PROJECT CLOSURE REPORT: HealtheIntent Population Health Management tool for cancer patients in primary care

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Date: First published June 2025

Version: Version 1.0

1. Executive Summary

Executive Summary

This project sought to develop and implement a population health management (PHM) tool to improve the quality and consistency of care for people living with and beyond cancer in North Central London (NCL). With the NCL ICB digital provider, Cerner, the NCL Cancer Alliance provided the clinical leadership to design a cancer care registry—intended as a primary care-facing resource to support personalised, proactive cancer care.

The work began in 2019 and involved extensive clinical and wider stakeholder engagement, culminating in the agreement of quality metrics aligned to national cancer care standards and electronic health record data. The registry was soft launched in February 2023, alongside bespoke implementation support and communication package tailored for general practice teams.

This registry represented, to our knowledge, the first cancer-specific registry of its kind in the NHS. A robust service evaluation was designed to assess uptake, quality improvement activity, coding changes, and early impacts on care quality and equity. However, before the evaluation could begin, the registry was planned for decommissioning due to wider system-level changes in digital infrastructure. The cancer care registry alongside the other Cerner population health tools would be terminated as of September 2025.

The registry project generated significant learning around stakeholder engagement, co-development, governance, and evaluation planning. This report shares that learning, along with the original evaluation protocol, to inform similar initiatives nationally. The work can contribute to academic and policy communities, in understanding how digital population health tools can support better cancer outcomes in primary care.

Intended Audience

This report is intended for a range of stakeholders are involved in the development, procurement, implementation, and evaluation of digital tools to support personalised cancer care. The primary audiences include:

- **North Central London Integrated Care Board (NCL ICB)**
- **NCL ICB Digital team**
- **The National Cancer Team (NHS England)**
- **Academics and researchers** – who may wish to build on this work to strengthen the evidence base around PHM tools and quality improvement in oncology.
- **Digital providers of PHM tools – to inform future design, governance, and implementation processes.**

This report is also shared in the public domain (NCLCA website) to support transparency and learning for other systems considering similar approaches.

2. Background and Rationale

Living with and beyond cancer—now more commonly referred to as personalised cancer care—has historically been a challenging area for implementing sustainable quality improvement in the NHS. While many people now live more than 10 years beyond a cancer diagnosis, not everyone experiences a good quality of life post-treatment. Outcomes vary significantly by tumour type, and many people face long-term physical, emotional, and social consequences of cancer and its treatment.

Research published by Macmillan in October 2019[i] found that 68% of people recently diagnosed with or treated for cancer in the UK did not feel they were receiving all the support they needed. This figure rose to 77% among those with treatable but not curable cancer—highlighting a substantial unmet need across this population.

NHS England (NHSE) has made a national commitment to deliver personalised cancer care interventions to all individuals diagnosed with cancer. Acute trusts are expected to report on delivery of these interventions through their Cancer Alliances. In primary care, general practitioners were required to record Cancer Care Reviews as part of the Quality and

Outcomes Framework (QoF) until the GP contract of 25/26[ii] (which retired this requirement). Another key element of personalised care—**Stratified Follow-Up (SFU)**[iii]—has been prioritised in national policy[iv], including the NHS Long Term Plan (of 2019)[v] and previous annual NHS Operational Planning and Contracting Guidance.[vi]

Despite these policy drivers and quality initiatives, there remains a lack of consistent engagement, limited data on implementation, and insufficient monitoring of the **quality of care** and **quality of life** for people living with cancer in the community.

At a local level in North Central London (NCL), cancer prevalence recorded in 2023/24 was 50,000 within a total population of approximately 1.8 million[vii]—meaning people living with cancer represent around 3.6% of the total population. This number has been growing and will continue to rise, with estimates suggesting that 1 in 2 people will develop cancer at some point in their lifetime. This represents a substantial and growing cohort, characterised by complex needs and inequalities in care provision.

Given this context, a population health management registry would offer a promising approach to better understand variations in care and outcomes, identify unmet needs, and monitor the quality-of-care delivery.

3. Objectives

This project set out to develop and implement a high-quality cancer care registry capable of supporting meaningful, direct patient care across the North Central London system. The registry aimed to capture key datasets aligned with recognised quality standards in personalised cancer care.

An essential objective was to design a bespoke communication, engagement, and support package to facilitate registry implementation. This was developed to complement broader implementation materials produced by Cerner, ensuring local relevance and utility for end-users.

