



Royal College
of Surgeons
of England
ADVANCING SURGICAL CARE

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



NHS
England



HQIP
Healthcare Quality
Improvement Partnership

 **NDRS**
NATIONAL DISEASE REGISTRATION SERVICE



GIG
CYMRU
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WALES | Rhwydwaith
Canser Cymru
Wales Cancer
Network



NATCAN
National Cancer Audit
Collaborating Centre

National Cancer Audit Collaborating Centre (NATCAN)

Julie Nossiter PHD
Director of Operations, NATCAN

31st October 2024

@NATCAN_news



NATCAN

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Issues with quality of cancer care in England & Wales NHS

- Deficits & inequalities in receipt of evidence-based care
- Cancer outcomes and experience of care varies between hospitals
- UK lags behind other countries in cancer outcomes
- Increasing waiting times



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

Funded by National Health Service (NHS) England and the Welsh Government initially for 3 years

Clinical Effectiveness Unit



Academic partnership since 1998
Clinical Effectiveness Unit (CEU)
supports 10 LSHTM academic
posts currently

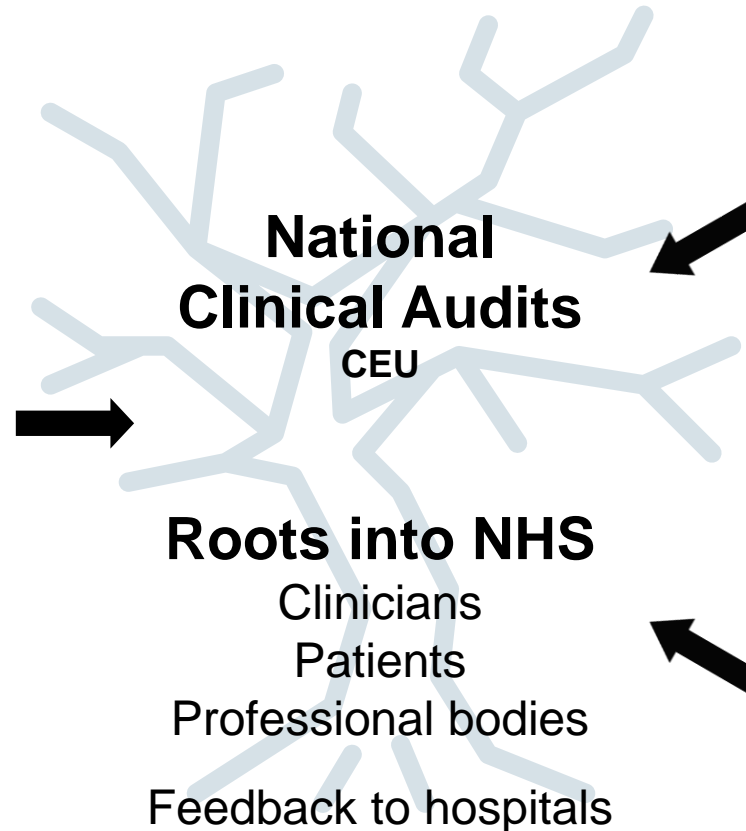
Career progression
Research Fellows to Professors



- Key feature is a multidisciplinary approach to audit and research, combining clinical and methodological expertise
- > 35 Clinical Fellows gained methodological & research skills



Grant-funded research projects and fellowships
In-depth methodological research 7 ongoing NIHR/MRC projects based at LSHTM (current funding £8.5M)



Journal articles
Focussed methodological topics 170 peer-reviewed CEU publications since 2018

LSHTM PhDs
Methodological development → clinical epidemiology Audit clinical fellows 13 ongoing PhDs 9 completed PhDs

Home of the ten national cancer audits in England & Wales

New cancer audits – contract started October 2022

- 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

Established cancer audits moved into NATCAN – throughout 2023

- Lung Cancer – 2005  **NLCA**
National Lung Cancer Audit
- OG Cancer – 2006  **NOGCA**
National Oesophago-Gastric Cancer Audit
- Bowel Cancer – 2010  **NBOCA**
National Bowel Cancer Audit
- Prostate Cancer – 2013  **NPCA**
National Prostate Cancer Audit



NATCAN: key features

- Close **clinical-methodological partnership**
- Close links with all **stakeholder groups**
 - Clinical professional bodies
 - NHS commissioners & regulators
 - Patients, charities, public
- Use of routine, **national (existing and linked) datasets** only
- **Audit delivery & QI informed by research & development:**
 - Methodological development
 - Clinical epidemiology
 - Health services research





NATCAN: innovations

- Use of **more timely, more frequent data**
 - Rapid cancer registration data (RCRD) as well as gold-standard registration data
- **Shorten delays & increase frequency of reporting** – quarterly
- **‘State of the Nation’ reports** (10 pages, 5 recommendations)
 - Previous Annual Reports often lengthy
 - Patient Summaries and infographics
- **Greater focus on Quality Improvement (QI)**
 - Define 5 QI goals mapped to 10 performance indicators
 - QI tools & activities: flexible and responsive, based on experience in CEU
 - Aiming to ‘close the audit cycle’ – design, implement & evaluate QI initiatives
 - Closely aligned with existing national initiatives for QI



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Collaborating Centre

NATCAN: progress so far & next steps

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**

From second year onwards (from Oct 2023)

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

From third year onwards (from Oct 2024)

- Design **QI initiatives**
- Roll out of **'full audit cycle' projects**



NATCAN team & stakeholders

NATCAN: Current Organisation



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HEALTHCARE QUALITY IMPROVEMENT PARTNERSHIP

Clinical Effectiveness Unit-RCSEng

NATIONAL CANCER AUDIT COLLABORATING CENTRE (NATCAN)

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 (Ajay Aggarwal), Director CEU (David Cromwell), Senior Statistician (Kate Walker), Senior Clinical Epidemiologist (Jan van der Meulen)

TECHNICAL ADVISORY GROUP

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

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

QUALITY IMPROVEMENT TEAM (working with all cancer audits)

PATIENT AND CARER PANELS (one for each cancer audit)

