Embedding the patient voice in the centre of a national quality improvement programme

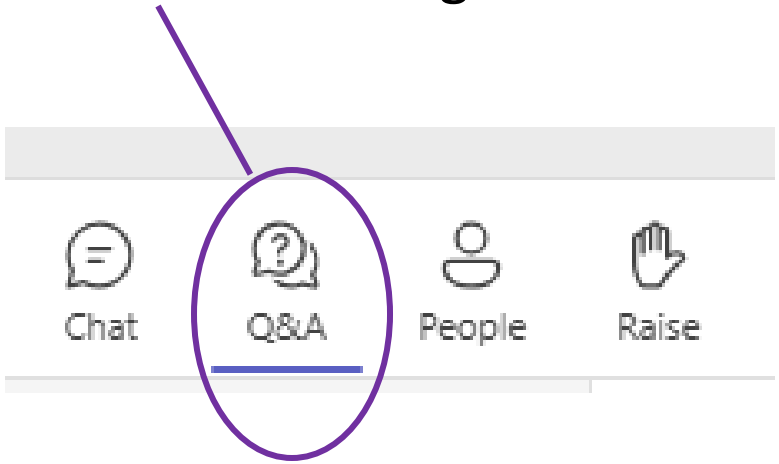
Learning from the National Cancer Audit Collaborating Centre (NATCAN)

22nd June 2026

NATCAN
National Cancer Audit Collaborating Centre

Housekeeping

- The webinar will be recorded and available on the NATCAN website
- Microphones are automatically switched off
- Questions will take place at the end of the session (rather than following each individual presentation)
- Please post your questions for the team in the Q&A box during the webinar



NATCAN
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9.30 – 9.35: **Introduction**

Chris Carrigan, Data Advisor, Use My Data (Chair)

9.35 – 9.45: **NATCAN – who we are and what we do**

- Julie Nossiter, Director of Operations, NATCAN

9.45 – 9.50: **Establishing Patient & Public Involvement (PPI) Forums across NATCAN**

- Verity Walker, Project Manager, NATCAN

9.50 – 9.55: **Living beyond pancreatic cancer**

- Christine Ashworth, National Pancreatic Cancer Audit (NPaCA) PPI Forum
- ***Video produced in collaboration with Pancreatic Cancer UK***

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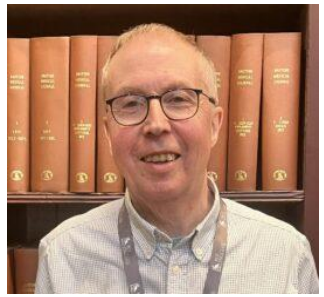
9.55 – 9.10: **Working with the National Lung Cancer Audit (NLCA) PPI Forum**

- Lauren Dixon, NLCA Clinical Fellow

10.10 – 10.20: **Experience of working with NATCAN and the National Non-Hodgkin Lymphoma Audit (NNHLA)**



- Frank Burroughs, NNHLA PPI Forum Chair

10.20 – 10.25: **Setting up NATCAN's Patient Involvement Network (PIN)**

- Vikki Hart, Senior Project Manager, NPaCA and NNHLA

10.25 – 10.30: **Q&A**

- Chris Carrigan, Use My Data (Chair)

National Cancer Audit Collaborating Centre (NATCAN) – who we are and what we do

22nd June 2026

Julie Nossiter, Director of Operations, NATCAN & Assoc Prof Cancer Services Research (Hon), LSHTM

NATCAN
National Cancer Audit Collaborating Centre

What is National Clinical Audit?

- Checks whether patients are receiving care that meets agreed standards and guidelines
- Uses NHS data to see how care is delivered
- Identifies what is working well and where improvement is needed
- Allows hospitals to compare their care with others (benchmarking)
- Helps improve safety, quality and outcomes for patients
- Shares learning across the NHS so patients everywhere benefit

NATCAN
National Cancer Audit Collaborating Centre

National Cancer Audit Collaborating Centre (NATCAN)

NATCAN aims to:

1. Provide **regular**, **timely** evidence to cancer services of **variations in care** in England & Wales
2. Identify **reasons for the variation** in care and help guide **quality improvement** initiatives
3. **Stimulate improvements** in cancer detection, access to treatment and outcomes

Commissioned by HQIP and funded by NHSE and the Welsh Government initially for 3 years, now extended to 30.09.27

HQIP Healthcare Quality Improvement Partnership

NHS England

Llywodraeth Cymru Welsh Government

NATCAN
National Cancer Audit Collaborating Centre

Home of the ten national cancer audits in England & Wales

- Kidney Cancer (NKCA National Kidney Cancer Audit)
- Non-Hodgkin Lymphoma (NNHLA National Non-Hodgkin Lymphoma Audit)
- Ovarian Cancer (NOCA National Ovarian Cancer Audit)
- Pancreatic Cancer (NPaCA National Pancreatic Cancer Audit)
- Primary & (NAoPri National Audit of Primary Breast Cancer)
- Metastatic Breast Cancer (NAoMe National Audit of Metastatic Breast Cancer)
- Lung Cancer (NLCA National Lung Cancer Audit)
- Oesophago-Gastric Cancer (NOGCA National Oesophago-Gastric Cancer Audit)
- Bowel Cancer (NBOCA National Bowel Cancer Audit)
- Prostate Cancer (NPCA National Prostate Cancer Audit)

Royal College of Surgeons of England
ADVANCING SURGICAL CARE

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

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NATCAN: key features

- Close **clinical-methodological partnership**
- Close links with all **stakeholder groups**
  - Clinical professional bodies
  - People with lived experience, charities
  - NHS commissioners & regulators
- Use of routine, **national (existing and linked) datasets** only
  - Public reporting of results
- Audit delivery & **Quality improvement informed by research & development**

Who we are: June 2026

NATCAN
National Cancer Audit Collaborating Centre

HEALTHCARE QUALITY IMPROVEMENT PARTNERSHIP

Clinical Effectiveness Unit-RCSEng

NATIONAL CANCER AUDIT COLLABORATING CENTRE (NATCAN)

LSHTM: NIHR, MRC funded health services research

CEU: NVR & Crane / health services projects

NHSE/ National Disease Registration Service Digital Health and Care Wales/Wales

NATCAN Board

Chair, HQIP, NHS England, Welsh Government, RCR, Macmillan Cancer Support, NDRS, WCN, RCSEng Patient & Public Group, NATCAN Executive

NATCAN Executive Team

Director of Operations (Julie Nossiter), Clinical Director (Tom Roques), Director CEU (David Cromwell), Senior Statistician (Kate Walker), Senior Clinical Epidemiologist (Jan van der Meulen)

Centre-level team members:
Project Manager (Verity Walker), Quality Improvement Clinical Fellow (Sugeeta Sukumar), Data Manager (Abhishek Dixit), Project Coordinators (Faine Chan, Aurelia Chen)

QUALITY IMPROVEMENT TEAM
(working with all cancer audits)

PPI FORUMS
(one for each cancer audit)

CLINICAL REFERENCE / ADVISORY GROUPS
(one for each cancer audit)

Lung
Clinical leads: Neal Navani (Respiratory medicine), Doug West (Surgery, SCTS), John Conibear (Oncology, RCR)
Senior Methodologist: David Cromwell/
Methodologist: Sarah Cook
Statistician/Data Scientist: Adrian Cook, Jessica Thomas
Clinical Fellow: Lauren Dixon
Audit Manager/Coordinator: Joanne Boudour/ Faine Chan

Prostate
Clinical leads: Alison Tree (Oncology, BUG), Noel Clarke (Surgery, BAUS)
Senior Methodologist: Jan van der Meulen,
Statistician/Data Scientist: Adrian Cook, Emily Mayne
Clinical Fellows: Arjun Nathan, Justin Liu, Matt Parry
Audit Manager/Coordinator: Aurelia Chen

Bowel
Clinical leads: Mike Braun (Oncology, ACP) Nicola Fearnhead (Surgery, ACPGBI)
Senior Methodologists: Kate Walker
Methodologist: Sarah Cook
Clinical Fellow: Adil Rashid, Leo Watton
Statistician/Data Scientist: : Angela Kuryba
Audit Manager/Coordinator: Karen Darley/Augusto Nembrini

OG
Clinical leads: Nigel Trudgill (Gastroenterology, BSG), James Gossage (Surgery, AUGIS) Tom Crosby/Betsan Thomas
Senior Methodologist: David Cromwell
Methodologist: Min Hae Park
Statistician/Data Scientist: : Amanda McDonell
Clinical Fellow: Olivia O'Connor
Audit Manager/Coordinator: Karen Darley/ /Augusto Nembrini

Primary Breast
Clinical leads: David Dodwell (Oncology, UKBCG), Keiran Horgan (Surgery, ABS)
Senior Methodologist: David Cromwell
Methodologist: Diana Withrow
Clinical Fellows: Jemma Boyle, Sarah Blacker, Liyang Wang
Statistician/Data Scientist: : Christine Delon
Audit Manager/Coordinator: Robert Deuce/ Augusto Nembrini

Metastatic Breast
Clinical leads: David Dodwell, Keiran Horgan, Mark Verill (Medical Oncology, UKBCG)
Senior Methodologist: David Cromwell
Methodologist: Diana Withrow
Clinical Fellows: Jemma Boyle, Georgina Hanbury, Liyang Wang
Statistician/Data Scientist: Christine Delon
Audit Manager: Robert Deuce/ Augusto Nembrini

Pancreatic
Clinical leads: Nigel Trudgill (Gastroenterology, BSG), Andrew Smith (Surgery, AUGIS), Ganesh Radhakrishna (RCR)
Senior Methodologist: David Cromwell
Methodologist: Min Hae Park
Clinical Fellow: Suzi Nallamilli
Statistician/Data Scientist: Amanda McDonell
Audit Manager/Coordinator: Vikki Hart/ Faine Chan

Kidney
Clinical leads: Amit Bahl (Oncology, BUG) Grant Stewart (Surgery, BAUS)
Senior Methodologist: Jan van der Meulen,
Clinical Fellow: Raghav Varma
Statistician/Data Scientist : Emily Mayne, Will Cunningham
Audit Manager/Coordinator: Aurelia Chen

Ovarian
Clinical leads: Agnieszka Michael (Medical Oncology, BGCS) Currently recruiting (Surgery, BGCS),
Senior Methodologists: Jan van der Meulen, Ipek Gurol Urganci
Methodologist: Andrew Hutchings
Clinical Fellow: Georgia Zachou
Audit Manager/Coordinator: Joanne Boudour/ Aurelia Chen

Non-Hodgkin Lymphoma
Clinical leads: Cathy Burton (Haematology, BSH) David Cutter (Oncology, BSH)
Senior Methodologists: Kate Walker,
Methodologist: Lu Han
Clinical Fellow: Ruhi Kanani
Statistician/Data Scientist: Kit Ying Yuen. Louise Reynolds
Audit Manager/Coordinator: Vikki Hart/Faine Chan

ABS, Association of Breast Surgery; ACPGBI, Association of Coloproctology of Great Britain and Ireland; AUGIS, Association ofUpper Gastrointestinal Surgeons; BAUS, British Association of Urological Surgeons; BSG, British Society of Gastroenterology; BSH, British Society of Haematology; BUG, British Uro-oncology Group; CEU, Clinical Effectiveness Unit; HQIP, Healthcare Quality Improvement Partnership; LSHTM, London School of Hygiene & Tropical Medicine; MRC, Medical Research Council; NHSE, National Hea Service England; NIHR, National Institute for Health and Care Research; NVR, National Vascular Registry; UKBCG, UK Breast Cancer Group; RCR, Royal College of Radiologists; RCSEng, Royal College of Surgeons of England; SCTS, Society for Cardiothoracic Surgery.