The project also aimed to identify how the Cancer Alliance could best support primary care users to optimise the tool for both individual patient care and broader population health benefit. This included identifying gaps in provision, enabling proactive care, improving data quality, and addressing inequalities.

Implementation models were explored, including a phased approach starting with a single borough or federation, with the potential to scale across all five boroughs should wider engagement be achieved.

A commitment to iterative learning and system-wide collaboration underpinned the project.

The development of a robust, multi-faceted evaluation plan was also a core objective, ensuring that both implementation processes and outcome measures were evaluated.

Finally, the project was designed with a forward-looking strategic vision: if successful, the registry could inform wider adoption across NHSE, supporting national ambitions for improved and equitable cancer care through population health management approaches.

4. Project Description

Between 2019 and 2023, the North Central London Cancer Alliance (NCLCA) worked in partnership with Cerner to define and develop a population health registry focused on people diagnosed with cancer. The aim was to co-design a tool that could support the delivery of high-quality, proactive cancer care, particularly within primary care settings. Clinical leadership and strategic input from the Alliance and system partners informed each stage of the tool's design and development.

The registry was developed to support **direct patient care only**, in line with the information governance arrangements in place at the time. This meant that registry data could not be used for secondary purposes such as research, commissioning, or analytics outside the boundaries of care provision.

As a non-provider organisation, the Cancer Alliance played a strategic role in supporting provider partners to adopt and optimise the tool. This included developing implementation resources, offering guidance, and aligning the tool's use with wider objectives for personalised cancer care and quality improvement.

To build momentum, the Alliance had planned to identify **early adopters** through a targeted engagement process with interested GP federations and trusts across NCL. Proposals were expected to be brought to the Alliance's Personalised Cancer Care (PCC) Delivery Group for input and coordination. A key focus of the Alliance's work was to support use of the registry within existing information governance (IG) frameworks, and to help system partners navigate these requirements.

At the time, the governance around population health intelligence activities—such as segmentation, risk stratification, and population needs assessment—was still evolving. The ICB had not yet established a formal IG oversight group, and previous dashboards had been implemented under COVID-19 emergency provisions. This project therefore presented an opportunity to recommend that such structures be developed to support broader, case-by-case discussion around data use.

Funded by the local Sustainability and Transformation Partnership (STP) - now called ICBs, the registry was intended as a long-term tool. The project created a unique opportunity to assess its implementation and impact through a planned evaluation framework that included both process and outcome measures.

As one of the first cancer care specific population health registries of its kind in the NHS, the project also carried **strategic relevance**. If successful, the model had the potential to inform similar developments across other Integrated Care Systems (ICSs), supporting a more standardised and data-driven approach to improving cancer care nationally.

The Stakeholder map is in the Supplementary documents, Item 1.

5. Development Process

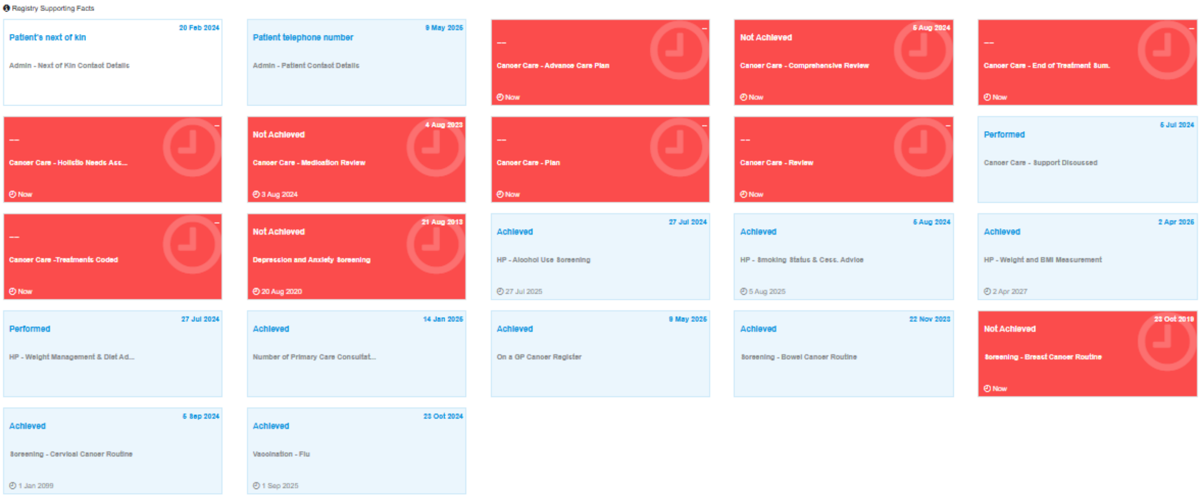
The development of the cancer care population health registry was a multi-year, collaborative effort between the North Central London Cancer Alliance (NCLCA) and Cerner, supported by local clinical and digital leadership. The initial concept was established in 2019, with the aim of creating a registry that could enable primary care teams to identify and address gaps in the quality of care for people living with and beyond cancer.

