



National data opt-out update

East of England IG Forum - April 2019

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Information and technology
for better health and care

Agenda

- Update on national data opt-out
- Patient information and setting service
- National data opt-out policy
- Becoming compliant
- Further information

Where we are now

- National data opt-out service launched to the public on 25 May 2018
- A secure way for patients to express their preference about the use of their confidential patient information (CPI) **for purposes beyond their individual care and treatment**
- Now for compliance....
- Any health and care organisation which processes and/or discloses data that originates within the health and adult social care system in England is required to consider if national data opt-outs should be applied to uses of CPI for purposes beyond individual care.
- All health and adult social care organisations must be compliant by March 2020



Your Data Matters to the NHS

Information about your health and care helps us to improve your individual care, speed up diagnosis, plan your local services and research new treatments.

In May 2018, the strict rules about how this data can and cannot be used were strengthened. The NHS is committed to keeping patient information safe and always being clear about how it is used.

You can choose whether your confidential patient information is used for research and planning.

To find out more visit: nhs.uk/your-nhs-data-matters



For more information about your data rights please visit the Your Data Matters campaign at ico.org.uk

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How your data is used

Your health and care information is used to improve your individual care. It is also used to help us research new treatments, decide where to put GP clinics and plan for the number of doctors and nurses in your local hospital. Wherever possible we try to use data that does not identify you, but sometimes it is necessary to use your confidential patient information.

What is confidential patient information?

Confidential patient information identifies you and says something about your health, care or treatment. You would expect this information to be kept private. Information that only identifies you, like your name and address, is not considered confidential patient information and may still be used: for example, to contact you if your GP practice is merging with another.

Who can use your confidential patient information for research and planning?

It is used by the NHS, local authorities, university and hospital researchers, medical colleges and pharmaceutical companies researching new treatments.

Making your data opt-out choice

You can choose to opt out of sharing your confidential patient information for research and planning. There may still be times when your confidential patient information is used: for example, during an epidemic where there might be a risk to you or to other people's health. You can also still consent to take part in a specific research project.

Will choosing this opt-out affect your care and treatment?

No, your confidential patient information will still be used for your individual care. Choosing to opt out will not affect your care and treatment. You will still be invited for screening services, such as screenings for bowel cancer.

What should you do next?

You do not need to do anything if you are happy about how your confidential patient information is used.

If you do not want your confidential patient information to be used for research and planning, you can choose to opt out securely online or through a telephone service.

You can change your choice at any time.

To find out more or to make your choice visit nhs.uk/your-nhs-data-matters or call **0300 303 5678**

[Home](#)

Overview

Choose if data from your health records is shared for research and planning

1. [Overview](#)
2. [Where confidential patient information is used](#)
3. [Where your choice does not apply](#)
4. [How to make your choice](#)

Your health records contain confidential patient information, which can be used to help with research and planning. If you would like this to stop, you can opt out of this yourself or on behalf of someone else. For example, if you are a parent or guardian of a child under the age of 13.

Your choice will only apply to the health and care system in England. This does not apply to health or care services accessed in Scotland, Wales or Northern Ireland.

This information is also available in [other languages and formats](#).

How to make your choice

Choose if data from your health records is shared for research and planning

1. [Overview](#)
2. [Where confidential patient information is used](#)
3. [Where your choice does not apply](#)
4. How to make your choice

Use this service to choose whether your confidential patient information can be used for research and planning.

If you choose not to allow your confidential patient information to be used for research and planning, this will be respected and applied by NHS Digital and Public Health England. These organisations collect, process and release health and adult social care data on a national basis.

Your decision will also be respected and applied by all other organisations that are responsible for health and care information by March 2020.

Making your choice

You can make or change your choice by using our online service or completing a paper form and posting it back to us. You can also ask for help using our telephone service. You must complete a paper form if you wish to make or change a choice on behalf of someone else.

