National Cancer Diagnosis Audit 2019

Privacy Notice

The National Cancer Diagnosis Audit (NCDA) confidentially reviews a selection of information about your diagnosis with cancer. The audit will run across the United Kingdom (UK) and follows a successful audit in 2017.

The audit is being led by Cancer Research UK (CRUK)¹ working in partnership with Macmillan Cancer Support² and the Royal College of General Practitioners (RCGP)³ and NHS organisations across the UK.

This project has been approved by the Public Benefit and Privacy Panel for Health and Social Care⁴ in Scotland (ref: 1819-0169).

This privacy notice explains how your personal data will be used in relation to the National Cancer Diagnosis Audit 2019.

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In partnership with:

1 https://www.cancerresearchuk.org/
2 https://www.macmillan.org.uk/
3 https://www.rcgp.org.uk/
4 https://www.informationgovernance.scot.nhs.uk/pbpphsc/
Why this audit is needed
CRUK and your GP are committed to improving care for people with cancer. This UK-wide audit will provide information which will support this ambition in the most effective way.

The audit will produce a valuable set of information for each GP practice taking part, which can be used to identify whether or not the staff working at this practice could make changes to improve how people are diagnosed in future. “Hopefully it will give GPs a chance to consider the diagnostic pathways of their cancer patients, and to see if the process could be sped up to enable earlier diagnosis” (Sue, patient representative).

It will also provide a combined set of information about all practices taking part, which can be used to improve broader understanding of doctors, health managers and policy makers about what happens when someone is diagnosed with cancer and identify what could be improved for individuals in the future.

More detail on the benefits of the audit is available on the NCDA website: https://www.cancerresearchuk.org/health-professional/diagnosis/national-cancer-diagnosis-audit/benefits-of-the-audit.

How your information will be used
NHS Analysts from Information Services Division (ISD)\(^5\), part of NHS National Services Scotland\(^6\), will collect data in Scotland and provide tailored feedback reports to GP practices.

More information about how ISD uses patient data is available online here: https://www.isdscotland.org/About-ISD/Confidentiality/

The Scottish Cancer Registry\(^7\) is responsible for the collection of information on all new cases of cancer arising in residents of Scotland. ISD will use this registry to identify people diagnosed with a new primary cancer between October 2018 and September 2019. ISD will then ask participating GP practices to submit selected information about the events leading to a diagnosis of cancer for these individuals. This information includes how often doctors or nurses at the practice saw these people and what kinds of tests were done before they were referred to a hospital doctor, for example.

GP practices will securely provide this information to ISD, using only a unique reference number relating to the audit to identify the individuals involved. Approved NHS analysts will then use this information to produce tailored feedback reports for each practice. These tailored feedback reports will contain an overview of information

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5 http://www.isdscotland.org/

6 https://nhsnss.org/

the practice submitted about how people were diagnosed with cancer. Summary reports will also be prepared for related organisations, such as NHS Boards. These feedback reports may be used for local improvement work by the organisations they have been shared with. The information shared will not identify you and reports will not be shared outside of the carefully selected partners we have stated here.

ISD will also separately store an identifiable list of the people whose data has been used in this audit. This is needed to make it possible to link the audit dataset to other health and social care data ISD holds about you in future. This can only be done by authorised NHS analysts working at ISD and is only done once the necessary approvals have been granted by the relevant NHS research, ethics and governance groups. You would not be contacted about these studies unless the approval requires this.

Approved researchers from the Universities of Edinburgh and Aberdeen are already using anonymised data collected from the last round of the audit in Scotland to further improve understanding and identify areas for improvement. These researchers will also get access to anonymised data from the NCDA 2019. These researchers will access the dataset through a secure, restricted environment called the national safe haven. A safe haven refers to both a physical location and to an agreed set of administrative arrangements to ensure the safety and secure handling of confidential patient identifiable information.

ISD will share a copy of the audit dataset for Scotland with Public Health England (PHE) who will create a merged UK dataset so that it is possible to analyse the situation across the UK. This dataset will not identify individual patients or GP practices. Further analysis relating to this part of the audit will be completed by approved PHE analysts.

The anonymised UK merged audit dataset will be available for wider research via the Office for Data Release (ODR). The anonymised audit dataset for Scotland will be available via the Public Benefit and Privacy Panel (PBPP) for Health and Social Care. In both cases, there is a very robust process in place to assess whether or not researchers should get access to the data.

It is illegal to use personal data without adequately meeting a legal condition under current Data Protection legislation. Our legal basis is that the use is necessary:

- for reasons of public interest in the area of public health;
- for providing health or social care or treatment or managing health or social care systems and services;
- for archiving, scientific or historical research, or statistical purposes - as long as appropriate safeguards are in place.

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8 [https://www.nhsresearchscotland.org.uk/research-in-scotland/data/safe-havens-2](https://www.nhsresearchscotland.org.uk/research-in-scotland/data/safe-havens-2)
How long your information will be stored for

ISD will retain a copy of the audit dataset and separately store the file identifying people whose data has been used in the audit for up to 10 years after the audit data collection has been completed.

PHE will retain a copy of the Scottish audit dataset and make the merged UK dataset available on the ODR for a period of up to 10 years after the audit dataset has been completed.

Scottish academics will retain access to their copy of the dataset until March 2022.

Retention by each of the organisations and individuals listed above will be reviewed by the NCDA Steering Group at the mid-point, to make sure that continued use is appropriate, relevant and timely.

Your rights

Data Protection legislation gives rights to individuals in respect of the personal data that organisations hold about them. These include the right:

- to be informed;
- of access;
- to rectification;
- to erasure;
- to restrict processing; and
- to object.

The Information Commissioners Office (ICO) provides more information on your rights under Data Protection legislation at ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/.

If you are unhappy with the way in which we are using your personal information, please contact our Data Protection Officer using the contact details below. If you are still dissatisfied, you have the right to complain to the ICO, see details on their website at https://ico.org.uk/ or by calling them on 0303 123 1113 (local rate call).

How to contact us

General enquiries:

- Email us at: ncda@cancer.org.uk. Or write to us at: NCDA team, Cancer Research UK, PO BOX 1561, Oxford OX4 9GZ
- More information about the National Cancer Diagnosis Audit is available at www.cruk.org/ncda.

If you are concerned about how your data is being used please contact:
Data Protection Officer
NHS National Services Scotland
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB
Email address : NSS.dataprotection@nhs.net
Telephone : 0131 275 6000