

The National Data Opt-out and what it means for cancer patients

November 2018

Background

On 25th May 2018 the NHS launched a new programme, the National Data Opt-out. This gives each of us the choice about how our NHS data is used, outside the process of actually treating us.

On the same day the new Data Protection Act (2018) came into force, enacting the contents of the European General Data Protection Regulation (GDPR) into UK law. The new law brings more control to each of us about how our personal data is used, and much larger penalties if our preferences are not respected. The National Data Opt-out is an additional control.

Why do we need the National Data Opt-out?

The need for a new National Data Opt-out was one of a series of recommendations made by the National Data Guardian and agreed by the Government. The recommendations are designed to improve transparency, choice and trust about how our NHS data is used.

What am I choosing?

The National Data Opt-out allows people to opt out of their confidential patient information being used for research and planning.

The NHS makes the following definitions:¹

- a) Confidential patient information identifies you and says something about your health, care or treatment.
- b) Information that only identifies you such as your name and address is not confidential patient information and may still be used.

Does the National Data Opt-out include cancer data?

The way that your Cancer Registration data is collected and held by the National Disease Registration Service (NDRS) at Public Health England (PHE) remains unaffected. If you do not want your cancer data to be held by the NDRS you need to opt out of this separately.^{2 3} You can opt out at any stage and have your registration data removed.

But the rules by which PHE can release your data were changed⁴ in September 2018.

Previously, PHE could release your confidential patient information for planning and research, unless you had opted out of Cancer Registration. The policy has changed so that releases from

¹ <https://www.nhs.uk/your-nhs-data-matters/>

² <https://www.gov.uk/guidance/national-cancer-registration-and-analysis-service-ncras#opt-out-of-cancer-registration>

³ <https://www.ndrs.nhs.uk/national-disease-registration-service/clinicians/opting-out-for-clinicians/>

⁴ <https://hansard.parliament.uk/lords/2018-09-06/debates/7111773F-C8AF-40CA-874F-847D58D2A1A0/NHSHealthcareData>

PHE are now subject to the National Data Opt-out instead of the Cancer Registration opt-out. This was announced in September 2018.⁵ PHE will now operate to the same processes as NHS Digital for their data releases.⁶

So, as a cancer patient, if you were happy to be involved in cancer registration and research but had opted out of the National Data Opt-out, your confidential patient information (your cancer data) can no longer be released by PHE to support planning and cancer research. This is a change to previous policy.⁷

As with NHS Digital, there are some circumstances where your confidential patient information held by PHE will still be used, and these are described in the Q&A later.

How will I find out what my choices are with the National Data Opt-out?

By 2020 all health and care organisations are required to apply National Data Opt-outs where confidential patient information is used for research and planning purposes.

NHS England launched a social marketing campaign to support the implementation of the National Data Opt-Out and to deliver the Government's commitment for communications to the public.

Work is ongoing by Public Health England to raise public awareness of the Cancer Registry and the Cancer Registration opt out.⁸

Previous studies⁹ showed that cancer patients were largely unaware of the Cancer Registry - 74% of people living with cancer had never heard of the Cancer Registry. Despite this low awareness, there is overwhelming support¹⁰ for collecting cancer data in this way, as well as a desire to learn about the use of data more broadly.

To keep abreast of these and future developments, please email getinvolved@usemydata.org.uk

For further information about Cancer52, please email info@cancer52.org.uk

Ref: 2018-11-26.1

⁵ <https://hansard.parliament.uk/lords/2018-09-06/debates/7111773F-C8AF-40CA-874F-847D58D2A1A0/NHSHealthcareData>

⁶ <https://digital.nhs.uk/services/data-access-request-service-dars/how-the-national-data-opt-out-affects-data-released-by-nhs-digital>

⁷ <https://hansard.parliament.uk/lords/2018-09-06/debates/7111773F-C8AF-40CA-874F-847D58D2A1A0/NHSHealthcareData>

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/754981/NCRAS_response_to_RICCR_october_2018_to_october_2019_actions.pdf

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/608571/NCRAS_Response_to_Informed_Choice_Review.pdf

¹⁰ <https://understandingpatientdata.org.uk/how-do-people-feel-about-use-data>

Questions and Answers:

What is 'confidential patient data/information'?

Confidential patient information identifies you and says something about your health, care or treatment. You would expect this information to be kept private. The fact that you have had cancer would be seen as confidential.

