: told they could be accompanied for diagnosis; dx_tactful: told diagnosis in a sensitive manner; dx_explanation: understood explanations about cancer diagnosis; dx_information; received written information about cancer; ttt_options: treatment options were explained; ttt_sidefx_expl: side-effects were explained; ttt_sidefx_support: offered support for dealing with side effects; ttt_sidefx_future: told about long-term side effects; ttt_involve: involved in treatment decisions; info_support_gp: received information on support groups; info_impact: informations on impact of cancer on daily activities; info_support_fin: informations on getting financial help; home_info: information to help care at home; home_service_during: care from health or social services during treatment; home_serv_after: care from health or social services after treatment; gp_info: general practitioner (GP) receiving information; gp_support: support from GP; overall_collab: professionals working well together; overall_careplan: receiving a care plan; overall_admin: administration of care.

Figure 3: Adjusted odds ratio and 95% confidence intervals of the seven patient characteristics for the 17 optional experiences of care



dx_test_info: received information before diagnostic test; dx_test_wait: waiting time before diagnostic test; dx_test_explanation: received explanations after diagnostic test; hosp_ignor: staff talking while ignoring patient during hospitalization; hosp_trust_dr: trust in doctors during hospitalization; hosp_fam_involve: opportunity for family to talk to doctors during hospitalization; hosp_trust_nurse: trust in nurses during hospitalization; hosp_enough_nurse: enough nurses during hospitalization; hosp_privacy: enough privacy during hospitalization; hosp_worries: found someone to talk about worries during hospitalization; hosp_pain: received help with pain during hospitalization; hosp_respect: treated with respect during hospitalization; hosp_post_info: received information about post discharge during hospitalization; hosp_post_contact: told whom to contact if worried during hospitalization; ambu_worries: found someone to talk about worries during outpatient care; ambu_documents: doctors had documents available during outpatient care; ambu_wait: waiting time during outpatient care.

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4.5 Policy brief and stakeholder dialogue on the collection and use of PREMs in cancer care to evaluate and improve the quality of cancer care *(article #3)*

Title of the published manuscript in the peer-reviewed journal Public Health Reviews: “Quality of Cancer Care in Switzerland: Going Beyond Traditional Quality Indicators by Collecting Patient-Reported Experiences of Cancer Care”

Chantal Arditi wrote the initial draft of the article, from the policy brief conceptualized by Chantal Arditi and Isabelle Peytremann Bridevaux.

Title of the full policy brief in Appendix 4: Policy Brief. Giving patients a voice about cancer care: should Switzerland do more to collect patients’ experiences of cancer care?”

The policy brief introduces the background and context of measuring patients’ experiences of care, followed by a definition of PREMs, explaining their different uses at the micro, meso and macro level, as well as presenting the different methods to collect and report on patient’s experiences. After a short review of the scientific literature, it presents the current collection of PREMs in Switzerland. The main challenge is then introduced: “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” in Switzerland (153). Two main recommendations are presented to fill this gap: i) develop a position statement on the importance and value of patients’ experiences of cancer care, and ii) collect patients’ experiences of cancer care at the national level, by implementing a national survey or by integrating data collection in cantonal cancer registries. The main barriers and facilitators reported in the literature for the implementation of the second recommendation are then summarized in a table.

During the 3-hour long stakeholder dialogue that took place on November 6, 2020 with eleven stakeholders from the French- and German-speaking parts of Switzerland, participants agreed with the first recommendation to develop a position statement, raising additional points needing clarification. While they agreed on the usefulness of a national program collecting PREMs in oncology, they disagreed on the integration of PREMs in cancer registries, some arguing that PROMs would be more beneficial. Finally, they selected the six most important barriers and facilitators in their opinion. The stakeholder dialogue was summarized in a separate document, not shown in this thesis (175).

In addition, we developed with our Patient Partner, Christine Bienvenu, a lay version of the policy brief for the general public, available in French (176) and German (177).

The policy brief, lay policy briefs, and summary of the stakeholder dialogue are available on the SLHS webpage: https://www.slhs.ch/en/policy-briefs-stakeholder-dialogues/our-topics/prems-in-cancer-care/.

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Quality of Cancer Care in Switzerland: Going Beyond Traditional Quality Indicators by Collecting Patient-Reported Experiences of Cancer Care

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Background: High-quality cancer care should be effective, safe, accessible, efficient, equitable, and responsive to patients' needs. In Switzerland, information on the safety and effectiveness of cancer care is available, but not on responsiveness. Systematic and comprehensive reports from patients on cancer care are missing and needed to complete the assessment of the quality of cancer care.

Evidence: Patient-reported experiences of cancer care are key to evaluate responsiveness of care and drive quality improvement initiatives in oncology practice. Studies have found that responsive care leads to more positive experiences of care, which can lead to more effective treatments and health benefits.

Policy Options and Recommendations: Our first recommendation is to develop a position statement on the importance and value of patient-reported experiences of cancer care. Our second recommendation is to systematically collect patients' experiences of cancer care at the national level, through a dedicated national cancer-specific measurement program or through the integration of patient-reported experiences measures in cancer registries.

Conclusion: The systematic collection of patient-reported experiences of cancer care provides essential information on what matters to patients in addition to traditional clinical information, including patients as partners of the overall assessment of healthcare performance.

Keywords: patient-reported measures, experiences of care, cancer care, quality of care, patient surveys, patient satisfaction, Switzerland

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BACKGROUND

One of the main objectives of a healthcare system is to improve the care and experience of care of people going through the system [1], by providing high-quality responsive care (also called patient- or people-centered care). Such 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 [2, 3]. Responsive 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. Responsiveness of care is also one of the six core dimensions of quality of care according to the widely used framework developed by the Organisation for Economic Co-operation and Development (OECD), along with effectiveness, safety, accessibility, efficiency and equity [4, 5].

In Switzerland, most efforts have focused on the collection of quality indicators pertaining to the effectiveness and safety dimensions of cancer care within acute care hospitals, such as annual quality indicators for acute care hospitals (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). Systematic and comprehensive reports from cancer patients themselves are missing. This is unfortunate since these reports are needed to complete the assessment of the quality of cancer care and evaluate whether current cancer care responds to the needs of patients across the care continuum, from the screening process to remission and follow-up.

Definition of Patient-Reported Experience Measures

Patients can report not only 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 [6] and are usually collected with standardized surveys. While patient-reported outcome measures (PROMs) assess the health result of care received (e.g., symptoms, quality of life), patient-reported experience measures (PREMs) assess experiences with the delivery of care (e.g., communication with nurses and doctors, discharge coordination—see **Table 1**) [7].

Purposes and Uses of Patient-Reported Experience Measures

PREMs have been increasingly collected worldwide, in clinical, economic and health services research, as well as in general assessments of health services and system performance. They have different purposes and uses at different levels. At the patient (micro) level, real-time patient feedback on experiences of care are usually collected at point-of-care, providing clinicians and other healthcare professionals with the opportunity to address concerns and improve perceptions and processes of care immediately [8]. At the institutional (meso) level, aggregated PREMs are used to drive quality improvement initiatives. They are also used to compare the performance of providers (benchmarking), to identify which care aspects insufficiently addressed, and to inform the general public to enable informed patient choice (public reporting) [9, 10]. At the national (macro) level, PREMs are used for monitoring responsiveness of health services, for reimbursement decisions and payments models, and for macro-level healthcare performance measurements, for example. The value of population level measures increases when they are linked to other surveillance data, such as clinical registries, billing and hospital discharge data.

Methods to Collect Patient-Reported Experience Measures

There are quantitative and qualitative methods to measure and collect patients' experience of care. 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. These surveys are designed to produce numerical data that can be analyzed statistically. Their 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 [9]. An important limitation of surveys is also that some patient groups are consistently underrepresented: those who do not speak the national language or with low (health) literacy and those with poor prognosis [11]. In addition, 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 [12]. Consequently, careful evaluation of risk adjustment strategies is required when patient experiences are compared across populations and providers.

TABLE 1 | Definition of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) (Switzerland, 2021).

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	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
Generic PROMs are intended to make comparisons between and within interventions, and across different diseases and sectors of care. They often focus on the person's health state, on "health-related quality of life (HRQoL)" or "Quality of Life (QoL)" in general	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., staff helped with 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)
Condition-specific PROMs are specific to a particular disease (e.g., diabetes), a domain (e.g., pain), or an intervention (e.g., knee arthroplasty). They 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	

Patients' experiences of care 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 [9]. However, these qualitative methods also have limitations: they require more time and expertise to collect and analyze data; they are more likely to reflect individual issues rather than more general and systematic issues; comparisons across populations and providers (e.g., hospitals) and over time are difficult to make; and results are less generalizable than quantitative results.

Reporting of Patient-Reported Experience Measures

Reporting can include instant alerts to healthcare professionals when using real-time feedback but also public reporting on website to inform consumers and publication of these measures in quality reports. The public reporting of patients' experiences of care is important, 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")" [7].

EVIDENCE

We searched the scientific literature for systematic reviews on the validity and reliability of PREMs, the effectiveness of their use to improve the quality of care and the association between positive experiences of care and patient outcomes.

Patient-reported experience measures need to be valid and reliable to be used for quality assessment of healthcare services, in combination with other aspects, such as the clinical relevance of the instrument and the domains of patient-reported experience that the instrument covers. In a recent systematic review of 88 instruments measuring patient experiences in healthcare in general [13], 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.

Two systematic reviews exploring how PREMs were collected, communicated and used to inform quality improvement initiatives [14, 15] concluded there was limited evidence on the effectiveness of interventions informed by patient feedback, as few studies were 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 [14].

Additionally, 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 [16]. 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 [17]. 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 associated with survival. However, authors cautioned about the methodological complexity of determining the relationship between cancer patient experience and subsequent survival [18].

POLICY OPTIONS AND RECOMMENDATIONS

Based on the literature presented above, this policy brief includes two recommendations to going beyond traditional quality indicators by collecting patient-reported experiences of cancer care. These recommendations were also discussed during a stakeholder dialogue that took place in November 2020 with eleven stakeholders representing patient associations, professional associations, educational institutions, quality associations, and hospitals.

The first recommendation is to develop and publish a position statement on the importance and value of patient-reported experiences of cancer care. This is useful to provide guidance for future initiatives on this topic and promote similar developments for other chronic conditions. Stakeholders agreed with this recommendation and added that it will push forward the importance of patients' experiences of care in the political agenda, clarify the concept of patients' experiences of care, and shed light on various stakeholders' interests. They suggested that the intended audience, objective of the statement and leadership would need careful preparation.

The second recommendation is to systematic collect, analyze and report patients' experiences of cancer care at a national level to gather the necessary data to evaluate responsiveness of cancer care and inform quality improvement policy and practice. We present two options for this recommendation, based on two frequent strategies emerging from the literature: 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 (PREMs).

Option 1: National Cancer-Specific Measurement Program

The first option is to develop and implement a dedicated national cancer-specific measurement program collecting experiences of care. For Switzerland, two options for the instrument were identified: the Swiss cancer-specific survey from the Swiss Cancer Patient Experience (SCAPE) survey or the future OECD's patient-reported indicators survey (PaRIS). The Swiss cancer-specific survey covering patient experiences across the care continuum was developed in 2018 for the multicenter SCAPE study in French-speaking Switzerland (www.scape-enquete.ch) [19] and later translated in German for the follow-up study SCAPE-2. The OECD's PaRIS survey includes a PREM section covering generic and common aspects of people-centered care: accessibility,

TABLE 2 | Barriers and facilitators for the implementation of patient-reported experience measures (PREMs) (Switzerland, 2021).

