



One Cancer Voice:

A manifesto for
people living
with cancer



#OneCancerVoice

An introduction to the manifesto

This manifesto has been developed by more than 20 charities across the cancer sector, on behalf of people with cancer, to recommend solutions for some of the biggest issues that the next Government will face.

Significant progress has been made in the last 50 years, transforming the prospects for people diagnosed with cancer. In the 1970s, only 1 in 4 UK patients survived their disease for ten years or more. By 2010, this had risen to 2 in 4, and survival continues to improve today¹. This is due to ground-breaking research, innovative new treatments and the tireless efforts of staff across our NHS.

However, there is still a long way to go. Cancer remains the leading cause of death in the UK, and a growing and ageing population means incidence continues to rise at an alarming rate¹. The system is already struggling to cope with demand – only 38% of NHS Trusts are currently meeting the key 62-day waiting time standard for referral to treatment². Unfortunately, cancer survival in the UK is still lower than in comparable countries around the world¹.

Whilst we have seen huge improvements in outcomes for some cancers, there is significant variation across different types. The average five-year survival for the six less survivable cancers is just 14%; for more common cancers it is 64%³. Rare and less common cancers account for 47% of diagnoses and yet 55% of cancer deaths⁴. We continue to face stubbornly low survival rates in some cancer types that have sadly seen very limited improvement over the past fifty years⁵.

And cancer rates are only going to grow – by 2035 the number of new UK cancer cases is projected to rise to over half a million a year¹. Many of these people have complex and varied needs; 70% of patients are living with one or more serious health condition other than their cancer, often as a result of treatment⁶. At the same time, many people experience physical, emotional and financial consequences of their diagnosis, which can remain the case for many years after treatment has ended⁶.

The next Government has an opportunity to drive up the UK's survival rates to be among the best in the world. With 1 in 2 people in the UK diagnosed with cancer at some point in their lifetime¹, this could improve millions of lives and touch every family in the country. To achieve this ambition, we need to:

- 1 Put the right staff in place
- 2 Diagnose cancer earlier
- 3 Ensure people living with cancer have access to the appropriate treatment and psychological support
- 4 Support people living with cancer beyond their treatment
- 5 Preserve the UK's status as a world-leader in cancer research
- 6 Prevent people from developing cancer.

As the population living with cancer grows, we must ensure that people are not just surviving longer, but living well too. The policy recommendations in this manifesto – based on our combined expertise, evidence and knowledge – should be viewed by any new Government not as an exhaustive list, but instead as a starting point for improving treatment and care for all people living with cancer.





Diagnosing cancer early

Recommendation 2: Prioritise early diagnosis and publish a plan setting out what the 2028 target means for different cancer types

Diagnosing cancer early (stages 1 and 2), when treatment is much more likely to be successful, is critical to achieving our shared ambition to improve survival for people affected by cancer. But survival in the UK continues to lag behind comparable countries, in large part because we tend to diagnose cancer at a later stage¹². Substantial effort, at pace, is therefore required to reduce late diagnoses and intercept cancer when it is most treatable. As outlined previously, significant improvements will not be made without sufficient workforce capacity.

The NHS Long Term Plan committed to a transformational shift in early diagnosis from just over half of all cancers diagnosed early to three quarters by 2028. We welcome this ambition. There are however concerns across the sector about how this target will be reached for each cancer type. Whilst we recognise the importance of having an overall vision, we must ensure that this is inclusive of all cancer types, particularly those which currently face far lower than average diagnosis rates. In pancreatic cancer, for example, only 20% of patients are diagnosed at stage 1 or 2¹³. For this reason, we need ambitious yet realistic targets for each cancer type.

The next Government should **ensure there is an Early Diagnosis Plan in place, specifying how the 2028 target will be reached and outlining specific targets for each cancer type**. This plan should also propose diagnostic ambitions for cancers where staging is an inappropriate measure, such as in certain blood cancers.

Early diagnosis is rarely discussed in the context of secondary cancers, which are often incurable but can be treated. The Early Diagnosis Plan should also **acknowledge the importance of diagnosing secondary cancers as quickly as possible, and include measures to improve diagnosis for these cancers**.

