National Care
Experience
Programme

International Review of National Cancer Care Experience Surveys

About the National Care Experience Programme

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. Patient and service user representatives and advocates are also involved at all levels of the programme's governance structures.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The programme implements the National Inpatient Experience Survey, the National Maternity Experience Survey, the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey and the National End of Life Survey.

The surveys aim to learn from people's feedback about the care received in health and social care services to find out what is working well, and what needs to be improved.

A National Care Experience Programme Survey Hub is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

Find out more at www.yourexperience.ie.

The National Care Experience Programme is in the process of developing a survey on cancer care, in response to the decision by the Programme's Steering Committee to prioritise the development of a model and methodology for cancer care, based on recommendations from the National Cancer Strategy 2017-2026.[1] The National Care Experience Programme Strategic Plan 2022 -2024 suggests that a National Cancer Care Experience Survey will provide important insights into the delivery of cancer services in Ireland.[2]

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1. Introduction

Understanding a patient's experience when they receive healthcare is essential to providing patient-centred care.[3] Evidence strongly indicates that patient experience surveys provide a useful measure of health system performance.[4] There has been an increased recognition of the importance of patient-reported experience measures (PREMs) across Organisation for Economic Cooperation and Development (OECD) member states in recent years.[3] A positive experience of healthcare is considered one of the key pillars of providing high-quality care, alongside clinical quality and safety outcomes.[5] Patient experience surveys provide an avenue for people who use health and social care services to become active participants in their own care experiences, which drives accountability across the healthcare system. Patient experience surveys can also be used to meet licencing requirements within health and social care settings and be used as a tool to provide assurance that care is being provided to a defined standard.[6]

Monitoring patients' views on cancer care service delivery allows for prioritisation of improvement initiatives and the evaluation of implemented quality initiatives.[7] Evidence has also demonstrated a more extensive benefit to stakeholders that use PREMs in their service delivery, including improved efficiency and lower staff turnover due to positive reinforcement for good practices.[8] The use of patient experience surveys that have been validated or implemented internationally also provides opportunities for benchmarking and international comparison of health services. Some OECD countries use their PREM surveys for regulation and accreditation purposes, including Canada, Denmark, France and Australia. The UK's Care Quality Commission (CQC) uses patient experience survey data to assess compliance against standards of quality across all healthcare providers. Additionally, countries use outcomes of their experience surveys to promote funding allocations in pay-for-performance hospitals, as seen in Korea and Norway.[4]

Most countries that undertake patient experience surveys have developed standardised methods for conducting their surveys, including target population, sampling, data collection modes and phrasing of survey questionnaire items. Similarly, countries are focusing on collecting care experiences from patients within certain healthcare settings or with certain diagnoses, to identify areas for focused quality improvement. Areas include mental health, nursing homes, in-patient, maternity care, diabetes, stroke and cancer.[4] There has also been a development of frameworks for monitoring patient experiences with care coordination, integrated care and follow-up care as part of a health system performance assessment framework. Standardising PREMs to accelerate the use of validated, standardised and internationally comparable patient-reported indicators have been prioritised by international bodies, including the OECD's Patient-Reported Indicators Surveys

(PaRIS) initiative, which seeks to develop, pilot and implement PREMS to monitor health system performance to prioritise patient-centred care, currently focusing on specific care areas including breast cancer, mental health and hip and knee replacements.[9]

In recent years there has been an increased focus and investment in the systematic, national-scale measurement of patient experiences across a range of health and social care services, to monitor and guide quality service improvements. The Health Information and Quality Authority (HIQA) was established in Ireland in 2007, under the Health Act 2007, which primarily aims to promote patient safety and quality of services provided throughout health and social care services.[10] Under HIQA's statutory remit, functions including planning and supporting sustainable improvements are established under the Health Act 2007, with Article 8 (1) (g) noting that HIQA operate schemes that ensure quality and safety in the provision of services delivered in Ireland.[10] The National Care Experience Programme was established to provide a platform for patient and service user voices to be heard within the health and social care setting. A partnership between the Department of Health, the Health Service Executive (HSE) and HIQA was established, with the first national patient experience survey conducted in 2017 relating to inpatient experiences within the acute setting. The Programme has since expanded its programme to include other areas of health and social care services, including maternity, end-of-life care, nursing homes, mental health and cancer.

In Ireland, national health policy highlights the importance of engaging with people who use health and social care services and capturing their care experiences to inform quality improvements in healthcare. The *National Cancer Strategy 2017-2026* commits to the engagement of persons using cancer services by employing a similar methodology used to deliver HIQA's National Inpatient Experience Survey.[11] The Irish *National Healthcare Charter* contains eight principles that aim to provide a shared understanding of the rights of people receiving healthcare. These principles include access, dignity and respect, safe and effective services, communication and information, participation, privacy, improving health and accountability.[12] Similar guidelines have been applied internationally, which outline the elements involved in ensuring the rights of people using health and social care services are upheld.[13]

Oncology quality measures based on cancer patient experiences tend to fall behind other areas of care experiences, perhaps due to the challenge of incorporating all aspects of cancer care into a single comprehensive, yet specific survey.[14] The term 'cancer' itself includes a vast array of diseases, each with differing aetiology, characteristics and treatment strategies. This results in a complex array of patient pathways, in which patient experiences of cancer services can vary significantly.

Care differs for patients with new diagnoses, to patients on active treatment for a number of years, or patients receiving cancer-related palliative supportive measures. Dependent on cancer pathology and stage of disease, patients can be referred to multiple differing treatment options, all tailored to each individual patient, from active surveillance or 'watch and wait', to multi-modality treatments. Patient care tends to transfer across multiple hospitals during their cancer treatment pathway, making it more difficult to assess experiences at a local level.

Established cancer patient experience surveys have used a number of techniques in their survey design to provide a suitably comprehensive survey, from multi-module surveys that are only related to one episode of care, to more extensive surveys that are associated with particular acute stages of a patients' cancer experience.[5, 14] For example, the European Organisation for Research and Treatment of Cancer (EORTC) validated two cross-cultural surveys; IN-PATSAT 33 and OUT PATSAT7, as cancer specific satisfaction surveys to evaluate the experiences of cancer patients in the in-patient and out-patient setting. The EORTC sets clearly defined patient contact with one of the healthcare settings to be considered eligible to complete the survey. Eligible patients for the out-patient survey are required to have received at least three of six cycles of chemotherapy, two weeks of radiotherapy, two cycles of targeted therapy or have follow-up care in the past 3-24 months. To complete the in-patient survey, a patient requires admission to an in-patient setting for a minimum of three days.[15]

It is important that care experience surveys adequately target the survey population, with appropriate questions that encapsulate the patient's perception of care, going beyond satisfaction measures to explore experiences of care.[16] Satisfaction measures alone are associated with more subjective, evaluative assessments that are subject to opinions which may not be congruent with measures that assess a healthcare facility's goal to provide high-quality patient care. It is therefore recommended that care experience surveys focus on assessing concrete and specific components of care during a specific timeframe, with limited questions regarding overall satisfaction measures. [16] A key step identified by each of the surveys addressed within this review document, is the continuous inclusion of patients and key stakeholders at each step of the survey design, to ensure the survey best reflects the areas of cancer care deemed most important to patients and service providers.

1.1 Aims and objectives

The aim of this international review is to identify and analyse international best practice with regard to the models and methodologies employed to deliver a national or regional cancer experience survey. To date, there is no standardised national approach to capture the experience of care of those who have received cancer care in Ireland.

This report identifies how international organisations are using patient experience data to support regulation, quality improvement initiatives and promote quality care within cancer services. Through identifying international best practice, this review will inform the National Care Experience Programme's optimal approach to implementing a national cancer care experience survey in Ireland.

1.2 Methodology

A targeted review of international cancer patient experience surveys was undertaken. The jurisdictions selected were chosen as a result of a desktop review that established which countries had availability of relevant information, relevant publications and access to key personnel. This review found that surveying patients using cancer services has been undertaken and is well established by many national or regional public health agencies, healthcare providers and academic institutions internationally. Five countries were selected to be reported in detail for this review. The selected surveys are undertaken at a national or regional level to evaluate the provision of cancer services.

1.3 Structure of the report

This document sets out the findings of the international review undertaken to inform the development of a national cancer experience survey for Ireland. It includes a summary of the findings and detail of surveys undertaken in each jurisdiction reviewed. The appendices include information on the context of health policy and background underlining the National Care Experience Programme's work on this survey along with information on the personnel consulted in each jurisdiction reviewed in this report. We would like to acknowledge the National Cancer Control Programme (NCCP) for their input into the development of the National Cancer Experience Survey. This report therefore identifies how organisations and agencies internationally collect and use cancer patient experience data associated with adult services. The surveys reviewed in this report are conducted in the following countries:

- England
- Scotland
- Australia (New South Wales)
- Switzerland
- United States of America (USA).

Findings for this scoping review were compiled on each country, from literature including technical reports, national policy documentation and peer-reviewed journal articles. Detailed discussions with key personnel within each country also took place. Table 1 in Appendix A lists the personnel who were consulted within each organisation.

Each country selected is examined in relation to their governance, operational and reporting processes. The review of each country also focuses on the:

- context of patients defined for inclusion in the survey and policy underpinning the surveying of patients utilising cancer services
- survey governance structures, model, methodology, and administration
- sample population, distribution and collection methods, and response rates
- outputs including what is reported and what impact the results have had if reported or known
- the key themes and domains of care evaluated by each survey.

2. Summary of findings

2.1 Objective

There was significant overlap between the overall objectives for conducting a cancer care experience survey across international jurisdictions. Each survey aims to provide an overview of the care experiences of people with cancer. Three of the jurisdictions have developed their care experience survey in line with national strategies or policy initiatives.[17, 18, 19] Care experience surveys allow these policy areas to be prioritised in the context of using the patient's voice to drive improvements in these areas. All jurisdictions noted that experience surveys provide an important stimulus to promote and drive continuous quality improvements in the quality of care delivered. Representatives of the jurisdictions consulted with also noted that these surveys provide an overview of patient experiences, which can be used as longitudinal data to critically assess performance improvements over time and indicate variation between health areas or between different groups of patients. Scotland for example, in line with their cancer strategy, have placed a focus on comparing low survivability cancers and reducing health inequality.[20, 21] The New South Wales Outpatient Cancer Clinics Survey (OCCS) highlights the importance that cancer patient experience surveys provide in the strengthening of accountability to provide quality care to patients, as they offer a reliable and fair benchmark across local and state levels.[21]

The English Cancer Patient Experience Survey (CPES) and Consumer Assessment of Healthcare Providers and Systems (CAHPS) cancer care surveys in the USA can empower patients to make more informed decisions about their cancer care providers. Results are provided at a local level in these jurisdictions, allowing for hospital level comparisons between survey results. As the USA also gathers information to inform accreditation organisations and healthcare purchasers, outcomes from this survey can inform financial decisions dependent on quality of care delivered.

2.2 Governance arrangements

Governance arrangements differ between countries. Countries including England and Scotland are overseen by state agencies. Other jurisdictions took a more academic approach, funding universities to carry out their surveys. These surveys, such as the CAHPS Cancer Care in the USA utilised strong, robust scientific methods to validate the survey questionnaire, using psychometric analysis.[14]

Some jurisdictions adopt a partnership approach to governance, which includes national policy maker involvement, government oversight and academic-led survey design. The CPES is commissioned by NHS England, conducted by the Picker

Institute and heavily relies on the experiences of the National CPES Advisory Group, which include patient representatives, clinicians, cancer charities, survey experts and NHS providers.

2.3 Data protection

The legislative requirements around data protection are a significant consideration for patient experience surveys, largely due to the requirement to collect personal data to conduct and distribute a survey. Each international comparator had varying methods for data sharing agreements and sharing of data with third parties.

Each of the jurisdictions follow their relevant state and federal laws with respect to patient privacy and confidentiality. In the case of OCCS, the Health Record and Information Privacy Act 2002 allow New South Wales (NSW) Health to release appropriate information for the purpose of conducting a patient experience survey.[23]

Consent requirements also differed, dependent on the country in question. In England and Scotland, both the CPES and SCPES respectively do not require patient consent for survey participation, as the data can be used based on service improvement provisions of the relevant data protection legislation.[24] Patients have the option to opt-out of surveys, by contacting survey vendors through Freephone or email options.[24] Consent is also not required for the SCPES under similar criteria.[25]

In New South Wales, explicit patient consent is also not required, as the survey is considered a quality service improvement initiative.

2.4 Ethical approval

Some surveys did not require ethical approval, as the surveys were covered under service evaluations, as opposed to research. Other countries had ethical approval underpinned by national health policy to evaluate care. The Scottish SCPES requires permission to use patient information for their survey, including the sharing of data to third parties to administer the survey. This is sought through a governance panel to ensure that public benefit is assured and privacy concerns have been considered.[26]

In the case of SCAPE-CH, the survey is conducted by Unisanté, a university in Switzerland, with partial funding from the Federal Commission for Quality and also participating hospitals. Ethical approval is sought from the university to their ethics committee to conduct the survey, to authorise that the survey is in line with Swiss Law on human research. Respondents provide written informed consent. Unisanté do not have ethical approval to receive direct patient contact information, so hospitals are required to contact their patient datasets directly.[27]

2.4 Communication

Depending on the survey in question, different jurisdictions applied differing communication plans. This was dependent on sampling methodologies selected and the establishment of the survey tool.

Surveys that utilised a census sampling approach had more detailed communication plans for their surveys, including CPES in England, which used posters to notify prospective patients of their upcoming survey. Other jurisdictions, such as New South Wales, applied more rigorous communication plans when they were initially commencing their cancer experience surveys, to provide exposure of the prospective survey to maximise response rates. Such communication efforts were reduced on subsequent iterations of the survey, with increased awareness of the survey and established response rates. Surveys that used a random sampling approach considered the use of branding ahead of a survey not relevant to the majority of patients that would be receiving their treatment during the survey period, so did not consider it appropriate.

All surveys discussed in the review used a mixed-mode (postal and online) approach to conducting the survey, bar one private hospital in Switzerland, which electively decided to apply an online-only approach to their survey participation.

A survey pack was sent out to all prospective participants in all jurisdictions. The survey packs contained the paper-based questionnaire, free-return stamped envelope and an invitation or survey cover letter. A reminder letter was sent by all jurisdictions, at a fixed time period from the initial letter, ranging from two weeks to one month after the initial letter. For surveys that sent out a further reminder letter, this second reminder only included the cover letter, prompting respondents to complete the survey. The third and final reminder letter, in the case of the OCCS and CPES surveys, contained the cover letter, questionnaire and stamped addressed envelope.

In the case of the Swiss survey, in the invitation letter an apology was included to the family, if a patient has passed away and a survey has been sent out.

All jurisdictions provided a Freephone number, to facilitate patient calls to complete the survey, or to answer any questions or concerns that respondents may have. Calls regarding patient queries largely concerned the patient’s eligibility to participate in the survey, querying their cancer diagnosis, help completing the survey [29] or informing the survey vendor that the prospective respondent had passed away or was too unwell to participate in the survey. Survey vendors had varying methods to manage patient calls. Largely, calls were managed in-house by the survey vendor. In the case of SCPES, there was both a central helpline to the call centre and local helpline to refer patients back to their hospital or area of care, to resolve their issue or concern locally.

2.5 The survey

2.5.1 Eligibility criteria

The eligibility criteria for each survey consisted of adults, over the ages of either 16 years or 18 years of age, depending on the country. Some comparators also provide independent paediatric cancer surveys, such as the NHS England Cancer Patient Experience Survey, however, these were outside of the scope of this review.

All surveys that had access to a patient’s diagnosis, specified the requirement for participants to have received a confirmed diagnosis of cancer. This is confirmed by using International Classification of Diseases (ICD)-10 codes, in the case of the English and Scottish surveys. In the absence of ICD-10 codes, comparators used national cancer registry data or requested that patients self-report their cancer diagnosis on the survey questionnaire. This led to requiring specific tumour groups to be defined during the survey methodological process.

Time is required between the defined sampling period and conduct of fieldwork, to allow for sufficient time for diagnostic codes to be assigned to patient datasets and for the datasets to be validated by participating hospitals. For international comparators that did not have access to ICD codes, patients were included if they received a particular course of treatment within the survey period. In the case of the Australian survey, as cancer diagnosis could not be identified, both cancer and non-cancer patients using outpatient cancer clinics were included in the eligibility criteria. In the case of the CAHPS Cancer Care survey, patients were only considered if they had at least two visits to the cancer centre within the previous 10 weeks, for any of the three main cancer treatment modalities, surgery, drug therapy or radiation therapy. Patients that were undergoing active surveillance or ablative treatments were not considered eligible. [14] In the case of the English, Scottish and Swiss surveys, they focused on inpatient or day-case procedures within a defined period of time, and asked patients to refer to their most recent episode of care for the survey. Out-patients were excluded from the eligibility criteria, due to limitations from the hospitals sources of patient data collection.

