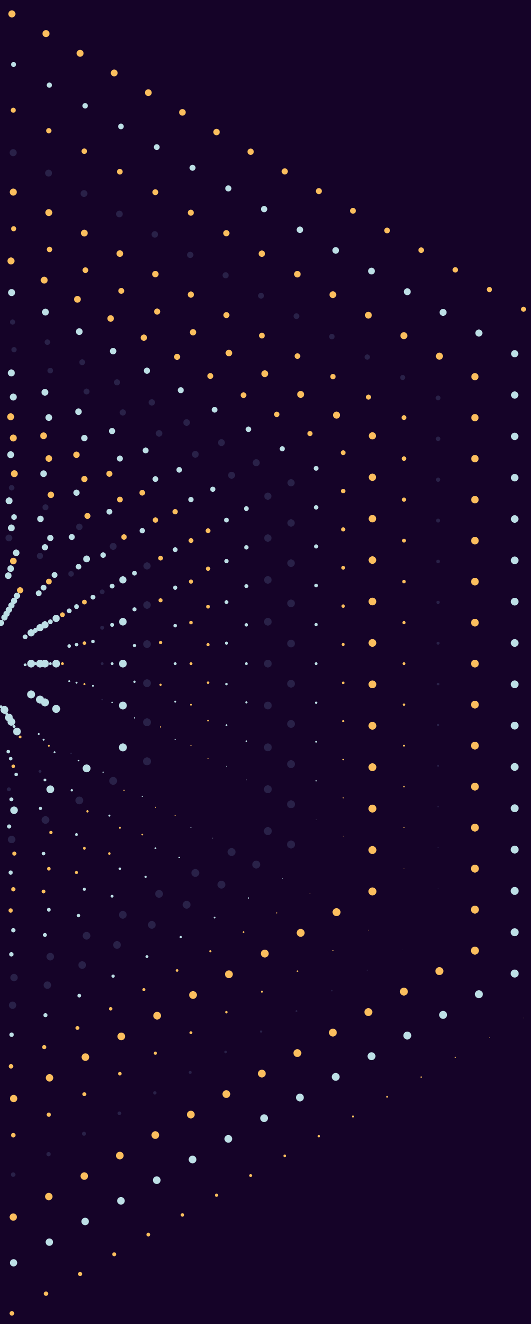

Action Guide For Efficient Cancer Care

An implementation toolkit

All.Can Changing cancer care together

September 2024

Acknowledgements

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Contents

EXECUTIVE SUMMARY

This collaborative work was conceived as a dynamic and actionable resource to empower stakeholders to drive improvements in the efficiency of cancer care delivery within their unique contexts.

Efficiency in cancer care is defined by All.Can International as 'care that delivers the best possible health outcomes using the human, financial, infrastructural and technological resources available, with a focus on what really matters to patients and society.'

All.Can and its community strive to create a more efficient, sustainable and people-centred approach to cancer care, emphasising collaboration, evidence-based and practical solutions.

A previous study conducted on behalf of All.Can International identified a set of eight internationally applicable metrics to improve the assessment and efficiency of cancer care delivery within local, subnational and national contexts.

The selection of valid and reliable metrics is not a guarantor of their use in practice. Rather, the process of implementing the efficiency metrics must be prioritised in order to firmly embed the use of the metrics in cancer care practice.

While these metrics are by no means exhaustive and should not be regarded as static, they were considered to be a consensual starting point for developing this Action Guide.

This Action Guide has three core aims:

1 → To offer **guidance, resources and recommendations** for implementing cancer efficiency metrics within the contexts of diverse users

2 → To provide a **non-linear tool,** whereby users can navigate according to their specific needs – for instance by accessing individual sections independently and by following the links within and across entry points or to external resources that support further readings

3 → To serve as a **living tool:** Collaboration is a core value underpinning the development of this Action Guide. To ensure that the content of the guide will remain relevant over time, we encourage continuous feedback and contributions from users, as new insights emerge and evidence evolves.

The Action Guide offers three entry points, which can be explored in no predetermined order:

- WHY is measuring and monitoring efficiency of cancer care relevant?
- WHAT cancer efficiency metrics should be prioritised? How are they conceptualised? What health system levers are key to supporting their implementation?
- HOW can users of this Action Guide pursue implementation efforts? This section provides a step-by-step approach to support implementation of the All.Can cancer efficiency metrics.

By embracing the Action Guide's living nature and leveraging its guidance, users at global, national or federal, subnational and local levels can facilitate a more efficient cancer journey for patients. Below is a visual representation of the Action Guide and how users can navigate it. Each entry point includes a link, as well as the five key steps within the How entry point.

Toolkit navigation system

Why

I want to set my goal focused on increasing efficiency in cancer care

What

I need to better understand efficiency metrics related health system components

How

I want to implement efficiency metrics in my context, so I need a step-by-step guide

Start with a clear goal

Assess your health system's preparedness

Identify key contextual factors

Involve stakeholders who need to be involved and act

Apply key recommendations for implementation

Share your feedback with All.Can

Other components of the toolkit

- Explore further
- Identify barries
- Identify facilitators
- Key steps for implementation
- Illustrative example
- Tips

INTRODUCING THE ACTION GUIDE

The case for efficiency in cancer care

Efficiency in cancer care is defined by All.Can International as 'care that delivers the best possible health outcomes using the human, financial, infrastructural and technological resources available, with a focus on what really matters to patients and society.'

Eight key efficiency metrics for cancer care were identified in a previous study conducted by the Health Value Alliance in partnership with the University of Southampton on behalf of All.Can International (1). While these metrics are by no means exhaustive and should not be regarded as static, they were considered to be a consensual starting point for developing this Action Guide.

Implementing efficiency metrics for cancer care can face many challenges when implementation takes place across different health systems or across the different levels of those systems — macro (policy), meso (organisational) and micro (clinical) levels.

Efficiency is considered a cross-cutting dimension of health system performance, together with equity, sustainability, and resilience. It is also a key policy goal in most countries (3).

The 8 key cancer efficiency metrics identified are:

- Time to diagnosis
- Percentage of cancers diagnosed through emergency presentation
- Primary care interval (number of days from date of first presentation in primary care with symptoms relevant to the final cancer diagnosis to date of first referral from primary care)
- Time from tissue diagnosis to treatment
- Percentage of patients documented as having seen a clinical nurse specialist
- Percentage of patients who received chemotherapy in the last 14 days of life
- Patient experience
- Patient involvement in decision making

Such challenges often relate to a lack of evidence-based, standardised metrics that enable comparisons of the care provided to people with cancer in different contexts. Comparisons are needed to inform decision making on healthcare and health policy by key actors in the system. Other challenges arise from limitations of data systems, poor data standardisation or lack of stakeholder buy-in, along with other systemic and contextual hindrances.

This Action Guide for Efficient Cancer Care is designed to support implementation efforts aimed at efficiency improvements in cancer care service delivery at global, national, subnational and local levels.

Guidance is needed to support stakeholders involved in the cancer care ecosystem in managing the process of implementing cancer care efficiency metrics.

The selection of valid and reliable metrics alone for improving cancer care efficiency is not a guarantor of their use in practice. Rather, the process of implementing the efficiency metrics must be prioritised in order to firmly embed the use of the metrics in cancer care practice. This can ensure a flow of actionable information on system performance.

Structure and aims of the Action Guide

The Action Guide was developed through a systematic and collaborative approach. The aim was to provide useful and actionable guidance to users as they implement measures to improve the efficiency of cancer care delivery in their particular context.

The Action Guide aims to (Figure 1):

- Offer **guidance, resources and recommendations** to stakeholders working to implement cancer efficiency metrics
- Provide a **non-linear tool,** whereby each user chooses the resources most relevant to their own needs
- Serve as a **living tool**, for which continuous iteration of the content and applications is encouraged and feedback and contributions are welcome.

In a **health system approach**, the **complex stakeholder interactions** need to align in order to implement innovations.

This Action Guide was conceived as **a non-linear tool** to enhance efficiency in cancer care services delivery. Users can navigate in the guide **according to their specific needs.**

Figure 1 - Structure and aims of the Action Guide

Guidance for implementation differentiated into 3 themes

- **Preconditions:** Based on the systematic work conducted and using a health systems approach
- **Barriers and enablers:** Identified from interviews with stakeholders from 21 countries and organised through the lens of implementation science

Non-linear tool

- User chooses entry points and specific resources
- Links among different sections
- Illustrative examples: Real-world implementation drawing on case studies identified within All.Can community

Living tool fostering a shared learning community

Ongoing feedback and contributions to enable continuous iteration and improvement of this guide

Intended users

This Action Guide has been developed in a collaborative approach on behalf of, and in close collaboration with, All.Can International and its community. The intended users of the guide are part of the broad network of stakeholders across the cancer care ecosystem (Figure 2).

To ensure effective implementation of key efficiency metrics in specific contexts, each user should consider whether additional stakeholders need to be engaged in the implementation efforts (see subsection Involve Stakeholders Who Need To Be Involved and Act.

Figure 2 Intended users of the Action Guide

Illustration of uses

Efficiency gains can be viewed from the perspectives of the broad range of stakeholders involved in the cancer care ecosystem.

Users of the Action Guide can identify their own specific aims and should then work towards aligning goals and strategies with other key actors to ensure successful implementation efforts.

Figure 3 Illustration of uses by intended users'

Hospital and department managers

Improved allocation of resources while achieving better clinical outcomes

Health and social care workers

Lower work burden and better working conditions, while improving health outcomes for people with cancer or a history of cancer

Insurers

Lower costs related to treatment as a result of more swift and appropriate care, with less complications and better outcomes

NGOs and other patient advocates

Improved processes of care and improved outcomes for people and their families

Policy-makers

Improved population health with economical and societal gains

Industry

Improved efficiency may contribute to make experimental medicines more accessible to patients

Citizens, patients, families

Improved outcomes after diagnosis of cancer, as well as positive care experiences

Societies of medical professionals

Improved work conditions of professionals and reduced administrative burden

Organisations with a role in cancer care

Improved outcomes, value for money, and enhanced people-centred care

Use of the Action Guide

Each user can navigate the Action Guide through different entry points, in no predetermined order, and can benefit from specific resources at each entry point. Choose the sections most relevant to your context and specific needs for efficiency improvement in cancer care delivery. This enables you to pursue more informed efforts and strategies to achieve your specific goals.

A Choose an entry point

This Action Guide for Efficient Cancer Care is organised around three entry points –what, why and how – to guide the efforts of stakeholders in improving cancer care efficiency (Figure 4).

Each entry point provides specific resources and guidance, with particular focuses:

- → WHY is the efficiency of cancer care relevant? This section poses questions to guide users in identifying their specific goals and to make them aware of the potential hindrances that could thwart the effective implementation of the efficiency metrics.
- → WHAT is the conceptualisation of selected cancer efficiency metrics, and what is their implementation status in the various All.Can member countries?
- → HOW can users of the Action Guide pursue implementation efforts? This section provides a step-by-step toolkit for the implementation of the All.Can Cancer Efficiency Metrics, organised into the 5 key steps shown below.

A

Why

I want to set my goal focused on increasing efficiecy in cancer care

What

I need to better understand efficiency metrics related health system components

How

I want to implement efficiency metrics in my context, so I need a step-by-step guide

Start with a clear goal

Assess your health system's preparedness

Identify key contextual factors

Involve stakeholders who need to be involved and act

Apply key recommendations for implementation

Figure 4 - Action Guide entry points

B Apply the toolkit

Each section of the Action Guide provides specific resources as part of the implementation toolkit.

Explore further

Explore further

Supplementary resources with clickable links to provide direct access to useful materials

Identify barriers

Identify barries

List of barriers that could hinder metrics implementation

Identify facilitators

Identify facilitators

List of facilitators that could facilitate metrics implementation

Steps for implementations

Key steps for implementation

Step-by-step guidance with actions related to specific sections

Illustrative example

Illustrative example

Get inspired with successful implementation examples

Tips

Tips

Practical tips to foster your implementation efforts

C Participate in this learning community

The Action Guide is intended as a 'living' tool, to which users can provide ongoing feedback and contributions. It encourages continuous iteration and the development of a shared learning community. Take part in building this learning community and share your implementation experiences and good practices.

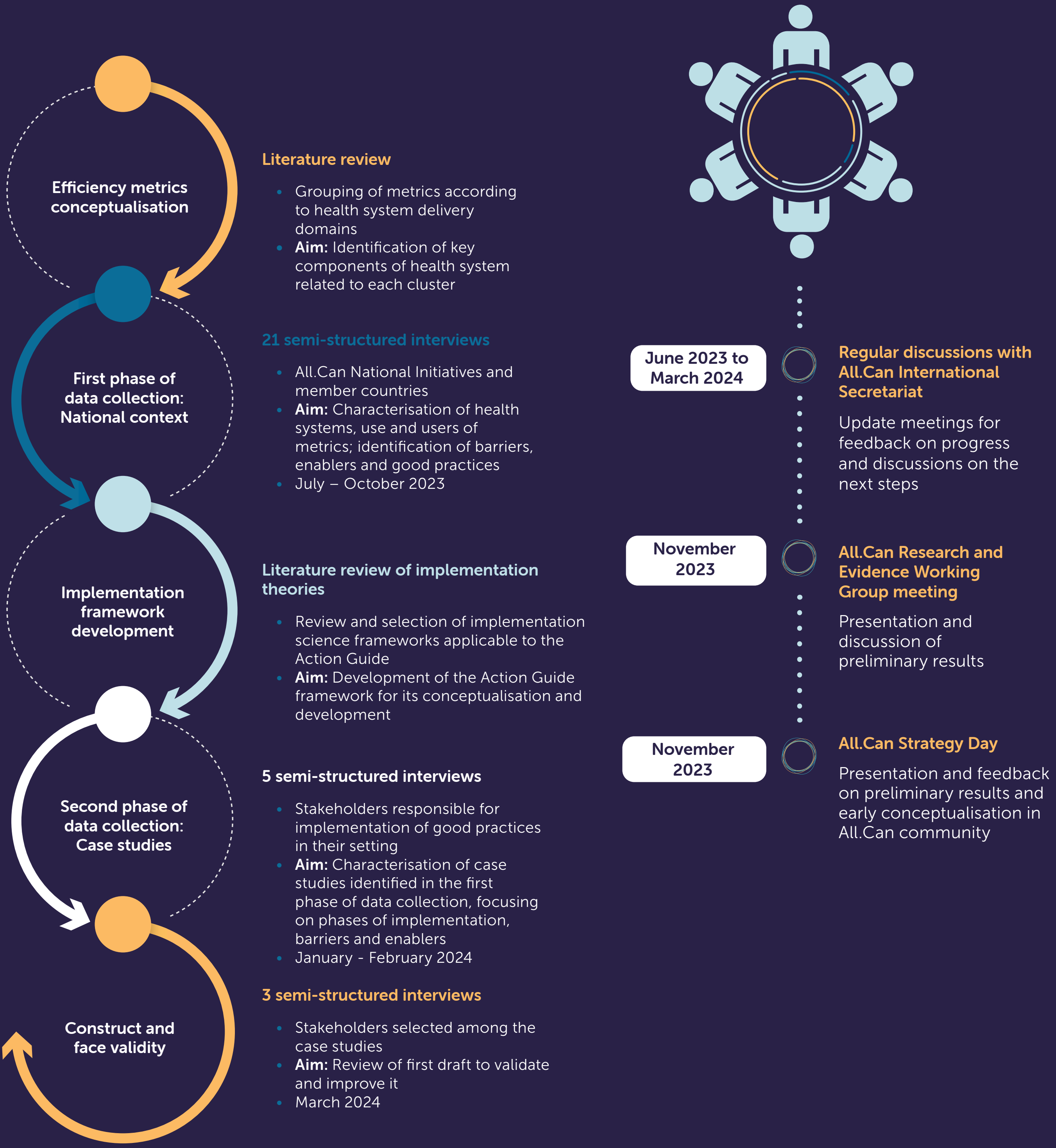
Share your feedback with

All.Can

Process of developing the Action Guide

The development of the Action Guide followed a multi-step approach in collaboration with All.Can International and its community (Figure 5). A detailed methodology description and a full list of interviewees can be found in Appendix 1 and Appendix 3, respectively.

Figure 5 – Methodology for developing the Action Guide



Efficiency metrics conceptualisation

Literature review

- Grouping of metrics according to health system delivery domains
- **Aim:** Identification of key components of health system related to each cluster

First phase of data collection: National context

21 semi-structured interviews

- All.Can National Initiatives and member countries
- **Aim:** Characterisation of health systems, use and users of metrics; identification of barriers, enablers and good practices
- July – October 2023

Implementation framework development

Literature review of implementation theories

- Review and selection of implementation science frameworks applicable to the Action Guide
- **Aim:** Development of the Action Guide framework for its conceptualisation and development

Second phase of data collection: Case studies

5 semi-structured interviews

- Stakeholders responsible for implementation of good practices in their setting
- **Aim:** Characterisation of case studies identified in the first phase of data collection, focusing on phases of implementation, barriers and enablers
- January - February 2024

Construct and face validity

3 semi-structured interviews

- Stakeholders selected among the case studies
- **Aim:** Review of first draft to validate and improve it
- March 2024

June 2023 to March 2024

Regular discussions with All.Can International Secretariat

Update meetings for feedback on progress and discussions on the next steps

November 2023

All.Can Research and Evidence Working Group meeting

Presentation and discussion of preliminary results

November 2023

All.Can Strategy Day

Presentation and feedback on preliminary results and early conceptualisation in All.Can community

1

WHY?

Efficiency as a key aim of implementation efforts

1.1 All.Can definition of efficiency in cancer care

What relevant elements are encompassed by this definition of efficiency?

… 'best possible health outcomes for each individual'

This definition of efficiency deliberately shifts the main focus within health systems from measuring inputs (as with cost measures) and volume of care (with process- or volume-based measures) to the adequate measurement of health outcomes – serving one of the key goals of health systems: improving population health.

… 'what really matters to patients and society'

This definition of efficiency focuses particularly on the evaluation of outcomes from the perspective of patients and society, aligning with the principles of people-centredness in healthcare.

… 'best possible care with the resources available'

This definition of efficiency has its roots in concepts such as the Triple Aim, introduced in 2008 in the United States (2), which focuses on care, health and cost. The three aims – which are regarded as simultaneous – are (i) improve the care experience, (ii) improve population health and (iii) reduce per capita health costs.

All.Can defines efficiency as 'care that delivers the best possible health outcomes using the human, financial, infrastructural and technological resources available, with a focus on what really matters to patients and society.'

Why?
What?
How?

Explore further

'Achieving high value for patients must become the overarching goal of health care delivery, with value defined as the health outcomes achieved per dollar spent. This goal is what matters for patients and unites the interests of all actors in the system.

'If value improves, patients, payers, providers, and suppliers can all benefit while the economic sustainability of the health care system increases.'

Source: Porter, M. E. (2010). What is value in health care? N Engl J Med, 363(26), 2477-2481.

Tips

Efficiency gains (increasing value-for-money) is a key policy option to ensure that health systems are more resilient to shocks, as stressed by the OECD report Fiscal Sustainability of Health Systems (2024).

Tips

Consider and explore the concepts of 'value' and 'value-based health system' when setting your goals and when aligning those goals with all relevant stake-holders.

'Value is a comprehensive concept that is an interaction between outcomes for people and patients, and the resources spent by health systems and societies to achieve these outcomes. Value is more than just monetary value and can be subjective.'

