

Monitoring and Evaluation Framework for the Cancer Strategy for Scotland 2023-2033 and Cancer Action Plan 2023-2026: August 2023



HEALTH AND SOCIAL CARE

Contents

Glossary of evaluation terms	3
1. Introduction and Context.....	5
1.1 Cancer Strategy for Scotland and Cancer Action Plan.....	5
1.2 Strategic priorities to improve health and reduce inequalities	5
1.3 Development of the monitoring and evaluation framework.....	6
2. Evaluation Purpose and Approaches.....	7
2.1 Evaluation for accountability and learning	7
2.2 Understanding and measuring change	10
3. Assessing Progress towards the Strategic Ambitions.....	13
3.1 Evaluation prioritisation and decision-making	13
3.2 Data and evidence to track progress over time	15
4. Assessing the Overall Impact of the Strategy	18
4.1 Overarching evaluation questions for the ten-year strategy	18
4.2 Key headline indicators to measure the extent of progress.....	19
5. Monitoring and Reporting Progress	23
5.1 Monitoring of activity and reporting of evaluation evidence	23
5.2 Knowledge Exchange and Learning.....	24
6. Appendices.....	25
Appendix 1: Advisory group members	26
Appendix 2: Metadata and data development for key headline indicators	27
Appendix 3: Strategic work in development to improve equalities data	44
Appendix 4: Key steps of change to achieve the strategic vision	45

Glossary of evaluation terms

This glossary sets out key terms used to describe evaluation activities. The definitions used here explain these terms in the context of the Cancer Strategy for Scotland 2023-2033 (strategy) and the Cancer Action Plan 2023-2026 (action plan).

Key Term	Definition
Activity	The actions (in the action plan) that are required to produce the desired outcomes for the strategy. (what we do)
Aim	A broad statement of intent setting out the purpose of the strategy. It summarises the difference the strategy wants to make.
Ambition	Linked to the Vision and Outcomes, a statement of how success will be created by addressing specific priorities.
Evaluation	Evaluation is a systematic assessment of the design, implementation and outcomes of an intervention. This can be at the level of a programme, action plan or strategy.
Headline Indicators	Metrics used to demonstrate higher level, longer term change or results linked to the Outcomes and Vision for the strategy.
Impact	The overall difference that the strategy makes. Describes higher level, longer term change resulting from the strategy and linking back to the Aim.
Inputs	The resources needed to deliver the programme of change associated with the strategy and action plan. (what we invest)
Monitoring	Monitoring is the systematic collection of data on specified indicators to provide an indication of the extent of progress and achievement of the strategy Ambitions, Outcomes and Vision.

Key Term	Definition
Outcomes	The results, effects or change produced by the strategy and action plan. (what we achieve)
<i>Outcomes – early and intermediate</i>	Steps along the way to end outcomes. They are often smaller changes that need to happen before the final, desired outcome can be reached.
Outputs	Specific, direct things that the action plan delivers or activities that occur through the use of the resources in the strategy and action plan. (what we get)
Process	The method, or step-by-step description, of how a task or activity is to be done. (how we do it)
Theory of change	A model of how the strategy and action plan are expected to contribute to change (or impact) through a sequence of early and intermediate outcomes.
Vision	Linked to the Aim, a statement of intent that describes the future goals and ambitions of the strategy.

1. Introduction and Context

1.1 Cancer Strategy for Scotland and Cancer Action Plan

This Framework outlines our intent to monitor and evaluate the [Cancer Strategy for Scotland 2023-2033](#) and the [Cancer Action Plan 2023-2026](#) published in June 2023.

The [Cancer Strategy's appendix covering Monitoring and Evaluation](#) sets out a strategic, evidence-based and outcomes-focused approach to monitor and evaluate progress towards the vision of improved survival and excellent, equitably accessible care. Key evaluation principles set out in the Cancer Strategy include proportionality, a focus on high priority data and addressing evidence gaps that can demonstrate the measurable contribution of the strategy to improving services, care and outcomes for people affected by cancer.

The Cancer Action Plan supports the Cancer Strategy by outlining the realistic and achievable actions that the Scottish Government (SG) will deliver in the first three years. Maintaining cancer as a priority, while recovery takes place in healthcare systems and the wider economy, is a necessary focus of these actions. As shown in the [Action Plan's Monitoring and Evaluation chapter](#), national priorities for early monitoring and evaluation will therefore include attention to the outputs and outcomes that we can expect to be delivered within three years as systems and services are stabilised.

1.2 Strategic priorities to improve health and reduce inequalities

The [Care and Wellbeing Portfolio](#) is the overall strategic reform vehicle for health and social care in Scotland. Monitoring and evaluation priorities will align with the Portfolio's aim to improve population health, reduce inequalities and improve health and care system sustainability. This aim aligns with the Cabinet Secretary for NHS Recovery, Health and Social Care's commitment in the [First Minister's Policy Prospectus published in April 2023](#) to prevent ill health and reduce inequalities.

The [Cancer Strategy's chapter on Cancer in Scotland](#) summarises data published by Public Health Scotland on cancer incidence, survival and mortality. The data show higher cancer risks for those living in the most deprived areas. We will monitor and evaluate the impact of policy actions on health inequalities, including for people living in socioeconomic deprivation. As part of its cross-cutting ambition to tackle health inequalities, the Cancer Strategy commits to an early focus on improving outcomes for minority ethnic groups and women. Consequently, we will analyse disaggregated and intersectional equality data whenever this is feasible.

The Framework will align with the monitoring of related Scottish Government health strategies and plans to improve population health that connect to specific actions in the Cancer Action Plan. Related strategies include the [Digital Health and Care Strategy](#), [Health and Social Care: Data Strategy](#), [Health and Social Care: National Workforce Strategy](#) and [Mental Health and Wellbeing Strategy](#). We will align monitoring activities with these published strategies and the forthcoming strategy for palliative and end of life care, and the forthcoming action plan for tobacco. Monitoring and evaluation for these related policies will be carried out separately, with data relevant to cancer, including data connected with actions relating to the prevention of more cancers, incorporated into evidence collated to report progress.

1.3 Development of the monitoring and evaluation framework

Analysts in the Health and Social Care Analysis Division have led the development of the monitoring and evaluation framework alongside policy officers in the Healthcare Quality and Improvement Division. An advisory group of experts provided guidance and advice to ensure a robust and proportionate approach. This group comprised experts from academia, public health, the health service, third sector, and officials from the Scottish Government. [Appendix 1](#) provides further details of the group membership.

2. Evaluation Purpose and Approaches

2.1 Evaluation for accountability and learning

What are the main purposes of a monitoring and evaluation framework?

Our monitoring and evaluation framework has two main purposes:

- 1) Accountability;
- 2) Learning.

As reflected in the [Magenta Book, which provides UK-wide government guidance on evaluation](#), evaluation has an important role in both accountability and learning. We have adopted a theory-based framework to inform the overall approach. This is based on a theory of how the Cancer Strategy is anticipated to create change (or impact) for people affected by cancer. Further information on ‘theory of change’ is provided in [Section 2.2](#) below.

What is the role of evaluation for accountability and learning purposes?

Evaluation activities can generate evidence to demonstrate the effectiveness, impact or wider outcomes of policy actions associated with the Cancer Strategy. This will provide accountability. Evaluation activities can support learning by generating evidence on what works, for whom, in what context, and why. We will consider evaluation that can contribute to these purposes. The Cancer Strategy is operating within complex systems, with uncertainty and variation inherent in the environments in which policy actions are being implemented. Understanding whether policy actions are working as expected, in specific contexts, and/or for particular groups, is likely to be relevant for evaluation, especially with the strategy’s aim to tackle health inequalities.

How will we evaluate the Cancer Strategy for accountability and learning?