Barriers	Facilitators
Patient (micro) level	
Questionnaire (Q) related	Questionnaire (Q) related
Length and complexity of Q	Parsimonious Q
Lack of availability of translated and culturally meaningful versions	Disease-specific and meaningful questions
Questions not relevant to patients' issues	Simple questions and scales (e.g., scale with verbal descriptors)
Compliance issues in completing the Q	Translations available
Literacy issues	Involving patients in designing the Q
Technology (electronic questionnaire)	Technology (electronic questionnaire)
Comfort level with technology & the internet (if electronic)	IT support available
Technical problems during completion	
Concerns over confidentiality and security	
Privacy concerns	
Over confidentiality of answers	
Over potential identification	
Patient health condition & abilities	
Too ill to answer (response bias)	
Disability (e.g. sight, hands)	
Provider and institutional (meso) level	
Data collection and use	Data collection and use
Lack of understanding the interpretation of the aggregated results	High response rate
Poor specificity of results	Repeated measures over time
Poor perceived reliability and validity of the measure	Providing training on use and interpretation of aggregated PREMs
Administrative burden	Disseminating positive survey findings to boost morale
Response and selection bias	Organization and logistics
Organization and logistics	Working culture supportive of improvement, change and patient views
Not enough staff	Dedicated meeting time to present results
For electronic surveys: lack of patient emails	Patient-centered work culture
No integration of electronic results into electronic health records	Leadership by senior member or having a coordinator in charge
Providers' beliefs & attitudes	Involving providers in the implementation process
Fear of change	Fully integrated electronic data
Feeling of being assessed and criticized in aggregated results	Communication
Lack of understanding of the added value of aggregated results	Providing timely feedback
Fear of increased workload	Providing results in an easily accessible format
Communication	Aggregated measures relevant to clinical management
Long delay between PREMs measurement and reporting	Financial
Technical problems when communicating the results	Financial incentives
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 Q or financial means to outsources the scientific validation	
National health system (macro) level	
Tension among stakeholders regarding data use for different purposes	Adopting a common standard and metric
Conflicting or competing priorities (nationally, regionally, within organizations)	Acceptability of usefulness of measures
Lack of national conceptual framework including PREMs	Including the results in the performance management system and financial targets
Lack of risk- and case-mix-adjustment strategies	Central coordination
Lack of effective reporting strategies	Gradual implementation
Lack of interoperability between systems	Support from e-health
Complexity of integrated data collection	Legal basis
Privacy legislation	
Costs of developing a national program, providing training, implementing program, analyzing data, communicating data	

communication, shared decision-making, and continuity and coordination, as well as measures of health literacy and patient engagement and activation [20]. The stakeholders added 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.

The strategy of having a dedicated national measurement program on experiences of cancer care has been adopted in several countries. For instance, the annual National Cancer Patient Experience Survey (NCPES) launched by the National Health Service in England in 2010, 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 cancer stakeholders groups. Another example is the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Cancer Care Survey in the USA, developed between 2009 and 2016 [21], which main purpose is to support the efforts of cancer centers and oncology practices to improve the patient-centeredness of cancer care, as well as to inform decisions made by providers and patients, for instance.

Option 2: Integration of PREMs in Cancer Registries

The second option is to integrate the collection of PREMs within the Swiss cancer registries, which systematically collect clinical data on the type and stage of the disease and the first treatment since 2020. 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.

The strategy of collecting patient experiences through registries has been chosen in a few countries, such as Sweden which has set up over a 100 national quality registries, 40% of which collect a patient experience measure [22, 23]. Whereas the purpose is to develop and ensure the quality of care, these registries are also used for clinical research and public quality reporting. Another example comes from The Monash Partners Comprehensive Cancer Consortium (MPCCC) in Australia, currently piloting the collection of PROMs and PREMs from pancreatic cancer patients integrated within the Upper Gastrointestinal Cancer Registry [24].

Implementation Considerations

The implementation of a national PREMs program or the integration of PREMs in registries should follow published guidelines and principles, such as those from the OECD [25]. The health department of New South Wales in Australia has also defined guiding principles within which patient-reported measures should operate [26]. Regarding registries, 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 [27].

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), institutional (meso) and national (macro) levels, summarized in **Table 2** [14, 28–33]. A recent Belgian report [29] highlighted the most important facilitators for successful PREMs implementation: 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. 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. The stakeholders additionally identified the following important facilitators: having simple, disease-specific and meaningful questions, using a short questionnaire tailored to patients' literacy level, having electronic health solutions available, and having a clear objective of using results to implement change. In Switzerland, implementing a wide-scale and coordinated measurement of patient-reported experiences of cancer care would be particularly challenging 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, as well as the need to consider three main national languages.

CONCLUSION

In this policy brief, we proposed two recommendations to promote the collection and use of patient-reported experiences of care and present two options to collect actionable measures on cancer patients' experiences of going through the healthcare system. Reports from patients on their experiences of care are essential to evaluate responsiveness of care, on the six key dimensions of quality of care. Indeed, the systematic collection of patient-reported experiences of cancer care enables to consider what matters to patients in addition to traditional quality indicators. It also includes patients as partners of the overall assessment of healthcare performance. However, only a few countries systematically collect this information. We present recommendations and options for Switzerland, but they are relevant for other countries as well. We focused on cancer care, as cancer is among the five most frequent non-communicable diseases in Switzerland and affects most individuals during their life course, either as a patient or as a caregiver to a family member or friend. However, the options presented for cancer care could be transferred and adapted to other frequent chronic conditions, such as diabetes and cardiovascular disease.

FULL POLICY BRIEF

The full policy brief is available on the website of the Swiss Learning Health System (https://www.slhs.ch/policy-briefs-stakeholder-dialogues/our-topics/prems-in-cancer-care/), along with the summary of the stakeholder dialogue that took place in November 2020, when eleven stakeholders representing patient associations, professional associations, educational institutions, quality associations, and hospitals, discussed the content and recommendations of the policy brief.

AUTHOR CONTRIBUTIONS

CA: Conceptualization, methodology, investigation, data curation, writing—original draft, review and editing, visualization. IP-B: Conceptualization, methodology, validation, project administration, writing—review and editing, supervision.

CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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5 Discussion

5.1 Summary and discussion of results

In order to evaluate responsiveness of cancer care, we successfully conducted the first multicenter survey of patient-reported experiences of cancer care, the SCAPE study, in four hospitals in the French-speaking part of Switzerland.

In the published article #1, we described the rates of positive experiences of care as reported by the 2755 patients diagnosed with an eligible cancer and their overall rating of cancer care. While the overall rating was fairly high at 8.5 on a 0-10 scale, we observed several areas of care poorly rated by patients, as expressed by a rate of positive experiences below 60%. Those areas were mainly related to communication, information and supportive care issues. We also showed that experiences of care varied by type of cancer, but not in a systematic manner: higher rates of positive experiences were reported for different types of cancer at different times in the care pathway. We suggest that these patterns are likely related to disease-specific factors, such as treatment burden and prognosis, where patients with poor prognosis tend to report worse experiences of care for instance (103, 111). Our study added valuable information to the growing literature on patient experiences with cancer care reported in other countries such as the UK (11, 103), Denmark (85, 94), Spain (92), Canada (82, 93) and the USA (111, 178), as well as on their use and usefulness to evaluate the responsiveness of care. Although our results reflect experiences reported by patients treated within the Swiss health care system, they are quite similar to the results from surveys conducted in other countries with different instruments. Issues related to communication and information, supportive care, or social and financial support, are often reported in patient experiences surveys as well as surveys on unmet needs (9, 22).

In the published article #2, we presented the five main themes of the free-text comments left by 844 respondents, resulting from the computer-assisted textual analysis of these comments. Two themes consisted in the detailed description of patient's unique cancer care journey expressed in a neutral and factual way. While one theme encompassed respondents' positive comments, expressing gratitude and praise, another theme encompassed mostly negative comments on medical care, the closest theme to what was collected with the closed-ended questions. It allowed us to identify areas for improvement not assessed in the closed-ended questions, such as the 'frequent staff changes' and lack of 'communication about complementary therapies'. It illustrated the need for ongoing and better care coordination and multifaceted support, a recurrent theme reported in other similar studies (117, 119, 129, 131). The last theme consisted in the description of the way cancer affected patients on a personal and emotional level, not measured in the closed-ended questions, but relating to the "lived experience" of cancer. The 'cancer and me' class was an illustration of the participants' need of 'feeling known and understood' (179), with particularly rich illustrations of the many challenges they faced. These results highlighted the importance of providing an opportunity for free-text to patients completing questionnaires.

In the drafted manuscript in section 0 examining patient characteristics independently associated with overall rating and experiences of cancer care, we found that sex, nationality, health literacy, preferences for making medical decisions, forgoing care due to cost (as a proxy of financial hardship), use of complementary medicine, and self-reported health were independently associated with overall rating of cancer care. The most important determinant was poor self-reported health status associated with low ratings and less positive experiences, concurring with results from previous studies (79, 93, 94, 101, 109-111, 113, 114). Having difficulties in understanding medical information also appeared to be an important contributor to disparities in care, adding new evidence to the existing evidence that low levels of health literacy in patients are associated with poor health outcomes and inadequate use of health care services (180, 181). Forgoing care due to cost was the third factor associated with lower rating of care and experiences of care, suggesting that cancer care in Switzerland is also affected by the cost burden put on patients as shown in a few other studies in the USA and the UK (72, 108, 111). The association between use of complementary medicine and poor rating of cancer care may reflect dissatisfaction and possibly distrust with conventional cancer care, although the causality cannot be determined from our cross-sectional design. The process of integrating complementary medicine in oncology centers is beginning in Switzerland, through integrative medicine approaches. Future studies could evaluate whether this negative association reverses in cancer centers with integrative approaches. Finally, none of the cancer-related characteristics (e.g. type of cancer, time since diagnosis, treatments received) were associated with overall rating of cancer care, suggesting that personal characteristics prevailed in the global evaluation of care. Whether these characteristics reflected differential norms in expectations of care or actually worse care cannot be answered by our findings, but could be researched through qualitative methods.

Finally, in the policy brief, we proposed two recommendations to promote the collection and use of patient-reported experiences of care in Switzerland: i) develop a position statement on the importance and value of patients' experiences of cancer care and ii) collect patients' experiences of cancer care at the national level, by implementing a national survey or by integrating data collection in cantonal cancer registries. We also presented the main facilitators for successful implementation of a national cancer PREMs program: "a patient-centered health care culture supported by management and politics, awareness of the value of patients' reports, involvement of patients in all steps, and sufficient financial resources" (153). On the other side, the unavailability of and high cost of human resources to collect patients' reports were presented as important barriers, as well as privacy and ethical concerns, an inadequate IT infrastructure, and Swiss federalism making it a challenge to adopt a common standard across the 26 cantonal health systems.

5.2 Strengths and limitations

This thesis has several strengths. It collected data from a mixed-mode survey (paper and online) following a mixed methods methodology, with the collection of both quantitative and qualitative data.

Regarding the quantitative data, the instrument used for the SCAPE study was a cancer specific experience questionnaire, evaluating key aspects of patient-centered cancer care across the cancer care pathway. The variance observed in participants' responses and limited number of items with a ceiling effect shows a methodological advantage in comparison to traditional satisfaction surveys. The response rate was in par with other similar studies in Switzerland and abroad, suggesting that the survey and questions appeared relevant for patients, many of whom thanked us at the end of the questionnaire. The study thus included a relatively large sample of cancer patients from both university and regional hospitals.

Regarding the qualitative data, the use of a computer-assisted textual analysis method was another strength of the SCAPE study, allowing rapid and comprehensive analysis of all free-text comments within a large survey sample in a time-efficient way. The themes of the qualitative data added information not collected with the quantitative results, reinforcing the need to offer space for open comments. The software used appears to be a valid tool, as some of the identified classes had also been reported in other studies using different approaches, both inductive and deductive and manual or computer-based methods (117, 119, 129, 131).

Including a PPI approach was another strength of the thesis. The patient associated in the SCAPE study played a key role in preparing the study material assuring it was relevant and comprehensible for patients, in answering patients’ inquiries with empathy and compassion, in preparing the study results for patients, as well as in providing a patient perspective in the analyses of both the qualitative and quantitative data and disseminating the results. She was also involved in making the lay version of the policy brief in plain language accessible to the public.

Including a policy brief in addition to scientific studies in the thesis is another strength, bridging science with policy and policymakers, as well as bringing different stakeholders together during the dialogue to validate and legitimize the recommendations of the policy brief. It also clarifies the different concepts of patient-reported outcomes (PROs), PROMs and PREMS for policymakers and the public, as these terms often generate confusion, even present in the scientific literature.

