

# National Data Opt-out Programme



Implementation update – Y&H SIGN - 14 Sep 2018

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**Information and technology**  
**for better health and care**

## Agenda

- Overview of national data opt-out and where we are post launch
- What health and care organisations should be doing now
- Next steps and further information

## What is the national data opt-out?

“A patient should be able to state their preference once (online or in person), confident in the knowledge that this will be applied across the health and social care system”

National Data Guardian, July 2016



## National data opt-out setting service

- The service to set a national data opt-out was made available on 25 May 2018 (public beta) providing a secure way for patients to express their preference about the use of their data **for purposes beyond their individual care and treatment**

[www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters)

- Patients can access the service online e.g. using a smartphone, tablet or personal computer
- A national telephone service is also available to support an assisted digital, on behalf of, and non-digital (paper) service
- Patients have access to information to make an informed choice about whether or not to share their data for reasons other than their individual care

# Manage your choice

Find out why your data matters

[Home](#)

## Overview

Find out why your data matters

1. Overview
2. [Benefits of data sharing](#)
3. [How your data is used](#)
4. [Manage your choice](#)

The NHS wants to make sure you and your family have the best care now and in the future. Your health and adult social care supports your individual care. It also helps us to improve health and care services in England.

Unless you have chosen to opt out, your confidential information can be used for research and planning. You can allow you to make or change your decision at any time. You can download a form to manage a choice on behalf of yourself or by proxy. For example, if you are a parent or guardian of a child under the age of 13.

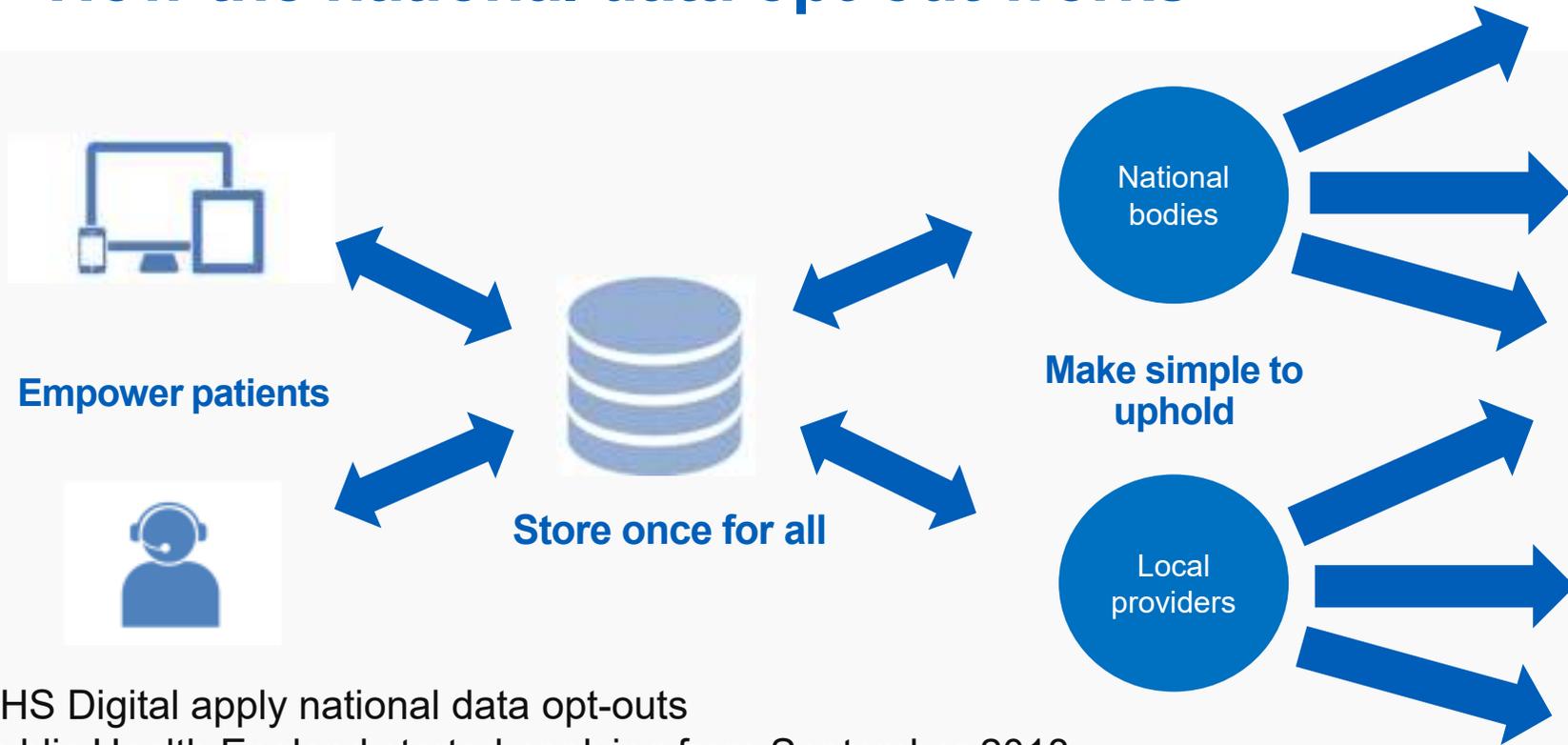
1. [Overview](#)
2. [Benefits of data sharing](#)
3. [How your data is used](#)
4. [Manage your choice](#)