Impact evaluation will be considered in order to understand progress towards the outcomes that are articulated in the strategy. Outcomes will take time to emerge. Evidence will be relevant to demonstrate: changes in attitudes and knowledge (short term outcomes), changes in behaviours and decision-making (medium term

outcomes), and overall policy impact or significant changes at population/ systems level (long term outcomes). If feasible, the 'counterfactual' should be considered, i.e. comparing the observed results with what would have happened if the intervention had not been implemented. Although positive outcomes are intended, there is always the possibility of unintended consequences or negative outcomes, which will also be considered across the duration of the strategy.

Process evaluation will be considered in order to understand how policies are operating in practice, and for different groups. This can provide evidence of how the inputs/ activities/ outputs are delivered to achieve the outcomes, with the aim of capturing learning to refine the design of any interventions or inform future policy design. For instance, to deliver equality of outcome and access, it may be important to assess if and how the strategy is reaching target populations for key interventions.

It may be appropriate to undertake economic evaluation, to understand whether a particular policy action is cost-effective and providing value for money.

Evidence from these different types of evaluation can be combined to inform decisions about whether to stop, change or extend policies in the next Cancer Action Plan. For instance, evidence from pilot projects can be used to inform further roll out or scaling up of initiatives. Evidence of whether a policy is impacting on inequalities and variation, and how, can be used to adapt initiatives in order to better serve people experiencing poorer outcomes and to tackle intersections of inequality.

It is important to note that evidence will always be partial with gaps and potential dissonance across different data sources. Firstly, this is due to the complexity of the systems and environments in which the Cancer Strategy is operating. This means that it will be impossible to measure and understand all potential factors that may have contributed to any observed change, and it may not always be possible to construct a 'counterfactual' (what would have happened if the Cancer Strategy was not operating). Secondly, data availability, data collection tools and the capacity of data management systems will evolve over time, which means that there will be gaps in evidence at earlier points in the strategy. Thirdly, proportionality is an important factor in considering what and how to evaluate, which means that we

cannot and should not evaluate everything. These contextual issues frame the evidence that we will gather and synthesise. We can still draw reasonable conclusions as to how policy actions are likely to be contributing to change as we consolidate evidence and articulate key learning.

What types of evaluation questions will support early evidence building?

Early evidence for the Cancer Strategy is likely to focus on the following process and impact questions:

- **Process evaluation:** Are the interventions being implemented and/or delivered as intended? How are they operating in practice? Are they working differently for different groups? If yes, why? How is the context influencing delivery?
- **Impact evaluation:** What measurable contribution to change is the intervention making? What is the scale of that change? Have different groups been impacted in different ways? Are there any unintended consequences or negative impacts?

These questions may also be useful for guiding local level evaluations to support learning against key indicators of success that can be shared across Scotland.

How will evaluation approaches evolve over the ten-year strategy?

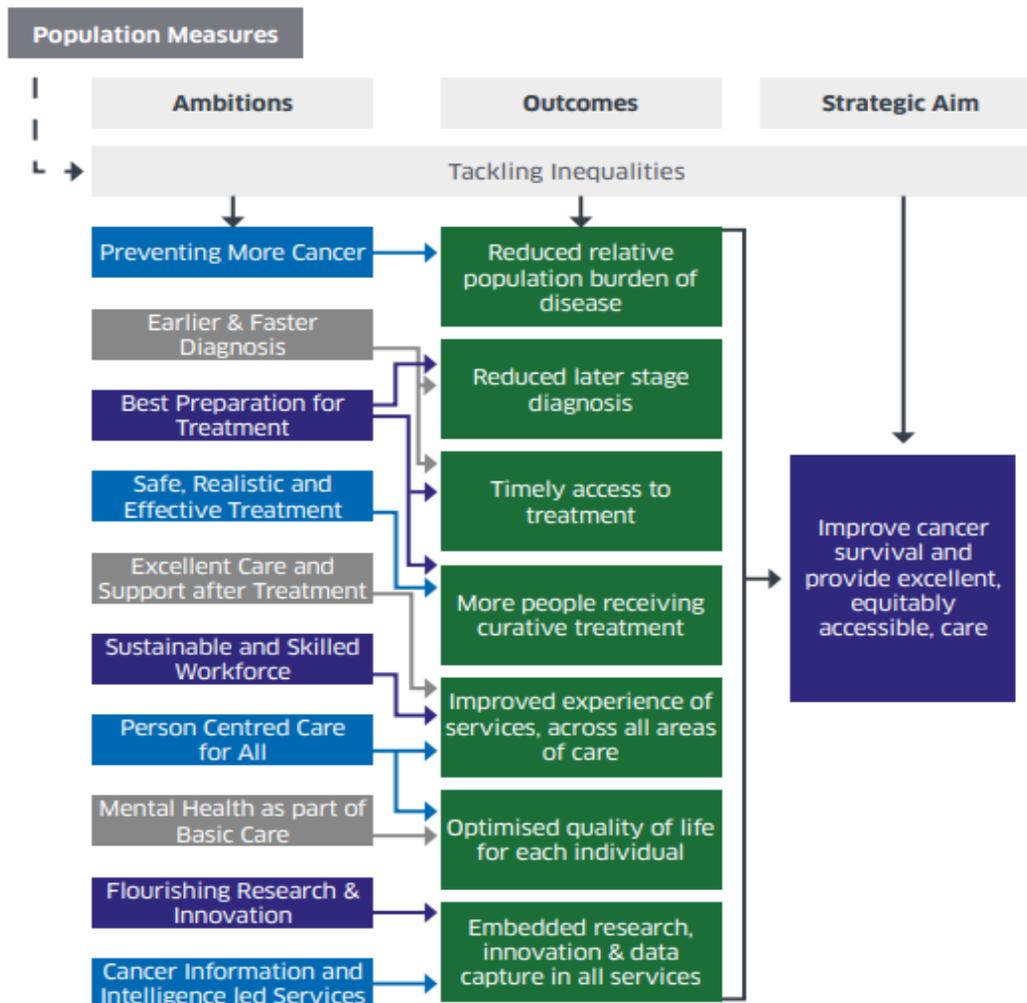
Since the Cancer Strategy will be delivered over ten years, it is likely that we will develop nested or hybrid evaluation designs that combine approaches. This will require a review of evaluation approaches and their feasibility at set timepoints, with processes in place to learn and respond, which will be outlined in [Section 5](#) below.

These approaches will build deeper understanding across time to determine how policy actions are contributing to change, and the extent of that change. Initial evaluation activities will focus on intervention or programme level change. As the evaluation evolves and evidence builds, we will seek to understand the impact of the totality of programme activities, including any impact on health and care systems.

2.2 Understanding and measuring change

How will we measure progress in relation to the strategy's ambitions?

As outlined in the Cancer Strategy, its success will be judged on the realisation of seven outcomes set out in the Outcomes Framework (Figure 1).



We will assess progress towards these seven key outcomes by measuring progress towards delivering on the 11 priority ambitions (cross-cutting and pathways) that are anticipated to create change. In many cases we would expect to see changes in attitudes/ knowledge in the short term, changes in behaviour/ decisions in the medium term, and wider impacts for policy/ society in the long term. Assessing progress is likely to involve a mixture of process and impact evaluation, and potentially economic evaluation, to understand if change is happening, and how.

How have we identified the key steps for achieving and measuring change?

The [Cancer Action Plan 2023-2026 sets out 133 actions](#) that are grouped around ten of the 11 priority ambitions, with actions on 'tackling inequalities' merged with actions for other ambition areas (a further three actions relate to governance rather than policy implementation). To measure progress effectively, a theory of change has been developed for each of these ten ambition areas. A theory of change is a model of how a policy or initiative is expected to contribute to change (or impact) through a sequence of early and intermediate outcomes. Theories of change help navigate complexity. A theory of change is never perfect, since it is necessarily perspectival and evolving. However, it is a useful tool with which to achieve the following results:

- Identify the key steps to produce change, and when they must happen,
- Stress-test assumptions with those who design and implement policy,
- Agree collectively what defines success and what it takes to get us there,
- Provide a timeline for outputs and expected outcomes from policy actions,
- Establish what we can (and cannot) measure in order to track progress,
- Map and prioritise the most useful indicators to measure progress,
- Set up a framework for what we need to track to assess progress,
- Establish any evidence gaps that may benefit from further research,
- Identify potential harms or unintended consequences to assess.

