

A New Cancer Strategy for Scotland

Cancer Research UK's consultation response, June 2022

Introduction

Cancer Research UK (CRUK) strongly welcomes the opportunity to respond to this call for evidence to inform the new cancer strategy for Scotland. In developing our response, we have drawn on our expertise from engaging with, and supporting the development of, other cancer strategies across the UK. Our response is informed by extensive intelligence, research, and insight, as well as by international best practice. We have also consulted with people affected by cancer in Scotland^a to ensure their experiences and views are reflected in our consultation response.

The value of a comprehensive national strategic approach to cancer transformation is internationally recognised in its ability to bring together the policies, leadership, and resources necessary to improve cancer outcomes. Scotland's last cancer strategy (2016) made significant progress towards its recommendations, and the most recent plan (2020) provided a necessary focus on recovering cancer services from the disruption of COVID-19.

Moving forwards, this new strategy has the potential to be a major milestone for people affected by cancer in Scotland, signalling a renewed drive and setting an ambitious roadmap towards better cancer outcomes. The proposed approach to the new strategy offers the opportunity to balance recovering from the impact of the pandemic in the short-term whilst creating opportunities to deliver cancer services in a better, more innovative and efficient way over the next ten years, ultimately transforming cancer outcomes. As cancer care becomes increasingly complex and incidence rises along with the ageing population, Scotland must be ready to adapt to a shifting environment and continue to deliver innovative new approaches to prevention, diagnosis, and treatment, driven by lifesaving cancer research. Our patient network consistently emphasised the scale of their ambition for the strategy, with their priorities spanning the cancer journey, prevention, and research. We must not waste this opportunity to deliver for everyone affected by cancer in Scotland.

Scotland has led the UK in implementing improvements for many areas across the pathway. Scotland has been world-leading in tackling alcohol harm through introducing minimum unit pricing in 2018, and was the first part of the UK to outlaw smoking in enclosed public places in 2006. During the pandemic, Scotland was at the forefront of rolling out innovations such as Cytosponge at pace, and the recovery of clinical trials has been faster and less fragile than recovery in other parts of the UK. We urge the Scottish Government to build on this momentum through the strategy and lead the way in driving transformation across cancer prevention, cancer services, and research. This will require using existing strengths as well as significantly enhancing key enablers of success.

Reducing cancer incidence and transforming cancer outcomes requires action across the pathway. To unlock the opportunities we set out below, there are three fundamental enablers of success which have been identified throughout our response and must be prioritised.

^a Twenty-five members of CRUK's Scottish patient involvement network (people affected by cancer living in Scotland) responded to an online survey about Scotland's new cancer strategy during May 2022. Their views have shaped our consultation response. When referred to directly, we have marked these responses as being from our 'patient network'.

Funding

It is essential that the Scottish Government allocates the necessary funding to fully deliver on the ambitions of this strategy. Publishing a ten-year strategy with funding in place will help ensure it delivers the meaningful improvements people affected by cancer deserve, as well as gain the confidence of the cancer community and wider public. As we have seen from the Scottish Government for previous cancer strategies, additional investment is needed to improve patient outcomes and unlock the benefits of innovative approaches and increased efficiency. There are also many ways to make progress within the current financial envelope, including more innovative approaches to the cancer workforce, a focus on spreading best practice more evenly, and legislative or regulatory changes that would reduce the overall burden of cancer by promoting cancer prevention.

The Scottish Government must match an ambitious strategy for cancer with sufficient and sustainable funding across the 10 years of the strategy to drive innovation, improve patient care and outcomes, and support more efficient models of care.

Workforce

Scotland has chronic shortages in the workforce specialities key to diagnosing and treating cancer. These shortages have hampered progress for years, with major shortages in diagnostic services meaning patients are waiting too long for a diagnosis. Moving forwards, an ageing population means growing demand for cancer services, and a growing number of patients with comorbidities and/or complex needs. It is, therefore, unavoidable that service capacity will need to expand to meet this need – even before accounting for existing shortages in the cancer workforce. It is vital that the strategy recognises the importance of expanding the cancer workforce to meet patient need now and in the future, and deliver on the ambitions of this strategy. This must be matched with sufficient and sustainable capital funding to ensure diagnostic and treatment capacity is meaningfully expanded across Scotland.

The Scottish Government should publish regular and transparent modelling of the current and future health workforce trends to support workforce planning. They must then set out long-term funding plans to deliver a sustained expansion of the cancer workforce to meet future demand for cancer services.

Data

Throughout our response, we highlight the vital importance of transforming data collection, collation, and analysis in Scotland. Data is fundamental to driving our progress against cancer. Data and data-driven technologies underpin every effort we make to understand and improve cancer prevention, diagnosis, and treatment, to prioritise resources and to address disparities. Recent transformational developments show what could be achieved here. For example, the Scottish Cancer Intelligence Framework offers significant opportunity to realise benefits for patients and services. However, much of this potential remains untapped due to fundamental issues right across the data lifecycle. Scottish Government should prioritise making improvements in the collection and reporting of specific datasets, as well as the underlying informatic and analysis infrastructure, to unlock better intelligence and data-driven action in the years to come. We set out further detail in question 13b.

The strategy must commit to providing timely, high-quality, transparent, and integrated data to enable a better understanding of the cancer landscape in Scotland and particularly where unwarranted variation exists.

CRUK would be pleased to discuss any of the issues raised in this document further. We look forward to continued engagement with this incredibly important initiative throughout the development and implementation of the strategy.

Consultation Response

Overall

Question 1a: What are the most important aspects of the cancer journey you would like to see included in a long-term strategy?

Scotland's new cancer strategy must be a comprehensive transformation programme. It should bring together the policies, leadership, and resource necessary to reduce the burden of cancer and improve cancer outcomes. Through taking an expansive approach, the strategy will ensure it is best placed to deliver for everyone in Scotland, by reducing the incidence of cancer, diagnosing more people early, and ensuring the best treatment and care for those who are diagnosed with cancer. This must be underpinned by efforts to bolster and support a thriving life sciences ecosystem which can maximise the potential and impact of cancer research.

The cancer strategy must cover cancer prevention, the entire cancer pathway, and research in order to deliver the holistic approach required to reduce the burden of cancer and transform cancer outcomes.

This approach will also support the identification of interdependencies between different parts of the pathway, ensuring that actions are effectively prioritised and sequenced. For example, diagnosing more cancers at an earlier stage is likely to increase demand on surgical services. Surgical training is a long process, and therefore ongoing reviews of demand and capacity will be key to planning service provision. Covering all parts of the cancer journey in the strategy supports identifying and planning for interlinked areas at an early stage, helping to efficiently deliver the action plans.

Question 1b: Are there particular groups of cancers which should be focused on over the next 3 or 10-years?

3 years

There are significant data gaps which hinders a full, up to date, understanding of the cancer landscape in Scotland, particularly where variation exists and improvements need to be made. ***The strategy must commit to providing timely, high-quality, transparent, and integrated data to enable a better understanding of the cancer landscape in Scotland and particularly where variation exists.*** This will be crucial to identifying which cancer sites or topics might need particular focus and what action to take. We set out our full recommendations for improving data collection in question 13.

However, it is still possible to prioritise certain sites to support equitable recovery from the impact of the COVID-19 pandemic. This is based on the data and insight we have, and also drawing reasonable parallels with other parts of the UK.

Below, we focus on five key cancer sites, on the basis that they have significant operational challenges, are high volume and/or currently have poor outcomes. These are our initial recommendations, and many of these recommendations are applicable to multiple cancer sites. It will also be important to think about which parts of the cancer pathway should be focus areas, moving away from a solely site-specific approach.

We understand that the Scottish Government will be undertaking clinical and wider engagement, which will be key to further identifying and prioritising short-term recommendations. CRUK would be pleased to support this process.

Breast cancer

Breast screening services in Scotland were paused during the beginning of the COVID-19 pandemic, from 30th March to 3rd August 2020.¹ The impact of this pause continues to be felt, with a substantial fall in the number of women invited for a routine breast screening appointment in 2020/21.² Of those who were invited during

the three-year period of 2018/19 - 2020/21, women from more deprived areas were less likely to attend screening, signalling inequalities in uptake.

The Department of Health and NHS Scotland should deliver insight-led activity, including campaigns, which reduce barriers to accessing screening programmes and health services, developed with and targeted towards these groups with lower uptake.

Self-referral to breast screening for asymptomatic women over the age of 71 remains suspended in Scotland. ***This issue must be kept under transparent review.***

The strategy should commit to exploring the implementation of an audit/quality performance indicators for secondary breast cancer, considering where learning from, or collaboration with, the forthcoming secondary breast cancer audit in England and Wales is appropriate.

Lung cancer

Lung cancer is the most common cause of death from in Scotland³ and is also a major source of health inequalities⁴. Research from the International Cancer Benchmarking Partnership (ICBP) shows that whilst Scotland has seen some of the greatest reductions in lung cancer incidence and mortality, they remain higher compared to other nations in the ICBP.⁵

It is welcome that lung cancer has been a priority for Scottish Government for many years – continued efforts to reduce the incidence of lung cancer and improve the outcomes of people who develop lung cancer are vital. Positively, an optimal pathway for lung cancer is in development, and we would like to see the equitable and timely spread of these standards throughout Scotland once agreed.⁶

The Scottish Government should conduct an assessment of the current primary care workforce mix and how it could be optimised to support increased referral for patients with suspected lung cancer. This includes ensuring that required Ionising Radiation (Medical Exposure) Regulations (IRMER) training is in place for those who can play a role in the lung cancer pathway.

The Scottish Government should invest in increasing radiologist numbers, to address current shortfalls and meet future demand, especially in the case of an expansion of direct access to CT for some symptomatic individuals and a positive recommendation on targeted lung screening from the UKNSC.

If targeted lung screening is recommended by the UKNSC, the Scottish Government should assess and address any issues in the quality and completeness of smoking status data in individual primary care records, ensuring primary care professionals routinely record smoking status.

The strategy should commit to ensuring that improvements in the provision of stereotactic ablative radiotherapy (SABR) outlined in the National Radiotherapy Plan result in timely and equitable access to SABR for patients with lung cancer as well as those with oligometastatic disease, including access to the specialist expertise required to deliver this treatment.

Prostate cancer

Prostate cancer is a complex disease; some cases are slow growing and unlikely to cause harm in a patient's lifetime, while others are aggressive and lead to death. In October to December 2021, 99.7% of prostate cancer urgent referrals met the 31-day standard, but only 53.1% met the 62-day – the second worst performing site.⁷ As imaging is a key diagnostic modality for prostate cancer, this reinforces the importance of investing in increasing radiologist numbers. Capacity challenges in pathology may also present a barrier to timely diagnosis⁸, and so workforce planning and investment must also expand pathologist numbers.

NHS Scotland should undertake evaluation and benchmarking of PSA usage to understand if guidelines are followed and whether there is local variation in order to inform guideline optimisation. This is particularly important for PSA given the known limitations of the test.

NHS Scotland should undertake benchmarking across boards to help identify and address unwarranted variation, such as pre-biopsy mpMRI usage, quality of mpMRI, and resection of low volume, low risk disease.

Upper GI

Common signs and symptoms of upper GI cancer are poorly recognised, particularly persistent indigestion or heartburn. Data from our Cancer Awareness Measure survey showed that in Scotland no one surveyed recalled unprompted indigestion or heartburn as a potential sign of cancer.⁹

NHS Scotland should encourage and support activity that aims to improve public response to signs and symptoms of upper GI cancers, particularly ongoing indigestion/heartburn, alongside continued primary care education and support on optimal use of urgent referral and routine pathways.

Evaluation of ECDCs may show some benefits for the upper GI pathway, as has been seen in other parts of the UK. This should therefore be monitored in ECDC evaluation and used to inform activity to improve upper GI outcomes.

Colorectal cancer

The diagnosis of colorectal cancer relies heavily on endoscopy, which has faced considerable challenges for some time which were then further exacerbated by the pause in procedures at the start of the pandemic.

NHS Scotland should encourage optimal use of existing GI diagnostics, particularly CT colonography, as a means of tackling the immediate endoscopy challenges and, along with other partners, should expedite research to further inform which symptomatic patients are most suited to colon capsule endoscopy, which to CTC, and which to endoscopy, based on FIT score and other factors.

Scottish Government and NHS Scotland should increase funding and support for research to inform risk stratification in the bowel screening programme and ensure that implications are quickly factored into, and prioritised within, national strategy and plans, such as IT infrastructure developments.

10 years

Lung cancer is the most common cause of death from cancer in Scotland. More deprived communities are particularly impacted, with lung cancer mortality rates three times higher in the most deprived areas compared to the least.¹⁰

Over the next ten-years, the strategy must prioritise reducing the incidence of and improving outcomes from lung cancer through improving prevention strategies and targeted action to reduce late diagnosis of lung cancer. Targeted lung cancer screening could play a key role here and is discussed further below.

All preventable cancers should be a focus area over the next ten years. Over 40% of cancers diagnosed in Scotland are attributable to modifiable risk factors¹¹ – acting to reduce the preventable causes now is key to the success and legacy of this cancer strategy in the future. Scottish Government must take concrete action to reduce peoples' risk of cancer through population-wide measures. In particular, bold action must be taken now to tackle the two biggest causes of cancer: tobacco and obesity, both of which disproportionately affect deprived groups.^{12,13} As well as being crucial for preventing cancers, this will support a healthier population such that, for those who do develop cancer, co-morbidity will be less likely to hamper diagnosis and, crucially, negatively influence the treatment options that a person has available to them.

Improving data collection and analysis over the first three years will further support the effective development of future action plans, ensuring a focus on the cancer sites or pathway elements and obstacles which present the biggest barrier to improving outcomes in Scotland.

Question 1c: What do you think we should prioritise over the short-term?

Data

Transforming data collection and analysis in Scotland must be an overarching priority for the strategy. It is essential that action is taken in the first three years to build a much stronger data infrastructure which can provide the insight and analysis required over the lifetime of the strategy and beyond. Without this, it will not be possible to meaningfully measure success over the coming years – including the pace of progress, the impact on different groups, and where action must go further.

In answer to questions 13 and 14, we have set out specific recommendations to transform the collection and reporting of specific datasets, and the underlying informatic and analysis infrastructure, as well as which parts of the cancer pathway must be measured as a priority.

Diagnostics

The pandemic brought great disruption to cancer services across Scotland, with screening programmes paused and diagnostic and treatment capacity seriously limited. Data suggests that there was an 8% fall in the number of cancer diagnoses made in 2020.¹⁴ The number of people waiting for key diagnostic tests has risen substantially compared to pre-pandemic levels, with three times as many people waiting more than six weeks for an endoscopy, and four times as many for radiology, in December 2021 compared to December 2019.¹⁵

But diagnostic capacity faced major challenges before the pandemic. The 62-day standard has only been met once since its introduction, with stronger performance against the 31-day treatment standard suggesting long diagnostic waits are the major barrier to improving performance.¹⁶ Scotland's diagnostic waiting times also compare poorly internationally, with Scotland having one of the longest diagnostic intervals for lung cancer compared to other ICBP countries.¹⁷

Recovering and expanding diagnostic capacity must be prioritised to ensure all patients can access timely diagnosis and begin treatment as soon as possible. Our patient network reinforced the focus on early and timely diagnosis as a priority area for action – one respondent emphasised that “waiting time absolutely must improve”.

In the short-term, the recommendations focussed on recovering breast, lung, prostate, upper GI, and colorectal cancer will help to support recovery in diagnostics, and opportunities to bring benefits to other cancer pathways should also be scoped and delivered. It is also essential that over the next three years, ambitious delivery plans to expand diagnostic capacity over the medium- to long-term are put in place. In particular, expanding the cancer workforce to ensure that it will keep pace with patient need and deliver the transformation to cancer services set out in the strategy will be the key enabler of success.

In answer to question 10, we set out our recommendations for expanding and strengthening the diagnostic workforce.

Inequalities

It's essential that tackling cancer inequalities is prioritised in the short-term. There is a real risk that innovative plans to transform services will maintain, or even exacerbate, existing cancer inequalities if plans to tackle them are not integrated into action plans from the outset. Improving data collection will also play a critical

role in understanding variation between population groups and geographics. Inaction on tackling inequalities would be a moral failure, letting down the people who carry the greatest burden of cancer in Scotland.