Use this service to request that your confidential patient information is not used beyond your own individual care.

If you decide to opt out, 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.

An opt-out will only apply to the health and care system in England. This does not apply to your health data where you have accessed health or care services outside of England, such as in Scotland and Wales.

# How the national data opt-out works

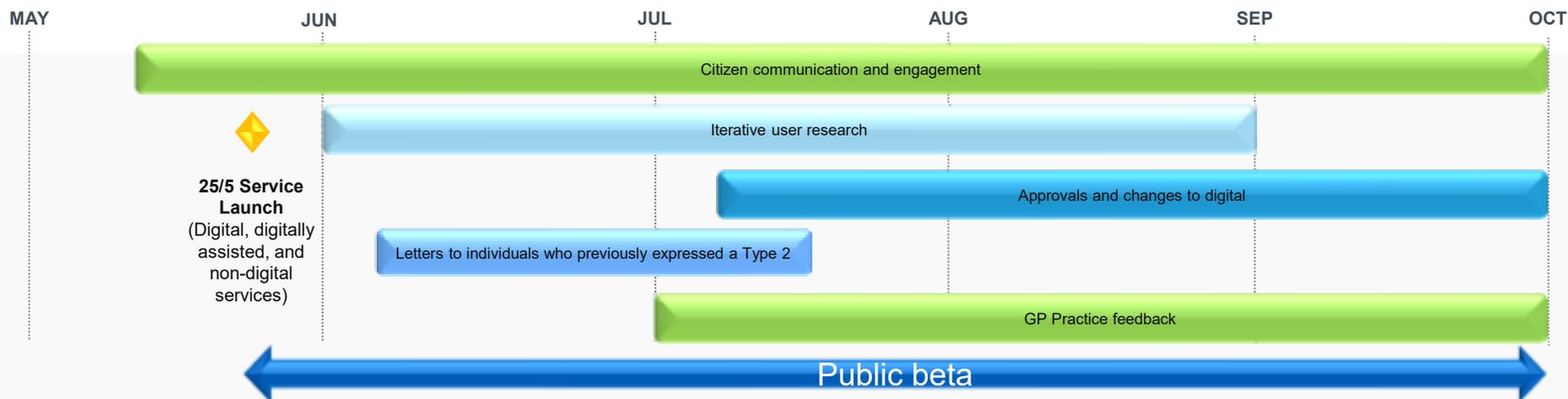


NHS Digital apply national data opt-outs

Public Health England started applying from September 2018

All other health & adult social care organisations will be expected to uphold by March 2020

# National data opt-out launch



## Key features

## Objective

### Public beta

User experience will be collected through monitoring user feedback and making improvements for 1 October 2018. This work will be assured by Government Digital Service (GDS).

### Type 2 transition

Type 2s can still be set in general practice over transition period until 1 October, but these will be converted on a monthly basis to national data opt-outs. These patients will be written to.

### Supporting GP Practices

GP Practice Reference Group to obtain feedback from the front-line.

