National Cancer Diagnosis Audit

How it works – FAQs

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Collecting the data

Which cases are eligible for this audit?

The NCDA collects data on patients diagnosed with a new primary cancer, regardless of cancer type, referral or diagnostic route, or use of private diagnostic care or treatment. Only non-melanoma skin cancer and non-malignant tumours (ICD-10 C44) are excluded.

The audit of cancers diagnosed through screening is optional. Patients whose cancer is recorded by the cancer registry as being detected via one of the national screening programmes (breast, cervical and bowel) are not included in the audit. Such patients may be present in your list of eligible patients, but you will not need to complete primary care data for these patients.

There may be a small number of cases, mainly bowel and possibly cervical, where the cancer registry does not have a record of the cancer being screen detected. Where you know this, please record this on the data form under 'Screen detected patient'. You won't have to complete the other data items for such patients.

How will practices know which patients to audit?

In national NCDA cycles, patients are identified through the national cancer registry in each nation and information is then made available to the GP practice for audit. There is no need to conduct GP system searches to identify cases.

When the national cycle is paused, practices can use the NCDA data proforma or NCDA Excel Template to carry out internal audits of cancer diagnosis at their practice. For internal practice audits, a GP system search to identify cases will be necessary. National cycles of NCDA have so far audited all cancer types. For internal audit, practices may wish to focus on common cancers with unmet needs, such as lung or bowel, on late stage diagnoses, or on certain pathways, such as emergency diagnosis routes.

How long does the audit take to complete?

GPs have fed back that collecting data on a single patient takes approximately 15 to 20 minutes. This will vary with patient complexity, the clinical system used, and familiarity with the NCDA data form.

The number of eligible cases varies by practice size and patient population. On average, a practice can expect 3-4 patients per month eligible for NCDA, which will mean a time commitment of under 2 hours per month for the audit. The workload can be split between multiple GPs at the practice, and data entry can also be supported by GP Trainees/Registrars under supervision of an experienced GP.

What minimum requirements are there to take part in national cycles of this audit?

GPs in England and Wales taking part in official cycles of the audit will need access to their own clinical system, and be able to access the data collection portal through a secure NHS internet connection (behind the NHS firewall).

GPs and practice staff will need to access an nhs.net or wales.nhs.uk email in order to register and successfully complete the GP verification processes. Computers must have an internet browser of Internet Explorer 8 or above to access the online portal.

In Scotland GPs taking part in the audit will need access to their own clinical system and access to their own nhs.net email address.

What data items are being collected?

The audit collects information on:

- Patient characteristics; ethnicity, communication difficulties, living arrangement, language competency, housebound status and co-morbidities

- Symptoms, test results and investigations ordered
- Date of referral, type of referral and number of referrals
- Avoidable delays in patient pathway
- Place and date of first presentation and number of consultations
- Safety netting
- The date a patient was seen by specialist and the data a patient was told they had cancer

How will data be collected?

In national NCDA cycles, in England and Wales data will be collected via a specifically designed data collection system (the NCDA portal). More information on how to access this system will be made available when the audit is live. In Scotland, data is being collected on Excel spreadsheets sent to the practice by Public Health Scotland.

Between audit cycles, practices can undertake the NCDA internally, using an Excel template or Word proforma. These are for practice internal use only and should be securely managed and stored within the practice as appropriate.

Does all the work need to be done at once?

The data for national cycles is collected on an ongoing basis. You can input data on patients as they come through, or you can submit data in instalments or all at once at the end of the data collection period.

During practice internal audit, it is up to the practice to decide whether to undertake ongoing, regular audit, e.g. of all new cancers diagnosed, or whether to select a group of patients to audit and then undertake that work in an agreed timeframe.

Who can complete audit reviews?

It is up to each practice how they decide to take part in the audit – whether all GPs review their own patients, whether they review each other's', or whether one GP leads on this on behalf of the others.

GP registrars and medical students may also complete the audit on behalf of the practice. The supervising GP will need to oversee and quality assure their work in order to ensure accurate data extraction and to maximise any practice learning opportunities during and following the audit. During national cycles of the audit, anyone accessing the data from cancer registries will need to satisfy the verification process requirements.

If a practice wishes to delegate the data collection to a non-clinical colleague, they will need to be satisfied that the individual concerned has good knowledge of medical terminology and is sufficiently trained to review clinical notes. There are some areas of the audit where only a GP can respond (where clinical judgment is required). Any non-clinical colleagues should be supported by a senior GP with this work.

