

State of Nation Report No Cancer Too Rare

Rare and less common cancers in national policy



INTRODUCTION

In the UK, 47% of all cancer diagnoses and 55% of all cancer deaths are from rare and less common cancers. That means that every year around 180,000 people will be diagnosed with a rare or less common cancer and more than 92,000 people will die from a rare or less common cancer.¹

Cancer52 represents the voice of rare and less common cancers. We are an alliance of over 100 patient charities united in their vision of a better future for everyone affected by rare and less common cancers.² We aim to promote improved diagnosis, treatment and support.

Cancer52's member charities work tirelessly to provide services and direct support to cancer patients; they contribute to and provide support and funds to NHS commissioned pathways to enhance and enable services to meet patients' needs.

200+

Rare and less common cancers are defined as the over 200 cancers other than the four most common: breast, bowel, lung and prostate.

In this State of Nation report we review policy developments since the 2024 General Election that will shape the next 10 years of cancer services, and we reflect on what these developments mean for Cancer52's priorities for the UK Government and for making rare and less common cancers a priority in national policy.

There are opportunities in the present and future to better meet patient needs, and increase survival and quality of life for the thousands of patients diagnosed and living with rare and less common cancers. Being a priority in national policy provides the platform to deliver change and drive improvements across the complexities of the health and social care system. This is an important step and critical to follow through into delivery.

¹ Cancer Research UK direct communication to Cancer52, March 2024

² <https://www.cancer52.org.uk/our-members>

Rare and less common cancers – unmet needs

People with rare and less common cancers face distinct and often ingrained challenges because of the broad scope of types of cancers, the diversity of rare and less common patient profiles including children and young people, and by definition, small patient populations.

It is critical that rare and less common cancers are given the space and focus needed to deliver improvements in care and outcomes to improve lives and support the government's wider policy agenda to build a stronger economy. Core to this is understanding the challenges faced by patients and the health and care system.

2024 Patient Survey

1,371

patients surveyed with rare and less common cancers, the report showed that



76.2% were generally satisfied with their care, but significantly lower when compared to the National Cancer Patient Experience Survey^{3,4}

88.9%

+ Positive insights

- **Effective treatments:** Some patients reported significant health improvements after receiving effective treatments.
- **Support systems:** Many patients expressed gratitude for the NHS and the support from family and friends. The role of charities in providing trusted support and information was also highly valued.
- **Lifestyle changes:** Some respondents talked of positive lifestyle changes which resulted from having had cancer and by taking a more proactive approach to health.

- Negative insights

- **Delays in diagnosis:** Many patients experienced delays in diagnosis, leading to advanced stages of cancer at detection, and a poorer experience overall.

- **Financial impact:** The financial burden of cancer was a significant issue, with many patients facing increased expenses and loss of income.
- **Emotional impact:** The emotional impact of cancer, including depression and anxiety, was profound for many patients.

Patient Survey Key Findings

24% of respondents had to see a **GP four times** or more before diagnosis.

50% felt their **diagnosis could have been quicker.**

31% of patients reported there was **no stage for their cancer type**, 20% reported that no stage was given.

98% reported a **negative impact on their lives**; 60% had a negative impact on **mental health**, 57% on **fitness** and 54% on their **social lives**.

73% reported receiving support and **helpful information from charities**, and 70% rely on **support from family and friends**.

Health inequalities also affect outcomes and experiences of rare and less common cancers; our patient survey also shows that:

- People from an ethnic minority community experience more negative impacts of their diagnosis than white people.
- People with a lower income reported lower satisfaction with their care
- People who do not own a home were more likely to experience negative impacts compared to those who do.
- People from a lone parent family generally reported significant financial difficulties and were much less likely to participate in a clinical trial.
- People who identify as heterosexual generally experience better care.
- People living with a long-term condition often face significant barriers, including in getting a diagnosis.⁵

³ Cancer52 Patient Experience Survey 2024, IQVIA, October 2024

⁴ National Cancer Patient Experience Survey 2023. National report (Quantitative). Published July 2024. Available: https://www.ncpes.co.uk/wp-content/uploads/2024/07/CPES23_Standard-National-Report_FINAL.pdf

⁵ Cancer52 A fair chance: reducing health inequalities for people with rare and less common cancers. November 2024

Rare and less common cancers – impact and priorities

Rare and less common cancers account for 47% of all cancers diagnosed and 55% of cancer deaths. This highlights a significant inequality faced by people diagnosed with these cancers. Although each individual cancer type is rare, together they affect a large proportion of people with cancer. For example:



Approximately 40% of those diagnosed with **ovarian cancer** in England and Wales had an emergency admission within 28 days before, and one in five of those diagnosed with at stage 2-4 receive no treatment.⁶



Every year in the UK, over 40,000 people receive a **blood cancer** diagnosis, and over 15,000 people will lose their life to this disease. Blood cancer is the most common cancer among children, teenagers and young adults, and overall, it is the UK's fifth most common cancer, and the third biggest cancer killer.⁷



Diagnoses of **womb cancer** have increased by 41% since 2001, likely linked to rising obesity rates.⁸



Around 4,200 **children and young people** (under 25) are diagnosed with cancer every year in the UK (or 12 diagnosed a day).⁹