For example, whilst the introduction of FIT testing in bowel screening led to an overall increase in uptake, major variation in uptake between the most and least deprived groups persists. Between May 2019 and April 2021, uptake in the bowel screening programme using FIT testing was 65%.¹⁸ However, uptake for the most deprived groups was just 53%, compared to 73% for the least deprived, with a similar trend seen across screening programmes.^{19,20} It is essential that any action to optimise cancer screening programmes targets inequalities from the outset, ensuring equitable benefit from improvements.

The strategy must commit to tackling inequalities in the short-term through prioritising the recommendations we set out in the Impact Assessment section to reduce inequalities, ensuring no one is left behind as the strategy drives progress across the pathway.

Type of document

Question 2

We strongly support the proposal to introduce a 10 year strategy, which is underpinned by three short-term action plans. The 10 year time horizon affords the opportunity to strive for radical improvements in cancer outcomes.

The Scottish Government must ensure that the strategy is supported by a clear accountability and measurement framework, with progress against the full ten-year strategy independently assessed and published annually.

Shorter-term action plans will help ensure the strategy can adapt to developments in service delivery and research. Developing these plans must also be an opportunity to identify where progress may be quicker than expected, and thus we could go further and faster, and to highlight areas where progress is slow and greater attention is needed.

The shorter-term plans should contain clear objectives, timelines for implementation, and transparent accountability frameworks, to ensure they will be effective, rigorous delivery plans.

The development of future plans must continue to be a transparent and inclusive process. Evaluation and plan development must therefore involve the whole cancer community, including cancer charities and people affected by cancer.

Vision, aims and principles

Question 3: Do you agree with this vision? Please explain your answer and provide any additional suggestions.

We agree with the broad principles of the vision, which touches on many important aspects of the cancer strategy including improving services, prevention, and addressing variation through delivering a consistent service.

However, this vision must build momentum and support across cancer services and the wider community, including the research and charity sectors, in order to ensure Scotland can lead the way in driving transformation. To do this, the vision must be ambitious and future-facing, underpinned by stretching targets which can drive action and collaboration. Moreover, aiming high – for example for world class cancer services – will be important for creating hope amongst people affected by cancer that the strategy will deliver meaningful change. At present, the vision does not fully deliver this.

Cancer research is also notably absent from the vision. A thriving life sciences ecosystem with a wide range of cancer research funders will be integral to improving outcomes over the next ten years and beyond and must not be overlooked.

The strategy should therefore adapt its vision to be more holistic and ambitious – we propose the following: “A world class cancer service that delivers high-quality care and support for everyone at risk of, or affected by, cancer, and a thriving cancer research sector, leading to improved cancer outcomes for the people of Scotland.”

Question 4: Do you agree with these goals? Please explain your answer and provide any additional suggestions.

We welcome these aims which cover prevention, the full cancer pathway, research, and addressing inequalities.

There are specific changes which would improve these aims to ensure they are targeting the right issue. The first aim, ‘(a) Slowing down the increasing incidence of cancer’, must be focussed on cancer prevention. We would expect some increase in cancer incidence due to an ageing population, which is inevitable.²¹ The aim should therefore be to reduce the prevalence of modifiable risk factors to slow down the increase in cancer incidence.

Secondly, we recommend that ‘rates’ is removed from ‘(e) Higher survival rates’, as survival is not measured as a rate. We would prefer to see this aim framed around people affected by cancer, focussing on increasing the proportion of people surviving their cancer.

The aims must also provide a mechanism to keep Scottish Government accountable for the strategy’s delivery, providing clear targets which progress can be measured against. To support this, some of these aims should be developed into more specific targets, as set out below.

Earlier diagnosis

In answer to question 15, we set out our vision for earlier diagnosis in Scotland. We propose that this vision has an ambitious target: ***By 2032, at least 80% of all stageable cancers should be diagnosed at Stage I and II.***

This vision must be supported by a supplementary target to reduce the proportion of cancers diagnosed in an emergency setting to match the best performing comparable countries – Scotland has one of the highest proportions of emergency presentations in eight cancer sites of the ICBP nations.²² Patients diagnosed via emergency presentation are more likely to have poor survival, even when accounting for the fact that they’re more likely to be diagnosed at a late stage.²³ Reducing emergency presentations is therefore critical for improving earlier diagnosis, survival, and patient experience.

At present, there is insufficient analytical resource, data, and infrastructure to routinely measure emergency presentation across all cancer sites. ***Within the next three years, Scottish Government should begin routinely publishing data on routes into diagnosis, especially emergency presentation by site and Health Board.***

Once this data is routinely collected and published with the analytical functions to understand current performance, an ambitious target should be introduced in the next 3 year action plan. This target should have the overarching aim of reducing the proportion of cancers diagnosed via emergency presentation to a world leading level.

Survival

We support the aim to improve cancer survival in Scotland over the course of this strategy. Research from the ICBP shows that survival in Scotland currently lags behind comparable countries and has also been slower to improve.²⁴

The aim for higher survival should therefore be framed as a bold target to improve cancer survival in Scotland so that it is amongst the best in the world.

Question 5: Do you agree with these principles? Please explain your answer and provide any additional suggestions.

We support these principles, which will be critical to building the right framework in the health and care system, and more widely, to deliver the strategy's aims. In particular, throughout our response we note the importance of putting patients at the centre and involving communities and service users, using data and evidence to drive improvements, and ensuring consistency for all regions and patient groups.

Scope and Framing

Question 6: Do you agree with these themes? Please explain your answer and provide any additional suggestions.

The proposed themes capture the key areas where action is required to reduce cancer incidence and transform cancer outcomes. We support these themes, and in our answers below set out the opportunities across the cancer pathway to drive improvement.

The framing of certain themes, however, could be adapted to ensure they best reflect the area they cover. 'Timely access to care' is focused specifically on diagnostics, and not on other aspects of care such as treatment. A more appropriate title for this section would therefore be 'timely cancer diagnosis'.

Research is pivotal to developing our understanding of how to improve the prevention, diagnosis, and treatment of cancer. It should therefore be a key focus of the new cancer strategy. At present, research is covered in the 'Data, technology and measurement' theme. However, given the importance of research to improving outcomes for patients, 'research' should be directly included in the section title to ensure it is recognised as a priority area. We suggest that 'technology' is replaced with 'research and innovation', as technology is one of a number of areas with great potential here.

Prevention

Question 8a: In your experience, what actions do you think would be most effective for helping to stop people getting cancer and reducing inequalities in cancer incidence?

Preventable disease and mortality continue to have a major impact on our nation's health, NHS Scotland, and the economy. This is also an issue of inequality: the two biggest causes of cancer – smoking and overweight and obesity²⁵ – are more prevalent in deprived groups. In Scotland, the most deprived groups had a 32% adult smoking rate compared to 6% in the least deprived in 2019.²⁶ A similar pattern emerges for obesity: around 36% of adults living in the most deprived areas were obese, compared with 23% of those living in the least deprived areas.²⁷

Given around 4 in 10 cancers are preventable²⁸ acting to reduce preventable causes of cancer now is key to the success and legacy of this cancer strategy in the future. We know there is strong support from cancer patients in Scotland to invest in cancer prevention. In a recent survey, our patient network highlighted the powerful impact prevention could play in positive health outcomes for people in Scotland if the Scottish Government invest: "[It is] hugely important, especially when actions to prevent cancer are also likely to also

reduce the numbers of other diseases ... heart problems, COPD, diabetes, liver disease etc. This investment must be whole system and [...] must not be diverted or delayed".

The Scottish Parliament has led the way with bold, world-leading, population-level policies that have positively impacted public health. Scotland was the first UK nation to introduce the ban on smoking in public spaces in 2006 and the first country in the world to introduce a minimum unit price (MUP) for alcohol, yet despite the Scottish Government committing to implement promotion restrictions on products high in fat, salt or sugar (HFSS) in 2019/2020, these still haven't come to fruition. **We encourage the Scottish Government to continue to be bold in their approach and aim to be a world leader in introducing policies that tackle the biggest preventable causes of cancer.**

Tobacco control

Tobacco is the biggest cause of cancer and preventable death in the UK.^{29,30} Decades of action have contributed to adult smoking prevalence in Scotland reaching a record low of 17% in 2019,³¹ but this masks significant inequality. Smoking is one of the leading drivers of health inequalities – which is why action by the Scottish Government to reduce smoking prevalence is vital.

The current target for a Smokefree 2034 is welcome, but we are not currently on track to meet it.³² The next Tobacco Control Strategy for Scotland must put us back on track towards this target by presenting comprehensive action at a national, regional and local level, to both limit the uptake of smoking and increase cessation support for people who do smoke. It would be welcome if this commitment was mirrored in the 10 year cancer plan.

Scottish Government action is critical to tackle smoking and meet the 2034 target. Data has shown that most people who currently smoke started in childhood or as teenagers,^{33,34,35} before they were old enough to understand the lifelong consequences of this addiction and how hard it is to quit.

Reducing tobacco related health inequalities

CRUK modelling based on 2018 data suggests that smoking prevalence in Scotland will reach 5% after 2050. Only the least deprived quintile will reach a 5% smoking prevalence by 2034, while the most deprived quintile's prevalence will still be around 20% in 2034.³⁶

Scotland will not be truly smokefree until all groups are smokefree. That's why CRUK is calling for the Scottish Government to set a subsequent target of 5% or less smoking prevalence in Scotland for all socio-economic groups, including the most deprived quintile.

Limiting Uptake

The Scottish Government has successfully implemented measures over the years aimed at reducing the appeal – and therefore the uptake – of tobacco products. To maximise their impact, the Scottish Government should work with the UK Government to rectify the loopholes used by the tobacco industry to undermine these measures.^{37,b} However, there is also evidence to show that the effectiveness some of these successful measures, like health warnings on cigarette packs, can decrease over time as people who smoke become more used to them. It is therefore important that the Scottish Government continues to explore bold new ways of reducing the attractiveness of tobacco products.

The Scottish Government should explore bold new measures to limit uptake of smoking, considering introducing the following over the ten-year period:

^b CRUK would be happy to share our (unpublished) response to the post implementation review of Standardised Packaging of Tobacco Products (SPoT) and Tobacco and Related Products 2016 (TRPR) regulations, which contains further detail on this topic.

- **Conditional registration:** Scotland have made welcome strides to conditional registration by becoming the first UK nation to introduce a tobacco and nicotine vapour products register.³⁸ An evaluation of the Scottish Tobacco Retail Register, conducted by ScotCen on behalf of Cancer Research UK, identified that the register is “functioning well and is achieving its policy aims” and can be a “beneficial component to a comprehensive tobacco control strategy”.³⁹ ScotCen found that the register has been well received and helped facilitate communication with retailers – which is helpful to tackle illicit tobacco. There are several options for conditional registration that the Scottish Government can explore:
 - One of which could be a fee to register, which some retailers believe could disincentive selling tobacco given the small profit margins.⁴⁰
 - Another option could be to only permit a limited number of tobacco retailers within a certain space, which could denormalise smoking by reducing product availability. Evidence also shows this could reduce inequalities if targeted to do so as research from Scotland shows that tobacco retailer density is higher in more deprived neighbourhoods, people are more likely to smoke where tobacco retailer density is high, and that density in more deprived areas is increasing.⁴¹

We would encourage the Scottish Government to work with researchers, legal experts and policy specialists to determine which conditions are most likely to deliver the intended impacts in the most practicable ways.

- **Maximum unit pricing:** Historically, tobacco companies have shifted the cost of tax increases on tobacco onto the consumer.⁴² They often increased their premium products (overshifting) while minimising the increase in price on their cheaper products (undershifting)^{43,44} – likely to avoid the most price sensitive consumers from stopping smoking. Introducing a maximum price on tobacco products would undermine the industry’s ability to have very cheap tobacco products, which could be beneficial for health inequalities.^{45,46,47 48} Capping the price of tobacco products could also be used as a mechanism to raise funds for public health, through shifting what were industry profits to the government through accompanying tax increases.⁴⁹ Importantly, any such measures would need to be coupled with cessation support for people trying to quit smoking as a result. The Scottish Government should look into this measure – with a particular focus on how it would affect tobacco-related health inequalities.
- **Pack inserts:** Evidence suggests that interventions that make cigarettes less appealing, with displaced cost to the manufacturer, are a prudent policy measure. This policy has already been rolled out in Canada,⁵⁰ with perception research undertaken in the UK.^{51,52} The Scottish Government should work with the UK Government to explore this measure.
- **Dissuasive cigarettes:** There is some evidence to suggest that dissuasive cigarettes are effective in making cigarettes less appealing to young people.^{53,54} The Scottish Government should work with the UK Government to explore this measure.
- **Raising the age of sale to 21:** The age of sale of tobacco is currently 18 in the UK, but recent reports have been calling for a consultation to increase the age of sale.⁵⁵ Evidence shows that many people who smoke start smoking before the age of 21, with smoking prevalence higher among the 18 to 21 age group than the general population.⁵⁶ By restricting the ability of this cohort to buy tobacco products, there may be potential to reduce uptake and thus decrease the adult smoking population. It is important to note that this should be about criminalising the sale, rather than the purchase of tobacco below the age of 21. The Scottish should call for the UK Government to consult on raising the age of sale of tobacco from 18 to 21.

Helping people to stop smoking

Most people who smoke want to stop,⁵⁷ but they need support to do so. This cancer plan should also consider how to maximise the role that primary care professionals could play in smoking cessation support. Doing so would accelerate progress against the Smokefree 2034 target in all socioeconomic groups, and the largest absolute benefits in health outcomes should be seen by the lower socioeconomic group given their higher smoking rates. CRUK modelling suggests that by 2039 this could lead to around 480,000 fewer cases of smoking related disease across the UK (230,000 in the most deprived groups alone).⁵⁸ It would also save the UK around £8bn in smoking related healthcare costs and save £14bn in costs to wider society.⁵⁹

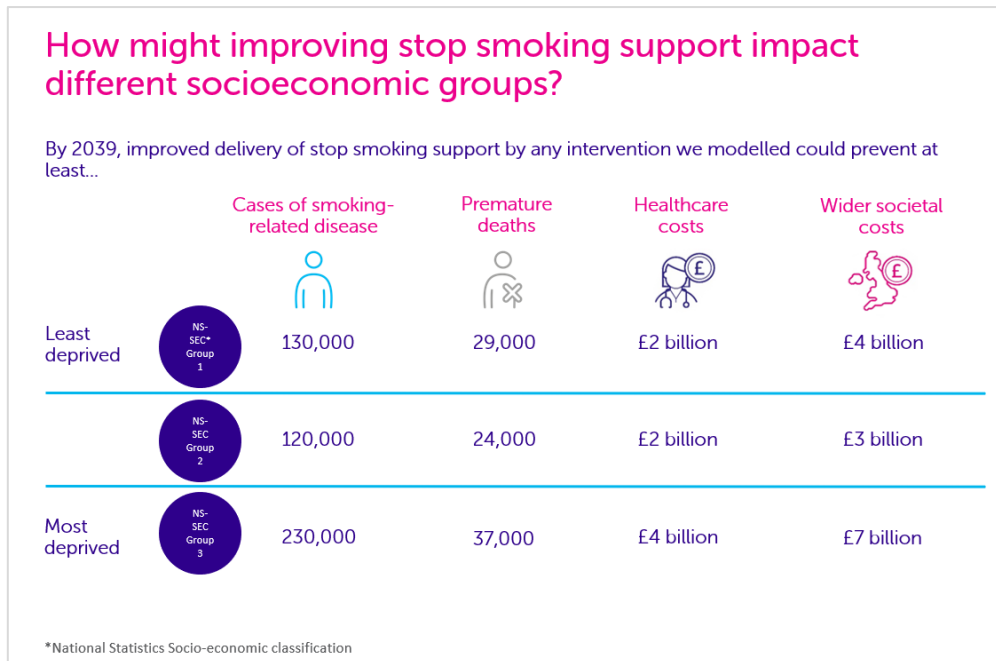


Figure sourced from *Making Conversations Count for All*. UK-wide analysis.

The cancer strategy should include a commitment to increasing smoking cessation support in primary care. This includes:

- **Ensuring all relevant primary care professionals have undertaken training in delivering Very Brief Advice (VBA) on smoking.**
- **Ensuring primary care professionals routinely deliver VBA on smoking in consultations with patients who smoke and record smoking status.**
- **Ensuring primary care professionals offer evidence-based interventions to patients to support them to stop smoking, including systematically referring them to a local stop smoking services for ongoing support where available, or prescribing pharmacotherapy for smoking cessation with brief advice.**

CRUK also believe Scotland should adopt improved smoking cessation support routinely in secondary care. This could be akin to the Ottawa Model or CURE programme for smoking cessation.

