Additional file 7 – Case studies' results of the All.Can Action Guide for Efficient cancer Care

Case study 1 – Global Standardised Cancer Quality and Value Assessment Model | The Health Value Alliance Cancer Performance Indicator (UK and Global)

PROBLEM What efficiency gap?	● **Cancer services are to come under continued strain in terms of both capacity and funding.** The World Health Organization (WHO) has estimated that the proportion of the world's population above age 60 will nearly double over several decades, from 12% in 2015 to 22% in 2050 **(1)**. Optimal cancer service delivery requires consistency, a high degree of efficiency, and clarity on how funding can result in optimal returns for all. The patient must remain at the centre of everything the industry does. Nonetheless, a variety of issues can erode capabilities for delivering optimal cancer care to all. These include: ● **Inconsistencies in how quality and value are perceived and measured.** The various stakeholders in the cancer care ecosystem have differing ways of defining and measuring outcomes, cost, risk, value and quality. This applies to patients, clinicians, hospitals, pharma companies, payers, insurers and the general public. Without alignment, one stakeholder's approach to achieving their own optimal outcomes could result in suboptimal outcomes for others. This creates imbalance and inefficiency and a diminishing cycle of returns for all – and especially for patients. ● **Wide variations in quality of care across contexts.** Around the world, a global 'postal lottery' of quality, outcomes, cost and value exists, and it is unsustainable. For example, across the UK there is a high degree of variability between regions and socioeconomic gradients, particularly affecting ethnic minorities, deprived regions and certain age bands **(2)**. Statistically speaking, where a person lives could currently determine how, and even whether, they live with cancer. ● **Waste is endemic across cancer systems.** The World Health Organization (WHO) estimates that as much as 40% of health spending is wasted through inefficiency **(3)**. The Organisation for Economic Co-operation and Development (OECD) has reported that some 20% of healthcare spending either fails to improve patient outcomes or even worsens them **(4)**. Over the past two decades, disjointed global healthcare systems and endemic waste has led to declining outcomes and value for all. ● **Funding cancer care is more and more challenging**. Cancer is becoming increasingly unaffordable and, under the current model, funding mechanisms are set to be radically reformed. Historically, the benefits of innovation have proved uncertain: one study has shown that, between 2008 and 2012, 67% of drugs were approved by the US Food and Drug Administration without evidence of improved survival or quality of life **(5).** Another study has found that 57% of cancer drugs approved by the European Medicines Agency between 2009 and 2013 had no supporting evidence of better survival or quality of life when they entered the market **(6)**.

- **Patient safety remains a concern.** According to the OECD, one in ten patients in OECD countries are harmed unnecessarily at the point of care. More than 10% of hospital expenditure goes to correcting preventable medical mistakes **(4)**.

SOLUTION
Context and scale

Global Standardised Cancer Quality and Value Assessment Model:

The Health Value Alliance
Cancer Performance Indicator

- **HVA's Goal:** Equitable access to cancer care that is wholly patient-centric and evidence-based, and which delivers optimal outcomes under a model that is sustainably affordable for all.

- **The Need:** Cross-sector leadership and collaboration between stakeholders to co-create an independent, data-driven model. This model should facilitate transparent and multidimensional assessment of quality outcomes, cost and value, and it should support a sustained learning environment.

- **HVA's Solution: The HVA Global Cancer Performance Indicator (CPI):** Powered by an advanced AI-driven analytics system – QALYfAI™ – the CPI will provide a standardised, non-biased platform for decision makers. It will enable them to assess, monitor and report on cancer service and innovation performance (quality, outcomes and value).

Phases of implementation

- **Creation of the CPI.** The 48-month CPI co-development programme commenced in April 2021 and is set to conclude in early 2025. It involves the following ten steps:

One: Performing academic work, using the All.Can metrics report **(7)** as a baseline, in order to

a) establish common definitions of quality, outcomes, cost and value
b) identify evidence-based measures for the assessment of quality, outcomes, cost and value
c) identify the sources of these measures to ensure they are accessible and real-world data.

Two: Bringing together stakeholders from across the cancer care ecosystem – including patients, clinicians, diagnostic services, clinical care services, government/state/insurance payers – with a common goal of designing a new approach to the assessment and presentation of cancer care quality and value.

