

Working together with the NENC Healthwatch Network

Listening, Learning, and Supporting Change

Personalised Cancer Care in Tees Valley



Navigating Change Together:

Supporting Better Health and Care for All

We are living through a period of significant transformation across the health and care system. From the way services are commissioned and delivered, to how care is accessed and experienced, change is happening at every level.

A key part of this shift is the growing emphasis on neighbourhood health, bringing care closer to where people live, and tailoring support to the needs of local communities.*

At Healthwatch Stockton-on-Tees, we recognise the dedication of those working tirelessly across the system to make these changes a reality. We also recognise our unique role as a bridge between people and decisionmakers, ensuring that the voices of local people are not only heard, but acted upon.

The insights we share in this report come directly from people with lived experience. They are meaningful contributions, shared with the hope of making things better for others. By working alongside our partners, we aim to help shape services that are fair, accessible, and truly centred around the needs of the people they serve.

*This approach aligns with the NHS Long Term Plan's commitment to integrated, community-based care.



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Navigating Change Together: Supporting Better Health and Care for All

Cancer Care Pathways Across Tees Valley

South Tees Hospitals NHS Foundation Trust

- Specialist centre for diagnostics, radiotherapy, chemotherapy, and surgery.
- Supported by Trinity Holistic Centre offering emotional and psychological support.

North Tees (North Tees & Hartlepool NHS Trust)

- Cancer pathway navigators support patients from referral through diagnosis.
- Holistic Needs Assessments and community support available.

Support Services

- Macmillan Cancer Support
 - South Tees: Offers hardship-related grants and financial support.
 Macmillan also provides information leaflets and volunteer-led support at their stall in the main entrance of James Cook Hospital, offering a valuable point of contact for patients and families.
 - North Tees: Does not currently receive funding for Macmillan hardship grants, a concern raised by Healthwatch.

Concerns Raised by Healthwatch

- Difficulty accessing GP appointments; symptoms not always recognised.
- Referral delays prior to Fast Track.
- Patients discharged quickly with limited emotional or practical support.
- Unequal access to financial support across regions.

How We Gathered Insight:

Our Approach

This report is based on qualitative engagement with 71 individuals who have accessed cancer services across Tees Valley.

Rather than using a structured survey, we invited people to share their experiences in their own words and on their own terms.

We gathered insight through:

- Case studies
- Focus groups
- Attendance at existing community groups
- Staff meetings

This approach allowed us to capture a wide range of lived experiences, including emotional, practical, and systemic challenges. While we did not collect full demographic breakdowns for every participant, the group included a mix of ages and genders and reflected diverse points along the cancer care pathway.

All feedback has been anonymised and shared with system partners to support service improvement. Trusts have responded to the recommendations relevant to their services.



71 individuals

Lived Experience: Patient Case Studies

Case Study 1: Breast Cancer

One woman shared her experience of attending a routine breast screening appointment, something she nearly skipped. She had no symptoms and was shocked to learn she had an aggressive lump. Thanks to the fast-track system, she was diagnosed quickly and underwent surgery within five weeks, followed by radiotherapy the next month.

While she praised the speed and professionalism of the staff, the pace of everything left her feeling overwhelmed and traumatised. The radiotherapy brought side effects she hadn't anticipated, and she found herself struggling emotionally. Although funding was available for trauma counselling through Butterwick Hospice, she was told she couldn't begin until her treatment ended. Access to this service typically requires a referral, often initiated by a healthcare professional or support worker."

Now discharged back to her GP, she finds it nearly impossible to get an appointment. Reception staff often tell her to come back another day or go to Urgent Care. She's on a waiting list for counselling, but no priority is given despite her ongoing distress. She's trying to rebuild her life, but the aftershock, loss of confidence, and lack of support make it incredibly difficult.

Case Study 2: Lung Cancer with Dental Impact

Another woman described how her symptoms began with a stiff neck and head. She repeatedly tried to get a face-to-face GP appointment but was turned away each time. Eventually, she insisted and was referred to a head and neck specialist. Within two weeks, she was diagnosed with lung cancer and told she would need intensive chemotherapy and radiotherapy.

She lives in Yarm and had to travel to Hartlepool for treatment. As she doesn't drive, she relied on hospital transport, which she was grateful for. The staff treated her with dignity and empathy, and the fast-track system worked well once she was in the specialist's care.

However, the intensity of the radiotherapy caused her teeth to rot. She had to have them all removed. Free dentures were painful and made eating difficult, so she took out equity release on her home to pay £20,000 for implants, and is now preparing to pay another £20,000 for the lower set.

She's now two years in remission but still struggling to come to terms with how cancer has affected every part of her life. Aftercare has been poor, and GP access remains a challenge. She credits Butterwick Hospice with helping her through the darkest times.

Lived Experience: Patient Case Studies

Case Study 3: Lung Cancer with Eye Complication

A third woman shared how she was diagnosed with lung cancer and began treatment quickly through the fast-track system. During treatment, she noticed something wrong with her eye and was referred to James Cook Hospital, then Friarage Hospital. She doesn't drive and had to rely on friends for transport, which was frustrating and exhausting.

