

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

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 definitions¹:

- 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?

Not at the moment. The National Data Opt-out currently covers only data that is held by NHS Digital. Cancer Registration data is collected and held separately by the National Disease Registration Service (NDRS) at Public Health England (PHE).

If you do not want your cancer data to be held by NDRS you can opt out of this separately². You can opt out at any stage and have your registration data removed.

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 doesn't apply³, and where your confidential patient information will still be used. Of interest from a cancer perspective opting out will not apply:

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.nhs.uk/your-nhs-data-matters/manage-your-choice/where-opt-outs-dont-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, like 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 who, and for what purpose.

For NHS Digital this is the *Register of Approved Data Releases*⁴ and for Public Health England this is the *PHE Data Release Register*⁵. Both registers contain any releases of data made, which may contain records relating to cancer diagnoses or treatments.

There are still some inconsistencies in the current situation. If a researcher approaches NHS Digital for data relating to cancer treatments, the National Data Opt-out would apply to the data release. If the same researcher went to NDRS to ask for cancer diagnoses and treatments, the National Data Opt-out would not apply but the Cancer Registration opt-out would.

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

The National Data Opt-out has until 2020 to establish itself across all NHS organisations.

NHS England has 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.

Previous studies⁶ have shown that cancer patients were largely unaware of the cancer registry, with 74% of people living with cancer had never heard of the cancer registry. Despite this low awareness, there is overwhelming support⁷ for collecting cancer data in this way as well as a desire to learn more about the use of data more broadly.

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

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

⁴ <https://digital.nhs.uk/services/data-access-request-service-dars/register-of-approved-data-releases>

⁵ <https://www.gov.uk/government/collections/public-health-england-data-release-register>

⁶

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

⁷ <https://understandingpatientdata.org.uk/how-do-people-feel-about-use-data>