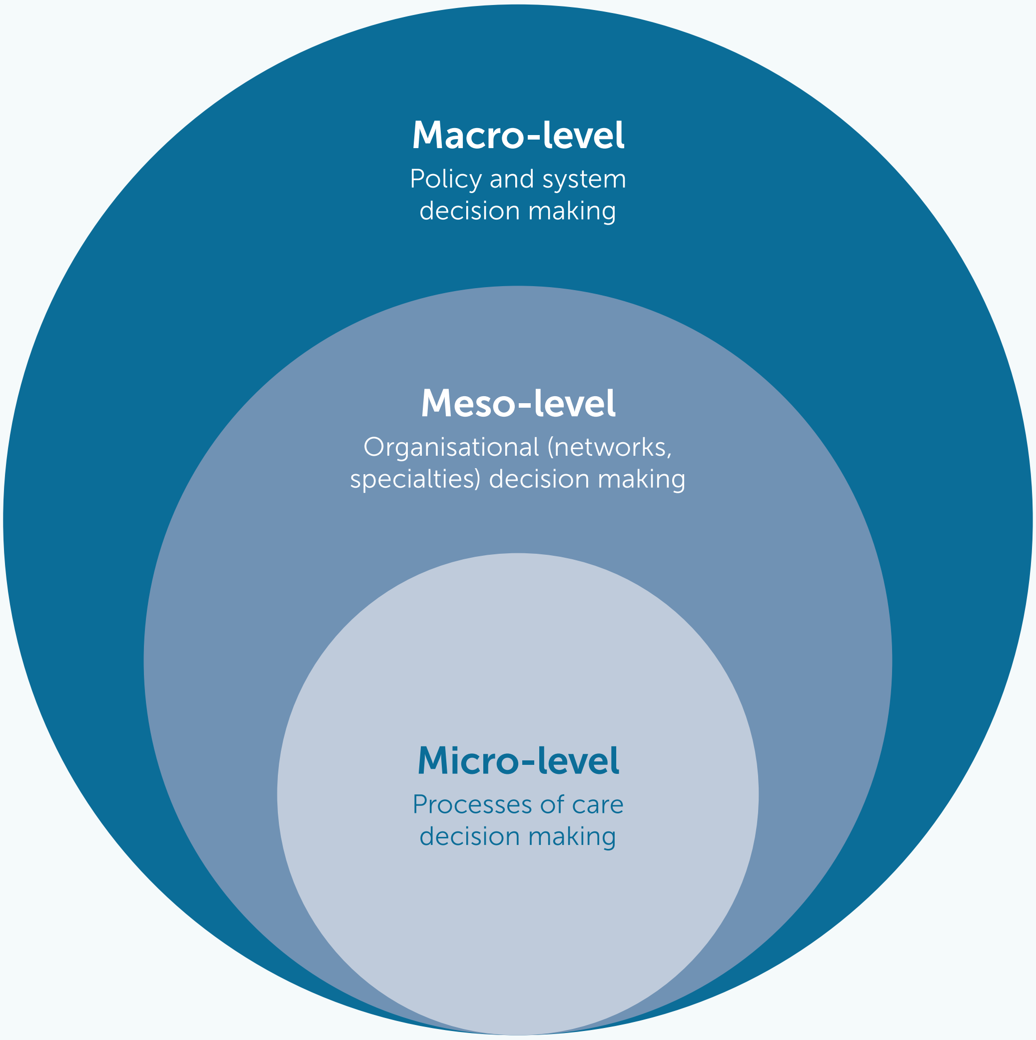
'A value-based health system is organised and resourced to maximise the health outcomes most important for patients and populations, while simultaneously making healthcare more sustainable, accessible and resilient.'

Source: European Alliance for Value in Health. (2022). Talking Value: A Taxonomy on Value-Based Healthcare (accessed 28-03-2024..

1.2 Efficiency goals can vary and apply to different levels

As a 'cross-cutting' dimension of health systems performance, efficiency is related to all components of performance, just as are the domains of equity, resilience and sustainability (3). Hence, the measurement of efficiency is important at all three decision-making levels of healthcare systems: micro, meso and macro (Figure 6).

Figure 6 – The three decision-making contexts of healthcare systems



Adapted from: Barbazza E, Klazinga NS, Kringos DS. Exploring the actionability of healthcare performance indicators for quality of care: a qualitative analysis of the literature, expert opinion and user experience. BMJ Qual Saf. 2021 Dec;30(12):1010-1020. Doi: 10.1136/bmjqs-2020-011247. Epub 2021 May 7. PMID: 33963072; PMCID: PMC8606459. Re-use permitted under CC BY. Published by BMJ (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8606459/figure/F1/).

The interviews conducted with the All.Can National Initiatives and member countries revealed a diverse array of **challenges and bottlenecks that can hamper cancer care efficiency.**

While all countries strive for more efficient care, some encounter specific challenges and hindrances in ensuring equal access to the health system, whilst others face problems in improving waiting times to diagnosis or treatment or improving patients' living conditions after cancer treatment.

Tips

Consider 'value' from the perspective of a broad range of actors within the cancer ecosystem (and the health system). Ensure alignment on which concrete goals you want to achieve in your setting.

'...various initiatives have usually approached the notion of value from the viewpoints of a limited range of actors in the health system and/or have focused on certain dimensions of value. These limited perspectives inhibit progress towards maximising the total value that could be achieved by the health system.'

Source: Smith PC, Sagan A, Siciliani L, et al. Building on Value-Based Health Care: Towards A Health System Perspective. European Observatory on Health Systems and Policies, Copenhagen, 2020. PMID: 33844486.

Explore further

The European Expert Panel on effective ways of investing in health (EXPH), in its report entitled Defining Value in 'Value-Based Healthcare' (2019), proposed to define value-based healthcare as a comprehensive concept, comprising 4 pillars of value: personal, technical, allocative and societal.

Source: European Commission (2019). Defining Value in 'Value-Based Healthcare'. Report of the Expert Panel on Effective Ways of Investing in Health (EXPH), Luxembourg: Publications Office of the European Union.

Explore further

'In any field, improving performance and accountability depends on having a shared goal that unites the interests and activities of all stakeholders.

'In health care, however, stakeholders have myriad, often conflicting goals, including access to services, profitability, high quality, cost containment, safety, convenience, patient-centredness, and satisfaction.'

Source: Porter, M.E. (2010). What is value in health care? N Engl J Med, 363(26), 2477-2481.

2

What?

What are the efficiency metrics and what do they entail?

2.1 All.Can key cancer efficiency metrics in practice

The previous study conducted on behalf of All.Can International by the Health Value Alliance in partnership with the University of Southampton(1) prioritised 8 key cancer efficiency metrics, as noted in the introduction.

The selection of metrics was based partly on their potential for implementation across cancer types in daily care. The aim was to improve the assessment and the efficiency of cancer care delivery from local to global levels.

Eight key efficiency metrics were prioritised from a larger set of metrics, which had been identified via three different search strategies: academic and grey literature publications, cancer registry websites (various national and one international registry) and stakeholder interviews.

The 8 key cancer efficiency metrics identified are:

- Time to diagnosis
- Percentage of cancers diagnosed through emergency presentation
- Primary care interval (number of days from date of first presentation in primary care with symptoms relevant to the final cancer diagnosis to date of first referral from primary care)
- Time from tissue diagnosis to treatment
- Percentage of patients documented as having seen a clinical nurse specialist
- Percentage of patients who received chemotherapy in the last 14 days of life
- Patient experience
- Patient involvement in decision making

Implementation of efficiency metrics in cancer care differs between countries where All.Can is represented

During the early stages of developing this Action Guide, we observed that the countries where All.Can is represented were at **different stages of development and maturity** in terms of implementing the eight key cancer efficiency metrics. Figure 7 shows the countries in which each of the key metrics was reported as being collected and monitored.

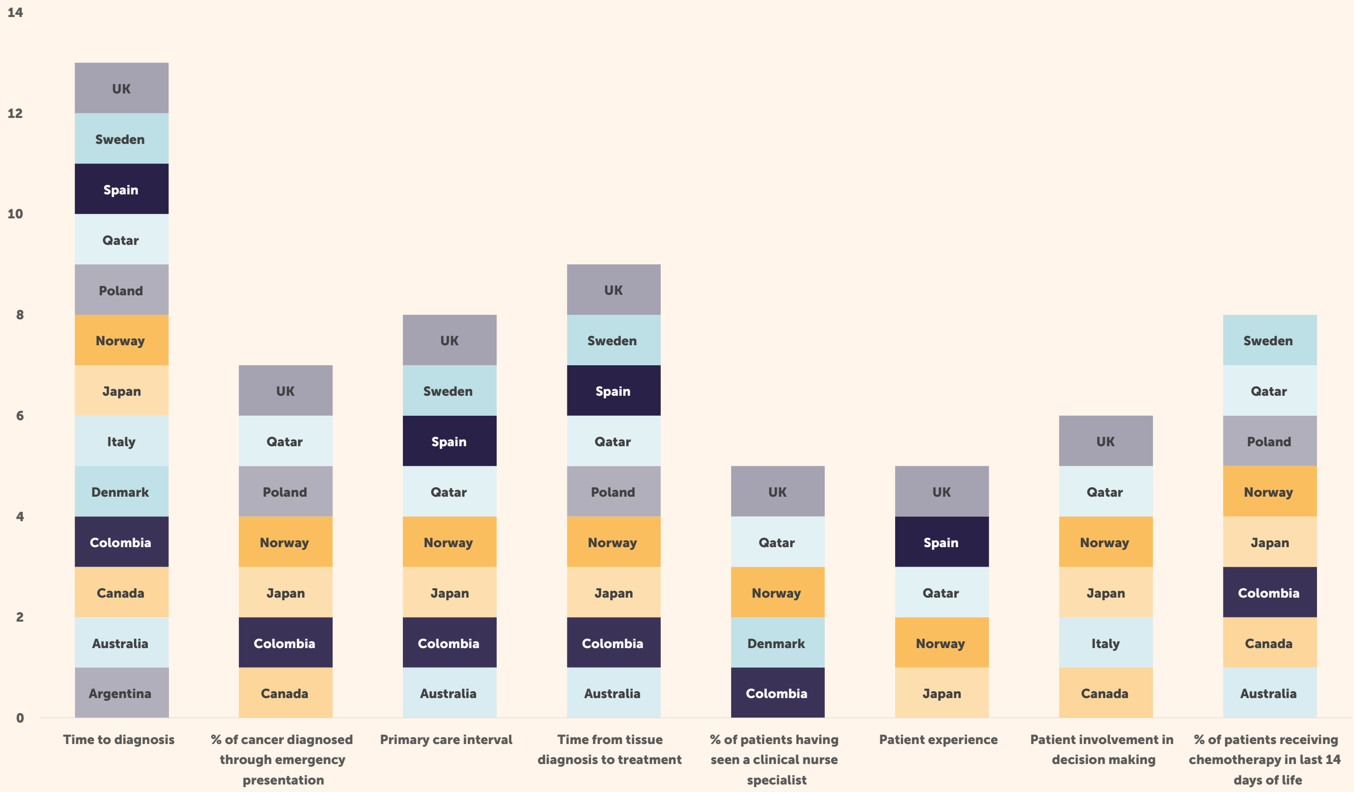
Amongst the 21 All.Can National Initiatives and members interviewed, the metric of **time to diagnosis** was the one most frequently being assessed (n = 13) The other four metrics related to the timeliness of cancer care were being assessed currently in fewer than half the countries interviewed.

Data for the metric that monitors the percentage of patients who have seen a clinical nurse specialist were collected in only 5 of the 21 countries.

As to the patient-reported metric of **patient involvement in decision-making**, fewer than one third of the countries were collecting and monitoring the data.

The metric assessing the percentage of patients receiving **chemotherapy in the final 14 days of life** was monitored in 8 of the 21 countries.

Figure 7 – Implementation of cancer efficiency metrics in countries with All.Can representation (21 interviewed countries)



Source: All.Can Cancer Care Efficiency Heatmap and interviews conducted with All.Can National initiatives

Note: Countries not shown in the figure were found not to be monitoring the metrics, or such information was not clear from the interview.

≡
Why?
What?
How?

‘Metrics’ and ‘indicators’ are tools to measure quality of care

While ‘metric’ and ‘indicator’ both relate to the measurement of some aspect of the quality of care, the term ‘indicator’ is more strongly connected to the managerial or policy purpose of the measurement.

Measuring the performance of health systems worldwide relies on the existence of quality indicators, which are ‘quantitative measures that provide information about the effectiveness, safety and/or people-centredness of care’ (4). As such, quality indicators must:

1. **provide a clear quality goal:** a statement of what quality goal or objective is being assessed
2. **provide a method for measurement:** methods for collecting the data and for calculating the indicator
3. **be an appraisal tool:** an explanation of how the indicator enables the appraisal of quality (4).

However, such attributes are not enough to ensure that indicators generate information and knowledge useful for decision-making. For this, indicators also need to be ‘actionable’.

> The actionability of indicators depends on two key constructs: fitness for purpose – the indicator’s ability to address a concrete information need – and fitness for use – its methodological quality, its suitability for the intended context, and its practical applicability (5).

Explore further

‘Operationalising the theoretical concept of quality by translating it into a set of quality indicators requires a clear understanding of the purpose and context of measurement.’

Source: Busse, R., Klazinga, N., Panteli, D., & Quentin, W. (2019). Improving Healthcare Quality in Europe.

Explore further

Explore the HealthPros practical guide to selecting and employing healthcare performance indicators that work. It provides a barometer for gauging the potential actionability of healthcare performance indicators.

Source: A Practical Guide towards Actionable Healthcare Performance Indicators: Selecting Healthcare Performance Indicators That Are Fit for Purpose and Use for Various Stakeholders, Healthcare Performance Intelligence Series no. 1.3 2022.

2.2 Conceptualisation of the 8 key cancer efficiency metrics

Considering the 8 All.Can cancer efficiency metrics as a starting point, we identified common themes that enabled us to group the metrics into 3 clusters (Figure 8): (1) timeliness of care, (2) coordination of care, and (3) patient-centredness.

The 3 clusters can be regarded as entry points for improving efficiency across health systems. The clusters include the following efficiency metrics:

- **Cluster 1 – Timeliness of care** includes the metrics of (1) time to diagnosis; (2) time from tissue diagnosis to treatment, (3) primary care interval, (4) percentage of cancers diagnosed through emergency presentation, and (5) percentage of patients who received chemotherapy in the last 14 days of life.
- **Cluster 2 – Coordination of care** includes the metric of (6) percentage of patients documented as having seen a clinical nurse specialist.
- **Cluster 3 – Patient-centredness** includes the metrics of (7) patient experience and (8) patient involvement in decision-making.

From metrics to clusters

All.Can 8 key efficiency metrics*

- Time to diagnosis
- Primary care interval
- Percentage of cancers diagnosed through emergency presentation
- Time from tissue diagnosis to treatment
- Percentage of patients who received chemotherapy in the last 14 days of life
- Percentage of patients documented as having seen a clinical nurse specialist
- Patient experience
- Patient involvement in decision making

*metrics identified in the study conducted by the Health Value Alliance in partnership with the University of Southampton on behalf of All.Can International

3 CLUSTERS | Entry points for efficiency improvements

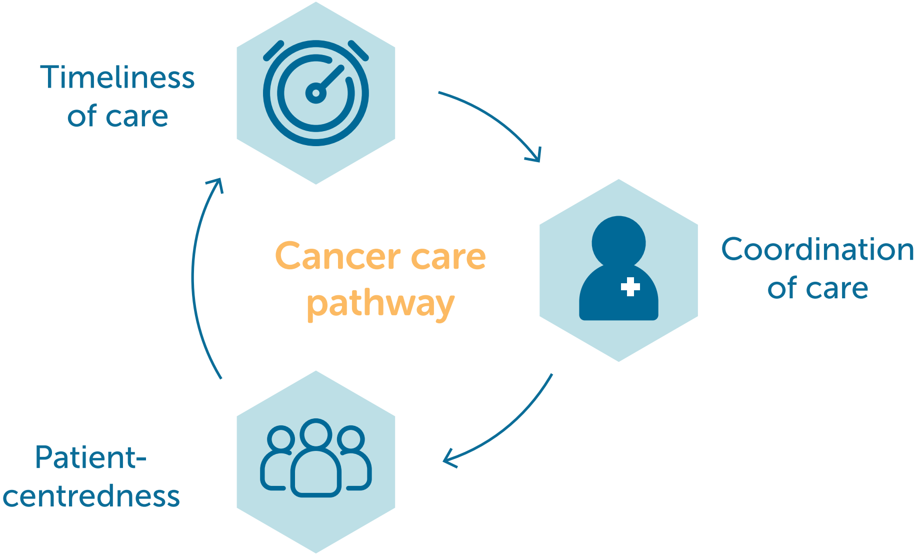


Figure 8 – Grouping of the 8 key metrics into 3 clusters for exploring efficiency in cancer care systems

Within the clusters, health system entry points will guide users of the Action Guide as they explore a cancer care system in their own contexts. Each entry point is paired with health system levers that can serve to strengthen data collection within the system (Table 1):

- **Health system entry points** were identified as overarching dimensions on which to focus in implementing efficiency improvements within a cluster.
- **Health system levers** were identified as key system elements to consider strengthening within each cluster in order to improve efficiency.

Table 1 – All.Can efficiency metrics are grouped into clusters, which map to specific health system entry points and levers

	CLUSTERS OF EFFICIENCY METRICS	HEALTH SYSTEM ENTRY POINTS FOR IMPROVING EFFICIENCY	HEALTH SYSTEM LEVERS Key system elements to strengthen for efficiency improvements
EFFICIENCY METRICS	Timeliness of care	Data infrastructure	Digitalisation and data ecosystem • Cancer registries with staging data • Unique patient identifier • Linkages to other databases Timely follow-up, supportive care, palliative care • Palliative care training • Early access to palliative care
	Coordination of care	Workforce and organisations	Cancer nurse specialists: regulation and access • Cancer navigators: regulation and access • Multidisciplinary tumour boards: organisation, access, monitoring • Comprehensive care centres • Task shifting and sharing
	Patient-centredness	Patient perspective	Patient-reported experience and outcome measures (PREMs and PROMs) • Standardised surveys • Systematic data collection • Linkages to registries Shared decision making

Cluster 1: Timeliness of care

Tips

This cluster concerns the ability of health systems

- to provide and monitor timely cancer care delivery, anchored in a developed data ecosystem
- to ensure continuity of care across the care trajectory.

Continuity of care across the various phases of a patient's care trajectory is a key factor to take into consideration in achieving timeliness of care.

a) Why is it important?

Timeliness of care depends on 'the health care system's ability to provide health care quickly after a need is recognized'(6) and is defined by its capability of 'reducing waits and sometimes harmful delays for both those who receive and those who give care' (7) (US National Academy of Medicine).

Delays in access to diagnosis and treatment of people with cancer have a heavy influence on the health outcomes for those patients.

Continuity of care refers to a smooth organisation of health care within providers and organisations, being closely related to care coordination(8). **Continuity of care is key to achieving efficient and patient-centred cancer care.** It comprises health promotion, prevention, diagnosis, treatment, survivorship, palliative care and end-of-life care.

