NKCA
National Kidney
Cancer Audit

NATCAN
National Cancer Audit
Collaborating Centre

# National Kidney Cancer Audit

# Quality Improvement Plan – September 2024

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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 and the Royal College of Nursing. 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

# Contents

# Executive Summary

The National Kidney Cancer Audit (NKCA) has been commissioned to evaluate kidney cancer care delivered in NHS hospitals across England and Wales. It aims to help NHS organisations to benchmark their kidney cancer care against measurable standards, to identify unwarranted variation in care, and to provide tools to help services improve quality of care for people with kidney cancer.

The NKCA Quality Improvement Plan sets out the scope, care pathway, five improvement goals and ten initial performance indicators for the NKCA. The NKCA team carried out the process of selection in close collaboration with our Clinical Reference Group (CRG) whose members represent all our stakeholder organisations including patient groups and professionals involved in kidney cancer care.

Based on this work, the NKCA includes:

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

The audit will cover the care pathway for patients considering both personal and tumour factors, supported by current guidelines, to receive personalised and evidence-based management.

**The following quality improvement goals have been identified for the NKCA:**

1. To increase regional equity in timely access to evidence-based kidney cancer services

2. To increase the use of renal tumour biopsy

3. To expedite treatment for patients with localized RCC at potentially high risk for recurrence (cT3+, 10cm+, cN1 tumours)

4. To increase use of surgery, if medically appropriate, for initially localised RCC at high risk of progression, while reducing the use of unnecessary radical surgery for low-risk RCC

5. To increase use of evidence based SACT treatment in eligible patients without increasing severe toxicity

The NKCA has identified ten initial indicators, mapped to these five improvement goals and clinical guidelines. It sets out improvement methods, improvement activities and approaches to evaluation of the Quality Improvement Plan.

# 1. Introduction

## 1.1 Aim and objectives of the Quality Improvement Plan

The NKCA Quality Improvement Plan builds on the previous Scoping Document which sets out the scope and care pathway of the NKCA and identified five key improvement goals. The Quality Improvement Plan defines ten performance indicators, and how they map to the NKCA quality improvement goals, national guidelines and standards. These performance indicators will be used by the NKCA to monitor progress towards its improvement goals and to stimulate improvements in kidney cancer care.

The Quality improvement Plan describes the approach taken to develop the NKCA improvement goals and performance indicators. In addition, it aims to set out the improvement methods and activities that will support implementation of the plan, including strategies for reporting and disseminating results, in addition to describing the approaches to evaluation.

The NKCA Quality Improvement Plan was developed in consultation with key stakeholders, including people with lived experience of kidney cancer and will be reviewed on an annual basis.

## 1.2 The National Cancer Audit Collaborating Centre

The 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 1st October 2022 to deliver six new national cancer audits, including kidney, ovarian, pancreatic, breast (two separate audits in primary and metastatic disease) and non-Hodgkin Lymphoma. Existing audits in prostate, lung, bowel, and oesophago-gastric cancers moved into NATCAN in 2023. The centre is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government.

The aim of the ten NATCAN 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.

Further information about NATCAN and key features of its approach to audit can be found in the Appendix.

# 2. Background on kidney cancer

## 2.1 Main issues in kidney cancer care and outcomes

Kidney cancer is the 7th most common type of cancer in the UK and incidence is at its highest in people aged between 65-75 years, with a 3:2 ratio of men to women diagnosed[1]. Risk factors include lifestyle factors such as smoking, obesity and hypertension, alongside diagnosis of a close relative (includes a person's parents, brothers, sisters or children).

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)[2]. 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.

Renal cell carcinoma is the most common type of kidney cancer in adults, accounting for 80% of all kidney cancers. There are different types of renal cell carcinoma, including clear cell (70-80%) papillary (5-10%) and chromophobe (3-5%)[3]. These are generally identified following pathology review of a tissue biopsy, and which have varying outcomes and are managed differently.

## 2.2 Care pathways

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
- Systemic Anti-Cancer Therapy (SACT)
- Thermal Ablation
- Radiation therapy

## 2.3 Guidelines on the management of NKCA cancer

The first NICE guidelines for kidney cancer are in development following sustained campaigning by Kidney Cancer UK (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 NKCA with a basis for developing its scope as well as baseline results to be used as benchmarks. Stakeholders for the NKCA and NICE kidney cancer guideline development will have complementary roles, being involved in both initiatives.

