

NHS Digital Services Data Access Request Service (DARS)

How the national data opt-out affects data released by NHS Digital

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Anyone wishing to apply for data should be aware that from 25 May 2018 NHS Digital removes certain patient records from data it releases, where a patient has registered a national data opt-out.

From this date patients and public in England have the constitutional right to opt out of their personal confidential information being shared by NHS Digital for purposes other than their own individual care:

"You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered".

Download the NHS Constitution for England.

Unlike the previous type 2 patient opt-outs which applies to data released by NHS Digital, the <u>national data opt-out</u> will, in time, apply to the data released by any health and care organisation.

As part of the data application process, we will confirm whether the data requested will have opt-outs removed. The consideration of whether opt-outs are removed is dependent upon the data being requested, the purpose and the legal basis under which those data are released.

NHS Digital is committed to supporting a patient's wishes and makes sure that national data optouts are applied. Read more about your personal information choices.

Please note that from 29 April 2016 NHS Digital has been applying type 2 patient opt-outs to data it releases. All existing type 2 patient opt-outs will now be migrated to become a national data opt-out.

When national data opt-outs are not applied to data

National data opt-outs are not applied to confidential patient information disclosed by NHS Digital when:

- 1. It is used to support the patient's individual care and treatment.
- 2. The patient has consented to the use of their information (whether before or after registering their national opt-out) for a specific purpose such as a research study.
- 3. A mandatory legal requirement, such as a court order or Care Quality Commission s64 power, exists.
- 4. The information released is not considered to be personal confidential information, such as patient demographics information only, unless the legal basis given for release of the information is section 251 of the NHS Act 2006.
- 5. The information is made available in anonymised form for example the data are either aggregate such as counts of information or it complies with the ICO's Anonymisation:

 managing data protection risk code of practice. Pseudonymised data requests that go through the DARS process so that a Data Sharing Framework Contract and Data Sharing Agreement are in place are considered to be compliant with the ICO code of practice.
- 6. The legal basis under which the information is released is Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 to support the management of communicable diseases and other risks to public health.

National data opt-outs will be upheld in data which are approved under section <u>251</u> of the <u>NHS</u> <u>Act 2006</u> unless the Health Research Authority Confidentiality Advisory Group specifically advises otherwise, as upholding objections is a standard condition of section 251 approvals.

The national data opt-out applies to confidential patient information which is subject to the common law duty of confidentiality. This means that the opt-out will continue to be upheld following the patient's death.

Find full details of when the national data opt-out will and will not be applied.

How national data opt-outs are applied

Records for patients who have registered a national data opt-out are identified using the NHS Number only.

Where a national data opt-out is applied the full record associated with the individual's NHS number, including the NHS number itself, will be removed prior to the data being released.

Customers must not attempt to identify individuals who have registered a national data opt-out under any circumstances whether by comparing different data releases or by any other means.

Understanding the likely impact of national data opt-outs

Number of records/number of patients removed

Customers receiving data from NHS Digital which have had national data opt-outs applied will also receive information to tell them the number of records and the number of individual patients that have been removed.

National data opt-out statistics

The number and rate of opt-outs are included within the <u>National data opt-out</u> statistical publication. This includes a breakdown of statistics by gender, age band, and at both clinical commissioning group and individual GP practice level.

National data opt-out analysis

To help customers understand the effects of national data opt-outs, we have produced some comparisons using Hospital Episode Statistics. The comparisons show aggregate totals for HES episodes before and after national data opt-outs have been applied, including totals by age bands, gender, broad ethnicity groups and also procedure and diagnosis groups (inpatients only). They are provided for each of the HES inpatient, outpatient and A and E 2017-18 data sets.

Guidance for researchers

We have published guidance to help researchers understand the impact of national data optouts on the data they receive for their research studies from health and adult social care providers in England.

Further information

National data opt-out

The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning.

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