Three: Achieving collaborative agreement on

a) the definitions of quality, outcomes, cost and value
b) the CPI value domains
c) the CPI measures under each domain
d) verified access to the data to enable measurement
e) supporting development of a common data model
f) providing access to these data.

Four: Creating the data framework, a technical infrastructure, the AI-supported analytics platform and the CPI reporting portal**.**

Five: Ensuring data access and processing.

Six: Reaching collaborative agreement on the standard reporting model.

Seven: Signing off by the collaborators.

Eight: Making the system go live in agreed geographies (initially UK, US and EU).

Nine: Preparing for full international deployment (from November 2024).

Ten: Deploying internationally (from early 2025).

STAKEHOLDERS involved

The CPI co-development programme involved the following collaborating stakeholders (referred to by HVA as **Value Pioneers)**:

AXA Health
Vitality Health·Life
Roche
All.Can International
NHS Imperial College Healthcare NHS Trust
Spire Healthcare
HCA Healthcare UK
GenesisCare
University of Southampton
The James The Ohio State University Wexner Medical Center
Check4 Cancer
PromTime
Institute of Cancer Policy
Kirontech
Perci
Commission on Cancer®

FACILITATORS

- **Funding:** The CPI co-development programme has been funded by financial input from collaborating insurers, hospitals and pharma companies, to ensure a balance of funding and avoidance of bias. Other entities provided support as knowledge partners or data partners.

AXA Health
Vitality Health·Life
Roche
All.Can International
NHS Imperial College Healthcare NHS Trust
Spire Healthcare
HCA Healthcare UK
GenesisCare
University of Southampton
The James The Ohio State University Wexner Medical Center
Check4 Cancer
PromTime
Institute of Cancer Policy
Kirontech
Perci
Commission on Cancer®

BARRIERS

- **Fragmentation:** Cancer systems are complex and notoriously fragmented. Bringing together stakeholders can be challenging**.**
- **Timing:** Stakeholders may be focused on other pressing issues, with limited or no capacity to support a new initiative**.**
- **Funding:** Competition for funding exists. A proposal must therefore present a compelling case on investment and return if it is to pique stakeholder interest.
- **Technical**: Data and analytics systems are complicated and costly to develop and deploy**.**
- **Data access:** Regional privacy and governance legislation varies, and typically it restricts access and use. The proposal must therefore contain a clear statement of purpose, the necessary consents, and an appropriate data governance model that can remain compliant.
- **Time:** Achieving sufficient scale takes time and resources, which can mean that outputs and benefits will not be realised for some time, even years after the programme commences. Such a time frame increases costs and can also be too lengthy for some stakeholders.
- **Pivoting:** A traditionally reactive disease care funding model must be pivoted towards a preventative and proactive healthcare model.
- **Competitive tension:** Some stakeholders in the cancer care ecosystem compete against one another. Bringing competing stakeholders into a collaborative model is challenging and requires a clear presentation of a ‘bigger picture’ in which everyone wins.
- **Apathy:** Change programmes inevitably require investment (human, technological and financial) and considerable effort. A completing proposal is needed to move stakeholders out of the status quo.
- **Critical mass**: An insufficient volume of stakeholder engagement can result in a lack of ‘presence’ and can constrain post-pilot adoption.

NEXT STEPS

What is next for the CPI?

- Continual onboarding of collaborators from across the cancer care industry around the world
- Continued evolution of the CPI metrics and reporting
- Ensuring that the CPI measures align with, and/or can augment, other whole-population registries, e.g. from the OECD, Public Health England, and EU- and US-focused systems.
- Continuing evolution of advanced predictive models to support the early identification and mitigation of treatment-related toxicities and late effects in patients (comorbidities).
- Supporting the assessment of innovative services, systemic anti-cancer agents and novel therapies, technologies, and digital health solutions to sustain care access through long-term cost–benefit demonstration and innovative access programmes.
- Supporting accreditation bodies through more real-time assessment of care service performance.
- Supporting country-specific cancer plan design, and ensuring that common data models are embedded in such plans and the associated registries.

Explore further	Read more about the Health Value Alliance Cancer Performance Index at the HVA website.

