



What Are We Waiting For?

Act now on long
cancer waits

Shirley, 56, from Essex, diagnosed with breast cancer.

MACMILLAN
CANCER SUPPORT

Summary

Record level waits for cancer tests and treatment across the UK are leaving tens of thousands of people in poor health and experiencing worse outcomes.

Performance against cancer waiting times targets in all UK nations fell to the worst on record in 2022. This crisis has been building over decades. Whilst the pandemic added huge pressure to health and care services, cancer care was affected by long delays for many years prior to this. Our dedicated cancer workforce has continued to do everything they can to support people with cancer under impossible pressures. But despite their best efforts, long waits for cancer tests and treatment have become normal.¹ This cannot continue – people with cancer have had enough.

New analysis by Macmillan Cancer Support suggests:

- **An additional 180,000 people – equivalent to a population the size of Ipswich - have waited 'too long' for vital tests to diagnose cancer and to start treatment over the past decade because of missed targets.²**
- **At least 100,000 people across the UK have faced worse cancer outcomes due to increasing delays in being diagnosed and starting treatment with their NHS cancer care.^{3,4}**
- **Long waits are particularly affecting some of England's most deprived areas.**

This is unacceptable. Thousands of lives are being put at risk across the UK due to lack of action by UK governments on long waits. Worrying delays in getting a diagnosis and starting treatment can lead to people's cancer continuing to grow and spread, jeopardising their physical and mental health, restricting their treatment options, and potentially reducing their chances of survival.^{5,6}

Macmillan is calling for decision-makers across the UK to take urgent action on long waits in cancer care.⁷ **Unless governments act now, we risk outcomes getting worse, at a time when more people than ever before are living with cancer. The system is letting them down.**

Longer term, eliminating cancer waits requires getting to grips with the workforce crisis and ensuring services are sufficiently funded to meet demand and deliver high quality cancer care throughout the UK. Meanwhile thousands of people face long anxious waits for urgent tests and treatments. We need our leaders to act now.

▮▮ Policy makers... have to understand what's going on in the real world. People are facing a cancer diagnosis and just can't seem to get the answers they need and are facing delays. Things have to start to change this year. ▮▮

Shirley, 56, from Essex, diagnosed with breast cancer in 2016.

Urgent government action

Governments across the UK must take urgent action on long cancer waits. We are calling on them to:

1. **Tackle inequalities in cancer delays and ensure that the poorest are not penalised by long waits**
2. **Enable everyone with cancer to progress through the system as quickly as possible**
3. **Provide local NHS services with the funding and support they need to reduce long waits in cancer care**
4. **Provide better tailored support for people experiencing long waits**

Governments across the UK must take urgent action on long cancer waits. We are calling on them to:

1. Tackle inequalities in cancer delays and ensure that the poorest are not penalised by long waits.

What is the issue?

Waits for cancer services across the UK vary significantly. We know that people in some areas are waiting longer, but it's often not clear why. Data on inequalities in access, outcomes and experiences of cancer services is not systematically collected and published. Without this data we struggle to understand who is waiting longest and why, and what action local and national policymakers can take to improve the situation.

New Macmillan analysis shows that hospitals in England that tend to diagnose larger proportions of people from the most deprived areas have poorer 62-day wait performance than hospitals that tend to diagnose larger proportions of people from the least deprived areas. In 2022, the average 62-day performance was **8 percentage points lower among the hospitals that diagnosed the largest**

proportion of the most deprived patients compared with hospitals that diagnosed the largest proportion of the least deprived patients (61 per cent vs 69 per cent).⁸

62-day wait performance target

All 4 UK nations set the standard that when cancer is first suspected, everyone should have a confirmed diagnosis and start treatment within 62 days (2 months).

What needs to happen?

UK/devolved governments must:

- **Identify which populations are facing the longest waits and act on this.** Governments must collect and publish demographic data as part of cancer waiting times statistics to build a robust understanding of inequalities amongst people who are experiencing long waits for cancer diagnosis and treatment.
- **Partner with health inequalities experts to harness what works.** By working with national and local health inequalities teams, cancer leads have an opportunity to design and implement programmes to reduce waits for marginalised populations, building on evidence of what we know works.

2. Enable everyone with cancer to progress through the system as quickly as possible.

What is the issue?

