



The All.Can Cancer Efficiency Metrics Study:

A collaborative policy research
project to identify a standard set
of metrics to measure cancer
care 'efficiency'.



Changing cancer care together

All.Can International is a not-for-profit organisation (ASBL) registered in Belgium. Its work is made possible with financial support from Bristol Myers Squibb (main sponsor), Roche (major sponsor), MSD and Johnson & Johnson (sponsors) and Baxter and Illumina (contributors).

About All.Can

All.Can is an international, multi-stakeholder, non-profit organisation aiming to identify ways we can optimise the use of resources in cancer care to improve patient outcomes. All.Can brings together representatives from patient organisations, policymakers, healthcare professionals, research and industry. It is made up of All.Can International as well as All.Can national initiatives established in 18 countries (at the time of writing).

Disclaimer

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In alignment with its statutes and bylaws, all activities and outputs of All.Can represent consensus of members, who have full editorial control.

Acknowledgements

All.Can International, the Health Value Alliance and the University of Southampton, UK, would like to thank the All.Can Research and Evidence Working Group for supporting the conceptualisation, methodology and iterative versions of this report. Also, thank you to the interviewees for their engagement and insights.



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This review has been produced by The Health Value Alliance in partnership with the University of Southampton on behalf of All.Can International. The author contributions are outlined below according to the internationally recognised Contributor Roles Taxonomy (CReDiT) system (<http://casrai.org/credit>).

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**"Efficiency would save lives,
like mine, which is by far the
most important thing to
patients."**

Patient

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Executive Summary



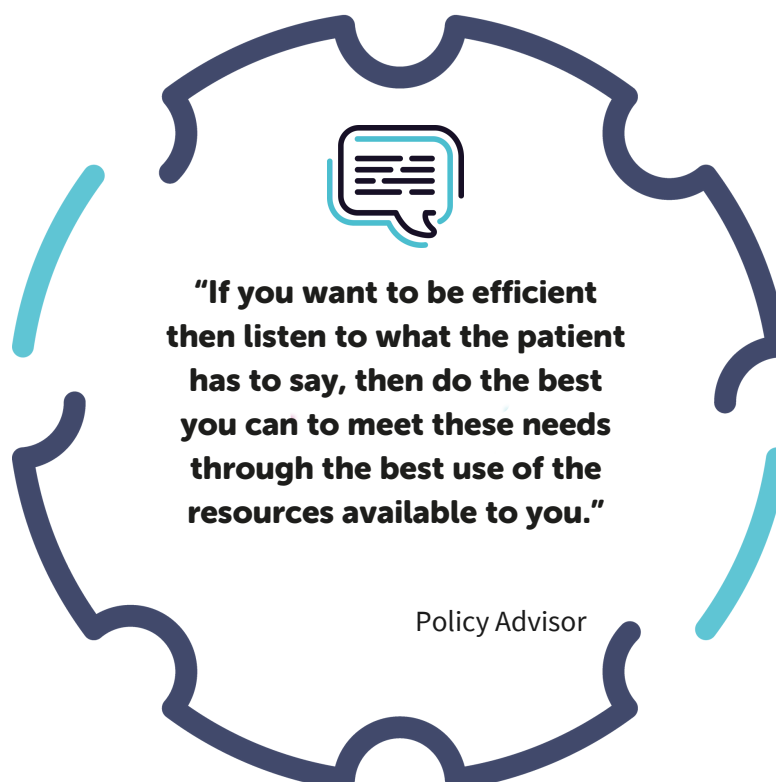
All.Can International defines 'efficiency' in cancer care as:

"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."

Inefficient cancer care is a leading factor in poorer outcomes for patients. According to the OECD, one-fifth (20%) of healthcare expenditure either does not improve people's health or could worsen their outcomes [106]. In addition, the World Health Organisation [75] estimates that 40% of health spending is wasted through inefficiency. [75].

However, building efficiency in cancer care is challenging and requires health systems to operate as highly effective, evidence-based and data-driven learning systems. This requires a common set of evidence-based metrics from which systems can choose and use, according to their own specific needs and circumstances.

Overall, this report sought to identify an evidence-based suite of core cancer care efficiency metrics that could be applied, albeit in varying ways, across many countries.



Through our research, we worked to identify key metrics that had a sound evidence base and were related to cancer efficiency. Furthermore, the metrics needed to be either used easily by healthcare practitioners in clinical settings or could be statistically analysed post-hoc from routinely collected patient and health-care data as part of the routine auditing process by registries or regulatory bodies.

Fundamentally, we sought not to replace the typical metrics used by state or insurance payers and clinical service providers but rather to augment them.

Our research combined the findings from **83 academic articles, 43 grey literature publications, 15 cancer registry websites, 1 international registry and 20 interviews** with different stakeholders from across the cancer care ecosystem.

This resulted in the identification of **13 core metric categories** as follows:

- | | |
|---|---|
| 1 Timeliness of care | 8 Patient experience and involvement in care |
| 2 Quality of care | 9 Survivorship |
| 3 Therapeutic alliance | 10 Financial toxicity |
| 4 Continuity of care | 11 Patient reported outcomes |
| 5 Palliative and end-of-life care | 12 Patient social environment and attitude |
| 6 Psychosocial oncology | 13 Innovation |
| 7 Information, support, and shared decision-making | |

Building on the **13 core metric categories** above, **24 metric themes were identified, to which 137 metrics were associated** (see Section 6 and Appendix 3). These metrics were chosen based on their ability to translate across cancer types and where the evidence suggested they could be incorporated into routine care to measure and elevate current levels of cancer care efficiency locally and globally.

While 137 individual metrics were identified, filtering these metrics to identify only those that were repeatedly presented in all three research sources (literature review, database review and stakeholder interviews) resulted in **eight key cancer efficiency metrics** being identified.

- **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'

It is also telling that the above findings align with All.Can's Patient Survey, performed in 2019 [72], which highlighted four crucial areas where respondents reported they experienced inefficiency, namely:

1. Swift, accurate and appropriately delivered diagnosis
2. Information, support, and shared decision-making
3. Integrated multidisciplinary care; and
4. The financial impact of cancer.

While this report presents metrics associated with cancer efficiency, as defined by the evidence review and stakeholder interviews, it is not designed to be an exhaustive assessment of efficiency in cancer care, something which is both multifaceted and multidimensional. In addition to the metrics highlighted, this report highlights limitations in the research and potential opportunities for further research, which could be performed to progress the insights presented here and to address areas that go beyond the scope presented here.

As is commonly known, what is not measured, cannot be improved. Put perhaps what is equally important is to measure the right thing in the right way.

1 Introduction



1.1 Efficiency in cancer care

Efficiency in cancer care is not just about money, but also time, quality of life, and missed opportunities for patients and their families.

In order to follow the principles of person-centred care (from All.Can's policy report: Harnessing data for better health care) [73], as well as improving cancer care efficiency, policymakers and practitioners first need to better define what health outcomes they are trying to achieve. Furthermore, they must ensure that these ambitions align with what matters most to patients and their families. The use of more transparent, high-quality and holistic data is imperative if a system-wide approach to continuously assessing and improving efficiency in cancer care is to be supported. According to All.Can, doing so will allow for a) the identification of practices that fall below national standards or lead to inequalities in cancer care, b) better coordination of multidisciplinary teams and resources and c) benchmarking to drive continuous improvement and accountability in meeting patients' needs.

All.Can's definition of efficiency - "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." - highlights the need to focus on resources, processes, and the human factors that matter most to patients and families as they traverse their cancer care journey. Therefore, to improve efficiency in a person-centred manner, there is a need to broaden the data we collect and evaluate, particularly making greater use of cancer-specific indicators of healthcare efficiency and quality, as well as patient-reported outcomes. Fundamentally, this approach must be adopted as routine and serve to inform decisions across the whole cancer care ecosystem, supporting (as opposed to detracting from) the delivery of high-quality, highly efficient cancer care.

Evidence gathered by All.Can [72-73] suggests that efforts to improve efficiency in cancer care should focus on establishing the long-term sustainability of cancer care, as well as improving areas of care where patients themselves report they have experienced inefficiency and have unmet needs. Without the wholesale adoption of reliable, valid and standardised metrics the fundamental foundations of a patient-centric, evidence-based, efficient, and globally sustainable cancer care model are jeopardised.

Various measures can, and should, be used to assess the efficiency, quality and equality of cancer care [2]. However, the traditional focus of healthcare systems and regulatory agencies on evaluating basic outcomes data, such as remission rate, recurrence rate and survival, can give an incomplete and even an inaccurate picture of care efficiency across the diversity of cancers [2]. As such, these core datasets should be continuously re-evaluated and, where appropriate, refined according to best evidence.

This study is a partnership between the University of Southampton and The Health Value Alliance (HVA) and is sponsored by All.Can International and supported by the All.Can Research and Evidence Working Group. The purpose of the study was to assess current evidence and grey literature with the aim of identifying a core set of internationally applicable metrics evidenced as being suitable for measuring cancer care efficiency. These metrics could then be used by stakeholders to define a baseline from which to monitor the efficiency of cancer care, according to their own circumstances and in a way that best meet their own specific needs. Furthermore, the measures presented could be used more broadly to better understand where healthcare systems might direct more focus when seeking to evaluate whether healthcare is being delivered efficiently.

The next sections will present a summary of the review approach and methodology and will be followed by a detailed account of the indicator themes and specific indicators that were derived from clinical literature, registry data and stakeholder interviews to cover multiple areas in cancer care.



About this report

This report seeks to offer an evidence-based view of metrics for the assessment of efficiency in cancer, aligned to the All.Can definition of efficiency. The report brings together an academic evidence review, assessment of major cancer registry metrics and the views of stakeholders from across the cancer care ecosystem. It describes what the literature is telling us about how we can measure efficiency to improve performance across the entire cancer care pathway. It also provides a set of metrics that, at the user's discretion, can be employed to measure and optimise efficiency and improve outcomes. Finally, the report offers a review of opportunities to progress this research and address areas that go beyond the scope presented here.

1.2 Report scope and limitations of scope

This report is not designed to be an exhaustive assessment of “efficiency” in cancer care, something which is both multifaceted and multidimensional and covers wide-ranging areas such as: provision, access, socio-demographics and socio-political issues, finance and funding, service provision and distribution, regulatory frameworks, and other specific elements relating to supply chain and operational aspects of the service infrastructure. Rather, this report seeks to deliver a set of metrics that may not be collected routinely in healthcare but which demonstrate sufficient evidence to suggest they should be considered for routine collection.

Although a thorough scoping review mapped what measures are currently associated with cancer care efficiency according to the inclusion/exclusion criteria, assessing whether those measures were the right measures for each stakeholder, in particular the patient/consumer, was out of scope for this report. Further research is recommended to assess the metrics presented and, in particular, to engage with patients/consumers and patient advocacy groups to review the metrics identified and their relevance and importance to these stakeholders.

Furthermore, the scope of this report has been limited to cancer care efficiency, from the point of presentation or suspicion of a diagnosis, through to final outcome. Therefore, the examination of metrics related to efficiency in cancer prevention, while being recognised as a critically important topic and of interest to All.Can, was considered to lie outside the scope of this report.

This report did not focus on routinely collected metrics but rather sought to identify a set of metrics that goes beyond those metrics already collected as minimum standards in healthcare. As such, routinely collected outcomes such as survival and Quality of Life (QoL) related measures were excluded.

This report is not designed to be a manual for the implementation of cancer care efficiency metrics. Rather, it serves as a reference for stakeholders to use when seeking to establish their own framework and set of real-world measures and baselines and subsequently implement a progressive assessment of efficiency in cancer care, serving their own organisational or personal aims and objectives.

Finally, this report is a foundational initiative that will evolve over time.

2 Methodology



2.1 Academic review methodology

The methodology used for identifying metrics and reporting real-world evidence of efficiency in cancer care involved a systematic search of medical databases along with an examination of cancer registry websites. This approach resulted in the retrieval of a wide sample of clinical and grey literature, much of which fell within the reports scope limitations.

The eligibility criteria for literature inclusion were developed based on All.Can's definition of efficiency [72] alongside the objective to include only core real-world measures i.e., indicators that can be derived from routine health and patient data to measure efficiency across all cancers.

A broad publication search captured literature focused on cancer care which were published within the last five years. The information extracted from full articles deemed eligible for the review included:

- a) individual study characteristics
- b) indicators and indicator types
- c) evidence of real-world application
- d) relevance to specific cancers and areas of cancer care, or themes
- e) relevance to All.Can's definitions of efficiency.

In parallel, clinical audits identified from databases and the web pages of cancer registries across different countries were reviewed to support the development of themes, sub-themes and associated metrics.



Results of review

The combined search strategy yielded a total of 126 publications which were included in the review, together with information from 16 registry websites. The breakdown was as follows:

- 83 academic articles
- 43 grey literature publications
- 15 national registries
- 1 international registry

The detailed methodology adopted for this study is included in the appendices of this report: Appendix 1 (Scoping review methodology) and Appendix 2 (PRISMA flowchart of the search strategy used for identifying real-world indicators of cancer care efficiency).

Academic articles:

Electronic database searches yielded an initial 2,109 publications on cancer care. An iterative assessment process based on the eligibility criteria resulted in 83 full-text articles being ultimately included in the review.

Grey literature publications:

Grey literature is defined here as information that is produced outside of traditional publishing and distribution channels or indexing databases. An assessment of grey literature linked to cancer registries, as well as 'snowball sampling' the reference lists of publications from databases, led to the identification of an additional 43 eligible publications.

Registries:

Information on registries examined for this report is provided in Appendix 4. For this report, efficiency metric categories, efficiency metric themes and efficiency metrics came from 15 national cancer registries - from the UK (England, Scotland, and Northern Ireland), Europe (Belgium, Cyprus, Estonia, Ireland, Slovenia, and Sweden), North America (USA and Canada) and Australasia (Australia and New Zealand), as well as one international registry.

2.2 Stakeholder interview methodology

In parallel with the academic review, a structured interview programme was performed with a small group of 20 participants from key stakeholders across the cancer care continuum and from multiple continents. These included patients (3), clinicians (3), hospitals, (3), payers (3) onco-pharma companies (3), onco-med-tech companies (2), diagnostic services (1), academics (1), policy houses (1) (see section 5).

A set of 11 interview questions were developed by the researchers, in consultation with the All.Can Research and Evidence Working Group, and approved by the University of Southampton Ethics Committee. Of these questions, 9 were relevant to all stakeholders, while 2 questions were targeted specifically to organisations or industry-related stakeholders (see appendix 5). These questions served to help researchers identify the stakeholders' perceptions of the best ways to measure and track cancer care efficiency in a way that was meaningful to each of these stakeholders.

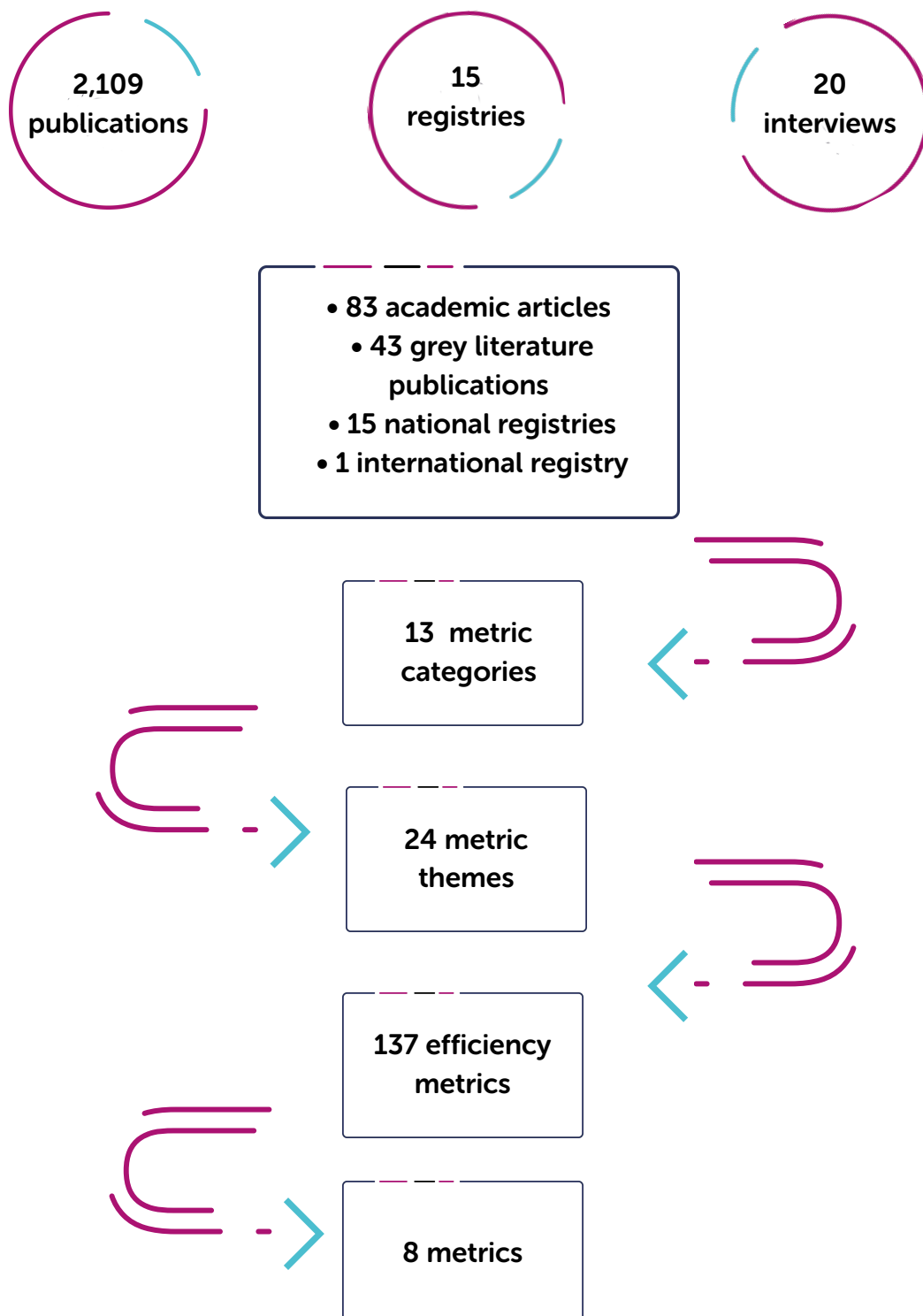
The responses given by the interviewees were then transcribed and analysed for key findings in line with All.Can's definitions of efficiency and the efficiency metric categories, efficiency metric themes, and efficiency metrics identified in the academic review.

