

# 10-Year Cancer Plan: Call for Evidence

## One Cancer Voice Cancer Charities' Consensus Statement

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**If the new 10-year Cancer Plan is to be successful in delivering world leading and transformative change then we believe it must meet the following 10 tests:**

1. The 10-year Cancer Plan has clear political leadership, is fully costed and funded throughout its lifetime, with an annual report published on progress made against its ambitions.
2. More cancers are prevented and England is 'smoke free' by 2030
3. The public is aware of the risk factors, signs and symptoms of cancer and act on them, leading to improvements in presentation. Emergency presentation is reduced to no more than 5%.
4. Progress towards early diagnosis is accelerated so that 78% of people are diagnosed at stage one or stage two and a 95% Faster Diagnosis Standard is met.
5. Every person with cancer can access the treatment they need, at the right time, for the best outcomes. Cancer Waiting Time targets are met in every part of the country.
6. By 2032, everyone with cancer is able to access a needs assessment and personalised care plan to support their health and wider wellbeing needs.
7. Workforce and equipment shortages are addressed so that every person with cancer has access to the specialist workforce they need when they need it.
8. Cases of cancer attributable to inequalities have meaningfully decreased.
9. Clinical research capacity is increased, health service staff have access to dedicated research time and training and all populations are given the opportunity to participate in clinical trials.
10. Data collection is timely, accessible, standardised and comprehensive and it is analysed and published swiftly to support the delivery and monitoring of all aspects of cancer across the pathway and cancer research.

As a cancer community of over 50 cancer charities, representing millions of people living with cancer, we welcome the Government's Call for Evidence to inform a new 10-year Cancer Plan and the opportunity for people living with cancer and the public to provide their views. People living with cancer must be at the heart of cancer care and support. They should be involved in their care and decisions about their treatment and they should be involved in the development of cancer services. Their views should inform the next Cancer Plan.

Drawing on our collective experiences from supporting people living with cancer, research, data and insight, we have developed this consensus statement, setting out what actions Government and the NHS need to take to ensure people diagnosed with cancer in England get the very best care and treatment.

There are around 313,000 new cancer cases in England every year, that's around 858 people diagnosed every day.<sup>1</sup> Cancer remains one of England's biggest killers with 137,234 people

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<sup>1</sup> <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/all-cancers-combined#heading-Zero>

dying of cancer in 2020.<sup>2</sup> This has increased by 8% since 2001 and will continue to increase as more people are diagnosed with the disease each year.<sup>3</sup>

This new Cancer Plan must be ambitious in scope to recover from the pandemic and to close the gap between England and the best performing countries in the world. The pandemic has affected cancer care, with an estimated 33,000 people missing from the system. Our survival continues to lag behind the best performing countries in the world. There is an urgent need to level up by focusing on inequalities across the cancer pathway so that everyone gets the very best cancer care.

## 1. Funding and accountability

**Test: The 10-year Cancer Plan is fully costed and funded and there is transparent and regular reporting of progress against commitments to improving cancer care and progress against them.**

- **There is clear political leadership at the most senior levels of government including the Prime Minister.**
- **A centrally agreed table of commitments and strategies is held and published by the Department of Health & Social Care, the NHS, the Treasury and other key stakeholders.**
- **The Government publishes an annual report on progress against the Cancer Plan throughout its lifetime so that all stakeholders, including people living with cancer, charities and health care professionals, understand Government commitments and progress against them.**
- **Cancer Alliances are resourced to work more closely with cancer charities.**

Resources in the NHS remain tight and new innovations cannot be expected to be funded from existing pots of money. The 10-year Cancer Plan must be fully costed and funded.