The Swiss cancer survey included patients that attended for a cancer-related treatment or follow-up within a six month sampling period. It was acknowledged that patients who had just recently received a diagnosis may not be able to complete the entire survey, as only certain areas of the survey would be relevant to their experience. The survey allowed for patients to refer to both one specific episode of care within the survey period and care received in the previous 12 months.

International surveys with more detailed access to patient information, including diagnostic and procedural information, were able to provide more detailed exclusion criteria. The rationale for such exclusion criteria were typically to reduce the distress caused by patients that may not have been explicitly notified that they had a cancer diagnosis. In these instances, ICD-10 codes including non-melanoma skin cancers (C44 classifications), rare haematological diseases (C84 classifications) and in the Scottish survey, D05 classifications for in-situ breast carcinomas were excluded.

The inclusion of private patients or private hospitals were dependent on the international comparator, and division of care in each respective country. Scotland and England both excluded private patients, and private hospitals from their surveys. In the case of Australia, public patients can be referred to private facilities for their cancer care services. Private hospitals that take a significant proportion of public patients in NSW which were included in the Australian survey. The OCCS consider their inclusion the most optimal way to provide a whole-of-system view of cancer services that cater to cancer patients in NSW. Including private facilities can incur additional financial and budgetary constraints, which can be a limitation for inclusion in national surveys. The SCAPE survey in Switzerland overcame budgetary restrictions by requesting all hospitals to fund 50% of the survey, which covers survey distribution and paper costs.

Both the NHS England and NHS Scotland surveys excluded patients who stayed in a maternity hospital or had conditions related to pregnancy or birth. Surveys also had defined exclusion criteria if patients had completed a previous survey within a set period of time. In NSW, patients should not have conducted another BHI survey within the previous six months. In the case of CAHPS Cancer Care, a patient was excluded if they participated in HCAHPS within the previous 51 days.[14]

2.5.2 Survey respondent selection

The English, Swiss and Scottish surveys use a census sampling approach. All patients that received care within the sampling period are eligible to participate in the survey. NHS England has no minimum or maximum sampling requirements. Patients are also included if they are undergoing either curative or palliative treatment.

The CAHPS Cancer Care survey uses billing data from the previous six months to randomly assign patients within the survey sampling period to either complete the survey module relating to surgery, radiation oncology or medical oncology. If one of the sampling frames is smaller than the desired frame, a census approach is adopted. The aim is to have equal numbers of respondents completing each module of the survey.[14]

In the case of OCCS a random sampling approach is used. A maximum of 700 patients per facility are included in the survey, and are randomly sampled from the chosen survey period. Facilities are only included if they could provide at least 50 eligible patients for sampling. Other surveys used suppression guidelines, in which particular survey results would not be published if they were below a certain threshold. Use of minimum sampling participants per participating hospital or suppression guidelines of results are important factors to consider with respect to maintaining patient anonymity.

2.6.3. Question pool and domains of care

The survey themes contained within each survey largely followed a cancer pathway-led approach, with the exception of the CAHPS Cancer Care survey. Three of the international comparators used the English CPES as a template for their survey. Although the issues addressed in these surveys were broadly similar, the focus of the surveys reflected the healthcare context for which the survey was developed. In the case of comparator countries with greater reliance on private insurance, there was a greater focus on the financial implications of cancer treatment. In England, the role of main support person or navigator is important in providing co-ordination of care, thus there is a priority on the accessibility of a main support person in the CPES survey. The main themes between each survey tool can be observed in Table 7, Appendix B.

Of the surveys based on the CPES, the number of themes identified ranged from nine for the Scottish survey, 14 for the CPES and OCCS surveys, and 17 themes in the SCAPE survey. The CAHPS Cancer Care survey focused on six dimensions of care, prioritising the patient experience of different treatment modalities.

The most commonly included domains of care included:

- deciding on the best treatment /shared decision making
- care planning
- support from hospital staff
- your treatment
- side effects
- involvement of family or friends
- discharge and follow-up
- financial implications
- overall care
- About your health.

The number of questions included in the questionnaires varied between 66 questions in SCPES to 128 questions in SCAPE-2. More recent iterations of surveys have focused on shortening questionnaires. For example, the Swiss and NSW surveys removed questions in their 2023/2024 surveys, with the SCAPE-CH survey being reduced from 128 questions to 90 questions.

All surveys included at least one overall experience or satisfaction question and at least two free-text or open-ended response questions. Surveys including SCPES had more open-ended questions at the end of specific themes of care for patients to provide more detailed answers regarding their care. The SCPES survey did not ask patients to provide feedback on an area of care that they felt could have been better, but instead provided the opportunity for patients to provide feedback regarding experiences during diagnosis, treatment, their role in shared decision making, hospital care and support from general practitioner (GP) and third sector organisations during their cancer treatment.

Although palliative care services and survivorship have been considered in national cancer strategies as important themes to consider in the context of cancer care, international surveys have not yet extended their remit to include these areas of cancer care. The difficulty appears to be the extensive area that both of these domains of care cover in the context of cancer, and the selection of patients included in the eligibility criteria of the surveys would limit survey responses.

2.6 Survey methodology

2.6.1 Mode of contact and timing

The mode of contacting patients to participate in a cancer care survey varied, with a mixed-mode approach typically used. Primary methods were postal-based surveys, with a trend towards more online formats in recent years. No international survey has yet moved to online formats in isolation, as there are concerns that digital literacy may restrict certain patient demographics from participating in a solely online survey.[28] Key stakeholders involved in survey developments are encouraging more online methodologies in the future, as it is associated with reduced financial burden and more timely access to reports and findings.

Death checks are extremely important in the context of a cancer care survey. All international comparators, with the exception of the CAHPS Cancer Care survey conduct rigorous death checks prior to distributing any survey material to prospective respondents. Each international comparator has a variety of methods to conduct their death checks, using death registers, seeking patient families to contact hospitals to notify them of a recent death, or using local newspaper or online death repositories. These methods of conducting death checks are limited, in that up-to-date information cannot be provided, and so it is unavoidable that some families may be inadvertently sent survey information when their family member has recently passed away. In the case of Switzerland, there is a two-three month delay in updating of the national database. Delays in updating of death registers and hospital databases are an inherent risk across all of the surveys mentioned in this review, each with differing methods for mitigating the distress caused by such events occurring.

All international surveys in this review sent out an initial survey pack, which is either conducted by survey vendors or the participating hospitals directly. This was followed by two reminder letters, sent at set intervals, which varied depending on the international comparator. All comparators recommended the use of reminder letters to promote response rates. Some comparators sent reminder letters to all respondents, where others sent reminders only to those that had not yet completed the survey. Full survey packs, including the paper questionnaire were most typically sent in the first pack and the final reminder letter, along with stamped addressed envelopes, for ease of postal returns.

The timing of survey fieldwork varied significantly between jurisdictions. The reasons for selected timeframes typically involved the time required for hospitals to compile their patient datasets. For surveys that have a set maximum number of participants using random sampling approaches, there are shorter times between survey period and fieldwork commencing, with OCCS only requiring one month to compile patient datasets. This survey also has significantly fewer exclusion criteria, which allows hospitals to extract patient datasets much more promptly, without requiring rigorous validation of the survey population. In the case of surveys with strict exclusion criteria, using ICD-10 codes to validate cancer diagnoses, time between the survey period and fieldwork ranges from five months to eight months. The advantages of having more time between the survey period and fieldwork commencing, is that it allows sufficient time for patients that only received a biopsy during the survey period to have received their diagnosis, and perhaps have commenced their treatment plan. Limitations of such gaps include ensuring good patient recall of events and their experiences.[30] The literature indicates that a greater time between medical events and a survey period increases the risk of poorer recall and lower reported patient experience measure results.[31] In the case of cancer patients with poorer prognosis, limiting the time between survey sampling period and fieldwork is important to increase the likelihood that this cohort of patients will be fit enough to participate in the survey, or have not passed away in the interim period.[32]

2.6.2 Response rate

Most surveys noted positive response rates from their cancer care surveys. A number of international counterparts suggested that cancer patients tend to have a strong desire to give back to cancer services, by providing their personal experience of the care they received. All surveys in this review, report response rate ranges of 48% to 62% annually. Although CAHPS Cancer Care has noted a reduction in response rates in recent years, OCCS note that cancer surveys typically report the highest response rates in comparison with surveys covering other health and social care backgrounds.

Surveys using a mixed-mode approach have reported higher uptake using postal surveys with CPES reporting 81.6% of survey respondents completing their 2021 survey via post and 18.4% online. Comparable figures were reported by SCPES, with 10% of surveys completed online. Other international surveys have moved towards a completely online format, including the Croatian National Cancer Patient Experience Survey. International comparators have noted a preference from stakeholders to move towards a more online-based approach, but this has not yet been adopted across the majority of survey jurisdictions.

2.6.4 Frequency

The frequency of data collection varied between jurisdictions. The CPES in England has been conducted annually since 2010. Annual surveys are also conducted in New South Wales using OCCS. Scotland have had three iterations of their survey, repeating the cancer survey every three-four years on average. CAHPS Cancer Care did not specify a set frequency for the implementation of their survey. The Swiss SCAPE survey has been repeated on three occasions since 2018. Each survey has committed to regular revisions of their survey design and content for relevance, with three of the five comparator countries commencing major reviews and updating their survey content between 2023 and 2024.

2.7 Outputs

Outputs vary depending on international comparator. Surveys including the CPES have very established outputs, in which survey findings are reports at four levels, including national, cancer alliance, integrated care board and trust level. Other surveys, such as SCAPE do not provide a national report, but send hospitals individual reports based on their results. They also publish their main results of the survey on their website, in an aggregated and interactive form.

NSW provides reports at NSW level, local health district level and hospital level. These are provided on the online Bureau of Health Information data portal. Results on the portal also include five-year trends to inform patient experience performance over time.

Outputs from the CAHPS Cancer Care survey are limited to published research articles based on the pilot conducted during the design and implementation of the survey.

In the case of SCPES, reports are published for each of the 14 NHS Boards, three regional cancer networks and at a national level. These results are published on an interactive dashboard on the SCPES website, which allows for easy comparison of results.

2.8 Impact

The impact of surveys varied across international comparators. Surveys that had mandated participation from a governmental level yielded tangible impact reports and publications, such as the NHS England CPES. None of the comparator countries require participating hospitals to respond to survey findings or conduct specific quality improvement initiatives. However, there is varied communication between survey contractors and participating hospitals, with CPES in England receiving annual follow-up from independent trusts regarding quality improvement initiatives that have been implemented, thus validating the impact of the survey in selected trusts, at a local level. In other jurisdictions, there was little evidence of this type of follow-up activity.

England

Background

In England in 2020, 288,753 new cancer diagnoses were registered. The majority of the cancer diagnoses (94%) registered related to 24 different types of cancer, with 51% of all registered cancers relating to breast, prostate, lung and bowel cancer.[33]

The Cancer Patient Experience Survey (CPES) is an annual survey which began in England in 2010. It built on previous surveys conducted in 2000 and 2004. The 2010 survey was commissioned by NHS England through Quality Health.[19]

Objective

The Cancer Patient Experience Survey was designed to meet a number of objectives. At a national level, the survey monitors progress on cancer care, assists commissioners and providers of cancer services to drive local quality improvements; and informs the work of stakeholder groups and local charities supporting cancer patients. The annual survey provides the NHS with an up-to-date overview of patient experiences of cancer services, at a local and trust level across England, including levels of variation across cancer services, cancer types and different socio-demographic groups.[34] Annual surveys also allow for trends in the data to be assessed, which enables commissioners to assess local improvements in cancer patient experience over a period of time. This encourages continuous improvement, by building on the results of previous surveys and enabling local providers and Cancer Alliances to critically assess their performance improvement, relative to other providers. Finally, the use of annual surveys empowers patients to make informed choices about where they should attend for cancer treatments.[35]

Governance arrangements

The survey is commissioned by NHS England and is conducted by The Picker Institute on their behalf. The Picker institute is responsible for technical design, data collection and analysis, with results published on the CPES website.[36]

The survey is overseen by the National CPES Advisory Group. The Group includes patient representatives, NHS providers, clinicians, cancer charities, survey experts, patient experience leads and NHS providers and commissioners. The Advisory Group makes recommendations to NHS England on the development of the survey design, with these recommendations then referred to the Cancer Programme Board. The Advisory Group has sub-groups which focus on specific aspects of the survey, including questionnaire content, technical design or reporting of survey findings.

The National Disease Registration Service (NDRS) collects and records data of people with cancer. Data is collected monthly from NHS Hospitals, including diagnosis, radiotherapy treatment and effectiveness of radiotherapy treatment. The NDRS also facilitates online self-registration.[37]

The research carried out by The Picker Institute is in accordance with the international standard for organisations conducting social research. The 2022 survey data was produced and published in line with the Code of Practice for Official Statistics. The Picker Institute is accredited to ISO 27001 and is compliant with the Data Security and Protection Toolkit which enables organisations to demonstrate that the way they hold, and process information meets information governance policies and standards.[35]

The survey

The sample

Samples are drawn directly from patient information systems in individual trusts, using the sampling criteria set for the survey. Each sample is uploaded to the Picker Institute online sample checking platform. A number of automated checks are conducted to ensure compliance with the sampling criterion. Once each sample has been approved, the datasets are combined and duplicates are removed. The most recent attendance to a trust is considered within the scope of the survey. The trust collects the following patient information:

- Trust code
- Patient Record Number (PRN)
- Title
- Initials / First name
- Surname
- Address 1
- Address 2
- Address 3
- Address 4
- Address 5
- Postcode
- NHS number
- Date of birth
- Gender
- Ethnic category
- Day of admission
- Month of admission
- Year of admission
- Day of discharge
- Month of discharge
- Year of discharge
- ICD-11 Chapter Code (if these are available)
- ICD-10 Chapter Code
- Main specialty

- Sub ICB Location code
- Patient classification
- Site code
- Site name

For the Picker Institute to receive patient demographic variables, they receive Section 251 approval from the Health Research Authority, which is a special legal instruction to collect patient data without requiring informed consent.[37] This legal instruction is granted under the Health and Social Care Act 2012. The Picker Institute is required to demonstrate compliance against certain data protection requirements, including having an approved application on the NHS Data Security and Protection Toolkit. This approval ensures that the Picker Institute holds and processes information that meets information governance policies and standards. Patients are provided with the option to opt-out of the survey, and this is facilitated by displaying notices and posters around each trust cancer service, during the sampling period.

The Picker Institute prioritise the use of ICD-10 or ICD-11 codes, as datasets can be collapsed into cancer types and tumour groups from the reported ICD codes. The tumour groups are noted in Appendix C.

Inclusion criteria: The sample for the most recent survey included all adult (aged 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged from an NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June 2022. Fieldwork was conducted between November 2022 and February 2023.

Census sampling is used within each participating trust. Trusts are mandated to participate, and the survey is completely funded by the NHS. All eligible participants within the sampling period of three months are free to participate, regardless of patient numbers within each organisation, with no specified minimum or maximum sampling frames per organisation. The Picker Institute recommend a clearly defined criteria for what constitutes ‘cancer-related treatment’, which can prove difficult to define for the inclusion criteria. This ensures that patients with a cancer diagnosis that receive an elective surgery for a non-cancer related procedure are not inadvertently included in the sampling frame. Areas of difficulty include patients that attend for reconstruction surgery years following a breast cancer diagnosis and subsequent cancer treatment.