NATCAN
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Working closely with patient charities

Audit PPI Forums

People and communities using health and care services are best placed to understand what they need, what is working and what could be improved [1]

- Lived experience is as valuable as clinical expertise in shaping health and care services
- Established for each audit, working collaboratively with patient charities

[1] How does the health and care system hear from people and communities? King's Fund, 2022

NATCAN: progress so far

First year (from Oct 2022)

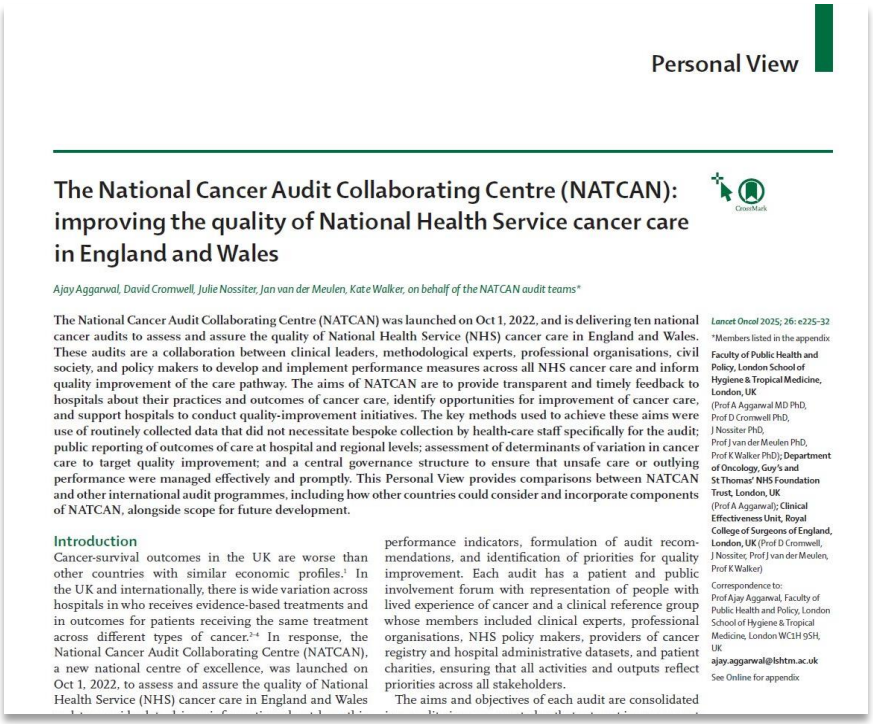
- Establish **organisational & governance structures**
- Develop NATCAN **communication strategy**
- Creation of **common data access channels**
- Establish **6 'new' audits**
- Move **4 'existing' audits** into NATCAN
- Recruitment for **PPI Forums**
- Audit **scoping & development**

Second year (from Oct 2023)

- Develop NATCAN **Quality Improvement (QI) plans for each audit**
- **Reporting & feedback** of audit results begins (quarterly & annual)

Third year onwards (from Oct 2024)

- Apply for & secure **two-year extension of funding**
- Develop & iterate **data dashboard**
- Design & roll out of **QI interventions**



Personal View

The National Cancer Audit Collaborating Centre (NATCAN): improving the quality of National Health Service cancer care in England and Wales

Ajay Aggarwal, David Cromwell, Julie Nossiter, Jan van der Meulen, Kate Walker, on behalf of the NATCAN audit teams*

The National Cancer Audit Collaborating Centre (NATCAN) was launched on Oct 1, 2022, and is delivering ten national cancer audits to assess and assure the quality of National Health Service (NHS) cancer care in England and Wales. These audits are a collaboration between clinical leaders, methodological experts, professional organisations, civil society, and policy makers to develop and implement performance measures across all NHS cancer care and inform quality improvement of the care pathway. The aims of NATCAN are to provide transparent and timely feedback to hospitals about their practices and outcomes of cancer care, identify opportunities for improvement of cancer care, and support hospitals to conduct quality-improvement initiatives. The key methods used to achieve these aims were use of routinely collected data that did not necessitate bespoke collection by health-care staff specifically for the audit; public reporting of outcomes of care at hospital and regional levels; assessment of determinants of variation in cancer care to target quality improvement; and a central governance structure to ensure that unsafe care or outlying performance were managed effectively and promptly. This Personal View provides comparisons between NATCAN and other international audit programmes, including how other countries could consider and incorporate components of NATCAN, alongside scope for future development.

Introduction

Cancer-survival outcomes in the UK are worse than other countries with similar economic profiles.[1] In the UK and internationally, there is wide variation across hospitals in who receives evidence-based treatments and in outcomes for patients receiving the same treatment across different types of cancer.[2–4] In response, the National Cancer Audit Collaborating Centre (NATCAN), a new national centre of excellence, was launched on Oct 1, 2022, to assess and assure the quality of National Health Service (NHS) cancer care in England and Wales

performance indicators, formulation of audit recommendations, and identification of priorities for quality improvement. Each audit has a patient and public involvement forum with representation of people with lived experience of cancer and a clinical reference group whose members included clinical experts, professional organisations, NHS policy makers, providers of cancer registry and hospital administrative datasets, and patient charities, ensuring that all activities and outputs reflect priorities across all stakeholders.

The aims and objectives of each audit are consolidated

Lancet Oncol 2025; 26: e225–32

*Members listed in the appendix

Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London, UK (Prof A Aggarwal MD PhD, Prof D Cromwell PhD, J Nossiter PhD, Prof J van der Meulen PhD, Prof K Walker PhD); Department of Oncology, Guy's and St Thomas' NHS Foundation Trust, London, UK (Prof A Aggarwal); Clinical Effectiveness Unit, Royal College of Surgeons of England, London, UK (Prof D Cromwell, J Nossiter, Prof J van der Meulen, Prof K Walker)

Correspondence to: Prof Ajay Aggarwal, Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London WC1H 9SH, UK
ajay.aggarwal@lshtm.ac.uk

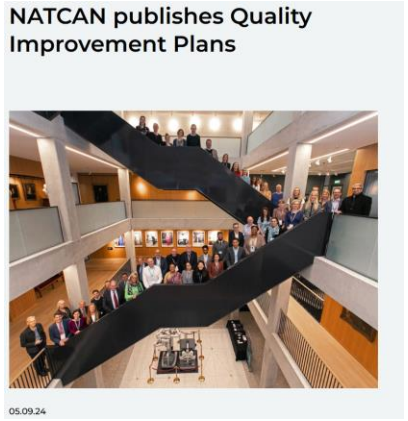
See Online for appendix

NATCAN Quality Improvement Plans

- Summer 2023 - Scoping Exercise
  - What are the major quality issues?
  - Defined the scope and care pathway for the ‘new’ cancer audits, refreshed for ‘established’ audits

- Spring 2024 – Continued this work to develop Quality Improvement (QI) Plans
  - Defined 5 QI goals & 10 Performance Indicators (metrics)
  - What is **measurable** with the data, and does it relate to the quality issue?
  - Is it **actionable**? Will we see any variation? Does it reflect potential deficits in the quality of care?
  - What can be done about the quality issue – is it **improvable**?

Published September 2024



Use of routine, existing, linked NHS data

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What information is used?

- Diagnosis and stage of cancer
- Treatments (surgery, chemotherapy, radiotherapy)
- Other health conditions
- Hospital stays, readmissions and complications

All patient identifiable information is removed (name, NHS number, date of birth, address, post code) before information is securely transferred to NATCAN

NHS England

GIG CYMRU NHS WALES
Perfformiad a Gwella
Performance and Improvement

NDRS
NATIONAL DISEASE REGISTRATION SERVICE

Use of routine, existing, linked NHS data

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England (annual & quarterly)

- Cancer Outcomes and Services Dataset (COSD)
- Cancer Registration data (NCRD*/RCRD)
- Hospital Episode Statistics (HES)
- Systemic Anti-Cancer Therapy (SACT) dataset
- National Radiotherapy Dataset (RTDS)
- Mortality data - Office for National Statistics (ONS)
- Medicines Dispensed in Primary Care (NHSBSA)*
- Somatic Molecular Testing Dataset*
- Cancer Waiting Times (CWT)
- Diagnostic Imaging Dataset (DIDS)*
- National Cancer Patient Experience Survey*

Wales (annual)

- CaNISC or Cancer Information System
- Patient Episode Database for Wales (PEDW)
- Radiotherapy Data available in Canisc
- Mortality data - Office for National Statistics (ONS)

NHS England

GIG CYMRU NHS WALES
Perfformiad a Gwella
Performance and Improvement

NDRS
NATIONAL DISEASE REGISTRATION SERVICE

*Available in England on an annual basis only

NPCA National Prostate Cancer Audit

NATCAN National Cancer Audit Collaborating Centre

Patient reported outcome measures (PROMs)

- PROMs determine patients' views of their symptoms, functional status and health-related quality of life (QoL)
  - measure safety and effectiveness of care
- NPCA carried out a patient survey
  - What are the outcomes reported by men after radical treatment for prostate cancer?
    - Views on experience of care
- Questionnaire developed in consultation with clinical and patient representatives
  - generic (EQ-5D-5L) and disease specific (EPIC-26) validated PROMs instruments
  - selected PREMs questions from National Cancer Patient Experience Survey (CPES)
- Successful patient engagement – high response rates
  - Overall: survey sent to 60,817 men – 73% responded (44,355)
- Data from the National Cancer Qol survey carried out by NDRS is currently unavailable to NATCAN
  - Hopeful these data will be available in due course

Patient reported experience measures (PREMs)

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What can patient-reported experience measures tell us about the variation in patients' experience of prostate cancer care? A cross-sectional study using survey data from the National Prostate Cancer Audit in England

Melanie Morris [1, 2], Adrian Cook [1], Joanna Dodkins [1], Derek Price [3], Steve Waller [1], Syreen Hassan [2], Arjun Nathan [1], Ajay Aggarwal [2], Heather Ann Payne [4], Noel Clarke [1, 5], Jan van der Meulen [2], Julie Nossiter [1]

- Variation in how care was experienced by men of different ages, ethnic and socioeconomic background
- PREMs are an important quality indicator and provide targeted information to hospitals of where improvements are needed in communication & support
- Patient involvement is key – co-authors

NPCA
National Prostate Cancer Audit

"It is not surprising to me that men in the higher risk group responded less favourably to the questions on whether their views on treatment were taken into account and whether they were involved as much as they wanted in care and treatment decisions. They would have felt less involved because, in order to attempt a cure, their clinicians would have lent towards those treatments which were likely to result, in their opinion, in a better outcome."