However, there are also some limitations. The quantitative results from data collected with the SCAPE study are limited by the inherent limitations of survey data, such as nonresponse bias. The results reflect experiences of care from patients who responded to the survey, who might not be representative of all patients. Previous studies using the NCPES instrument have shown that survey respondents tend to be younger, of higher socio-economic background and in better health (57-59) compared with non-respondents. Collected data was also limited to patients who transited within one of the four hospitals involved in recruitment, although the hospitals included both university and regional hospitals. In addition, surveys in cancer care are surveys of survivors by design, as patients with short survivals do not have the opportunity to participate (57, 59, 71). Another limitation was the availability of the questionnaire in French only, limiting the participation of patients not speaking the language well, who may experience care differently (182). Regarding cancer representativeness, compared with the distribution of incident cases available from the Federal Office of Statistics for the French- and Italian-speaking region of Switzerland (21) (Federal Statistical Office [FSO], 2020), individuals reporting breast cancer were overrepresented in our sample, while individuals reporting prostate cancer were underrepresented. Finally, the eligibility criteria regarding the type of cancer was restricted to the six most frequent types for statistical and feasibility reasons, limiting the generalization to other types of cancer.

Unlike the CAHPS and NCPES surveys which are linked with cancer registry data enabling researchers to study more complex research questions and to use more precise clinical information on patient’s cancer (type, stage, etc.) (58, 63), we had to rely on self-reports of cancer diagnosis and treatments. Although self-reports are extensively used in epidemiological and clinical studies and shown to be valid and sensitive (183, 184), the clinical details available in the SCAPE study were limited.

Another limitation of the thesis was related to the structural design of the instrument. We had planned to proceed with the psychometric validation of the instrument, but were confronted with the structure of the instrument, which contains many filter questions with sections that do not apply to all patients, as well as the possibility to answer ‘Don’t know/can’t remember’ or ‘not applicable’ (considered as ‘not informative’ answers). This hinders traditional factor analyses as most patients do not complete the full questionnaire (only 162 patients replied to all subsections) and not all patients provide informative answers to all questions. We abandoned those analyses, as the number of patients we could include was too low, making the analyses unstable. Nevertheless, a study aiming to uncover the structure of the NCPES survey using factor analysis was recently published (60), using imputation techniques for the ‘not informative’ answers and restricting their analyses to the ‘core’ questions, using a large sample of NHS patients (n= 71’186). Their exploratory factor analysis suggested that the survey's core questions contains five latent factors: factor 1 included five items about treatment explanations and shared decision-making; factor 2 included four items about care coordination and administration; factor 3 included five items about diagnosis; factor 4 included two items about timeliness of investigations; and factor 5 included two items about aftercare and support. Authors concluded that their results supported the structure of the questionnaire, covering a range of relevant aspects of care and patient experiences.

5.3 Challenges and lessons learned

One of the major challenge of the SCAPE study was access to hospital patient data, which is not allowed for research teams outside hospitals due to patient confidentiality and protection laws. Thus, researchers need to rely on hospital teams to identify patients, which adds work for them and increases the risk of systematic errors if identifications strategies differ between hospitals. Although the SCAPE team discussed with each hospital the best strategy to identify patients, there were some errors and some patients without a confirmed diagnosis of cancer received a questionnaire, unfortunately. In one hospital, 13 patients contacted the hospital after receiving the questionnaire to declare they had not been diagnosed with cancer; this event triggered an announcement to the Ethics commission who declared it a serious event. Apology letters and personal phone calls by the head of the oncology department were sent to these patients.

Another important challenge in the current situation of data access and availability in Switzerland was related to the thorough check of deceased patients, to avoid sending a questionnaire to grieving families. The four participating hospitals did not have the same procedure for this check: one hospital had access to the cantonal population registry, but with a 3 or 4 month-delay in notification; the other three hospitals did not have that access and relied on their internal database and the manual check of clerks and receptionists for the death announcements in local journals. After sending out the questionnaires, we were informed by mail, by phone or by post of 185 deceased patients not identified previously. The invitation letter did address this possibility in the second paragraph, by apologizing in advance. Since 2018, more hospitals have now access to the federal population registry, improving the detection of deceased patient bearing the 3-month delay issue.

An additional challenge was the identification of eligible cancer diagnosis for ambulatory patients in hospitals using electronic databases, as diagnostic cancer codes (CIM-10 codes) are used for hospitalized patients only, for billing purposes. In one hospital, ambulatory patients were selected according to the ambulatory billing clinics (urology, senoloy, thoracic, gastrointestinal, dermatology, hematology), which included patients with ineligible cancers: 273 patients reported an ineligible cancer in the questionnaire, in addition to the 34 patients who informed us by contacting the hotline or sending the coupon back. This also lowered the sample for the main analyses, as we had to exclude these respondents of the analyses along with respondents who ticked “don’t know” or didn’t answer the question (n=365 in total), representing 12% of the respondents.

Valuable lessons for future studies were learned from the SCAPE study and the feasibility analyses. First, we found that reminders were useful to increase the response rates (i.e. by 11 percentage points). In addition, we found that both the socio-demographic characteristics and the overall rating of care of respondents completing the questionnaire before and after the reminder differed. The overall rating was lower in late respondents (after reminders), similarly to findings from previous studies showing that early responders are more likely to give positive evaluations, underscoring the importance of reminders (185, 186). Another lesson was related to online respondents, who were also less likely to report positive experiences for one third of the questions and overall rating of care, similarly to results from Pham and colleagues (105). Finally, the examination of the completion and missing data rates across the different sections and questions were useful to identify which sections were the most relevant for respondents and which questions were frequently not answered by patients. All these results were useful for planning the following cancer surveys in Switzerland.

5.4 Implications for future research

The results presented in this thesis have provided new insights into the level of cancer care responsiveness in the French-speaking region of Switzerland, as well as new insights into the variation of experiences by type of cancer, the socio-demographic determinants of overall rating and experiences, and the added-value of free-text comments.

Another aspect worth investigating in future research is looking at the “drivers” of overall rating of care, i.e. the specific experiences of care most associated with the global evaluation of care. This would provide useful information for both questionnaire development (such as developing a short version including the important drivers) and improvement efforts by highlighting areas with the greatest potential to improve overall satisfaction. Although previous studies have investigated drivers of patient experiences using the same instrument (98) or other instruments (94, 102, 187), their results differ, suggesting that drivers may be regional and context-dependent.

Future research could also undertake the psychometric validations of the SCAPE instrument if more data are collected to ensure sufficient sample size, replicating the methodology used in the recent study of the CPES (60) to investigate whether the structure of the questionnaire is similar using data from a different country and health care system.

Our results could also guide future qualitative research on patient experiences using focus groups or interviews, investigating the role of some determinants identified in the study, such as the use of complementary medicine and its role in determining experiences of care.

Finally, our experience with the SCAPE study described in section 4.1 and the challenges we encountered described in section 5.3 provided useful insight for planning future surveys. A first important lesson is the usefulness of reminders to increase the response rate and gather feedback from patients who differ from the patients replying first in regards to socio-demographic characteristics and levels of positive experiences. Another useful information for future surveys is the characteristics and rate of patients choosing to reply online (7%), reducing the required amount of work required to handle paper data (i.e. receiving paper questionnaire, entering paper data into an electronic database, correcting incorrect paper entries (e.g. patients ticking two answers when only one is allowed), archiving paper questionnaires). In addition, our analyses of the free-text comments identified some dimensions of care that were not assessed in the closed-ended questions, such as cancer repercussion on finances and the lack of support in the "after-care" period, suggesting the need for additional questions in the instrument.

Based on our experience, the preliminary results and successful implementation of the SCAPE study, we initiated in 2020 a second study, SCAPE-2, expanding the survey to the German-speaking region of Switzerland, and initiated in 2022 a third study, SCAPE-CH, further expanding the study to the Italian-speaking region and aiming to develop a long-term plan for the regular measurement of PREMs in oncology. These research and implementation projects are briefly presented below.

5.4.1 SCAPE-2 and SCAPE-CH

The primary objective of SCAPE-2 was to describe patient-reported experiences with cancer care in two linguistic regions of Switzerland, scaling up the SCAPE study to the German-speaking region of Switzerland. The secondary objectives were: 1) to demonstrate the feasibility of conducting the survey at the national level; 2) to examine the variation of experiences by linguistic region, cancer center, and type of cancer; and 3) to validate the French and German versions of the SCAPE-2 questionnaire. We first revised the French version of the SCAPE-1 questionnaire based on patients' comments on the SCAPE-1 questionnaire, results of the item analyses showed in section 4.1; the review of the original NCPES questionnaire performed in 2018 by Picker Europe (188); and review of the dimensions and questions included in other widely used cancer patient experiences of care presented in section 1.2.4. These elements were discussed during a workshop with various cancer stakeholders, and a new version was agreed upon, including three news sections on follow-up, the impact of COVID-19 on respondents and cancer care, and the financial impact of cancer. After adapting and translating the questionnaire in German, we sent the questionnaire to 6873 patients from eight hospitals, the same four in the French-speaking part of Switzerland and four new hospitals in the German-speaking part (one university hospital and three cantonal hospitals), between September and October 2021. The response rate was 49%, with 3220 completed questionnaires.

Following the SCAPE-2 study, we planned the SCAPE-CH project, which aims to implement the SCAPE survey on a national level in a perennial manner. Funded by the Federal Quality Commission, it aims to generate reliable data to stimulate the development of continuous quality improvement initiatives in cancer care. It started in October 2022, managed by Unisanté and the Laboratoire des Patient·e·s en Oncologie (IUFRS and Swiss Cancer Center Leman), for a period of two years. The SCAPE questionnaire will be translated into Italian, and a shorter version will also be produced in all three languages, based on the "drivers" and structure analyses. The short versions will be sent to patients of 20 oncology centers in Switzerland (including both public and private hospitals) in September 2023 and the results will be available in June 2024. Another aim of SCAPE-CH is to publish a position statement on PREMs in cancer care, as recommended in the *policy brief.*

5.5 Implications for clinical practice

As mentioned in the introduction, one of the main objectives of patient surveys is to inform clinical practice about the extent to which care is responsive to patients' clinical and social needs, from the patients' perspective, and detect what areas of care need to be improved for whom. This information is key to help quality improvement initiatives in determining priorities and target patient groups at higher risk of a less positive experiences.

Our results from the analyses of both quantitative and qualitative data shown in the published article #1 and #2 highlighted several areas of cancer care where the responsiveness of cancer care can be improved: i) communication of cancer diagnosis, especially regarding the receipt of written information and the involvement of family or friends; ii) advice and support with short- and long-term side effects; iii) the faulty communication, with particular emphasis for communication around side effects and complementary therapies, iv) information about available social and financial support for patients who might need this help; v) the discontinuity of care due to the frequent changes of junior physicians; and vi) the lack of support from health care professionals after the end of treatment. Communication around the cancer diagnosis is a difficult exercise and the frequent source of unmet needs, as highlighted in other studies (23). The provision of tailored information for each patient and his/her relatives remains a challenge to date, despite its important impact on quality of life, anxiety and depression (189).

Information and support on side effects is another frequently reported problem area in cancer care (68, 190), requiring specific interventions to facilitate self-management of symptoms (191). Programs are currently being implemented in Switzerland (192), and should be further developed, implemented and evaluated. In response to communication issues, cancer care coordination interventions such as multidisciplinary teams, patient navigation, home telehealth, self-management education and nurse case management could be beneficial to improve the responsiveness of care in this area (193-196).

Our findings that patient experiences vary by type of cancer and that overall rating is predicted by socio-demographic characteristics is further useful information for clinical practice, suggesting that improvement strategies should be tailored to types of cancer and cancer trajectories and take into account the needs of patients in poorer health, with lower health literacy, and facing financial hardship in particular. For instance, inpatient care for individuals with colorectal and lung cancer was consistently rated the lowest, suggesting that inpatient care for these patients would benefit the most from more patient-centered care responding to their specific needs. Patients with lower health literacy could benefit from tailored information to ensure that cancer care is explained in a comprehensible way. The identified determinants of overall rating are also important information for hospital management and when comparing performance of cancer centers. Indeed, the distribution of the identified patient-related characteristics among patients cared for in cancer centers can have an impact on their global results in patient surveys. Cancer centers serving patients from lower socioeconomic background and with poorer health could advocate for more means to improve the responsiveness of their care.

The positive comments in the free-text comments are also useful in clinical practice when providing feedback to hospitals and healthcare teams, as they allow to help staff identify how they are valued with meaningful quotes and what they are doing well, providing motivation to continue. They could also be used to inform a “safety II culture” approach, which builds on ‘things that go right’ instead of focusing primarily on critical incidents and adverse events (197).