3 Main findings



3.1 Overview

Although our research captured a large range of evidence, particular interest was paid to identifying core themes. These were identified based on overlaps between the research evidence, the registry/audit data and the stakeholder interviews. As can be seen below, this process ultimately resulted in the identification of eight core metrics (full details can be found in Section 6):



3.2 Efficiency metric categories

The 13 efficiency metric categories identified in this report are:

Timeliness of care: enabling swift diagnosis, through an easier route, efficient referral to specialist services and early treatment initiation

Quality of care: ensuring physician adherence to national guidelines, coordination of specialists and resources, availability of multidisciplinary teams, and routinely collecting patient-reported outcomes and perceptions of care

Therapeutic alliance: representing the relationships and prognostic understanding between patients, caregivers and clinicians, and involves each stakeholder being sufficiently informed of their options and ensuring they align with patient interests

Continuity of care: optimising routes to care and ensuring adequacy of follow-up and improving the patient's overall experience of continuity of care

Palliative and end-of-life care: improving patients' and families' perceptions of care quality and monitoring the aggressiveness of end-of-life care*

Psychosocial oncology: providing early psychosocial screening and treatment for high-risk patients and assessing the impact of cancer on family relationships

Information, support, and shared decision-making: improving physician communication with patients, the patient's role in decision-making, and the relationship and understanding between patients, caregivers, and oncologists

Patient experience and involvement in care: involving patients in their own care and using their feedback to improve the quality-of-care services

Survivorship: providing holistic needs assessment, and providing adequate mental and social support for patients and family, and addressing the concerns and care perceptions of those living with or beyond cancer (survivors)

Financial toxicity: addressing both the direct financial impact of cancer on patients' and their families, and managing cancer care cost inflation.

Patient reported outcomes: providing timely, structured and longitudinal holistic needs, quality of life, condition-specific and symptoms-specific assessments

Patient social environment and attitude: socio-demographic characteristics such as literacy and poverty, outlook on life, personal support networks

Innovation: the introduction of new technologies, drugs, processes etc.

* Aggressiveness of care (AOC) is defined by the following factors: 1) starting a new chemotherapy regimen within the last month of life, 2) chemotherapeutic treatment within the 14 days before death, 3) more than one emergency department visit within the last month of life, 4) more than 14 days hospitalisation within the last month of life, 5) more than one hospital admission within the last month of life, and 6) admission to intensive care unit (ICU) within the last month of life [53].

3.2.1 Category prominence

Of the 13 metric categories identified, the most prominent of these i.e., where the greatest overlap existed between the categories identified in the research and the count of times these category themes were mentioned in stakeholder interviews, were:

- **Timeliness of care** (34 counts in stakeholder interviews): Relates to swift diagnosis, optimising routes to diagnosis, appropriate and clinically indicated diagnosis, efficient referral to specialist services, and early treatment initiation
- **Quality of care** (34 counts in stakeholder interviews): Relates to coordination of specialist resources, and the role of multidisciplinary teams
- **Financial toxicity** (30 counts in stakeholder interviews): Relates to problems a cancer patient has around the cost of treatment

These findings from stakeholder interviews also align with All.Can's patient survey on cancer care efficiency [72], which highlighted four crucial areas where respondents reportedly experienced inefficiency, and which therefore represent opportunities where the above indicators could be applied to improve practice, namely:

- Swift, accurate and appropriately delivered diagnosis
- Information, support, and shared decision-making
- Integrated multidisciplinary care
- The financial impact of cancer.

3.3 Efficiency metric themes

Building on the 13 core metric categories **24 efficiency metric themes were identified:**

- Swift diagnosis
- Optimising routes to diagnosis
- Appropriate and clinically indicated diagnosis
- Efficient referral to specialist services
- Early treatment initiation
- Physician adherence to national guidelines
- Coordination of specialist resources
- Role of multidisciplinary teams (MDTs)
- Patient-reported outcomes (PROs) in routine care
- Patients' perceptions of care quality
- Adequacy of follow-up pathways
- Patients' experiences of continuity of care (COC)
- Patients' and families' perceptions of palliative care and end-of-life care
- Aggressiveness of end-of-life care
- Psychosocial screening of high-risk patients
- Impact of cancer on family and patient relationships
- Patients' perceptions of physician communication
- Patients' experiences with decision-making
- Relationship between patients, caregivers, and oncologists
- Patient satisfaction, experience, and involvement in care
- Collaborating with patients to improve care quality
- Social support for patients and family
- Survivors' concerns and perceptions of support
- Financial impact of cancer on patients

3.4 Efficiency metrics

Ultimately, the academic review and stakeholder interviews identified **137 metrics associated with efficiency in cancer care**. Appendix 3 provides information on the entire suite of metric categories, themes and metrics, including detail on the original sources of the data, and whether the metric is based real-world and/ or clinically validated.

Of the 137 metrics extracted from peer-reviewed journal articles, 67 were based on real-world data and 14 on data obtained using clinically validated patient-reported outcome measurements (PROMs). 34 metrics were captured from grey literature and are already known to come from clinically reliable measures, since healthcare systems and cancer registries already collect them to monitor outcome statistics, care quality and efficiency across countries in the global north.

The metrics identified were based on their ability to translate across cancer types and where the evidence suggested they could be incorporated into routine care to measure and elevate current levels of cancer care efficiency locally and globally.

4 Exploring the evidence



4.1 Overview

As previously discussed, the evidence review and stakeholder interviews gave rise to 13 efficiency metric categories.

The first part of this section explores seven of those categories in more depth. These seven were the categories that appeared in BOTH the evidence review and the stakeholder interviews.

The second section will cover the remaining six categories which, whilst important, were identified either by the review, or by the interviews, but not by both.

4.2 Efficiency metric categories with consistent evidence

The review of efficiency metric categories, efficiency metric themes and associated efficiency metrics across the registry reviews, research literature and stakeholder interviews showed that there was an overlap in the **prevalence** of evidence and the **importance** given by the interviewees in seven of the 13 metric categories. Each will be discussed individually in the following subsections:

4.2.1 Timeliness of care

a) Swift diagnosis

Studies. Included publications that used real-world patient data to evaluate the factors underlying delays in diagnostic intervals i.e., time to diagnosis, across multiple cancers include a clinical audit [3], four retrospective studies [4-7], two cohort studies [8, 9] and two cross-sectional studies [10, 11].

Two Spanish studies assessed cancer registry-based data to identify variables from first symptoms until diagnosis in lung cancer [3] and lymphomas [5]. Respectively, the studies demonstrated that delays in diagnostic intervals for lung cancer in Spain exceeded international guidelines reflecting operational inefficiencies – and that the outpatient settings, compared to the hospital route, provides a slower but more cost-effective diagnosis that is not detrimental to patients.

Ozawa et al [4], investigated the diagnostic intervals in brain cancer, and used '**times for patient presentation**', '**general practitioner (GP) referral**' and '**specialist consultation**' as metrics for assessing the 'total pathway interval'. They revealing that diagnostic intervals were longer for patients presenting to GPs with non-specific symptoms, such as headaches and memory problems, compared to patients presenting with the more suspicious "fits, faints or falls".

Other considerations in diagnostic speed include whether delays occur at the patient-level or the system level. Van Erp et al [6] assessed gastroesophageal diagnostic routes in the Netherlands, highlighting that prolonged intervals between 'first symptoms to time to diagnosis' were responsible for diagnostic delays.

A similar analysis of multidisciplinary tumour board (MTB) registries and patient records from affiliated institutions in the US [7] identified regular and effective MTBs were linked to both 'speed to diagnosis' and 'speed to treatment'.

Other proxy metrics of 'time to diagnosis' that were applied to real-world data to measure care efficiency in lung cancer [12], as well as pancreatic cancer [11], ovarian cancer [8], oesophageal cancer [9], colorectal cancer [13, 14] and cancer in general [10], included: 'time from suspicious imaging to completion of staging'; 'days from first abnormal imaging to biopsy and treatment initiation' and 'alignment between patient worry and GP suspicion'.

Grey literature. Indicators for detecting cancer earlier were identified in two UK audits [15, 16] and six cancer registries and associated statistic reports (Canadian Cancer Registry (CCR); National Cancer Registration and Analysis Service (NCRAS); Cancer Registry of Republic of Slovenia; National Program of Cancer Registries; Australian Cancer Database (ACD); and the New Zealand Cancer Registry) [77, 79, 81, 86, 89, 92].

Two UK audits used the Diagnostic Interval (DI), defined as 'the number of days from first relevant presentation to the date of diagnosis in cancer registry' as an indicator forming part of the patient diagnosis pathway in primary care in England [16] and in Scotland [15].

National cancer registries collect staging information as part of their standard dataset. In the 15 included registries, six report on stage at diagnosis. In Canada, 'the percentage of [cancer] cases by sex and stage' is reported in two infographics for lung cancer (Statistics Canada 2019), and breast and pancreatic cancer (Statistics Canada 2018) in the context of understanding how advanced the cancer is at diagnosis.

The National Cancer Registration and Analysis Service (NCRAS) – England report on a stage at diagnosis indicator ('percentage of all stageable cancers diagnosed that are recorded as presenting as a stage I and II as opposed to stage III or IV') that is intended to measure progress towards the ambition that 75% of all stageable cancers will be diagnosed at stage I or II by 2028 [81].

The Scottish Cancer Registry and Intelligence Service (SCRIS) report on 'the percentage of a stage of cancer found amongst the total number of incidences found', excluding non-invasive cancers [88].

In England and Scotland, two audits of the primary care diagnosis pathway in England [16] and Scotland [15] assessed the primary care interval (PCI), defined as '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'. The assessments sought to understand delays in the primary care cancer diagnosis pathway, which showed the pathway was influenced negatively by cancer type and patient sex.

Similar to the SCRIS, the 2018 annual report of the Cancer Registry of Republic of Slovenia [17] reports on the 'cancer incidence by stage'. Furthermore, the USA National Program of Cancer Registries (Centers for Disease Control and Prevention 2021) reports on invasive cancers by 'number of cases by stage of diagnosis' in the context of factors, such as type and stage of cancer, affecting treatment and survival [92].

While the Australian Institute of Health and Welfare Canberra report on Cancer in Australia [111], which draws on the Australian Cancer Database (ACD) [77], does not report on 'stage at diagnosis', it does consider stage at diagnosis in the context of survival (Australian Institute of Health and Welfare 2021).

As well as stage at diagnosis, two registries report on cancers that have been 'diagnosed early, at stage I/II'. In Canada and England, 'the percentage of cancer cases diagnosed at stages I and II' is reported for lung cancer (Statistics Canada 2019), and breast cancer and prostate cancer (Statistics Canada 2018), as well as for all cancers in general (NCRAS - England, CancerStats).

b) Optimising routes to diagnosis

Studies. Included publications that demonstrated the need for a better route to diagnosis for cancer patients included two retrospective studies [18, 19], a cross-sectional study [11], a cohort study [20] and a population-based study [21].

Kuiper et al [20], suggests that diagnosis of cancer can be made more efficient if attention is given to patients exhibiting 'healthcare seeking behaviour' in the preceding months, such as:

- 'Primary healthcare use', (volume by population), and
- 'Mean monthly number of GP consultations' (including the total intervals).

The impact of the route to diagnosis on the efficiency of cancer diagnosis was demonstrated in other real-world studies of colorectal cancer [21], as well as all cancer in general [19, 22], and in paediatric cancer [18]. Associated indicators that could signal inefficiency in those areas include:

- 'Percentage of patients receiving first-time diagnosis after an emergency presentation'
- 'Percentage of emergency presentations after accident and emergency referral vs GP referral'
- 'Cancers diagnosed through emergency presentation'
- 'The first point of contact for symptom presentation'
- 'Interhospital referral rate'

Grey literature. 5 main efficiency metrics have been reported within the context of understanding the routes to cancer diagnosis and monitoring the progress made to detect cancer sooner. 4 national cancer registries and 2 published audits have contributed to this theme.



Sub-optimal and highly inefficient routes to diagnosis, such as emergency presentation, have been shown to be factors in low one-year net survival.

In England, the NCRAS [81] Cancerstats website uses the indicator 'percentage of cases by route to diagnosis'. The metric is reported in the context of how different routes can lead to later cancer diagnosis and lower cancer survival. One sub-optimal route, 'emergency presentation', has been shown to be a factor in low one-year net survival. In this context, the NCRAS Cancerstats website has a specific indicator to monitor the 'proportion of tumours diagnosed by emergency presentation per year'.

The Swedish National Cancer Registry together with the Swedish National Board of Health and Welfare National Patient Register supports reporting on neoplasm diagnoses within in-patient care by 'length of stay', 'number of admissions', and 'number of patients'.

c) Appropriate and clinically indicated diagnosis

Most cancer registries collect data on 'the basis of diagnosis'. In relation to appropriate diagnosis, two audits evaluating the English [16] and Scottish [15] primary care diagnosis pathways used 'primary care-led investigations ordered by the GP as part of the diagnostic assessment prior to referral'. The indicator was used in the context that direct access for GPs to diagnostic tests could contribute to achieving diagnosis resolution within 28 days of referral [16].

In the USA, an audit of breast imaging used three indicators within the context of understanding cancer detection and rate of referral:

1. 'The percentage of abnormal screening exams that result in a diagnosis of cancer within a year'
2. 'Percentage of all diagnostic exams recommended for biopsy and cancer diagnosed in a year'
3. 'Benign tissue diagnosis in whom no cancer is diagnosed within a year' [25].

d) Efficient referral to specialist services

Several countries have screening programmes specifically for breast, cervical and colorectal cancers to detect cancer earlier in high-risk groups.

In Scotland, the SCRIS reports on its three screening programmes through Public Health Scotland [88]. One of the key performance indicators is screening uptake, which is defined as 'percentage of people with screening test result, out of those invited'.

Similarly in England (NCRAS) [81], screening uptake defined as 'the percentage of people eligible for screening who were screened' is one of the key metrics used to measure the effectiveness of the English screening programmes.

In other countries' cancer registries e.g., the Estonian Cancer Screening Registry [84], the Netherlands Cancer Registry [110] and the Australian Institute of Health and Welfare [111], participation rates are monitored through 'the number of people screened in a year as a percentage of the eligible population for each respective programme'.

Studies. Included publications using real-world patient data to quantify variables of specialist referral across different referral pathways (including diagnostic screening, treatment and surgery, and palliative care) include two retrospective analyses [26] [27], a randomised controlled trial (RCT) [28], a computational analysis [29], a journal editorial [30] and a cross-sectional study [10].

The RCT by Peabody et al. [28] identified 'screening and referral rates' as a metric for demonstrating the utilisation of colonoscopy as an early screening technique for colorectal cancer. The study highlighted that only one-third of colorectal cancer patients were referred for colonoscopy, demonstrating two third of patients for whom guidelines recommended colonoscopy referral to look for colorectal cancer, were not referred. A recent British Medical Journal editorial on urgent referral services [30] suggested that physician adherence to guidelines should be monitored by measuring referral rates and intervals.



In 2015, only 40% of patients in the UK presenting with the six 'alarm' symptoms of cancer were referred to specialists within the 14-day window recommended by NICE.

In 2015, 40% of patients in the UK presenting with the six 'alarm' symptoms of cancer were referred to specialists within the 14-day window recommended by NICE. Adherence to guidelines has since increased, and so have the referrals (based on evidence in 2018/19 of a 10% increase in the two-week referral rate).

Muller et al [26] revealed ethnic disparities in genetic screening practices across the US, where minorities appeared to face a barrier to diagnosis of Lynch syndrome (an inherited type of colorectal cancer) by being less likely to be referred for germline testing for markers of the syndrome following tumour tissue biopsy, a standard guideline for high-risk patients.

This highlighted the potential for use of metrics defining the '**volume or percentage of ethnic mix**' in screening to highlight ethnic disparities in screening programmes.

The need to continue assessing efficiency and equality in cancer referral pathways is critical and could be achieved by cross-ethnic, cross-country or cross-regional comparisons of metrics such as:

- 'percentage of patients receiving urgent referral within 14 days of presentation'
- 'concordance of referral practices with national guidelines'

Another national cohort study in the UK [31] showed that, over a five-year period, patients in England who were diagnosed with one of the most common cancers (lung, colorectal, breast or prostate) from the highest referring practices had a 'lower hazard of death', regardless of the type of cancer; these practices saw a low proportion of ethnic minority patients. This suggested a metric such as 'volume of referral between ethnic groups' could help identify disparities in referral.