A 'Scotland model' for smoking cessation in secondary care should include:

- all people admitted to hospital having their smoking status digitally recorded;
- if they smoke, patients should be provided with personalised stop smoking support and treatment on an opt-out basis; and
- there should be clear referral pathways for ongoing support following discharge, including to Quit Your Way services.

This should be implemented and monitored as a matter of priority, given its impressive results in other areas, such as the Greater Manchester CURE programme.⁶⁰ While we recognise that there are likely to be some up-front resource implications, evidence suggests that applying an Ottawa/CURE-like Model in secondary care would be highly cost-effective in the long term. Estimates from the CURE programme put conservative cost-savings at almost £10 million per year and an additional 84 beds per day available across the area.⁶¹ Similar findings are reflected by the Royal College of Physicians which estimates that, if implemented across all NHS hospitals in England, the Ottawa Model would achieve net-savings of between £30 to £60 million after one

year.⁶² Implementation of an Ottawa/CURE-like Model would also align NHS Service provision across England and Wales, given roll out of the systematic stop smoking support in secondary care is part of the NHS Long Term Plan by 2023/2034⁶³ and is a suggested action for the Welsh Government's Tobacco Control Strategy for Wales.⁶⁴ However, it is important there is sufficient resourcing for smoking cessation services in order to support any increase in demand as a result of implementing a systematic secondary care smoking cessation service.

The Scottish Government must also continue to ensure that e-cigarettes regulation is evidenced-based and maximises the potential for cessation whilst minimising the risk of uptake by people who have never smoked and young people in particular. E-cigarettes are a relatively new smoking cessation tool. They are not risk free and their long-term effects are unknown. However, the long-term harms of tobacco are indisputable and e-cigarettes represent an opportunity for harm reduction. Evidence to date indicates that e-cigarettes are not only far less harmful than tobacco smoking^{65,66,67,68,69,70} but can also help people to stop smoking.^{71,72,73,74,75,76} and avoid relapse.

In our response to the Scottish Government's recent consultation on advertising and promotion of vaping products^c, we urged the Scottish Government to consider the impact of potential regulation on both young people/never-smokers on the one hand and people who smoke on the other.

Specifically, we:

- Highlighted that Cancer Research UK believes a balanced approach should be taken towards marketing of e-cigarettes where people who smoke have access to high-quality information and to help them to make informed choices on smoking cessation tools, but marketing is not targeted at young people or adults who do not smoke.
- Voiced our concerns that restricting nominal pricing of e-cigarettes would risk making these products more difficult to access for people from more deprived backgrounds and may therefore create barriers towards switching from smoking to vaping.
- Supported the proposal to remedy the loophole in the law which allows free distribution of e-cigarettes to under 18s.

Smoking cessation services

We welcome the Scottish Government's focus on smoking cessation services, given people attempting to quit using these services, which offer specialist behavioural support in combination with pharmacotherapy, are around three times more likely to stop smoking successfully than those attempting to quit unaided.^{77,78} **It is crucial more people are signposted and referred to these services through avenues like *Quit Your Way*.**⁷⁹ While the focus on deprived areas is welcome as part of the Local Delivery Plan Standard, and quit attempts are consistently high, Scotland as a whole has not met the 12-week quit target since 2015/16.⁸⁰ **It will therefore be important that any measures to increase footfall are disproportionately aimed at the most deprived groups. We also need research to understand what tailored interventions could effectively enhance support for those in lower socioeconomic groups and reduce inequalities.**

There is also an opportunity for to integrate smoking cessation support with other cancer innovation. CRUK have also recently responded to the UK National Screening Committee (UKNSC) recommendation in favour of a national targeted lung screening programme ([see below for more information](#)). The UKNSC's focus on smoking cessation as an integral part of the screening programme is welcomed, alongside their recommendation to provide smoking cessation advice to all participants in the programme. ***If recommended by the UKNSC, we encourage the Scottish Government to implement the UKNSC's recommendation.*** The

^c We would be happy to share CRUK's response to the Scottish Government's consultation on advertising and promotion of vaping products.

Government will need to ensure that smoking cessation services are available to refer patients into, and that services have enough capacity and resources to cope with any additional demand for stop smoking support resulting from targeted lung screening. Collaboration with stop smoking services leads, as well as wider public health and other stakeholders, early in the planning process for targeted lung screening rollout will be paramount to this.

Increased investment in tobacco control

To prevent more smoking-related cancers, there must be adequate and sustainable investment in tobacco control measures, but there is no clear funding mechanism for the 10 year strategy.

That's why the Scottish Government should work with the UK Government to introduce additional funding for tobacco control, for example, through a Smokefree Fund.

This would use industry funds, without their interference, to help make smoking obsolete. The industry have the funds to pay for the damage they cause: the four largest tobacco manufacturers make around £900 million of profits in the UK each year.⁸¹ Funds generated from this charge, which would be administered by the UK Government, should be used to help deliver the necessary components for tobacco control to achieve smokefree targets across the UK, such as funding universal stop smoking services and anti-smoking mass media campaigns. ASH has estimated that £315.2 million would be needed to pay for national, regional and local tobacco control activity for UK-wide measures.⁸² More information on the Smokefree Fund can be found in CRUK's recent report, '[Funding the Smokefree Generation](#)', which explored stakeholder views on why a dedicated tobacco control fund is needed and how one could be implemented. The Scottish Government should work with the UK Government to set up this fund, opt-into it once established and, importantly, commit to ensuring that any revenue gathered from it is dedicated towards tobacco control measures.⁸³

Smokefree zones

Research suggests that the social norm change approach is effective at reducing tobacco consumption, adult smoking, and youth uptake^{84,85,86} hence why smoke-free environments can play a part in denormalising smoking. However, we believe that there are other actions that the Scottish Government can implement that will have a greater impact on discouraging uptake, promoting cessation and tobacco control more widely. **That's why instead of expanding to new smokefree zones, the Scottish Government should build on other actions with this saved resource, time and capacity. For example, building on the smoking cessation provision in secondary care so it is akin to the Ottawa Model or CURE project (more detail in question 8b).**

Obesity

Overweight and obesity is the biggest preventable cause of cancer after smoking, responsible for around 2,200 cancer cases in Scotland each year.⁸⁷ Obesity is linked to 13 different types of cancer, including two of the most common – bowel and breast – and two of the hardest to treat – pancreatic and oesophageal.⁸⁸

In Scotland, around 36% of adults living in the most deprived areas are obese, compared with 23% of those living in the least deprived areas. Moreover, these inequalities have widened, with recent data showing the gap between the proportion of children at risk of overweight or obesity in the most deprived areas increasing at a greater rate than those in the least deprived areas.⁸⁹

As such CRUK is strongly supportive of the Scottish Government in tackling obesity, as a key driver of health disparities and preventable cancer incidence.

Current commitments

CRUK is highly supportive of current and proposed restrictions on the promotion and advertising of HFSS products. The marketing of unhealthy food and drink have powerful effects on the consumption of these products. Data shows that the more young people are exposed to the advertising of HFSS food and drink, they more they consume those products.⁹⁰ The same is true of promotions- with households who make greatest use of price promotions tending to buy more unhealthy food than those who don't.⁹¹ Promotions also uniquely promote overconsumption rather than sensible stockpiling. People who buy crisps or biscuits on multi-buy will eat them more quickly and often purchase again the following week, while people who buy non-consumables on multi-buy are not likely to overconsume thereafter.⁹² Moreover, these promotions encourage shoppers to spend more not less⁹³ – for the most disadvantaged this could be hugely detrimental.

To this end the Scottish Government should:

- **Work with the UK Government to ensure broadcast and online advertising restrictions on HFSS products are implemented in full and on 1 January 2023 as originally planned. The Scottish Government must hold firm and lead the UK in ensuring measures to tackle obesity are delivered to protect the health of all people in Scotland and across the UK.**
- **Deliver on their 2021/22 Programme for Government commitments (postponed from 2019/20) to restrict the promotions of unhealthy products. It is disappointing that despite commitments from the Scottish Government these measures have been repeatedly delayed. Scotland should seize the opportunity to set an example in the UK and make these health protecting measures mandatory.**
- **Work with local authorities, transport companies and media agencies to restrict advertising HFSS products on sites they manage such as bus shelters, stations and inside buses and trains. Similar restrictions in place on Transport for London services saw promising results.⁹⁴**

Future policies

Scotland has a strong foundation to build on to tackle obesity, having already committed to halving childhood obesity by 2030. However, recent modelling by CRUK shows that rates of obesity are projected to rise in Scotland, as well as a potential widening of inequalities between the most and least deprived groups. This translates to 1.6 million adults who would be obese by 2040.⁹⁵ If the Scottish Government is to seize the opportunity to lead the UK with pioneering policies to tackle obesity and reach their target, more must be done. **CRUK supports the measures recommended by the Obesity Health Alliance in their 10-year Healthy weight strategy⁹⁶ and calls on the Scottish Government to implement the recommendations that are actionable by devolved Governments, in particular:**

- **Ensure only healthier food and drink products can be associated with sports, with new restrictions to prevent unhealthy products and brands from sports sponsorship of all kinds**
- **Implement measures in the built environment that promote healthier behaviours**

Alcohol

Alcohol minimum unit pricing

Alcohol is a known carcinogen causing seven types of cancer,^{97 98} including two of the most common – bowel and breast – and one of the hardest to treat – oesophageal.⁹⁹ The more a person drinks the greater their risk of cancer. Reducing the number of people who drink at harmful levels is therefore important for reducing the number of avoidable cancers in Scotland.

Harm from alcohol is also disproportionately experienced by the least well off in our society. People from the most deprived group in Scotland are seven times more likely to be admitted to hospital¹⁰⁰ and four times more likely to die due to alcohol¹⁰¹ than those from the least deprived group.

Minimum Unit Pricing is an evidence based and effective measure in reducing alcohol harm. A major review of the evidence into MUP, which synthesised over 100 systematic reviews and meta-analyses, showed that increasing the price of alcohol is associated with falls in both alcohol consumption and alcohol-related harm.¹⁰² This review noted that ‘minimum pricing strategies may constitute an effective part of a broad public health strategy to deal with alcohol-related problems.’¹⁰³ Scotland has been a leading nation in tackling alcohol harm since introducing MUP in 2018. In the first full year after the introduction of MUP there was a 3.5% reduction in off-trade sales per adult¹⁰⁴ and a 10% reduction of alcohol-specific deaths- the lowest level since 2013.¹⁰⁵ **CRUK therefore supports MUP to regularly rise in line with inflation and to be reviewed regularly to ensure it remains effective.**

HPV vaccination

There is strong evidence that the human papillomavirus (HPV) vaccine prevents cervical cancer. In the first study of its kind, funded by Cancer Research UK, rates of cervical cancer in women in their 20s who were offered the bivalent Cervarix HPV vaccine at age 12 to 13 in England were 87% lower than those who did not receive the vaccine.¹⁰⁶ This is why it is so essential that all those who are eligible receive their HPV vaccine.

While some disruption to the programme was expected due to school closes as a result of the COVID-19 pandemic, there is a lot of regional variation in HPV vaccine uptake, with areas of deprivation having lower coverage across the UK. Previous evidence has also shown that ethnic minority groups and those in non-mainstream schools are much less likely to receive the vaccine.¹⁰⁷ In Scotland, by the end of the school year 2020/21, while coverage of the first dose of the HPV vaccine was close to or over 90% by the end of S4 in each of the deprivation categories, females from the most deprived areas were less likely to receive the second dose compared to those from the least deprived areas (80% vs. 90%). For S2 pupils, Lothian, Greater Glasgow & Clyde, and Forth Valley also reported the lowest coverage by NHS board, with Lothian and Greater Glasgow & Clyde having less than 1% of females and males with two doses.¹⁰⁸ These immunisation programmes were disrupted by the national lockdowns, which is a likely cause of these vast variations in coverage. **CRUK welcomes the effort by NHS Boards that are running catch-up programmes for any pupils not offered the vaccine during 2020/21. As well as ensuring HPV vaccination coverage gets back to pre-pandemic levels, we urge the Scottish Government to focus on areas and groups with lower uptake to strengthen programme delivery, increase coverage rates, and reduce inequalities.**

Timely access to care

Question 9b: In your experience, what aims or actions would you like to see under any of these areas?

Screening

Cancer screening is critical to driving earlier diagnosis of cancer. The importance of accelerating improvements in screening was repeatedly raised by CRUK’s patient network. Respondents highlighted screening as a priority for cancer in Scotland over the next ten years, and, for many, as the most important aspect of the cancer journey to include in the long-term strategy. The rapid implementation of future recommendations made by the UK National Screening Committee (UKNSC) will help Scotland continue to drive progress. There is also huge promise in exploring innovative approaches to screening over the coming years, for example targeted or risk-stratified screening programmes. To enable faster progress in screening, several steps need to be taken.

Public Health Scotland should ensure that the needs of cancer screening programmes, both current and future, are routinely factored into IT planning, development and horizon scanning. This should include considering:

- **Synergies across different screening programmes**

- **Opportunities for alignment to support engagement and sustainability**
- **Innovative models of service delivery.**

We welcome the expansion of the remit of the UKNSC to include targeted screening. Innovative and targeted screening programmes have the potential to contribute to early diagnosis and improved outcomes. One example is a national targeted lung screening programme. If recommended by the UKNSC, this programme could support the earlier diagnosis of lung cancer, and should be implemented as a matter of urgency, with high quality smoking cessation services integrated into the pathway.

New cancer screening programmes inviting participants based on characteristics other than age and gender, or changes to existing programmes, present unique challenges in building public understanding and confidence in the programme. They have the potential to be controversial if members of the public believe they are missing out on a potentially lifesaving health intervention even if on a population level a reasonable balance of benefits and harms is maintained. The Scottish Government should effectively engage with the public prior to introducing such programmes, or significant changes to existing programmes, to ensure public confidence. As an innovative new programme, targeted lung screening presents an opportunity for Scotland to be a driving force in the UK on screening policy if they commit to rapidly implementing the UKNSC recommendation.

If recommended by the UKNSC, the Scottish Government should rapidly implement targeted lung screening and ensure [smoking cessation](#) is an integral part of the programme. CRUK has recently submitted a response to the UKNSC consultation making recommendations for the implementation of the programme which we would be happy to share.

New approaches such as targeted lung screening will rely on the data being available to effectively target/segment parts of the population. Cancer screening standards should be optimised to focus attention on reducing inequalities in uptake and ongoing engagement with other elements of the screening pathway. It is important to note that targeted lung screening would not include all patients who develop lung cancer, particularly among never smokers, and so efforts to optimise the diagnosis of lung cancer through patient presentation and recognition and referral of symptomatic disease will continue to be vital.

Early Detection & Diagnosis

Research and innovation is critical to enabling earlier and faster diagnosis. Scotland has a strong track record of leading the UK in rolling out innovations – with Cytosponge and the Scottish Capsule Programme (SCOTCAP) for colon capsule endoscopy being implemented at pace.

There are good reasons for this, and to ensure Scotland remains a leader in the UK for rolling out new innovations they should continue to pursue and build on the model they have used.

Scotland effectively embedded real time evaluation into the implementation of these innovations, vitally ensuring this evaluation was fast, responsive and patient centric – with a strong focus on patient acceptance. This was evident in the rollout of SCOTCAP, where significant steps were taken to redesign both the test and the delivery in response to patient feedback – for example redesigning the recording equipment bag and ensuring patient expectations for waiting times and invasiveness were managed.¹⁰⁹

Further, a strong focus on implementation was evident throughout the SCOTCAP process, for example in IT system readiness prior to implementation and in the role of clinical champions to encourage acceptance by clinical staff. A strong focus on implementation was encouraged by an innovation partnership model including the company that makes PillCam, the NHS, academic researchers and the software designer.¹¹⁰ This enabled the team to quickly transition from evaluation to rollout. The establishment of the new National Centre for Sustainable Delivery for Health and Social Care (CfSD) in Scotland was a positive step for Scotland recognising

that research, innovation and the redesign of services will be central to NHS services going forward, and should provide a platform to build on the strong track record Scotland has in recent years.