References

1. **World Health Organization.** Newsroom / Fact sheets / Detail / Ageing and health. [Online] 01 10 2022. [Cited: 12 04 2024.] https://www.who.int/news-room/fact-sheets/detail/ageing-and-health.

2. **Imperial College London.** Risk of dying from cancer varies widely across regions in England. *Imperial.* [Online] 11 12 2023. [Cited: 12 04 2024.] https://www.imperial.ac.uk/news/250053/risk-dying-from-cancer-varies-widely/.

3. **World Health Organization.** Health systems financing: the path to universal coverage. *The World Health Report.* [Online] 22 11 2010. [Cited: 12 04 2024.] https://iris.who.int/bitstream/handle/10665/44371/9789241564021_eng.pdf?%20%20sequence=1&isAllowed=y.

4. **OECD.** Tackling Wasteful Spending on Health, OECD Publishing, Paris. [Online] 2017. [Cited: 12 04 2024.] https://doi.org/10.1787/9789264266414-en.

5. *Cancer Drugs Approved on the Basis of a Surrogate End Point and Subsequent Overall Survival: An Analysis of 5 Years of US Food and Drug Administration Approvals.* **Kim C., Prasad V.** 12, s.l. : JAMA Intern Med, 2015 Dec, Vol. 175, pp. 1992-4.

6. *Availability of evidence of benefits on overall survival and quality of life of cancer drugs approved by European Medicines Agency: retrospective cohort study of drug approvals 2009-13.* **Davis C, Naci H, Gurpinar E, Poplavska E, Pinto A, Aggarwal A.** j4530, 2017 Oct 4, BMJ, Vol. 359. PMID: 28978555; PMCID: PMC5627352..

7. **All.Can International.** ***The All. Can Cancer Efficiency Metrics Study: A collaborative policy research project to identify a standard set of metrics to measure cancer care'efficiency'.".*** **[Online] 2022. [Cited: 20 02 2024.] https://eprints.soton.ac.uk/468679/1/Final_The_All.Can_Cancer_Efficiency_Metrics_Study_2_.pdf.**

Case study 2 – Canada’s oncology nurse navigators

PROBLEM
What efficiency gap?

- **Complexity** of the cancer care pathway, relative to other aspects of healthcare, has led to difficulties for patients in navigating their care.
- **Long diagnosis-to-treatment times** are seen in some jurisdictions, which are attributed to suboptimal communication between patients, general practitioners and specialists.
- **Inefficiencies** acknowledged by the provincial and territorial healthcare systems have exacerbated access issues, especially in remote areas.

SOLUTION
Context and scale

ONCOLOGY NURSE NAVIGATORS

- **Goal:** To accelerate the process of referrals, from investigation to diagnosis and treatment, in order to reduce wait times and to support and guide patients and their families through their cancer journey.

- **Approach:** Nurse navigators are predominately ‘generalists’, meaning they are not tied to a specific cancer phase, subpopulation or site, although some are also profiled to support particular focuses like adolescents, breast cancer or indigenous groups.

- **Context and scale of the initiative:** The implementation of oncology nurses is jurisdiction-specific, though it typically involves tailored training of nurses according to a jurisdiction-specific resource such as a manual.

Phases of implementation

- **Initial introduction.** Oncology nurse navigators in the Canadian context drew inspiration from developments in the United States. Oncology nurse navigation emerged in the early 2000s through bottom-up, jurisdiction-specific nurse navigator initiatives.
- **Early efforts.** Efforts to coordinate the further development of oncology nurse navigation ensued from an annual conference of the Canadian Association of Nurses in Oncology, where a working group on oncology nurse navigators was initiated.
- **Rollout.** The ways that nurse navigators have been implemented vary in each of Canada’s jurisdictions, for instance in terms of timing and approach in piloting and upscaling.
- **Sustainability and scale-up.** In 2018, oncology nurse navigators were formally recognised as a ‘programme’ rather than a ‘service’. Considerable heterogeneity remains among Canadian jurisdictions in terms of ‘how’ (the ways navigation is organised), ‘who’ is engaged (profiles of professionals) and ‘what’ is included (types of services). The recognition of oncology nurse navigators by the Canadian Partnership Against Cancer has also served to formalise and accelerate their presence.

