Which cancer patients in England experience long waits to treatment, and why?

Summary for health leaders and policymakers

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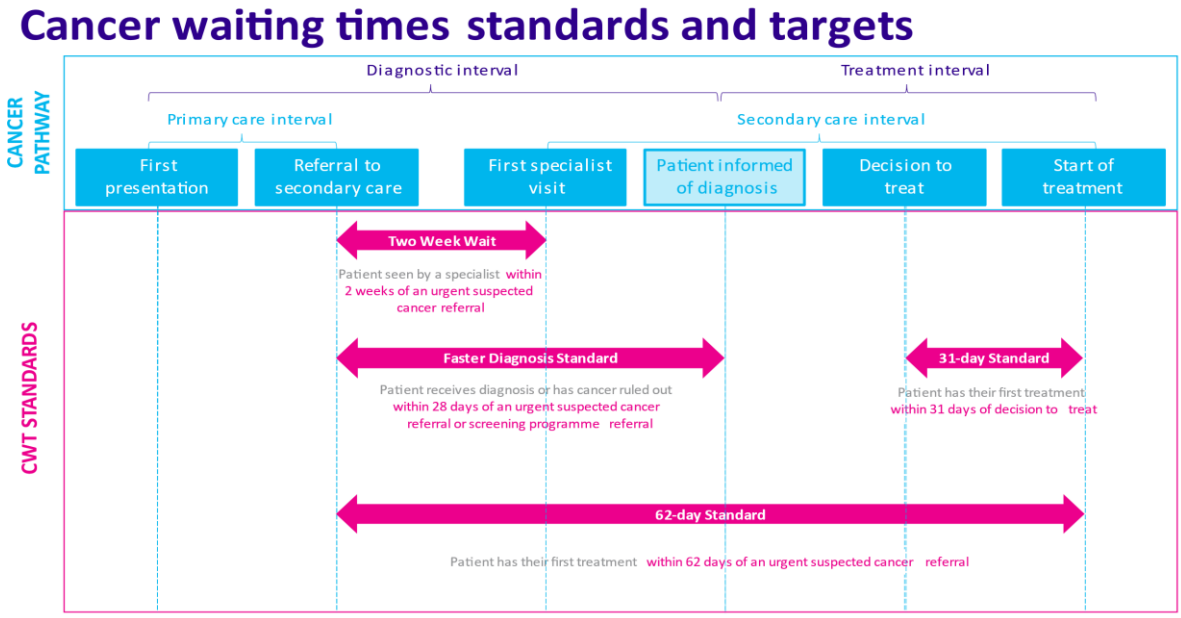
- NHS England has a target that at least 85% of patients should start their first treatment for cancer within 62 days of an urgent GP referral for suspected cancer. However, performance against this target has significantly deteriorated over recent years. In more recent times while we have seen welcome progress against cancer recovery targets and some success in meeting the Faster Diagnosis Standard, performance against the 62-day standard has remained well below the 85% target.
- This innovative research looks beyond regular data on performance against Cancer Waiting Time targets, focusing on the patients facing the very longest waits for treatment and looks to understand the reasons behind those delays.
- The number of patients on this pathway waiting over 104 days – referred to as 'long waiters' – has been increasing in recent years. **The likelihood of being a long waiter in April to September 2022 has increased by more than 3 times since 2017/2018**. Lengthy waits for care can leave patients anxious to get a diagnosis and start treatment, and in some instances, delays of even a few weeks could significantly impact patient outcomes.
- **Despite the best efforts of NHS staff, the figures paint a picture of a health system under strain** with 'provider-initiated delays' the most commonly reported driving factor of delays between referral and starting treatment.
- **The impact of these delays is not being felt equally.** Patients living in the most deprived areas are 33% more likely to wait over 104 days than those in the least deprived areas.
- **While there are challenges across the whole pathway, the greatest service pressures exist in diagnostic services.** There was variation in the average time patients spent at each stage of the referral to treatment pathway by cancer site, but for all cancer sites the average period from referral to patients receiving their diagnosis was longer than that from a decision to treat to the start of treatment.
- **The Government and health service must take action to address the growing trend of patients facing unacceptably long waits for cancer diagnosis and treatment** with targeted investment in workforce and equipment, coupled with service reform. More must also be done to understand why patients in deprived areas are more likely to be waiting longer, and action taken to appropriately resource services reflective of need.
- **There is a huge opportunity for the new UK Government to make this moment a real turning point for cancer, by delivering on their Health Mission commitment to bring cancer waiting times down. But to achieve this, will require bold leadership and political will, and a long-term, fully funded strategy to improve and reform cancer services.** We set out our proposals for cancer research and care in *Longer, better lives*, Cancer Research UK's manifesto and Programme for UK Government.