Recommendation 3: Ensure the successful roll-out and sustained expansion of Rapid Diagnostic Centres nationwide

We welcome the last Government's commitment to Rapid Diagnostic Centres (RDCs), which will play a vital role in ensuring people with cancer receive a timely diagnosis. We must support GPs to make full use of national guidance on recognising cancer symptoms, and ensure the new RDCs are working effectively for patients with serious but non-specific symptoms. The benefits of expanding RDCs beyond this patient group and to new methods of referral should be clearly explored and established ahead of the next phase of development.

We ask any future Government to **ensure that RDCs receive sustained funding across every Cancer Alliance** (beyond the initial central funding allocation) **and are effectively embedded into the wider health system**, via GP referrals. It is imperative that investment encompasses the **latest diagnostic equipment**, as identified in the Long Term Plan.

Putting the right staff in place

Recommendation 1: Take immediate action to increase investment in the cancer workforce so staff can meet the growing demand for care

There is broad agreement across the cancer sector today that addressing the NHS staffing crisis should be an immediate priority for any future Government. We desperately need a plan of action as pressure continues to pile up on the existing overworked staff, and patients are being let down.

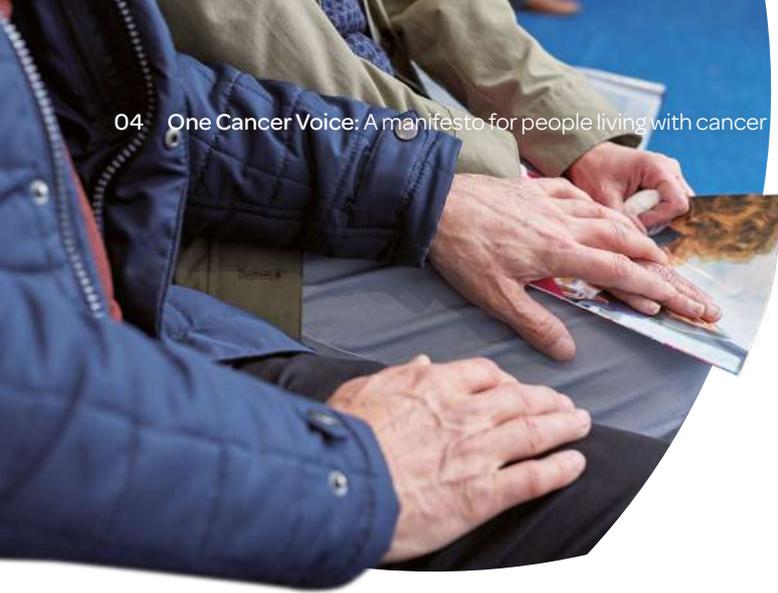
Workforce was identified in the 2015 Cancer Strategy for England as a "make or break" issue⁷, yet four years later remains unresolved. The impact of staffing shortages is vast: 1 in 10 diagnostic posts are currently unfilled in the NHS⁸, the estimated shortfall of radiologists is forecast to rise to 1,867 (31% shortfall) by 2023⁹, and vacancy rates are as high as 15% for chemotherapy nurses¹⁰.

The Long-Term Plan sets out that every person with cancer will have access to a Clinical Nurse Specialist (CNS) or other care worker by 2021. We know that this service can be critical in coordinating care and providing psychological support. However, a recent survey of over 2,000 people with secondary breast cancer found that a quarter of respondents had not seen a Clinical Nurse Specialist since diagnosis¹¹.

The NHS People Plan is an important opportunity to solve this problem. It is critical that the plan fully addresses staff shortages, rising demand and the ambitions to improve survival. The plan must be backed by the necessary long-term investment. Recent funding announcements for the NHS, including more kit for screening and diagnosis, are steps in the right direction but haven't included plans for the education and training needed to deliver more, much needed, staff.

To meet rising demand – and give the future Government any chance of meeting its target of diagnosing 3 in 4 cancers at an early stage by 2028 – we need a cancer workforce that is sufficiently resourced. We are therefore **urgently calling on the next Government to commit to a long-term and data-driven cancer workforce plan, backed by increased investment to enable the NHS to train and employ more staff**.