Our results have also triggered direct local improvement initiatives in the participating hospitals, which have been implemented and communicated to patients in the *patient leaflets.* For instance, one hospital reactivated the systematic assessment of patient difficulties with the ‘distress thermometer’ tool (198), which allows patients to share their difficulties and problems with the nurse, who can then give advice or refer them to other services to receive support. Two hospitals modified the convocation letter sent to patients by adding the information that patients are invited to come accompanied if he or she so wishes, in direct response to the low score found on the question about this in the SCAPE questionnaire. In addition, one of the participating hospital used the quantitative and qualitative data from the SCAPE study to identify unmet needs relating to hospitality specifically and to implement an innovative intervention integrating a hospitality perspective to improve the experience of care for patients with cancer and their informal caregiver (Hospitality WE-CARE project (199)).

There are some remaining challenges to improve the use of patient experience surveys by clinical practice for improvement purposes. For instance, there is a time lag between survey administration and reporting of results, delaying the implementation of service improvement and potentially decreasing the relevance of the results. In addition, surveys of patient experience on their own are not sufficient to change and improve practice as shown in the introduction in section 1.4.1. As suggested by Coulter and colleagues, “collecting data is not enough; they must be used to improve care” (200). Translating findings from patient experiences to improvements in clinical practice requires multiple interventions, sustained over time, with sufficient funding, among other facilitators and barriers highlighted in reviews on the barriers to using results from PREMs surveys to implement change and improve care (140-145).

5.6 Implications for policymaking

One of the main challenges policymakers face today is how to deliver high-quality, high-value and patient-centered care in a context of limited resources and increasing costs, as conceptualized for instance in the value-based healthcare model (VBHC) where patient experiences of care and outcomes that matter to patients represent the core values (201). Policymakers are thus increasingly interested in gathering patient experience data to assess providers against a range of indicators valued by patients and to stimulate quality improvement (29). This is also the case for Switzerland, where PREMs have been recently recognized as important measures to collect and publish in a national public dashboard to evaluate the quality of care and as tool to ensure that the health care system is patient-centered, as mentioned in the new strategy for Quality Development in Health Insurance of the Federal Council (159). The results of the SCAPE study are thus directly useful for policymakers, as the review of the main barriers and facilitators to the implementation of PREMs presented in the *policy brief.* Indeed, these barriers and facilitators, as well as the recommendations and principles for establishing national systems of patient experience measurement published by the OECD (16, 202, 203) and the New South Wales government in Australia (204) presented in the *policy brief*, provide guidance for policymakers for the successful implementation of PREMs in Switzerland. It is also worth mentioning that some of the more complex barriers are common to most health research in Switzerland, i.e. the lack of interoperability between systems, the complexity of integrated data collection, privacy legislation and legal basis. Based on the review of the literature and local policy documents, another recommendation would be to develop a national and conceptual framework on the quality of cancer care, including patient-reported experiences of care among other important elements like patient-reported outcomes, to guide future policies on cancer care.

5.7 Conclusion

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, as one of the essential indicators of the quality of the health system and as one of the essential data used to inform quality improvement initiatives. These measures are important to determine whether the health system is delivering responsive care and meeting the needs of patients and their loved ones. These measures are particularly important in the care of people with chronic diseases such as cancer, as care is often on the long-term and complex, involving a multitude of health professionals.

The SCAPE study was the first investigation of patient-reported experiences of cancer care that went beyond institutional and monocentric surveys in Switzerland and was a landmark project in the quality improvement landscape of Swiss cancer care. With the SCAPE study, patients were offered a unique opportunity to evaluate whether current cancer care was responding to their needs, including support and psycho-social aspects. We have contributed to generating new knowledge about cancer care perceived by patients in Switzerland, about the determinants of the experiences, and offered guidance for improvement initiatives. The SCAPE study also played a direct role in improving aspects of cancer care in the participating cancer centers, which implemented various concrete actions based on our results, such as modifying convocation letters and reactivating a tool to help patients in distress. Our study also led to the creation of an innovative hospitality intervention in one of the participating cancer centers.

This work was also the cornerstone for further research and surveys on the responsiveness of cancer care, allowing us to secure two other grants. The first research grant was to conduct the SCAPE-2 study in 2021 including patients from two linguistic regions of Switzerland (i.e. in the French- and German-speaking regions). The second grant from the Federal Quality Commission is for the SCAPE-CH project, which aims to implement the SCAPE survey in all three main linguistic regions and set forth the bases for the sustained and regular measurement of PREMs in oncology. The publication of the position statement on the importance of PREMs in cancer care is also part of the SCAPE-CH project, following the recommendation of the policy brief in this thesis.

Lastly, this research was innovative in involving patients as partners in research and disseminating lay results to participating patients. As co-investigator, Christine Bienvenu acted as an expert patient partnering with the research team throughout the whole process. All participating patients who expressed an interest were informed about the study results and their impact on quality improvement initiatives. This happened before patient and public involvement (PPI) was required for studies in Switzerland and played an important role in the development of the Laboratoire des Patients en Oncologie (https://patientlab.ch/), a PPI infrastructure affiliated to the Swiss Cancer Center Leman.

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7 Appendices

7.1 Appendix 1 List of publications and communications

List of publications related to the thesis

Peer-reviewed

2022 **Arditi C**, Eicher M, Peytremann-Bridevaux I. Socio-demographic and health-related determinants of patients' overall rating and experiences of cancer care. BMC Cancer. 2022 (under submission)

Arditi C, Eicher M, Colomer-Lahiguera S, Bienvenu C, Anchisi S, Betticher D, Dietrich PY, Duchosal M, Peters S, Peytremann-Bridevaux I. Patients' experiences with cancer care in Switzerland: results of a multicenter cross-sectional survey. Eur J Cancer Care. 2022; e13705. doi: 10.1111/ecc.13705

Arditi C, Peytremann-Bridevaux I. Quality of Cancer Care in Switzerland: Going Beyond Traditional Quality Indicators by Collecting Patient-Reported Experiences of Cancer Care. Public Health Rev. 2022; 43:1604813. doi:10.3389/phrs.2022.1604813

2020 **Arditi C**, Walther D, Gilles I, Lesage S, Griesser AC, Bienvenu C, Eicher M, Peytremann-Bridevaux I. Computer-assisted textual analysis of free-text comments in the Swiss Cancer Patient Experiences (SCAPE) survey. BMC Health Serv Res. 2020; 20(1):1029. doi:10.1186/s12913-020-05873-4

Reports / short reports

2021 **Arditi C** & Peytremann-Bridevaux I. Policy Brief. Giving patients a voice about cancer care: should Switzerland do more to collect patients' experiences of cancer care? Swiss Learning Health System. 2021. https://www.slhs.ch/media/n2tje2rc/premsonco_policybrief_final.pdf

Arditi C & Peytremann-Bridevaux I. Summary of the Stakeholder Dialogue on 'Giving patients a voice about cancer care: should Switzerland do more to collect patients' experiences of cancer care?' Swiss Learning Health System. 2021 https://www.slhs.ch/media/qpol4hw2/premsonco_sd_final.pdf

Arditi C, Bienvenu C & Peytremann-Bridevaux I. Vers une meilleure écoute des patient·e·s : la Suisse doit faire davantage pour tenir compte des expériences de soins des personnes atteintes de cancer. Note d'orientation courte tout public. Swiss Learning Health System. 2021. https://www.slhs.ch/media/szxnh2yf/premsonco_laypolicybrief_fr.pdf

Arditi C, Bienvenu C & Peytremann-Bridevaux. Krebspatient:innen besser zuhören. Die Schweiz muss den Behandlungserfahrungen von krebskranken Personen mehr Beachtung schenken. Ein kurzer Policy Brief für die breite Öffentlichkeit. Swiss Learning Health System. 2021. https://www.slhs.ch/media/ywmmtwwr/premsonco_laypolicybrief_de.pdf

Arditi C, Eicher M, Peytremann-Bridevaux I. For the first time in Switzerland, a large-scale study gives patients a voice in cancer care. in *Cancer Research in Switzerland. Edition 2021*. Swiss Cancer Research foundation and Swiss Cancer League. 2021. pp 105-108 https://www.krebsliga.ch/ueber-uns/publikationen/forschungsbericht/-dl-/fileadmin/downloads/forschung/research-report-cancer-research-in-switzerland-2021.pdf

Arditi C. Programme de recherche sur les services de santé. Le point de vue des patientes et des patients in *Rapport annuel 2020.* Recherche Suisse contre le cancer. 2021. pp 20-21. https://www.recherchecancer.ch/a-propos-de-nous/publications/rapports-et-bilans-annuels/-dl-/fileadmin/downloads/jahresbericht/rapport-annuel-recherche-suisse-contre-le-cancer-2020.pdf

Patient leaflets with SCAPE results

https://www.h-fr.ch/sites/default/files/2020-10/CP_unisant%C3%A9_26102020_DE.pdf

https://www.hug.ch/sites/interhug/files/departements/scape_livret_resultats_hug.pdf

List of conference communications related to the thesis

2021 **Swiss Public Health Conference 2021**, August 2021 (online & Bern). Arditi C, Peytremann-Bridevaux I. Policy Brief. Giving Patients a Voice about Cancer Care: Should Switzerland Do More to Collect Patients' Experiences of Cancer Care? (Poster)

ISQUA's 37th International Conference, July 2021 (online). Arditi C, Peytremann-Bridevaux I, Eicher M. What can a patient experience survey tell us about cancer care in Switzerland? (Poster)

MASCC/ISOO 2021 Annual Meeting, June 2021 (online). Arditi C, Eicher M, Peytremann-Bridevaux I. Patients' experiences with cancer care in western Switzerland: results from a multicenter survey (E-poster)

2020 **Swiss Public Health Conference 2020**, August 2020 (online). Arditi C. What do cancer patients think of their care? (3-minutes oral presentation, finalist for the SSPH+ ScienceFlashTalk),

Swiss Public Health Conference 2020, August 2020 (online). Arditi C. What can a patient experience survey tell us about cancer care in Romandy? (Poster)

List of publications not related to the thesis

2022 Lê Van K, **Arditi C**, Terrier L, Ninane F, Rochat S, Peytremann-Bridevaux I, Eicher I, Schaad B. A conceptual model for integrating hospitality into supportive care. J Supp Care Cancer (drafted)

2021 **Arditi C**, Coendoz S, Labud H, Wojtusciszyn A, Peytremann-Bridevaux I. Suivi clinique et paracliniue du diabète - Prise en charge multidisciplinaire du diabète : recommandations pour la pratique clinique. Rev Med Suisse. 2021; 17(755):1804.

Arditi C, Coendoz S, Labud H, Wojtusciszyn A, Peytremann-Bridevaux I. Bilan initial du diabète - Prise en charge multidisciplinaire du diabète : recommandations pour la pratique clinique. Rev Med Suisse. 2021; 17(753):1717.

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7.2 Appendix 2: List of grants

2022 **Arditi C** (Principal Investigator (PI)), Peytremann-Bridevaux I (coPI), Eicher M (coPI). Implémentation à l'échelle nationale de l'enquête Swiss Cancer Patient Experiences (SCAPE-CH), Commission Fédérale pour la Qualité (CFQ), peer-reviewed, CHF 178'200

Arditi C (main applicant), Peytremann-Bridevaux I (co-applicant), Eicher M (co-applicant). The Swiss Cancer Patient Experiences-2 (SCAPE-2) study: a national survey. ISREC Fondation Recherche Cancer, CHF 70'000

Arditi C (main applicant), Peytremann-Bridevaux I (co-applicant), Eicher M (co-applicant). Soutien pour les livrets de résultats pour les participant·e·s à l'étude *Swiss Cancer Patient Experiences – SCAPE-2*. Roche Pharma, CHF 6'000

2020 **Arditi C** (PI), Peytremann-Bridevaux I (coPI), Eicher M (coPI). The Swiss Cancer Patient Experiences-2 (SCAPE-2) study: a national survey, Swiss Cancer Research and Accentus Foundation, peer-reviewed, CHF 220'000

7.3 Appendix 3: SCAPE questionnaire

SCAPE
SWISS
CANCER PATIENT
EXPERIENCES
VÉCU DES PATIENTS EN
SOINS ONCOLOGIQUES

QUESTIONNAIRE SUR LE VECU DES PATIENTS EN SOINS ONCOLOGIQUES

Instructions

Veuillez lire attentivement chaque question et toutes les réponses possibles. Veuillez cocher clairement la réponse qui correspond le mieux à votre point de vue, avec un stylo noir ou bleu.

