

National Data Opt-out

What is the opt-out scheme?

The national data opt-out allows a patient to choose if they do not want their confidential patient information to be used for purposes beyond their individual care and treatment - for research and planning. Patients, or people acting for them by proxy, have control over setting or changing their own opt-out choice, and can change their mind at any time.

How does someone opt-out?

Anyone can access, review, or change their opt-out status online at digital.nhs.uk. When a patient sets an opt-out choice, it is recorded against their NHS number on the Spine. It will remain unless the patient changes their mind, even after they have died.

Is the opt-out different to GDPR?

GDPR relates to the legal basis for using or disclosing data. GDPR law is unchanged by the national data opt-out.

How do I know if a patient has chosen to opt-out?

NHS Digital has developed a technical service which enables organisations to check if their patients have a national data opt-out. This service can be used in two ways:

- 1) Organisations can submit a list of NHS numbers that they need to disclose and the service looks these up against the central repository of national data opt-outs. It returns a “cleaned list” of those that do not have a national data opt-out i.e. it removes the NHS numbers for those with a national data opt-out. This is most suitable for one-off and infrequent disclosures of data.
- 2) Organisations can submit the NHS numbers for all patients with whom they have a legitimate relationship and then store temporarily the list of patients who do not have an opt-out at the current time and whose data they may be able to disclose.

Who is responsible for checking if a patient has chosen to opt-out?

It is the responsibility of the organisation sharing the data to confirm whether a patient has chosen to opt-out. We recognise that the practicalities of checking the opt-outs for clinicians entering data in the clinic are complex. We are actively exploring with HQIP ways in which we can support this centrally.

What about opt-outs after data have already been submitted?

A national data opt-out does not apply retrospectively, meaning it does not need to be applied to data that have already been processed.

Does having the s.251 approval override a patient opt-out?

No. A patient can choose for their data not to be used for purposes other than their direct clinical care, irrespective of confidential advisory group s.251 approval.