CEU: NVR & Crane / health services projects

LSHTM: NIHR, MRC funded health services research

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

Lung cancer	Prostate cancer	Bowel cancer	OG cancer	Breast cancer: Primary	Breast cancer: Metastatic	Pancreatic cancer	Kidney cancer	Ovarian cancer	Non-Hodgkin Lymphoma
<p>Clinical leads: Neal Navani (Respiratory medicine), Doug West (Surgery, SCTS), John Conibear (Oncology, RCR)</p> <p>Senior Methodologists: David Cromwell</p> <p>Statistician/Data Scientist: Adrian Cook, Ella Barber</p> <p>Clinical Fellow: Lauren Dixon</p> <p>Audit Manager: Joanne Boudour</p>	<p>Clinical leads: Alison Tree (Oncology, BUG), Noel Clarke (Surgery, BAUS)</p> <p>Senior Methodologists: Jan van der Meulen, Tom Cowling</p> <p>Statistician/Data Scientist: Adrian Cook, Emily Mayne</p> <p>Clinical Fellow: Joanna Dodkins</p> <p>Audit Manager: Marina Parry</p>	<p>Clinical leads: Mike Braun (Oncology), Nicola Fearnhead (Surgery, ACPGBI)</p> <p>Senior Methodologists: Jan van der Meulen, Kate Walker</p> <p>Clinical Fellow: Adil Rashid, Leo Watton</p> <p>Data Scientists: Angela Kuryba, Helen Blake</p> <p>Audit Manager: Karen Darley</p>	<p>Clinical leads: Nigel Trudgill (Gastroenterology, BSG), James Gossage (Surgery, AUGIS), Tom Crosby/Betsan Thomas</p> <p>Senior Methodologist: David Cromwell</p> <p>Methodologist: Diana Withrow</p> <p>Clinical Fellows: Jemma Boyle, Sarah Blacker, Liyang Wang</p> <p>Data Scientist: Christine Delon</p> <p>Audit Manager: Jibby Medina</p>	<p>Clinical leads: David Dodwell (Oncology, UKBCG), Keiran Horgan (Surgery, ABS)</p> <p>Senior Methodologist: David Cromwell</p> <p>Methodologist: Diana Withrow</p> <p>Clinical Fellows: Jemma Boyle, Sarah Blacker, Liyang Wang</p> <p>Data Scientist: Christine Delon</p> <p>Audit Manager: Jibby Medina</p>	<p>Clinical leads: David Dodwell, Keiran Horgan, Mark Verill (Medical Oncology, UKBCG)</p> <p>Senior Methodologist: David Cromwell</p> <p>Methodologist: Diana Withrow</p> <p>Clinical Fellows: Jemma Boyle, Sarah Blacker, Liyang Wang</p> <p>Data Scientist: Christine Delon</p> <p>Audit Manager: Jibby Medina</p>	<p>Clinical leads: Nigel Trudgill (Gastroenterology, BSG), Andrew Smith (Surgery, AUGIS), Ganesh Radhakrishna (RCR)</p> <p>Senior Methodologist: David Cromwell</p> <p>Data Scientist: Suzi Nallamilli</p> <p>Clinical Fellow: Amanda McDonell</p> <p>Audit Manager: Vikki Hart</p>	<p>Clinical leads: Amit Bahl (Oncology, BUG), Grant Stewart (Surgery, BAUS)</p> <p>Senior Methodologists: Jan van der Meulen, Tom Cowling</p> <p>Clinical Fellow: Raghav Varma</p> <p>Data Scientist: Emily Mayne</p> <p>Audit Manager: Marina Parry</p>	<p>Clinical leads: Sudha Sunder (Surgery, BGCS), Agnieszka Michael (Medical Oncology, BGCS)</p> <p>Senior Methodologists: Jan van der Meulen, Ipek Gurool Urganci</p> <p>Clinical Fellow: Georgia Zachou</p> <p>Methodologist: Andrew Hutchings</p> <p>Audit Manager: Joanne Boudour</p>	<p>Clinical leads: Cathy Burton (Haematology, BSH), David Cutter (Oncology, BSH)</p> <p>Senior Methodologists: Kate Walker, Methodologist: Lu Han</p> <p>Clinical Fellow: Ruhi Kanani</p> <p>Data Scientist: Ella Barber</p> <p>Audit Manager: Vikki Hart</p>

ABS, Association of Breast Surgery; ACPGBI, Association of Coloproctology of Great Britain and Ireland; AUGIS, Association of Upper 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 Health 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.

Clinical – methodological partnerships

Views of all stakeholders shape the Audits



Who We Are

 x10 cancer audits	 x33 clinicians	 x17 academics
 x6 managers to ensure the audits run smoothly		
 x1 NATCAN board comprising 18 members	 x1 NATCAN executive team	
 x10 Patient and Public Forums	 x10 Clinical Reference Groups	
 x20 patient charities who we work closely with	 x12 clinical professional organisations who we collaborate with	
 15 years + working on cancer audits within the Clinical Effectiveness Unit at the Royal College of Surgeons of England		





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Scoping & Quality Improvement plans



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NATCAN Quality Improvement Plans

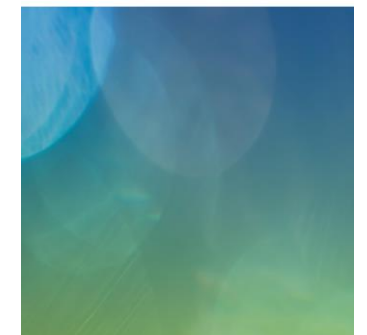
- Summer 2023 - Scoping Exercise with key stakeholders
 - Defined the scope and care pathway for the 'new' cancer audits
 - Refreshed the scope for the 'established' audits
- Spring 2024 – Continued this work to develop Quality Improvement Plans
 - 5 QI goals mapped to national guidelines and standards
 - 10 performance indicators – measurable, actionable, improvable
 - Improvement methods and activities that will support implementation of QI plans
 - Strategies for reporting and disseminating results
 - Published September 2024



NATCAN publishes Quality Improvement Plans



NKCA
National Kidney Cancer Audit
Quality Improvement Plan – September 2024





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Data & Performance Indicators

Use of routine, national cancer datasets

England

Cancer Outcomes and Services Dataset (COSD)

National Cancer Registration data (NCRD & RCRD)