- In **England**, NHS cancer waiting times are now entering their 10th year of decline.⁹
- In January 2023, cancer waiting times in **Wales** were the worst on record, with only 50 per cent of people starting their treatment on time.¹⁰
- In **Scotland**, the most recent cancer waiting times statistics published for October to December 2022 showed only 72 per cent people started treatment within 62 days which is the lowest since records began.¹¹
- In **Northern Ireland** in 2022, only 39 per cent of people started their first definitive treatment within 62 days from an urgent referral for suspected cancer from their GP - the worst year on record.¹²

Because services are so short-staffed and under-funded, people are being forced to navigate complex health services and advocate for themselves to get the care they need. They tell us they are having to push for appointments, tests and results, as otherwise they do not know how long they would be stuck in the system waiting to hear. People like Shirley, who was diagnosed in November 2016 with bilateral breast cancer and continues to face challenges with delays to her care years after her active treatment ended.

Among those with cancer in the UK diagnosed within the past 10 years who have experienced delays with their NHS cancer care, **one in three (32 per cent) have had to chase up delayed scan or test results¹³**, while one in four (25 per cent) have had to make multiple phone calls or visits to get a medical appointment¹⁴ and similar numbers (26 per cent) have had to provide repeat information.¹⁵

Two in three people with cancer in the UK diagnosed within the past 10 years who have experienced delays with their cancer care (66 per cent) say their physical or mental health has deteriorated or **they have experienced stress or anxiety about their treatment or care as a result¹⁶ – equating to more than 300,000 people with cancer** across the UK.¹⁷

One in five (23 per cent) people with cancer in the UK who have been diagnosed in the past decade and experienced long waits for NHS cancer care said they believe their cancer had progressed or got worse, leaving some with an incurable diagnosis, or that they'd been left with fewer treatment options.¹⁸

“ I had to continuously follow up with my healthcare teams after experiencing delays to results, appointments, and information about my medication. The stress of having to chase is not good for people when they have enough going on already, especially when you throw in all the financial concerns for people going through cancer at the minute. ”

Shirley, person living with cancer

Support roles like patient navigators, link workers and care coordinators can help people to find their way around the system more easily and signpost to help. Macmillan's own programmes have provided specific support to people from marginalised groups.¹⁹ These roles also benefit the wider system, leading to reduced GP visits and hospital and A&E attendances.²⁰ However, this support is something of a lottery. Among people diagnosed with cancer in the UK within the past 10 years who have experienced long waits or delays with their NHS cancer care, **fewer than two in five (36 per cent) had received support from a health professional to coordinate their care to help manage the impact of these waits or delays**²¹, and a further one in three (34 per cent) had not received this kind of support but would have liked to.²²

What needs to happen?

UK and devolved governments must:

- **Increase national funding to help people with cancer move through the system as quickly as possible.** That could be more support roles (link workers, care coordinators) to help people navigate through the health and care system more quickly, chase up appointments and

results. It could be providing support and information in a format that people can understand and access.

- **Champion support packages that enable people to get help with the things that are important for them, at a time and place that's right for them.**

Macmillan has pioneered person-centred approaches to cancer care which meet individual health, wellbeing and financial needs. Macmillan's Improving the Cancer Journey programme, delivered in partnership with the Scottish Government, aims to provide everyone diagnosed with cancer with a comprehensive assessment of their health and wider wellbeing needs and signposted them to support via a link worker by 2023. This model is successfully meeting people's wider needs and has reached people in more deprived areas.²³ We need devolved governments to back this model and roll it out across the UK.



3. Provide local NHS services with the funding and support they need to reduce long waits in cancer care.

What is the issue?

Shortages of funding and staff are the root cause of many of the challenges across the NHS. There is considerable variation between waits in different regions of the UK. Services that face some of the longest waits are also linked with acute staff shortages, backlogs from the pandemic and wider system pressures. These factors have also been associated with more deprived areas in England.²⁴

Across the UK, **staff shortages are particularly severe amongst specialist cancer professionals.**²⁵ These gaps have been compounded by nursing staff being redeployed during and following the pandemic and high sickness-related absence levels, increasing pressure on staff and services.²⁶

Targeted national support can make a difference. In England, for example, hospitals with the worst cancer waits have been able to access national support packages: national team oversight, extra funding, dedicated NHS and independent sector staffing and facilities for cancer diagnosis and treatment.²⁷ These hospitals have been able to cut waiting lists for people waiting over two months by 45 per cent cumulatively, 30 percentage points more than trusts not given this support.²⁸ **This support should be available to hospitals facing long delays throughout the UK.**

What needs to happen?

UK/devolved governments must:

- **Provide dedicated funding and support** to bring down 2 month waits for cancer services in each UK nation.

- **Keep cancer professionals in frontline cancer care**, not redeploying them to non-cancer roles.
- **Fund more administrative and wider support roles** to help services run smoothly and allow professionals to spend more time with patients.

