

# 10-year Cancer Plan for England

Cancer Research UK response, April 2022

## Introduction

Cancer Research UK strongly welcomes the opportunity to respond to this call for evidence to inform the new 10-year plan for cancer in England.

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. This plan has the potential to be a major milestone for cancer patients, signalling a renewed drive and setting an ambitious roadmap towards better cancer outcomes. We must not waste this opportunity.

We welcome and share the ambition set by the Secretary of State for Health and Social Care. We have long known that despite the progress we have made, UK cancer outcomes consistently lag comparable countries. Progress is sub-optimal nationally, but national metrics mask the size of the challenge – given the scale of unwarranted variation regionally and socio-demographically, in both outcomes and the pace of innovation.

This is a particularly timely moment to focus on cancer, given the scale of the impact the pandemic has caused on people affected by cancer across the country. Our clinical contacts tell us the pressure has never been higher, and people with cancer were less likely to rate their care highly during the pandemic than before. This pressure is mirrored in regular record low performance against operational targets – though the referral to treatment target has been missed since 2015. The NHS remains a main issue of concern for voters, and there is declining confidence in the NHS regarding cancer performance<sup>1</sup>.

Our aging population also brings further urgency. By 2035 we expect to see 500,000 people a year diagnosed with cancer, almost half of whom will be over 75 – and therefore more likely to have complex needs and comorbidities. We must act now so that our cancer services are prepared.

There are some welcome ambitions already in place, such as the ambition to diagnose 75% of patients at stage I or II by 2028. However, we are not on track to meet this target, staying around 54% for the previous few years. If we continue on our current trajectory, we will fall 21 percentage points short – which equates to 65,700 patients being diagnosed late instead of early in 2028 alone. Again, there is significant variation. If we levelled up every Cancer Alliance to be in line with the best performing, the proportion of patients diagnosed early would increase by 4 percentage points to 58%, more than 8,000 additional patients diagnosed early each year.

These challenges are not insurmountable. Other countries have radically improved their standing, and across a 10-year timeframe, so could we. Our first step should be considering how to make our ambition a tangible goal, by which we can measure our progress over the coming years, set the pace and govern our progress. As well as answers to the specific questions posed in the consultation, we have presented our recommendations for how to manage this process.

However, it cannot be ignored that it will be difficult to make such a step-change in UK outcomes without strong political leadership and the necessary long-term investment. The number of specialist cancer staff and diagnostic equipment is lower in the UK than in the countries with outcomes that we aspire to, and all too often we are hampered in our ability to adopt innovation quickly because of capacity constraints.

We have therefore proposed some recommendations which do require additional investment, and others which require reform instead – there are still many ways to make progress within the current financial

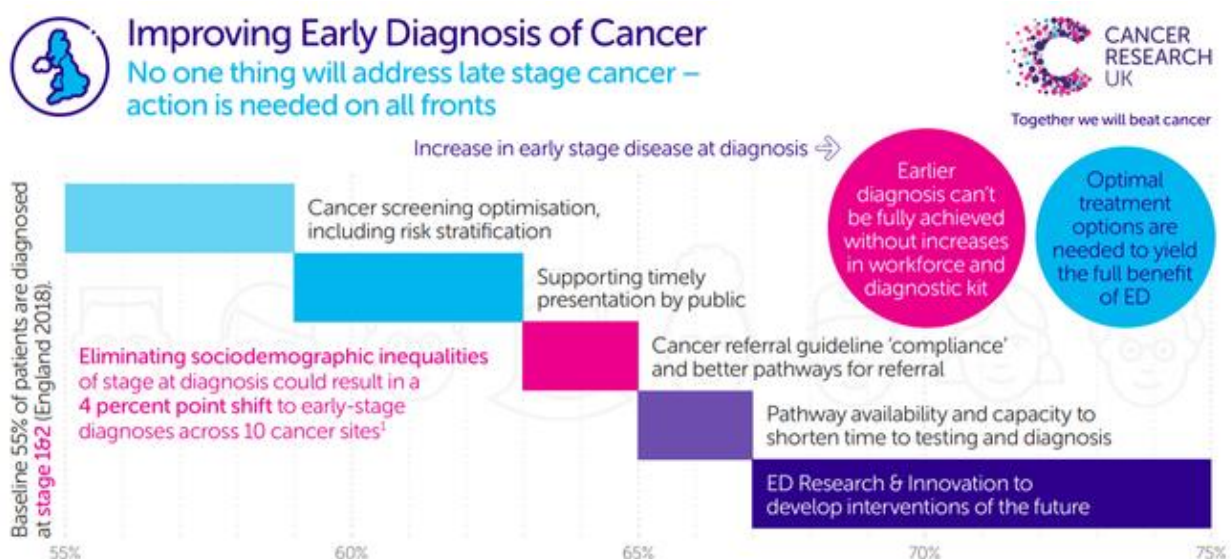
envelope. These include more innovative approaches to the cancer workforce, a focus on spreading best practice more evenly, and legislative or regulatory changes that would reduce the overall burden of cancer by promoting cancer prevention – an area where we should be far more ambitious. For tobacco control for instance, this should include exploring bold new ways to reduce tobacco uptake – including pack inserts, dissuasive cigarettes, minimum and maximum pricing, and raising the age of sale of tobacco to 21.

Finally, we must play to the UK's strengths, namely research. This is critical in the long-term, because in the long-term it is science and research which brings us hope. Every day we understand more about cancer, and finding new and better ways to prevent, diagnose and treat it. Data and technology are transforming what's possible, and could unlock huge transformation in the years to come if properly harnessed. This is a natural strength which we must exploit: the UK science base is world-leading in its impact<sup>ii</sup> and cancer is the most successful field of UK commercial clinical research<sup>iii</sup>. If properly harnessed – and if the NHS is ready to implement new ideas quickly – our home-grown innovation could transform our cancer outcomes.

This paper sets out clear, actionable recommendations for how we can realise the potential of a comprehensive, fully funded 10-year cancer plan for England. We have also provided links to more detailed publications at the end of this document, as well as a full list of references. The timelines have not allowed for detailed costing of these recommendations; however, we would be pleased to continue to work with the Department of Health and Social Care to refine these ideas over the coming months.

In addition, we have two supplementary documents. One document is our assessment of the innovation pipeline, spanning early detection, diagnosis and treatment, which we hope will be informative particularly as DHSC assesses more transformative changes that could be possible in the latter half of the ten-year timeframe specified. Our second document contains a list of site-specific recommendations for driving earlier diagnosis within five cancer sites, supported by data packs and evidence reviews in those sites. These recommendations were made at a series of roundtables with clinicians, medical leaders and NHS service managers, hosted by Cancer Research UK and chaired by former National Cancer Director Professor Sir Mike Richards.

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 plan.



*CRUK analysis of the route to reaching the ambition for 75% of cancers diagnosed early.*

## Making the ten-year cancer plan a reality

### A framework for success

The cancer plan's 10-year time horizon affords the opportunity to strive for radical improvements in cancer outcomes. To realise this opportunity, the plan must be based around clear, stretching ambitions that can act as a catalyst for change. This will help create a coalition around a shared vision of change – a coalition comprising cancer services, the wider health and care system, the research community, charities, and people affected by cancer. We have proposed two overarching ambitions, however we would welcome further work being commissioned to define the goal of the plan.