Correct : ☒

Merci de cocher qu'une seule réponse par question, à moins qu'il ne soit précisé que plusieurs réponses sont possibles, et de répondre à toutes les questions posées, sauf si les instructions disent de sauter une question.

Les questions doivent être répondues par la personne nommée dans la lettre d'invitation jointe à ce questionnaire. Si cette personne a besoin d'aide pour remplir le questionnaire, un·e proche peut l'aider mais les réponses doivent être données de son point de vue – pas du point de vue de la ou du proche.

C'est votre opinion qui compte ; il n'y a pas de réponse juste ou fausse. Il est important de répondre honnêtement afin que nous puissions avoir une vision claire et réelle de la situation. Vos réponses étant codées, c'est l'occasion de partager ce que vous avez vécu sans qu'on puisse vous identifier. N'hésitez pas à nous faire part de vos commentaires additionnels à la fin du questionnaire.

Merci de ne pas mettre votre nom sur le questionnaire pour garantir le codage de vos réponses. Le numéro situé en bas de chaque page est votre numéro personnel utilisé pour regrouper les pages du questionnaire lors de leur traitement et pour enregistrer votre participation.

Nous vous **remercions** de votre contribution et du temps que vous passerez à répondre au questionnaire. **Votre participation** est **précieuse** et **importante**.

Déclaration de consentement

En renvoyant le questionnaire complété, je déclare :

- ✓ Avoir été informé·e par écrit des objectifs et du déroulement de l'étude SCAPE
- ✓ Prendre part à cette étude de façon volontaire et accepter le contenu de la feuille d'information qui m'a été remise sur l'étude SCAPE
- ✓ Avoir eu suffisamment de temps pour prendre ma décision
- ✓ Avoir reçu des réponses satisfaisantes aux questions que j'ai posées en relation avec ma participation à l'étude SCAPE
- ✓ Accepter que les spécialistes compétents de l'hôpital et de la Commission d'éthique compétente puissent consulter mes données brutes afin de procéder à des contrôles, à condition toutefois que la confidentialité de ces données soit strictement assurée
- ✓ Savoir que les données fournies dans ce questionnaire seront analysées et conservées **sous forme anonymisée** par l'Institut universitaire de médecine sociale et préventive à Lausanne ; **aucune information permettant de m'identifier ne sera transmise à des tiers**
- ✓ Savoir que **je peux, à tout moment et sans avoir à me justifier, révoquer mon consentement** à participer à l'étude **sans que cela n'ait de répercussion défavorable sur la suite de ma prise en charge**. Les données du questionnaire recueillies jusque-là seront tout de même analysées sous forme anonymisée.

CONSULTATIONS CHEZ UN MEDECIN *avant la première consultation à l'hôpital pour le cancer*

1. Combien de fois avez-vous vu un médecin pour le problème de santé causé par le cancer avant que l'on ne vous réfère à l'hôpital ?

1 ☐ **Aucune fois** – Je suis allé·e directement à l'hôpital

2 ☐ **Aucune fois** – Je suis allé·e à l'hôpital après un dépistage du cancer

3 ☐ **Aucune fois** – J'étais déjà hospitalisé·e pour un autre motif

4 ☐ J'ai vu un médecin **1** fois

5 ☐ J'ai vu un médecin **2** fois

6 ☐ J'ai vu un médecin **3** ou **4** fois

7 ☐ J'ai vu un médecin **5** fois ou **plus**

8 ☐ Je ne sais pas / je ne m'en souviens plus

2. Que pensez-vous de la période d'attente **avant** votre premier rendez-vous avec un médecin de l'hôpital ?

1 ☐ J'ai été vu·e dès que cela m'a semblé nécessaire

2 ☐ J'aurais dû être vu·e un peu plus tôt

3 ☐ J'aurais dû être vu·e beaucoup plus tôt

4 ☐ Je ne sais pas / je ne m'en souviens plus

3. Combien de temps s'est écoulé entre le moment où quelque chose vous a semblé anormal et votre première consultation chez un médecin ?

1 ☐ Moins de 1 mois

2 ☐ Entre 1 et 3 mois

3 ☐ Entre 4 et 6 mois

4 ☐ Plus de 6 mois

5 ☐ Tout me semblait normal

6 ☐ Je ne sais pas / je ne m'en souviens plus

EXAMENS DIAGNOSTIQUES

4. Au cours des 12 derniers mois, avez-vous eu un ou plusieurs examens diagnostiques pour le cancer, tels qu'une endoscopie, une biopsie, une mammographie ou un scanner ?

1 ☐ Oui → **allez à la question 5**

2 ☐ Non → **allez à la question 9**

En pensant à la dernière fois que vous avez eu un examen diagnostique pour le cancer…

5. Avant l'examen, aviez-vous toutes les informations dont vous aviez besoin concernant cet examen ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Je ne sais pas / je ne m'en souviens plus

6. Globalement, que pensez-vous du temps d'attente entre la prescription de cet examen jusqu'à sa réalisation ?

1 ☐ C'était adéquat

2 ☐ C'était un peu trop long

3 ☐ C'était beaucoup trop long

4 ☐ Je ne sais pas / je ne m'en souviens plus

7. Est-ce que les résultats de cet examen vous ont été expliqués de manière compréhensible ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non, je n'ai pas compris les explications

4 ☐ Je n'ai pas eu d'explications mais j'en aurais voulu

5 ☐ Je n'ai pas eu besoin d'explications

6 ☐ Je ne sais pas / je ne m'en souviens plus

8. Est-ce que cet examen a eu lieu au CHUV ?

1 ☐ Oui

2 ☐ Non

3 ☐ Je ne sais pas / je ne m'en souviens plus

ANNONCE DE LA MALADIE

9. Qui a été la première personne à vous annoncer que vous étiez atteint d'un cancer ?

1 ☐ Mon médecin de famille / généraliste

2 ☐ Un médecin spécialiste du cancer (p. ex. oncologue)

3 ☐ Un autre type de médecin spécialiste (p. ex. dermatologue, gynécologue, pneumologue)

4 ☐ Un chirurgien

5 ☐ Un infirmier

6 ☐ Autre(s) personne(s)

10. Est-ce qu'on vous a dit que vous pouviez être accompagné·e d'un membre de votre famille ou d'un·e ami·e, lors de l'annonce du cancer ?

1 ☐ Oui

2 ☐ Non

3 ☐ Je ne sais pas / je ne m'en souviens plus

11. Que pensez-vous de la manière dont on vous a annoncé que vous aviez un cancer ?

1 ☐ Cela a été effectué avec tact

2 ☐ Cela aurait dû être effectué avec **un peu plus** de tact

3 ☐ Cela aurait dû être effectué avec **beaucoup plus** de tact

4 ☐ Je ne sais pas / je ne m'en souviens plus

12. Avez-vous compris les explications au sujet de ce qui vous arrivait ?

1 ☐ Oui, j'ai tout à fait compris

2 ☐ Oui, j'ai compris en partie

3 ☐ Non, je n'ai pas compris

4 ☐ Je ne sais pas / je ne m'en souviens plus

13. Lors de l'annonce du cancer, est-ce que l'on vous a donné des **informations écrites** sur le type de cancer que vous aviez ?

1 ☐ Oui, et c'était **facile** à comprendre

2 ☐ Oui, mais c'était **difficile** à comprendre

3 ☐ Non, mais j'aurais aimé en recevoir

4 ☐ Je n'ai pas eu besoin d'informations écrites

5 ☐ Je ne sais pas / je ne m'en souviens plus

DECISION DU MEILLEUR TRAITEMENT POUR VOUS

14. Est-ce que les options de traitement vous ont été expliquées avant le début de votre traitement contre le cancer ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Il n'y avait qu'un seul type de traitement adapté à ma situation

5 ☐ Je ne sais pas / je ne m'en souviens plus

15. Est-ce que les effets indésirables possibles du ou des traitements vous ont été expliqués de manière compréhensible ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non, je n'ai pas compris les explications

4 ☐ Je n'ai pas eu d'explications, mais j'en aurais voulu

5 ☐ Je n'ai pas eu besoin d'explications

6 ☐ Je ne sais pas / je ne m'en souviens plus

16. Est-ce que l'on vous a proposé des conseils pratiques et/ou du soutien pour faire face aux effets indésirables de votre ou vos traitements ?

1 ☐ Oui, tout à fait
2 ☐ Oui, dans une certaine mesure
3 ☐ Non, mais j'aurais aimé qu'on m'en propose
4 ☐ Je n'ai pas eu besoin de conseils pratiques ou de soutien
5 ☐ Je ne sais pas / je ne m'en souviens plus

17. Avant le début de votre ou vos traitements, est-ce que l'on vous a aussi parlé des effets indésirables pouvant survenir plus tard et pas seulement dans l'immédiat ?

1 ☐ Oui, tout à fait
2 ☐ Oui, dans une certaine mesure
3 ☐ Non, mais j'aurais aimé qu'on m'en parle
4 ☐ Je n'ai pas eu besoin qu'on m'en parle
5 ☐ Je ne sais pas / je ne m'en souviens plus

18. Avez-vous été impliqué·e autant que vous le souhaitiez dans les décisions concernant vos soins et traitements ?

1 ☐ Oui, tout à fait
2 ☐ Oui, dans une certaine mesure
3 ☐ Non, j'aurais aimé être plus impliqué·e
4 ☐ Je ne sais pas / je ne m'en souviens plus

CONSULTATION INFIRMIERE

19. Est-ce que l'on vous a proposé une consultation infirmière pour vous aider et vous conseiller à faire face au cancer ?

1 ☐ Oui, et elle a eu lieu → **Allez à la question 20**
2 ☐ Oui, mais elle n'a pas eu lieu
3 ☐ Non, mais j'aurais aimé
4 ☐ Non
5 ☐ Je ne sais pas / je ne m'en souviens plus

} **Allez à la question 22**

20. A quel point cela a-t-il été facile ou difficile de contacter un infirmier de la consultation infirmière ?

1 ☐ Très facile
2 ☐ Plutôt facile
3 ☐ Ni facile, ni difficile
4 ☐ Plutôt difficile
5 ☐ Très difficile
6 ☐ Je n'ai pas essayé de contacter un infirmier de la consultation infirmière
7 ☐ Je ne sais pas / je ne m'en souviens plus

21. Lorsque vous avez posé des questions importantes à l'infirmier durant la consultation infirmière, avez-vous obtenu des réponses compréhensibles ?

1 ☐ Toujours
2 ☐ Souvent
3 ☐ Parfois
4 ☐ Rarement
5 ☐ Jamais
6 ☐ Je n'ai pas posé de questions
7 ☐ Je ne sais pas / je ne m'en souviens plus

SOUTIEN AUX PERSONNES ATTEINTES DE CANCER

22. Est-ce que le personnel de l'hôpital vous a donné des informations sur des groupes de soutien ou d'entraide destinés aux personnes atteintes de cancer ?

1 ☐ Oui

2 ☐ Non, mais j'aurais aimé avoir des informations

3 ☐ Cela n'a pas été nécessaire

4 ☐ Je ne sais pas / je ne m'en souviens plus

23. Est-ce que le personnel de l'hôpital a discuté avec vous ou vous a donné des informations sur l'impact du cancer sur vos activités quotidiennes (par exemple sur votre vie professionnelle ou votre formation) ?

1 ☐ Oui

2 ☐ Non, mais j'aurais aimé une discussion ou des informations

3 ☐ Cela n'a pas été nécessaire

4 ☐ Je ne sais pas / je ne m'en souviens plus

24. Est-ce que le personnel de l'hôpital vous a donné des informations sur la façon d'obtenir une aide financière ou des prestations auxquelles vous pourriez avoir droit ?

1 ☐ Oui

2 ☐ Non, mais j'aurais aimé des informations

3 ☐ Cela n'a pas été nécessaire

4 ☐ Je ne sais pas / je ne m'en souviens plus

OPERATIONS

25. Au cours des 12 derniers mois, avez-vous eu une **opération liée au cancer** (par exemple ablation d'une tumeur / masse ; pose / retrait de porth-a-cath) ?