4. Provide better tailored support for people experiencing long waits.

What is the issue?

A cancer diagnosis can affect a person's whole life, including their physical and emotional health, finances and even their employment. Long waits without additional support can make all these challenges more difficult to deal with, which risks leaving people in crisis. Teams of dedicated cancer professionals including specialist cancer nurses and Allied Health Professionals (AHPs) are vital to providing tailored support and to people feeling involved and included in decisions about their care.

Prehabilitation and rehabilitation services support people to prepare ahead of, during and after cancer treatment. Macmillan led the development of national prehabilitation guidance which recommends exercise, emotional and nutrition support along with behaviour change support.²⁹

Prehabilitation helps people get well and stay well, including:

- Improved 1-year survival rates,
- Reduced hospital stays,
- People having an increased sense of empowerment and control over their health,
- Cost savings for health systems.

Despite national commitments on personalised support, many people with cancer cannot access AHPs like physiotherapists and dieticians, who are key to delivering prehabilitation programmes. Shortages of other dedicated professionals including specialist cancer nurses are leaving too many people isolated and unsupported which can lead to poor outcomes, including increased numbers of people presenting at A&E in a crisis and serious mental health impacts.³⁰

What needs to happen?

UK/devolved governments must:

- **Deliver support programmes so that everyone can get help with whatever cancer throws up while they wait for tests and treatments.** This should include funding prehabilitation and rehabilitation programmes which have been shown to maximise the effectiveness of treatment and improve long-term health.
- **Invest in specialist cancer nurses, AHPs and support staff** to ensure everyone with cancer can access personalised care and support to address their wider physical and psychological health needs and money and work concerns.

Macmillan estimates that by 2030, the gap in the specialist cancer nursing workforce in the UK will be:

- 3,371 nurses in England
- 100 nurses in Northern Ireland
- 348 nurses in Scotland
- 166 nurses in Wales³¹

Longer term action

Governments' action on these four areas will go some way to tackling long waits. Ultimately these support measures won't eliminate long cancer waits – these are caused by chronic NHS underinvestment and staff shortages.³²

If devolved governments are serious about tackling long waits and transforming cancer care, they must address these seismic challenges with long-term funding settlements for cancer care and fully-funded plans that set out the extra staff required to meet the future needs of people with cancer.

At Macmillan, we give people with cancer everything we've got. If you're diagnosed, your worries are our worries. We will move mountains to help you live life as fully as you can.

And we don't stop there. We're going all out to find ever better ways to help people with cancer, helping to bring forward the day when everyone gets life-transforming support from day one.

We're doing whatever it takes. But without your help we can't support everyone who needs us. To donate, volunteer, raise money or campaign with us, call 0300 1000 200 or visit macmillan.org.uk.