While we wholeheartedly welcome a new Cancer Plan, we must acknowledge that the existing NHS Long Term Plan with its cancer commitments has not yet run its course. It is important that we learn the lessons from previous plans and that previous investments, initiatives and actions are properly evaluated. Some targets have slipped.<sup>4</sup> It is vital that data on progress towards previous commitments is regularly published to ensure greater accountability and transparency. **A centrally agreed table of commitments and strategies should be published by the Department of Health & Social Care, the NHS, the Treasury and other key stakeholders**

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<sup>2</sup> <https://commonslibrary.parliament.uk/research-briefings/sn06887/>

<sup>3</sup> <https://commonslibrary.parliament.uk/research-briefings/sn06887/>

<sup>4</sup> For example, The NHS Long-Term Plan included a commitment to improve access to clinical trials for teenagers and young adults with cancer, achieving an overall participation rate of 50% by 2025. However, at present there is no data publicly available to show progress towards this commitment. It also included a commitment to roll out personalised care for all cancers by 2021 but this slipped to 2022.

**and progress against the plan reported at least annually.** We must build on what has come before.

The National Cancer Board has led efforts to improve cancer care over the last few years and we welcome the opportunity for continued charity sector representation on it, to bring the patient voice and foster collaboration.

We support Cancer Alliances and believe they are best placed, alongside ICSs, to improve cancer outcomes and tackle inequalities. Where cancer charities have been able to work with them, effective partnerships have built consensus, shared best practice and promoted cancer charity resources. **We would like to see these bodies resourced so they can work even more collaboratively with cancer charities** who offer a wealth of information and resources, as well as providing support to people with cancer.

## 2. Prevention

**Test: By 2032, there is a reduction in incidence of cancer.**

- **A comprehensive Tobacco Control Plan and help provided for people to quit smoking, particularly in deprived areas. England is SmokeFree by 2030.**
- **NHS-funded tobacco treatment services offered to all inpatients, pregnant women and people accessing long-term mental health and learning disability services.**
- **Controls and restrictions on junk food advertising and promotions as well as support for people to maintain a healthy weight.**
- **A comprehensive alcohol strategy to reduce drinking in the UK to levels where the risks are minimal.**
- **Raising awareness of the risk and causes of cancer.**

4 in 10 cancers could be prevented.<sup>5</sup> More must be done to tackle the factors that can cause cancer. Tackling smoking and overweight and obesity, the first and second leading causes of cancer respectively and key drivers of health inequality, should be the first areas to address in order to level up health outcomes to tackle disparities.

**A robust and comprehensive tobacco control strategy** is needed with sustainable funding for measures that help prevent people from starting to smoke and supports those that do to stop. This should include regular mass media campaigns designed to encourage people who smoke to stop, and discourage tobacco use to reduce uptake. Comprehensive access to local stop smoking services, which offer people the best chance of successfully quitting, are also needed. Sustainable and increased funding for stop smoking services as well as other tobacco control measures is essential if we are to make smoking obsolete. As the producers of such a harmful product, the tobacco industry should be required to pay a fixed annual charge for the costs of the damage it causes.

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<sup>5</sup> <https://www.cancerresearchuk.org/about-cancer/causes-of-cancer>

Reducing the burden of obesity requires a comprehensive approach that addresses the environmental causes of obesity, empowers people to make and maintain healthier habits and provides evidence-based treatment to those who need it. There is overwhelming evidence that foods high in fat, sugar and salt (HFSS) marketing impacts children's eating habits, influencing the type of food children choose, how much of it they eat, and can lead to them 'pestering' parents to buy unhealthy products. Ensuring robust and comprehensive marketing restrictions will be critical to tackling childhood obesity. The Obesity Health Alliance's *Healthy Weight Strategy* (2021) sets out a range of evidence-led measures that Government should take over the next decade to reduce overweight and obesity and thus the risk of associated cancer, morbidity, disability and premature death in adulthood.

Further measures to prevent cancer include raising awareness of the risks and causes of cancer, action to tackle inequalities in access and uptake of the HPV vaccine, reducing alcohol consumption, investing in research to better understand populations at higher risk of developing cancer and how routine screening for those at risk could be adopted across the NHS, including the risks of familial and hereditary cancers.