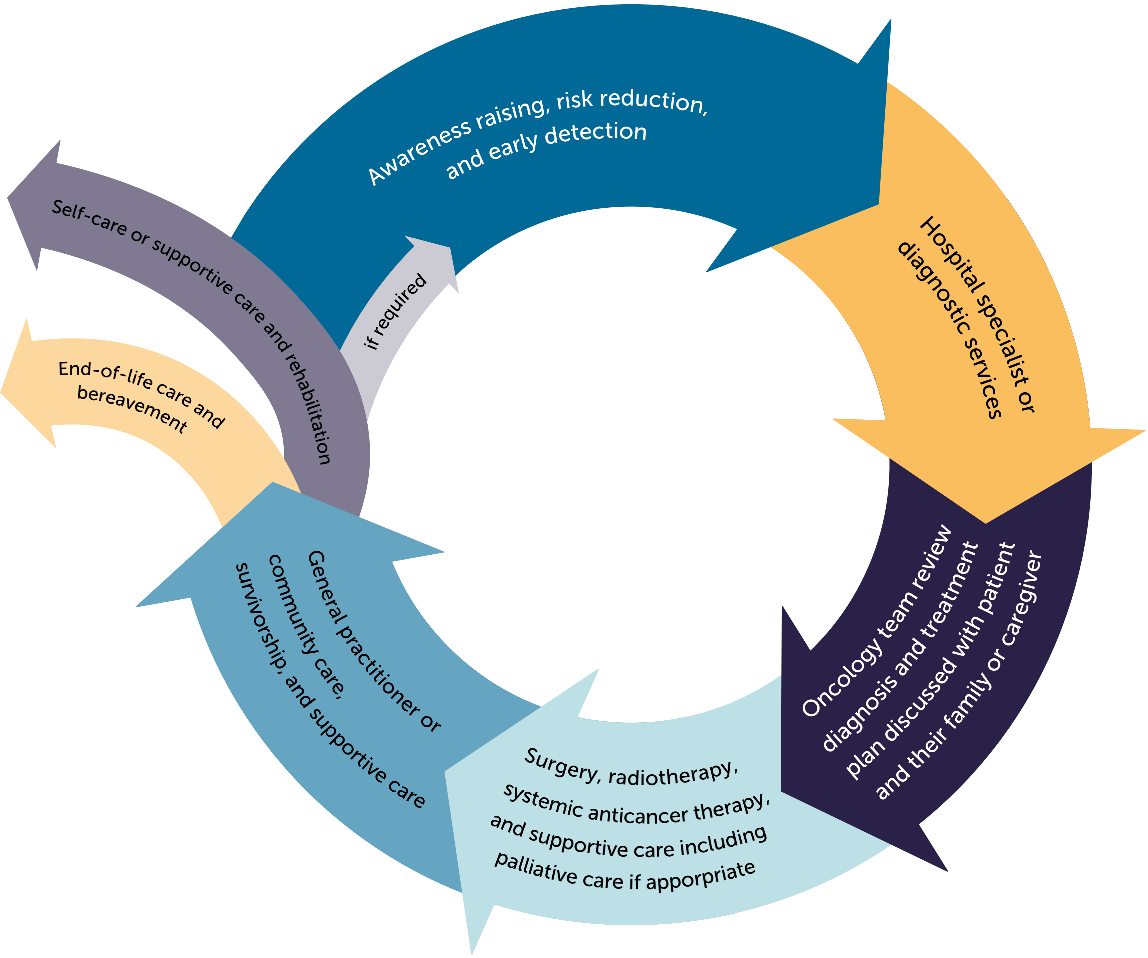
Coordinated care provision involves a smooth organisation of care across healthcare providers and organisations(8).

Innovative efforts in the development of the data ecosystem can have an major impact in achieving timeliness of care.

Tips

Explore the cancer care continuum as a framework to identify priorities along the care trajectory – from prevention to survivorship or end of life – adopting a people-centred approach to enable and empower people with cancer or a history of cancer with regard to their health.

- ■ Health, promortion, prevention, and screening
- ■ Referral
- ■ Diagnosis and treatment
- ■ Treatment and support services
- ■ Follow-up and support services
- ■ End-of-life care
- ■ Survivorship



Source: Young, A. M., Charalambous, A., Owen, R. I., Njodzeka, B., Oldenmenger, W. H., Alqudimat, M. R., & So, W. K. (2020). Essential oncology nursing care along the cancer continuum. The lancet oncology, 21(12), e555-e563

b) Which health system levers can strengthen timeliness of care and its monitoring?

- **Cancer registries** have a pivotal role in (i) the collection of cancer data at regional or national levels and (ii) producing intelligence to inform actions of different stakeholders in the cancer care system. Cancer registries are regularly updated and, if they include staging information, they can facilitate the monitoring of access, quality of care, and outcomes.
- **Linkage of cancer registries** to other data sources, such as pathology databases, insurance databases or electronic health records, enriches the volume of available data about people with cancer. Linkage can ensure a complete, up-to-date overview of the efficiency of a cancer care system at the regional or national levels.
- **Unique patient identifiers** are unique codes assigned to individual people, which enable linkage of data across various databases, such as those with mortality or insurance data. **Timeliness of care** relies on the continuity of care delivery across the care trajectory, which includes timely supportive care, palliative care and end-of-life care.

A mature data ecosystem is key to monitoring timeliness and safeguarding continuity of care. Specifically, the development of cancer registries, their linkage to other databases, and the use of unique patient identifiers (UPIs) to foster interoperability.

Supportive care is defined as the *‘prevention and management of the adverse effects of cancer and its treatment.*

This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through treatment to post-treatment care’(9) by the Multinational Association of Supportive Care in Cancer (MASCC).

- **Early supportive care can enhance the rehabilitation of people with cancer, their survivorship, secondary cancer prevention and end-of-life care** (9). The provision of supportive care is therefore relevant across the continuum of care.

Incorporating high-quality palliative care into standard oncology practice is key to ensuring comprehensive cancer care.

Palliative care can be defined, according to the (US-based) National Comprehensive Cancer Network (NCCN),

- ‘as an approach to patient/family/caregiver-centred healthcare that focuses on optimal management of distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family/caregiver needs, values, beliefs, and cultures.
- ‘The goal of palliative care is to anticipate, prevent, and reduce suffering; promote adaptive coping; and support the best possible quality of life for patients/families/caregivers, regardless of the stage of the disease or the need for other therapies.
- ‘Palliative care should begin at diagnosis; be delivered concurrently with disease-directed, life-prolonging therapies; and facilitate patient autonomy, access to information, and choice.’(10)

Illustrative example

Case study 1 – Cancer Performance Indicator, Health Value Alliance, UK

To address the wide variation in quality of care across contexts, the high percentage of health spending waste, and the increasingly challenging financing of cancer care, the Cancer Performance Indicator (CPI) in the United Kingdom is the Health Value Alliance's reporting platform that allows decision-makers to assess, monitor and report on cancer service and innovation performance (quality, outcomes and value). **The CPI provides a standardised, independent, evidence-based, non-biased and transparent platform.**

The benefits of combining early palliative care with usual cancer care are well established. These include quality-of-life improvement, better control of symptoms, improvement in anxiety and depression levels, as well as prognostic awareness, improved or equal survival rates, and lower or equal costs.

The clinical guidelines of the American Society of Clinical Oncology suggests that 'every patient with advanced cancer should be seen by a palliative care interdisciplinary team within 8 weeks of diagnosis – establishing a new standard of care.'(11)

Incorporating high-quality palliative care into standard oncology practice contributes to improved end-of-life care.

- End-of-life care is defined as 'care for people with advanced disease once they have reached a point of rapid physical decline, typically the last few weeks or months before an inevitable death as a natural result of a disease.'(12)
- Focusing on a person-centred approach to the end of life implies timely cessation of cancer-modifying treatments and avoids superfluous interventions.

Tips

The role of nurses and palliative care teams are essential to support end-of-life care of people with cancer and their families. The End-of-Life Nursing Education Consortium (ELNEC) provides a method to broaden nursing knowledge about end-of-life care.

Explore further

The OECD report Time for Better Care at the End of Life (2023) focuses on the relevance of considering end-of-life care a policy priority.

The report defines 5 key priorities to improve performance in end-of-life care within health systems:

- Access to timely end-of-life care
- People-centred care
- High-quality care focused on providing comfort
- Appropriate financing with shared financial burden
- Well governed and evidence-based care

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Why?
What?
How?

Explore further

The Lancet Oncology Commission on Integration of Oncology and Palliative Care (2018) advocates a full integration of palliative care to achieve the best patient care. To do so, the commission proposes a range of options, including

- the use of standardised care pathways
- the use of multidisciplinary teams
- improving training
- changes at the system level towards better coordination of the activities of professionals.

Explore further

A range of clinical practice guidelines related to supportive and palliative care can support clinical teams and policymakers. These include:

- ESMO Clinical Practice Guidelines: Supportive and Palliative Care.
- Guidelines for Integration of Palliative Care into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update (2016)
- Using the New ASCO Clinical Practice Guideline for Palliative Care Concurrent with Oncology Care Using the TEAM Approach | American Society of Clinical Oncology Educational Book (ascopubs.org) (2017)
- Palliative Care in the Global Setting: ASCO Resource-Stratified Practice Guideline | JCO Global Oncology (ascopubs.org; guideline for resource-constrained settings)
- NCCN Guidelines for Palliative Care (US), *Journal of the National Comprehensive Cancer Network*

Explore further

In the Netherlands, there are regional and national initiatives towards improving sharing healthcare and research data:

- The Health Data Space Amsterdam (HDSA) is a regional healthcare platform for data sharing. It was launched on 18 March 2024 as the result of collaboration between three Dutch hospitals: Amsterdam UMC, OLVG and Antoni van Leeuwenhoek. The HDSA aims to improve the secondary use of health data (in particular for scientific research) and intends to be connected to the national infrastructure that is in development.
- Health RI is an organisation pursuing efforts to create a national network of data exchange and re-use in the Netherlands, notably for research, policy and innovation. It is to serve as a national coordination point for agreements on the re-use of health data and for promoting cooperation between all parties.
- CumuluZ is a national partnership working to build the national heath data infrastructure for data exchange.

Explore further

- In the context of the Cancer IT programme of the eHealth Strategy for Ireland, the Irish National Cancer Information System (NCIS) is a single national digital system that stores information about care provided to people with cancer. It was implemented in 2019 and is currently live in 18 sites across Ireland.
- The NCIS includes a range of functionalities, such as (i) supporting the prescription and the prescription verification of systemic anti-cancer therapy and supportive treatment and (ii) supporting pharmacists to document the compounding and dispensing of systemic anti-cancer therapy. This ensures timely access to records about cancer treatment. The NCIS also supports the planning, scheduling and reporting of multidisciplinary cancer team meetings.

Cluster 2: Coordination of Care

Tips

This cluster focuses on patients' access to skilled healthcare workers and on the organisation of care in specialised centres. It therefore involves the regulation of and access to

- oncology nurse specialists
- cancer patient navigators
- multidisciplinary tumour boards
- comprehensive care centres
- task shifting and sharing.

a) Why is it important?

The availability of skilled healthcare workers and specialised care throughout a well coordinated care journey is fundamental to ensuring effectiveness and equity of care.

Effectiveness refers to the 'degree of achieving desirable outcomes, given the correct provision of evidence-based healthcare services to all who could benefit but not to those who would not benefit' (8). Effectiveness is a fundamental subdimension of quality of care.

The equity dimension in health policies involves ensuring an appropriate distribution of services and resources, in line with the needs identified and with a particular focus on vulnerable groups of the population (3).

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Why?
What?
How?

b) Which health system levers can support the implementation of coordinated cancer care and its monitoring?

Oncology nurse specialists are recognised as a speciality in high-income countries, with an increasing number of roles to meet the numerous needs of people with cancer.

- **The responsibilities of oncology nurses span all phases of the** continuum of care. This includes functions such as advanced practitioner, oncology nursing researcher, oncology clinical trials nurse, and nurse navigator (13).
- **Supportive care is one key role of oncology nurses,** with the aim of preventing or managing psychological and physical symptoms, as well as side-effects from cancer and from treatment.
- **As nurse navigators,** the role of oncology nurses focuses on the facilitation of access to services across the continuum of care, including cancer awareness, as well as supporting the families of people with cancer.
- **Advanced oncology nurses**, such as nurse practitioners and clinical nurse specialists, have a heterogeneous scope of practice across countries and regions. In some cases they can prescribe medication. Other roles include physical examination, working in chemotherapy assessment clinics, communicating results of imaging exams and performing some invasive procedures. (13)
- **Implementation of survivorship plans and providing palliative care** can be other roles of an oncology nurse within a team.
- **Access to oncology nurses varies widely across contexts.** For instance, advanced nursing was reported in 16 of 21 countries in western Europe and in only 2 of 17 countries in eastern Europe (13). There is a significant lack of advanced practice nursing in low-income countries, where it is virtually non-existent (13).

Cancer patient navigators provide individualised support and guidance to persons with cancer, their families and informal carers. Their work seeks to overcome health system barriers and enable timely access to medical care and psychosocial care of high quality along the continuum of care.

Patient navigation has a critical role in supporting patients along the care trajectory, streamlining timely and comprehensive cancer care. Patient navigators are recognised as an element of high-quality, people-centred cancer care.

- **Their roles and responsibilities** are varied, according to the specific needs identified. These might include coordinating appointments, facilitating communication among patients, families and healthcare providers, providing interpretation services, facilitating financial support, and helping arrange transportation. Patient navigators may be healthcare professionals, such as nurses or social workers, or non-clinical members of the community (14).
- **The benefits of cancer patient navigators** are numerous. They have been shown to improve coordination of care, adherence to treatment (notably in vulnerable populations) and clinical outcomes. They are known to reduce the numbers of visits to emergency departments as well as hospitalisations, thereby ultimately reducing healthcare costs (15).

Illustrative example

Case study 2 - Canada's oncology nurse navigators

In Canada, oncology nurse navigators emerged in the early 2000s. They accelerate the process of referrals, facilitate access to care (especially for patients in remote areas) and help reduce waiting times.

Illustrative example

Case study 3 - Argentina's cancer patient navigators

In Argentina, patient navigators have been supporting people with cancer since 2010. Currently there are 4 cancer navigation programmes for breast, cervical, colorectal and paediatric cancers. Patient navigators seek to reduce inequalities in access to healthcare services within the cancer care pathway in particular by reducing barriers to timely diagnosis and treatment.

Multidisciplinary tumour boards (MDTBs) are groups of healthcare providers with differing types of expertise (multidisciplinary) and professions (multiprofessional) who meet to discuss a person's cancer diagnosis and treatment options and arrive at optimal recommendations for the diagnosis and treatment of cancer (16). MDTBs are now recognised as being a key element of good practice in cancer care.

Benefits related to MDTBs have been reported for various oncological diseases, notably reflected in higher percentages of patients receiving an appropriate staging of cancer and receiving treatment according to clinical guidelines (16).

Multidisciplinary tumour boards help to **ensure more comprehensive decision-making** and improve **coordination and continuity of care.** By fostering shared decision making, they can contribute to **more patient-centred** cancer care delivery.

Tips

Become acquainted with the diversity of roles and responsibilities of oncology nurses in the article 'Essential Oncology Nursing Care along the Cancer Continuum'.

Young, A. M. et al. (2020). The Lancet Oncology, 21(12., e555-e563

Explore further

- Lung Cancer Nursing UK, Crucial, Complex, Caring: A Professional Development Framework for Lung Cancer Nurse Specialists. November 2021.
- Explore the characteristics of multidisciplinary tumour boards and their impact on the cancer care continuum in this literature review: 'The Impact of Tumor Board on Cancer Care: Evidence from an Umbrella Review'

(Specchia, M.L., Frisicale, E.M., Carini, E. et al. The impact of tumor board on cancer care: evidence from an umbrella review. BMC Health Serv Res 20, 73 (2020). https://doi.org/10.1186/s12913-020-4930-3.

Why?
What?
How?

Cluster 3: Patient-centredness

Tips

This cluster focuses on the ability of health systems to

- collect, monitor and use patient-reported experiences and outcome measures (PREMs and PROMs) in cancer care
- effectively implement shared decision making and foster patient safety.

a) Why is it important?

Patient-reported measures include metrics designed to assess experiences and outcomes from the perspectives of patients, as well as their involvement in decision-making during care.

- **Regular and standardised collection and monitoring of data using patient-reported measures can ensure that the care provided is aligned with people’s needs and preferences**. Such procedures are also useful in decision-making. They enable clinical progress and quality of life to be monitored in objective ways (using PROMs). Performance of health services and systems can be monitored and areas for improvement identified. Care can be better tailored to the needs, preferences and expectations of people with cancer.

Patient-reported measures enable shared decision making. Patient involvement in decision-making implies collaboration between patients and healthcare providers, whereby patients play a central role in decisions affecting their own health.

- **Shared decision making** enhances patient autonomy, improving both care experiences and adherence to treatment, and it also reduces decision-related anxiety.

Patient safety is a fundamental dimension of quality. It is defined as ‘the reduction of risk of unnecessary harm associated with healthcare to an acceptable minimum’. An acceptable minimum of patient safety ‘refers to the collective notions of current knowledge, resources available and the context in which care was delivered and weighed against the risk of non-treatment or alternative treatment’ (17). Safety from the perspective of healthcare professionals is also a relevant component to take into consideration.

Tips

Providing patient-centred care encourages **patients and families to have an active role in decision making,** collaborating with providers to customise their care plan according to their personal health needs and prioritised outcomes.

The **7 elements from the figure below represent key factors** in the definition of patient-centred care.

Source: 'What is patient-centered care?' NEJM Catalyst. 2017.

Why?
What?
How?

Tips

Explore the use of resources developed to support shared decision making, which improves the ability of people with cancer to choose their treatment according to their individual values and needs:

- The Transition and Patient Empowerment Innovation, Education and Research Collaboration (TIER) is an international collaboration working to empower people to better manage their condition, as well as promoting good practices and sharing resources.
- NHS England has developed a Summary Guide for implementing shared decision making.
- The SHARE Approach is a training programme developed by the American Agency for Healthcare Research and Quality to support healthcare professionals in incorporating shared decision making into their practice.
- The American Society of Clinical Oncology provides an Educational Book entitled Shared Decision Making in the Care of Patients with Cancer (Shickh, S., Leventakos, K., Lewis, M. A., Bombard, Y., & Montori, V. M. (2023). Shared Decision Making in the Care of Patients with Cancer. American Society of Clinical Oncology Educational Book, 43, e389516.)

Illustrative example

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

The National Cancer Patient Experience Survey (NCPES) in England was initiated to address

- the lack of a systematic way to explain and monitor the experience of cancer patients during care delivery
- the need to produce reliable and comparable data across sites and locations regarding the experience of people with cancer

The NCPES operates nationally, funded by NHS England. Its development involved significant amounts of work in various phases, notably in developing the most appropriate tools to be employed for the system. The first national survey was carried out in 2010.

Every 5 years, the survey is reviewed for updating as needed. The current priority is increasing diversity in the representation of groups.

Illustrative example

Case study 5 – Swiss Cancer Patient Experiences (SCAPE) studies, Switzerland

The Swiss Cancer Patient Experiences (SCAPE) survey was initiated to address to following challenges:

- the lack of a standardised instrument to measure patient experience in cancer care in Switzerland
- the need to monitor health system performance from the patient perspective
- the need to embed patient-reported measures in specialised cancer centres

A research team from the University of Lausanne developed the SCAPE surveys in cooperation with the Institute of Higher Education and Research in Healthcare and the Department of Epidemiology and Health Systems. Research began with 4 hospitals in the French-speaking region and is currently implemented in 21 oncology centres in the French-, German- and Italian-speaking Switzerland.

b) Which health system levers can support patient-centredness in cancer care?