***We propose two overarching ambitions as a foundation:***

- 1. A commitment to transform cancer survival in England by at least doubling the rate of improvement in cancer survival for all cancer types combined.***
- 2. By 2032 aim for the incidence of cancers diagnosed at stage III and IV to be no greater than 20%. This should be supported by supplementary targets, such as:***
  - a. An ambition to reduce the proportion of cancers diagnosed in an emergency to below 10% by 2032.***
  - b. A trajectory to raise the threshold for the Faster Diagnosis Standard – to 80% in 2023, rising to 85% in 2025, 90% in 2027 and 95% by 2029.***

***This plan must be associated with a rigorous delivery plan, developed and owned by the Department of Health and Social Care and NHS England. This plan should contain:***

- Clear objectives, with timelines for implementation for each part of the plan and clear objectives***
- A transparent accountability framework with robust and regular reporting mechanisms, including independent scrutiny and assessment of progress***

***Progress against this plan should be assessed and published annually. This process should be independent. There should be regular, planned points across the lifecycle of the plan, when the overall strategy is reviewed and updated. This will ensure there is opportunity to review and update the strategy in light of external events, as well as to reflect and build on learnings. This should 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.***

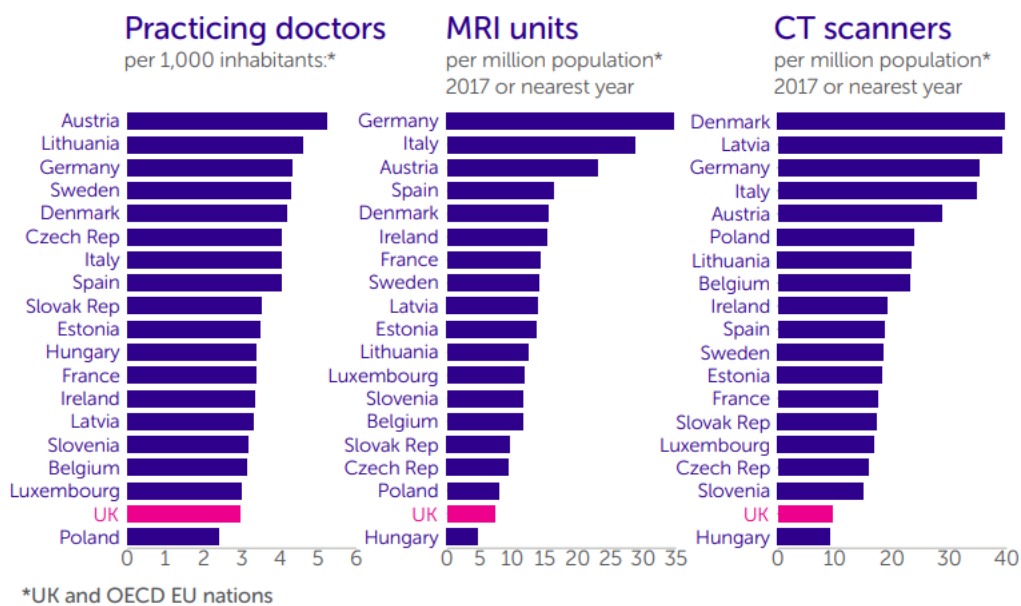
***For this evaluation and accountability to be meaningful, it must be an inclusive process involving the whole cancer community including cancer charities and people affected by cancer. We would recommend that as part of the governance framework for this plan, there is an external scrutiny board with independent leadership and with clinicians, service leaders, patient groups and people affected by cancer represented.***

### Investing in transformation

The success or otherwise of previous cancer plans and strategies has been dependent on those plans being adequately funded.<sup>iv</sup> However, in more recent years, transformation funding for cancer services has been in some cases limited to annual funding and/or contingent on performance. This has made sustainable progress more challenging, with short-term, reactive funding hindering effective longer-term planning and delivery.<sup>v</sup> Publishing a ten-year plan without any funding puts its impact in jeopardy, and risks missing an opportunity to deliver the meaningful improvements people affected by cancer deserve, and risks losing the confidence of the cancer community in the plan itself. Sufficient investment for transformation in cancer services is vital not only to improve patient outcomes, but also to unlock the benefits of innovative approaches and increased efficiency.

Significant investment in establishing Community Diagnostic Centres was a welcome recent step in expanding diagnostic capacity. We know that England lags behind comparable countries in diagnostic capacity. International Cancer Benchmarking Partnership (ICBP) data shows that UK has the lowest number of PET-CT scanners 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.<sup>vi</sup> Capital investment in Community Diagnostic Centres will therefore play a crucial role in addressing these shortages through expanding imaging capacity. However, it's also positive that this will afford opportunities for innovation in models of care and improve patient care in the process.

## UK is lagging behind comparable EU countries



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 plan for cancer with sufficient and sustainable funding across the 10-years of the plan to drive innovation, improve patient care and outcomes, and support more efficient models of care.***

Funding arrangements must incentivise activity to deliver the plan's ambitions by enabling investment across multiple years in staff and services. NHS England has now introduced a blended approach to funding, with the 'aligned payment and incentive' approach offering funding certainty through a 'fixed element' based on previous levels of activity, alongside a 'variable element' which provides extra funding where activity exceeds these expected levels. There is a risk that this model penalises struggling areas, which must be managed – and struggling areas should be offered greater support and resource to improve capacity.

***DHSC, together with NHS England, must ensure that the variable element of the aligned payment and incentive approach to revenue funding does not disadvantage overstretched areas, but rather actively supports and resources expanding NHS capacity and promoting best practice.***

***Activity-based payments through the national tariff should be used to support increased activity in screening programmes.***

Alongside revenue funding, it is also vital that welcome capital investment across this Spending Review period not only supports recovery in cancer services, but also helps deliver the ambitions of this 10-year plan.

***DHSC and NHS England must ensure that plans for capital investment, through the £1.5 billion to support elective recovery and £2.3 billion to transform diagnostic services, support recovery in cancer services and deliver the ambitions of this cancer plan. In particular:***

- ***Plans for Community Diagnostic Centres (CDCs) must be clear in how they will prioritise tests key for cancer diagnosis, to ensure long waits for tests are tackled. Particular attention should be paid to plans for CDCs in areas struggling most to achieve the Faster Diagnosis Standard and 62-day urgent referral to treatment Cancer Waiting Times target, to ensure they deliver for patients facing the longest waits.***
- ***Endoscopy, one of the areas hardest hit by the pandemic, must be prioritised in the expansion of wider diagnostic capacity given clear, significant pressures on endoscopy capacity. Capacity for other key gastrointestinal imaging such as CT colonography should also be addressed.***
- ***Investment to support elective recovery must have cancer at its heart, with a particular priority placed on ramping up delivery of cancer surgery. New surgical hubs could play an important role in this.***
- ***Funding for elective recovery must also include targeted resources and support to address the challenges faced by the cancer pathways and NHS providers worst impacted by COVID-19. This should also include measures to address regional and demographic inequalities.***

***Across the lifetime of the 10-year plan, Government must ensure that there is sustainable capital investment in order to expand capacity and ensure the capital is in place to support innovative new approaches and technologies in cancer services. In particular, this should include:***

