

# Cancer Strategy for Scotland 2023-2033



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Despite recent advances, cancer remains the largest burden of disease across Scotland and has seen an ongoing increase in incidence. However, alongside this trend, we are seeing reduced death rates, with an 11% reduction over the last 10 years.<sup>1</sup> Looking forward, cancer incidence is projected to increase due to Scotland's ageing population, with the risk of developing cancer more common among older people, which requires increases in diagnostic and treatment capacity for each person with cancer.<sup>2</sup>

In line with the First Minister's Policy Prospectus published in April 2023, we are focusing on improving cancer outcomes through better prevention and diagnosis. We continue to strive for earlier diagnosis as we know this is critical to improving outcomes and survival. As well as being able to provide more curative treatment. we also recognise the importance of treatments to extend life and the provision of holistic palliative care. All of these aims must be underpinned by the principles of person-centred care and an understanding of what matters to every individual with cancer.

We have listened to your views through a public consultation and focus groups, and through engagement with national, regional and local networks of clinical and management representatives. Thank you so much for taking the time to share them. Our strategic intent is now clear – to improve cancer survival and provide excellent, equitably accessible care.

Our 10-year vision for our health service is that More cancers are prevented, and our compassionate and consistent cancer service provides excellent treatment and support throughout the cancer journey, and improves outcomes and survival for people with cancer.

This strategy has people living with cancer, their families and carers at its very heart, with a focus on reducing inequities in access to cancer care and cancer outcomes, recognising each person's time of need. Focussing on all people with cancer, the strategy aligns with the <u>Cancer Strategy for Children</u> <u>and Young People 2021–2026</u> that reflects the distinct needs of children and young people.

Our focus on the four key principles of person-centred care – compassion, personalisation, coordination and enablement – provides the foundation for our approach.<sup>3</sup> By 2033 we will improve cancer survival, particularly among the currently less-survivable cancers such as lung cancer. Strong public health interventions will mean more cancers are prevented, and those who require diagnosis and treatment will have prompt access to quality services, all with the strategic focus of improved survival and excellent care, no matter where someone lives. To all those who have been involved in developing this strategy, and will be involved in its delivery, I thank you for your invaluable work and contributions. I've been very clear that cancer must remain a priority within our NHS, as well as delivering this strategy along with the associated Cancer Action Plan for Scotland 2023-2026. It will be crucial to continue this prioritisation, while taking all opportunities to further improve experience of our cancer services.



Michael Matheson MSP Cabinet Secretary for NHS Recovery, Health and Social Care

#### 1.1 Our Vision and Strategic Aim

Cancer remains one of Scotland's single biggest health challenges, affecting every one of our citizens in some way throughout their lifetime. In recent times there have been huge changes in our understanding of the disease and how to improve its prevention. diagnosis and treatment, and it is incumbent on governments across the world to keep pace with the most up-to-date ways of managing cancer within their populations. The scope of these possible interventions is wideranging, from evolving our public health system to continuing the search for better scientific understanding: introducing new case-finding and treatment techniques; and doing what really matters to people with cancer by building care and treatment around their specific needs and preferences.

The challenge remains formidable. Cancer survival has improved in Scotland but not at a satisfactory rate. The necessary coalition of effort to meet this challenge is complex, involving many organisations and thousands of individuals. Strong and clear coordination of this effort is required at all levels, and this strategy will provide common direction for all. Our vision for cancer in Scotland in 10 years' time is:

By 2033 every person with cancer will have access to the comprehensive support they need, clinical and nonclinical, reflecting what matters to them. Digital and technological advances will allow people with cancer to access services in different ways, attending clinical settings only where necessary, with wider support provided in ways that work best for them. There will be less unwarranted variation in service delivery and clinical management across Scotland. Systems will integrate to provide efficient and effective care founded on national clinical consensus. Increasing numbers of people with cancer will have access to curative and other cancer treatments, with full supportive and palliative care available where a cure is not possible, all underpinned by a culture of Realistic Medicine. People will be well informed about prevention, signs and symptoms, and people with cancer will be informed about their treatment and care and possible outcomes. People with cancer will know how to access the support they need and be clear about the next step in their journey.

More cancers are prevented, and our compassionate and consistent cancer service provides excellent treatment and support throughout the cancer journey, and improves outcomes and survival for people with cancer.

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Our strategic aim is to **improve cancer survival and provide excellent**, **equitably accessible care** underpinned by the following outcomes:

- a. Reduced relative population burden of disease
- b. Reduced later stage diagnosis
- c. Timely access to treatment
- d. More people receiving curative treatment
- e. Improved experience of services, across all areas of care
- f. Optimised quality of life for each individual
- g. Embedded research, innovation and data capture in all services.

We will aim to reduce inequalities in all these areas.

#### 1.2 Steps to Success

As we publish this strategy, the NHS is under enormous pressure following the impact of the COVID-19 pandemic and the long-term challenges of an ageing population. This requires an increase in diagnostic and treatment capacity for each person with cancer. These pressures are felt across a range of other services and organisations that are crucial to cancer care. NHS Boards across Scotland continue in the 'recovery' phase of the 2020 Remobilise, Recover, and Re-design framework. This phase has been included in The NHS Scotland Deliverv Plan Guidance for Boards as they set out their Medium Term Plans (three vears) and define their Annual Deliverv Plan (12 months). During the Medium

Term Plan, success of the strategy will be to recover and stabilise systems and services, maintaining cancer as a priority while necessary recovery takes place in health systems and the wider economy. Actions to recover and stabilise services are covered in our first three-year action plan 2023-2026 and aligned with the Medium Term Planning guidance.

Concurrently, it will be necessary to renew our services and approaches to cancer control. This means working collaboratively with people who use services to develop new models of care, and delivering the changes needed to better meet what matters to the people NHS Scotland cares for. Planning for renewal and redesign phases will be underway to help shape and build on recovery phase.

We will develop plans for longer term redesign of services as part of a wider transformation framework that will guide our service development, further harnessing the potential of innovations, integrating many more of our systems, removing associated barriers and, where the evidence is clear, embracing novel treatments and digital opportunities.

#### 1.3 Development of the Strategy

Our public consultation and engagement events during the development of the strategy provided evidence of a strong appreciation of existing cancer services, as well as recognition of the fundamental impact of earlier diagnosis and safe, effective treatment. The

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respondents included people with lived experience of cancer, healthcare professionals, academics, private and third sector representatives amongst others. Those who took part emphasised the importance of action across the whole cancer pathway from prevention to pre-treatment and post-treatment. In addition, respondents also told us that there needs to be a strong focus on the key cross-cutting enablers such as a well-resourced and skilled workforce, capacity for research and innovation, and comprehensive data and intelligence systems. The strongest recommendations emerging from the consultation related to the holistic aspects of providing high quality care. This means putting the person with cancer at the centre of the response. providing holistic care (including psychological support), providing excellent communication and applying the principles of Realistic Medicine.

#### 1.4 Interconnectivity with wider Health and Social Care

This strategy is for all people affected by cancer, but the distinct needs of children and young people are specifically covered by the **Collaborative and Compassionate Cancer Care: Cancer Strategy for Children and Young People (2021)**, delivered through the Managed Service Network for children and young adults.

In addition to that document, the delivery of the strategic ambitions here will be interdependent with a range of other strategic aims in health and

beyond. This strategy cannot stand alone, nor can it supersede wider strategies. Rather it complements, links to and will operate within the broader health aims of the Scottish Government. It is accompanied by a 3-year Cancer Action Plan and underpinned by actions in Annual Delivery Plan guidance to Boards alongside Medium Term Planning with longer-term planning and redesign. Actions will change, adapt or be superseded by innovations as yet unknown, and will reflect the change needed in evolving contexts, including NHS capacity and the ability to make new financial investments. Embedding research and focused data collection will help to build a 'learning health system' and will be supported by key drivers including the Scottish Health Industry Partnership (SHIP) and the Accelerated National Adoption (ANIA) Pathway.<sup>4</sup>

Cancer control will be key to meeting Scotland's National Performance **Outcome** that we are healthy and active, not only through providing treatment and care for those with cancer, but also through a variety of population measures that will help prevent cancers in the future. These will be addressed through plans, strategies and interventions targeted at specific cancer risk factors including tobacco, obesity and alcohol. There are clear, inextricable links between health inequalities and poverty. Our long-term approach is through the national mission to tackle child poverty: **Best Start**, **Bright** Futures (2022). It aims to reduce health inequalities in the long-term by reducing child poverty now.

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#### We will continue the direction of travel laid out in the <u>National Clinical Strategy</u> for Scotland (2016):

- planning and delivering integrated primary care services, like
   GP practices and community hospitals, around the needs of local communities
- restructuring how our hospitals can best serve the people of Scotland
- making sure the care provided in NHS Scotland is the right care for an individual, that it works, and that it is sustainable
- changing the way the NHS works through new technology
- supporting people to practice Realistic Medicine

The National Clinical Strategy recognises that people often lack a full understanding of the prognosis or outlook for their illness (or the risk of developing a harmful event). They might well make different decisions if they were fully informed about their condition and the treatment options available. Indeed, in many cases, they may choose less aggressive treatment rather than more. This aspect needs to be better reflected in clinicians' discussions with patients about treatment options. A reinvigorated Realistic Medicine approach will support this element of the cancer strategy.

During the pandemic many new and innovative ways of working were developed to support the continued delivery of critical services. These were born out of necessity but, in many cases, they also delivered improvements. We

want to build on this work, as set out in the NHS Recovery Plan (2021). This will support innovation in and redesign of services to ensure that more people with cancer receive person-centred care in the right place, at the right time, and in a way and that enables staff to deliver high quality care and treatment. As set out in our steps to success, research, innovation and the redesign of services will be integral to recovery and stabilisation. There are a range of partner organisations that are central to this including the Centre for Sustainable Delivery, NHS National Services Scotland and its Scottish Cancer Network, the Digital Health and Care Innovation Centre, Healthcare Improvement Scotland, and the Scottish Health Industry Partnership. All their work will be rooted in the principles of Realistic Medicine and aligned with broader Scottish Government care and wellbeing programmes. Our **Health and** Social Care: National Workforce Strategy (2022) will ensure we have a skilled and sustainable workforce to support delivery of our health and social care services. Success will be required across all pillars of that strategy to meet our strategic aims.