Information that only *identifies* you (such as your name and address) is not confidential patient information and may still be used.

As an example, sending an NHS questionnaire out to a random sample of the public would need to use names and addresses, but would NOT be seen as a use of confidential patient information.

However, sending a questionnaire out to patients with a previous diagnosis of cancer would be seen as using confidential patient information, because it would only go to people who were known to have had cancer.

What is 'personal data'?

The term "personal data", in terms of the General Data Protection Regulation (GDPR), means any information relating to an identifiable person who can be directly or indirectly identified, in particular by reference to an identifier.

This definition provides for a wide range of personal identifiers to constitute personal data, including name, identification number, location data or online identifier, reflecting changes in technology and the way organisations collect information about people.

What is 'pseudonymisation'?

Pseudonymisation (the removal or replacement of identifiers) is a way of effectively reducing the risk of re-identification, but the data should be considered 'personal' under the GDPR.

Pseudonymisation may involve replacing your name or other identifiers which are easily attributed to you with, for example, a reference number. Someone could tie that reference number back to you if they had access to the relevant information, so technical and organisational measures need to be put in place to ensure that this additional information is held separately.

The Information Commissioner's Office (ICO) clearly states that "information which has had identifiers removed or replaced in order to pseudonymise the data is still personal data for the purposes of GDPR".

So pseudonymisation is effectively only a security measure. It does not change the status of the data as personal data. Pseudonymised personal data remains personal data and within the scope of the GDPR.

Data which has previously flowed from NHS Digital and Public Health England as 'pseudonymised' now needs to be seen as personal, requiring safeguards. A practical resolution

to this question is still being worked on by officials from NHS Digital, NHS England and the Information Commissioner's Office.

Is there a difference between what data is held about me by the Cancer Registry and by NHS Digital?

PHE will hold and generate data, which NHS Digital does not have, about your precise diagnosis, the stage of the disease, the pathology report and very detailed treatment information, including details of any surgical procedures, radiotherapy and chemotherapy.

NHS Digital only collects data about parts of your hospital activity, admissions and discharges, plus your outpatient appointments and any A&E attendances. It also collects this (and other) data for non-cancer activity. NHS Digital has a specific legal responsibility to be the safe-haven of health and care information, as described in the Health and Social Care Act 2012.¹¹

PHE will share a summary of your cancer diagnosis with NHS Digital.

Are there any other changes I should know about?

Some questions remain, in particular about what might be considered to be 'personal data' and what might be considered to be 'anonymised'.

Under the General Protection Data Regulation (GDPR), personal data that has been pseudonymised can still be considered as 'personal data', depending on how difficult it is to attribute the pseudonym to an individual. This is a complex problem to work through and has not yet been comprehensively addressed.

The Information Commissioner's Office (ICO)¹² states that "personal data is information that relates to an identified or identifiable individual".

A previous complaint in 2012 (prior to the GDPR) was made to the ICO, that information provided by NHS Digital to companies and non-NHS organisations, was only pseudonymised, and the identity of patients could be uncovered and their privacy breached.¹³ The ICO did not uphold the complaint, but also commented "We made it clear that our code is only a guide and it is for organisations to decide in any given case whether they are satisfied that data are anonymised."

¹¹ <http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

¹² <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/what-is-personal-data/>

¹³ <https://www.digitalhealth.net/2016/12/nhs-digital-sees-off-patient-privacy-challenge/>

Are there other areas where the National Data Opt-out doesn't apply?

There is a full list of circumstances where the National Data Opt-out currently does not apply¹⁴, and where your confidential patient information will still be used. Of interest from a cancer perspective, opting out will not apply:

- where the information is used for purposes relating to your individual care
- where the confidential patient information does not contain your NHS number if obtaining the number would involve disproportionate effort
- if you have given consent for your data to be used for a specific reason, such as a medical research study
- where data is anonymised which means you cannot be identified from the information
- to national patient experience surveys sent out before April 2019
- to data shared with Public Health England for the National Cancer Registration Service and National Congenital Anomalies and Rare Diseases Registration Service

Can I see who uses my data and for what purposes?

Any data about you which is held and released by NHS Digital and Public Health England is shown on a register, showing details of what was released to whom, and for what purpose.

