



**NKCA**

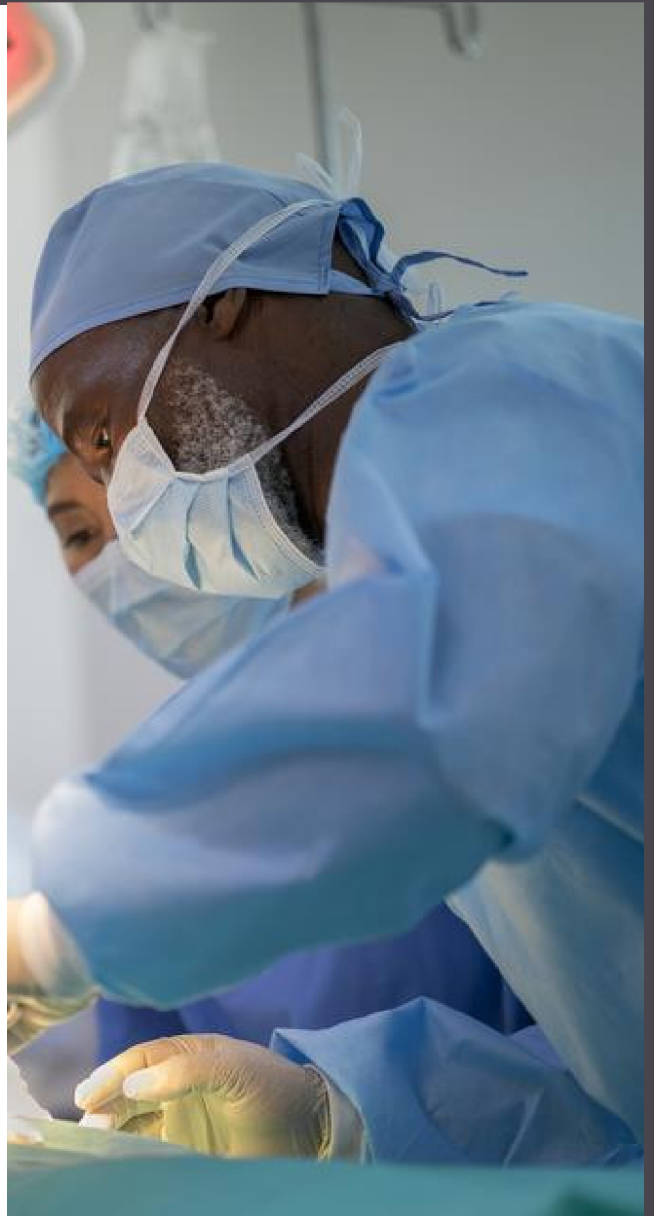
National Kidney  
Cancer Audit

# National Kidney Cancer Audit

## Scoping Document

November 2023

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**NATCAN**

National Cancer Audit  
Collaborating Centre



Royal College  
of Surgeons  
of England  
ADVANCING SURGICAL CARE

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Healthcare Quality  
Improvement Partnership

The National Cancer Audit Collaborating Centre (NATCAN) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). NATCAN delivers national cancer audits in non-Hodgkin lymphoma, bowel, breast (primary and metastatic), oesophago-gastric, ovarian, kidney, lung, pancreatic and prostate cancers. HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical, and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.

<https://www.hqip.org.uk/national-programmes>

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# The National Kidney Cancer Audit (NKCA)

## Scoping document

### 1. Executive Summary

The National Kidney Cancer Audit will report on kidney cancer care in England and Wales, with a particular focus on areas of the patient pathway which could be improved. Previous assessments have provided evidence and baseline results, which the audit will build upon, using patient-level clinical data from all English and Welsh providers through a range of national electronic data feeds. Five quality improvement goals have been set, in close partnership with audit stakeholders and aligning with complementary national initiatives, which cover the patient pathway from diagnosis to treatment and outcome, and importantly, patient experience of care. The audit aims to reduce inequity in access to the most up to date care, increase the use of biopsies during the diagnostic process, ensure patients are treated appropriately for the stage of their disease by reducing unnecessary surgery, expediting treatment where needed and adapting when the standard of care changes, increasing the rate of kidney cancer cure and finally improving the overall experience of care for patients. These goals will form the basis for selecting the ten quality performance indicators the audit will report on, again, in collaboration with audit stakeholders. The chosen quality performance indicators will be measurable, clinically relevant and statistically robust, and reported on at both the national and provider level on an annual and quarterly basis.

### 2. Background

The National Kidney Cancer Audit is part of the National Cancer Audit Collaborating Centre ([NATCAN](#)), a national centre of excellence to strengthen NHS cancer services by looking at treatments and patient outcomes in multiple cancer types across England and Wales. Further details on NATCAN and its structure and approach to audits can be found in the Appendix.

The aim of the audits is to:

1. Provide regular and timely evidence to cancer services of where patterns of care in England and Wales may vary.
2. Support NHS services to increase the consistency of access to treatments and help guide quality improvement initiatives.
3. Stimulate improvements in cancer detection, treatment and outcomes for patients, including survival rates.