Background

The number of people being referred in England under an urgent GP referral for suspected cancer has been increasing year on year since the pathway was introduced. Around 2,890,000 people were referred under this pathway in 2022/2023, up from around 1,950,000 in 2017/2018. Anyone referred on this pathway who goes on to have a diagnosis of cancer is measured on the 62-day pathway[1]. NHS England set out a target that at least 85% of patients should start their first treatment for cancer within 62 days of a referral for suspected cancer. However, performance against this target has been deteriorating and it has not been met since December 2015 – and while in 2024 we have seen some other cancer targets met, performance against the 62-day target has remained poor.

Alongside this deterioration in performance, the number and percentage of patients with cancer on this pathway waiting longer than 104 days to start treatment has been increasing, with substantial changes seen during and since the pandemic.

Figure 1: Intervals in the cancer patient diagnostic and treatment pathway, and Cancer Waiting Times standards reported on for England for the time period of the data used in this analysis (the Two Week Wait standard was retired in October 2023 and the 31- and 62-day standards expanded to cover first and subsequent treatments and a wider range of source of referrals respectively)



Patients waiting longer than 104 days is a concern on both an operational and patient outcome level. NHS guidance states that a review should be carried out for every patient who waits longer than 104 days to understand and identify whether delays were

[1] Since October 2023, the 62- day pathway was expanded to also include breast symptomatic referral, urgent cancer screening programme referral or consultant upgrade.

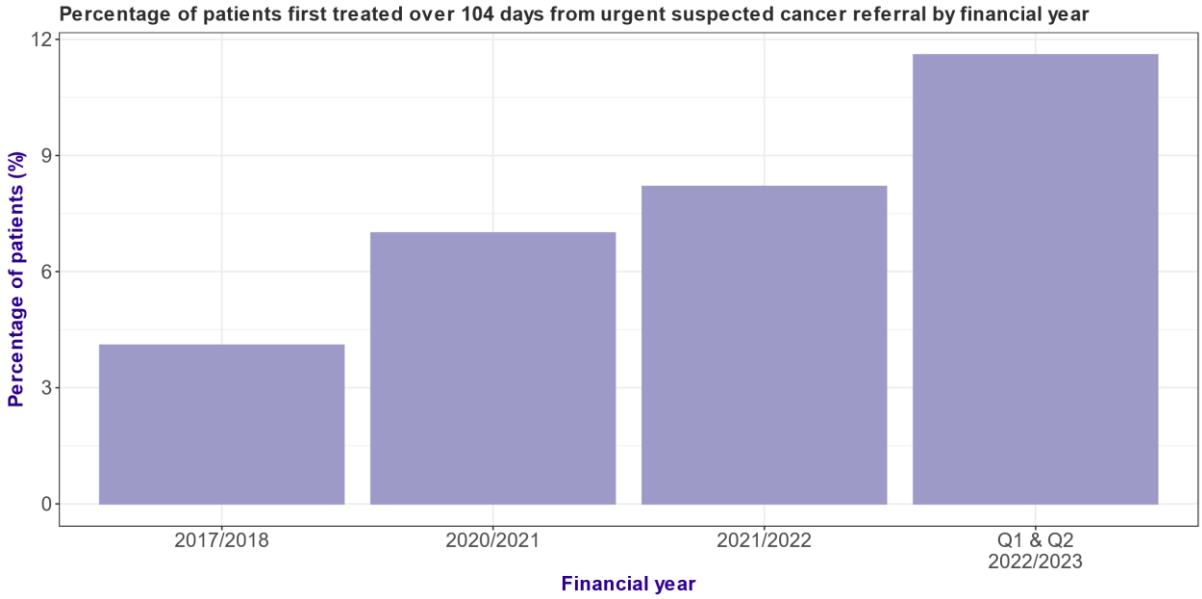
avoidable. While investigating the impact of delays on patient outcomes is complicated, studies have suggested that delays of even a few weeks could significantly impact cancer mortality for some cancer types (Hanna, et al., 2020). In addition, lengthy waits for cancer diagnosis and treatment have implications for patient experience and mental health (Limb, 2023; Brookes & Baker, 2023).