As Scotland builds back from the COVID-19 pandemic, we urgently need to tackle the long-standing inequalities in health and wellbeing that have been exacerbated by COVID-19. To do that we have established the <u>Care and</u> <u>Wellbeing Portfolio</u> that brings together work aimed at improving population health and reducing health inequalities, through health and social care and wider public sector service reform. The Portfolio seeks to create the best

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environment to stimulate national and local action to tackle these issues and takes a systematic approach to planning and delivering care and wellbeing. The work set out in this strategy will make an important contribution to these challenges. The diagram below sets out the overall Portfolio mission and outcomes, cross-government priorities that in turn improve health, and the programmes and enabling functions that support delivery.

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# **Care & Wellbeing Portfolio**

**Portfolio Aim** 



Together the Care & Wellbeing Programmes and Enablers provide a comprehensive and progressive health and social care reform package.

Cancer Strategy for Scotland 2023-2033

continued

The increase in digital health planned for before the pandemic and significantly accelerated as part of our response - will increasingly become a choice for people accessing services and for the staff delivering them. It will allow more people to manage their condition(s) at home, enable remote pre- and post-operative assessments, as well as allowing people with cancer to manage their recovery from home. The Digital Health and Care Strategy will be the key driver in all of this and we will engage on its commitment to develop a Digital Front Door (DFD). The DFD work will be a key enabler for people interacting with health and social care services in Scotland. This development aims to allow anyone to manage appointments and conduct routine 'transactions' online. Digital technology can also facilitate the collection and capture of patient-reported outcomes and experience measures (Patient Reported Outcome Measures (PROMS) and Patient Reported Experience Measures (PREMS)).

#### The Scottish Cancer Network (SCN)

will be at the heart of our strategic ambitions. There is evidence that those countries with empowered and clinically led central cancer agencies delivering clear government-owned plans have seen greatest success in cancer control.<sup>5</sup> The SCN will continue to be at the forefront of defining clinical management pathways for cancer from the point of diagnosis. These unique pathways encompass treatment and care right through to the end of life, setting out clinically agreed best practice, and assuring people with cancer of common standards of care, no matter where they live. The SCN will also host national networks, where national integration and collaboration for specific cancers can make best use of expert resources and improve outcomes for people with cancer. It will drive 'Once for Scotland' work, where appropriate, and work closely with regional networks where work is better delivered at that level.

This work will be underpinned by the Scottish Cancer Quality Programme, which will define and drive quality of care in Scotland, using agreed quality performance indicators (OPIs) that meet our strategic aims and wider measures to define quality of treatment and care. Clinically agreed priority indicators linked to our strategic aims will be closely monitored, working with Healthcare Improvement Scotland. The programme will continually review how these indicators are being met, with ongoing international benchmarking to ensure best evidence and comparators are being used in setting standards. All this work will be in clear sight of our overall strategic aim to improve cancer survival and provide excellent. equitably accessible care.

#### The **Centre for Sustainable Delivery**

(CfSD) has been established to pioneer new, more sustainable ways of delivering services, including improving access for people with cancer. CfSD will be particularly important in driving innovation through their ANIA pathway. It will be key to supporting NHS recovery by reducing unnecessary demand for services, maximising available capacity and developing new pathways of care that are more

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efficient, effective and patient-focused. It will maximise value for people with cancer by devising ways of avoiding waste and will facilitate consistent, high-quality healthcare across Scotland, where possible. The CfSD will build on and accelerate work on redesigning optimal diagnostic pathways, growing Scotland's network of Rapid Cancer Diagnostic Services (RCDS), facilitating the introduction of innovative techniques (for example, Cytosponge), maximising diagnostic capacity, and optimising theatre capacity.<sup>6</sup>

#### 1.5 Realistic Medicine, Person-Centred Care and 'What Matters'

Our primary focus must continue to be on achieving the outcomes that matter to people with cancer. In practising Realistic Medicine. health and care professionals work in partnership with people they care for. People must be involved in decisions made about their care by health and care professionals who understand and respect what matters to them. Desired outcomes are delivered through shared decision making and discussion about the potential benefits and harms of different treatment options, including the option to do nothing. This approach allows people to make an informed choice about their care, and helps reduce regret about treatment decisions.

In cancer services particularly, these guiding principles are tested daily by the complexities of some treatments that can carry significant adverse effects. Realistic Medicine encourages health and care professionals to go beyond explaining risks to considering the impacts, both positive and negative. that a treatment may have on the individual and their families. Making decisions as a partnership increases the likelihood that care is in tune with a person's personal preferences and will improve psychological wellbeing and outcomes. Ultimately, practising Realistic Medicine will enable cancer services to continue to be one of the most compassionate areas of the health and care service, providing the highest quality care that people with cancer value.

#### Additionally, Delivering Value Based Health & Care: A Vision for Scotland

(VBH&C) will help deliver personcentred care, reduce harm and waste and eliminate unwarranted variation in access to health and care, treatment and outcomes. VBH&C also encourages health and care colleagues to be creative and think carefully about how we optimise the use of the resources we have for maximum benefit.

Getting It Right for Everyone (GIRFE) is a proposed multi-agency approach of support and services from young adulthood to end of life care. GIRFE reflects similar values to this strategy. It provides a more personalised way to access help and support when it is needed – placing the person at the centre of decision making to achieve the best outcomes, with a joined-up, coherent and consistent multi-agency approach.

continued

'What matters' is the ongoing reminder that what matters to people with cancer needs to be truly reflected in our thinking and delivery. Evidence from people with cancer has shown that while clinical outcomes are clearly important, so too is treatment and care that reflect their personal preferences and what matters to them. Collectively this means:

- Equity of access to services the treatment and care that people with cancer can access does not vary in quality depending on where they live, or because of characteristics including gender, ethnicity, disability or socio-economic status (see Tackling Inequalities).
- Non-clinical needs are supported a cancer diagnosis entails a clinical pathway for the person with cancer, but it also can have enormous impacts on their physical, mental and spiritual wellbeing as well as areas such as finances, social interactions, employment, housing and access to wider services (see Person-Centred Care for All).

Information and communication

 regular, clear and inclusive
 information can benefit people with
 cancer and the service provider,
 facilitating shared decision making
 and an understanding of what
 happens next, in line with the
 principles of Realistic Medicine (see
 Best Preparation for Treatment and
 Excellent Care After Treatment).

Our aim is to ensure people with cancer are at the heart of service design. To achieve this, we will codesign whenever possible and we will regularly seek people's voices through direct feedback, for example through the Scottish Cancer Patient Experience Survey and Care Opinion. We will support the generation of relevant and actionable data on both person-centred processes of care and person-centred outcomes. This will further enhance our understanding of quality and value, and what matters, from the perspective of people affected by cancer.

How the person at the centre interacts with services and policies and what we are trying to achieve through this strategy is shown here, noting that many components may be influenced but not controlled.

continued

#### Individual/Patient

Knowledge, behaviour, prior experience Culture Socio-economic status Geographical location

#### Interpersonal/Support Structures

Family, friends, colleagues Social support networks

#### **Organisational/Cancer Services**

Prevention programmes Diagnostic pathways Pre-treatment Safe, effective treatment Post treatment support Workforce Location

#### Community

Interface of primary, secondary care and third sector Research Support (including psychological) for long term conditions

#### Policy

National Performance National Clinical Strategy NHS Recovery Plan National Workforce Strategy Digital Health and Care Research & innovation, Data intelligence systems Staffing, resources Realistic Medicine

continued

#### **1.6 Governance and Delivery**

To support a more integrated and coherent approach to planning and delivery of health and care services, we have developed the NHS Scotland Delivery Plan Guidance that sets out prioritised high-level deliverables and intended outcomes to guide detailed local, regional and national planning, and inform improvement work. The <u>Remobilise, Recover, Re-design Framework</u> (<u>RRR</u>) was published on 31 May 2020, and set out the approach for health boards to safely and gradually prioritise the resumption of paused services.

This NHS Scotland Delivery Plan and associated approach to planning supports the **transition from recovery into a renewal phase** of services. This is a key part of strengthening and developing strategic and operational planning across health and care. The planning work will be supported and overseen by the NHS Scotland Delivery Group in conjunction with regular performance reporting and planning review cycle.