### 3. Public Awareness, Engagement and Action

**Test: The public are aware of the risk factors, signs and symptoms of cancer and act on them, leading to improvements in presentation, supporting the early diagnosis ambition.**

- **Three public behaviour and engagement campaigns are run each year by the NHS.**
- **Integrated Care Systems (ICSs) and Cancer Alliances work to ensure Health Care Professionals (HCPs), particularly in primary care, have training, resources and clinical decision support tools to support increased awareness of signs, symptoms and risk factors of cancer, including for non-specific symptoms and secondary cancers.**

Ensuring people are aware of the risk factors, signs and symptoms of cancer can help to ensure people are diagnosed earlier with improved chances of survival. We welcome the recent and continuing investment in awareness campaigns by the NHS such as the *HelpUsHelpYou* campaign and the work to raise awareness about prostate cancer.<sup>6</sup> Evaluation data on these campaigns should be shared so that the cancer community has a better understanding of what is and isn't effective at raising awareness. Campaigns should focus on non-specific symptoms as cancers associated with these symptoms can be harder to spot, along with reassurance messages that GPs want to see patients with worrying, unusual or persistent symptoms. They should focus on action and behaviour change, rather than just awareness. It is critical that there

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<sup>6</sup> [https://prostatecanceruk.org/risk-checker.html?gclid=Cj0KCQiA64GRBhCZARIsAHOLriLxQ3wG68dkSzBJD6BQ5pKvT6vaIJAIR3\\_TFbtWTIQgVyS3zNIUg-saAiyHEALw\\_wcB](https://prostatecanceruk.org/risk-checker.html?gclid=Cj0KCQiA64GRBhCZARIsAHOLriLxQ3wG68dkSzBJD6BQ5pKvT6vaIJAIR3_TFbtWTIQgVyS3zNIUg-saAiyHEALw_wcB)

is multi-year funding committed to this activity, so that at **least three campaigns can be delivered each year.**

Coupled with this, Government and NHSE must take action to ensure that local health bodies, such as ICSs and Cancer Alliances, have **resources and clinical decision support tools to increase awareness of symptoms and risk factors amongst primary care healthcare professionals themselves and support them with referrals**, in an effort to speed-up patient referrals especially for cancers with vague and non-specific symptoms and for the signs of secondary cancer.

## 4. Early Detection and Diagnosis

**Test: 78% of people are diagnosed at stage one or stage two and the 95% Faster Diagnosis Standard is met.**

- **Development of proxy measures for cancers that are not staged.**
- **Optimisation of current screening programmes, and timely adoption of new population or risk-stratified screening programmes where evidence supports.**
- **Investment in diagnostic capability.**
- **Roll out of Community Diagnostic Centres (CDCs) to include people with non-specific symptoms.**

We support the Government's ambitions for 75% of cancers to be diagnosed at stage one or two by 2028 and this should be extended to 78% by 2032. It is important that all cancers are included in this target. This means that for cancers that cannot be staged, **proxy measures must be developed**. The collection of staging data must be improved for many cancers and the data must be broken down by cancer type so that cancers doing better at earlier diagnosis do not mask the progress of cancers that are performing poorly. Data on emergency presentations and routes to diagnosis should also be used as trackers of progress. Emergency presentations should be reduced to no more than 5%. By 2032 The Faster Diagnosis Standard should be met for 95% of suspected cancer referrals across the country, and all the diagnostic information that can inform treatment decisions should be made available within 28 days.

Cancer screening programmes are vital in ensuring prevention and earlier detection in asymptomatic populations, giving the best possible chance of early treatment and cure. Existing cancer screening programmes should continue to be improved and promoted to tackle inequalities and barriers in access and uptake. Improvements recommended by the 2019 Richards review of adult screening programmes should be fully implemented. In particular, urgent upgrades need to be made to the IT infrastructure in cervical and breast screening programmes, where progress is being severely limited. Where evidence supports, new population or risk stratified screening programmes should be rolled out swiftly. We welcome innovations such as the Targeted Lung Health Check, non-specific symptom pathways and the pilot liver checks to further move the dial on early diagnosis.