STAKEHOLDERS involved

Implementation involved a **broad range of stakeholders**, including:

- Canadian Nursing Association
- Canadian Association of Nurses in Oncology
- Jurisdiction-specific nurse navigators
- Canadian Partnership Against Cancer
- Healthcare professionals (general practitioners, radiologists, oncologists)

FACILITATORS

- **Training nurse navigators** that have previous experience with oncology has been shown to have a positive effect on retention.
- **Coordination with professional networks** facilitates communication, alignment, exchange, development training, and establishment of a common identity for oncology nurse navigators.
- **Political willingness** is central to scale-up and sustainability.
- **Active promotion of role and activities** among healthcare professionals and patients is necessary, as nurse navigators need to be their own champions and to advocate for their roles.
- **Data** must be made available to quantify improvements in wait times.
- **Time** for implementation must be sufficient, as there is a natural maturity period and time frame to build awareness and recognition.
- **Trust and reputational awareness** need to be built through the local word-of-mouth exchanges between patients.
- **Exchange of experiences** should be ensured, so as to enhance learning potential to draw from lessons and materials across jurisdictions.

BARRIERS

- **Dependency on self-referrals**, word of mouth and social contacts often remain the primary entry point to connecting with an oncology nurse navigator.
- **Referral into the system** is a major bottleneck, as the first contact still depends in large part on self-referrals, word-of-mouth contacts and/or awareness amongst healthcare providers.
- **Lack of awareness** continues to be a challenge, as patients have often not known about the nurse navigator role and wished they could have connected earlier. Early referrals to nurse navigators are particularly advantageous because the initial stages of cancer constitute a period of especially high anxiety for patients. Similarly, there are challenges in jurisdiction where the nurse navigator role is new, as healthcare providers may not be aware of the role and fail to refer patients in time.
- **Heterogeneity** across jurisdictions leads to considerable differences in roles and tasks of navigators across Canada.
- **Caseload** is increasing in provinces and territories where the role is more established, and such jurisdictions now face the challenge of securing more funding to increase the number of nurse navigator posts.
- **Workload** is also changing as cancers and their treatment plans become increasingly complex and as new medications become available, hence requiring additional support by navigators in treatment.

NEXT STEPS

- **Standardisation** of roles across jurisdictions must be increased.
- **Further collaboration** is needed amongst healthcare providers, professional associations and policymakers in order to share good practices.
- **Implementation research** is needed to strengthen the **evidence base on the effectiveness** of nurse navigators and their contribution to improving patient experiences.

Explore further

Read more about Canada’s experience with oncology nurse navigators in this All.Can Practice Case Study.

Case study 3 – Argentina’s cancer patient navigators

PROBLEM
What efficiency gap?

Inequalities in access to healthcare services exist across the cancer care pathway in Argentina, exacerbated by social and economic inequalities and cultural and religious differences. The greatest impact is on **vulnerable populations**.

Complexity and fragmentation characterise the health system, making it more difficult for patients to navigate along the care pathway.

SOLUTION
Context and scale

NATIONAL CANCER NAVIGATION PROGRAMME

● **Goals**: To reduce obstacles to timely diagnosis and treatment, and notably the barriers within the health system itself. The navigation programme promotes incorporation of the cancer navigation strategy across public and private institutions in Argentina.

● **Approach:** Cancer navigators facilitate the process of medical care to patients with cancer throughout their care pathways. They strive to ensure that patients correctly understand information they receive with regard to appointments, consultations and decision making.

Cancer navigators have two main roles:
1) Intervention: Navigators actively seek out patients who miss appointments, so as to identify and overcome delays in care delivery and barriers to care access and continuity. The navigators also manage communication channels between patients, families and healthcare providers; they provide guidance and support to patients in adhering to their care pathways (e.g. in scheduling procedures); they produce periodic reports; and they provide public education.
2) Monitoring: Navigators also oversee care continuity without active intervention.

The most common navigator tasks may differ between public and private hospitals, due to the differing populations in those settings:
- In public hospitals, cancer navigators may detect delays in appointments and identify causes for them, such as financial barriers to treatment or other problems that preclude access to care in the hospital.
- In private hospitals, patients from distant provinces may need support in finding nearby accommodation.