In a clinical audit of lung cancer, the UK National Lung Cancer Audit (UK NLCA) used 'percentage of patients seen by specialist palliative care' to monitor the value the impact early routine involvement of palliative care services has on patients with lung cancer and inform future audits) [32].

The Health System Performance Assessment in Belgium provides a palliative and end-of- life care indicator 'percentage of patients who died within one week after start of palliative care', which is used to monitor delays in delivering palliative care for patients with terminal cancer.

Grey literature: Indicators contributing to this theme were derived from three audits from the UK and Australia, and two registries in the Netherlands and Belgium..



e) Early treatment initiation

The importance of timely treatment, and assessing its timeliness with metrics, to the improvement of cancer patient outcomes was reported in three retrospective studies [33], [34], [35], a program evaluation [36], an observational study [37], an expert panel [38], an international patient survey [39], and a review [40].

In the US, the National Cancer Database showed that ‘time to treatment initiation’ (TTI) was associated with a significant increase in patients’ absolute risk of mortality at early diagnosis across multiple cancers (including breast, renal, pancreatic, and colorectal). This was also reflected in studies in Australia, Canada, Europe, and the UK [39] [40].

In a retrospective study of US patients with laryngeal cancer by Swegal et al [35] showed the ‘time to start of post-operative radiation therapy after surgery’ from]; and ‘time from tissue diagnosis to treatment of lung cancer as an indicator of ‘30-day mortality following the completion of treatment’. These were supported by expert panel on indicators in lung cancer care by Kim et al [38].

Aas et al [33] used ‘time from diagnosis to radical prostatectomy’ to retrospectively evaluate treatment over an eight-year period using procedure intervals from the patient data of the Cancer Registry of Norway and Norwegian Prostate Cancer Registry.

Differences in treatment procedure intervals, measured through ‘median time from diagnosis to surgery’, were observed among US patients with pancreatic cancer. Azap et al [34] showed that the variation in treatment intervals among Medicare patients in the US appeared to be based on ‘patient age’ and ‘sex’, and highlighted biasing against older and female patients.

In the context of screening procedures, Stawinski et al [36] evaluated a Direct Access Colonoscopy referral program to determine whether it was ‘time-effective’, using the metric ‘time from referral to procedure’.

In Belgium, ‘time between incidence date and start date of primary oncological treatment’ is used in complex oesophageal surgery [78]. In the Netherlands, Santeon sub-categorises the interval between diagnosis to treatment into two process indicators: ‘duration from diagnosis to discussion of treatment plan’ and ‘duration from treatment plan discussion to starting treatment’ [105].

In an international clinical audit of prostate cancer radiotherapy across six hospitals in Poland, Portugal, Italy and Spain, the core quality indicator ‘percentage of patients who completed the treatment in the prescribed time’ was used to understand delays and interruptions to treatment [41].

4.2.2. Quality of care

The indicators captured from clinical literature and registries that could be widely adopted by healthcare professionals, regulators, and policymakers to monitor and improve the quality of cancer care have already shown effectiveness in evaluating coordination of care resources and the roles of multidisciplinary teams (MDTs) (Appendix 3).

a) Coordination of specialist resources

Studies. The Delphi study by Benito et al [42], highlighted that the periodic evaluation and refinement of Continuity of Care and Care Coordination, which includes coordination of specialist resources, is "...crucial for quality improvement and should allow a measuring system to be established that would allow a comparison of outcomes for all population-based cancer screening programs." [42].

The new set of core metrics based on expert consensus as to what should be updated for routine collection includes:

- 'adequacy of referral of the target population from screening program to other services'
- 'waiting time for referral to other services'
- 'understanding of the screening program by professionals'
- 'effective information flow between professionals'.

Grey literature. One indicator derived from audits and other grey literature was: 'percentage of patients included in a clinical trial', as reported in the international clinical audit by Lopes de Castro et al [41].

b) The role of multidisciplinary teams (MDTs)

Studies. In the review of registry-derived cancer quality indicators by Takes et al [40] the 'presence of a multidisciplinary team' was considered 'a simple but key metric of care efficiency and quality.

The emphases and approaches to the adoption of MDTs in cancer care varies between countries, with some still attempting to establish MDTs in this field). Coordination of MDT meetings, where all decision-makers involved in a patient's care can hold discussions and agree on the best care strategies to pursue for this patient, should be standard for healthcare settings. This allows for the pursuance of improved efficiency and concordance in cancer care, provided the MDTs are held at regular intervals, are of high quality, and involve the necessary diversity of professionals (for instance, clinical nurse specialists) [47].

In France, the importance of MDTs was highlighted by Patrikidou et al [43] in an evaluation of a multidisciplinary cancer clinics for prostate cancer patients, concluding that the presence of an MDT was associated with improvement in multiple patient-reported metrics, including: 'patient satisfaction', 'percentage of active participation', 'percentage of shared decision-making', and 'percentage agreeing that the MDT influenced final decisions'.

As such, incorporating MDT consultation early in the patient pathway has been shown to help ensure efficiency of care quality and improve patient-reported outcomes across the care pathway.

Grey literature. Five indicators were found from grey literature, including four cancer registries and five audits in relation to the role of MDTs, which are broken down into two areas; the role of the MDT as part of the cancer care pathway, and the role of the CNS.

In the context of the involvement of MDTs, the main indicator reported in grey literature was: the 'percentage of patients discussed at a MDT meeting' [32, 41] and New Zealand Ministry of Health 2019.

In the Netherlands, the 'percentage of patients discussed in a MDT meeting prior to the start of treatment' [48] [49] [50].



c) Clinical Nurse Specialist (CNS) and the MDT

Evidence from publications and registries supports the involvement of a clinical nurse specialist (CNS) in multidisciplinary care. Studies by Kerr et al [44] and Salamanca-Balen et al [46] both highlight that CNS involvement was associated with a better patient experience care e.g., easier access to care and timelier patient referral, reduced healthcare utilization and healthcare costs, regardless of cancer type. This suggests that gathering statistics on the '**availability of CNS**' or '**staffing levels of CNS**' across health services can serve as a simple core metric for assessing of care quality [45].

Grey literature. The four indicators that report on the progress towards ensuring involvement of a CNS were:

- '**percentage of patients given the name of a CNS to support them through their treatment**'
- '**percentage of patients reporting that that their CNS was easy to contact**'
- '**percentage of patients documented as having seen a CNS**'
- '**percentage of patients where a CNS was present at diagnosis**'



4.2.3 Continuity of care (CoC)

Real-world metrics for measuring efficiency of continuity of care (CoC) in cancer captured from clinical literature and registries can be used across cancers to ensure adequacy of follow-up pathways and to improve patients' experiences of CoC (Appendix 3).

a) Adequacy of follow-up pathways

Studies. A national GP survey by Hurtaud et al [51] revealed a gap in the CoC practices in France, where almost 27% of patients demonstrated a 'loss of CoC' in the first year, with almost 22% revealing further losses the year after. This study shows that assessing the adequacy of CoC – which has previously been defined as a patient-reported outcome [52] – can be made efficient and part of routine auditing of primary care practices by measuring operational indicators such as the above.

b) Patient experience of continuity of care

A Swedish patient survey on breast cancer by Plate et al [52] revealed CoC is strongly associated with global health-related quality of life in patients.

Grey literature. Through the National Cancer Patient Experience Survey, NCRAS England [81] ask patients whether they were '**given clear written information about what they should or should not do after leaving hospital**'. This metric affords the opportunity to identify patients seeking support from named entities and these entities engaging when approached by patients. This may allow root cause assessment of whether efficiency or efficiency erosion is associated with CoC in these instances.

4.2.4 Palliative and end-of-life care

While the previous section has shown that Continuity of Care is important for improved efficiency following a diagnosis of cancer, the over-exuberant pursuance of active care strategies in other parts of the care pathway, such as palliative and end-of-life (EoL), may not add value to patients' interest and can in fact be detrimental to them. This was suggested by two publications [53, 54] and a healthcare auditing agency (Healthy Belgium) [93] who assessed aggressiveness of EOL in cancer patients.

In a cross-sectional study of a tertiary comprehensive cancer care center in Germany, Tönnies et al [53] analysed the frequency of caregiver-reported 'aggressiveness of care' (AoC) suggesting AoC could be assessed using indicators such as:

- 'New chemotherapy regimen starting less than 30 days before death'
- 'The last dose of chemotherapy within 14 days of death'
- 'More than one day intensive care unit stay within the last month of life'

AoC was reported to be 'frequently occurring' in Europe, reportedly being experienced by 30% of patients in their last months of life, with 20% starting a new chemotherapy regimen in that period. Experience of AoC for caregivers was associated with decisional regret – a psychosocial metric for identifying 'distress or remorse after a healthcare decision' that can be associated with bereavement, depression, and anxiety [55].

This suggests that CoC in the form of extended therapeutic care at EoL may not only worsen quality of life and quality of death in patients, but also have detrimental effects on the psychological wellbeing of caregivers (and likely patient families too).

Furthermore, AoC could use considerable resource and cost implications for the cancer care system. Indeed, Mullins et al [54] made a link between CoC and AOC by showing that indicators of the latter, 'chemotherapy in the last two weeks of life' and 'not enrolling in hospice care', were associated with higher CoC measures in the Bice-Boxerman Continuity of Care Index.



4.2.5 Information, support and decision-making

The way in which new cancer patients receive news about their diagnoses or information on treatment options can determine how informed they consider themselves to be and affects their willingness and ability to make decisions relating to their own care. **Therefore, ensuring that information is communicated in a way that is timely, considerate, and understandable for the patient is crucial in the therapeutic alliance between physicians and patients.**

From the reviewed publications and registry data, indicators of patients' perceptions of physician communication emerged and were gathered as outcomes, electronic patient-reported outcomes (ePROs), and experience indicators.

a) Patients' perceptions of physician communication

Studies. Two publications [56] [57] demonstrated that patient-reported outcomes (PROs) could be translated into metrics for measuring the adequacy of physician communication.

In the US, a survey by Barkin et al [56] of real-world patient experiences with pancreatic enzyme replacement therapy found that 28% and 31% of patients respectively felt that detailed information on the therapies available and how they work was not provided by oncologists, with 83% of patients reporting to have searched for information online. Based on these findings, the **'percentage of patients feeling that detailed information was provided by their physician'** and **'percentage of patients who stated they had searched for information online'** were identified as metrics that could be incorporated into routine patient satisfaction assessment to evaluate how satisfied patients were with the communication they had received across segments of or their cancer care pathway.

Physician communication was evaluated via ePROs as part of a cluster-randomised trial (PRO-TECT) testing the clinical utility and user perceptions of a digital system for ePRO collection in advanced and metastatic cancer patients undergoing treatment at community oncology practices in the US [57]. This trial demonstrated that for 70% of patients' the use of electronic Patient Reported Outcomes (ePROs) improved their experience of communication with their clinicians, while 77% reported that the symptom management system allowed them to feel more in control of their own care. These findings not only support the incorporation of digital PROM systems for symptom monitoring into routine care but also demonstrated that qualitative patient feedback data e.g., ratings of **'quality of discussions with clinicians'** and **'feeling in control of own care'**, can be harnessed to derive patient-centered indicators of care quality and incorporated into routinely collected PROMs in cancer.

Grey literature. One key patient experience measure was reported through the Scottish cancer registry [88], based on Scottish Cancer Patient Experience Survey, was: 'percentage of patients who reported that they had been given a care plan'. This was reinforced by The Health System Performance Assessment in Belgium who assessed the percentage of positive responses to, 'physician provided easy-to-understand explanation' [93].

4.2.6 Patient voice in patient care

Publications and registries were both found to provide real-world examples of metrics that can evaluate whether patients are satisfied with, and are sufficiently involved in their own care, and focus on the patients' experiences and the level of their involvement in clinical decision-making.

a) Patient satisfaction, experience, and involvement in care

Studies. Two publications identified relevant indicators of patient satisfaction and involvement in care: a cross-sectional study [58] and a review on cancer care quality by Takes et al [40].

In the Netherlands a survey of Danish men by Birkeland et al [58] suggested that 'patient involvement in decision-making' should be used as an indicator of the strength of the therapeutic alliance between patient-oncologist, determining the effectiveness of shared decisions in individual patient cases.

According to the review by Takes [40], reported experience / satisfaction measures (PREMs) should be standardised as indicators of the quality of cancer care delivery, which could be achieved using validated questionnaires that already exist.

Grey literature. In Scotland, the patient experience indicator 'overall, how would you rate your care?' (% positive), is taken from the Scottish Cancer Patient Experience Survey [15]. NCRAS England [81] has a series of patient experience indicators drawing from the National Cancer Patient Experience Survey, tracks 'overall experience of care (average score 0-10)', and 'patient treated with dignity and respect (percentage of positive responses)' and 'patient involvement in decisions in care and treatment (percentage of positive responses)'. In Belgium the Health System Performance Assessment [93], tracks 'physician involving patients in decisions about care and/or treatment (percentage of respondents)' and 'physician giving opportunity to ask questions or raise concerns (percentage of respondents)'.

4.2.7 Financial toxicity and the financial impact of cancer

According to the National Cancer Institute (NCI) [108], financial toxicity (or financial distress) describes '**problems a cancer patient has related to the cost of treatment**'. This depends on the socioeconomic/ financial status of the patient, the severity of the cancer, and the healthcare system providing the cancer care. Additional factors included insurance, the need for legal services or even loss of employment. Fundamentally, additional costs associated with a cancer diagnosis could have a serious financial impact on the patient and dramatically worsen their quality of life. According to the publications and registries reviewed, metrics that monitor the financial impact of cancer on patients are important and are described below.

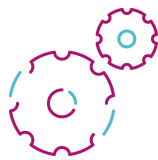
a) Financial impact of cancer

Studies. The Labor Insurance Database and Taiwan Cancer Registry [59] in Taiwan is a dedicated registry for gathering metrics on financial toxicity resulting from diagnosis of cancer where the cancer is a direct result of 'occupational' (work-place) exposure to carcinogens. The core metrics collected was '**change in employment status**', encompassing change in department or job position, employment suspension, or salary adjustment.



Research by Macmillan Cancer Care UK [69] highlighted that 4 in 5 cancer patients living in England are hit with an average cost of £570 a month because of their diagnosis, a sum comparable to a monthly mortgage payment. Another online Macmillan article entitled 'Cured, but at what cost?' [68] highlights that patient are then further exposed to costs, reporting that around 500,000 people in the UK face poor health or disability after cancer treatment.

Newton et al [96-97] and Slavova-Azmanova et al [98] present that individuals diagnosed with cancer in rural Western Australia experienced significant out-of-pocket expenses following their diagnosis.



4 in 5 cancer patients living in England are hit with an average cost of £570 a month as a result of their diagnosis – a sum comparable to a monthly mortgage payment.
Macmillan Cancer Care UK

Casilla-Lennon et al [60] used the University North Carolina Health registry to highlight that financial toxicity was being experienced by patients with bladder cancer, where 24% of patients reported they were “having to pay more for medical care than you can afford”. Furthermore, the authors found that these patients were also more likely to report having to delay care due to affordability and time issues. Importantly, patients reporting financial toxicity also scored significantly lower in routine PROMs, both in physical and functional wellbeing subscales, suggesting indicators on financial toxicity should be a standard inclusion in PROM and HQOL assessments.

Grey literature. The model showed the estimated economic burden associated with cancer care in the USA reached 2019 \$21.1 billion in 2019 [61]. The American Cancer Society, National Cancer Institute, Centers for Disease Control and Prevention, and North American Association of Central Cancer Registries, calculated patient economic burden using measures by assessing: ‘**patient out-of-pocket cost**’ and ‘**patient time costs associated with travelling for and receiving cancer care**’ [61].

4.3 Efficiency metric categories with evidence gaps

The review of metric categories, metric themes and associated metrics across the registry reviews, research literature and stakeholder interviews showed that there is sometimes a gap between the identification of themes relating to an aspect of efficiency and readily available sources of evidence and metrics to measure them. This was the case in the six areas below. In addition, in the case of the stakeholder interviews, the category of "therapeutic alliance" did not come up at all.

Each of the six will be discussed individually in the following subsections:

- **Survivorship:** in particular, social support for patients and family, and survivors' concerns and perceptions of support
- **Psychosocial oncology:** the psychological and social consequences of cancer diagnosis and involves supporting patients through the cancer care pathway and survivorship
- **Therapeutic alliance:** the personal bond, trust, shared therapeutic goals and the understanding between the patient, their caregiver and their clinician around all aspects of diagnosis, prognosis and care
- **Patient reported outcomes:** in particular, the use of digital PROMs methods (ePROs) for remote symptom monitoring and proactive (patient-triggered) engagement after the episode of care has completed, for longitudinal and remote needs monitoring
- **Innovation:** encompassing the delivery of novel therapies and medical devices, remote patient monitoring technologies and digital engagement, and the improvement in care service delivery
- **Patient social environment and societal and individual attitudes:** concerns the differing socio-economic environments, health service infrastructure and stigma, myths and taboos that affect the cancer care continuum and outcomes

4.3.1 Survivorship living well with and beyond cancer

In cancer, survivorship focuses on the long-term health and wellbeing of patients. Here, continued monitoring of holistic needs – including the fear of cancer recurrence - and support to prevent isolation and loneliness is crucial to mitigate poor psychosocial outcomes. Fear of cancer recurrence (FCR) is one psychological outcome that has been widely reported in literature and, if left unaddressed, can cause long-term detriment to patients' livelihoods and functionality.