**The Government must invest to replace and expand diagnostic equipment and radically reform how diagnostic services are delivered if the early diagnosis ambition is to be met.** £1.3 billion in capital funding is required to bring CT, MRI and PET-CT equipment capacity to the average across comparable OECD countries.<sup>7</sup>

We welcome the development of Community Diagnostic Centres as recommended by the 2020 Richards Review and the Delivery Plan for Tackling the Elective Backlog. As part of rolling out CDCs, cancer diagnostic pathways must be integrated within them and there must be further clarity on what proportion of funding will be spent on cancer. **People with non-specific symptoms of all ages must be able to access CDCs**, as has proven successful for the Rapid Diagnostic Centre programme. This is particularly important for people with rare and less common cancers. The ability to self-refer should be piloted and evaluated and evaluations of how RDCs and CDCs are performing for people with suspected cancer. GPs and primary care professionals must be better supported to recognise the non-specific signs and symptoms of cancers, through training and the development of clinical decision support systems.<sup>8</sup>

## 5. Treatment

**Test: By 2032, every person with cancer can access the treatment they need.**

- **Modelling of impact of early diagnosis ambition and new treatments in the pipeline on treatment pathways and workforce.**
- **Investment in genetic testing, PET-CT scans and specialist workforce.**
- **Commitment to prehabilitation and rehabilitation.**
- **Cancer waiting times targets are met.**

People with cancer should have timely treatment yet cancer waiting times targets have consistently not been met for over six years.<sup>9</sup> Action must be taken by investing in the workforce so that targets are met everywhere.

Looking at the ten year treatment pipeline we anticipate significant advancements in precision medicines and the use of multiple therapies simultaneously. It is crucial that NICE has the capacity to deliver timely appraisals of all cancer medicines to ensure swift access for patients. including for drugs licensed through the new oncology specific Project Orbis route.

To ensure patients benefit from the life extension and quality of life gains of these new treatments there needs to be **investment in ensuring access to genetic testing, PET-CT**

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<sup>7</sup> Policy Exchange, 'A Wait on Your Mind?', 2021. <https://policyexchange.org.uk/wp-content/uploads/A-Wait-on-Your-Mind.pdf>

<sup>8</sup> For example, GP decision making tools such as the QCancer tool. QCancer has been designed with the aim of developing machine learning tools to identify combinations of symptoms in health records which generate a risk score and a red flag for cancers with non-specific symptoms such as pancreatic cancer. <https://www.qcancer.org/>

<sup>9</sup> <https://news.cancerresearchuk.org/2021/09/22/cancer-target-missed-for-55000-patients-over-six-years/>

**scans and in the specialist workforce** (particularly CNSs) who can support the growing population living longer with more complex treatment regimes. **Modelling must be undertaken to understand the impact of the early diagnosis ambition on the demand for treatment modalities** and workforce to ensure patients have swift and appropriate access to cancer treatment. For example, if more people are diagnosed with bowel cancer at stage one, more surgery will be required.<sup>10</sup>

There needs to be a **commitment to re- and pre-habilitation**, as a standard of care, for patients regardless of whether they receive treatment. This can optimise access to and tolerance of treatment, looking at aspects such as physical activity, nutritional optimisation and psychological support.<sup>11 12</sup>

## 6. Personalised care

**Test: By 2032, everyone with cancer is able to access a needs assessment and personalised care plan to support their health and wider wellbeing needs.**

- **Implementation of recommendations of NHS Psychosocial Task and Finish Group**
- **Personalised care provided throughout the cancer journey, including people with less survivable cancers and secondary cancers.**

There is considerable evidence that people have experienced a wide variety of unmet needs during their cancer journey, including psychosocial needs and wider health and wellbeing.<sup>13</sup> **The new Cancer Plan must reaffirm the commitments made in the NHS Long Term Plan of everyone getting the personalised care they need.** The new plan needs to ensure that personalised care is accessible to everyone with cancer throughout their journey and that it makes a meaningful difference to their experience and outcomes. This means that people can continue to access follow up support and help after their treatment has finished, when they have a treatable but not curable cancer, and at end of life around advanced care planning.