Cancer navigators can be people from the community with or without a university degree.

Context and scale of the initiative: In 2010, the National Cancer Institute **(Instituto Nacional del Cáncer Argentina)** was created, which depends on the National Ministry of Health. Since its start, the INC has been responsible for promoting the incorporation of cancer navigation programmes in Argentina.

Phases of implementation

A total of 4 cancer navigation programmes are in place: for breast, cervical and colorectal cancer and for paediatric cancers. Since the start of the national programme, regional programmes have been rolled out in increasing numbers of Argentinian provinces:
- Cervical cancer: implemented in 3 provinces in 2010 and in 19 by 23
- Breast cancer: implemented in 2 provinces in 2016 and in 7 by 2019
- Colorectal cancer: implemented since 2014 in 4 provinces. Its protocol has not yet been published.

STAKEHOLDERS involved

Implementation included a **broad range of stakeholders:**

- Cancer institutes in various jurisdictions
- Private hospitals
- *Casas de la Provincia* ('Houses of the Province': Local government offices)
- Drug banks

FACILITATORS

- **Political will and financial investment**, notably focusing on social inequalities in a broader sense
- **Navigation protocols and procedure manuals for cancer navigation:** Such documents ensure standardisation in the practice of care navigation across health institutions and jurisdictions, as well as evaluation of the programmes.
- **Training** ensures better performance by cancer navigators
- **High levels of acceptance and satisfaction with the navigation programme among patients and their families**

BARRIERS

- **Work overload**, causing problems such as lack of time to register information
- **Lack of regulation** of the navigator role in some regions
- Role of navigators is **not widely accepted amongst medical teams**
- **Lack of resources**, mostly in public hospitals, including:
  - resources to pursue diagnosis and/or treatment
  - lack of computers or internet access to perform administrative tasks
- **Health system delays**, for instance in time to diagnosis
- **Cultural barriers** that hinder the acceptance of some patients from vulnerable populations

NEXT STEPS

The **number of provinces** implementing the programme is expected to **continue increasing** in the future.

The **protocol for the navigation in colorectal cancer** is yet to be published. Its implementation is to be scaled up to other jurisdictions.

Explore further

- Protocol to implement the Navigator Strategy in Programmatic Context (cervical cancer), National Cancer Institute Argentina, 2019
- Programme manual for navigation breast cancer patients, National Cancer Institute Argentina, 2023
- First International Seminar on Cancer Navigation, organised by the National Cancer Institute Argentina, December 2023

Case study 4 – England's National Cancer Patient Experience Survey

PROBLEM
What efficiency gap?

Lack of a systematic way to explain and monitor the experience of cancer patients during care delivery.

Need to produce reliable and comparable data across sites and locations regarding the experience of patients with cancer.

SOLUTION
Context and scale

National Cancer Patient Experience Survey – NCPES

● **Goals**: To assess and monitor people's experience of cancer care in England, as expressed by their needs and preferences. To monitor progress at local, regional and national levels. To improve quality of care based on the patients' perspective.

Outputs of the survey are processed and prepared for use across the health system: for national purposes; for local and system application; for NHS trusts, cancer alliances and integrated care boards; and for the general public (in lay language).

● **Approach:** .

- The National Cancer Patient Experience Survey (NCPES) **operates nationally** in England, funded by NHS England.
- The survey has been **conducted** since 2019 by Picker Institute Europe, on behalf of NHS England. Results can be consulted on the National Cancer Patient Experience website.
- **NHS trusts** (organisational units of the National Health Service) are the counterparts participating in the survey. Trusts are **mandated** to participate, allowing cross-comparisons can be made. All trusts employ the **same methodologies** to ensure comparability.
- Every NHS trust in England takes part in the survey – a total of 132 trusts in 2023.
- A **sampling protocol** is in place, with patients selected during a 3-month survey window each year. Sampling of patients is carried out through the NHS trusts. Samples are then developed on the basis of this pool of selected participants. The coordination team then contacts patients directly to take part in the survey.
- Target **participants** are contacted in a 3-stage postal mailing procedure:
  - initial invitation, enclosing the questionnaire and covering letter
  - reminder letter
  - repeated reminder, again enclosing the questionnaire and covering letter.

