

NBOCA | National Bowel
Cancer Audit

National Bowel Cancer Audit

Scoping Document

November 2023



NATCAN

National Cancer Audit
Collaborating Centre



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HQIP

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>



The Association of Coloproctology of Great Britain and Ireland (ACPGBI) is the professional body that represents UK colorectal surgeons. ACPGBI assisted in the clinical interpretation of the data presented in the 2022 Annual Report.

National Bowel Cancer Audit (NBOCA) Scoping 2023

This document outlines in section 1 the background of the National Bowel Cancer Audit (NBOCA), its move into the new National Cancer Audit Collaborating Centre (NATCAN), and the purposes of this scoping exercise. Section 2 describes the existing scope and design of NBOCA and Section 3 outlines the proposed scope and design of NBOCA within NATCAN, which we have sought stakeholder feedback on. Section 2 and 3 are both structured in terms of (1) scope, (2) reporting, (3) quality improvement, (4) performance indicators and QI targets, (5) data provision and (6) engagement with patients and the public.

Current version: Updated 29 March 2023, incorporating feedback from a scoping meeting held on 22 March 2023, and feedback sent by email on the first version of this document. Areas identified by stakeholders as being of key importance are highlighted in grey in Section 3.

1. Background and purposes of the meeting

1.1 Future contracting of NBOCA

The contract for the National Gastrointestinal Cancer Audit Programme (GICAP) at the Royal College of Surgeons of England, which is made up of NBOCA and the National Oesophago-Gastric Cancer Audit (NOGCA), came to an end on 31 May 2023. From 1 June 2023 both NBOCA and NOGCA moved into the National Cancer Audit Collaborating Centre (NATCAN) at the Clinical Effectiveness Unit (CEU) of the Royal College of Surgeons of England (RCS England).

1.2 NBOCA team and partnerships

[NBOCA](#) is a methodological clinical partnership based at the Clinical Effectiveness Unit of the Royal College of Surgeons of England (CEU). NHS England's CARMS provides project management and technical infrastructure, including data provision, data collection and communications with providers.

Clinical leadership is provided by the Association of Coloproctology of Great Britain and Ireland (ACPGBI). This is supported by twice yearly meetings of the stakeholders in the Clinical Advisory Group, including clinicians from across the patient pathway, patients, charity representatives and commissioners. A Patient and Carer Panel provides the patient perspective. These trusted long-term relationships ensure the clinical relevance of NBOCA work, engagement with clinicians, and impact on quality improvement initiatives.

NBOCA is a member of the International Colorectal Cancer Collaboration (ICORC) which it was key to establishing in 2021. ICORC aims to make international comparisons to guide areas of focus for quality improvement, and learn across audits on e.g., methodology, indicators, clinical focus, and communications.

1.3 The National Cancer Audit Collaborating Centre (NATCAN)

[NATCAN](#) is 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 in October 2022 to deliver five new national cancer audits. Over time it will deliver all of the national cancer audits in the National Clinical Audit and Patient Outcomes Programme (NCAPOP), commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government.

The [CEU](#) at RCS England is a collaboration between RCS England and the London School of Hygiene & Tropical Medicine. It delivers clinical 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 improve outcomes for patients. They have also promoted improvement initiatives within NHS cancer services and identified areas of best practice.

NHS England and the Welsh Government have funded NATCAN for an initial period of three years. The aim of these 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.

1.4 NBOCA within NATCAN

NBOCA moved into NATCAN through a variation to the contract between HQIP and RCS England. The main changes to the contracted deliverables when NBOCA moved into NATCAN were:

- Use of existing data only
- 10 page annual “State-of-the-Nation” reports with maximum of 10 performance indicators
- No reporting of individual consultant outcomes
- No short reports (with in-depth topics reported through peer-reviewed publications instead)
- Greater Quality Improvement (QI) focus
- More frequent more timely reporting

Within NATCAN NBOCA retains its own Project Team of methodologists, clinicians and project managers, its own Clinical Advisory Group of stakeholders, and its own Patient and Carer Panel. Governance is at Centre level with an overarching Board and Executive Team across NATCAN. NATCAN will also have a Clinical Director, Technical Advisory Group and Quality Improvement Team which will each work across the Centre. NBOCA will ensure that there is effective communication from the NBOCA clinical leads into the NATCAN Board.

