

# **National Data Opt-out: Factsheet 5 – Setting a national data opt-out**

This is one of a series of factsheets about data uses and the national data opt-out

Published 25 May 2018

# Factsheet 5 – Setting a national data opt-out

## Purpose

This factsheet provides information about who can set a national data opt-out, what is needed to set an opt-out and how to access the service. It also provides details of how the national data opt-out should be applied alongside other opt-outs available to patients.

## The national data opt-out (offered to the public as ‘Your Data Matters to the NHS’)

The national data opt-out allows a patient to choose that they do not want their **confidential patient information** to be used for purposes beyond their individual care and treatment.

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

The national data opt-out is a simple option that a patient who wishes to opt out needs to set only once, and which will then be applied across the health and care system.

A patient can change their national data opt-out choice at any time, using either of the services below.

## How to set a national data opt-out choice using the online service

Before using the online service, patients who wish to set a national data opt-out will need to have the following information to hand, so that their identity can be confirmed:

- NHS number – patients can find their NHS number on a letter from their GP practice or other NHS service, on a prescription, or via online access to GP practice services (such as for booking appointments or requesting repeat prescriptions)
- Mobile phone number or email address provided previously at a GP practice or other NHS service.

If a patient has difficulty providing this information, they can still use the telephone service, when other means of confirming identity can be discussed.

Using any device which can connect to the internet such as a computer, tablet, or mobile phone, patients can go to: [www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters) and follow the guidance on the page.

The online service is available 24 hours a day, 7 days a week.

## How to set a national data opt-out choice using the telephone service

If a patient is unable to use the online service, or would prefer not to, they can telephone **0300 303 5678** to register a national data opt-out.

According to Ofcom, the UK’s communications regulator, calls to 0300 numbers should cost no more than calls to a normal personal or business geographic landline number (numbers starting with 01 or 02), whether calling from a landline, or mobile phone.

The telephone service is available 9am to 5pm, Monday to Friday, excluding English bank/ public holidays.

## Confirmation

Once the process has been completed, the patient will receive a confirmation that their national data opt-out choice has been set, using email, SMS text, or letter as per their chosen communication method.

## Who can choose to opt-out?

Anyone registered for care or treatment with the NHS in England with an NHS number can have a national data opt-out set and of those anyone aged 13 and over can set their own national data opt-out if they wish to.

People with parental responsibility for children under the age of 13 such as parents or legally recognised guardians can act as a proxy and set or change a national data opt-out on the child's behalf.

People who have a formal legal relationship with a patient such as someone who has a legal power of attorney or a court appointed deputy can act as a proxy and set or change a national data opt-out on the patient's behalf.

To set or change a national data opt-out as a proxy, the person acting as the proxy will need to use the telephone service on 0300 303 5678.

## **How national data opt-out information is used**

NHS Digital provides the national data opt-out service on behalf of the health and care system and publishes more information at: <https://set-national-opt-out.service.nhs.uk/privacynotice> about how it processes the opt-out data to provide this service.

## **Other opt-outs**

Some patients will have a "type 1" opt-out registered with their GP practice, which prevents their confidential patient information leaving the practice for purposes beyond their individual care. These existing "type 1" opt-outs will continue to be respected until 2020, when the Department of Health and Social Care will consult with the National Data Guardian on their removal. For more information about the role of the National Data Guardian see: <https://www.gov.uk/government/organisations/national-data-guardian>.

Some patients will have registered a "type 2" opt-out with their GP practice, to prevent their confidential patient information from leaving NHS Digital for purposes beyond their individual care. When the national data opt-out service launches in May 2018 these opt-outs will have been converted to a national data opt-out. In the period June 2018 to July 2018 the patients aged 13 and over will have received a letter to inform them about the conversion of their "type 2" opt-out. Individuals who want to continue to be opted out will not need to take any action.

The Summary Care Record (SCR) is an important electronic patient record to support a patient's individual care. The national data opt-out does not prevent data being uploaded to the SCR as the national data opt-out applies only to purposes beyond individual care and treatment. If a patient chooses to opt out of having an SCR, they must ask their GP practice to record a specific SCR opt-out code in their patient record held at the GP practice. More information about the SCR can be found at: <https://digital.nhs.uk/summary-care-records>.

Patients may also have registered other forms of opt-out at their GP practice or with another health or care provider. These other opt-outs must still be considered by the organisation responsible for sharing the data and applied in accordance with the policy for the specific opt-out.

Where a patient has a national data opt-out in place as well as another form of opt-out, the national data opt-out must still be considered for data uses beyond the patient's individual care and treatment, in accordance with the national data opt-out policy.