Given the current pressures facing staff, the next Government should also **ensure that as we prepare to leave the European Union, any changes to the immigration system do not risk undermining the NHS Long Term Plan's ambitions to increase overseas recruitment to support the workforce**.



The new Government should also continue to focus on **supporting effective and early GP referrals under the NICE NG12 guideline for the recognition and referral of suspected cancer**. This will depend on GPs being able to access the relevant training to make appropriate referrals, on the availability of direct access diagnostic tests where required, and on there being capacity in diagnostic services to deliver increasing numbers of diagnostic tests. It is also important that the next Government **prioritises the research and development of early diagnostic tools available in primary care**, including cytosponge, saliva, breath, urine and blood tests.

We also remain concerned about access to RDC's for young people, who can often experience rare and hard to diagnose cancers and are more likely to face barriers around diagnosis when visiting their GP¹⁴. Future UK governments should **ensure GPs are equipped with appropriate, tailored information about the signs and symptoms of cancer in children and young people**, to ensure swift referral to RDCs.

Recommendation 4: Implement the recommendations outlined in Professor Sir Mike Richards' review of national screening programmes

Screening programmes play an important role in the prevention and early diagnosis of cancer. Following two high-profile screening incidents in November 2018, Professor Sir Mike Richards was commissioned to conduct a review¹⁵ of the adult screening services in the UK.

We recognise the challenges currently facing screening services across the country – including reduced uptake and outdated infrastructure – and **call on the next Government to implement the recommendations of Sir Mike's review with urgency**. In particular, the next Government should clarify the remit of a new single advisory body covering both targeted and population screening approaches, and establish new governance arrangements for the implementation and ongoing management of screening programmes once recommended by the new advisory body.

The next Government should also **ensure the successful optimisation of FIT for bowel screening** – including by increasing the sensitivity and lowering the screening age to 50 – and **develop the Targeted Lung Health Check programme**. If these initiatives are to succeed, more NHS diagnostic staff will be needed to deliver them.

Cancer treatment and psychological support

Recommendation 5: Improve access to treatments so every person diagnosed with cancer is given the best chance

Every person diagnosed with cancer should have access to the best, evidence-based treatment that is appropriate for them. We want to see swift and equitable approval and uptake of the most innovative new treatments, so that people with cancer can benefit as quickly as possible.

The Cancer Drugs Fund has improved markedly in recent years and since the 2016 reforms, NICE has approved more cancer medicines than ever before. In the ongoing review of NICE methodology and processes, the focus must be on making sure patients are put at the heart of how it assesses the value of new medicines.

Decisions about treatment should be shaped around each patient's individual circumstances, incorporating social as well as medical factors. Once a treatment has been approved, every person who could benefit should be able and supported to access it.

We call on the next Government to **ensure every person with cancer has swift access to the best, evidence-based treatment that is appropriate for them**. This includes eligible patients having access to **new precision treatments as well as testing** provided through the National Genomics Medicine Service.

Recommendation 6: Prioritise the emotional and psychological needs of people diagnosed with cancer

The importance of good emotional and psychological support for people diagnosed with cancer cannot be overstated. A recent study found a 20% increased risk of suicide for people with cancer compared to the general population¹⁶, whilst 79% of young people feel that their cancer diagnosis had a 'serious' impact on their emotional wellbeing¹⁷. The psychological impact of cancer can affect patients at all stages. Even after treatment, people with brain cancer often live with the fear of progressive neurological deficit, loss of identity and behaviour and personality change. Unfortunately, services are currently struggling to meet demand – half of respondents in a survey of pancreatic cancer patients said that they had one or more unmet psychological or supportive care need(s)¹⁸.

We echo growing calls across the sector for **better emotional, mental health and psychological support for people with cancer**, and want to see best practice applied around the four-tier model for psychological support services¹⁹.