A key milestone in the development process was the stakeholder workshop held in September 2020. This session brought together a range of clinicians and system leaders to define and agree on a set of quality indicators for cancer care. These metrics were based on structured data already captured within the electronic health record system (EHRS) and were aligned with existing national and local cancer care priorities. The indicators aimed to reflect meaningful standards for personalised cancer care and were designed to be measurable and actionable within clinical workflows.

Following this, a phased development process took place between 2020 and 2022. There was a large pause in 2020-2021 due to the COVID-19 pandemic. Once the landscape had settled, work on the registry was re-commenced. This included multiple rounds of registry build, testing, validation, and refinement. Clinical engagement was sustained throughout to ensure that the registry was not only technically sound but also relevant and practical for frontline use. Throughout this period, the registry evolved from a conceptual prototype into a fully functioning tool that could be embedded into routine care pathways.

By early 2023, the registry was technically complete and ready for wider implementation across North Central London. Communication and engagement materials were developed by the Alliance to support rollout in primary care[viii] (see Supplementary item 2). These resources were designed to complement Cerner's more general training materials and included locally tailored guidance to ensure that practices could understand the tool's purpose, use it effectively, and link it to ongoing quality improvement initiatives.

Image 1: HEI Cancer care registry tile view – all quality indicators (QI) on one screen. (Red= QI not met)



Registry Supporting Facts

20 Feb 2024
Patient's next of kin
Admin - Next of Kin Contact Details

9 May 2025
Patient telephone number
Admin - Patient Contact Details

--
Canoer Care - Advance Care Plan
Now

5 Aug 2024
Not Achieved
Canoer Care - Comprehensive Review
Now

--
Canoer Care - End of Treatment Sum.
Now

--
Canoer Care - Holistic Needs Ass...
Now

4 Aug 2023
Not Achieved
Canoer Care - Medication Review
3 Aug 2024

--
Canoer Care - Plan
Now

--
Canoer Care - Review
Now

5 Jul 2024
Performed
Canoer Care - Support Discussed

--
Canoer Care -Treatments Coded
Now

21 Aug 2018
Not Achieved
Depression and Anxiety Screening
20 Aug 2020

27 Jul 2024
Achieved
HP - Alcohol Use Screening
27 Jul 2025

5 Aug 2024
Achieved
HP - Smoking Status & Cess. Advice
5 Aug 2025

2 Apr 2025
Achieved
HP - Weight and BMI Measurement
2 Apr 2027

27 Jul 2024
Performed
HP - Weight Management & Diet Ad...

14 Jan 2025
Achieved
Number of Primary Care Consultat...

9 May 2025
Achieved
On a GP Cancer Register

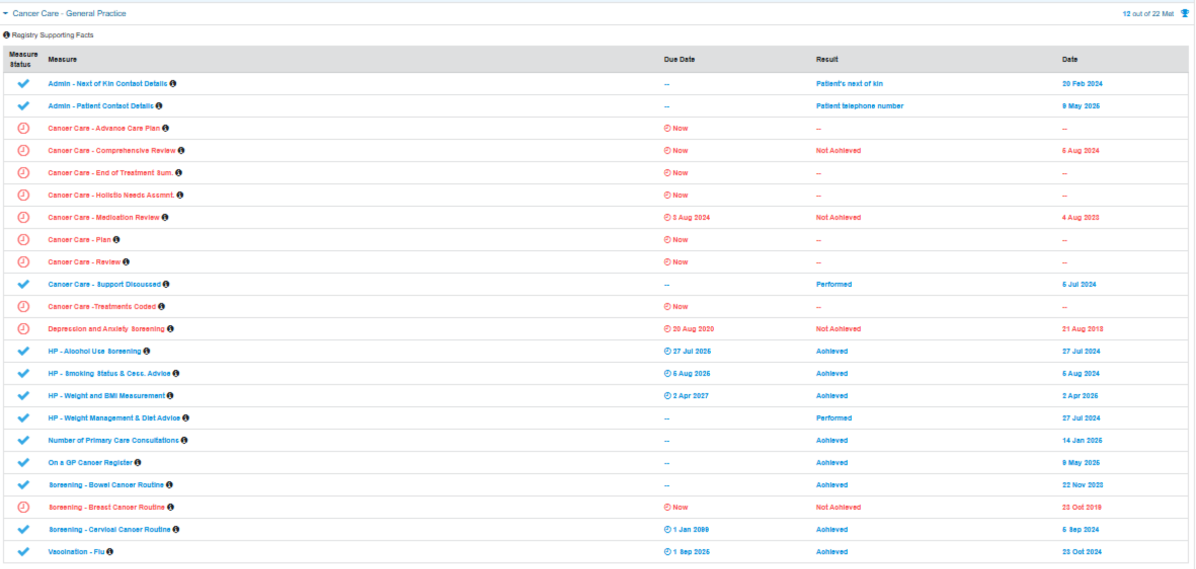
22 Nov 2023
Achieved
Screening - Bowel Cancer Routine