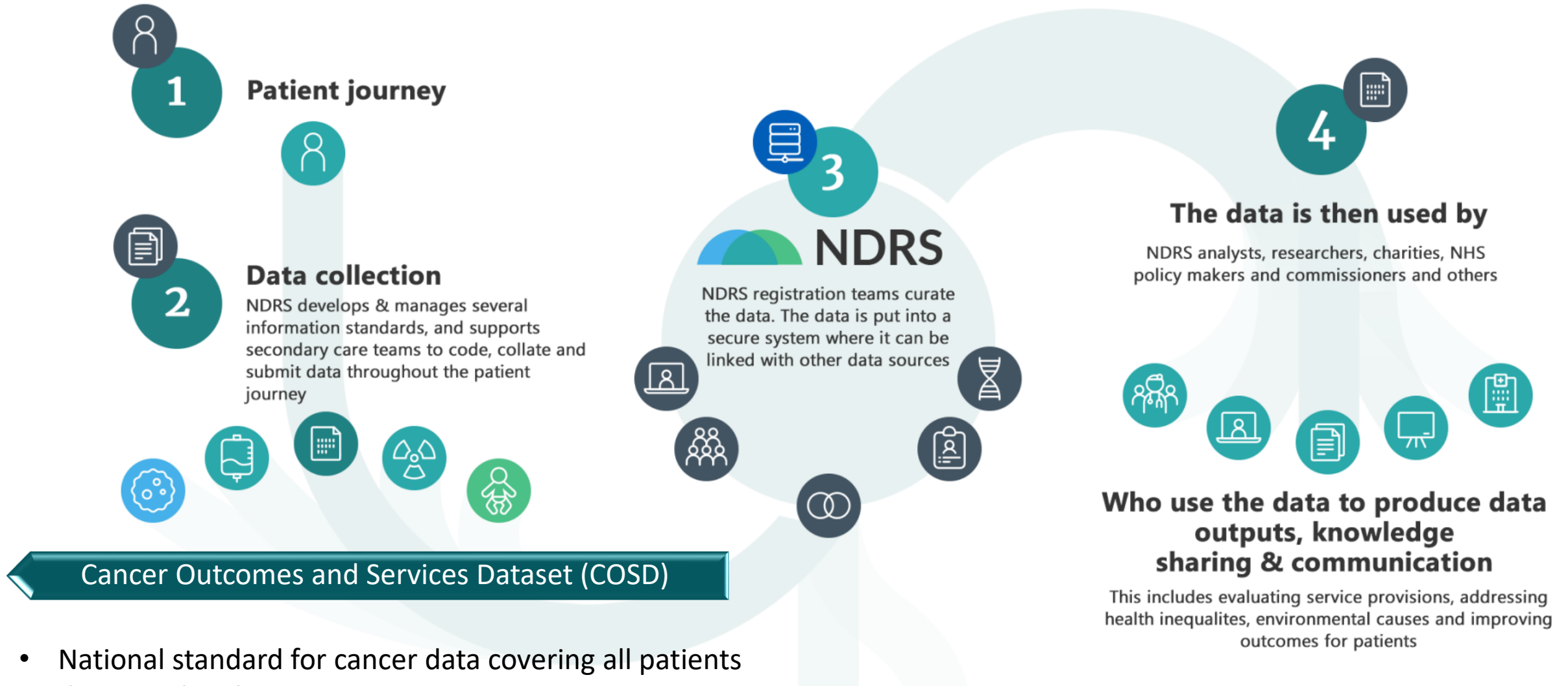


Wales

CaNISC or Cancer Information System

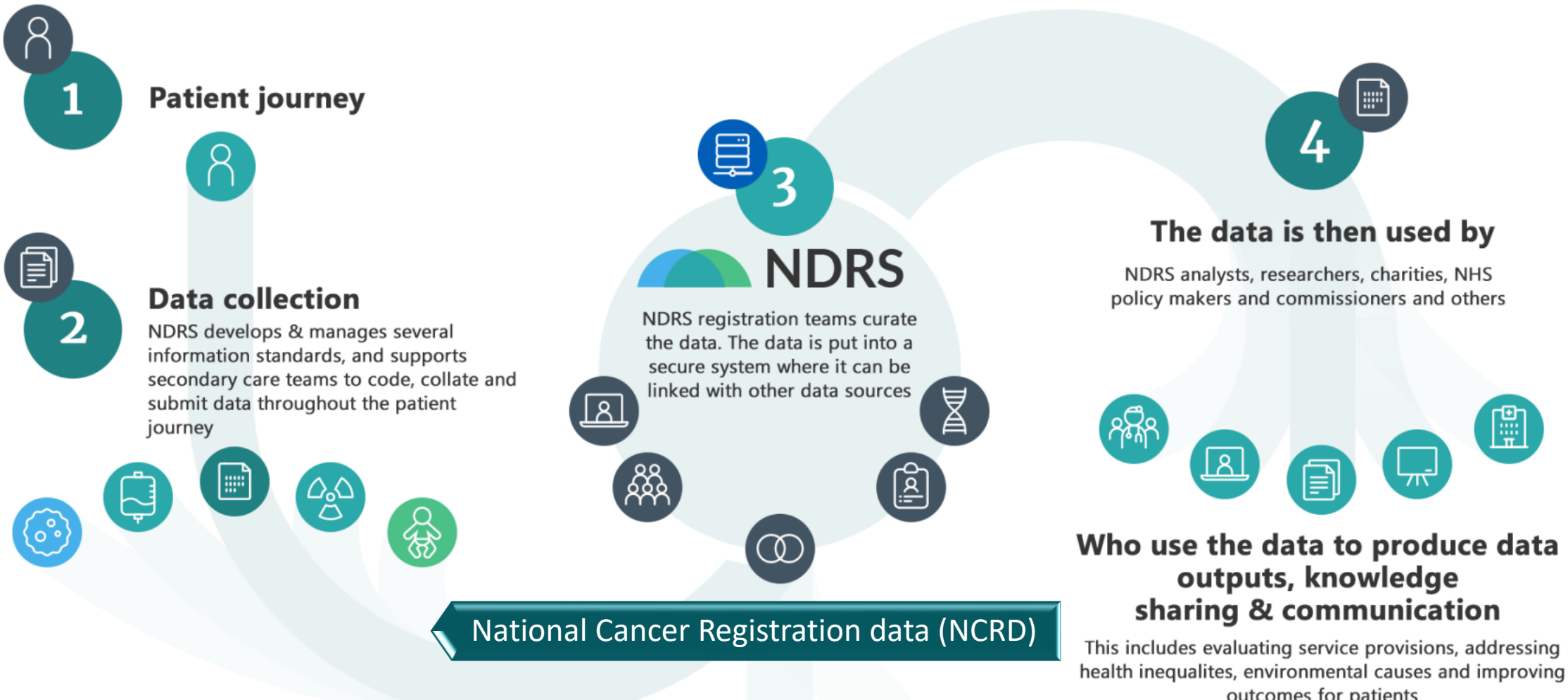


- Only existing, routinely collected data are utilised – no bespoke manual, data entry
- Model first developed by the National Prostate Cancer Audit in 2013
- Lung (2015), bowel & OG (2024) moved from a model based on their ‘own’ core dataset & bespoke data portal
- Single, data application in each country across all diagnostic codes



- National standard for cancer data covering all patients diagnosed with cancer or receiving cancer treatment in or funded by the NHS in England
- Site-specific & generic data items
- Submitted from different hospital & pathology systems on a monthly basis

*Slide adapted from NDRS presentation during COSD Roadshows 2024



- ‘Gold-standard’ Cancer Registration data (NCRD)
- Available on an annual basis
- Considerable delay between the last recorded episode and the data being available for analysis (> 24 months following diagnosis)





Rapid Cancer Registration Data (RCRD): England

- Key innovation in 2020/21 in response to Covid pandemic
- Contains proxy tumour registrations from 2018 onwards and some associated events on the cancer patient pathway
- Provides a quicker, indicative source of cancer data compared to the National Cancer Registration Data (NCRD)
- Available on a quarterly basis
- Much shorter delay: 3-4 months following diagnosis
- Challenges
 - Lower case ascertainment
 - Contains only limited data items
 - Focuses on data items generic across cancer sites



Linkage to routine, national datasets: annual



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- Administrative hospital data and cancer treatment data for describing diagnostic pathway patterns, treatments received and clinical outcomes

England

Cancer Outcomes and Services Dataset (COSD)

National Cancer Registration data (NCRD)

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

CaNISC or Cancer Information System

Patient Episode Database for Wales (PEDW)

Radiotherapy Data available in Canisc

Mortality data - Office for National Statistics (ONS)

Linkage to routine, national datasets: quarterly



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- Administrative hospital data and cancer treatment data for describing diagnostic pathway patterns, treatments received and clinical outcomes

England

Cancer Outcomes and Services Dataset (COSD)

National Cancer Registration data (RCRD)

Hospital Episode Statistics (HES)

Systemic Anti-Cancer Therapy (SACT) dataset

National Radiotherapy Dataset (RTDS)

Mortality data - Office for National Statistics (ONS)

Cancer Waiting Times (CWT)

HES – inpatient, outpatient, A&E

- Clinical information about diagnoses and procedures
- Patient information, such as age group, gender and ethnicity
- Administrative information, such as dates and methods of admission and discharge
- Geographical information such as where patients are treated and the area where they live

RTDS

- Radiotherapy treatment (region, dose, fractions)

SACT

- Systemic anti-cancer treatment (regimens, dose, duration)

Audit delivery & quality improvement is informed by research & development



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Indicator development

Accurately measure care by provider
Valid? Technically rigorous?