Patient-reported experience measures (PREMs) aim to capture patients' perspectives of care experiences, focusing on dimensions such as communication with care providers, access and continuity of care, and overall satisfaction with the care provided.

Patient-reported outcome measures (PROMs) evaluate patients' symptoms and quality of life, frequently measuring pain levels and emotional well-being.

Condition-specific PROMs are designed for specific conditions, such as cancer. Cancer-specific PROMs are tailored to the symptoms most related to cancer and its specific diagnostic and treatment procedures.

To fulfil the goals of such measures, there is a need for standardised data collection, data analysis, and reporting, as well as some more specific requirements:

- The use of standardised surveys is a key step to ensure standardised data collection
- Ensuring systematic and regular data collection, including other measures in clusters 1 and 2, enables regular monitoring of health system performance
- Linkages to registries ensure that these data can be made available to support decision-making

Explore further

Explore the 'Uses of Patient Reported Experience Measures on Health Systems' in this review and the impact on different health system levels.

Source: Gilmore, K. J., Corazza, I., Coletta, L., & Allin, S. (2023). 'The uses of patient reported experience measures in health systems: A systematic narrative review'. Health Policy, 128, 1–10.

Why?
What?
How?

Explore further

Explore ICHOM's specific cancer sets of PROMs available for specific cancers: Advanced Prostate Cancer; Breast Cancer; Colorectal Cancer.

OECD promotes the collection of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) under the PaRIS initiative (Patient-Reported Indicator Surveys), for example collecting PROMs before and after surgery for breast cancer.

Tips

Preventable medication-related harm and patient safety

In a healthcare system, more than 1 in 20 patients are exposed to preventable medication-related harm. Patients in low- and middle-income countries have an almost twofold risk of experiencing such harm (Medication without Harm: Policy Brief. Geneva: World Health Organization; 2023).

WHO has initiated its third Global Patient Safety Challenge: Medication without Harm. In the Strategic Framework of the Global Patient Safety Challenge, it identifies 4 domains – patients and the public, health care professionals, medicines, and systems and practices of medication – and 3 key action areas within each domain: polypharmacy, high-risk situations, and transitions of care.

The OECD Health Working Paper 'The Economics of Medication Safety: Improving Medication Safety through Collective, Real-Time Learning' (2022) presents a range of policy options to improve medication safety:

- developing real-time data sharing and patient access to data
- strengthening pharmacovigilance and systems for review of drug utilisation
- collecting patient experience about medication-related harms and adverse effects
- expanding the roles of pharmacies and pharmacists
- investing in the promotion of good prescribing practices and e-prescribing systems

Health system levers could be strengthened by All.Can members

In all countries where All.Can is represented, health system levers could be strengthened, notably with regard to the patient-centredness cluster. That emerged from data generated from our interviews with 21 All.Can National Initiatives and members (table 2).

For monitoring and ensuring timeliness of care (cluster 1): Cancer registries are present in most of the countries. However, only a few registries include cancer staging information, and few countries have unique patient identifiers implemented to allow linkages between databases.

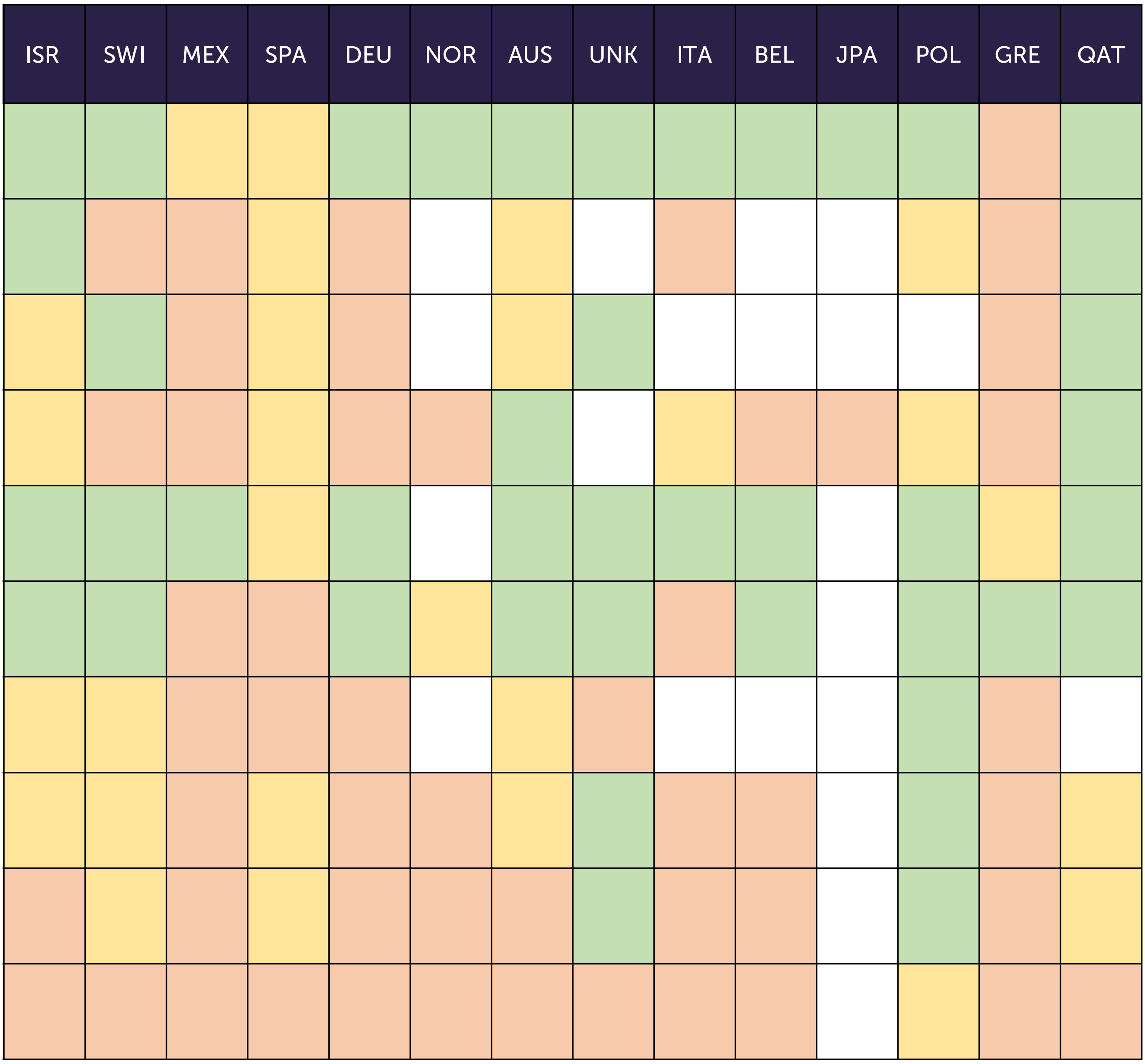
For monitoring and ensuring coordination of care (cluster 2): Multidisciplinary tumour boards (MDTBs) are in place in most countries represented in the All.Can community. However, oncology nurse specialists have not been implemented as swiftly. Task shifting and sharing among professionals is largely underdeveloped.

For monitoring and ensuring patient-centred care (cluster 3): Most countries lack widespread implementation of patient-reported measures, with only pilot projects or research projects in place in many contexts.

Table 2 – Mapping of health system levers among All.Can National Initiatives and members (21 interviewed countries)

Theme	Interview themes	ROM	CAN	COL	SWE	ARG	DNK	KOR
Timeliness of care	Existing cancer registries	🟨	🟩	🟩	🟩	🟩	🟩	🟩
	Staging data	🟧	🟧	🟩	🟩	🟨	🟩	⬜
	Unique patient identifier	🟧	🟨	⬜	🟩	🟧	🟩	🟩
	Linkages to other databases	🟧	🟨	⬜	🟩	🟧	🟩	🟧
Coordination of care	Multidisciplinary team	🟨	🟩	🟩	🟩	🟩	🟩	🟨
	Oncology nurse specialist	🟩	🟩	🟩	🟩	🟧	🟩	🟨
	Task shifting	🟧	🟨	⬜	🟨	🟨	🟨	🟨
Patient-centredness	PREMs / PROMs	🟧	🟨	🟧	🟨	🟧	🟨	🟨
	Standardised surveys	🟧	🟨	🟧	🟧	🟧	🟨	🟧
	Linkages to registries	🟧	🟧	🟧	🟨	🟧	🟨	🟧

🟩 Yes/Exist
🟨 Somewhat/ Regional
🟧 No/Not in place
⬜ Unclear



ISR	SWI	MEX	SPA	DEU	NOR	AUS	UNK	ITA	BEL	JPA	POL	GRE	QAT
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🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧	🟧		🟨	🟧	🟧

Note: The health system levers referred to in the table reflect the interview guide used for the interviews in the All. Can National Initiatives (Appendix 2).

3

HOW?

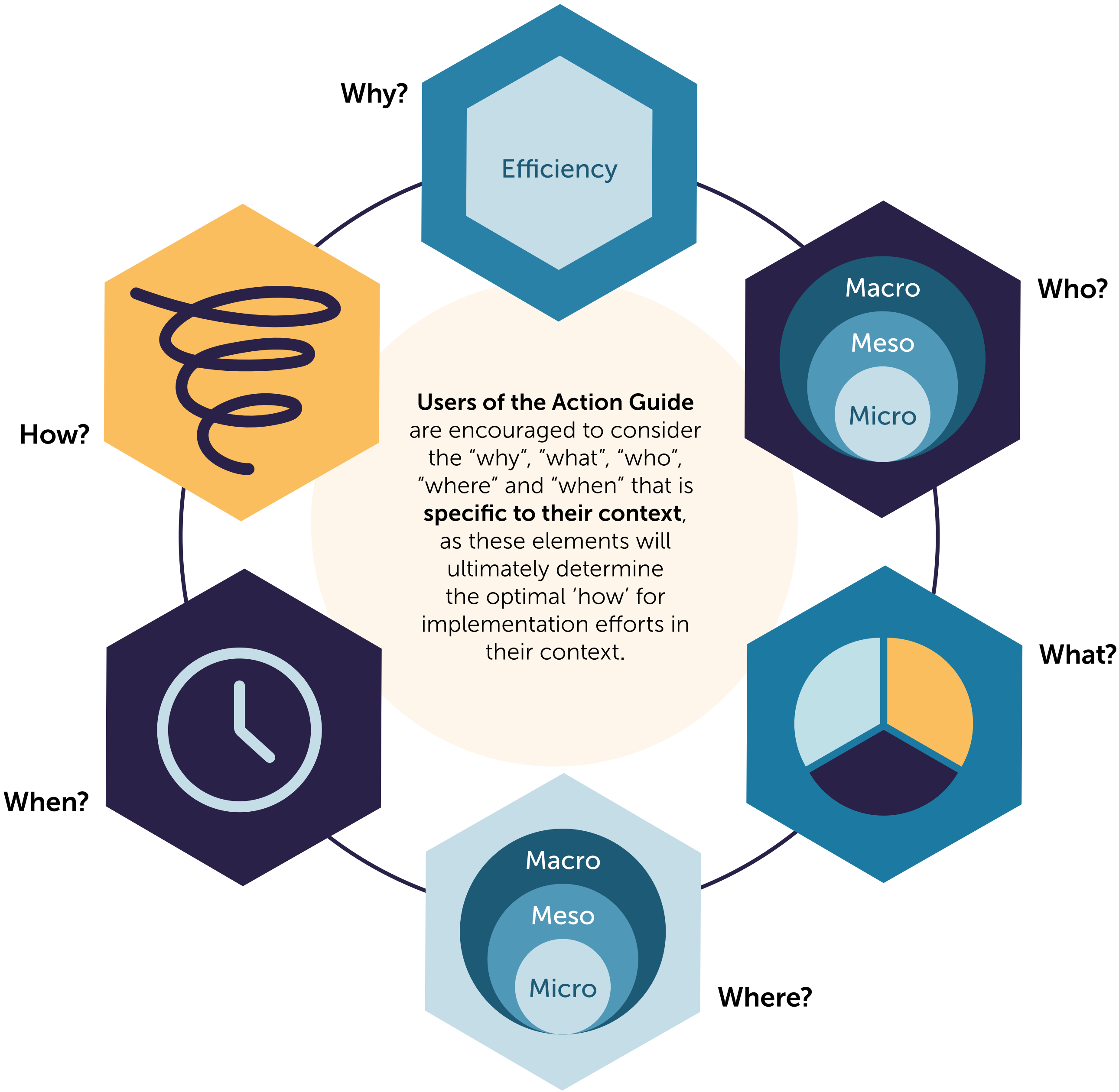
Implementation toolkit:
Translate vision into strategy

This section presents a toolkit for the implementation of the All.Can Cancer Efficiency Metrics, which we have differentiated into 3 clusters.

The toolkit adopts a non-linear approach, enabling different users to tailor application of the metrics to their own specific needs and context. References to supplementary resources are suggested; these may encourage deep dives into specific topics.

The guidance provided here focuses on the policy (macro) and organisational (meso) levels of action, drawing on the findings we made during our systematic creation of this Action Guide. We have co-developed the guide in cooperation with the All.Can community.

This section offers a structured guide for action to pursue effective metrics implementation. It takes into account the inherent complexity of key stakeholders' interactions within the cancer care ecosystem.



Users of the Action Guide are encouraged to consider the "why", "what", "who", "where" and "when" that is **specific to their context**, as these elements will ultimately determine the optimal 'how' for implementation efforts in their context.

Figure 9 – Pertinent questions and complex interaction to consider during metrics implementation efforts

Unveiling your efficiency path in cancer care: A step-by-step guide

This section provides a roadmap for optimising cancer care efficiency within your unique context. By following this **structured approach**, you should be well positioned to identify and overcome any serious roadblocks in **your specific efficiency path in cancer care**.

The roadmap is organised in five key steps:

Start with a clear goal

Assess your health system's preparedness

Identify key contextual factors

Involve stakeholders who need to be involved and act

Apply key recommendations for implementation

1. Start with a clear and shared goal

This step involves asking leading questions to identify the specific care efficiency improvements desired by each user of the Action Guide. What aspect of efficiency are you aiming to improve? What specific outcome or benefit is envisaged? Additionally, you will work towards pinpointing any critical bottlenecks that could impede progress.

- Align with key stakeholders to ensure that your cancer care efficiency goals resonate with all of the parties involved. While building a shared vision, map potential bottlenecks to your shared goal.

2. Assess your health system's preparedness: Preconditions for implementation

The preconditions for implementing improvements to a health system are listed per cluster of metrics – timeliness of care, coordination of care and patient-centredness. In each cluster, preconditions are distinguished into three levels: elementary, intermediate and advanced. These levels enable you to evaluate the health system's preparedness for metrics implementation.

- Users can verify which preconditions are already in place in their context, thus allowing them to identify their starting point for implementation and where the most significant gaps for implementation may be.

3. Identify key contextual factors

During our interviews with actors in the All.Can community (All.Can Members and National Initiatives), we identified relevant barriers and enablers that are present at the macro-level of health systems (the policy decision-making context). We have further differentiated these here through an implementation science lens.

- Users will be able to identify, at the macro-level (the policy decision-making context), what barriers and enablers affecting implementation exist in their context, thereby highlighting which enablers should be strengthened and which barriers must be overcome.

4. Involve stakeholders who need to be involved and act

On the basis of your assessment of health system preconditions (Step 2) and the key contextual factors driving the system and acting as barriers and enablers for metrics implementation (Step 3), this subsection provides guidance in identifying the most important stakeholders with a potential role in implementing the key efficiency metrics in your own context.

- In view of variations across countries and specificities in health systems, users are advised to engage with relevant stakeholders in their context to ensure that their implementation efforts will be effective.

5. Apply key recommendations for implementation

In this step, key recommendations for implementation are provided. These are differentiated per cluster of metrics – timeliness of care, coordination of care, patient-centredness.

- Taking into account the evaluated preconditions for implementation in the health system, and building on the barriers and enablers identified in their own context, users can now formulate actionable recommendations for implementing metrics in each cluster.

≡
Why?
What?
How?

3.1 Start with a clear and shared goal

Setting a clear and shared goal with all the stakeholders involved is an essential step towards achieving efficiency gains in cancer care delivery. To effectively employ the toolkit provided in this Action Guide, users should first consider three questions:

a) What concrete gains in efficiency do you want to achieve in your context?

The focus could encompass various levels of the health system:

System level

- Reducing delays in patients' access to diagnosis and treatment of cancer
- Reducing inequalities in access to diagnosis and treatment across subpopulations or across regions and jurisdictions
- Evaluating quality of care and ensuring equitable care provision across regions
- Improving patient involvement in decision making
- Ensuring assessment and monitoring of patient experiences and outcomes relating to cancer

Organisational level

- Improving coordination among primary and secondary care providers
- Improving coordination among general hospitals and specialised cancer centres
- Reducing bureaucratic work for the workforce
- Reducing medication errors
- Improving patient involvement in decision making
- Ensuring assessment and monitoring of patient experiences and outcomes relating to cancer

b) What are the underlying problems or bottlenecks that cause or exacerbate inefficiencies?

Some of the options below could be considered:

System level

- Underdevelopment of the health information system in terms of monitoring delays and inequities
- Physical infrastructure deficiencies
- Workforce shortages at different health system levels (policy, organisational or clinical levels) or lack of specific skills

Organisational level

- Poor coordination or communication among key stakeholders (including primary healthcare providers, hospital professionals, general hospitals, and specialised or comprehensive care centres)
- Underdevelopment of the health information system
- Difficulty in changing the behaviour of specific stakeholders

c) What steps should I take to achieve the desired goal?

The step-by-step guidance presented in the following sections is differentiated according to the 3 clusters presented in the 'WHAT' section:

Cluster 1: Primary focus on strengthening the health system data ecosystem to ensure timeliness of care

Cluster 2: Primary focus on patients' access to coordinated care

Cluster 3: Primary focus on strengthening patient-centredness and patient safety across the health system

Assess your health system's preparedness

Identify key contextual factors

Involves stakeholders who need to be involved and act

Apply key recommendations for implementation

Tips

Users can pursue different avenues to achieve efficiency gains, depending on their context. At the same time, because the clusters of metrics contain some overlap, the recommendations provided can be cross-cutting. Hence, while following the guidance and recommendations focused on one cluster, users will most likely be improving efficiency across different clusters.

Why?
What?
How?

3.2 Assess your health system's preparedness, focusing on key preconditions – *Preparedness checklist for metrics implementation*

Drawing on the interviews conducted and desk review, we have identified sets of health system preconditions that are most relevant in preparing the implementation of key efficiency metrics in each of the 3 clusters.

This section presents a preparedness checklist that Action Guide users can apply to their context, be it at a national, federal, regional or organisational level.

For each respective cancer efficiency cluster, users can apply the sets of guiding questions specified below. Within each cluster, these address the relevant basic, intermediate and advanced preconditions, which are distinguished by their background colour.

Basic preconditions	Basic requirements to build upon in each of the health system domains identified
Intermediate preconditions	More sophisticated requirements to prepare the system for metrics implementation
Advanced preconditions	Desired level of health system preparedness for implementing the metrics

Tips

Our structuring of the preparedness checklist, which highlights preconditions at 3 levels, should guide the user in prioritising implementation efforts in their own context, be it at a national, federal, regional or organisational level.