Recommendation 7: Fully deliver on the NHS Long Term Plan commitment to provide stratified follow-up pathways for people with cancer

A cancer diagnosis doesn't end when the treatment does, so we must ensure that appropriate follow-up pathways are in place for people after their treatment, particularly those who are worried their cancer may have recurred.

Post-treatment issues are widespread: 88% of women experience at least one long-term consequence of their cervical cancer treatment²⁰, some men with prostate cancer report feeling “abandoned” by the healthcare system once their treatment is complete²¹, and only 54% of people with blood cancer who felt they needed emotional and psychological support after a stem cell transplant actually received it²². This is unacceptable and more needs to be done to support people after their treatment has ended.

Starting with people who have been diagnosed with breast cancer, the NHS Long Term Plan committed to putting in place stratified follow-up pathways for all clinically appropriate cancers by 2023²³. However, research in 2018 found that only 49% of Trusts were delivering these pathways for breast cancer patients²⁴ and there is no further evidence to suggest a wider roll out, nor plans to evaluate the impact of these new pathways.

We ask the next Government to support GPs and Cancer Alliances to **ensure people have access to a follow-up pathway that suits their needs, with rapid access to clinical support if they're worried their cancer may have recurred.**

Life beyond treatment: supporting people living with cancer

Recommendation 8: Protect people with cancer from the wider impact of their diagnosis

Having cancer can move someone from a position of relative security to one of distress within a short space of time. The financial implications of a cancer diagnosis can often be a significant part of this shift. This is particularly true for the families of children and young people with cancer, as they need to travel to specialist facilities which are often further away. The cost of the ‘cancer commute’ to a young person’s family is £180 per month when their treatment is their most intense²⁵. The next Government should **commit to a Young Cancer Patient Travel Fund** to ensure children and young people are able to access the treatment they need.

Evidence suggests that people living with cancer aren’t clear about what support they can ask for from their bank and only 11% of cancer patients currently disclose their diagnosis²⁶. The next Government should **introduce a legal duty of care to ensure all financial service providers support people living with cancer** by offering measures to help them manage the financial impact of a diagnosis. This could include flexibility on mortgage payments, interest freezes on credit cards or loans and ensuring customers are signposted to financial help early.

People with cancer also face social care needs that are currently not being met. The funding announced in the spending review is the bare minimum needed to shore up a system under extreme stress. We call on the next Government to **urgently reform the social care system, including a commitment to provide care free at the point of use for people of all ages.** This would give people living with cancer the assurance that their basic needs will always be met, especially for those approaching end of life.

Keeping the UK’s status as a world-leader in research

Recommendation 9: Retain the UK’s status as a world-leading location for research

International trials are an essential part of medical research. They are especially important in rare diseases and for children and young people, where single countries may not have sufficient patients to run trials alone. Clinical trials also offer hope to those with few treatment options, such as people living with incurable cancers. As we consider our future relationship with the EU, the next Government must ensure that the UK maintains its position as a world-leader in this field.

The UK’s clinical research environment is built on international collaboration, benefitting from a shared regulatory system with other EU Member States. 4,800 UK-EU trials took place between 2004 and 2016²⁷ and it is **imperative that the ability for researchers to work across borders is protected.**

We call on the future Government to **make seeking as close as possible a relationship between the UK and EU on clinical trials a negotiating priority for the future relationship.** This includes building on the commitment to participate with the EU Clinical Trial Regulation (CTR) and seeking access to the underpinning portal and database²⁸.

It is also important that every patient is aware of the research opportunities that are open to them. Some evidence suggests that people living with cancer believe they are not being given enough information about their options for clinical trials. A recent survey of over 2,000 people with secondary breast cancer found that more than half said they had not been given sufficient information on trials²⁹. And research with kidney cancer patients has shown that most people are not aware of clinical trials as a route to treatment, or what they involve³⁰. We therefore call on the next Government to **ensure people living with cancer are aware of the research options available to them, and have timely access to relevant trials.**