NHS England releases monthly data summarising performance against Cancer Waiting Times (CWT) targets (NHS England, 2024). However, these releases do not provide demographic breakdowns or allow an understanding of why lengthy waits are occurring. This project, carried out by CRUK in partnership with the National Disease Registration Service (NDRS), part of NHS England, has used the detailed CWT dataset (NHS England, 2024) and the Rapid Cancer Registration Dataset (NHS England, 2024) to look at the demographics and other characteristics associated with patients who waited longer than 104 days in 2017/2018, 2020/2021, 2021/2022 and the first two quarters of 2022/2023, and the reported reasons for delay, to inform efforts to reduce the variation in long-waits and decrease their frequency overall, to ensure all patients receive timely treatment.

What does the research tell us?

The likelihood of being a long waiter has increased by more than 3 times since 2017/2018

Figure 2: Graph showing the percentage of patients who received their first treatment for cancer over 104 days from urgent suspected cancer referral, by financial year of start of treatment



- **Over 1 in 10 (12%) of patients who started cancer treatment between April and September 2022 (the most recent data available at the time of analysis) had waited over 104 days from urgent suspected cancer referral to treatment**. The more recent, publicly available monthly CWT statistics show that the percentage of patients waiting over 104 days remained at this high level in 2023, with 13% of patients waiting over 104

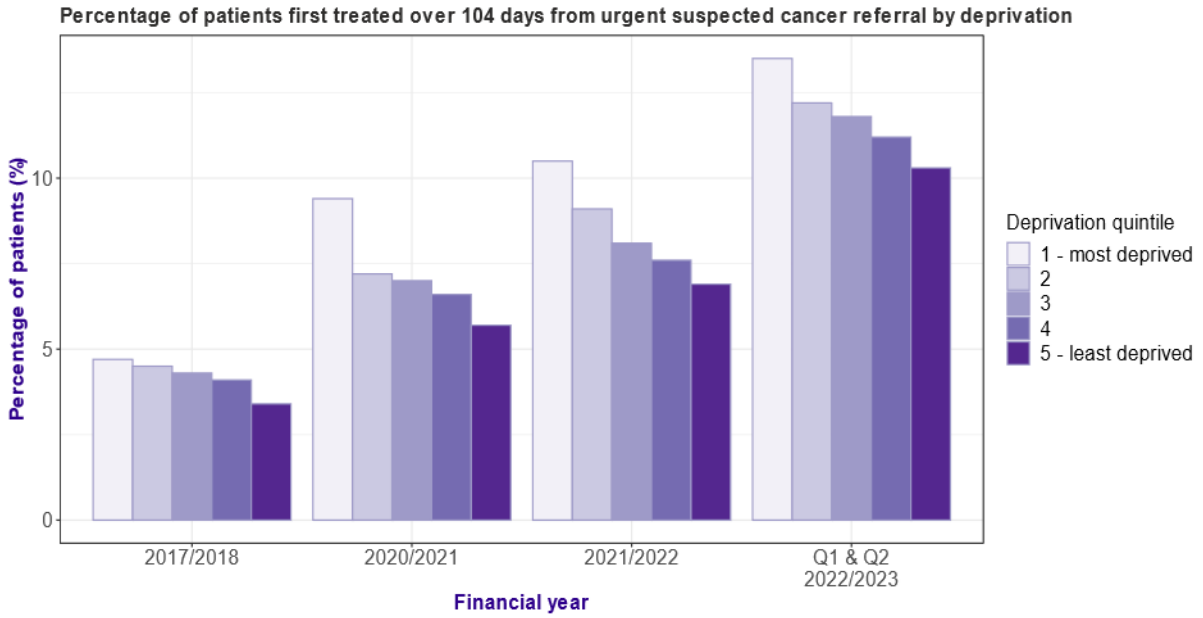
days from January to December 2023. There have been some decreases in the most recent months, with 11% of patients waiting over 104 days in May 2024.