In 2020-2022, only 1% of people diagnosed with **kidney cancer** in England had consented for a clinical trial.¹⁰



Each year more than 13,000 people are diagnosed with a **brain tumour**. Just 13% of adults survive for five years after a high-grade brain tumour. Brain tumours are the biggest cancer killer of children and adults under the age of 40.¹¹



In a survey of primary **bone cancer** patients, three quarters (76%) said they were given at least one misdiagnosis.¹²

⁶ National Ovarian Cancer Audit State of the Nation Report 2025. Published September 2025. Available: [NOCA-State-of-the-Nation-Report-2025.pdf](https://www.noca.org.uk/wp-content/uploads/2025/09/NOCA-State-of-the-Nation-Report-2025.pdf)

⁷ Blood Cancer UK, based on the average annual number of blood cancer cases or deaths due to blood cancer in the UK during 2019, 2021 and 2022, as reported by NHS England, Northern Ireland Cancer Registry, Public Health Scotland and Public Health Wales. National Disease Registration Service. Children, teenagers and young adults UK cancer statistics report 2021. Available: <https://digital.nhs.uk/ndrs/data/data-outputs/cancer-publications-and-tools/ctya-uk-cancer-statistics-report-2021>.

⁸ The Endometrial Cancer Audit Pilot (ECAP) Baseline Report. Published April 2025. Available: <https://digital.nhs.uk/ndrs/data/data-outputs/cancer-publications-and-tools/ecap-baseline-report#highlights>

⁹ Young Lives Vs Cancer, accessed 17 Feb 2026 <https://www.younglivesvs-cancer.org.uk/wp-content/uploads/2024/04/A-Manifesto-for-Children-and-Young-People-with-Cancer.pdf>

¹⁰ National Kidney Cancer Audit (NKCA) State of the Nation Report 2025. London: National Cancer Audit Collaborating Centre, Royal College of Surgeons of England, 2025.

¹¹ The Brain Tumour Charity, accessed 17 Feb 2026 Statistics about brain tumours | The Brain Tumour Charity

¹² Patient Survey 2020. Bone Cancer Research Trust. Available: https://www.bcrct.org.uk/assets/uploads/BCRT_2020PatientSurvey_SPREAD.pdf

In 2024 we published a pre-election manifesto 'The Other Half' setting out our collective priorities for a new government.¹³ Whilst every cancer is different, there are shared challenges which affect people with rare and less common cancers, including poorer patient experiences, delays to diagnosis and under-investment. There can also be barriers to accessing specialist care and new, more effective, treatments.

In the manifesto, we set out the following three priorities:

Priority 1

Reduce the number of deaths from rare and less common cancers by 15% by 2040, saving 80,000 lives, and address the health inequalities that contribute to poorer outcomes.

Priority 2

Increase early diagnosis of rare and less common cancers which will improve patient experience, quality of life and help save more lives.

Priority 3

A new national mission on rare and less common cancers with patient involvement at its core.

These priorities have been the backbone to Cancer52's work with the government, including calling for a national cancer plan to be produced, contributing to the consultations and processes to draft the national cancer plan and engaging our community to rally support and amplify the voice of rare and less common cancers in policy development.

A National Cancer Plan for England

On 4th February 2026, the UK Government published a new National Cancer Plan for England.¹⁴ This is a 10-year plan that builds on a suite of policy developments announced by the government since its election in 2024, and details plans to transform cancer care and outcomes in England by 2035.

For the first time, this National Cancer Plan for England has a dedicated chapter focused on rare and less common cancers. There is also a chapter dedicated to children and young people with cancer, which is welcomed.

The core ambition of the plan is for England to become a global leader on cancer survival by 2035, meaning that by 2035, three in every four people diagnosed with cancer will be cancer-free or living well after five years. That translates to 320,000 more lives saved over the course of the plan.

'Our goals will only be possible if we make real progress on children and young people's cancer, and rare and less common cancers... Our modelling shows that our survival goal is only possible if we improve outcomes on cancers where survival has remained stubbornly low for decades'.

National Cancer Plan for England p.9

¹³ The Other Half. A manifesto to transform outcomes for people with rare and less common cancers. Cancer52, March 2024. Available: www.cancer52.org.uk/single-post/cancer52-s-manifesto-the-other-half

¹⁴ The National Cancer Plan for England: delivering world class cancer care. Published February 2026. Available: <https://assets.publishing.service.gov.uk/media/698315a35a7e802e96d343a4/national-cancer-plan-for-england-delivering-world-class-cancer-care.pdf>

There are 91 actions in total in the plan, all of which will have relevance for rare and less common cancers, of these 13 are specifically for rare and less common cancers (see page 6 and 7). These actions, and others in the plan address the priorities set out by Cancer52:

Priority 1

Reducing deaths: the plan makes improving survival in rare cancers a formal ambition.

Priority 2

Increasing earlier diagnosis: the plan explicitly changed metrics on measuring earlier diagnosis to include reduction of emergency diagnosis, reduce late stage 3 and stage 4 diagnosis and a proactive approach in research to improve detection of rare cancers through multi-cancer early detection tests (MCEDs).

Priority 3

National mission on rare and less common cancers: the plan sets out two new leadership roles; a national lead for rare cancer and an NIHR national specialty lead for rare cancers.