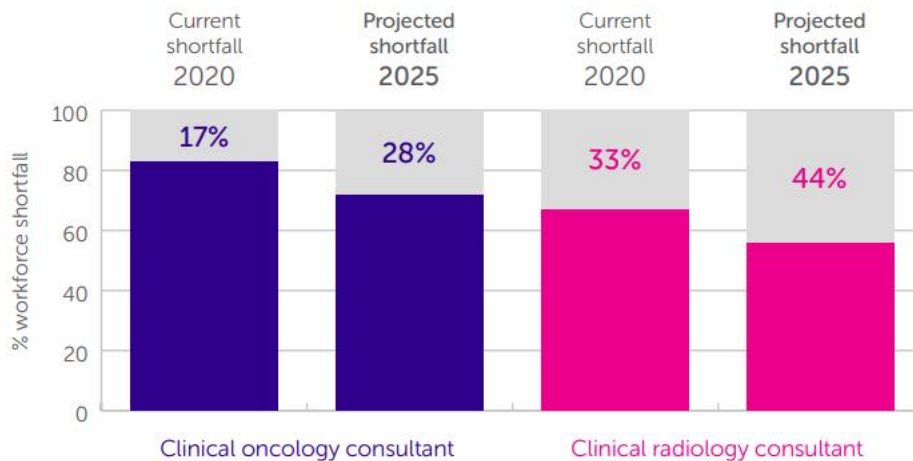
- ***Providing the investment to deliver the uplift in diagnostic capacity between 2020 and 2025 set out in the Richards Review of diagnostic services in England***
- ***Ensuring sufficient core capital funding to Integrated Care Systems to ensure NHS Trusts can replace their stock of key diagnostic equipment at the end of its lifespan and continually expand capacity as needed throughout the 10-year lifespan***
- ***A commitment to putting in place a central process for the rolling replacement of radiotherapy machines at the end of their lifespan (as recommended later in this paper)***
- ***Ongoing central investment to continually improve digital capabilities across the NHS, including improving interoperability within and across different care settings, and digitisation in diagnostic and screening services, factoring actual or likely innovation requirements into IT development at the earliest reasonable opportunity***
- ***DHSC and NHS England must ensure there is sufficient transformation funding throughout the lifetime of the strategy to support Integrated Care Systems and Cancer Alliances to test innovative approaches and technologies and build the capabilities to role these out in the long-term***

## Workforce

There are chronic shortages across the NHS in specialties key to diagnosing and treating cancer, which have hampered progress for several years. We must invest today to build a cancer workforce fit for the future of cancer care as a priority, or risk these workforce shortages continuing to severely limit the NHS's capacity to close the gap with the best-performing countries and ultimately improve cancer outcomes for years to come.



## There isn't enough NHS workforce to meet future demand



Source: The Royal College of Radiologists – [www.rcr.ac.uk/workforce](http://www.rcr.ac.uk/workforce)

England's population is growing older – by 2035, the number of people estimated to be diagnosed with cancer in the UK is expected to reach over half a million per year, with 46% of all cancers diagnosed in people aged 75 and over.<sup>vii,viii</sup> An ageing population means growing demand for cancer services, and a growing number of patients with comorbidities and/or complex needs. It is unavoidable that service capacity will need to evolve accordingly, and fundamentally to expand, to meet this need.

While a shift to a greater focus on prevention is welcome, the benefits of this on service demand will only be seen in the long-term. Driving earlier diagnosis is also critical for improving outcomes, and should ease future demand – but to do this, we must have the capacity to scan and check more patients. This is hampered by major shortfalls in diagnostic capacity due to workforce shortages right now. There are some opportunities to use new service models, skills mix approaches and new roles to use the workforce more efficiently, however the need for workforce expansion and funding is unavoidable.

***NHS England's upcoming 10-year plan for the health and social care workforce must set out long-term funding plans to deliver a sustained expansion of the cancer workforce to meet future demand for cancer services.***

CRUK modelling has found that to deliver on the trajectory set out in the 2018 Strategic Framework for Cancer Workforce of a 45% growth in the cancer workforce<sup>ix</sup> by 2029, the Government must invest an extra £216m in workforce education and training for these key specialties across the next 3 years. It takes a minimum of three to five years to train newly qualified staff as specialists in key cancer professions – in addition to a degree – meaning this investment is needed now. The situation has become more urgent over the course of the pandemic, in light of the retention and morale issues currently facing the NHS workforce as a whole.

To ensure enough staff are trained to meet future demand, robust workforce planning supported by regular, independently verified projections of the future supply and demand of the health workforce is key.

***The Government should model current and future health workforce trends to support workforce planning, as proposed in recent amendments to the Health and Care Bill.***

## Driving equitable improvements in outcomes

Inequalities currently present a huge barrier to improving cancer outcomes. There are inequalities at every stage of the cancer pathway – from prevention, to diagnosis, to treatment and care – including socio-economic, environmental and genetic risk factors as well as regional factors that impact the quality of care received, diagnosis, and treatment, and these all contribute to stark differences in incidence and outcomes.<sup>x</sup> They are persistent, and impact multiple population groups, due to factors beyond individual control such as socio-economic status, ethnicity, disability status, gender identity, and social and cultural factors, amongst others. Addressing these disparities must be a priority, ensuring that progress made does not leave anyone behind. We welcome the focus on early diagnosis of cancer in NHS England’s Core20Plus5 approach to tackling inequalities. However, inequalities must also be addressed throughout the cancer pathway.

This requires improving the consistent and sustained collection of data to support a better understanding of cancer inequalities. 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. Challenges with data have been highlighted as a key barrier to implementing the Core20PLUS5 model addressing inequalities.<sup>xi</sup>

***DHSC and NHS England must share guidance and best practice approaches to support Integrated Care Systems and Cancer Alliances to improve data quality and availability, alongside the resource needed to deliver this.***

The cancer plan should target support to ICSs with poorer cancer screening engagement, early diagnosis and cancer survival outcomes to ensure that each ICS/Cancer Alliance achieves the same outcomes as the best performing one(s).

***The cancer plan should propose specific funding opportunities for the development and piloting of evidence-based interventions to reduce disparities, based on open calls for innovation. If proven successful, further funding will then be essential for the roll out of these interventions by Integrated Care Systems and Cancer Alliances to address poorer outcomes within marginalised groups and regional disparities in cancer services.***

***The cancer plan should make clear how the department, NHS England and NICE will work together to further ensure guideline-concordant care.***

NICE guidelines across prevention, cancer recognition and referral and treatment provide clear recommendations for practice but there continues to be considerable variation in their implementation resulting in patients receiving less than optimal care. With guidelines a key driver of good practice, it is essential that efforts to support, assess and ultimately achieve their implementation in practice, are improved.

## Harnessing the potential of data to improve cancer outcomes

Data and data-driven technologies can drive research into the causes of cancer, improve the effectiveness of diagnosis and treatments, and optimise NHS services. The NHS in England is in a strong position to harness this potential, due to the unique structure of the NHS being a single national provider with population-level datasets and a large, diverse population.<sup>xii</sup> However, much of the potential of data is untapped in England. There are many reasons for this, including problems with IT and data management infrastructure; uneven data quality; poor integration and interoperability; and complex processes governing how data is accessed. Government and NHS England must deliver improvements in the quality, completeness, timeliness, linkage, and interoperability of health-related data; and the safe, secure, and responsible access to health-related data for research and healthcare.

***The cancer plan should include a commitment to develop a comprehensive strategy for cancer data to address access, data quality, timeliness, dataset linkage and data infrastructure.*** Please see our more detailed response to question five for specific recommendations relating to data.