23 Oct 2019
Not Achieved
Screening - Breast Cancer Routine
Now

5 Sep 2024
Achieved
Screening - Cervical Cancer Routine
1 Jan 2099

23 Oct 2024
Achieved
Vaccination - Flu
1 Sep 2025

Image 2: HEI Cancer care registry list view – all quality indicators on one screen. Red=not met



Cancer Care - General Practice

12 out of 22 Met

Registry Supporting Facts

Measure Status	Measure	Due Date	Result	Date
✓	Admin - Next of Kin Contact Details	--	Patient's next of kin	20 Feb 2024
◷	Admin - Patient Contact Details	--	Patient telephone number	9 May 2025
◷	Cancer Care - Advance Care Plan	Now	--	--
◷	Cancer Care - Comprehensive Review	Now	Not Achieved	5 Aug 2024
◷	Cancer Care - End of Treatment Sum.	Now	--	--
◷	Cancer Care - Holistic Needs Assmnt.	Now	--	--
◷	Cancer Care - Medication Review	3 Aug 2024	Not Achieved	4 Aug 2023
◷	Cancer Care - Plan	Now	--	--
◷	Cancer Care - Review	Now	--	--
✓	Cancer Care - Support Discussed	--	Performed	5 Jul 2024
◷	Cancer Care -Treatments Coded	Now	--	--
◷	Depression and Anxiety Screening	20 Aug 2020	Not Achieved	21 Aug 2018
✓	HP - Alcohol Use Screening	27 Jul 2025	Achieved	27 Jul 2024
✓	HP - Smoking Status & Cess. Advice	5 Aug 2025	Achieved	5 Aug 2024
✓	HP - Weight and BMI Measurement	2 Apr 2027	Achieved	2 Apr 2025
✓	HP - Weight Management & Diet Advice	--	Performed	27 Jul 2024
✓	Number of Primary Care Consultations	--	Achieved	14 Jan 2025
✓	On a GP Cancer Register	--	Achieved	9 May 2025
✓	Screening - Bowel Cancer Routine	--	Achieved	22 Nov 2023
◷	Screening - Breast Cancer Routine	Now	Not Achieved	23 Oct 2019
✓	Screening - Cervical Cancer Routine	1 Jan 2099	Achieved	5 Sep 2024
✓	Vaccination - Flu	1 Sep 2025	Achieved	23 Oct 2024

The registry was made available to any provider organisation in NCL that had completed the necessary onboarding steps. Although initially focused on primary care, the access model was expanded to include secondary care, allowing for broader use across the cancer pathway.

However, despite the significant progress in development and readiness for implementation, the project faced a major change in late 2023 when the decision was made to decommission the registry platform as part of wider digital transformation changes within the Integrated Care Board (ICB). This decision, which was outside the control of the Alliance, meant that the planned service evaluation could not proceed.

Nonetheless, the development process itself yielded important learning. It demonstrated the feasibility of building a clinically relevant population health registry for cancer, clarified the challenges of aligning technical, governance, and strategic drivers, and highlighted the level of ongoing support and coordination required to enable uptake in primary care settings.

6. Service Evaluation Plan

The service evaluation was designed to assess the real-world use and impact of the Cancer Care Registry across North Central London (NCL), with a focus on how it could drive improvements in personalised cancer care (PCC). The evaluation was built on a logic model framework (see supplementary document, item

The evaluation aimed to understand:

- How the registry was used in primary care following implementation support and training.
- Whether use of the tool led to quality improvement activity (e.g. identifying care gaps, patient recall).
- Whether this translated into improved data quality (e.g. coding of CCRs, care plans).
- The broader impact on care processes, workflow, and potential spread to other clinicians or practices.