## 2.4 Variation in care and outcomes

An audit of the quality of kidney cancer services in England during 2017-2018 funded by KCUK was published in 2022[4] 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[4].

The audit found that over a fifth of patients were diagnosed at an advanced stage with the spread of cancer to other parts of the body. The rate and type of surgery offered to patients as well as the number of metastatic patients who received systemic therapy varied by NHS Trust. It also found a quarter of Trusts recruited no patients to clinical trials. Alongside the quality performance indicators assessed, the audit found increasing incidence of kidney cancer, and an increase in the mortality rate. Age-standardised five-year relative survival in adults (aged 15+) measured between 2000 and 2007 placed England 26th and Wales 23rd out of 29 European countries.

Kidney Cancer UK also runs annual patient surveys, the latest of which published in 2024 reported that for 31% of patients, it took over three months from first seeking medical advice to diagnosis and 23% 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.

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[1] Cancer Research UK, *Kidney cancer statistics* https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer, Accessed April 2024.

[2] Vasudev NS, Wilson M, Stewart GD, et al. Challenges of early renal cancer detection: symptom patterns and incidental diagnosis rate in a multicentre prospective UK cohort of patients presenting with suspected renal cancer. BMJ Open. 2020 May 11;10(5):e035938. doi: 10.1136/bmjopen-2019-035938.

[3] Cancer Research UK, *Stages, types and grades of kidney cancer* https://www.cancerresearchuk.org/about-cancer/kidney-cancer/stages-types-grades/types-grades, Accessed April '24

[4] Kidney Cancer UK, *Quality Performance Audit of kidney cancer services in England*. June 2022. https://www.kcuk.org.uk/publication/kidney-cancer-uk-accord-full-report/, Accessed April 2024

# 3. Approach to developing the Quality Improvement Plan

This NKCA Quality Improvement Plan builds on the NKCA Scoping Document which set out the patient inclusion criteria and audit scope (Section 4) as well as five improvement goals for the NKCA (Section 5). This Quality Improvement Plan outlines ten performance indicators that have been mapped to clinical guidelines and the five improvement goals (Section 5).

In Sections 6 and 7, improvement methods and improvement activities are outlined. Finally, Section 8 sets out the approaches to evaluation of the Quality Improvement Plan. Given that this is the first national audit of kidney cancer in England and Wales, the Quality Improvement Plan is expected to evolve over subsequent years.

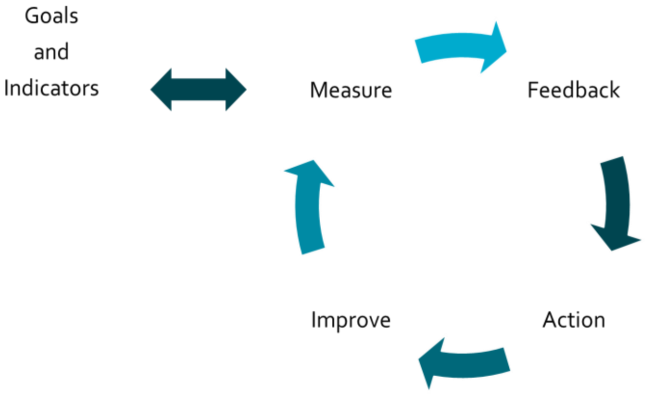
## 3.1 Approach to developing the audit scope

All performance indicators will conform to our founding NATCAN principles. These principles are that all 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 performance indicators 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).

## 3.2 Approach to prioritising performance indicators

Clinical Performance Feedback Intervention Theory (CP-FIT)[5] states that developing improvement goals and performance indicators are the first steps in the audit and feedback cycle (Figure 1).

Figure 1: The audit and feedback cycle



Using the five quality improvement goals outlined in its Scoping Document, the NKCA developed a list of 37 candidate performance indicators for the performance of NHS providers. Prioritisation of ten indicators from this list of candidates was informed by the following set of key principles.

The audit and feedback cycle is only as strong as its weakest link: to enhance the NKCA's ability to inform improvements in care, its performance indicators must have three properties:

- **Measurable** so that they can be the basis of credible feedback about performance. This property means that the indicators can be defined with available data in a valid, reliable, and fair manner that allows performance to be attributed to a specific unit.[6]
- **Actionable** so that feedback translates into action to improve care. Indicators should therefore be important and address a specific pathway of care that is clear to all stakeholders. Stakeholders should understand the drivers of variation in performance within this pathway and control the levers for change. These changes should be evidence-based and address policy priorities.