Key recommendations related to rare and less common cancers in the plan include:

- We will **increase recruitment to clinical trials**, particularly for patients with rare cancers, from poorer areas, and from ethnic minority groups, who have been less able to join clinical trials in the past.
- We will give **Cancer Alliances and trusts the data they need to drive improvement**. We will share more **granular data, including on rarer cancers**, breaking broader categories down wherever possible to identify whether there are specific performance issues.
- **English survival rates are among the best in Europe** across all cancers by 2035, **including for rare and less survivable cancers**.
- A **reformed National Cancer Board** chaired jointly by Department of Health and Social Care (DHSC) and an independent representative... The board will also add new members to monitor the impact of the plan on **health inequalities, rarer cancers, and children and young people's cancers**.
- Government, public health teams, primary care staff and Cancer Alliances will collaborate on **HPV vaccine uptake**... All this will contribute to us delivering on our commitment to eliminate cervical cancer by 2040. These vaccinations will also **protect against six other rarer cancers that are also linked to HPV**. **Will act on UV radiation and alcohol harm**.
- We will spearhead further efforts to discover and develop effective screening tests **for rare cancers using multi-cancer early detection tests**. As well as liquid biopsies will **analyse breath, saliva and urine tests**.
- Will expand and improve **cervical screening, including self-sampling**... And **expand lung scans** because smoking is a risk factor for other cancers. **Community liver health checks** to continue.
- **Some rare cancers, such as brain and pancreatic cancer, have stubbornly low survival rates** – and few treatment or diagnostic breakthroughs. We need **new diagnostic tools, research into biomarkers, and targeted therapies** to achieve any major changes to survival. **Genomics and data** will be particularly important enablers to progress.
- **Health inequalities** will be hardwired into the plan to narrow health inequalities. People from poorer parts of the country are more likely to be diagnosed late and less likely to get the best care, while people with disabilities, LGBT+ people and people from some ethnic groups are less likely to access screening and clinical trials.

Rare and less common cancers – actions and commitments

Commitment	Responsible organisation	Timeframe
Action 1: Make improving survival in rare cancers a formal ambition		
Maintain our focus on rare and less common cancers by ensuring we improve our performance against 14 less common cancers in CONCORD data	NHSE/DHSC	Across life of plan
Action 2: Appoint a national lead for rare cancers		
Appoint a national clinical lead for rare cancers	NHSE/DHSC	2026
Action 3: Improve data granularity and transparency on rare cancers		
Improve data on rare cancers to ensure transparency and support the NHS to speed up diagnosis and treatment	NHSE/DHSC	2027
Define and count recurrent cancers, starting with metastatic breast cancer	NHSE/DHSC	2026
Action 4: Reduce emergency diagnosis of rare cancers		
Reduce the number of patients who are diagnosed in emergency settings, where it is not clinically appropriate	NHSE/DHSC	Across life of plan
Action 5: Take proactive approaches to early diagnosis in rare cancers		
Support research improving detection of rare cancers in Multi-Cancer Early Detection tests (MCEds)	DHSC	2026
Develop case-finding programmes for rare and less common cancers	NHSE/DHSC	2028
Action 6: Support GPs to identify rare cancers more reliably		
Take a more proactive approach in primary care to support earlier diagnosis of rare and less common cancers, including use of new AI support tools	NHSE/DHSC	2028
Action 7: Prioritise access to specialist treatment for patients with rare cancers		
Ensure that patients with rare and less common cancers across the country have access to high quality, specialist and evidence-based care, including genomic testing	NHSE/DHSC	Across life of plan
Action 8: Work with charities to improve post treatment support		
Ensure that patients with rare and less common cancers have access to a clinical nurse specialist and appropriate support	Regions, ICBs, Trusts	Across life of plan
Action 9: Explore novel procurement routes for diagnostics or treatments for rare cancers		
Explore novel procurement routes for diagnostics or treatments for rare cancers	DHSC/NHSE	2026
Action 10: Make rare cancers a research priority		
Make rare cancers a priority for DHSC and NIHR	DHSC	2026
Support research improving detection of rare cancers in Multi-Cancer Early Detection tests (MCEds)	DHSC	2026

Commitment	Responsible organisation	Timeframe
Action 11: Increase spending on rare cancer research		
Increase spending on rare cancer research	DHSC/NHSE	Across life of plan
Support the Tessa Jowell Brain Cancer Mission to extend its approach to other rarer cancers	DHSC	2027
Action 12: Accelerate movement from foundational research to innovative treatments		
Invest in innovations for rare cancers and support entrepreneurship of researchers	DHSC	2026
Action 13: Implement the Rare Cancers Bill to expand trial access		
Appoint an NIHR national speciality lead for rare cancers, automatically contact patients with rare cancers, and review market authorisations for drugs for rare cancers	DHSC/NHSE	2029

RARE CANCERS ACT 2026

The Rare Cancers Act 2026 was initially introduced as a Private Members' Bill by Scott Arthur MP in 2025, and gained backing by the government and all major political parties.