In practice this means that everyone with cancer has the opportunity to:

- Talk to a trusted health professional shortly after being diagnosed about any concerns they might have in relation to their cancer and physical health, emotional wellbeing, cultural and religious needs, work, education and money situation.

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<sup>10</sup> For example, 93.5% of stage I bowel cancer patients will have surgery to remove their tumour as part of their treatment. This drops to only 31.5% of stage IV bowel cancer patients

<sup>11</sup> <https://cdn.ps.emap.com/wp-content/uploads/sites/3/2021/11/Prehabilitation.pdf>

<sup>12</sup> <https://cdn.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/1532-10061/prehabilitation-for-people-with-cancer-tcm9-353994>

<sup>13</sup> Cancer nursing on the line

<https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/4323-10061/cancer-nursing-on-the-line-why-we-need-urgent-investment-in-the-uk>



- Jointly develop a care plan to address these concerns, based on shared decision making principles<sup>14</sup>
- Review these concerns and the care plan at key points in their treatment and recovery, to ensure concerns are addressed as much as possible

It is vital that access to psycho-social support throughout the pathway is prioritised alongside all other aspects of care.<sup>15</sup> Cancer care and follow up must be age appropriate and tailored according to people's unique needs (for example, taking into account needs relating to language, religion or disability), from children and young people to older people. The Government must work to achieve excellent psychosocial care in cancer alongside cancer charities. **The recommendations of the NHS Psychosocial Task and Finish group should be incorporated into the Cancer Plan** and progress on its implementation reported annually.

Patients living with metastatic or secondary cancer experience unique challenges due to their prognosis and the complexity of their treatment and care. A personalised approach needs to consider and address the specific needs of patients who are living with metastatic cancer to ensure they live well for as long as possible. This should include ensuring they have access to the treatments that they need quickly, enabling them to participate in clinical trials and research, ensuring they are supported by a CNS and that the NHS understands more about their experiences through the effective introduction of the National Cancer Audit Collaborating Centre.

Particular attention is needed for people with rare and less common cancers, with less survivable cancers or secondary cancers to ensure timely access to psychosocial support services at the point of diagnosis. Moreover, patients with less survivable cancers are at high risk to suicide and this risk is even higher in the first six months from diagnosis.<sup>16</sup>

## 7. Workforce

**Test: By 2032, every person with suspected cancer will be seen by a specialist in a timely manner, meeting Cancer Waiting Time targets. For those diagnosed with cancer they will have swift access to a CNS and specialist workforce to support their treatment and care.**

- **Workforce planning to deliver timely care.**
- **Annual publication of workforce projections.**

<sup>14</sup> NICE guideline [NG197] 17 June 2021

<sup>15</sup> For example. Jacobson et al., (2021) finds that psychological distress in teenage and young adult cancer patients is associated with both increased morbidity and reduced concordance with treatment regimes, which can adversely affect quality of life and potentially prognosis.

<sup>16</sup> Henson, Katherine E et al. *Risk of Suicide After Cancer Diagnosis in England*. JAMA psychiatry vol. 76,1 (2019): 51-60. doi:10.1001/jamapsychiatry.2018.3181, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6583458/>

The NHS cannot improve outcomes for people with cancer while workforce shortages continue to persist. There needs to be workforce planning to deliver timely care and the ambitions of the 10-year plan.

The NHS was under-resourced before the pandemic. 1 in 10 diagnostic posts were vacant<sup>17</sup> and modelling developed by Macmillan demonstrates the specialist cancer workforce needs an additional 3,371 nurses in England by 2030.<sup>18</sup> Modelling by the Royal College of Radiologists predicts shortages of close to 6,000 clinical radiologists and 700 clinical oncologists by 2030.<sup>19</sup> With the number of people diagnosed with cancer each year in the UK projected to grow to over 500,000 in 2035, up 40% on 2014 levels, it is vital that we have sufficient NHS staff to diagnose, treat and care for cancer patients.<sup>20</sup> People with cancer also need the support of a multidisciplinary team, including dedicated dietitians, psychologists, paramedics, psycho-oncologists, GPs, primary care teams and support workers. For the less survivable cancers as well as secondary cancers, it is imperative that support from these professionals is provided promptly, without extensive waiting lists, because of the very poor prognosis of these illnesses, complex support needs and the speed at which people die.