Data Dashboards

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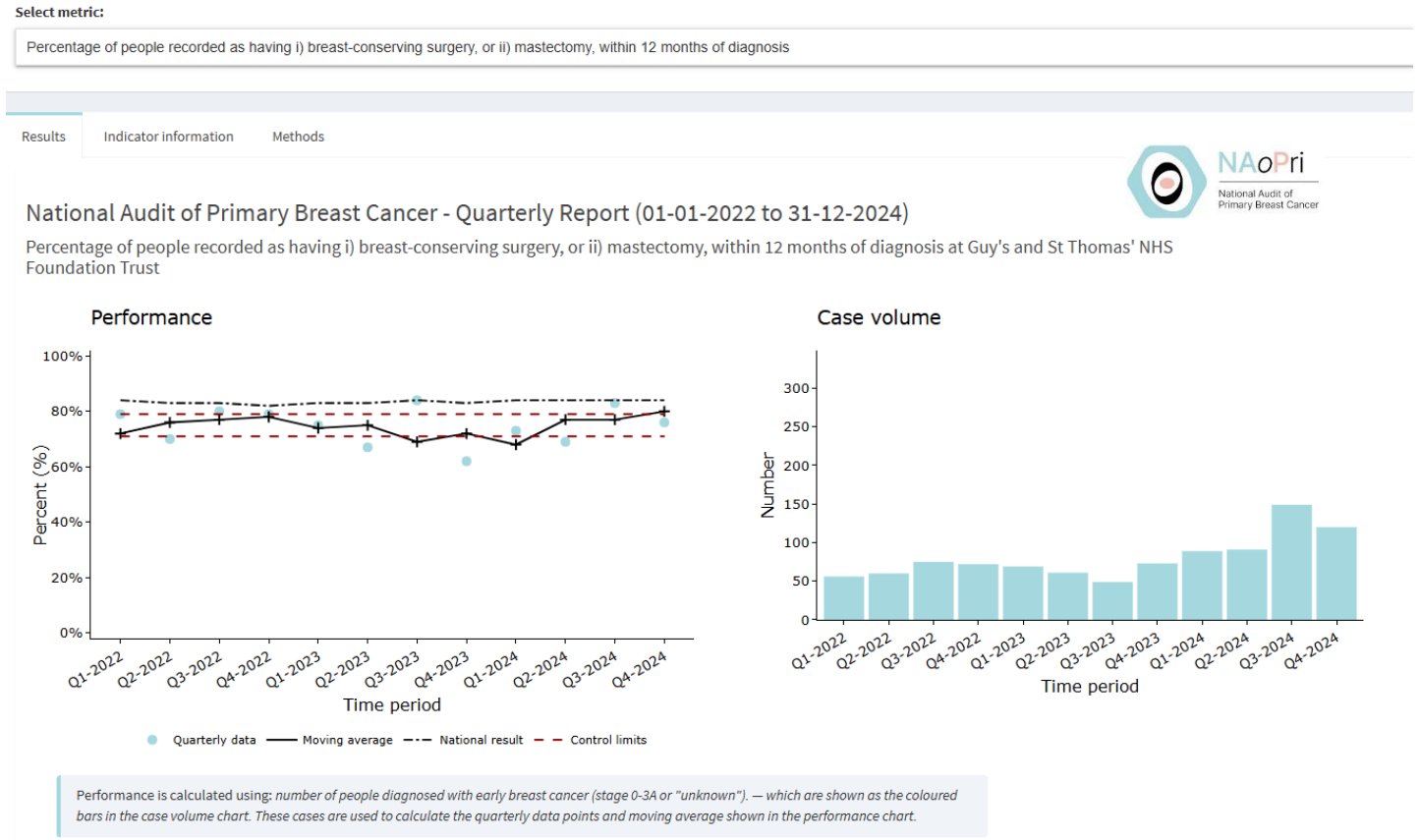
Quarterly reporting provides information on:

- **Data quality (completeness)** of key data items captured in the rapid cancer registration data at NHS trust level
- Range of **performance indicators** at NHS trust and Cancer Alliance level

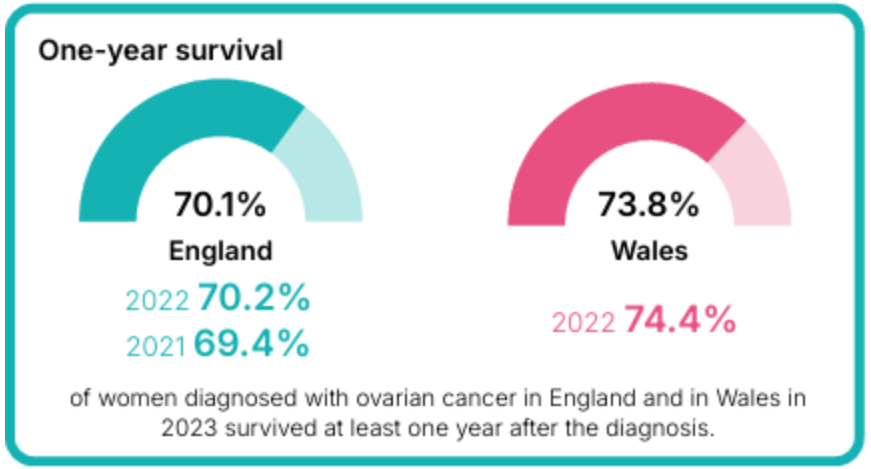


NATCAN Annual State of the Nation Reports

- Provides a concise overview of care received across England and Wales
- Describe national patterns of care against measurable standards
- Provide five key recommendations for action
  - Accompanying provider-level results
- Patient summary developed with PPI Forums

"The treatment you get, how quickly you get it, and how well you are supported is subject to far too much variation across England and Wales. **NATCAN** are doing an exceptionally thorough job of demonstrating that – it's our role as a clinical community to do something about it."

Richard Simcock, Chief Medical Officer, Macmillan Cancer Support



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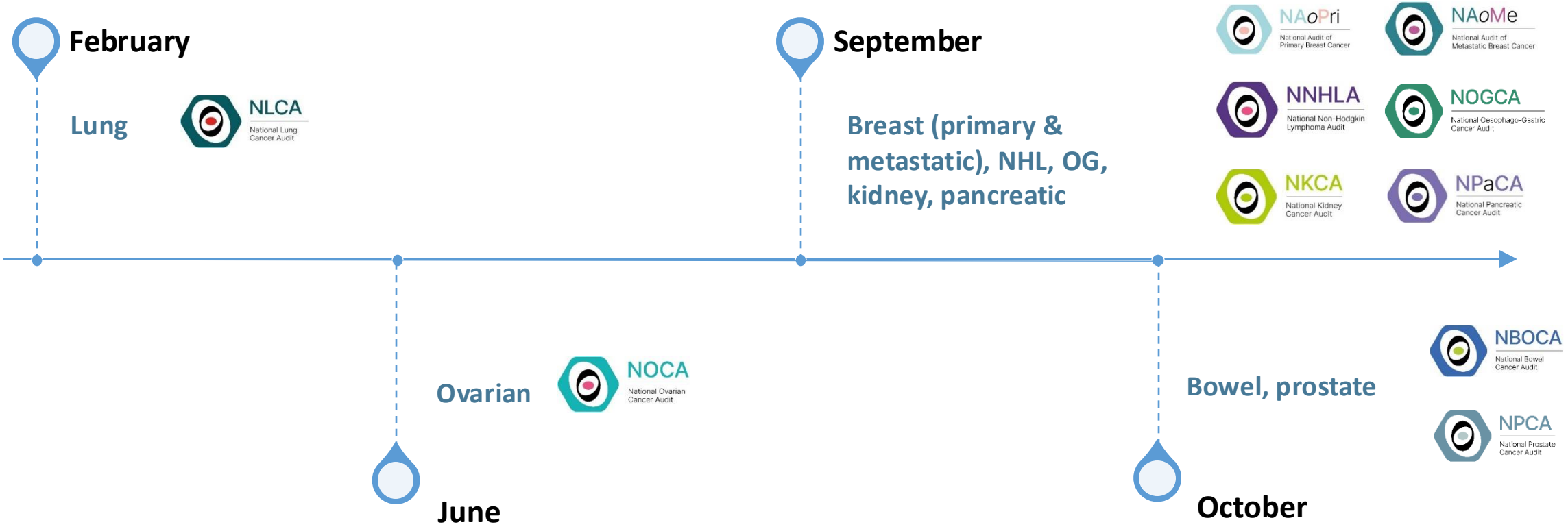
State of the Nation publications 2026/2027



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NOCA Quality Improvement Intervention

The NOCA team is launching a Quality Improvement (QI) intervention in autumn 2025.