  Each attempt includes an online link. The fieldwork comprises a total of 12 weeks.

● **Context and scale of the initiative**:

- **The Department of Health and Social Care (then Department of Health) were the original developers of the survey**, which conforms to the NHS national cancer strategy.

- The Cancer Reform Strategy (CRS) published in 2007 set out a commitment to establish a new programme to operate NHS Cancer Patient Experience Survey.
- The survey involves patients with virtually all types of cancer, excluding only a tiny number of ICD-10 codes.
- A survey for patients younger than age 16 was implemented in 2020.

Phases of implementation

Developing the National Cancer Patient Experience Survey involved significant amounts of scoping work and other efforts in various phases, notably in **developing the most appropriate tools to be employed** for the system. Similar work was performed again later for the under-16 survey.

- **The first national survey was carried out in 2010, and the survey has been conducted yearly since 2012.**
- The 2010 survey built upon a previous survey undertaken in 2000 involving over 65,000 cancer patients and upon a smaller survey undertaken in 2004 with 4,300 patients.
- After a review of the questionnaire in 2015, **another major revision of the survey was made in 2021**, with input from a broad range of stakeholders, including doctors, people with experience of cancer, and cancer charities.

STAKEHOLDERS involved

Implementation has involved a **broad range of stakeholders**, including:

- Healthcare professionals
- People with past experience of cancer
- Cancer charities
- Patient advocates

FACILITATORS

- **Political commitment**, including policies addressing the need to report patient experience – such as the NHS England Long Term Plan and the National Cancer Strategy. Commitment is also evidenced by the **funding and prioritisation of these efforts over time.**
- **Stakeholders' wide recognition** that quality of care, person-centred care and patient experience must be understood from the **voice of personal experience**.
- **A long tradition** of collecting and applying patient experience data. From as early as 2000, the Care Quality Commission and the Picker Institute were working together to design and establish the NHS Patient Survey Programme, the first-ever national survey programme for patient experience.
- **Strong embedding of patient data in the system:** National surveys feature heavily in work of the Care Quality Commission, the regulators and inspectors for health and social care.
- **Patient data is well established as a mechanism for accountability:** When organisations are inspected, data from patient experience is considered as an indicator of organisational performance.

	• **Involvement of patients at all stages of the process** to determine what form the survey will take, how people will be contacted and other practical aspects. All new questions are tested on people with varying levels of literacy and from different age, ethnicity and cancer categories. • **Involvement of the National Cancer Patient Experience Advisory Group and cancer charities as key stakeholders in promoting the survey**, thus enhancing the legitimacy of the survey • **NHS trusts have a key enabling role** in supporting the process as well as the application of the survey results.

BARRIERS	• **Underrepresentation of segments of the population:** Continuing efforts are in place to ensure representative responses from the entire public, and additional ways are explored to reach people through different means. • **Subsamples of specific populations are often small,** and especially of vulnerable groups like people with learning disabilities. The survey may thus insufficiently capture the experience of all population segments. • **Patient opt-out policy**: In a key policy change regarding consent to data collection, a general national data opt-out has been introduced. Although the NCPES has been granted a general exemption, patients may still opt out of the NCPES specifically.

NEXT STEPS	**Every 5 years, the survey is reviewed for updating as needed.** The **current priority** is **increasing diversity in the representation of groups,** such as different language groups. (Currently, administering the survey in languages other than English is possible only in a time-consuming telephone process.)

Explore further	• All details about the survey are reported on the National Cancer Patient Experience Survey website. • The 2022 National Report is available online.

Case study 5 – Swiss Cancer Patient Experiences – SCAPE surveys, Switzerland

PROBLEM
What efficiency gap?

Lack of a standardised instrument to measure patient experience in oncology: In Switzerland, there was no standardised instrument to assess patient-reported experience measures (PREMs) in cancer care. The national data collection instrument available at the time, called a ‘patient satisfaction measure’, was composed of only 6 questions, insufficient to evaluate patients’ needs and experiences of care.

Limited understanding of underlying factors driving inequalities in quality of care across the various Swiss communities: People in different communities, such as the French- or German-speaking populations, often rate health system performance differently. This prompts the question: Is there a real discrepancy in the quality of care provided or are the different views explained by cultural factors?