Exclusion criteria: includes a comprehensive list from a clearly defined sampling criteria. The survey excludes patients without a confirmed diagnosis of cancer, including those that have been provided with a ‘holding diagnosis code’, with diagnostic results pending. Persons under the age of 16 years are excluded from the survey, as there is a specific children's and young person's survey, which commenced in 2016 and has differing sampling criteria and questionnaire. Persons without a UK postal address or not enough address information are excluded, to mitigate the risk of sending the survey to the incorrect address. Patients are also excluded if they are currently inpatients, as the survey is sent to a home address. Certain ICD 10 or 11 codes are included in the survey. A small set of ICD-10 codes are not eligible, including non-melanoma skin cancers, myelodysplastic syndrome (MDS) and T/NK lymphomas. The exclusion of certain ICD codes typically relates to cases where previous iterations of the survey found high rates of people contacting the CPES informing them that they were never diagnosed with cancer. In the case of non-melanoma skin cancers, these low-grade lesions are often surgically managed by day case outpatient clinics, and in the case of MDS, there is anecdotal evidence that not all patients are informed by their clinicians that they have a low grade form of cancer. Sending surveys to these individuals has resulted in unnecessary distress, if they have not previously been notified that they have cancer. Patients can be excluded from participating in the survey, if they have opted out. [38] Posters displayed in each participating trust provide information for patients to contact the Picker Institute to opt out of the survey. Private patients are also excluded from the survey design, with the exception of the period of time during the COVID-19 pandemic, where public patients were transferred for care from the NHS to private hospitals, as a continuity plan during that time. As the NHS completely funds the CPES, concerns from private hospital engagement include expenses placed on private hospitals to participate, and the publishing of organisation level reports based on patient feedback from the survey. Outpatients are also excluded from the survey sampling criteria, as there is relative inconsistency across trusts recording of outpatient appointments, some record (systemic anti-cancer therapy) SACT as out-patients, where others do not.

This most recent iteration of the survey contained 52 questions related to specific points during a patient's cancer journey. The questionnaire was reviewed in 2021 to reflect changes to cancer services and commitments to cancer care as detailed in the NHS Long Term Plan.[39]

Distribution and collection

The survey uses a mixed-mode approach. Questionnaires were sent by post, with two reminders where necessary, but also included options to complete the questionnaire online or by Freephone.

There is a four month gap between the defined three month sampling period and conducting the fieldwork for the survey. This is due to mechanics of compiling the sample from each trust. The Picker Institute hosts webinars explaining the sample before opening the sampling portal, this is typically conducted one to two months after closing of the sampling period. Distribution of the survey does not take place until all participating trusts have submitted their samples.

When patient data is received, it is sent through a secure NHS-compliant online network. It is stored on secure servers.

Communication

Response rate

The survey is conducted annually, with the most recent survey conducted in 133 NHS trusts.

In 2022, out of 115,662 people, 61,268 people responded to the survey, yielding a response rate of 53%.

Patients with cognitive impairments or learning difficulties are not excluded from participation in the survey. Family members or carers can complete the survey on their behalf, but it is requested that the survey be responded to from the perspective of the patient. In CPES, they do not ask who filled out the questionnaire.

Customer support lines

A Freephone helpline and email were available for respondents to opt out, ask questions about the survey, enable them to complete their questionnaire over the phone and provide access to a translation and interpreting facility for those whose first language was not English.

The Picker Institute have processes around people who were not aware that they had been diagnosed with cancer before receiving an invitation letter. If a patient calls the Picker Institute informing staff that they were incorrectly sent the survey, as they do not have cancer; the Picker Institute will investigate the call with the hospital in question, if the caller provides their unique survey code. They ask the hospital to investigate whether the person has cancer or whether people without cancer were inadvertently included in the sample. If the Picker Institute receive two calls from a trust where patients say they do not have cancer, they will pause further mailing until the patient sampling database is checked. It is the responsibility of the trusts to get back to these patients and close the feedback loop.

It was noted that the reasons for people thinking they do not have cancer can vary, including; patients not being clearly communicated with, not understanding their diagnosis, and some patients not accepting their diagnosis.

Outputs

The survey findings are produced at four levels, national, cancer alliance, integrated care board and trust level. In addition to this standard set of reporting outputs, a national webinar is held after publication. This webinar provides opportunities for learning about the national results, hearing from stakeholders and sharing of best practice.

For CPES 2022, a custom-built interactive reporting system for the survey was designed, providing the survey with greater functionality and flexibility for reporting.

Within each of the reporting levels noted above, results are provided for sub-groups where numbers allow, following NHS England's guidance on suppression.[40] The determined sub-groups are a combination of variables from the sample, data linked to information held by Office for National Statistics (for example using postcode from the sample to determine deprivation quintile), and survey responses (such as ethnicity). For trusts with larger population samples, they will receive very detailed reports from the Picker Institute, including breakdown of sub-groups; age, ethnicity, gender, cancer type, and area-level deprivation (IMD quintile). For trusts with smaller sampling sizes, suppression rules can apply. This is to mitigate the risk of a patient being identifiable from published reports. There needs to be more than 10 responses to any given questions within a particular sub-group for a breakdown to be provided.

At Cancer Alliance, integrated care board, and trust level, the Picker Institute presents adjusted and unadjusted scores. Adjusted scores allow for fair comparisons to be made between different organisations as these scores are adjusted to take into account the proportion of patients within the five sub-groups: age, ethnicity, gender, cancer type, and area-level deprivation (IMD quintile). Unadjusted scores are used to see the actual responses from patients relating to the organisation and also to track trends over time. Where possible, trends are presented.

As well as providing organisations with quantitative results, the Picker Institute also analyse the free-text comments from the survey. Each individual NHS trust receive a spreadsheet containing all of the free-text comments for their trust. These comments are divided into sub-group variables, to enable filtering of comments into particular areas or topics. These spreadsheets are not published.

The ownership of actions from these findings sits at various levels, dependant on reporting level. Cancer Alliances bring together leaders from hospital trusts and other health and social care organisations, to facilitate changes for cancer patients within their local area. Cancer Alliance level reports provide useful insights into care experiences in specific geographical areas. The Cancer Improvements Collaborative sets national themes of quality improvement initiatives to focus on, based on outcomes from the annual survey reports.

Quality improvement outputs are more ad-hoc at a local level, with some organisations promoting more of a quality improvement focus than others. Local projects cover a range of themes and patient cohorts, which can result in local improvements based on local level reported outcomes. Picker do not have a defined agreement for receiving output data, but they do discuss with Cancer Alliances how they used the survey to inform quality improvement changes. The Picker Institute use educational platforms and tools to promote such quality improvement initiatives, such as the use of video case studies on how organisations have used the results from the CPES to improve care.

The questionnaire

The 73-item questionnaire uses both closed and open-ended questions, with 61 questions regarding one of the key themes identified, two open-ended questions and 10 questions regarding patient's condition and socio-demographics. The questionnaire follows the cancer patient experience pathway, using 13 key themes. The themes identified by cognitive testing includes the following:

- Support from GP practice
- Diagnostic tests
- Deciding on the best treatment
- Support from a main contact person
- Care planning
- Support from hospital staff
- Hospital care
- Your treatment
- Immediate and long-term side effects
- Support while at home
- Care from your GP practice
- Living with and beyond cancer
- Overall NHS care.

The questions under each theme largely follow a 4-7 point Likert scale format, dependent on each particular question.

Routing questions are used within the survey. For example, if a patient did not have a main contact person, they would be unable to complete the questions under 'Support from a main contact person' and would so be referred to the questions on the following theme.

The survey also asks for an overall rating of care, on a scale of 0-10. Patients are then given the opportunity to complete two free-text questions, regarding experiences that were found to be positive, and areas of care that could have been better.

With respect to the patient condition specific questions and socio-demographic questions, the following questions are asked:

- When patient was first treated for this cancer
- Was cancer metastatic at diagnosis
- Current extent of cancer disease
- Year of birth
- Sexual orientation
- Gender
- If gender is the same as sex registered at birth.
- Chronic pre-existing co-morbidities
- If pre-existing co-morbidities impact ability to complete daily tasks
- If English is their first language
- Ethnic group.

Patients included in the survey include patients diagnosed within six months to more than five years from diagnosis. Patients are asked to specify if their cancer had metastasised, or spread from its primary location at diagnosis or whether the patient had primary disease initially, but cancer has since spread to other areas of the body.

In the survey, the questions regarding ‘Your treatment’ ask the patient to specify all the treatment they received over the previous 12 month period, breaking treatments down into surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy or none of these.

Key lessons learned and recommendations

The survey currently does not include people who have solely had outpatient appointments during the sampling window. There are a number of valid reasons for this and why a different feedback mechanism to CPES is required. The coding of ICD-10 codes for outpatient appointments is varied, so there is uncertainty that all patients selected to participate in the survey are actually eligible. Because the survey does not include outpatients, it means that we may be excluding people having certain types of treatment more commonly coded as an outpatient appointment by the NHS.

Once trusts draw their patient list many like to undertake a validation exercise by clinical team (either a spot check or a check of the full sample) to ensure that the sampling criteria has been followed and key that everyone has a confirmed diagnosis of cancer (rather than holding codes and so on). For trusts that have a large sample of patients, this activity can take time so it needs to be factored into the timetable.

The Picker Institute suggested looking into treatment types as an alternative to diagnosis to identify groups, if required. Free-text questions to ask patients to specify their cancer diagnosis prove difficult to validate, as patients with ongoing or metastatic cancer diagnoses may be unsure of what to document on the questionnaire.

During fieldwork, the Picker Institute noted that they get phone calls and emails to the helpline from around 100 people, notifying them that they do not have cancer and wanting to know why they have received the survey. There is a process in place for investigating these cases to ensure that not only can the individual patients be followed up with quickly but so that any potentially sampling issues are identified. In the majority of cases, the patients do have cancer (rather than there being errors in sampling) and they have just not recognised their diagnosis as such (for example, a patient could have a very low-grade cancer or the terminology used when communicating the diagnosis was not understood (especially if the word cancer was not explicitly used).

The process for investigating ‘no cancer’ cases tends to be that if they get more than one reporting case, the Picker Institute puts their mailings on hold until they have been investigated (just in case the trust has sampled incorrectly). Due to these types of calls (and really generally for a cancer survey) it is important that call handlers of the helpline are fully briefed on the sensitivities and how to respond.

The ability to run death checks throughout fieldwork is also important. The day before each mailing, the Picker Institute runs a death check to ensure that they remove any patient that has unfortunately died. This is to, as much as is possible, stop a mailing being received by a member of the deceased’s family.

Timing of the survey is also important. Fieldwork for the CPES has typically spanned the Christmas period. It was noted that the mailing dates before and after Christmas are strategically placed so that they do not fall too close to Christmas as its recognised that this can be emotionally upsetting for people. Avoiding this period for fieldwork would be recommended.

Australia – New South Wales

Background

Data on the incidence of cancer is collected by state and territory population-based cancer registries (PBCRs). This data is aggregated at a national level and is published by the Australian Institute of Health and Welfare.[41] New South Wales (NSW) published a report in 2010 on cancer incidence and mortality, noting that cancer incidence and mortality increased between 2009 and 2010, with a current lifetime risk of developing cancer by the age of 85 years old being 1 in 2 for men and 1 in 3 for women, with 39,484 new cases diagnosed in 2010.[42] The report also stipulates the cancer incidence and mortality of NSW Aboriginal and Non-Aboriginal peoples, noting that the rate of cancer incidence is 1.4 times higher amongst Aboriginal populations.[42]

Data on cancer patient experiences are regularly collected by certain jurisdictions in Australia. The Bureau of Health Information (BHI) is the statutory agency responsible for reporting the performance of New South Wales Health.[18]

The New South Wales Patient Survey Program oversees a suite of surveys that collect patient experiences across NSW. The survey program began sampling patients in NSW public health facilities from 2007 onwards. Up to mid-2012, the program was coordinated by the NSW Ministry of Health (Ministry) and questionnaires were provided under licence by National Research Corporation (NRC) Picker.[43] Responsibility for the NSW Patient Survey Program was transferred from the Ministry to the Bureau of Health Information (BHI) in 2012. The BHI was established by the NSW Government to provide an independent report on the performance of the health system. BHI has a contract with Ipsos, a survey vendor to develop and administer the surveys and support data collection, while BHI conducts all survey analysis.[44]

The Outpatient Cancer Clinics Survey (OCCS) reports and reflect the experiences of patients across 49 outpatient cancer clinics in New South Wales each year. The OCCS was reviewed in 2022, with a narrative summary report published by The Sax Institute. The survey was reviewed in the context of international surveys and how the current survey aligns with the NSW cancer strategy, ‘NSW Cancer Plan 2022-2027’.[18]

Objective

The aim of the NSW Patient Survey Program is to measure and report on patients’ experiences in public healthcare facilities in NSW on behalf of the Ministry and local health districts. The state survey is guided by the BHI’s Strategic Plan 2023-2026, which ensures that all patient surveys maximise benefits to patients and deliver value for the NSW health system.[45] The NSW Patient Survey Program was designed to strengthen accountability and inform improvements in quality of care delivered to patients. The surveys provide a source for reliable and fair benchmarks and trend analysis across NSW, at a local health district, hospital level and state level for patient experience performance. Patient experience survey results can be used to track strategic priorities identified in strategic plans for improving overall patient experiences, relative to policy initiatives. The survey enables reliable analysis of patient experience across different population groups, including Aboriginal people and people from linguistically diverse communities or regional areas. The surveys also provide a source for key performance indicators for local health districts that are used in their performance management processes. The Outpatient Cancer Clinics Survey (OCCS) asks people who have attended a public outpatient cancer clinic to share their experiences of care. Results are published to ensure that patients' voices drive improvements in both experiences and outcomes of care.

Governance arrangements

The Bureau of Health Information (BHI) manages the survey program on behalf of NSW health and local health districts (LHDs). BHI follows all relevant state and federal laws with respect to patient privacy, including the Health Records Information Privacy Act 2002, Health Privacy Principles and Privacy and Personal Information Act 1998. These Acts regulate the collection, use, storage and disclosure of personal information.[46] The Health Record and Information Privacy Act 2002 allows NSW Health to release appropriate information for the purpose of conducting a patient experience survey. The Privacy Act also provides disclosure of information without consent from the person, when there is a justifiable secondary purpose for using the information.[23]

The current survey vendor is Ipsos Public Affairs, contracted from 2022-2025. Using the information provided, Ipsos are responsible for the preparation of survey materials, packing and distribution of materials, data entry, processing and provision of a dataset to BHI. NSW Health randomly selects the patients who are sent the survey, and Ipsos mail the survey to selected prospective respondents. Ipsos receive the following information from the survey population:

- Survey type
- Hospital or local health district attended
- Title, first and surname of patient
- Address, including postcode.

Once fieldwork is completed, all information is deleted. No patient identifiable information is published, this is achieved by grouping responses together and defining a suppression limit. The suppression limit is fewer than 30 responses to any single question.[47]

The survey

The typical BHI survey development process includes a review of sampling methodology, engagement of stakeholders, development of the questionnaire through patient focus groups, patient comments from previous surveys, literature reviews, advisory committee meetings of subject matter experts and consultation with partner organisations. The OCCS development process differed from the standardised process, due to a tighter timetable, in which patient focus groups and cognitive testing was not conducted.[48] BHI and Cancer Institute NSW conducted a review of key literature, including quality standards and policy documents, key stakeholder engagement and questionnaire refinement based on analysis of previous surveys. The researchers also selected survey questions from validated questionnaires in other jurisdictions, namely the NHS Cancer Patient Experience Survey.

The initial OCCS went through the following developmental stages, review of key literature including policy documents and quality standards. Key stakeholder engagement, statistical analysis of previous survey years and questionnaire refinement, which was co-ordinated between staff in BHI, Ipsos and The Cancer Institute NSW. The most recent iteration of the survey, The Outpatient Cancer Clinics Survey 2023 was undertaken as part of the NSW Patient Survey Program. The survey was designed in collaboration with the Cancer Institute NSW and BHI conducted all analyses.[47]

The finalised survey from 2015 included 14 themes, across 77 questions. There were two free-text questions, querying the best part of care received at the cancer clinic, and an area of care that requires improvement. Of the closed-ended questions, 10 refer to socio-demographic characteristics of the patient. The remaining 65 quantitative questions are broken up into 14 themes across the cancer care continuum, from initial diagnosis, to attending the clinic and overall treatment experiences.[48]

A module consisting of seven questions about virtual care appointments in a hospital or outpatient clinic was added to the Outpatient Cancer Clinics Survey 2021. The module asks any patients who had appointments over the telephone or by video call, rather than in person, to complete it. Through this module, the 2021 survey provides insights in relation to patients' virtual encounters with a hospital or outpatient clinic, including all their experiences of virtual care over the past 12 months.