The NKCA will produce yearly State of the Nation reports, evaluating the chosen quality performance indicators (QPIs) across England and Wales and providing overall pictures of service delivery, and quarterly data updates enabling regular review of clinical performance and, with time, assessment of impact of quality improvement initiatives.

Clinical leadership of the National Kidney Cancer Audit is provided by representatives from the British Association of Urological Surgeons (BAUS) and British Uro-Oncology Group (BUG). NKCA's Clinical Reference Group (CRG) is formed of members representing patient groups and professionals

involved in kidney cancer care. The CRG meets twice a year to advise on the clinical direction of the audit, the interpretation of its findings and the dissemination of results. In addition, the NKCA has its own Patient and Public Involvement (PPI) Forum, drawn from patient and carer groups.

### **3. Main issues in kidney cancer care and outcomes**

Kidney cancer is the 7<sup>th</sup> most common type of cancer in the UK and incidence is at its highest in people aged between 60-70 years, with a 3:2 ratio of men to women diagnosed. Risk factors include lifestyle factors such as smoking, obesity and hypertension, alongside diagnosis of a close family member.

Approximately 60% of patients who present with kidney cancer are asymptomatic or have an incidental presentation (kidney cancer diagnosed due to investigations for unrelated symptoms). Imaging, initially ultrasound or a CT scan, may identify suspected kidney cancer masses, whilst a tissue biopsy, which provides a more definitive diagnosis and supports treatment decision making, is not always performed prior to first treatment.

There are different types of kidney cancer, generally identified following pathology review of a tissue biopsy, and which have varying outcomes and are managed differently.

Depending on overall clinical assessment, treatment options include:

- Active surveillance, where repeat imaging is performed to assess changes in tumour size
- Surgery, where all or part of the kidney is removed, using open, robotic or laparoscopic approaches
- Thermal ablation
- Systemic therapy (with targeted treatments or immunotherapy)
- Radiation therapy

### **4. Aims and objectives of NKCA scoping document**

This scoping document describes the scope of the audit:

- Identify which areas of kidney cancer care will be included in the audit
- Describe approach used to develop scope from review of existing guidance
- Capture stakeholders' views on the planned scope
- Determine which data sources will provide the required information
- Provide the basis for the healthcare quality improvement plan

#### **a. Audit inclusion criteria**

There is one ICD-10 code corresponding to a diagnosis of kidney cancer (C64) which will form the basis of our audit inclusion criteria. ICD-10 C64 represents malignant neoplasm of kidney, except renal pelvis. There are histologically different subtypes of kidney cancer, identified following pathology review of tumour tissue, however they are all included in the C64 code. The diagnostic and treatment dilemma of the renal mass without tissue diagnosis as well as diagnosis of oncocytoma will be discussed and included if possible from data currently available.

#### **b. Methodology to define quality improvement goals**

An [audit of the quality of kidney cancer services in England](#) during 2017-2018 funded by Kidney Cancer UK (KCUK) was published in June 2022 and included authors from our Clinical Reference Group. It reported that approximately ~9,000 cases of kidney cancer are diagnosed in England every year. This audit reported on six quality performance indicators including type of treatment received at early and late (metastatic) stages, survival following surgery, as well as access to clinical trials and found unwarranted variation in all investigated areas, meaning there are opportunities for quality improvement in many aspects of kidney cancer care.

Briefly, the audit found that over a fifth of patients were diagnosed at an incurable stage, that the rate and type of surgery offered to patients as well as the number of metastatic patients who received systemic therapy was variable by Trust. It also found that a quarter of Trusts recruited no patients to clinical trials. Alongside the quality performance indicators assessed, the audit found an increasing incidence of kidney cancer, as well as an increase in the mortality rate. [Age-standardised five-year relative survival in adults \(aged 15+\) measured between 2000 and 2007](#) placed England 26<sup>th</sup> and Wales 23<sup>rd</sup> out of 29 European countries. Kidney Cancer UK also runs annual patient surveys, [the latest of which published in 2023](#) reported that for 31% of patients, it took over three months from first seeking medical advice to diagnosis and 22% of patients said they had initially been misdiagnosed. 48% of responders reported their kidney cancer was found incidentally and 43% were diagnosed when their tumour had already reached stage 3 or 4.

The first NICE guidelines for kidney cancer are [in development](#) following sustained campaigning by KCUK. An NHS [Getting It Right First Time \(GIRFT\) guide to kidney cancer care](#) was published for the first time in June 2023 and provides guidance for stages 1-3 of the patient pathway. It describes how a good kidney cancer service should function and identifies actions healthcare teams can take to ameliorate their service. Both the KCUK audit and GIRFT guide identified areas of kidney cancer care which could be improved and provide the national kidney cancer audit with a basis for developing its scope as well as baseline results to be used as benchmarks. Stakeholders for both the NKCA and NICE kidney cancer guideline development will have complementary roles, being involved in both initiatives.