Additionally, the late effects of cancer (symptoms, side-effects and co-morbidities resulting from a cancer and its treatment), which can present months or years after treatment, can cause considerable burden to patients, their families and/or their carers. Examples include, erectile dysfunction, incontinence, neurocognitive changes, neuropathies, and heart problems, to name just a few. Late-effects can not only be physically debilitating but can severely disrupt patient, family and carer quality of life, relationships, and affect an individual's ability to work or carry out normal daily tasks that they were capable of prior to their diagnosis and treatment.

4.3.2 Psychosocial oncology

Psychosocial oncology concerns the psychological and social consequences of cancer diagnosis and involves supporting patients through the cancer care pathway and survivorship by providing psychological screening and multidisciplinary allied supportive care.

Evidence that efficiency is monitored and maintained in this area of cancer care is currently lacking. Early screening of psychological and psychosocial risk following diagnosis of cancer (i.e., the likelihood of poor psychological outcomes, such as depression and anxiety, and isolation) has been shown to be associated with improved QoL and psychosocial outcomes. This is especially true for vulnerable patient groups, such as adolescents and young adults, children, and the elderly [62-66].



4.3.3 Therapeutic alliance

The therapeutic alliance concerns the personal bond, trust, shared therapeutic goals and the understanding between the patient, their caregiver and their clinician around all aspects of diagnosis, prognosis and care [109].

Agreement (shared decision making, facilitated by informed consent) at each stage of the care process and ensuring that everyone's decisions align with patient's best interests is the ideal scenario. However, for this to be achieved, appropriate information systems must be in place, and this includes routine PROM collection.

4.3.4 Patient reported outcomes measures (PROMs)

A major theme in the publication and stakeholder interviews was the need for increased incorporation of PROMs into routine care – the term “PRO-cision medicine”, where PROMs are considered both diagnostic and predictive, has even been coined [67].

There was evidence of routine PROM collection from some registries and audits. However, a broader use of a more comprehensive set of PROMs associated with both psychosocial and physical aspects of patient wellbeing in the real world is needed to improve patient-led monitoring and management of symptoms, and to address the patients' holistic needs (i.e., self-efficacy).

The adoption of trialed digital systems for collecting routine PROMs for symptom and adverse events reporting (e.g., ePRO version of PRO-CTCAE [57]) and patient apps collecting these data may enable clinicians to remotely monitor patients. This would allow clinicians to proactively respond to patient-reported adverse events, symptoms or concerns (e.g., by requesting face-to-face appointments or arranging appropriate referrals) rather than waiting for patients to either self-refer or present with critical unmet-needs, particularly via emergency routes.

4.3.5 Innovation

Innovation is a broad term and is multifaceted, encompassing the delivery of novel therapies and medical devices, remote patient monitoring technologies and digital engagement e.g., electronic patient reported outcomes measures (ePROs), the improvement in care service delivery and innovations associated with improved efficiency, such as new medical service coding structures.


Tracking the effectiveness of an innovation is challenging and depends a) on the innovation being adopted and b) the purpose of the innovation. Tracking could include for example, adoption and utilisation rates, cost and return on investment (ROI) and time to ROI, effect on patient engagement with services, such as readmission rates and emergency department visits. Also, subjective measures such as patient satisfaction levels and improved patient reported outcomes, to name a few.

4.3.6 Patient social environment and societal and individual attitudes

Different countries have different socio-economic environments and health service infrastructure, the existence of and access to these can dramatically affect the cancer care continuum and outcomes, which is often reflected in global cancer care service utilisation, and outcomes tables. In addition, in some parts of the world, cancer is associated with a significant amount of stigma, myths and taboos. These stigma, myths and taboos can affect: [70]

- patient awareness, which is often hampered further by a lack of education
- personal health attitudes around e.g., tobacco use
- healthcare seeking behaviours, where healthcare is available

The social environments and societal and individual attitudes can also have a fundamental effect on cancer incidence, morbidity and mortality in some regions and populations [71]. However, the breadth and complexity and multi-factorial nature of metrics associated with patient environment made inclusion of the metrics associated with this report unrealistic. Further research is recommended here.



"We must continually innovate because it's a never-ending biological chess match between our strategies, our tools to fight cancer and the biological ways that cancer tries to evade being eliminated. The challenge is how to fund this."

Clinician - Pharma

5 Stakeholder interview findings



5.1 Overview

The purpose of the stakeholder interviews was to gather the views from across some of the key stakeholder groups in the cancer care ecosystem and to cross-reference these with the findings from the literature review. This approach would help to determine whether there was academic evidence backing up the stakeholder views and identify any gaps. In addition, the interviews afforded the researchers an opportunity to identify any additional emerging efficiency metric themes and associated efficiency metrics that were not forthcoming from the academic review.

5.2 Interview methodology

A small purposive sample of interview participants, representing stakeholders from across the cancer ecosystem, was engaged, with approximately nine key stakeholder categories represented as follows:

- Patients*, clinicians, hospitals, payers (including both insurance and state), onco-pharma, onco-med-tech, diagnostic services, academics, policy designers.

A minimum of two stakeholders were sought from each stakeholder category, with each representing a separate geography (country or continent).

It is to be noted that the majority of stakeholder interviews were conducted with those on the design, supply and cancer provision sectors. Patients, while being a pivotal stakeholder group, were not engaged with more than other stakeholder groupings (by number of participants) (see Section 1.2 - Report scope and limitations of scope). Having completed the academic review and interviews, an opportunity has been identified to take the efficiency metrics directly to patients and carers for the viewpoints of those consuming the services, and this has been discussed further in Section 8 – Opportunities.

The term 'Patients' refers to individuals diagnosed with cancer who were either undergoing or had completed cancer treatment at the time of interview, engaged with via Patient Advocacy / Health Consumer Groups.

5.3 Interview question set

A set of 10 interview questions were developed by the researchers, in consultation with the All.Can REWG, and approved by the University of Southampton Ethics Committee. Nine of these questions were relevant to all stakeholders, with two questions targeted specifically to organisation or industry-related stakeholders (see appendix 5). These questions were as follows:

	Stakeholder interview questions
1.	How do you/does your organisation define efficiency in cancer care?
2.	Is efficiency in cancer care important to you/your organisation? If so, why?
3.	What measures do you personally think are most important to be collected and analysed for examining and improving efficiency in cancer care?
4.	(organisation / industry interviewees only) What measures, if any, does your organisation currently collect and use to examine and improve efficiency in cancer care?
5.	(organisation / industry interviewee only) Are any of measures you personally think are important not being collected/ used by your organisation. If not, why not?
6.	What gaps do you think exist that affect the delivery of optimally efficient cancer care?
7.	In your opinion, what can be done to bridge the/these gap(s)? And do you/ or does your organisation currently do any of these things?
8.	Who else do you think is responsible for bridging this/these gap(s) and how?
9.	What three words/ phrases would you use to describe what optimal cancer care would look like?
10.	Is there anything else that you think we should consider that we haven't covered in the questions in order to better understand efficiency in cancer care?

5.4 Number of interviews and stakeholder representation

A total of 20 interviews were carried out across the nine stakeholder groups, as follows:

Stakeholder	Number interviewed	% of total cohort
Patients	3	15%
Clinicians	3	15%
Hospitals	3	15%
Payers e.g. insurers	3	15%
Onco-pharma	3	15%
Onco-med-tech	2	10%
Diagnostic Services	1	5%
Academics	1	5%
Policy Designers	1	5%
Total	20	100%

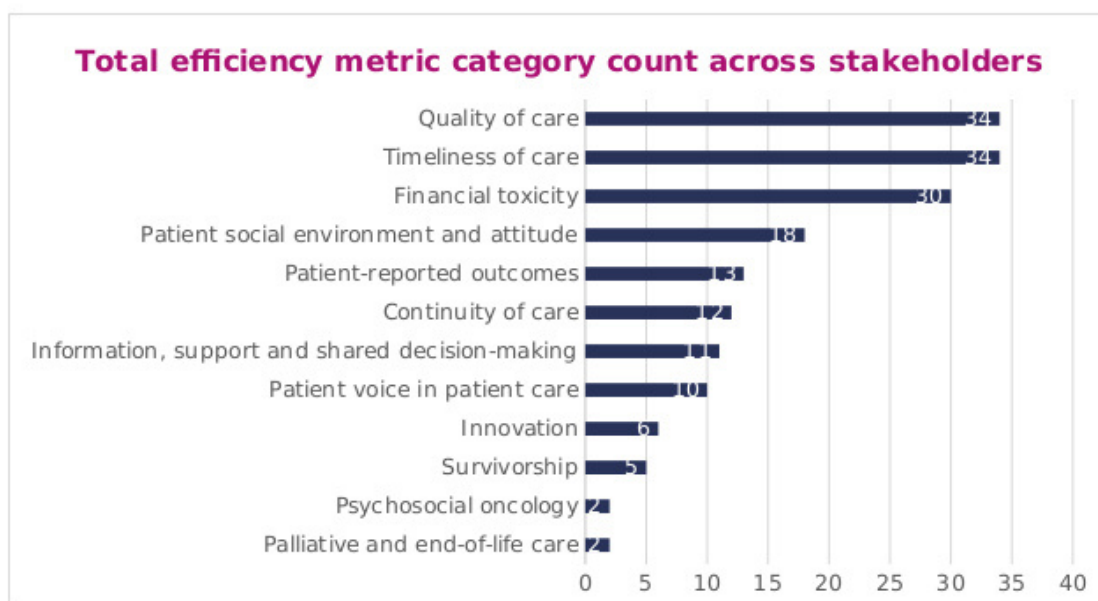
5.5 Interview responses by efficiency metric category

The interview responses were aligned to the core efficiency metric categories that emerged from the academic and grey literature reviews. In the case of the category of "therapeutic alliance", this not appear at all in the interviews.

However, three new metric categories did appear. These were:

- Patient Reported Outcomes (PROs, including Quality of Life)
- Patient social environment and attitude, including: wellbeing (emotionally and mentally), positive/negative attitude, tailored care and illiteracy and lack of engagement with the system
- Innovation: Adoption and availability of technologies, drugs, processes etc

A count of the number of times a category was mentioned in the interview was collated, as follows:



The table on the following page presents the number of times the interviewee from each stakeholder group mentioned a category when answering the questions in the interview.

While stakeholder engagement was limited and, therefore, so too was statistical power, mapping the metric categories by count (number of times the metric was mentioned by the interviewee) did afford some insight into what was considered important to stakeholders when responses are taken in total.

A significantly higher number of interviews would afford more statistically robust insights, however. Furthermore, a significantly increased number of patients/consumers would provide greater clarity as to the theme prevalence and importance as perceived by the patient/consumer (See Section 8 – Opportunities).

Metric category	Metric Theme	Patients	Clinicians	Clinical Services	Hospitals	Insurers	Academics	Onco-tech	Pharma	Policy Design	Total
Timeliness of care	Swift diagnosis (time intervals etc)	3	1	4	1			2	4		
	Accurate diagnosis (tissue staging, imaging etc)	2		1			1	1	2		
	Route to diagnosis (emergency, GP-referred etc)			1							
	Referral to specialist services (for screening, treatment, palliative care)	1		1	1			1			
	Expediting treatment (time intervals, cancer stage at treatment)	2			1			3	1		34
Quality of care	Adherence to care quality targets (national targets)	1	1		1		4	1	1		
	Adherence to national guidelines (of physicians, services)	1	1				2		1		
	Better coordination of care (physician knowledge of services, etc)	1	1	2		1	2	4	2		
	MDTs			1							
	Patient perception of care quality (proms)					1	1		1		31
Therapeutic alliance	Dyadic measures (patient-oncologist, caregiver-oncologist)										
	Tryadic measures (patient-caregiver-oncologist, TA measures)			1							
	Prognostic understanding										1
Continuity of care	Routes to follow-up (A&E visit, GP-referred visit, triage pathways)	2						2			
	Timeliness of follow-up	1	1	3				1			
	Role of clinical nurse specialists (any relevant measures)	1						1			12
Palliative and end-of-life care	Patient and family perception of care quality					2					
	Caregiver perception of EOL (grief, regret, role of oncologist)										
	Aggressiveness of care										2
Psychosocial oncology	Early screening of psychosocial risk in patients										
	Screening family and caregivers										
	Impact of cancer on patients and family (including PROMs)										
	Family and caregiver bereavement										0
Information, support and shared decision-making	Adequacy of information and health literacy	4		2		1			1	2	
	Quality of physician communication (patient perceptions included)	4		1							
	Decision-making and patient preference (including PROMs)	3			1					2	21
Patient experience and involvement in care	Patient satisfaction, experience and involvement in care (not the same sources as PROMs)	1		1	1	3	1		1		
	Collaborating with patients to improve care quality	2									10
Patient-reported outcomes	Routine PROMs/PREMs		1	2			2	1	1		
	Clinically validated PROMs/PREMs			1					1		
	Incorporation of PROMs into routine care (including barriers)		1				1	1			
	ePROs and patient self-management			1							13
Survivorship	Social support for patients and family			1							
	Survivor concerns and perception of support	1				1					
	Fear of cancer recurrence	1				1					5
Financial toxicity	Cost-effectiveness of care		7	2	5	3	4		2		
	Financial impact on patient	1	1	1	2	1		1			30
Patient needs	Illiteracy and lack of engagement with the system	1		1				1			
	Wellbeing (emotionally and mentally), positive/negative attitude, tailored care	3			1	1					8
Innovation	New technologies, drugs, processes etc		1		3			2			6

6 Efficiency metrics



While 137 individual metrics were identified, filtering these metrics to identify only those that were repeatedly presented in all three research sources (literature review, database review and stakeholder interviews) resulted in **eight key cancer efficiency metrics** being identified.

- **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'

A full list of all the metrics provided by the study is provided on the following pages.

Metric category	Metric theme	Metric
Timeliness of care	Swift diagnosis	<ul style="list-style-type: none"> Time to diagnosis; (e.g., days) Cancers diagnosed at stage I-II; (e.g., %) Stage at diagnosis (e.g., average and patient volume (total) by stage)
	Optimising routes to diagnosis*	<ul style="list-style-type: none"> % patients receiving first-time diagnosis after an emergency presentation; % emergency presentations after A&E referral vs emergency GP referral; % cancers diagnosed through emergency presentation; Healthcare seeking behaviour; (e.g. % of defined behaviours observed) First point of contact for symptom presentation; (e.g. % of patients by contact) Interhospital referral rate; (e.g. n=x patient referred between hospitals) % of cases by route to diagnosis; % of patient receiving an inpatient care diagnosis; Screening uptake; screening coverage; (e.g., % of population) Patient ability to undergo treatment once diagnosed (e.g., volume or % of diagnosed)
	Appropriate and clinically indicated diagnosis	<ul style="list-style-type: none"> % of cases by basis of diagnosis; % of patients diagnosed via microscopically verified cancers Positive Predictive Value (PPV) (e.g., PPV value by population)
	Efficient referral to specialist services	<ul style="list-style-type: none"> Referral rate for diagnostic/genetic screening; (e.g., n=x of patients referred) % patients receiving urgent referral within 14 days of presentation; Short-term mortality risk; (e.g. of % of patient diagnosed) Rate of palliative care consults; (e.g. % of n=x of palliative care population) Rate of hospice referrals; (e.g. absolute value or % of defined population) Days spent in hospice care; (absolute value, e.g., days) Primary care interval; (absolute value, e.g., <i>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 to diagnostic services</i>) Patients seen by specialist palliative care; (e.g. absolute value or % of defined population) Referral to first clinic visit; (e.g. absolute value or % of defined population) Duration from first clinic visit to diagnosis; (absolute value, e.g. n=x days) % patients who died within one week after start of palliative care; (e.g. absolute value or % of defined population) Cancer over-screening (e.g. absolute value or % of defined population)
	Early treatment initiation	<ul style="list-style-type: none"> Time from referral to procedure; (absolute value, e.g. n=x days) Time to surgical care; (absolute value, e.g. n=x days) Time from tissue diagnosis to treatment; (absolute value, e.g. n=x days) 30-day mortality following completion of treatment; (absolute value, e.g. n=x days or number of patient or %

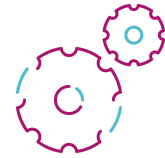
		<ul style="list-style-type: none"> of defined population) Time to treatment initiation; absolute value, e.g. n=x days) Time to start of post-operative therapy; (absolute value, e.g. n=x days) Patients who completed the treatment in the prescribed time; (absolute value) Duration from diagnosis to discussion of treatment plan; (absolute value, e.g. n=x days) Duration from treatment plan discussion to starting treatment; (absolute value, e.g. n=x days)
Quality of care	Physician adherence to national guidelines	<ul style="list-style-type: none"> Concordance of referral practices with national guidelines; (e.g. ,% of defined population) Adherence to treatment guidelines (e.g.,% of defined population and regimen) Observed-to-expected ratio for adherence to treatment guidelines; Appropriate treatment; (e.g. % or volume - requires a baseline) Guidance-concordant screening rate (e.g. % or volume - requires a baseline)
	Coordination of specialist resources	<ul style="list-style-type: none"> Referral of the target population from screening programme to other services; (e.g. absolute value, n=x or % of defined population) Waiting time for referral to other services; (absolute value, n=x days) Understanding of the screening program by professionals; (e.g. volume or % of patient answering Y/N in satisfaction questionnaire, or 1-10 rating) Effective information flow between professionals; (dichotomous categorical variable e.g., Y/N) Patients treated with new technologies (%); Patients included in clinical trial (dichotomous categorical variable e.g., Y/N)
	Role of multidisciplinary teams (MDTs)	<ul style="list-style-type: none"> Presence of a MDT; (absolute value e.g., Y/N) Patient experience of multidisciplinary consultation; (patient experience score specific e.g., 1-10 score on MDT satisfaction) Availability of Clinical nurse specialists (CNS); (dichotomous categorical variable e.g., Y/N) Nurse specialist-reported confidence with multidisciplinary team settings; (CNS experience score specific e.g., 1-10 score on CNS MDT satisfaction) % patients given the name of a CNS; CNS caseloads per year; Dedicated contact person who supervises the patient and is known to the patient (absolute value e.g., Y/N or % of defined population); % patients discussed in a MDT meeting prior to the start of treatment; % patients discussed at a MDT meeting; CNS easy to contact; Patients documented as seen by a CNS; (% or absolute value n=x) CNS present at diagnosis
	Patient-reported outcomes (PROs) in routine care	<ul style="list-style-type: none"> Emergency department visits; (n=x) Frequency of hospitalisations; (n=x or and or % of defined population) Palliative care visits; (n=x or and or % of defined population) Psychosocial oncology visits; (n=x or and or % of defined population)