1.5 Purposes of this scoping exercise

This scoping exercise, run by the CEU at the RCS, aims to ensure that the proposed future scope and design of NBOCA within NATCAN considers the needs of stakeholders whilst driving local and national quality improvement in services and outcomes for bowel cancer patients. Specifically, the aims are to:

- Refine the intended healthcare quality improvement plan,
- Quantify improvement goals,
- Determine the targeted set of specific performance indicators,
- Identify the data sources best able to achieve these.

2. Existing NBOCA approach

2.1 Existing scope of NBOCA

NBOCA started in its current format in 2010 as a surgical audit reporting on short-term outcomes. It has since worked to broaden its clinical scope to better drive quality improvement. This requires a better understanding of:

1. **Complex patients:** heterogeneity in terms of e.g. deprivation, ethnicity, age, frailty, molecular subtypes of bowel cancer, and comorbidities.

2. **Complex pathways/ service structure:** e.g. multi-modal treatment options, patients having non-curative treatment, not all diagnosing hospitals offer all specialist services, capacity constraints.
3. **Cancer as a chronic disease:** Patients are living longer with bowel cancer requiring longer-term outcomes to be measured and quality of life becoming increasingly important.

Methodological development work has been key to achieving a better understanding of these issues in order to develop relevant, accurate performance indicators in an appropriate cohort of patients, improve risk-adjustment, and report at the relevant level of provider.

2.2 Existing NBOCA reporting

NBOCA drives local quality improvement by providing annual feedback on the performance of bowel cancer services through provider dashboards on its website, and by providing hospitals/trusts with quarterly reports. The annual reports, aimed at clinicians, commissioners, regulators and other professional stakeholders, describes the national picture of bowel cancer care. A patient version of the annual report is written in collaboration with the NBOCA Patient and Carer Panel. The [2022 NBOCA annual report](#) identified wide variation in care and reduction in providers meeting the QI targets.

Since 2013 NBOCA has published outcomes at individual surgeon and trust/hospital level for English NHS trusts on the [ACPGBI website](#) as part of the Clinical Outcomes Publication (COP) programme. The COP process was suspended due to the COVID-19 pandemic at surgeon level, with results fed back directly to individual trusts/hospitals about their surgeons' performance to support local quality assurance processes.

[Short Reports](#) provide results of in-depth analyses on focussed topics that are priorities among the audit's stakeholders, including: patients diagnosed under 50 years old with advanced cancer; capture of chemotherapy in routine clinical data; capture of critical care in routine clinical data.

An annual [organisational survey](#) provides up-to-date information about the services available at each hospital/trust/MDT. This is presented in the provider dashboards on the audit website and is used to understand variation in treatments and outcomes of bowel cancer patients.

2.3 Existing Quality Improvement (QI) Plan

NBOCA has a [Quality Improvement Plan](#) targeted at improving patient experience and cancer outcomes. It aims to involve all members of the multidisciplinary clinical team, covering all areas of the patient pathway, from diagnosis and peri-operative care to adjuvant and neoadjuvant oncological management, stage IV disease and end of life care. NBOCA is responsible for providing trusts/hospitals/MDTs with relevant metrics (currently 12 listed in 2.4 below) across the patient pathway. For each metric a national and a mirrored local MDT QI target has been set.

Each year NBOCA runs a QI workshop at the ACPGBI Annual Meeting and runs QI webinars, aiming to stimulate the use of the Audit's output for local QI. The NBOCA website directs providers to QI tools, including links to various quality improvement pages on the RCS website and other online material. It is also developing a QI intervention in collaboration with the RCS on timely closure of temporary ileostomy.