We will also draw on [quality performance indicators from the Scottish Kidney Cancer audit](#), currently on their fourth edition (2019) having been first developed in 2012. Finally, newly developed performance indicators will be discussed to address further areas where variation in standard of care may exist and where quality improvement can be directed.

### **c. Stakeholder input into developing audit scope**

The core NKCA project team consists of two clinical leads (urology and oncology), a methodological lead, a data scientist, clinical fellow (commencing February 2024) and project manager, but the audit scope is being developed in close collaboration with our Clinical Reference Group (CRG) whose members are representatives from all our stakeholder organisations, which include professional organisations and Royal Colleges such as the British Association of Urological Surgeons, British Uro-oncology Group, Royal College of General Practitioners, Royal College of Radiologists, Royal College of Pathologists, UK Oncological Nurses Society, commissioners such as NHS England, Wales Cancer Network and HQIP, and patient charities such as Kidney Cancer UK and Action Kidney Cancer.

The first meeting of the CRG took place on Thursday 14<sup>th</sup> September 2023, which was a scoping meeting to obtain feedback on the audit scope from our stakeholders. Written comments were also reviewed. Following stakeholder consultation, the proposed scope and healthcare improvement goals have been revised to incorporate the comments received.

#### **d. Data sources**

NATCAN's data partners, National Disease Registration Service (NDRS) and the Wales Cancer Network (WCN), provide clinical data: NDRS collects patient-level clinical data from all English NHS providers through a range of national electronic data feeds. The NKCA (via a NATCAN data request) receives Cancer Registry data annually and quarterly extracts of Rapid Cancer Registration Data (RCRD), linked at patient level to items of several routinely collected datasets, including the Cancer Outcomes and Services Dataset (COSD), the Hospital Episode Statistics (HES) data sets, the Radiotherapy Data Set (RTDS), the Systemic Anti-Cancer Treatment (SACT) data set and the Office for National Statistics (ONS) data set.

The data collection process in Wales differs from England. Similar data is captured through a national system and uploaded to the Wales Cancer Network, only after sign-off by a designated clinician. The NKCA also receives these data annually, linked to the Patient Episode Database for Wales (PEDW).

For patients in Wales, NKCA will continue to use national cancer data from the Cancer Network Information System Cymru (CaNISC), which is in the process of being replaced by Cancer Information System for Wales. As the replacement work is ongoing, it is unclear exactly what data will be available, or how frequent and timely it will be.

NATCAN has requested a single resource of linked datasets for all cancer audits. NATCAN staff are working to build relationships with NDRS as well as hospital staff to support them to improve their data. Reporting of data items will be used as an incentive for providers to improve data quality. Development work will be needed to balance the improved timeliness of reporting using RCRD against reduced case ascertainment and data completeness.

A Secure Research Environment (SRE) for cancer data is being developed in NHS England which would be particularly beneficial if it gave quicker access to the data. However, the SRE would need to hold Welsh cancer data because the statistical analysis will require a single dataset that combines data from both countries.

For accurate and timely benchmarking it is essential that the NDRS and Welsh cancer data that is being used by NKCA:

- (i) includes all of the data items required to measure and risk-adjust performance indicators
- (ii) is timely
- (iii) has a high-level of case-ascertainment
- (iv) has high levels of data completeness
- (v) is accurate

#### **e. Service mapping**

Using Hospital Episode Statistics Admitted Patient Care (HES APC) data we conducted preliminary analyses to start to map kidney cancer services in England, focussing on patients diagnosed with kidney cancer between 1<sup>st</sup> April 2018 and 31<sup>st</sup> March 2019. HES APC has limitations especially when used on its own, so we view our findings only as an indication which will be honed with other data sources to be obtained in the future:

- Diagnostic scans and biopsies were widely performed
  - 118 and 86 trusts respectively were recorded to have performed these diagnostic investigations for more than 5 patients a year
- Our research found that 65% of all kidney cancer patients received surgery of some form and surgery was widely performed with 89 trusts having recorded performing it on more than 5 patients a year
  - 47% of all patients underwent a radical nephrectomy and 88 trusts performed it on more than 5 patients a year
  - 15% of all patients underwent nephron sparing surgery and 48 trusts performed it on more than 5 patients a year
  - Only 3% of all patients underwent thermal ablation and 16 trusts performed it on more than 5 patients a year
- 12% of patients received systemic therapy which was also widely available as 56 trusts recorded providing it for more than 5 patients a year
- Only 0.5% of patients received some form of radiotherapy

## **5. Audit scope**

### **a. Audit patient inclusion criteria**

- Patients with a recorded diagnosis of ICD-10 code C64 (malignant neoplasm of kidney, except renal pelvis)
- Age at diagnosis  $\geq 18$  years old
- Diagnosis or treatment took place in an English NHS trust or Welsh NHS Health Board

### **b. Identification of quality improvement goals**

An overarching principal of the quality improvement goals are that pathways of care consider both personal and tumour factors so that patients receive personalised, evidence-based management according to current guidelines. System factors, such as the involvement of a Cancer Nurse Specialist in patient care, also play a role in ensuring personalisation of care. As such metrics become assessable, the audit will be able to appraise the appropriateness and adherence to personalised care pathways.