Methods - The evaluation proposed a mixed-methods approach using:

- Quantitative data from EMIS Web (coded activity and documentation).
- Registry usage data via Cerner.
- Qualitative data from participating practices, including surveys, interviews, and case studies.
- HEI data analysis, where available, to assess trends in indicator completion.

A full version of the evaluation protocol can be found in Supplementary documents Item 4. Items 5 and 6 are further resources that were developed to deliver the protocol.

7. Change in Circumstances

While the Cancer Care Registry was successfully developed and soft-launched in February 2023, a significant change in circumstances impacted the delivery of the planned service evaluation. In late 2023, the provider for the registry, was decommissioned by the North Central London Integrated Care Board (ICB) as part of broader changes to digital infrastructure and provider contracts.

This decision meant that continued access to the registry could not be guaranteed, and essential components of the evaluation—such as consistent usage data and longer-term tracking of quality indicators—were no longer feasible within the intended timeframe. As a result, the full evaluation was paused.

Despite this, the process was invaluable in demonstrating what it takes to design, build, and begin to implement a novel population health tool for personalised cancer care, and these lessons can inform future efforts to scale similar approaches across the NHS.

8. Lessons Learned

This project generated valuable learning on the development and implementation of a population health management tool to support personalised cancer care in the community. The experience has highlighted both strengths in delivery and areas where future work would benefit from changed approaches.

What Went Well

- **Co-development with Cerner/HEI:** The tool was developed through a collaborative process.
- **Stakeholder Engagement to involvement:** From the outset, the project benefited from strong and consistent engagement across sectors. Clinicians, informatics leads, public health, programme managers and more, who supported the iterative development and validation.
- **Validation Process:** The quality metrics included in the registry were co-designed and underwent rigorous review. Alignment with QOF measures gave the tool credibility and utility.
- **Academic support:** The service evaluation protocol was developed robustly, with guidance from academic partners.
- **Planning and Governance:** A strong evaluation design was developed, including a logic model, clear metrics, and a mixed-methods approach. Governance processes around information governance and intended usage was scoped out.

What Didn’t Go Well

- **Premature Decommissioning:** The most significant challenge was the unexpected decommissioning of the Cerner platform by the ICB before the service evaluation could be run. This decision curtailed the ability to test and generate evidence of the registry’s impact.

- **Slow Technical Turnaround:** Requests for change or technical adjustments with the registry, were subject to long turnaround times by the provider. This delayed progress and limited the responsiveness of the project during key stages of development and rollout.

Key Barriers Encountered

- **System-Level Decisions and Platform Stability:** The decision to decommission the digital platform was made at a system level and lay outside the control of the project team. However, it had a direct and significant impact on the project's delivery, continuity, and long-term sustainability.
- **Limitations in Data Access and Usage Monitoring:** The project team was unable to obtain disaggregated usage data specific to the cancer registry. Cerner's reporting capabilities only allowed for aggregate-level uptake data across all registries, limiting the ability to assess tool utilisation and engagement at the registry level.
- **Misalignment with National Clinical Frameworks:** The cancer registry's patient cohort definitions did not align with established frameworks such as the Quality and Outcomes Framework (QOF). This misalignment created a disconnect between registry data and primary care performance metrics, which in turn affected clinical confidence and usability.
- **Delays in Technical Delivery:** The turnaround time for requested updates (such as cohort definitions) and modifications to the registry was longer than anticipated. These delays affected the pace of development and delivery and constrained the project's ability to iterate based on early feedback.

9. Recommendations

Based on the experiences and findings of this project, we offer the following recommendations for future initiatives aiming to improve personalised cancer care through population health management tools.

1. PHM tool design should centre on end-user needs and clinical workflow
Future development of PHM tools should begin with understanding of the end user, have clear use cases and a clear picture of the environment in which they will be used. This includes co-designing with frontline staff, mapping existing workflows, and ensuring the tool integrates in daily practice. Tools that are perceived as disruptive or burdensome are less likely to be adopted or sustained.

2. Invest in socialisation and implementation interventions
The new registry and its technical deployment are the beginning; successful uptake depends

on structured implementation which is resourced appropriately. Drawing on evidence-based interventions from training material, inhouse training support to incentive schemes, should be considered.