Cluster 1: Timeliness of care – Leading questions to assess preconditions for metrics implementation

The list of preconditions for metrics implementation in this cluster focuses on three key components: (a) legal frameworks and strategy, policy context, funding; (b) data governance; and (c) data use and performance monitoring.

a) Legal frameworks and strategy, policy context and funding	Tick if applicable
Is there a cancer control plan or strategy in place, and is its implementation being monitored at national or federal or regional levels?	
Where in the system does the responsibility lie for developing national strategic plans? And for implementing and monitoring them?	
Is there a national or federal political debate or clear political will to invest in improving the national health data ecosystem?	
Has funding been allocated at national, federal or regional levels to invest in improving the national health data ecosystem, and in particular the cancer data ecosystem?	
Is there national, federal or regional regulation of training and organisation for supportive care in oncology?	
Is there national, federal or regional regulation of training and organisation for palliative care, including end-of-life care, in oncology?	
Are national, federal and regional approaches aligned with respect to long-term cancer control plans?	
Are legislation and regulations in place pertaining to cancer data registration and cancer care performance? Is implementation of these monitored at national and regional levels?	
Have standardised patient pathways per cancer type been developed and implemented? If so, do they include • supportive and palliative care? • interdisciplinary cooperation? • roles, responsibilities and referral processes?	
Are national and regional long-term cancer control plans or strategies regularly updated?	
Are there digital health strategies in place at national, federal or regional levels?	
Are there digital health strategies specific to cancer in place at national or federal levels?	
Are legislation and regulations pertaining to cancer data registration and cancer care performance aligned at national and regional levels?	
Are standardised care pathways developed, implemented and updated on a regular basis?	
Are there standards defining maximum waiting times in terms of time to diagnosis and time to treatment (for instance through standardised care pathways)? Is the monitoring of such standards regulated?	
Is timeliness compliance monitored in standardised patient pathways per cancer type, for example for waiting times for appointments, time to diagnosis, and time from diagnosis to treatment?	
Are indicators reflecting timeliness of cancer care available to the public?	
Are indicators reflecting quality of care, including adverse events associated with medication, available to the public?	
Are there national, federal, regional or organisational strategies to monitor and reduce preventable medication-related harms, and specific strategies focused on cancer drugs?	

b) Data governance	Tick if applicable
Is cancer data specifically included in a national strategy for data collection?	
Are there one or more specific organisations responsible for building and maintaining healthcare data infrastructure, and specifically for cancer data? Which organisations?	
Cancer registry: Has a national or federal cancer registry been implemented?	
Cancer registry: Are organisations responsible for the diagnosis of cancer mandated to report to the registry?	
Is 5-year cancer survival monitored at national and regional levels?	
Cancer registry: Does the national or federal cancer registry include data about the staging of cancer at diagnosis?	
Have electronic patient records been implemented at the national or federal level?	
Are there national, federal, regional or organisational policies in place to promote digitalised cancer medication management, including e-prescription, e-preparation and e-administration?	
Does a national unique patient identifier exist which enables database linkages?	
Is it possible to link clinical data across different databases? Examples are cancer registries, mortality data, electronic health records, hospital data and primary care data.	
Is interoperability available amongst electronic health records across the country or region? (Interoperability means 'the ability of systems to connect and exchange information with each other, in either implementation or access, without limitation' (18).	
Is an electronic patient portal with clinical information available to people?	
Cancer registry: Is your cancer registry updated regularly or does it have close-to-real-time data?	
Cancer registry: Does your cancer registry include data about the quality of care provided? Does it include medication administration data?	
Cancer registry: Does your cancer registry include data on patients' education level, disability, unemployment and geographical area?	
Is there a digitalisation strategy in place with respect to cancer medication, interfaced with electronic health records, and specifically including e-prescription, e-preparation and e-administration? In what percentage of cancer centres has this been implemented?	
Has a digitalisation strategy been implemented with respect to cancer medication, which includes data on medication-related harm, and specifically on adverse events associated with cancer treatment?	

c) Data use and performance monitoring	Tick if applicable
Is performance data relating to cancer care available for decision making at national or federal, organisational and clinical levels?	
Are electronic health records and cancer registries linked, making it possible to monitor the effectiveness of novel cancer drugs?	
Does linkage exist between public health databases (such as with screening data), primary healthcare databases, and hospital electronic health records, including pathology data and data on access to palliative care?	
If clinical databases are linked, is the time component present in these databases, enabling the timeliness of cancer care delivery to be monitored?	
Are mechanisms of feedback and learning in place, focused on the performance of the healthcare system?	
Is relevant performance data promptly available to managers and policymakers as close to real time as possible?	
Is national, federal, regional or organisational data monitored and reported with respect to preventable medication-related harms associated with cancer drugs?	
Do patients have access to data about preventable medication-related harms?	
Does your national, federal or regional data infrastructure routinely collect data from your local electronic health records to enable effectiveness research on clinical outcomes of novel therapies?	
Is data monitored at national, federal, regional or organisational levels regarding timely access to palliative care for people with cancer who require it?	

Tips

Assess and improve 'digital health readiness' in your context

Monitoring timeliness and continuity of care must be an intrinsic part of the data ecosystem in every healthcare setting.

The concept of digital health readiness can provide useful insights to improve the preconditions for implementing efficiency metrics. Three dimensions of a health system's digital health readiness are:

- Analytic readiness (ability to use metrics to generate action)
- Health data readiness (ability to collect, access and analyse data)
- Human factor readiness (ensuring sufficient human resources and digital literacy amongst the general public, healthcare providers and policymakers)

Source: OECD (2023), Health at a Glance 2023: OECD Indicators, Paris: OECD Publishing , https://doi.org/10.1787/7a7afb35-en.

Why?
What?
How?

Explore further

European Health Data Space, a European Commission initiative to support the use of health data to improve healthcare, research, innovation and policy making.

OECD's Health at a Glance 2023 includes a special focus on digital health, notably exploring the concept of 'digital health readiness' to enable application of digital means to improve outcomes, patient experiences and care efficiency.

The Lancet Oncology Series paper 'Cancer Control in Latin America and the Caribbean: Recent Advances and Opportunities to Move Forward' and the Economist Impact whitepaper The Future of Cancer Care: Health System Sustainability in Latin America both recognise the need to strengthen the cancer data infrastructure and develop digital health analytics in order to evaluate and improve the quality and sustainability of cancer care delivery in Latin American countries. Improving digital health literacy amongst healthcare workers and patients is one key element in improving oncology service delivery.

Explore further

The WHO report Digital Health in the WHO European Region: The Ongoing Journey to Commitment and Transformation builds on the 2022 survey about digital health in Europe. It presents a range of policies and discusses barriers and facilitators in implementing digital health across WHO member states.

Source: World Health Organization. (2023.. Digital Health in the WHO European Region: The Ongoing Journey to Commitment and Transformation.

Explore further

The global standard provided by the Electronic Medical Record Adoption Model (EMRAM) enables users to assess, on a scale from 0 to 7, the digital maturity of hospitals worldwide. The EMRAM model assesses clinical outcomes, patient involvement and the clinical use of EMR, and it provides a roadmap for improving digitalisation.

Tips

Advocate and work to achieve data interoperability in your context, so as to enable digital transformation and improve health outcomes.

Most medical databases lack interoperability, being siloed databases with incompatible systems. This impedes the ability to share, analyse and monitor health data.

Interoperability of health IT systems can serve many purposes, such as medical communication, health research and international cooperation. (30)

How can interoperability improve digital medicine

AI and Big Data

- Provide algorithms with clear data structure and semantics
- ensure validity of analysis results
- create trust in digital technologies

Medical Communication

- enable easy information retrieval
- avoid medical errors caused by communications barriers
- reduce documentation burden

Research

- Improve the use of real-world data (e.g for large-scale observational studies)
- create new research hypotheses (with data mining and AI)
- enable remote development of analysis scripts

International Cooperation

- pool data accross organisations (e.g. rare diseases, precision medicine)
- tackle global public health issues (e.g. infection control, epidemics)
- provide global access to new technologies

Source: Lehne M, Sass J, Essenwanger A, Schepers J, Thun S. 'Why Digital Medicine Depends on Interoperability'. NPJ Digit Med. 2019 Aug 20;2:79. doi: 10.1038/s41746-019-0158-1. PMID: 31453374; PMCID: PMC6702215.

Why?
What?
How?

Explore further

The eHealth Network provides guidelines on the electronic exchange of health data to enable cross-border interoperability of electronic health records across EU member states.

Various electronic cross-border health services are being implemented in member states: e-prescription and e-dispensation, patient summaries, lab results and reports, medical imaging studies and reports, and hospital discharge reports.

Source: https://health.ec.europa.eu/ehealth-digital-health-and-care/eu-cooperation/ehealth-network_en, accessed 28 March 2024.

Explore further

The Cancer Performance Indicator (CPI) initiative, developed by the UK's Health Value Alliance, provides a globally applicable, AI-supported measurement model to support data-driven and value-based care delivery. It enables cancer services to generate relevant insights for benchmarking outcomes and performance.

The CPI provides standardised measures to assess quality, outcomes and value, including key core measures which are supported by secondary measures to provide further context and explanation.

The 7 core CPI measures are:

1. Patient timeliness
2. Pathway
3. Intervention
4. Patient experience
5. Clinical outcomes
6. Survivorship experience
7. Financials

Explore further

The Lancet Oncology Series paper 'Cancer Control in Latin America and the Caribbean: Recent Advances and Opportunities to Move Forward' identifies specific barriers in the countries studied, such as financing of healthcare and inequalities in access to healthcare and palliative care.

Tips

Explore the Support Tool to Strengthen Health Information System developed by the WHO.

Source: World Health Organization (2021.. Support Tool to Strengthen Health Information Systems: Guidance for Health Information System Assessment and Strategy Development.

Tips

The Multinational Association of Supportive Care in Cancer (MASCC)

- Certifies oncology centres of excellence that provide high standards of supportive care for people with cancer worldwide
- Develops clinical practice guidelines on supportive care to people with cancer.

Tips

The European Association for Palliative Care (EAPC) has published 'Revised Recommendations on Standards and Norms for Palliative Care in Europe' (2022), a valuable tool to support advocacy efforts for palliative care in Europe and abroad.

Why?
What?
How?

Cluster 2: Coordination of care – Leading questions to assess preconditions for metrics implementation

The list of preconditions for metrics implementation in this cluster focuses on six key components: (a) workforce capacity, (b) oncology nurses, (c) cancer patient navigators, (d) task sharing and substitution, (e) multidisciplinary teams, and (f) comprehensive cancer centres.

a) Workforce capacity	Tick if applicable
Is there a national political debate and/or clear political will to invest in improving working conditions, well-being and safety for the health system workforce, and to address deficiencies if needed?	
Have workforce shortages in the cancer care ecosystem been identified in your context? Examples to be considered , although they may differ by health system, include medical oncologists, general surgeons and specialised cancer surgeons, doctors specialised in specific cancers, pathologists, radiation oncologists, radiographers, radiotherapists, oncology nurses, palliative care specialists and nurses, patient navigators, and psychologists. • Is the number of professionals either per 10,000 people with cancer, per 100,000 of population, or both being monitored? If shortages are identified, are there dedicated plans for different professional roles?	
Are there policies in place to address workforce shortages, if necessary?	
Are there policies in place to improve working conditions, well-being and safety for the workforce?	
Are policies to address workforce shortages being implemented and monitored?	
Are policies to improve working conditions, well-being and safety for the workforce being implemented and monitored?	
Do the communication channels between general practitioners and secondary care professionals allow for timely referral and feedback?	
At national or federal levels, is funding available to incentivise, scale up and disseminate approaches designed to improve care coordination?	

b) Oncology nurses	Tick if applicable
Is there a national political debate and/or clear political will to regulate the role of oncology nurses?	
Is the role of cancer care nurse regulated in your context?	
Is there a minimum standardised number of oncology nurses (for instance per 100,000 of population) defined at federal, national, regional or organisational levels? How is the appropriate ratio of nurse staffing defined and regulated?	
How is the average oncology nurse-to-patient ratio defined and regulated with regard to the administration of chemotherapy?	
Is this minimum standardised number of oncology nurses (for instance per 100,000 of population) monitored at the different levels?	
Is the average oncology nurse-to-patient ratio applying to the administration of chemotherapy monitored at the different levels?	
Are there regulations at national or regional levels applying to the role of cancer care nurses, in particular with regard to their autonomy and mandate?	
Do oncology nurses have direct access to oncologists and other physicians? Do they have direct contact with patients and their families and carers?	

b) Oncology nurses	Tick if applicable
Is patient access to oncology nurses monitored at the national level, enabling trends to be monitored in reliable ways? For instance, can administrative data be used to monitor whether oncology nurses are involved in care delivery?	
Is there data available to monitor the impact of oncology nurses on the outcomes and care experiences of people with cancer?	
Are digital medication traceability systems in place to minimise the risk of medication-related harm to patients and to minimise administrative burdens for oncology nurses? What percentage of cancer centres have implemented digital medication traceability systems?	

c) Cancer patient navigators	Tick if applicable
Is there a national political debate and/or clear political will to regulate the role of cancer patient navigators?	
Are cancer patient navigators regulated in your context at national, regional or organisational levels?	
What is the ratio of patient nurse navigators to 100,000 of population in your context and how is the appropriate ratio of nurse staffing defined and regulated?	
Are regulations aligned at national or regional levels with respect to the roles and mandates of cancer patient navigators, such as in access to clinical data, occupancy rates or waiting lists?	
Is there data available to monitor the impact that cancer patient navigators have on patients' outcomes and care experiences?	
Do cancer navigators manage the care pathways of people with cancer from diagnosis to the end of follow-up?	

d) Task sharing and substitution	Tick if applicable
Is there a national political debate and/or clear political will to regulate task sharing and substitution among health professionals?	
Does task sharing and substitution take place among cancer professionals in some contexts?	
Are national legislation and regulations in place pertaining to task substitution among cancer professionals?	

e) Multidisciplinary tumour boards	Tick if applicable
Are there national legislation and regulations in place pertaining to the composition of multidisciplinary tumour boards per cancer type, including details about which professional groups and disciplines are required to be involved?	
Are there national legislation and regulations ensuring that the clinical cases of people with cancer are discussed in a multidisciplinary tumour board?	
What types of multidisciplinary teams (MDTs) are prevalent at national, federal, regional or organisational levels? Examples are MDTs within the hospitals, MDTs across different hospitals for the full care trajectory, and tumour boards per cancer type.	
Are multidisciplinary teams available for people diagnosed with all cancer types that require multidisciplinary discussion?	
Is there national-level monitoring of the extent to which clinical cases of people with cancer are discussed in a multidisciplinary team following a definitive cancer diagnosis? Are any exceptions explained?	
Has patient access to multidisciplinary teams or tumour boards been integrated into quality assurance mechanisms?	

f) Comprehensive cancer centres	Tick if applicable
Are there political discussions at national, federal or regional levels about the implementation of comprehensive cancer centres (CCCs) in your country or region?	
For European countries only: Is there a national plan to participate in the EU network, developed by the EU CraNe Joint Action, which links recognised national comprehensive cancer centres (CCCs) in EU member states?	
Are national legislation and regulations in place about composition, implementation and access with regard to comprehensive cancer centres?	
Are there certified comprehensive cancer centres in your context?	
Do comprehensive cancer centres cover the whole population of the country?	
Are comprehensive cancer centres certified?	

Explore further

To explore the responsibilities and roles of patient nurse navigators, and how they can improve the coordination of care, consult the following resources:

- A systematic review (2023. that identifies and synthesises the evidence on patient navigation across the cancer care pathway is the article 'Patient Navigation across the Cancer Care Continuum: An Overview of Systematic Reviews and Emerging Literature' (Chan RJ et al., CA Cancer J Clin. 2023 Nov-Dec;73(6.:565-589. doi: 10.3322/caac.21788. Epub 2023 Jun 26. PMID: 37358040).
- Policy Brief from the European Observatory on Health Systems and Policies, What Are Patient Navigators and How Can They Improve Integration of Care? (Budde, H., Williams, G. A., Scarpetti, G., Kroezen, M., & Maier, C. B. 2022)
- A literature review 'Patient Navigation Services for Cancer Care in Low-and Middle-Income Countries: A Scoping Review' (2019. provides an overview of cancer patient navigation in low- and middle-income countries (Dalton, M. et al. (2019.. PLoS One, 14(10., e0223537.).
- Care Navigation: A Competency Framework, a report developed by Health Education England (2016).
- Resources from the American Cancer Society about Patient Navigation in Cancer Care

Explore further

Comprehensive cancer centres – Definition and quality standards

- The definition of 'comprehensive cancer centre' encompasses three central pillars: clinical care, research and education. Ensuring multidisciplinary care and clear governance within a broader structure are also fundamental components.
- Accreditation programmes by the Organisation of European Cancer Institutes (OECI), the National Cancer Institute of the United States and Deutsche Krebshilfe have defined the characteristics of such centres through accreditation programmes.
- OECI has defined a total of 100 quality standards as core standards for cancer care and research centres. These are being implemented since 2020.

Sources: Kehrloesser, S. et al. (2021., 'Analysing the Attributes of Comprehensive Cancer Centres and Cancer Centres across Europe to Identify Key Hallmarks'. Mol Oncol, 15: 1277-1288. https://doi.org/10.1002/1878-0261.12950; Oberst, S., Van Harten, W., Sæter, G., De Paoli, P., Nagy, P., Burrion, J. B., ... & Philip, T. (2020). '100 European Core Quality Standards For Cancer Care And Research Centres'. The Lancet Oncology, 21(8., 1009-1011.

Explore further

The Standard for Comprehensive Cancer Care Networks (CCCN) was proposed by the European Joint Action Innovative Partnership for Action Against Cancer (iPAAC) (2018–2021.

- The iPAAC Joint Action has developed sets of standards (SoS) for CCCNs as well as some tumour-specific standards (for colorectal and pancreatic cancer care networks). The SoS provide a list of requirements with which partners of comprehensive cancer care networks (CCCNs) should comply.

Why?
What?
How?

Explore further

The American Commission on Cancer (CoC) is dedicated to establishing standards to govern cancer care delivery, focusing on quality, multidisciplinary care and comprehensive care. The main goals are:

- To establish standards of cancer care delivery.
- To measure quality of cancer care delivery through surveys that assess compliance to those standards and through the collection of standardised data from CoC-accredited organisations.
- To monitor treatment and outcomes with the use of data.
- To develop educational activities to improve cancer care delivery across the care pathway.

Tips

Follow the development of the national comprehensive cancer centres in Europe

Anchored in the ambitions and goals of the Europe's Beating Cancer Plan, the European Commission aims to:

- Establish an EU network linking recognised national comprehensive cancer centres (CCCs) in EU member states by 2025.
- Ensure that 90% of eligible patients have access to comprehensive cancer centres by 2030 (Flagship 5 of Europe's Beating Cancer Plan).
- The EU Joint Action Network of Comprehensive Cancer Centres (CraNE) (October 2022–September 2024) is conducting preparatory work towards these goals.

Tips

The WHO Medication without Harm policy brief defines concepts relevant to medication safety, as well as policy options to improve medication safety globally.