1 ☐ Oui → **Allez à la question 26**

2 ☐ Non → **Allez à la question 29**

En pensant à la <u>dernière</u> fois que vous avez eu une opération liée au cancer…

26. Avant l'opération, aviez-vous toutes les informations dont vous aviez besoin concernant votre opération ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Je ne sais pas / je ne m'en souviens plus

27. Après l'opération, est-ce que l'on vous a expliqué d'une manière compréhensible comment cela s'était passé ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non, je n'ai pas compris les explications

4 ☐ Je n'ai pas eu d'explications mais j'en aurais voulu

5 ☐ Je n'ai pas eu besoin d'explications

6 ☐ Je ne sais pas / je ne m'en souviens plus

28. Est-ce que cette opération a eu lieu au CHUV ?

1 ☐ Oui

2 ☐ Non

3 ☐ Je ne sais pas / je ne m'en souviens plus

SOINS ET TRAITEMENTS A L'HOPITAL
(durée de plus de 24 heures)

29. Au cours des 12 derniers mois, avez-vous été opéré·e ou hospitalisé·e au moins une nuit pour des **soins ou traitements liés au cancer** ?

1 ☐ Oui → **Allez à la question 30**

2 ☐ Non → **Allez à la question 42**

En pensant à la <u>dernière</u> fois que vous avez été opéré·e ou hospitalisé·e au moins une nuit pour des soins et traitements liés au cancer…

30. Est-ce que des **médecins et infirmiers** ont parlé devant vous comme si vous n'étiez pas là ?

1 ☐ Oui, souvent

2 ☐ Oui, parfois

3 ☐ Non

31. Faisiez-vous confiance aux **médecins** qui se sont occupés de vous ?

1 ☐ Oui, à tous

2 ☐ Oui, à certains

3 ☐ Non, à aucun

32. Lorsqu'un membre de votre famille ou un proche voulait parler à un **médecin**, est-ce que cela a été possible ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Ma famille ou mes proches n'ont pas voulu parler à un médecin

5 ☐ Je n'ai pas voulu que ma famille ou mes proches parlent à un médecin

6 ☐ Aucun membre de ma famille ou proche n'a été impliqué

33. Faisiez-vous confiance aux **infirmiers** qui vous se sont occupés de vous ?

1 ☐ Oui, à tous

2 ☐ Oui, à certains

3 ☐ Non, à aucun

34. A votre avis, y avait-il assez d'**infirmiers** en service pour s'occuper de vous à l'hôpital ?

1 ☐ Il y en avait toujours assez

2 ☐ Il y en avait presque toujours assez

3 ☐ Il y en avait parfois assez

4 ☐ Il y en avait rarement assez

5 ☐ Il n'y en avait jamais assez

35. Avez-vous eu assez d'intimité lors des discussions au sujet de votre maladie ou de votre traitement ?

1 ☐ Oui, toujours

2 ☐ Oui, parfois

3 ☐ Non

36. Durant votre hospitalisation, avez-vous trouvé un membre du personnel pour parler de vos inquiétudes et de vos craintes ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Je n'ai pas eu d'inquiétudes ou de craintes

37. Pensez-vous que le personnel de l'hôpital a fait tout ce qu'il pouvait pour vous aider à gérer votre douleur ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Je n'ai pas eu de douleur

38. Globalement, pensez-vous qu'on vous a traité·e avec respect et dignité durant votre hospitalisation ?

1 ☐ Oui, toujours

2 ☐ Oui, parfois

3 ☐ Non

39. Est-ce que l'on vous a donné des **informations écrites** sur ce que vous deviez faire ou ne pas faire après avoir quitté l'hôpital ?

1 ☐ Oui, et c'était **facile** à comprendre

2 ☐ Oui, mais c'était **difficile** à comprendre

3 ☐ Non, mais j'aurais aimé en recevoir

4 ☐ Je n'ai pas eu besoin d'informations écrites

5 ☐ Je ne sais pas / je ne m'en souviens plus

40. Est-ce que le personnel de l'hôpital vous a dit qui contacter si vous aviez des inquiétudes quant à votre maladie ou votre traitement après avoir quitté l'hôpital ?

1 ☐ Oui

2 ☐ Non, mais j'aurais aimé

3 ☐ Cela n'a pas été nécessaire

4 ☐ Je ne sais pas / je ne m'en souviens plus

41. Est-ce que cette opération ou hospitalisation a eu lieu au CHUV ?

1 ☐ Oui

2 ☐ Non

3 ☐ Je ne sais pas / je ne m'en souviens plus

SOINS ET TRAITEMENTS AMBULATOIRES A L'HOPITAL OU SOINS EN HOPITAL DE JOUR

(durée de moins de 24 heures)

42. Au cours des 12 derniers mois, avez-vous été **traité·e pour le cancer** à l'hôpital, en **ambulatoire** ou en **hôpital de jour** ?

1 ☐ Oui → **Allez à la question 43**

2 ☐ Non → **Allez à la question 47**

En pensant à la <u>dernière</u> fois que vous avez été traité·e pour le cancer à l'hôpital, en ambulatoire ou en hôpital de jour…

43. Durant votre traitement en ambulatoire ou en hôpital de jour, avez-vous trouvé un membre du personnel pour parler de vos inquiétudes et de vos craintes ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Je n'ai pas eu d'inquiétudes ou de craintes

44. Lors de votre **dernier** rendez-vous en ambulatoire avec un médecin de l'hôpital, les documents nécessaires tels que les notes du dossier médical, les radiographies et les résultats des tests, étaient-ils disponibles ?

1 ☐ Oui

2 ☐ Non

3 ☐ Je n'ai pas eu de rendez-vous avec un médecin de l'hôpital

4 ☐ Je ne sais pas / je ne m'en souviens plus

45. Dans l'ensemble, que pensez-vous du temps passé en salle d'attente lors des rendez-vous pour une consultation ou un traitement lié au cancer en ambulatoire à l'hôpital ?

1 ☐ C'était beaucoup trop long

2 ☐ C'était un peu trop long

3 ☐ C'était à peu près correct

4 ☐ C'était correct/rapide

5 ☐ Je ne sais pas / je ne m'en souviens plus

46. Est-ce que ce traitement en ambulatoire ou en hôpital de jour a eu lieu au CHUV ?

1 ☐ Oui
2 ☐ Non
3 ☐ Je ne sais pas / je ne m'en souviens plus

RADIOTHERAPIE ET CHIMIOTHERAPIE

47. Au cours des 12 derniers mois, avez-vous eu des séances de **radiothérapie ?**

1 ☐ Oui → **Allez à la question 48**
2 ☐ Non → **Allez à la question 51**

48. Avant les séances de radiothérapie aviez-vous toutes les informations dont vous aviez besoin les concernant ?

1 ☐ Oui, tout à fait
2 ☐ Oui, dans une certaine mesure
3 ☐ Non
4 ☐ Je ne sais pas / je ne m'en souviens plus

49. Une fois la radiothérapie commencée, avez-vous reçu des informations compréhensibles sur ses résultats ?

1 ☐ Oui, tout à fait
2 ☐ Oui, dans une certaine mesure
3 ☐ Non, je n'ai pas compris les informations
4 ☐ Je n'ai pas eu d'informations, mais j'en aurais voulu
5 ☐ Il est trop tôt pour savoir si ma radiothérapie donne des résultats
6 ☐ Je n'ai pas eu besoin d'informations

50. Est-ce que ces séances de radiothérapie ont eu lieu au CHUV ?

1 ☐ Oui
2 ☐ Non
3 ☐ Je ne sais pas / je ne m'en souviens plus

51. Au cours des 12 derniers mois, avez-vous eu une **chimiothérapie** ?

1 ☐ Oui → **Allez à la question 52**
2 ☐ Non → **Allez à la question 55**

52. Avant la chimiothérapie aviez-vous toutes les informations dont vous aviez besoin la concernant ?

1 ☐ Oui, tout à fait
2 ☐ Oui, dans une certaine mesure
3 ☐ Non
4 ☐ Je ne sais pas / je ne m'en souviens plus

53. Une fois la chimiothérapie commencée, avez-vous reçu des informations compréhensibles sur ses résultats ?

1 ☐ Oui, tout à fait
2 ☐ Oui, dans une certaine mesure
3 ☐ Non, je n'ai pas compris les informations
4 ☐ Je n'ai pas eu d'informations, mais j'en aurais voulu
5 ☐ Il est trop tôt pour savoir si ma chimiothérapie donne des résultats
6 ☐ Je n'ai pas eu besoin d'informations

54. Est-ce que cette chimiothérapie a eu lieu au CHUV ?

1 ☐ Oui
2 ☐ Non
3 ☐ Je ne sais pas / je ne m'en souviens plus

SOINS A DOMICILE ET SOUTIEN

55. Est-ce que les médecins ou infirmiers ont donné à votre famille ou vos proches toutes les informations dont ils avaient besoin pour vous aider à prendre soin de vous à domicile ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Ma famille ou mes proches n'ont pas souhaité ou n'ont pas eu besoin d'informations

5 ☐ Je n'ai pas voulu que ma famille ou mes proches soient impliqués

6 ☐ Aucun membre de ma famille ou proche n'a été impliqué

56. Durant votre traitement contre le cancer, avez-vous reçu assez de soins et de soutien de la part des services de santé ou sociaux (p. ex. infirmiers ou aides de soins à domicile, assistants sociaux ou physiothérapeutes) ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Je n'ai pas eu besoin d'aide des services de santé ou sociaux

5 ☐ Je ne sais pas / je ne m'en souviens plus

57. Une fois votre traitement contre le cancer **terminé**, avez-vous reçu assez de soins et de soutien de la part des services de santé ou sociaux (par exemple infirmiers ou aides de soins à domicile, assistants sociaux ou physiothérapeutes) ?

1 ☐ Oui, tout à fait

2 ☐ Oui, dans une certaine mesure

3 ☐ Non

4 ☐ Je n'ai pas eu besoin d'aide des services de santé ou sociaux

5 ☐ Je suis encore sous traitement

6 ☐ Je ne sais pas / je ne m'en souviens plus

SOINS AU CABINET DE VOTRE MEDECIN DE FAMILLE / GENERALISTE

58. A votre connaissance, votre médecin de famille / généraliste avait-t-il assez d'informations sur votre état de santé et votre traitement lié au cancer reçu à l'hôpital ?

1 ☐ Oui

2 ☐ Non

3 ☐ Je n'ai pas de médecin de famille / généraliste

4 ☐ Je ne sais pas / je ne m'en souviens plus

59. Pensez-vous que votre médecin de famille / généraliste et son équipe (infirmiers, assistants médicaux) ont fait tout ce qu'ils pouvaient pour vous soutenir durant votre traitement contre le cancer ?

1 ☐ Oui, tout à fait

2 ☐ Oui, la plupart du temps

3 ☐ Non, ils auraient pu en faire plus

4 ☐ Le cabinet de mon médecin de famille / généraliste n'était pas impliqué

5 ☐ Je n'ai pas de médecin de famille / généraliste

L'ENSEMBLE DE VOTRE PRISE EN CHARGE

60. Est-ce que les différentes personnes qui vous ont traité·e et soigné·e (comme votre médecin de famille / généraliste, médecins hospitaliers, infirmiers de l'hôpital et infirmiers des soins à domicile) ont bien travaillé ensemble pour vous offrir les meilleurs soins possibles ?

1 ☐ Oui, toujours

2 ☐ Oui, la plupart du temps

3 ☐ Oui, parfois

4 ☐ Non, jamais

5 ☐ Je ne sais pas / je ne m'en souviens plus

61. Est-ce que l'on vous a donné un plan de soins ? *C'est un document qui présente vos besoins et objectifs pour soigner le cancer. C'est un accord ou un plan entre vous et les professionnels de santé pour vous aider à atteindre ces objectifs.*

1 ☐ Oui
2 ☐ Non
3 ☐ Je ne sais/comprends pas ce qu'est un plan de soins
4 ☐ Je ne sais pas / je ne m'en souviens plus

62. Dans l'ensemble, comment évalueriez-vous la gestion de votre prise en charge (courrier reçu au bon moment, médecins ayant les bons documents, etc.) ?

1 ☐ Très bonne
2 ☐ Bonne
3 ☐ Ni bonne, ni mauvaise
4 ☐ Assez mauvaise
5 ☐ Très mauvaise
6 ☐ Je ne sais pas / je ne m'en souviens plus

63. Depuis l'annonce de votre diagnostic, est-ce que quelqu'un vous a demandé si vous aimeriez participer à une recherche sur le cancer ?