The most recently published survey in 2023, had further content changes including the addition of a module regarding virtual care received from your GP. Questions included the quality and quantity of virtual calls with a person’s GP, and whether these appointments improved the co-ordination of care between outpatient clinics and primary care. Additionally, following the 2021 survey, the sampling month was changed from November to January, with sampling occurring in early 2023.[44]

The 2023 survey contained 90 questions over 14 themes, including two free-text questions. These qualitative questions focused on what patients perceived as the best part of their care, and what area of care needed improvement. All free-text comments were provided to local health districts to inform local improvements.

Response options varied from a 3 to 5 point Likert scale, using the phrases 'Yes, definitely', 'Yes to some extent' and 'No' most commonly.

The sample

The survey included 43 NSW facilities, including three private facilities that deliver care to public patients.[44]

The survey questionnaire is sent to eligible patients who received services at outpatient cancer clinics.

Inclusion criteria: The eligible population (cancer and non-cancer) included patients aged 18+ years who had an appointment (in-person or virtual) at one of the included NSW outpatient cancer clinics during the defined survey month, with the most recent survey based on care received in January 2023. The date of attendance was used to define eligible patients to participate in the survey. Where patients had multiple visits in that month, they were sampled based on their most recent visit. Patients who had virtual care appointments (held over the phone or by video call) were included, as well as patients who received in-person care, to adapt to the changes in care delivery during the COVID-19 pandemic.

Exclusion criteria: Multidisciplinary case conferences where the patient was not present were excluded. The sampling frame was checked against the following criteria to identify patients for exclusion:

- invalid address (including those with addresses listed as hotels, motels, nursing homes, community services, army quarters, jails and unknown)
- invalid name (including 'twin', 'baby of')
- invalid date of birth
- on the 'do not contact' list
- sampled in the previous six months for any BHI patient survey
- mode of separation of death for a subsequent admission to hospital
- recorded as deceased according to the NSW Registry of Birth Deaths & Marriages and or activity and performance reporting data collections, prior to the sample being provided to the survey vendor.

The sampling frame is passed through a series of exclusion checks to identify patients to be excluded, facilities and outpatient clinics undergo a similar exclusion process. Facilities are only included in the survey if there are a minimum of 50 patients eligible for sampling, or where the inclusion of the facility would assist in the reporting of LHD-level results. Hospitals are excluded if they are unlikely to achieve at least 30 responses. In 2023, clinics in 43 facilities were selected for sampling.[44]

A maximum of 700 patients per facility were sampled. All patients attending facilities which had fewer than this target number across all included clinics were invited to undertake the survey (census sampling), while random sampling occurred in facilities with more than 700 patients, with selection stratified by clinic.[44] The sampling frame for the Outpatient Cancer Clinics Survey 2023 was based on data in the Ministry's Enterprise Data Warehouse for Analysis Reporting and Decisions (EDWARD) non-admitted patient (NAP) activity data.[44]

Any question must have a minimum of 30 respondents at the reporting level (facility, LHD or NSW) for results to be reported. This is to ensure that patient confidentiality and privacy are protected. If there is fewer than 30 respondents, the results were suppressed.[44]

Structure

BHI also reports the results by specific groups, as follows:

- age group
- gender
- education level
- language spoken at home
- rurality of facility – urban, rural
- cancer type
- Longstanding health condition: 'had condition/s', 'none reported.

Facilities are classified as either urban or rural using the Accessibility and Remoteness Index of Australia, which is used by the Australian Bureau of Statistics.[44]

In Australia, patients switch their cancer care a number of times during their cancer journey. BHI felt they would not adequately capture the whole cancer journey without including private facilities.

Distribution and collection

NSW Health randomly selects the patients who are sent the survey questionnaire. Using patient information supplied by the NSW Health, Ipsos mails surveys to people who have recently received healthcare services in NSW.[46]

Selected patients are invited to complete the questionnaire by either returning the hard-copy questionnaire or by submitting an online response. For all surveys from the NSW Patient Survey Program, BHI selects a representative sample of patients to participate in each of its surveys. An invitation, reminder letter and questionnaire are posted to patients approximately one to three months after their hospital or clinic visit. This delay allows for them to reflect on their experiences and to answer questions about their experience after they have completed their care.

Ipsos Public Affairs Ltd is contracted by BHI to conduct the fieldwork for the survey. This ensures the privacy of patients is maintained. Through the sampling process, NSW Health randomly selects the patients and sends information to Ipsos for the purpose of mailing. The following patient information is provided to Ipsos:

- Survey type, for example outpatient, emergency patient
- Hospital attended
- Local health district of hospital attended
- Title, first name and surname of patient
- Unit/street number; street/road name; suburb; state and postcode.

A first reminder letter is sent to all patients after the initial survey pack, with a final reminder letter in the subsequent month if no response is received. This aims to improve response rates. Any resultant data is then anonymised and undergoes quality assurance checks before being securely transferred to BHI servers for processes which are password protected with restricted access to authorised staff only.

BHI are limited in the information provided, as the survey is based on the out-patient setting only. As a result, the survey is unable to differentiate between patients that received care in these clinics for cancer related treatment or not, as diagnostic information is not available.

There is a lag of six-to-eight weeks between the survey sample month and distribution of the survey. This is to draw the sample using a centralised data system, which is conducted by the Ministry of Health.

Communication

BHI historically had a communication plan for all surveys, including dissemination of posters to participating facilities, to promote the organisation and the survey. Such communication plans are not routinely conducted at present, as patients are not census sampled, so many people attending clinics will not be invited to participate in the survey. BHI will be reviewing communication plans in the future. Potential communication plans include advertising the survey at self-check in kiosks in the outpatient clinics.

However, it is noted by BHI that cancer patients tend to be very engaged in the surveys, as they want to give back to health and social care services providing cancer care.

Response rate

For the Outpatient Cancer Clinic Survey 2023, of the eligible population of 37,142 people, 21,026 or 57% were selected for sampling. Of this cohort, 20,870 or 99% of the sampling population were mailed the survey. Ipsos received 8,280 responses, which infers a 40% response rate.

In 2023, clinics in 43 facilities were selected for sampling. Of the patients attending outpatient cancer clinics for treatment for reasons other than cancer, such as haematological-related services which are unrelated to blood cancers, represented 18% of the total respondents.[44]

Customer support lines

For the duration of the fieldwork period, prospective respondents to the survey can contact Ipsos on a free-phone survey helpline, between Monday-Friday, 9am – 8pm. There is also an option to email patient queries. Patients can request to see their responses or request for their information to be deleted.

It was noted that the phone line receives significant activity during the sampling period, typically regarding the clinic name noted on the cover letter of the survey. Respondents may have another name for the outpatient clinic. Other calls relate to patients having passed away in the interim period between survey sampling period and distribution of the survey. Death checks are completed before distributing each reminder of the survey, but unfortunately death registry data is not updated daily, so these calls still occur.

The highest proportion of calls occur after the reminder letters are sent out. Patients call advising they have already completed the survey and was to make sure it has been received. Otherwise, patients call advising they are too unwell to complete the survey. When this occurs, the patient is added to the ‘do not contact’ list for future surveys.

Outputs

The results of the survey are reported annually. Public reports highlight key NSW level findings in relation to patients' experiences across a range of aspects of care. There are annual BHI reports on the BHI Data Portal, and data analysis is provided by the Cancer Institute NSW for their 'Reporting for Better Cancer Outcomes Program'.[49] Results are available for individual facilities, local health districts and NSW at a state level.

The results available on the BHI data portal include five-year trends to inform trends at a NSW, local health district and hospital level for patient experience performance. There are supplementary data tables available and technical supplement detailing the survey methodology. BHI does not receive any confidential patient information and only publishes aggregated data and statistics. Any question must have a minimum of 30 respondents to be reported. This ensures that reliable estimates can be calculated. When the number of respondents is below 30, results are suppressed. These suppressed results still contribute to information provided at a NSW-level and LHD-level.

Data can be made available to researchers for secondary research through secure research environments.

In 2023, BHI has introduced a new statistical approach to support fairer assessment of hospital performance based on patient experience measures and to improve precision when flagging hospital performance as significantly higher (green) or significantly lower (red) than the NSW result in the snapshot report and supplementary data tables.[44]

The reporting of private facilities is conducted, as private facilities in NSW are contracted to provide services to public patients. Private centres can differ in administrative and organisational arrangements provided when compared to public facilities. Although they are contracted out to provide public healthcare, they are not governed by LHDs. It is therefore not advised to compare results from these facilities with public facilities within the survey. The private hospital results are also not included in LHD-level results, but are included in the overall NSW results.[44]

BHI also reports the results of specific groups, including age, gender, educational level, primary language spoken, rurality of cancer facility; broken up by urban or rural definition, cancer type and longstanding health conditions.

The questionnaire

The following themes were included in the survey design:

- Appointment at the clinic
- The physical environment

- The health professionals
- Planning your care
- Your care and treatment
- Respectful care
- Complications
- Smoking behaviour
- Overall care
- Payments for your care
- About your health
- Virtual care
- GP virtual care
- About you.

As BHI do not have diagnostic information available, patients are required to self-report their diagnosis on the questionnaire. BHI had clinical input from their funding partner, the Cancer Institute when refining the cancer-related tumour groups to include in the survey. The survey also requires patients to document whether it is the first time they have been diagnosed with cancer and how the current cancer diagnosis has responded to treatment. Patients included in the survey can note if they were first diagnosed with cancer within the past three months or greater than five years ago. They can also report if they have not received any treatment for their condition. The following cancer tumour groups were included in the survey:

Table 1: Breakdown of tumour group selection

Prostate	Breast	Bowel (colon, rectum, colorectal)	Lung	Skin / melanoma	Upper gastrointestinal
Gynaecological	Brain or spinal column	Head and neck	Blood (bone marrow)	Other (bone, mesothelioma, thyroid)	The type of cancer is not yet known

The inclusion of financial expenses as a theme is included in the survey. This theme covers a broad range of financial out-of-pocket expenses, including medication, accommodation, travelling, fuel, and parking expenses, which would apply to all patients, regardless of public or private care.

The survey also includes questions regarding the physical environment within each clinic, whether waiting and treatment rooms were comfortable. Within the theme of health professionals, questions included the co-ordination of medical history information between colleagues, their ability to work as a team and whether sufficient care was provided to discuss any worries or fears.

The theme of virtual care was addressed in the 2021 survey, with questions extending to virtual care in the GP practice in 2023.

Socio-demographic questions in the survey include: age, gender, education level, language spoken, requirement of translator and pre-existing co-morbidities.

Key lessons learned and recommendations

The cohort of participants involved in the OCCS is generally engaged, with strong response rates. Experiences with care and treatment are generally positive, and some of the highest across the BHI's suite of patient surveys.

Private hospitals with a high proportion of public patient referrals are included in the survey. Initially, BHI anticipated only surveying the public patients in private clinics, but this was too complex to facilitate. Therefore, all patients treated in the three designated private hospitals were randomly selected to be surveyed. Buy-in for private hospital engagement is very good and positive. Performance scores have been better in private than public hospitals, particularly when considering cleanliness, waiting areas and discharge or care planning. Private hospitals can use this for marketing purposes. In Australia, patients switch their cancer care a number of times during their cancer journey. BHI felt they are not adequately capturing the whole cancer journey if not including private facilities.

BHI have conducted the OCCS annually, with minor changes typically made between iterations. However, in 2023, a major review of the survey contents was conducted. The survey was reduced in length with significant changes to content. At the time of writing, the updated questionnaire was undergoing cognitive testing, with a draft questionnaire available later in 2024.

With regards to the sampling cohort, BHI cannot identify cancer patients, as services included in the survey are in the outpatient setting. The sampling structure doesn't allow for only cancer patients to be identified and included. BHI only receive an administrative data set, with no access to a patient's diagnosis. Therefore, survey samples are strongly guided by the clinics. The clinics use random sampling, but around 20% of patients do not have cancer. Therefore, BHI have to tailor their survey to include cancer and non-cancer patients. The 2024 survey will include a cancer specific module asking a range of questions about patient's experience with cancer care across different services. Further information will be provided in early 2024 on this revised survey, including recommendations.

The OCCS do not include questions on survivorship yet, as the survey cannot differentiate where a patient is in their cancer journey, or if a patient has had cancer or not. Therefore, for many patients completing the survey, survivorship may not be applicable. Instead, the survey has focused on additional elements that impact experience of cancer services, such as the financial impact of cancer on patients, car park facilities and other environmental factors. BHI note that the results of experience surveys to date have been very positive annually. It is therefore important to reflect and ask whether questions are being selected that will identify areas that impact a patients experience.

There is a drive towards a more online format for the survey in the future, as invested stakeholders are interested in moving more online, not only for financial purposes, but for the reporting of more timely data. At the moment, BHI send surveys by post, with a unique QR code to complete the survey online. Uptake for online survey is usually 40-50% of respondents.

Switzerland

Background

Healthcare in Switzerland is universal and highly decentralised, with states providing a key role in daily operations. Healthcare is regulated by federal law. It is not tax-based or funded by employers, but is paid for through a mandatory health insurance scheme by Swiss residents with an annual cap for all services. Basic health and accident insurance covers a range of treatments, but many people supplement healthcare with additional private insurance.[50]

At the time of writing, the most recently published cancer incidence data from Switzerland is based on the latest available data from 2013 to 2017. Newly diagnosed annual cancer incidence is reported within this period to be approximately 23,100 males and 19,650 females. Demographic changes, including an ageing population, are noted as key contributors to the reported increasing incidence. Cancer mortality rates have deceased amongst both men and women, as noted in the third Swiss Cancer Report 2021, which the Federal Statistical Office (FSO), the National Agency for Cancer Registration (NACR) and the Childhood Cancer Registry (NCCR) have jointly compiled.[51]

The first cancer patient experience survey was conducted in 2018, amongst French-speaking hospitals in Switzerland (SCAPE-1).[27] Subsequently, the second iteration of the survey, SCAPE-2 extended its scope in 2021 to include French and German speaking hospital areas in Switzerland. A third iteration of the survey, SCAPE-CH, was conducted in 2023, which extended further to Italian-speaking areas. The SCAPE questionnaire is based on the NHS Cancer Patient Experience Survey, with adaptions to fit the Swiss context.[27] The survey has been adapted into four languages thus far, French, German, Italian and English.

Objective

The SCAPE survey aims to collect the care experiences of people with cancer to assess the extent to which the health system meets their needs.

The survey results provide an insight into the experiences of cancer care and can guide the development and implementation of interventions and models of care to improve cancer care by identifying areas of care that are less well evaluated by patients.

Objectives set for each iteration of the survey are noted below:

SCAPE-1

- Objective 1: to describe care experiences of people affected by one of the six most common cancers in Switzerland (that is, breast, prostate, lung, colon, skin, or blood cancer) treated or followed in four hospitals in the French-speaking Switzerland
- Objective 2: to explore the variation of care experiences according to the type of cancer
- Objective 3: to validate the questionnaire in French

SCAPE-2

- Objective 1: to describe care experiences of cancer patients (all types) treated or followed up in eight hospitals in the French and German-speaking Switzerland
- Objective 2: to assess the feasibility of a national survey
- Objective 3: to explore the variation of care experiences according to language region, hospital and type of cancer
- Objective 4: to validate the questionnaire in French and German

SCAPE-CH

- Objective 1: to describe care experiences of people with cancer (all types) treated or followed up in twenty-one oncology centres in the French, German and Italian-speaking Switzerland
- Objective 2: to have a complete view of the quality of cancer care in Switzerland
- Objective 3: to validate the questionnaire in Italian
- Objective 4: to stimulate the development of continuous quality improvement initiatives in cancer care

Governance arrangements

The survey is conducted by Unisanté, University Center for General Medicine and Public Health, in partnership with the University Institute for Care Training and Research (IUFRS), in Lausanne.[27]

The survey is partially funded by the Federal Commission for Quality (CFQ) and partially by the participating centres. The CFQ is an independent extra-parliamentary commission. It supports the Federal Council in developing the quality of medical services within the framework of the Federal Health Insurance Act.[52] Each participating hospital funds 50% of the survey, typically covering paper costs.

Ethical approval is sought by Unisanté from their ethics committee. The Ethics committee on research involving humans of Canton of Vaud (CER-VD), which issues authorisation for research involving humans within the scope of Swiss law on Human Research approved the study.[53] Unisanté do not have ethical approval to receive direct patient contact information. Hospitals therefore recruit patients and send survey packs from each participating hospital. All patient information (name, address, DOB and contact number) is not distributed to Unisanté. Unisanté provide survey packs to each hospital.

