



**Understanding  
Patient Data**

# Patients' understanding of health data use

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**Insurance bosses buy medical records of all NHS hospital patients** *Care.data: How did it go so wrong?*

Your medical data is for sale, and there's nothing you can do about it

**Why Google DeepMind wants your medical records**

**How Private Is Your Personal Health Data?**

Insurer to sell data-driven product in privacy-conscious Germany

Hacker selling 655,000 medical records on the Dark Web

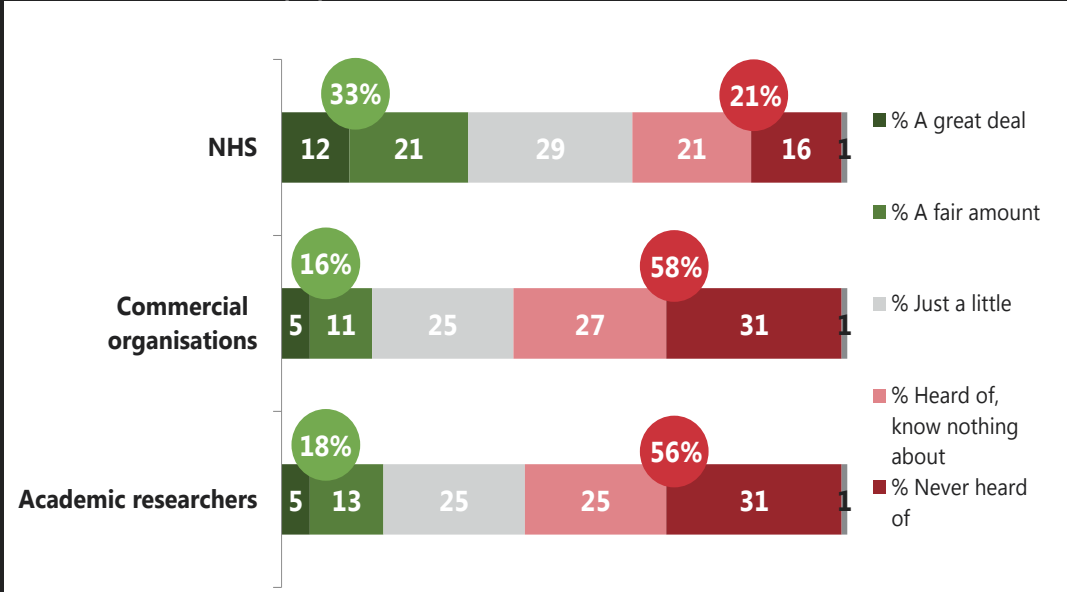
**Revealed: Google AI has access to huge haul of NHS patient data**

Boots, Tesco and Superdrug to get access to NHS medical records 2

# Context in the UK

## Some awareness of health data usage, but little depth of understanding

How much, if anything, would you say you know about how the following organisations use health data for these purposes?\*



Base: 2,017 GB adults, aged 16+

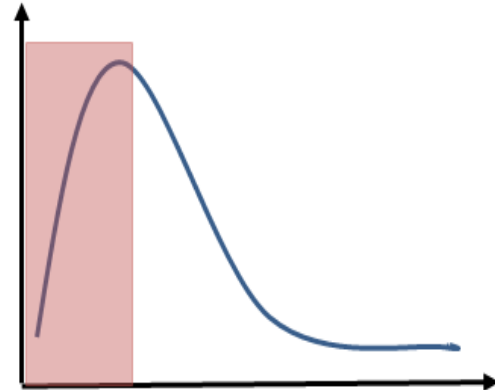
Ipsos MORI  
Social Research Institute

\*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust

I knew nothing about this until today. At first I was concerned, but now I've heard more I'm reassured. It's important that data is used in this way by the NHS.