# Communications - patients / public

## “Your Data Matters to the NHS”

nhs.uk

### Landing page

Web page setting out: overview; who uses your data; how data is protected; benefits of data sharing and how to opt out.



### Poster

Displayed in public areas inc. GP Practices, hospitals, pharmacies and dentists.



### Handout

Available in health and care providers, setting out how information is used; benefits of data sharing; and the opt-out choice



### Type 2 letter

Sent to patients with a type 2 objection. With a copy of the handout and dedicated helpline number.



### Opt-out setting guidance

Instructions on how to opt out.



### Easy Read

A simplified graphic version of the handout



### Screen text

Information for patient waiting room display screens



### Contact centre scripts

Information provided to patients who ring the contact centre.



### NHS Digital transparency notice

How opt-out data is processed by NHS Digital



# 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](https://nhs.uk/your-nhs-data-matters)



For more information about your data rights please visit the Your Data Matters campaign at [ico.org.uk](https://ico.org.uk)

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

## 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.

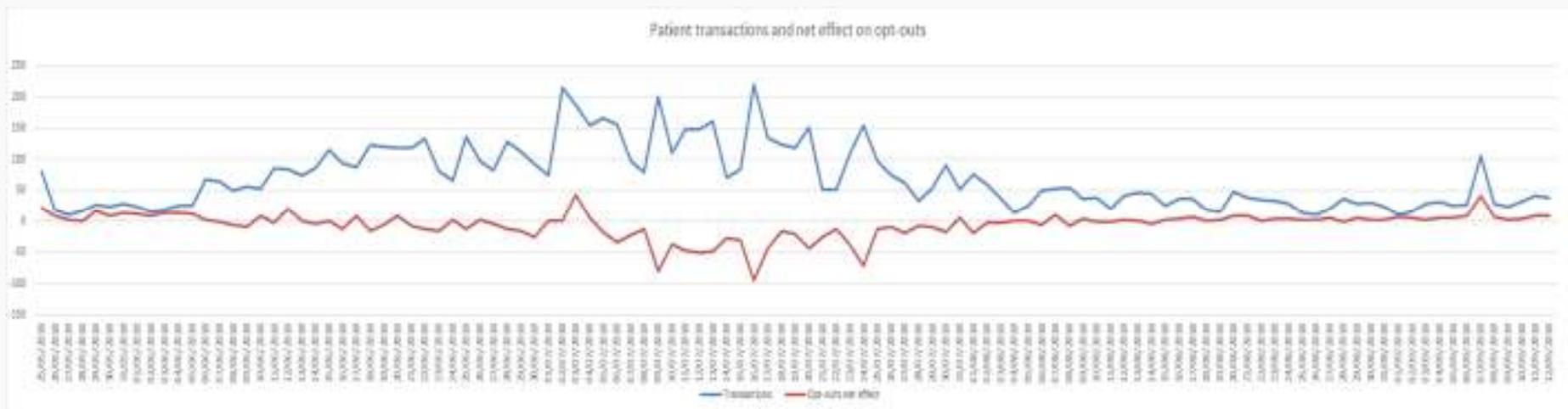
If you do not want your confidential patient information to be used for research and planning, you can choose to opt out securely online or through a telephone service.

You can change your choice at any time.

To find out more or to make your choice visit [nhs.uk/your-nhs-data-matters](https://nhs.uk/your-nhs-data-matters) or call 0300 303 5678

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# National data opt-out activity



- Between 25 May 2018 and 12 September 2018:
  - 7770 service transactions
  - 3338 supported use for research and planning
  - 4432 chose to opt out
  - Some transactions re-stated an existing choice
  - 90% digitally