# 1. Do you have any suggestions for how to raise awareness of the causes of cancer and how it can be prevented?

## **The problem**

*Around 4 in 10 cancers are preventable.<sup>xiii</sup> This is also an issue of inequality: smoking alone is responsible for half the difference in life expectancy between the lowest and highest income groups in England, and remains the leading cause of cancer deaths.<sup>xiv</sup>*

## **The solution**

*Acting to reduce preventable causes now is key to the success and legacy of this cancer strategy in the future. Raising awareness of these causes is important, for example, through properly funded behavioural change media campaigns that discourage people from starting to smoke and encourage those who do to stop. However, on their own they will not be enough to enable people to live a healthy life. The Government must also 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,<sup>xv</sup> both of which disproportionately affect deprived groups.*

*As well as being crucial for preventing cancers, the measures listed below 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.*

## **Smoking**

The current target for a Smokefree 2030 is welcome, however we are not currently on track to meet it. The next Tobacco Control Plan 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.

Government action is critical to counter smoking and meet this target. Most people who currently smoke started in childhood,<sup>xvi,xvii,xviii</sup> before they were old enough to understand the lifelong consequences of this addiction and how hard it is to quit.

## **Limiting Uptake**

Over the years, the UK has successfully implemented several regulations aimed at reducing the appeal – and therefore the uptake – of tobacco products. To maximise their impact, DHSC should rectify the loopholes used by the tobacco industry to undermine these measures<sup>xix,1</sup>. However, there is also evidence to show that the effectiveness some of these measures, like health warnings on cigarette packs, can decrease over time as people who smoke become more used to them. It is therefore also important that the UK Government continues to explore new ways of reducing the attractiveness of tobacco products.

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

- ***Pack inserts:*** Current evidence suggests that interventions that make cigarettes less appealing, with displaced cost to the manufacturer, are a prudent policy measure. This evidence is outlined in a recent

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<sup>1</sup> 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.

APPG on Smoking and Health report<sup>xx</sup>, endorsed by CRUK, that called for mandated pack inserts encouraging people who smoke to quit, citing strong public support for the measure.

- **Dissuasive cigarettes:** There is some evidence on dissuasive cigarettes to suggest that they are effective in making cigarettes less appealing to young people.<sup>xxi,xxii</sup> This evidence is outlined in a recent APPG on Smoking and Health report,<sup>xxiii</sup> endorsed by CRUK.
- **Raising the age of sale to 21:** The age of sale of tobacco is currently 18 in the UK, but recent reports, including the APPG on Smoking and Health report,<sup>xxiv</sup> have been calling for a consultation to increase in the age of sale. 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.<sup>xxv</sup> So 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.
- **Maximum unit pricing:** Historically, tobacco companies have shifted the cost of tax increases on tobacco onto the consumer.<sup>xxvi</sup> They often increased their premium products (overshifting) while minimising the increase in price on their cheaper products (undershifting)<sup>xxvii,xxviii</sup> – likely to avoid the most price sensitive consumers from stopping smoking. *Additional papers of interest and considerations in references.*<sup>xxix,xxx,xxxi,xxxii,xxxiii</sup> By introducing a maximum price on tobacco products, there would likely be a reduced price differential between premium and economy products, which would be beneficial.<sup>xxxiv,xxxv</sup> 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. CRUK is developing our policy position on this measure – with a particular focus on how it would affect tobacco-related health inequalities.

### Helping people to stop smoking

Most people who smoke want to stop, but they need support to do so. There is evidence-based cessation treatment available, and promising commitments to expand access in the NHS Long Term Plan. ***This cancer plan is an opportunity to restate a commitment to implementing these commitments in full.***<sup>xxxvi</sup>

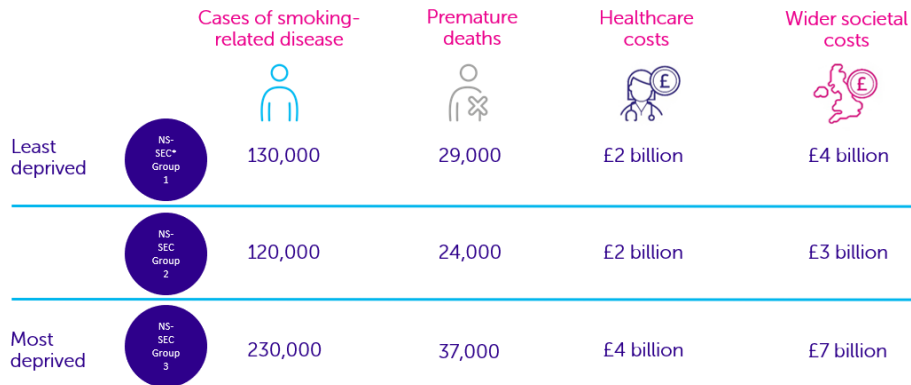
The cancer plan should also consider how to maximise the role that primary care professionals could play in smoking cessation support. Doing so would accelerate progress against the Smokefree 2030 target in all socioeconomic groups, and the largest absolute benefits in health outcomes should be seen 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 (230,000 in the most deprived groups alone). It would also save the UK around £8bn in smoking related healthcare costs and save £14bn in costs to wider society.<sup>xxxvii</sup>

***The cancer plan 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.***

## How might improving stop smoking support impact different socioeconomic groups?

By 2039, improved delivery of stop smoking support by any intervention we modelled could prevent at least...



\*National Statistics Socio-economic classification

Figure sourced from [Making Conversations Count for All. UK-wide analysis.](#)

UK 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.

### Increased investment in tobacco control

The effectiveness of the above interventions is dependent on local stop smoking services being available for primary care professionals to refer their patients to. These services provide the best chance of stopping successfully<sup>xxxviii,xxxix,xl</sup>, yet, in 2021, only 67% of local authorities in England commissioned a specialist service open to all local people who smoke<sup>xli</sup>, as a result of financial pressure from the reduction in the public health grant.<sup>xlii</sup>

To prevent more smoking-related cancers, there must be adequate and sustainable investment in these specialist services – and in tobacco control measures more widely. **CRUK proposes the introduction of a Smokefree Fund, using a ‘polluter pays’ model to fund the measures and services at a local, regional and national level required to ensure that smoking is no longer a burden in 10 years.** A Smokefree Fund would put a fixed annual charge on the tobacco industry – using their funds, without their interference, to pay for the damage tobacco products cause.<sup>xliii</sup> A Smokefree Fund should be introduced as an additional source of funding to the restoration of the public health grant, which is not only required in the long-term for public health functions other than tobacco control, but is also essential for tobacco control activities in the short-term, until a legislated fund is secured and implemented in practice.

### Reducing tobacco related health inequalities

It is imperative that existing tobacco-related health inequalities are addressed, and are not allowed to worsen. CRUK modelling using data from 2018 shows that the most deprived groups in England won’t achieve the Smokefree 2030 target until the mid-2040s.<sup>xliv</sup> Delivering the above recommendations would improve this, however we would also welcome an explicit commitment to reduce these inequalities – because England will not be truly smokefree until all groups are smokefree.

***The cancer plan must commit to reducing disparities in smoking prevalence, by setting a target of reaching less than 5% smoking prevalence for all socioeconomic groups by 2040 at the latest and putting a clear plan in place to reach this target.***

*N.B. Further detailed policy recommendations in this area can be found within CRUK's briefing on tobacco and health inequalities <sup>xlv</sup> and our reports, Making Conversations Count for All<sup>xlvi</sup> and Funding a Smokefree Generation. <sup>xlvii</sup>*

## Obesity

Obesity is the second leading risk factor for cancer and rates are rising in the UK. There are complex causes, however the environment around us plays an important role in guiding our choices and determining how easy it is to maintain a healthy weight. As with smoking, there is a welcome target in place – to halve childhood obesity by 2030 – however this will not be met without Government action. To tackle obesity and turn the tide on rising rates, Government must accelerate its efforts.