The CfSD should conduct an evaluation of the innovation partnership model, with a view to replicating and building on this fast, responsive, and patient centric model of real-world evaluation for other innovations and continue Scotland's position as a leader in ED&D innovation. Following real-world evaluation, Scottish Government should consider how NHS capacity could be expanded to roll innovations out more quickly and equitably across the country.

The early detection and diagnosis (ED&D) research pipeline has a wide range of promising innovations. While much more research is needed, multi-cancer early detection (MCED) tests and polygenic risk scores which, alongside other patient and lifestyle factors, could further improve efforts to identify those at increased risk of disease.

The Scottish Government and NHS should provide the funding and support for a range of early detection research, identifying promising research and developing a pipeline that enables those innovations to be brought into the Scottish NHS at pace to ensure promising tests can be investigated at scale and in a real-world setting. For example, Scotland should aim to lead the way in comparing in a real world setting more than one Multi-Cancer Early Detection (MCED) test – driving forward a partnership that tests the model across the UK.

ECDCs

Providing quick access to diagnostic tests for patients whose symptoms are non-specific but concerning can help support the faster diagnosis of cancer. We therefore welcome the piloting of Early Cancer Diagnostic Centres (ECDCs) in Scotland, with their emphasis on giving patients with non-specific symptoms individualised assessments with the aim of achieving a diagnosis or ruling cancer out.

There is robust qualitative and quantitative evaluation currently ongoing for the three pilots. We also welcome that the Scottish Government has allowed the pilot sites some space to deliver ECDCs in a way they believe will work best for their patients.

Following the evaluation of the pilot sites, the Scottish Government should prepare to ensure the quick rollout of ECDCs and provide the resourcing that will be required to do so. It will be important to evaluate whether the resources given to the pilot sites is sufficient. As ECDCs spread, it will be important to effectively communicate their role to the clinical community and public, to ensure that they receive the clinical and public buy-in required for an effective implementation process.

The Scottish Government and the NHS must continue to share the robust ECDC evaluation process – embedding lessons and supporting the spread of ECDCs to other regions throughout Scotland. Building on this evaluation, the strategy should set clear and ambitious targets for rolling out ECDCs for all regions of Scotland.

Primary care

Access to primary care is vital to receiving a cancer diagnosis for many patients; based on the 2019/2020 National Cancer Diagnosis Audit, 65% of patients with a cancer diagnosis first presented with symptoms to primary care.¹¹¹ Our patient network repeatedly highlighted how important prompt GP referral is to support early diagnosis, as well as ensuring clear clinical guidelines and diagnostic pathways for GPs. However, many patients have significant issues accessing primary care in Scotland, with longstanding challenges such as a lack of primary care workforce capacity and rurality in certain regions of Scotland, some of which were exacerbated by the pandemic.¹¹²

Positive steps have been taken in recent years to tackle shortages within the GP workforce in Scotland. The 2018 GP contract aimed to make being a GP more attractive to recruit and retain more GPs, while the Scottish Government has said they are on track to meet their commitment to increase the size of the GP workforce by 800 by 2027. The number of GPs in Scotland increased by 74 in the year to 30 September 2021.¹¹³ However, following the pandemic, there is more that needs to be done, and this momentum must not be lost.

The recommendation in question 10 for the Scottish Government to set out long-term funding plans to deliver a sustained expansion of the cancer workforce must include the primary care, in particular the GP, workforce.

Rurality in Scotland presents some significant challenges in accessing primary care for people in some communities. In recent years, there has been a positive focus on tackling the issues associated with rurality and primary care, for example through the Remote and Rural General Practice Working Group. In January 2020, the Shaping the Future Together report made recommendations for improving the work done to tackle the unique challenges faced by those delivering primary care in rural settings.¹¹⁴

The Scottish Government should conduct a review of the progress made against the Shaping the Future Together report, and consider where further action is required in light of the pandemic to improve access to primary care in rural areas.

Expanding the number of different roles within primary care and adopting skill-mix approaches to use that workforce more efficiently can help support primary care capacity and ensure all patients get the care they need. The recent National Workforce Strategy for Health and Social Care in Scotland demonstrated the Scottish Government's commitment to a multi-disciplinary team workforce in primary care. The primary care multidisciplinary team workforce increased from 313 in March 2018 to 2,463 in March 2021.¹¹⁵ New roles could be developed that can support the early diagnosis of cancer, which is a gap in current efforts to increase the use of new roles in primary care in Scotland. By developing primary care roles dedicated to improving cancer early diagnosis, Scotland has the potential to lead the UK towards a more innovative primary care model that works for cancer.

The Scottish Government should conduct an assessment of the current primary care workforce mix and how it could be optimised to support increased referral for cancer, in particular considering where roles dedicated to improving cancer early diagnosis from primary care could be developed.

[Question 9c: Please explain your answer and provide any additional suggestions.](#)

[Responding promptly to signs and symptoms](#)

The strategy should include measures to help people respond promptly to cancer signs and symptoms, encouraging timely help seeking. Awareness, while vital, is not sufficient for encouraging help seeking behaviour and attitudinal and other barriers must also be considered and addressed. It is also important to encourage everyone to seek help, and tackle the barriers to people doing so.

Results from CRUK's Cancer Awareness Measures survey highlighted key barriers to help-seeking in Scotland which should be considered in the development of public awareness campaigns.¹¹⁶ The top reported barriers to help-seeking were practical barriers, such as difficulties getting an appointment, and worries about wasting healthcare professional time. Campaigns by the Scottish Government must therefore reassure people that their GP wants to see them and encourage them to keep trying to make an appointment, whilst being sensitive to concerns about service capacity.

Many respondents were also unsure how long to wait before contacting their doctor about changes in their health. Campaigns should help address this by giving specific time frames for what is considered timely help-

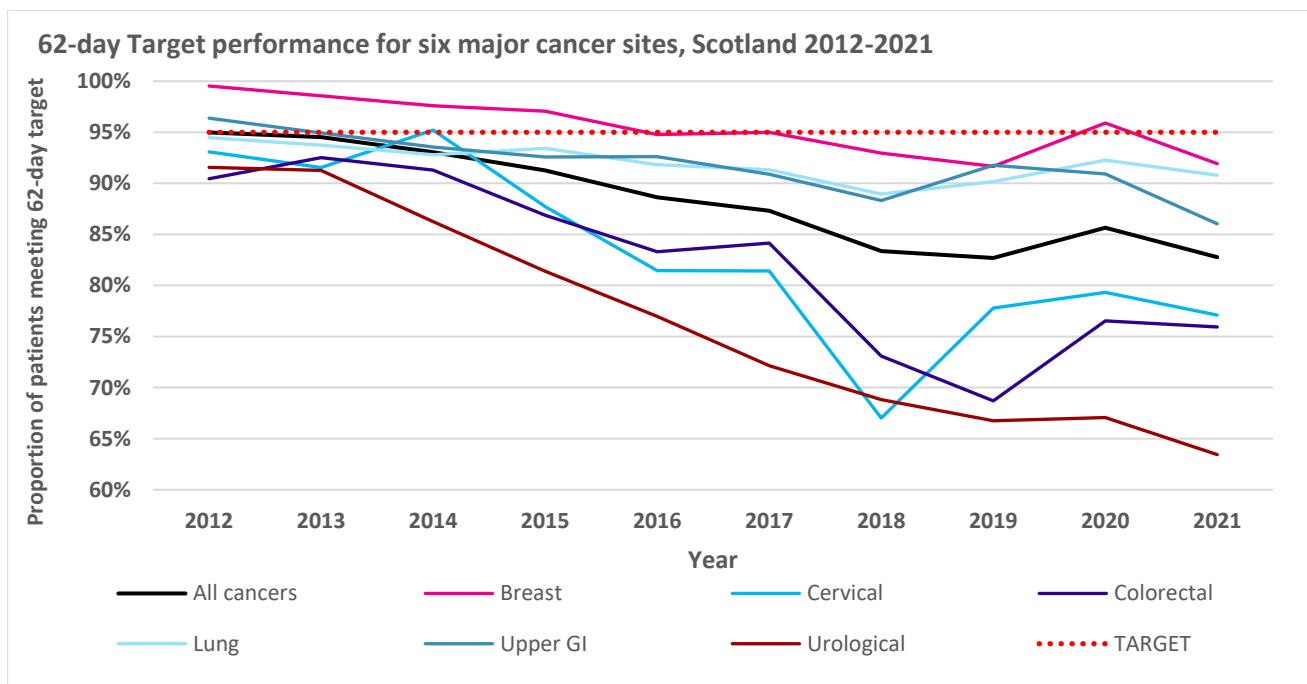
seeking for different symptoms, and encouraging timely help-seeking for symptoms that don't go away. Public activity can also be used to support positive engagement with cancer screening programmes, and could help to address inequalities. Robust evaluation of campaigns and other activity is important, to ensure they are reaching the groups they aim to reach and achieving their aims.

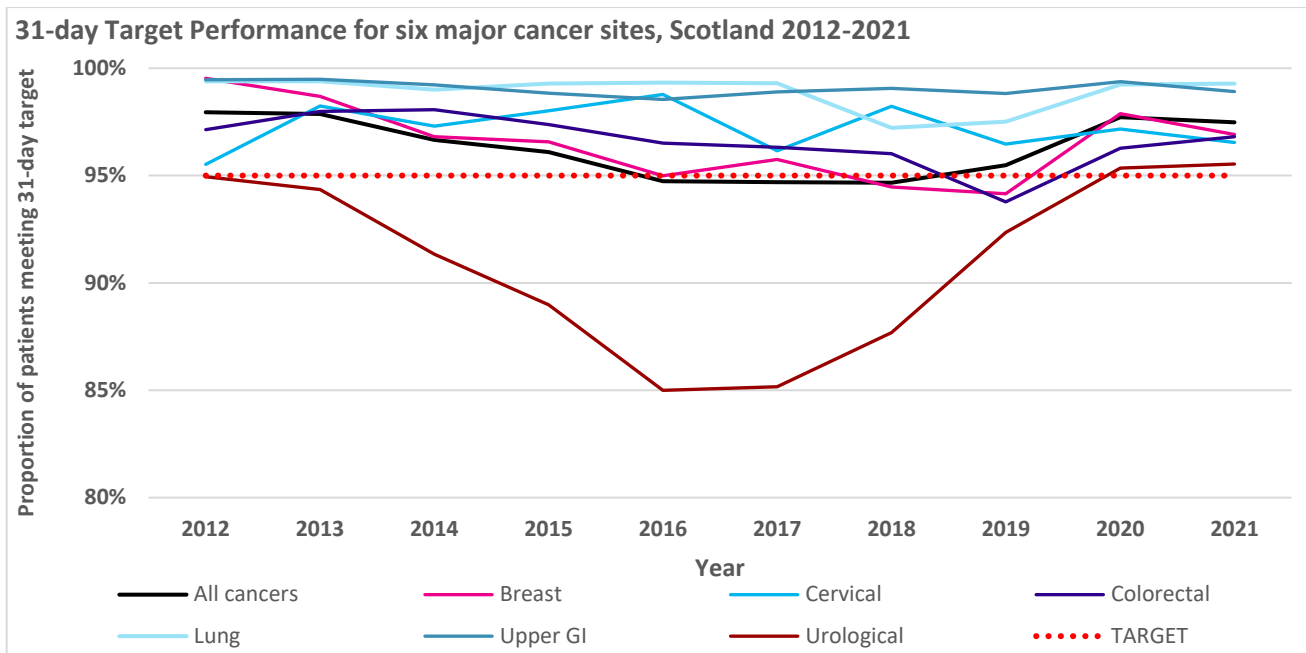
The Scottish Government has produced several cancer awareness campaigns in recent years, for example targeting people with lung cancer symptoms following lower referrals due to the pandemic. They should evaluate the impact of these campaigns to build on where they have worked well, while working with third sector partners to ensure these are as effective as possible.

The cancer strategy should make a commitment to sustained, multi-year funding for public awareness campaigns and activity encouraging positive health behaviours.

[Monitoring and reporting the interval between receiving an urgent suspected cancer referral or screening referral and a diagnosis or having cancer ruled out](#)

NHS Scotland's target that 95% of eligible patients should wait no more than a maximum of 62 days from urgent suspected cancer referral to first treatment has not been met since 2013 for all cancers combined – no individual cancer site has consistently met the 62-day target since its introduction.¹¹⁷ In spite of this poor performance, the target for 95% of patients diagnosed with cancer to start treatment within 31 days of the decision to treat has seen much better performance – with all cancers combined performing above the 95% target since its introduction in 2012 and all individual sites performing above as of 2020. This demonstrates that the significant bottleneck in the cancer pathway for patients in Scotland is in diagnostic services.





Note: For 31 and 62-day Target Performance by Cancer Site for all available sites, Scotland 2012-2021, see [Appendix 3](#).

We propose that NHS Scotland considers introducing a new cancer waiting times target for 95% of people who receive an urgent suspected cancer referral or have been picked up through cancer screening, to have cancer ruled out or receive a diagnosis within 28-days. Given ongoing difficulties in cancer services, exacerbated by the pandemic, it would be appropriate to phase the introduction of this target – for example initially aiming to meet an 80% threshold, while setting out a clear plan and timeline for meeting the higher target.

In introducing the new target, the Scottish Government should evaluate the implementation of the Single Cancer Pathway in Wales and the Faster Diagnosis Standard in England, for example looking at how to secure alignment between different standards and cancer pathways, and considering which patients may not be captured.

Measuring the time taken for someone to receive a definitive diagnosis or ruling out of cancer could offer significant benefits. This would be a meaningful target – both clinically and to patients – that could help catalyse and monitor diagnostic performance, providing further incentives to accelerate a part of cancer pathway that is meaningful to patients and encouraging the faster diagnosis of more cancers. It would enable evaluation of how the full diagnostic pathway is performing. Using one clear headline performance figure would also be helpful for clear communication with patients helping improve patient experience by setting clear expectations and helping ensure they receive a diagnosis as soon as possible during what can be an incredibly anxious time.

[Innovative models of care](#)

Shifts in how the public and patients engage with the health service could also support earlier diagnosis. New models of care involving pharmacy teams in the assessment and/or referral of patients, and pathways which facilitate a patient to self-refer into diagnostic or other settings are areas with significant interest.

New models of care must be subject to pragmatic but robust evaluation. They must be driving the desired impact for patients while not exacerbating inequalities by facilitating entry and diagnosis for the more health-engaged.

The Scottish Government should deliver engagement programmes, in particular targeting the less health-engaged, to prepare the public for shifting models of care, ensuring they are engaged in, and equipped to respond to and get the most out of, new routes to cancer diagnosis.

High quality care

Question 10: In your experience, what aims or actions would you like to see under any of these areas?

Workforce

Scotland has chronic shortages in the workforce specialities key to diagnosing and treating cancer. Recent figures from the BMA Scotland found that the consultant vacancy rate in the NHS in Scotland could be as high as 15%, with no improvement made over the last year (when vacancies excluded from official figures are included).¹¹⁸ Shortages are evident across the cancer pathway; for example, the Royal College of Radiologists (RCR) 2020 UK-wide census estimated that there was a 33% shortfall in the UK's clinical radiologist workforce and a 15% shortfall in the clinical oncology consultant workforce.^{119,120} Similarly, the most recent UK workforce census by the Royal College of Pathologists found that 68% of the hospitals in Scotland that use locums do so because of insufficient applicants for vacancies.¹²¹

These have hampered progress for years. It is vital that the strategy includes long term planning and investment to build a cancer workforce fit for the future as a priority, or risk workforce shortages continuing to severely limit the Scotland's capacity to close the gap with the best-performing countries. This was also recognised by our patient network, who highlighted the importance of investing in the workforce to make it quicker and easier to get cancer tests and treatments.

It is unavoidable that service capacity will need to grow to meet the additional need caused by Scotland's ageing population – even before accounting for existing shortages in the cancer workforce – with the number of people aged 65 and over projected to grow by 30% by mid-2045.¹²² The older we get, the more likely we are to develop cancer.¹²³ An ageing population means growing demand for cancer services, and a growing number of patients with comorbidities and/or complex needs.

In March, CRUK welcomed the Scottish Government's National Workforce Strategy for Health and Social Care in Scotland, which set out a positive vision for growing the cancer workforce. However, to achieve this vision, detail is needed on how the strategy would be implemented at the pace necessary to turn the positive ambitions to tackle shortages in the cancer workforce into a reality. Central to this, will be a long-term funding settlement that provides cancer services in Scotland with the workforce required to meet their goals.