## Health and care organisations and the opt-out

# Information for 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>

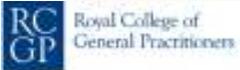
# Your workforce

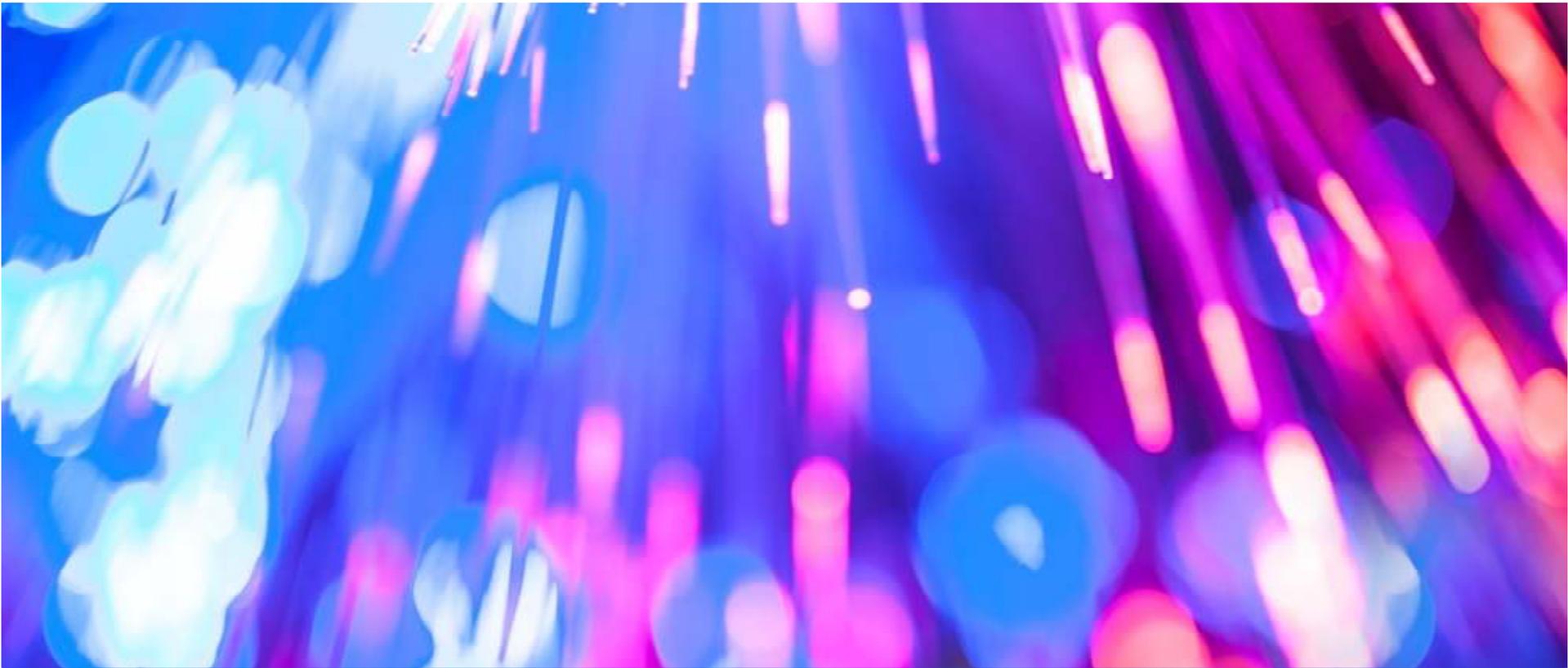
Please ensure:

- 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 the 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](http://www.nhs.uk/your-nhs-data-matters) or the telephone helpline (telephone number is in the handouts and on the website)

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

# Workforce-facing products

Workforce group	Approach
Health and social care professionals	<ul style="list-style-type: none"> <li>• Dedicated NHS Digital national data opt-out web page</li> <li>• Factsheets: Data use and patient choice; when it applies; what it applies to; how it is applied; setting; how this fits with DPA</li> <li>• Monthly newsletters</li> <li>• Q&amp;As</li> </ul>
GP Practices 	<ul style="list-style-type: none"> <li>• Patient Data Choices project is a collaboration with the RCGP to develop: an e-learning package; a toolkit; videos and regional and national events. It is led by a clinical champion.</li> </ul>
Nurses, Midwives and Care Staff  	<ul style="list-style-type: none"> <li>• Tailored resources for nurses, midwives and care staff including a prompt card and pocket guide badged by the RCN &amp; RCM</li> </ul>
Health and social care specialists inc. IG	<ul style="list-style-type: none"> <li>• Regular bulletins to national and professional bodies</li> <li>• Organisational readiness checklists</li> <li>• National data opt-out Operational Policy Guidance document</li> </ul>
Registered providers and public bodies	<ul style="list-style-type: none"> <li>• Chief Executive letters</li> <li>• Data Security &amp; Protection Toolkit</li> </ul>