		<ul style="list-style-type: none"> Intensity of nine common cancer physical and psychological symptoms; Symptom severity; (intensity scale score) Quality of life of cancer patients; (e.g., scale score or % of patients scoring n=x on scale) Actionable distress; (e.g., scale score or % of patients scoring n=x on scale) Nutritional status; (e.g., specific toolkit score or % of patients scoring n=x on scale) Severity of pain; (e.g., scale score or % of patients scoring n=x on scale) Physical, mental and social health; (e.g., specific toolkit score or % of patients scoring n=x on scale) Patient-reported adherence; (e.g., specific toolkit score or % of patients scoring n=x on scale) Non-adherence; (e.g., specific toolkit score or % of patients scoring n=x on scale) Risk of non-adherence; (e.g., specific toolkit score or % of patients scoring n=x on scale) Treatment satisfaction; (e.g., specific toolkit score or % of patients scoring n=x on scale) 30-day readmission rate; (e.g., absolute number or % of defined population) Patient activation; (e.g., specific toolkit score or % of patients scoring n=x on scale) Patient concerns; (e.g., specific toolkit score or % of patients scoring n=x on scale) Perceived social support (e.g., specific toolkit score or % of patients scoring n=x on scale)
	Patients' perceptions of care quality	<ul style="list-style-type: none"> Medical-technical competence; (e.g., specific toolkit score or % of patients scoring n=x on scale) Physical technical conditions; (e.g., specific toolkit score or % of patients scoring n=x on scale) Identity-oriented approach; (e.g., specific toolkit score or % of patients scoring n=x on scale) Socio-cultural atmosphere; (e.g., specific toolkit score or % of patients scoring n=x on scale)
Continuity of care (COC)	Adequacy of follow-up pathways	<ul style="list-style-type: none"> Patient-initiated follow-up; (e.g., absolute value n=x or % of population) Frequency of GP consultations; (e.g., n=x) Interval between GP consultations; (e.g., absolute value, n=x days) Patients with regular follow-up post treatment; (e.g., n=x patients)
	Patients' experiences of COC	<ul style="list-style-type: none"> Level of continuity of care experienced; (e.g., specific toolkit score or % of patients scoring n=x on scale) Provision with contact details post hospital; (e.g. absolute value n=x patients reported Y/N) GP support during treatment
Palliative care (PC) and end-of-life care (EOL)	Patients' and families' perceptions of PC and EOL	<ul style="list-style-type: none"> Availability of palliative care; (e.g.; clinical service provider reported Y/N and details, correlated with patient/ family/ care measures) Parents' quality rating of care; (e.g., specific toolkit score or % of patients scoring n=x on scale) Parent satisfaction; (e.g., specific toolkit score or % of patients scoring n=x on scale) Chance to plan the location of death; (e.g. specific measure in patient experience toolkit, absolute value n=x and/or % of population) Physician availability; (e.g. specific measure in patient experience toolkit, absolute value n=x and/or % of

		<p>population)</p> <ul style="list-style-type: none"> • Availability of psychosocial support; (e.g.; clinical service provider reported Y/N and details, correlated with patient/ family/ care measures) • Number of hospital stays during last month of life (absolute value n= x days)
	Aggressiveness of EOL	<ul style="list-style-type: none"> • New chemotherapy regimen starting <30 days before death; (e.g. absolute value Y/N or n= x days) • More than 1 day ICU stay within last month of life; (e.g. absolute value Y/N or n= x days) • % patients who received chemotherapy in the last 14 days of life(e.g. absolute value n=x(%)) NB: a high % would be an indicator of high levels of aggressiveness and therefore of poor efficiency.
Psychosocial oncology	Psychosocial screening of high-risk patients	<ul style="list-style-type: none"> • Psychosocial risk; (e.g., n=x % of population presented with) • Consequences of screening; (e.g., n=x % of population presented with defined psychosocial presentation) • Actionable distress; (e.g., n=x % of population presented with) • Psychiatry consultation; (e.g., n=x % of population had) • % patients reporting opportunity for discussing concerns
	Impact of cancer on family and patient relationships	<ul style="list-style-type: none"> • Perceived psychosocial care and support; (e.g., absolute value e.g. % of population reporting Y/N to having their psychosocial care screening or adequate psychosocial support) • Current caregiver QoL; (e.g., specific toolkit score n=x on scale) • Partner coping; (e.g., specific toolkit score n=x on scale) • Current perceived financial security; (e.g., absolute value e.g. Y/N or %) • Parenting concerns; (e.g., absolute value e.g. % of population reporting Y/N and details) • Relationship strain; (e.g., absolute value e.g. % of population reporting Y/N and details) • Social constraints; (e.g., absolute value e.g. % of population reporting Y/N and details) • Impact of event; (e.g., absolute value e.g. % of population reporting Y/N and details) • Dyadic adjustment; (e.g. specific score on a Dyadic Adjustment Scale (DAS)) • Social problem solving; (e.g., % of specific population reporting difficulty solving social problems) • Sibling bereavement (e.g., % of population reporting death of a sibling or difficulty dealing with death of a sibling)
Information, support, and decision-making	Patients' perceptions of physician communication	<ul style="list-style-type: none"> • % patients feeling that detailed information was provided by their physician; • % patients informed on how their therapy works; • % patients searching for information online; • Patient perception of quality of discussions with clinicians; (e.g., specific question and score (e.g., 1-10) on a patient satisfaction questionnaire) • Feeling in control of own care; (e.g., specific question and score e.g., (e.g., 1-10) on a patient satisfaction questionnaire) • Nurse perception of efficiency of patient discussions; (e.g., specific question and score (e.g., 1-10) on a health professional satisfaction questionnaire) • % patients who responded positively to level of doctor-patient communication; • Patient experience of administration of care; (e.g., specific

		<p>question and score (e.g., 1-10) on a patient satisfaction toolkit)</p> <ul style="list-style-type: none"> Patients given a care plan (e.g., absolute value (n=x) or % of patients stating Y/N on a patient satisfaction questionnaire)
	Patients' experiences with decision-making	<ul style="list-style-type: none"> Decisional regret; (e.g., % of patients stating Y/N on a patient satisfaction questionnaire) Patient preference for physician role; (e.g., specific question and score (1-10) on a patient satisfaction toolkit)
	Relationship between patients, caregivers, and oncologists	<ul style="list-style-type: none"> Therapeutic alliance; (e.g., specific question and score (e.g., 1-10) on a patient satisfaction toolkit) Patient-physician discordance in goals of care ; (e.g., specific question and score (e.g., 1-10) on a patient satisfaction toolkit and free text details)
Patient voice in patient care	Patient satisfaction, experience, and involvement in care	<ul style="list-style-type: none"> Patient experience; (e.g. Patient involvement in decision-making; (e.g., specific question and score (e.g., 1-10) on a patient satisfaction toolkit) Patient treated with dignity & respect (e.g., specific question and score (e.g., 1-10) on a patient satisfaction toolkit)
	Collaborating with patients to improve care quality	<ul style="list-style-type: none"> Patient involvement in support, organisation of care and improvement of administrative processes; (e.g., specific question(s) and score (e.g., 1-10) on a patient satisfaction toolkit) Collaboration with patient organisations
Survivorship	Social support for patients and family	<ul style="list-style-type: none"> Supportive care needs (e.g., specific question and details (which could be categorised) on a patient satisfaction toolkit)
	Survivors' concerns and perceptions of support	<ul style="list-style-type: none"> Perception of risk of recurrence and mortality; (e.g., specific question and score (1-10) on a Patient Reported Outcomes Measurement (PROM) questionnaire) Fear of cancer recurrence; (e.g., specific question and score (1-10) on a Patient Reported Outcomes Measurement (PROM) questionnaire) Utilisation of and satisfaction with psychosocial care (e.g., specific question (measuring volume of utilisation), and score (1-10) on a patient satisfaction questionnaire)
Financial toxicity	Financial impact of cancer on patients	<ul style="list-style-type: none"> Change in employment status; (e.g., specific question and Y/N on a Patient Reported Outcomes Measurement (PROM) questionnaire) Patient-reported financial toxicity; (e.g., specific question and Y/N on a Patient Reported Outcomes Measurement (PROM) questionnaire) Patient economic burden (net out of pocket and time costs) (e.g., specific question and Y/N and/or estimated monetary value on a Patient Reported Outcomes Measurement (PROM) questionnaire)

7 Out of scope



7.1 Missing metrics

Conducting a cross-reference of the registries, academic research and stakeholder interviews enabled alignment of findings into efficiency metric category, metric theme, and metrics. No metrics for the themes of 'Patient environment and attitude', and 'Innovation' were found in any of the research or stakeholder interviews, even though there were mentioned as important areas to consider.

7.2 Traditional clinical metrics

This study deliberately excluded measures such as overall survival (for example, the Survival Index) [95], disease-free-survival (DFS), quality of life (QoL) and other traditional clinical metrics on the grounds that:

1. These have already been extensively researched and are already routinely collected as minimum standards in healthcare services (e.g., the UK NHS); and
2. These outcomes can be affected by factors unrelated to efficacy, in particular the type of cancer. They therefore cannot be easily generalised across all cancers, and so cannot act as generalised indicators of cancer care efficiency (as an example, median survival outcomes will vary considerably between pancreatic and breast cancer).

7.3 Cost-benefit and cost-effectiveness

While 'cost-benefit' seeks to determine whether the outputs outweigh the costs of a given policy, 'cost-effectiveness' is taken here to concern the costs of achieving a given outcome from a policy. Those outcomes may be broader than the outputs and they may differ in value depending on who is assessing them.

Both financial analyses are relevant to patient care as they are fundamental foundations of a financially sustainable healthcare ecosystem. Moreover, both are known to be affected by patient outcomes. Additionally, traditional clinical metrics, cost-benefit and cost-effectiveness are metrics that are routinely collected across the healthcare ecosystem, from assessment of interventions to policy change. This report therefore focuses primarily on indicators that relate to what patients report and perceive as being important, and which can augment the more conventional indicators of efficiency (such as cost-benefit, cost-utility and cost-effectiveness).

8 Opportunities



8.1 Overview

Overall, the research collaboration between All.Can International, HVA and the University of Southampton sought to identify an evidence-based suite of core indicators of cancer care efficiency has led to the discovery of metric categories, metric themes and 137 metrics. Additionally, the results of the research has provided a rich evidence base of core real-world metrics which can be applied, albeit variably, across countries.

By aggregating the data on efficiency indicators and instruments from the research and the efficiency themes derived from the research and stakeholder interviews, we sought to identify key efficiency metrics that could either be used easily by healthcare practitioners in clinical settings (for instance, through collection of patient statements and PROs) or that could be statistically analysed post-hoc from routinely collected patient and health-care data as part of the routine auditing process by registries or regulatory bodies.

8.2 Implementation

All the metrics identified in this report can be translated across many cancer types and ultimately implemented into routine practice. The metrics highlighted offer a foundation for stakeholders to establish their own standard set of efficiency metrics that best suits their needs and ambitions, with the benefit of an evidence-based body of rationale for the inclusion of each metric.

Utilising these metrics in this way would serve to elevate current standards of patient-centred care by identifying opportunities to:

- a) **Improve outcomes for patients:** the delivery of accessible, patient-centred, evidence-based, high quality cancer care achieves the best possible outcomes for all cancer patients with the resources available)
- b) **Optimise allocation of resources:** using available resources in such a way as to achieve optimal outcomes equitably distributed across the system and population
- c) **Use data to continuously learn:** using newly available data to contribute to an adaptive and learning healthcare system that strives for continuous improvement to benefit cancer patients and their families.

8.3 Opportunities

8.3.1 Obsolete measures

The presented list of metrics could be used to identify obsolete measures that may no longer be useful or relevant to current cancer care and where these measures can be removed or replaced by a more relevant, current and standardised set of metrics, such as those presented in this report.

8.3.2 Identifying sub-optimal efficiency

The assessment of efficiency also includes the identification of areas or practices in cancer care that lead to erosion of efficiency. This can, paradoxically, include measures that are designed to improve efficiency from an organisational perspective, but which have detrimental effects on the delivery of patient-centric care, and which can adversely affect outcomes and cost-effectiveness of care e.g., an over-focus on operational efficiency driven by organisational service or patient throughput targets.

In addition, sub-optimal efficiency could be associated with 'reactive healthcare' i.e., care that is initiated only because of the presentation of a problem by a patient, especially via an emergency care route. In addition, there exists a potential to measure the cancer diagnosis pathway in its entirety to determine the optimal route to diagnosis, identifying root cause for delays and sub-optimal routes of presentation and accounting for loco-regional factors e.g., sociodemographic, infrastructure, screen availability and uptake and primary care and diagnostic services. The UK National Awareness and Early Diagnosis Initiative in England (NAEDI) [99] sought to show that delays in diagnosis lead to patients being diagnosed with more advanced disease and poorer 1-year and 5-year survival, especially in ethnic minority populations.

8.3.3 Promoting preemptive and proactive care

Identification of 'reactive' care i.e., where care is only associated and focused on the presentation of an issue, and not causation or prevention measures, could highlight where the adoption or improvement of predictive care and proactive care is needed. Furthermore, where risk is identified e.g., through patient reported outcomes assessments, some form of preemptive measure/s and their success when employed, could be assessed.

8.3.4 Inequitable funding in organisations

As highlighted by two of the stakeholders interviewed, the revenue generated from oncology departments can be significantly greater than other hospital departments and therefore can serve as a “cash cow” for the hospital. Oncology revenues can then be utilised to fund accident and emergency departments or new building projects, for example.

In the current economic climate, where mixed or sole funding models are becoming more common (including caps on reimbursement by insurers) some stakeholders are benefiting financially from reimbursement models that support FFS and any unjustified AoC. Further study into AoC and financial consent, identifying key metrics, is suggested.

8.3.5 Assessing social environment and attitudes

The social environment and attitudes of individuals in different regions and populations can have a fundamental effect on cancer incidence, morbidity and mortality. However, the breadth, complexity and multi-factorial nature of the metrics associated with social environments and the attitudes of individuals made inclusion of associated metrics in this report unrealistic. Further research is recommended here, for example, assessing key stakeholders in particular social environments to select what is relevant to that stakeholder in that specific environment.



8.3.6 Assessing the effect of innovation on efficiency

As discussed in the body of the report, tracking the effectiveness of an innovation is challenging. However, standardised models could be adopted from institutions that develop, trial and deliver innovation to the market, using a standard set of metrics including PROMs, HQL, Quality Adjusted Life Years (QALYs) and other defined endpoints, to showcase their effect on cancer care efficiency. This could be aligned with efficiency metrics, assessed for validity and socialised for potential adoption as a standard approach innovation value assessment, particularly from the patient's perspective.

8.3.7 Implications for cancer registries

Cancer registries collect data on patient characteristics. This information is used to report on aspects such as national cancer burden associated with distinct groups within the population, such as age, sex, geography, and other personal characteristics. In Canada and New Zealand, for instance, cancer registries report on specific ethnicities within the population with the aim of monitoring inequalities in cancer burden within these groups and inform appropriate health initiatives.

The review of registries highlighted a need for more consideration of **ethnic minority populations**, the **incidence of comorbidities** and a more comprehensive collection of **patient-reported outcomes and specific care needs**, if the monitoring of efficient cancer care was to be improved.



9 Potential next steps



9.1 Overview

The limitations of scope of this review meant it could not be exhaustive. Therefore, potential next steps for the implementation and evolution of the metrics presented in this report as presented could be as follows:

9.2 International expert collaboration

Assembling a Delphi panel of experts (including patients and patient advocacy groups) or adapting previous approaches [74] to international consultation exercises to gain consensus from healthcare practitioners, payers, industry and researchers on the best indicators and most representative indicators to incorporate into existing datasets is recommended.

9.3 Addressing Quality of Life (QoL)

Quality of Life (QoL) can have significant implications on patients, their families, their carers and the healthcare ecosystem as a whole. However, QoL was one area where further review was deemed necessary. Further assessment of the plethora of QoL toolkits (including questions included in PROMs and experience questionnaires) and the significance of QoL as an indicator of efficiency in cancer care, is indicated. For example, assessing QoL as a prognostic indicator or how QoL affects return to work, health service utilisation, cost: benefit of innovation or even survival is recommended.

