



# National Data Opt-out Programme

28th March 2018



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

**Matt Spencer and Sara Buck**

# Overview

- Better use of information and data has the potential to transform health and care for everyone, but people want to know that their privacy and rights are safeguarded, understand how and when information about them is shared, and, be able to make an informed choice about whether to share their data or not.
- It was in this context that the Secretary of State for Health commissioned a review on data security and data sharing in the health and social care system by Dame Fiona Caldicott, the National Data Guardian for Health and Care (NDG).
- This independent review of data security, consent and opt-outs was published July 2016, followed by a public consultation that ran until September 2016.
- Government response published on 12 July 2017.
- The National Data Opt-out Programme is implementing a service to allow people to set a preference, which will be upheld by all health and care organisations.
- The work takes place in the context of the drive to develop a digitised health and care system that offers patients more control and choice over the care they receive, improves their experience, provides them with better outcomes and delivers a more efficient health and care system.

# NDG Review and Government's response

## National Data Guardian Review – Key Points & Recommendations

- You are protected by the law
- Information is essential for high quality care
- Information is essential for other beneficial purposes
- You have the right to opt out of your personal confidential information being used for these other purposes beyond your direct care:
  - Providing local services and running the NHS and social care
  - Supporting research and improving treatment and care
- This opt-out will be respected by all organisations that use health and care information
- Explicit consent will continue
- The opt-out will not apply to anonymised information
- Arrangements will continue to cover exceptional circumstances

The Government response to the National Data Guardian Review supports the recommendations



# Does the national data opt-out apply to..?

## Data shared for planning and research purposes

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 & 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



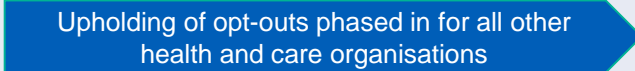

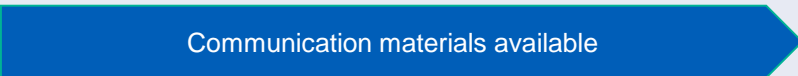


***This does not identify you personally***

## More detailed information will be provided on:

- Formal proxies who are able to register a national data opt-out on someone else's behalf such as parents, people with powers of attorney and those representing patients who lack capacity
- The maximum period of time that is permissible for a national data opt-out to be upheld after it has been set by a patient
- How the national data opt-out will apply where the data being used is not held in an electronic format such as in paper records and microfiche
- What is classed as personally identifiable data
- The point at which data being used for purposes beyond individual care and treatment needs to be considered for the national data opt-out
- The scope and definition of individual care
- The list of mandatory legal requirements, to which the op-out would not apply
- How the national data opt-out applies to data supporting payment processing (eg invoice validation)

# Implementation Timetable

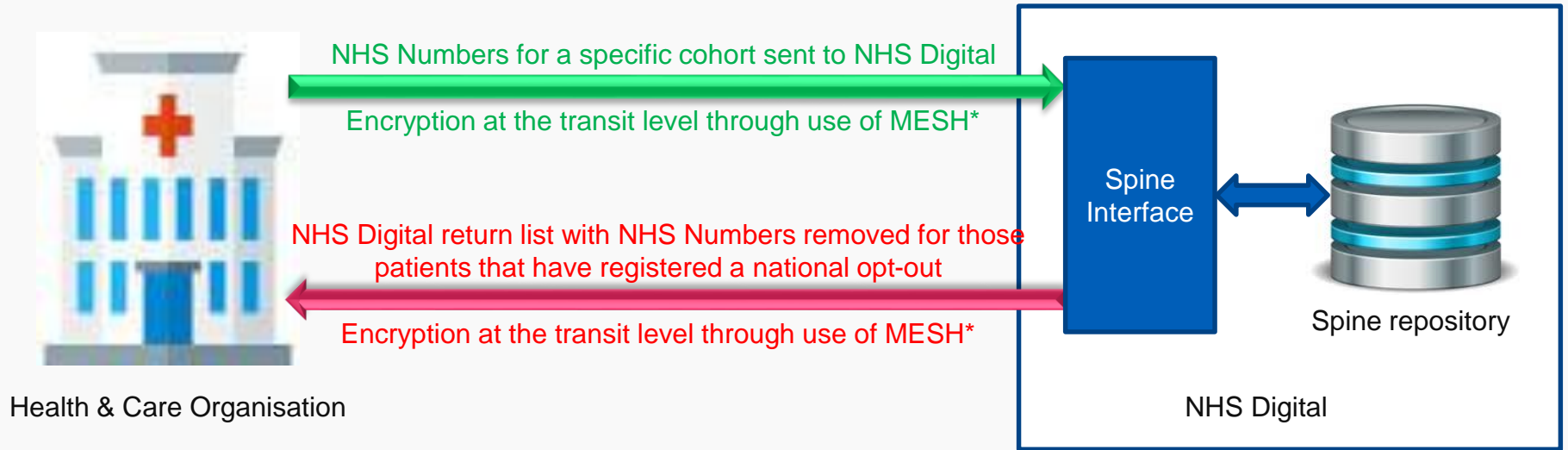
Area	Previously	Jan – Mar 2018	Apr – Jun 2018	Jul 2018 – Mar 2019	Apr 2019 – 2020
Opt-out preparations	Awareness raising	Readying organisations for implementation			
Opt-out service testing	Build opt-out service	Test opt-out service			
Setting opt outs				 25/05/18 Opt-outs can start being set from this date	
Applying opt-outs				 25/05/18 Opt-outs upheld by NHS Digital	 Upholding of opt-outs phased in for all other health and care organisations
New Data Protection Legislation (GDPR)				 25/05/18 New data protection legislation comes into effect	
Communications strategy	Develop strategy	Develop materials			 Communication materials available

