

National Data Opt-out Implementation Newsletter



March 2018



We are now focusing on helping to get organisations ready for implementing the national data opt-out. This newsletter will: update on our recent activity, give answers to the top 5 questions we've been asked, and give key dates for the next stages of the programme.

Top 5 Questions [\(click on the link to view each answer\)](#)

1. [If a patient doesn't opt-out, does this implicitly mean they have opted-in or consented to a data use?](#)
 2. [Will a patients opt-out status be flagged on the Personal Demographics Service \(PDS\)? Are you working with system suppliers so that the necessary changes to their systems can be made?](#)
 3. [What are the exclusions \(for identifiable data flows\) where the opt-out will not apply?](#)
 4. [Will GP practice staff have to do anything to record the national data opt-out? \(they had to specifically code Type 1 & 2 opt outs\)](#)
 5. [How do the new General Data Protection Regulations \(GDPR\) affect the National Data Opt-out?](#)
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Policy update

The Secretary of State has agreed that the national data opt-out will be introduced alongside the new data protection legislation on **25 May 2018**. It has also been agreed to present the national data opt-out as a **single question** to cover both research and planning. **Type 2 opt-outs** (which

currently prevent identifiable data from leaving NHS Digital) will be converted to the new national data opt-out when it is introduced in May. Patients with type 2 opt-out will be contacted directly about this change.

Recent activity

We've delivered over 70 presentations nationwide across health and social care. We've held webinars on local data sharing and on our potential upholding solutions. If you have events or meetings coming up and would benefit from a discussion on the national data opt-out, then [please get in touch](#)

Engagement survey

We are going live with the National Data Opt-Out in three months. Before then we want to make sure we keep you informed on the latest developments. We are planning a series of webinars and events. Please complete our survey to let us know what topics you'd be interested in and how best to communicate with you.

<https://www.surveygizmo.eu/s3/90069282/National-Data-Opt-Out>

Technical solution pilots

We are working with our delivery partners to develop a solution which will allow health and care organisations to apply national data opt-outs. We would like to work with as many organisations as possible to pilot this solution over the summer of 2018. If you would like to volunteer, [please get in touch](#)

Communications products

The communication products for patients and the health and care workforce are currently going through our review and approval process. These products include the narrative for a poster and a patient handout, and draft versions of factsheets containing further information.

Answers

If a patient doesn't opt-out, does this implicitly mean they have opted-in or consented to a data use?

No – lack of an opt-out does not equate to an opt-in or to giving consent. Any processing of personal data will need to be lawful, fair and transparent including meeting the requirements of the

Data Protection Act (DPA) and the Common Law Duty of Confidence (CLDC).

The DPA requires that the collection and processing of data is fair, lawful and transparent. This means there must always be a legal basis under the data protection legislation and the CLDC must be met. For health and care data any organisations collecting, or processing data will need a legal basis under the DPA and it is expected under the new data protection legislation most will be able to identify both a condition under GDPR Article 6 (for personal data) and a condition under GDPR Article 9 (special category of data).

To meet the CLDC there must be either:

A mandatory legal requirement that enables the CLDC to be set aside, such as The Children Act 1989 which requires information to be shared in safeguarding cases

A court order where a judge has ordered that specific and relevant information is provided, and to whom

An overriding public interest; or

Consent

Patients may provide consent for a specific use of their data e.g. a specific clinical research study which will satisfy the common law duty of confidence so would override the national data opt-out.

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Will a patient's opt-out status be flagged on the Personal Demographics Service (PDS)? Are you working with system suppliers so that the necessary changes to their systems can be made?

The national data opt-out will be stored in a dedicated repository on the NHS Spine, this will not be directly accessible via PDS.

We are working with our delivery partners to develop a solution (known as the external upholding solution) to provide access to national data opt-outs. This solution should meet the requirements of all health and care organisations / processes, but we are working with organisations to identify volunteers who are prepared to act as pilot sites and verify the service. It's important that organisations consult the national data opt-out policy to assess whether their data flows need to have the opt-out applied and the impact on local processes. Please let us know if you would be willing to act as a pilot site for the external upholding solution when it becomes available.

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What are the exclusions (for identifiable data flows) where the opt-out will not apply?

Certain exclusions will apply. This includes the following categories:

Where there is a mandatory legal requirement for the data to flow e.g. CQC has powers of inspection and entry to require documents, information and records, or

An overriding public interest e.g. where it is judged that the benefit of providing the information outweighs the rights to privacy for the patient concerned and the public good of maintaining trust in the confidentiality of the service.

More information can be found on the [National Data Opt-out website](#).

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Will GP practice staff have to do anything to record the national data opt-out? (they had to specifically code Type 1 & 2 opt outs)

No. If a patient approaches their GP practice, they can be signposted to further information available nationally including how to register a national data opt-out. This will be available via a national web-site and contact centre.

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How do the new General Data Protection Regulations (GDPR) affect the National Data Opt-out?

The national data opt-out will sit alongside the new General Data Protection Regulations /Data Protection Bill 2017 and is not replaced or changed by it.

More information on how the opt-out fits into the legal framework can be found on the national data opt-out website here.

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Get in touch

If you have any comments or questions on any of the updates above or about the work of the National Data Opt-out Programme, please contact us at: newoptoutenquiries@nhs.net

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