In developing these theories of change, analysts have worked with policy teams to map the outputs that we expect to deliver and the short term outcomes that we expect to achieve. The associated medium term and long term outcomes that follow logically from these short term outcomes have also been mapped and align with the periods covered by the second and third Cancer Action Plans. Assumptions and external factors that may influence these outcomes have been considered as part of the process.

How does theory of change development relate to the overall strategic vision?

Assessing progress towards the strategic ambitions will provide a step towards understanding impact in relation to whether and how the overarching vision for the Cancer Strategy is being achieved over time in relation to more cancers being

prevented, better survival, excellent care, and reduced inequalities. These ambition-level theories of change are live working documents that will be kept under review and updated on an ongoing basis as evidence emerges over the course of the action plan.

The ambition-level theories of change have fed into an overarching theory of change that summarises the key steps of change that we anticipate happening over ten years to achieve the strategic vision. [Appendix 4](#) provides a summary of these anticipated changes, showing how each ambition will lead to the high level summary outcomes that are set out in Figure 1 above. The advisory group (see [Appendix 1](#)) reviewed and contributed to this overarching theory of change. The theory of change will necessarily evolve over time as interventions are implemented and assumptions are refined in light of emerging evidence.

3. Assessing Progress towards the Strategic Ambitions

3.1 Evaluation prioritisation and decision-making

How will we make decisions about which policy initiatives to evaluate?

Table 1 shows an Evaluation Decision Tool¹ with criteria that will assist us to determine where evaluation activities would be best focused during the timeline of the first Cancer Action Plan 2023-2026. The questions for each of the criteria will be used to assess the appropriateness and value of evaluation, and are intended as a discussion-based tool to support decision-making.

Decisions, including a pre-screening of actions, will be based on the strategic priorities and evidence gaps established through the theory of change work. Evidence gaps may be linked to either the ambition-level or overarching theories of change, or to underpinning assumptions about how change may happen. The tool also helps us to take account of other practical considerations, such as feasibility, when deciding whether and what to evaluate.

These priority criteria will be reviewed when the second and third Cancer Action Plans are published to ensure that the criteria continue to represent the most pressing data and evidence needs at those timepoints. Establishing evaluation priorities for each action plan will provide the flexibility to design the best evaluation approaches and methods to address accountability and learning requirements as they emerge across the timeline of the Cancer Strategy.

Criteria for interventions that are likely to require substantial evaluation will include strategically important interventions, high cost interventions, where there are high levels of uncertainty/ risk, and evaluations with high potential for learning. Low-risk and well-evidenced interventions will require light-touch monitoring and evaluation to ensure they have been delivered as intended and achieved the predicted outcomes. This may include strengthened performance monitoring.

¹ The Evaluation Decision Tool has been adapted from the following sources:
[Department for International Development, DFID Evaluation Strategy 2014-2019](#)
[UK Government, The Magenta Book: Central Government Guidance on Evaluation, March 2020](#)

Table 1: Evaluation Decision Tool to support the prioritisation of evaluation evidence relating to Actions in the Cancer Action Plan for Scotland 2023-2026

Criteria	Questions
Pre-screening	Initial review for all actions: Would evaluation address an evidence gap established via theory of change development? <i>If yes, continue these questions.</i>
Strategic Evaluation Priorities	Would evaluation fill a strategically important evidence gap aligned to the vision for improved survival?
	Is the intervention aligned to the priority to improve outcomes through earlier diagnosis (key to the vision for survival)?
	Would evaluation fill a strategically important evidence gap aligned to the vision for equitably accessible, excellent care?
	Will the evaluation provide evidence for the intervention's impact on health inequalities?
Evidence Base	Does the intervention put the person affected by cancer at its centre, reflecting value-based and Realistic Medicine?
	Would evaluation contribute knowledge and learning about effectiveness at both national and local level?
Scale Up and Learning	Is the intervention innovative and/or not tried previously, requiring evidence about its efficacy?
	Is the intervention a pilot where the evaluation outcome will influence future funding or scale up?
Uncertainty, Risk and Cost	Will evaluation findings contribute evidence across a number of interventions or a broad thematic area?
	Is there a high level of uncertainty and/or risk associated with the intervention(s) (including possible negative consequences)?
Utility and Timeliness	Is the intervention (or its potential roll out) high cost – requiring a significant investment of financial or other resources?
	Will evaluation findings be used to feed into policy making and programme improvement?
	Will the evaluation be completed within three years/ will interim findings be available in time to inform key decision-making?

Criteria	Questions
Feasibility and Evaluability	Is it feasible to conduct an evaluation (i.e. in terms of resource, proportionality and potential burden on health services)?
	Is the intervention evaluable (i.e. able to be evaluated with collectable/ measurable evidence)?

Some interventions that are low-risk and well-evidenced may still have high potential for filling a strategically important evidence gap. For example, it may be important to understand the impact of a well-evidenced intervention that aims to reduce health inequalities where that evidence is not sensitive to the local context in which the intervention is operating. Routine monitoring of many actions is possible through existing processes and governance. We will use existing data sources whenever possible, such as Public Health Scotland cancer datasets and [Cancer Quality Performance Indicators \(QPIs\)](#), to take a proportionate approach to minimise reporting burden.

Once priority evaluation areas are agreed, we will develop broad evaluation questions for commissioning evaluations. Thematic evaluations may be commissioned to address evaluation priorities across a number of interventions or a broad thematic area. This will include consideration of strategic evidence gaps and high priority data beyond intervention or programme level, such as evidence for overall progress and impact of the Cancer Strategy. Scoping work may be required to assess the evaluability of a particular intervention or programme of activity, or to establish the existing evidence base on which to design evaluation activities around an identified data need or evidence gap. The most relevant methodological approaches and specific methods for answering the evaluation questions will be selected, with attention to the evaluation purposes and criteria set out in Table 1.

3.2 Data and evidence to track progress over time

How will we track the progress of change over time?

The ambition-level theories of change will help us to track progress by monitoring planned outputs and evaluating outcomes associated with the 133 policy actions.

They provide a bridge between the policy actions and the data we will need to track progress over time.

As part of the theory of change development work, we have identified available data and potential forthcoming data that would indicate progress in relation to short term outcomes, i.e. those outcomes we anticipate happening by the end of the first Cancer Action Plan (2026). Key indicators for assessing progress in relation to the strategic outcomes and vision are outlined in [Section 4.2](#), with detailed information about existing data and development priorities for these metrics provided in [Appendix 2](#).

Quantitative data will show the extent of any change. Qualitative data will provide depth of understanding about the complexity of context and mechanisms. This will include evidence about the contribution of policy to any changes, and whether interventions are having the desired effects and reaching the people we want to reach. In the context of inequalities, qualitative evidence will be important to determine whether interventions are having an effect on reducing barriers and improving access for people who experience disadvantage, inequity and poorer outcomes.

What will be our approach to gathering and analysing data?

We will refresh these metrics at regular review points to enable reflection and updating in light of developments, including work that is ongoing in the Scottish Government to improve data (see [Appendix 3](#)). Further work will be required at the end of the first Cancer Action Plan to establish what data and evidence will indicate progress in relation to medium and long term outcomes. It is important to note that we cannot measure every aspect of change since not all changes are either collectable or measurable. Further, it is not feasible to measure all those things that are collectable or measurable. We will therefore focus on identifying those data or evidence that are most crucial to establish whether and how change is happening in line with the priority criteria outlined in [Section 3.1](#).

In line with a proportionate approach that minimises reporting burden, we will address data needs via routine data collection, such as repeated surveys, whenever

possible. For instance, the [Cancer Prehabilitation Survey](#) will be repeated to evaluate any changes in how prehabilitation and rehabilitation services are operating. Where new analysis or bespoke research is required, approaches will be designed to answer evaluation questions proportionately to minimise burden, using the Evaluation Decision Tool referenced in [Section 3.1](#).