Robust workforce planning supported by regular projections of the future supply and demand of the health workforce can help to ensure enough staff are trained to meet future demand. The Workforce Strategy included welcome measures to improve the planning capacity of health boards and HSCPs, focusing on the quality of workforce data, but more regular, transparent, national modelling would help to tackle the workforce issues faced by the NHS across Scotland and support a comprehensive, 'Once for Scotland' approach to workforce planning that averts any risk in regional variation in capacity and capability in workforce planning. This is vital both to ensure that the workforce has the capacity to meet future demand, and that they have the skills to make best use of the innovations that have the potential to improve cancer outcomes.

The Scottish Government should publish regular and transparent modelling of the current and future health workforce trends to support workforce planning. They must then set out long-term funding plans to deliver a sustained expansion of the cancer workforce to meet future demand for cancer services.

There is evidence of regional variation in the cancer and diagnostics workforce in Scotland, with the RCR finding that the North of Scotland has just 6.4 clinical radiology consultants and specialty trainees per 100,000

population compared to 10 and 10.2 per 100,000 population in South East and South West Scotland respectively.¹²⁴ As highlighted by our patient network, this is not good enough – “your health shouldn’t be decided by your postcode”.

In some professional groups, Scotland has taken positive action to tackle this variation in recent years. The ScotGem GP training centre, in which consultants take time away from a clinical setting to deliver training, and later offers rotational training placements across rural Scotland, has made strides to ensuring there is sufficient capacity in primary care across Scotland. Evaluating this model to consider in which other professions it could be applied could help tackle variation in the cancer workforce in Scotland.

The Scottish Government should implement, and robustly evaluate, targeted measures to tackle regional variation in the cancer workforce in Scotland. These could include financial support for new trainees to incentivise them to locate in more rural areas, investment in digital infrastructure that will make local shortages less burdensome, for example digital pathology, or training schemes that encourage placements in rural areas of Scotland.

A clear focus on supporting retention in the Scottish cancer workforce will also be vital to ensure that already limited capacity is not lost. This was a key gap in the Workforce Strategy, with no specific section highlighting how to support retention despite its central role in maintaining capacity within the existing cancer workforce. Normalising and embedding flexible working practices is one area that can aid wellbeing and retention in the health workforce. Healthcare providers should evaluate existing flexible working practices, and where they aid the wellbeing of staff without jeopardising patient care, normalise and embed them, including investment to support implementation. Healthcare providers should carve out time and provide incentives – for example clearer opportunities for career progression – for continuous professional development in the cancer workforce, with support from national bodies to do so.

A more comprehensive understanding of why people are leaving the cancer workforce is a prerequisite to an effective plan to reduce this. Both nationally and locally, standardised data on why people leave jobs in the cancer workforce should be collected, to feed into future policies that aim to minimise burnout and maximise retention.

The development of comprehensive plans to maximise staff wellbeing and skills, and to improve retention, should be embedded into Health Boards existing reporting mechanisms. For example, they should evaluate existing flexible working practices, and where they aid the wellbeing of staff without jeopardising patient care, normalise and embed them, including investment to support implementation. Healthcare providers should carve out time and provide incentives – for example clearer opportunities for career progression – for continuous professional development in the cancer workforce, with support from national bodies to do so.

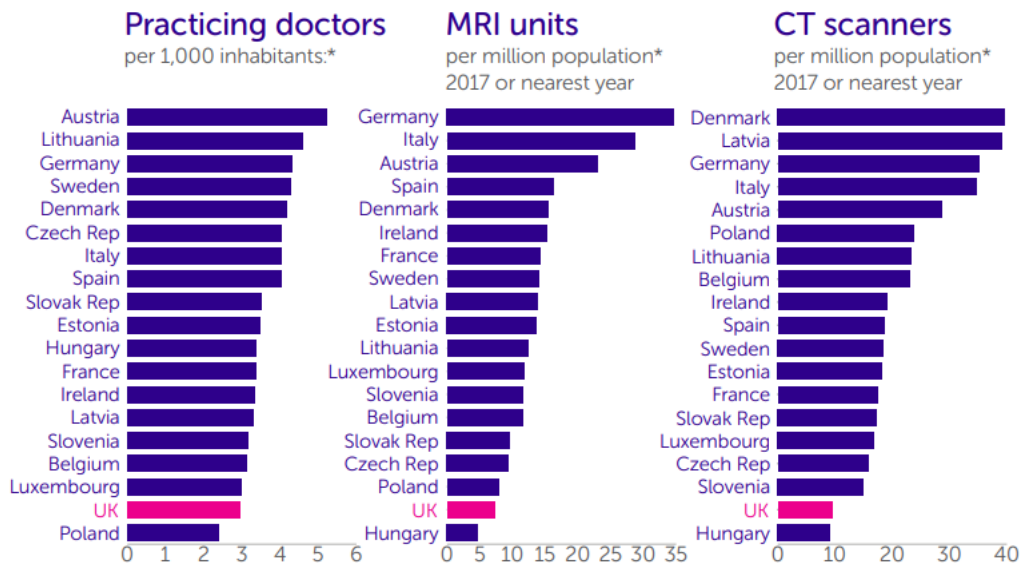
Capital investment

Alongside investment and planning to expand the cancer workforce, investing in the Scotland’s health infrastructure – key diagnostic and treatment equipment, facilities and IT systems – is vital.

A world class cancer service must have strong foundations. At present, this is far from the case – NHS Scotland faced a £1 billion backlog in 2019 (capital budget £288m)¹²⁵. There are widespread reports of inadequate building infrastructure and core health facilities hampering basic service delivery as well as wider innovation.^{126,127} Capital spending is therefore essential to stop further deterioration of health service facilities and ensure they provide the necessary foundation for improving cancer care.

But capital investment must go further and substantially expand diagnostic and treatment capacity. We know that Scotland, along with the rest of the UK, lags behind comparable countries in diagnostic capacity. ICBP data shows that Scotland has one of the lowest numbers of PET-CT scanners relative to its population of the ICBP countries, and has also been slow to acquire them, despite their increased sensitivity allowing for more accurate diagnosis and staging compared to CT scanners.¹²⁸ To deliver high quality, timely care, it is essential that the strategy expands capacity to close the gap with the best-performing countries and ensure cancer services are equipped to keep up with patient need.

UK is lagging behind comparable EU countries



*UK and OECD EU nations

Source: BMA analysis of OECD Data, NHS Digital Workforce Statistics. Note: Data included for available countries only excluding Iceland, Norway and Switzerland. Includes general practice. OECD "Health at a glance 2019: OECD indicators".

The Government must match an ambitious cancer strategy with sufficient and sustainable capital funding to maintain and expand health infrastructure across Scotland, supporting the roll-out of more innovative, efficient care.

In particular, this should include:

- ***Sufficient core capital funding to ensure Health Boards can replace their stock of key diagnostic equipment at the end of its lifespan and continually expand capacity as needed throughout the 10 year period***
- ***Ongoing central investment to continually improve digital capabilities, including improving interoperability within and across different care settings, and digitisation in diagnostic and screening services***

Service delivery

A 'Once for Scotland' approach will be invaluable to ensuring Health Boards work collaboratively to deliver high quality care for those affected by cancer across the country. Regional Cancer Networks have a vital role in supporting collaboration across geographies and ensuring a unified strategic approach to service planning and delivery, while retaining flexibility to address local priorities. During the pandemic, collaboration across NHS Scotland played an invaluable role in keeping services running and ensuring patients could be seen. Moving forward, the benefits of putting patients first and collaborating to ensure they receive the best care possible must be maintained.

Joining up IT systems and data standards will ensure that patient information is consistently recorded across Scotland. This will support more effective monitoring and comparisons of performance and variation, and can be used to identify and learn from best practice care.

Aligning approaches to recognition and referral will also help improve quality of care, ensuring that as referral guidelines are updated, they are applied and adhered to consistently to provide high quality management for all.

The strategy should commit to collaboration between the Scottish Government, Cancer Networks and Health Boards to ensure coordination in the interests across Scotland. In particular, this should focus on collaborating at a national level in areas where a unified approach will bring significant benefits, such as IT systems and cancer recognition and referral.

Inequalities

In answer to question 16, 'Impact Assessment', we set out actions which should be taken to understand the issue better and address any inequalities in Scotland, based on our understanding of inequalities in patient experience in the rest of the UK.

Accessibility

Ensuring that patients experience accessible, high quality care, wherever they live, is essential. In answer to question 16, 'Impact Assessment', we set out recommendations which the strategy should commit to in order to ensure this.

Safe, effective treatments

Question 11b: In your experience, what aims or actions would you like to see under any of these areas?

Surgery

The next ten years will see rising demand for cancer surgery as cancer incidence increases and efforts to improve early diagnosis hopefully results in a shift in stage at diagnosis. ***The cancer strategy must therefore commit to ensuring that capacity keeps pace with demand, implementing ongoing reviews of capacity, demand and workforce requirements to support planning and delivery of all services required for cancer surgery, including high dependency or intensive care required for patients following complex procedures.***

Optimal configuration of surgical services and pathways is different for different cancer types. Centralisation and specialisation may offer significant benefits in the form of improved surgical and cancer outcomes, but is not appropriate for all types of cancer surgery and may in fact create challenges for patient access. Separation of elective and acute surgeries using surgical hubs helped to keep surgical services running during the COVID-19 pandemic and similar centres i.e. new treatment centres may have a role to play in increasing surgical capacity, but again are unlikely to be appropriate for all types of cancer surgery.

The strategy should commit to identifying where the delivery and organisation of cancer surgery services in Scotland can be optimised, considering the patient population and geography, workforce, kit, capacity and infrastructure requirements, and the potential impact of service reconfiguration on the adoption of innovation. Strategies to mitigate any potential challenges in patient access to services should also be a key consideration. Reconfiguration of cancer surgery services has been successfully implemented in several different countries, including centralisation of ovarian cancer surgery in Scotland, providing insight into how and for which cancer types and procedures this may be the best outcomes for patients.

Radiotherapy

Similarly to cancer surgery, the demand for radiotherapy is likely to increase over the next ten years as cancer incidence increases and there is a shift towards earlier diagnosis. Innovations in the planning and delivery of radiotherapy are also likely to impact capacity in radiotherapy services. These shifts will require ongoing reviews of demand, capacity, and optimal workforce requirements to plan and optimise radiotherapy provision.

CRUK welcomed the ambition in *Recovery and Redesign: An Action Plan for Cancer Services* (2020) to work with the Scottish radiotherapy community to develop a national plan for Scotland's radiotherapy service, and the subsequent convening of the National Radiotherapy Programme Board in 2021. If implemented and funded appropriately, the recently published National Radiotherapy Plan for Scotland has the potential to drive improvement in radiotherapy services over the next few years. ***The cancer strategy should therefore outline how the actions in this plan will be taken forward, particularly those relating to optimisation of the workforce and improving specialist training.***

As the National Radiotherapy Plan runs until 2025, the cancer strategy should also set out clear, longer-term plans for radiotherapy services, including planning for the evaluation and implementation of new technologies (such as those discussed in the attached paper on the EDD and treatment innovation pipeline).

Systemic anti-cancer treatment

Pathways to adoption are more clearly defined for systemic anti-cancer treatments, but with the increasing complexity of newer approaches such as immunotherapies, histology-independent drugs and combination treatments, it is important that regulatory and Health Technology Assessment (HTA) pathways continue to evolve to maintain timely access to innovative treatments for patients. Furthermore, across a number of countries, there is a trend towards increasing volumes of medicines receiving regulatory approval on the basis of immature, early phase trial data and expedited approvals. Increasingly stratified and smaller patient populations can also make it challenging to determine effectiveness and value via randomised controlled trials (RCTs). These factors create challenges in determining medicines' long term clinical benefit and cost-effectiveness at the point of HTA.

Flexible pricing mechanisms such as outcome-based payment (OBP) can speed up access to some licensed medicines with immature trial data. OBP can also help to address rising cancer medicine prices¹²⁹ by ensuring the NHS only pays for the outcomes that are achieved for individual patients. However, limitations with data capture, data infrastructure, and healthcare professionals' capacity limit the ability to establish optimal flexible pricing schemes such as OBP.¹³⁰ This is especially the case for patient reported outcomes measures (PROMs), which despite being collected and recorded within patient health records in some settings, are not collected in a usable way.¹³¹

As part of the strategy, the Scottish Government and NHS Scotland should work with relevant stakeholders to identify and implement appropriate pilot studies to determine opportunities and barriers to OBP in Scotland in the next 3-5 years. This should build on recent research by the University of Edinburgh, DATA-CAN, and others recommending three options for piloting OBP, including a retrospective feasibility study, a prospective pilot study, and a PROMs methodology study¹³². In the next ten years, these pilots should generate intelligence and knowledge to determine the optimal implementation of national level OBP schemes.

Data, technology and measurement

Question 13b: In your experience, what aims or actions would you like to see under any of these areas?

Data

Data is fundamental to our progress against cancer. Data and data-driven technologies underpin every effort we make to understand cancer, prioritise resources and identify disparities. However, much of this potential is untapped due to fundamental issues right across the data lifecycle.

In any discussions about the use of health data for purposes beyond direct patient care, public trust and confidence is fundamental – and cannot be taken for granted. Mistakes – real or perceived – could negatively impact research and outcomes. While consultation with people affected by cancer highlights strong support for data being used to improve patient outcomes and experience¹³³, this must not be taken for granted. ***We recommend that the strategy commits to ongoing, meaningful patient and public engagement and involvement with regards to data collection, safeguarding and use. This includes ensuring that public engagement reaches an audience that accurately reflects the demographics of the population. Communications should address key areas of concern for patients, and include details on who will use data, for what purpose, what controls and sanctions are in place, and the options people have to opt-out, as well as the benefits of data use.***

This is essential for ensuring equitable outcomes and representation of all groups. England’s recent attempt to launch the GP Data for Planning and Research (GPDPR) programme exemplifies the risk of getting this wrong, where the use of National Data Opt Outs increased by more than a million in the first month after its announcement. The GPDPR programme has subsequently paused its launch until the programme can meet a set of tests for improving public and patient confidence.¹³⁴ If large numbers of people opt out of sharing their data, it risks reducing the completeness and quality of the datasets. This can have a major impact on the representativeness of the data, potentially increasing inequalities in outcomes for cancer patients as well as negatively effecting research, specifically into rare diseases where incidence is already low and further shrinking of data could compromise analyses.

Concerns have focused on the intended use of data, who is using it and what controls and protections are in place. These concerns can only be addressed through meaningful, ongoing public engagement, with an audience that accurately reflects the demographics of the population, and which is conducted in partnership with researchers, clinicians and charities.

Consultation with people affected by cancer highlights strong support for data to be used to improve research, patient outcomes and patient experience. For example, 94% of those who responded to our patient involvement network consultation said they support the use of data related to their care being used to improve cancer services and research. Many recognised the importance and value of their data to improving the experience and care of others:

“Any data which can be used to help prevent cancers or improve the care for others should absolutely be used”

“I feel that anything that can be gained and used to help others based on my own experience means I didn't suffer for no reason.”

While the stated areas of focus for data are sensible, there are important additions that would either underpin or enable the focus areas that we would expect to feature prominently in the strategy. **Below details our recommendations for the collection and reporting of specific datasets, and the underlying informatic and analysis infrastructure.**

Cancer datasets

There are significant limitations to using some of the key datasets for cancer due to issues with completeness and timeliness. In its first 3 years, the strategy must prioritise providing timely, high-quality, transparent, and integrated data to enable a better understanding of the cancer landscape in Scotland and particularly where

variation exists. This is crucial to understand where improvements need to be made, and to measure and drive forward the progress set out in the rest of the strategy.