SOLUTION
Context and scale

Swiss Cancer Patient Experiences – SCAPE surveys

- **Goals**: The research team set out to identify questions for a patient experience questionnaire for people with cancer. The resulting questionnaire was translated and culturally adapted for various Swiss communities. The primary aim was to **develop a standardised tool to assess the experiences of patients diagnosed with cancer in Switzerland**.
- **Approach:** The surveys are **centrally coordinated by a research team** from two research institutions, Unisanté and IUFRS, affiliated with the University of Lausanne. The research team **invites healthcare providers from a range of hospitals** to assist in the surveys; their main role is **to forward the survey materials to eligible patients** from their respective hospitals. The preparation of the survey materials, the data analysis and the communication of results are centrally coordinated by the research team.
- **Context and scale of the initiative**: The initiative began by testing the initial version of the survey in **4 French-speaking hospitals** in 2018. Data collection was scaled up to **21 French-, German- and Italian-speaking hospitals and clinics** in 2023. The phases of implementation are described below.

Phases of implementation

1) Identification of the survey instrument

A **literature review** was conducted to identify questionnaires used in other countries. The National Cancer Patient Experience Survey (NCPES) from NHS England was selected as the most comprehensive instrument. It enables evaluation and improvements in quality of care within a short time frame, and it includes questions on experiences along the entire care pathway, as well as on interprofessional aspects. The decision was based on empirical considerations and not on psychometric properties of questionnaires.

2) Translation and cultural adaptation of the survey instrument

followed international guidelines and included consultations with both healthcare providers and patients. Patient representatives were included in the whole survey process. This was one of the first projects with **patient and public involvement (PPI)** activities in the two research institutions.

3) Invitations to hospitals to participate in the survey

The **research team recruited hospitals** by contacting healthcare professionals from hospitals that had oncological centres. **Hospitals were given responsibility for selecting eligible patients and sending the survey materials**. Patients could complete the questionnaire on paper or online.

The SCAPE surveys:

- SCAPE 1 (data collected October 2018 to March 2019, funded by the foundation Swiss Cancer Research): It included patients diagnosed with one of the **6 most frequent cancers** in Switzerland (breast, prostate, lung, colon, skin and blood cancer) in **4 French-speaking hospitals**. All patients who had attended the participating hospital within the six-month time frame were included in the recruitment.
- SCAPE 2 (data collected September 2021 to March 2022, funded by Swiss Cancer Research): This included patients diagnosed with **any type of cancer** from **8 hospitals**: the 4 French-speaking hospitals from the first wave plus 4 German-speaking hospitals. Each hospital invited up to 900 patients for recruitment within the six-month time frame.
- SCAPE-CH (data collected September 2023 to March 2024, partially funded by the Federal Quality Commission, website publication of results expected in July 2024): It included patients diagnosed with **any type of cancer** from **21 hospitals**, including one Italian-speaking one. The survey instrument was available in **4 languages**: French, German, Italian and English. Each hospital invited up to 900 patients for recruitment within the six-month time frame.

STAKEHOLDERS involved

- **Healthcare providers from the oncology departments** of different hospitals – often the medical oncologist in charge of the department or sometimes an oncology nurse with a research role. The research team appoints one person as the chief contact in each hospital.

FACILITATORS

Facilitators related to the start of the project:

- **Funding:** A key factor was that **Swiss Cancer Research** had issued an open call for health services research projects in oncology and cancer care, and it matched what the SCAPE project intended to do. After 4 hospitals had agreed to participate, the research group submitted the proposal and obtained funding for two years, which enabled the start of the project and its implementation in 4 French-speaking hospitals. Swiss Cancer Research also funded SCAPE-2.
- The **launch of the specialised cancer centres** at Lausanne University Hospital was a key **driver in standardising the assessment** of patient experiences.
- **Patient and public involvement** was secured from the start of the project for all phases of the project.
- **Personal (and institutional) network:** Creating a **broad network was key**. The invitations to different hospitals were mostly carried out **through professionals previously known to the researchers**. Ensuring principal investigators with leading roles in relevant healthcare organisations in Switzerland was an important enabler in securing professionals' willingness to begin participation.