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[5] Brown B, Gude WT, Blakeman T, van der Veer SN, Ivers N, Francis JJ, et al. Clinical Performance Feedback Intervention Theory (CP-FIT): a new theory for designing, implementing, and evaluating feedback in health care based on a systematic review and meta-synthesis of qualitative research. Implement Sci 2019;14:40.

[6] 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;125:857-65.

- **Improvable** so that actions have the desired effect on patient care. There should therefore be clear scope for improvement (low baseline levels or large unwarranted variation) in a large population and a receptive context, with no unintended consequences. Some interventions may have demonstrated improvements to certain indicators in existing literature.

Some of these properties are difficult to know in advance of selecting and investigating a performance indicator (such as existing levels of performance, the drivers of low performance, or interventions that can improve care). In addition, clinical practice and its context may change over time so that properties of indicators also change (such as whether they relate to a policy priority). Therefore, the NKCA's goals and performance indicators are likely to evolve over time too. Recommendations will also evolve and become more focused as the NKCA learns through the audit and feedback cycle.

## 3.3 Data provision

The NKCA will use information from routine national health care datasets. These capture details on the diagnosis, management and treatment of every patient newly diagnosed with kidney cancer in England and Wales. Further details on data acquisition can be found in the Appendix.

## 3.4 Data limitations

For accurate and timely benchmarking, it is essential that data used by the NKCA:

1. Includes all the data items required to measure and risk-adjust performance indicators
2. Is timely
3. Has a high-level of case-ascertainment
4. Has high levels of data completeness
5. Is accurate.

For patients treated in England, Rapid Cancer Registration Data (RCRD) linked to other national healthcare datasets, will be used for quarterly reporting. This dataset is mainly compiled from Cancer Outcomes and Services Dataset (COSD) records and is made available more quickly than the gold standard National Cancer Registration Data (NCRD). The speed of production means that case ascertainment and data completeness are lower, and the range of data items in the RCRD is limited. This may restrict the extent to which risk adjustment can be applied to performance indicators used for quarterly reporting. For patients treated in Wales, no equivalent of RCRD is currently available.

## 3.5 Stakeholder involvement

The core NKCA project team consists of two clinical leads (urology and oncology), methodological leads, a data scientist, clinical fellow and project manager, but the audit scope has been 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 14th 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 quality improvement goals were revised to incorporate the comments received.

During the second meeting with the CRG on Thursday 29th February 2024, feedback was provided on the five improvement goals and ten performance indicators selected. Thereafter written comments were also reviewed and taken into account.

## 3.6 Service provision

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 1st April 2018 and 31st 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 in the future reports:

- Diagnostic scans and biopsies were widely performed (19% patients undergoing a diagnostic biopsy)
- 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

# 4. Audit scope

## 4.1. Patient inclusion criteria

The eligibility criteria for including patients in the NKCA is defined as follows:

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

## 4.2. Care pathway

An overarching principle of the 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 involvement of a cancer nurse specialist, also play a role in ensuring personalisation of care. As such metrics become assessable, the audit will be able to appraise the appropriateness of and adherence to personalised care pathways.

Equally embedded in these 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.

## 4.3. Initiatives

NATCAN's performance indicators uphold principles of clinical relevance, methodological robustness, and technical rigor, fostering collaboration with data partners in England and Wales for continuous improvement and assessment.

As described previously, the audit is building on previous assessments of kidney cancer care in the UK and has drawn on these to develop the current ten performance indicators.

| Organisation | Initiative |
|---|---|
| Scottish Cancer Taskforce, National Cancer Quality Steering Group 2019 (v4) | 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. |
| Getting It Right First Time 2023 | 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. |
| Kidney Cancer UK Accord Report 2022 | 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. |