Endnotes

1. Macmillan monthly press releases responding to NHS England Cancer Waiting Times Data. Available at <https://medium.com/macmillan-press-releases-and-statements>. Key cancer waiting time target set to be missed in England, BBC, 7 March 2023. Available at: <https://www.bbc.co.uk/news/health-64876835>
2. Each nation uses a broadly similar 62 day wait target quantity, measuring the percentage of people who have an urgent referral for cancer who are then treated within 62 days. We calculate "excess" waits by subtracting the actual percentage of people treated within the target time from the percentage operational target value. For England, where the target is 85 per cent, over 111,000 people between Jan 2014 and Dec 2022 experienced excess waits. For Wales, where the target is 75 per cent, over 10,000 people between Jun 2019 and Dec 2022 experienced excess waits, when the new target was introduced. For Scotland, where the target is 95 per cent, over 50,000 people between Jan 2014 and Dec 2022 experienced excess waits. For Northern Ireland, where the target is 95 per cent, over 13,000 people between Jan 2014 and Dec 2022 experienced excess waits.
3. Macmillan Cancer Support/YouGov surveys of 4,096 adults in the UK who have had a cancer diagnosis. Fieldwork was undertaken between 4th - 28th November 2022 (2,020 adults) and 20th March - 8th April 2023 (2,076 adults). The surveys were carried out online. The figures have been weighted and are representative of people living with cancer in the UK (aged 18+). Surveys included 2,654 people who've been diagnosed within the last ten years and use the NHS for their cancer care. Question wording in relation to people facing the worse cancer outcomes was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. What, if anything, has been the impact of this? Please select all that apply". 6 per cent of those diagnosed within the last ten years had experienced delays and selected at least one of the following options: My cancer has progressed and/or spread, My cancer symptoms have got worse, My cancer is now incurable, I have fewer treatment options, Surgery is no longer an option for my cancer.
4. The survey results from [3] are extrapolated using 10 year prevalence figures published by each UK nation. The total UK 10 year prevalence is 1,791,209, a total of England (1,522,090), Scotland (142,355), Wales (79,578) and Northern Ireland (47,186). Data from: England: <https://www.cancerdata.nhs.uk/prevalence>, Wales: <https://public.tableau.com/views/Cancerincidenceofnewcasesandprevalencepeoplelivingafterradiagnosisofcancerforclusternetworks/Wales/Introduction>, Scotland: <https://www.publichealthscotland.scot/publications/cancer-incidence-in-scotland/cancer-incidence-in-scotland-cancer-incidence-and-prevalence-in-scotland-to-december-2019> Northern Ireland: <https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/All-Cancers-excl-non-malignant-melanoma-skin/> (Accessed May 2023).
5. Hanna T P, King W D, Thibodeau S, Jalink M, Paulin G A, Harvey-Jones E et al. Mortality due to cancer treatment delay: systematic review and meta-analysis, BMJ 2020; 371. Available at: <https://www.bmj.com/content/371/bmj.m4087>.
6. As [3]. Macmillan Cancer Support/YouGov surveys included 556 people who've been diagnosed within the last ten years and experienced delays to their NHS cancer care (i.e. they've either had to 'wait several weeks to see a specialist after their first GP referral for suspected cancer' or they've had to 'wait several months to start cancer treatment after diagnosis'). Question wording in relation to people seeing their health deteriorate was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. What, if anything, has been the impact of this? Please select all that apply". 66 per cent of those who had experienced delays selected at least one of the following options: My mental health has worsened, My physical health has worsened, It's made me feel stressed and/or anxious about what this means for my cancer treatment and care, My cancer has progressed and/or spread, It's prolonged the length of my treatment, My cancer symptoms have got worse, My cancer is now incurable, I have fewer treatment options, Surgery is no longer an option for my cancer, I'm worried I won't get the care and treatment I need.
7. This briefing and the campaign focusses on the 62-day target: that no-one should wait more than 2 months/ 62 days to start cancer treatment from the date of their urgent referral. Similar targets are in place in all four UK nations.
8. The 30 trusts who tend to diagnose higher proportions of people who live in the most deprived neighbourhoods (Quintile 1 - most deprived) had statistically significantly worse 62 day wait target performance than the 30 trusts who tend to diagnose higher proportions of people who live in the least deprived neighbourhoods (Quintile 5 - least deprived) in 2022. The former trusts also showed a larger drop in 62 day wait target performance compared to 2017 and 2019, suggesting widening gaps between trusts.
The National Disease Registration Service publishes the number of cancer diagnoses in English NHS trusts between 2017 and 2020, stratified by deprivation quintile. Annual waiting times performance of each trust in 2017, 2019 and 2021 was combined with the deprivation data. Deprivation is measured using the England Index of Multiple Deprivation (2019).