4. Assessing the Overall Impact of the Strategy

4.1 Overarching evaluation questions for the ten-year strategy

As indicated in [Section 3.1](#), evaluation questions to assess progress towards the strategic ambitions will be decided when evaluation activities are prioritised and commissioned with a focus on high priority data and urgent evidence gaps. Across the duration of the strategy, it will be important to consider how evidence is building to understand the overall impact of the strategy.

How will we understand the overall impact of the ten-year strategy?

Overarching impact evaluation questions are set out below:

- 1) To what extent are we making progress towards each high-level outcome?
- 2) To what extent is survival improving?
- 3) What progress has been made in achieving excellent care?
- 4) What progress has been made in achieving equitably accessible care?
- 5) What impacts have national programmes of cancer care and linked investment had on people affected by cancer and what matters to them?
- 6) What impacts have national programmes of cancer care and linked investment had on reducing health inequalities?
- 7) What impacts have national programmes of cancer care and linked investment had on the workforce who are delivering services and support?
- 8) What impacts have national programmes of cancer care and linked investment had on system capacity in NHS Boards?
- 9) What factors have supported or hindered the effectiveness of new models of care (including local contextual variation, external factors, unforeseen events)?
- 10) What impacts have national programmes of cancer care had on other parts of the wider health and social care system? And wider system changes on cancer care?

These questions relate to outcomes for people affected by cancer and the workforce, as well as to wider system level outcomes. The key steps for change shown in [Appendix 4](#) focus on outcomes for people affected by cancer as articulated in the Outcomes Framework (see Figure 1). As discussed in [Section 2](#), part of impact

evaluation will involve understanding the impact of the strategy as a whole. In addition to building evidence on contribution from the evaluation of interventions and programmes of work, system mapping or modelling work may be required to understand the overall impact of the strategy within complex systems. Such approaches will be considered as part of regular reviews of evaluation approaches that will occur at set timepoints. Review points are discussed further in [Section 5](#) in relation to the monitoring and reporting of evaluation evidence.

4.2 Key headline indicators to measure the extent of progress

How will we measure the extent of impact on survival and excellent care?

In addition to combining evaluation findings of individual interventions or programmes, key headline indicators have been established to measure progress towards the intended high-level outcomes and vision for the ten-year strategy. We will monitor each indicator at national level to assess if outcomes are improving, and to what extent. These metrics will provide evidence to address Questions 1 and 2 above. The indicators selected are focussed primarily on outcomes (e.g. survival, quality of life), given the nature of the Outcomes Framework (see Figure 1). However, there are some indicators that by necessity are focussed on system level metrics (e.g. waiting times statistics).

Table 2 sets out the headline indicators for assessing the extent of progress. These indicators have been developed in conjunction with analysts in Public Health Scotland (PHS). Many of the indicators selected are based on data already collected by PHS and the National Records of Scotland (NRS). The use of existing datasets enables us to set a baseline position prior to the launch of the Cancer Strategy although the impact of COVID-19 will mean careful interpretation for some data. These indicators will be reviewed annually. Monitoring will not be limited to headline indicators and we will consider other important data.

Table 2: Headline indicator descriptions and data sources

Strategic Vision / Outcome	Indicator Description	Currently Published National Data	National Data in Development
A. Improved cancer survival	Estimates of overall survival and age-standardised net survival at 1-year and 5-years	Extraction of cancer registration data (PHS), and population and deaths data (NRS)	
	Reduction in age-adjusted mortality rates to capture improvements in both incidence (rates) and net survival	Cancer mortality data are provided by NRS, on their website.	
B. Reduced relative population burden of disease	Burden of disease (disability adjusted life years) relative to other disease in the overall population	Extraction of electronic health records (Scottish Morbidity Records and NRS Vital Events)	
C. Reduced later stage diagnosis	Diagnosis at disease stages III and IV (incidence by stage for 16 cancers)	Extraction of cancer registration data (PHS)	
D. Timely access to treatment	Cancer waiting times	Cancer waiting times statistics – adjusted and unadjusted waits (PHS)	

Strategic Vision / Outcome	Indicator Description	Currently Published National Data	National Data in Development
E. More people receiving curative treatment	Potential indicator: Curative treatments recorded		Data development is an action in the Cancer Action Plan 2023-2026
F. Excellent care/ Improved experience of services, across all areas of care	Potential indicator: Experiences of services and care		Measurement will be defined and developed during the Cancer Action Plan 2023-2026
G. Optimised quality of life for each individual	Potential indicator: Health-related quality of life		Measurement will be defined and developed during the Cancer Action Plan 2023-2026
H. Embedded research, innovation and data capture in all services	Potential indicator: Access to clinical trials or data on cancer intelligence		Measurement will be defined and developed during the Cancer Action Plan 2023-2026
I. Equitably accessible care/ Reduced health inequalities in all areas above	Data broken down by equalities, socioeconomic and geographic characteristics	Data sources above, and cancer incidence (Scottish Cancer Registry and PHS)	PHS and the Scottish Government are progressing work to improve data

[Appendix 2](#) provides detailed metadata for all currently published data that will be used as key headline indicators for tracking the extent of progress in these areas.

The following information is provided in that metadata document:

- Indicator description,
- Baseline/ comparability across time,
- Collection frequency and details (including time lag),
- Data source (or data gap if no current sources of existing data),
- Data breakdowns,
- Robustness and data limitations.

[Appendix 2](#) also provides further information on metrics that are in development, as indicated in Table 2. This includes further information about data quality and comparability across time. These metrics will be updated at the first annual review point for the Cancer Action Plan 2023-2026 (see [Section 5.1](#) below for further information on our plans for reporting).

How will we measure impact on reducing health inequalities?

Many areas of the public sector, including different parts of the Scottish Government, are progressing work to improve their equality evidence. Where possible, headline indicators and other metrics to be used in our monitoring and evaluation framework will be disaggregated by equalities, socioeconomic, and geographic characteristics, reflecting the cross-cutting aim to reduce health inequalities in all areas. Further strategic work is in development, set out in [Appendix 3](#), which will improve our ability to monitor and evaluate data and evidence on health inequalities relating to cancer.

5. Monitoring and Reporting Progress

5.1 Monitoring of activity and reporting of evaluation evidence

How will we report on progress across the period of the first action plan?

As indicated at the beginning of this Framework, a key purpose of evaluation is for accountability (see [Section 2.1](#)). Regular monitoring will be undertaken by the Cancer Policy Team in the Scottish Government and reported to the Scottish Cancer Strategic Board as ‘owners’ of the Cancer Strategy and associated Action Plans. An annual update on progress will summarise key developments. This policy publication will include an analyst-led section that will provide an update on available published evaluation findings (interim and final), progress relating to key headline indicators (see [Section 4.2](#)) and relevant data developments at the time of reporting. This approach will enable us to feed interim evidence into the policy cycle to determine what, if any, actions need to be adapted.

An evaluation report will be published at the end of the first Cancer Action Plan. The evaluation report will document progress towards the strategic ambitions and any early evidence that provides any indication of the overall impact of the Cancer Strategy (see [Section 4.1](#)). This will include a synthesis of published data and evaluation findings to assess progress towards the outcomes and vision of the strategy. This timepoint will allow us to assess any measurable change in relation to short-term outcomes once the first Cancer Action Plan is complete (see [Section 3.2](#)), and to report on trends in headline indicators (see [Section 4.2](#)). The overarching theory of change (see [Section 2.2](#)) will be updated, if necessary, using the available data and evidence. The report will articulate any new evaluation criteria, data gaps or considerations for new approaches to support the evaluation of actions in the second Cancer Action Plan and overall impact of the Cancer Strategy in the following years.