Facilitators related to ensuring the participation of healthcare professionals and patients:

- The **research team provides** **feedback to patients and hospitals** through reports to the hospitals and lay language reports for patients. (Patients are to indicate whether they wish to receive results.) The **hospitals participating in the first waves** were satisfied with the work conducted and were **willing to take part in following waves**.
- **Reminders:** These are a highly relevant factor in boosting response rate and obtaining more comprehensive data. The research team did a comparative analysis of respondents before and after the reminder and found variations between the two groups in the feedback given.

Facilitators related to the coordination and sustainability of the project:

- **Central coordination:** The research team coordinates with all the participating centres, thus facilitating the work and reducing the burden for healthcare providers.
- **The use of a unique standardised questionnaire for the entire country** facilitates comparison among different organisations.
- **'Hotlines' to inform patients:** When a patient receives the invitation letter, there are two hotlines available to answer questions: one ***central hotline***, run by the research team, and a ***local hotline***, where a health professional known to the patient can be contacted directly.
- **Building and strengthening relationships with the healthcare professionals and the teams involved:** Demonstrating the quality of the work conducted and adhering

to the time frames and the milestones in the survey process are key to ensuring trust and strengthening the relationships with the teams involved.

- **Perseverance:** Some tenacity is necessary in engaging and retaining healthcare providers.
- **Legal obligation for healthcare providers to develop and assess quality:** A recent amendment to the Swiss health insurance act specifically requires quality development and assessment by all healthcare providers. The quality strategy pursued by the Swiss Federal Council also prescribes the implementation and application of insights from patient-reported experience and outcome measures. This facilitates adherence to the SCAPE surveys.

BARRIERS

- **Lack of direct access to patient data by researchers in Switzerland:** The research team must therefore **recruit patients through healthcare professionals in the oncology departments** of participating hospitals, who identify the suitable candidates for the survey. This hampers quality control with respect to the inclusion criteria for patients in the survey.
- **Each hospital has its own medical and administrative information systems, which are not always updated regularly:** Assessment of patient eligibility for survey recruitment thus remains a challenge. And data protection regulations prevent the research team from assisting hospitals with patient selection.
- **Decentralised healthcare system:** Duties and responsibilities in the Swiss healthcare system are divided among federal, cantonal and municipal governments; each of the 26 cantons has **its own cantonal health laws.** Hence, the lack of harmonised health legislation among all cantons also impedes implementation of a unified information system.
- **Cancer registries are still in development:** Although each canton is mandated to have a cancer registry, these have not yet been fully developed. In addition, there are still considerable delays between the time of cancer diagnosis and the registration of the cancer in registries. This hinders inclusion of PREMs in the registries.
- **Motivating healthcare professionals to participate:** The research team relies on the motivation of each medical team in the various hospitals to take part, since participation is not mandatory. Persuading and effectively engaging medical teams regarding the relevance of assessing PREMs is a key success factor.
- **Translation and cultural adaptation of the survey** was a challenge, due mainly to
  1) **national differences in healthcare systems.** As healthcare pathways and organisations vary considerably from country to country, designing the Swiss surveys to has proved challenging.

2) the **language diversity in Switzerland**, with its four official languages.

- **Relying on paper-based invitation letters and questionnaires:** The process of distributing a paper-based questionnaire sent to individual patients by post is **costly and time-consuming** (printing, postage, mailing). Although participants can complete the questionnaires online, only 10% to 12% do so.
- **Burden to patients:** (1) Some patients may receive multiple invitations to each wave of the SCAPE survey; this is unavoidable due to privacy regulations. (2) Response rates have been 44% in the first survey, 49% in the second and 49% in the third.
- **Funding to ensure sustainability for the survey:** **The long-term sustainability of the survey is a key challenge.** Currently, the Federal Quality Commission is funding 50% of the project and hospitals fund the other 50%. However, it is not yet certain how a next iteration of the survey can be funded.

NEXT STEPS

The most relevant next step and challenge involves **securing funding to guarantee the sustainability** of the SCAPE surveys in the long term.

Explore further

- **SCAPE website**
- **Patient lab website**, a patient and public involvement reference centre in cancer research affiliated to the Swiss Cancer Center Léman. It promotes transdisciplinary partnership involving patients, informal carers and public participants during all phases of research.