<u>Programmes of Change and Transformation</u> Care and Wellbeing, DHAC, Innovation, etc.

continued

Planning Framework – response to national policy & strategy set by Scottish Government						
A lens to view the different planning and delivery functions that take place nationally • What drives activity in each category below?						
	Policy/Strategy	Planning/ Coordination	Operational Delivery			
National	<ul> <li>Policy imperatives drive model</li> <li>Require national standardisation</li> <li>Reflective of interdependencies with other policy areas</li> </ul>	<ul> <li>Sustainability &amp; resilience risks</li> <li>Scarce clinical skills</li> <li>Improving clinical outcomes</li> <li>Collaborative approach adds value</li> <li>Cost reduction</li> </ul>	Quaternary Clinical Services • Complex clinical services • Low volumes of patients • Scarce clinical skills • High cost Once for Scotland			
			<ul> <li>Single approach</li> <li>System wide approaches add value</li> <li>Clinical and non-clinical</li> </ul>			
Regional/ inter- regional	<ul> <li>Strategies need aligned to deliver policy</li> </ul>	<ul> <li>Sustainabillity &amp; resilience risks</li> <li>Scarce clinical skills</li> <li>Improving clinical outcomes</li> <li>Collaborative approach adds value</li> <li>Cost reduction</li> </ul>	<ul> <li>Subsidiarity &amp; proportionality</li> <li>Regional approach</li> <li>System wide approaches</li> <li>Clinical and non-clinical</li> <li>Equitable access an issue</li> </ul>			
Local	<ul> <li>Strategies need aligned to deliver policy</li> </ul>	Local operational service planning	<ul><li>Most Services</li><li>Board/sub-board delivery</li></ul>			

continued

The Scottish Government will have oversight of overall strategic progress and direction of this strategy. The Scottish Cancer Strategic Board will 'own' the strategy and associated action plans, and review progress against them. Beyond this, ownership of actions and delivery will be undertaken as appropriate at national, regional and local levels. Collaboration and integration between health boards, including regional working and regional networks, will be vital in enabling this. Once for Scotland approaches will be a core principle to all our work. Where decisions and agreement on action. guidelines or service design is required

at a national level for work that is universally applicable across Scotland, then it will be undertaken only once and not replicated at other levels. This will free up resources at regional and local level, avoid duplication of effort at a time when the service is particularly hard pressed, make for clearer future decision making, and support equitable access. However, many other aspects of delivery will be carried out at a local or regional level, reflecting local services, geographies, populations and the needs of the individual with cancer. PHS publishes a wide range of statistics including cancer incidence, survival and mortality. These cancer statistics include analysis by tumour type, gender, age and deprivation.

Cancer Research UK (CRUK) publishes a wide range of important research.

#### Incidence 2.1



Cancer incidence in Scotland, 1997-2021. Number of cases and age-standardised incidence rate by sex.8

Year of diagnosis

1. All cancers excluding non-melanoma skin cancers (ICD-10 C00-C97 excluding C44).

2. Age-adjusted incidence rates per 100,000 population, calculated using the 2013 European Standard Population.

There were 35,379 new cancers registered in Scotland (17,600 male; 17.779 female) in 2021 (an increase of 5.5% compared with 2019). This is inline with a long-term trend of increasing number of cancer diagnoses over time. The rate, or risk, of new cancers also increased to 644 per 100,000 (an increase of 3.1% compared with 2019) and was higher than expected from the

long-term trend. These statistics for 2020 and 2021 need to be seen in the context of the pandemic and will continue to be monitored closely.

The risk of all cancers (excluding nonmelanoma skin cancers) has historically been higher in males than females. The gap has steadily decreased over time; it reached its lowest in

## **Cancer in Scotland**

continued

2019 with a difference of 14.9% and slightly increased to 16.9% in 2021. To understand the implications of these trends over time, each cancer needs to be considered separately, alongside the contrasting patterns between the number and rate of cancer between the sexes.

Lung cancer is the most common cancer, although breast and prostate cancers are the most common in females and males, respectively.

Data from 2021 show increased cancer risks for those living in the most deprived areas: a person living in the most deprived areas of Scotland is 30% more likely to develop cancer than one living in the least deprived areas, although this does vary by cancer type. This overall pattern is strongly influenced by higher rates of smoking-related cancers in more deprived areas. For example, lung cancer is three times more common in the most deprived areas compared with the least deprived areas in Scotland.

When looking at cancer staging, the earlier a person is diagnosed with cancer, the more likely they are to have a good outcome. Four out of five breast cancers (78%) were diagnosed at an early stage (I or II). In contrast, two-thirds of lung cancers (66%) and more than two in five colorectal cancers (44%) were diagnosed at a late stage (Stage III or IV). There was convincing evidence that socio-economic deprivation increased the likelihood of being diagnosed with more advanced cancers of the cervix, breast in females, head and neck, and prostate.



Cancer of the trachea, bronchus and lung (ICD-10 C33-C34) Age-standardised incidence rates by SIMD 2020 deprivation quintile, persons.<sup>9</sup>

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#### 2.2 Survival

# Age-standardised net survival at 1 year after diagnosis, for cancers diagnosed in Scotland during 2010-2014 or 2015-2019.<sup>10</sup>



Data published in 2022 allows us to look at both the 1-year and 5-year survival outcomes at the same time. Survival for all cancer patients combined (excluding non-melanoma skin cancers) improved, at both one and five years, between

2010-14 and 2015-19, by around two percentage points for males and one percentage point for females.

During the five-year period 2015-19, for adults who were diagnosed with

#### **Cancer in Scotland**

continued

cancer, two thirds of males (69%) and females (72%) survived for at least one year, while 2 in 5 males (44%) and 1 in 2 females (51%) survived for at least five years. This varies by cancer types, however, with 1-year survival ranging from around 20% to almost 100%. Reasons for improved cancer survival include diagnosis at an earlier stage and use of more effective treatments.

#### 2.3 Mortality





Year of death registration

#### **Cancer in Scotland**

continued

Between 2012 and 2021, the overall risk of dying from cancer has decreased but the number of deaths due to cancer has increased over the same period. This largely reflects Scotland's aging population as the risk of developing cancer is more common among older people.

Between this 10 year period, the ageadjusted cancer mortality rate for all cancers combined decreased by 11%, with a greater decrease in males (14%) than in females (7%). The continuing decrease in cancer mortality rates is consistent with long-term trends. Therefore, it appears that the pandemic did not adversely impact cancer mortality rates in 2021.

Lung cancer was the most common cause of death from cancer in Scotland (3959 deaths in 2021). Almost a quarter of all deaths from cancer in Scotland were attributed to lung cancer, 45% more deaths than colorectal cancer, the next most common cause of death from cancer.

People living in the most deprived areas were 74% more likely to die from cancer, compared with the least deprived. The possible reasons for these patterns are complex and reflect modifiable and non-modifiable risk factors for developing cancer, uptake of screening, access to treatments and other health conditions.

#### 2.4 Projections

Around 35,400 people are diagnosed with cancer in Scotland each year – more than 4 people every hour. Based on CRUK research, the number of cases is projected to rise by nearly one fifth, to around 42,100 new cases per year in 2040.<sup>12</sup> This would continue the longterm trend of an increasing number of cancer diagnoses over time.

#### 3.1 Our Strategic Priorities

Our strategy will strengthen core elements of the cancer pathway while focussing on cross-cutting issues that will enable success. It will reflect valuebased and Realistic Medicine, putting the person affected by cancer at the heart of our approach.

We aim to reduce inequalities across all our ambitions, strive for consistency through a Once for Scotland approach where appropriate, and ensure services are sustainable (in programmes, environmentally, and in resourcing).

The strategy aims to anticipate and reflect the changes over the next 10 years expected in cancer incidence, most common types, treatment options including more precision medicine (where treatment reflects people's genes), and how our health systems diagnose and treat cancer.

We will focus on cancer types that are the largest burden and have worse outcomes. These include lung and other less-survivable cancers (brain, liver, oesophagus, pancreas, stomach) that have seen very little progress in the last five decades. Lung cancer remains Scotland's single biggest cause of cancer mortality and continued focus and action to address this are paramount.

#### A focus on lung cancer

Lung cancer is the single biggest cause of cancer mortality in Scotland and will require the focus applied to it in the National Cancer Plan 2020 to continue with vigour in the long term. Improved survival will require leadership, prioritisation, resourcing and strong action. The required actions will be set out in each action plan accompanying this strategy and include preventative measures such as smoking cessation services and robust tobacco control: earlier and faster diagnosis, including targeted screening and delivering Scotland's optimal diagnostic pathway; access to specialist treatment; and ongoing research, investment in innovation and further data and intelligence gathering.

continued

#### 3.2 Our Strategic Aims

To meet our strategic aim of improved cancer survival and providing excellent, equitably accessible care, we have set out eleven ambitions addressing both crosscutting and cancer pathway priorities, describing our 10-year vision for each. Our eleven priority ambitions are presented without hierarchy:

#### Pathway

- 1. Preventing More Cancers
- 2. Earlier and Faster Diagnosis
- 3. Best Preparation for Treatment
- 4. Safe, Realistic and Effective Treatment
- 5. Excellent Care and Support after Treatment

#### **Cross-cutting**

- 6. Sustainable and Skilled Workforce
- 7. Person-Centred Care for All
- 8. Tackling Inequalities
- 9. Mental Health as part of Basic Care
- 10. Flourishing Research and Innovation
- 11. Cancer Information and Intelligence-led Services



continued

These ambitions relate to our vision and intended outcomes as follows (recognising that the relationship amongst the elements is far more complex than can be displayed in a diagram and that a number of elements are interconnected):



continued

In addition to an ambition on Cancer Information and Intelligence-led Services, under every other ambition we have included a box on 'Data for Success'. These are not intended to be comprehensive but to highlight the importance of data in determining priorities and in monitoring the implementation and outcomes of our ambitions and actions, including where we would like to do more such as addressing inequalities.

continued

## 3.3 Our Strategic Ambitions



Ambition 1: Preventing More Cancers Our 10-year vision

Scotland is a place where the new generation of young people do not want to smoke. It is a place where everyone eats well and has a healthy weight, underpinned by a population that is more physically active. Alcohol is no longer a major cause of cancer. The incidence of preventable cancers, such as cervical cancer, is reduced.

#### This means that:

- We live in a Tobacco-Free Scotland, reducing smoking rates to below 5% by 2034
- We live in a Scotland where more people are more active more often, in line with our

Active Scotland Outcomes Framework

- Diet-related health inequalities are significantly reduced, supported by the actions in our 2018 Diet and Healthy Weight Delivery Plan, including legislation to restrict promotions of less healthy food and drink at the point of sale
- People have better informed health-seeking behaviour (know how, when and where to seek help)
- High HPV vaccination coverage is maintained for girls and boys.

continued

Successful implementation of evidencebased prevention strategies targeted at harmful health behaviours could prevent approximately 40% of cancers. Based on these estimates, around 13,000 Scotland cancer cases could be prevented each year.<sup>13</sup>

- Smoking is the most significant cause of preventable cancer in Scotland (18%).<sup>14</sup>
- Obesity is linked to around 2,200 cases of cancer a year in Scotland. Maintaining a healthy weight reduces the risk of 13 types of cancer, including breast, bowel and liver.<sup>15</sup>
- Physical activity is beneficial for the prevention of some cancers including breast, colon, endometrial, kidney, bladder, oesophageal, and stomach.
   Decreasing time spent sedentary may also lower the risk of endometrial, colon, and lung cancers. Physical activity before and after a diagnosis of breast, colorectal and prostate cancer is beneficial for survival outcomes.<sup>16</sup>
- There is a clear relationship between alcohol consumption and increased risk of developing certain cancers: in 2015, approximately 6.5% of deaths were attributable to alcohol consumption: 28% of these were from cancer.<sup>17</sup>
- There is strong evidence that physical activity before, during and after cancer treatment can reduce anxiety, depressive symptoms and fatigue, and improve health-related quality of life and physical function.