# 5. Quality improvement goals & performance indicators

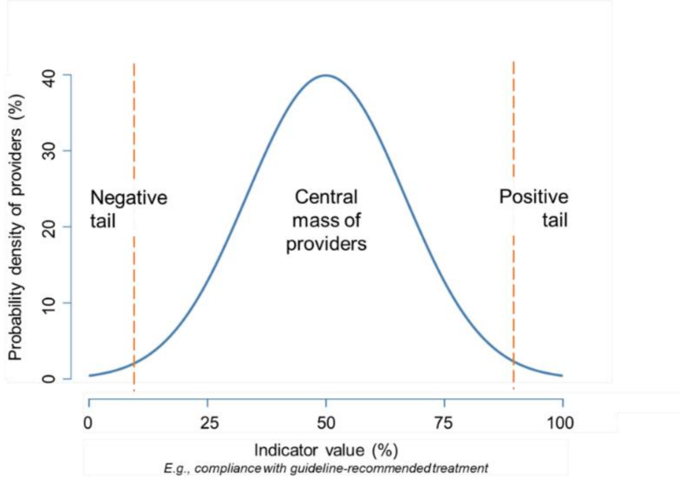
| **Quality improvement goal** | **Performance indicators*** | **National Guidance/standards** |
|---|---|---|
| To increase regional equity in timely access to evidence-based kidney cancer services | Percentage of people with kidney cancer with the data completeness measure recorded for MDT meeting<br>Percentage of people with kidney cancer who are consented for a clinical trial (England only)<br>Percentage of people who are treated within 31 days of a decision-to-treat/Percentage of people who are treated within 62 days of an urgent referral | Scottish QPI4<br>Accord QPI 5; GIRFT; Scottish QPI14<br>NHS England |
| To increase the use of renal tumour biopsy | Percentage of people with a small renal mass (≤4cm) who have a biopsy (England only)<br>Percentage of people who have a biopsy to confirm histological diagnosis before non-surgical treatment | GIRFT<br>Kidney Cancer UK Consensus Statement; Scottish QPI2 |
| To expedite treatment for people with localised RCC at potentially high risk for recurrence (i.e. cT3+, 10cm+, cN1 tumours) | Percentage of people with a T3+ and/or 10cm+ and/or N1 and M0 renal cell carcinoma (RCC) who have a radical nephrectomy within 31 days of diagnosis | GIRFT |
| To increase use of surgery, if medically appropriate, for initially localised RCC at high risk of progression, while reducing the use of unnecessary radical surgery for low-risk RCC | Percentage of people with T1b-3NxM0 RCC (T2-3NxM0 RCC for Wales) who have surgery<br>Percentage of people with T1aN0M0 RCC who undergo nephron sparing treatment | Accord QPI2<br>Scottish QPI7 |
| To increase use of evidence based SACT treatment in eligible patients without increasing severe toxicity | Percentage of people presenting with M1 RCC who have initial SACT within 12 months of diagnosis<br>Percentage of people who die within 30 days of starting SACT treatment | Accord QPI 4; Scottish QPI9<br>Scottish QPI15 |

* The NKCA will publish initial performance indicators in the first State of the Nation Report published in September 2024. Additional indicators will be reported in quarterly reports and future State of the Nation reports. The publication of indicators is aligned with data availability and completion of robust, methodological development work including appropriate risk-adjustment models.

# 6. Quality improvement Framework

The figure below shows a hypothetical example of how a performance indicator may be distributed across NHS providers nationally at a single time point. This distribution can be separated into three domains: the negative tail (suggestive of worse performance), the central mass (centred on the national average, for example), and the positive tail (suggestive of better performance).

Figure 2: Distribution of performance indicator



Each domain is associated with a different set of methods for improving healthcare:

Negative tail

*Example methods: Regulation and public reporting of outliers*

- Clinical audit has traditionally focused on the negative tail to improve healthcare. This approach implies that some NHS providers are doing something systematically wrong that can be resolved through direct intervention. Such intervention may be necessary to assure minimum standards of care and to reduce inequality between the best and worst performing NHS providers. Cancer audits that pre-date NATCAN have formally reported negative outliers (see Appendix).

Central mass

*Example methods: Statistical process control and iterative testing of interventions*

Most providers exist in the central mass of the distribution (by definition) which may present the greatest scope for improving average levels of care nationally. Methods in this domain suggest that all providers can improve their performance, regardless of baseline levels. Longitudinal monitoring provides feedback about whether improvements occur or not.