While we welcomed the commitment of ‘hundreds of millions’ to tackle NHS workforce shortages made in the spending review, the details of how this money will be spent should be published. A national ‘designated body’ should regularly publish workforce projections and there should be a duty on the Secretary of State for Health and Social Care to respond to projections with a plan for what the Government will do. As part of this Cancer Plan, it is imperative that HEE’s forthcoming 15-year Workforce Plan aligns with the Plan’s ambitions.

## 8. Inequalities

**Test: By 2032, cases of cancer attributable to inequalities have meaningfully decreased.**

- **Data is collected on protected characteristics including age, gender, ethnicity, and sexuality as well as other aspects of inequality, such as socio-economic group, and published in an accessible and timely manner.**
- **Development and implementation of Timed Site-Specific Cancer Pathways for all cancer types.**
- **Removal of geographical variation in survival between Cancer Alliances.**

<sup>17</sup> NHS England and Improvement, 2019. Interim NHS People Plan

[https://www.longtermplan.nhs.uk/wpcontent/uploads/2019/05/Interim-NHS-People-Plan\\_June2019.pdf](https://www.longtermplan.nhs.uk/wpcontent/uploads/2019/05/Interim-NHS-People-Plan_June2019.pdf)

<sup>18</sup> <https://www.macmillan.org.uk/get-involved/campaigns/save-our-support#355157>

<sup>19</sup> <https://www.rcr.ac.uk/press-and-policy/policy-priorities/workforce/why-we-need-investment-radiology-and-oncology-trainees>

<sup>20</sup> Smittenaar, C. R., K. A. Petersen, K. Stewart, and N. Moitt, ‘Cancer Incidence and Mortality Projections in the UK until 2035’, *British Journal of Cancer*, 115.9 (2016), 1147–55

<https://doi.org/10.1038/bjc.2016.304>

- **Reduction of variations in care between those who are managed by specialised services and those who are treated locally and not always by cancer-site specialists.**

Over 30,000 extra cases of cancer in the UK each year can be attributed to socio-economic deprivation; experiences and survival outcomes are worse for the most deprived groups.<sup>21</sup> Inequalities in cancer care treatment and outcomes exist throughout the cancer pathway. We welcome the focus on early diagnosis of cancer in the Core20Plus5 approach to tackling inequalities. However, **inequalities must be addressed throughout the cancer pathway.**

Patients often have different experiences in care and treatment when they are managed locally and not in specialised services.<sup>22</sup> Further work is needed to develop targeted interventions to address where this variation exists between cancer sites, addressing specific barriers facing each cancer site. The one-year cancer survival index for England also shows that variation exists geographically across Cancer Alliances – ranging from 72.1% to 76.7% for 2018.<sup>23</sup> **Targeting additional funding through ICSs to level up this geographic inequality so that each Alliance achieves the same indexed survival as the best Cancer Alliance would contribute substantially to improving the rate of improvement in cancer survival.**

**Inequalities between cancer types must also be tackled.** Progress on survival for some cancers have not shifted in the last few decades and remain very low; for example, whilst one-year survival averages at 74% across cancer types, for less survivable cancers such as pancreatic cancer, one-year survival is only 25%.<sup>24</sup> Further work is needed to develop targeted interventions to address where this variation exists between cancer sites, addressing specific barriers facing each cancer site. **The development of Timed Site-Specific Cancer Pathways is one solution.** These clinically agreed pathways are designed to improve patient outcomes, by encouraging best practice, reducing variation, and reducing delays in diagnosis, staging, supportive care and treatment. They are also designed to meet established waiting time targets.