Reducing these risks, and their contribution to inequalities in cancer incidence, is being addressed through strategies and plans such as the **Tobacco Control Action Plan (2018).** (with a new one due to be published in 2023), the Diet and Healthy Weight Delivery Plan (2018) including support for families to make healthier choices: the **Active Scotland Delivery Plan** that supports work to reduce the risk of cancer and contributes to prehabilitation and rehabilitation; and the **Alcohol** Framework 2018 that guides actions to reduce alcohol consumption, including increasing awareness of the link between alcohol and cancer.

Skin cancer is one of the most common cancers in the world. Excluding nonmelanoma skin cancers (which are more common), malignant melanoma is the 5th most common cancer in Scotland with increasing rates, particularly in males.<sup>18</sup> Exposure to ultraviolet light from the sun is thought to cause most melanomas and non-melanoma skin cancer.<sup>19</sup> Prevention is through reducing exposure to ultraviolet light from the sun, artificial tanning sunbeds and sunlamps.

continued

Primary cancer-specific prevention strategies include human papilloma virus (HPV) vaccination. HPV vaccination policy is based on recommendations from the Joint Committee on Vaccination and Immunisation (JCVI) and is being offered in Scotland to all girls and boys in the first year of secondary school. Evidence from England is that the vaccine reduces cervical cancer incidence by almost 90% in those who were vaccinated aged 12 to 13.20 In Scotland, this equates to the prevention of around 450 cervical cancers and around 17,200 cases of precancerous conditions over an 11-year period.<sup>21</sup>

Secondary prevention of cancer means the early detection and treatment of disease before signs and symptoms are apparent – <u>see also 'Optimise Screening'</u> <u>under Earlier and Faster Diagnosis</u> <u>Ambition</u>.

#### **Data for success**

We will interpret health behaviour surveys and use data to better understand public health interventions that are likely to reduce cancer risks.



#### Ambition 2: Earlier And Faster Diagnosis Our 10-year vision

Later stage disease (stages III and IV) has reduced by 18 percentage points. A focus will remain on reducing the health inequality gap, particularly those from areas of deprivation.

Beyond preventing cancers, earlier and faster diagnosis plays the most fundamental role in cancer control. It is vital to further improve cancer survival rates in Scotland which, despite progress in the last 10 years, continue to lag behind international counterparts. This is particularly important for less survivable cancers. Those from areas of deprivation are often more likely to be diagnosed with cancer, particularly at a later stage, and are less likely to take part in screening when invited.

Currently around 42% of cancers are diagnosed at stage III and IV in Scotland, with variation amongst cancer types and socioeconomic groups.<sup>22</sup> Realising our vision would mean that 24% of cancers were diagnosed at stage III and IV in year 10. Based on the latest data available at the time of publication, this would mean around 5000 fewer people in Scotland diagnosed with later stage disease in year 10.

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.

There are challenges in meeting the two current cancer waiting times (CWT) standards in NHS Scotland. Latest published data (Q4 2022) show that 72% of people with cancer received first treatment within 62 days of an urgent suspicion of cancer (USC) referral, and 94% received first treatment within 31 days of a decision to treat being made.

We are now treating 36% more on the 62-day pathway than 10 years ago

continued

(4262 in Q4 2022 compared to 3144 in Q4 2012), and 18% more on the 31-day pathway (6757 in Q4 2022 compared to 5711 in Q4 2012). Embedding all eight key principles of the Effective Cancer Management: Framework (2021) will remain a priority for health boards' cancer management teams to diagnose cancer earlier and faster – improving waiting times performance, experience and outcomes for people with cancer.

Our response to the challenge of diagnosing cancer earlier and faster will require action in a range of areas through our national whole systems Detect Cancer Earlier (DCE) Programme, including:

#### Improve Public Education and

**Empowerment:** Raise awareness of possible signs, symptoms and risk factors of cancer – tumour site and non-specific – to empower people to seek help in a timely manner. Break down engrained behaviours and attitudes including fear of cancer that can often act as a barrier to earlier diagnosis, with a focus on reducing the health inequality gap.

**Support primary care:** Primary care plays a pivotal role in the diagnosis of cancer. The vast majority of people with cancer will develop symptoms prior to diagnosis so it is imperative to continue to support primary care clinicians in identifying and appropriately referring those with a suspicion of cancer. That support must highlight the role of socio-economic and health inequalities in cancer and the implications of unmet need in relation to earlier diagnosis. Primary care has unique capacity to deliver prevention and early intervention. For example, many recommendations in the **Primary**  Care Health Inequalities Short-Life Working Group: report (2022) should contribute to earlier and faster diagnosis for those at greatest need, especially by addressing unmet need and earlier, increased engagement with primary care by individuals who otherwise might not seek care and support.

**Optimise Screening:** Screening will continue to keep up with technological innovation and emerging clinical evidence to ensure the people of Scotland have access to the most effective screening tools possible, including taking forward recommendations from the UK National Screening Committee on targeted lung screening and exploring the use of selfsampling for cervical screening. It will be a responsive, person-centred system that facilitates equality of access and encourages uptake in all groups. To direct and support this work the first Equity in Screening Strategy has been produced by National Screening Oversight in collaboration with NHS and Third Sector partners and sets out a vision to achieve equity for all those eligible for screening. A whole system approach will be taken to ensure that reducing inequalities is recognised by all as a priority. Outcomes will include increased awareness and understanding of screening programmes. with targeted information for underserved groups. Health professionals across the screening programme will have a greater understanding of the reasons for inequalities in the system and effective ways to address them. A strategic approach will be taken to identify, address, and remove barriers to participants across the entire screening pathway. Data collection and

continued

presentation around inequalities will be improved, for example through the development of a Screening Intelligence Platform, to help target evidence-based interventions. Robust evaluation of actions will be undertaken to facilitate scaling up of effective interventions.

**Enhance Diagnostics:** The early diagnosis or exclusion of cancer is essential to reduce anxiety for people with cancer and their families as well as to guide clinical care. This requires timely access to the most appropriate and effective diagnostic tests, both in primary and secondary care. Further innovation and redesign of diagnostic services including diagnostic imaging, endoscopy, PET-CT and pathology will be required to facilitate timely access to tests as well as introducing new, effective diagnostic tests as they emerge. Oversight and governance are undergoing redesign with the planned launch of a Diagnostic Strategic Network, which will provide the strategic direction to ensure diagnostic services are equipped to support the recovery efforts and personcentred, sustainable and innovative future delivery. Ongoing delivery of the Endoscopy and Urology Diagnostic Recovery and Renewal Plan (2022) remains a priority.

Harness Data: Continuous improvement in the provision of timely, high-quality, transparent, and integrated data will enable an improved understanding of barriers to earlier diagnosis and variation (geographical, socio-economic, ethnicity and other equalities data). This includes having more timely staging data available for all stageable cancer types. **Invest in Innovation:** Research and innovation have a key role to play in improving earlier diagnosis rates, such as biomarkers (including volatiles), artificial intelligence and multi-cancer early detection tests (MCEDs). Identifying promising research and developing a pipeline that enables innovations to be brought into NHS Scotland, to help diagnose cancer earlier and faster, will ensure improvements can be rolled out and embedded at pace. This will be supported by Chief Scientist Office and the SHIP, including the Scottish Cancer Consortium and the ANIA Pathway. and will require coordination across multiple partners, including industry and academia.

#### **Data for success**

We will measure progress through a number of sources, ensuring the inequality gap is narrowed throughout, including:

- Number of cancers diagnosed through unwarranted emergency presentations
- Cancer waiting times publications
- Independent qualitative data and insight to monitor public understanding of possible signs and symptoms of cancer
- Breakdown by <u>Scottish Index of</u> <u>Multiple Derivation (SIMD)</u> where possible

continued

# "

#### The importance of a Rapid Diagnosis

An interim evaluation of the Rapid Dagnostic Service carried out by the University of Strathclyde found that the one-to-one contact with dedicated healthcare staff and the timeliness of cancer or non-cancer diagnosis are particularly valued. In consequence, overall patient satisfaction with the new service is high. Patient safety and clinical effectiveness (not least in terms of cancers detected) appears to be good.

#### As a user of the service **<u>said</u>**:

"It was like a whirlwind, not of destruction/confusion, but reassurance and comfort. Everything happened quickly, in a very organised way, giving me confidence that the people who would be caring for me knew what they were doing and would be there for me."



# Strategy Ambitions continued



Ambition 3: Best Preparation For Treatment ("Pre-Treatment") Our 10-year vision

Every person diagnosed with cancer in Scotland is provided with timely, effective and individualised care to best prepare them for treatment. This begins with prehabilitation and holistic needs assessment, and continues throughout the individual's pathway of care, including appropriate follow up. A comprehensive range of cancer genomic tests is available to all those who could benefit.

Pre-treatment encompasses the stage between the point of diagnosis and the initiation of treatment. Additional information and support from the point of suspicion of cancer can improve overall experience, reduce anxiety and, in some instances, positively impact overall outcomes. Shared decision making, holistic needs assessments, information provision and signposting should be considered from the earliest point.