2.4 Current performance indicators and QI targets

[Performance indicators](#) are defined in detail and mapped to guidelines. These indicators were developed and evaluated according to four explicit criteria, including validity, statistical power, technical feasibility, and fairness¹. The results of methodological development to improve the relevance and accuracy of the audits'

¹ Geary RS et al. 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.

performance indicators are published in peer-reviewed journals^{2,3}. Provider-level indicators, adjusted for case-mix⁴, are compared using funnel plots, allowing “potential outliers” to be identified.

The local QI targets selected in the NBOCA Quality Improvement Plan to deliver on the national targets are:

1. >80% case ascertainment
2. >70% data completeness of seven items for risk adjustment in patients having surgery
3. Annual resectional rectal cancer surgery volume of more than 20 patients
4. >95% colorectal cancer patients seen by Clinical Nurse Specialist (CNS)
5. <10% risk-adjusted unplanned return to theatre after colorectal cancer resection
6. 10% to 60% rate of neoadjuvant treatment in rectal cancer patients undergoing resection
7. >50% rate of adjuvant chemotherapy after colon cancer resection
8. >50% colorectal cancer operations via laparoscopic approach
9. <15% risk-adjusted 30 day unplanned readmission rates after colorectal cancer resection
10. <35% diverting ileostomies after rectal cancer surgery unclosed by 18 months
11. >70% risk-adjusted survival at 2 years after colorectal cancer resection
12. <6% risk-adjusted mortality after colorectal cancer resection

In addition NBOCA reports these performance indicators on its provider dashboards:

- Potentially curative patients undergoing major resection
- Surgical patients with at least 12 lymph nodes excised
- Risk-adjusted length of stay longer than 5 days
- Negative circumferential resection margins
- Rectal cancer patients undergoing APER/ Hartmanns

2.5 Existing data provision

NBOCA uses existing data sources wherever possible to reduce the burden of data collection. It provides hospital staff access to their own audit data for checking through the Clinical Audit Platform (CAP) system. The audit dataset is linked annually at patient level to routine hospital data (HES and PEDW), and datasets provided by the National Disease Registration Service (Cancer Registry, Systemic Anti-Cancer Therapy (SACT), and the Radiotherapy Data Set (RTDS)). The audit now has approval to link to routinely collected Genomics data, the Diagnostic and Imaging Dataset (DIDs), Cancer Waiting Times data (CWT), the Cancer Quality of Life survey, and the Rectal Cancer Oncological Complete Response Database (OnCoRe).

2.6 Existing engagement with patients and the public

NBOCA has a very active Patient and Carer Panel that meets at least twice per year, one of which is to review the design and content of the annual Patient Report. The chair of the panel sits on the Clinical Advisory Group, which also includes representatives from Bowel Cancer UK and Bowel Research UK.

Examples of the impact the patient representatives have had on the audit includes:

- Advising on the purpose, content and wording of the Patient Reports
- Disseminating audit publications, e.g., promoting NBOCA work through charities
- Reviewing the content and style of the patient-oriented pages of the NBOCA website

² Boyle JM et al. Measuring variation in the quality of systemic anti-cancer therapy delivery across hospitals: A national population-based evaluation. *Eur J Cancer*. 2023 Jan;178:191-204. doi: 10.1016/j.ejca.2022.10.017.

³ Boyle JM et al. Validity of chemotherapy information derived from routinely collected healthcare data: A national cohort study of colon cancer patients. *Cancer Epidemiol*. 2021 Aug;73:101971. doi: 10.1016/j.canep.2021.101971.

⁴ Walker K, Finan PJ, van der Meulen JH. Model for risk adjustment of postoperative mortality in patients with colorectal cancer. *Br J Surg*. 2015 Feb;102(3):269-80. doi: 10.1002/bjs.9696.

- Helping to guide audit priorities, e.g., lynch syndrome; timely closure of stoma.