Equally embedded in these quality improvement goals are ambitions to identify and address the health inequalities which can lead to excessive variation in treatment and outcomes, such as levels of deprivation and variation in socioeconomic status. Finally, patients' experience of care, including quality of life assessments during the course of treatment, will also be assessed as part of the audit.



1. to reduce inequity in access to evidence-based kidney cancer services
2. to increase the use of renal tumour biopsy
3. to reduce over-treatment and under-treatment of kidney cancer patients at all stages of patient pathway
  - a. to reduce the risk of morbidity or mortality of unnecessary surgery for benign tumours or low risk RCC in comorbid patients
  - b. to expedite treatment of patients with potentially high risk for recurrence localised RCCs (i.e. cT3+, 10cm+, cN1 tumours)
  - c. to increase evidence-based SACT treatment based around cancer prognosis and co-morbidities
4. to increase the rate of kidney cancer cure
5. to improve the overall experience of care for patients with kidney cancer, in particular the availability of specialist cancer nurses and the involvement of patients in decisions about their treatment

## 6. Next steps

### a. Develop quality performance indicators mapped to QI goals

All QPIs will conform to our founding NATCAN principles. These principles are that all of our activities are clinically relevant (close collaboration between clinical and academic experts), methodologically robust (using the best epidemiological and statistical approaches to carry out fair comparisons) and technically rigorous (using data science in order to drive quality improvement). Finally, the selected QPIs need to be measurable with the data that we have access to, as well as regularly assessed in our quarterly reporting, so will be developed in close collaboration with our data partners in England (NDRS) and Wales (WCN).

As described previously, the audit is building on previous assessments of kidney cancer care in the UK and will draw on these to develop QPIs. Please note, these will be finalised after further feasibility work is conducted once the appropriate data extracts are received.

Organisation	Initiative	Year	URL
Scottish Cancer Taskforce, National Cancer Quality Steering Group	Better Cancer: Ambition and Action (2016) details a commitment to delivering the national cancer quality programme across NHS Scotland, with a recognised need for national cancer QPIs to support a culture of continuous quality improvement.	2019 (v4)	<a href="#">Click here</a>
Getting It Right First Time	The GIRFT Academy developed this guide on the management of kidney cancer to outline what comprises good practice and how to adjust a service to deliver improvement.	2023	<a href="#">Click here</a>
Kidney Cancer UK Accord Report	This audit measures the quality of kidney cancer services in England and assesses if there is a need for a NICE guideline and quality standard on kidney cancer, neither of which has been developed to-date.	2022	<a href="#">Click here</a>

We will use frameworks for ideal attributes of QPIs that are available from existing literature to inform the selection of a smaller set of indicators.<sup>1</sup> For example, indicators should not be subject to excessive random variation and should not be highly influenced by contextual factors. There should also be clear opportunities for improvement and well-defined interventions that can result in improved performance as measured by the indicators.

We will synthesise the attribute frameworks to define a final set of attributes with which to systematically assess indicators for inclusion. This set will include statistical attributes which cannot be known for each indicator *a priori*. Therefore, the selection of a final set of QPIs will involve an iterative process of selecting a candidate QPI, investigating its definition and statistical attributes in available data, including/discarding that indicator, and repeating the cycle for another indicator. For example, one key attribute of an indicator is that there is sufficient statistical power to identify true differences in performance (rather than concluding that they are explained by random variation), which is improved with larger sample sizes.

The definitions of some indicators will also require further investigation of their validity. For example, it may be necessary to examine the agreement between two or more datasets (such as HES and SACT) in the recording of systemic therapies, or to examine how a process indicator is associated with patient outcomes or structural healthcare characteristics. This highlights the complementary link between audit and research. The validation and research process will be tailored to each indicator.

Potential QPIs that the project team believe are important and deliverable are included below (in parentheses are the source of the QPI), arranged according to patient pathway stage. These were reviewed by NKCA stakeholders at the scoping meeting and will be finalised following receipt of initial datasets from NDRS.

Data quality:

1. >X% data completeness of items for risk adjustment in RCC patients. [NBOCA QI]

Diagnosis:

2. >95% of patients with RCC receiving active treatment undergo pre-treatment cross-sectional imaging of the chest, abdomen +/- pelvis. [Scottish QPI1]

Staging and biopsy:

3. >90% of patients with RCC where surgery is not the primary treatment have a histological diagnosis before treatment, via biopsy. [Scottish QPI2]
4. >98% of patients with RCC are staged pre-treatment using the TNM staging system. [Scottish QPI3]
5. Number/proportion of patients with a small renal mass have a biopsy. [new]

MDT:

6. >95% of patients with RCC are discussed at MDT meeting before definitive treatment. [Scottish QPI4]

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<sup>1</sup> For example, such frameworks can be found in:

Bottle A, Aylin P (2017) *Statistical Methods for Healthcare Performance Monitoring*. Boca Raton; CRC Press.

Mainz J. (2003) Defining and classifying clinical indicators for quality improvement. *International Journal for Quality in Health Care* 15(6):523-530.