Collaborative working across health, care and third sectors enables early identification and access to the care and support that suits an individual's needs at the time that is right for them. Our partnership with Macmillan, and "Improving the Cancer Journey" will continue over the next 10 years to achieve future sustainability within the Health and Social Care Partnerships and Local Authorities. This programme alongside other initiatives like the Single Point of Contact optimise collaborative working. We will work with the Scottish Cancer Coalition and other relevant partners to ensure an accessible directory of support services is available for everyone affected by cancer in Scotland.

continued

Prehabilitation prepares people for cancer treatment and includes exercise. nutrition, psychological support, and assistance with alcohol and tobacco reduction/avoidance. It aims to improve quality of life, maximise treatment rates and minimise side effects of treatment. It should be delivered as outlined in the Key Principles – Prehabilitation for Scotland. Holistic needs assessments should be used to identify the concerns that a person with cancer has and to understand their needs. This should inform the development of a personalised care and support plan. that addresses current needs and is anticipatory for the future. That will ensure the right information is shared at the right time, and that people with cancer are signposted to relevant services.

Advances in genomic medicine should also be used to help clinicians deliver precision medicine and ensure that people with cancer receive the most appropriate treatment and avoid unnecessary side-effects. The Scottish Genomic Test Directories already include a range of genetic tests for cancer treatments, with further development of these directories anticipated in the coming years.

#### **Data for success**

We will use qualitative and quantitative data to measure experiential, clinical and system-level outcomes.

We will map prehabilitation programmes and develop a minimum dataset.

We will monitor the uptake of the Improving the Cancer Journey initiative and the number of holistic needs assessments conducted.

continued



#### The Value of Prehabilitation (Prehab)

Having never been to Maggie's before, Ian was referred by his oncologist before starting his treatment for oesophageal cancer. At that time, he felt a bit anxious and in limbo with regards to treatment, as surgery depended on chemotherapy working well. However, he was glad to receive reliable information about his role in recovery and improving treatment outcomes. As a result, Ian felt more confident managing his physical health, emotional wellbeing, and diet and nutrition. He also found it comforting to hear about another person's experience – including the ups and downs – of treatment for oesophageal cancer.

Since the prehab workshop, Ian has been back to Maggie's on multiple occasions, as have several family members who wanted to provide support to Ian and access support...

... for themselves. As Ian is now approaching his surgery, he revisits the information and techniques he's learned.

"You think, you know, I'm going for an operation here, what do I need to look at specifically for my operation? I need to keep my fitness up. I need my mindset right."

Of Prehab at Maggie's, he says: "... It's quite strange how well Prehab fits with Maggie's... if you look at the main aspects that come out of the Prehab course in particular, every single one of your learning outcomes is something that's taught, or supported, or part of the main Maggie's ethos, in a way. It's in your curriculum. It's naturally there."


# Strategy Ambitions continued



Ambition 4: Safe, Realistic And Effective Treatment Our 10-year vision

All people with cancer have equitable access to treatments, with minimal variation in care. Where someone's cancer can potentially be cured, they have access to the best available treatment to achieve this. Pathways benefit from new technologies and tests allowing earlier treatment and leading to better outcomes. The Scottish Cancer Network is at the centre of this work, developing national clinical management pathways for all people with cancer.

Safe and effective treatments are critical to improving outcomes for each person with cancer and improving overall quality of life. Cancer care encompasses various treatment methods, broadly surgery, radiotherapy and systemic anticancer treatment (SACT) – dependent on an individual's precise diagnosis. The management of an individual's cancer may not involve any of these treatments, where that has been decided between the individual and their clinical team.

Surgery remains the single most effective treatment for solid tumour

cancers. People requiring cancer surgery are increasingly benefiting from treatment in specialist centres, by teams who frequently perform a particularly complex operation and gain experience and expertise in doing so. We require service providers to collaborate and integrate regionally and nationally to ensure we maximise the potential for the most skilled and knowledgeable surgeons. Evidence shows this approach leads to better clinical outcomes for people with cancer, as well as fewer complications and less time in hospital. People with cancer requiring complex operations are usually very receptive

continued

to being treated by highly specialist teams, even where it involves increased travel, but it is crucial that they are appropriately supported in doing so (practically, financially and emotionally as required). Robotic assisted surgery makes significantly smaller incisions than required for traditional surgery. reducing the risk of complications. shortening recovery times and allowing hospitals to treat more patients. This will become routinely available for a wider range of operations throughout Scotland, facilitated by greater integration of services and regional working.

Radiotherapy is received by 40% of all people with cancer who are cured.<sup>23</sup> The National Radiotherapy Plan (2022) outlines 13 kev actions to ensure that Scotland continues to have a world-class radiotherapy service. We will continue to roll out advanced treatment, including Stereotactic Ablative Radiotherapy (SABR) to those who would benefit, maximise the potential of Artificial Intelligence (AI) to support treatment planning, and agree national protocols and approaches to hypofractionation. We will continue to assess current evidence on the use of photons and proton beams and develop a longterm view of patient access to proton therapy.

SACT encompasses the treatment of cancer with chemotherapy and immunotherapy drugs. Both have the potential to cure some cancers (and can be used in combination with surgery and radiotherapy to improve outcomes) as well as providing disease and symptom control and extension of survival. Cancer medicines account for the highest proportion of new medicines introduced within NHS Scotland each year, with a fast rate of growth in their availability, a high risk of side effects and associated high costs. The pressure on SACT services to deliver these new medicines continues to increase. The number of patients receiving SACT has seen a steady increase over the last few years. In comparison, the increase in patient appointments has seen an even sharper increase over the same time period.<sup>24</sup>

The Scottish Medicines Consortium

(SMC) is the national source of advice on the clinical and cost-effectiveness of all newly licensed medicines for NHS Scotland. The National Cancer Medicines Advisory Group (NCMAG) was established to improve equity of access to safe and effective off-label and off-patent uses of cancer medicines (i.e. used outwith their licence) through provision of national advice for cancer medicines not covered by the remit of the SMC. The work of NCMAG will continue, alongside the SMC, to improve medicines access. Alongside this there will be a renewed focus on SACT services to support sustainable delivery with appropriately increased resource. Allied to SACT delivery, and in order to maximise the opportunities of precision medicine, we aim to offer comprehensive genomic tests to appropriate people with cancer at an earlier stage in their clinical pathway.

The Cancer Medicines Outcome Programme (CMOP) helps assess the ongoing safety, effectiveness and value of cancer medicines (including off-label)

continued

in Scotland. Alignment of CMOP with the Scottish Medicines Consortium, National Cancer Medicines Advisory Group and the Scottish Cancer Network will ensure national cancer medicines intelligence informs clinical practice and enhances person-centred care.

There will be an ongoing need for services for people with cancer who develop an acute cancer-related illness presenting in an emergency setting or acute complications from ongoing treatments. The <u>Acute Oncology Service</u> (AOS) in NHS Scotland: Principles (2022) document will guide the development of new models to provide people with cancer requiring emergency care a direct route to cancer services.

Underpinning all cancer treatment is patient safety. All services in the NHS will be delivered in ways that take into account the <u>Scottish Patient Safety</u> <u>Programme</u> and meet the obligations set out under legislation, such as the <u>Patient</u> <u>Rights (Scotland) Act 2011 (legislation.</u> <u>gov.uk)</u> organisational duty of candour.

#### **Data for success**

We will continue to measure the number of patients receiving SACT and radiotherapy to monitor workloads, demands and requirements.

We will better measure cancer surgery workload.

We will measure outcomes through patient experience and outcome surveys as well as through the CMOP.

We will better monitor the introduction of new cancer medicines and their impact on the health service to help guide the introduction of new medicines.

We will disaggregate data as much as possible by ethnicity and equality characteristics.

# Strategy Ambitions continued



Ambition 5: Excellent Care And Support After Treatment Our 10-year vision

Personalised support and care post-treatment are core considerations in cancer management pathways: this includes rehabilitation, early detection of recurrence, and supportive and palliative care. People affected by cancer are informed and supported to adequately manage side effects of treatment with the appropriate tools, including an electronic treatment summary.

All individuals requiring rehabilitation have access to meaningful, person-centred rehabilitation that will support them to live well and support a good quality of life, regardless of their stage on the cancer pathway. Follow-up is standardised in the SCN's clinical management pathwavs. is evidence-based for each cancer type and individual (including secondary cancers) and covers patient-initiated requests for review. Every person with cancer in Scotland requiring palliative care receives wellcoordinated, timely and highquality care, including care around death. Bereavement support is provided for families and carers based on their needs and preferences.

continued

Treatment, even with curative intent, is not always the end of care. Some people may need continued support by the NHS and others, including the third sector, to maximise their quality of life. More people are living with cancer, and treatment can cause anticipated side effects and complications that have a significant impact. Supported selfmanagement, rehabilitation, palliative and supportive care are therefore essential, along with consistent approaches to follow up, in line with individuals' clinical needs.

Good rehabilitation is part of the whole cancer pathway to support individuals to recover or adjust so that they achieve their full potential to live well with cancer. The Once for Scotland Rehabilitation Approach (2022) provides a framework for good rehabilitation that puts the individual at the centre and builds on the concept of Realistic Medicine to provide a personalised approach that is outcomes-focused and supported by a shared decision making process. Rehabilitation includes activities, interventions and information resources that support self-management and facilitate access to services that address growing or complex needs, from as early as possible through to after treatment. Rehabilitation has the potential to maximise quality and quantity of life whilst reducing disease burden.

Palliative care, care around death, bereavement care, and support for carers are integral parts of the cancer journey experienced by people and their families. Palliative care includes anticipatory care planning, early supportive and palliative care in parallel with cancer treatment, symptom management, and specialist palliative care. Palliative care is integrated across health boards, Health and Social Care Partnerships and the third sector, involving primary care, hospitals, hospice care, social care and family support. Our vision for palliative care will be reflected in a new Palliative and End of Life Care Strategy.