- Patients starting treatment between April and September 2022/2023 were **over 3 times more likely to wait over 104 days** compared to those in 2017/2018, when the analysis was adjusted for cancer type, gender, age, deprivation and trust of decision to treat. This indicates that the increase in the percentage of patients waiting over 104 days seen in monthly CWT statistics likely cannot be solely explained by potential changing patient characteristics.

Patients living in the most deprived areas were more likely to wait over 104 days for treatment

- **Patients living in areas in the most deprived quintile had the highest percentage waiting over 104 days for treatment and were 33% more likely to wait over 104 days compared to those in the least deprived quintile, when gender, age, cancer site, financial year and trust of decision to treat were controlled for**. The association between deprivation and waiting over 104 days was present for most cancer types, including breast, lung, colon, rectal, melanoma skin, non-melanoma skin and prostate cancer.

Figure 3: Graph showing the percentage of patients who received their first treatment for cancer over 104 days from urgent suspected cancer referral, by financial year of start of treatment and deprivation quintile



The likelihood of being a long waiter varies significantly by cancer type

- There was substantial variation in the likelihood of waiting over 104 days by cancer site. Patients starting treatment for breast or skin cancer were the least likely to have waited over 104 days, while those starting treatment for lower gastrointestinal or urological cancer were the most likely. This highlights areas for investigation to identify

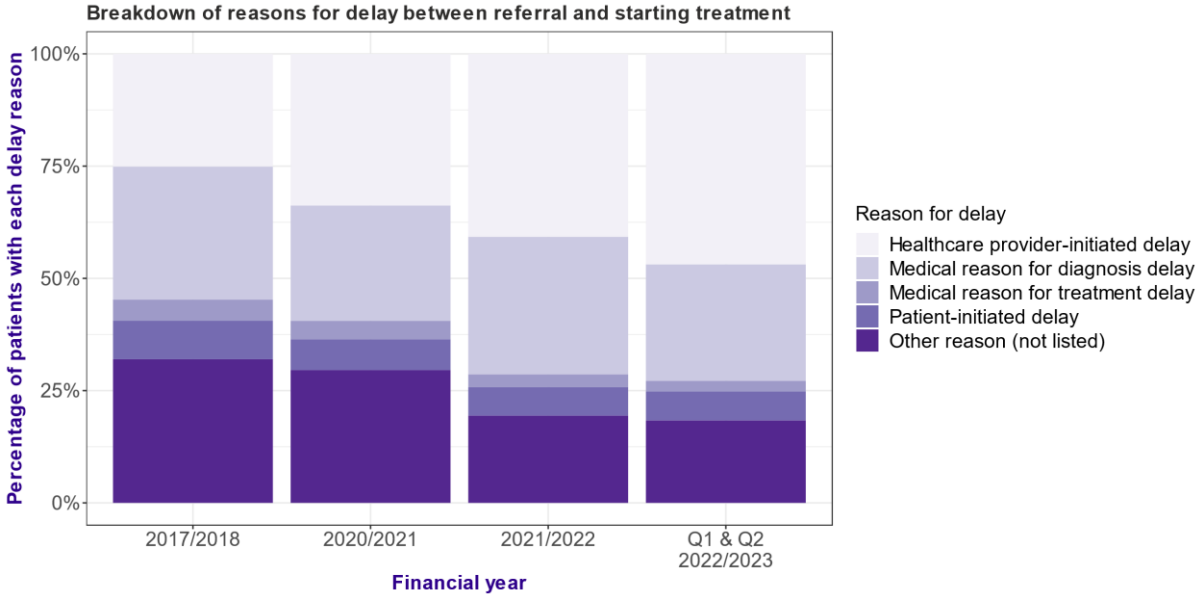
why certain site pathways are performing better than others, and whether other pathways could be improved to this level.