Informing your patients

Please ensure you:

- Display the 'Your Data Matters to the NHS' poster, and make handouts available to patients
- Review existing patient materials (posters, leaflet, website) and remove any that are out of date so that patients have the latest information about data uses beyond individual care and the national data opt-out
- Check locally produced materials for accuracy if they refer to opting out, such as registration forms, questionnaires
- Consider using the screen text for electronic displays in reception/waiting areas
- Consider using the recommended standard text about the wider uses of health and care data, alongside or within Privacy Notices

All resources are available at: <https://digital.nhs.uk/national-data-opt-out>

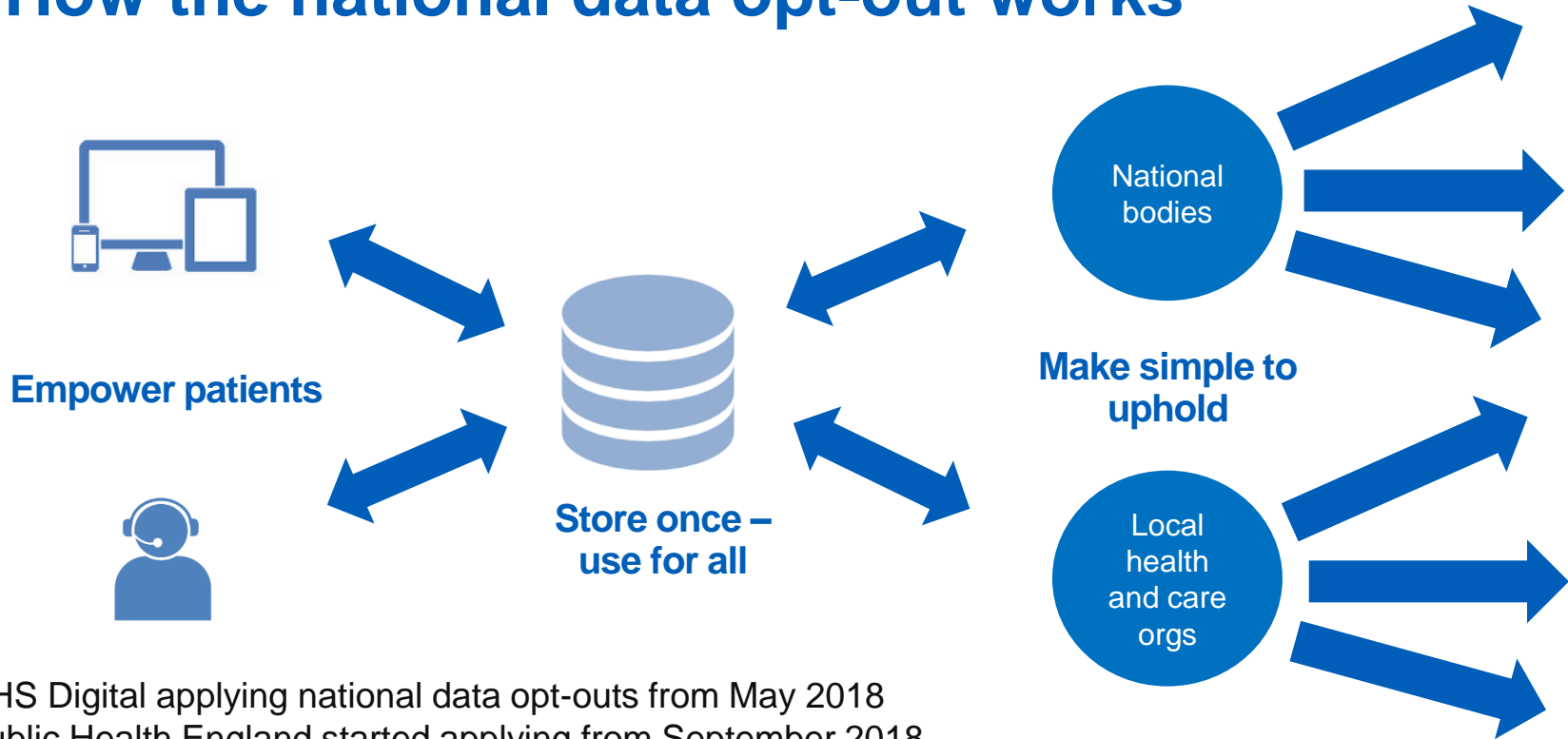
Informing your workforce

Please ensure:

- Your Information Governance lead, Caldicott Guardian, Data Protection Officer are aware of the national data opt-out
- Your organisation has policies and procedures in place for handling enquiries about data use and opt-outs, which includes the national data opt-out
- Clinicians and staff who deal with patients understand your policy and procedures for enquiries about data use and are aware of the national data opt-out
- Clinicians and staff know to direct patients who ask for further information to the handouts, the NHS website at www.nhs.uk/your-nhs-data-matters or the telephone helpline (telephone no is in the handouts and on the website)

Materials for workforce and specialists needing more detail are available at: <https://digital.nhs.uk/services/national-data-opt-out-programme/guidance-for-health-and-care-staff>

How the national data opt-out works



NHS Digital applying national data opt-outs from May 2018

Public Health England started applying from September 2018

All other health and adult social care organisations must be compliant by March 2020

What does it mean to 'be compliant'?