Risk adjustment

Fair comparisons

Methods for reporting

Timely reliable feedback, statistical power

Understanding variation

Establishing drivers of variation in care

Drive local quality improvement



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Reporting & dissemination



NATCAN Reporting: Quarterly

Data Quality Indicators– published in April & July 2024

- Provide a local perspective on data completeness & identify where improvements are needed
- Data items chosen in collaboration with audit's clinical and methodological experts



Clinical Performance Indicator (PI) reports – published in October 2024

- Timely reporting of initial subset of PIs outlined in each audit's QI Plan, allowing providers to track progress of local QI activities
- Development work, in consultation with stakeholders, is in progress to determine which additional PIs are appropriate for quarterly reporting using RCRD and linked, routine hospital data

NATCAN Reporting: Quarterly Online Interactive Dashboards



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Search...

Reports and publications > Resources > **Data and statistics >** What's new? > Quality improvement >

Home > Data and statistics

Data and statistics

The National Lung Cancer Audit (NLCA) publishes a range of statistics about how NHS services in England and Wales diagnose and treat adults with lung cancer.

Access the Dashboard here >

- Iterative approach to development
- Encourage use and feedback
- User comments guide changes in the next quarter
- Lung – April 2024
- NHL – Sept 2024
- Breast (primary & metastatic), kidney, ovarian, pancreatic – January 2025

NLCA

- Home
- Quarterly report <
- Performance Indicators
- State of the Nation report <
- Contact us
- Updates
- Acknowledgements

NLCA National Lung Cancer Audit

NATCAN National Cancer Audit Collaborating Centre

Introduction

The purpose of the National Lung Cancer Audit (NLCA) is to evaluate the patterns of care and outcomes for patients with lung cancer in England and Wales, and to support services to improve the quality of care for these patients.

The NLCA is part of the National Cancer Audit Collaborating Centre (NATCAN), the home of the ten national cancer audits in England and Wales. This national centre of excellence was established to strengthen cancer services by evaluating the process of diagnosis and treatment, and patient outcomes in multiple cancer sites.

In England, the NLCA receives information from the National Cancer Registration and Analysis Service (NCRAS). NCRAS collects patient-level data from all NHS acute providers on patients with cancer using a range of national data-feeds. This includes the Cancer Registration datasets and the Cancer Outcomes and Services Dataset (COSD). COSD data are submitted to the National Cancer Data Repository (NCDR) monthly via Multidisciplinary Team electronic data collection systems. The information held in the registration dataset is compiled from a number of sources, and clinical sign-off of data submitted to NCRAS is not mandated in England.

For this collection of dashboards, the NLCA was provided with data from the Rapid Cancer Registration Dataset (RCRD). This dataset is compiled mainly from COSD records, and is made available more quickly than the complete cancer registration dataset. However, the speed of production means that the range of data items is limited and several standard data items in the complete registration dataset are unavailable. It also does not have complete coverage of all patients diagnosed with lung cancer in England during the reporting period. The RCRD was linked to other national health care datasets, including Hospital Episode Statistics (HES) admitted patient records, the National Radiotherapy Dataset (RTDS), the Systemic Anti-Cancer Therapy Dataset (SACT), and the Office for National Statistics (ONS) death register.

This collection of dashboards allocates patients to English NHS organisations based on the "trust at diagnosis". The allocation of patients to NHS trusts is based on the best information available when the RCRD is produced; this can result in some misallocation of patients, particularly to tertiary centres which do not typically diagnose large numbers of people with lung cancer. It was not possible to allocate patients to NHS organisations based on the "site first seen", as done in previous reports, because the RCRD did not contain this data item. The algorithm used previously to determine "site first seen" could not be used with the data supplied for these analyses, and we encourage NHS trusts to ensure the COSD field "place first seen" is completed to enable this approach in future.

Dashboard overview

This app contains two sets of dashboards; one set are supplementary resources to accompany the **State of the Nation Report** and the other set form the basis of our **Quarterly Report**



bitly



NLCA

National Lung
Cancer Audit



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Quarterly Report - Performance Indicator Dashboard

Overview

This dashboard aims to provide a local perspective on patterns of lung cancer care across England and to highlight variation over time. It will be updated on a quarterly basis.

It presents performance indicators over a 3-year time period at quarterly increments. Performance indicators were selected from the State of the Nation report, chosen on advice from the audit's clinical experts and considering those that could respond to changes made over the short term.

The intended audience is NHS trusts; by presenting repeated measurement of performance indicators over time, the audit aims to support them to track progress alongside local quality improvement activities.

- **Data source:** Rapid Cancer Registration Dataset (RCRD)
- **Time period:** Q1 2021 - Q4 2023 (01Jan2021-31Dec2023)

User selected inputs

Select NHS Trust:

Airedale NHS Foundation Trust

Select indicator:

Proportion of patients diagnosed via emergency presentation

Proportion of patients diagnosed via emergency presentation

Proportion of patients seen by lung cancer nurse specialist (LCNS)

Proportion of patients with complete disease stage data

Proportion of patients with NSCLC (stage IV) who initiated systemic anticancer therapy within 21 days of diagnosis

Proportion of patients with NSCLC who had curative treatment (Stage I-II, PS 0-2)

Proportion of patients with NSCLC who had curative treatment (Stage IIIA, PS 0-2)

Proportion of patients with NSCLC who had systemic anticancer therapy (stage IIIB-IV, PS 0-1)

Proportion of patients with stage four disease



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Quarterly Report - Performance Indicator Dashboard

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- **Time period:** Q1 2021 - Q4 2023 (01Jan2021-31Dec2023)

User selected inputs

Select NHS Trust:

Airedale NHS Foundation Trust

Track performance overtime

Select indicator:

Proportion of patients diagnosed via emergency presentation



NHS Trust results

Cancer Alliance results

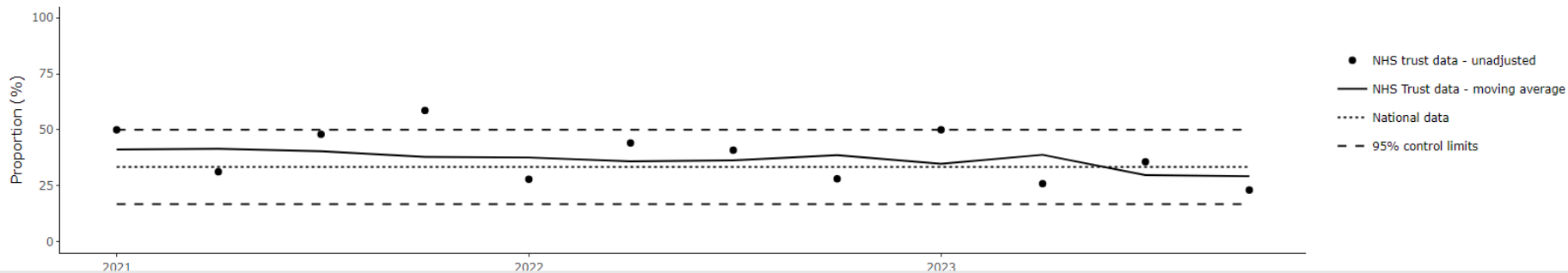
Comparison: Trusts in a Cancer Alliance

Indicator information

Methods information

National Lung Cancer Audit

Proportion of patients diagnosed via emergency presentation at Airedale NHS Foundation Trust