7. Number of patients with cT3+, 10cm+, cN1 tumours have surgery within 4 weeks of diagnosis. [GIRFT]
8. XX% patients with small renal masses/cancers are deferred more than 4 weeks prior to treatment. [new]

Service quality:

9. >95% suspected kidney cancer patients seen by Clinical Nurse Specialist (CNS). [NBOCA QI]

Primary treatment:

10. >50% of patients with T1aN0M0 RCC undergo nephron sparing treatment (thermal ablation or robotic / laparoscopic / open partial nephrectomy). [Scottish QPI7]
11. <2% of patients die within 30 or 90 days of minimally invasive (thermal ablation) or operative treatment for RCC. [Scottish QPI8]
12. More than 30 renal surgical resections are performed by a Trust over a 1 year period. [GIRFT]
13. XX% of patients with T1b-3NxM0 RCC should undergo radical nephrectomy (RN) (either by open or laparoscopic procedure) if medically appropriate. [Accord QPI 2a]
14. XX% patients with T1a or T1b kidney tumours should receive Nephron Sparing Surgery (NSS) or radical nephrectomy (RN) or ablation if possible. [Accord QPI 2b]
15. XX% patients with M0 kidney cancer are alive 12-month after RN or NSS. [Accord QPI 3b]. Stratified by T stage and surgery type. [Accord QPI 6a]
16. XX% patients are alive 90-day after RN or NSS in the six months post-diagnosis. [Accord QPI 3c]
17. <XX% risk-adjusted 30 day unplanned readmission rates after kidney cancer surgery. [NBOCA QI]

Adjuvant treatment:

18. X% of eligible patients have adjuvant treatment. [new]

Follow-up:

19. X% patients with RCC have remote follow-up. [new]
20. X% of high risk RCC patients (high stage/grade) undergo CT scanning >1x per annum. [new]

Metastatic disease treatment:

21. X% of patients presenting with advanced and/or metastatic RCC receive initial SACT within 12 months of diagnosis. [Scottish QPI9]
22. >90% of patients with metastatic RCC are assigned a valid prognostic score following diagnosis. [Scottish QPI10]
23. <5% of patients with RCC die within 30 days of SACT treatment. [Scottish QPI15]
24. XX% metastatic kidney cancer patients receive systemic anticancer therapy or active surveillance. [Accord QPI 4]
25. Centres offering SACT treat more than XX patients per year with RCC. [new]
26. X% mRCC patients have potentially curative approaches i.e. surgery, SABR, TA. [new]

Palliative care:

27. >95% patients referred/received to palliative care or enhanced supportive care clinic in last year of life. [NBOCA QI]

Clinical trials:

28. Number of patients diagnosed with renal cancer that are consented for a clinical trial / research study. [Scottish QPI14]

Potential QPIs that the project team believe are important but aren't certain are deliverable within data constraints are included below (in parentheses are the source of the QPI).

Staging and biopsy:

1. XX% of patients where there is any concern about post-operative CKD 3+ have a DMSA scan undertaken. [GIRFT]

Primary treatment:

2. >50% of patients with T1a RCC undergoing partial nephrectomy achieve trifecta (ischaemia time less than 25 minutes, negative surgical margins (R0 or R1) and no complications\*). [Scottish QPI13]
3. Less than XX% of patients having surgery for an oncocytoma. [new]
4. 0% of patients die within 30 or 90 days for surgery for lesion found post-operatively to be an oncocytoma. [new]
5. >XX% robot-assisted partial nephrectomy, open radical nephrectomy for venous tumour thrombus and cytoreductive nephrectomy are performed in high volume referral centres. [GIRFT]
6. Frail patients do not undergo surgical treatment. [new]
7. More than 15 renal surgical resections are performed by a surgeon over a 1 year period. [Scottish QPI12]

Follow-up:

8. 100% of patients with clear cell RCC are assigned a risk of recurrence score (Leibovich score etc) following radical nephrectomy. [Scottish QPI11]
9. X% patients with RCC under the age of 45y are referred to medical genetics. [new]

## **b. Healthcare improvement plan**

The healthcare improvement plan will build on this scoping document, outlining ten NKCA performance indicators and how they map to the healthcare improvement goals, alongside strategies for reporting and disseminating results from the NKCA.

The two principal strategies for reporting NKCA results include:

1. A short "state of the nation" report for NHS Trusts/Health Boards within England and Wales. These reports will highlight where services should focus quality improvement activities.
2. An indicator dashboard on the NKCA website that contains NHS organisational-level results. These dashboard indicators will facilitate benchmarking and the monitoring of performance at regular intervals so improvements in performance can be tracked.

These outputs will be accompanied by a range of healthcare improvement tools that will support their use by national, regional, and local stakeholders. Details of healthcare improvement tools, methods and activities will be outlined in the healthcare improvement plan. These will be disseminated to our various stakeholders in direct (email communication, quarterly NKCA Newsletters, workshops) and indirect ways (website, social media).