The planning for further updates and reports beyond the timeline of the first Cancer Action Plan will be communicated in the evaluation report, with the intention to produce a further three-year evaluation report in 2029, and a final evaluation report that synthesises evidence and provides a digest of key learning across the timeline

of the strategy as of 2033. As data builds, conducting an evidence synthesis will enable us to consider how policy actions have contributed to impact. A summary of planned outputs during the first Cancer Action Plan 2023-2026 is provided in Figure 2. Further outputs will be specified in future updates.

Figure 2: Planned outputs to report progress



5.2 Knowledge Exchange and Learning

How will we share learning from monitoring and evaluation activities?

As indicated in [Section 2.1](#), learning is a key purpose of the evaluation of this strategy. As articulated in the Cancer Action Plan 2023-2026, we will apply [Healthcare Improvement Scotland's concept of learning systems](#) to understand progress and share learning. This approach supports a commitment to capture and share good quality evidence-based learning as it emerges across Scotland. It will be important to consider what variation tells us about the system, specifically what is working and not working, and to share this learning across the system. And it will be important to understand local priorities for evaluation, learning and evidence needs. Specific mechanisms for supporting Learning Systems will be developed with stakeholders. This will ensure an ongoing interface to strengthen connections between national policy and local service delivery given their interdependency in realising the ambitions and vision set out in the Cancer Strategy. This may take the form of sharing learning from local approaches and examples of 'what works', in addition to sharing national level evidence to support good practice.

6. Appendices

Appendix 1: Advisory group members

The following table lists the advisory group members who contributed their expertise to guide our approach to monitoring and evaluating the Cancer Strategy.

Advisory group members who provided expertise and guidance

Name	Role	Organisation
Gregor Mcnie	Unit Head, Cancer and Rehabilitation Unit (Chair)	SG Healthcare Planning & Quality
Rachel Anderson	Principal Research Officer, Population Health	SG Health & Social Care Analysis
Gregor Boyd	Unit Head, Healthcare and Workforce	SG Health & Social Care Analysis
Emma Dunlop	Research Associate, Institute of Pharmacy & Biomedical Sciences	University of Strathclyde
Samantha Harrison	Head of Strategic Evidence & International Cancer Benchmarking Partnership Research Lead	Cancer Research UK
Aisha Macgregor	Senior Social Researcher, Whole Systems Intelligence	SG Whole Systems Intelligence Analysis
Nicola McCloskey-Sellar	Regional Manager, South East Scotland Cancer Network	South East Scotland Cancer Network
David Morrison	Director of Scottish Cancer Registry	Public Health Scotland
Paul Nairn	Regional Planning Manager	NHS Highland
Sasia Pryor	Cancer Service Manager & Chair of Cancer Managers Forum	NHS Grampian

Appendix 2: Metadata and data development for key headline indicators



Strategic Vision: By 2033 we will improve cancer survival

Indicator(s): Estimates of overall survival and age-standardised net survival at 1-year and 5-years; Age-adjusted mortality rates to capture changes in both incidence (rates) and net survival.

Method(s) of data collection: Extraction of cancer registration data (PHS), and population and deaths data (NRS).

Data source(s): Cancer registration (Scottish Cancer Registry) and NRS population and deaths datasets. This [technical report on Cancer Survival in Scotland](#) shows technical documentation including methodology, data sources and clinical coding information. This [update on Cancer Mortality in Scotland, Appendix 1](#) explains age-adjusted mortality rates.

Data definitions (e.g. numerators, denominators, standardisation):

Cancer - Survival.

An individual patient's survival time is the time from date of diagnosis to date of death or censoring. Censoring is when a patient was lost to follow-up and their last known vital status was 'alive' (censoring may occur due to embarkation from Scotland or because the patient remained alive at the time analysis was performed, so-called 'administrative censoring'). Survival analysis accounts for the fact we do not know the (eventual) survival times of these censored patients. Survival analysis estimates parameters from the distribution of survival times. Overall survival is an estimate of the probability a patient will be alive at a given time after diagnosis. It is an estimate of survival from all causes of death, including non-cancer causes. Net survival is an estimate of the probability a patient will be alive at a given time after diagnosis, after making an adjustment for the impact of non-cancer causes of death. It is a useful measure for comparing cancer survival between populations, sub-population groups, and time periods, between which 'background' non-cancer mortality rates may differ. Overall and net survival are usually expressed as percentages between 0-100% and often interpreted as proportions. These measures are typically presented in both non-standardised and age-standardised forms. Age-



Headline Indicator A

standardisation is used to adjust for the effect of any differences in the age profiles of the populations being compared.

Cancer - Mortality.

Age-adjusted mortality rates; based on the number of death registrations in each of the calendar years, the following rates are calculated for cancer mortality. Crude rate: The total number of people with an illness (or who die) in a country or region, divided by the total population of that country or region, and is normally expressed 'per 1,000', 'per 10,000' or 'per 100,000'. Making comparisons on the crude rate can be misleading if the age structures of the populations of the countries or regions are quite different. Areas with larger percentages of younger people are unlikely to have as high levels of death as areas with larger percentages of older people – and therefore if there is no adjustment for these differences the wrong conclusion may be drawn about the health of an area simply because of the age-structure of the population. European Age-Sex Standardised Rates (EASRs) allow us to make comparisons between different geographical areas as they allow the effects of having different age structures in either the same population over time or different geographies to be removed. European Age-Sex Standardised Rate (EASR) uses European Standard Population (ESP) 2013 for each 5-year age group, the crude rate is calculated and then the weighted average of all age groups is taken based on the weightings of the 2013 ESP, to give the overall EASR.

Baseline/ comparability across time:

Cancer - Survival.

Estimates are best compared within studies to ensure the same methods are applied to different groups/time periods. PHS survival reports typically focus on new registrations but include a time series of cohorts to ensure methodological updates are applied to previous data. Survival is typically reported for single-year and five-year cohorts (to ensure sufficient cohort sizes for robust estimates). The pre-pandemic cohorts of 2019 and 2015-2019 provide natural baselines. Underdiagnosis and delayed diagnosis due to the pandemic will complicate analysis and interpretation for 2020 and 2021 data.

Headline Indicator A



Cancer - Mortality.

Reports data since 1995. NRS moved from the World Health Organisation International Classification of Disease (ICD) version ICD-9 to ICD-10 in 2000. ICD codes have been back-mapped to 1995 as accurately as possible for continuity of reporting. Comparisons across the UK are produced by Cancer Research UK, and the most recent mortality statistics can be found on their [Cancer Statistics for the UK](#) page.

Comparison of Scottish and UK cancer data to that of other countries is a complex process because of the wide variation in data collection and coding practices, as well as variation in the quality and completeness of data. The International Agency for Research on Cancer maintain an online resource, the [Global Cancer Observatory](#), that is searchable for comparative data. It may be misleading to focus too much attention on any apparent changes in mortality between 2020 and 2021; it is more informative to examine trends observed over a number of years. Striking changes from one year to the next may occur in the case of rare cancers, but these are likely to reflect random fluctuation caused by small numbers of cases - in such cases, it is even more important to examine mortality rates for a number of years aggregated together, rather than focusing on a single year.

Collection frequency and details (including time lag): To be confirmed.

Publication: To be confirmed.

Data breakdown:

Cancer - Survival.

Data can be broken down by sex, age group, and Scottish Index of Multiple Deprivation (SIMD). Estimates of overall survival and age-standardised net survival at 1-year and 5-years are available for most cancer groups by sex and age group for the period 2015-19, published in 2022. (Note a modified update focussing on the impact of the pandemic, for periods 2018-19 and 2020, was published in May 2023). Estimates of overall and age-standardised net survival at 1-year and 5-years are available for the period 2013-17 by sex and SIMD (for cancers with sufficient cohort sizes), last published in 2021. PHS will explore whether it is possible to estimate net survival by stage at 1-year and 5-years.



Headline Indicator A

Cancer - Mortality.