To ensure confidentiality of data, a specific coding procedure is applied to patient datasets. Personal information (name, address, date of birth and patient number) is replaced by a five-digit code. The data collected within the questionnaire contains this five-digit code, not personal identifiable data. The key to the coding data is kept within a password-protected document, which is only accessible to the local co-ordinator of the participating hospital. Each participating hospital mails the questionnaire to their selected database of eligible patients identified for the survey. The survey pack is sent to each patient's home.

The survey stipulates that the questionnaire must be completed by the person named on the invitation letter. There is a question within the questionnaire asking whether a patient required help filling out the questionnaire. Answers completed by friends or relatives need to be completed from the perspective of the patient.

The survey

For the initial SCAPE survey, the diagnostic inclusion criteria was limited to six cancer types that have high prevalence in Switzerland. Patients selected for the survey were decided by each participating hospital through a manual review of patient databases. The initial SCAPE survey was based on the 2016 NHS Cancer Patient Experience Survey (CPES), which was translated to French and adapted. The survey consisted of 94 closed questions, broken down into three sections; experiences of care, health status and socio-demographic characteristics. The first section based on the CPES included 14 themes related to the patient cancer pathway, from cancer diagnosis to follow-up care in the community. Most questions followed a 4-5 point Likert scale response, with 10 questions requiring a binary response. Areas omitted from the NHS survey included ‘having a contact person’, as this navigator role has not been implemented in Swiss hospitals. A patient partner was involved in the initial survey design and research process. They participated in pre-testing of the questionnaire and drafting the materials sent to patients when distributing the questionnaire.

The second iteration of the survey (SCAPE-2) extended its scope to include all cancer diagnoses, and amended the survey contents to include questions regarding the COVID-19 pandemic. The second iteration of the survey consisted of 128 questions, covering 18 themes, with four open-ended questions.

The third iteration (SCAPE-CH) uses a shorter version of the questionnaire used in SCAPE-2. Questions regarding the COVID-19 pandemic were removed and questions concerning after-care were also added, which is similar to the most recent survey changes to the CPES survey.

The survey uses a mixed methods approach and can be completed on paper or online, using a unique QR code. The SCAPE-CH survey is anticipated to take 20-30 minutes to complete.

The sample

For SCAPE-CH eligible respondents were selected by each hospital using random sampling. Nine hundred patients per hospital were chosen for sampling.

Inclusion criteria:

For the SCAPE-2 survey, adult patients (18 years old +) were included in the sampling. Patients could be diagnosed with any type of cancer, and must have been admitted or seen at one of the participating hospitals as an outpatient or inpatient, for a cancer-related treatment, care or follow-up, within the survey period. The survey period selected was a six month time period, between January 1 and June 30 2021. A similar inclusion criteria was selected for the SCAPE-CH survey, including Italian-speaking regions, with three versions of the survey, in French, German and Italian.

The survey includes all cancer related procedures, biopsy, tumour removal, mastectomy reconstruction, port-a-cath insertion/removal. The survey outlines sections of the survey that are asking questions about a patient’s most recent experience in the hospital or more general care provided over the previous 12 months. If a patient has only received a biopsy diagnosis by the time of survey distribution, then the patient will only complete the survey areas that are applicable to them.

Exclusion criteria:

As the SCAPE survey does not have access patients' ICD codes, patients are required to self-report their cancer diagnosis on the questionnaire, which can be difficult in the case of synchronous primaries, or patients with advanced disease. The survey specifies for patients to note their most recent diagnosis. Options are also provided for patients to note the extent of their disease, giving the options for primary disease, recurrence, or secondary cancers that were not related to their primary diagnosis. Unisanté acknowledges that there is no way of clarifying that the information provided is valid, and is noted as a limitation of self-reported information. However, the literature argues that self-reports of cancer diagnosis and treatments have been used extensively in clinical and epidemiological studies, and are reported to be both valid and sensitive.[54, 55, 56]

Patients document their cancer diagnosis in the survey, by selecting one of the following pre-determined cancer types listed under the following groups:

Table 2: Breakdown of Cancer Groups

Mouth/throat	Brain	Colon/rectum/colorectal	Stomach	Leukaemia
Melanoma	Myeloma	Lung/bronchus/trachea	Oesophagus	Ovary
Prostate	Testicles	Thyroid	Uterus	Bladder
Breast	Kidney	Liver	Lymphoma	Pancreas

Distribution and collection

The SCAPE-CH questionnaire was sent to approximately 15,000 people who were followed-up or treated between January 1 and June 30, 2023 in participating oncology centres, based on administrative data from participating centres. The survey was distributed in September 2023, to the patient's home. A reminder letter was posted to non-response participants in October 2023.

Eligible individuals received the invitation letter, the information sheet, the paper questionnaire and a pre-stamped return envelope. The invitation letter contains the ID number and the code needed to complete the questionnaire online. If a patient does not wish to participate in the survey, they can send an email indicating their unique survey number found on the invitation letter, call the central survey hotline or check the box 'I do not wish to participate in investigation SCAPE-CH' on the questionnaire.

In total, 22 hospitals agreed to participate in the most recent survey in 2023. There is no mandate for participation in the cancer survey, unlike other experience surveys in Switzerland, such as the inpatient survey. Both public and private hospitals participated in the SCAPE-CH survey.

As the survey is partially funded by the participating hospitals, one centre in Basel used an online-only format to distribute the survey to patients. This hospital had access to patient email addresses and had a culture of reporting Patient Reported Outcome Measures (PROMs) regularly.

Communication

Unisanté did not provide a communication plan, as no flyers or notices are distributed to hospitals in advance of the survey.

The survey uses inclusive language. The survey packs do not contain a cancer related logo on the stamped addressed envelope.

Death checks are conducted by participating hospitals. Database updates for death notices in Switzerland have a lag time of two to three months, therefore hospitals have to look through their own internal databases and local newspapers (in the case of small regional hospitals). In the invitation letter an apology is included to the family, if a patient has passed away and a survey has been sent out.

Response rate

For the SCAPE-2 survey, of the 6,873 patients invited to participate in the survey, across eight hospitals, 3,220 people completed and returned the questionnaire, yielding a 47% response rate. This was a higher response rate than the first iteration of the survey, of 44%. Response rates for the SCAPE-CH were not yet published at the time of writing.

Customer support lines

A central customer support line is provided by Unisanté, and the ethics committee recommend a local hotline is provided by each participating hospital. Both support lines provide cover Monday to Friday during the survey period.

Most of the calls received are related to non-cancer diagnosis. Patients seen for haematological concerns in the ambulatory setting (in a hospital) tend to be the largest cohort of individuals sent the survey with a non-cancer diagnosis. There is a manual review of all eligible patients, which is conducted by each hospital before sending out the survey, but inclusion of patients with non-cancer diagnosis still occur.

To mitigate the stress that patients experience if they incorrectly receive a survey, the survey can only be sent to patients between Monday and Thursday. No surveys are sent on a Friday, as there is no Freephone call cover over the weekend.

The ethics committee have also requested that each incidence of a non-cancer related phone call that is received, needs to be reported to the ethics committee for discussion and review. Unisanté do not have patient details, so any follow-up with the patient is conducted by the hospital in question.

Outputs

There is no national report published regarding outputs from the survey. Hospitals receive a local / individual hospital report.

The main results of the survey are presented on the survey website, in an aggregated and interactive form. Patients are also given the option to receive these results personally by email or post, which is indicated at the end of the questionnaire. Patients are asked to document their email address or name and address at the end of the survey, for results to be sent.

Participating centres also receive the results for their centre, with the overall results for all centres as a comparison.

Unisanté publish journal articles using data from the survey, which are published to inform quality improvements. Unisanté also analyse the open-ended data and send these back to individual hospitals.

The hospitals do not need to inform Unisanté of quality improvement initiatives. However, after the first iteration of the survey in 2018, a participating hospital implemented a quality improvement initiative, to advise patients receiving a cancer diagnosis to bring a support person to accompany them, based on qualitative feedback from the survey.

The suppression guidelines are limited to 20 responses. If there are less than 20 responses from any question, the results are suppressed for confidentiality.

The questionnaire

The SCAPE-2 questionnaire was based on the NHS Cancer Patient Experience Survey. The survey was edited to fit the Swiss context, and translated into French and German. The second iteration of the survey consisted of 128 questions, covering 18 themes, with four open-ended questions. Quantitative questions followed a Likert scale, following a 4-5 scale item.

The themes identified in the survey are as follows:

- Consultation with a family doctor (GP)
- Diagnostic examination
- Announcement of the illness
- Decision on the best treatment
- Operation

- Care and treatment in hospital (duration of more than 24 hours)
- Ambulatory care and treatment, day-case hospital care (duration of less than 24 hours)
- Radiotherapy and chemotherapy
- Nursing consultation
- Home care and support
- Follow-up after cancer treatment
- Care at your GP
- Support for people with cancer
- All of your care
- COVID-19 pandemic - Tele-consultations
- State of your health
- Personal information
- Financial impact of cancer.

With respect to the patient condition specific questions and socio-demographic questions, the following questions are asked:

- Gender
- Age
- Nationality
- Primary language spoken
- Marital status
- Living situation
- Level of education
- Current professional occupation
- Chronic health condition
- Health Literacy
- Overall health
- Difficulty paying household bills in the previous 12 month period?
- Over the past 12 months have you forgone treatments due to financial cost?

In the survey, there is also an additional five questions relating to the financial impact of cancer on the respondent, including impact on job security, family having to take unpaid leave to provide support and whether the patient needed to take out loans to support cancer costs. As universal healthcare is provided in Switzerland through a mandatory health insurance capacity in Switzerland, this is independent of income, in which lower income families may be disproportionately impacted by healthcare costs. The priority of financial implications due to healthcare costs therefore may be deemed more important to patients, than in countries where care is provided to the general public by general taxation. The Organisation for Economic

Cooperation and Development (OECD) reports that Switzerland has the highest rate of out-of-pocket expenditure within OECD countries.[53]

The survey also uses the FACT-G7 (Functional Assessment of Cancer Therapy – General 7 Item) questionnaire, a previously validated quality of life measure, to evaluate participant health status.[57]

The survey asks patients to note all types of treatment they received for their cancer diagnosis, with options including the following:

Table 3: Breakdown of treatment procedures

Surgery	Chemotherapy	Radiotherapy	Hormone Therapy	Immunotherapy
Targeted Therapy	Bone marrow or stem cell transplant	Other	I have not yet received treatment	I don't know

They also ask patients about any complementary therapies they have used, including aromatherapy, Chinese medicine, homeopathy, meditation, kinesiology, osteopathy or other.

Treatment-related questions include whether the patient has had radiotherapy or chemotherapy within the past 12 months in the particular hospital that distributed the survey. The survey asks if the patient received all the information they require about their treatment, and once treatment commenced, that they were provided with understandable information and results when required. They are also asked if they were provided with practical advice to manage side effects during treatment.

Within the theme of 'All of your care', the survey addresses the integration of cancer care service provisions, asking patients if members of the multi-disciplinary team worked well together to provide the best possible care. They also query if the patient received a written care plan and whether information provided was ever confusing or contradictory. The survey addresses the integration of services by asking patients to recall if their medical records were unavailable at the time of a treatment appointment, or if test results were ever repeated unnecessarily. The survey also addresses participation in clinical trials, evaluating whether participation in a trial was offered by health professionals, or if they participated in a trial within the past 12 months.

The SCAPE-2 survey also has four free-text questions, asking if there was any aspect of care that the patient particularly appreciated during their cancer treatment, if there was anything that could be improved and any other additional comments.

Key lessons learned and recommendations

Unisanté recommend the importance of providing positive feedback to participating hospitals, particularly the free-text questions.

Self-reported diagnosis is a limitation that needs to be acknowledged, when there is no access to ICD codes.

As there are patients that receive the survey that have not been diagnosed with cancer, Unisanté only allow for the survey to be distributed between Monday – Thursday, to allow for patients that have incorrectly received the survey to contact the helpline on a Friday. They provide both a central and local helpline, that patients can contact the hospital directly, if they chose to do so. There can be errors in coding the diagnosis in hospitals; haematology ambulatory clinics in hospitals account for largest cohort of non-cancer diagnosis patients included in the survey. There is a manual review of all patients included, but some are still missed. This should be considered when conducting a cancer care survey.

Death checks are important. The national database has a two to three month lag in updating information. Internal databases from local hospitals are reliant on hospital staff being aware of a death occurring. Include an apology in the invitation letter, if a family are sent a survey and their loved one has passed in the interim period.

Not all hospitals provide the same approach to distributing the survey, with the hospital in Basel proceeding with an online only methodology for SCAPE-CH. Unisanté advises using a mixed-mode approach for sending the survey, paper and online. Although the percentage of online respondents has increased in recent surveys, two methods of response are still recommended.

It was also advised that having a clearly defined survey scope will greatly reduce difficulties associated with the survey distribution. For example, including patients that have been diagnosed a long time ago, inclusion of all cancer types and procedures.

United States of America

Background

In the USA, there are approximately 1.8 million new cancer cases diagnosed annually, with over 600,000 deaths. The most recently published rate of cancer incidence is 442.4 per 100,000 men and women annually, based on data published by the National Cancer Institute (NCI) from the period of 2013-2017. [58] NCI's surveillance, epidemiology and end results (SEER) programme collects and publishes cancer incidence and survival data from population-based cancer registries that cover approximately 35% of the US population.

Healthcare in the USA is primarily covered by private healthcare facilities, where most Americans receive their coverage from private health insurance. There are two major federal government health insurance programmes, Medicaid and Medicare, which offer coverage for seniors, those with certain disabilities, and those with poorer economic status.[59] The adoption of the Affordable Care Act in 2010 improved coverage of those uninsured by private health insurance by extending the eligibility criteria for Medicaid.[59]

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) is an Agency for Healthcare Research and Quality (AHRQ) programme that began in 1995. The CAHPS programme is a federal initiative, sponsored by the Department of Health and Human Services. CAHPS was established to improve the scientific understanding of patient's experience within healthcare in order to advance the delivery of safe, patient-centred care.

Each CAHPS survey follows a similar development process, involving input from patients and key stakeholders. The survey development process includes literature reviews, focus groups with patients, cognitive testing of survey questions and testing of labels for CAHPS measures that are reported to patients. Finally, field testing is conducted to ensure that all surveys generate reliable and valid data.[14]

The AHRQ released the CAHPS Cancer Care Survey in 2016. The survey was developed by the American Institutes for Research and the Mayo Clinic, with funding provided by the AHRQ, the Outcomes Research Branch of the NCI and the California Health Care Foundation.[60]

Objective

The primary purpose of the CAHPS Cancer Care Survey is to support cancer centres, hospitals and healthcare systems to improve their patient-centeredness, concerning cancer care. The information gathered from the survey can also inform decisions made by accrediting organisations and payers of healthcare, including insurance providers, patients and their families. The CAHPS Cancer Care Survey was designed with a focus on patient experience, rather than satisfaction.[14]

The current objectives of the CAHPS programme are as follows:

- Promote a deeper understanding of patient experiences across a number of healthcare settings.
- Develop standardised surveys that allow organisations to collect comparable data across institutions.
- Support the dissemination of results to improve healthcare quality
- Promote the support of patients making more informed decisions about their care.
- The surveys are used by health systems, GP practices, hospitals, and other healthcare providers to identify their own strengths, weaknesses and to help develop strategies for improving patients' experiences with care delivered in their facilities.

For many of the CAHPS surveys, the Centres for Medicare and Medicaid Services (CMS) is the organization that sponsors the national implementation of a survey. In some cases, such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), CMS also uses the survey scores along with other quality measures to help determine payment incentives, which reward high performers.[61] Additionally, to achieve CAHPS goals, AHRQ partner with research organisations with expertise in survey design, public reporting and quality improvement. Currently AHRQ work with academic bodies including the RAND Corporation and Yale University, School of Public Health.[62]

Governance arrangements

For many of the CAHPS surveys, the Center for Medicare and Medicaid Services (CMS) is the organisation that sponsors the national implementation of surveys, sets policies for survey administration, analyses the data and publishes results, both public and privately on their website. CMS have the authority to mandate hospitals to participate in care experience surveys, as is the case of the HCAHPS.

Implementation and reporting of the CAHPS Cancer Care survey is not mandatory. Therefore, buy-in for the survey has been limited, with a lot of infrastructure required to facilitate public reporting of survey findings. Currently there is no comparative database specifically for the CAHPS Cancer Care survey. The CAHPS Cancer Care survey measures were designed with comparability to measures from the CAHPS Clinician and Group Survey, to enable survey users to compare their scores between the Cancer Care Survey and CAHPS Clinician and Group Survey Database.