Specifically, CRUK recommends that the cancer strategy commits to:

- **Maintain high quality reporting of cancer incidence and mortality, wherever possible broken down by tumour site and socio-economic characteristics.**
- **Extend publicly available staging data to all cancers combined as well as a wider range of cancer site specific data. Data should be published routinely and regularly, with information on individual staging categories available.**
- **Consider additional measures which place renewed focus on diagnosis for patients alongside maintaining and further understanding variation in Cancer Waiting Times data.**
- **Continue to improve the completeness, accuracy and consistency of primary care data relevant to informing the cancer pathway and patient care and integrate this with other patient data to allow for analysis of the whole cancer pathway.**
- **Consider routinely publishing data on routes into diagnosis, especially emergency presentation by site and Health Board**
- **Consider integrating PROMS into QPIs rather than treating as separate priorities.**
- **Improve the quality and availability of data relating to health inequalities, and utilise this to improve population health and patient outcomes. Data should be routinely collected on protected characteristics including age, gender, ethnicity and sexuality, and socio-economic group as well as other aspects of inequality, and published in a timely and accessible manner. Data should also be collected to better understand any inequity of access to cancer care and research for those living in Scotland's urban areas and rural communities.**
- **Consider collaboratively developing a set of agreed minimum indicators for understanding the entire cancer pathway in Scotland.**

Informatics and analysis

Broadly speaking, any future strategy for cancer should seek to align with and support the delivery of the transformative plans captured in the Scottish Cancer Intelligence Framework (SCIF), which is being delivered primarily via Public Health Scotland. **This includes delivering on the ambitions to:**

- **Deliver a 'Once for Scotland' approach, joining up intelligence across systems, and support interoperability at local and national levels.**
- **Place an emphasis on financial resourcing to attract and retain high quality analytical staff.**
- **Ensure any adjunct cancer workforce plan includes cancer analysts and data scientists as a distinct resource category.**
- **Ensure proportionate emphasis on effective resourcing of MDT data management and Health Board level data collection.**
- **Ensure GPs and other primary care health professionals and services are aware of, engaged with and able to utilise the primary care data opportunities presented by SPIRE, both across the full primary care pathway and at the interface with secondary care.**

CRUK welcomes the recent developments to the Scottish Cancer Registration and Intelligence Service (SCRIS) that aim to make cancer data more readily available and make data on waiting times, screening, diagnosis, and treatment more easily linked to the Registry. **CRUK recommends that the strategy builds on this momentum to:**

- ***Harness the increased data and intelligence available through SCRIS and continue to develop SCRIS ambitiously and incrementally to meet patient and clinical needs, and support service improvement.***
- ***Continue to progress the ambition to harness primary, secondary and social care data.***
- ***Ensure sufficient capacity and capabilities to generate intelligence from data.***
- ***Realise the benefits of having a national view of SACT data in Scotland.***

Acting on the opportunities outlined here in the short to medium term would provide an evidence base to measure and monitor progress in the longer-term timeframe of the strategy. Longer term, the Scottish cancer strategy must ensure there are continual improvements in cancer data collection and use. This should include working towards real-time or near real-time datasets over the 10 year timeframe as well as improving the ability to collect, store and integrate diverse patient datasets such as imaging data, genomic data, GP records and electronic health records.

Data is fundamental to driving research into cancer risk, biology, the development of effective ways to diagnose and treat cancer, and optimising cancer care. Research access to cancer data is integral to reducing cancer incidence and improving patient outcomes. ***Therefore, the cancer strategy must include an overarching commitment to improve access to data for research. This should include commitments to:***

- ***The development of service level standards for data access for research***
- ***Collaboratively developing a data sharing and access framework, bringing together the health system, data custodians, academic and industrial researchers, and patients.***
- ***Working with Scottish data controllers and authorities on ensuring that data can be accessed within TREs and secure environments. It is essential that these are interoperable with other TREs, including CRUK's TRE that is UK wide in scope.***

Fundamental to the above, the Scottish government must ensure Information Governance arrangements maximise data utilisation for the benefit of the public. ***We also recommend that NHS Scotland explore a streamlined, rapid process for appropriately accredited stakeholders including researchers, third sector and NHS.*** It will be essential to embed meaningful public involvement and engagement in such exploration from the outset.

Quality Performance Indicators (QPIs)

Audit and quality improvement play an important role in improving the delivery and quality of care but is typically not timely enough to positively impact on the care and outcomes of current patients. In order to support the delivery of world leading services for all cancer patients, the new cancer strategy should commit to transforming the capacity and capability of systems to enable near real-time monitoring of data on cancer care. Development and implementation of the required infrastructure, training and resource will support timely assessment of both individual patients' care and local, regional and national performance. This in turn would support the identification and implementation of best practice, commissioning, benchmarking of services, and evaluation of new technologies/approaches.

In the shorter-term the strategy should commit to improving the current approach to audit and quality improvement in Scotland. This should include:

- ***the review process, reporting and impact of the cancer QPIs,***
- ***approaches for identifying and sharing best practice, and***
- ***the identification and piloting of alternative approaches to audit and quality improvement, learning from best practice in Scotland and internationally.***

Scotland is well placed to deliver considerable improvements to the collection and use of QPIs and could therefore set a precedent for the rest of the UK.

Multidisciplinary teams (MDTs)

As cancer incidence has increased, the number of patients to be discussed in MDT meetings has significantly increased. The complexity of patients' conditions and of their treatment options has also increased. MDTs may therefore struggle to find the time to have full discussions about individual patients, meaning that patients are discussed for a few minutes only, potentially without the input of the whole MDT or without consideration of key information such as patient preferences, comorbidities etc. This is likely to disproportionately affect more complex patients.

Research commissioned by Cancer Research UK¹³⁵ in England produced several recommendations to help streamline MDTs and improve the quality of discussions. These included establishing a triage process to identify patients that should follow well-established protocols, allowing more time for complex patients to be discussed. This modernised way of working was since accepted and successfully piloted by NHS England. The reforms proposed would ensure a more person-centred discussion at each MDT and would free up precious capacity.

The Innovative Healthcare Delivery Programme at the Usher Institute is carrying out welcome work to improve the efficacy and effectiveness of MDTs by improving access to clinical data.¹³⁶ In anticipation of increased pressure on MDT meetings' time for discussion of individual cases, ***the cancer strategy should include measures to review the quality and effectiveness of MDTs, ensuring that evaluations and learnings from current activity are captured. The piloting of approaches to streamline and improve the quality of discussions should be considered, where appropriate, learning from and building on ongoing activity such as the Regional MDT Improvement Programme in the West of Scotland Cancer Network.***

MDTs also offer the opportunity for an alternative approach to capturing rapid information on stage at diagnosis. Capturing the staging information shared with patients during an MDT meeting could feed into more timely staging data collection. data collection. data collection. data collection. data collection. data collection.

Research, technology, and innovation

Scotland has a strong research base for its size, significantly overperforming in competitive research funding per capita.^{137,138} As well as benefiting patients, life sciences research is a key component of the Scottish economy. Between 2010-2017, the sector's turnover grew by 90% to reach £6.5bn and is expected to contribute £8bn to the Scottish economy by 2025.¹³⁹ As well as these research strengths to draw on, Scotland's Health Boards are at a scale that provides a critical mass but with relative simplicity. Therefore, there is an opportunity to rapidly adopt new innovations and drive real improvements in the clinical research environment that may not be possible in other parts of the UK. However, there are barriers to be addressed in Scotland to enable a collaborative and competitive research environment, improve the availability of clinical research funding, ensure healthcare professionals can engage in research and enable more patients access to research.

One barrier is the ability of Scottish universities and research organisations to compete with the increasing critical mass of research expertise at larger research institutions in the UK and internationally.¹⁴⁰ Increasing collaboration within Scotland and ensuring long-term strategic support for research infrastructure is a solution to this and would enable researchers in Scotland to compete more effectively for major research funding. An example of this collaboration across Scotland is the new CRUK Scotland Centre which was announced this year. By collaborating and pooling resources and expertise, this new centre is maximising the value of Scotland's

clinical and scientific resources.¹⁴¹ While existing collaborations are positive, medical research is becoming increasingly competitive and so we urge Scottish Government to be more ambitious in strengthening its research base so it can truly compete with the largest research clusters globally.

As part of the cancer strategy, we would like to see a commitment for the Scottish Government, including the Chief Scientist Office (CSO) and the Scottish Funding Council (SFC), to work collaboratively to pool resources across the country to create Scotland-wide research infrastructure that has the potential to be world-leading.

Clinical trials

An immediate priority is the recovery of clinical cancer research from COVID-19. Most cancer clinical trials paused recruitment during the pandemic's first wave, and recruitment remains 43% below pre-pandemic levels.¹⁴² The UK's recovery is now being outpaced by other countries such as Italy and Spain, and 3 in 10 people working in the UK on clinical cancer research say they are more likely to leave the field in the next five years due to their experiences during the pandemic. Intelligence from our research networks shows that recovery in Scotland was faster and was less fragile than recovery in other parts of the UK. Scotland could be well placed to lead the way in developing a more robust, quality driven approach to their national portfolio of clinical trials. To do this they would need to implement a national portfolio management board, incentivise quality studies (e.g. innovative trial design) and manage the portfolio robustly.

As part of the cancer strategy, the Scottish Government should commit to producing a national cancer research strategy that closely aligns with national cancer services remobilisation planning. The strategy should be developed with Scotland's areas of research strength in mind and based on a diversity of views through co-design with academia, government, the NHS, industry and the third sector.

Recovery alone is insufficient to improving cancer outcomes; clinical research capacity must also expand. One key concern is the development and retention of clinical researchers and the lack of opportunities for health professionals to engage in research. It is crucial that research time is expanded to allow health professionals to take part in research. It has been highlighted that the number of CSO Clinical Academic Fellowships available is lower than the NIHR Academic Clinical Fellowships, limiting the number of health professionals that can take part in research. Our research has shown that challenges in the wider NHS workforce were beginning to impact clinical research.¹⁴³ It is crucial that these gaps are addressed to allow patients to take part in research. ***As part of the cancer strategy, we would like to see the following commitments:***

- ***NHS Scotland should operate a pilot scheme that offers a cohort of NHS staff contracts that include dedicated time for research.***
- ***Scottish Government should uplift long-term funding for the Chief Scientists Office (CSO). At a minimum, these funding increases should be in-line with broader uplifts in public R&D investment and keep pace with future increases in inflation.***
- ***The Scottish Government, NHS Health Boards and CSO should work with the medical research community to develop sustainable approaches to ensure health service staff have sufficient time to develop, undertake and participate in research.***
- ***Health Boards should embed research into their strategies for staff recruitment and retention, and workforce development planning. These local efforts should be reinforced by ambitious national strategies for supporting clinical research that recognise the NHS as an indispensable part of the research environment***

Our report published in 2021, *Creating Time for Research*, found that funding for clinical research is often 'skewed towards larger Health Boards with established research capacity and expertise'.¹⁴⁴ As a result, cancer trials are typically clustered in urban centres with specialist infrastructure and personnel, which creates stark

regional differences in patients' access to research. The results of the Scottish Cancer Patient Experience Survey (CPES) show that less than 20% of patients in Scotland had a discussion about taking part in research, which is low compared to the average across the UK.^{145,146} The Scottish Government is working to increase public participation in health research through the NHS Research Scotland (NRS) research networks which aims to increase the number of trials available to patients across Scotland. Several members of our patient network noted they had never been involved in discussions about clinical trials, suggesting there is a "lack of knowledge of how to get involved" and that the onus is often on patients to research trial options. It is therefore crucial that the CSO, NRS and the Scottish Government continue to take steps to increase research participation. ***As part of the cancer strategy, we would like to see the following commitments:***

- ***NHS Scotland should continue to promote engagement in health research and should seek further opportunities to increase the number of conversations with patients about clinical research participation to be more in line with other UK nations.***
- ***Scottish Government should take steps to make clinical cancer research more accessible and inclusive by working with UK Government to review the regional distribution of research and building on its investment in widening opportunities for careers in clinical research. Consideration should be given to accessibility and inclusivity challenges unique to Scotland.***
- ***Lessons should be learnt from COVID-19 to make cancer trials more accessible, including by investing in the workforce and infrastructure required to deliver decentralised clinical trials.***

Scotland must ensure it has a future-oriented research environment that enables delivery of innovative research efficiently and equitably. Due to the size and setup of the research and the health system in Scotland, there is potential for Scotland to have a single front-door for clinical studies. For example, Scotland has the potential to streamline the costing and contracting of clinical research in the NHS which is one of the most significant bottlenecks to fast and efficient clinical trial set-up.¹⁴⁷ Costing is a key source of inefficiency when setting up clinical trials, especially non-commercial trials. A trial must agree separate costings with each site involved in the study. This decentralised approach makes costing much more complex, as the Sponsor must coordinate across multiple sites, which, in turn, makes the process time-consuming and inefficient. Contracting creates similar inefficiencies in trial set-up. When negotiating site agreements, trial Sponsors must negotiate with each participating site individually, making site-specific adjustments to the contract where needed. The requirement to contract with multiple sites further decentralises the process of setting up trials, which delays patient access to innovative treatments and technologies. A single contract across all sites in Scotland would give Scotland a competitive advantage when Sponsors are determining the location for studies. ***As part of the cancer strategy, we would like to see the following commitment:***

- ***NHS Scotland should explore innovative ways to streamline the setup of clinical trials including investigating whether it is possible to set up a single national contract for clinical trial Sponsors.***

One recurring issue encountered in trials relates to the challenges with reuse of data collected in trials for further research. This challenge could be addressed by the development of standardised models of consent which enable secondary uses. In addition, ensuring linkage and interoperability between clinical records and research data holdings would ensure large-scale data movement and replication can be minimised.

Genomics

There is clear potential for genomic testing to improve outcomes for patients along the whole cancer pathway. Testing for cancer can be used in the contexts of risk management and early diagnosis – identification of those with inherited cancer risk – and precision medicine – providing more precise diagnosis and prognoses, and targeted interventions. With support and investment from Governments, the UK can be a world leader in genomics for research and clinical practice.

There are several precision medicines for cancer already approved for use in the NHS and more are expected as precision medicines make up the majority of industry drug development pipelines. To ensure that cancer patients can benefit from the transformative potential of genomics and access genetic testing as part of routine care, Scotland needs to ensure testing services are fit for purpose for cancer. This will require clear governance structures that identify leadership and accountability for implementing genomic testing services for all cancer patients in Scotland. The lack of clarity about who should be delivering on the promise to ensure cancer patients have timely access to genomic testing is holding up progress and has resulted in insufficient investment.

In addition to improving care and outcomes for cancer patients, genomic data is fundamental to advancing cancer research. NHS Scotland is in the enviable position, due to its size and health governance structures, to become a world leader in terms of completeness and richness of its cancer datasets. However, without genomic data that is integrated and linked with other cancer patient data, Scotland is currently lagging behind other countries.

For Scotland to provide the best care for cancer patients and utilise its strengths for cancer research, CRUK recommends that:

- ***The strategy includes a commitment to develop a longer-term genomics strategy, aligned with Genome UK but setting out a vision for Scotland, considering its strengths and population geography. This should include specific commitments on areas covered in the major review and the Informing the Future of Genomic Medicine in Scotland report, and ensure equitable access to testing across all cancer patient groups and their geographies.***
- ***In the short term, NHS Scotland should ensure that cancer patients have access to the genomic tests in the directory. Timely genomic analysis (a pan-cancer NGS panel at minimum) should be available for all cancer patients to inform both standard of care and allow recruitment to genomically stratified clinical trials.***
- ***NHS Scotland should also review health governance structures for research to ensure any gaps that exist in the oversight of key areas are filled, such as genomics.***

Question 13c: Is there any technology that you would like to see introduced to improve access to cancer care?

To ensure the benefits from technological innovations and developments are realised, Scottish Government and NHS Scotland should engage with a range of stakeholders, including researchers, clinicians, and funders, to develop a stronger understanding of the pipeline for new technologies and innovations. They must also ensure that learning from the Innovative Healthcare Delivery Programme is implemented and embedded, and used to further innovate and explore opportunities within PHS.

Alongside the other areas highlighted in question 13b, the deployment of AI platforms, including those utilising machine learning methods, should be considered as a cross-cutting technology, especially for diagnostics and risk stratification. While the deployment of technology in care settings offers the potential for enhanced quality and more efficient provision of care, evidence indicates the biggest gains are to be made by deploying current and emerging AI and machine learning for diagnosis leading to better use of existing therapeutic interventions. Deploying these technologies may also help clear the backlog and deploy existing human capacity more efficiently.

There are many examples of new technologies that could be beneficial to cancer care. Alongside our response we have attached a paper which sets out the innovation pipeline for treatment and early diagnosis.

Outcomes

Question 14: What suggestions do you have for what we should measure to make sure we are achieving what we want to in improving cancer care and outcomes?

Timely, high-quality, transparent and integrated data are fundamental to measuring progress against the strategy and ensuring actions are leading to meaningful improvements in care and outcomes.