Data can be broken by sex, age group, and SIMD. European and world age-standardised, as well as crude rates, are available for 45 different cancer types, broken down by sex and 5-year age group from 1995-2021.

Robustness and data limitations:

Cancer - Survival.

Overall survival and net survival estimates are not reported if the population at risk is too small. Age-standardised estimates are not reported if survival could not be estimated robustly for the age-specific groups required for their calculation. Age-standardisation is first attempted with five age groups, but, if any of these cohorts are too small, age groups may be merged to form four age groups. The COVID-19 pandemic has had unusual and complex impacts on cancer registration data, including through under-diagnosis and delayed diagnosis of cancers. Understanding these impacts will require careful analysis and interpretation.

Cancer - Mortality.

Registry data are subject to validation at data entry and quality assurance procedures. See the Cancer Information FAQs. Reported data are compared to previous years' figures and to expected trends. At time of extraction, data for the most recent year are estimated to be complete.

Headline Indicator B



Outcome: Reduced relative population burden of disease

Indicator(s): Burden of disease (disability adjusted life years) relative to all causes of other disease, infection and injury in the overall population.

Method(s) of data collection: Extraction of electronic health records (Scottish Morbidity Records and National Records of Scotland Vital Events).

Data source: Scottish Burden of Disease (SBoD) study dataset. Technical documentation, including methodology, data sources and clinical coding information, is published by the [Scottish Public Health Observatory](#).

Baseline/ comparability across time: Baseline year 2019; future data points will be comparable with baseline.

Collection frequency and details (including time lag): Data estimation and publication cycle to be confirmed.

How data can be broken down: Data available by sex and 5-year age group. Data may be available by SIMD quintile, if deemed suitable following statistical disclosure control.

Robustness and data limitations: In order to provide a measure of accuracy and relevance of the estimated disease disability adjusted life years (DALYs) to users, a measure of data quality has been developed for the SBoD study. This measure assigns a RAG (Red; Amber; Green) status to each disease or injury indicative of the accuracy and relevance of the estimates. Estimates of cancer burden are classed as Green: highly accurate and relevant. This indicates that the estimates have been derived using relevant and robust data sources with only a small degree of adjustments performed to the input data. Success in areas such as cancer survival may increase the measured non-fatal burden of disease: more screening and earlier diagnosis may increase the incidence of cancer, and better survival may increase the prevalence of cancer.



Headline Indicator C

Outcome: Reduced later stage diagnosis

Indicator(s): Diagnosis at disease stages III and IV (incidence by stage for 16 cancers).

Method(s) of data collection: Extraction of Cancer registration data (PHS).

Data source: Cancer registrations. [Cancer Incidence in Scotland data up to 2021](#) is published by PHS.

Data definitions (e.g. numerators, denominators, standardisation): Data as per 2021 incidence publication released in March 2023 contains the number of diagnoses at stages I, II, III, IV, and unknown for the 16 most common cancer types diagnosed in Scotland.

Baseline/ comparability across time: Baseline year 2021; future data points will be comparable with baseline.

Collection frequency and details (including time lag): Incidence publication approximately each April with a table included on numbers and percentages for each stage by deprivation, in line with the earlier diagnosis vision.

Data breakdown: Data available by sex, stage and SIMD quintile.

Robustness and data limitations: The earlier diagnosis vision is for later stage disease (stages III and IV) to be reduced. A focus will remain on reducing the health inequality gap, particularly those from areas of deprivation. This vision currently looks at all tumour groups combined but there will be differences across groups in relation to the level of reduction. It is recognised that not all cancers can be conventionally staged so additional measurements, such as emergency presentations, will be required to track progress and improvements in other cancer types, including blood and neurological cancers.

Headline Indicator D



Outcome: Timely access to treatment

Indicator(s): Cancer waiting times.

Method(s) of data collection: Cancer waiting times (CWT) statistics – adjusted and unadjusted waits (PHS).

Data source: National Cancer Waiting Times Data.

Data definitions (e.g. numerators, denominators, standardisation):

Cancer Waiting Times - 62-day standard.

Numerator = The number of patients receiving their first treatment within 62 days of the Board receiving the urgent suspicion of cancer (USC) referral.

Denominator = The number of eligible referrals made under the performance standard.

Cancer Waiting Times - 31-day standard.

Numerator = The number of patients receiving their first treatment within 31-days of a decision to treat.

Denominator = The number of eligible referrals made under the performance standard.

Note: See the [CWT Data & Definitions Manual](#) for further detail on how the numerator and denominator are defined for both standards depending on the standard, source of referral and type of first treatment.

National Cancer Waiting Times Data: 95% of all eligible patients should wait no longer than 31 or 62 days for cancer treatment.

Baseline/ comparability across time: To remain relevant to the changing set of targets (as published in the Scottish Government's [Better Cancer Care, An Action Plan](#) in 2008), the cancer waiting times statistics published previously by PHS were replaced with a new series of figures. The first set of these new figures relating to these targets were published in June 2010. Performance against these targets was achieved by March 2011, the timescale agreed by the Scottish Government. These

Headline Indicator D



targets were considered as National Standards from April 2012 and continue to be published on a quarterly basis.

Collection frequency and details (including time lag): CWT data is submitted monthly, based on the previous month of treatment, and quarterly.

Cancer Waiting Times - Monthly Submissions.

This is for Performance Management purposes only. These data are submitted monthly and are based on patients treated within a specified monthly time period.

Cancer Waiting Times - Quarterly Submissions.

This is for publication purposes and submitted quarterly. These data are based on patients treated within a three-month time period.

Data breakdown: See [CWT Data & Definitions](#) manual for all variables collected and ways data can be broken down. As these are patient level data, they can also be linked by postcode to derive SIMD.

Robustness and data limitations: The quality of these statistics is considered fit for publication; data quality aspects are described within each publication. [Fit for Purpose \(FFP\) exercises](#) have been carried out by PHS for the 62-day performance and have shown that completeness of the 62-day cohort is within an acceptable range and is fit for publication. Case ascertainment is assessed each quarter for the 31-day standard. The latest figures can be found within Table 1 in the list of tables on the report publication page. PHS regularly carries out data quality exercises to ensure that data are recorded in an accurate and consistent manner across NHS Scotland. Information on these exercises can be found on the PHS website. In early 2012, PHS Cancer Waiting Times undertook a data quality project to assure that data submitted for Bowel Screening patients are recorded accurately and consistently. The [Data Quality Assurance findings](#) from this project were published by the former NHS Scotland Information Services Division (ISD). Responsibility for collating and submitting the data to PHS lies with the NHS Board that received the patient's initial referral to secondary care. Information on data quality, service issues and accuracy specific to this publication can be found in Appendix 2 of the CWTs quarterly report. The most recent such report is [Cancer Waiting Times in NHS Scotland: 1 January - 31 March 2023](#).

Headline Indicator D



The Data Quality Assurance team within PHS carry out data quality exercises on cancer waiting times data. Completeness: patients will only be included in the database if they have a valid Community Health Index (CHI) number. A patient will be excluded from reporting against the Cancer Waiting Times standards for the following reasons:

1. The patient chooses to have any part of their pathway outwith NHS Scotland. If this is before the decision to treat, they will be excluded from the 62-day standard; if after the decision to treat, they will be excluded from both standards.
2. The patient died before treatment.
3. The patient refused all treatment.
4. The patient was deemed a clinically complex case by the lead cancer clinician of the responsible NHS Board.



Headline Indicator E

Outcome: More people receiving curative treatment

Indicator(s): In development.

Data development: Data development is an action in the first plan. Number of curative treatments recorded in national Systemic Anti-Cancer Therapy (SACT) data could be a potential indicator to provide some relative assessment of progress. Radiotherapy data are also available. Work will be undertaken by PHS to assess the feasibility of measuring surgical treatments from acute care data and multidisciplinary team data.

Data source: The national SACT dataset which combines and standardises data from the five local instances of the Chemotherapy Electronic Prescribing and Administration Systems (CEPAS) ChemoCare in Scotland.