The aim is to incentivise research and investment into the treatment of rare cancers by:

- Appointing a named individual responsible for overseeing the delivery of research into rare cancer treatments.
- Placing a duty on the government to review the Orphan Drug Regulations, with respect to rare cancer treatments.
- Ensuring that patients can be easily contacted about relevant research and clinical trials, thereby improving access to trials and the quality of trials in the UK.

These commitments form an important part of the National Cancer Plan for England; it has been a timely and critical contribution to improving outcomes for rare cancers. The Bill debates in both House of Commons and Lords demonstrated a strong level of support for improvements in outcomes for people diagnosed with rare cancers and recognised the barriers to improvements across research, access to clinical trials and treatments.^{15,16}



¹⁵ Rare Cancers Bill. Volume 763: debated on Friday 14 March 2025 House of Commons. Available: <https://hansard.parliament.uk/commons/2025-03-14/debates/E91AEAE3-F8A5-4BFE-989D-312B576D93A5/RareCancersBill>

¹⁶ Rare Cancers Bill. Volume 851: debated on Friday 16 January 2026. House of Lords. Available: <https://hansard.parliament.uk/Lords/2026-01-16/debates/729889FB-76CC-44C0-A0D2-9F576BB8F526/RareCancersBill>

Health policy developments

Since the 2024 General Election, there have been significant policy changes that set an important direction for the future of cancer services in the UK.

The Labour Party set out in its election manifesto a mission-driven approach to government, this included building an NHS fit for the future – the commitments included cutting waiting times with 40,000 more appointments every week, doubling the number of cancer scanners, a new Dentistry Rescue Plan, 8,500 additional mental health staff and a return of the family doctor.

LABOUR PARTY: MISSION-DRIVEN GOVERNMENT

On being elected, the Labour government expanded on the national missions, which is built on five missions: ¹⁷

- 1 Kickstart economic growth.
- 2 Build an NHS fit for the future.
- 3 Safer streets.
- 4 Break down the barriers to opportunity.
- 5 Make Britain a clean energy superpower.

The **health mission** specified a milestone to end hospital backlogs to meet the NHS standard of 92% of patients in England waiting no longer than 18 weeks for elective treatment. ¹⁸

Three major shifts for the NHS were articulated here with a goal to have fewer lives lost to the biggest killers – including cancer. ¹⁹

BUILD AN NHS FOR THE FUTURE

NHS there when people need it



Improving access to health and care services, including cutting waiting times.

Fewer lives lost to biggest killers



Reducing early deaths from cancer, heart disease, stroke, and suicide.

Fairer Britain, where everyone lives well longer



Addressing the underlying drivers of ill-health and tackling health inequalities.

(1) Hospital → Home

(2) Analogue → Digital
(+ building the workforce of the future)

(3) Treatment → Prevention

DARZI REVIEW

The Labour government's goals and milestones were informed and underpinned by an independent investigation of the NHS by Lord Darzi, which reported in September 2024. ²⁰

Lord Darzi diagnosed that the NHS is in 'serious trouble' and found that the NHS had not been able to meet waiting times in cancer services and other vital services since 2015.

There was also a section specifically about cancer, which stated that:

- Survival rates at 1-year, 5-years and 10-years have improved.
- The rate of improvement slowed substantially during the 2010s.
- The UK has appreciably higher cancer mortality rates than other countries.
- No progress was made in diagnosing cancer at stage I and II between 2013 and 2021.
- Since then, rates have risen with notable improvements in the early detection of lung cancer.
- Only around 60% of the 35,000 genomic tests were being completed.
- The 62-day target for referral to first treatment had not been met since 2015.

Lord Darzi concluded that despite the challenge, the NHS's 'vital signs remain strong' and could be repaired with strategies to improve the nation's health and reforms to social care.

¹⁷ Build an NHS fit for the future – The Labour Party. 2024. Available: <https://labour.org.uk/change/build-an-nhs-fit-for-the-future/>

¹⁸ 5 Missions for a Better Britain. Build a Better NHS. Labour. Available: <https://labour.org.uk/wp-content/uploads/2023/05/Mission-Public-Services.pdf>

¹⁹ Plan for Change. Milestones for mission-led government. 5th December 2024. Page 28. Available: https://assets.publishing.service.gov.uk/media/6751af4719e0c816d18d1df3/Plan_for_Change.pdf

²⁰ Independent Investigation of the National Health Service in England. Lord Darzi. September 2024. Available: <https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england>

²¹ 10 Year Health Plan for England: fit for the future. July 2025. Available: <https://assets.publishing.service.gov.uk/media/6888a0b1a11f859994409147/fit-for-the-future-10-year-health-plan-for-england.pdf>

10 YEAR HEALTH PLAN FOR ENGLAND: FIT FOR THE FUTURE

The government opened a large-scale public consultation to develop a 10-year health plan, a policy development to address concerns and turn around the NHS.

The 10 Year Health Plan confirmed the government's aim to reduce the number of lives lost to the biggest killers including cancer, and makes reference to the upcoming national cancer plan, particularly its role in increasing access and uptake of screening services.²¹

The 10 Year Health Plan majors on three radical shifts: hospital to community, analogue to digital, and sickness to prevention.