1 ☐ Oui
2 ☐ Non, mais j'aurais aimé qu'on le fasse
3 ☐ Non
4 ☐ Je ne sais pas / je ne m'en souviens plus

64. Dans les 12 derniers mois, avez-vous participé ou participez-vous actuellement à une étude clinique pour le cancer ?

1 ☐ Oui
2 ☐ Non

65. Comment évalueriez-vous l'ensemble de votre prise en charge ?

Très mauvaise										Très bonne
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0	1	2	3	4	5	6	7	8	9	10

VOTRE ETAT DE SANTE

Nous souhaiterions en savoir un peu plus sur le cancer pour lequel vous avez été traité·e dans les 12 derniers mois et sur votre état de santé actuel

66. Quel est le **principal** type de cancer pour lequel vous avez été traité·e dans les 12 derniers mois ? (*Cochez une seule réponse*)

1 ☐ Sein
2 ☐ Prostate
3 ☐ Poumon
4 ☐ Côlon / rectum / colorectal
5 ☐ Leucémie
6 ☐ Lymphome
7 ☐ Mélanome
8 ☐ Myélome
9 ☐ Autre : ______________________________
10 ☐ Je ne sais pas

67. Le cancer reporté ci-dessus est :

1 ☐ Un 1er cancer
2 ☐ Une récidive d'un cancer traité dans le passé (cancer diagnostiqué, traité et guéri avant, mais qui est de retour)
3 ☐ Un 2ème ou 3ème cancer (complètement différent d'un cancer diagnostiqué avant)

68. Est-ce que le cancer reporté ci-dessus avait déjà atteint d'autres organes ou parties du corps (cancer métastatique) lorsque l'on vous a annoncé le diagnostic de cancer ?

1 ☐ Oui
2 ☐ Non, mais le cancer s'est propagé après
3 ☐ Non, et le cancer ne s'est pas propagé
4 ☐ Je ne sais pas

69. A quand remonte le premier traitement contre le cancer reporté ci-dessus ?

1 ☐ Moins d'un an
2 ☐ 1 à 5 ans
3 ☐ Plus de 5 ans
4 ☐ Je ne sais pas / je ne sais plus

70. Quel type de traitement avez-vous reçu contre le cancer reporté ci-dessus ? *(Plusieurs réponses possibles*)

1 ☐ Chirurgie
2 ☐ Chimiothérapie
3 ☐ Radiothérapie
4 ☐ Hormonothérapie
5 ☐ Immunothérapie
6 ☐ Thérapie ciblée
7 ☐ Greffe de moelle osseuse ou de cellules souches
8 ☐ Je n'ai pas encore reçu de traitement
9 ☐ Je ne sais pas

71. Avez-vous suivi une ou plusieurs des thérapies de médecine complémentaire suivantes pour le traitement du cancer reporté ci-dessus ? (*Plusieurs réponses possibles)*

1 ☐ Aucune
2 ☐ Aromathérapie, fleurs de Bach, phytothérapie
3 ☐ Ayurvéda, médecine traditionnelle chinoise (y compris acupuncture)
4 ☐ Homéopathie, médecine anthroposophique, naturopathie
5 ☐ Hypnose, méditation, sophrologie
6 ☐ Kinésiologie, reiki, biorésonance
7 ☐ Ostéopathie, massages thérapeutiques, réflexologie, shiatsu
8 ☐ Autre

72. Au cours de 12 derniers mois, combien de fois avez-vous été traité·e pour le cancer reporté ci-dessus **en ambulatoire** ou en **hôpital de jour** ?

1 ☐ 0 fois
2 ☐ 1-2 fois
3 ☐ 3-5 fois
4 ☐ 6-10 fois
5 ☐ Plus de 10 fois

73. Au cours de 12 derniers mois, combien de fois avez-vous été **hospitalisé·e** pour le cancer reporté ci-dessus ?

1 ☐ 0 fois
2 ☐ 1 fois
3 ☐ 2 fois
4 ☐ 3 fois et plus

74. Avez-vous suivi un traitement médical au cours des 12 derniers mois ou êtes-vous actuellement en traitement pour un ou plusieurs problèmes chroniques de santé autres que le cancer ? (*Plusieurs réponses possibles*)

1 ☐ Aucun
2 ☐ Arthrose ou rhumatisme
3 ☐ Cholestérol élevé dans le sang
4 ☐ Dépression, anxiété
5 ☐ Diabète
6 ☐ Hypertension
7 ☐ Maladie cardiovasculaire ou cardiaque
8 ☐ Maladie chronique du rein
9 ☐ Maladie pulmonaire chronique (asthme, BPCO, bronchite chronique, emphysème)
10 ☐ Migraine
11 ☐ Ostéoporose
12 ☐ Rhume des foins ou autre allergies
13 ☐ Ulcère gastrique, duodénal
14 ☐ Autre

75. Dans l'ensemble, pensez-vous que votre santé est :

1 ☐ Excellente
2 ☐ Très bonne
3 ☐ Bonne
4 ☐ Médiocre
5 ☐ Mauvaise

76. FACT-G7 (Version 4)

Vous trouverez ci-dessous une liste de commentaires que d'autres personnes atteintes de la même maladie que vous ont jugés importants. **Veuillez indiquer votre réponse en tenant compte des <u>7 derniers jours</u>**.

Je manque d'énergie	1 ☐ pas du tout 2 ☐ un peu 3 ☐ moyennement 4 ☐ beaucoup 5 ☐ énormément
J'ai des douleurs	1 ☐ pas du tout 2 ☐ un peu 3 ☐ moyennement 4 ☐ beaucoup 5 ☐ énormément
J'ai des nausées	1 ☐ pas du tout 2 ☐ un peu 3 ☐ moyennement 4 ☐ beaucoup 5 ☐ énormément
Je suis préoccupé·e à l'idée que mon état de santé puisse s'aggraver	1 ☐ pas du tout 2 ☐ un peu 3 ☐ moyennement 4 ☐ beaucoup 5 ☐ énormément
Je dors bien	1 ☐ pas du tout 2 ☐ un peu 3 ☐ moyennement 4 ☐ beaucoup 5 ☐ énormément
Je suis capable de profiter de la vie	1 ☐ pas du tout 2 ☐ un peu 3 ☐ moyennement 4 ☐ beaucoup 5 ☐ énormément
Je suis satisfait·e de ma qualité de vie actuelle	1 ☐ pas du tout 2 ☐ un peu 3 ☐ moyennement 4 ☐ beaucoup 5 ☐ énormément

77. Durant le mois dernier, vous êtes-vous senti·e souvent triste, déprimé·e, desespéré·e ?

1 ☐ Oui
2 ☐ Non

78. Durant le mois dernier, avez-vous souvent ressenti un manque d'intérêt et de plaisir dans la plupart des activités que d'habitude vous appréciez ?

1 ☐ Oui
2 ☐ Non

79. Lorsque vous obtenez une information écrite à propos d'un traitement médical ou de votre état de santé, rencontrez-vous des problèmes de compréhension ?

1 ☐ Toujours
2 ☐ Souvent
3 ☐ Parfois
4 ☐ Occasionnellement
5 ☐ Jamais

80. En général, comment préférez-vous prendre des décisions médicales concernant le cancer ?

1 ☐ Je préfère prendre moi les décisions
2 ☐ Je préfère que mon médecin et moi prenions les décisions ensemble
3 ☐ Je préfère que mon médecin prenne les décisions

INFORMATIONS PERSONNELLES

Merci de répondre aux questions ci-dessous, qui nous permettront de mieux comprendre les résultats.

81. Vous êtes :

1 ☐ Une femme
2 ☐ Un homme

82. Quel âge avez-vous ? _______________

83. Quelle est votre langue principale, c'est-à-dire la langue dans laquelle vous pensez et que vous savez le mieux ?

1 ☐ Français
2 ☐ Allemand (ou suisse-allemand)
3 ☐ Italien
4 ☐ Autre : ________________________________

84. De quelle nationalité êtes-vous ? (*Plusieurs réponses possibles*)

1 ☐ Suisse
2 ☐ Européenne
3 ☐ Extra-européenne

85. Quel est votre état civil ?

1 ☐ Célibataire
2 ☐ Marié·e / partenariat enregistré
3 ☐ Séparé·e / divorcé·e / partenariat dissous
4 ☐ Veuf/veuve

86. Qu'est-ce qui décrit le mieux votre situation de vie actuelle ?

1 ☐ Je vis seul·e
2 ☐ En couple sans enfant à la maison
3 ☐ En couple avec enfant(s) à la maison
4 ☐ Famille monoparentale
5 ☐ Je vis avec une ou des personnes apparentées (p. ex. père, mère, frère, sœur, oncle, tante)
6 ☐ Je vis avec une ou des personnes non apparentées (p. ex. colocataires)
7 ☐ Autre (p. ex. en institution)

87. Quelle est la formation le plus élevée que vous avez terminée ?

1 ☐ Aucune scolarité / école obligatoire
2 ☐ Ecole de culture générale / maturité gymnasiale / maturité professionnelle / école normale ou pédagogique
3 ☐ Apprentissage (CFC) / école professionnelle à plein temps / formation professionnelle élémentaire
4 ☐ Maîtrise, brevet ou diplôme fédéral / école technique ou professionnelle / école professionnelle supérieure / école technique supérieure
5 ☐ Université, haute école spécialisée ou pédagogique, école polytechnique fédérale
6 ☐ Autre : __________________________________

88. Qu'est-ce que qui décrit le mieux votre situation professionnelle actuelle ?

1 ☐ Activité professionnelle à plein temps (80%-100%)

2 ☐ Activité professionnelle à temps partiel (<80%)

3 ☐ En formation (écolier·ère, étudiant·e, apprenti·e)

4 ☐ En recherche d'emploi (inscrit·e au chômage ou non)

5 ☐ Femme/homme au foyer

6 ☐ En invalidité (p. ex. rentier·ère AI) ou en arrêt maladie prolongé

7 ☐ A la retraite (AVS, autre pension) ou autre rentier·ère hors rentes d'invalidité

8 ☐ Autre

89. Durant les 12 derniers mois, avez-vous eu de la peine à payer les factures du ménage (impôts, assurances, téléphone, électricité, carte de crédit, etc.) ?

1 ☐ Oui

2 ☐ Non

90. Au cours des 12 derniers mois, avez-vous renoncé à certains soins à cause du prix à payer ?

1 ☐ Oui

2 ☐ Non

91. Quel modèle d'assurance obligatoire des soins (LAMal) avez-vous actuellement ?

1 ☐ Modèle standard

2 ☐ Modèle alternatif : médecin de famille, consultation téléphonique avant visite médicale (Telmed), réseau de soins / cabinet de groupe (HMO)

3 ☐ Je ne sais pas

92. Quelle est votre couverture d'assurance maladie en cas d'hospitalisation ?

1 ☐ Assurance de base

2 ☐ Assurance semi-privée

3 ☐ Assurance privée

4 ☐ Je ne sais pas

93. Vous avez rempli ce questionnaire :

1 ☐ Seul·e

2 ☐ Avec l'aide d'un·e proche

94. J'autorise le CHUV à transmettre mon nom et mon adresse à l'IUMSP pour l'envoi par courrier des principaux résultats à la fin de l'étude. *Votre nom et votre adresse ne seront pas utilisés pour d'autres raisons.*

1 ☐ Oui

2 ☐ Non

95. Si vous souhaitez partager des expériences que vous avez vécues liées au cancer que nous n'avons pas abordées dans ce questionnaire ou si vous avez des suggestions d'amélioration des soins liés au cancer, n'hésitez pas à le faire sur la page suivante.

Merci d'avoir rempli ce questionnaire !

Veuillez S.V.P. nous le renvoyer rempli en utilisant l'enveloppe pré-affranchie à l’adresse suivante :
IUMSP / UES / SCAPE, Biopôle 2, Rte de la Corniche 10, 1010 Lausanne

7.4 Appendix 4: Policy Brief. Giving patients a voice about cancer care: should Switzerland do more to collect patients’ experiences of cancer care?

Swiss Learning
Health System

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

Chantal Arditi, Isabelle Peytremann Bridevaux

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Keywords

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Table of contents

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.