Can I do the data entry at home or must it be done from surgery premises?

GPs will need access to their clinical system to complete the audit, and they will need to comply with their Information Governance good practice requirements. GPs in England and Wales will need to complete the audit in a location that has a secure N3 internet connection (connected to the NHS internet, behind the NHS firewall) to satisfy Public Health England's data security requirements.

Audit feedback and outputs

How will this improve clinical practice?

Completing the audit allows practices to reflect on their clinical practice and practice-based systems and processes. Specific insights may include:

- Types of delay
- Where delays occur
- Factors contributing to multiple consultations
- Impact of patient characteristics
- Overview of presenting symptoms by key tumour types to highlight complexities
- Presenting symptoms by place of presentation
- Identification of good practice

What levels of feedback will be available?

During national cycles of the audit, the audit team provides confidential, tailored feedback reports to all participating practices. In England, feedback is also available at PCN, CCG and Cancer Alliance levels if participation in the local area is high enough to allow creation of such reports. In Wales and Scotland, feedback is also available at Health Board level if participation in the local area is high enough to allow creation of such reports.

What feedback will GP practices receive?

During national cycles of the audit, tailored practice reports issued to all participating practices compare practice findings to the national average, as well as a cluster of similar practices (where possible) and regional averages (e.g. Cancer Alliance). Data presented in practice reports include:

- Place of first presentation
- Time from presentation to referral
- Number of pre-referral consultations with GP
- Use of primary care-led diagnostic tests
- Types of referrals, incl. detailed breakdown of emergency referrals
- Summary of avoidable delay data

"The practice reports produced were excellent and a valuable tool for discussion at both practice and cluster level. We aim to repeat the audit again for all of our cluster practices this year." – GP from Glasgow

"The report was surprising in some ways, and undoubtedly practice-changing." GP from Caterham

What feedback will other organisations receive?

Tailored CCG, Cancer Alliance, STP, and Health Board reports can be made available where participation levels are high enough to ensure that individual practices are not identifiable from reports (as the audit is not used for performance management).

Data presented in these reports include:

- Place of first presentation
- Time from presentation to referral and diagnosis
- Number of pre-referral consultations with GP
- Use of primary care-led diagnostic tests
- Types of referrals, incl. detailed breakdown of emergency referrals
- Summary of avoidable delay data

Patient consent and information security

Do we have to ask patients' permission?

Direct patient consent is not required to take part in national cycles of the NCDA:

- In England and Wales, this is not required as the audit data is being collected by Public Health England/Public Health Wales under regulation 2 of the Health Service (Control of Patient Information) Regulations 2002* permitting the collection of identifiable cancer data for purposes of surveillance and analysis of health and disease in this area.
  *See for example: http://www.legislation.gov.uk/uksi/2002/1438/contents/made
- In Scotland, this is not required as the audit data will be pseudo-anonymised on transfer out of the practices. The data protection act (schedule 2 and 3) does not make the requirement for consent for identifiable data processing absolute and the audit process has been approved by the Public Benefit and Privacy Panel.

All practices taking part in national cycles of the NCDA will be provided with posters to display in waiting areas with further information about the audit and cancer registration, as well as advice on how to opt out if they wish to. National opt outs from cancer registration are automatically applied to the data collection in England by Public Health England and no data are collected on patients who have opted out of cancer registration.

Who will have access to the audit data?

In national audit cycles, GP practices submit data securely to their relevant public health organisation (Public Health England, Public Health Wales, Public Health Scotland, Northern Ireland Cancer Registry). In England, a small number of Public Health England staff within National Cancer Registration and Analysis Service (NCRAS) have access to the data to prepare audit outputs. This also applies to Wales, where in addition a small number of Public Health Wales staff have access to the data to support preparation of outputs. In Scotland, a small number of staff at Public Health Scotland (formerly Information Services Division Scotland) will have access to the data to prepare outputs. And in Northern Ireland, a small number of staff at the Northern Ireland Cancer Registry will have access to the data for analysis purposes. All these staff are trained in all relevant aspects of data handling and security.