User selected inputs

Select NHS Trust:

Airedale NHS Foundation Trust

Select indicator:

Proportion of patients diagnosed via emergency presentation

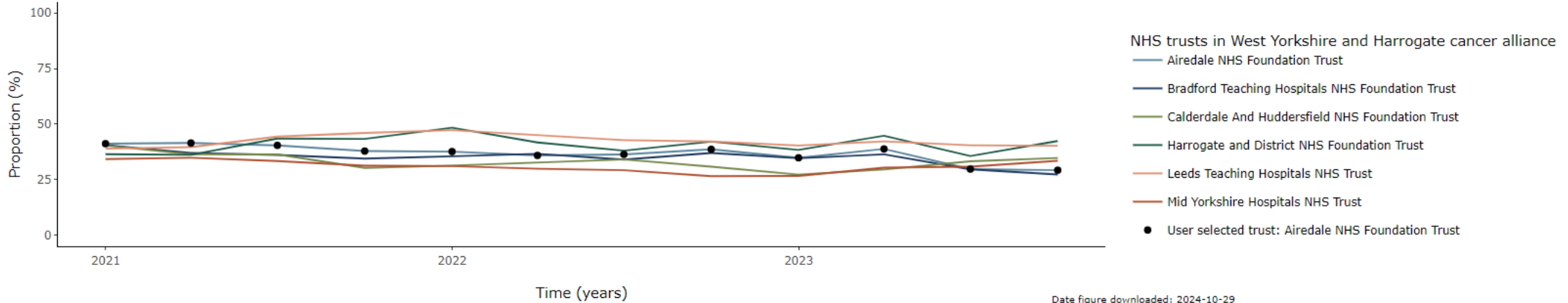
Regional comparison

NHS Trust results Cancer Alliance results **Comparison: Trusts in a Cancer Alliance** Indicator information Methods information

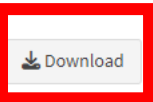
The user has selected Airedale NHS Foundation Trust, which is within the West Yorkshire and Harrogate cancer alliance. The figure and table below present the moving average for all trusts within the West Yorkshire and Harrogate cancer alliance. Trusts with insufficient data calculate the moving average may not appear in the plot. Please see the methods tab for further information

National Lung Cancer Audit

Proportion of patients diagnosed via emergency presentation at NHS trusts in West Yorkshire and Harrogate cancer alliance



Date figure downloaded: 2024-10-29
Data: Q4 2020 - Q3 2023 (01Oct2020 - 30Sept2023)





NATCAN Reporting: Annual 'State of the Nation' Reports

The first results from six new national cancer audits have been published



12.09.24

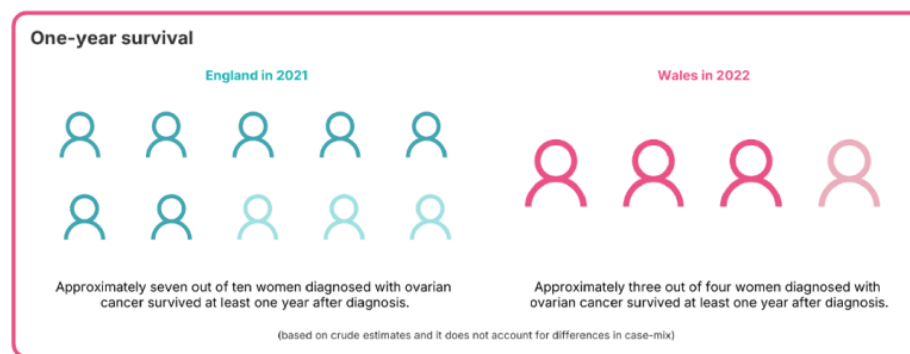
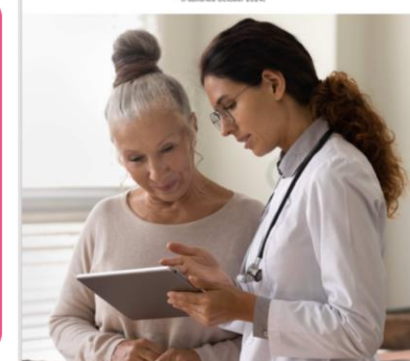
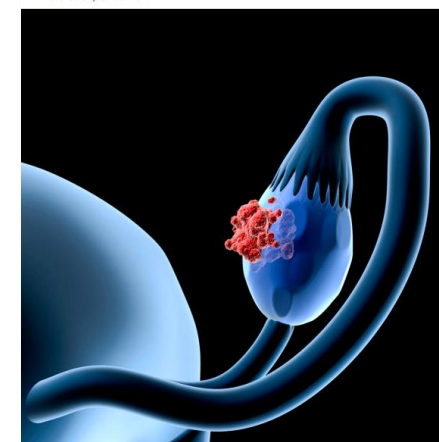
The first results from six new national cancer audits in breast (primary and metastatic), ovarian, pancreatic, non-Hodgkin lymphoma and kidney cancer have been published by the National Cancer Audit Collaborating Centre (NATCAN).

Read the reports here:

- [National Kidney cancer Audit \(NKCA\)](#)
- [National Audit of Metastatic Breast Cancer \(NAoMe\)](#)
- [National Ovarian Cancer Audit \(NOCA\)](#)
- [National Non-Hodgkin Lymphoma Cancer Audit \(NNHLA\)](#)
- [National Pancreatic Cancer Audit \(NPaCA\)](#)
- [National Audit of Primary Breast Cancer \(NAoPri\)](#)