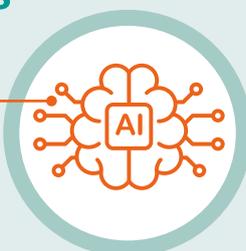
Alongside these shifts the plan also sets out the five big bets representing the most direct and impactful technological levers for transforming NHS care delivery:

- 1 Health data will flow seamlessly and securely.
- 2 AI is each health professional's trusted assistant.
- 3 Personalised health journey will begin at birth.
- 4 Wearables are your personal health custodian.
- 5 Robots will deliver care with unprecedented precision.

The plan recognises the rapidly evolving landscape in cancer care transformation including genomic analysis of liquid biopsies, advances in cell and gene therapy, AI-enhanced imaging, and multi-cancer early detection tests.

Five big bets

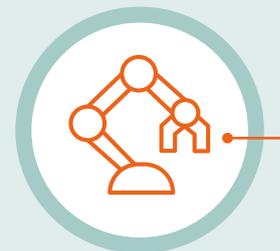
AI to drive productivity, supporting patient choice and liberating staff



Wearables to make care 'real time' and become standard in preventative, chronic and post-acute treatment



Robotics to support precision, transforming patient care from surgery to rehabilitation



Data to deliver impact, flowing seamlessly and securely to enable earlier diagnosis and better research



Genomics and predictive analysis for pre-emptive, personalised care starting from birth

Key announcements for rare and less common cancers:

- **Eliminating cervical cancer.** Increase uptake of HPV vaccinations among school-leavers to consign cervical cancer to history by 2040. Send self-sampling kits to women who miss cervical screening invitations, boosting uptake by enabling private home testing.
- **Innovative immunotherapy.** Partner with universities and industry to deliver 10,000 personalised mRNA cancer vaccines in clinical trials over the next five years, scaling further as efficacy is proven. Prepare the NHS to generate research evidence and plan implementation of mRNA vaccines for cancer treatment.
- **Early detection breakthroughs.** Fast-track evaluation and rapid implementation of multi-cancer early detection blood tests, aiming for proof of effectiveness within five years.
- **Prevention paradigm.** Leverage genomics and AI to predict disease risk years before symptoms appear, shifting the NHS from reactive care to proactive wellness. Expand the NHS Genomic Medicine Service to universal newborn genomic screening and population-based polygenic risk scoring. Build a unified genomic record linked to the Single Patient Record, viewable via the NHS App, giving each citizen control over their genomic data.
- **Precision diagnostics and treatment.** Roll out universal cancer genomics: offer comprehensive molecular profiling and liquid-biopsy early detection to all cancer patients.
- **Empowering patients and workforce.** Enhance the NHS App to enable delivery of personalised health coaching, risk-stratified screening reminders, and AI-driven advice. Train Neighbourhood Health Service staff in genomic counselling to support informed decision-making.

LIFE SCIENCES SECTOR PLAN AND INDUSTRIAL STRATEGY

The Life Sciences Sector Plan (LSSP) closely links the government's missions on growth and health.²² Following the Industrial Strategy, which set out the government's ambitions for the UK to be the leading life sciences economy in Europe by 2030 and the third most important life sciences economy globally, only behind the US and China, by 2035.

The plan focuses on three core and interconnected pillars:



The LSSP includes a specific action to deliver the ambitions of the government's Healthcare Goals programme including cancer with each programme being led by ministerially appointed international experts in collaboration with partners across the public, private and charitable sectors. The aim is to reflect the significant health and economic burdens felt through cancer and other diseases. Each Goals programme will be focused on delivery of quantifiable and timebound KPIs and sit within the Office for Life Science.²³

CIVIL SOCIETY COVENANT

A key approach the government will take in the development and delivery of policy change is to work in partnership with civil society. The Civil Society Covenant aims to set out a new model of partnership and create an environment in which civil society is respected, supported and listened to by government.²⁴

For cancer services the National Cancer Plan states that the plan is "powered by partnership".²⁵

Specifically, there will be partnership with cancer charities on Health and Growth Accelerators to support patients to stay in and return to work. Plus a focus on partnerships to deliver neighbourhood cancer care and co-design targeted campaigns and to deliver Diagnosis Connect, which will ensure patients are referred directly to trusted charities and support organisations at the point of diagnosis. There will also be a collaborative national approach to setting research priorities and increasing spending on rare cancer research.

²² Life Sciences Sector Plan. UK Government. Available: https://assets.publishing.service.gov.uk/media/688c90a8e8ba9507fc1b090c/Life_Sciences_Sector_Plan.pdf

²³ Cancer Healthcare Goals. Updated 16th December 2025. Available: [Cancer Healthcare Goals - GOV.UK](https://www.gov.uk/government/news/cancer-healthcare-goals)

²⁴ PM set to reshape how Government works with communities to tackle Britain's biggest challenges - GOV.UK Published 16th July 2025. Available: <https://www.gov.uk/government/news/pm-set-to-reshape-how-government-works-with-communities-to-tackle-britains-biggest-challenges>

²⁵ DHSC, The National Cancer Plan for England: delivering world class cancer care, p.6 <https://assets.publishing.service.gov.uk/media/698315a35a7e802e96d343a4/national-cancer-plan-for-england-delivering-world-class-cancer-care.pdf>

Conclusion

Since 2024 there has been significant change in policy for health, cancer and rare and less common cancers. The government will now be moving into implementation, and this is critical for the delivery of real change that has potential to improve quality of life and save more lives.