***The cancer plan should include a commitment to implementing the measures set out in the Obesity Health Alliance's 10-year Healthy Weight Strategy.<sup>xlviii</sup> This must include:***

- ***Delivering planned obesity policies in full and without delay, starting with the promotion and advertising restrictions of products high in fat, salt, or sugar.***
- ***Exploring further measures that would support healthier behaviours, as identified in the strategy. These include measures that would reduce the amount of advertising people are exposed to of unhealthy food, incentivising purchasing of healthier food and strengthening both policymaking on obesity and the delivery of weight management services.***

We would also encourage consideration of measures that would support people to maintain a healthy weight while reducing air pollution, which is also a risk factor – for example reducing dependency on cars and encouraging walking and cycling; as well as the adoption of national and local strategies to reduce outdoor air pollution.<sup>xlix</sup>

Action to target these causes of cancer, and others like alcohol, is essential to reduce the future burden of cancer on patients, the NHS and the economy, and ultimately level up health across the UK.

Alcohol is linked to seven types of cancer, including two of the most common (bowel and breast) and one of the hardest to treat (oesophageal).<sup>1</sup> Recent data suggests that 4% of all new cancer cases are caused by drinking alcohol. To prevent more cancer cases and deaths, it is critical that the public's understanding of these risks is improved through better labelling requirements for alcoholic drinks. Other public health strategies such as restricting the marketing, affordability and availability of alcohol can also prevent alcohol-driven cancer by reducing consumption at a population level.

## 2. Do you have any suggestions for how to raise awareness of the signs and symptoms of cancer?

### *The problem*

*Despite welcome ambition on early diagnosis, our rate of progress is inadequate. CRUK's Cancer Awareness Measure September 2021 survey found that the most common reason people delay speaking to a health professional, and therefore a significant barrier to help seeking behaviour, is because they found it difficult to get an appointment.*

### *The solution*

*We welcome a focus on public engagement and timely help seeking within the call for evidence. However, help seeking is complex and while awareness of symptoms is important, there are many other factors which are critical to achieving timely patient presentation. We have therefore presented a broader perspective in our response to this question.*

### Public awareness campaigns

Welcome recent examples include the 'Help Us Help You' campaigns to encourage cervical screening uptake, and to dispel fear around help-seeking for potential cancer symptoms. The current requirement for year-by-year funding approvals can compromise a strategic approach to campaign planning – meaning a longer-term funding approach could deliver better results and facilitate more engagement from the service.

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

Positive steps to tailor campaigns, ensuring they are reaching the right audiences, should continue – for example, helping tackle health inequalities by targeting groups shown to have lower uptake. Robust evaluation of public awareness campaigns is also essential, to ensure campaigns are reaching the groups they aim to. To conduct this evaluation, we must address the gap in GP attendance data to assess the behavioural elements of presentation.

### Making Every Contact Count (MECC)

It is important to take every opportunity available to raise awareness of the signs and symptoms of cancer and encourage help seeking behaviour. The principle of Making Every Contact Count (MECC) is where the health service and wider community organisations use the day-to-day interactions that organisations and people have, to support positive changes to people's health and wellbeing. Until now, this has focused on tackling the causes of ill-health, for example smoking or obesity, with fewer examples relating to early diagnosis. However, this could also support help seeking behaviours, to get people with cancer diagnosed earlier. Locally, there have been some positive recent examples, such as during the COVID-19 vaccination campaign, but through greater coordination across the health service and wider community including charities, more progress can be made.

***NHS England should embed the MECC principle across NHS services to support help seeking behaviours, building on the successes of this approach to support the COVID-19 vaccination campaign.***

### Access to primary care

Improving access to primary care, and ensuring people know that they can get an appointment if they are worried about cancer, is therefore vital to ensuring people seek help. The most significant barrier to accessing primary care is a lack of capacity, notably caused by shortages in the GP workforce. It is vital that the

Government targets resources to increase capacity in primary care, by growing the GP and wider primary care workforce.

There have been welcome moves to expand the number of different roles within primary care and adopt skills mix approaches to use that workforce more efficiently. To this end, Primary Care Networks (PCNs) have been given funding for additional roles to take on some responsibilities traditionally held by GPs. However, the Additional Role Reimbursement Scheme has not identified specific roles that can support the early diagnosis of cancer, which is a gap and risks missing opportunities to deliver against ambitions set out in the PCN service specification on improving cancer early diagnosis.

***NHS England should conduct an assessment of the current primary care workforce mix and how it could be optimised to support increased referral for cancer. As part of this, roles should be identified to be supported with funding through the Additional Role Reimbursement Scheme.***

#### 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, for example a Community Diagnostic Centre (CDC), are areas with significant interest.

It is vital that all new models of care are subject to pragmatic but robust evaluation, to ensure that they are driving the desired impact for patients and do not exacerbate inequalities by facilitating entry and diagnosis for the more health-engaged. It is also vital 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.



### 3. Do you have any suggestions for how to get more people diagnosed quicker?

#### ***The problem***

*Chronic workforce shortages cause bottlenecks in diagnostic capacity, which in turn are a significant barrier to earlier diagnosis. As demand increases in the coming years, these shortages are likely to worsen – impairing our ability to take evidence-based measures to drive earlier diagnosis, such as implementing direct access to tests or optimising screening programmes.*

#### ***The solution***

*Given the significant increases in demand that will follow over the coming years, our strong preference would be an expansion of the cancer workforce. However, there is also potential in innovative ways to increase workforce productivity – which would complement an increase in workforce numbers. We would encourage a focus on pathway and programme change – such as streamlining cancer pathways, optimising cancer screening and harnessing the potential of innovation. However, again it should be noted that any efforts to increase testing would have implications for capacity.*

#### **Streamlining cancer pathways**

Best practice timed pathways (BTPs), which have clear milestones and support the delivery of the Faster Diagnosis Standard (FDS), can spur transformative change. We welcome the commitment from the cancer programme that BTPs will be produced for all cancer sites by March 2024 and are keen to work with NHSE on this. We would also like to see a more ambitious trajectory for driving earlier diagnosis for all cancers.

***The cancer plan should commit to a trajectory to a more ambitious target for the Faster Diagnosis Standard that will drive improvements through the 10-year strategy – to 80% in 2023, rising to 85% in 2025, 90% in 2027, to the originally proposed 95% by 2029.***

***NHS England should regularly publish its analysis of the impact on cancer patients of this target, and how performance varies across the country.***

Community Diagnostic Centres (CDCs) have the potential to transform our approach to elective diagnostic services – shifting planned diagnostics from acute sites into the community, increasing productivity and improving access to help tackle health inequalities. To meet this potential, CDCs must be supported by sufficient diagnostic capacity, including workforce, digital and IT infrastructure, and sited in community settings to support equitable access.

As cancer services change to support earlier diagnosis, it is important that referral guidelines remain up to date. As evidence builds, it is important to consider where NICE cancer recognition and referral guidelines (NG12) should be updated, as well as exploring ways of optimising the use of referral guidelines, including ensuring GPs have timely access to, and reporting of, key diagnostic tests. We would also welcome further exploration of direct access to tests and less restrictive referral processes – although it must be noted that many of these innovations would require greater diagnostic capacity. There are several specific areas where NG12 guidance and pathways should be updated, which are noted in our supplementary paper on site-specific diagnostic pathways.

