

Public Consultation

Cancer Programme Patient Level Data Collection

What we do

The [NHS Cancer Programme](#) leads projects to improve cancer services in England in line with the NHS Long Term Plan ambitions:

- By 2028, 55,000 more people each year will survive their cancer at least five years after diagnosis.
- By 2028, the proportion of patients diagnosed with cancer at stage one and two will rise from just over half to three quarters.

This is done through funding and implementing new cancer services, pathways, tests and treatments.

NHS England collects information (data) from new cancer services (sometimes called pilots) on people who use them. This is called patient level data. NHS England uses this data to monitor and make improvements to these services for patients, for example, diagnosing more cancers earlier and providing more treatment options for patients to give them a better chance of surviving cancer.

NHS England processes, stores, and analyses this data in line with UK GDPR principles:

1. Processing should be lawful, fair and transparent.
2. Personal data shall be collected for specified, explicit and legitimate purposes.
3. Personal data must be adequate, relevant and limited to what is necessary.
4. Personal data shall be accurate and kept up to date.
5. Personal data shall be kept for no longer than is necessary.
6. There must be appropriate security in place in respect of the personal data.

How will my data from cancer services be used?

Your information will be used by NHS England for monitoring and evaluation. This means NHS England will be using your data for a secondary purpose. Your data will be pseudonymised before it is made available to any NHS England analyst for analysis. This is

a process to remove personal identifiers from the data, for example, replacing your NHS number with random values. This means you will not be able to be identified from the information that is made available for analysis.

There may be times when NHS England contracts external research organisations to undertake evaluations of their Cancer Programme Pilots. In these cases, these organisations would be able to access your pseudonymised data following a [Data Access Request Service \(DARS\) request](#). This is a formal requesting procedure that ensures that patient level data is only provisioned when there is a legal basis to do so and through a Secure Data Environment.

[Secure Data Environments](#) uphold the highest standards of privacy and security of NHS health and social care data when used for research and analysis. They allow only approved users to access and analyse pseudonymised data and ensure that no patient level data leaves the environment (outside of NHS England).

A Data Sharing Agreement (DSA) is required before users can access data using the NHS England Secure Data Environment.

How will my data be protected?

To process personal data, the GDPR and the Data Protection Act 2018 require that there is a legal basis. NHS England is receiving a [Direction](#) from the Secretary of State, providing a legal basis to collect service user level data from Cancer Programme pilots.

There are very strict rules about who can access confidential patient information, [how it must be protected](#), and what it can be used for. Before information is shared with other organisations, they must satisfy our [Data Access Request Service](#), which states they will store it safely and legally, and that their reason for using it will benefit health and care.

Information is never passed to marketing or insurance companies without your consent. We publish all our data releases on our [data release register](#).

NHS England publishes a [privacy notice](#) on its website to describe how your data is used, protected stored and processed.

National Data Opt-Out

The National Data Opt-Out introduced in 2018 enables patients who complete a National Data Opt-Out form to have their personalised (identifiable) NHS data to be removed from the data for research or planning purposes. This only applies to identifiable data.

National data opt-outs also do not apply to data submitted to NHS England where these are required under s259 of the Health and Social Care Act 2012 following a Direction from the

Secretary of State or NHS England. This means that patient data for all Cancer Programme pilots can be included in this collection.

What are the benefits?

Using this way of working allows NHS England to diagnose cancer earlier and provide more treatment options to give people a better chance of surviving cancer, through:

- Checking and making sure cancer services are working as well as they should be.
- Performing flexible and detailed analysis of cancer services and outcomes for patients.
- Linking data from cancer services with other data in health records to give a better understanding of joined up health and social care activity and outcomes across the population.
- Reduce health inequalities.
- Monitoring improvements to cancer services and outcomes for patients.

Why your views matter

NHS England keeps the nation's health and social care data safe and uses it to improve understanding, monitoring and planning. The more people who take part in this consultation, the more useful the results will be to help us understand how the public feel about how their data is used.

We do not require any information that will identify you as part of this survey.

We hope we have provided the correct amount of information for you to get a good understanding of how your data is used and the right amount of information to enable you to provide your feedback and comments to the four questions below.

NHS England will use your feedback to try to address any concerns raised.