Some key messages are:

- Workforce shortages, as well as fatigue, burnout and poor environmental conditions, contribute to medication errors.
- Many policy options are available to reduce the frequency and consequences of medication errors.
- Patients in low- and middle income countries suffer more serious consequences from medication harms than those in high-income countries.
- Many policy options, such as the development and implementation of targeted national action plans focusing on medication safety, are proposed.

Explore further

The Global Coalition for Radiotherapy was established during the early stages of the COVID-19 pandemic, in April 2020, involving radiation oncologists around the world. The coalition develops advocacy efforts focused on improving care delivery related to radiotherapy for people with cancer, notably to vulnerable populations.

Explore further

Clinical guidelines for cancer are developed and supported by a range of stakeholders internationally.

European Commission initiatives for breast, colorectal and cervical cancers aim to provide evidence-based clinical guidelines and quality assurance schemes throughout the care pathway:

- Breast Cancer: Evidence-based guidelines on screening, diagnosis, treatment, rehabilitation, follow-up and palliative care are available, as well as a quality assurance scheme across the cancer pathway.
- Colorectal Cancer: Evidence-based guidelines on screening and diagnosis are available; guidelines on colorectal cancer care and quality assurance guidelines are in development.
- Cervical Cancer: Clinical practice guidelines and a quality assurance scheme are under development.
- The European Cancer Organisation has launched the programme Essential Requirements of Quality Cancer Care, publishing papers on various tumour types, developed by European experts, which provide organisational specifications on providing high-quality care across the care pathway.
- European Society of Medical Oncology clinical practice guidelines.
- The National Comprehensive Cancer Network (US) provides clinical practice guidelines by cancer type, which are updated regularly.
- American Society of Clinical Oncology (ASCO) likewise provides regularly updated clinical practice guidelines by cancer type.
- Cancer Council Australia provides evidence-based clinical practice guidelines.
- Alberta Health Services provides a Guideline Resource Unit for health professionals offering clinical practice guidelines.
- 'Advanced Breast Cancer Guidelines in Latin America' (2024).
- A collaborative methodology was applied to develop resource-adapted guidelines focusing on Sub-Saharan Africa: 'Toward Optimization of Cancer Care in Sub-Saharan Africa: Development of National Comprehensive Cancer Network Harmonized Guidelines for Sub-Saharan Africa'.

Explore further

Explore further evidence about medication safety in international reports, the role of digitalisation of cancer medicines to improve efficiency, and some successful examples in Europe:

- The Economics of Medication Safety: Improving Medication Safety through Collective, Real-Time Learning (OECD Health Working Papers 2022. reports that 1 in 10 hospitalisations in OECD countries may be a consequence of a medication-related event, and that 1 in 5 hospital inpatients experience harms associated with medication.
- The booklet Digital Medication Management in Healthcare Settings: An Opportunity for the European Union: Call for Action by the Alliance for the Digitalisation of Medication Management in European Hospitals to Support the Digitalisation of Hospitals' Medication Management Pathways, published by the European Health Management Association (EHMA; 2022., also highlights the benefits of implementing digitalisation and automation of medication management in European healthcare systems.
- Unlocking the Potential of Digitalisation in Cancer Care – No Stopping Us Now!, European Cancer Organisation, 2021.
- The Spanish ONCOptimal project (Optimizing Efficiency in Oncology Day Hospitals, 2023. was developed to provide recommendations to optimise efficiency in Spanish oncology day hospitals. It highlights the pertinent role of electronic prescription systems and electronic medication preparation systems, as well as barcode medication administration to reduce waiting times and improve care efficiency.

Why?
What?
How?

Explore further

The American Society of Clinical Oncology (ASCO) suggests a broad range of actions to address shortages of healthcare workers, so as to ultimately ensure access to oncology care. These include:

- Expanding training options, such as oncology fellowships.
- Expanding the use of advanced practice providers, in particular nurse practitioners and physician assistants. These have joined the oncology care teams in US oncology practices.
- Broadening the role of general practitioners, particularly in the survivorship phase of the care pathway.
- Redesigning service delivery.

Source: https://society.asco.org/sites/new-www.asco.org/files/content-files/news-initiatives/documents/2023-workforce-brief.pdf; https://ascopost.com/issues/november-10-2023/how-asco-is-tackling-the-need-to-improve-workforce-diversity-and-the-looming-oncology-workforce-shortage/; accessed 29 March 2024.

Explore further

Various health systems face workforce shortages, whilst a range of policies and organisational models can be implemented to secure professionals.

The EU and OECD's report Beating Cancer Inequalities in the EU: Spotlight on Cancer Prevention and Early Detection (2024. has shown that:

- a) Most EU+2 countries face workforce shortages in their cancer ecosystems. The report highlights various policies adopted by countries to secure professionals.
- b) A number of OECD Countries have concentrated cancer care delivery by establishing comprehensive cancer centres, as well as cancer care networks with different organisational models.

Source: OECD (2024), Beating Cancer Inequalities in the EU: Spotlight on Cancer Prevention and Early Detection, OECD Health Policy Studies, Paris: OECD Publishing, https://doi.org/10.1787/14fdc89a-en.

Explore further

The new EU Regulation on Health Technology Assessment (HTA) for cancer medicines has established that clinical HTA reviews (evaluation of added benefit) will be performed jointly at EU level for the first time from January 2025.

Source: https://health.ec.europa.eu/health-technology-assessment/regulation-health-technology-assessment_en, accessed 5 April 2024.

Cluster 3: Patient-centredness – Leading questions to assess preconditions for metrics implementation

The list of preconditions for metrics implementation in this cluster focuses on two key components: (a) legal frameworks and strategy, policy context and funding; (b) Data governance, use, and reporting.

a) Legal frameworks and strategy, policy context and funding	Tick if applicable
Is there some political debate about involving patients in decision making about cancer care?	
Is there some political debate about embedding patient-reported measures in the health data ecosystem, and in particular for cancer?	
Has consideration been given to patient-reported measures in the national cancer control plan?	
Are patient organisations and representatives involved in the development of long-term cancer control plans?	
Is there legislation in place pertaining to the involvement of the patient in decision making about cancer care?	
During or after a multidisciplinary team discussion about a specific case, is the patient engaged in the discussion so as to enable shared decision making?	
Are there national or federal, regional or organisational initiatives that collect PROMs in standardised ways?	
Are there national, federal, regional or organisational initiatives that collect PREMs in standardised ways?	
Are there policies in place for patients and their families and carers to provide them with education and access to information with respect to prevention, early detection, understanding of the disease, and involvement in decision making relating to treatment?	
Is there a standardised national, regional or organisational approach to collecting PROMs?	
Is there a standardised national, regional or organisational approach to collecting PREMs?	
Are the PROMs data collection efforts coordinated at national or federal levels?	
Are the PREMs data collection efforts coordinated at national or federal levels?	

b) Data governance, use, and reporting	Tick if applicable
Do patients have access to their clinical data?	
Is the collection of PROMs embedded in the health data infrastructure through electronic health records, and in particular for cancer?	
Is the collection of PREMs embedded in the health data infrastructure through electronic health records, and in particular for cancer?	
Are PROMs embedded in cancer registries?	
Are PROMs and PREMs data used for quality assurance and improvement initiatives?	
Are incentive mechanisms utilised to ensure the systematic gathering of patient-reported data?	

Why?
What?
How?

3.3 Identify key contextual factors

Drawing on the interviews conducted with many representatives from the All.Can community, this section highlights the **significant barriers and enablers per cluster of metrics** at the macro (policy) level of health systems.

To facilitate action and to guide implementation efforts, we have grouped barriers and enablers according to five of the 'attributes of context' distinguished by the Implementation in Context (ICON) Framework proposed by Squires and colleagues (26), listed below.

1. Community influences refers to societal influences at large, for instance:

- **Pressure from peer organisations** (outside entities with a degree of affinity or competition with your organisation) to implement an intervention
- Public influences, which depend on public knowledge and attitude relating to the topic

2. Intercommunity, interorganisational and intersectoral relationships are reflected in interactions or partnerships among communities, organisations or sectors, including:

- **Intersectoral collaboration**: Partnerships and collective actions by various health groups aimed at improving population health
- **Community health outreach:** Collaboration between organisations and communities to improve health equity
- **Coordinated action:** Communication and tailoring of interventions by different organisations.

3. Political influences arise from the impact of government or public activities, including:

- **Politics:** Political landscape and interactions amongst people in power and their competitors
- **Political climate**: Public mood and available options with regard to current political issues

4. Regulatory influences stem from the actions of regulatory organisations based on legislation or legal mandates, for instance:

- **Legislation and regulations** outlining roles and responsibilities of stakeholders
- **External policies, directives, mandates and regulations**: Requirements and principles defined and enforced by external bodies, often with binding standards
- **Industrial influences**, such as unionisation
- **Accreditation standards**: Criteria and standards predetermined to enable certifications for healthcare delivery

5. Regional and global influences on health arise from the impact of regional, national or worldwide occurrences, such as pandemics, natural disasters or climate change.

Cluster 1: Timeliness of care – Barriers and enablers

In the All.Can community, most of the identified enablers and barriers that affect metrics implementation in the timeliness of care cluster involve regulatory and political issues (Figure 10).

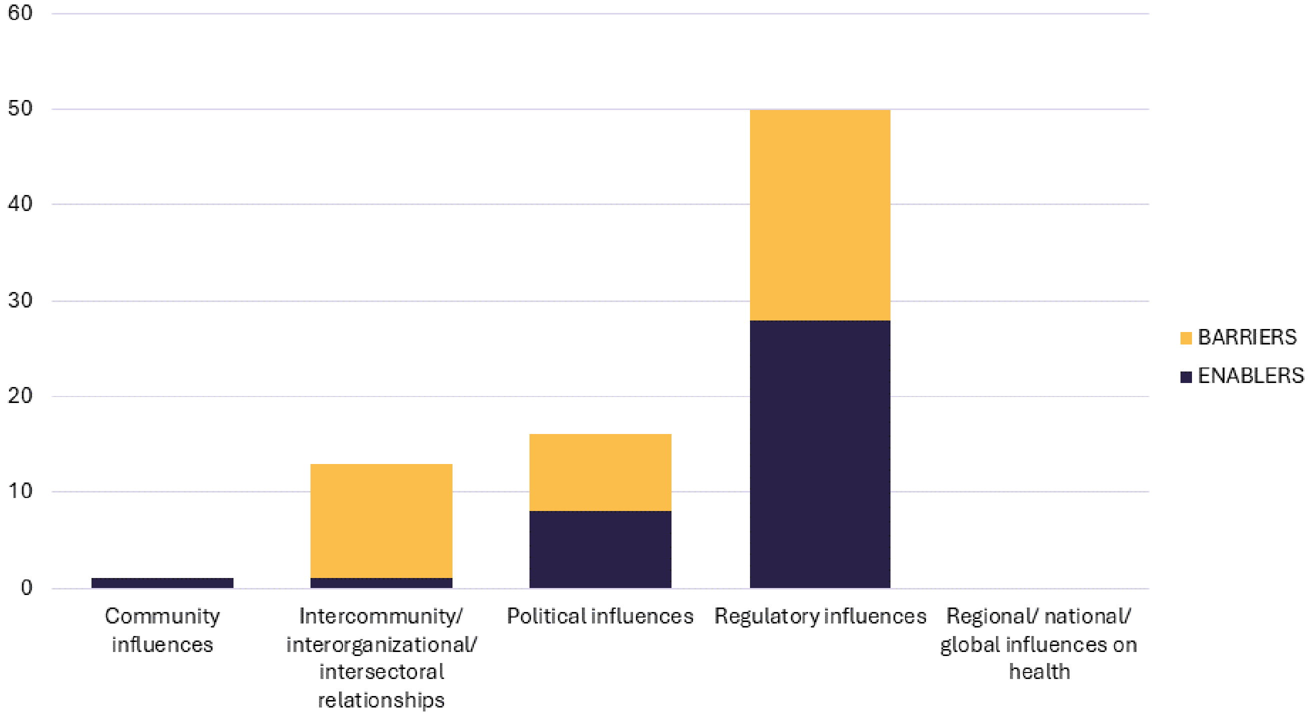


Figure 10 – Enablers and barriers affecting cluster 1 metrics – timeliness of care – at the external health system level (ICON Framework), N = 80

Identify Facilitators

The most important enablers for metrics implementation identified in the timeliness of care cluster were associated with external policies, directives, mandates and regulations, notably:

- Regulation and implementation of standardised cancer care pathways
- Development and implementation of long-term national strategic planning documents
- Integration and feedback mechanisms

Other relevant enablers associated with policies and regulations were:

- Centralisation of data collection in a single organisation
- Reporting mechanisms to national health institutes
- Quality assurance mechanisms (with penalties for hospitals not complying)
- Clarity of the strategic anchoring of efficiency metrics
- Nationwide unique patient identifier
- Secondary use of clinical data

Political will was the most important enabler identified in association with the political influence feature.

Coordination with primary care and peer organisational pressure were also identified as enablers.

Tips

Regulatory and political issues are key to metrics implementation efforts focused on timeliness of care, notably:

- Implementation of standardised cancer care pathways.
- Development and implementation of long-term national strategic planning documents.

Identify Barriers

The most significant identified barriers affecting metrics for timeliness of care were likewise associated with regulatory influences:

- Lack of a national unique patient identifier enabling data linkage
- Lack of a national approach regarding cancer data, and specifically:
    - No access to data for secondary purposes
    - Lack of electronic health records
    - Lack of a mandated requirement to enter data in cancer registry
    - Pathways not standardised at national level
    - Lack of a mandated requirement to monitor indicators

Barriers associated with intercommunity, interorganisational or intersectoral relationships were also identified, notably:

- Lack of interoperability in different databases (data siloing)

As to political influences, the most significant barriers identified were the mandates between national and regional jurisdictions or provincial and federal jurisdictions.

Tips

» Regulatory issues, notably the **lack of a national approach with respect to cancer data**, may pose challenges to metrics implementation focused on timeliness of care.

» A further significant barrier to implementation is a **lack of interoperability between databases.**

Cluster 2: Coordination of care – Barriers and enablers

In the All.Can community, common enablers and barriers affecting metrics implementation in the coordination of care cluster are associated with regulatory issues (Figure 11).

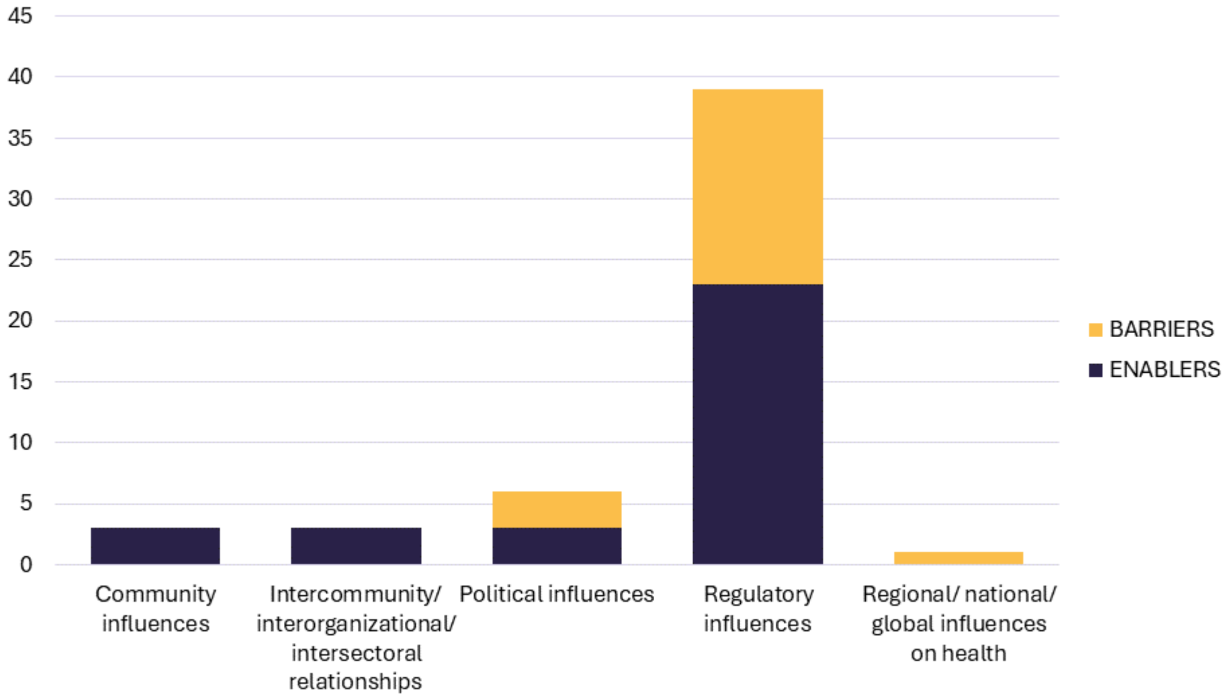


Figure 11 – Enablers and barriers affecting cluster 2 – coordination of care – at the external health system level (ICON Framework), N = 52

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Why?
What?
How?

Identify Facilitators

The most important enablers identified with respect to metrics implementation in the coordination of care cluster were associated with regulatory influences, notably:

- Regulation of profiles and responsibilities for multidisciplinary teams
- Regulation of the professional role of oncology nurses
- Mandated focal point (care coordinator)

Other enablers identified as relevant were:

- Quality assurance mechanisms favouring the use of multidisciplinary teams
- Certification procedures that ensure minimum requirements for multidisciplinary teams
- Centralisation of cancer care in specialised centres
- Professionalisation of a family medicine specialisation in oncology ('general practitioners in oncology')
- Standard care pathways supporting the institutionalisation of multidisciplinary teams

Some community influences were also identified as relevant enablers, particularly:

- the existence of a national association of oncology nurses engaged in implementation efforts

Tips

Regulatory issues are key to metrics implementation efforts focused on coordination of care, notably:

» Multidisciplinary team profiles
» Regulation of the professional role of oncology nurses
» Regulation of care coordinators.

Identify Barriers

The most significant barriers to metrics implementation identified in the coordination of care cluster were likewise associated with regulatory influences, affecting the following issues:

Oncology nurses

- Lack of a legal framework for the oncology nurse role
- Role of care coordinator absent or underexplored
- Variability across jurisdictions in the scope of practice for oncology nurses
- Lack of national prioritisation of regulation for oncology nurses

Multidisciplinary teams (MDTs)

- Lack of regulation of profiles and responsibilities for MDTs
- Heterogeneous regulation of MDTs across regions or jurisdictions
- Lack of centralisation of cancer care in specialised centres

Task shifting

- Lack of regulation concerning task shifting and task sharing

General workforce issues

- Shortages in workforce

Tips

Regulatory issues pose significant challenges to metrics implementation in the coordination of care cluster, notably:

» Lack of a legal framework for the role of oncology nurses

» Lack of regulation concerning task shifting and task sharing

» Lack of regulation of profiles and responsibilities of multidisciplinary teams

Cluster 3: Patient-centredness – Barriers and enablers

In the All.Can community, the institutionalisation of patient-centredness, for instance by embedding patient-reported metrics at health system and organisational levels, is strongly dependent on political and community influences (Figure 12).