After the data collection is complete, the data collected from participating nations in the UK will be pseudo-anonymised to produce a UK-wide merged dataset. For this purpose, pseudo-anonymised data from Scotland will be transferred to Public Health England, and Public Health Scotland and Public Health England will become data controllers in common. A small number of Public Health England staff within the National Cancer Registration and Analysis Service will have access to the pseudo-anonymised data from Scotland to produce the merged dataset. Neither individual patients, nor individual GPs or GP practices, can be identified from this dataset. This pseudo-anonymised dataset is made available to researchers via the Office for Data Release (ODR). Analysts hoping to use the NCDA dataset in future will be required to seek appropriate ethics and information governance approvals through ODR before being allowed to access the data.

Between national cycles, where practices carry out internal audits, only practice staff will have access to the data captured within the practice for their audit. The practice may decide to share some data with others in their PCN, but this is at the discretion of the practice.

Who will the reports be shared with?

In national audit cycles, NCDA reports for practices and PCNs are only shared with participating staff who are registered for the audit. In England and Wales these are shared securely through the NCDA portal. In Scotland and Northern Ireland, these are disseminated by Public Health Scotland and Northern Ireland Cancer Registry, respectively, directly to practices through secure NHS mail.

What are the information governance arrangements for this data collection?

During national cycles of the audit:

- In England the data transfer takes place under regulation 2 of the Health Service (Control of Patient Information) Regulations 2002* permitting the collection of identifiable cancer data for purposes of surveillance and analysis of health and disease in this area. This will be confirmed and approved by Public Health England's Office of Data Release for each cycle. To be satisfied the data is being accessed by the appropriate people Public Health England will sign off the GP verification processes.
- In Wales, data transfer will take place under existing agreements with Public Health England; however a data sharing agreement specific to this project will also be signed by Public Health Wales and Public Health England.
- In Scotland, the data transfer has been approved by the Public Benefit and Privacy Panel for Health and Social Care (PBPP). The PBPP encompass the previous Community Health Index Advisory Group(link is external) (CHIAG), NHS National Services Scotland Privacy Advisory Committee(link is external) (PAC), and National Caldicott Guardians(link is external). Their remit is to be a governance structure in NHS Scotland to provide delegated decision making on behalf of NHS Scotland Chief Executive Officers and the Registrar General.

During audit design the principles of fair processing under the Data Protection Act were applied, and only the minimum amount of necessary data is being collected. The data may, in the future, be used for further audit and research purposes in the same way as patient data collected for purposes of cancer registration. Appropriate approvals will be sought for any further research.

*See for example: http://www.legislation.gov.uk/uksi/2002/1438/contents/made(link is external)

For practice internal audit:

Data are being reviewed, collected and managed by the practice internally and the collection is classed as a practice internal audit.

Will the data on delays be shared with GMC, CQC or any other organisation?

No. Apart from being contrary to principles by which any clinical audit is conducted, we could not make a judgement of relative seriousness of any delay from the data we receive, so reporting individual cases to the GMC or any other organisation would not be possible.

What assurances can you give that the audit won't be subject to Freedom Of Information Requests if a practitioner delay is found?

The data being collected in the NCDA is being inputted and stored in the National Cancer Registry and patients cannot be linked to a GP, only to a practice.

There are general principles of anonymity that inform the release of our data analyses and these ensure that no individual patient, practitioner or combination of patient and practice is identifiable. The purpose of clinical audit is that it is a professionally led quality improvement process, not a regulatory or performance management process, so practices will be able to reflect on their performance, against defined criteria and standards where we are able to provide them. We would not be raising anything with the CQC or any other authority.

If the patient has died the Data Protection Act is not relevant and a subject access request for the data could not be made. However, the data could be requested under FOI and the usual section 40 exemption for personal information would not apply for the patient. Section 40 may still apply for the GP if this was judged to be a request for information about them jointly with the patient. If this data was also judged to be confidential and part of the patient's medical record, then the precedent[1] seems to be that exemption 41 would apply and we wouldn't release these data. It is very hard to make any absolute guarantees without understanding the full case, but it would be

unlikely an FOIA would be granted. Irrespective of this, Public Health England would not be seen as the primary record holder and so may not be aware of the patient's wishes for confidentiality after their death; the request would be referred back to the GP surgery. The exception would be where PHE has been instructed to release the data under a court order.

It's important to remember if a patients relatives were sufficiently motivated to investigate the possibility of medical negligence, they are more likely to simply request the GPs records, via a solicitor.

References:
[1] ICO. Information about the deceased 2013 v1.1