A full set of recommendations for improving cancer datasets is provided in answer to question 13b, which should be implemented as a priority in the first action plan.

Diagnosis

Improving early diagnosis must be a priority for the ten-year strategy. To ensure that progress is being made towards the overarching target, cancer staging data must be significantly improved – including covering all cancer sites combined and providing breakdowns by demographics. There are also key indicators of progress, such as shorter waiting times for diagnostic services and reduced emergency presentations, where data collection and monitoring must be improved too. In question 9c and 13b, we set out specific recommendations for this.

Treatment

SACT data collection and analytical capabilities in Scotland are high quality. This means that there is a real opportunity for Scotland to lead the way in understanding variation in chemotherapy treatment. A better understanding of where unwarranted variation exists should then be used to develop, pilot and roll out innovations to reduce such variation in subsequent action plans.

The strategy should commit to a project assessing variation in access to and use of SACT, using this analysis to develop interventions to reduce unwarranted variation in subsequent action plans.

Earlier Diagnosis Vision

Question 15a: What would you like to see an Earlier Diagnosis Vision achieve?

Too many cancers in Scotland are diagnosed at too late a stage, when treatments are less likely to be effective. An Earlier Diagnosis Vision should achieve the comprehensive action required to transform early diagnosis of cancer in Scotland, including ED&D research and innovation, evidence-based and innovative cancer screening programmes, patients promptly seeking help in the event of symptoms, optimised recognition and referral and streamlined pathways and targets.

We propose the following Early Diagnosis Vision:

By 2032 Scotland will lead the world in cancer early diagnosis, with at least 80% of all cancer patients diagnosed at Stage I and II.

This will be achieved through harnessing the power of early detection and diagnosis research and innovation, achieving the full potential of optimised screening programmes and diagnostic pathways, ensuring everyone seeks help when they need it, and guaranteeing diagnostic services have the capacity to see every patient promptly.

Importantly, any vision must be underpinned by clear, targeted actions to achieve it. To radically transform early diagnosis, action is needed on all fronts – no one action, reform, intervention or technology will be a ‘silver bullet’. Implementing the recommendations in the Timely Access to Care section of this consultation response would play a significant role in meeting these ambitions, and so should be central to an Earlier Diagnosis Vision.

Question 15b: Should the Earlier Diagnosis Vision set itself a numerical target?

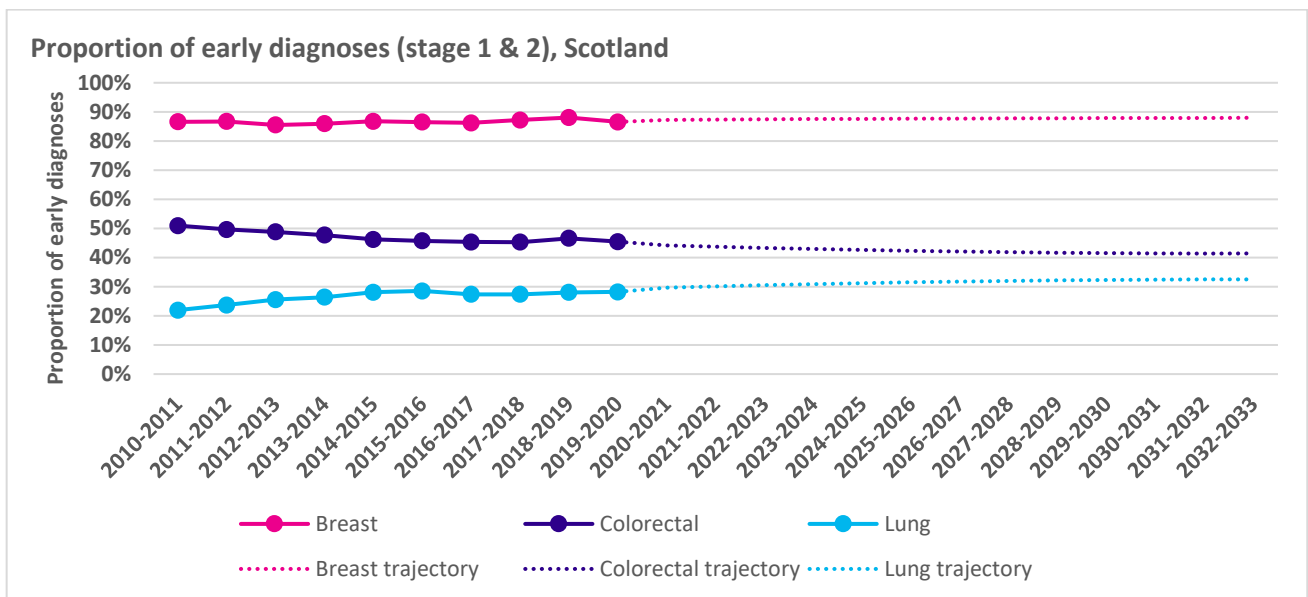
A vision with a 10 year time horizon, with 3 year implementation plans, provides the opportunity to aim for a significant shift to diagnosing more cancers at an earlier, more treatable stage. An ambitious plan based around clear, stretching numerical targets could support this significant shift, and so we would support the Earlier Diagnosis Vision setting itself an ambitious target for the proportion of cancers diagnosed at an early stage or reducing the proportion of cancers diagnosed at a late stage by 2032.

We would propose: By 2032, at least 80% of all stageable cancers should be diagnosed at Stage I and II.

Assuming timely access to optimal treatment, achieving this goal would transform cancer survival in Scotland, significantly increasing the number of patients diagnosed at a more treatable stage – and the numerical target can act as the catalyst to this improvement. However, in proposing this ambitious numerical target, two caveats are important to note.

Firstly, our ability to propose a robust target is hindered by the lack of cancer staging data published by the Scottish Government. Currently, the Scottish Government only publishes staging for the three cancer sites they primarily focus on: lung, bowel and breast. Our proposed target is for all stageable cancers, meaning our understanding of the current situation is incomplete without the improvements to data discussed elsewhere.

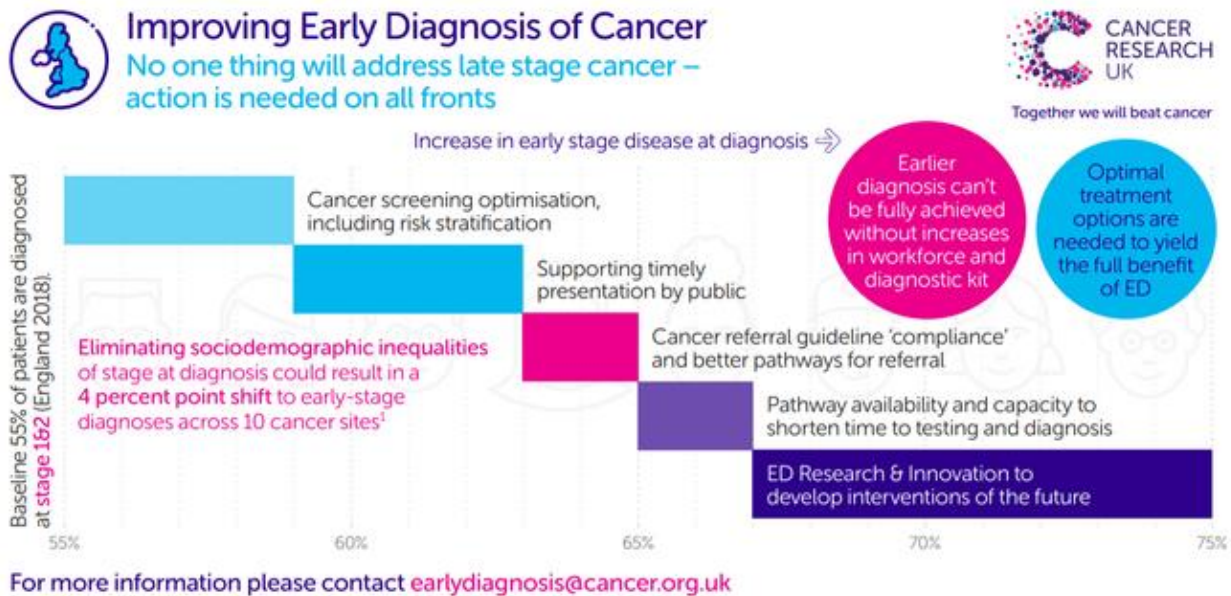
Therefore, after 3 years, the target proposed in the cancer strategy should be reviewed to ensure it is still supporting the shifts in action and research that are essential to delivering improved outcomes for patients. For this review to be meaningful, it must be an inclusive process involving the whole cancer community including cancer charities and people affected by cancer.



Note: This graph shows the proportion of cases diagnosed early for breast, colorectal and lung cancers as reported from 2010-11 to 2019-20, and projected values from 2020-21 to 2032-33. Projected values were calculated using a linear regression model with attenuation. The attenuation combines values predicted by the linear model, with the last 3 years observed data, in a weighted average. The weighting is 90:10 predicted to observed in the first projected year, changing incrementally each year to reach 50:50 in the last projected year.

Secondly, this is a highly ambitious target. To achieve it, we will need to go beyond what we already know works and make significant progress in ED&D research and innovation. As shown in the graph above, there is a wide degree of variation in early diagnosis (diagnosis at stage I and II) between the cancer sites we have staging data for in Scotland. Based on initial estimates of trajectories in early diagnosis for three sites, we anticipate the proportion of early diagnoses for breast cancer will remain relatively stable at 88% by 2032, the

proportion of patients with lung cancer diagnosed early will increase slightly to 33%, while the proportion of early diagnoses for colorectal cancer will decrease to 41% if no further action is taken to improve early diagnoses. Available data was limited, therefore these estimates are provisional and should be interpreted cautiously, but they demonstrate the scale of the challenge over the next 10 years. Similarly, the infographic below, *Improving Early Diagnosis of Cancer ‘Waterfall’ Infographic (England, Scotland, and Wales Edition, 2021)*, shows how early diagnosis research and innovation will be essential to meeting any ambitious early diagnosis target, as proposed here. As well as significantly increasing capacity, the development and adoption of research and innovation is vital to transforming the early diagnosis of cancer in Scotland and so should be at the heart of the cancer strategy.



Note: Bowel screening optimisation, targeted lung screening/health checks & further optimisation of screening including risk stratification have been merged into one row named ‘Cancer screening optimisation, including risk stratification’. Translational ED research and ED discovery and innovation have been merged into one row named ‘ED Research & Innovation to develop interventions of the future’.

Question 15c: Should the earlier cancer diagnosis vision focus on specific cancer types?

In the cancer strategy, we would not support a continuation of the current narrow focus of the Scottish Government on lung, bowel and breast cancer. It is more meaningful to people affected by cancer to have a target inclusive of all cancers, rather than a narrow focus on those three.

The narrow focus on these sites has been accompanied by an overly narrow reporting of data for certain parts of the cancer pathway. This has had consequences for our understanding of where improvements need to be made in cancer services in Scotland. For example, a lack of staging data on cancers other than lung, bowel and breast limits our ability to monitor and assess which sites need targeting when aiming to increase the proportion of cancers diagnosed at an earlier, more treatable stage – and in reality, there are gaps across all sites, whether that’s in research, adoption or implementation.

Measures currently being implemented, such as the EDCs discussed above, have the potential to support the faster diagnosis of many cancers other than the three sites highlighted. By adopting an overly narrow approach, we risk missing out on all the benefits of these measures. Whereas, if the Scottish Government collects, monitors and reports data for many more sites, and this is matched with sufficient investment across cancer services and research, it will be better able to deliver faster diagnosis and treatment for more patients, and it will help achieve the ambitious ED targets proposed in the answer to Q15a.

There are some cancer sites for which interventions and innovations have the potential for significant improvements in early diagnosis and cancer outcomes, and there are also some which are significant drivers of inequalities in cancer outcomes. For example, as shown in the graph earlier in this section, lung cancer outcomes are significantly poorer than many other sites, while earlier in this submission we have highlighted interventions that could improve outcomes, for example a national targeted lung screening programme. However, implementing interventions that focus on such sites should not come at the expense of a wider focus that aims to deliver improvements for all people affected by cancer.

The strategy should have a broader focus on which ED interventions map onto which cancer sites, to gain a more comprehensive understanding of how outcomes can best be improved and where the innovation, adoption and implementation pipeline needs to be strengthened.

Question 15f: What does good earlier cancer diagnosis look like for you?

Good earlier cancer diagnosis means not only increasing the proportion of cancers diagnosed at stage 1 and 2, it is also crucial to reflect change through a reduction of the absolute numbers of late-stage diagnoses. It also means more patients promptly starting cancer treatment after receiving a diagnosis and all patients having equal opportunity to be diagnosed with cancer at an earlier stage.

To achieve good earlier cancer diagnosis, it must lead to the reduction of late-stage diagnosis. If the focus is solely on improving earlier diagnosis, it may lead to some cancers that may not have been harmful being diagnosed at the expense of other, more pernicious sites. Taking a broader look at what good earlier diagnosis looks like, that considers the reduction of late-stage diagnosis rather than simply focusing on the headline figure, is therefore vital.

Diagnosing people affected by cancer at an earlier more treatable stage, and ensuring that there are clear pathways so they then promptly receive lifesaving treatment, is central to delivering improvements in cancer outcomes, and to reducing the anxious waits for people affected by cancer. We have suggested an ambitious target of diagnosing 80% of cancers at Stage 1 or 2 by 2032 – a shift that would transform cancer outcomes in Scotland. However, this will require comprehensive action across the cancer pathway, with research and innovation at the heart of achieving this goal.

Ensuring that all patients have equal opportunity to be diagnosed at an early stage, thereby tackling inequalities in cancer diagnosis and outcomes, is also central to good earlier cancer diagnosis. This means taking action to tackle the unfair barriers some groups face in accessing cancer services – for example disparities in participation in national screening programmes. These inequalities are discussed further in question 16.

Impact Assessments

Question 16a: In your experience, are there aspects of cancer diagnosis, treatment or care that affect people from marginalised groups differently? If there are negative effects, what could be done to prevent this happening?

There are inequalities across the cancer pathway through prevention, diagnosis, treatment, and care, contributing to stark and unacceptable differences in cancer incidence and outcomes. Fundamentally this means that for some marginalised groups, their chances of getting cancer, and their experience and outcomes of cancer, are worse because of factors and circumstances beyond their control. Targeted action is essential to reducing these inequalities and ensuring no one is left behind as Scotland drives progress across cancer services.

Diagnosis

There is evidence of lower participation rates in the bowel screening programme for some ethnic minority groups and for people with a learning disability compared to those without a learning disability¹⁴⁸ in Scotland. Research has also found that transgender men and non-binary people report a number of barriers to attending cervical screening appointments.¹⁴⁹

Any actions to improve early diagnosis through the strategy must not exacerbate inequalities in participation, stage, or outcome, and should seek to meaningfully reduce the gap between the groups with the highest and lowest uptake and outcomes.

The Scottish Government and NHS Scotland should run activity and share resources which reduce barriers to accessing cancer screening programmes, developed with and targeted towards groups with lower uptake. To ensure their efficacy, this material should be co-designed with the targeted communities, including people who don't have cancer, as well as being based on best practice interventions.¹⁵⁰

Treatment

Older people are less likely to receive many different types of treatment.¹⁵¹ Some of this variation can be accounted for by patients choosing not to pursue active treatment. However, there may also be some patients who are simply not being offered curative treatment that could benefit them, because assumptions have been made about their fitness based on their age.¹⁵²

Health systems must collect quality data covering treatment intent, performance status, and comorbidities to build a stronger understanding of where a lack of curative treatment is based on clinical assessment and where it might be based on assumptions about patients' health and suitability for treatment.

Patients face a number of barriers when accessing clinical trials – these barriers disproportionately impact certain groups, who are subsequently under-represented in cancer research. Potential barriers exacerbating inequalities include onerous demands of patients, such as frequent travel, which can deter patients with disabilities, and occasions where healthcare professionals discount elderly and disabled patients as research participants despite their eligibility. This exacerbates health inequalities, because clinical trials are an important way of accessing treatment for rare cancers.

As part of its commitments on research, the strategy should commit to monitoring who is participating in clinical trials in Scotland to understand where targeted action is needed to improve access.