# How it will work



NHS Digital will uphold all opt-outs from 25 May 2018  
All other health & care organisations will be expected  
to uphold the opt-out by 2020

# Upholding Solution – accessing Spine



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





# Communications

# The health and care system layer

## Workforce facing products

### Workforce group

### Approach we are taking

Health and social care professionals

- Dedicated NHS Digital national data opt-out web page
- Factsheets: Data use and patient choice; when it applies; what it applies to; how it is applied; setting; how this fits with DPA
- Monthly newsletters
- Q&As

GP Practices



- 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.

Nurses



- Tailored resources for nurses including a prompt card and pocket guide badged by the RCN

Health and social care specialists inc. IG

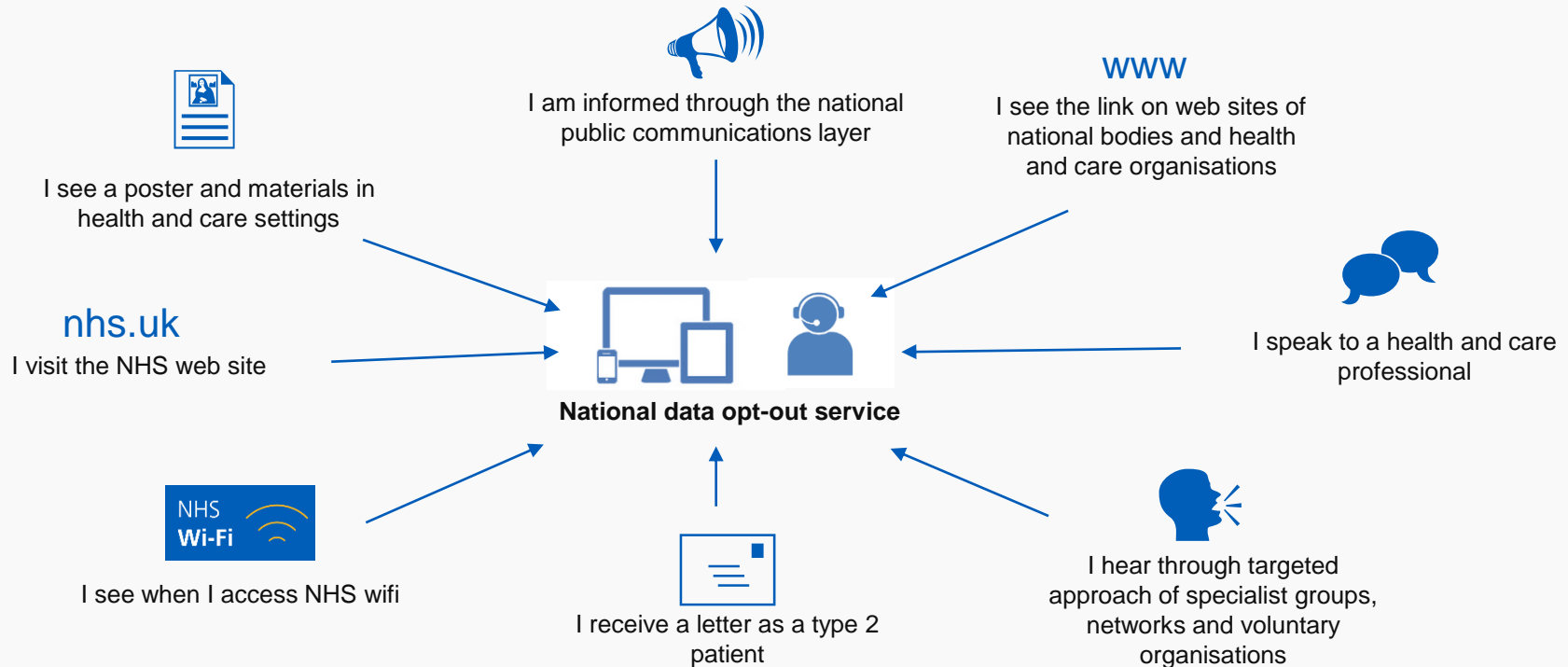
- Regular bulletins to national and professional bodies
- Organisational readiness checklists
- Policy guide