## **7. Appendix**

### **a. Overview of the National Cancer Audit Collaborating Centre (NATCAN)**

The National Kidney Cancer Audit (NKCA) is part of the National Cancer Audit Collaborating Centre (NATCAN), a new national centre of excellence to strengthen NHS cancer services by looking at treatments and patient outcomes across the country. It was set up on 1 October 2022 to deliver six new national cancer audits, including the NKCA. The centre was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government, with funding for an initial period of three years.

NATCAN is based within the Clinical Effectiveness Unit (CEU), the academic partnership between the Royal College of Surgeons of England (RCS Eng) and the London School of Hygiene & Tropical Medicine (LSHTM). The CEU is recognised as a national centre of expertise in analytic methodology and the development of administrative and logistic infrastructure for collating and handling large-scale data for assessment of health-care performance.

Prior to the launch of NATCAN, the CEU was already the sole provider of national cancer audits in the NHS in England and Wales, incorporating audits in [prostate](#), [lung](#), [bowel](#), and [oesophago-gastric](#) cancers, and recently completed an audit of [breast cancer in older patients](#). These audits have helped provide a wider understanding of cancer treatments across England and Wales and have improved services and infrastructure leading to improved outcomes for patients. By consistently placing quality improvement (QI) at the centre of all audits, initiatives which promote QI within NHS cancer services have been developed and areas of best practice identified.

The audits which the CEU already provided have joined NATCAN ([bowel](#), [oesophago-gastric](#) and [prostate](#)) or will, in the near future ([lung](#)), bringing the number of NATCAN audits to ten. This critical mass of knowledge and expertise enable it to respond to the requirements of the funders and stakeholders.

### **b. Key features of NATCAN's audit approach**

The design and delivery of the audits in NATCAN has been informed by the CEU's experience delivering national audits, built up since its inception in 1998. Key features of all audit projects within the CEU include:

- Close clinical-methodological collaboration
- Use of national existing linked datasets as much as possible
- Close collaboration with data providers in England (National Disease Registration Service [NDRS], NHS England [NHSE]) and Wales (Wales Cancer Network [WCN], Public Health Wales [PHW])
- A clinical epidemiological approach, informing quality improvement activities
- "Audit" informed by "research"

All these features will support NATCAN's focus on the three "Rs", ensuring that all its activities are clinically relevant, methodologically robust, and technically rigorous.

### **c. Organisational structure of NATCAN**

i. Centre Board

NATCAN has a multi-layered organisational structure. [NATCAN's Board](#) provides top-level governance and oversees all aspects of the delivery of the contract, ensuring that all audit deliverables are produced on time and within budget and meet the required quality criteria. The Board also provides the escalation route for key risks and issues. It will also consider NATCAN's strategic direction. The Board will meet at 6-monthly intervals and will receive regular strategic updates, programme plans, and progress reports for sign-off. Risks and issues will be reported to the NATCAN Board for discussion and advice.

ii. Executive Team

[NATCAN's Executive Team](#) is chaired by the Director of Operations (Dr Julie Nossiter) and includes the Clinical Director (Dr Ajay Aggarwal), the Director of the CEU (Prof David Cromwell), the Senior Statistician (Dr Kate Walker), and the Senior Clinical Epidemiologist (Prof Jan van der Meulen) with support provided by NATCAN's project manager (Ms Verity Walker). This Executive Team is responsible for developing and implementing NATCAN's strategic direction, overseeing its day-to-day running, and coordinating all activities within each of cancer audits. This group meets monthly. The Executive Team will provide 6-monthly updates to NATCAN's Board.

iii. Advisory groups

The Executive Team will be supported by two external groups. First, the Technical Advisory Group including external senior data scientists, statisticians, and epidemiologists as well as representatives of the data providers (NDRS, NHSD and WCN, PHW), co-chaired by NATCAN's Senior Statistician and Senior Epidemiologist, will advise on national cancer data collection, statistical methodology, development of relevant and robust performance indicators to stimulate QI, and communication to practitioners and lay audiences.

Second, the Quality Improvement Team includes national and international experts who have extensive experience in QI and implementation research. This team will provide guidance on the optimal approaches to change professional and organisational behaviour. It will be chaired by NATCAN's Clinical Director and managed by the Director of Operations.

This set up will provide a transparent and responsive management structure allowing each audit to cater for the individual attributes of the different cancer types, while also providing an integrated and consistent approach across the NATCAN audits. The integrated approach will result in efficient production of results through sharing of skills and methods, a common "family" feel for users of audit outputs, and a shared framework for policy decisions and, project management.

iv. Audit Project Teams

Audit development and delivery is the responsibility of each Project Team. The Project Team works in partnership to deliver the objectives of the audit and is responsible for the day-to-day running of the audit and producing the deliverables. It will lead on the audit design, data collection, data quality monitoring, data analysis and reporting.

Each cancer audit Project Team is jointly led by two Clinical Leads representing the most relevant professional organisations, and senior academics with a track record in health services research, statistics, data science and clinical epidemiology, affiliated to the London School of Hygiene and Tropical Medicine. In addition, each audit will have a clinical fellow, who contributes to all aspects of the audits, reinforcing the audits’ clinical orientation and contributing to capacity building.