Patient experience

There are challenges to understanding inequalities in patient experience in Scotland. In the most recent Scottish Cancer Patient Experience survey, almost all the respondents described their ethnic group as white (99%), which means it is not possible to understand how experiences of care differed between ethnic groups.¹⁵³ However, it is fair to assume that similar challenges are likely to exist for some groups in both England and Scotland. In latest England's National Cancer Patient Experience Survey, respondents from Asian, Black, Mixed and Other backgrounds reported a poorer average rating of care compared to White respondents (survey categories).¹⁵⁴ In particular, Asian respondents and Black respondents scored lowest on questions regarding how information was communicated with them and the support they had access to.

NHS England is currently working closely with ethnically diverse communities through their Cancer Experience of Care Improvement Collaborative to understand and improve their experience of care through co-designing projects.¹⁵⁵ We recommend that NHS Scotland considers how to apply this approach to improve the care experience of those more likely to be marginalised.

More broadly, the last Scottish Cancer Patient Experience Survey was run in 2018, and before that 2015. The significant gaps between these surveys means that it is particularly difficult to understand the experience of

care that cancer patients in Scotland have – this is a particularly acute problem given the impact the COVID-19 pandemic has had on patient care across the NHS. While it is not a substitute to building in the views of people affected by cancer across the work of this strategy, this national exercise offers vital learnings and it is important that the frequency of these surveys is increased, so that service transformation is led by the experiences and needs of people affected by cancer from every background.

The cancer strategy should increase how frequently the Scottish Government runs the Scottish Cancer Patient Experience, with targeted engagement and outreach measures to ensure that the diversity of experiences in the Scottish cancer community are captured.

To ensure that the strategy is best placed to tackle inequalities – across all the groups covered in question 16 – continued engagement with people affected by cancer in Scotland is essential. Multiple respondents from our patient network called for the Scottish Government to consult with a “diverse population” in order to put “patients at the heart of [the strategy]” and to gain a breadth of insight. ***The Scottish Government must involve patients from a wide range of population groups in the drafting process for the strategy and future action plans, to help ensure the strategy considers the diverse range of cancer experiences and can address inequalities.***

Question 16b: Similarly, is how we manage cancer different for wealthy or poor people? What could be done to do this better?

There is a wealth of evidence that indicates people from more deprived areas have worse experiences and cancer outcomes, experiencing inequalities at every part of the cancer pathway. As with the discussion on marginalised groups above, targeted action and monitoring is essential to ensuring no one is left behind as this strategy is implemented.

It’s also important to note that the data breakdown for socio-economic inequalities are not sufficiently detailed in Scotland. However, there are consistent themes and areas where Scotland will likely face similar challenges, which have been identified as areas for action.

Incidence

The two biggest causes of cancer – smoking¹⁵⁶ and overweight and obesity¹⁵⁷ – are more prevalent in deprived groups. In turn, this drives significant inequalities in cancer incidence in Scotland. It is estimated that there are around 4,500 extra cases of cancer in Scotland attributable to socio-economic deprivation each year.¹⁵⁸ Scotland also has the largest deprivation gap in cancer incidence of all UK nations. In Scotland, cancer incidence rates are 32% higher in the most versus least deprived areas¹⁵⁹; the gap is 17% in England¹⁶⁰, 20% in Wales¹⁶¹, and 13% in Northern Ireland.¹⁶²

In answer to question 8, we set out a broad range of actions to tackle inequalities in cancer risk factors, including our call ***for the Scottish Government to set a subsequent target of 5% or less smoking prevalence in Scotland for all socio-economic groups, including the most deprived quintile.***

Diagnosis

There is a large discrepancy in participation in cancer screening by socio-economic deprivation. In Scotland, between May 2019 and April 2021, uptake in the bowel screening programme was 65%.¹⁶³ However, uptake for the most deprived communities was just 53%, compared to 73% for the least deprived, with similar trends seen across breast and cervical screening programmes.^{164,165} More deprived groups also face greater barriers to accessing health services. Data from our Cancer Awareness Measure shows that, in Scotland, people from more deprived groups were less likely to recognise certain signs and symptoms of cancer when prompted than those in less deprived.¹⁶⁶ The most common barriers to seeking help in more deprived groups in Scotland were

finding it difficult to get an appointment, and difficulty getting an appointment at convenient time.¹⁶⁷ Additionally, data from England show that more deprived groups are 50% more likely to be diagnosed following an emergency presentation, with the risk increasing with every deprivation quintile.¹⁶⁸

The Department of Health and NHS Scotland should run activity which reduce barriers to accessing screening programmes and health services, developed with and targeted towards these groups with lower uptake.

Treatment

We know that there is socioeconomic variation in treatment for different cancer types in other UK nations, but it is unclear whether similar variation is seen in Scotland.¹⁶⁹ It is important to understand whether this is the case, and if so, what is driving this variation and its impact on outcomes.

Health systems must collect quality data covering treatment intent, performance status, and comorbidities to build a stronger understanding of where lack of curative treatment is based on clinical assessment and where it might be based on assumptions about patients' health and suitability for treatment.

Question 16c: Is the experience of cancer different for people living in rural or island communities? What could be done to prevent any negative impacts?

People affected by cancer living in rural or island communities risk facing greater barriers to accessing diagnostic and treatment services. It is essential that these barriers are addressed, whilst ensuring high-quality service delivery is not compromised.

Our patient network raised the importance of tackling a “postcode lottery” in cancer care across Scotland, with many raising concerns that where you live impacts your access to diagnostic and treatment services. A consistent call was to improve equity of access through ensuring services are delivered consistently across Scotland, including sharing resources and best practice, and reviewing and addressing staffing shortages across health boards. The strategy must reflect this ambition.

“Ensure no one type of cancer or one geographical area fares better than others. We should all be striving to make care across different social, ethnic and geographical areas equal” – Person affected by cancer in Scotland, consulted by CRUK.

Diagnostics

Networking services can maximise workforce and equipment, particularly important in communities where capacity is sparser. In Scotland, networking radiology, which will allow specialist clinicians to interpret images anywhere in the country whilst patients are cared for near home, has made positive progress. ***The Department of Health should prioritise funding for quality IT systems which are interoperable across different care-settings to support continued networking efforts.***

Pathology plays a major role in the diagnosis of cancer and, as demand increases, capital investment in IT and digital infrastructure will be vital.¹⁷⁰ Digital imaging has the potential to transform our approach to pathology. Sharing slides digitally rather than physically can reduce turnaround times and ensure that rural and island communities can utilise expertise nationally, maximising limited capacity and ensuring equal access.¹⁷¹ However, at present, digital capabilities are far below what is required for a seamless digital pathology system, meaning these innovative approaches cannot be put into widespread practice.¹⁷² ***Pathology services must be made fit for a modern health service through the expansion of digital pathology, and further research should be undertaken to understand the investment needs and how this should be delivered over the long-term.***

Rurality in Scotland presents some challenges in accessing primary care and diagnostic services for people in some communities. We discuss how to address these challenges in questions 9 and 10.

Treatment

Previously, we have undertaken research to understand patient views on travelling for treatment in England. This survey of patients in England found the majority of respondents were supportive of travelling to get the best quality treatment. However, this is very hypothetical; a patient's response is likely to be very dependent on how well they are, how far they must travel, their caring responsibilities and the support they have available to them.

Centralisation and specialisation in treatment services may help improve surgical and cancer outcomes, but it may also create challenges for patient access, particularly for rural and islands-based populations who may face barriers to accessing specialist cancer care because of travel.

Steps must be taken to ensure all patients diagnosed with cancer are supported to access high quality treatment. One key mechanism is enabling patients to plan appointments in advance, which makes it easier for patients to arrange transport and develop a routine. Patients have also suggested that further support could be provided for follow-up or out-patient appointments closer to home. For example, if treated away from their local hospital, some patients have said that it would be useful to have a treatment card which detailed their radiotherapy plan so that they could bring this to their local GP or hospital if they had any side-effects.

To ensure every patient undergoing cancer treatment gets the support they need, service providers must provide personalised support to those living in rural and island communities, including with arranging advanced appointments and providing summaries of their treatment plans.

About Cancer Research UK

Cancer Research UK is the world's largest independent cancer charity dedicated to saving lives through research. Our long-term investment in state-of-the-art facilities has helped to create a thriving network of research at 90 laboratories and institutions in more than 40 towns and cities across the UK supporting the work of over 4,000 scientists, doctors and nurses.

In 2020/21, we invested over £30 million in research in Scotland, at our two research centres in Glasgow and Edinburgh (now the CRUK Scotland Centre, with laboratories in Edinburgh and Glasgow) as well as in Aberdeen, Dundee, and Stirling. Cancer Research UK is at the heart of communities across Scotland, with around 80 high street shops supported by hundreds of volunteers, and annual fundraising events such as Race for Life bringing together thousands of our supporters to help us beat cancer.

Produced by colleagues in the Policy, Information and Communications Directorate at Cancer Research UK. For more information, or any questions, please contact David Ferguson (Public Affairs Manager) – David.Ferguson@cancer.org.uk.

Appendix 1 – Further Resources for Consideration

Cancer Research UK – Prevention materials

- E-cigarette Flavour Rapid Review – available on request
- CRUK’s response to post implementation review of Standardised Packaging of Tobacco Products (SPoT) and Tobacco and Related Products (TRPR) regulations – available on request
- [CRUK tobacco control reports](#)
- [CRUK obesity reports](#)

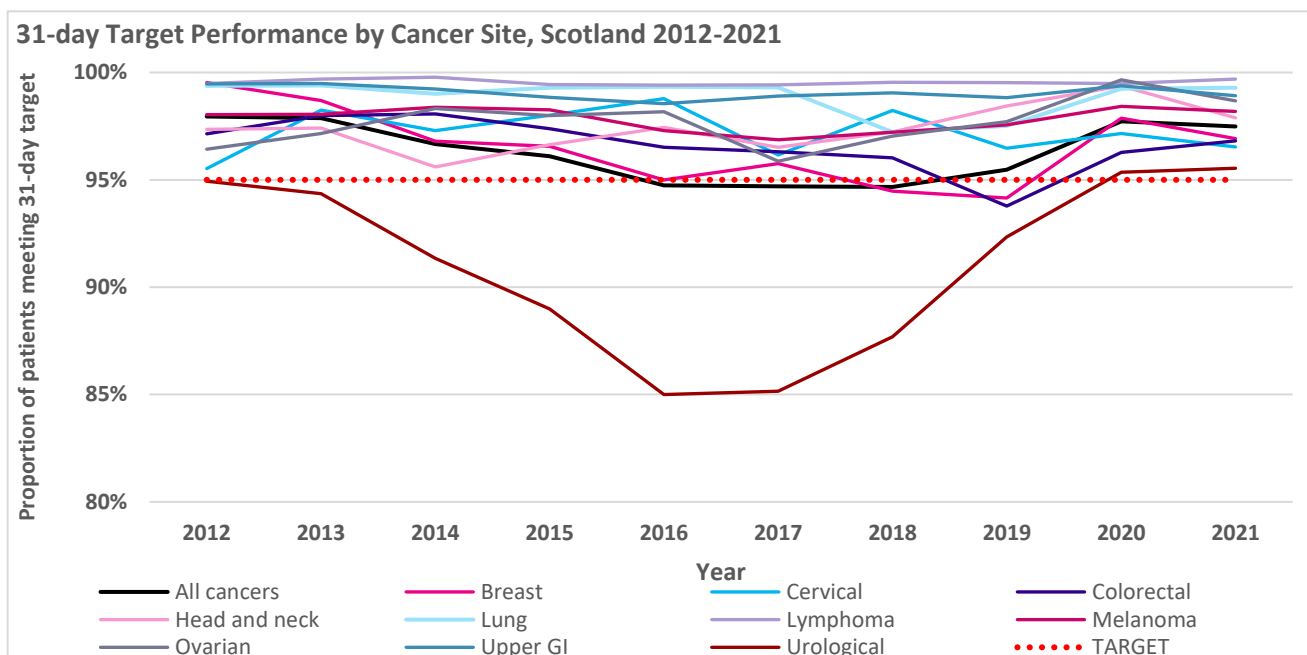
Cancer Research UK – NHS cancer services materials

- CRUK policy statement on maximising the potential of the current cancer workforce (2021) – available on request
- Driving transformation through a comprehensive cancer strategy (2020) – available on request
- [CRUK outcome-based payment for cancer drugs policy and research](#)

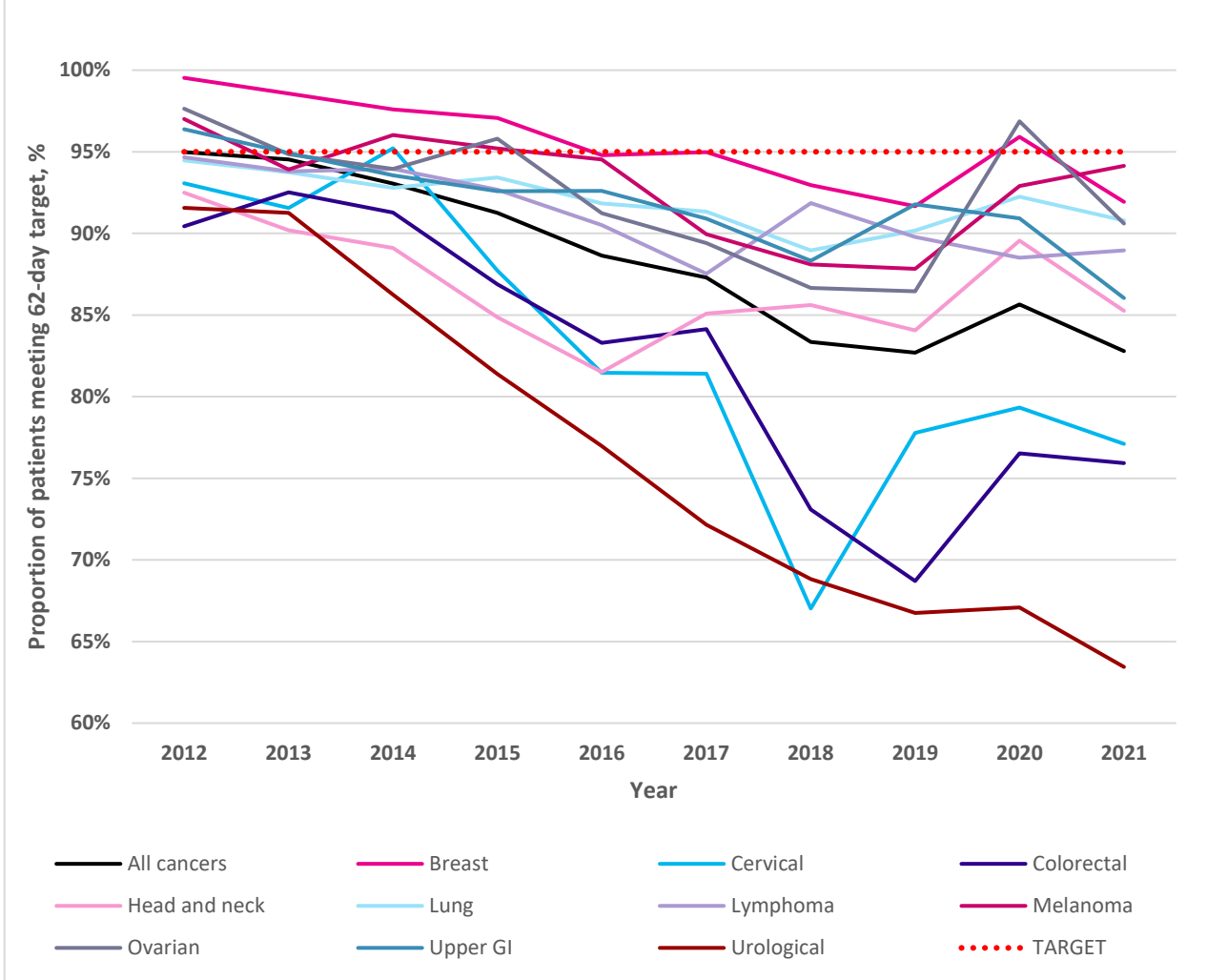
Cancer Research UK – Research and data materials

- [Bench to Bedside: Creating a Collaborative Research Environment in Scotland \(2019\)](#)
- [Creating Time for Research \(2021\)](#)
- [Beyond Recovery: the case for transforming UK clinical cancer research \(2022\)](#)

Appendix 2 – 31 and 62-day Target Performance for expanded number of cancer sites



62-day Target Performance by Cancer Site, Scotland 2012-2021



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