The importance of spiritual care and the role of spirituality for health and wellbeing is becoming better understood. Spiritual wellbeing enhances and integrates all other dimensions of health, including physical, mental, emotional and social.

A Cancer Treatment Summary is a document produced by secondary cancer care professionals in collaboration with a person with cancer, for them and their GP practice. It provides information including possible treatment toxicities, side effects and consequences of treatment. signs and symptoms of a recurrence, and any actions for primary care. By co-producing and keeping a copy, the summary is also designed to support patient self-management, guide decision making, improve a sense of control, and reduce anxiety that can be particularly associated with end of treatment.

Collaborative working across health, care and the third sector can enable early identification and access to the care and support that suits an individual's needs at the time that is right for them. Cancer Patient Experience Surveys (CPES) carried out

continued

in Scotland indicate that this process is not universally experienced, and many feel inadequately supported following treatment. We will optimise collaborative working, meet holistic needs and improve quality of life by embedding rehabilitation and treatment summaries in cancer pathways, regularly re-assessing needs and sharing proactive care planning.

#### **Data for success**

We will measure accessibility to a broad range of tailored rehabilitation services that are outcomes-focused and centre on the individual.

We will explore how best to measure quality of palliative care in cancer using validated outcome measures for service providers, patients and carers such as the <u>Resolve</u> toolkit, and the <u>Carer Support Needs Assessment Tool</u> <u>Intervention</u>.

# "

#### Steven's\* Story about Palliative Care

"Marie\* had the back pain for months until she fell and ended up in hospital. That's when they found out it was breast cancer and it had gone to her bones and her liver too. Marie was 42 and Tom\* just 10. But the tests were done fast, and we got an urgent appointment with the cancer specialist. The ward staff tried hard to control the pain but Marie got worse and confused too. They sent for the palliative care team which scared us, but the doctor explained that they work with other teams to help people like us and they did. New pain killers and letting us talk – about the medicines, the cancer, and everything else.

For two years, Marie did well with the different cancer treatments, got back to work and was her usual self. Then the cancer took off again. First in the lungs and then her brain. The cancer doctors did all they could. It was our district nurse who talked about hoping for the best but thinking about what would matter if Marie got worse. So hard for us to tell Tom, but his head teacher helped. The palliative care nurses worked with our GP to get on top of the breathlessness and headaches. Marie enjoyed the day hospice, and it gave me a break. We did struggle with making plans when we didn't know exactly what would happen or when, but it was worth it.

We had to go to the hospital once when Marie had a bad chest infection, and she got better. The palliative care team visited, and everyone worked hard to get us home. Marie's sister came, friends helped, and we had the nurses, home carers, and the GP too. It wasn't easy but we managed, and it was the right place for us. Tom is doing ok. I have friends I can talk to, and my boss has been great."

\*not their real names

# Strategy Ambitions continued



Ambition 6: Sustainable And Skilled Workforce Our 10-year vision

A sustainable, skilled workforce with attractive career choices and fair work, where all are respected, supported and valued, whether they work wholly or partly in cancer services.



continued

Our strategy aligns with the Health and Social Care: National Workforce Strategy (2022). Our workforce is central to implementing our vision and delivering a whole system approach to improving health and wellbeing outcomes. At every stage of the journey to improve cancer survival, we need appropriately skilled and supported health and social care staff.

Strengthening our workforce means addressing the workforce journey through five pillars: plan, attract, employ, train and nurture.

The cancer workforce comprises a wide range of healthcare professionals, some of whom are cancer specialists and some for whom cancer is a component of their job. The NHS workforce has faced significant pressures and sustained actions are required – from planning for and attracting into the workforce, through to support and development of staff, including their mental health and wellbeing. We will model cancer workforce requirements taking account of where and how people with cancer most often use services. including primary care, and how these change as service delivery evolves. We will continue to grow the number of training places to expand the workforce we need for our strategic ambitions. Trainee places will be located in line with greatest need and to ensure that career opportunities within Scotland are offered to those qualifying here.

Alongside this growth, it will be vital to make fundamental changes to how our workforce is best deployed, ensuring that all professionals are doing the work they are best placed to do while recognising some tasks may be undertaken more appropriately by others. Technological advances and digital solutions will change how our workforce operates and how people with cancer access services, for example, increased use of telemedicine (clinical care provided remotely).

It will be crucial to maximise the retention of our workforce, providing support for mental health and wellbeing, providing flexibility in roles as individuals approach retirement, and increasingly collaborating and integrating roles across departmental or Board boundaries. Job plans require capacity within them for continual professional development, research (where relevant), and governance.

#### **Data for success**

We will need granular cancer workforce data to be able to complete a workforce review in oncology. We also need an understanding of where people with cancer meet the health system and how this may evolve in order to develop workforce requirements.

We will model training and staffing requirements and measure retention and retirement data.

continued



Ambition 7: Person-Centred Care For All

Our 10-year vision

People with cancer are at the heart of all decisions and actions involving them. They are given the opportunity to co-design their own care plan, and information including a treatment summary is readily available. A single point of contact (SPOC) is at the centre of this. Where possible, diagnostic tests and treatment are situated close to home and travel to specialist care is fully supported, making use of the continued advancement in new technologies.

Value-based health care and Realistic Medicine mean outcomes are delivered through shared decision making and discussion about the potential benefits and harms of different treatment options, including the option to do nothing. This approach allows people to make an informed choice, as well as reducing waste and potential harm. Shared decision making and informed consent are fundamental to good practice: involving people in decisions about their care strengthens their ability to self-manage. In addition, evidence

shows that they value their care more and experience less regret.

People with cancer have a potentially life-changing diagnosis and immediately become 'patients' that are served by a health system. The system and its staff need to treat and care for the individual person rather than the 'patient' or 'tumour', recognising each one's preferences and needs. There are four principles underpinning person-centred care that should be central to all cancer services:

continued



- **Dignity, compassion and respect** ensuring all interactions are founded on kindness and our shared humanity.
- Personalised
  - carefully listening to the things that matter most to people
  - setting personal goals about treatment, care and daily life
  - identifying personalised action or activities to help achieve personal goals.
- Enabling
  - providing information in a way that is meaningful and easy to understand
  - supporting people to make the right decisions based on the things that matter most to them
  - supporting people to undertake activities and actions to help them achieve their goals helping people to live well on their own terms.

#### • Coordinated

- supports people to get support and treatment in a timely manner
- enables collaboration between services and professionals
- creates opportunities to combine interactions, for example through co-location.

A single point of contact (SPOC) has the potential to improve access to care and timely reporting of results; ease navigation through care pathways; improve communication and experience, shared decision making and patient-reported outcomes; and positively impact our workforce by releasing capacity to provide more proactive and expert care.

Getting It Right for Everyone (GIRFE) reflects similar values, providing a more personalised way to access help and support with a joined-up, coherent and consistent multi-agency approach. This will be a practice model across acute, community and social services going forward.

continued

#### **Data for success**

We will need to develop a concise framework that outlines the key structures and processes that support a person-centred approach. We will develop metrics that measure processes such as shared decision making, and whether a 'good' personal outcome was achieved throughout the cancer journey, including supportive and palliative care.

We will continue to use PROMs and will also use the person-centred measurement framework using quantitative and qualitative data to better understand quality of care from the perspective of the person with cancer and their family.

We will monitor the availability of a single point of contact and measure the optimal model of delivery to inform future practice.

# "

### The Importance of a Single Point of Contact

A person affected by cancer <u>shared their experience</u> anonymously via Care Option. They highlighted the need for a single point of contact and the impact it could have:

"I was expecting to receive an appointment for a routine CT scan, before my next oncology appointment. Waiting for appointments to come through the post is on my mind for weeks around the appointment time, as I never quite know when to expect the letter or when the appointment will be. Knowing that a scan is imminent also brings to mind the what if questions, such as what if something shows up this time and the cancer is active again? So it's an anxious time...

... I had to make 5 calls to 'strangers' to finally understand why I didn't have an appointment for my CT scan. I had to be on the ball and assertive. That's a big ask for many patients who may be too ill, or lack confidence to ask for what they need. It took 2 weeks to get a resolution. That's two weeks of worry and frustration for me, and 5 calls the NHS had to manage.

We need the Single Point of Contact to be rolled out to all cancer patients. How much nicer it would be to call one person, who might even be friendly and helpful, and be able to trust that they will look into the matter and update me. What a relief!"



continued



Ambition 8: Tackling Inequalities
Our 10-year vision

A reduction in inequality in cancer incidence, access to services, experience and outcomes.

'Inequalities' denotes differences between groups and 'inequities' denotes unjust differences between groups. Inequalities disadvantage people and limit their chance to live longer, healthier lives.<sup>25</sup> If services are not provided equitably (process) then inequalities will remain (outcome). Some inequalities in cancer are more associated with specific factors (such as poorer survival in the elderly compared to vounger people with cancer) whereas others are more systemic. For example, there is approximately 20% poorer uptake of cancer screening in the most deprived areas compared to the least deprived: those living in the most deprived areas are three times more likely to develop lung cancer: cancerrelated deaths are 74% higher in the most deprived population than the least deprived.26

Both specific and systemic aspects need to be addressed.

Additional factors such as sex, age and ethnicity can influence cancer risk, access to services and outcomes, and the relationship amongst them is complex. Reducing inequalities means applying a broad, societal approach as well as targeting specific actions to disadvantaged groups along the cancer pathway. <u>Best Start, Bright</u> <u>Futures (2022)</u> aims to reduce health inequalities in the long-term by reducing child poverty now.