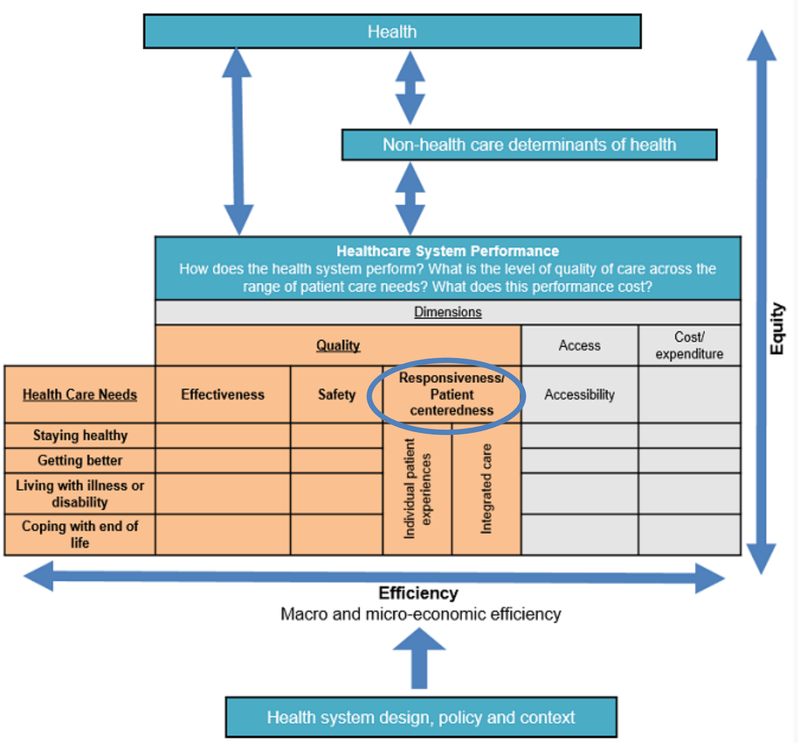
Patient-centered health system

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

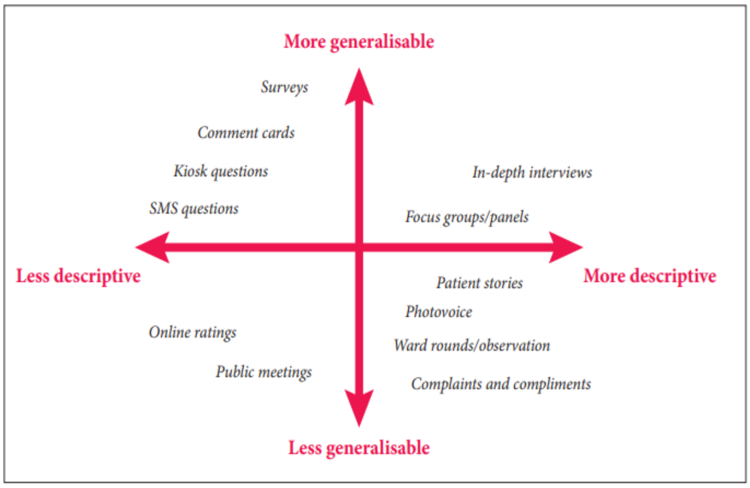
Methods of collecting patients’ experiences of care

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

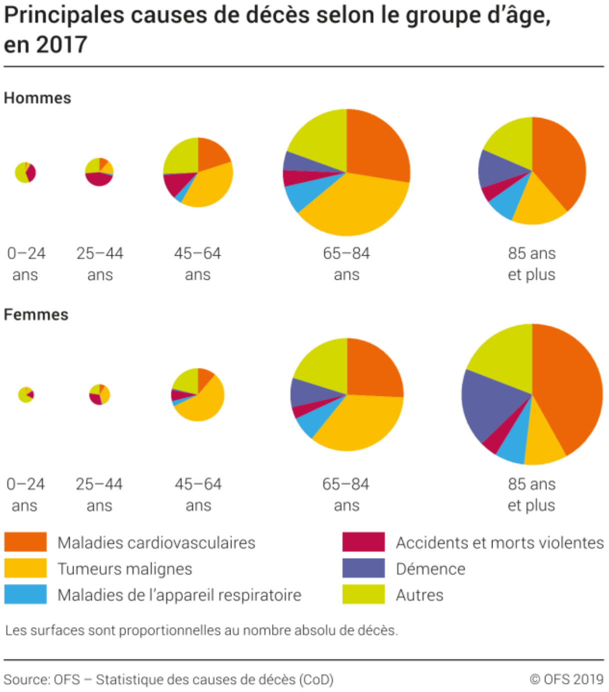
Consultation skipped due to costs
Medical tests, treatment or follow-up skipped due to costs
Prescribed medicines skipped due to costs
Waiting time of more than four weeks for getting an appointment with a specialist
Patients reporting having spent enough time with any doctor during the consultation
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



Principales causes de décès selon le groupe d’âge, en 2017

Les surfaces sont proportionnelles au nombre absolu de décès.

Source: OFS – Statistique des causes de décès (CoD) © OFS 2019

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

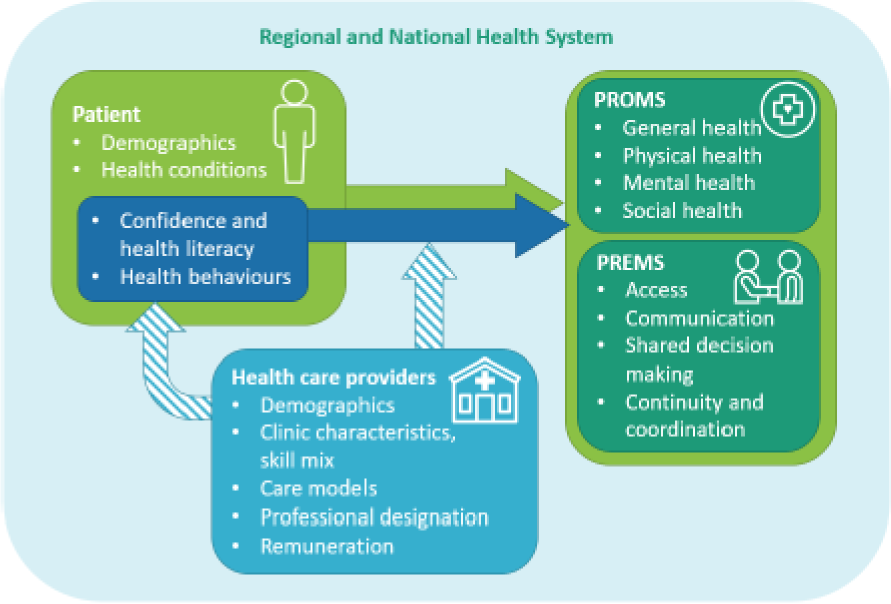
In 2018, the Swiss Cancer Patient Experience (SCAPE) study launched the first cross-sectional multicenter survey among patients diagnosed with the six most frequent cancers from four large cancer centers in French-speaking Switzerland (www.scape-enquete.ch). Data were collected with a self-administered 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

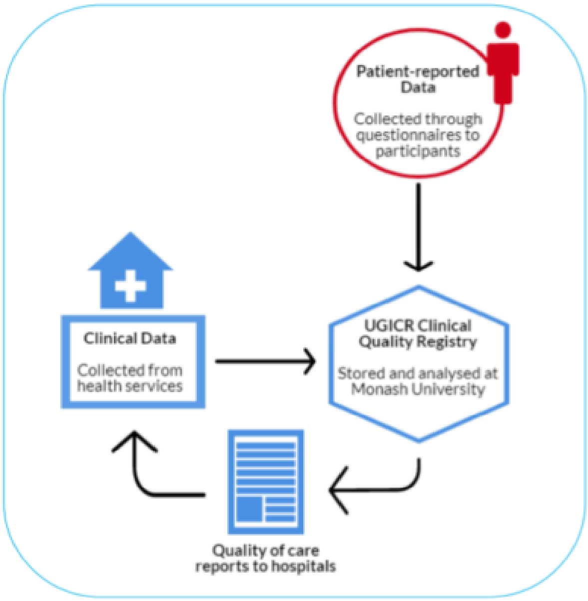
Sweden has set up over a 100 national quality registries, around 40% of which collect a patient experience measure (35). These government-administered quality registries collect information on individual patients' problems, interventions, and outcomes of interventions in a way that allows the medical 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	• Leadership by senior member or having a coordinator in charge • Involving providers in the implementation process • Fully integrated electronic data
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	
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

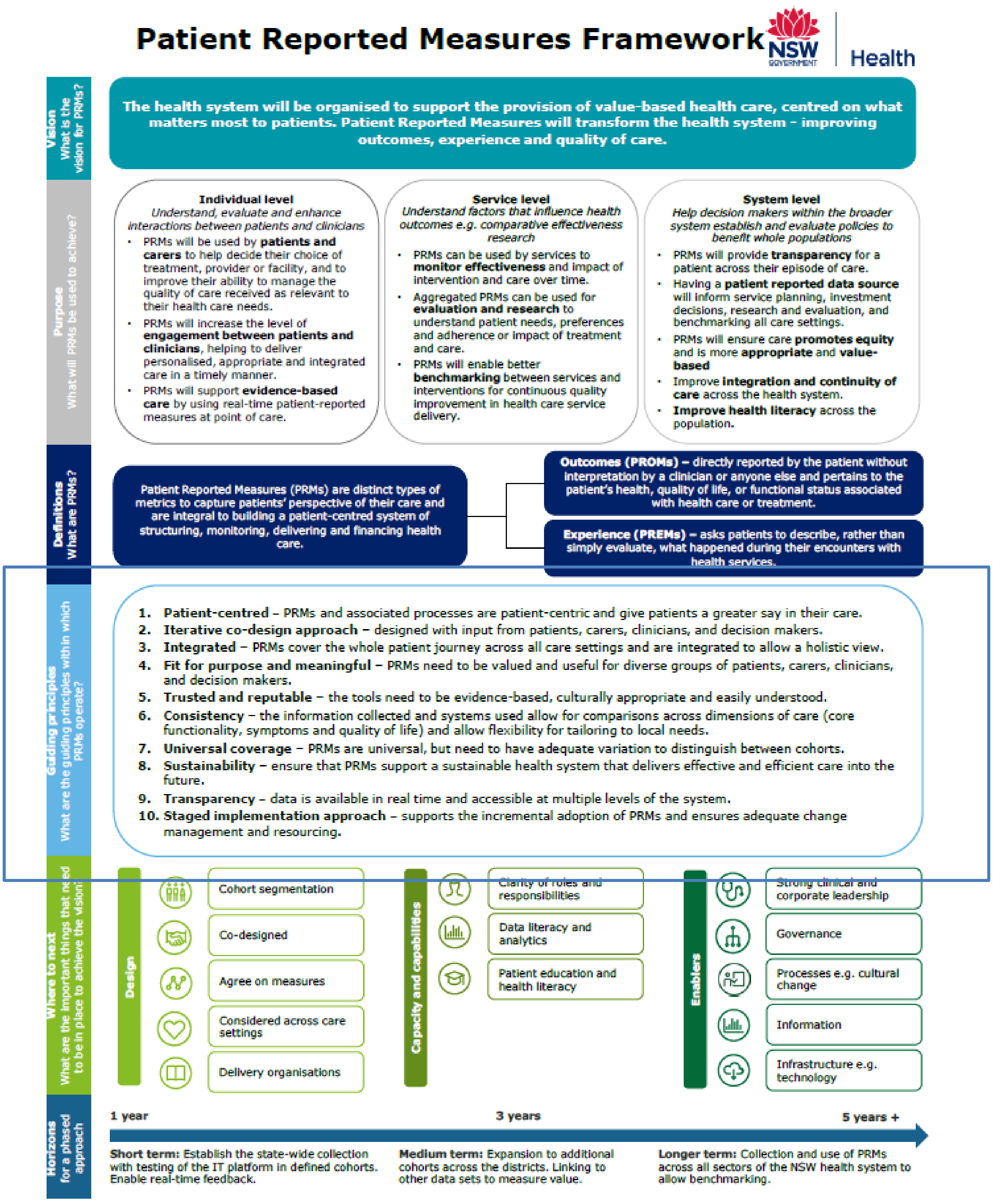
Methodological efforts by countries to develop and use systematic ways of measuring patient experience information are diverse and plentiful. Experience indicates that countries are keen to copy and adjust questions and questionnaires applied elsewhere. Given the OECDs work in this field and its position 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

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

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

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

Swiss Learning
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