## Cancer screening

Cancer screening is critical to driving earlier diagnosis of cancer. Driving faster implementation of recommendations made by the UK National Screening Committee (UKNSC) would drive faster 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 factors need to be in place. These include factoring actual or likely requirements into IT development at the earliest reasonable opportunity, considering synergies across different screening programmes and opportunities to facilitate alignment to support engagement and sustainability, and exploring innovative models of delivery, including consideration as to the role of CDCs.

We welcome the expansion of the remit of the UKNSC to include targeted screening. Where targeted screening recommendations are not deemed to fall within their remit there must be a clear and timely handover to NICE.

Targeted Lung Health Checks (TLHCs) could support the earlier diagnosis of lung cancer, and should be implemented if recommended by the UKNSC, with high quality smoking cessation services integrated into the pathway. New approaches such as TLHCs will rely on the data being available to effectively target parts of the population, ensuring inequalities are not exacerbated. 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 and so efforts to optimise the diagnosis of lung cancer through patient presentation and recognition and referral of symptomatic disease will continue to be key.

## Adopting innovation

Identifying new and novel ways of detecting and diagnosing cancer through research and innovation is critical to enabling earlier and faster diagnosis.

There are many interesting areas of early detection and diagnosis (ED&D) research. These include multi-cancer early detection (MCED) tests and polygenic risk scores which, alongside other patient and lifestyle factors, could help to identify those at increased risk of disease – although much more research is needed. The ED&D research pipeline is brimming with a wide range of promising innovations. MCED tests, including GRAIL's Galleri test, have potential to expand the range of screen-detectable cancers and identify them at earlier stages – although no single intervention will be a silver bullet.

***The Government and NHS should support a variety of early detection research, to ensure promising tests can be investigated at scale and in a real-world setting.***

***The cancer plan should also commit to exploring a model of earlier roll-out for tests showing impact, including within a research framework, followed by real-world evaluation of longer-term impact. If the evidence then supports the role of these interventions, there should be earlier dialogue about how capacity could be expanded to rolling them out more quickly and equitably across the country.***

***The cancer plan should commit to establish parameters for innovators across academia and industry, with clarity on the clinical need and information on the characteristics and requirements, such as sensitivity, specificity and time to test result, which are most likely to be clinically and cost-effective.***

## 4. Do you have any suggestions for how to improve access to and experiences of cancer treatment?

### **The problem**

*UK stage-specific survival is lower than comparable countries<sup>li llii</sup>, indicating that as well as early diagnosis, it is also essential that we improve access to high-quality treatment. However, while we know that there is variation in access to treatment, it is difficult to identify the extent to which this variation is unwarranted with the data currently available. Patient fitness can impact access to treatment, for example, but data on comorbidity, performance status, treatment intent, and other relevant measures are either lacking or of inadequate quality. As with diagnostics, capacity constraints slow adoption of innovation and hamper progress.*

### **The solution**

*Better capture of data on cancer stage at decision to treat as well as 31- and 62-day waiting times, broken down by more cancer types and by type of first treatment would improve identification and understanding of variation in access. Real time data across cancer centres should be made standard practice. We would hope that closer working between NHSE and NHSD will improve the completeness and timeliness of datasets to enable data capture and analysis of these factors – but this must be made a priority. Further solutions are presented below, including relating to workforce, equipment and innovation.*

### **Access to specialist expertise**

The 2015 Cancer Strategy for England described multidisciplinary teams (MDTs) as the ‘gold standard’ of cancer services. However, their service model has not evolved, despite patient numbers and complexity of pathways growing significantly since their introduction in the 1990s.

This has meant that MDT meetings have been lasting for several hours, with only a few minutes available to discuss each patient. As a result, these discussions often only involve a few people, and often do not include information such as the patient’s preferences, comorbidities or whether the patient is suitable for a clinical trial.<sup>liv</sup> CRUK proposed a modernised way of working for MDTs in a 2017 report, which 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.

***Cancer Alliances, in coordination with the NHSE Cancer Programme, should accelerate the implementation of the NHSE guidance for streamlining MDT meetings<sup>lv</sup> to improve the quality and benchmarking of MDT discussions, patient access to specialist expertise, patient experience, and clinical care.***

### **Surgical capacity**

Rising cancer incidence combined with a shift towards diagnosing more cancer at earlier stages will increase demand on surgical services in the future. Surgical training is a long process which can take up to eight years after graduation. Therefore, ongoing reviews of demand, capacity, and optimal workforce requirements are key to planning and optimising service provision.

Over the course of the pandemic there has been a protection of capacity through surgical hubs, which is welcome. However, this model does not benefit all cancer surgeries, and needs to be balanced with ensuring equitable access.

International evidence suggests there is suboptimal treatment for some types of cancer in the UK<sup>lvi</sup>, potentially driven by less willingness to treat using radical approaches, lack of performance monitoring, and availability of critical care beds<sup>lvii</sup> (of which England has fewer per capita than the OECD average<sup>lviii</sup>).

***The cancer plan must ensure cancer services have consistent access to the specialist expertise and infrastructure required to provide specialist surgery to all patients who would benefit. This includes access to timely data, that would enable clinical audits and quality improvement.***

#### Adoption of innovation in surgery and radiotherapy

Innovations in treatment and service delivery promise kinder and more effective treatment options for patients. However, innovations are not always adopted equally across the NHS and routes to adoption for some modalities are poorly defined or not fit for purpose. Processes for evaluating, adopting and implementing innovative cancer treatments must therefore continue to improve and evolve to ensure equitable and timely access for patients.

This should include comprehensive horizon scanning for early identification of promising innovations and mechanisms for services to signal clinical need to the research community, for example where unmet need exists and treatment options are lacking.

Improvement in data capabilities will also be required to enable use of real-world evidence in understanding the benefits of innovations to patients and services, particularly for innovations where other methods such as clinical trials are not appropriate or feasible.

***NHS England, in conversation with clinicians and researchers, should clearly define and resource routes to adoption for different types of innovation, including outlining accountability and responsibilities of the relevant partners as well evidence and cost-effectiveness requirements.***

***NHS England should review the radiotherapy tariff to ensure this does not act as a disincentive for the adoption of innovations requiring fewer patient visits or additional planning e.g., hypofractionated or image-guided radiotherapy.***

***NHS England should continue to support and improve Radiotherapy Operational Delivery Networks and to facilitate sharing of best practice, quality improvement and evaluation of innovations and consider where similar approaches could be supported for other modalities.***

Trusts rely on up-to-date equipment to deliver innovative high-precision forms of radiotherapy and to evaluate new technology and techniques. Despite being a recommendation in the 2015 Cancer Strategy, there is still no coordinated process for replacing old radiotherapy machines. There has been welcome investment, including £130 million in 2016 and £32 million in 2021-22. However, ad hoc replacement is an inequitable and an unsustainable solution, especially when no incentives exist for Trusts to replace the machines themselves.

***The cancer plan should contain a commitment to putting in place a coordinated and funded process for the rolling replacement of radiotherapy machines at the end of their lifespan.***

#### Access to new medicines

For medicines, where adoption pathways are more clearly defined and research better funded, the increasing complexity of new approaches, such as immunotherapies and combination treatments, means regulatory and Health Technology Assessment (HTA) pathways must continue to evolve to ensure patients can access these.

The focus on innovative licensing arrangements and new international regulatory partnerships such as Project Orbis and the Access Consortium are welcome, and the former has delivered accelerated licensing for a number of new cancer medicines since the Medicines and Healthcare products Regulatory Agency (MHRA) joined in 2021. However, as the MHRA's regulatory policy evolves, it must avoid significantly diverging from that of the European Medicines Agency (EMA). For example, divergence on licensing risks causing medicines

to be launched later in the UK compared to the EU while divergence on batch-testing and other regulations risks disrupting the flow of medicines entering the UK from the EU.