The publication of the National Cancer Plan for England was strongly called for and has been widely welcomed. It certainly presents a step change for rare and less common cancers which opens opportunities to deliver real change that can improve lives and outcomes.

Throughout the last two years of significant policy development and change, Cancer52 has sought to be a consistent, constructive and persistent presence advocating for the rare and less common cancer community. We have taken every opportunity to engage and inform policy as it has been consulted on through our responses to key consultations, engagement with NHS England and the Department of Health and Social Care at events and meetings, and working alongside our cancer charity partners Cancer Research UK and Macmillan Cancer Support on the National Cancer Plan Steering Group.

The next 10 years offer hope and challenges; it will be critical for funding and workforce development to meet the bold ambitions to deliver on the plan as well as the government's wider goals on working in partnership and growth.

Cancer52 will continue its role to hold government to account on the actions and goal of parity for rare and less common cancers. As a voice for the community and working with member charities to engage and inform we will provide insights, evidence, checks and balances that will be essential to the delivery of the National Cancer Plan for England.



Appendix

Cancer52 Specific calls

National Cancer Plan for England

PRIORITY 1: Reduce the number of deaths from rare and less common cancers by 15% by 2040, saving 80,000 lives

Establish a national target to reduce deaths from rare and less common cancers, making a 15% reduction in deaths by 2040 a reality and save 80,000 lives

p.9: Our goals will only be possible if we make real progress on children and young people's cancer, and rare and less common cancers. We cannot deliver aspirations as ambitious as those in this plan without transforming outcomes for children and young people, and on rare cancers. Our engagement highlighted that government policy has often insufficiently focused on these areas, which need a bespoke approach. Our modelling shows that our survival goal is only possible if we improve outcomes on cancers where survival has remained stubbornly low for decades.

p.23 English survival rates are among the best in Europe across all cancers by 2035, including for rare and less survivable cancers.

p.73 Alongside our central ambition to improve survival, we will aim to drive up survival on rare cancers. Our commitment is, by 2035, to be in the top quartile across 28 countries for survival for 14 less common cancers, as measured by the CONCORD project.⁹⁷ This will mean that we need a significant effort to improve survival for cancers like brain, ovarian, pancreatic, and stomach cancer, where we currently rank in the bottom 2 quartiles.

Publish national and regional data on cancer and health inequalities to develop and implement cross-cutting strategies

p.19 We will share more granular data, including on rarer cancers, breaking broader categories down wherever possible to identify whether there are specific performance issues. We have started to publish new data on whether the Faster Diagnosis Standard is met for patients who are diagnosed with cancer to support a more targeted approach to improvement.

p.73 We will measure our performance, and outcomes, on rare cancers in more detail – and act on this data more decisively. This will include disaggregating some rare cancers in performance data – recognising frustrations expressed to us by cancer charities and researchers that, for example, gynaecological cancers are grouped together in performance data, rather than split out into cervical, ovarian and other cancers separately. Through the NDRS Get Data Out programme, we will expand the data available to the public and researchers by publishing increased information on incidence, routes to diagnosis, treatments and survival.⁹⁸ We will use the Get Data Out programme to make data on rare cancers more granular, extending the publication of regular data to more individual rare and less common cancers by 2027.

p.73 We will increase specificity of data to help us understand where interventions are needed, and how to make those interventions as effective as possible. Publishing regular data on performance and outcomes will boost transparency and help ensure we can be held accountable for our rare cancer ambitions.

p.75 we will prioritise rare cancers in cancer manuals. Emerging from our survival goal, the first wave will include an equal balance of rare cancers where survival has been slowest and the most common cancers. It is in the combination of both that we will maximise progress.

Align responsibility in Cancer Alliances on health inequalities with leadership on rare and less common cancers

p. 31 from this year, Cancer Alliances will partner with local Health and Wellbeing Boards and the wider cancer community to co-design targeted local awareness campaigns, and to signpost people to support services. The Neighbourhood Early Diagnosis Fund will be used to reduce inequalities for people in deprived areas and among ethnic groups with lower early diagnosis rates.

p.37 A reformed National Cancer Board chaired jointly by DHSC and an independent representative of the wider cancer community will track progress and provide regular updates to ministers. Ministers will publish an annual summary of progress, along with a more in-depth report after 3 years to assess where the plan needs updating and refreshing. The board will also add new members to monitor the impact of the plan on health inequalities, rarer cancers, and children and young people's cancers.

p.75 We will prioritise access to specialist treatment for patients with rare cancers. Patients with rare cancers will benefit from a move to specialist multi-disciplinary teams, that cover multiple providers. This will allow them to benefit from the input of specialist centres and so access to the best evidence-based care. For some rare cancers, patients are less likely to have access to specialist centres and MDTs. We will prioritise these cancers, such as head and neck cancers and pancreatic cancers, for this new multi-provider model. Cancer Alliances will support networking and coordination between providers and facilitate the development of these MDTs.