3. Proposed Future Approach

3.1. Proposed future scope

With increasingly granular, more timely data, NBOCA plans to better drive local quality improvement through its provision of more frequent timely feedback of performance indicators. As highlighted earlier, the key issues to be overcome in order to provide relevant, accurate risk-adjusted performance indicators are:

1. Complex patients
2. Complex pathways/ service structure
3. Cancer as a chronic disease

1. Understanding determinants of **variation in care and outcomes** is needed to interpret patterns of treatment variation and to provide more accurate, more appropriately risk-adjusted indicators to better inform quality improvement. NBOCA will expand work on understanding the impact of frailty⁵, cognition⁶, and co-morbidity^{7,8} on patient pathways and outcomes as well as inequalities in care and outcomes⁹. Advanced stage at diagnosis in young patients will be further explored. Development work will be carried out **using genomics data to identify molecular sub-types of bowel cancer**. We will explore **variations in treatments by stage and age**, taking into consideration the issue of small numbers when reporting by sub-groups, as well as the requirement to limit the number of performance indicators that we report on.

2. Work will continue to **broaden the clinical scope of the audit**, wider to include patients on all care pathways, and to understand the impact of service structure on care and outcomes. Examples include: variation in imaging; patients receiving second- or third-line therapies after disease progression; rectal cancer patients with “watch and wait” pathways; total neoadjuvant therapy (TNT) for rectal cancer patients; providing different follow-up pathway options; patients with stage IV cancer undergoing liver resection; access to mental health services; differences in care and outcomes for patients treated in “hub” versus “spoke” hospitals; capacity constraints which have been further exacerbated by the COVID-19 pandemic.

3. Cancer recurrence is an outcome of key importance to patients and is much needed to understand the impact of heterogeneity in treatment pathways. An NIHR-funded project started in 2022¹⁰ aiming to develop and validate approaches to identify other indicators of cancer recurrence in routinely collected national data. The Cancer **Quality of Life Survey** will be used to provide information on patient reported outcomes, once it becomes available at patient-level to be linked to other datasets. The impact of cancer and its treatment on **mental health** has been identified by stakeholders as a key outcome and development work is needed to capture this

⁵ Jauhari Y, Gannon MR, ..., Cromwell DA. Construction of the secondary care administrative records frailty (SCARF) index and validation on older women with operable invasive breast cancer in England and Wales: a cohort study. *BMJ Open*. 2020 May 5;10(5):e035395.

⁶ Kuryba AJ et al. Severity of Dementia and Survival in Patients Diagnosed with Colorectal Cancer: A National Cohort Study in England and Wales. *Clin Oncol (R Coll Radiol)*. 2023 Jan;35(1):e67-e76. doi: 10.1016/j.clon.2022.08.035

⁷ Cowling TE, Cromwell DA, Bellot A, Sharples LD, van der Meulen J. Logistic regression and machine learning predicted patient mortality from large sets of diagnosis codes comparably. *J Clin Epidemiol*. 2021 May;133:43-52.

⁸ Kuryba AJ et al. Outcomes of colorectal cancer resection in patients with inflammatory bowel disease: a national population-based analysis in England and Wales. *Colorectal Dis*. 2022 Aug;24(8):965-974. doi: 10.1111/codi.16133.

⁹ Vallance, AE.; Kuryba, A.; van der Meulen, J.; Walker, K. Socioeconomic differences in selection for liver resection in metastatic colorectal cancer and the impact on survival. *EJSO*. 2018; 44(10):1588-1594.

¹⁰ Identifying Cancer Recurrence within Patient Care Pathways across Linked National Clinical Datasets, NIHR HSDR, PI K Walker, Co-PI J van der Meulen. 2022-2024.

3.2 Proposed future reporting

The main obstacle to NBOCA driving local quality improvement is timely reporting. The two priorities for reporting for the audit will be providing:

1. More granular, **more frequent, more timely** reporting on the provider dashboards of the website. Development work will be carried out to improve the data visualisation of the provider dashboards, showing change over time and increasing interactivity.
2. More concise “state of the nation” annual reports limited to 10 performance indicators, as specified in the NATCAN contract. These reports will be responsive to arising clinical issues and the areas identified in the QI initiatives of the audit. NBOCA will work closely with data providers, HQIP, NHSE and Welsh Government to improve the timeliness of the “state of the nation” annual reports.