Positive tail

*Example methods: Positive deviance*

- Some NHS providers perform exceptionally well despite similar constraints to others, which presents opportunities to learn how this is achieved. 'Positive deviance' approaches assert that generalisable solutions to better performance already exist within the system. Such solutions are therefore more likely to be acceptable and sustainable within existing resources. These approaches aim to identify local innovations and spread them to other settings (see Appendix).

The NKCA will select which methods to implement to improve kidney cancer care after investigating the distributions of its performance indicators (outlined in section 5). This includes the distribution of performance indicators between providers at a given time point and within providers over time. It also includes investigation of variation at the patient, hospital, and regional levels to see where most variation exists and which variables help to explain it (see Appendix for more detail).

# 7. Improvement activities

Improvement activities and outputs of the NKCA will be aligned to this Quality Improvement Plan. The NKCA will: (1) engage in key collaborations, (2) align with other initiatives in kidney cancer care, and (3) provide outputs to support quality improvement at the national, regional and local level.

The two principal strategies for reporting NKCA results are producing:

- A short 'State of the Nation' (SotN) report for NHS Trusts/Health Boards within England and Wales. This annual report publishes five key recommendations and highlights where services should focus quality improvement activities. These recommendations will be at the Cancer Alliance level where applicable and be formed between audit teams, clinical reference groups and major national stakeholders.

- A quarterly dashboard facilitates benchmarking and the monitoring of performance at regular intervals so improvements can be tracked over time.

## 7.1 National and regional

The NKCA undertakes various activities that directly support national stakeholders and regional NHS organisations to tackle system-wide aspects related to the delivery of high-quality kidney cancer services:

| Stakeholder | NKCA activity |
|---|---|
| *NATIONAL* | |
| NHS England and Wales | Identify issues and make recommendations, on the organisation and delivery of kidney cancer services, which might involve national leadership. Recommendations published in audit's State of the Nation reports. |
| National incentives | Provide the Care Quality Commission (CQC), Care Inspectorate Wales, and Getting It Right First Time (GIRFT) with information to support local visits to NHS organisations and options for aligning recommendations. |
| Professional organisations | Identify issues and make recommendations regarding the delivery of kidney cancer care that fall within the remit of the professional organisations. |
| *REGIONAL* | |
| Cancer Networks / Alliances / Vanguards | Support the monitoring role of Welsh Cancer Networks and the English Cancer Alliances / Integrated Care Boards by publishing results for their region/area. |

At a national level, the NKCA team will also provide the National Cancer Registration and Analysis Service (NCRAS) Data Improvement Leads (in England), and the Wales Cancer Network with information to help them support their NHS organisations to improve the quality of their routine data submissions.

## 7.2 Local

The NKCA supports local NHS cancer services in their care of kidney cancer patients in the following ways:

| **NKCA feedback activity** | **Description** |
|---|---|
| Annual "State of the Nation" Reports | State of the Nation reports that allow NHS organisations in England and Wales to benchmark themselves against clinical guideline recommendations and the performance of their peers. |
| Web-based dashboard | Presents results for individual NHS organisations that allows the user to compare the results of a selected provider against a peer organisation. |
| Local Action Plan template | Allows NHS organisations to document how they will respond to the State of the Nation Report recommendations. |
| Data case studies | Examples of different approaches used by NHS trusts in England to ensure their Cancer Outcomes and Services Dataset (COSD) submissions to NCRAS are as complete as possible. |
| Outlier Process | Reporting of NHS provider values that are more than three standard deviations from the expected level of performance (i.e. deemed a potential outlier). In future audit rounds the NKCA will carry out an outlier process linked to their annual SotN report working with providers whose performance was an outlier for being too low. This process includes closer investigation of the data, identifying possible explanations for low performance, and efforts to improve care. |
| Improvement Case Studies | Examples of different approaches used by NHS trusts to improve care quality or recommendations identified from review of processes at positive or negative outliers, with a specific focus on the pathway of care (see actionable earlier) |
| Interventions | This will include possible interventions that have been identified in the literature linked to the performance indicators assessed by the audit or include interventions developed by Trusts/Alliances in the NHS. |
| Targets | Recommendations may include targets or thresholds for performance indicators e.g. XX % expected to receive treatment. |
| Materials supplementary to the State of the Nation Report | Including tools for improving data completeness. |

## 7.3 Improvement tools

The NATCAN website includes a Quality Improvement Resources page with links to the RCSEng website and other web-based material that direct healthcare providers to various quality improvement tools including:

- 'How to' guides including quality improvement methodology
- Links to existing resources
- Links to training courses for quality improvement
- Good practice repository with contact information where possible

## 7.4 Improvement workshops

The NKCA team plans to organise an annual national workshop to highlight key components of the diagnostic and treatment pathways. The topic for the workshop will be selected in consultation with the CRG and patient representatives focusing on the NKCA improvement goals.