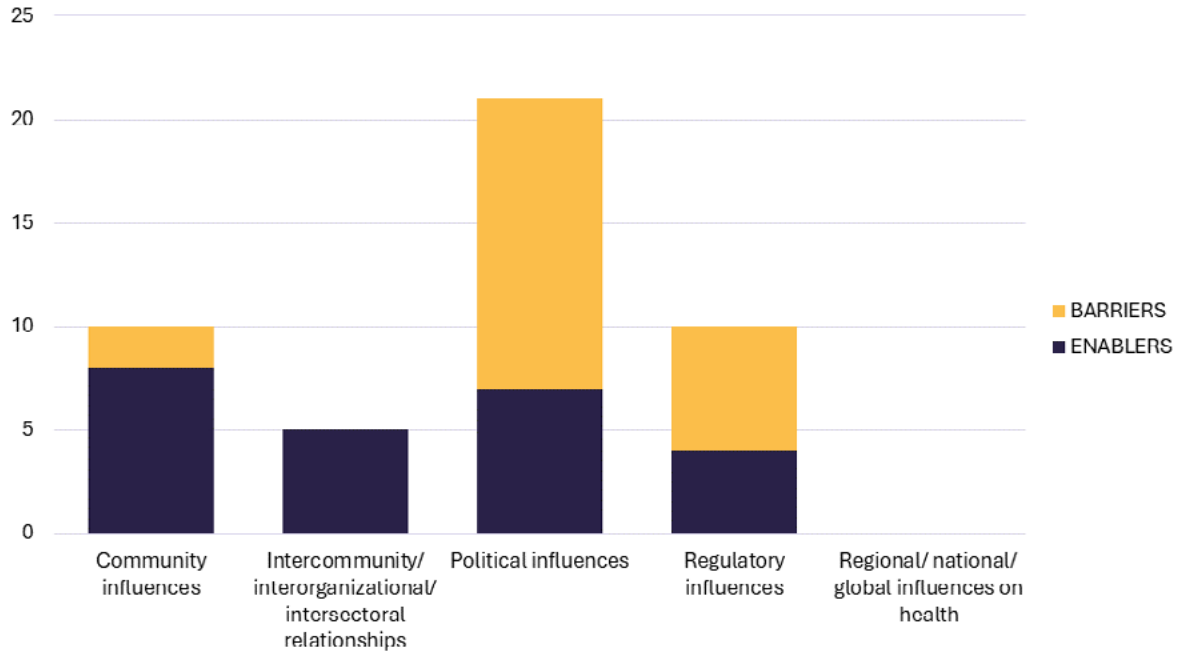

Figure 12 – Enablers and barriers of cluster 3 – patient-centredness – at the external health system level (ICON Framework), N = 46

Identify Facilitators

The most important identified enablers of the implementation of patient-centredness-related metrics were associated with community influences, notably:

Advocacy efforts by patient groups and non-governmental organisations

- Organisational will to include the patient perspective

Other relevant facilitators identified were:

- Political will
- Linkage of the use of metrics to other functions
- Use of standardised tools (national or international)

Tips

Key enablers of metrics implementation focused on patient-centredness are:

- Political will
- Advocacy efforts by patient groups and non-governmental organisations
- Linkage of the use of metrics to other functions
- Use of standardised tools

Identify Barriers

The most significant identified barriers to institutionalisation of patient-centredness-related metrics were associated with political influences, notably:

- The absence of a national approach to systematically collecting patient-reported data

Other relevant barriers were:

- Unclear strategic purpose and use of the metrics
- Lack of political will and funding

Other barriers identified as relevant were associated with regulatory influences, and particularly:

- Lack of standardised tools
- Lack of embedding in existing cancer registries or databases
- Lack of enforcement mechanisms
- Lack of feedback mechanisms

Some community influences were regarded as barriers, namely:

- Low levels of health literacy
- Societal advocacy groups without connections to the healthcare system

Tips

Political influences, notably the **lack of a national approach to systematic data collection,** pose challenges to metrics implementation focused on patient-centredness.

3.4 Involve stakeholders who need to be involved and act

A detailed assessment of stakeholders that are more likely to enable, or to hinder, implementation efforts, as well as their interrelationships and their receptivity to change, is at the foundation of successful implementation efforts.

In this section, leading questions are provided per cluster, guiding users of this Action Guide in identifying key actors that can help address barriers and enablers affecting the implementation of efficiency key metrics in the users' specific contexts.

Explore further

Models for stakeholder mapping could help identify individuals or groups with differing attitudes towards the implementation of efficiency metrics, shedding light on their interrelationships and on their power to help or hinder implementation efforts.

One example is COSMOS (2020), a methodology for healthcare stakeholder mapping, which specifically targets healthcare providers and administrators involved in the organisation and provision of care. It provides a visual approach to identifying stakeholders, their power, and their amenability towards metrics implementation.

Source: Bernstein, S.L., Weiss, J. & Curry, L. 'Visualizing Implementation: Contextual and Organizational Support Mapping of Stakeholders (COSMOS)'. Implement Sci Commun 1, 48 (2020). https://doi.org/10.1186/s43058-020-00030-8

Explore further

Ensuring commitment from all stakeholders, including members of the public, health workers and politicians, is key to ensuring change.

'The task of those in charge of the health system must be to support those delivering and receiving care to ensure that the right mix of health workers, with the right skills and technology (including medicines), are in the right facilities, in the right place, at the right time to meet the needs of the (potential) patient. If this is to happen, health workers and managers must be incentivised, encouraged, and supported to work with patients, carers, families, and communities to co-create solutions, while those at higher levels of the system must facilitate this process. This requires a new approach to health systems, based on a commitment to include all stakeholders, invest the resources needed for change, and innovate with new models of care.'

Source: Kluge H, Azzopardi-Muscat N, Figueras J, McKee M. 'Trust and Transformation: An Agenda for Creating Resilient and Sustainable Health Systems', BMJ 2023; 380 :p651 doi:10.1136/bmj.p651

Cluster 1: Timeliness of care – Key actors

Leading questions to identify key stakeholders in your specific context (in some instances these may also be combinations of stakeholders)

a) National or federal levels

National cancer policy and cancer control plan

- Who are the key actors influencing **national cancer policy?**
    - What other parties could be engaged and acquire more influence on cancer policy at the national level?
- Who is responsible for the elaboration and updating of **long-term national cancer plans?**
    - Who else should be involved in the **development and regular updating of such documents?** Consider a broad range of stakeholders, such as patient advocates, professional associations and health insurers.
- Who should be involved, at the national level, in the development and implementation of **standardised care pathways** per cancer type?

National health data ecosystem

- What parties would need to be involved to **improve the data infrastructure at the national level?**
    - Is the process of data collection centralised in a single organisation, or are multiple organisations involved?
    - What parties could work to improve the interoperability of cancer databases?
- Who should be involved in the **development of cancer metrics?**
- Who are the key actors with influence on the **use of healthcare performance indicators?**
    - Who is authorised to **regulate the use of the metrics?**

b) Regional or organisational level

Health data ecosystem

- At your hospital or in your region, what parties would need to be involved to improve the **data infrastructure?**
    - Are hospital managers aware of its relevance and are they developing efforts to improve the data ecosystem in their hospitals?
- Which organisations are more advanced in the use of metrics in your context, and which could provide support and training to **peer organisations?**

Coordination with primary care

- At your hospital or in your region, what parties would need to be involved to improve the **communication and coordination with primary care** professionals?

Tips

Cluster 1 - Timeliness of care: Examples of relevant stakeholders identified in our interviews in the All.Can community

- National government
- Provincial or regional governments
- National public health institutes
- National cancer institutes and regional cancer agencies
- Institutes for health information
- Cancer research centres
- Insurance companies
- Healthcare organisations
- Civil society organisations

≡
Why?
What?
How?

Cluster 2: Coordination of Care – Key actors

Leading questions to identify key stakeholders in your specific context (in some instances these may also be combinations of stakeholders)

a) National level

Workforce capacity

- Who are the major providers of cancer care in your context, per cancer type?

Oncology nurses

- Which organisation is responsible for the regulation of the oncology nurse profession, and the nurses' roles and responsibilities?
- Which organisation would be able to develop regulations about task substitution amongst cancer professionals?

Cancer patient navigators

- What patient organisations could raise awareness and advocate at the national level for the need to develop patient navigation in cancer care?
- What network organisation of healthcare professionals, for instance a nurses' organisation, could raise awareness and advocate at the national level for the implementation of cancer navigators, for ensuring the exchange of good practices and for alignment of different projects?
- Which organisation should be responsible at the national level for the regulation of cancer navigators, their roles and responsibilities, as well as ensuring standardisation?
- Which organisations would need to be involved to improve the communications and coordination between primary and secondary care professionals?

Task substitution

- Which organisation(s) should be responsible for the regulation of task sharing and substitution in cancer care delivery, as well as for ensuring alignment at national and regional levels?

Multidisciplinary teams

- Which organisation should be responsible for regulating the organisation of multidisciplinary teams per cancer type?
- Which organisation should regulate equitable patient access to multidisciplinary teams?

Comprehensive cancer centres

- Which organisation(s) should be responsible for regulating the organisation and monitoring of comprehensive cancer centres?

b) Regional or organisational level

Oncology nurses

- What parties would need to be involved to implement or develop the role of oncology nurses at the regional or hospital level? (Consider patient organisations, academic institutions, hospital managers, oncology managers and nurse coordinators.)

Cancer patient navigators

- What parties would need to be involved to implement or develop the role of cancer patient navigation at regional or hospital levels? (Consider patient organisations, academic institutions, hospital managers, oncology managers and nurse coordinators.)

Multidisciplinary teams

- What parties would need to be involved to implement or improve access to multidisciplinary teams at the regional or hospital level? (Consider patient organisations, academic institutions, hospital managers, oncology managers and nurse coordinators.)

Comprehensive cancer centres (CCCs)

- What parties would need to be involved to ensure compliance with standards governing CCCs and the certification of your region’s centres or your own centre? (Consider patient organisations, hospital managers, oncology managers and nurse coordinators.)

Tips

Cluster 2 - Coordination of care: Examples of relevant stakeholders identified in our interviews in the All.Can community

- National associations of oncology nurses
- National cancer institutes
- Ministries of health
- National governments
- Non-governmental organisations
- Patient advocacy organisations

≡
Why?
What?
How?

Cluster 3: Patient-centredness – Key actors

Leading questions to identify key stakeholders in your specific context (in some instances these may also be combinations of stakeholders)

a) National or federal levels

Political will and funding

- Which stakeholders could help initiate or foster a **political debate on the involvement of patients in decision making** about cancer care?
    - More specifically, what patient advocacy groups or non-governmental organisations in your context could contribute to the political debate and to the efforts to embed patient measures in the systematic data collection efforts?
- What are the most important research funding organisations in your context, and do they consider patient input to be a requirement for research projects?

National approach to patient-reported data collection

- What people or organisations could be engaged in **efforts to develop the health data infrastructure** to ensure that electronic health records incorporating patient-reported measures can be linked to cancer registries and other public health databases, such as mortality databases?
- Are there successful pilot projects in place that could be scaled up to the regional and/or national level?

Use of standardised tools for patient-reported data collection

- What people or organisations could be engaged in **efforts to standardise patient reported measures in data collection?**

Involvement of patient groups and non-governmental organisations

- What parties representing patients, their families and private citizens could be involved in decision making?

b) Regional or organisational level

Use of standardised tools for patient-reported data collection

- What parties could contribute to the standardisation of patient-reported measures, for instance by helping make existent international surveys applicable in your context?

Involvement of patient groups and non-governmental organisations

- What are the most important research funding organisations in your context, and do they consider patient input to be a requirement for research projects?

Organisational will to include the patient perspective

- What parties representing patients, their families and citizens could be engaged in promoting patient empowerment?

Tips

Cluster 3 - Patient-centredness: Examples of relevant stakeholders identified in our interviews in the All.Can community

- Governments
- Patient associations
- Not-for-profit organisations
- Funding organisations
- Religious groups
- Non-governmental organisations
- Organisations responsible for national cancer strategy
- Healthcare organisations and hospitals
- Specialised survey companies

3.5 Apply key recommendations for implementation

Building on the preconditions identified as most relevant to implementation and taking into account the significant barriers and enablers influencing each cluster, this section provides key recommendations for metrics implementation in the three clusters we have distinguished.

The recommendations are provided in one table for each cluster. They correspond to important preconditions within the components relevant to implementation (first column) and the most significant contextual factors related to each precondition –in particular the enablers (second column).

Importantly, in order to make use of the recommendations below, users should consider issues outlined in previous sections, including

(a) their own specific and shared goal,

(b) the preconditions in their unique health system,

(c) significant contextual factors acting as barriers and enablers, and

(d) the essential stakeholders that need to be engaged in their context.

Cluster 1: Timeliness of care – Key recommendations to optimise metrics implementation

At national, federal, regional levels

Key components for preconditions	Enablers	Recommendations
Legal frameworks and strategy, policy context, funding	→ **National cancer control plan**	• Ensure the development and timely updating of long-term national strategic cancer plans. These should prioritise the inclusion of supportive care, palliative care and end-of-life care within standard care pathways, thus ensuring comprehensive support for people with cancer throughout their care trajectories. • Institutionalise standardised cancer care pathways per cancer type, including: ∘ the regulation of issues affecting timeliness of care and ∘ the existence of mechanisms for monitoring and ensuring timeliness.
	→ **National health data ecosystem, including a national approach to cancer data collection**	• Invest in the development of national health data governance frameworks, specifying the purpose and use of health data by different users. • Develop efforts to legislate and regulate cancer data collection at the national or federal level. • Ensure that funding is available to develop the cancer data infrastructure as part of the overall health data infrastructure. • Ensure alignment of national or federal and regional regulations pertaining to cancer data registration and cancer care performance.
Data governance	→ **Interoperability among databases**	• Invest in developing and promoting the maturity of electronic health records (EHRs) and in particular: ∘ the implementation of a unique patient identifier at national level to enable linkage of healthcare databases and notably the interoperability of cancer registries with other health and care databases.. ∘ the creation of an integrated data infrastructure linking primary and secondary care. ∘ the linkage of EHRs with patient portals that patients can access and contribute to.
Data use and performance monitoring	→ **Mechanisms of feedback and learning**	• Invest in the availability of near real-time performance data, underpinned by specified purposes and uses – notably, quality assurance and improvement mechanisms across the cancer care pathway at national or federal, organisational and clinical levels. • Develop data collection that facilitates the monitoring of inequalities in both access to and quality of cancer care. ∘ This includes prioritising the collection and analysis of data as well as the capability of disaggregating data, for instance by geographical area, sex, gender, education, employment status and disability. • Ensure transparency and accountability by publicly reporting cancer care performance data, whilst developing mechanisms for people to exercise voice. • Co-design action plans to improve patient safety in cancer drug administration by leveraging digital solutions, such as e-prescription, e-preparation and e-administration, and by ensuring interface with electronic health records.

At organisational level

Key components for preconditions	Enablers	Recommendations
Legal frameworks and strategy, policy context, funding	→ **Data ecosystem to monitor timeliness of care**	• Invest in your organisation's data ecosystem to effectively monitor the timeliness of the care pathway. This includes recording key dates along the cancer care pathway, such as: ∘ the date of cancer pathology diagnosis. ∘ the date of the first cancer treatment and the dates of all subsequent treatments. ∘ the date of first contact with an oncology nurse specialist. • Establish mechanisms to identify and track people newly diagnosed with cancer in the emergency department.
	→ **Coordination with primary care**	• Prioritise strengthening the coordination and communication between healthcare professionals involved in the cancer care pathway, particularly those working in primary and secondary care, to ensure timeliness of care.
	→ **Availability of supportive and palliative care**	• Make workforce training and patient and carer training available for supportive, palliative and end-of-life care. • Ensure that mechanisms are available to activate such resources in an effective and timely manner.

By communities and patient advocates

Key components for preconditions	Enablers	Recommendations
Legal frameworks and strategy, policy context, funding	→ **Cancer control plan or strategy**	• Advocate for timely access to supportive care, palliative care and end-of-life care as policy priorities in national oncology policies.
	→ **National health data ecosystem**	• Advocate for enhancing both the health data ecosystem and the timeliness of care delivery at national, regional and local levels. This may include: ∘ advocating for legislation and regulation supporting cancer data collection, while ensuring that aspects related to data ownership and people's rights to authorise use of their personal data for care and research are considered. ∘ implementing transparent reporting systems. ∘ setting measurable targets for improvement. ∘ creating oversight bodies to monitor progress and ensure that political leaders are held accountable for driving positive change.

Cluster 2: Coordination of care – Key recommendations to optimise metrics implementation

At national, federal, regional levels

Key components for preconditions	Enablers	Recommendations
Workforce capacity	→ **Monitoring and addressing workforce shortages in the cancer care ecosystem**	• Ensure that the monitoring and improvement of cancer workforce capacity and capabilities are a national priority. This entails: ∘ monitoring workforce capacity on a regular basis. ∘ documenting in detail workforce shortages that compromise care delivery, so as to determine whether specific policies are needed. ∘ developing strategies to improve the retention of workforce, concentrating on improving working conditions and promoting safety and well-being. ∘ evaluating compliance with regulations governing oncology nurse specialists and cancer patient navigators within your context.
Oncology nurses and cancer patient navigators	→ **Regulation of the professional role of oncology nurses**	• Establish a legal framework for the role of oncology nurse specialists and cancer care navigators and their fit in the cancer care pathway to enhance coordination of care. ∘ If applicable, ensure that they have similar roles, mandates and power at subnational levels. • Broaden the engagement of these professionals along the cancer care pathway in discussing policies to address the burden of cancer and to improve efficiency in cancer care.
Task sharing and substitution	→ **Regulation concerning task sharing and substitution**	• Implement regulations for task sharing and substitution to enable seamless care experiences along the cancer care pathway. ∘ Ensure harmonisation of task sharing and substitution regulations across regions and jurisdictions.
Multidisciplinary tumour boards	→ **Regulation of multidisciplinary tumour boards**	• Regulate the composition of and access to multidisciplinary tumour boards within the cancer care pathway to ensure that quality standards are met. ∘ Ensure harmonisation of regulations across regions and jurisdictions.
Comprehensive cancer centres (CCCs)	→ **Centralisation of cancer care in specialised centres**	• Regulate the centralisation of cancer care delivery in certified CCCs. • Monitor patient access to specialised care in certified CCCs, ensuring equal access to care in these centres.

At organisational level

Key components for preconditions	Enablers	Recommendations
Workforce capacity	→ **Monitoring and addressing workforce shortages**	• Co-develop strategies to make the organisation sufficiently competitive to attract and retain talent, notably by nurturing a workplace underpinned by a robust safety culture.
Oncology nurses and cancer patient navigators	→ **Capacity building for oncology nurses and care navigators**	• Facilitate specific training for oncology nurse specialists and cancer care navigators that enables them to work in better coordination with other professionals along the care pathway. • Establish the role of cancer care navigators, ensuring sufficient capacity and power for a meaningful impact on the care trajectories of people with cancer. • Monitor access of people with cancer to cancer care navigators and the impact of these professionals on care outcomes and experiences.
Task sharing and substitution	→ **Regulation concerning task sharing and substitution**	• Co-develop action plans within your organisation to implement task sharing and substitution amongst professionals, underpinned by quality-of-care values.
Multidisciplinary tumour boards	→ **Regulation of multidisciplinary tumour boards**	• Ensure that the composition of multidisciplinary tumour boards in your organisation and/or the access to multidisciplinary tumour boards outside your organisation conforms to national or international guidelines and good practices per cancer type. • Ensure the functioning of the multidisciplinary tumour boards, notably in terms of capacity and patient access.