- There was also variation by specific site within overall site groupings.
- There was also variation in the association between patient characteristics and likelihood of being a long waiter by site. For example, there was no significant variation in likelihood of being a long waiter by age group for patients with breast cancer, while younger and older patients were less likely to be long waiters compared to those aged 60-69 for a number of sites including kidney, liver and prostate. There were also a large number of sites where likelihood of being a long waiter increased with increasing age group such as colon, melanoma skin and rectal but patients with in situ breast or pancreatic cancer had lower likelihood of being a long waiter with increasing age.

The most common reason for delay between referral and treatment was healthcare provider-initiated delay

- The CWT dataset includes information about what was judged to be the main 'reason for delay' where a patient did not meet the 62-day referral to treatment standard.
- The most common classification of reason for delay in April to September 2022/2023 was 'healthcare provider-initiated delay'. This delay classification was largely made up of the reasons 'elective capacity inadequate', 'outpatient capacity inadequate' and 'healthcare provider-initiated delay to diagnostic or treatment planning'.

Figure 4: Graphs showing the reasons for delay, among those waiting over 104 days, between referral and starting treatment



- There was variation in the most common reason for delay by site, with healthcare provider-initiated delay being the most common reason for urological and skin cancer, but medical reason for diagnosis delay being the most common reason for those with breast, haematological and lung cancers. Gynaecological, head and neck,

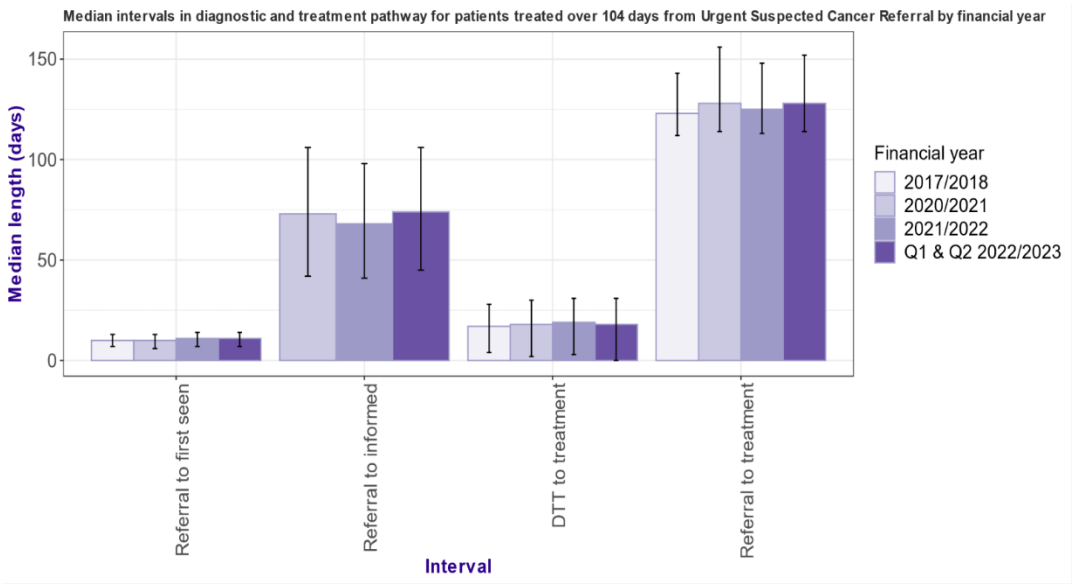
lower gastrointestinal, sarcoma and upper gastrointestinal had similar percentages for healthcare provider-initiated delay and medical reason for diagnosis delay.