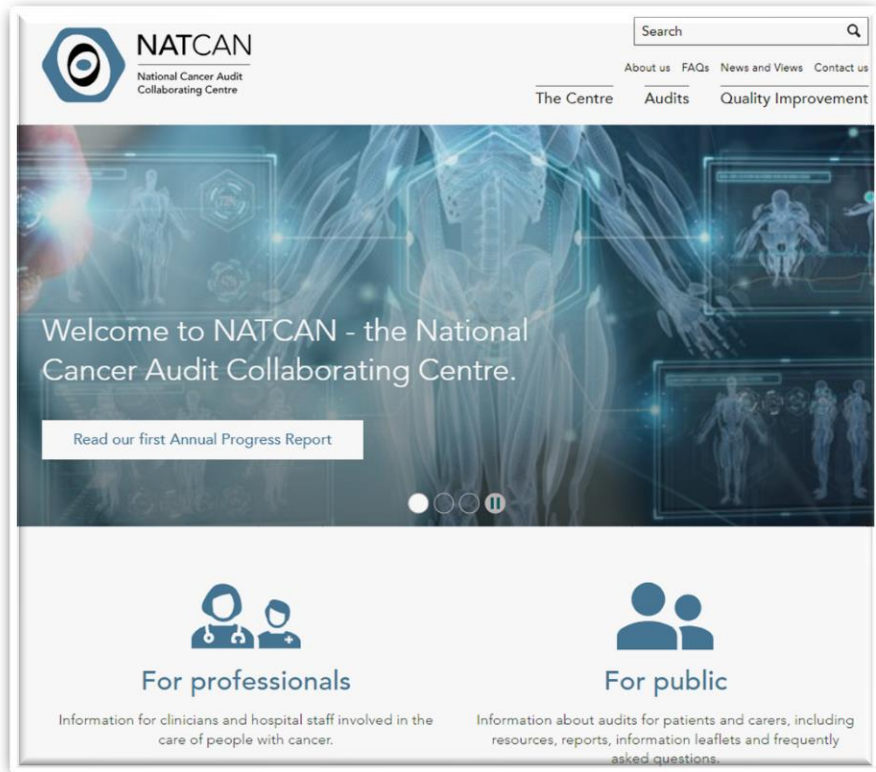


- Provides a concise overview of care received across England and Wales
- Describe national patterns of care against measurable standards
- Provide five key recommendations for action
- Accompanying provider-level results
 - benchmarking and identify unwarranted variation in care and outcomes
- Patient summary also available



NATCAN website

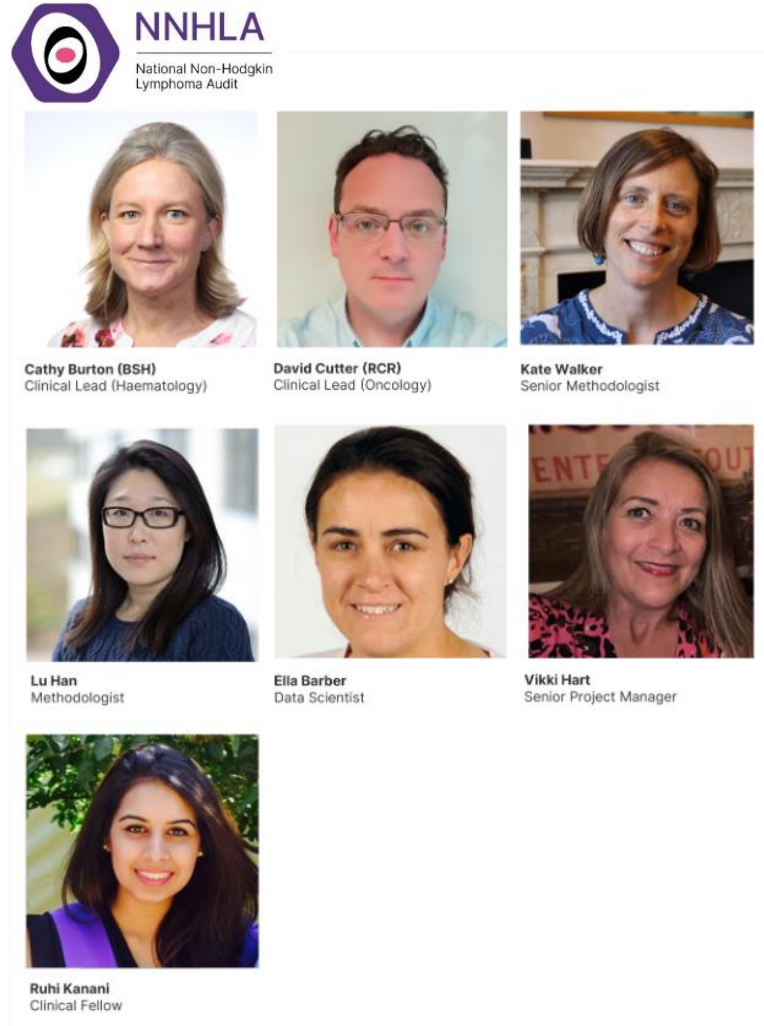
- All stakeholders can explore our comprehensive range of information and resources
- Latest updates and announcements



www.natcan.org.uk



- Audit team pages



- Interviews



Cathy Burton, Clinical Lead (Haematology), National Non-Hodgkin Lymphoma Audit



Rincy George, Policy Officer, Blood Cancer UK

[@NATCAN_news](https://twitter.com/NATCAN_news)



NATCAN: next steps 2024/25

- **Innovations in reporting & feedback**
 - Design and rollout of interactive dashboards across all audits
 - Further development will expand features of the dashboards
 - Downloadable reports, bespoke design responding to needs of each type of end-user
- **Stimulating improvement of cancer services**
 - Each audit will design & implement a national QI initiative
 - QI tools for local teams to identify good practice / areas of weakness
 - National programme of QI workshops / webinars
 - Part of a development & research programme of QI methods
- **And beyond...**
 - Addition of other cancer types
 - Expand datasets – primary care data, **PROMs**
 - UK wide
 - International collaborations



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National Prostate Cancer Audit: use of PROMs