By communities and patient advocates

Key components for preconditions	Enablers	Recommendations
Workforce capacity	→ **Monitoring and addressing workforce shortages**	• Advocate for safety culture improvements, in particular regarding staff well-being and working conditions.
Oncology nurses and cancer patient navigators	→ **Regulation of oncology nurses and care navigators**	• Co-design policies that leverage the utilisation of oncology nurses and cancer care navigators in the care trajectories of people with cancer. • Engage with national associations of oncology nurses so as to be actively involved in implementation efforts for utilisation of oncology nurses and cancer care navigators.
Multidisciplinary tumour boards	→ **Regulation of multidisciplinary tumour boards**	• Co-design policies that enhance access to multidisciplinary tumour boards.

Why?
What?
How?

Cluster 3: Patient-centredness – Key recommendations to optimise metrics implementation

At national, federal, regional levels

Key components for preconditions	Enablers	Recommendations
Legal frameworks and strategy, policy context, funding	→ **Political will and funding**	• Ensure sufficient capacity and funding to initiate, monitor and assess pilot projects aimed at implementing standardised and systematic collection of PREMs and PROMs across the entire cancer care pathway – from prevention to survivorship and including patient financial toxicity issues. Consider the upscaling of these measures.
	→ **National approach to patient-reported data collection**	• Develop a national approach to people-reported data collection such as patient-reported outcome (PROMs) and experiences of care (PREMs) measures, specifying clear purposes and uses in order to inform quality improvement initiatives.
	→ **Use of standardised tools for patient-reported data collection**	• Ensure adequate alignment between national and regional approaches to implementing the systematic collection of standardised PROMs and PREMs, including the feasibility of utilising already existing national or international standardised instruments to collect patient-reported measures.
	→ **Involvement of patient groups and non-governmental organisations**	• Actively involve ordinary citizens and patients in designing the health system and driving its performance (e.g. in developing medication safety action plans). Involve organisations representing patients, their families and communities in health policy making.
Data governance, use, and reporting	→ **Embedding of patient-reported metrics in cancer registries or databases**	• Develop the health data infrastructure to ensure that capabilities for collection of patient-reported data are embedded in electronic health records. Ensure adequate capacity to enhance interoperability and linkages to cancer registries and other public health databases, such as mortality databases.
	→ **Enforcement and feedback mechanisms**	• Consider the possibility of enforcement mechanisms for the systematic collection of patient-reported data and ensure that this data is considered in feedback mechanisms.

At organisational level

Key components for preconditions	Enablers	Recommendations
Legal frameworks and strategy, policy context, funding	→ **Use of standardised tools for patient-reported data collection**	• Develop partnerships to design and employ standardised questionnaires to collect information about PROMs and PREMs.
	→ **Involvement of patient groups and non-governmental organisations**	• Nurture the engagement of organisations representing patients, their families and communities in standards and guideline development.
Data governance, use and reporting	→ **Organisational will to include the patient perspective**	• Develop initiatives to provide easy-to-understand information about patients' clinical situation and to promote shared decision making. • Develop digital portals to ensure patients' access to medical information from your organisation.

By communities and patient advocates

Key components for preconditions	Enablers	Recommendations
Legal frameworks and strategy, policy context, funding	→ **Political will and funding**	• Advocate for increased political will and funding allocation that can help improve patient-centredness in the cancer care system, including synergies with broader measures such as patients' right to be forgotten and their return to work.
	→ **High levels of health literacy**	• Promote and develop initiatives to promote patient empowerment and health literacy, with a specific focus on fostering shared decision making.
Data governance, use and reporting	→ **Clear purpose and use of the metrics and linkage to other functions**	• Advocate for the monitoring of equity in access and quality of care, focusing particularly on vulnerable populations.

ILLUSTRATIVE EXAMPLES – *Get inspired by successful case studies*

Case study 1 – Cancer Performance Indicator, Health Value Alliance, UK

Global Standardised Cancer Quality and Value Assessment Model

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 (19).

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 (20). 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 (21). 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 (22). 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 (23). 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 (24).

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 (22).

Solution
Content and scale

Global Standardised Cancer Quality and Value Assessment Model:

The Health Value AllianceCancer 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 – QALYfAITM – 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:

1. **Performing academic work, using the All.Can metrics report (1) 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.
2. **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.**
3. **Achieving collaborative agreement on**
    - **d.** the definitions of quality, outcomes, cost and value
    - **e.** the CPI value domains
    - **f.** the CPI measures under each domain
    - **g.** verified access to the data to enable measurement
    - **h.** supporting development of a common data model
    - **i.** providing access to these data.
4. **Creating the data framework, a technical infrastructure, the AI-supported analytics platform and the CPI reporting portal.**
5. **Ensuring data access and processing.**
6. **Reaching collaborative agreement on the standard reporting model.**
7. **Signing off by the collaborators.**
8. **Making the system go live in agreed geographies (initially UK, US and EU).**
9. **Preparing for full international deployment (from November 2024).**
10. **Deploying internationally (from early 2025).**

Stakeholders

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®

Identify 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.

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

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
Content 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

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)

Identify 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.

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 greatestimpact is on vulnerable populations.

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

Solution
Content 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 people 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

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

Identify 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.

- 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 people with cancer.

Solution
Content 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:

    1. initial invitation, enclosing the questionnaire and covering letter
    2. reminder letter
    3. 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

Implementation has involved a broad range of stakeholders, including:

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

Identify 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.)

- 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
Content 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

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.

Identify 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

- national differences in healthcare systems. As healthcare pathways and organisations vary considerably from country to country, designing the Swiss surveys to has proved challenging.
- 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.

- 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.

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APPENDICES

Appendix 1 – Methodology to develop the Action Guide

Phases of development	Method, aims and time period
1. Conceptualisation of Efficiency Metrics	**Method:** Literature review **a.** Previous work conducted by All.Can was the starting point of this conceptualisation, namely: All.Can efficiency metrics study and All.Can Heat Map. **b.** Analysis of efficiency metrics, namely by grouping metrics in categories according to health system domains and by identifying relevant factors essential for implementation of metrics in different health systems. **Aims:** 1. Grouping of metrics according to health system delivery domains 2. Identification of the key components of the health system related to each theme/cluster of metrics **Time period: July 2023 – Aug 2023**
2. Characterization of implementation of metrics across cancer systems – First round of interviews (National experts)	**Method:** 18 Semi-structured interviews and 3 written replies (21 countries) • national experts from All.Can National Initiatives and Member countries • interviews conducted online with duration of 1 hour • interviews conducted in English by 2 elements of the research team **Aims:** 1. Characterisation of health systems 2. Characterisation of use and users of metrics 3. Identification of barriers, enablers, and good practices related to the use of metrics **Time period: July - October 2023**
3. Application of implementation science to the Action Guide	**Method:** Literature review of implementation theories **Aims:** 1. Selection of implementation framework(s) applicable to the Action Guide 2. Development of the Action Guide framework **Time period: October – December 2023**
4. Characterisation of good practices – Second round of interviews	**Method:** 5 Semi-structured interviews with experts responsible for the implementation of good practices in their context (case studies identified in the first round of interviews) **Aim:** • In-depth characterization of good practices related to the clusters of efficiency metrics, focusing on phases of phases of implementation, barriers and enablers **Time period: January-February 2024**

Phases of development	Method, aims and time period
5. Construct and face validity	**Method**: 3 semi-structured interviews with stakeholders selected among the case studies interviews conducted online with duration of 30 minutes interviews conducted in English by 2 elements of the research team **Aim:** Review of first draft of the Action Guide, to validate and improve first draft, specifically to provide feedback on: 1. Ability of the Action Guide to support and guide stakeholders in implementation efforts in their own contexts, , by providing clear, structured, and useful guidance 2. Adequacy and completeness of guidance and resources provided **Time period: March 2024**
6. Regular meetings and feedback from All.Can community	**Moments and type of interaction with All.Can community:** **June 2023 – April 2024:** Regular discussions with All.Can International Secretariat (virtual) • Monthly update meetings with All.Can International for feedback on the progress and discussions on the next steps **2 November 2023:** All.Can Research & Evidence working group meeting (virtual) • Presentation and discussion of preliminary results **14 November 2023:** All.Can 'Strategy Day' (in-person presentation and discussion with All.Can community) • Presentation of preliminary results • Discussion and input from All.Can community in a panel **March 2024 – April 2024:** 2 Meetings with the broader All.Can community (virtual) • Earlier versions of the Action Guide shared before the meetings • Presentation and discussion of the earlier versions of the Action Guide • Feedback from All.Can community received in the virtual meetings and in written form
7. Update and conclusion of the Action Guide, based on the data collection and feedback from All.Can community (May 2024)	

Appendix 2– Interview guide for the first round of interviews (National experts)

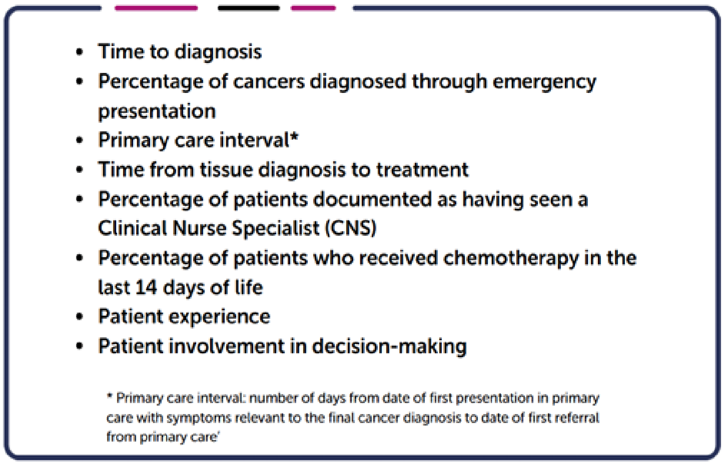
Overview of follow-up interview regarding the All.Can Cancer Policy Heatmap Survey

July 2023

The Health Services and Systems Research Group at the Amsterdam University Medical Centres (University of Amsterdam) is collaborating with All.Can International to strengthen the implementation of cancer efficiency metrics. The research team is composed of Niek Klazinga, Dionne Kringos, Óscar Brito Fernandes, Erica Barbazza, Damir Ivanković and Ana Sofia Carvalho. The primary aim of this collaborative project is to create an Efficiency Metrics Implementation Action Guide that provides a framework for the implementation of previously published cancer efficiency metric categories (All.Can cancer efficiency metrics study):

Following the recent All.Can International Cancer Policy Heatmap Survey, we would like to request your engagement in the development phase of the Efficiency Metrics Implementation Action Guide. The engagement of All.Can National Initiatives and Members will take place via two rounds from July to September 2023.

In Round 1, we would like to invite key informants to discuss the responses received to the All.Can International Cancer Policy Heatmap Survey.



- **Time to diagnosis**
- **Percentage of cancers diagnosed through emergency presentation**
- **Primary care interval***
- **Time from tissue diagnosis to treatment**
- **Percentage of patients documented as having seen a Clinical Nurse Specialist (CNS)**
- **Percentage of patients who received chemotherapy in the last 14 days of life**
- **Patient experience**
- **Patient involvement in decision-making**

* Primary care interval: number of days from date of first presentation in primary care with symptoms relevant to the final cancer diagnosis to date of first referral from primary care'

- In a virtual in-depth country-based discussion based on the answers to the All.Can International Policy survey, we want to explore: 1. how the cancer care pathway (early detection, diagnosis and staging, treatment, and outcomes) is implemented in your country and; 2. how cancer efficiency metrics are being considered.
- Specifically about the All.Can cancer efficiency metrics, a presentation containing the key findings derived from the survey is available here. An extended version of this presentation covering the full extent of the survey is also available for your reference.
- Additionally, we will ask for your support in identifying key informants for Round 2 of engaging with All.Can National Initiatives and Members.

In Round 2, we seek to explore good practices in your country related to the implementation and use of cancer-related efficiency metrics.

For your information, and for you to prepare for the virtual in-depth discussion, below you will find some of the questions that will be explored. The questions are grouped into three general themes that draw from a re-clustering of the All.Can efficiency metrics from a use perspective.

Theme	Leading questions
Overview of uses and signalling functions of time related efficiency metrics	• Where in the cancer care pathway in your country is each of the 8 core efficiency metrics present? ∘ What are their functions? ∘ Who needs (uses) this information? • Many of the core efficiency metrics capture whether certain actions are done in/on time. How are these data recorded in existing cancer registries or databases to calculate these metrics? ∘ Is a patient identifier available to allow database linkages? • Are staging data being collected? Where and by whom? ∘ Do you use a patient identifier with capabilities of linking this information to other cancer databases?
Workforce	Are multidisciplinary teams (MDT) institutionalised in your country's cancer care pathway? • How are MDT operationalised? • What professional roles are included in MDT? ∘ Is oncology nurse a specialty in your country? • Is sharing responsibilities (task shifting) occurring at any stage of the cancer care pathway?
Patient-centred perspective (PROMs/PREMs)	• Are patient-reported outcome and experience measures collected across the cancer care pathway? ∘ If yes, what method is employed (e.g., nationally or internationally standardised survey/measures)? ∘ Are these data embedded in existing cancer registries or databases? ∘ Are these data collected in a systematic manner?

Output of your participation and confidentiality

Your participation will help create an "Efficiency Metrics Implementation Action Guide" closer to the expectations and needs of All.Can National Initiatives and Members. The discussions from the interviews will be embedded anonymously for the purpose of developing the Action Guide, including any written outputs related to the project, such as reports and research articles. Your personal details will be handled with strict confidentiality and will be used by the organisers only for coordination purposes. You will be asked to provide your consent before the beginning of the event to confirm your understanding and agreement to participate.

Location, time, language

The interview will be held virtually and will last up to 60 minutes. Please use this link to select a day/time that suits you. Once a date/time has been agreed, we will share a link to the meeting. The meeting will be recorded for the purposes of detailed note taking. The discussions will be held in English. Yet, any follow-up written responses may be in the language preference of responding informants.

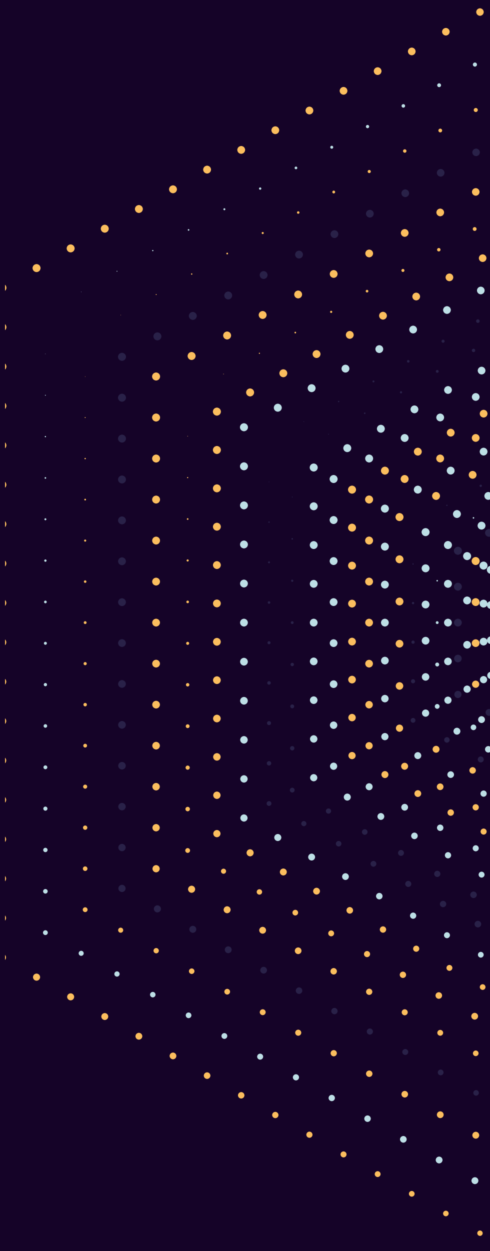
If you have any questions regarding the All.Can Cancer Efficiency Metrics Implementation Action Guide and your participation, do not hesitate to reach out to the research team via:

Óscar Brito Fernandes
Health Services and Systems Postdoctoral Researcher
Amsterdam UMC, University of Amsterdam

Appendix 3 – Characteristics of the national experts consulted

Country	All.Can National Experts affiliations	Perspective/ type of stakeholder	Name
Romania (Individual Member)	President of InoMed, NGO focused on innovation in the healthcare sector Policy advisor	Association (patient, professional) Researcher, MD	Marius Geantă
	Politehnica University of Bucharest	Researcher	Adriana Boată
Canada (National Initiative)	Save Your Skin Foundation	Association (patient, professional)	Taylor Tomko
Canada (National Initiative)	All.Can Canada Save Your Skin Foundation	Association (patient, professional)	Leah Stephenson
Colombia (National Initiative)	"Fundación Rasa" "Pacientes Colombia" (Colombia's patients)	Association (patient, professional)	Gustavo Campillo
Sweden (National Initiative)	Upsala radiation clinic Member of professional societies radiation oncology and oncology	Health professional (Oncologist and Radiotherapy expert) Association (patient, professional)	Kjell Bergfeldt
Argentina (National Initiative)	Healthcare communication company (private)	Industry/ health company Health professional	Eugenia De La Fuente
	Healthcare communication company (private)	Industry/ health company Health professional (MD)	Jimena Worcel
			Julia Ismael
Denmark (National Initiative)	Lead agency	Industry/ health company	Peter Albæk
	Lead agency	Industry/ health company	Frederikke Qvist Matthiesen
Korea (National Initiative)	Gachon University Gil Medical Center in Seoul, Korea	Health professional (MD) Researcher	Inkeun Park
	Macoll Consulting group	Industry/ health company	YL Lim (Michele)
Israel (National Initiative)		Association (patient)	Guy Tavori
Switzerland (National Initiative)		Association (patient, professional)	Sara Käch

Country	All.Can National Experts affiliations	Perspective/ type of stakeholder	Name
		Health professional Researcher Policy-maker/ stakeholder	Roger van Moos
Mexico (National Initiative)	Fundsalud – "Mexican Health Foundation"	Association (patient, professional) Health professional	Alejandra Almeida
Spain (National Initiative)	Cariotipo	Association (patient, professional)	Sofía Carias
	Cariotipo	Association (patient, professional)	Sofía Briganty
Norway (National Initiative)	**Ole Tom Nomeland** (AdHoc Management)	Association (patient, professional)	Ole Tom Nomeland
Germany (National Initiative)	ESOP European Society of Oncology Pharmacy	Association (professional) Health professional	Klaus Meier
		Researcher	Mirjam Crul
Australia (National Initiative)	National cancer hospital and Royal Melbourne Hospital University of Melbourne	Health professional Researcher	Christobel Saunders
Italy (National Initiative)		Industry/ health company	Giovanni Lambri
Qatar (Individual Member)	National Cancer governance board	Health professional Researcher	Hadi Mohamad Abu Rasheed
Greece (National Initiative)	Hellenic Cancer Federation – ELLOK	Government health agency Association (patient)	George Kapetanakis
Belgium (National Initiative)		Health professional	Pia Cox Written reply
Japan (Individual Member)		Association (patient)	Kenichi Oi
			Kazuo Kijima
		Industry/health company	Shinichi Sugimoto
Poland (National Initiative)		Association (patient)	Szymon Chrostowski Written reply
United Kingdom (National Initiative)		Industry/health company	Francesca Berry Written reply



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