Scotland's geography means there are particular challenges in providing equity of access to some rural and island communities. Improving the accessibility of services through the location of services and use of digital technology,

continued

providing transport, maintaining support structures, ensuring affordability and increased focus on cultural competence of services are all measures likely to reduce inequalities. Speciality outreach services can improve access and selfreported health.<sup>27</sup>

We will reduce inequities in access. experience and outcomes for individuals and groups experiencing socio-economic inequalities, racism and discrimination. We will do so by improving the way we collect and use data and evidence to monitor equity of access, experience and outcomes for marginalised and minoritised groups, and targeting action where it is needed most. In line with our commitments under the **Race** Equality Framework and Action Plan (2016-2030), the Expert Reference Group on Covid-19 and Ethnicity, and the **Women's Health Plan**, we will have a specific, early focus on improving outcomes for minority ethnic groups, women and people living in the most deprived areas of Scotland.

We will promote healthy living by reducing alcohol, tobacco and drug use while encouraging active and healthy living, which will reduce the risk of developing cancer and enhance treatment outcomes and survival, in those at highest risk (see Preventing More Cancers).

#### We will improve inclusive

communication and outreach to people who may not access screening although they wish to. Targeted screening (for example, for lung cancer as recommended by the National Screening Committee in September 2022) and new methodologies (such as cervical smear self-sampling) will be explored, to help reduce the screening inequalities gap (see Earlier and Faster Diagnosis). Inequalities funding has been used to develop an intelligence platform bringing together data from each screening programme to help identify common trends and identify inequality. This work will be continued to help develop processes to reach people currently excluded, by identifying and removing barriers.

Disparities in access to diagnostic and treatment services will be improved using new technology that facilitates alternative siting of services and remote consultations (see Flourishing Research and Innovation). We will make sure that efforts to add more digital elements into the health system are proportionate to ensure that nobody is left behind, while meeting the expectations of those who want to interact in this way. People with cancer will not be disadvantaged by the cost of travel or loss of paid working days.

Primary care, and especially general practice, has unique capacity and coverage in our communities to address entrenched health inequalities, and we aim to maximise its potential. Good quality prevention and early intervention in primary care are key to reducing preventable ill health, including cancer.

There will be more equal access to anticipatory care planning, palliative care, care around death and bereavement support. We will improve access to research and clinical trials

continued

for minority ethnic people and those that are currently underrepresented in clinical trials.

By practising Realistic Medicine, NHS Scotland can ensure we deliver the right care in the right place, reduce waste and harm, and redirect resources to where they will add the most benefit. We will promote equity of access to care and utilise a whole system approach that puts people's needs at its heart. This is a vital step in reducing health inequalities.

#### **Data for success**

We will strengthen our ability to more closely monitor and to take action to address inequalities along the full cancer pathway.

We will better identify, monitor and address the healthcare needs, experiences, access and outcomes for marginalised and minority groups.



Ambition 9: Mental Health As Part Of Basic Care Our 10-year vision

Dependent on need, proactive and comprehensive psychological and mental health interventions and support are available and accessible, from those trained at informed to specialist practice types, to all people affected by cancer and their families.

People recently diagnosed with cancer, those receiving treatment, those who have completed treatment, those receiving palliative care and those who are caring for people with cancer all report that the emotional aspects of cancer can be some of the most challenging. The post-treatment phase can be a particularly volatile time for mental wellbeing, and in almost half of all cancer cases, emotional effects are cited as more difficult to cope with than physical and practical effects.<sup>28</sup>

People affected by cancer can be better equipped emotionally and psychologically to face the challenges that lie ahead with the right

psychological and spiritual support in the right place, by the right person, at the right time. The psychological and spiritual needs of the individual vary by personal circumstances and characteristics as well as cancer type and how they present. Access should be equitable regardless of geographical or socio-economic factors, ethnicity, gender, disability or other equality characteristic. By delivering personcentred care and psychologically focused care, we can empower people with cancer and potentially reduce the sense of loss of control that is commonly associated with cancer and its treatment.

continued

#### The <u>Psychological Therapies and</u> <u>Support Framework for People affected</u>

by Cancer provides service providers across Scotland with guidance to enable equitable and efficient access to psychological support, and a mechanism to monitor success and challenges at local, regional and national levels. A new Mental Health and Wellbeing Strategy for Scotland and a new National Specification for Psychological Therapies and Interventions will be published in 2023, which will recognise the mental health impacts on people of all ages affected by long term conditions including cancer. These tools should be embedded in all cancer care.

#### **Data for success**

We will measure and monitor mental health in established cancer care pathways.

We will measure mental health through qualitative experiential data.

We will identify waiting times for psychological care through the psychological therapies national waiting times standard and use indicators from the new National Specification for Psychological Therapies and Interventions once published.



Ambition 10: Flourishing Research And Innovation Our 10-year vision

Equitable access to clinical trials has become integral to the management of treatment options. Where relevant, health professionals have allocated research time, adequate laboratory support, and are working in partnership across academia, industry and the third sector. Qualitative and non-RCT research are providing relevant, quality evidence to inform best care. Routine cancer data are available to support this.

More complex molecular tests ensure people with cancer have access to a portfolio of precision oncology and clinical research. Laboratories have capacity to support research, including clinical trials.

New technologies are being used to strengthen the full cancer patient pathway, with alternative methods for consultations and information-sharing leading to greater choice and convenience for people with cancer. The application of artificial intelligence (AI) has grown. Multidisciplinary networks are making the best use of scientific and clinical expertise to translate innovation into clinical practice. Health boards make robust, evidence-based decisions based on Scottish Health Technologies Group (SHTG) advice, leading to improved outcomes and more efficient use of resources.

continued

Research and innovation are a core part of the NHS. They play a key role in improving earlier diagnosis rates (see Earlier and Faster Diagnosis), enabling people with cancer to access new treatments at an earlier stage and influencing health planning and policy. Public Health Scotland (PHS) facilitates research studies through centres and the electronic Data Research and Innovation Service (eDRIS). Strong links between research in cancer and related fields such as primary care, mental health and palliative care are important, including qualitative and non-RCT research.

We live in a time of extraordinary innovation in technology that provides opportunities to diagnose and treat people with cancer. These range from the genomics revolution in diagnostics and treatment, to advances in the use of AI, 5G, Internet of Things in healthcare through to the apps, tools and products that we now use in our everyday lives. Recent health service examples include the use of video appointments such as **Near Me** and the use of drones in supply chains.<sup>29</sup> In March 2022, we reached 1.5 million Near Me appointments across Scotland, saving an estimated 49 million travel miles for patient, families and staff.

Our approach to digital health will be guided by the <u>Digital Healthcare</u> <u>Strategy (2021)</u>. The Digital Front Door work will be a key development for people interacting with health and social care services in Scotland.

The SHIP aims to strengthen Scotland's innovation activities in health and social care with a focus on early-stage innovation. The CfSD's ANIA Pathway aims to fast-track proven innovations into the healthcare frontline on a Once for Scotland basis, with an early focus on innovations for delivery of care in cancer. The SHTG in Healthcare Improvement Scotland provides evidence-informed advice on the use of health technologies. It works, as others, in partnership with NHS Local Board and Regional Test Bed infrastructure to ensure that products, services and processes developed are relevant and effective for NHS Scotland.

#### **Data for success**

We will need a standardised suite of performance measures for the clinical research community and simple key performance indicators for health boards.

Service data and patient outcome data is needed to monitor new technologies.

continued



Ambition 11: Cancer Information And Intelligence Led Services

### Our 10-year vision

There is a more integrated cancer intelligence platform along the full cancer pathway. This creates a responsive system that efficiently supports data collection. retrieval and use for clinical management, surveillance, evidence generation and policy development, which is aligned to the move towards a single electronic health record. Ouality Performance Indicators will be a key driver of an overall cancer services improvement agenda. aligning with optimal pathways and national clinical management pathways. Data collection and analysis of measures including PROMs (patient-reported outcome measures) and PREMs (patientreported experience measures) are integrated into service provision to facilitate person-centred care and shared decision making. This means:

- Improved completeness, quality, timeliness and use of data (diagnostic, clinical, inequalities and experience) along the patient pathway.
- Data definitions are consistent across Scotland, the UK and beyond.
- The Cancer Medicines Outcome Programme (CMOP) is a national, world-leading cancer intelligence asset capable of recording and analysing realworld medicines use, and disease-specific outcomes data at patient and population levels.
- Data interpretation and utilisation skills are core for the cancer workforce. The

continued

workforce is prepared and delivering services with the most appropriate and advanced technologies (including virtual and asynchronous appointments).

 Systems used to support the delivery of cancer services continue to have information governance assurance, and cyber and data security at their core. By working with regulators and applying agreed standards, improved data infrastructure allows greater efficiency of clinical practice and knowledge flow, and data utilisation.

Cancer data capture and use should be seamless across all health and social care settings, make best use of technology, and provide timely intelligence to those who need it. along the full cancer pathway. Data are fundamental to understanding the whole system of cancer control and care. They support service delivery and redesign including person-centred decision making, and policy and planning. They are required for audit, quality improvement, research and primary prevention. PHS operates the Scottish Cancer Registry and Intelligence **Service**, collects Quality Performance Indictor Data as well as reporting on a range of audits and cancer services (see Appendix 2).

The Innovative Healthcare Delivery

**Programme** (IHDP), in collaboration with PHS and NSS, has worked over the past seven years to transform access to cancer data in Scotland. with the aim of harnessing NHS Scotland's rich data assets to improve cancer patient outcomes. IHDP is now an integral part of PHS. New data sources have been added to the Scottish Cancer Registry as well as the creation of wrap-around intelligence services. The SCRIS project has catalysed many developments in the processing and supply of national cancer data, such as the national publication of SACT utilisation data during the pandemic to allow monitoring of recovery. SCRIS provides a secure, single point of entry to an increasing number of 'ioined up' national cancer datasets and broad range cancer-related information. The datasets cover 17 cancer indicators. with work ongoing to obtain further ones such as lifestyle risk factors and selective primary care data: workforce planning: diagnostics and laboratory data; multidisciplinary team (MDT) data; rehabilitation data: patient-reported outcome measures (PROMs); and data relating to recurrence and secondary cancers. The new Cancer Intelligence Platform being developed by PHS and NSS will allow all these evolving data to be hosted and accessible in the vears to come. Better co-ordination and joining up of the cancer data science community, including in analytical work, will ensure the most efficient use of resources across cancer services. supported by PHS.