The delivery of the audit is coordinated by an audit manager who is supported by NATCAN’s wider infrastructure. Data scientists with experience in data management and statistics and methodologists with experience in performance assessment and QI work across audits.

NKCA project team membership

1. *Amit Bahl* - Clinical Lead (Oncology); Consultant Clinical Oncologist, University Hospitals Bristol
2. *Grant Stewart* - Clinical Lead (Surgery); Professor of Surgical Oncology, University of Cambridge and Honorary Consultant Urological Surgeon, Addenbrookes Hospital
3. *Jan van der Meulen* - Senior Methodologist
4. *Thomas Cowling* - Senior Methodologist
5. *Emily Mayne* - Data scientist
6. *Marina Parry* – Senior Project Manager

v. Audit Clinical Reference Groups

Each audit has a Clinical Reference Group representing a wide range of stakeholders. This group will act as a consultative group to the Project Team on clinical issues related to setting audit priorities, study methodology, interpretation of audit results, reporting, QI, and implementation of recommendations.

NKCA clinical reference group membership (as of 29<sup>th</sup> September 2023)

1. NHS England
2. Wales Cancer Network (WCN)
3. National Disease Registration Service (NDRS)
4. Healthcare Quality Improvement Partnership (HQIP)
5. Get it Right First Time (GIRFT)
6. British Association of Urological Surgeons (BAUS)
7. British Uro-oncology Group (BUG)
8. Royal College of Radiologists (RCR)
9. Royal College of General Practitioners (RCGP)
10. Royal College of Pathologists (RCPATH)
11. UK Oncological Nursing Society (UKONS)
12. Kidney Cancer UK (KCUK)
13. Action Kidney Cancer (AKC)

vi. Audit PPI Forums

Patients and patient charities are involved in all aspects of the delivery of the cancer audits. Each audit will also have a standalone Patient and Public Involvement (PPI) Forum to provide insight from a patient perspective on strategic aims and specific audit priorities. This will include shaping the development of each audit’s quality improvement initiatives by ensuring this work is relevant

from a patient perspective. A key activity of the PPI Forums will be to actively participate in the production of patient-focussed audit outputs (including patient and public information, patient summaries of reports, infographics and design and function of the NATCAN website), guiding on how to make this information accessible.

Effective collaboration within the centre and across audits facilitates the sharing of expertise and skills in all aspects of the delivery process, notably: designing the audits, meeting information governance requirements, managing and analysing complex national cancer data to produce web-based indicator dashboards / state of the nation reports, and supporting quality improvement. This organisation creates “critical mass” and audit capacity that is able to respond to the requirements of the funders (NHS England and Welsh Government) and the wider stakeholder “family”.

#### **d. Data acquisition**

The NATCAN Executive Team is working closely with data providers in England (National Disease Registration Service, NHSE) and in Wales (Wales Cancer Network, PHW) to establish efficient “common data channels” for timely and frequent access to datasets, combining data needs for all cancers into a single request in each Nation and only using routinely collected data, thereby minimising the burden of data collection on provider teams.

##### **i. Annual and quarterly data**

NATCAN will utilise two types of routinely collected data in England. First, an annual “gold-standard” cancer registration dataset, released on an annual basis with a considerable delay between the last recorded episode and the data being available for analysis, and second, a “rapid” cancer registration dataset (RCRD), released at least quarterly with much shorter delays (3 months following diagnosis). The CEU’s recent experience with English rapid cancer registration data, in response to the COVID pandemic has demonstrated the latter’s huge potential,<sup>2</sup> despite a slightly lower case ascertainment and less complete staging information.

NATCAN will utilise these data across all cancers linked to administrative hospital data (Hospital Episode Statistics/Systemic Anti-Cancer Therapy/Radiotherapy Data Set/Office National Statistics among other routinely collected datasets) for describing diagnostic pathway patterns, treatments received and clinical outcomes.

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<sup>2</sup> Nossiter J, Morris M, Parry MG, Sujenthiran A, Cathcart P, van der Meulen J, Aggarwal A, Payne H, Clarke NW. Impact of the Covid-19 pandemic on the diagnosis and treatment of men with prostate cancer. *BJU Int.* 2022 Jan 25. doi: 10.1111/bju.15699.