**Next steps – understanding the policy  
and upholding the opt-out**

# Summary of Operational Policy Guidance

- Covers health and adult social care in England only
- Applies to publicly funded or co-ordinated care
- Type of data – Confidential Patient Information
- Purpose and legal basis underpins application of opt-out:
  - Purposes beyond individual care
  - Applies when S251 (reg 2 or 5) is legal basis for the disclosure
- Anyone registered on PDS (ie with data in English system) can opt-out
- Formal proxies can set opt-out on behalf of others – eg LPA and parents/guardians
- Young people can set their own opt-out from age 13
- Previous type 2 opt-outs have been migrated to national data opt-outs
- Type 1s continue until 2020 when they will be reviewed

# Applying the national data opt-out

## 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 a 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, until April 2019 – pending a further decision on the way forward for surveys
- ‘Assuring Transformation’ data flows, until programme closure

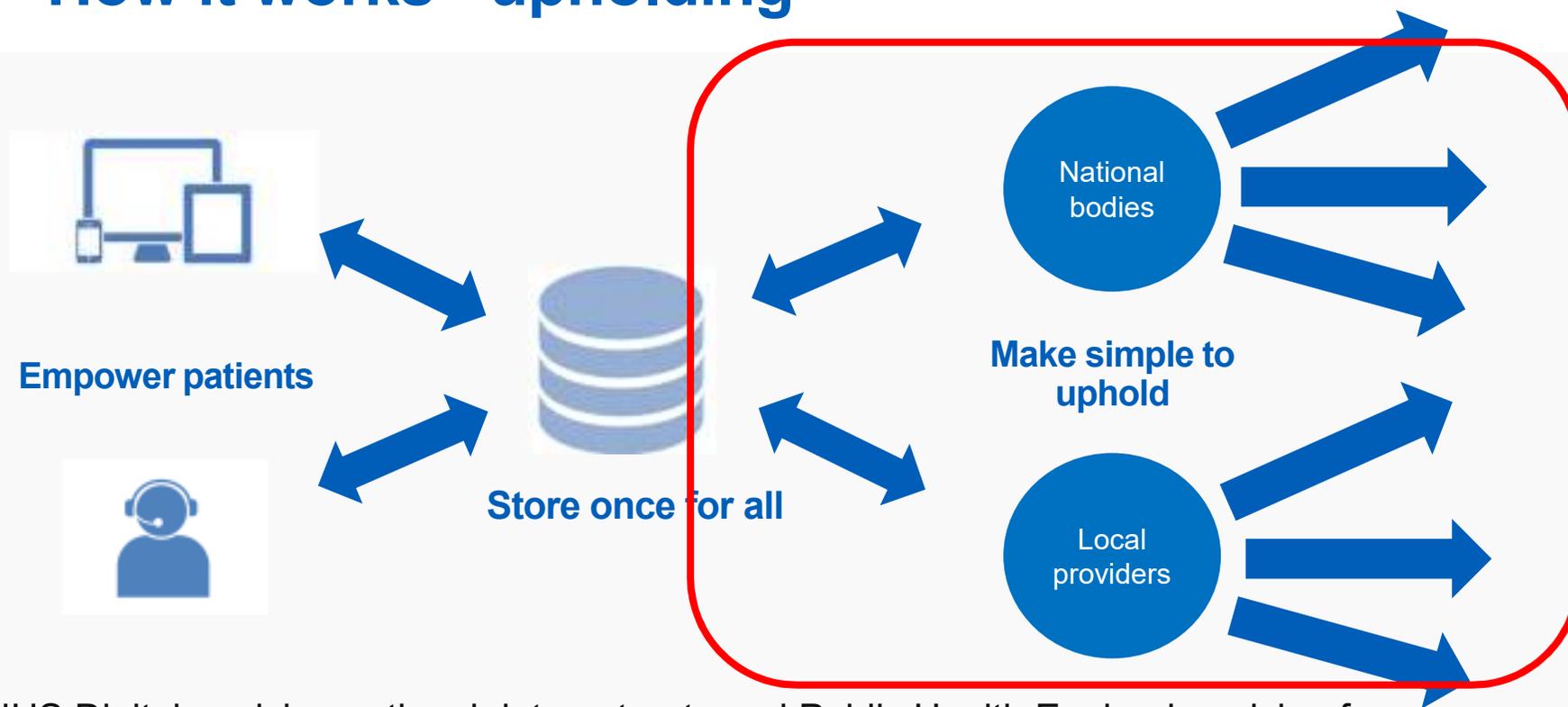
# Practical considerations

- Responsibility for application is on data controllers (including joint), data processors act under instruction