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The CMOP provides an opportunity for NHS Scotland to gather cancer medicines intelligence where there is uncertainty, about 'real world' outcomes (as opposed to those reported in clinical trials). This is done for both new and established medicines, from supporting the early health technology assessment phase of new medicines, through to the ongoing monitoring of medicines in routine use. Quality Performance Indicators will be a key driver of an overall cancer services improvement agenda, aligning with optimal pathways and national clinical management pathways.

#### National Cancer Strategy 10-Year Outcomes Framework

An Outcomes Framework has been developed to identify the outcomes that matter as expressed through consultation and engagement with people affected by cancer. This Framework sets out the 11 cross-cutting ambitions that are anticipated to create change around seven key outcomes to achieve the strategic aim of improved cancer survival and excellent, equitably accessible care.





These seven outcomes that we expect to see at the end of 10 years connect with the overarching vision for the strategy:

More cancers are prevented, and our compassionate and consistent cancer service provides excellent treatment and support throughout the cancer journey, and improves outcomes and survival for people with cancer.

## Key Principles for Evaluating the National Cancer Strategy

Evidence gathered through monitoring and evaluation will be required to assess how far the activities associated with the ambitions are progressing. A Monitoring and Evaluation Framework is being designed to cover the duration of this 10-year strategy. A strategic, evidence-based approach will assess progress towards the strategy's seven key outcomes via the 11 cross-cutting ambitions. The focus is on national (macro) level activities and how these are translated at NHS Board (meso) level to take a Once for Scotland approach to strive for consistent and sustainable services.

Given the system pressures in the NHS and economic pressure on public finance, the evaluation approach will be proportionate and connect with existing monitoring and evaluation activities in NHS Boards. It will focus on measuring actions that are fundamental to achieving the overarching vision. This includes attention to areas where less progress has been made, such as less survivable cancers, and ongoing inequalities in screening and diagnosis, as documented in the <u>National Cancer</u> <u>Plan: Progress Report</u>. It also requires attention to outcomes for people on Waiting Lists and for those who are referred for an Urgent Suspicion of Cancer, some of whom will start a cancer pathway but will not be diagnosed with cancer.

Developing high quality evidence is a fundamental principle underpinning guidance on policy evaluation as set out in The Magenta Book: Guidance for Evaluation. High quality evidence can increase our understanding of what works, maximise the chance of achieving the strategy's ambitions. and reduce delivery risk. Given the system pressures highlighted above. it will be important to use existing collection and analysis of routine datasets where possible to minimise the burden of reporting for NHS Boards. The evaluation will also use **data already** being gathered to support commitments in the National Cancer Plan (2020).

New evaluation activities will focus on analysing high priority data and addressing evidence gaps that can demonstrate the measurable contribution of the strategy to improving services, care and outcomes. The question of what is most significant to measure to understand success will be considered across all decisions about data and evidence. Evaluation will also engage with potential unintended consequences. The success of the strategy will be judged on the realisation of the seven outcomes as evidenced through data and indicators. This will include quantifiable metrics for what is measurable. Qualitative data will capture evidence of experiences, why something works (or not), and the impact for people affected by cancer and the workforce. In prioritising analysis and evidence, evaluation will focus on new models of care or changes that involve significant investment, systemic change or risk.

Where gaps in evidence are identified, new data collection will be proportionate and focus on evidence that can satisfy us that progress is being made in relation to the outcomes as they connect with the strategic aim of the strategy. Consideration will be given to how any new data collection aligns with existing monitoring and surveillance requirements for other health care policies and strategies. This approach will support coordinated policy development across health conditions with the objective of delivering high quality services and care for people with cancer in Scotland.

## Steps for Developing the Evaluation Framework

The work to develop an Evaluation Framework will be an iterative process that engages stakeholders in mapping out intended and potential unintended consequences of planned activities, and identifying how change can be measured using management information, research and evaluation. Stakeholders in this process include, NHS Planners, Regional Cancer Network Managers, Public Health Scotland and the Scottish Cancer Coalition. A working group of analysts, clinical advisors, managers, and planners and policy officials has been established to deliver this Evaluation Framework.

#### **Theory of Change**

'Theory of Change' describes how and why change is expected to happen and considers the evidence and assumptions underpinning the theory. It focuses on the bigger picture. A Theory of Change model will underpin the development of this Monitoring and Evaluation Framework, to understand how and why a desired change is expected to happen in a particular context. The **Realistic Medicine Approach in Scotland** recognises that health services alone cannot tackle all the factors that influence good population health. Therefore, evaluation activities will take account of this complexity as reflected in Guidance for Handling Complexity in **Policy Evaluation.** 

A Logic Model can be created from a Theory of Change to map out the expected pathways or steps to realise the intended outcomes and the evidence required to demonstrate whether change has happened. A Logic Model specifies what goes in (Inputs), what is delivered (Activities), what comes out (Outputs) and what the results will be from these (Outcomes). While a Logic Model is by necessity a simplified graphic that sets out key inputs and activities that will contribute to outputs and outcomes, it is important



to recognise that pathways are not linear. With attention to inequalities across all aspects of the strategy, it will be important to understand variation within pathways for different groups of people and communities.

Mapping pathways to change will involve setting out the inputs, activities and outputs associated with the outcomes that will contribute to realising the strategy's aim. It will take time for evidence of progress to build. Therefore, outcomes will be considered in the short, medium and longer term. Short term outcomes of the 10-Year strategy will be linked to the first 3-year National Cancer Action Plan.

The following steps outline the approach that will be used to develop the Evaluation Framework:

- Setting out the short and medium term outcomes that will follow from the inputs, activities and outputs to contribute towards the long term outcomes.
- Identifying key indicators and evidence to track progress, assess whether outcomes are achieved and measure potential unintended consequences.
- Creating a visual 'Logic Model': a simplified schematic that demonstrates how inputs, activities and outputs relate to the anticipated outcomes and aim.

 Linking indicators and evidence to existing data sources, and identifying any significant gaps in evidence that are high priorities for new data collection or analysis.

This step-by-step process will involve working through the detail of how a change in outcomes is anticipated to happen in the short, medium and long term.

Definitions:

- Inputs: resources needed to deliver a programme of change (what we invest)
- Activities: actions required to produce the desired outcomes (**what we do**)
- Outputs: direct, tangible effects of activities that are delivered (what we get)
- Outcomes: desired results of this programme of change (what we achieve).

## **Appendix 2: Current Data Sources**

Cancer Dataset	Source Organisation	Туре
Patient and carer experiences of services	Care Opinion	Patient Experience/ Quality of Care
Focus groups	Health and Social Care Alliance Scotland	Patient Experience/ Quality of Care
Quality Performance Indicators (QPIs)	Healthcare Improvement Scotland (HIS) (Regional Cancer Networks, PHS, Scottish Cancer Network)	Patient Experience/ Quality of Care
Cancer Patient Experience Survey	Scottish Government	Patient Experience/ Quality of Care

# Appendix continued

Cancer Dataset	Source Organisation	Туре
Scottish Cancer Registry	Public Health Scotland	Population/
Information on all new cancer cases in Scotland since 1958. Original source of most PHS cancer datasets.	(PHS)	Screening/Access/ Diagnosis/ Treatment/ Outcomes/Pathways
Breast Cancer Screening		Epidemiology of disease
Bowel Cancer Screening		uisease
Cancer Stage Distribution		
Cervical Cancer Screening		
Detect Cancer Early Staging		
Diagnosis Audit		
Diagnostic Waiting Times		
Cancer Waiting Times for confirmed cancers		
All Urgent Suspected Cancer referrals		
Incidence		
<u>Mortality</u>		
<u>Survival</u>		
Systemic Anti-Cancer Treatment (SACT) activity		
Waiting Times for Treatment		
Radiotherapy		
Rapid Cancer Diagnosis Service		
Barrett's Dataset		
Cytosponge		
Colon Capsule Endoscopy		
Endoscopy Surveillance		
Post-colonoscopy cancer rates – for symptomatic and screened bowel cancers		
Pathology data		

The development of this new strategy began in the first quarter of 2022 looking at what the scope should be, in terms of breadth of topics as well as timelines. The vision and aims for the strategy were considered along with the principles that would underlie our strategic outlook. These early ideas were put out to consultation from April to June 2022 bringing in 257 responses from individuals and organisations including the general public, frontline workers and managers, the private sector and the third sector.

Analysis of these responses showed general agreement with what was proposed with additional suggestions.<sup>30</sup>

Recurrent themes were:

- Ensuring equal access tackling unequal access driven by one's place of residence and socio-economic status
- **Prevention** promoting healthier lifestyles and raising cancer awareness
- Facilitating earlier diagnosis
- **Person-centred approach** placing the people with cancer and their cancer journey experiences at the centre of the new cancer strategy
- Research and innovation respondents reflected repeatedly on the need to conduct more research so that innovative treatments and evidence-based approaches to care can be made available to people with cancer
- Workforce support responses acknowledged the efforts and commitment of the workforce, but mentioned that the workforce needs greater support by;
  - recruiting more staff and professionals with expertise currently missing
  - providing the workforce with more training opportunities to improve skills
  - making provisions for the emotional support of staff in cancer care
- Secondary, rare and less survivable cancers
- Survival improved survival has received large agreement as a key aim.



We discussed these issues further at a series of roundtable focus groups over September and October, meeting with over 20 people with lived experience of cancer. We had regular engagement with the Third Sector through the Scottish Cancer Coalition and through two focus groups. These confirmed the main findings of the consultation but some new themes, issues and nuances emerged, which were taken into account in the drafting of the strategy. Views of clinical and service providers were obtained through the public consultation and through regular engagement with our cancer networks, experts and governance groups.



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