Level of concern



Amount of information

# Understanding Patient Data



Using patient data is essential to deliver better care and improve our health

[How data is used →](#)



Data must be kept safe and secure to protect your confidentiality

[How data is kept safe →](#)



Everyone should be able to find out how patient data is used and why, and who decides

[What you need to know →](#)



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# Aims of *Understanding Patient Data*

- To support discussions with public, patients and clinicians about uses of health data by:
  - providing objective evidence about benefits, risks and safeguards
  - helping people make informed decisions
  - developing advocates who can champion responsible use of data
  - working with the media to present a more even-handed portrayal
  - bringing together a range of existing initiatives
  - examining emerging issues from new data-driven technologies
  - providing analysis about public attitudes

# Funding



# Supporters





# Work streams

## Resources and tools

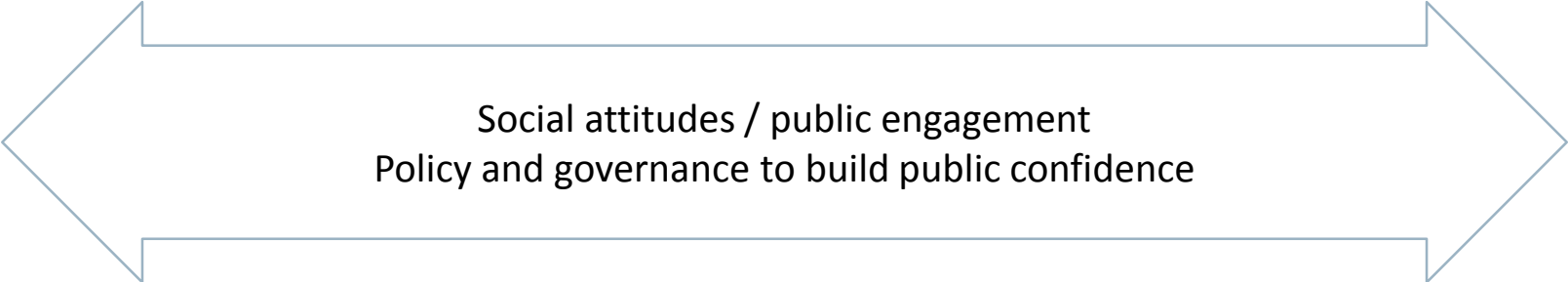
- Case studies
- Risks
- Safeguards
- FAQs
- Myth-busters
- Mapping data flows

## Developing advocates

- Clinicians/HCPs
- Patients
- Public
- Researchers
- Policy makers
- Media

## Horizon scanning

- New digital technologies
- Linking data across sectors
- Balancing privacy and public benefit



Social attitudes / public engagement  
Policy and governance to build public confidence



# Case studies

There is a wide range of ways that patient data can be used to deliver better care and improve health. Explore the case studies to learn more. Please let us know if you have good examples to share.

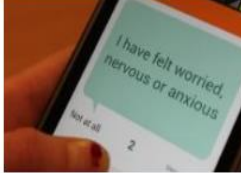
IMPACT OF WORK

- Diagnostics (7)
- Individual care (13)
- Patient safety (8)
- Planning (13)
- Policy (9)
- Treatment and prevention (22)
- Understanding disease (13)

DISEASE TYPE OR POPULATION GROUP


- Asthma (0)
- Autism (1)
- Cancer (0)
- Cardiovascular disease (0)
- COPD (2)
- Dementia (2)
- Diabetes (2)
- Genetic diseases (1)
- Infectious disease (4)
- Mental health (2)

SOURCES OF DATA



Helping people with psychosis

INDIVIDUAL CARE   PLANNING



Investigating trends in diabetes

UNDERSTANDING DISEASE   DIAGNOSIS  
TREATMENT AND PREVENTION   PLANNING  
POLICY



Whooping cough vaccination during pregnancy

INDIVIDUAL CARE  
TREATMENT AND PREVENTION  
PATIENT SAFETY

Does pain get worse in bad weather?  
Using smartphone data to analyse the potential relationship between weather and pain

UNDERSTANDING DISEASE

Improving pharmacist access to healthcare data  
Allowing pharmacists access to Summary Care Records with patient consent

INDIVIDUAL CARE   PLANNING

Involving patients in motor neurone disease research  
Evaluating the effectiveness of a treatment through online forum data

TREATMENT AND PREVENTION   PATIENT SAFETY



# “Toolkit”: what people want to know

1. Why it is important to use patient data?
2. What happens to your data (and who sees it)?
3. What are the risks?
4. What are the safeguards?
5. Is the data identifiable?
6. What's allowed?
7. What's not allowed?
8. Why do companies need access to data?
9. What choices do you have?
10. How can you find out more?