NKCA will seek to develop closer links with NHS improvement groups, Cancer Alliances and vanguards and work with them on how to use improvement workshops to:

- Support local kidney cancer services to develop local improvement plans
- Share examples of good practice
- Evolve the methods of feedback used by NKCA

## 7.5 Designing a national quality improvement initiative

Using the Rapid Cancer Registration Dataset, the NKCA will design a national Quality Improvement initiative aiming "to close the audit cycle" following an approach commonly referred to as the "plan-do-study-act" method[7].

The design and methodology underpinning this Quality Improvement initiative will be available in the next iteration of the Quality improvement Plan further to consultation with NKCA stakeholders.

## 7.6 Patient and Public Involvement

The NKCA Patient and Public Involvement Forum is an advisory group of patients who have had kidney cancer, survived kidney cancer or are a friend, family member and/or carer to a kidney cancer patient.

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[7] NHS England and NHS Improvement, *Online library of Quality, Service Improvement and Redesign tools* https://aqua.nhs.uk/wp-content/uploads/2023/07/qsir-pdsa-cycles-model-for-improvement.pdf, Accessed April 2024

This group will help the NKCA project team by ensuring the voice of patients is central to the direction and delivery of the Audit.

This includes:

- Establishing a standalone NKCA Patient and Public Involvement (PPI) Forum, a key stakeholder group developed in consultation with the patient charities – Kidney Cancer UK and Action Kidney Cancer
- Members of the NKCA PPI Forum will be regularly consulted on the design of the audit and the communication of its results. Members will:
    - Be active participants in the production of audit outputs
    - the development and review of patient information materials and summaries of the State of the Nation reports
    - co-development and/or co-authorship of scientific papers that explore NKCA results
- Undertake a key advisory role in developing the NKCA section of the NATCAN website to ensure that patients and the public can easily find relevant results together with appropriate explanatory information.
- Shape the development of the NKCA quality improvement goals, activities and outputs by ensuring this work is relevant from a patient perspective.

## 7.7 Communication & dissemination activities

The NKCA will communicate regularly with stakeholders, including patients and the public in the following ways:

Newsletters

- The NKCA Newsletter is distributed to key stakeholders on a quarterly basis, highlighting quality improvement methods and tools (where appropriate). These are also all published on the NKCA website

- Project team members also contribute items for newsletters created by medical associations, patient associations.

Website and Social Media

- The NKCA website will be reviewed and updated on a monthly basis (as appropriate).

- NKCA Twitter account will tweet (and retweet) about key resources, publications or topics of interest to our stakeholders, including tools to aid quality improvement.

Conferences and Publish Articles in Medical Journals

- The NKCA will present audit results at national conferences such as those organised by the British Association of Urological Surgeons (BAUS), the British Uro-Oncology Group (BUG) and publish articles in medical journals and other media.

- Publish peer-reviewed publications of the results of methodological development, clinical epidemiological investigations of determinants of variation, mapping of the structure of kidney cancer services, and assessments of the impact of the NKCA's quality improvement activities and initiatives.

# 8. Evaluation

The NKCA will report year-on-year progress against improvement goals to the audit's Clinical Reference Group and in the SotN reports on an annual basis. This will focus on describing how values of performance indicators have changed over time at a national level.

To evaluate the impact of specific NKCA or other national interventions on the performance of NHS providers, quasi-experimental methods (when allocation of providers to certain groups cannot be controlled) or experimental methods (when group allocation can be controlled) will be used.

The NKCA will examine the opportunities for and strengths and limitations of quasi-experimental and experimental evaluation methods once it is more fully established.

# Appendix

## 1. National Cancer Audit Collaborating Centre (NATCAN)

The National Kidney Cancer Audit is part of the National Cancer Audit Collaborating Centre (NATCAN), a national centre of excellence launched on 1 October 2022 to strengthen NHS cancer services by looking at treatments and patient outcomes in multiple cancer types across the country. The centre was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government with funding in place 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. 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.