The survey

The CAHPS Cancer Care Survey was developed with a rigorous scientific process, as per the standard CAHPS survey development process. This included literature reviews, stakeholder focus groups, cognitive testing of survey questions and two-phase field testing to ensure the survey was reliable and valid. This was conducted by the American Institutes for Research (AIR) and the Mayo Clinic, with the support of additional funders. The first phase of the survey was sponsored by AHRQ's CAHPS programme and the National Cancer Institute (NCI). This project was conducted between October 2009 and March 2013. The initial version of the survey contained 73 questions, with 41 questions related to patient experiences over eight domains of cancer care, including access, communication, shared decision making, patient self-management and patient safety. This was drafted with input from stakeholders, and survey developers. Questions were cognitively tested after the draft survey was compiled.[14] The California Health Care Foundation (CHCF) also funded market research and provided financial support to fund the initial field test. The second phase was conducted between January 2014 and February 2016 and the CHCF also funded the second field test of the revised survey questions.[14]

Based on the results from the first field test and additional input from key stakeholders, revisions were made to the initial survey design, to align more with the format of the CAHPS Clinician and Group Survey. Testing was conducted with patients who had previously received cancer treatment and the survey was also translated into Spanish and field-tested in four cancer centres in California. Findings from the field test informed the finalisation of the survey design, which was approved by AHRQ in 2016.[14]

The survey consists of three independent survey instruments, specific to a particular treatment modality, radiation oncology, medical oncology or cancer surgery. All three instruments capture aspects of the experience of care that are important to patients who have received cancer treatment. The survey instruments include six dimensions of cancer care, evaluating the quality of the care received and the cancer care team. The survey can be used to compare cancer centres to benchmarks.

The finalised survey is a 73-item questionnaire, which includes an overall experience of care rating, on a 0-10 scale, with 41 questions related to six domains of cancer care. There is an additional supplementary module, which can be added to the survey, which includes 16 questions under three further domains of care. The care domains include:

- Communication
- Shared decision-making
- Exchanging information
- Access to care and information
- Coordination of care
- Supporting patient self-management

- Patient safety and adverse events
- Caregivers and family.

There are additional administrative and demographic items, which account for the remaining 16 questions.[14]

The CAHPS Cancer Care Survey was designed to assess experiences of adult patients with a confirmed diagnosis of cancer, that had cancer related treatment provided in either an outpatient or inpatient setting, including community oncology practices, cancer centres in community hospitals and comprehensive cancer centres at academic medical centres.

The sample

Inclusion criteria: The target population is defined as adult patients (aged 18 years and older) who have a confirmed diagnosis of cancer and received active treatment for that cancer in an outpatient or inpatient setting within the past six month period. Active treatment includes radiation therapy, drug therapy or cancer surgery. The patient can be at any point in the cancer care continuum, and the intent of the treatment can be curative or palliative. Patients could have been receiving treatment for any length of time, provided some treatment was delivered within the sampling period to be included in the sampling frame. While patients may receive care from multiple care providers, the survey and cover letter will direct respondents to consider the care received from the centre which they were sampled from.[64]

Exclusion criteria: Patients that received only a diagnosis, not treatment, a second opinion, follow-up care or hospice care at the specified cancer centre.

Patients with squamous cell and basal cell carcinoma were excluded.[14]

Breast carcinoma in situ (ICD-10 D05) (all treatment modalities), cervical carcinoma in situ (surgery treatment modality) are also excluded.[64]

The CAHPS team recommends using billing data to identify patients for inclusion in the sampling frame, as this information is most commonly available across cancer providers. It is recommended to use the following data:

- ICD-10 Clinical Modification (CM) diagnostic codes for malignant neoplasms
- ICD-10 Procedure Classification System (PCS) procedure codes for inpatient billing data
- Current Procedural Terminology (CPT) codes for Professional and Outpatient facility billing data.

It is noted that certain cancer drugs can be administered for non-cancer treatment, such as autoimmune diseases. The survey recommends including participants that have a chemotherapy or immunotherapy administration procedure code and be associated with a malignant neoplasm diagnosis code to avoid inclusion of such patients.[64]

In accordance with ICD codes, the following patient specific data is recommended to administer the survey to prospective respondents:

- Unique patient ID or medical record number
- Patient name
- Date of birth
- Gender
- Address (full address, ZIP code)
- Telephone number (where available)
- Email address (where available)
- Name and unique ID of site/medical group/provider where patient was seen
- Type of treatment from which patient was sampled.

The sample protocol relies on hospital administrative data, which is subject to information available in each respective hospital setting. As this can result in a risk of including patients that may not have been diagnosed with cancer, to mitigate the negative impact that this would cause, the first three survey questions are specifically designed to confirm survey eligibility. CAHPS cancer care team then advise to confirm eligibility of the sampling frame by conducting checks on a random subset of the sample prior to distribution of the survey. The CAHPS survey developers also recommend including acknowledgements in written materials sent to patients, and telephone scripts that note there is a risk of misidentifying cancer patients.

The use of tumour registries for sampling frames are not advised as they are limited to patients that have been newly diagnosed or are receiving their first course of treatment. This would exclude participants with recurrent disease or receiving subsequent lines of treatment. Also, tumour registry data in the United States typically have a six month time-lag in reporting cases. This would result in patient sampling that does not meet the eligibility criteria of receiving care within the previous six months.[64]

The CAHPS Cancer Care guidance document clearly specifies a sampling frame algorithm for eligible types of cancer surgery, broken into cancer types. [64]

Table 4: Sampling Frame Guidelines for Cancer Surgery Sites

Bladder	Brain	Breast	Cervical	Colon	Endometrial
Oesophagus	Liver	Lung	Pancreas	Rectum	Stomach

It is noted that in the case of participants that are inpatients during the sampling period, their date of service is often listed on billing data, but not date of discharge. It is recommended that hospitals use additional information available to minimise the risk of surveying a person that has not yet been discharged from hospital care.

The survey field period can range from six to 14 weeks, depending on time required to reach the desired response rate. The CAHPS cancer survey recommends that data collection should not be closed early, if target number of responses is reached. [64]

For the survey participants, patients are randomly selected to complete a particular survey module. If a patient has received both drug therapy and surgery, they would be randomly assigned one survey module to complete, and be removed from the other sampling frame. If a particular treatment modality has a smaller sampling size in a particular hospital, patients can be manually assigned to complete the survey pertaining to that treatment modality.

For hospitals that administer other CAHPS surveys, such as the mandated HCAHPS survey, CMS requests a waiting period of 51 days before conducting the fieldwork for the CAHPS Cancer Care survey.

Distribution and collection

The AHRQ CAHPS guidelines recommend administering web surveys in conjunction with postal or phone follow-up calls. AHRQ do not recommend administering surveys using an online forum only. This is due to the possibility of certain patient demographics having limited access to the internet, which can result in misrepresentation of the patient population [65]

The CAHPS Cancer Care Survey acknowledges that administrative errors in recruiting patients to participate in the survey can occur. In order to address this, three questions at the start of the survey are used to confirm eligibility. It is also recommended that a cover letter explaining the survey is included, as well as an email message or telephone script with specific language that mitigates the risk of emotional distress for patients that have been incorrectly identified. [64] CAHPS Cancer Care provide examples to incorporate into survey materials, including the following:

> “If you feel a survey about cancer care does not apply to you or that you were selected by mistake, please call 1-xxx-xxx-xxxx to talk to a representative at [Reporting Unit/Survey Vendor].”
>
> “If you feel a survey about cancer care does not apply to you or that you were selected by mistake, please disregard this survey.”[64]

Death checks are not routinely completed prior survey distribution. The survey does reach patients that have passed away, however the number of this cohort is small.

Both random sampling and census sampling are used for assigning each survey module to patients. Methods chosen are dependent on hospital sampling size frames for each treatment modality. A hospital must have 200 potential respondents in each treatment modality, if analysing results by modality. Alternatively, 200 completed questionnaires are required in total if reporting overall results at a faculty level.[64]

Communication

Although there is no defined communication plan for the CAHPS cancer care survey, the guidance document advises on certain recommendations when distributing a survey.[64]

For mail surveys, the guidance document recommends sending the questionnaire with a cover letter and a postage paid envelope. The guidance document recommends the letter is authored by a recognisable organisation to increase likelihood of patient response. The CAHPS survey has templates drafted and available online for participating hospitals to tailor their letters and emails in a consistent manner to the CAHPS Cancer Care Survey guidelines.

The survey recommends sending a postcard reminder to non-respondents 10 days after initial postage of the questionnaire. It is noted that some vendors prefer to send the first reminder to all participants, three to five days after the initial mailing of the survey. This postcard serves as a thank you to those that have already responded to the survey, and a reminder to those who have not. It is also recommended to send a second questionnaire in the second reminder, with a post-paid envelope three weeks after the first reminder postcard.[64]

The guidance document also notes that although the CAHPS Cancer Care Survey was not tested on telephone only approaches to conduct the survey, they noted that the survey can be modified for telephone administration. They note that it is important that interviewers are trained before they being interviewing, to mitigate bias in the survey. They also advise attempting to contact each respondent at least six times by telephone.

The CAHPS Cancer Care Survey does not recommend an email-only approach to conducting the survey. They recommend that regardless of response rate by email, a full mail or telephone protocol for non-respondents should be conducted following the email approach, to ensure all patients included in the sample have been provided with an opportunity to participate. For an email protocol, the guidance document recommends sending a reminder email to non-respondents 7-10 days following the initial email. A second reminder email can then be sent to those not responding two to three weeks after the initial email. It is advised to provide a final follow up to non-respondents via mail or telephone two-to-three weeks after the second reminder.

Response rate

As the survey has not been mandated by CMS for hospital implementation, hospitals that have completed the CAHPS Cancer Care Survey have not been mandated to publish their results publically.

The target response rate for the survey is set to 40%.[64] Assuming a 40% response rate is achieved, a sample size of 500 is required to achieve 200 completed surveys. It has been noted that achieving response rates has become increasingly difficult in recent years for the CAHPS surveys.

The second field trial conducted by AHRQ in 2016 reported 50% response rate, including late responses, when considering mail-only modes and 53% when considering a web-mail mixed-mode survey approach. This resulted in a sample of 1,675 participants that completed one of the three surveys.

Customer support lines

CAHPS Cancer Care recommend setting up a Freephone number, which is publicised on all correspondence sent to participants. The phone line should have a designated trained project staff member that can respond to questions. It is recommended that a log of these calls is recorded, to review them retrospectively.

Outputs

Outputs from the CAHPS Cancer Care Survey are limited to published research articles based on the piloting of the design and implementation of the survey. CAHPS Cancer Care does not mandate hospital reporting. Responses of 10 and fewer are suppressed.

The questionnaire

The CAHPS Cancer Care survey is broken up into three modules, with a supplementary module, if required. Patients are either randomly assigned a cancer treatment module to complete, or are manually assigned a cancer treatment module, depending on the size of the sampling frame. Patients are only required to complete one of the three treatment modules, depending on selection.

Each treatment module contains three initial questions, pertaining to whether the respondent has been correctly allocated a cancer care survey, and if the patient has received treatment in the hospital or cancer centre noted at the top of the questionnaire. Each module contains five themes each are individualised to the treatment modality in question. In the case of the cancer surgery questionnaire, the following themes are addressed:

- Contacting your cancer surgery team
- Your care from this cancer centre
- Your cancer surgery team

- Clerks and receptionists at this cancer centre
- About you.

The questions within each treatment domain are answered using a 3 or 4 point Likert scale. Questions under the themes of 'contacting your cancer surgery team' and 'your care from this cancer centre' address the accessibility of the cancer centre to schedule appointments, contacting the patient, providing clear instructions and advice regarding sides effects and involvement of family and friends in their care.

The majority of questions are focused within the theme of 'your cancer surgery team'. Areas addressed include whether staff listened, showed respect and spent sufficient time with the respondent. The questionnaire addresses the co-ordination of additional tests, such as blood tests, or X-rays, whether these results were provided to you, were staff aware of important medical history, and whether staff managed any issues or side effects during cancer surgery treatment. Issues included pain management, energy levels, emotional concerns, and potential additional services required to manage cancer care at home, including home help or special medical equipment.

With regards to socio-demographic questions and questions about the patient, the following items were addressed:

- Besides cancer surgery, did you receive other types of cancer treatments or services from this cancer centre?
- How do you prefer to make decisions about your cancer treatment?
- In the last six months, did you have an overnight hospital stay for your cancer?
- In general, how would you rate your overall health?
- In general, how would you rate your overall mental or emotional health?
- What is your age?
- Are you male or female?
- What is the highest grade or level of school that you have completed?
- Are you of Hispanic or Latino origin or descent?
- What is your race?
- Did someone help you complete this survey?
- How did that person help you?

Within the supplementary module, there are three themes identified, access, information from providers and shared-decision making. They account for an additional 16 questions. With respect to access, this focuses on the patient's ability to contact the department within working hours and the timeliness of receiving an answer to any medical questions or concerns. It also addresses time spent waiting for appointments for treatment. When considering information to providers, this focuses on whether the patient received a care plan when commencing their cancer journey, whether the patient was informed about how the cancer treatment would impact their normal daily activities and whether the patient was informed in an understandable way about any medication that was prescribed within the past six months. Within the theme of shared-decision making, the survey evaluates whether multiple treatment options were discussed with the patient, including advantages and disadvantages to each option. It also addresses the level of involvement that the patient had in decision making regarding their chosen treatment plan. The questions in the supplementary modules varied between a three and five point Likert scale, dependent on the question.

Key lessons learned and recommendations

It is important to find a balance between the burden on the health system, patients and taxpayers.

Buy-in is important for hospitals to take on the survey. Having defined benchmarks is of primary importance to improve quality of care delivery.

There tends to be variations in care depending on the particular care setting in the USA. Having a survey can provide benefit in the standardisation of care provided.

Scotland

Background

Public Health Scotland (PHS) publishes data regarding cancer incidence, morbidity and mortality, the most recently published information at the time of writing was from 1997-2021.[66] Cancer statistics are broken down by tumour type, gender, age and deprivation. In 2021, 35,379 new cancers were diagnosed, which is a 5.5% increase since 2019. Data published in 2022 reported that one and five year survival rates improved in Scotland between 2010-2014 and 2015-2019. However, those living in the most deprived areas have increased cancer risks and are 30% more likely to develop cancer, particularly lung cancer. Similarly, the research indicates that those living in most deprived areas are more likely to be diagnosed with more advanced stage of disease, particularly lung cancer, cervical, breast, head and neck and prostate cancer.[66]

The Scotland Cancer Strategy 2023-2033 notes that cancer is Scotland's single biggest health challenge. The strategy is focused on four key principles of patient-centred care, with those living with cancer, their families and carers at the centre of the strategy. Compassion, personalisation, coordination and enablement are the principles underpinning the strategy approach. The strategy aims to reduce inequalities in the access of cancer care, improving cancer outcomes and prioritising less-survivable cancers, such as lung cancer. The cancer strategy aims to provide excellent, equitably accessible care, with one of the key objectives to provide improved experience of services, across all areas of care.[66] In this regard, the Scottish Cancer Patient Experience Survey aligns with the core purpose of the strategy. The strategy drives the national survey to provide up-to-date information regarding patient's experiences of cancer services which are responsive to people's individual preferences and needs. The strategy also notes the important role that digital technology can play in facilitating the improved collection of patient reported experience measures (PREMS).

Objective

The Scottish Cancer Patient Experience Survey (SCPES) is a national survey which is jointly funded by the Scottish Government and Macmillan Cancer Support. The Macmillan Cancer Support Group provide significant benefit in providing a voice to service users' needs and providing a platform to ensure patients are involved in survey development and improve awareness of the national survey. The survey is run in partnership with the Information Services Division (ISD), part of NHS National Services Scotland. It is part of a suite of national surveys developed by the Scottish care experience survey programme.

The SCPES was first designed in 2015 and was based on the Cancer Patient Experience Survey run by NHS England. The contents of the second iteration of the survey were updated to ensure that questions incorporated wider changes to health policy, such as the inclusion of questions around person-centred behaviours. A third iteration of the survey is currently under development, with anticipated distribution and publishing in 2024. The survey addresses patients' experiences of their cancer care journey, from attending their GP, to the support they received after diagnosis, and their subsequent treatment and supportive care. The survey aligns with the National Cancer Strategy 2023-2033, to ensure person-centred care that prioritises compassion, personalisation, co-ordination and enablement. [66]

The survey has both local and national improvement objectives, to provide a viewpoint on the quality of health and care services from the perspectives of persons using cancer services. [67]

The survey's specific objectives were:

For local improvement

- To provide feedback to cancer centres regarding to their patient's experiences, relative to prior surveys and in comparison to other hospitals
- To provide NHS Boards with experience outcomes of their respective board areas and any variation between boards.
- To provide Regional Cancer Networks with information on patient experience within network areas and indicating any variation between networks.