Any health and care organisation which processes and/or discloses data that originates within the health and adult social care system in England is **required to consider if national data opt-outs should be applied** to uses of confidential patient information (CPI) for purposes beyond individual care.

Being compliant is:

- a) Having processes and controls in place to authorise uses of CPI for purposes beyond individual care
- b) Considering application of national data opt-outs as part of that process
- c)
- d)

Summary of operational policy guidance

- Type of data – Confidential Patient Information
- Covers health and adult social care in England only
- Applies to publicly funded or co-ordinated care
- Purpose and legal basis underpins application of opt-out:
 - Purposes beyond individual care
 - How the Common Law Duty of Confidentiality is met
 - Applies when S251 (reg 2 or 5) is relied upon

Full operational policy guidance at

<https://digital.nhs.uk/national-data-opt-out>

When does the national data opt-out apply?

Applies to data shared for planning and research purposes

Single option that covers: Research – finding ways to improve treatments and identify causes of and cures for illnesses
Planning – to improve and enable the efficient and safe provision of health and care services



This identifies you personally

Data shared for an individual's care and treatment

E.g. where data is shared between the health and care professionals in a hospital and in a GP practice



This identifies you personally

Legal requirement / public interest / consent

E.g. There is a mandatory legal requirement such as a court order, to protect the greater interests of the general public, or there is explicit consent



This identifies you personally

Data is anonymised

The data shared is determined to be compliant with the ICO Anonymisation: managing data protection risk code of practice



This does not identify you personally

When does the national data opt-out NOT apply?

- Communicable diseases and risks to public health i.e. Regulation 3 Control of Patient Information Regs 2002
- Data flowing to ONS for statistical purposes
- Flows to PHE for National Cancer Registration Service and National Congenital Anomalies and Rare Diseases Registration Services
- Data for provision and oversight of national population screening programmes
- National patient experience surveys (CPES and CQC)
- 'Assuring Transformation' data flows, until programme closure

Clinical audit – local / national

Opt-out will NOT apply to local clinical audit

- Falls within the definition of individual care, as set out in the NDG review *“It includes the assurance of safe and high-quality care and treatment through local audit...”*
- NDG review also set out that data can be used for local clinical audit under implied consent, when undertaken by a team or professional with a legitimate relationship for the patient’s care

Opt-out will apply to national clinical audit (unless covered by another exemption)

Payments, Invoice Validation and Risk Stratification

- Payments and invoice validation
 - Anonymised data to be used wherever possible
 - Will NOT apply to **non-contracted** invoice validation
 - WILL apply to purposes which rely on s.251 support*
- *Other than approvals where CAG have waived the standard condition to apply opt-outs
- Risk stratification
 - Will NOT apply to data anonymised in line with the ICO code of practice on anonymisation
 - Will NOT apply to risk stratification for case finding, where carried out by a provider involved in an individual's care (or data processor). This is to be treated as individual care for purposes of the opt-out
 - WILL apply to purposes which rely on s.251 support



What you need to do to be compliant, and why!

What does it mean to be compliant?

Any health and care organisation which processes and/or discloses data that originates within the health and adult social care system in England is required to consider if national data opt-outs should be applied to uses of confidential patient information (CPI) for purposes beyond individual care.

Being compliant is:

- a) Having processes and controls in place to authorise uses of CPI for purposes beyond individual care
- b) Considering application of national data opt-outs as part of that process
- c) Having the **technical ability** to submit and receive NHS numbers using MESH
- d) Having the **technical and business processes in place** along with the controls to make sure the updated list of NHS numbers is applied before data is used/disclosed

Organisation can then provide patient-facing information to confirm compliance with national data opt-out policy (eg within its Privacy Notice)

What if I don't need to apply opt-outs?

An organisation may establish they do not have any **current** data uses which require the application of national data opt-outs.