Endnotes

9. Macmillan analysis of NHS England Cancer Waiting Times data shows year on year decline in performance against the 62 day wait target, from 87.4 per cent in 2012 to 62.3 per cent in 2022. Available at: <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>
10. Performance against the percentage of patients starting their first definitive treatment in the month within 62 days of first being suspected of cancer. A small improvement was observed in February 2023 (52.5 per cent) and March 2023 (55.3 per cent). Performance measure has been reported since June 2019. Available at: <https://stats.wales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times/Monthly/suspectedcancerpathwayclosedpathways-by-localhealthboard-tumoursite-agegroup-gender-measure-month>
11. Public Health Scotland Cancer Waiting Times. Available at: <https://www.publichealthscotland.scot/publications/cancer-waiting-times/cancer-waiting-times-1-october-to-31-december-2022/>
12. Department of Health, Northern Ireland Cancer Waiting Times. Available at: <https://www.health-ni.gov.uk/articles/cancer-waiting-times>
13. As [6]. Question wording was as follows: "You have experienced delays to your cancer treatment/ care because of long NHS waiting times. Which, if any, of the following apply to you because of this?" 32 per cent of those who had experienced delays selected 'I've had to chase up delayed scan or test results'.
14. As [6]. Question wording was as follows: "You have experienced delays to your cancer treatment/ care because of long NHS waiting times. Which, if any, of the following apply to you because of this?" 25 per cent of those who had experienced delays selected 'I've had to make multiple phone calls / visits to get a medical appointment'.
15. As [6]. Question wording was as follows: "You have experienced delays to your cancer treatment/ care because of long NHS waiting times. Which, if any, of the following apply to you because of this?" 26 per cent selected of those who had experienced delays 'I've had to provide repeat information that I had already provided at least once before'.
16. As [6]. Question wording in relation to people seeing their health deteriorate was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. What, if anything, has been the impact of this? Please select all that apply". 66 per cent of those who had experienced delays selected at least one of the following options: "My mental health has worsened, My physical health has worsened, It's made me feel stressed and/or anxious about what this means for my cancer treatment and care, My cancer has progressed and/or spread, It's prolonged the length of my treatment, My cancer symptoms have got worse, My cancer is now incurable, I have fewer treatment options, Surgery is no longer an option for my cancer, I'm worried I won't get the care and treatment I need".
17. As [3]. Question wording in relation to people seeing their health deteriorate was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. What, if anything, has been the impact of this? Please select all that apply". 18 per cent of those diagnosed within the last ten years had experienced delays and selected at least one of the following options: My mental health has worsened, My physical health has worsened, It's made me feel stressed and/or anxious about what this means for my cancer treatment and care, My cancer has progressed and/or spread, It's prolonged the length of my treatment, My cancer symptoms have got worse, My cancer is now incurable, I have fewer treatment options, Surgery is no longer an option for my cancer, I'm worried I won't get the care and treatment I need. Results have been extrapolated using 10 year duration prevalence, described in [4].
18. As [6]. Question wording in relation to people facing worse cancer outcomes was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. What, if anything, has been the impact of this? Please select all that apply". 23 per cent of those who had experienced delays selected at least one of the following options: My cancer has progressed and/or spread, My cancer symptoms have got worse, My cancer is now incurable, I have fewer treatment options, Surgery is no longer an option for my cancer.
19. Evaluation of Improving the Cancer Journey, Final Report, Edinburgh Napier University, 2020. Available at: <https://www.napier.ac.uk/research-and-innovation/research-search/outputs/evaluation-of-improving-the-cancer-journey-final-report>. A review of the implementation of the national optimal lung cancer pathway, Pathways Matter, October 2019. Available at: <https://www.uklcc.org.uk/sites/default/files/2021-06/UKLCC-Pathways-Matter-Report.pdf>
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Endnotes

21. Macmillan Cancer Support/YouGov surveys of 2,076 adults in the UK who have had a cancer diagnosis. Fieldwork was undertaken between 20th March - 8th April 2023. The survey was carried out online. The figures have been weighted and are representative of people living with cancer in the UK (aged 18+). Survey included 270 people who've been diagnosed within the last ten years and experienced delays to their NHS cancer care (i.e. they've either had to 'wait several weeks to see a specialist after their first GP referral for suspected cancer' or they've had to 'wait several months to start cancer treatment after diagnosis'). Question wording was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. To help you manage the impact of waits or delays and help you prepare for any treatment when it did/does start, which of the following services or support have you received? - Support from a health professional to coordinate my cancer care and appointments, e.g. act as a single point of contact, etc.". 36 per cent of those who had experienced delays said that they had received this support.
22. As [21]. Question wording was as follows: "You have experienced waits of several weeks or months, or delayed appointments, during your cancer treatment and care. To help you manage the impact of waits or delays and help you prepare for any treatment when it did/does start, which of the following services or support have you received? - Support from a health professional to coordinate my cancer care and appointments, e.g. act as a single point of contact, etc.". 34 per cent of those who had experienced delays said that they hadn't received this support but would have liked to.
23. Evaluation of the Improving the Cancer Journey programme, Macmillan and Edinburgh Napier University, 2020
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26. Written evidence submitted by Macmillan Cancer Support, May 2022. Available at: <https://committees.parliament.uk/writtenevidence/108596/pdf/>
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28. Acceleration in cutting the 62-day wait, NHS England, Cancer Stakeholder Bulletin 06 April 2022. Available at: <https://cancerstakeholderbulletin.cmail19.com/t/d-e-zhhyuz-jrihdhluhi-z/>
29. Includes advice on exercise, diet, wellbeing support and access to physiotherapists or speech and language therapists. Any support is delivered through a personalised approach at universal, targeted and specialist level. Available at: https://cdn.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/1532-10061/prehabilitation-for-people-with-cancer-tcm9-353994?_ga=2.140867890.1890866557.1680505682-762993215.1590247767
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31. Cancer nursing on the line, Macmillan 2021
32. Strategies to reduce waiting times, Kings Fund 2022. Available at: [Strategies to reduce waiting times 2022.pdf \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/publications/strategies-to-reduce-waiting-times-2022)
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