Our goal is to increase the **proportion of women diagnosed with ovarian cancer after an emergency admission who receive any treatment (surgery and/or chemotherapy).**

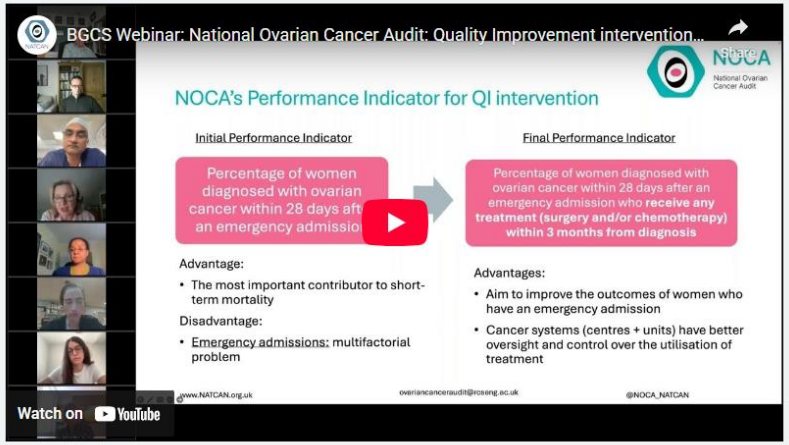
The NOCA is working in collaboration with the British Gynaecological Cancer Society (BGCS) to share best practice, please watch our webinar here. In addition, all Gynaecological Cancer Systems in England and Wales will receive a feedback letter and short report from NOCA.

Please take a look at the poster below for more information:

NOCA QI Intervention Poster

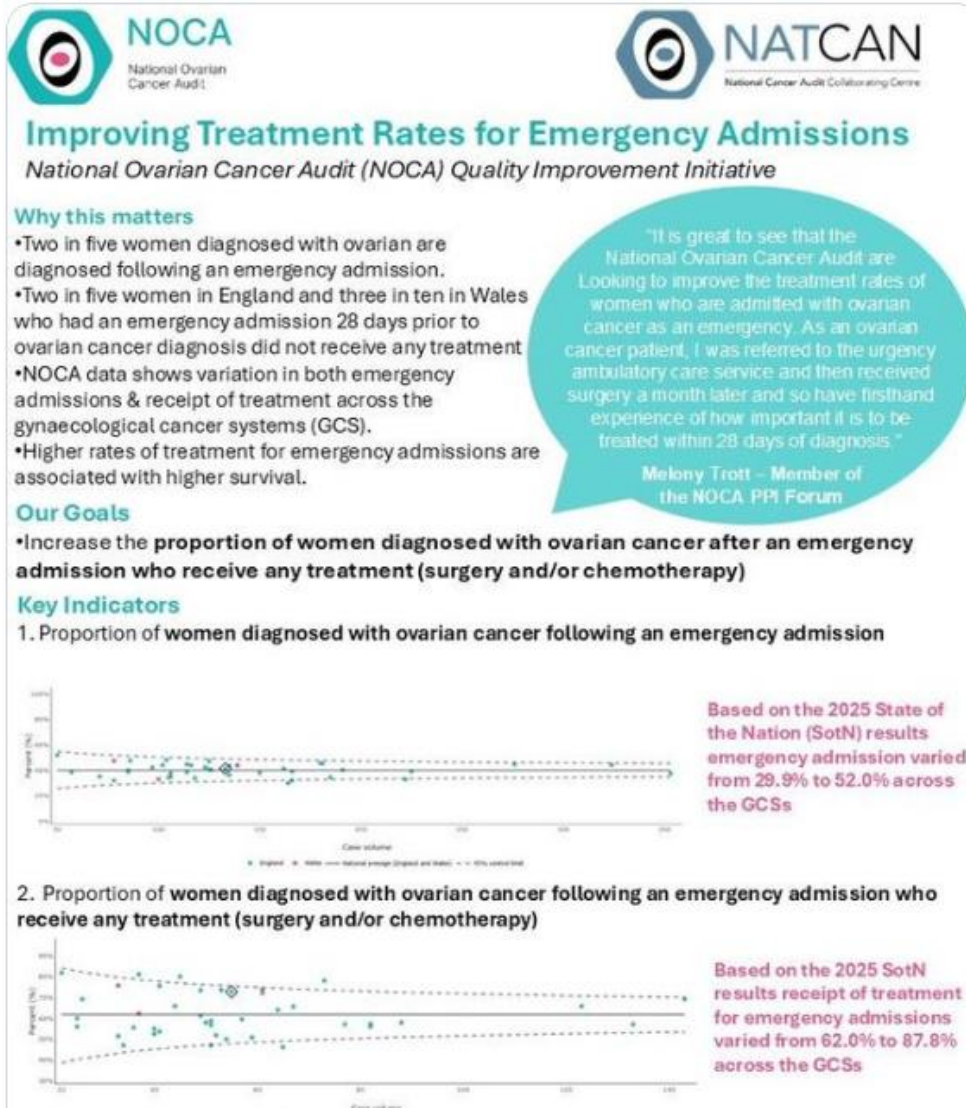
NOCA QI Intervention Response Log

National Ovarian Cancer Audit: Quality Improvement intervention 2025

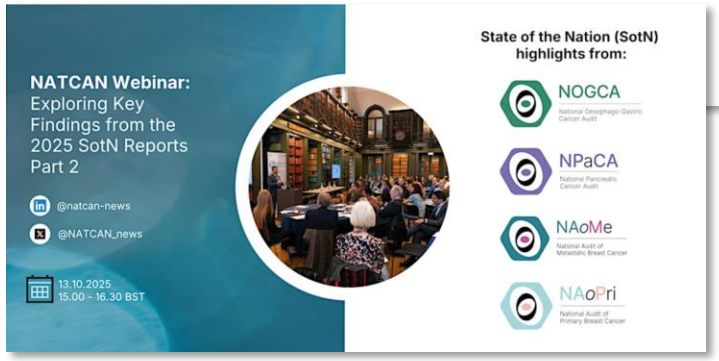


National Ovarian Cancer Audit
@NOCA_NATCAN

🚨 NOCA has launched a Quality Improvement intervention to help improve treatment for women diagnosed with ovarian cancer following emergency admission.
A huge thank you to all the trusts who have responded!
Find more details here on responses so far : buff.ly/AyiWGrc



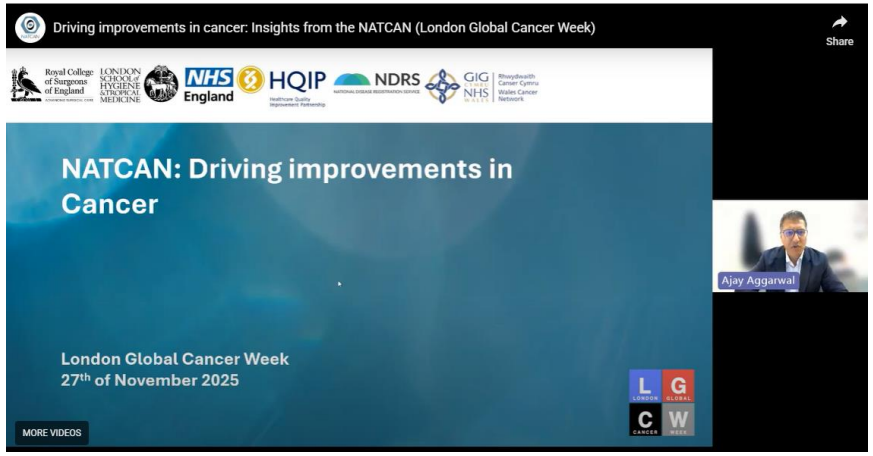
Engagement with clinical community



NATCAN Audits Lunchtime Webinars hosted by RCR, October & November 2025

Centre-level conferences & webinars

NHSE Cancer Manager Conference, October 2025



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Engagement with clinical community

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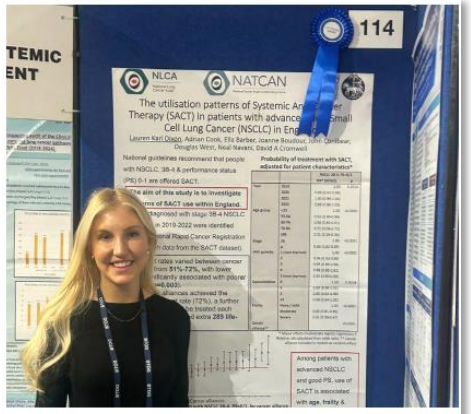
Members of the NAoPri team at the 2025 ABS Conference



NLCA Clinical Fellow Lauren Dixon with her prize-winning abstract at the BTOG Conference 2025


Nicola Fearnhead, NBOCA Surgery Lead, chairing the panel discussion on Close It Quick at the ACPGBI Annual Meeting

Audit team presentations at national conferences & workshops/webinars hosted by professional organisations

Kate Walker, NNHLA Senior Methodologist, at the British Society of Haematology's 65th Annual Scientific meeting.

Raghav Varma, NKCA Clinical Fellow, presenting at the BUG Annual Meeting

National Patient Data Awareness Day 2025

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- Attended first use My data conference 2025
- Launch of National Patient Data Awareness Day
- NATCAN selected to present in Data Soapbox

‘Celebrating the use of patient data’

> “We don’t use names or NHS numbers. But every number in our data represents a person – a life, a family, a story. And we have a responsibility to use that information with purpose, to make care better, fairer, and faster for everyone.”
>
> **Olivia Connor,** National Oesophago-Gastric Audit (NOGCA) Clinical Fellow, speaking at the ‘Soapbox Competition’ at the inaugural National Patient Data Day conference

* use MY data
a trusted voice in patient data

Vikki Hart and Olivia O’Connor representing NATCAN at the 2025 National Patient Data Day conference

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NATCAN: next steps

- **Strengthen engagement with clinical communities and people with lived experience**
- **Further innovations in reporting & feedback**
  - Further development of interactive dashboards will expand features of the dashboards
    - Launch central dashboard
    - Begin quarterly reporting in Wales
- **Stimulating improvement of cancer services**
  - Evaluation of QI intervention by each audit
    - QI tools for local teams to identify good practice / areas of weakness
    - QI workshops / webinars
- **And beyond…**
  - Re-tender for NATCAN beyond October 2027
  - Addition of other cancer types
  - Expand datasets – primary care data, PROMs
  - UK wide
  - Collaborations – national & international

NATCAN PPI (Patient & Public Involvement) Forums

Verity Walker, Centre Project Manager

22nd June 2026

Summary of PPI (Patient & Public Involvement) forums for Each Audit

- Consultative group, representing the patient's view

- Members are involved in the production of audit outputs including:
  - ✓ Patient & public information materials
  - ✓ Summaries of the annual State of the Nation reports.
  - ✓ Audit infographics to aid the dissemination of key information
  - ✓ Co-development and co-authorship of scientific papers that explore audit results.