The “state of the nation” annual reports will use the “gold-standard” cancer registration datasets, which are currently only released on an annual basis. Outlier reporting will continue following NBOCA’s [Outlier Policy](#). The provider dashboards will be updated quarterly using rapid cancer registration data (RCRD).

We will seek external advice from web designers who have experience in handling complex quantitative information. Special attention will be paid to the appropriate representation of the uncertainty in indicator values (i.e., the “signal-to-noise” ratio) so that organisations are not erroneously labelled as either positive or negative outliers. This is a key element especially for quarterly reporting given that numbers of patients and relevant events will be smaller than in the conventional state of the nation reports.

3.3 Proposed Quality improvement implementation

NBOCA will continue to drive forward its increased focus on QI, as outlined in 2.3 above, including its QI intervention on **temporary ileostomy use and closure** being developed together with the RCS.

Methodological rigour will guarantee that QI initiatives are built on robust indicators that can support local decision making and service provision. Investigations of the determinants of variations in care and outcomes will provide evidence to guide all QI initiatives. We will draw on the established evidence on effective audit effective feedback.¹¹ Resources and support will be provided for more effective local responses to feedback.

With the move into NATCAN comes opportunities for cross-audit innovations. We will build on the approaches already used by NBOCA and other CEU cancer audits, but extend them in a number of innovations:

1. The use of rapid cancer registration data that allow timely and frequent (at least quarterly) reporting to cancer services, alongside concise annual “State-of-the-Nation” reports.
2. Development of the visualisations in the interactive provider dashboards to allow continuous monitoring of provider performance over time and allowing more bespoke reporting.
3. QI projects that aim to “close the audit cycle”, a first at national level. These will be designed by the NATCAN’s QI Team, and supported by experts from the University of Leeds (Professor Robbie Foy and Dr Sarah Alderson) who have extensive experience in methods to change professional and organisational behaviour.

3.4 Proposed performance indicators/ QI targets

All 12 of the local QI targets listed in 2.3 will continue except the case ascertainment target which will not be needed with the move to using cancer registry data. **Work will continue to aim QI targets at all members of**

¹¹ Ivers N, Jamtvedt G, Flottorp S, et al. Audit and feedback: effects on professional practice and healthcare outcomes. Cochrane Database of Systematic Reviews 2012, Issue 6. Art. No.: CD000259. DOI: 10.1002/14651858.CD000259.pub3.

the multidisciplinary team. The following additional 6 QI targets will be introduced once data are available / methodological development work is completed:

1. Participation in and recruitment to at least one NIHR portfolio trial in rectal organ preservation
2. >95% patients referred to palliative care or enhanced supportive care clinic in last year of life
3. <20% patients receiving palliative systemic treatment in final 30 days of life
4. >95% of patients with synchronous liver metastases discussed at specialist liver MDT
5. >80% patients with Stage IV disease with genetic tumour profiling (*KRAS*, *NRAS*, *BRAF*)
6. >90% patients with mismatch repair immunohistochemistry or microsatellite instability

Further performance indicators will be developed to meet the aim of broadening the scope of the audit to include all patient pathways and to report cancer as a chronic disease. Examples of this include complications of oncological treatments, such as severe acute toxicity, longer-term outcomes such as recurrence, and patient-reported long-term outcomes.

The broadening scope of NBOCA comes with an increasing number of performance indicators/ context-providing measures. A wide set of indicators is needed to avoid the undesired consequence of focussing on one area of quality to the detriment of another area. However, it is important to prioritise areas for local quality improvement. From 2024 reporting onwards the audit is required to restrict to 10 performance indicators in its State-of-the-Nation reports. Other QI measures will continue to be provided to Trusts/MDTs/hospitals as contextualising measures. NBOCA will continue to report a full range of performance indicators/ context-providing measures on its provider dashboards and tables of provider results. As described in the NBOCA QI Plan, providers will be asked to select key performance indicators for local QI. The State-of-the-Nation reports will be responsive to current need and, guided by stakeholders, will focus on reporting on a few key indicators and change over time.