For NHS Digital this is the *Register of Approved Data Releases*¹⁵ and for Public Health England this is the *PHE Data Release Register*¹⁶. Both registers contain any releases of confidential patient data made, which may contain records relating to cancer diagnoses or treatments.

In July 2017 the Department of Health published 'Your Data: Better Security, Better Choice, Better Care'. A statement within the document stated that:

"By December 2018, people will be able to access a digital service to help them understand who has accessed their summary care record. By March 2020, people will be able to use online services to see how their personal confidential data collected by NHS Digital has been used for purposes other than their direct care."

¹⁴ <https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/where-opt-outs-dont-apply/>

¹⁵ <https://digital.nhs.uk/services/data-access-request-service-dars/register-of-approved-data-releases>

¹⁶ <https://www.gov.uk/government/collections/public-health-england-data-release-register>

How do the different opt-outs affect how my data is used?

Table 1: “I have NOT opted out of Cancer Registration...”

...but I <i>have</i> opted out of the National Data Opt-out	...and I have also NOT opted out of the National Data Opt-out
<p>You will be registered on the cancer register at Public Health England in identifiable form.</p> <p>Your data will be included by Public Health England in cancer statistics which they produce.</p> <p>Your data received by NHS Digital from clinical services will be held by NHS Digital.</p> <p>Public Health England will share parts of your cancer registration record (such as the date of diagnosis, the detailed diagnosis code and the stage of disease) with NHS Digital.</p> <p>Your hospital activity data, such as surgical procedures (in a dataset called HES - Hospital Episodes Statistics), will still be released in identifiable form by NHS Digital to Public Health England.¹⁷</p> <p>Your confidential patient data will NOT be released by NHS Digital to be used for planning and research.</p> <p>Your confidential patient data WILL NOT be released by Public Health England to support planning and cancer research.</p>	<p>You will be registered on the cancer register at Public Health England in identifiable form.</p> <p>Your data will be included by Public Health England in cancer statistics which they produce.</p> <p>Your data received by NHS Digital from clinical services will be held by NHS Digital.</p> <p>Public Health England will share parts of your cancer registration record (such as the date of diagnosis, the detailed diagnosis code and the stage of disease) with NHS Digital.</p> <p>Your hospital activity data, such as surgical procedures (in a dataset called HES - Hospital Episodes Statistics), will be released in identifiable form by NHS Digital to Public Health England.</p> <p>NHS Digital may release your confidential patient data to support planning and cancer research.</p> <p>Your confidential patient data may be released by Public Health England to support planning and cancer research.</p>

¹⁷ “The activity of cancer registration (under the specific Regulation 2 held by PHE) is currently not covered by the National Data Opt-Out (as Cancer Registration runs its own opt-out process) therefore NHS D will send all HES data to PHE for inclusion in the NCRAS data set. It is at the point of dissemination of confidential patient information from the cancer registry that opt-outs will be applied” Source: PHE, Sept 2018

Table 2: “I have opted out of Cancer Registration...”

...and I have <i>also</i> opted out of the National Data Opt-out	...but I have NOT opted out of the National Data Opt-out
<p>You will NOT be registered on the cancer register, held by Public Health England. Any cancer data that Public Health England receive about you will be deleted immediately.</p> <p>Because Public Health England delete your data, it will NOT be used by Public Health England in any cancer statistics and it will NOT be sent by Public Health England to NHS Digital.</p> <p>Your data WILL still be held by NHS Digital, though this will not include particular parts of your cancer data such as the date of diagnosis, the detailed diagnosis code and the stage of disease (as these would be generated by Public Health England and sent to NHS Digital).</p> <p>Your confidential patient data will NOT be released by Public Health England to be used for planning and research.</p> <p>Your confidential patient data will NOT be released by NHS Digital to be used for planning and research.</p>	<p>You will NOT be registered on the cancer register, held by Public Health England. Any cancer data that Public Health England receive about you will be deleted immediately.</p> <p>Because Public Health England delete your data, it will NOT be used by Public Health England in any cancer statistics and it will NOT be sent by Public Health England to NHS Digital.</p> <p>Your data received by NHSD from clinical services will still be held by NHS Digital, though this will not include particular parts of your cancer data such as the date of diagnosis, the detailed diagnosis code and the stage of disease (as these would be generated by Public Health England and sent to NHS Digital).</p> <p>Your confidential patient data can be released by NHS Digital to be used for planning and research.</p>