- Have a key advisory role in developing the audit web pages

- Audit quality improvement goals, activities, and outputs

Recruitment Approach

- The audits primarily worked with patient charities to recruit members:
  - ✓ Liaised closely with patient charities and took a collaborative approach.
  - ✓ Charities tapped into their existing patient networks.
  - ✓ Some charities used their social media and pop-up adverts on their websites to reach a wider audience.
  - ✓ Sharing resources and expertise to support recruitment efforts (ToR, advert, expression of interest forms, and patient booklets).

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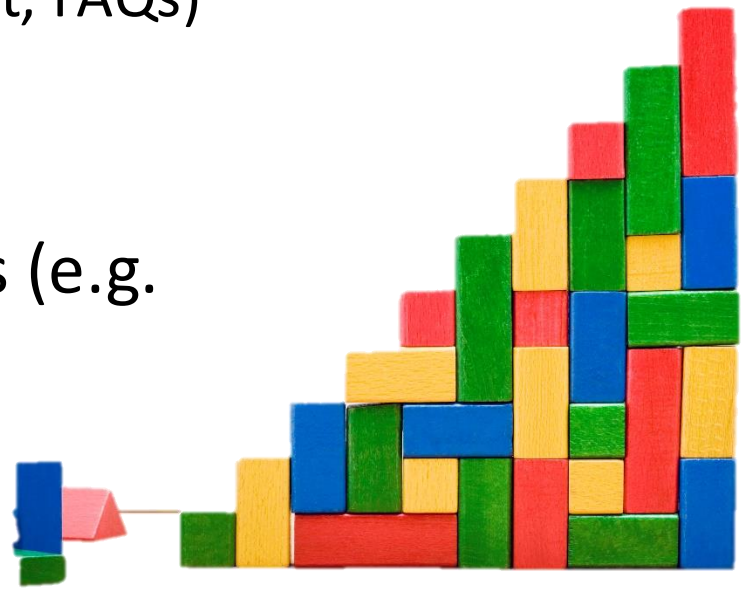
Setting Up PPI Forums

- Undergoing recruitment with the patient charities
- Producing documentation
  - ToRs, recruitment adverts, welcome material (booklet, FAQs)
- Arranging the first group meeting
- Ensuring diverse representation across all groups (e.g. stage, treatment, regionally)
- Confirming the PPI Chair



Activities and Involvement

- Patient summaries of reports
- Website content (blogs, newsletters)
- Patient information & resources

NOCA National Ovarian Cancer Audit

NATCAN National Cancer Audit Collaborating Centre

National Ovarian Cancer Audit
State of the Nation Patient and Public Report 2026

An audit of care received by women diagnosed with ovarian cancer between 1 January 2022 and 31 December 2023 in England and 1 January 2022 and 31 December 2024 in Wales.

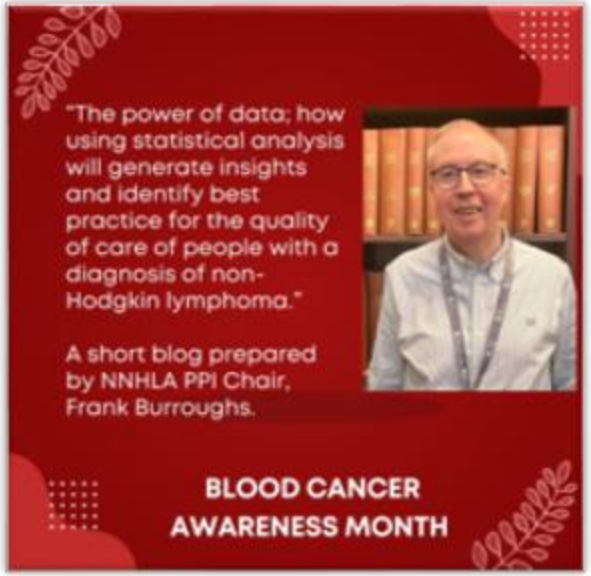
Published June 2026

Receipt of any treatment (surgery and/or chemotherapy) for women with emergency admission prior to diagnosis*

59.7% E England 2022 **61.3%**

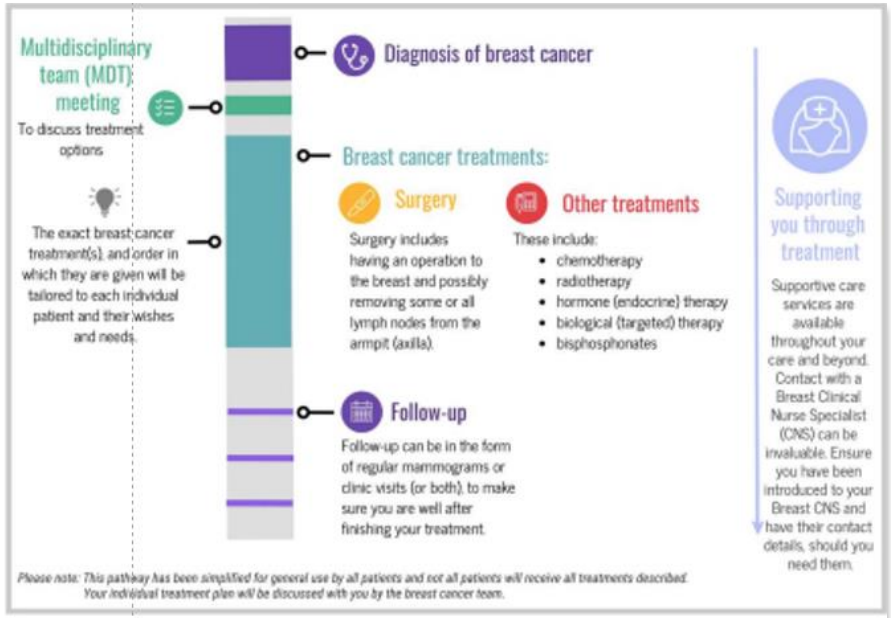
70.1% W Wales 2023 **71.0%**

of women who had an emergency admission prior to ovarian cancer diagnosis in England (E) in 2023 and in Wales (W) in 2024 had any treatment recorded within three months of diagnosis.



The picture to the right shows the sequence of steps in a typical breast cancer pathway, from diagnosis to treatment, in English and Welsh hospitals.

Over the page you will find information on each of these steps in the pathway along with some prompts for questions you may find useful to ask.



Activities and Involvement

- Quality improvement (QI) interventions
  - Shaping QI priorities
  - Supporting QI activities
  - Events
- Website and data dashboard development

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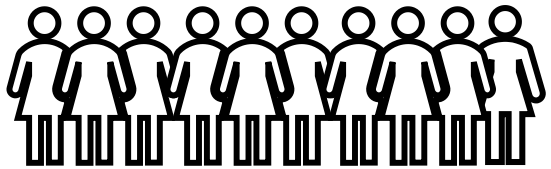
Representation Overview

- We aim to have diverse representation across all groups
  - Geographical location
  - Stage
  - Gender
  - Age
  - Ethnicity
  - Treatment

- We keep current membership under review and address any gaps by undertaking further recruitment with support from our charity stakeholders



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Next Steps…

- Reviewing representation & continued recruitment
- Working with PPI reps during retender for NATCAN
- Working with our centre level PPI group (PIN)
- Continuing to work closely with our patient charity stakeholders

Christine – living beyond pancreatic cancer

NATCAN
National Cancer Audit Collaborating Centre

National Lung Cancer Audit
Patient & Public Involvement Forum

Lauren Dixon
NLCA Clinical Fellow
22nd June 2026

NLCA@rcseng.ac.uk

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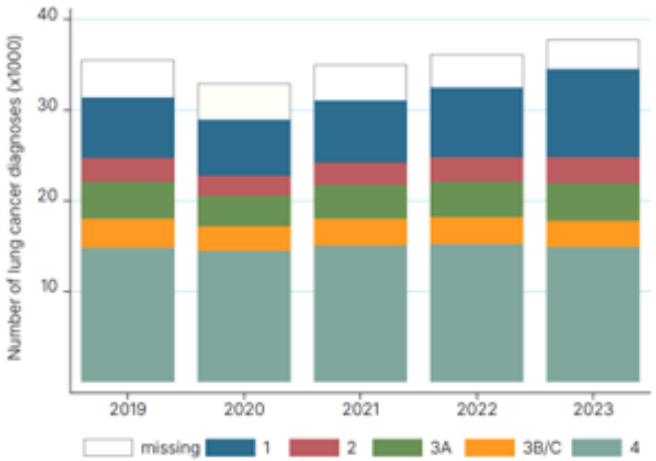
National Cancer Audit Collaborating Centre

NLCA
National Lung Cancer Audit

What is NLCA?

The National Lung Cancer Audit (NLCA) evaluates the patterns of care and outcomes for people with lung cancer in England and Wales, and to support NHS services to improve the quality of care for these individuals.



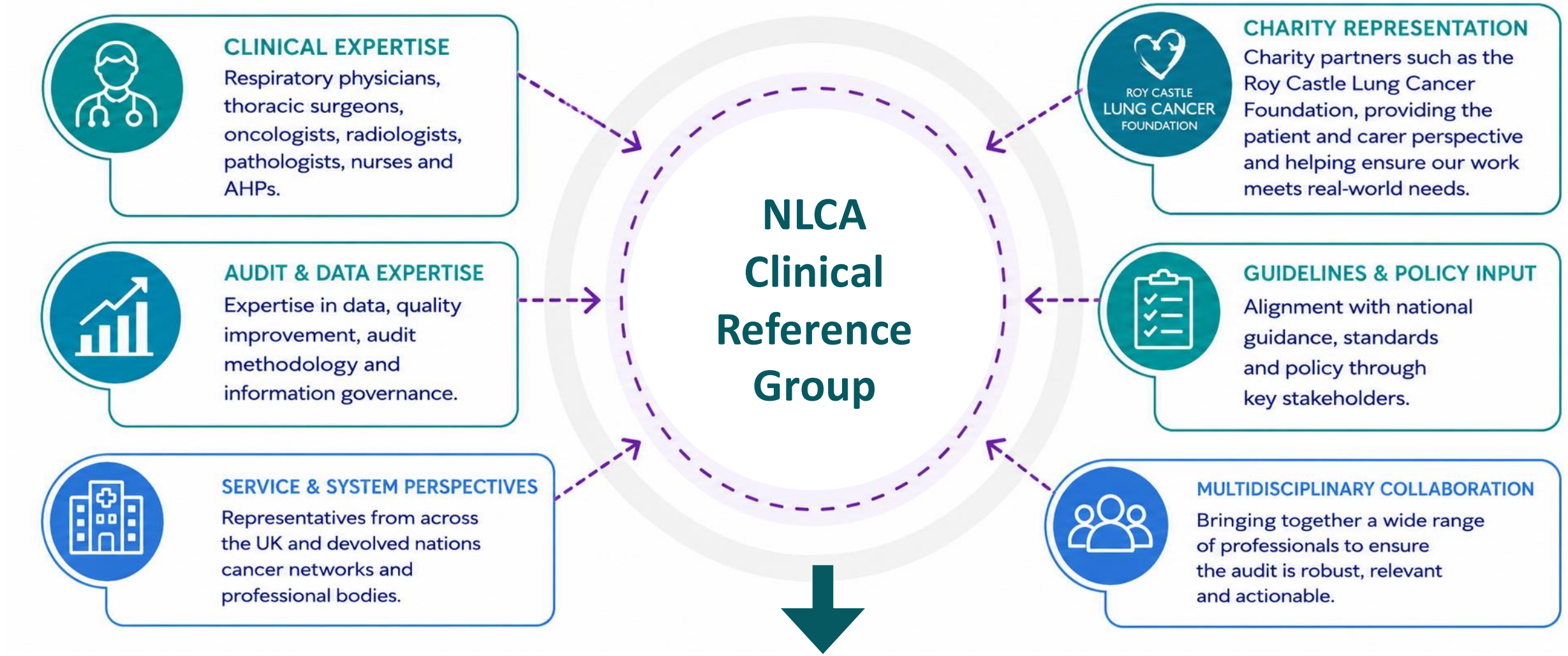
www.natcan.org.uk/audits/lung/

NLCA@rcseng.ac.uk

Why do we need a PPI forum?