National results

- Provide national results for the survey
- Report variation between local health areas and evaluate changes in both positive and negative experiences over time
- Indicate areas for improvement and areas of excellence
- Identify variations in patient experiences comparing different groups of patients, focusing primarily on low-survivability cancer sites and inequality.

Governance arrangements

The SCPES is commissioned by the Scottish Government, who has oversight over the governance of the survey. The survey has a three-tiered organisational structure, with an oversight group, a policy group and sub-group, which are responsible for revisions of the survey material and obtaining approval for the survey implementation and approval. This sub-group comprises of policy analysts, Macmillan representatives and patient representatives. The survey is run in partnership with Macmillan Support Centre and Public Health Scotland.

To gain permission to use patient information for the survey, including the sharing of data to contractors to administer the survey, approval is sought from the Public Benefits and Privacy Panel (PBPP). The PBPP is a governance panel that scrutinises applications to access NHS Scotland health data, ensuring that public benefit and all privacy concerns have been considered in the proposal.[68]

The survey materials were revised ahead of the 2018 survey to improve engagement with respondents and to ensure compliance with the General Data Protection Regulation, in line with changes made to other surveys in the programme. This included improving the information provided to survey recipients in the cover letter and also introducing a privacy notice for the survey.

Approval for the 2024 iteration of the survey was sought by PHS in 2023. This approval was sought to ensure the survey was in compliance with the General Data Protection Regulation and to provide approval to use NHS data to identify the survey sample and contact prospective respondents. The approval process with the PBPP is complex and required resubmissions of the application before approval was reached by the PBPP, subject to implementation of key conditions. The patient information leaflet for the Scottish Cancer Registry required updating and revision of the Macmillan's Cancer Support Centre involvement and access permissions to survey respondent data was required. To provide reassurance that respondent data could not be used commercially, access to respondent data has been restricted. The PBPP balances public benefit with potential risk to privacy, ensuring that all access to NHS data will provide a tangible benefit to society.[68]

Patients do not need to consent to survey participation, as PHS can use the data based on service improvement provisions in relevant legislation.

The Scottish Government contracted Quality Health Ltd to administer the survey. Quality Health Ltd has indepth experience of NHS surveys, and has provided support for other care experience survey work both in Scotland and elsewhere in the UK. ISD provided support for the administration of the survey. For the 2024 survey, Iqvia is the external contractor having recently acquired Quality Health Ltd.

With respect to the data collected in 2018, data transfers containing patient names and addresses were transferred securely and were limited to variables required to post the survey pack to individuals and identify which hospital their sample was related to. All data was stored and accessed in accordance with data confidentiality protocols, as noted in the privacy notice for the survey. The names and addresses of people who were selected for the survey were stored securely by Quality Health Ltd until the end of the fieldwork period, when they were then destroyed. Once processed, all questionnaires are stored by Quality Health Ltd, and archived until they reach their agreed destruction date.

The survey

Prior to each iteration of the survey, there has been cognitive testing of the survey items through the Scottish Cancer Coalition (charitable group), and Macmillan Support Centre. For the 2024 survey, around 20 interviews with patients were conducted. Involvement of clinical stakeholders further identified methods to amend the survey eligibility criteria, to reduce the number of patients that have been incorrectly identified as cancer patients to participate in previous iterations of the survey.

The sampling frame for all iterations of the survey is the national dataset containing records of hospital activity, otherwise referred to as SMR01. This is used to identify adults (aged 16 years +) with an inpatient or day case record with a mention of cancer during the sampling period. The sampling period in each iteration of the survey has been nine months, with the first survey distributed between 1 January 2014 and 30 September 2014. To ensure that patients had a confirmed diagnosis of cancer and to mitigate the risk of sending the survey to incorrect participants, validation of the list was completed using the Scottish Cancer Registry (SMR06). This sample identified patients who had a cancer registry diagnosis between the 1 July 2013 and 31 March 2014 and who were alive at 31 July 2015. Patients that appeared on both registries within the time periods were included in the sample.[68]

For the 2024 survey, the sampling strategy was changed, as PHS has access to more up-to-date data than with previous surveys. The Community Health Index (CHI) is a population register, which is used to uniquely identify a person on the index. The CHI database is now updated daily, which reduced time required to access patient data. There is now a six-to-eight month gap between hospital admission and contacting patients to participate in the survey. The sample will be drawn from cancer admission hospital data, and validated against Scottish cancer registry data, as with previous iterations of the survey. This validation process avoids people without a cancer diagnosis being contacted. In the past, people that have been inadvertently contacted, has resulted in parliamentary questions (PQs).

ICD-10 codes are used, which are further broken down into 11 tumour groups, during the analytical stages of the survey. The 2024 survey has further broken down these tumour groups into low survivability cancers, which is aligned to the Scottish Cancer Strategy 2023-2033 priorities. The finalised tumour group breakdown is not yet available for the 2024 survey.

Table 5: Breakdown of Tumour Group 2018

Brain/Central nervous system	Breast	Colorectal/Lower gastrointestinal	Gynaecological	Haematological	Lung
Head and neck	Prostate	Sarcoma	Skin	Upper gastrointestinal	Urological

Up-to-date information regarding the 2024 survey was not publicly available at the time of writing this report. Based on the 2018 iteration of the survey, the questionnaire consists of 66 survey items, with 55 questions over nine cancer themes. There are five demographic questions and six free-text questions.

The sample

The 2018 survey was administered to all 14 NHS Boards and the Golden Jubilee National Hospital. Direct sampling from the Scottish Cancer Registry (SMR6) is not permitted for this postal survey. Therefore, the primary sampling frame used is the national dataset containing records of acute hospital activity (SMR01).[68] Census sampling is used, providing all eligible patients the option to participate, to ensure a sufficiently large response rate.

Clinicians have been involved in further amendments to the eligibility criteria for the 2024 survey, but this information is not yet publicly provided. The PHS have taken clinical advice on what ICD-10 codes to include. The inclusion and exclusion criteria noted in this report will be based on the 2015 and 2018 surveys.

Inclusion criteria: For the 2018 survey, ISD use a national dataset containing records of acute hospital activity (SMR01) to identify those aged 16 or over with an inpatient or day case record with any mention of cancer between 1 January 2017 and 30 September 2017. Where a person had more than one hospital record meeting the above criteria, the most recent hospital episode was selected. This ensured that each person only appeared in the sample once.

To confirm the diagnosis of cancer, validation was completed using SMR06. Prospective participants needed to be listed on hospital records within the survey time frame and have a confirmed Scottish Cancer Registry diagnosis between July 2016 and March 2017.

Exclusion criteria:

- Patients who are known to be deceased.
- Privately funded patients receiving care in NHS or private hospitals.
- Patients treated in a private hospital/hospice.

- Scottish NHS patients treated in hospitals outside of Scotland but whose care was commissioned by an NHS Board.
- Patients who were not resident in Scotland.
- Patients who stayed in hospital for termination of pregnancy and/or conditions relating to pregnancy and childbirth.
- Patients who stayed in a hospital maternity unit.
- Patients who were resident in a long-stay hospital.
- Patients who were being treated for a mental health condition in a mental illness hospital.
- Patients who were being treated in a learning disabilities unit.
- Patients with an ICD10 code of C44 and all other C44 classifications (non-melanoma skin cancers).
- Patients with an ICD10 code of C84 and all other C84 classifications (rare haematological cancers with complex clinical definitions).
- Patients with an ICD10 code of D05 and all other D05 classifications (in situ breast cancers).
- Addresses were obtained from the CHI database and checked to ensure that they were complete. Any records where the address was incomplete were removed from the sample.
- If an individual appeared on the SMR6 dataset, but did not have a cancer registry diagnosis, they were excluded from the sample.

Once the list of eligible patients has been compiled, ISD eliminate any duplications or incomplete records to determine the final sample frame.

This sampling approach is consistent with the sampling methodology used in the 2015 survey, with the additional exclusion of ICD-10 code: D05. This change was made following feedback from the customer support desk calls, which showed a high proportion of calls querying diagnosis with patients within this tumour identification. The decision was made that due to the variation in clinical definition of in-situ breast cancer types, inclusion of this patient cohort led to unnecessary distress and anxiety for these individuals. Therefore, this tumour type was excluded from future surveys. The 2018 survey noted that using a similar sampling methodology between surveys, ensures a consistent approach, and better facilitates robust comparisons over time.

It is noted that surgical procedure or treatment received is not factored into the survey sampling methodology. Hospital admission data is the main criteria used for sampling. Therefore, patients included in the survey may have just received their biopsy and diagnosis within the sampling frame.

Distribution and collection

The survey uses a mixed-mode approach. Questionnaires were sent by post, with two reminders where necessary. The survey also included an option to complete the questionnaire online.

A Freephone helpline and email were available for respondents to opt out, ask questions about the survey, enable them to complete their questionnaire over the phone and provide access to a translation and interpreting services for those whose first language was not English. The breakdown of respondents for the 2018 survey, were 85% postal responses, 13% online and 1% phone, with 0.04% of those requiring translations.[68]

The survey pack was distributed to all eligible people within the 14 participating health boards during the fieldwork period. The survey pack consisted of a survey letter, a paper questionnaire, freepost return envelope, information leaflet including details for the survey customer helpline in a range of languages. All of this information was sent out during the initial mail-out period. The first reminder was sent out three weeks later to non-responders, which included a survey letter and information leaflet. Finally, a second reminder was sent out one month after the first reminder. This mail out included a survey letter, paper questionnaire, freepost return envelope and information leaflet including details of the survey helpline in a range of languages. [7]

Individuals included in the 2018 survey were sampled on the 1 August 2018. The sampling and mail-out process extended from this date until the final mailing on 7 November 2018. To avoid sending a survey to a family of someone who may have died during the extraction date and mail-out dates, death checks are routinely completed to avoid sending questionnaires to family members of people who had recently died. The list of people in the initial sample were checked against the National Records of Scotland death register to identify people who had recently died, so they could be removed from the sample. The list of people sampled were also shared with Atos Origin Alliance, who host the CHI database and the NHS central register. Atos Origin Alliance could conduct death checks and send notifications to ISD during the mail-out period. ISD would then notify the external contractor, Quality Health, who would remove patients from the mail-out list.

For the 2018 survey, Scotland’s death register was updated within eight days of a date of death. This meant that there may have been instances where there was a delay between actual date of death and the date that is available on the CHI and NHS databases. As a result, there was four cases of a questionnaire being sent to someone who had died shortly after death checks had been conducted, and the person’s family contacted the survey team to notify them of this. The register has recently been updated, and deaths are registered more promptly than previously. Death checks can now be conducted the morning of a mail-out, to ensure the most up-to-date relevant patient information is available. This will be utilised during the 2024 survey.

Both the 2015 and 2018 survey identified patients that had passed away in the interim sampling period, noting the importance of conducting robust death checks prior to each mail-out.

Communication

With respect to the 2015 and 2018 survey, Quality Health Ltd was responsible for handling customer calls. Iqvia, is the external contractor for the upcoming survey for 2024.

Over the course of the survey fieldwork in 2015, 42 patients requested that they were not eligible to take part in the survey, via support calls. The reason was typically that patients reported they did not receive hospital treatment for cancer. In cases where patients requested additional information regarding their inclusion in the survey sample, staff from the respective NHS board made every effort to contact the patient to discuss their concern.

For the 2024 survey, the contractor will handle patient calls initially, but there is a complex flow diagram for patient referrals to handle calls regarding patient concerns and queries. The contractor will refer patients appropriately, to Public Health Scotland, the respective hospital or to their GP. This is noted as a difficult task, as patients routinely travel for their treatment, so their addresses are often not reflective of the hospital they attended.

Public Health Scotland has a governance group, with access to a list of persons to contact from each participating hospital group. If required, PHS can refer patient queries to the most applicable person on the list. They endeavour to complete the communication loop with regards to patient concerns as best they can, to avoid upsetting patients and causing undue distress, despite staffing limitations.

Response rate

For the 2018 survey, of the 8,302 people in the final sample, 8,090 were considered eligible. A total of 5,001 surveys were returned completed, giving an overall response rate of 62 per cent, which is comparable to the 2015 survey, with a response rate of 61%.[68]

Customer support lines

During the fieldwork in 2015, the survey helpline received a total of 291 calls. Sample participants mostly called to advise that they wanted to opt-out of the survey. A small cohort of those sampled queried their eligibility for the survey. Of these individuals, seven people wanted their call escalated, in which their call was referred to the respective NHS Board regarding their query. The remaining 20 individuals did not pursue the query any further. All participants that contacted the helpline had their details regarding their eligibility double-checked against the Scottish Cancer Registry. The 2018 survey noted fewer eligibility question calls when compared to 2015, which was attributed to the change in exclusion criteria for ‘breast in situ’ tumours, under the D05 ICD-10 code criterion.

Outputs

Reports are published for the 14 NHS Boards, three regional cancer networks and at a national level. Results are available and published on an interactive dashboard on the survey team’s website.

The PHS have disclosure rules that they adhere to. The general rule is not to publish results based on less than 20 respondents, to ensure anonymity of results. In certain cases, they suppress less than five responses within a cell.

The survey asked respondents a number of free-text comments throughout the survey, specifically asking if there was anything else they would like to note about their experiences at various stages of their cancer care journey. For the 2018 survey, over 3,300 respondents completed at least one of these free-text comments. Analysis of these comments were conducted and reported separately from national results published.[69]

There is no requirement for participating hospitals to provide feedback on quality improvement initiatives or reports, based on findings from the survey material. Response material is however published by health boards and academics, from a national level to hospital-specific data.

For persons that wish to use survey outcomes for secondary research, the PHS provide a spreadsheet with disclosure rules.

The questionnaire

The Scottish Cancer Patient Experience Survey questionnaire is based on the NHS Cancer Patient Experience Survey. The survey was edited to fit the Scottish context, with amendments prior to each iteration of the survey, to ensure the questionnaire is fit for purpose and relevant. The second iteration of the survey consisted of 66 questions, covering nine themes, with six free-text box questions.

The themes identified in the survey were as follows:

- Getting diagnosed
- Finding out about your cancer
- Deciding on the best treatment for you
- Operations, radiotherapy and chemotherapy
- Hospital care
- Support from health and social services
- Other support
- Your overall experience.

With respect to the patient condition specific questions and socio-demographic questions, the following questions are asked:

- Gender
- Sexual orientation
- Ethnic background
- Current professional occupation
- Chronic health condition.

Within the theme of ‘other support’ the focus was primarily regarding whether health and social care professionals referred patients to self-help groups during their treatment, or received information regarding charities or voluntary organisations. This section addressed the emotional and psychological support offered to patients undergoing cancer treatment and whether the hospital staff or third sector organisations could provide sufficient emotional support during their course of treatment. There was a single question that addressed the information provided regarding financial aids or benefits that cancer patients are entitled to, during their cancer treatment.

Within the theme of overall experience, the survey addressed questions including being provided with options to participate in cancer research, coordination of care, including healthcare professionals having your medical records and test results at the right time. This section also addresses involvement of family or support persons in their care and travelling to appointments.

The theme of survivorship or long-term support was not addressed in this survey.

For the 2024 survey, focus groups have amended questions within the survey. The questionnaire still follows the CPES survey, with similar themes to those addressed in this report. The finalised questionnaire for the 2024 survey is not yet available for publication.

Key lessons learned and recommendations

The key lessons learned from the third iteration of the survey relate to information governance. There was more scrutiny regarding access to patient database information and ensuring data protection.

Partnership with Macmillan Support Group was found to have been very positive in bringing across the needs of people using services.

Conclusion

From the international comparators, it is apparent that the largest discrepancy across jurisdictions related to the inclusion and exclusion criteria. Each survey has a different perspective on acceptable risk appetite, which the National Care Experience Programme will need to closely evaluate for the Irish context. Based on learned experience from NHS England and Scotland, close clinician involvement in determining the inclusion and exclusion criteria will be imperative to mitigate the likelihood of patients without a cancer diagnosis being incorrectly contacted to participate in the survey. Alternatively, other options including an opt-in survey method could be explored to address this risk.