At Friarage Hospital, she was told there was nothing to worry about. But her symptoms worsened, and she pushed for another referral. This time, she was sent to Sunderland, where she was told she had a hole in her retina, one that had grown significantly since her earlier appointments. Sunderland Eye Infirmary is one of the UK's leading providers of eye health services and the only dedicated Eye A&E in North East England.

She was devastated to learn that the issue hadn't been treated earlier because she was undergoing cancer treatment. She believes that if it had been addressed sooner, she wouldn't still be experiencing problems. Although her eye is improving slightly, she still has a long way to go.

Butterwick Hospice has been her lifeline. They followed up on her behalf, made calls, and kept her on track. She feels she's lost a lot of independence and confidence. Constant exhaustion limits her social life, and the only interaction she has now is through the support group at Butterwick.



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Key Themes from Engagement

Through this wider engagement, several consistent themes emerged. These reflect both the strengths and challenges within the current cancer care landscape, and highlight areas where improvements could make a real difference to people's experiences.

The following key themes were identified:



Variation in staffing levels across sites within the same NHS Trust, leading to concerns about equity of access.

2.

Loss of fast-track counselling services in some areas, resulting in long waits for mental health support.

3.

Uncertainty around fixed-term staffing contracts, potentially affecting staff retention and service continuity.

4.

Lack of access to hardship funds in some areas, increasing the burden on staff to find alternative support for patients.

5.

Rising demand for fast-track cancer support, highlighting the need for additional staffing and resources.

6.

Inconsistent access to support services based on location, including differences in availability of charity and community-based support.

7.)

Restrictions on cross-boundary access to communitybased support services, limiting patient choice and continuity.

Collaborative Action & System Response

Healthwatch Stockton-on-Tees is pleased to note that the Integrated Care Board (ICB) has responded positively to the findings in this report. The ICB has confirmed that Healthwatch's insights are being used to inform strategic commissioning plans and provider discussions, demonstrating the real-world impact of patient voice in shaping future cancer care.

Examples of Positive Change

Recent initiatives include:

- A targeted cervical screening programme led by the Cancer Care Facilitator, aimed at increasing uptake through personalised conversations.
- Implementation of the ACCEND framework to support cancer workforce development, retention, and standardised care competencies.

Mental Health and Psychosocial Support

The ICB's 'Improving Mental Wellbeing in Cancer' project is helping to build integrated networks across Tees Valley, with the new Stockton Wellbeing Hub offering additional support. These developments reflect a growing recognition of the emotional and psychological needs of cancer patients.

Improving Co-ordination and Equity

A Local Clinical Interface Group has been established to improve coordination between hospitals and primary care. The University Hospital of Tees model is also helping to standardise care across the region, addressing concerns about variation in access and experience.

Ongoing Engagement

We welcome the ICB's commitment to ongoing collaboration and encourage all system partners to continue listening, learning, and acting on the voices of those affected by cancer.

ICB Response Summary: Working Together to Improve Personalised Cancer Care

The North East and North Cumbria Integrated Care Board (ICB) has welcomed the Healthwatch Stockton-on-Tees report, recognising its value in shaping future service delivery. The ICB acknowledges both the positive feedback and the challenges raised, and confirms that the insights will inform strategic commissioning plans and discussions with providers and social care partners.

Key areas of impact and collaboration include:

- Primary Care Networks (PCNs) across Stockton-on-Tees have made strong progress in employing additional roles such as Cancer Care Coordinators and Social Prescribers, supporting personalised care and early diagnosis.
- The ICB has appointed a Cancer Care Facilitator and Community
 Development Worker to raise awareness and improve services, including targeted screening programmes.
- The ACCEND framework is being implemented to support workforce development, retention, and standardised cancer care competencies.
- Mental health support is being strengthened through the 'Improving Mental Wellbeing in Cancer' initiative and the opening of the Stockton Wellbeing Hub.
- A Local Clinical Interface Group is improving coordination between hospitals, with examples including enhanced discharge information for prostate cancer patients.
- The ICB is committed to addressing access inequalities, including travel support schemes and enhanced GP access through evening and weekend appointments.
- National initiatives such as Jess's Rule are being promoted to improve diagnostic accuracy and responsiveness.

The ICB emphasises its ongoing commitment to working with Healthwatch and system partners to ensure patient voices continue to shape equitable, responsive, and person-centred cancer care across Tees Valley.

The full response from the ICB can be found here: <u>NENC ICB response to HWS Personalised Cancer Care in Tees Valley Report.</u>

University Hospital Tees Response

Lead Cancer Nurses, University Hospital Tees



The Lead Cancer nurses for University Hospitals Tees thank Healthwatch Stockton-on-Tees for providing the opportunity to comment on their recent Cancer Care report.

As a group we acknowledge that there are some gaps in services and challenges across the Tees Valley. Considering the key themes identified within the report, they are also reflected in our own National Cancer and Patient Experience survey results and the actions proposed are already being incorporated into our current work streams.