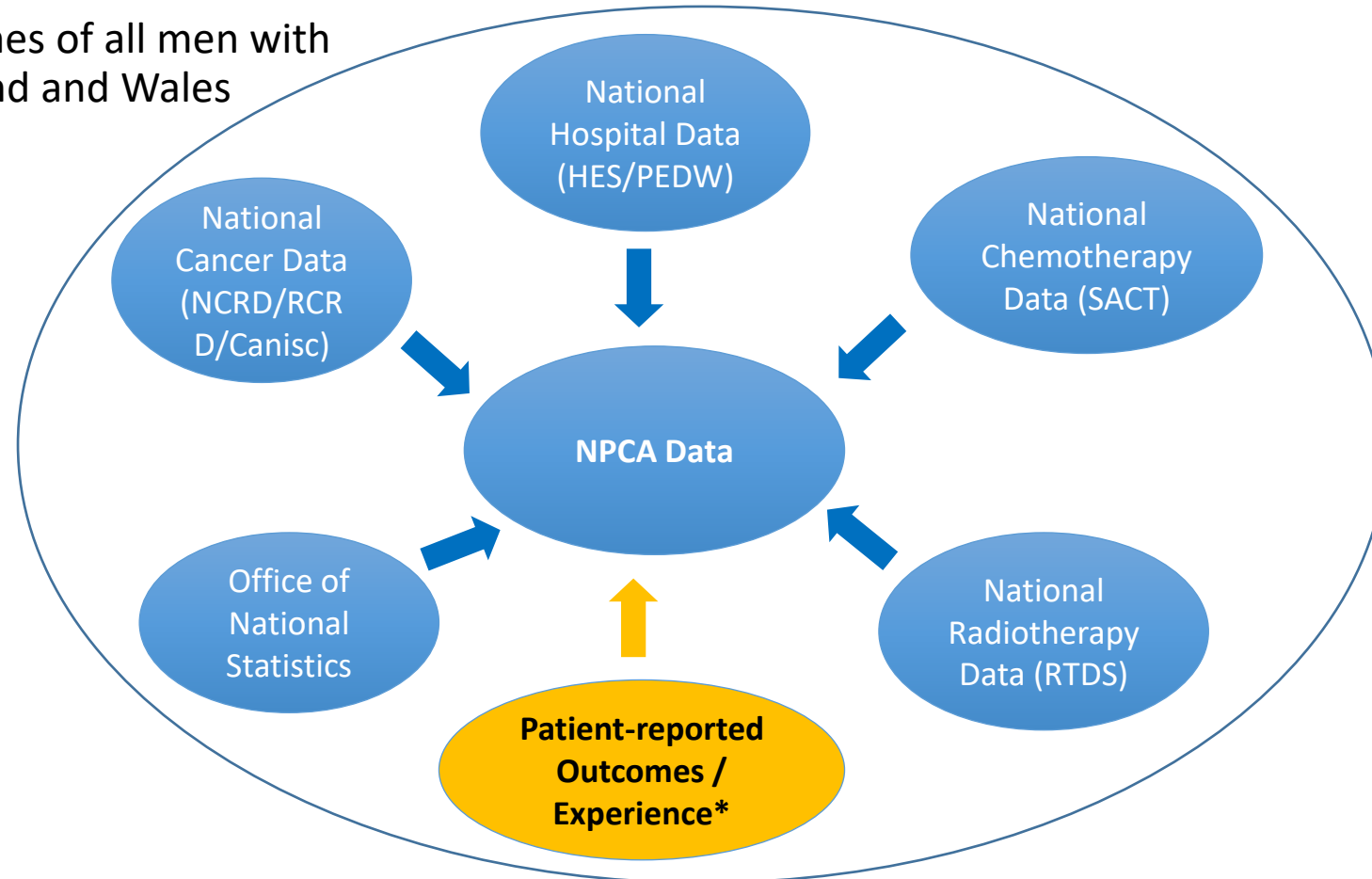
NPCA

National Prostate
Cancer Audit

National Prostate Cancer Audit: routine, national data



- Evaluates the care and outcomes of all men with newly diagnosed PCa in England and Wales



- One of the largest PROMs/PREMs programmes
- Contemporary evidence on functional outcomes from *large-scale, real-world clinical practice*

*Funding has not been prioritised to continue this programme

Background

- Patients undergoing radical treatments for localised prostate cancer (PC) usually survive for many years
 - adverse impact on **sexual, urinary or bowel functioning**
- PROMs determine patients' views of their symptoms, functional status and health-related QoL
 - measure **safety** and **effectiveness** of care
 - **early** performance assessment
- PREMs focus on aspects of the humanity of care received
 - measure **experience** of care
- PROMs/PREMs: measure the **quality of clinical care**

NPCA patient survey

- Aims: to determine variation among providers in men's
 - functional outcomes after radical treatment
 - 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)
- Survey sent to men at least 18 months after diagnosis:
 - who had radical treatment or who were on active surveillance
 - **First round:** diagnosed between 1st April 2014 – 30th September 2016 in England and 1st April 2015 – 30th September 2016 in Wales
 - **Second round:** diagnosed between 1st April 2018 – 30th September 2018 in England & Wales
- Successful patient engagement – high response rates
 - Overall: survey sent to 60,817 men – 73% responded (44,355)

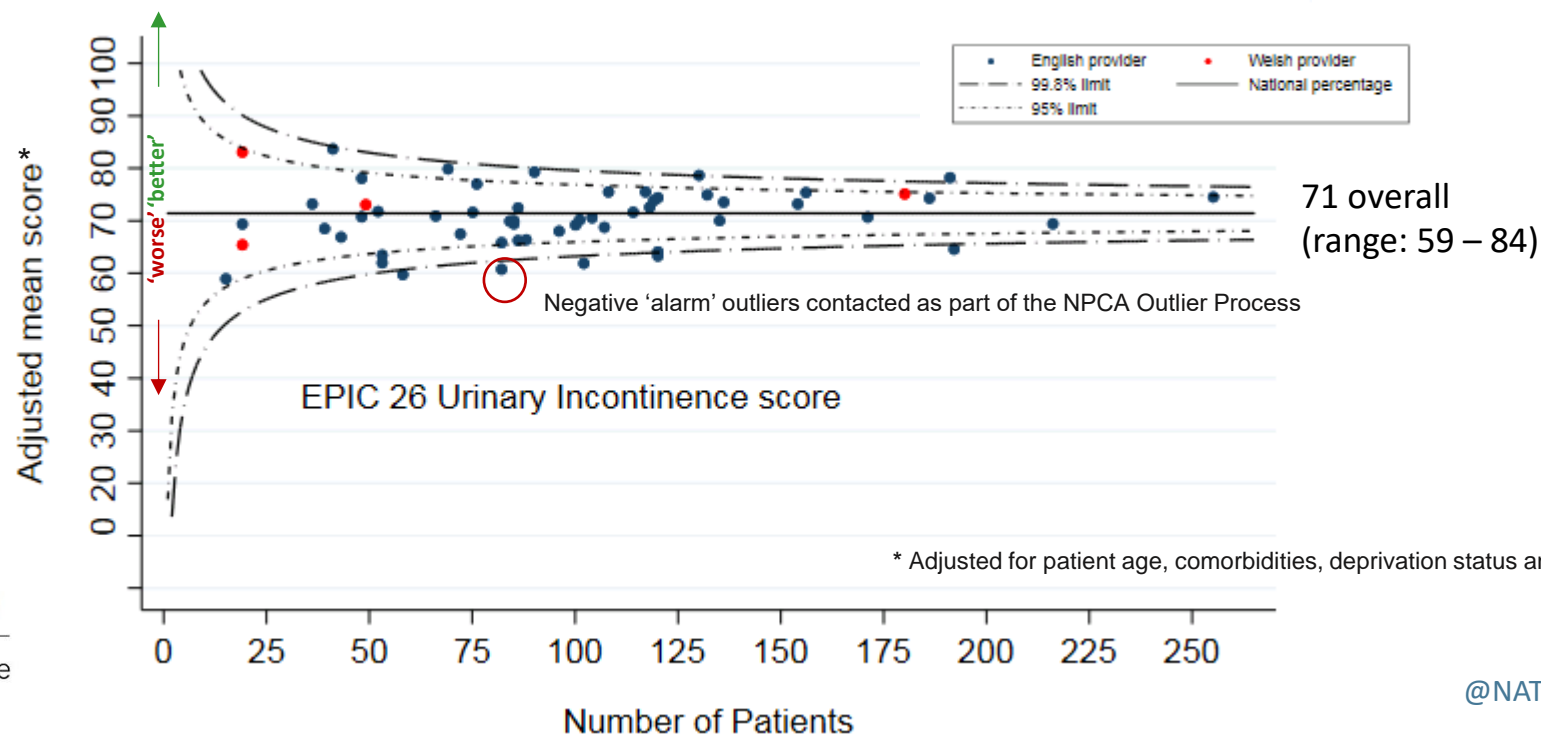
What are the outcomes reported by men after radical treatment for prostate cancer?