9.4 Exploring the perspectives of the healthcare consumer

While the metrics presented in this report offer a list derived from stakeholder engagement and a thorough academic review, further engagement with consumers of cancer care i.e., patients, their families and their carers, could provide another dimension and additional validation to the metrics set. This could serve to highlight those efficiency metrics that are of most importance to consumers, and potentially ranking these in order of importance. This could be facilitated by 9.5 and 9.6 below.

9.5 Collaborating with patients and patient advocate groups

Collaborating with patient and patient advocate groups, such as the European Cancer Patients Coalition (ECPC), to promote the involvement of patients in improving cancer care efficiency and quality e.g. by establishing a more robust 'PPI' (patient and public involvement) component to policy and research could take this further. Such an approach has been carried out by the National Institutes of Health and Care Research (NIHR) in the United Kingdom [94], supporting service decision-making to help ensure the needs of the public are considered and research policy and services evolve.

9.6 Mapping metrics to consumer experience

Expanding on consumer perspectives, mapping metrics to patient experience could afford an improved understanding of how the metric does or does not affect experience and vice versa. This could improve our understanding of the value of correlation between the metrics and patient satisfaction i.e., which affects which and how? Furthermore, this analysis could provide insight into how the metric is related to how healthcare consumers make decisions and how they consume care e.g., did they experience shared decision making with their clinician, and what was the effect of a Yes or No answer on other metrics.

9.7 Learning from other disease areas

Assessing data collected from other diseases and what could usefully be included in cancer care efficiency assessments could afford additional learning opportunities. This could ensure that, for example, the needs of people with multiple long-term conditions (existing prior to cancer, exacerbated by cancer treatment or occurring because of cancer treatment) are taken into consideration. This approach could also help registries to improve the data they collect, share data between different disease registries and support more detailed population assessment.

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Appendix 1

Scoping review methodology and criteria for indicators

Systematic database searches, combined with snowballing and scoping of online cancer registries, were conducted to retrieve journal articles and grey literature. Reporting of findings for the academic report followed recommended scoping review methodology [101, 102] which involved: (1) defining the purpose of the review and research questions; 2) identifying relevant publications and grey literature; 3) iteratively selecting relevant publications through title, abstract and full-text screening; 4) extracting and charting data from publications and grey literature; 5) collating, summarising and reporting findings; and 6) discussions with expert consultants, who were not involved in extraction and summarising of data, about the relevance, rigor and review of the findings.

Eligibility criteria

Eligibility criteria were developed based on consensus between authors and expert consultants on the key definitions in the research question “What core real-world measures are associated with efficiency in cancer care?”, whereby:

- Core represented data captured from datasets or analyses that already are or can realistically be applied to multiple/all cancer types
- Real-world represents ‘data relating to patient health status and/or delivery of health care’ [104] that is routinely collected from different sources for clinical, research and audit or policy purposes
- Measures represent quantitative/observational data that can be translated into simple metrics of quality or efficiency in cancer care. This will include clinically validated measures that could be easily and reliably incorporated into routine care
- Efficiency represents the patient-centred definition of efficiency derived from All.Can’s patient survey [72], which focuses on improving outcomes for patients, optimising allocation of resources and using data to continuously learn.

By necessity of the research question, the publication search had to be broad; however, to be pragmatic and ensure manageability, this broad search was restricted to records published in the last five years (2017-2022). Many of these records nevertheless referenced core measures that had been historically/routinely used in cancer care before 2018, and as such these measures are reflected in this review.

Inclusion criteria

To be included, publications had to be written in English and originate from English-speaking countries in the Northern hemisphere (including Europe) or Australasia.

Publications relevant to human cancer were included if they focused on any of the following aspects of cancer care: the patient pathway (symptoms and referral, screening and diagnosis, treatment and rehabilitation, follow-up and survivorship, palliative care, and end-of-life care); multidisciplinary care (alliance of healthcare teams and carers); psychosocial care and peer support; communication and shared-decision making; guidelines and adherence; and the financial impact of cancer. Original research publications were not limited by study type but had to include real-world cancer measures collected in clinical/controlled settings (e.g., trials, cohort, cross-sectional studies) or retrospectively analysed from patient data such as electronic health records, registry datasets, linked data, audit data and national survey outputs. Secondary analyses of trials were included if the original trial record was missing from search results. Non-research articles using real-world data (RWD) such as published audits, clinical reports, clinical expert opinions (e.g., editorials, supplements) were included. Delphi studies were included if they provided quantifiable consensus data on indicators by real-world healthcare professionals.

Inclusion of cancer care measures (referred to in the review as indicators) was based on evidence of their real-world application or validation in clinical settings. Effort was made to focus as far as possible on (a) core indicators (i.e., those that are, or could be, clinically transferable without too much difficulty across all cancers, (b) operational or process measures that relate directly to the care pathway efficiency concerns raised in the All.Can patient survey [72], and (c) measures reflecting the experiences, perceptions and preferences of patients, families, and caregivers. Examples of the above include (a) cost-effectiveness outcomes, (b) care quality indicators, and (c) patient-reported outcomes. Scale-based (e.g., Likert-type, dichotomous) indicators represented by or derived from established patient questionnaires or instruments (e.g., Psychosocial Assessment Tool) were also included, as well as clinically validated questionnaires or instruments that could be easily incorporated into routine practice. Structural indicators, such as hospital volume, were excluded as infrastructural resources are outside the scope of this review.

Exclusion criteria

Publications were excluded if they were not written in English or if originating from non-English-speaking countries, except for one study [5] published in the *Journal of Occupational and Environmental Medicine*, which offered the only real-world evidence of a national occupational cancer survivor registry that monitors, and provides support with, the effects of cancer on employment. Conference/symposia abstracts, clinical protocols, clinical answers, and clinical outcome assessments (Cochrane Library) were excluded. Case reports or case series were excluded as they lack sufficient statistical evidence for effectiveness/generalisability, and inconclusive studies or studies citing small samples, methodological bias, inconsistency, or low-moderate rigour were excluded. Ongoing trials, pilots and preliminary reports were excluded.

Clinical studies focused more on clinical medicine than care in cancer, such as intervention effectiveness, efficacy or effect studies were excluded unless they included cancer care indicators in the abstracts. Studies on cancer prevention strategies (e.g., biomarkers, HPV vaccines) and epidemiological studies were excluded for manageability and to narrow scope as closely as possible to the patient pathway. Publications examining malpractice complaints, health insurance, value-based care, methodology for clinical research and trial participation were excluded, as were specific therapy frameworks, studies on secondary disease, smoking cessation trials (if lung cancer), and studies relating to cancer care during the Covid-19 pandemic. Qualitative observational studies using semi-structured interviews, questionnaires, or surveys to generate data that was too abstracted (e.g., not scale-based) to translate into clinically applicable and reproducible cancer care indicators were also excluded.

Regarding indicators, we have deliberately excluded from our review studies that have examined measures such as QoL and related QALY/HQALY, statistics such as survival rates, and other traditional clinical metrics on the grounds that: (i) these have already been extensively researched and are already routinely collected as minimum standard in healthcare services (e.g., the NHS); and (ii) these outcomes can be affected by endogenous factors and do not easily generalise across all cancers, so cannot act as generalisable indicators of cancer care efficiency (as an example, median survival outcomes will vary considerably between pancreatic and breast cancer – although we are aware of the recent cancer survival index from the Centers for Disease Control and Prevention, which accounts for a number of confounding factors such as age, sex and cancer type (Johnson et al. 2017, CDC [103])). Indicators collected by instruments that have not been sufficiently validated for reliability (test-retest, internal consistency, content/criteria, etc.) in clinical settings were excluded. Finally, basic economic metrics, such as treatment and care costs, lacking further analysis to reflect efficiency or financial toxicity (e.g., cost-effectiveness, ICER) were excluded.

As a caveat, it is important to mention that many health performance indicators that are routinely collected in other areas of healthcare could be realistically applied to cancer care (especially, to address inefficiencies or unmet need); however, any indicators that were not evaluated in a cancer-specific context (e.g., captured from evidence focused more on pancreatitis than pancreatic cancer) had to be excluded from the review as they would not be supported by real-world evidence of applicability to cancer.

Search strategy

Systematic database searches were conducted between February and April 2022. To test search terms and keywords, limited searches were conducted in Embase and Cochrane Library to check the availability and relevance of titles and abstracts. Based on this, search term and keyword combinations were developed and iteratively tested across a wider search.

The search strategy included cancer, neoplasm and oncology MeSH headings and additional terms for identifying publications relevant to the care pathway and patient-centred care. Specific search strategies were applied according to individual database rules (for instance, search qualifiers like 'treatment' and 'nursing' were applied to cancer terms to narrow searches in Cochrane Library). Filters were applied to retrieve publications (a) in the English language, (b) that used human participants only, (c) published in the last five years (2018-2022), and (d) linked to full-text articles. Where possible, book chapters and associated data were excluded.

The electronic databases used for the full search of publications were Embase, Medline, PubMed, and Cochrane Library is shown below. Google Scholar was also used to obtain publications – particularly grey literature – that may not be captured in other databases and the search strategy was adapted accordingly to retrieve article titles and abstracts ('snippets'). The search strategy used for databases and Google Scholar is depicted in Table 1.

Publication selection

Citations identified through electronic database searches were exported with title and abstract into Endnote 20 (Clarivate, UK) and duplicates removed. Search records were screened against eligibility criteria by KC and KEL, first by title and abstract, and then if eligible by full-text articles. Interrater agreement (calculated for 10% of double-screened records) was 94%, with any disagreements about inclusion or exclusion of a given record resolved through discussion and consensus.

Data extraction and analysis

A structured data extraction form was developed in Microsoft Excel and piloted on two publications for relevance and richness of data. Data from each full-text article was extracted by KC to include information on: a) authors, year of publication and lead author country, b) publication type and study type (if research), c) specific indicators and indicator types cited, d) whether indicators were based on RWD, e) type of cancer, and d) area of cancer (e.g., diagnosis, therapeutic alliance). Information supporting the appraisal of the data was also extracted, including a) whether the data is relevant to All.Can's definitions of cancer care efficiency (and the evidence for this), b) whether the authors referred to efficiency in cancer care, f) whether the indicators were used effectively in the contexts of studies (and the evidence for this), d) links to real-world datasets (if applicable), and e) whether based on the above the publication should be included in the review. Where publications were then excluded, information deemed relevant for background or discussion was utilised.

The breadth of the research topic and the inclusivity of All.Can's person-centred definition of cancer care efficiency [72], which was incorporated into the search strategy, meant that, despite setting a five-year publication date limit, the literature search generated a significantly larger sample of hits (>2000) than would normally be expected for a scoping review. To ensure data screening and extraction were manageable but remained rigorous in the time given, extraction of individual full-text articles continued until 'saturation' was reached – i.e., when no more new indicators could be extracted, and all remaining articles cited indicators that had already been extracted in specific real-world contexts. At that point the remaining literature, if eligible, was partially extracted (author, date, article type, indicator (and whether real-world), type of cancer and area of cancer care) to support main findings in the report. If during that process new real-world indicators were identified from publication titles/abstracts, those publications were fully extracted. Since only a minority of eligible publications remained at the time screening saturation was reached (~14%) and only 26 were subsequently included to support review findings, this extraction method was not considered to have sacrificed robustness of evidence for the report.

Assembly of the complete suite of indicators cited in publications and grey literature (Table 1, Appendix 3) included importing extracted data from Excel into a table in Microsoft Word. Column titles were as follows: Theme, Sub-theme, Indicator, Indicator type, Indicator data sources, Real-world (RW) or clinically validated, References (from main report). Where possible, specific indicators from literature were generalised for the table. Numbers in superscript were used to indicate for each indicator the corresponding indicator type, data source, whether it is RW or validated, and the reference. For indicators derived from registries or grey literature (using the search strategy below), links to specific registry web pages were listed in the main report. Where indicators came from publications, original data sources were included (e.g., registries, healthcare systems, organisations, national surveys, audits).

Audits

To identify potentially relevant audits drawing on data from cancer registries, the Pubmed database was searched in April 2022. Search terms were tested to check availability, and relevance of titles and abstracts. Keywords and MeSH headings from relevant papers were used to modify the search strategy, which was subsequently checked against MEDLINE and Embase to inform the final search strategy. The final search strategy for Pubmed, Ovid MEDLINE (R: 1996 to April Week 3 2022) and Ovid Embase (1996 to 2022 Week 15) can be found in Table 2 below. A search filter was applied to only yield documents a) published in the last five years (2017-2022), b) written in the English language, c) involving humans, and d) that had an abstract.

Table 1. Systematic search strategy for identifying publications from databases and Google Scholar

Search terms	Search engine
<p>1. Subject heading: Neoplasm OR cancer* OR oncolog*</p> <p>AND</p> <p>2. Subject heading: patient preference OR satisfaction OR outcome assessment OR patient-reported outcome* OR patient-centred care OR patient-centred outcome* OR patient-centred outcomes research OR quality OR patient participation OR patient acceptance of healthcare</p> <p>AND</p> <p>3. Keywords: quality of care OR specialist consultation OR patient involvement OR patient-centred communication OR symptom management OR patient care management OR cancer recurrence OR follow-up OR continuity of care OR time to diagnosis OR time to referral OR psychology OR family psychology OR psychosocial OR caregiver-oncologist OR patient-oncologist OR social care OR social support system* OR health expenditures OR healthcare costs OR efficiency (AND care AND indicator OR real-world (AND care AND indicator))</p> <p>Filters: Abstract, Full text, Clinical Trial, Meta-Analysis, Randomized Controlled Trial, Review, Systematic Review, in the last 5 years, English, Humans</p>	<p>Embase, Medline, PubMed</p>
<p>See above: 1 AND 2 AND 3</p> <p>Qualifiers: diagnosis DI, nursing NU, psychology PX, therapy TH, secondary SC, standards ST, legislation & jurisprudence LJ, education ED</p> <p>Topic filter: cancer</p> <p>For Cochrane trial registry search, instead of topic filter: 1 AND 2 AND 3 AND "cancer"</p> <p>Filters: reviews and trials, last 5 years, allow word variations, no Cochrane group limit, English.</p>	<p>Cochrane Library</p>
<p>Find articles</p> <ol style="list-style-type: none"> 1. with the exact phrase: [keyword from 3] 2. with at least one of the words: cancer OR oncology OR neoplasm OR tumour 3. where my words occur: anywhere in the article 4. Return articles dated 2018-2022 	<p>Google Scholar</p>

Table 2. Search strategy for audits published in bibliometric databases

Search terms	Database
<p>1. Main heading: neoplasm.sh OR neoplas*.ab,ti OR cancer.ab,ti</p> <p>AND</p> <p>2. Main heading: (registries.sh OR registr*.ab,ti) AND (Clinical audit.sh OR audit.ab,ti)</p> <p>FILTERS: Last five years (2017-2022); English language; Abstract; Humans</p>	<p>Pubmed</p> <p>MEDLINE</p> <p>Embase</p>

Search results were exported into Endnote 20 (Clarivate, UK) and duplicates removed. Search results were screened against eligibility criteria by KEL on title and abstract first, and then on full-text, where available.

Indicators were extracted by KEL into a structured form in Microsoft Excel, which recorded the following: a) Year of publication; b) Relevant country/countries; c) citation; d) data source; e) Indicators cited; f) Type of cancer; g) Indicators that meet inclusion criteria; and h) Authors' rationale for use (if stated).

Cancer registries

National-level and international core cancer registries from Europe, North America and Australasia were scoped for relevant indicators by KEL. For Europe, the European Network of Cancer Registries (ENCR) was used as a basis to identify relevant registries. Other relevant registries were identified based on discussion within the team or snowballing from the literature/international registry websites/web searches. The European Cancer Information System (ECIR) reports that there are almost 200 population-based cancer registries in most European countries alone. This review therefore excluded specific cancer, and regional and local cancer registries to ensure that the review remained proportionate against the timeframe for delivery. As a caveat, real world indicators within regional and specific cancer registries associated with efficiency in cancer care, according to All.Can's definition, will not have been extracted here. However, due to the mixed-methods nature of this scoping review, it is likely that this will be kept minimal. Other grey literature was identified from snowballing registry websites.

Registry websites and associated grey literature were scoped for any audits or reports that included indicators. Where indicators were available, these were extracted into two structured data extraction forms in Microsoft Excel, for registries and grey literature.

The registry form recorded the following: a) Registry name; b) Indicators mentioned or reported on; c) indicators within scope of this review; and d) Further relevant registry information, such as rationale for indicator use. The grey literature form recorded: a) Title of the literature; b) Citation; c) Area of cancer; d) Indicators mentioned; e) Indicators relevant to inclusion criteria; and d) Further details on rationale or considerations.