As a newly developing hospital group we recognise that many of our challenges in relation to providing personalised cancer care are the same and we are committed to working collaboratively to ensure equity across the Tees Valley.

The arrival of Maggies on the James Cook University
Hospital site will enhance the support offered to patients.



National Picture

Across England, there are growing concerns about how personalised cancer care is delivered. While many areas are doing great work, there are some key challenges being reported nationally that reflect what we've heard locally:

- Uneven support across areas, some patients have better access to services than others, even within the same Trust.
- Mental health and emotional support, reduced funding has led to longer waits for counselling.
- Staffing pressures, shortages and contract uncertainty make it harder to retain experienced staff.
- Less focus on personalised care, national changes have reduced funding and dedicated teams.
- National surveys show only half of NHS staff feel personalised care is delivered consistently.

Recommendations

- Investigate differences in staffing, funding, and access to ensure fair service delivery.
- Review service boundaries across Tees Valley to improve consistency in access.
- Provide clear communication around staffing contracts to support retention.
- Explore alternative mental health support options to reduce waiting times.
- Ensure equitable access to financial support for patients across all areas.
- Plan for increased demand by reviewing workforce capacity.
- Improve continuity of care post-discharge.
- Strengthen coordination between hospitals to avoid delays in secondary issues.
- Explore options to improve access to community and hospital transport, particularly for patients undergoing intensive treatment or living in rural areas.

Our Role and Next Steps

This report will be shared with key partners, including the Integrated Care Board (ICB) and the Local Authority, to inform ongoing discussions around personalised cancer care and service equity across the region.

Healthwatch Stockton-on-Tees will continue to:

- Listen to local people and share their views with those making decisions.
- Support system partners by providing insight and feedback.
- Monitor changes and highlight what's working—and what needs attention.

We're proud to be part of this journey, and we're grateful to everyone who shared their experiences with us. Your voice matters, and together, we can help shape a health and care system that works for everyone.

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Concerned about Cancer Symptoms?

Here's what you can do.

If you notice something unusual, like a lump, bleeding, pain, weight loss, or a cough that won't go away, don't ignore it. These symptoms don't always mean cancer, but it's important to get checked early.

You can find clear advice at:

https://www.nhs.uk/conditions/cancer/

Need a GP Appointment Outside Normal Hours?

Evening and weekend appointments are available for anyone registered with a GP in Stockton-on-Tees. These are part of the Enhanced Access Service, run by Hartlepool & Stockton Health. Visit their website here: <u>Hartlepool & Stockton Health</u>.

Appointment Times:

Weekdays: 6.30pm – 9.00pmWeekends: 9.00am – 5.00pm

To book:

- Call your GP practice during normal hours
- Or call NHS 111 after 6pm they'll help you find the right appointment

Need Help Navigating Services?

Healthwatch Stockton-on-Tees can help you understand your options, raise concerns, or find support.

Call: 0300 180 0660

Email: info@healthwatchstocktonontees.co.uk

Web: healthwatchstocktonontees.co.uk

You're not alone. We're here to help you get the care you need.

Further Support and Information

Butterwick Hospice Counselling Services

Butterwick Hospice offers emotional and psychological support as part of its holistic care approach. Their Family Support Service provides:

- One-to-one counselling
- Bereavement support
- Group sessions

These services are available to individuals, carers, and family members at both Stockton and Bishop Auckland sites.

Bishop Auckland

Call: 01388 603003

Email: <u>butterwickhosp.butterwickbishopauckland@nhs.net</u>

Address: Woodhouse Lane, Bishop Auckland, DL14 6JU

Web: Butterwick Counselling Services

Stockton-on-Tees

Call: 01642 607742

Email: info@butterwick.org.uk

Address: Butterwick Hospice, Middlefield Road, Stockton on Tees, TS19 8XN

Web: Butterwick Counselling Services

Macmillan Information and Support

James Cook University Hospital

The Macmillan Information Centre at James Cook provides a drop-in service offering:

- Emotional support and a listening ear
- Advice on benefits and financial support
- Signposting to local and national services
- Literature in multiple formats and languages

Further Support and Information

Macmillan Information and Support

James Cook University Hospital

The centre is staffed by healthcare professionals and trained volunteers. No appointment is needed.

Call: 01642 835674

Email: stees.macmillaninfocentre@nhs.net

Address: North Entrance, James Cook University Hospital, Marton Road,

Middlesbrough, TS4 3BW

Web: Macmillan Information Centre

University Hospital North Tees

Call: 01642 383041

Email: <u>nth-tr.cancerinformationcentre@nhs.net</u>

Address: University Hospital of North Tees, Hardwick, Stockton on Tees, TS19 8PE

Web: Macmillan Information Centre

University Hospital of Hartlepool

Call: 01642 383041

Email: <u>nth-tr.cancerinformationcentre@nhs.net</u>

Address: University Hospital of Hartlepool, Holdforth Road, Hartlepool, TS24 9AH

Web: Macmillan Information Centre

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