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<sup>21</sup> [https://news.cancerresearchuk.org/2022/02/15/health-inequalities-we-have-a-moral-duty-to-reduce-them/?utm\\_source=twitter&utm\\_medium=social\\_organic&utm\\_campaign=cruktwitter&utm\\_term=health\\_w\\_ealth](https://news.cancerresearchuk.org/2022/02/15/health-inequalities-we-have-a-moral-duty-to-reduce-them/?utm_source=twitter&utm_medium=social_organic&utm_campaign=cruktwitter&utm_term=health_w_ealth)

<sup>22</sup> For example, RICOCHET#, a national prospective audit of pancreatic cancer showed that access to a vital tablet to manage malnutrition were more likely to be prescribed to people who were seen by pancreatic cancer specialists compared to those who were treated locally.

<https://pubmed.ncbi.nlm.nih.gov/34053863/>

<sup>23</sup>

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/indexofcancersurvivalforclinicalcommissioninggroupsinengland/previousReleases>

<sup>24</sup> Allemani, Claudia, Tomohiro Matsuda, Veronica Di Carlo, Rhea Harewood, Melissa Matz, Maja Nikšić, and others, 'Global Surveillance of Trends in Cancer Survival 2000–14 (CONCORD-3): Analysis of Individual Records for 37 513 025 Patients Diagnosed with One of 18 Cancers from 322 Population-Based Registries in 71 Countries', *The Lancet*, 391.10125 (2018), 1023–75

<[https://doi.org/10.1016/S0140-6736\(17\)33326-3](https://doi.org/10.1016/S0140-6736(17)33326-3)>

We would welcome a renewed commitment to the implementation of existing pathways and the development of new Pathways in all cancer types.<sup>25</sup>

More data and evidence is needed to better understand the inequalities that exist in cancer diagnosis, treatment and care. There needs to be a comprehensive and standardised approach to data collection. **Data should be routinely collected on protected characteristics including age, gender, ethnicity and sexuality as well as other aspects of inequality, such as socio-economic group, and published in a timely and accessible manner.**

## 9. Research

**Test: There is a supportive climate for cancer research, and people with cancer of all ages and backgrounds are given the opportunity to participate in clinical trials.**

- **Cancer is a top priority in the UK's R&D portfolio.**
- **The UK is able to attract and retain global talent and has a diverse, highly skilled research workforce.**
- **People of all ages and backgrounds are offered the opportunity to take part in clinical trials and cancer research.**

While diagnosing more cancers earlier will help to improve cancer outcomes, this is only possible if people with cancer have access to treatments as well. Developing new, innovative treatments that extend or improve life will help us level up with the best performing countries in the world. There is an urgent need to support more research on early detection and treatment of cancers with poor outcomes such as pancreatic cancer and other less survivable cancers as well as metastatic cancers (for example, secondary breast cancers). The NHS should be ready to absorb any new innovations coming through the pipeline to ensure that no time is wasted to make new tests and treatments available.

**People with cancer should be given the opportunity to take part in clinical trials wherever possible;** there is currently patchy access across the country.

The Government must therefore support cancer research in the UK by:

- fulfilling commitments for 2.4% of GDP to be spend on R&D by 2027, including committing to increase annual public R&D investment to £22bn by 2027
- improving clinical research capacity by Increasing health service staff's access to dedicated research time and training and embed research into health service workforce strategies
- delivering on the cancer commitments in the Life Sciences Vision and Clinical Research Delivery Vision, including increasing multi-year funding for the National Institute of Health Research

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<sup>25</sup> For example, the National Optimal Lung Cancer Pathway - <https://rmpartners.nhs.uk/our-work/early-diagnosis/earlier-diagnosis-of-lung-cancer/national-optimal-lung-cancer-pathway-nolcp/>

- making cancer a top priority in the UK's R&D portfolio.
- widening access to research so that people with cancer have the opportunity to be involved across the whole pathway
- investment to ensure the right multidisciplinary input and engagement via partnerships within the research community (including health service and implementation researchers).