In such cases these organisations can declare 'compliance' with the national data opt-out policy if they have:

- Processes in place to continue to review and identify if opt-outs need to be applied, **and**
 - recognise they would need to implement the technical capabilities should the need be identified, **or**
 - put in place those technical capabilities just in case

Organisation can then provide patient-facing information to confirm compliance with national data opt-out policy (eg within its Privacy Notice)

How the national data opt-out works



NHS Digital and Public Health England are already applying national data opt-outs
All other health and adult social care organisations must be compliant by March 2020

Check for National Data Opt-outs service



Health and Care Organisation

Provider will supply only NHS Numbers within a specific dataset

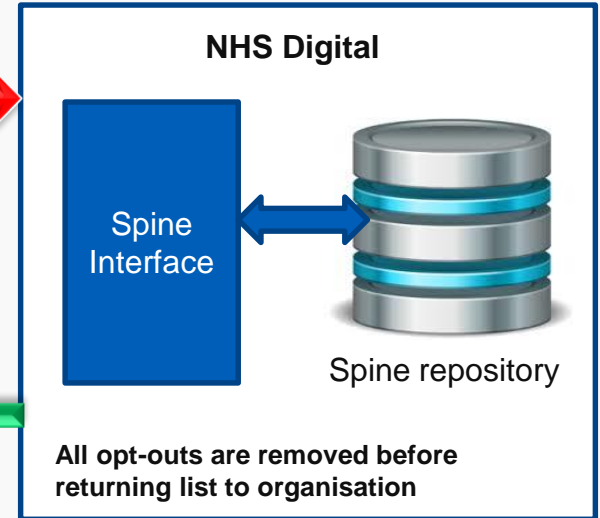


Encryption at the transit level through use of MESH*

NHS Digital return list of NHS Numbers where no national data opt-out is set



Encryption at the transit level through use of MESH*



To help GP practices to become compliant, the 4 GP system suppliers have been commissioned to embed this service into their systems.

* MESH = Messaging Exchange for Social Care and Health
Encryption at the business level not required

Supporting organisations with compliance



NHS Digital – compliant since May 2018



Data Services for Commissioners Regional Offices (DSCROs) - compliant since May 2018



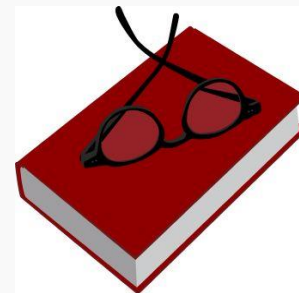
Public Health England – compliant since September 2018

- Other national organisations: in progress
- **NHS Trusts: February 2019 – August 2019**
- GP practices and CCGs: May – October 2019
- Local authorities and adult social care: April 2019 - March 2020
- Others (eg pharmacies, NHS dental/opticians): October 2019 – March 2020

Compliance resources

Guidance on our compliance page to help:

- understand what being compliant with the national data opt-out policy means
- plan the tasks and actions required, e.g.
 - consider and update data use and release policies and procedures
 - to support technical implementation
 - communicating compliance internally and externally



Coming soon (currently testing with organisations)

- examples of real data uses and position on whether opt-outs apply to help assessing own data uses
- information to help with DPIAs

National data opt-out: compliance implementation guide

Page contents

Summary

[Before you start](#)

[Actions to take to achieve compliance](#)

[1. Assess data disclosures and update procedures](#)

[2. Decide whether to implement the technical solution](#)

[3. Implement the technical solution](#)

[4. Plan and document how your](#)

