

National Data Opt Out - Notes

What is the National Data Opt Out?

The National Data Opt Out service allows patients to opt out of their confidential patient information being used beyond their individual care and treatment (e.g. being used for research and planning).

It allows patients to choose to withhold their confidential patient information used for purposes beyond their individual care and treatment.

The service allows patients to set, view and change their choice and this can be accessed by the patient through a website run by NHS Digital.

Patients who do not wish to opt out **do not** need to do anything.

What is confidential patient information?

Confidential Patient Information is categorised as:

1. Identifiable, or likely identifiable (e.g. from other data in possession of the recipient);
2. Given in circumstances where the individual is owed a duty of confidence; and;
3. Conveys some information about the physical or mental health or condition of an individual.

It might include things like name and address or demographic data along with any clinical data.

When does the National Data Opt Out Policy apply?

When any healthcare organisation which processes and/or disseminates data that originates with the health and social adult care system in England, it is required to consider if the national data opt outs should be applied to disclosures of confidential patient information for purposes beyond individual patient care.

The policy applies when confidential patient information is used for purposes beyond the individual's care and treatment. Additionally, it also applies in the following circumstances when:

- Confidential information is used for purposes **beyond an individual's care and treatment such as researching new treatment or planning for future services**
- **AND**
- The legal basis to use the data is approval under regulation 2 or 5 of the Control of Patient Information Regulations 2002, Section 251 of the NHS Act 2006
 - Regulation 2 – Processing for medical purposes relating to diagnosis or treatment of cancer;
 - Regulation 5 – Processing for general medical and research purposes.

This includes those patients receiving NHS Healthcare in a private health facility, adult social care providers and private/voluntary sector organisations providing care on behalf or through an NHS contract.

When does the National Data Opt Out Policy Not Apply?

The policy does not apply when the data is being used:

- Anonymously
- When the data relates to the individual care and treatment of a patient;
- When data is provided under a mandatory legal requirement (such as a court order, or where CQC use their statutory powers, safeguarding concerns);
- Where there is an overriding public interest (on a case by case basis in conjunction with discussion between practice manager, Caldicott Guardian and Data Protection Officer);
- When the patient has given explicit consent (even if this was before signing the National Data Opt Out);
- When data is provided to the following organisations who operate a separate opt out mechanism:
 - The National Cancer Registration Service;
 - [The National Congenital Anomalies and Rare Diseases service](#)
 - [UK Biobank](#)
- Where the data is not confidential patient information;
- Where the data is used for specific purposes (screening and immunisation data – this includes screening in pregnancy/new born babies/diabetic eye screening/cervical screening/breast screening/bowel cancer screening/AAA screening), risk stratification for case finding or information to support payment/invoice validation);
- Through the provision of privately funded health care;
- To records uploaded to the Summary Care Record.
- To records uploaded to CHIE (previously the Hampshire Health Record)

Who needs to be compliant with the policy?

All health and care organisations, including those regulated by the CQC including ambulance services, adult care homes, hospitals, secure facilities, services in the home, doctors, GPs and dentists, child health, community and mental health services as well as Defence Medical Services, opticians and pharmacists

When do we need to be compliant?

All NHS organisations must be compliant by March 2020.

How does a patient register their choice?

Previously, the Surgery was able to update patient's choices ourselves and read codes were added to their record. However, this is no longer possible. Patients now must use the National data Opt Out service to log whether they wish for their information to be shared.

They can do this online, but will require:

1. An NHS Number or a postcode registered with your GP Surgery
2. Mobile phone number or an email address that has been provided to a GP or another NHS service

Additionally, the patient will also need to be over 13 years of age (people with parental responsibility can act as a proxy for anyone under this age).

Their choice will take up to 21 days to take effect once registered on the website.

Alternatively, a patient can telephone 0300 303 5678 to register a national data opt out (9am-5pm – Monday to Friday). People acting as a proxy must use this telephone service.

Where can a patient make their choice?

Patients need to logon to the national website to make their choice at the following website:

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

Where can patients find out more information?

Information about the National Data Opt Out is also available on the Testvale Surgery website at:

<http://www.testvalesurgery.com/confidentiality/>

Additionally, patients can find out additional information by searching for “National Data Opt Out” or “Your Data Matters to the NHS” through a search engine, or looking on the Information Commissioners website at www.ico.org.uk

Whose responsibility is it to ensure compliance?

It is the data controller’s responsibility to ensure that the National Data Opt Out is applied prior to making any disclosures of personal confidential information when releasing information from a search.

The National Data Opt Out Policy must be considered **every time** data is disclosed by health and care organisations for purposes beyond the individuals care and treatment;

Opt outs

Some patients will have opt outs already recorded:

Type 1 Opt Out - This prevents their confidential information leaving the practice beyond their individual care for **research or future planning**. These will be respected until September 2020 when they will be removed;

Type 2 Opt Out – This prevents confidential patient information from leaving NHS Digital for purposes beyond their individual care. This has been converted to a National Data Opt Out

Summary Care Record – The National Data Opt out does not prevent data being uploaded to the Summary Care Record. In this case the patient must inform the practice who will ensure that their records is updated to prevent the SCR data extracts from taking place

CHIE – the national data opt out does not prevent data being uploaded to CHIE. Patients will need to inform the practice who will ensure that their record is updated to prevent the extract from taking place.

What are EMIS doing to help?

EMIS will launch new software which will apply National Data Opt Out functionality. This will be launched in version 9.5.1 and we will be notified when this has happened.

What do I need to do?

If anyone asks you about the National Data Opt Out, you need to be able to do the following:

1. Refer them to the website nhs.uk/your-nhs-data-matters website;
2. Ensure that they know this in order to proceed, that they need to know their NHS number which we can help them with if they can show us ID/Proof of Address
3. Ensure they have an up-to-date email address or mobile phone number in their GP practice record, as this will be used to verify their identity when they use the service – so take it from them and update the system if necessary;
4. Signpost to the Surgery Website where there is further information at <https://www.thegrangesurgery.org.uk/>
5. Ask them to call the Practice Manager/IT Manager for a more detailed conversation.

What will we do next?

1. Put information on the website;
2. Review the requirements and develop a process;
3. Write to patients who have previously opted out and sign posted them to the new NHS Digital Website