Ethical approval

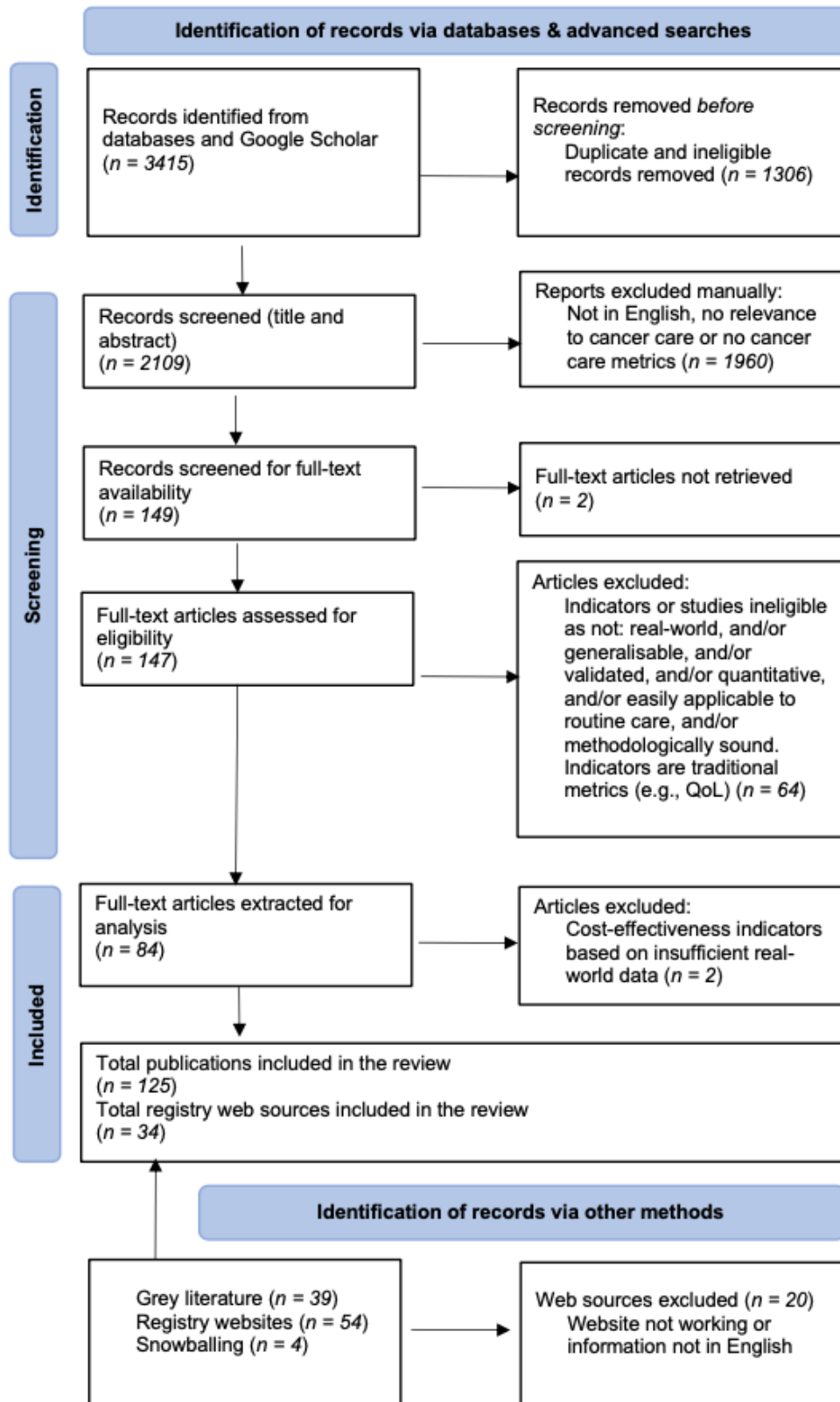
The ethics application was written, prepared and coordinated by KEL for the stakeholder interviews undertaken by HVA project team members from the Faculty of Medicine Ethics Committee (ID 71286).

Dissemination and consultation

The search strategy and interim review findings were presented to HVA and All.Can for feedback on eligibility criteria and appraisal of the evidence. Weekly discussions were held with expert consultants throughout the design and delivery stage of the review. The final draft was disseminated for approval to all stakeholders.

Appendix 2

PRISMA flowchart of the search strategy used for identifying indicators of cancer care efficiency



Appendix 3

Comprehensive suite of real-world indicators of cancer care efficiency

Table 1 - Comprehensive suite of indicators captured from review of the evidence. Numbers in superscript (X) indicate corresponding information for each indicator, including indicator type, original indicator data sources, whether they are real-world or clinically validated, and references. Asterisks (*) indicate the overlapping themes from publications and registries. Crosses (†) indicate overlapping indicators from publications and registries.

Metric category	Metric theme	Metric	Metric type	Metric data sources	Real-world (RW) or clinically validated	References (from main report)
Timeliness of care*	Swift diagnosis	¹⁻⁵ Time to diagnosis [†] ; ⁶ Cancers diagnosed at stage I-II; Stage at diagnosis	¹⁻⁵ Outcomes; ⁶ Process indicators	¹ Lung Cancer Rapid Diagnostic Unit (Spain); ² National Audit of Cancer Diagnosis in Primary Care; Netherlands Cancer Registry; Multitumour board registries (USA); Addenbrooke's Hospital cohort data of Christopher et al; International Cancer Benchmarking Partnership (cancerresearchuk.org); ³ Thoracic Triage Panel referral program (Canada); ⁴ Danish National Patient Register; ⁵ Scottish and English General Practices and Scottish Cancer Registry; Hospital Episodes Statistics and Cancer Waiting Times datasets; ⁶ Canadian Cancer Registry (CCR); National Cancer Registration and Analysis Service (NCRAS); Cancer Registry of Republic of Slovenia; National Program of Cancer Registries Australian Cancer Database (ACD); New Zealand Cancer Registry; National Program of Cancer Registries; Canadian Cancer Registry (CCR)	¹⁻⁶ RW	¹ Leiro-Fernandez et al 2019; ² Ozawa et al 2018; Baun et al 2019; Bosch et al 2018; Cavallin et al 2018; van Erp et al 2020; Muthukrishnan et al 2020; Virgilsen et al 2022; Christopher et al 2019; Price et al 2020; ³ Common et al 2018; ⁴ Virgilsen et al 2021; ⁵ Murchie et al. 2020; Swann et al. 2018; ⁶ Links to specific registry web pages in main report

Optimising routes to diagnosis	¹ % Patients receiving first-time diagnosis after an emergency presentation; ² % Emergency presentations after A&E referral vs emergency GP referral; % cancers diagnosed through emergency presentation ¹ ; ³ Healthcare seeking behaviour; ⁴ First point of contact for symptom presentation; ⁵ Interhospital referral rate; ⁶ Percentage of cases by route to diagnosis; ⁷ Inpatient care diagnosis; ⁸ Screening uptake; screening coverage; ⁹ Patient ability to undergo treatment once diagnosed	^{1,3,5,6,7} Outcome s; ^{2,8,9} Process indicators	¹ Pediatric Oncology Unit of Sapienza University; ² Routes to Diagnosis (England); National Cancer Registration and Analysis Service - England; ³ National Cancer Registry-PHARMO GP Database (Netherlands); ⁴ Danish National Patient Register; ⁵ Dutch ColoRectal Audit; ⁶ National Cancer Registration and Analysis Service (England), ⁷ Swedish National Cancer Registry; ⁸ National Cancer Registration and Analysis Service (England); Scottish Cancer Registry and Intelligence Service (SCRIS); Australasian Association of Cancer Registries; Estonian Cancer Screening Registry; Netherlands Cancer Registry; ⁹ National Cancer Registration and Analysis Service (England)	¹⁻⁹ RW	¹ Schiavetti et al 2022; ² Herbert et al 2019; Topping et al 2019; ³ Kuiper et al 2021; ⁴ Virgilsen et al 2022; Warps et al 2021 ²⁻⁸ Links to specific registry web pages in main report
Appropriate and clinically indicated diagnosis	¹ Percentage of cases by basis of diagnosis; ² % Microscopically verified cancers; ³ Primary care-led investigations prior to referral ⁴ Positive Predictive Value	^{1,4} Process indicators	¹ Cyprus Cancer Registry; Estonian Cancer Registry; Swedish National Cancer Registry; ² Malta National Cancer Register; National Cancer Registry Ireland & The United Kingdom and Ireland Association of Cancer Registries, Cancer Registry of Republic of Slovenia; ³ Scottish and English General Practices & Scottish Cancer Registry; Hospital Episodes Statistics and Cancer Waiting Times datasets; ⁴ National Mammography Database and Breast Cancer Screening Consortium	¹⁻⁵ RW	¹ Pavlou and Demetriou 2016; ² Murchie et al 2020; Swann 2018; ⁴ D'Orsi 2020 ¹⁻² Links to specific registry web pages in main report
Efficient referral to specialist services	¹ Referral rate for diagnostic/genetic screening; ² % Patients receiving urgent referral within 14 days of presentation; ³ Short-term mortality risk; rate of palliative care consults; rate of hospice referrals; days spend in hospice care ⁴ Primary care interval ¹ ; ⁵ Patients seen by specialist palliative care; ⁶ Referral to first clinic visit; ⁷ Duration from first clinic visit to diagnosis; ⁸ % Patients who died within one week after start of palliative care; ⁹ Cancer over-screening	^{1,4} Outcomes; ^{5,9} Process indicators	¹ RCT data of Peabody et al 2019; medical data of University of Chicago, Rush University, University of Miami, and University of Pennsylvania (USA); ² NICE guidelines; ³ Northwest Medical Specialties (USA); Cancer Registry database at the Watson Clinic LLP Cancer and Research Center; ⁴ Danish National Patient Register; Scottish and English General Practices and Scottish Cancer Registry; Hospital Episodes Statistics and Cancer Waiting Times datasets (England); ⁵ UK National Lung Cancer Audit & Victorian Comprehensive Cancer Centre and associated Western and Central Melbourne Integrated Cancer Service; ^{6,7} Santeon Dutch Hospital Group data; ^{8,9} Healthy Belgium	¹⁻⁹ RW	¹ Peabody et al. 2019; Muller et al 2018; ² Keenan et al 2021; ³ Gajra et al 2022; Mulville et al 2018; ⁴ Virgilsen et al 2021; Murchie et al 2020 ; Swann et al 2018; ⁵ Mileshkin et al 2019; Keane et al 2018; ^{6,7} Santeon 2017; ^{8,9} Healthy Belgium
Early treatment	¹ Time from referral to procedure; time	¹ Outcomes; 2,3Quality	¹ Direct Access Colonoscopy program (Netherlands);	1-6RW	¹ Stawinski et al 2021;

	initiation	to surgical care; ² Time from tissue diagnosis to treatment ¹ ; 30-day mortality following completion of treatment; time to treatment initiation; ³ Time to start of post-operative therapy; ⁴ Patients who completed the treatment in the prescribed time; ⁵ Duration from diagnosis to discussion of treatment plan; ⁶ Duration from treatment plan discussion to starting treatment;	indicators; ^{4,6} Process indicators	² Medicare data (USA); Evaluation of Cancer Outcomes Barwon South West Registry; National Cancer Database; National Cancer Database; Cancer Benchmarking Partnerships; Clinical Practice Research Datalink; Addenbrook's Hospital cohort data of Christopher et al; Belgium Cancer Registry; ³ Medicare-linked data (USA) ⁴ Wielkopolskie Centrum Onkologii (Poland); the Instituto Português de Oncologia (Portugal); the Università degli Studi del Piemonte Orientale (Italy); and the three hospitals of Institut Català d'Oncologia (Spain): ICO-Hospitalet, ICO-Badalona, and ICO-Girona; ^{5,6} Santeon Dutch Hospital Group data;		² Kim et al 2019; Khorana et al 2019; Menon et al 2019; Aas et al 2019; 2020; Price et al 2020; Takes et al 2020; Azap et al 2020; Belgium Cancer Registry; ³ Swegal et al 2020; ⁴ Lopes de Castro et al 2021;
Quality of care*	Physician adherence to national guidelines	¹ Concordance of referral practices with national guidelines; ² Adherence to treatment guidelines ³ Observed-to-expected ratio for adherence to treatment guidelines; appropriate treatment; ⁴ Guidance-concordant screening rate	^{1,4} Outcomes; ² Process indicator ³ Quality indicator	¹ NICE guidelines; ² World Health Organisation; American Academy of Otolaryngology-Head and Neck Surgery Foundation; Institute of Medicine and Guidelines International Network; ³ Medicare-linked data (USA); ⁴ US National Health Interview Survey data of Suk et al	¹⁻⁴ RW	¹ Keenan et al 2021; ² Takes et al 2020; Christopher et al 2019; ³ Swegal et al 2020; ⁴ Suk et al 2022
	Coordination of specialist resources	¹ Adequacy of referral of the target population from screening program to other services; waiting time for referral to other services; understanding of the screening program by professionals; effective information flow between professionals; ² Patients treated with new technologies (%); ³ Patients included in clinical trial	¹ Care quality indicator; ^{2,3} Process/care quality indicators	¹ Delphi survey of nurses from cancer screening programs (Spain) & the Catalan Institute of Oncology (Catalonia); ^{2,3} Wielkopolskie Centrum Onkologii (WCO) in Poznan, Poland; the Instituto Português de Oncologia (Portugal); the Università degli Studi del Piemonte Orientale (Italy); and the three hospitals of Institut Català d'Oncologia (ICO) in Spain: ICO-Hospitalet, ICO-Badalona, and ICO-Girona; National Cancer Registration and Analysis Service, Public Health England, CancerStats	¹⁻³ RW	¹ Benito et al 2018; ² Lopes de Castro et al 2021 ³ Lopes de Castro et al 2021; Public Health England 2018
	Role of multi-disciplinary teams (MDTs)	¹ Presence of a MDT; ² Patient experience of multidisciplinary consultation; ³ Availability of Clinical nurse specialists; ⁴ Nurse specialist-reported confidence with multidisciplinary team settings; ⁵ % Patients given the name of a CNS ¹ ; CNS caseloads per year; Dedicated contact person who supervises	¹ Process indicator; ² Patient-reported outcome; ³ Statistic; ⁴ Self-reported outcome; ⁵ Outcome; ⁶ Process; ⁷ Experience; ⁸ Process	¹ European MDT units; ² Gustave Roussy Prostate Cancer Multidisciplinary Clinic (France); ³ NHS England; ⁴ English National Lung Cancer Audit; ⁵ National Cancer Patient Experience Survey 2017 (UK); National Cancer Registration and Analysis Service (NCRAS England); Santeon Dutch Hospital Group data; ⁶ Dutch Lung Cancer Audit; Dutch National Breast Cancer Audit; UK National Lung Cancer Audit and Victorian Comprehensive Cancer Centre and associated Western and Central Melbourne Integrated Cancer	¹⁻⁹ RW	¹ Takes et al 2020; ² Patrikidou et al 2018; ³ Kerr et al 2021; ⁴ Stewart et al 2021; ⁵ Taylor et al 2019; Santeon 2017; ⁶ Beck et al 2018; Spronk et al 2017; Ismail et al 2020; Mileskin et al 2019; ⁷ Lopes de Castro et al 2021;

		the patient and is known to the patient (%); ⁶ % Patients discussed in a MDT meeting prior to the start of treatment; % Patients discussed at a MDT meeting; ⁷ CNS easy to contact; ⁸ Patients documented as seen by a CNS; ⁹ CNS present at diagnosis		Service; Wielkopolskie Centrum Onkologii (Poland); the Instituto Português de Oncologia (Portugal); the Università degli Studi del Piemonte Orientale (Italy); and the hospitals of Institut Català d'Oncologia (Spain): ICO-Hospitalet, ICO-Badalona, and ICO-Girona; National Cancer Registration and Analysis Service, Public Health England, CancerStats; Northern Ireland Cancer Registry; ⁷ NCRAS (England); Scottish Cancer Registry and Intelligence Service; ^{8,9} UK National Lung Cancer Audit; Victorian Comprehensive Cancer Centre and associated Western and Central Melbourne Integrated Cancer Service; National Cancer Registration and Analysis Service, Public Health England, CancerStats		^{5,7} Links to specific registry web pages in main report Hawkins et al 2021 ^{8,9} Mileschkin et al 2019; PHE 2018
	Patient-reported outcomes (PROs) in routine care	¹ Emergency department visits; frequency of hospitalisations; palliative care visits; psychosocial oncology visits; ² Intensity of nine common cancer physical and psychological symptoms; symptom severity; ³ Quality of life of cancer patients; ⁴ Actionable distress; nutritional status; severity of pain; ⁵ physical, mental and social health; ⁶ patient-reported adherence; non-adherence; risk of non-adherence; treatment satisfaction; ⁷ 30-day readmission rate; ⁸ patient activation; ⁹ patient concerns; ¹⁰ Perceived psychosocial care and support	^{1,7} Outcomes; ^{2,3,4,5,6,8,9,10} PROs and electronic (e)PROs	¹ RCT data by Howell et al; Ontario Cancer Registry; ² Edmonton Symptom Assessment System, Cancer Care Ontario (cancercareontario.ca); Common Terminology Criteria for Adverse Events, National Cancer Institute Cancer Therapy Evaluation Program (ctep.cancer.gov); ³ EORTC QLQ-C30 Questionnaire, EORTC Quality of Life (qol.eortc.org); ⁴ Distress Thermometer, National Comprehensive Cancer Network (nccn.org); Mini Nutritional Assessment, Nestle Nutrition Institute (mna-elderly.com); Brief Pain Inventory, MD Anderson Cancer Center (mdanderson.org); ⁵ PROMIS, Health Measures (healthmeasures.net); ⁶ Beliefs About Medicines Questionnaire of Home et al; RCT data of Hershman et al 2021; ⁷ Duke Cancer Center (USA); ⁸ Patient Activation Survey, Insignia Health (insigniahealth.com); RCT data of Lidington et al 2020; ⁹ Patient Concerns Inventory, Edge Hill University (UK); ¹⁰ Duke-UNC Functional Social Support Questionnaire (sabi.unc.edu)	^{1,2,3,4,5,7,8,9} RW ; ⁶ Validated; ¹⁰ RW and validated	¹ Howell et al 2020; Hildenbrand et al 2022; ^{2,3,4,5} reviewed by Anatchkova et al 2018; Hildenbrand et al 2022; Trojan et al 2021; Plate et al 2018; Poudel et al 2021; ⁶ Hershman et al 2021; Pandey et al 2019; ⁷ Hildenbrand et al 2022; ⁸ Lidington et al 2020; ⁹ Rogers et al 2018; ¹⁰ Poudel et al 2021
	Patients' perceptions of care quality	¹ Medical-technical competence; physical technical conditions; identity-oriented approach; socio-cultural atmosphere	¹ Patient-reported outcomes	¹ RCT data of Singer et al 2019; radiation oncology clinics at Memorial Sloan Kettering Cancer Center (USA)	¹ RW	¹ Singer et al 2019; Shaverdian et al 2021
Continuity of care (COC)*	Adequacy of follow-up pathways	¹ Patient-initiated follow-up ² Frequency of GP consultations; interval between GP consultations; ³ Patients with regular follow-up post treatment;	¹ Healthcare pathway	¹ NHS England; ² National GP Survey (France); ³ Wielkopolskie Centrum Onkologii (Poland); the Instituto Português de Oncologia (Portugal); the Università degli Studi del Piemonte Orientale (Italy); and the three hospitals of	¹⁻³ RW	¹ Newton et al 2019; ² Hurtaud et al 2019; ³ Lopes de Castro et al 2021;