3.5 Data provision in the future NBOCA within NATCAN

NBOCA will only use data collected in the Clinical Audit Platform (CAP) for patients diagnosed up until 31 March 2022. For patients diagnosed from April 2022 onwards, NBOCA will use existing national cancer data from the NDRS for patients in England. For patients in Wales, NBOCA 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 will request a single resource of linked datasets for all cancer audits, including NBOCA. This reduces the workload for NDRS in data provision and the workload for NATCAN data managers in checking and preparing the data for analysis. 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 Data Environment (SDE) for cancer data is being developed in NHS England which would be particularly beneficial if it gave quicker access to the data. However, the SDE 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 to be used by NBOCA: (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 and (v) is accurate.

Initial work to assess the NDRS data against these five requirements is summarised below. Further in-depth validation work will be needed for English and Welsh data.

Data item comparison

Data items available in NBOCA are compared to those in Cancer Registry and the Rapid Cancer Registry data (RCRD) in England in the Appendix. All but 6 NBOCA data items are available in Cancer Registry datasets already, or will be from 2024, and 2 of these 6 are available already through linkage to other datasets.

Note that a wider range of data items is available from other datasets from NDRS, and these will be received and linked at patient-level quarterly, for example HES, SACT, RTDS, CWT, DIDs, and genomics data. It is not yet clear when these cancer datasets will be available from Wales, or how frequent they will be.

Timeliness versus case-ascertainment and data completeness

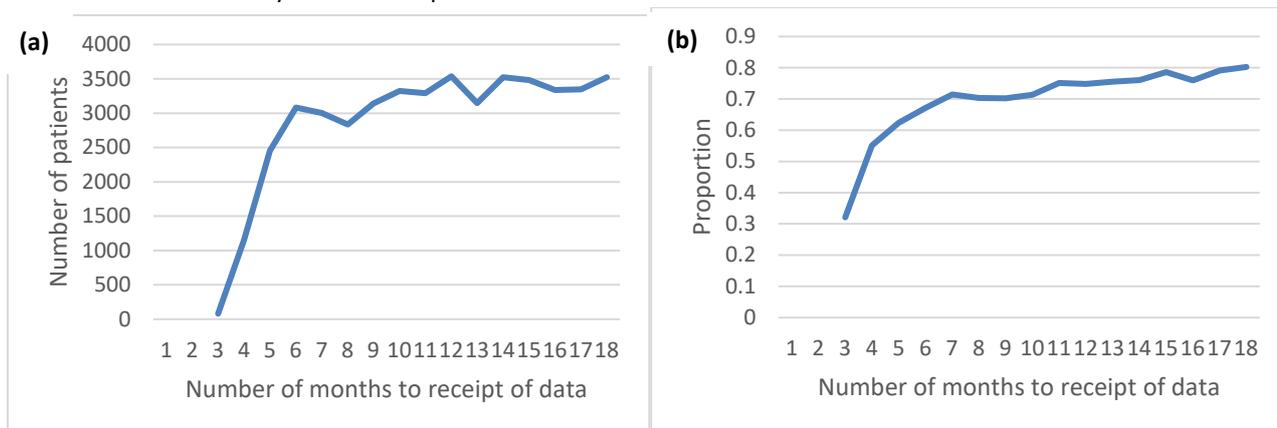
Gold standard cancer registration data is considered to have 100% case ascertainment but has a lag of around 20-22 months from diagnosis to release of the data. NBOCA data has an estimated case ascertainment of 95%. Rapid cancer registration data (RCRD) is much more timely but not as complete. Figure 1 below shows that around 6 months after diagnosis the case ascertainment and staging completeness of RCRD becomes reasonable and increases more slowly after this.