NLCA
National Lung Cancer Audit

Before our PPI forum in 2023, NLCA was shaped by a wide range of expert input through the clinical reference group…



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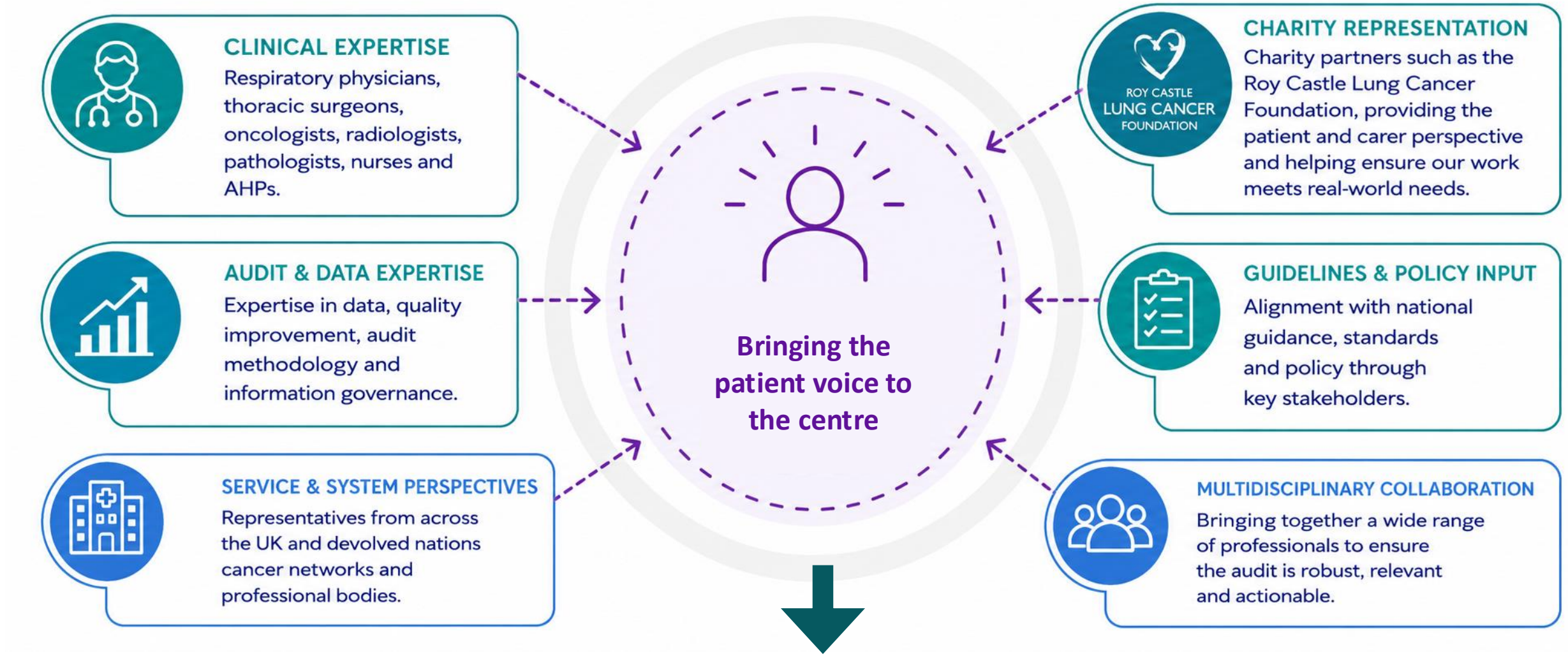

Building the PPI forum

NLCA
National Lung Cancer Audit

1

We started the journey

Established the need for a PPI forum to ensure the patient voice is at the heart of the NLCA.

2

ROY CASTLE LUNG CANCER FOUNDATION

RUTH STRAUSS FOUNDATION

Partnered with trusted charities

Worked with the Roy Castle Lung Cancer Foundation and the Ruth Strauss Foundation to reach and support a diverse range of people affected by lung cancer.

3

Promoted the opportunity

Created an advert and promoted widely online and through our charity partners and networks.

4

Invited applications

Interested individuals completed an application form to tell us about themselves and what they could bring.

5

Careful selection

We reviewed applications and selected a diverse group of members with lived experience of lung cancer or caring for someone who has.

6

PPI forum established

The NLCA PPI forum was established in 2023 and is now an integral part of the audit.

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National Lung Cancer Audit

NLCA | National Lung Cancer Audit

Patient and Public Involvement (PPI) Forum

Welcome Booklet

Royal College of Surgeons of England · HQIP Healthcare Quality Improvement Partnership · BTOG · Society for Cardiothoracic Surgery in Great Britain and Ireland

Introductory Pack

As well as this booklet, your pack should also include the following:

- Our most recent NLCA State of the Nation Report
- Our most recent NLCA Patient and Public Report
- Terms of Reference

Meetings

PPI Chair

Clinical leads & fellow

Patients

Methodologists, data scientists & statisticians

Relatives, friends & carers

Project manager & co-ordinator

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National Lung Cancer Audit

PPI Contribution to reports

NLCA
National Lung Cancer Audit

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National Lung Cancer Audit
State of the Nation 2026

An audit of care received by people diagnosed with lung cancer between 1 January 2024 to 31 December 2024 in England and Wales.

Published February 2026

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www.natcan.org.uk/audits/lung/

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PPI Contribution to reports

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💡 **PPI Question**: How can we help patients understand NLCA outputs?

This report was prepared by members of the NLCA project team

Neal Navani, NLCA Senior Clinical Lead
John Conibear, NLCA Oncology Lead
Doug West, NLCA Thoracic Surgical Lead

Clinical Effectiveness Unit, RCS England
Lauren Dixon, NLCA Clinical Fellow
Joanne Boudour, NLCA Senior Project Manager
Faine Chan, NLCA Project Coordinator
Adrian Cook, NCLA Senior Statistician
Sarah Cook, NLCA Methodologist
David Cromwell, NLCA Methodologist

We would like to thank and acknowledge the members of the National Lung Cancer Audit Patient and Public Involvement Forum and Roy Castle Lung Cancer Foundation for their guidance in producing this report.

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NLCA National Lung Cancer Audit
NATCAN National Cancer Audit Collaborating Centre

State of the Nation Patient and Public Report 2026

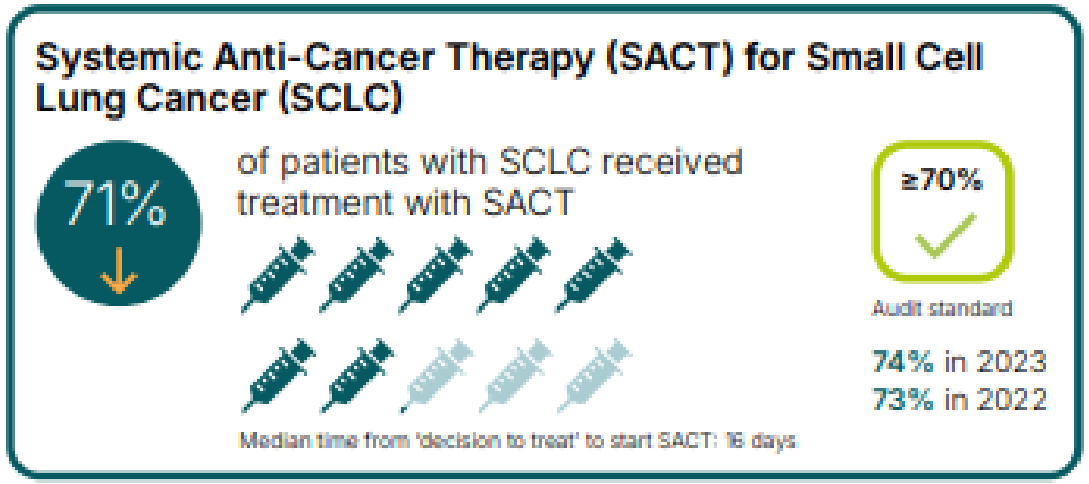
Results of the National Lung Cancer Audit for people diagnosed with lung cancer in England and Wales during 2024
(Published 2026)