***The MHRA must continue to align with the EMA on medicines licensing and regulation to ensure UK patients' continued timely access to cancer medicines.<sup>lix</sup>***

Across a number of countries, there is a trend towards increasing volumes of medicines receiving regulatory approval on the basis of early phase trial data and expedited approvals. This can create challenges in determining their clinical benefit and cost-effectiveness at the point of Health Technology Assessment.

Flexible pricing mechanisms such as outcome-based payments (OBP) can speed up access to some licensed medicines with immature trial data. It can also help address rising cancer medicine prices<sup>lx</sup> by ensuring the NHS only pays for outcomes that are achieved for individual patients. However, limitations with data capture limit the ability to establish optimal flexible pricing schemes such as OBP.<sup>lxi</sup>

***NHS England should invest to improve the data capture of core patient outcomes (survival; disease progression, relapse, or recurrence; and short-term side effects) in the Systemic Anti-Cancer Therapy (SACT) dataset. They should furthermore ensure patients can report long-term side effects and their ability to return to normal activities through patient reported outcome measures (PROMs) data collection infrastructure (for example via online patient portals).***

***DHSC, in conversation with Trusts and industry, should further investigate the optimal organisation and governance of Outcomes Based Payment schemes.***

Recent years have seen a range of welcome initiatives that aim to improve patient access to medicines. These include the Innovative Licensing and Access Pathway (ILAP), the Innovative Medicines Fund (IMF), the NHSE Commercial Framework, the NICE Methods and Process Review, and the Cancer Drugs Fund (CDF). Government, NHSE, NICE, and other system partners should ensure the access landscape remains joined up across initiatives and involved organisations to avoid fragmentation and overlap.

***The cancer plan should include a more robust framework for how patient access to innovative cancer medicines is measured and assessed, and who by.***

## 5. Do you have any suggestions for how can we maximise the impact of research and data regarding cancer and cancer services in England, including how we can translate research and data into practice sooner?

### *The problem*

*The UK is a leader in cancer research, bringing progress for patients and wider benefits to the economy. However, there are also improvements to be made. The UK's capacity to deliver clinical cancer research was overstretched long before COVID-19 but has been badly worsened by the pandemic. There is also further to go expanding R&D spend and supporting the commercialisation and adoption of innovation generated through research.*

*Data underpins every effort to understand cancer and improve outcomes, and the UK is well placed to be ambitious on data. However, too often, research is limited by delays in access to data, long waits between data collection and publication, poor linkage and inadequate infrastructure. This potential is untapped.*

### *The solution*

*A thriving life sciences and broader R&D ecosystem that can attract and retain global talent and benefits from investment from a range of funders is fundamental to maximising the impact of cancer research. The UK currently punches above its weight in cancer research, leveraging its internationally renowned discovery and translational science base to identify, develop and launch new technologies and treatments. CRUK is a vital part of the cancer R&D ecosystem – we fund nearly 50% of non-commercial UK cancer research. Cancer is also the most successful field in UK commercial clinical research, which drives economic growth through innovation and attracts new investment into the UK science base.<sup>lxii</sup> The pandemic has presented a once-in-a-generation opportunity to transform for the better and accelerate progress through research.*

*CRUK has been pleased to engage with UK Government-led initiatives seeking to make improvements in the R&D environment including the Future of Clinical Research Delivery vision, Life Sciences Vision, and US-UK Cancer Summit. Likewise, plans to boost health research funding to £2 billion per year are very welcome. Now it is vital to deliver on these plans to maximise the impact of and translate cancer research into practice sooner.*

### ***The cancer plan should bolster the Government's commitment to cancer R&D by:***

- ***Launching a review of fiscal incentives for increased R&D investment in cancer research, as well as collaboration between private and not-for-profit research organisations. This would also support the Government's ambition to reach 2.4% GDP spent on R&D.***
- ***Working with industry and academic partners to address the barriers to commercialisation of cancer research.***
- ***Contributing to a strategy to increase the diversity of the UK research workforce, and ensure it has the capability and capacity to advance research.<sup>lxiii</sup>***
- ***Ensuring a significant proportion of the £95m allocated to the Life Sciences Vision is used to take forward the Vision's Cancer Mission.***
- ***The Prime Minister and Secretary of State for Health and Social Care should maximise the opportunity of the upcoming US-UK Cancer Summit by ensuring it is associated with clear commitments to drive transformative transatlantic collaboration on cancer research, with meaningful funding attached. This should build on existing bilateral cancer research efforts including CRUK's flagship Cancer Grand Challenges initiative<sup>lxiv</sup>.***

The Life Sciences Vision sets ambitions for the UK to be a testbed for oncology innovation and be a global leader in the development and commercialisation of immuno-oncology, cancer vaccines and diagnostics.



These ambitions are welcome, but barriers exist to achieving them. For preventative and therapeutic cancer vaccines, these may have potential in the long-term and the UK could be a leader in this field, but more research is needed for instance into underpinning immune-biology and appropriate therapeutic combinations. Early detection and diagnosis (ED&D) research holds great promise - we set out how to deliver on this below.

### Clinical research

An immediate priority is clinical cancer research's recovery from COVID-19. The majority of cancer clinical trials paused recruitment during the pandemic's first wave, and recruitment remains 43% below pre-pandemic levels.<sup>lxv</sup> The UK's recovery is now being outpaced by other countries such as Italy and Spain,<sup>lxvi</sup> 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.<sup>lxvii</sup> To support clinical cancer research activity, especially scientifically-rich clinical trials that meet unmet patient needs, DHSC's Managed Recovery programme should prevent further disruption to research, increase researchers' access to resources needed to deliver cancer clinical trials, and set itself clear targets.

***Recovery alone is insufficient to improve cancer outcomes; clinical research capacity must also expand. To achieve this, the cancer plan should include commitments for:***

- ***NHS England to operate a pilot scheme that offers a cohort of NHS staff contracts that include dedicated time for research***
- ***The National Institute for Health Research's annual budget to be increased from £1 billion to £1.4 billion by 2025***
- ***NHS England to work with health research funders and academia to increase NHS staff's access to research training***
- ***The UK Government to take steps to make clinical cancer research more accessible and inclusive by reviewing the regional distribution of research and building on its investment in widening opportunities for careers in clinical research***
- ***NHS England to embed clinical cancer research into everyday practice by incorporating research into workforce strategies and developing metrics to better capture the impact of NHS research***

It is vital that the cancer plan prioritises quality over quantity in its support for clinical research. For the UK to achieve world-class cancer outcomes for all, it must have a future-oriented research environment that enables delivery of innovative research efficiently and equitably. To achieve this, the cancer plan should include commitments for the UK Government to:

- ***Streamline the set-up and delivery of non-commercial clinical cancer research and invest in expanding the capacity of local NHS R&D offices.***
- ***Learn from COVID-19 to make cancer trials more accessible, including by investing in the workforce and infrastructure required to deliver decentralised clinical trials.***
- ***Work with Cancer Research UK and others in the sector to conduct a review exploring the future of cancer research, including an evaluation of the Genomic Medicine Service's capacity to facilitate cancer trials.***

### Early detection and diagnosis research

Research is essential to improve early detection and diagnosis (ED&D), but it has faced a historic lack of funding. Increased investment and cross-sector collaboration are required in:

- Biology of early and pre-cancers, to minimise unnecessary burdens on people and the NHS.

