7. Rare and less common cancers

While some rare cancers do have high survival rates (e.g. testicular c.95% 5-year survival), the pattern in England still remains that the cancers with the lowest survival rates – and where improvements have been very limited for decades – are those that are rare or less common. This underpins findings, as in recent research by Cancer52, showing that the 47% of patients diagnosed with a rare or less common cancer (defined as cancers outside of breast, prostate, bowel and lung cancers) make up a disproportionate 55% of cancer deaths.[95]

In some cases, this is down to simple biology – some rare cancers are simply harder to diagnose or treat. Yet, there are also indications of unwarranted variation – including lower research investment in rare cancers, less awareness of symptoms among patients and clinicians, and less sustained focus in government policy.[96]

Patient Voice

"My mum was diagnosed with pancreatic cancer in A&E – I tried to reassure her that published survival rates must be out of date as progress must have been made. But I was so very wrong! [...] My mum died just 7 months after diagnosis in 2020."

Call for evidence respondent

This isn't fair. This government believes it must pull every lever available to it to improve outcomes across all cancer types, both rare and more common. That is why we have designed a headline survival commitment so ambitious as to depend on sustained

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[95] Cancer52. Health inequalities report. cancer52.org.uk (viewed on 08 January 2026).
[96] NHS England. Cancer Survival in England. digital.nhs.uk (viewed on 13 January 2026).

improvements across all cancer types, including many where survival has been stagnant for decades. Progress on rare cancers is foundational to this plan.

We will give rare cancers real parity

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.

Action 1. To catalyse progress, climbing up the international rankings on rare cancers is a formal ambition of this plan.

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.

Action 2. 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.

This national clinical lead will have a clear mandate to speak up for rare cancers, and to provide clinical advice and support for the delivery of the actions in this chapter. They will sit on the National Cancer Board that will oversee delivery of this plan and advise ministers directly and independently on what action should be taken to improve outcomes.

We will enable progress through better, more accessible data

Data is how we avoid flying blind in our improvement attempts. If we do not know where the problems are, or where there are the biggest opportunities to do better, we will not make progress. Worse, we will find it harder to deliver the transparency and accountability that patients want and deserve, and that the 10 Year Health Plan committed to.

Action 3. 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. We will define and count recurrent cancers, starting with metastatic breast cancer.

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.

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[97] Allemani, C. and others, Global surveillance of trends in cancer survival 2000–14 (CONCORD-3), The Lancet 2018: volume 391, p.1023-1075. (viewed on 12 January 2026).

[98] NHS England. 'Get Data Out – data stories' digital.nhs.uk (viewed on 12 January 2026)

Case study: Improving identification of patients with metastatic cancer – Greater Manchester Cancer Alliance

Patients with metastatic cancer are living longer thanks to new treatments, creating a growing cohort with complex needs. A Cancer Experience of Care Improvement Collaborative project sought to improve experience for those with metastatic breast cancer. It found these patients are often poorly identified within national datasets, with important information fragmented across multiple data sources.

To address this, Greater Manchester Cancer Alliance, working in partnership with Greater Manchester ICB, has developed an algorithm that scans several datasets within the Greater Manchester Analytical and Data Science Platform, alongside a longitudinal patient record viewer. This approach enables more accurate identification of patients with metastatic breast cancer at a system-wide level, rather than relying on individual provider records.

By improving visibility of this patient group, the system creates opportunities to better understand their holistic health needs, patterns of service use, and overall outcomes. This in turn supports more effective service planning and resource allocation, ensuring that care is better aligned to the needs of this important and growing population.

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.

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 priories will help incentivise systems and providers to focus on earlier diagnosis of blood and brain cancers.

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.

Patient Voice

"My partner knew instinctively that he was at high risk of developing pancreatic cancer given that he lost his father, his paternal aunt and two sisters to the disease and yet there was no screening or genetic testing available to him."

Call for evidence respondent

Action 6. We will help GPs identify rare cancers more reliably.

GPs may only see patients with a specific rare cancer once or twice in their career. This makes diagnosis more difficult. AI-driven clinical decision support tools and safety nets offer an opportunity to help GPs pick up on patients who might be at greater risk. This will be reinforced by Jess's Rule, which will encourage GPs to reflect, review, and re-think repeat symptoms that could indicate cancer.[99]

We will speed up access to targeted and personalised therapies for rare cancers

The pace of advance in new treatments for some rare cancers has often been too slow, for too many years. But, more recently, we have begun to see some welcome, major advances. CAR-T (Chimeric Antigen Receptor) cell therapy (pioneered in the UK) has offered hope to many people with previously incurable blood cancers. More sophisticated radiotherapy treatments and advances in personalised medicine – supported by genomic testing – have led to better outcomes and fewer side effects for many.[100] The emergent challenge is variation in access to the best and most innovative treatment. The NHS has long struggled to get innovations to everyone, as quickly as possible – or as quickly as in other health systems. Given poor current outcomes for rare cancers, we must prioritise breaking with this trend.