Figure 1

(a): Number of people diagnosed with CRC by months from diagnosis to data receipt.

(b): Proportion of records with staging data by months from diagnosis to data receipt.

Source: RCRD received by NBOCA in September 2022.



Data completeness

Data completeness of a selection of key data items in the gold standard cancer registry data compared to NBOCA in patients diagnosed April 2017 to March 2021.

Data item	N patients	Data completeness %	
		NBOCA	Cancer Registry
Stage 1-4 all patients*	120,220	85.2	92.7
Stage 1-4 surgical patients*	67,035	91.4	96.1
Nodes examined colon cancer surgical patients	47,379	94.6	94.3
Nodes examined rectal cancer surgical patients	16,003	93.8	73.4
Tumour grade in surgical patients	67,035	86.4	94.7

* Cancer registry staging is "Stage best"

Data quality

Agreement between NBOCA and the gold standard cancer registry data is reported for a selection of key data items in patients diagnosed April 2017 to March 2021.

Data item	N patients	Agreement %
Diagnosing trust (NHS trusts only)	120,220	94.2
Surgical trust (NHS trusts only)	67,035	99.1
Diagnosis date within 7 days	120,220	62.0
Date surgery within 1 day	67,035	97.4
Stage 1-4 all patients	120,220	87.5
Tumour site (colon/ rectosigmoid/ rectum)	120,220	93.5

3.6 Future engagement with patients and the public

NBOCA will continue its close collaborative working with patients through its existing Patient and Carer panel, with the chair a member of the clinical advisory group. The Patient and Carer Panel is working to recruit carers and to ensure it has representation within Wales. NBOCA will work to ensure that there is effective communication from the patient and carer panel into the NATCAN Board. We will also ensure that the patient representation on the NATCAN Board includes patients who have had cancer.

Changes to the scope and design of NBOCA, and further development of the provider dashboards, will require input from the panel to ensure that the needs of the patient and the public are met. Patients will be needed to help direct the specific questions for each topic. A key focus in the future will be to ensure that all NBOCA findings are made available to the public, including those published in peer-reviewed publications rather than Short Reports. Finally, NBOCA will explore how patients can provide the patient perspective in the writing of peer-reviewed publications.

Appendix

Available in NBOCA and Cancer Registry /COSD and RCRD	Available in NBOCA and Cancer Registry /COSD	NBOCA only
Age	Performance Status	CPEX anaerobic threshold
Sex	Referral source	Mismatch repair status***
Organisation first seen, treatment provider	Clinical Nurse Specialist seen	Immediate postoperative care***
Date diagnosis, date surgery	Tumour height above anal verge	Local invasion polypoid tumours
ICD10 major site	Synchronous cancer	Local invasion sessile tumours
Primary procedure	MDT meeting type	Monitoring intent**
TNM stage (pre-treatment)*	Care plan intent, planned treatment, curability, no treatment reason	NCEPOD surgical urgency [†]
TNM stage (final pathology)*	BMI	TaTME [†]
Tumour type	Vascular or lymphatic invasion	Pelvic sidewall clearance [†]
	Metastatic site	
	Lesion size	
	ASA grade	
	Consultant	
	Surgical access	
	Unplanned return to theatre	
	Circumferential excision margin status	
	No. nodes examined, no. positive	

	Differentiation by worst area	
	Recurrence/ progression type and date	

COSD: Cancer Outcomes and Services Dataset

RCRD: Rapid Cancer Registration Dataset

* Cancer Registry staging: individual imaging/pathology TNM variables/ overall stage at diagnosis available for some patients along with a combined "best" 1-4 stage; RCRD: "best" stage only

** Monitoring intent no longer in COSD, but monitoring variables available within other COSD items

*** Available through linkage to other data

† Will be available in COSD v10 from 2024

The following data items are available in the Cancer Registry but not in NBOCA:

Available in Cancer Registry data but not NBOCA
Ethnicity
Route to diagnosis
Basis of diagnosis
Excision margin
Clinical Nurse Specialist type