- Men were asked questions related to urinary, bowel and sexual function (EPIC-26)
- The answers to the questions were used to generate a validated summary score for each domain from 0-100
 - Higher scores represent better function
- Linked patient survey data to routine clinical data
 - Patient characteristics, tumour characteristics, disease status
 - Risk-adjustment for case-mix to enable provider comparisons



Outcomes reported by men after surgery

- On a scale of 0 to 100 where 100 is the best possible function:
 - Men rated their urinary function 71 out of 100
 - Men rated their sexual function 23 out of 100
- This varied by surgical centre:



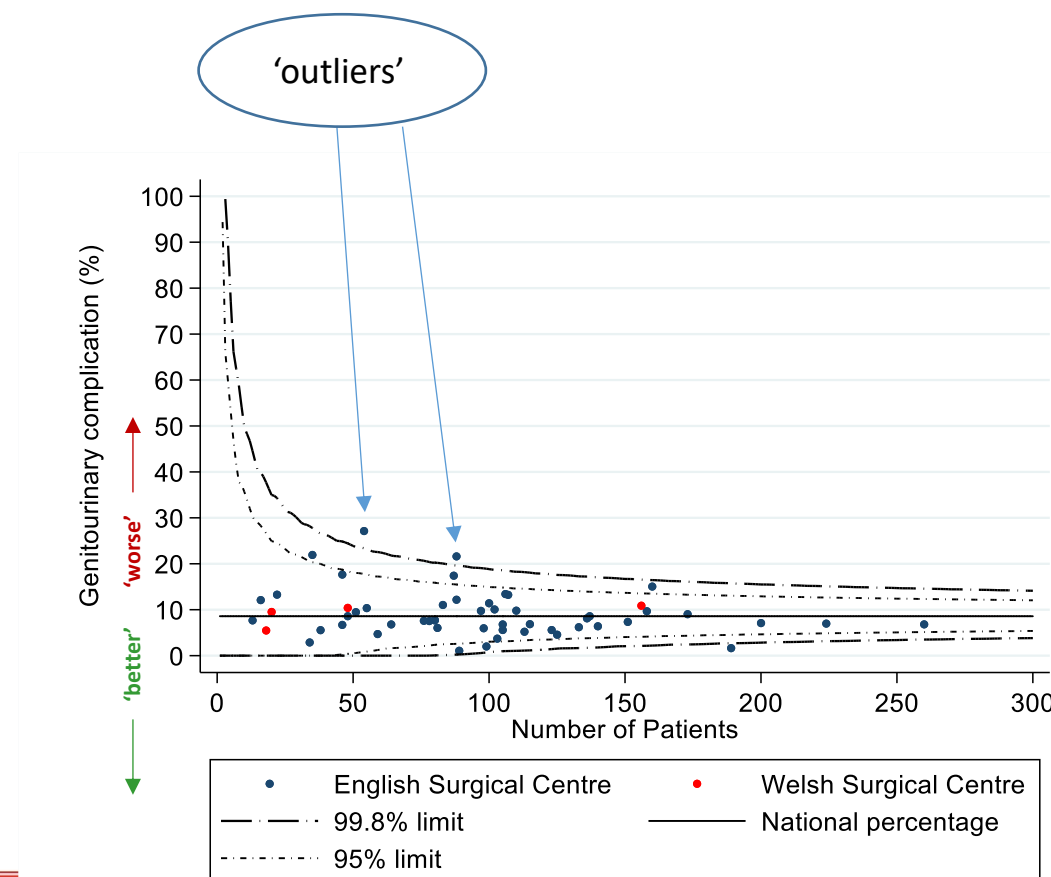
Patient survey – key findings

- Significant variation in care experienced by patients, hospital outcomes and unmet morbidity burden following surgery and radiotherapy
- Men report poor sexual function after radical treatment (surgery: rated 23/100; radiotherapy: rated 17 - 100)
- Men may also report problems with urinary incontinence after surgery (rated 71/100) or bowel issues following radiotherapy (rated 85/100)



Treatment Outcome Reporting

- Urinary toxicity after surgery
 - Performance Indicator, 2 years after surgery
 - PROMs (EPIC – Urinary Domain)
- Gastrointestinal toxicity after radiotherapy
 - Performance Indicator, 2 years after radiotherapy
 - PROMs (EPIC – Bowel Domain)
- Sexual function after surgery/radiotherapy
 - PROMs (EPIC – Sexual Domain)
- 90-day readmissions after surgery



Changes in practice - compare outcomes between different treatment strategies in a “real-world” setting



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BJU International

National cohort study comparing severe medium-term urinary complications after robot-assisted vs laparoscopic vs retropubic open radical prostatectomy

Arunan Sujenthiran*, Julie Nossiter*, Matthew Parry*†, Susan C. Charman*†, Ajay Aggarwal†, Heather Payne†, Prokar Dasgupta§, Noel W. Clarke†, Jan van der Meulen† and Paul Cathcart**

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BJC

British Journal of Cancer (2018) 118, 489–494 | doi: 10.1038/bjc.2017.454



FULL PAPER

Keywords: prostate cancer; robot-assisted; laparoscopic; open retropubic; radical prostatectomy; patient reported; functional outcomes

Robot-assisted radical prostatectomy vs laparoscopic and open retropubic radical prostatectomy: functional outcomes 18 months after diagnosis from a national cohort study in England

Julie Nossiter^{*,1,2}, Arunan Sujenthiran², Susan C Charman^{1,2}, Paul J Cathcart³, Ajay Aggarwal^{1,2}, Heather Payne⁴, Noel W Clarke^{5,6} and Jan van der Meulen^{1,2}

Changes in practice - compare outcomes between different treatment strategies in a “real-world” setting



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Comparison of Treatment-Related Toxicity With Hypofractionated or Conventionally Fractionated Radiation Therapy for Prostate Cancer: A National Population-Based Study

A. Sujenthiran ††*, M. Parry †§*, J. Nossiter †, B. Berry †, P.J. Cathcart ‡, N.W. Clarke ||, H. Payne ¶, J. van der Meulen §, A. Aggarwal §**

original reports

Patient-Reported Functional Outcomes After Hypofractionated or Conventionally Fractionated Radiation for Prostate Cancer: A National Cohort Study in England

Julie Nossiter, PhD^{1,2}; Arunan Sujenthiran, MD²; Thomas E. Cowling, PhD¹; Matthew G. Parry, MBChB, MSc²; Susan C. Charman, MSc¹; Paul Cathcart, MD³; Noel W. Clarke, MBBS, ChM^{4,5}; Heather Payne, MBBS, MD⁶; Jan van der Meulen, PhD¹; and Ajay Aggarwal, MD, PhD^{7,8}



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Patient survey – key learnings

- PROMs are important for audits of services that aim to improve/protect functional outcomes (NPCA) >>measure of *safety*
- Provide additional information over and above what clinical data/routinely collected data provide
 - Changes in clinical measures may not always translate into benefits for patients
- Important tool to measure impact of ongoing changes in practice on outcomes
- Clinicians/providers accept PROMs as authoritative information
- Patients want PROMs – patient centred care and shared decision making

Feedback from the NPCA PPI Forum:

'Patients need to understand the likelihood, severity and duration of the side effects from potential treatment options in order to make an informed decision about initial treatment'



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Thank you!

Acknowledgements

NATCAN teams, Board, Executive,
Stakeholders, Patients