## 10. Data

**Test: By 2032, data collection is timely, accessible, standardised and comprehensive and it is analysed and published swiftly to support the delivery and monitoring of all aspects of cancer across the pathway and cancer research.**

- **Investment in data analysts and informatics both locally (at point of collection) and nationally.**
- **Target for registration data.**
- **Data disaggregated for all cancer types and ages.**
- **People are tracked through their cancer journey.**

The past two years have shown the vital importance of timely data and clinical audit to effectively manage Covid-19. We believe the same needs to be done for cancer. Data collection needs to be comprehensive and standardised and it needs to be analysed and published in a timely manner. It needs to be disaggregated for all cancer types and ages (including those aged under 25) in an accessible way.

There are gaps in data collection. For example, cancer registrations are not comprehensive. Stage data is used to assess the 75% ambition. The Government should set a target for cancer registrations for each cancer type. We welcome the continuation of the Cancer Patient Experience Survey and the development of the Quality of Life survey; these must both collect and report on data relating to inequalities. These surveys need to be designed so that they include people with cancers with poor outcomes such as less survivable cancers and secondary cancers or alternative approaches found. They should be representative of communities who are disabled, LGBTQ+, have specific language, cultural and religious needs, a range of ages and from different socioeconomic backgrounds.

Where data is collected, too often it is not made available to researchers in a timely manner nor is it published swiftly enough. There needs to be a review and standardisation of data access pathways, investment in data access infrastructure and staff and data analysts (including NCRAS, CADEAS) so that data is available speedily.

We would also welcome commitment to the improvement and expansion of existing national cancer audits and the creation of new audits for other site specific cancers, including rare and

less common cancers.<sup>26</sup> The plan should set out a vision of how audits produced by the National Cancer Audit Collaborating Centre should be informed by charities and patient insight, their scope includes the whole patient pathway and how they can meaningfully influence change within the NHS.

There is an opportunity to develop mechanisms so that people with cancer (with their permission) can be tracked throughout their cancer journey. This would create better opportunities for data analysis and research, and enable clinical professionals to access patient records regardless of where the patient was seen, and facilitate clinical trials.

The importance of public trust cannot be overstated. The Government must ensure meaningful, transparent and ongoing public engagement related to data use and sharing. This must reach an audience that accurately reflects the demographics of the population.

**On behalf of:**

 Jeannie Rigby Director <b>Action Bladder Cancer UK</b>	 Rose Woodward Founder <b>Action Kidney Cancer</b>	 Henny Braund Chief Executive <b>Anthony Nolan</b>	 Gemma Peters Chief Executive <b>Blood Cancer UK</b>
 Genevieve Edwards Chief Executive <b>Bowel Cancer UK</b>	 Will Jones Chief Executive <b>Brainstrust</b>	 Sue Farrington Smith MBE Chief Executive <b>Brain Tumour Research</b>	 Baroness Delyth Morgan Chief Executive <b>Breast Cancer Now</b>
 Pamela Healy OBE Chief Executive <b>British Liver Trust</b>	 Jane Lyons Chief Executive <b>Cancer52</b>	 Professor Frank Chingwundoh MBE Chairperson <b>Cancer Black Care</b>	 Robin Pritchard Co-Director <b>Cancer Care Map</b>

<sup>26</sup> An example of good practice being the National Lung Cancer Audit, (<https://www.rcplondon.ac.uk/projects/national-lung-cancer-audit>), which has recently reported data for 2019 and 2020, based on the Rapid Cancer Registration dataset.

John Symons  
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Chief Executive Officer  
**Children with Cancer UK**

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**CLL Support Association**

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**Grace Kelly Childhood Cancer  
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**Hope for Tomorrow**

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**Myeloma UK**

Tony Hebbon  
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**Neuroblastoma**

Alastair Richards  
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**North West Cancer Research**

Tamara Kahn  
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**Oracle Cancer Trust**

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Laura Kerby  
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**Prostate Cancer UK**

Mike Grundy  
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**Roy Castle Lung Cancer  
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Chief Executive  
**Sarcoma UK**

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**Solving Children's Cancer**

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Rachael Gormley  
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Rachel Kirby-Rider  
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