3. Clear and relevant USE cases
One persistent barrier to adoption is the lack of a clear and compelling narrative around why a new tool is necessary and what it aims to improve. Greater support—through guidance, exemplars, and evidence summaries—should be made available to help local teams build robust cases for change when introducing digital innovations.

4. Conduct a comprehensive scoping of grey literature and existing initiatives
People considering similar initiatives, should review relevant literature (peer and grey) and lessons learned from other systems. This reduces duplication and enables new projects to build on prior efforts, drawing insights from what has worked and what has not, in similar contexts.

5. Align with national strategy
Projects should be aligned with national strategic priorities and engage early with national and regional leads. Doing so may open avenues for funding, governance support, and faster adoption pathways.

6. Embed academic partnerships early to support evaluation
Robust evaluation is essential to demonstrating the value and real-world impact of PHM tools. Early engagement with academic institutions enables high-quality evaluation design and may strengthen grant applications or peer-reviewed dissemination. Academics are encouraged to contribute to building the evidence base in this emerging area.

7. Contingency planning
Given the complexity and fluidity of the NHS, projects must anticipate change. This includes preparing for platform transitions, contractual shifts, or tool decommissioning. Mitigations could include developing modular components, aligning with broader ICS digital strategies, and ensuring that data portability and exit plans are considered during procurement or project setup.

10. Next Steps

As the digital landscape within Integrated Care Boards (ICBs) continues to evolve, there is a timely opportunity to ensure that the significant learning, assets, and infrastructure developed through this project are not lost. The work completed to date—encompassing stakeholder co-design, rigorous validation, a structured implementation approach, and a detailed evaluation framework—**represents a valuable foundation that can be repurposed.**

ICBs and their digital teams are encouraged to review the registry's design, outputs, and associated implementation materials with a **view to adapting the tool for integration into their current or future digital architecture.** Although the Cerner platform has now been decommissioned, many of the registry's core design principles and logic should be transferable to alternative systems. This includes quality indicators, coding standards, patient stratification models, and population health dashboards.

Furthermore, the **project's evaluation materials**—such as logic models, survey tools, and stakeholder engagement strategies—**are transferable** and can be used to accelerate similar programmes elsewhere. These resources provide a tested blueprint for implementation science-informed evaluation, which can be adapted to suit different geographies, cancer pathways, or digital platforms.

There is also an opportunity for ICBs and regional digital leads to engage with the national cancer programme and academic partners to explore the **feasibility of a national template registry model**, informed by this early innovation work. By building on the foundation laid here, systems can continue to pursue personalised cancer care at scale, reducing variation, improving data quality, and supporting better outcomes for people living with and beyond cancer.

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[i] http://r20.rs6.net/tn.jsp?f=001kX9wt3OoP86l1kcVQsq7DCKRl7AaxaEde1mDqo2c4DcG8WC2lRUSGzE3thQsPYWtBY-t5vlWOPvj66VWW5GV-rIUbjnJSYAbGGtfT_-aAFlObT-tnlAw1k_6FvjW0RvI2Z5zAxrTRFglHv-vNI5SX035iIrXQmiwOA52HYcinhXO7L6HoXxM6LEGvhuuW_ExAHkhniEh1-3bnfSDVes51Q==&c=ZwsDjhzbS7YZVKQTGpDlfjs5R5Ccw1uI8v8ziItoCfVppnyfjb2ugA==&ch=UeQbN_HmG5ofe27iilYiNoPYb6Dx5rx8u2oNQL_GQdw2Kh4UYh_PpA

[ii] https://www.england.nhs.uk/publication/quality-and-outcomes-framework-guidance-for-2025-26/

[iii] https://www.england.nhs.uk/publication/implementing-personalised-stratified-follow-up-pathways/

[iv] https://www.england.nhs.uk/cancer/living/#:~:text=Providing%20personalised%20stratified%20follow%2Dup%20care&text=Personalised%20Stratified%20Follow%2DUp%20(PSFU,wellbeing%20in%20the%20long%2Dterm.

[v] https://www.gov.uk/government/news/nhs-long-term-plan-launched

[vi]

[vii] https://fingertips.phe.org.uk/search/cancer#page/0/gid/1/pat/223/par/E40000003/ati/221/are/nE54000028/iid/276/age/1/sex/4/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1/page-options/car-do-0

[viii] https://www.nclcanceralliance.nhs.uk/our-work/primary-care-2/cancer-care-registry/#:~:text=It%20links%20together%20health%20and,a%20patient%20has%20already%20received.