- **A higher percentage of long waiters met the 31-day decision to treat to treatment standard compared to the 28-day referral to diagnosis standard (the "Faster Diagnosis Standard (FDS)")**
- In April to September 2022/2023, the percentage of patients waiting over 104 days to start treatment who met the FDS of 28 days from referral to being informed of diagnosis was around 12%, while the percentage who met the standard of 31 days between decision to treat (DTT) and starting treatment was around 76%.
- This indicates that the majority of patients waiting over 104 days are meeting the 31-day target and so suggests that the greatest delays are usually occurring prior to a DTT. However, the percentage meeting the 31-day standard for those waiting over 104 days is still far below the target of 96% and the overall performance of 92% in the same time period so treatment is still an important target for reducing long waits.
- There was variation in performance against these targets by specific site, although the highest percentage meeting the 28-day FDS was 32% for oesophageal cancer and the lowest percentage meeting the 31-day standard was 50% for kidney cancer.
- This aligns with the data from the monthly CWT releases, where performance against the 28-day standard (~76% for Urgent Suspected Cancer Referrals in May 2024) is lower than against the 31-day standard (~92% for first treatment in May 2024).

Delays in securing a full diagnosis were the main driver of long waits

- Among those waiting over 104 days, **the average time from urgent suspected cancer referral to a patient being informed of diagnosis was 74 days**. In contrast, the average time from decision to treat (DTT) to the patient starting treatment was much shorter at 18 days. There was also an average of around 32 days from a patient being informed of diagnosis to the date of DTT. The time from DTT to treatment was around 1/7th of the total time from referral to treatment for patients who waited over 104 days.
- There was variation in the average time patients spent at each stage of the referral to treatment pathway by site, but the average time from referral to informed of diagnosis was longer than from DTT to treatment for all sites.

Figure 5: Graph of the median (interquartile range) intervals in the diagnostic and treatment pathways among patients waiting over 104 days to treatment, by financial year of start of treatment



How can we address the issues this research shows?

The significant challenges that the NHS in England has experienced in achieving Cancer Waiting Time (CWTs) standards, despite the efforts of dedicated staff across the health system and a large degree of focus from NHS England, are well known. The standard for 85% of patients to begin treatment within 62 days from an urgent cancer referral has not been achieved nationally since 2015, and recent years have been among the worst on record.

However, this research offers an important and much more granular lens on those patients who are facing the very longest waits for cancer care, with thousands of cancer patients waiting over 104 days to start cancer treatment and the likelihood of being a long waiter having increased by more than 3 times since 2017.

Government investment in key staff and infrastructure, coupled with reform to services, is needed to address long waits

The significant increase in 'healthcare provider-initiated delays' reflects a health system creaking at the seams, due to rising cancer incidence and insufficient investment in growing capacity to meet this rising demand and deliver timely care over many years. The finding that the longest median waits are experienced while waiting for diagnostic tests and results indicates that the bottleneck in the system remains within diagnostic services – exacerbating an already anxious time for patients as they await tests that may show they have cancer. But in addressing the most pressing issues, government and NHS

England must take care not to simply move the bottleneck– but rather make strategic investment in capacity across the cancer pathway.