NATCAN was set up on 1 October 2022 to deliver six new national cancer audits, including kidney, ovarian, pancreatic, breast (two separate audits in primary and metastatic disease) and non-Hodgkin Lymphoma. Existing audits in in prostate, lung, bowel, and oesophago-gastric cancers moved into NATCAN in 2023. This critical mass of knowledge and expertise enable it to respond to the requirements of the funders and stakeholders.

The aim of the ten NATCAN 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.

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, 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.

Organisational structure of NATCAN

*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.

*Executive Team*

NATCAN's Executive Team is chaired by the Director of Operations (Dr Julie Nossiter) and includes the Clinical Director (Prof Ajay Aggarwal), the Director of the CEU (Prof David Cromwell), the Senior Statistician (Prof 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.

*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.

*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.

*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.

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 performance 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".

*Audit PPI Forums*

Patients and patient charities are involved in all aspects of the delivery of the cancer audits. Each audit has 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.

## 2. Data provision

The NATCAN Executive Team has worked closely with data providers in England (NDRS, NHSE) and in Wales (WCN, 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.

*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,[8] 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 for National Statistics among other routinely collected datasets, see Figure 1) for describing diagnostic pathway patterns, treatments received and clinical outcomes.

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

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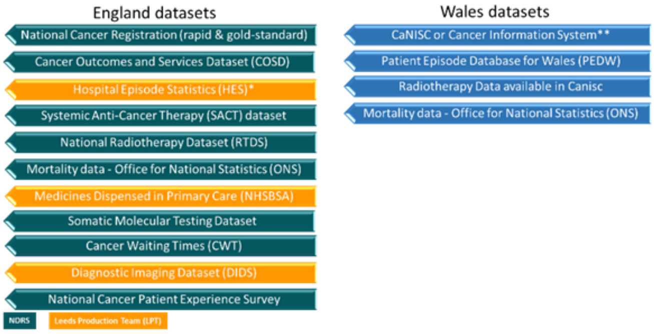
[8] Nossiter J, Morris M, Parry MG, Sujenthiran A, Cathcart P, van der Meulen J, Aggarwal A, Payne H, Clarke NW. Impact of the Covid-19 pandemic on the diagnosis and treatment of men with prostate cancer. BJU Int. 2022; doi: 10.1111/bju.15699

Figure 1. National datasets available to NATCAN



* Includes inpatient and outpatient data and Emergency care Dataset (ECDS).

** NHS Wales will use Welsh registry information for the initial years data for the audit. NATCAN submitted a request for historical data from the Welsh Cancer Registry in Q4 2023 (not received to date). From 2022 data submissions will be from either Canisc or the new cancer dataset forms.

## 3. Quality improvement Framework – Supplementary information

### Negative tail

*Regulation and public reporting of outliers*

National cancer audits that pre-date NATCAN have used a formal process for reporting outliers publicly. This process includes contacting outliers before publication to: (1) verify the data, (2) identify the reasons for the low level of performance identified, and (3) determine what corrective interventions have been put in place. The findings are reported publicly and may inform care practices in other NHS Trusts.

### Central mass

*Statistical process control and iterative testing of interventions*

Most providers exist in the central mass of the distribution (by definition). Just because something is common it does not mean that it is alright: performance may be systematically below an achievable standard nationally for example (such as 75% of eligible patients receiving a particular treatment). We recommend that individual providers verify their performance data and undertake internal audits to assess areas for improvement and consider evaluation of their processes of care.

### Positive tail

*Positive deviance*

Positive deviants may perform consistently better than comparators over time or demonstrate a clear upward trend in performance between two time points. It may be possible to learn from these providers to identify practices of care that have driven high levels of performance. This could include care protocols or factors related to system organisation which may inform quality improvement amongst providers in the negative tail and central mass of performance.

### Determinants of variation

To support targeting of improvement interventions and recommendations, the audit will analyse particular patient, hospital and regional factors associated with variation in processes and outcomes of care. For example, for the utilisation of a particular evidence-based treatment, factors associated with utilisation may include advanced age, social deprivation and frailty, clinician preferences, and regional policies. Findings may be reported at an aggregated national or regional (alliance) level and can support NHS Trusts to target interventions or evaluation at particular patient populations.