We also need the next Government to support the NHS to engage in research. Patients in research-active institutions have better outcomes and are more likely to benefit from earlier access to new treatments, technologies and approaches³¹. Whilst the NHS Consultant Contract allocates dedicated time to undertake research³², many clinicians cite a range of barriers, including time constraint and financial pressures, that prevent them from carrying this out³³. Any future Government should **ensure NHS England, in collaboration with Trusts, is supported to minimise barriers to clinicians conducting research.**

Recommendation 10: Prioritise association with the European Medicines Agency, in particular on the licensing of new medicines

We echo organisations across the health sector in advocating for the vital role played by the European Medicines Agency (EMA) in approving new medicines whilst ensuring they are safe, effective and of a high-quality. We firmly believe that the Medicines and Healthcare products Regulatory Agency (MHRA) and EMA are stronger when they work together. There is significant concern that exiting the EU could lead to the UK leaving the EMA entirely, including its regulatory framework for medicines. This could risk delays to patients getting the newest, potentially lifesaving treatments, as companies will have to submit separate marketing authorisation applications to the EMA in the EU, and to the MHRA in the UK.

The future UK Government **must therefore prioritise seeking the closest possible future relationship between the EMA and the MHRA**, and ensure there will be no delays to patient access to new medicines, whatever the Brexit outcome.

Recommendation 11: Incentivise a step change in data collection for rare and less common cancers

Good quality data is vital in driving forward and improving early diagnosis and treatment, and important strides have been made in improving the breadth and quality of data collected in recent years.

We believe that current data sources do not properly reflect the scale of the challenge for improving care and treatment for rare and less common cancers. Data completion targets for cancer are often met by mainly including the most common tumour types. As such, other cancers aren't well recorded and rare and less common cancers suffer.

For example, according to Public Health England statistics, only 27% of sarcoma patients have had their TNM data (a system used to describe the amount and spread of cancer in a patient's body) recorded³². Without drastic improvement in data collection for rare and less common cancers, it will be difficult to take action to improve early diagnosis in a fully informed way, and impossible to show an accurate picture of any shift in diagnosis rates.

This improvement will require the NHS to support staff to collect the data we need, and incentivise NHS organisations to invest in IT systems to facilitate data collection. More support is also needed for national disease and treatment registries outside of the NHS which play a vital role in collecting outcome data for patients. We are therefore calling on the next Government to **incentivise a step change in data collection for rare and less common cancers**.

Preventing cancer from developing

Recommendation 12: Sustainably fund local Stop Smoking Services and implement Chapter Two of the Childhood Obesity Plan in full

After decades of successful action on tobacco control, only 14.7% of UK adults were smokers in 2018³³. Despite this progress smoking remains the biggest preventable cause of cancer in the UK, with more than a quarter of all cancer deaths attributable to smoking³⁴.

Since 2013, local authorities have been responsible for commissioning Stop Smoking Services, which offer smokers the best chance of quitting – three times more likely than going cold turkey³⁵. However, years of cuts to the public health grant have meant many councils have had to cut their services. Now only 56% of councils commission a Stop Smoking Service open to all local smokers³⁶.

If we are to prevent new cancer diagnoses and meet the Government's target for a smokefree England by 2030, public health funding must be restored. One potential funding mechanism is the 'polluter pays' model, which places a levy on the tobacco industry to fund work to reduce the number of people who smoke.

It should be recognised that reducing funding for smoking cessation services is a false economy: every £1 spent is estimated to save £10 in future healthcare costs and health gains³⁷. On this basis, we call on the future Government to **prevent cancer, and provide sustainable funding for Stop Smoking Services as a matter of urgency**.

Overweight and obesity is the biggest preventable cause of cancer after smoking and causes around 22,800 cases of cancer every year in the UK³⁸. In 2018, the Government committed to halving childhood obesity by 2030, set out in the Childhood Obesity Plan. We call on any future Government to **uphold this ambition and implement the plan in full**, without further delay. As an essential first step, the next Government should **protect children from junk food marketing on TV, online, in-store and on the street, including through a 9pm watershed**.

As the number of people living with cancer continues to grow rapidly, **we need urgent action from the next Government to implement the recommendations found in this manifesto**. We can, and must, do more to support people with cancer to live longer, healthier, happier lives.



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