While there has been some welcome action in recent years to try and address capacity constraints – notably with investment in diagnostic and workforce capacity through Community Diagnostic Centres and the publication of the NHS Long Term Workforce Plan – this research adds yet more evidence to persistent long diagnostic waiting lists and challenges in many diagnostic pathways that action to date has not gone far enough. Further targeted investment in the areas we know will make a difference – in the cancer workforce, key equipment and facilities – is vital.

Addressing inequalities must be a priority

That long waits are not being felt equally across areas of different socio-economic status risks further compounding the stark inequalities in cancer incidence and outcomes which have resulted in the most deprived communities far too often bearing the greatest burden of the devastating impact of cancer.

As the percentage of long waiters is not felt equally across the country and between different cancer types, it is vital that that investment, resource and focus reflect varying need in the most deprived areas and for the cancer types that see the greatest number of long waiters.

There has been welcome progress through the targeted intervention NHS England has made in the NHS trusts that have faced the greatest challenges against CWT standards, through the 'tiering' model. Looking forward, it is important that any gains made on improving performance are consolidated and built upon through sustainable improvements to service and system capacity, and a wider focus on population health measures that will ensure greater sustainability in the longer term.

For example, Integrated Care Systems (ICSs) should be supported to accelerate locally tailored approaches to reducing inequalities. Ensuring that services have good access to data underpins much of this work, with more research to improve our understanding of what cancer inequalities exist and how we can address them.

Beating cancer means beating cancer for everyone

While this research offers a fresh insight on patients facing the longest waits for cancer care, many of the driving factors are not new. In *Longer, better lives*, Cancer Research UK's manifesto for cancer research and care, we explore many of the same issues, and make our recommendation in greater detail on how they can be addressed.

CWTs are important not just because they are a description of 'what good looks like'. They represent minimum expectations that people should have for their cancer care in the health service. They also provide a vital indicator of the health of cancer services – which this report suggests are under intense strain.

The new UK Government's manifesto commitment to meeting all NHS waiting time standards, including for cancer, by the end of the Parliament is welcome. With these commitments comes a real opportunity for the new Government to make this moment a real turning point for cancer. But to drive the scale of improvements and reforms needed in cancer services to achieve this commitment over the next 5 years will require a robust, ambitious and long term dedicated cancer strategy. Cancer Research UK has significant expertise in national cancer planning and stands ready to support the UK Government to develop and deliver a new national cancer strategy.

This analysis highlights the importance of data for health service research

The detail in this analysis reveals important associations and suggests where patients are spending the most time in the pathway and potential reasons for delay. This illustrates the importance and utility of rich data for starting to understand the reasons that patients may be waiting over 104 days.

The increased granularity of the data used for this project allowed further breakdowns of the broad site groupings used for the monthly CWT releases. This indicated that there was also variation in the likelihood of waiting over 104 days within these broad sites.

However, this analysis is at a high level and more research would be needed to confirm and further interrogate these findings. Particularly useful avenues might be corroborating analysis of reasons for delay and pathway intervals using other data sources and further investigation of the time spent between a patient being informed of diagnosis and getting a decision to treat.

About Cancer Research UK

We're the world's leading cancer charity, dedicated to saving and improving lives through research. We fund research into the prevention, detection and treatment of more than 200 types of cancer through the work of over 4,000 scientists, doctors and nurses. In the last 50 years, we've helped double cancer survival in the UK and our research has played a role in more than half of the world's essential cancer drugs. Our vision is a world where everybody lives longer, better lives, free from the fear of cancer.

The research paper this briefing is based on is: *Cancer Research UK – National Disease Registration Service partnership. Which cancer patients experience long waits to treatment, and why? Analysis of patients waiting over 104 days from urgent suspected cancer referral to first cancer treatment in England, for 2017/2018, 2020/2021, 2021/2022 and 2022/2023. Published July 2024.*

You can find the full research paper published here.
cancerresearchuk.org/sites/default/files/long_waiters_report_24

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