				Institut Català d'Oncologia (ICO) in Spain: ICO-Hospitalet, ICO-Badalona, and ICO-Girona		
	Patients' experiences of COC	¹ Level of continuity of care experienced; ² Provision with contact details post hospital; ³ GP support during treatment	¹ Self-reported outcome; ^{2,3} Experience indicator	¹ National Swedish Breast Cancer Quality Register and real-world survey data of Plate et al; ^{2,3} National Cancer Registration and Analysis Service (England)	^{1,2} RW	¹ Plate et al 2018; ^{2,3} Links to specific registry web pages in main report
Palliative care (PC) and end-of-life care (EOL)*	Patients' and families' perceptions of PC and EOL	¹ Availability of palliative care; parents' quality rating of care; parent satisfaction; chance to plan the location of death; physician availability; availability of psychosocial support; number of hospital stays during last month of life	¹ Self-reported outcomes	¹ Survey of Caring for Children with Cancer survey & paediatric oncology data (Germany); Nova Scotia Cancer Registry (Canada)	¹ RW	¹ Zernikow et al 2019; Lees et al 2019
	Aggressiveness of EOL	¹ New chemotherapy regimen starting <30 days before death; more than 1 day ICU stay within last month of life; ^{1,2} % Patients who received chemotherapy in the last 14 days of life ¹	¹ Caregiver-reported outcomes; ² Outcomes	¹ Cancer Registry of the National Center for Tumor Diseases (Germany); Medicare data (USA); ² Heathly Belgium	^{1,2} RW	¹ Tonnies et al 2021; Mullins et al 2021; ² Links to specific registry web pages in main report
Psycho-social oncology	Psychosocial screening of high-risk patients	¹ Psychosocial risk; ² Consequences of screening; ³ Actionable distress; ⁴ Psychiatry consultation; % of patients reporting opportunity for discussing concerns;	^{1,2} Patient-reported outcomes; ⁴ Outcomes	¹ Psychosocial Assessment Tool (psychosocialassessmenttool.org); RCT data of Barrera et al; ² RCT data of Bodtger et al; ³ Distress Thermometer, National Comprehensive Cancer Network (nccn.org); Dana-Farber/Boston Children's Cancer and Blood Disorders Center patient data	¹ RW and validated; ² Validated; ^{3,4} RW	¹ Barrera et al 2020; ² Bodtger et al 2021; ³ Draeger et al 2018; Lally et al 2019; ⁴ Zheng et al 2021
	Impact of cancer on family and patient relationships	¹ Perceived psychosocial care and support; current caregiver QoL; partner coping; current perceived financial security; parenting concerns; relationship strain; ² Social constraints; impact of event; ³ Dyadic adjustment; social problem solving; ⁴ Sibling bereavement	¹ Self-reported outcomes; ² Patient-reported outcomes; ³ Self-reported outcomes; ⁴ Self-reported outcomes	¹ Social Support Survey, RAND Medical Outcomes Study (rand.org); Caregiver Quality of Life Index scale, Measurement Instrument Database for the Social Sciences (midss.org); Coping Orientation to Problems Experienced Inventory, NovoPsych (novopsych.com.au); ² Social Constraints Scale of Lepore & Ituarte; Impact of Event Scale of Horowitz et al; ³ Dyadic Adjustment scale, Addiction Research Center, University of Wisconsin-Madison (arc.psych.wisc.edu); Social Problem-Solving Inventory-Revised, MHS (mhs.com); ⁴ Child Behavioural Checklist, American Psychological Association (apa.org)	^{1,4} RW; ^{2,3} Validated	¹ Borstelmann et al 2020; Links to specific registry web pages in main report ² Lally et al 2019; Lim et al 2021; ³ Malcarne et al 2018; ⁴ Hoffman et al 2018
Information, support, and decision-making*	Patients' perceptions of physician communication	¹ % Patients feeling that detailed information was provided by their physician; % of patients informed	¹ Outcomes; ² Electronic patient-reported outcomes; ^{3,4,5} Experience	¹ Real-world survey data of Barkin et al; ² PRO-CTCAE ITEM, National Cancer Institute Healthcare Delivery Research Program (healthcaredelivery.cancer.g	^{1,2} RW	¹ Barkin et al 2021; ² Basch et al 2020; ³ Swann et al 2018;

		on their therapy works; % of patients searching for information online; ² Quality of discussions with clinicians; feeling in control of own care; nurse perception of efficiency of patient discussions; ³ % patients who responded positively to level of doctor-patient communication; ⁴ Patient experience of administration of care; ⁵ Patients given a care plan;	indicators	ov); ³ GP Patient Survey (England); ^{4,5} Scottish Cancer Registry and Intelligence Service (SCRIS)		^{4,5} Links to specific registry web pages in main report
	Patients' experiences with decision-making	¹ Decisional regret; ² Patient preference for physician role;	¹ Patient-reported outcomes; ² Outcomes	¹ Decisional Regret Scale, the Ottawa Hospital patient decision aids (decisionaid.ohri.ca); Dana-Farber Cancer Institute patient survey data (Boston); ² Real-world survey data of Radhakrishnan et al	^{1,2} Validated	¹ Bisseling et al 2018; ² An et al 2019;
	Relationship between patients, caregivers, and oncologists	^{1,2} Therapeutic alliance; ³ Patient-physician discordance in goals of care	^{1,2} Self-reported outcomes; ³ Outcomes	¹ Working Alliance Inventory (wai.profhovath.com); Society for Psychotherapy Research; ² Human Connection Scale of Mack et al; ³ Visual analogue scale of Douglas et al	^{1,2} Validated	¹ Bisseling et al 2018; ² An et al 2019; ³ Douglas et al 2019
Patient voice in patient care*	Patient satisfaction, experience, and involvement in care	¹ Patient experience score ¹ ; ² Patient involvement in decision-making ¹ ; ³ Patient treated with dignity & respect	^{1,2} Outcomes; ³ Patient-reported experience measures	¹ Dutch Head and Neck Audit Group; Oncology Outpatient Clinic, Maastricht University Medical Center (Netherlands); GP Patient Survey (England); National Cancer Registration and Analysis Service (NCRAS England); Scottish Cancer Patient Experience Survey; ² Real-world survey data of Birkeland et al; NCRAS England; ³ NCRAS England	^{1,2} RW	¹ Takes et al 2020; Swann et al 2018; ² Birkeland et al 2021; ^{1,3} Links to specific registry web pages in main report
	Collaborating with patients to improve care quality	¹ Patient involvement in support, organisation of care and improvement of administrative processes; collaboration with patient organisations	¹ Quality indicators	¹ Organisation of European Cancer Institutes & European Cancer Patients Coalition; survey data of Miqueu et al	¹ RW	¹ Miqueu et al 2019
Survivorship	Social support for patients and family	¹ Supportive care needs	² Self-reported outcomes	¹ Supportive Care Needs Survey Short Form 34 of Boyes et al 2009	¹ Validated	¹ Sender et al 2020
	Survivors' concerns and perceptions of support	¹ Perception of risk of recurrence and mortality; ² Fear of cancer recurrence; ³ Utilisation of and satisfaction with psychosocial care	^{1,2} Patient-reported outcome; ³ Self-reported outcome	¹ Surveillance, Epidemiology and End Results Program survey data(USA); ² Fear of Cancer Recurrence Inventory of Simard et al 2009; Fear of Progression Questionnaire of Herschbach et al 2005; Delphi survey of Mutsaers et al; ³ Patient survey data of Sender et al	¹ RW; ² Validated	¹ Chen et al. 2020; ² Butow et al 2018; ³ Sarizadeh et al 2018; Jeppesen et al 2018; Mutsaers et al 2020; Gotze et al 2019; ³ Sender et al 2020

Financial toxicity*	Financial impact of cancer on patients	¹ Change in employment status; ² Patient-reported financial toxicity; ³ Patient economic burden (net out of pocket and time costs)	¹ Outcomes; ² Patient-reported outcomes; ³ Outcomes	¹ Labor Insurance Database & Taiwan Cancer Registry; ² University North Carolina Health Registry/Cancer Survivorship Cohort; ³ Surveillance, Epidemiology, and End Results-Medicare and Medical Expenditure Panel Survey	¹⁻³ RW	¹ Lim et al 2022; ² Casilla-Lennon et al 2018; ³ Yabroff et al 2021
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Appendix 4

Characterisation of the cancer registries interrogated for real-world indicators of care efficiency

Cancer Registry	Country	Characteristics	Web links
Canadian Cancer Registry	Canada	The Canadian Cancer Registry collects and reports on cancer data from provincial/territorial cancer registries (PTCR) on persons diagnosed with cancer who reside in Canada. The registry reports to Statistics Canada, and its main objective is to produce standardised and comparable incidence data to support health planners and decision-makers.	www.statcan.gc.ca
The National Cancer Registration and Analysis Service (NCRAS)	England	The NCRA forms part of the National Disease Registration Service (NDRS) and is managed by National Health Service (NHS) Digital. NCRA collect data from across the NHS on all cancers that occur in people living in England to create a population-based cancer registry that supports public health and healthcare, supplying clinical audits to improve outcomes for those diagnosed with cancer	http://www.ncin.org.uk/home ; https://www.cancerdata.nhs.uk/
The Scottish Cancer Registry; Scottish Cancer Registry and Intelligence Service (SCRIS)	Scotland	The Cancer Registry in Scotland collects data on new diagnosis of cancer occurring in Scotland including primary malignant neoplasms, carcinoma in situ, neoplasms of uncertain behaviour and benign brain and spinal cord tumours to monitor changes in incidence and survival over time. The Scottish Cancer Registry and Intelligence Service (SCRIS) is a collaboration between Public Health Scotland and the Innovative Healthcare Delivery Programme (IHDP) to expand data for the Scottish Cancer Registry, with the aim of improving access to cancer data across Scotland and improve cancer outcomes.	https://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry/ ; https://beta.isdscotland.org/topics/scottish-cancer-registry-and-intelligence-service-scris/
Cancer Registry of Republic of Slovenia (CRS)	Slovenia	The Cancer Registry of Republic of Slovenia (CSR) was founded in 1950 and is a population-based registry which forms part of the Epidemiology and Cancer Registry managed through the Oncology Institute Ljubljana. The registry collects and processes data on all new cases of cancer and survival, monitors diagnosis, and contributes towards monitoring treatment by creating indicators to evaluate the treatment quality of oncology patients.	https://www.onko-i.si/rrs
Belgium Cancer Registry	Belgium	The Belgium Cancer registry collects, manages, analyses and reports on cancer data derived from Belgian hospitals with an oncological care programme and services for pathology, anatomy, and health insurance funds. The registry provides data to support reporting on incidence, prevalence and survival, evaluations of screening programmes and treatment quality, and to support research.	https://kankerregister.org/
Cyprus Cancer Registry	Cyprus	The Cyprus Cancer Registry collects data on new cancer cases in Cyprus along with other data on treatment and therapy from the Bank of Cyprus Oncology Centre (BOCOC), including public and private sector cases. The registry reports on progress made on data quality and steps for new data integration, as well as cases incidences.	https://www.moh.gov.cy/

Estonian Cancer Registry	Estonia	The Estonian Cancer Registry collects data on cancer incidence from all physicians who diagnose or treat cancer working in Estonia, including forensic pathology experts. The registry links up with the Estonian Population Register and Estonian Causes of Death Registry to track patients over time. The registry collects data on all malignant, in situ, benign/uncertain tumours, as well as tumours of lymphoid, haematopoietic, and related tissue reporting data through that National Institute for Health Development, Statistic Estonia and in international databases.	https://en.tai.ee/en/r-and-d/registers/estonian-cancer-registry
Estonian Cancer Screening Registry	Estonia	The Estonian Cancer Screening Registry records data on breast, cervical and colorectal screening programmes from the Estonian National Health Information System, recording information on screening participation, results, and treatment. This data is used to evaluate the efficiency and quality of the screening programmes, and to undertake epidemiological research to shape policy and to plan resources.	https://en.tai.ee/en/r-and-d/registers/estonian-cancer-screening-registry
National Cancer Registry Ireland (NCRI)	Ireland	The National Cancer Registry Ireland is a public body which collects and classifies information on all new cancers in Ireland, as well as the primary course of cancer treatment in order to monitor trends and cancer outcomes, support research and planning and management of services, and to provide cancer statistics.	https://www.ncri.ie/
New Zealand Cancer Registry (NZCR)	New Zealand	The New Zealand Cancer Registry collects information on all primary malignant cancers diagnosed, excluding squamous and basal cell skin cancers, in New Zealand. The registry provides information on incidence and mortality and supports the basis for survival studies and research programmes, as well as monitoring screening programmes to support policy formulation. The registry does not collect information on treatment.	https://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys/collections/new-zealand-cancer-registry-nzcr
Northern Ireland Cancer Registry (NICR)	Northern Ireland	The Northern Ireland Cancer Registry is funded by the Public Health Agency for Northern Ireland. The registry collects information on malignant and certain non-malignant tumours diagnosed in Northern Ireland including treatment. The registry provides timely information on cancers occurring in the population to inform research, planning and education to improve outcomes.	https://www.qub.ac.uk/research-centres/nicr/
Swedish National Cancer Registry	Sweden	The Swedish National Cancer Registry collects data on newly detected malignant cases of cancer every year in Sweden from healthcare providers who register diagnoses into one of six regional registries associated with oncological centres in the medical regions of Sweden.	https://www.socialstyrelsen.se/en/statistics-and-data/registers/national-cancer-register/
The United Kingdom and Ireland Association of Cancer Registries	UK & Ireland	The United Kingdom and Ireland Association of Cancer Registries aims to promote and develop cancer registration in England, Wales, Scotland, Northern Ireland, and the Republic of Ireland. It does this by creating a liaison between the different national cancer registries to agree policies, national initiatives, information procedures and practices for cancer registration to improve the consistency, accuracy, availability, quality assurance of cancer registration.	https://www.ukiacr.org/about/about-ukiacr

National Program of Cancer Registries (NCPR)	USA	The National Program of Cancer Registries is administered by the Centres for Disease Control and Prevention. The program funds state and territorial cancer registries in the USA and collect data on cancer occurrence, initial treatment, and outcomes. Together with the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Programme, data is collected for the entire USA population to support researchers, clinicians, policy makers, health professionals and the public to monitor and inform cancer burden and prevention, and to evaluate programs.	https://www.cdc.gov/cancer/npcr/index.htm
Australian Cancer Database (ACD)	Australia	The Australian Cancer Database (ACD) is produced by the Australian Institute of Health and Welfare and collects data from different jurisdictions' central cancer registries on newly diagnosed primary malignant cancers in Australia, excluding basal and squamous cell carcinomas of the skin. The ACD reports national cancer statistics on incidence, trends, projections, survival, and prevalence in publications to understand how to prevent, detect and treat cancer, and to monitor outcomes and impact of policies.	https://www.aihw.gov.au/about-our-data/our-data-collections/australian-cancer-database

Appendix 5

Stakeholder interview questions

A set of 10 interview questions were developed by the researchers, in consultation with the All.Can REWG, and approved by the University of Southampton Ethics Committee. These questions served to help researchers identify the best ways to measure and track cancer care that are meaningful to patients, from the perspectives of different individuals and organisations.

	Stakeholder interview questions
1.	How do you/does your organisation define efficiency in cancer care?
2.	Is efficiency in cancer care important to you/your organisation? If so, why?
3.	What measures do you personally think are most important to be collected and analysed for examining and improving efficiency in cancer care?
4.	(organisation / industry interviewees only) What measures, if any, does your organisation currently collect and use to examine and improve efficiency in cancer care?
5.	(organisation / industry interviewee only) Are any of measures you personally think are important not being collected/ used by your organisation. If not, why not?
6.	What gaps do you think exist that affect the delivery of optimally efficient cancer care?
7.	In your opinion, what can be done to bridge the/these gap(s)? And do you/ or does your organisation currently do any of these things?
8.	Who else do you think is responsible for bridging this/these gap(s) and how?
9.	What three words/ phrases would you use to describe what optimal cancer care would look like?
10.	Is there anything else that you think we should consider that we haven't covered in the questions in order to better understand efficiency in cancer care?