Data definitions (e.g. numerators, denominators, standardisation): Number of patients receiving curative treatment out of all patients receiving treatment; increase in number of patients receiving treatment recorded as curative.

Baseline/ comparability across time: Data are considered to be complete from 2014 onward. Changes in the definition of the term 'curative' may influence data over time. A good baseline would be to reach national consensus on what should be considered curative and measure the first year post consensus as baseline.

Collection frequency and details (including time lag): Annual.

Data breakdown: Data can be broken down by geography, tumour type.

Robustness and data limitations: The National SACT dataset is still being validated by PHS and local analysts. An ongoing quality assurance process has been put in place and there is a continuous evaluation process of which variables are fit for reporting. Treatment intent is currently not considered to be of robust enough quality for reporting, however, quality has improved over time and

Headline Indicator E



awareness has been raised with prescribers in the preparation of the SACT 30-day mortality publication.



Headline Indicator F

Vision: Excellent care

Outcome: Improved experience of services, across all areas of care

Indicator(s): In development.

Data development: Measurement will be defined and developed during the first action plan. A new [Scottish Cancer Patient Experience Survey](#) (SCPES) will be completed in 2024 and will be used as the basis for measuring experience of services and care. Exact indicators (specific question responses) will be agreed at this time. Examples could include overall experience, travelling to appointments, emotional and psychological support received, or receiving adequate information. Looking ahead, either a SCPES or a similar survey tool will be repeated during the next Cancer Action Plan. Other potential sources of data on experience include [Care Opinion](#), and Patient Reported Experience Measures (PREMs) collected as part of specific evaluation activities.

Data source: SCPES or equivalent survey dataset.

Data definitions (e.g. numerators, denominators, standardisation): Respondents are individuals aged 16 or over, who had an inpatient hospital record with a mention of cancer and a confirmed cancer diagnosis within a specific timeframe.

Baseline/ comparability across time: Baseline year 2024; we will be looking back at the 2015 and 2018 surveys when we report in 2024 to understand progress/ areas for focused improvement.

Collection frequency and details (including time lag): Ad hoc, every 3-5 years with approximately 1 year time lag.

Data breakdown: Data can be broken down by age group, sex, sexual orientation, ethnicity, SIMD and rurality.

Robustness and data limitations: Some small numbers when data broken down, e.g. ethnicity.



Headline Indicator G

Outcome: Optimised quality of life for each individual

Indicator(s): In development.

Data development: Measurement will be defined and developed during the first action plan. Potential methods include building on available data such as Euro-QoL (EQ-5D), pulling data nationally from [Holistic Needs Assessments](#).

Data source: Survey results, Holistic Needs Assessment reports, Patient Reported Outcome Measures (PROMs).

Data definitions (e.g. numerators, denominators, standardisation):

Respondents will potentially be individuals aged 16 or over and with a confirmed cancer diagnosis.

Baseline/ comparability across time: Will depend on appropriate source. Unlikely to have comprehensive baseline.

Collection frequency and details (including time lag): Ad hoc. Potential time lag depending on agreed methodology.

Data breakdown: Some disaggregation likely. Will depend on agreed methodology.

Robustness and data limitations: Will depend on agreed methodology. Given there is no single standalone tool, there are likely to be limitations.



Outcome: Embedded research, innovation and data capture in all services

Indicator(s): In development.

Data development: Measurement will be defined and developed during the first action plan. Options include looking at access to clinical trials using data from the [EDGE clinical research management system](#); or measuring the range of data available on the PHS Cancer Intelligence Platform. This work will build on [recommendations by the Equity of Access Short Life Working Group](#).

Data source: Potentially EDGE; PHS dashboards.

Data definitions (e.g. numerators, denominators, standardisation): Will depend on measure(s) and methodologies chosen. Clinical trials' data will potentially include number of trials and number of participants in trials.

Baseline/ comparability across time: The baseline will depend on the indicators and methodologies chosen: baseline is likely to be 2023. Comparative data should be available going forward.

Collection frequency and details (including time lag): Annual, minimal time lag.

Data breakdown: The ability to provide breakdowns will be considered when determining suitable indicators.

Robustness and data limitations: There is no current standardised measure for this outcome.

Headline Indicator I



Vision: Equitably accessible care

Cross-cutting aim: Reduced health inequalities in all areas above

Indicator(s): In line with this cross-cutting aim, wherever possible, we will monitor data broken down by equalities, socioeconomic and geographic characteristics. This will include analysis of: sex and age group, SIMD quintile, and geography if possible, subject to statistical disclosure control. The data breakdowns that are currently possible for each key headline indicator are provided above. In addition to monitoring equalities data for the headline indicators specified above, we will monitor cancer incidence amongst those aged under 75 years and cancer deaths for those aged 45-74 years. This will help us to understand absolute and relative inequalities between the most and least deprived areas in Scotland. See [Appendix 3](#) for a summary of planned strategic work.

Data source: [Annual updates of the long-term monitoring of health inequalities headline indicators](#) are published by the Scottish Government. Scottish Cancer Registry (SCR) and Public Health Scotland. [Technical documentation about the methodology of long-term monitoring of health inequalities](#) has been published by the Scottish Government.

Data definitions (e.g. numerators, denominators, standardisation): European age-standardised rates of new cases of cancer amongst those aged under 75 years. European age-standardised rates of deaths from cancer amongst those aged 45-74 years. The relative index of inequality (RII) indicates the extent to which health outcomes are worse in the most deprived areas compared to the average throughout Scotland. It looks only at the income and employment domains of the SIMD, called the Income Employment Index (IEI). Absolute inequalities are measured by looking at changes in the gap between those living in most and least deprived areas in Scotland. It is possible for absolute inequalities to improve, but relative inequalities to worsen. Rates are age-standardised in order to show patterns over time on a consistent basis, taking account of changes in the age distribution of the Scottish population, therefore more clearly showing any underlying trend.

Headline Indicator I



Baseline/ comparability across time: Baseline year 2020 for cancer incidence data. Baseline year 2021 for cancer deaths; future data points will be comparable with baseline.

Collection frequency and details (including time lag): Annual.

Data breakdown:

Cancer - Incidence Rate aged under 75 years.

All Cancers - cancer defined as all malignant neoplasms excluding non-melanoma skin cancer. The following ICD coding was used: ICD10 'C00-C96' excluding 'C44' (the Scottish Cancer Registry does not use code 'C97').

Prostate cancer (males only) - ICD-10 C61

Breast cancer (females only) - ICD-10 C50

Cancer of the trachea, bronchus and lung- ICD-10 C33-C34

Colorectal cancer- ICD-10 C18-C20

Cancer - Deaths aged 45-74 years.

All cancers - cancer defined as all malignant neoplasms excluding non-melanoma skin cancer. The following coding was used: ICD10 (2000 onwards) 'C00-C97' excluding 'C44'.

Prostate cancer (males only) - ICD-10 C61

Breast cancer (females only) - ICD-10 C50

Cancer of the trachea, bronchus and lung- ICD-10 C33-C34

Colorectal cancer- ICD-10 C18-C20

Robustness and data limitations: Aggregate data are provided by PHS for cancer incidence and cancer deaths. Scottish Government statisticians carry out quality assurance checks on the aggregate data, comparing it with past trends and against other published data, such as national level data published by NRS or PHS.

Appendix 3: Strategic work in development to improve equalities data

In April 2021, the Scottish Government launched the [Equality Data Improvement Programme \(EDIP\)](#) to strengthen the equality evidence base through the sharing of learning and good practice, and through priority data development projects. To date, key outputs of the EDIP include the publication of [updated guidance on the collection of equality data](#) and [an evidence synthesis to improve understanding of intersectionality and how it can be applied](#).