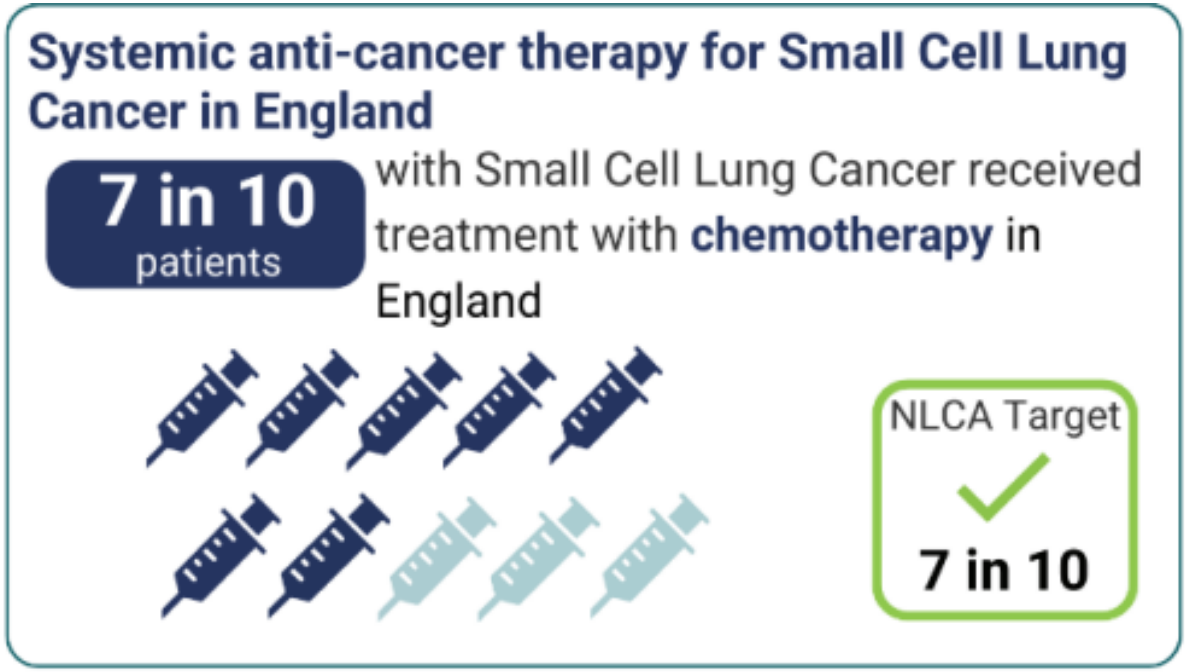
www.natcan.org.uk/audits/lung/

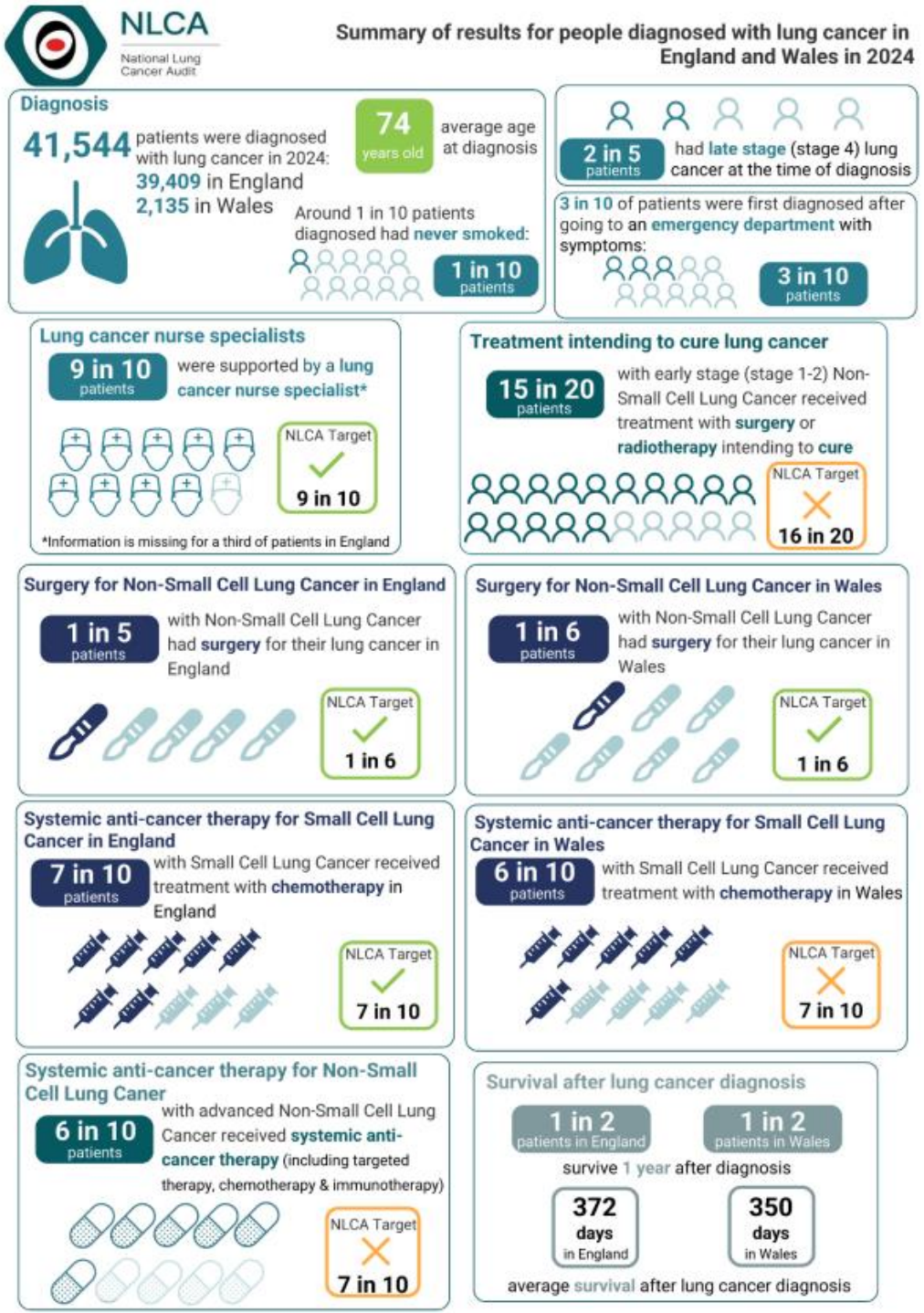
PPI Contribution to reports

NLCA
National Lung Cancer Audit

💡 **PPI Question**: Can we present data in more meaningful ways?







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Contribution to research

PPI Question: Why do some patients receive treatment while others do not?

Open access Original research

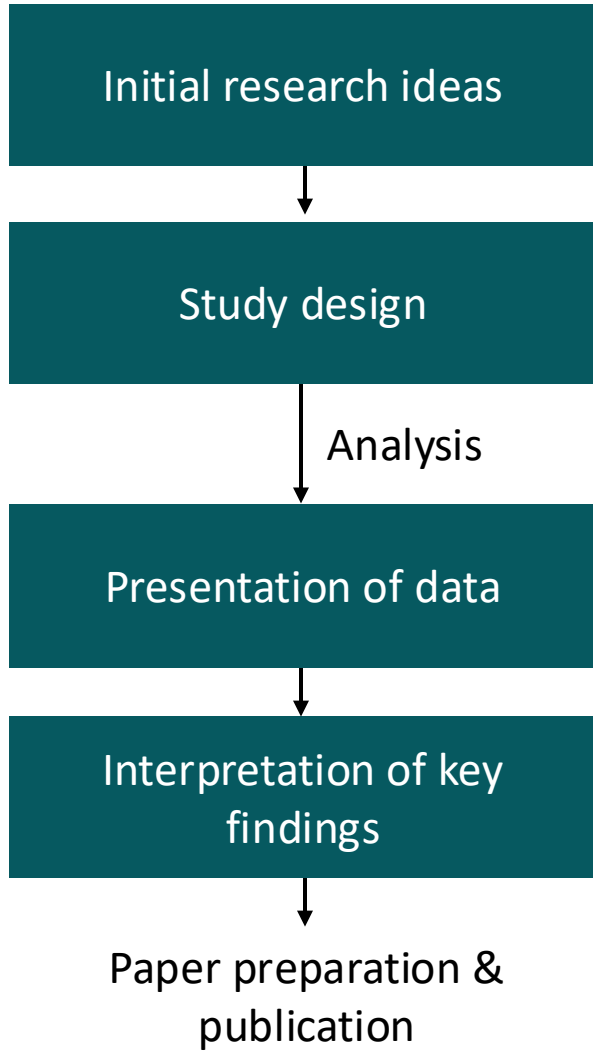
BMJ Oncology

Utilisation patterns of systemic anticancer therapy (SACT) in patients with advanced non-small cell lung cancer (NSCLC) in England

Lauren Kari Dixon ,[1,2] Adrian Cook,[1] Sarah Cook,[1,3] Ella Barber,[1] Joanne Boudour,[1] John Conibear,[4] Douglas West,[5] Neal Navani,[6,7] David A Cromwell[1,3]

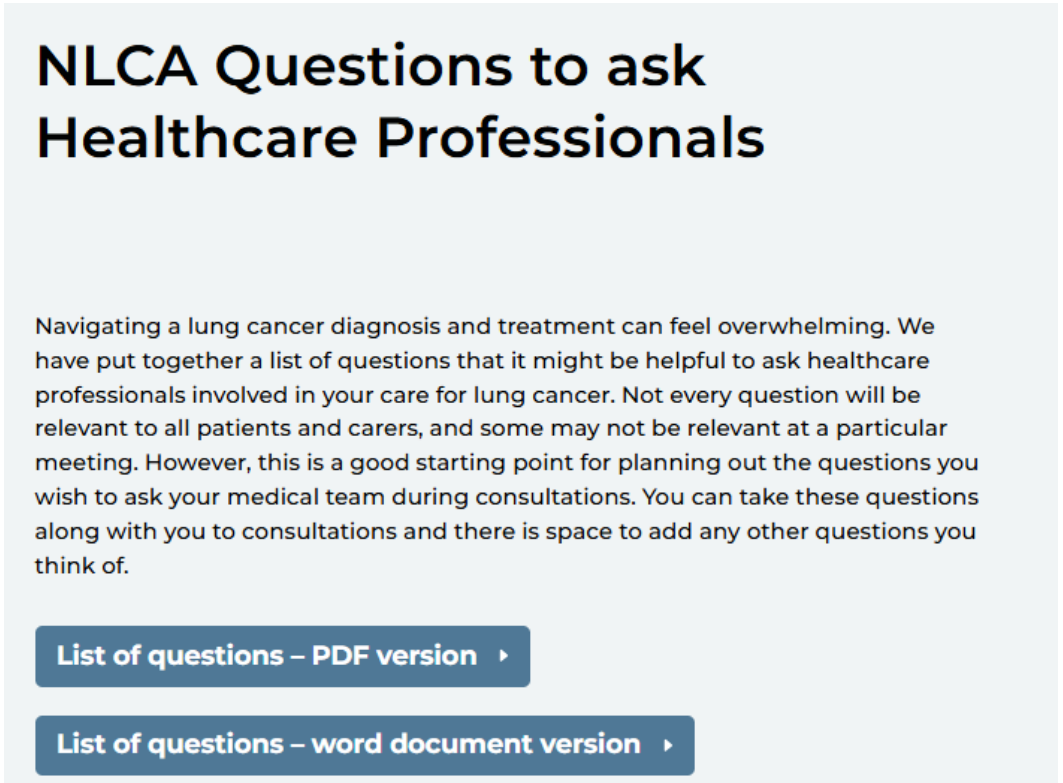
Acknowledgements

We thank the members of the National Cancer Audit Collaborating Centre (NATCAN) for their support and guidance throughout this work, and the members of the National Lung Cancer Audit (NLCA) Patient and Public Involvement (PPI) Forum for their valuable insights, which have helped shape the interpretation and presentation of these findings.