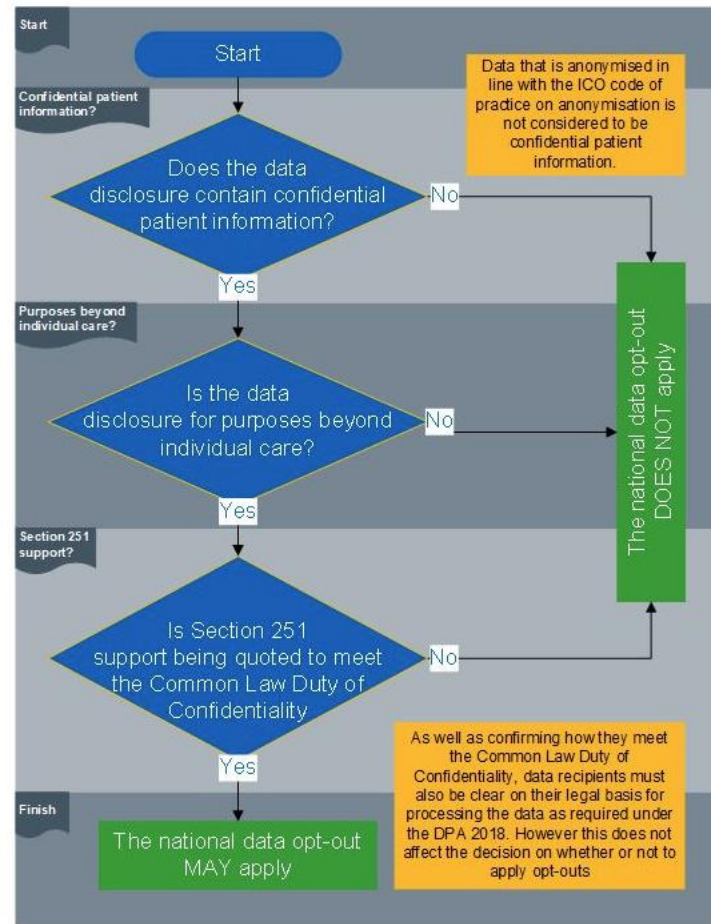
Summary

This guidance takes you through the steps you need to achieve [compliance with the national data opt-out policy 2020](#), when all health and care organisations in England

Completing these steps means:

- you will comply with [Information Standard DCB3058: national data opt-outs](#)
- you will be able to complete the evidence item 'compliance with the national data opt-out policy' in the [Data Security and Toolkit](#) for 2019/20.

The flow diagram below illustrates the key questions to take into account when determining this.



Embedding opt-out compliance

Information Standard for national data opt-out compliance

- Mandates compliance with the policy and use of the Check for National Data Opt-outs service in accordance with required specification. All health and social care bodies must have regard to published information standards.

NHS Digital Code of Practice on Confidential Information

- Adding information about complying with national data opt-out policy. Defines the steps that organisations must, should and may take to ensure that confidential information is handled appropriately. All health and social care bodies must have regard to the Code of Practice.

DSP Toolkit (2019/20)

- Update to current content on national data opt-out to change it to a self assessment statement of compliance. Will require supporting evidence e.g. Privacy Notice statement if declaring compliance.

ICO position

- Indicate a failure to implement the national data opt-out policy would be considered against the principle of lawfulness, fairness and transparency.



Key messages for NHS Trusts

NHS Trusts must be compliant by March 2020

- Assess data disclosures and update procedures
 - Current data disclosures assessed to identify any that will be within scope of national data opt-out policy
 - Process for handling new requests updated to make sure policy is considered before disclosure
- Decide whether to implement the technical solution
 - Data disclosures assessed, decision if need to implement the technical solution in order to apply national data opt-outs
- Implement technical solution to access the Check for National Data Opt-outs service
 - Messaging Exchange for Social Care and Health (MESH) client software installed, MESH mailbox in place
- Plan and document procedures to apply national data opt-outs
 - Processes for creating a list of NHS numbers that need to be checked, creating files to send to service
 - Processes for using the returned files to create an updated set of data and confirming opt-outs have been applied.
 - Data Protection Impact Assessment (DPIA) completed
 - Processes documented and included in standard operating procedures (or equivalent)
- Communications and declaring compliance
 - Internal, external (other organisations), patient communications.

Further information and resources: <https://digital.nhs.uk/national-data-opt-out>

Key messages for GP practices (and CCGs)

www.nhs.uk/your-nhs-data-matters (and telephone, print-and-post service) live since 25 May 2018.

- National data opt-out is set by patient themselves, cannot be set by the practice.
- Previous 'type 2' opt-outs were converted, and patients informed by letter from NHS Digital.
- Type 2 opt-out codes (XaaVL/9Nu4.) must not be used.
- TPP and EMIS have inactivated codes in browsers. Vision/Microtest have not yet* @ March 2019

Actions for practices

- Display 'Your Data Matters to the NHS' posters and patient handouts, use display screen videos, and ensure practice team are aware.
- Review other materials about data use and opt-outs (posters, leaflets, website, privacy notice, registration forms) and remove/update any that are out of date (eg 'care.data', type 2 opt-outs).
- Check for entries of XaaVL/9Nu4. in patient records after 11 October 2018. If found, practice must contact the patient to inform them and signpost to nhs.uk service.
- Prepare to work towards compliance, by March 2020.

Further information and patient materials: <https://digital.nhs.uk/national-data-opt-out>

Further information

For more information, workforce and patient resources, or to join our mailing list, go to the National Data Opt-out Programme web pages:

<https://digital.nhs.uk/national-data-opt-out>

To contact us about becoming compliant or any other enquires, email: newoptoutenquiries@nhs.net or dawnfriend@nhs.net (local contact)

The 'Your Data Matters to the NHS' patient-facing service:

www.nhs.uk/your-nhs-data-matters