- Applies to electronic (structured and unstructured) and paper format
- Continues to apply after a person has died
- Whole record must be removed from data being used
- NHS Number (key to record removal)
- Opt-outs are applied at a point in time, not retrospectively
- Records containing information about multiple individuals
- Applies to cross border flows – unless otherwise exempt
- Statistical publication available

## Payments, Invoice Validation and Risk Stratification

- Payments and invoice validation
  - Will NOT apply to **non-contracted invoice validation**
  - WILL apply to purposes which rely on s.251 support
- 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

## How it works - upholding



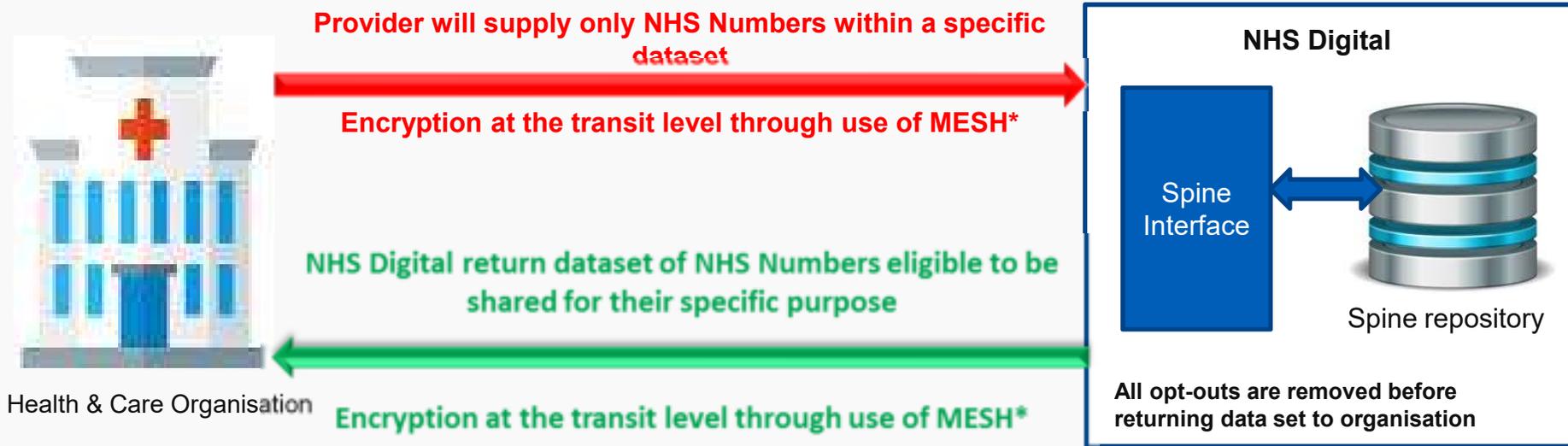
NHS Digital applying national data opt-outs and Public Health England applying from September 2018

All other health & adult social care organisations will be expected to uphold by March 2020

## Upholding – how you can get involved

- Working with trusts and GP practices
- Engaging with other organisation types, local data sharing schemes, LHCREs
- Intention is to deliver a working solution during September 2018
- Plan to deploy solution in pilot sites over the Autumn 2018
- We are looking for volunteer pilot sites...