Action 7. 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.[101] 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.

Further, 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.

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.[102]

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[99] UK Government. Jessica Brady's legacy inspires new life-saving GP safety rule. gov.uk (viewed on 08 January 2026).

[100] NHS England. NHS Genomic Medicine Service. england.nhs.uk (viewed on 13 January 2026).

[101] Specialised Healthcare Alliance. Rarer Cancers. shca.info (viewed on 13 January).

[102] UK Government. Patients with long-term conditions to receive help from charities. gov.uk (viewed on 08 January 2026).

Patient Voice

"Having been the 'medical project manager' for a family member for another illness I can vouch that it is not easy managing such illnesses and knowing what is available, when and where from, especially as this illness had no NHS pathway. This would be especially true for rare cancers and cancers affecting children and young people."

Call for evidence respondent

We will deliver research breakthroughs for the least survivable cancers

To make more progress in the fight against many rare cancers we need to increase research. That means more research must be a core part of the solution. Specifically, we need to break the barriers to research – including difficulties recruiting to clinical trials; lower commercial viability; and less researcher focus, profile and capacity.

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.

Patient Voice

"The cancer treatments available on the NHS for my rare cancer are over 50 years old. Newer treatments are slow to be adopted, despite being valuable to numerous other cancer patients."

Call for evidence respondent

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.

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.

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[103] National Institute for Health and Care Research (NIHR). Invention for Innovation (i4i) Programme. nihr.ac.uk (viewed on 13 January 2026).

[104] National Institute for Health and Care Research (NIHR). NIHR launches £13.7m investment in brain tumour research. nihr.ac.uk (viewed on 08 January 2026).

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.

Case study: 5G Platform

The 5G (next-Generation aGile Genomically Guided Glioma platform) study is a world-first adaptive clinical trial platform for brain tumours.[105] This pioneering research aims to accelerate the development of new treatments for glioblastoma, an aggressive form of brain cancer, by precisely targeting drugs to each patient's disease. Every patient has their genome sequenced in real time, allowing treatment or drug combinations to be based on the specific genetic makeup of their tumours.

The 5G trial platform is funded by Cancer Research UK and the Minderoo Foundation hosted by NIHR biomedical research centres (BRCs). It allows multiple drugs to be trialled simultaneously. This adaptive design means drugs can be changed as real-time data is collected, benefiting both the trial and improving outcomes for participants.

This initiative aims to address the lack of significant breakthroughs in brain cancer treatment over decades.

Action 12: We will accelerate the move from foundational research to delivering innovative treatments for patients.

We will tackle the problem that early stage research isn't pulled through into translational research that actually delivers new diagnostics and treatments for patients as often as it should be. We will link up discovery science and translational researchers, connecting the research infrastructure and increase collaboration. For brain tumours specifically, this year we will co-fund the CRUK Brain Tumour Centres of Excellence this year, which exemplify this approach.[106]

To accelerate the move from bench to bedside, we will support researchers to commercialise their findings. The THRIVE (Translate Healthcare Research through InnoVation and Entrepreneurship) Programme helps researchers turn their findings into actionable innovations and to bring them to market. We will run a targeted call of this programme for rare cancer researchers in 2026, so that they are encouraged to bring innovative treatments to the NHS faster.

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

The current clinical trial model doesn't work for rare cancers and patients with the disease, who find it too difficult to access breakthrough treatments that might help them. We will invigorate trials for rare cancers through our new clinical trials model. This will include the full implementation of provisions in the Rare Cancers Bill starting in 2026 and over the next 3 years. We will designate an NIHR national specialty lead for rare cancers research who will support delivery of rare cancers research and ensure strategic oversight and continuous improvement of the research portfolio.

We will automatically contact patients with rare cancers to offer them the opportunity to be part of clinical trials through a tailored version of NIHR's Be Part of Research service.

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[105] Cancer Research UK. £3m for world-first trial to revolutionise brain cancer treatment. news.cancerresearchuk.org (viewed on 08 January 2026).

[106] Cancer Research UK. £8m more for our Brain Tumour Centres of Excellence. news.cancerresearchuk.org (viewed on 08 January 2026).

Be Part of Research will allow patients to find trials through the NHS App and make it easier for them to sign up. We will also review the law related to market authorisations for drugs for rare cancers and compare the UK’s regulations against other countries.

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 diagnoses of rare cancers.		
Reduce the number of patients who are diagnosed in emergency settings, where it is not clinically appropriate	NHSE/DHSC	Across the life of the 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 the life of the 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

Commitment	Responsible organisation	Timeframe
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
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 specialty lead for rare cancers, automatically contact patients with rare cancers, and review market authorisations for drugs for rare cancers	DHSC/NHSE	2029