- Cancer risk, to improve early detection and prevention. CRUK is exploring how multimodal big data and AI can transform understanding of who is at most risk, but we cannot do it alone: partnership and co-investment with public research funders is crucial.
- Multi-cancer early detection tests and their potential impact on population, patients and health services. Crucially, these tests can only form part of a wider picture of investment and action.

There are significant barriers to overcome to ensure commercialisation and adoption of ED&D innovations, including a complex regulatory landscape, inappropriate reimbursement and an unclear health economic model.

***The cancer plan should include a commitment from DHSC to:***

- ***Address market failure through an action plan to remove barriers, incentivise industry investors and accelerate adoption. This work should be developed in collaboration with relevant Government departments, agencies and devolved nations equivalents.***
- ***Initiating the development of a comprehensive health economic model for ED&D to incentivise R&D and support adoption, delivered through a cross-sector working group.***

## Cancer data

Data is fundamental to our progress against cancer. Data and data-driven technologies underpins 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.

Cancer data is particularly rich; national screening datasets are very comprehensive while cancer registry data contains decades' worth of high-quality data integrated with other healthcare datasets. But we cannot be complacent: there are significant limitations to using some of the key datasets due to completeness and timeliness, and to maintain its internationally recognised status, there need to be continual improvements in cancer data and a look to the future with genomics data and personalised medicine.

***The cancer plan should include a commitment to develop a comprehensive strategy for cancer data. This should involve insight-gathering across different sectors, and actions to address access, data quality, timeliness, dataset linkage and data infrastructure. This review should include an assessment of how data on protected characteristics could be captured is required, with meaningful public and patient engagement to inform this work.***

More timely and linked cancer data would turbocharge our ability to improve cancer services. The latest national staging data for England is for 2019, and data from the rapid registration dataset is significantly lacking completeness. Two years since the start of the pandemic, we are still not yet able to assess fully the impact of the first wave on early diagnosis of cancer – beyond anecdotal or local level data.

A comprehensive approach to COVID-19 monitoring was at the heart of the UK's pandemic response. The same commitment to speed and accessibility for cancer data would be pivotal in transforming quality improvement, cancer research and healthcare delivery, but action is required to make this a reality.

***The cancer plan should include a commitment to creating and continually improving a rapid cancer dataset to capture all relevant cancer diagnostic activity, ensuring that relevant clinical and academic partners are consulted and engaged in its development, production, and management.*** This is critical to the success of the cancer plan and should learn from the success of COVID-19 monitoring.

This rapid dataset should link together and make improvements to existing datasets such as screening data, diagnostic imaging data, National Endoscopy Dataset and the Cancer Waiting Times (CWT) dataset and build on initiatives already demonstrating progress locally. Where beneficial, we should be working towards real-time or near real-time datasets over the course of the 10-year timeframe.

***NHS England and DHSC should commit to ensuring improvements in data completeness in rapidly available datasets, for instance an initial capture of stage at diagnosis or first treatment.*** For the majority of cancers, this could be captured as part of the MDT discussion.

Data access is another issue which is hampering progress in cancer research. While strict controls on access are essential to ensure that patient data is used in a secure and privacy protecting manner, and therefore to build and maintain public trust, CRUK analysts have faced extreme delays when making legitimate data access requests.

For instance, CRUK has been involved in the NCRI's COVID-RT study, which seeks to understand changes in radiotherapy schedules during the pandemic and then explore the impact of these changes on patient outcomes. This requires bringing together data from cancer centres across the UK and therefore data from all four of the UK cancer data custodians. Discussions to gain access to pseudonymised data from national data custodians – data that was specifically collected for this study by the centres – have been ongoing with some data custodians for 15 months and to date we have only received data from one centre in Northern Ireland. Given the ongoing importance of research into Covid-19 and the nature of a fast moving and evolving pandemic, delays of this kind act as a serious barrier to bringing benefits to patients.

We also note that repeated restructures of data-processing organisations have long hampered the ability to maintain a supportive system for data access. Most recently, there was a two-month pause while datasets were transferred from Public Health England to NHS Digital. This exacerbated delays to legitimate requests and created a backlog to all applications. We are therefore concerned about the impact of the subsequent transfer of datasets to NHS England.

***The Department of Health and Social Care should place increased focus on improving the timeliness of access to data for research and service improvement. This should include:***

- ***Exploring a streamlined, rapid process for appropriately accredited stakeholders including researchers, third sector and NHS.*** This would need to ensure meaningful public involvement and engagement from the outset.
- ***Providing further, ongoing guidance and support for individuals who are responsible for making decisions about data access,*** to avoid what CRUK perceives as an overly rules-based approach.
- ***Ensure researchers' access for planners and researchers to primary care data by keeping up momentum on work to meet the tests required to allow implementation of the GP Data for Planning and Research programme.*** Meaningful public communications and engagement, working with the charitable sector, will be central to the success of this programme and ensuring public confidence in the approach.
- ***Putting mechanisms in place to ensure that changes in data custodians (e.g. the current merger of NHS Digital into NHS England) do not affect the speed of processing legitimate access requests.***

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 experience<sup>lxviii</sup>, this must not be taken for granted.

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 research, specifically into rare diseases where numbers are low. The effect can be swift, for example in the first full month after concerns were raised about the GP Data for Planning and Research programme, National Data Opt Outs increased by more than a million.

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.

## About Cancer Research UK

Cancer Research UK (CRUK) is the world's largest cancer charity dedicated to saving lives through research. In 2020/21, we spent £421 million on new and ongoing research projects. We support research into over 200 types of cancer, and our vision is to bring forward the day when all cancers are cured. 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.

## Appendix 1 – Further Resources for Consideration

### Cancer Research UK – Prevention materials

- Policy Priorities for Tobacco Control – available on request
- [Tobacco and Health Inequalities Briefing](#) (2021)
- [Local Tobacco Control Policy Statement](#) (2021)
- 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](#)
- CRUK Briefing on Youth Obesity Polling Survey – available on request

### Cancer Research UK – NHS cancer services materials

- CRUK cancer workforce cost modelling for England briefing (2021) – available on request
- CRUK policy statement on maximising the potential of the current cancer workforce (2021) – available on request
- CRUK [response to the Health and Social Care Select Committee Expert Panel Assessment of NHS Cancer Services in England](#) (2022)
- CRUK response to NHS England's Clinical Review of Standards for Cancer (2022) – available upon request
- CRUK [policy position and consultation response to the Innovative Medicines Fund consultation](#) (2022)
- CRUK [Making Outcome-Based Payment a Reality in the NHS. Phase 2: Practical Considerations](#) (2021)
- CRUK [Making Outcome-Based Payment a Reality in the NHS](#) (2019)
- Driving transformation through a comprehensive cancer strategy (2020) – available on request

### Cancer Research UK – research and data materials

- Cancer Research UK response to DCMS [consultation on Data: A new direction](#) (2021)
- [Cancer Research UK response to Health and Social Care Data Strategy](#) (2021)
- [Beyond recovery: The case for transforming UK clinical cancer research](#) (2022)

- Cancer Research UK briefing on early detection and diagnosis research (2022) - available on request
- Cancer Research UK response to Research, Development and Innovation (RDI) Landscape Review (February 2022) - available on request
- Cancer Research UK response to S&T inquiry on Diversity in STEM (January 2022) – available on request
- Cancer Research UK response to Lords S&T consultation on delivering a UK science and technology strategy (March 2022) – available on request

## Appendix 2 - References

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