Patient & public resources

💡 **PPI Question**: What questions should I ask my healthcare team?



NLCA Patient Questions to ask Healthcare Professionals

Navigating a lung cancer diagnosis and treatment can feel overwhelming. Below is a list of questions that it might be helpful to ask healthcare professionals involved in your care for lung cancer. Not every question will be relevant to all patients and carers, and some may not be relevant at a particular meeting. However, this is a good starting point for planning out the questions you wish to ask your medical team during consultations. You can take these questions along with you to consultations.

Information:

- What written information will I receive about the management of my cancer?
- Can I decide how much information I should receive about the management of my lung cancer?
- Can I bring a relative or friend to my consultations?
- When will someone explain to me what treatment options are available? Who will this be?
- Please can I have the contact details for relevant patient-support organisations?

Diagnosis:

- What type of lung cancer do I have?
- What stage is my lung cancer?
- Has my cancer already spread from my lungs? Is the cancer likely to spread in the future?
- What tests am I likely to have and what are they for?
- How long do the results of the tests take to come through?

Patient & public resources

💡 **PPI Question**: How can we help patients understand NLCA outputs?

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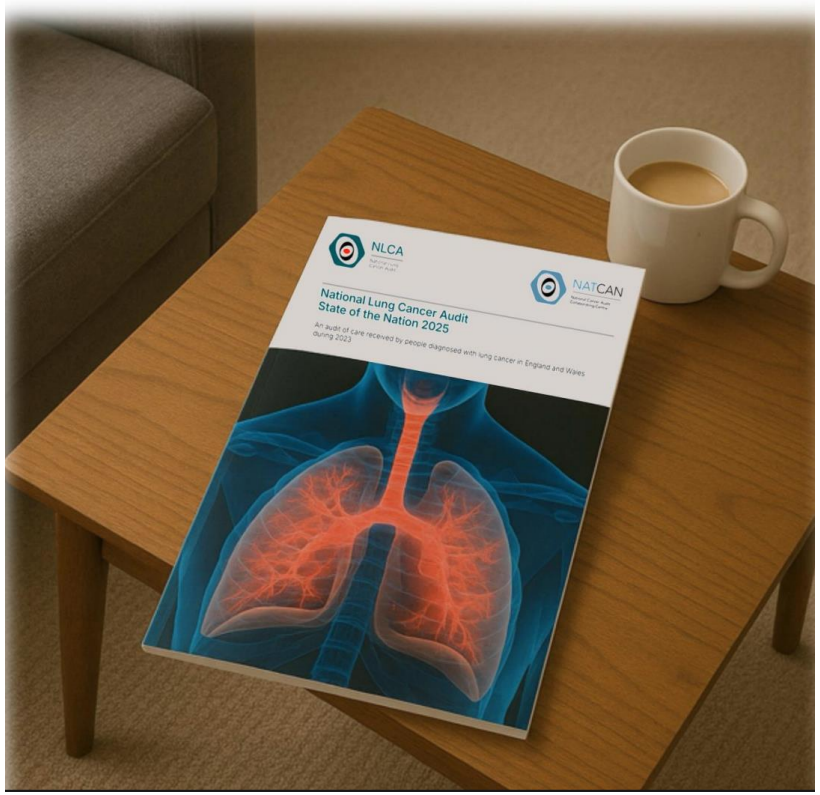
NATCAN National Cancer Audit Collaborating Centre

A patient guide to statistics used in the National Lung Cancer Audit



5. What a percentage means

Percentages help us describe information in a way that's easy to compare.

For example: If we say 30% of patients had surgery, that means 30 out of every 100 people with lung cancer received surgery.

Other examples:

- 5 out of 10 patients = 50% (or a half)

- 1 out of 4 patients = 25% (or a quarter)

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Mean

The mean is what most people call the average. You add up all the numbers and then divide by how many numbers there are.

Example: If the ages of five patients are 60, 65, 68, 70, and 72, the mean age is (60 + 65 + 68 + 70 + 72) ÷ 5 = 67.

Median

The median is the middle number when all the numbers are arranged from smallest to largest.

Example: For the ages 60, 65, 68, 70, and 72, the median is 68 because it's in the middle. Half the patients are younger than 68, and half are older.

The median is often used for things like age because it isn't affected by very young or very old ages.

Mode

The mode is the number that appears most often in a group.

Example: If the ages are 60, 65, 65, 68, and 70, the mode is 65 because it appears twice.

Each of these numbers helps describe a group in a different way. Sometimes one is more useful than the others depending on the information.

10. Key Messages to Remember

- Statistics help us understand lung cancer care so we can improve it.
- They describe groups of people, not individuals.
- **You are not a number. Your care is personal.**

Contribution to quality improvement

PPI Question: Does every patient have access to a lung cancer nurse specialist?

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LUNG CANCER NURSING UK

Improving Access to LCNS Care

National Lung Cancer Audit Quality Improvement Initiative, in collaboration with Lung Cancer Nursing UK

10 Steps to Improving Access to LCNS Care:

1. Review your data in the NLCA Dashboard
Review your local results in the NLCA Dashboard: is there anything from the list below that can improve your service?

2. Train All Staff
Ensure every LCNS understands how to complete COSD fields accurately. Include training for new starters (e.g. Y1, Y3, Y4 categories).

3. Monthly Validation
Nominate an LCNS to validate data each month with cancer services support.

4. Check Caseloads
Review LCNS:patient ratio. Aim for ≤1:40 (NOLCP recommendation).

5. Review Job Plans
Ensure weekly activity covers all clinical settings. Highlight gaps to management.

6. Build the Case
Develop business cases with managers to increase LCNS staffing to NOLCP levels.

7. Administrative Support
Introduce admin support so LCNSs can focus more time on clinical care.

8. Strengthen MDT Links
Communicate with the wider MDT about the LCNS role and its impact on quality care.

9. Collaborate with CNS Teams
Work with other CNSs to share knowledge, avoid duplication, and improve patient experience.

10. Patient Feedback
Run local patient surveys to identify gaps and address needs.

Together we can improve care
By working collaboratively, we can ensure that every patient with lung cancer benefits from the support of an LCNS.

Contact us:
natcan.org.uk/audits/lung
nlca@rcseng.ac.uk
lcnuk.org

"Think beyond the data. Think about what the data actually means."

Where next?

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National Lung Cancer Audit

NLCA
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"The patient voice needs to be front and centre in the cancer treatment conversation, and I am convinced that the PPI teams in NATCAN ensure that this continues to be the case."

Duncan, PPI Chair for the National Lung Cancer Audit (NLCA)

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Frank Burroughs

Chair – PPI Forum

National NHL Audit – NATCAN

Volunteering with NATCAN has given me the opportunity to contribute to a project that is likely to have a lasting impact on the lives of NHL patients

Activities I have been involved with include:

- Attending and presenting at Quality Improvement events bringing all ten audits together
- Giving my experience as feedback for the patient and public version of the audit's annual State of the Nation report
- Writing a blog on the patient's perspective of data driven quality improvement in healthcare, and the future potential this offers
- Feeding back thoughts and ideas to help shape the latest version of the NATCAN dashboard
- Chairing the PPI Forum and engaging with other volunteers to make sure the patient voice influences the audit and and helps to determine future priorities

Being involved in the audit is a highly rewarding experience – challenging and fun in equal measure – and none of it would be possible without the data!

People Involvement Network – PIN

Presenter: Vikki Hart, Senior Project Manager

Date: Monday 22nd of June, 2026

people involvement network

people
involvement
network

NATCAN
National Cancer Audit
Collaborating Centre

What is PIN?

A new, exciting, **highly-collaborative and supportive space**, where a **community** of like-minded individuals, with extensive and varied, professional and personal, **lived-experience** of the impact of a cancer diagnosis, can **expand** on the excellent work being undertaken by the individual audit, PPI Forums.

people involvement network

NATCAN
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WHY INITIATE A NEW NETWORK?

"The Network will be invaluable in helping to **facilitate collaborative working** and the **sharing of good practice** between audits, and in **supporting new work** on the horizon for NATCAN. I am looking forward to seeing what possibilities arise because of this important new initiative."

Lesley Goodburn, PPI Chair for the National Pancreatic Cancer Audit (NPaCA).

people involvement network

MEMBERSHIP

Core Members Group

This currently consists of the Chairs of the current 10 National cancer audits sitting within NATCAN, and a small number of NATCAN representatives.

Future Expansion Plans

Expanded to include representation from:

- Charity partners
- National Patient-focussed organisations
- Funder representation
- Potentially other members of the public.

people involvement network

PIN ACTIVITIES TO DATE

- ✓ Discussed and agreed on a name and identify for the network
- ✓ Supported wider research activities e.g. providing feedback to HQIP
- ✓ Representing NATCAN at conferences/events e.g. Frank's support today
- ✓ Provided feedback on the design of the new NATCAN, Patient and Public Involvement focussed web pages – https://www.natcan.org.uk/ppi

people involvement network

NEXT STEPS/ACTIVITIES

- ✓ Second meeting of the group planned for August
- ✓ Develop a short, annual newsletter
- ✓ Establishing a social media presence
- ✓ Supporting wider research activities and future opportunities
- ✓ Providing feedback on the design of the NATCAN combined data dashboards planned for the Autumn
- ✓ Exploring opportunities for influencing policy
- ✓ Consideration given to expanding PIN membership
- ✓ Implementation of speaker programme plans

people involvement network

EXAMPLE SPEAKER PROGRAMME

Speaker	Example Topic
NHS England	Explaining the work of the Cancer Treatment Variation Group
NDRS	Explanation of data flows and how the data is processed
useMYdata	Why correctly acknowledging patient data matters
NATCAN	Past, Future and Present view of our work
PPI Chair	How to engage communities and raise awareness
Data Scientist	How we interpret data and present our results

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Thank you!

Connect with us

Acknowledgements:

NATCAN PPI Forums, Project teams, Board, Executive, Stakeholders

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