PRIORITY 1: Reduce the number of deaths from rare and less common cancers by 15% by 2040, saving 80,000 lives

<p>Align responsibility in Cancer Alliances on health inequalities with leadership on rare and less common cancers</p>	<p>p. 31 From this year, Cancer Alliances will partner with local Health and Wellbeing Boards and the wider cancer community to co-design targeted local awareness campaigns, and to signpost people to support services. The Neighbourhood Early Diagnosis Fund will be used to reduce inequalities for people in deprived areas and among ethnic groups with lower early diagnosis rates.</p> <p>p.37 A reformed National Cancer Board chaired jointly by DHSC and an independent representative of the wider cancer community will track progress and provide regular updates to ministers. Ministers will publish an annual summary of progress, along with a more in-depth report after 3 years to assess where the plan needs updating and refreshing. The board will also add new members to monitor the impact of the plan on health inequalities, rarer cancers, and children and young people's cancers.</p> <p>p.75 We will prioritise access to specialist treatment for patients with rare cancers. Patients with rare cancers will benefit from a move to specialist multi-disciplinary teams, that cover multiple providers. This will allow them to benefit from the input of specialist centres and so access to the best evidence-based care. For some rare cancers, patients are less likely to have access to specialist centres and MDTs. We will prioritise these cancers, such as head and neck cancers and pancreatic cancers, for this new multi-provider model. Cancer Alliances will support networking and coordination between providers and facilitate the development of these MDTs.</p>
<p>Prevent more rare and less common cancers by taking decisive action on smoking, obesity, excessive alcohol consumption and protection from harmful sun exposure</p>	<p>p.40 Public health, school immunisation teams, primary care and Cancer Alliances will collaborate on tailored campaigns to increase take-up of the HPV vaccine among boys and girls, particularly in underserved populations. From 2026, they will promote new schemes to enable young people who missed out on the HPV vaccination at school to have it administered at their local pharmacy. All this will contribute to us delivering on our commitment to eliminate cervical cancer by 2040. These vaccinations will also protect against 6 other rarer cancers that are also linked to HPV.</p> <p>p.40 We will act on UV radiation and alcohol harm.</p> <p>p.40 We will also tackle harmful alcohol consumption by introducing new mandatory health warnings and nutritional information on alcohol labels.</p>

PRIORITY 2: Increase early diagnosis of rare and less common cancers which will improve patient experience, quality of life and help save more lives

<p>Increase the proportion of rare and less common cancers diagnosed at an early stage (stage I and stage II)</p>	<p>p.24 Increasing the proportion of cancers diagnosed at stage 1 and 2. Our survival ambition is premised on achieving at least a 20 percentage point increase in early diagnosis above the 2019 level by 2035.</p> <p>p.74 Action 5. We will take a more proactive approach to early-stage diagnosis of rare cancers. Some rare cancers, like pancreatic and liver cancer, have less easily identifiable symptoms at an early stage. As a result, they have lower rates of early diagnosis, and so worse outcomes. From this year, we will extend new, more proactive approaches to identifying people who are at greatest risk of developing these cancers – based on family history, symptoms or behavioural risk factors, and offer them regular checks.</p>
<p>Develop a way to track early diagnosis of non-stageable cancers and include in national targets</p>	<p>p.24 Reducing the proportion of cancers diagnosed in an emergency setting. This is a check that we are making progress in the diagnosis of some blood, brain and other rarer cancers which cannot be staged.</p> <p>p.74 Action 4. We will reduce the number of rare cancers diagnosed in emergency settings. Some rare cancers, such as leukaemia and brain cancers, do not behave like other cancers, which have solid tumours (and so can be staged based on their spread around the body). These cancers are not captured by our current measure for improving early diagnosis, which is based on increasing the proportion of cancers diagnosed at stage 1 and 2. As a result, it is harder to measure whether we are diagnosing these cancers early enough, and whether we need to prioritise further intervention or investment. We will address this by publishing regular data on the number of these cancers diagnosed in emergency settings, as a proxy for late or ineffective diagnosis. Moreover, adding this to the basket of early diagnosis metrics we priorities will help incentivise systems and providers to focus on earlier diagnosis of blood and brain cancers.</p>

Cancer52 Specific calls

National Cancer Plan for England

PRIORITY 2: Increase early diagnosis of rare and less common cancers which will improve patient experience, quality of life and help save more lives

<p>Establish a target to reduce the number of patients diagnosed with a rare or less common cancers at late-stage (stage III and stage IV)</p>	<p>p.24 Reducing the number of people with cancer diagnosed at stage 3 and 4 (measured as an age-standardised rate per 100,000). This is a check that the increase in early diagnosis is leading to meaningful improvements in outcomes.</p>
<p>Evaluate 'non-specific symptoms pathways' and 'community diagnostic centres' to ensure more rare and less common cancers are being diagnosed early</p>	<p>p.7 we will expand the community diagnostic estate, while boosting productivity, use digital pathways and technology to end outpatients as we know it, and use innovation to speed up treatment decisions.</p> <p>p.12 Action 1. We will expand the community diagnostic estate – while also prioritising productivity, value and convenient access.</p> <p>p.74 We will catch rare cancers earlier, including for cancers where staging is difficult. Early diagnosis is a key thread in this National Cancer Plan. That is for good reason – there is no path to world leading cancer survival, without world leading early diagnosis. While our overall early diagnosis aspirations will also benefit patients with rare and less common cancers, there are some specific actions we can and should take.</p>