# The upholding solution



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

## Upholding – pilot sites

- **Phase 1:** analysis of information flows to assess suitability for pilot
- **Phase 2:** deployment:
  - MESH configuration
  - Local communication
  - Application of upholding solution against each information flow
  - Possible phasing of information flows within pilot timeframe

# Assessing information flows

## Information Flow Mapping Proforma

Information flow	Information Recipient	Recipient Type	Purpose of Release	Legal Basis for Release (if applicable)	Format	NHS Number included? (Always, Where present, Never)	Frequency of Release	Typical Release Volume
e.g Commissioning and payment for Direct Care	e.g Southampton City CCG	e.g Commissioner	e.g Payment	e.g s251	e.g .csv file extract	Always	e.g Monthly	e.g 10,000 records per release. 2MB File size

If you are interested in being involved with the upholding solution pilot, please contact us: [newoptoutenquiries@nhs.net](mailto:newoptoutenquiries@nhs.net)

## Working towards the March 2020 deadline

- Start considering your data uses beyond individual care and whether you think any would need to apply opt-outs
- Contact us if you think you will have to, or if you aren't sure and need some further help to understand the policy in line with your own specific data uses
- We can meet with you (1-2-1 or in your local groups) to help with understanding the application of the policy, technical implementation, and to think about any necessary process and business changes to the way you handle data
- If you think you'll need to apply opt-outs start identifying who in your organisation will need to get involved i.e. who will:
  - Determine when opt-outs need to apply in line with the policy
  - Manage the usage/dissemination of data for purposes beyond individual care
  - Understand the technical solution and how to implement into the organisation
  - Lead on the decision as to when the organisation should implement the 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>

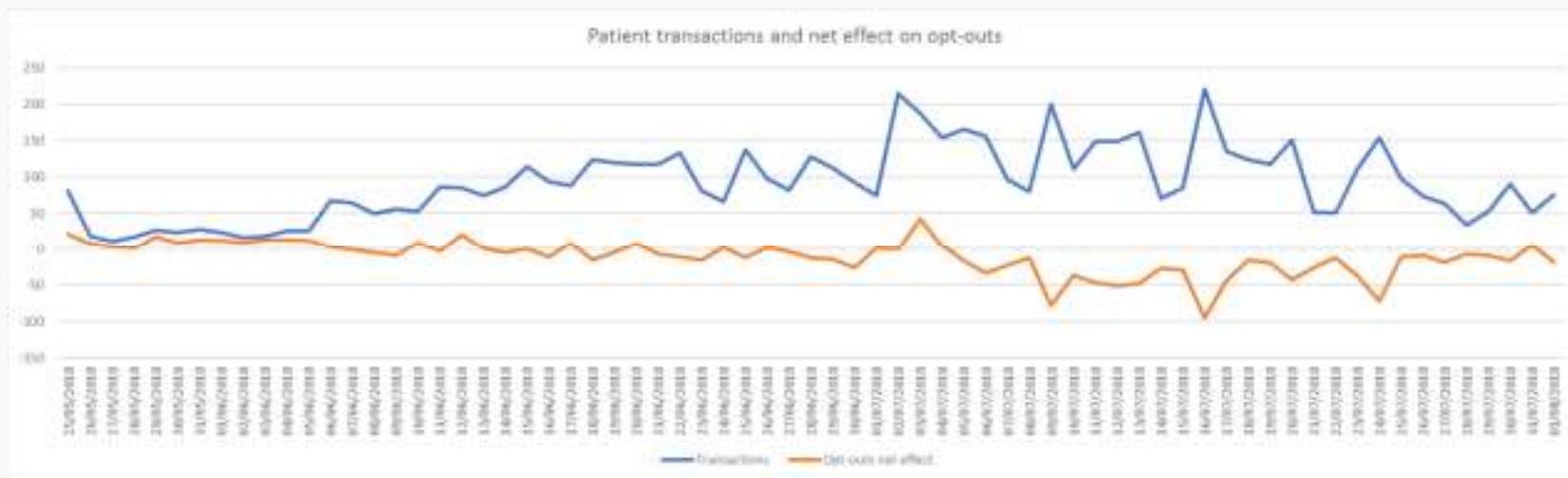
To contact us about upholding or any other enquires, email:

[newoptoutenquiries@nhs.net](mailto:newoptoutenquiries@nhs.net)

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

[www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters)

# National data opt-out activity



- Between 25 May 2018 and 31 July 2018:
  - 6285 service transactions
  - 2838 supported use for research and planning
  - 3447 chose to opt out
  - Some transactions re-stated an existing choice
  - 91% digitally