The Picker Institute recommended the clearly defined criteria of what constitutes a 'cancer related procedure'. Each survey has taken different approaches to this. All surveys consider all SACT and radiation therapy procedures in their survey as well as cancer surgery that is provided under radical and palliative intent. In the case of CPES, they have stricter defined criteria for additional cancer related treatments, such as including procedures for anaemia, malignant pleural effusions, infections caused by cancer, poor nutrition and urinary procedures caused by cancer. They exclude procedures that are not directly related to a patient's cancer diagnosis, and also note not to include reconstruction surgery, if it is conducted years following initial treatment for a cancer diagnosis. In the case of SCAPE, all cancer-related procedures collected from participating hospitals are included, from biopsy, to tumour removal, mastectomy reconstruction and port-a-cath insertion and removal. Similarly, with SCPES, patients may have only received a biopsy and confirmed cancer diagnosis to be deemed eligible to participate in the survey. SCPES personnel also accepted that many areas covered in the survey design may not be applicable to these patients. As the CAHPS Cancer Care survey requires all patients to have received at least two episodes of care within the survey sampling period, biopsy, follow-up and hospice care are excluded as cancer-related procedures. Due to limitations in data information provided in Switzerland and Australia, there are no procedures excluded in these surveys.

If diagnosis cannot be confirmed using ICD-10 codes, which is the case with surveys conducted in OCCS and SCAPE, patients are required to self-report their own cancer diagnosis. With respect to questions that ask the patient to self-report their diagnosis, there is no opportunity to validate the answer, which can lead to variability or answers that may not best reflect the patient's current condition. If ICD-10 codes cannot be provided in the Irish context, to ensure that we can accurately inform on rarer or metastatic cancers, it is important to have a broad range of tumour groups and follow-up questions to ensure that all cohorts and stages of cancer are included in the survey. This may include questions regarding when the patient was first diagnosed with cancer and whether the cancer has since spread to other areas of their body.

All surveys consider a range of socio-demographic and personal health-related questions to provide analysis of care experiences relative to different socio-economic and cultural backgrounds. Many international comparators have taken special consideration to their own marginalised groups; for example, Aboriginal persons in Australia. Additional consideration should be provided with respect to marginalised groups in Ireland, such as members of the Traveller community in the context of a national Irish survey. Applying the PROGRESS or PROGRESS + acronym to identify characteristics that stratify health opportunities and outcomes may be beneficial, to ensure experience outcomes are compared when comparing socio-demographic differences between groups, including marginalised or vulnerable groups.[70]

Most surveys have recommended a mixed-mode approach for conducting a cancer care survey. While uptake of online surveys has increased in recent years (SCAPE-CH) this is not noted across the board (CAHPS) and so, caution should be advised, to ensure the survey respondents accurately reflects the population demographic of cancer patients. International comparators have reported a drive from key stakeholders towards the promotion of online methods of conducting national surveys, not only for ease of access compared to postal modes, but the provision of more timely access to data and report analysis.

The majority of cancer surveys have not expanded to include questions on survivorship or palliative care support services. CAHPS Cancer Care noted that they have drafted a specific survivorship survey, due to the extensive nature of the field. Scottish counterparts noted that it can be difficult to have a scope defined that includes both recent experiences of cancer services and a definite experience of survivorship. It is likely that if themes of survivorship are included in the survey, response rates for that theme may be lower, as it would not yet be applicable to all respondents. The CPES provide questions regarding living beyond cancer, asking questions about what information was provided with information and support between completing treatment and the first follow-up appointment. The survey also asks whether information was provided about cancer recurrence symptoms and what to do regarding any concerns following active treatment. There has been no inclusion of palliative care in any of the surveys, perhaps due to the diverse nature of palliative care supports or that patients may not have been referred to palliative care during their active treatment.

The majority of international surveys have included the financial strain or impact that out-of-pocket expenses, including travelling or paying for accommodation or car parks have impacted a patient's overall experience of their cancer journey. In countries with higher levels of private insurance cover, the questions regarding the financial impact on cancer care extended to whether a patient decided not to proceed with certain treatments, due to the anticipated cost (CAHPS). Similarly, other surveys considered the impact that a cancer diagnosis has on the entire family, as they consider if family or carers needed to take time off work to facilitate the care of their loved one, during cancer treatment.

With respect to inclusion of private hospitals in a national cancer experience survey, there are differing opinions, depending on scope of the survey or healthcare landscape. In New South Wales in Australia, BHI notes that the inclusion of private hospitals in their survey provides a whole-of-service view of the cancer healthcare landscape, which would otherwise fall short. BHI notes that patient experiences reported in private hospitals has been historically more positive than corresponding public hospitals in the locality, which provides a boost for private hospital engagement, as the experience surveys can be used as positive promotional tools for the facility. The cancer surveys conducted in England and Scotland exclude private hospitals, noting that the experience surveys reflect the care received by public hospitals under NHS care.

However, as BHI found, inclusion of only public patients treated in a private setting may prove to be too administratively burdensome. Therefore, a decision will need to be made to either exclude public patients that are treated in the private setting, or extend the scope of the survey to include all private cancer centres, subject to hospital buy-in and financial affordability to extend the survey to private institutions.

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Appendix A: List of international comparators

Table 6: List of International Comparator Calls

Country	Name	Position / Affiliation
England	Jenny King	Chief Research Officer, The Picker Institute
Australia	Nadine Hackl	Lead Researcher on the NSW Patient Survey Program, Bureau of Health Information
Switzerland	Chantal Arditi	Principal Investigator, Centre for Primary Care and Public Health (Unisanté)
USA	Roxanne Jensen	Program Director, National Institute of Health
Scotland	Euan Smith	HSC Analysis, Directorate for Population Health

Appendix B: Themes of care across cancer patient experience surveys

Table 7: Domains of care across cancer surveys

Survey Domains	**CPES 2023**	**CAHPS Cancer Care**	**NSW OCCS**	**SCAPE-CH**	**SCPES 2018**
GP	✓			✓	✓
Diagnosis	✓			✓	✓
Finding out you had cancer	✓			✓	
Support from a main contact person	✓	✓			
Deciding on the best treatment / Shared decision making	✓	✓		✓	✓
Care Planning	✓	✓	✓		✓
Support from hospital staff	✓	✓		✓	✓
Hospital care	✓			✓	✓
Your treatment	✓	✓	✓	✓ (4 questions in each modality)	✓
Immediate and long term side effects	✓	✓	✓		✓

Co-ordination of care		✓		✓	
Customer Service		✓			
Involvement of family / friends		✓		✓	
Access to care		✓		✓	
Discharge and follow-up	✓			✓	✓ (3 questions in overall)
Overall care	✓	✓		✓	✓
Appointment at the clinic			✓		
The physical environment			✓		
Health Professionals			✓		
Respectful care			✓		
Complications			✓		
Smoking Behaviour			✓		
Financial / Payment for your care		✓	✓	✓	✓ (one question)
About your health	✓		✓	✓	✓
Virtual care			✓	✓	
Surgery		✓			
Radiation Therapy		✓			
SACT / Drug Therapy		✓			

Emergency Department experiences				✓	
Information received					
Availability of interpreters		✓			
Co-operation, extra-medical services				✓	✓
Hospital Standards (cleanliness, physical environment, food)					
Patient Safety					
COVID-19				✓	
Holistic Support Services				✓	
GP care	✓			✓	
Home care				✓	
Clinical Trials/Research				✓ (1 question)	✓ (1 question)

Appendix C: National Cancer Patient Experience Survey - tumour groups

Table 8: NHS Breakdown of Tumour Groups

Tumour group	Cancer type (for case mix adjustment)	ICD code	Description
Brain / CNS	Brain	C71	Malignant neoplasm of brain
Breast	Breast	C50	Malignant neoplasm of breast
	DCIS	D05	Carcinoma in situ of breast
Colorectal / LGT	Rectal	C19, C20	Malignant neoplasm of recto-sigmoid junction (C19) and of rectum (C20)
	Colon	C18	Malignant neoplasm of colon
	Anal	C21	Malignant neoplasm of anus and anal canal (C21)
	Small Intestine	C17	Malignant neoplasm of small intestine
Gynaecological	Ovarian	C56	Malignant neoplasm of ovary
	Endometrial	C54, C55	Malignant neoplasm of corpus uteri (C54) and of uterus, part unspecified (C55)
	Cervical	C53	Malignant neoplasm of cervix uteri
	Vulva / vaginal	C51, C52	Malignant neoplasm of vulva (C51) and vagina (C52)
Haematological	Non-Hodgkins lymphoma	C82, C83, C84, C85	Follicular [nodular] non-Hodgkin's lymphoma (C82), diffuse non-Hodgkin's lymphoma (C83), Mycosis Fungoides (C84) other and unspecified types of non-Hodgkin's lymphoma (C85)
	Multiple myeloma	C90	Multiple myeloma and malignant plasma cell neoplasms
	Leukaemia	C91, C92, C93, C94, C95	Lymphoid (C91), myeloid (C92), monocytic (C93), and other leukaemia of specified (C94) and unspecified (C95) cell type
	Hodgkins lymphoma	C81	Hodgkin's disease
Head and Neck	Thyroid	C73	Malignant neoplasm of thyroid gland
	Laryngeal	C32	Malignant neoplasm of larynx
	Oropharyngeal	C01, C09, C10	Malignant neoplasm of base of tongue (C01), tonsil (C09) and oropharynx (C10)
	Oral	C02, C03, C04, C06	Malignant neoplasm of other / unspecified parts of tongue (C02), gum (C03), floor of mouth (C04) and other parts of mouth (C06)
	Parotid	C07, C08	Malignant neoplasm of parotid gland (C07) and other / unspecified major salivary gland (C08)
Lung	Lung	C33, C34	Malignant neoplasm of trachea (C33) and bronchus and lung (C34)
	Mesothelioma	C45	Mesothelioma
Prostate	Prostate	C61	Malignant neoplasm of prostate

Sarcoma	Soft Tissue Sarcoma	C46, C48, C49	Karposi's sarcoma (C46). Malignant neoplasm of retroperitoneum and peritoneum (C48) and other connective and soft tissue (C49)
	Bone Sarcoma	C40, C41	Malignant neoplasm of bone and articular cartilage of limbs (C40) and of bones and articular cartilage of other and unspecified sites (C41)
Skin	Melanoma	C43	Malignant melanoma of skin
Upper Gastro	Oesophageal	C15	Malignant neoplasm of oesophagus
	Stomach	C16	Malignant neoplasm of stomach
	Pancreatic	C25	Malignant neoplasm of pancreas
	Liver	C22	Malignant neoplasm of liver and intrahepatic bile ducts
	Gall Bladder	C23	Malignant neoplasm of gall bladder
Urological	Bladder	C67	Malignant neoplasm of bladder
	Renal	C64	Malignant neoplasm of kidney, except renal pelvis
	Penile	C60	Malignant neoplasm of penis
	Testicular	C62	Malignant neoplasm of testis
	Ureteric	C65, C66	Malignant neoplasm of renal pelvis (C65) and ureter (C66)
Other	Secondary	C77, C78, C79	Secondary and unspecified malignant neoplasm of lymph nodes (C77), of respiratory and digestive organs (C78) and of other and unspecified sites (C79)
	Any Other		All other codes C00, C05, C11, C12, C13, C14, C24, C26, C30, C31, C37, C38, C39, C47, C57, C58, C63, C68, C69, C70, C72, C74, C75, C76, C80, C86, C88, C96, C97

Appendix D: CAHPS Cancer Care Sampling Frame Algorithms for Cancer Surgery

Bladder surgery: algorithm and codes

A person with bladder cancer would be eligible to receive the Cancer Surgery Survey if the following criteria were met in the 6 months prior to being sampled:

Source of Billing Data: Professional and Outpatient Facility

1. The person had a primary ICD-10 CM diagnosis of malignant neoplasm of the bladder, C67.* (i.e., C67.0, C67.1, C67.2, C67.3, C67.4, C67.5, C67.6, C67.7, C67.8, C67.9; Exhibit 1-1)

2. The person has any CPT procedure code in Exhibit 1-2 associated with (i.e., on the same billing line) a primary diagnosis of C67.*,

and

3. The date of discharge is before the sample date.

Source of Billing Data: Inpatient Facility

1. The person had a primary ICD-10 CM diagnosis of C67.*,

and

2. The person has any ICD-10 PCS procedure code for excision or resection of bladder (Exhibit 1-3). The procedure must be associated with a primary diagnosis of C67.*,

and

The discharge date is before the sample date

Table 9: Bladder Cancer Surgery: Diagnosis Codes and Descriptions

ICD-10 CM Diagnosis Code	Description
C67.0	Malignant neoplasm of trigone of bladder
C67.1	Malignant neoplasm of dome of bladder
C67.2	Malignant neoplasm of lateral wall of bladder
C67.3	Malignant neoplasm of anterior wall of bladder
C67.4	Malignant neoplasm of posterior wall of bladder
C67.5	Malignant neoplasm of bladder neck
C67.6	Malignant neoplasm of ureteric orifice
C67.7	Malignant neoplasm of urachus
C67.8	Malignant neoplasm of overlapping sites of bladder
C67.9	Malignant neoplasm of bladder, unspecified

Table 10: Bladder Cancer Surgery: CPT Codes and Descriptions

CPT Code	Description
51520*	Cystotomy; for simple excision of vesical neck
51525*	Cystotomy; for excision of bladder diverticulum, single or multiple (separate procedure)
51530*	Cystotomy; for excision of bladder tumor
51550	Cystotomy for excision, incision, or repair of ureterocele
51550	Cystectomy, partial; simple
51555	Cystectomy, partial; complicated (e.g., postradiation, previous surgery, difficult location)

51565	Cystectomy, partial, with reimplantation of ureter(s) into bladder (ureteroneocystostomy)
51570	Cystectomy, complete; (separate procedure)
51575	Cystectomy, complete; with bilateral pelvic lymphadenectomy, including external iliac, hypogastric, and obturator nodes
51580	Cystectomy, complete, with ureterosigmoidostomy or ureterocutaneous transplantations
51585	Cystectomy, complete, with ureterosigmoidostomy or ureterocutaneous transplantations; with bilateral pelvic lymphadenectomy, including external iliac, hypogastric, and obturator nodes
51590	Cystectomy, complete, with ureteroileal conduit or sigmoid bladder, including intestine anastomosis;
51595	Cystectomy, complete, with ureteroileal conduit or sigmoid bladder, including intestine anastomosis; with bilateral pelvic lymphadenectomy, including external iliac, hypogastric, and obturator nodes
51596	Cystectomy, complete, with continent diversion, any open technique, using any segment of small and/or large intestine to construct neobladder
51597	Pelvic exenteration, complete, for vesical, prostatic or urethral malignancy, with removal of bladder and ureteral transplantations, with or without hysterectomy and/or abdominoperineal resection of rectum and colon and colostomy, or any combination thereof
52234	Cystourethroscopy, with fulguration (including cryosurgery or laser surgery)

	and/or resection of; SMALL bladder tumor(s) (0.5 up to 2.0 cm)
52235	Cystourethroscopy, with fulguration (including cryosurgery or laser surgery) and/or resection of; MEDIUM bladder tumor(s) (2.0 to 5.0 cm)
52240	Cystourethroscopy, with fulguration (including cryosurgery or laser surgery) and/or resection of; LARGE bladder tumor(s)
52355*	Cystourethroscopy, with ureteroscopy and/or pyeloscopy; with resection of ureteral or renal pelvic tumor
52500*	Transurethral resection of bladder neck (separate procedure)

*CPT code was added after the second field test and has not been field tested.

Table 11: Bladder Cancer Surgery: PCS Codes and Descriptions

ICD-10 PCS Procedure Code	**Description**
0TBB0ZZ	Excision of Bladder, Open Approach
0TBB4ZZ	Excision of Bladder, Percutaneous Endoscopic Approach
OTBX0ZZ	Excision of Bladder Neck, Open Approach
0TBC4ZZ	Excision of Bladder Neck, Percutaneous Endoscopic Approach
0TTB0ZZ	Resection of Bladder, Open Approach
0TTB4ZZ	Resection of Bladder, Percutaneous Endoscopic Approach
0TTB8ZZ	Resection of Bladder, Via Natural or Artificial Opening Endoscopic
0TTC0ZZ	Resection of Bladder Neck, Open Approach
0TTC4ZZ	Resection of Bladder Neck, Percutaneous Endoscopic Approach
0TTC8ZZ	Resection of Bladder Neck, Via Natural or Artificial Opening Endoscopic

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