# The language problem

## Patient Data Glossary

<h3><u>Data</u></h3> <p>Anonymous</p> <p>Anonymised</p> <p>Non-disclosive</p> <p>De-identified</p> <p>De-identified for limited use</p> <p>Non-identifiable</p> <p>Unidentifiable</p> <p>Special categories</p> <p>De-linked anonymised (DPR-sensitive)</p> <p>Irreversibly de-identified</p> <p>Highly sensitive</p> <p>Pseudonymised</p> <p>Pseudonymous</p> <p>Coded</p> <p>Key-coded</p> <p>Encrypted</p> <p>Masked</p> <p>Derived</p> <p>Disclosive</p> <p>Re-identifiable</p> <p>Identifiable</p> <p>Sensitive</p> <p>Patient-level</p> <p>Individual-level</p> <p>Personal</p> <p>Personally identifiable</p> <p>Confidential</p> <p>Personal confidential</p> <p>Confidential personal</p> <p>Aggregated</p> <p>Summary</p> <p>Medical records / GP records</p> <p>Patient data</p> <p>Post-mortem / care records</p> <p>Historical data</p>	<h3><u>Processes</u></h3> <p>Anonymisation</p> <p>Pseudonymisation</p> <p>Coding</p> <p>De-identification</p> <p>Re-identification</p> <p>Encryption</p> <p>Redaction</p> <p>Removal of identifiers</p> <p>Aggregation</p> <p>Data linkage</p> <p>Disclosure control</p> <p>Data sharing</p> <p>Data access</p> <p>Data transfer</p> <p>"Data harvesting"</p> <p>Data destruction</p> <p>Data deletion</p> <p>Data retention</p> <p>Fair Processing</p> <p>De-anonymisation</p> <p>Mass/Sigmas re-identification</p>	<h3><u>Context</u></h3> <p>Informed</p> <p>Explicit</p> <p>Broad</p> <p>Implied</p> <p>Historic</p> <p>s25 approval</p> <p>selecting function</p> <p>opt-out</p> <p>objection</p> <p>- Type 1</p> <p>- Type 2</p> <p>Generic</p> <p>one-time</p> <p>Dynamic</p> <p>Specific</p> <p>Unambiguous</p> <p>Passive</p> <p>tick &amp; click</p> <p>Default</p> <p>Blanket</p> <p>Implicit</p>	<h3><u>Governance</u></h3> <p>Managed</p> <p>Restricted access</p> <p>Controlled</p> <p>Restricted</p> <p>Data access agreement</p> <p>Information sharing agreement</p> <p>Data transfer agreement</p> <p>Data sharing agreement</p> <p>Data sharing framework contract</p> <p>Trusted Third Party</p> <p>Accredited access facility</p> <p>Safe haven</p> <p>safe settings</p> <p>Supervisory Authority</p> <p>HRA Single Approval (BRC + local)</p> <p>Data Protection Officer</p> <p>Patient confidentiality</p> <p>Accredited researcher</p> <p>Approved researcher (ONS - s25 + 31A30 + 32A)</p> <p>IG Toolkit</p> <p>ISO 27001</p> <p>Data Controller</p> <p>Data Processor</p> <p>Caldicott Guardian</p> <p>Senior Information Risk Owner</p> <p>Information Asset Owner</p> <p>Privacy Notice (fair processing law)</p> <p>Microdata Release Audit (2015)</p> <p>KARD (2015)</p> <p>CACR (HRA)</p> <p>RECS (Gov/NSA)</p> <p>Information Governance Rules</p> <p>Trustworthy Research Environments</p>
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★ "Direct care" vs Secondary purposes/uses

★ spreadsheet language

"an identifiable patient receiving individual care from a defined clinical professional"

everything else = 2<sup>nd</sup> use

★ Caldicott definition: (2015)

"a clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals"