Registered providers and public bodies

- Chief Executive letters
- Data Security and Protection Toolkit

# The health and care system layer

## How will a person find out that they have a choice?



We will evaluate and refine communications on an on-going basis

# The health and care system layer

## Patient facing products

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. It will also contain a copy of the handout.



### Opt-out setting guidance

Instructions on how to opt-out.



### NHS Digital transparency notice

How opt-out data is processed by NHS Digital



### Infographic

Graphic to convey opt-out process.



### Contact centre scripts

Information provided to patients who ring the contact centre.

# Key Communication Release Dates

Materials	Route	Date
Workforce materials	NHS Digital webpage	25 April 2018
Handouts and posters	Starter pack delivered to providers	11 May 2018
Data use information and access to set opt-out	NHS.uk landing page	25 May 2018
Privacy Notice for the opt-out system	NHS Digital webpage	25 May 2018

The background of the slide is an abstract, vibrant composition. It features a dense field of out-of-focus light spots (bokeh) in shades of cyan, blue, and magenta. Interspersed among these spots are numerous thin, vertical streaks of light, primarily in purple and pink, that create a sense of motion and depth. The overall effect is a dynamic and colorful digital aesthetic.

# Accessibility Approach

# Approach

- Voluntary sector engagement
  - To understand the needs of different groups
  - To develop approach
  - To test communications, approach and opt-out routes
  - To support communications
- Healthwatch
- NAPP

# Accessibility - Materials

The handout will be produced in the following formats:

- **Easy read** – available online/via email and in print
- **Large print** – available online/via email/on request
- **Audio** – available online/via email/CD on request
- **Braille** – available on request
- **BSL** – available online/via email/DVD on request
- **Language translations** – available online/via email/on request
- **Video** – available online



# Accessibility - Online

- The programme is undertaking a Government Digital Service (GDS) assessment
- The digital service will meet level AA of the Web Content Accessibility Guidelines (WCAG) 2.0.
- The service will be tested with members of the public, including groups who may face additional barriers, including disabled people, homeless people, older people and people who use assistive technologies
- The programme will take all reasonable steps to ensure that the system meets the needs of all or provide an alternative route if appropriate.

## Accessibility - Helpline

- Translation service for callers who are unable to converse in English.
- Next Generation Text Service (NGTS) for those with hearing impairments.
- The Helplines Partnership will provide audit and training.

# Accessibility – Tailored materials

- Young people
- Carers
- BME groups
- Voluntary sector resource
- Helplines resource



**Being ready for 25 May 2018**

## What do I need to do for the 25 May 2018

- Who in my organisation needs to be aware of the national data opt-out?
- What do I do with the materials that have been provided?
- Is my organisation ready to receive questions from patients about the national data opt-out?
- Update my organisation privacy notice

# More information

**National Data Opt-out Programme web pages & to join our mailing list**

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

**National data opt-out enquiries mailbox** [newoptoutenquiries@nhs.net](mailto:newoptoutenquiries@nhs.net)

**Understanding Patient Data - Wellcome Trust**

<https://understandingpatientdata.org.uk>

**Information Governance Alliance (IGA) information on GDPR:**

<https://digital.nhs.uk/information-governance-alliance/General-Data-Protection-Regulation-guidance>