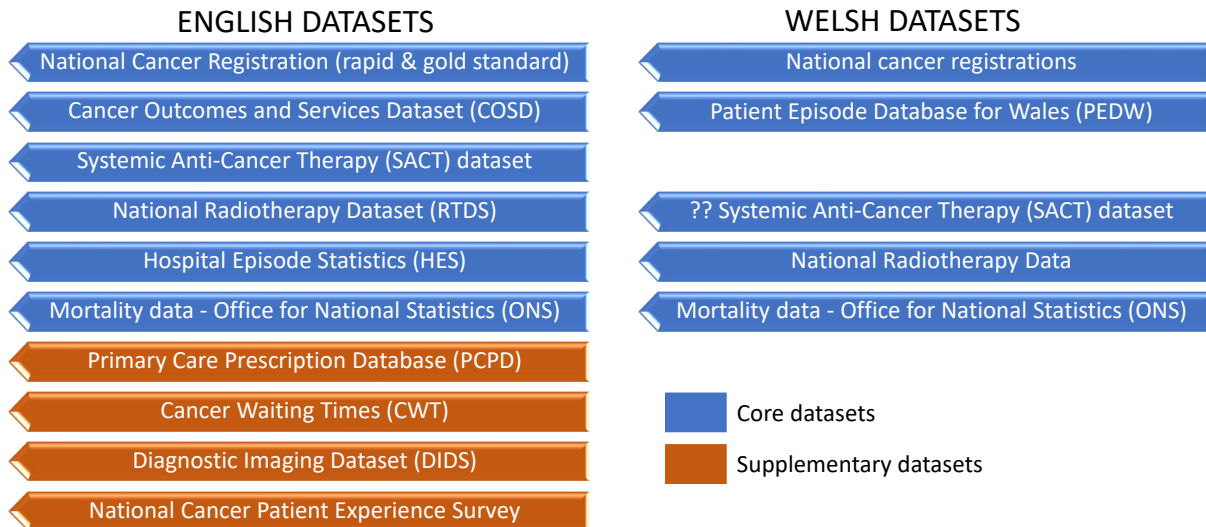


Figure 1: National datasets available to NATCAN.

An equivalent data request will be made to the Wales Cancer Network (WCN)/Public Health Wales (PHW).

ii. Information governance

NATCAN will comply with legislation and good practice principles to ensure data security and patient confidentiality. The patient-level information received and managed by NATCAN is treated as confidential. When analysing data to produce information on patient care and outcomes, NATCAN audit teams use de-identified data and so individual patients are not identifiable.

HQIP and NHSE are joint data controllers for the linked de-identified dataset that is supplied to NATCAN for analysis.

**e. Reporting**

Individual cancer audits will produce:

- Annual ‘*State of the Nation*’ reports for NHS Trusts/Health Boards within England and Wales. These reports will highlight where local services should focus quality improvement activities.
- NHS organisational-level results (as well as national and regional results) as a dashboard on the NATCAN website. These dashboard results will be refreshed on a quarterly and annual basis, and the website will include the facility to download activity summaries and outcomes as short PDF documents and presentations.

These outputs will be supported by a range of tools that will support their use by local services and other stakeholders, including slide sets and QI resources. Additional outputs include peer-reviewed publications and presentations at national and international meetings. Newsletters will be disseminated to announce the publication of new results to clinical teams and audit stakeholders.

Summaries of the ‘*State of the Nation*’ reports from each cancer audit will be prepared for patients and the general public and available on the NATCAN website, in addition to information for patients.

Patient representatives in the PPI Forums and Clinical Reference/Advisory Groups of each cancer audit will provide input into the development of the audit outputs.

Publication of comparative local outcomes, along with the associated commentary, allow patients to understand the quality of care being offered and enable them to ask Trusts/Health Boards and clinical teams how they plan to put right any deficiencies identified via the audits.

i. Healthcare improvement

A priority for each audit in NATCAN is the development of a healthcare improvement plan that includes explicit QI goals aiming to improve cancer outcomes as well as the patient experience. These plans will be built around clinically relevant and methodologically robust performance indicators that each audit will develop and disseminate.<sup>3</sup>

The healthcare improvement plan will also set out the key drivers for each QI goal, alongside national and local improvement tools.<sup>4</sup> NATCAN will ensure that its healthcare improvement programme will be closely aligned with related activities implemented by other relevant organisations (e.g., CQC and Getting it Right First Time in England, and NHS Quality Improvement and Patient Safety in Wales).

Each audit within NATCAN will complete at least one national QI initiative using the RCRD, aiming “to close the audit cycle” following an approach commonly referred to as the “plan-do-study-act” method.<sup>5</sup> This will be a first at national level and we envisage that it will become a core element of involvement for the NATCAN QI Team.

Again, NATCAN will build on the CEU’s longstanding experience in targeting and designing QI implementation approaches, ensuring that the audit feedback information and recommendations truly reach the clinicians who can act on it, also incorporating specific action plans.

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<sup>3</sup> Geary RS, Knight HE, Carroll FE, Gurol-Urganci I, Morris E, Cromwell DA, van der Meulen JH. A step-wise approach to developing indicators to compare the performance of maternity units using hospital administrative data. *BJOG*. 2018 Jun;125(7):857-865. doi: 10.1111/1471-0528.15013.

<sup>4</sup> Foy R, Skrypak M, Alderson S, Ivers NM, McInerney B, Stoddart J, Ingham J, Keenan D. Revitalising audit and feedback to improve patient care. *BMJ*. 2020 Feb 27;368:m213. doi: 10.1136/bmj.m213.

<sup>5</sup> Taylor MJ, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. *BMJ Qual Saf*. 2014 Apr;23(4):290-8. doi: 10.1136/bmjqs-2013-001862.