PRIORITY 3: A new national mission on rare and less common cancers with patient involvement at its core

<p>Publish and fully fund a cancer strategy, including an explicit focus on rare and less common cancers</p>	<p>p.73 We agree with the many charities and patients who expressed the view, in our call for evidence and wider engagement, that rare cancers have not received equal weighting in government policy. We are determined, through this plan, to give them an even footing. To be clear, that does not mean we will let up in our focus on supporting people with more common cancers. But alongside that we unequivocally commit that people with rare cancers will be a priority for the NHS for the full course of this plan's duration.</p>
<p>Establish a rare and less common cancers national taskforce and lead in every Cancer Alliance</p>	<p>p.9 We will appoint a national lead for rare cancers and ensure we drive up survival rates to match the top nations in Europe.</p> <p>p.37 A reformed National Cancer Board chaired jointly by DHSC and an independent representative of the wider cancer community will track progress and provide regular updates to ministers. Ministers will publish an annual summary of progress, along with a more in-depth report after 3 years to assess where the plan needs updating and refreshing. The board will also add new members to monitor the impact of the plan on health inequalities, rarer cancers, and children and young people's cancers.</p> <p>p.73 To hold us accountable on this, to marshal progress and resources, and to build salience and profile, we will designate a new national lead for rare cancers.</p>
<p>Invest in the rare and less common cancer workforce, increasing capacity and recognising the need to retain the specialty and expertise of this workforce</p>	<p>p.75 Action 8. We will work with rare cancer charities to get patients the right support after treatment. Many rare cancer charities provide excellent services to patients, because they often have more expertise for their specific tumour group. We will work with these charities to provide guidance for clinical nurse specialists and other staff so that they can provide the best possible support. As part of stage 2 of the development of the Diagnosis Connect Programme, we will work with cancer charities, including those from rare cancers, so that patients can be connected to patient led communities and sources of expert support and advice.</p>

PRIORITY 3: A new national mission on rare and less common cancers with patient involvement at its core
Prioritise investment in life sciences research and innovations for rare and less common cancers, including in genomics and multi-cancer screening tests

p.8 We will increase recruitment to clinical trials, particularly for patients with rare cancers, from poorer areas, and from ethnic minority groups, who have been less able to join clinical trials in the past.

p.9 We will explore novel procurement routes for diagnostics or treatments for rarer cancers to pull through breakthrough diagnostics or treatments for the rare cancers with the most stubbornly low survival rates.

p.9 We will make rare cancers a priority for research by implementing the Rare Cancers Bill and supporting the Tessa Jowell Brain Cancer Mission to extend its approach to other rare cancers.

p.56 We will spearhead further efforts to discover and develop effective screening tests for rare cancers using multi-cancer early detection tests.

p.57 Some rare cancers, such as brain and pancreatic cancer, have stubbornly low survival rates – and few treatment or diagnostic breakthroughs. We need new diagnostic tools, research into biomarkers, and targeted therapies to achieve any major changes to survival. Genomics and data will be particularly important enablers to progress.

p.76 Action 9. We will explore novel procurement routes for diagnostics or treatments for rare cancers. Active industrial strategy is a priority for this government. And that means using government levers to create markets and stimulate innovation in strategic, priority areas. For rare cancers, such as brain, pancreatic, and liver cancers, where breakthroughs have been limited, we will explore innovative procurement mechanisms to stimulate innovation in cancer diagnostics and treatments, such as advance market commitments and advance purchase agreements.

p.76 Action 10. We will make rare cancers a research priority. We will make increasing research into rare cancers a priority for DHSC and NIHR (with the support and oversight of our new national lead for rare cancers research). This will include a focus on diagnostics, biomarkers and targeted therapies to increase early diagnosis and deliver new, more effective treatments. We will incentivise inclusion of rare cancers in future trials of multi-cancer early detection tests, so that they can detect rare cancers to a greater level of sensitivity. We will use NIHR's Invention for Innovation funding grants to fund research that deliberately over-recruits patients with rare cancers – helping ensure we have the right data to know whether MCEDs work for rare cancers and ensuring that patients with these cancers benefit from this breakthrough technology.¹⁰³ This will be supported by the OLS Early Diagnosis Cancer Research Fund, which will focus on new cancer diagnostic technologies for less common cancers.

p.76 Action 11. We will increase spending on rare cancer research. This will begin with £13.7 million for the NIHR Brain Tumour Research Consortium.¹⁰⁴ Through this and other significant funding initiatives and partnerships in brain tumour research we will greatly accelerate the amount of high quality, innovative research taking place in the UK that will deliver the next wave of breakthroughs.

p.77 We will build on this by expanding successful models for rare cancers. The Tessa Jowell Brain Cancer Mission (TJBCM) has developed a mission-led approach, bringing together the clinical community to drive innovation and upskill the workforce to increase research, as well as improving treatment quality. The TJBCM has done outstanding work to expand the network of trials for brain cancer and has helped to define excellence and drive up standards across the country. We will support the TJBCM to extend its approach to other rare cancers, driving the expansion of research into rare cancers.

p.77 Action 13: We will implement the provisions of the Rare Cancers Bill in full to give patients access to clinical trials.



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