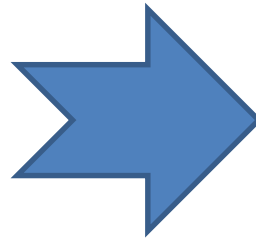
## Our first project question and focus

**What is the best vocabulary to use to talk about the use of data for care, treatment and research?**



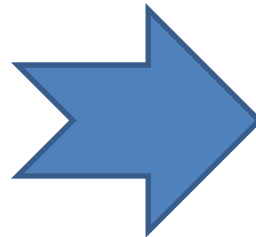
# Talking about uses of data

“Primary” uses



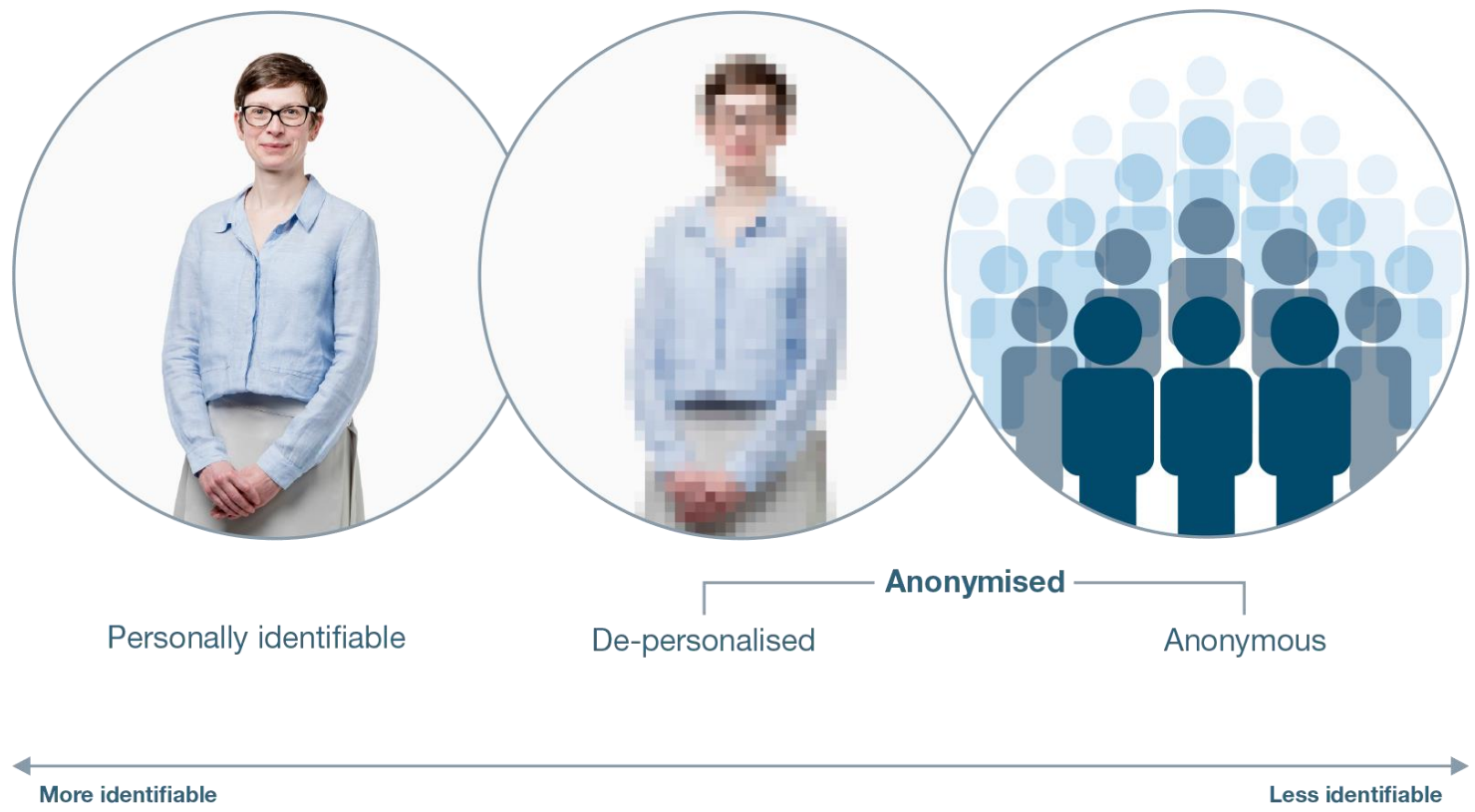
Individual care

“Secondary” uses



Improving health,  
care and services  
through research  
and planning

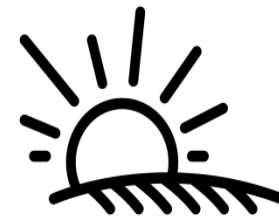
# Spectrum of identifiability





# What's on the horizon for patient data?

- New and emerging digital technologies
- Linking patient data with different sources
  - Is patient data different?
- Balancing individual interests and public benefit



*What do we need to do now to ensure patients, clinicians and the public can have confidence in responsible use of data to improve health and care?*

# Thank you

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 @Patient\_Data