In March 2023, the Scottish Government published [Scotland's Equality Evidence Strategy 2023-2025](#), marking the conclusion of the first phase of the EDIP. The strategy sets out a refreshed vision, along with a comprehensive three-year improvement plan. Alongside completing the specific actions set out in this strategy, Scottish Government analysts will continue to improve disaggregated and intersectional equality data collected through survey and administrative sources and present this evidence in their own analytical outputs and on the [Equality Evidence Finder](#). These equality data improvements will be driven forward throughout the lifetime of the Equality Evidence Strategy. The full list of commitments from Health and Social Care in the EDIP is available in [Annex D: Tables of Actions to Improve the Equality Evidence Base - Scotland's Equality Evidence Strategy 2023-2025](#).

On women's health data, there is a commitment in the EDIP to improve the quality and availability of data on women's health. This looks at identifying data gaps, ascertaining women's health data needs, identifying what barriers exist, and what data collection practices need to change to improve the availability and quality of data in this area. The work has already produced research findings such as this publication on [Women's Experiences of Discrimination and the Impact on Health](#).

Work is also progressing on improving the ethnicity data held by Health and Social Care. Public Health Scotland recently published their second annual report on [Monitoring Racialised Health Inequalities in Scotland: Data and Evidence](#) and the Scottish Government recently published its [Anti-racism in Scotland: Progress Review 2023](#) with [a chapter on Health and Housing within that report](#).

Appendix 4: Key steps of change to achieve the strategic vision

The ambition-level theories of change have fed into an overarching theory of change that summarises the key steps of change that we anticipate happening over ten years to achieve the strategic vision. The infographic below provides a summary of these anticipated changes, showing how each ambition will lead to the high level summary outcomes that are set out in Figure 1 (Page 10), which connect to the vision of improved survival and excellent, equitably accessible care. The theory of change will necessarily evolve over time as interventions are implemented and assumptions are refined in light of emerging evidence.

Cancer Strategy for Scotland – Steps of Change across 10 Years towards the vision of improved survival and excellent, equitably accessible care

Preventing more cancer



1-3 years

- Optimised HPV vaccination, including targeted approaches
- Improved knowledge of health behaviours associated with increased risk for some cancers



4-6 years

- Higher and more equitable coverage of HPV vaccination
- People adopt healthier lifestyles, with reduced smoking and alcohol use leading to reduced risk



7-9 years

- The incidence of cervical cancer is reduced
- Risk factors for some cancers are reduced

Reduced relative population burden



1-3 years

- Optimised screening, including risk stratification
- Improved awareness of signs and symptoms of cancer amongst the public, and sense of empowerment to seek help
- Improved education for primary care to effectively manage and refer people with a suspicion of cancer
- Optimised quality and efficiency in diagnostic pathways with a Once for Scotland approach
- Enhanced diagnostic capacity and improved access, including improved testing turnaround



4-6 years

- Increased participation in national screening programmes
- People present earlier with a suspicion of cancer
- Equitable access to enhanced diagnostic services, including for people with non-specific cancer symptoms
- Faster pathways to diagnosis, with less unwarranted variation



7-9 years

- Earlier access to treatment
- Fewer cancer diagnoses via emergency admissions
- Reduced later stage disease, particularly among people from areas of deprivation
- People experience improved clinical outcomes

Reduced relative population burden; Reduced later stage diagnosis; Timely access to treatment; More people receiving curative treatment; Improved experience of services

Earlier & faster diagnosis

Cancer Strategy for Scotland – Steps of Change across 10 Years towards the vision of improved survival and excellent, equitably accessible care

Best preparation for treatment



1-3 years

- Increased understanding of the role of prehabilitation amongst a wider variety of stakeholders
- Wider coverage of universal prehabilitation services in clinical management pathways
- Genomic testing and interpretation is signposted in clinical management pathways



4-6 years

- Prehabilitation screening and assessment are carried out routinely with appropriate management plans
- Improved support and access to prehabilitation services across Scotland for defined pathways
- More precision and effective treatments are delivered



7-9 years

- People respond better to treatment and are more resilient to the effects of treatment due to better overall health
- People experience fewer side effects from treatment
- People experience improved clinical outcomes

Timely access to treatment; More people receiving curative treatment; Improved experience of services; Optimised quality of life



1-3 years

- Increased service integration across specialisms, regionally and nationally where appropriate
- Optimised quality of cancer treatment and therapy via clinical management pathways
- Clearer relationship between national cancer and medicines groups
- More coherent single source of data and evidence on cancer medicines and real world outcomes
- Appropriate and equitable access to expanded surgery, radiotherapy and chemotherapy treatment options



4-6 years

- Reduced unwarranted variation in treatment across services
- Fewer complications and less time spent in hospital
- Appropriate adoption of new treatments that is aligned to clinical capacity
- More equal access to appropriate treatment



7-9 years

- More consistent and equitable treatment provided
- People experience improved clinical outcomes

More people receiving curative treatment; Improved experience of services

Safe, realistic & effective treatment

Cancer Strategy for Scotland – Steps of Change across 10 Years towards the vision of improved survival and excellent, equitably accessible care

Excellent care & support after treatment



1-3 years

- Improved knowledge of the rehabilitation landscape and embedding the six principles of good rehabilitation into practice
- Improved knowledge of the principles of good practice for palliative care and care around death



4-6 years

- Improved rehabilitation practice across services
- Improved supportive care, palliative care and care around death across services



7-9 years

- People have access to holistic rehabilitation that supports them to live well with fewer side effects and better recovery
- People receive well-coordinated, timely and high-quality palliative care and care around death

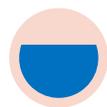
Improved experience of services; Optimised quality of life

Sustainable & skilled workforce



1-3 years

- Better understanding of workforce numbers and gaps
- More staff are attracted and retained through Workforce Strategy and review
- More staff are trained in care/support relevant to cancer



4-6 years

- Optimised deployment of staff across cancer services
- Increased capacity to diagnose and provide care from additional staff capacity



7-9 years

- People feel well supported by a sustainable, skilled workforce

Improved experience of services; Optimised quality of life, Embedded research, innovation & data capture in all services

Cancer Strategy for Scotland – Steps of Change across 10 Years towards the vision of improved survival and excellent, equitably accessible care

Person-centred care for all



1-3 years

- Improved psychosocial care is delivered via holistic needs assessments, care planning and realistic medicine
- People experience easier navigation through pathways with single point of contact operating
- People have access to the right support and information to make the right decisions about their care



4-6 years

- Improved support that is timely, relevant, appropriate, and sufficient for people's needs
- People feel more knowledgeable about care and treatment, including the benefits and the harms of treatment



7-9 years

- People are at the centre of their care and have a strengthened ability to self-manage via support
- People are able to make shared decisions that are right for them, and experience less regret

Improved experience of services; Optimised quality of life

Mental health as part of basic care



1-3 years

- Staff feel well supported and confident about how to deliver/signpost psychological care and treatment
- Improved understanding of service demand and capacity for psychological care and treatment



4-6 years

- Services incorporate appropriate psychological care and treatment into routine pathways of care



7-9 years

- People have the network of care they need to manage the psychological impact of a cancer diagnosis

Improved experience of services; Optimised quality of life

Cancer Strategy for Scotland – Steps of Change across 10 Years towards the vision of improved survival and excellent, equitably accessible care

Flourishing research & innovation



1-3 years

- Improved understanding of how to increase equitable access to clinical trials
- Increased awareness and uptake of Scottish Health Technologies Group advice
- New technologies for diagnosis and treatment are identified and supported



4-6 years

- Increased involvement and improved equity of access to clinical trials
- Higher rates of implementation and optimisation of effective diagnostic tools and treatments



7-9 years

- Cancer diagnosis, treatment and care are routinely informed by evidence-based advice

Embedded research, innovation & data capture in all services

Cancer information & intelligence led services



1-3 years

- More data and better intelligence are available to policy makers, clinicians, health managers and the public



4-6 years

- Comprehensive cancer data (with limited time lag) supports optimised clinical, policy and managerial decision-making



7-9 years

- Cancer diagnosis, treatment and care are supported by high quality data and intelligence

Embedded research, innovation & data capture in all services



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