Understanding Patient Data

Patients' understanding of health data use

NHS-HE Forum

16th May 2017, London

Dr. Natalie Banner

Policy Adviser, Wellcome Trust

n.banner@understandingpatientdata.org.uk

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

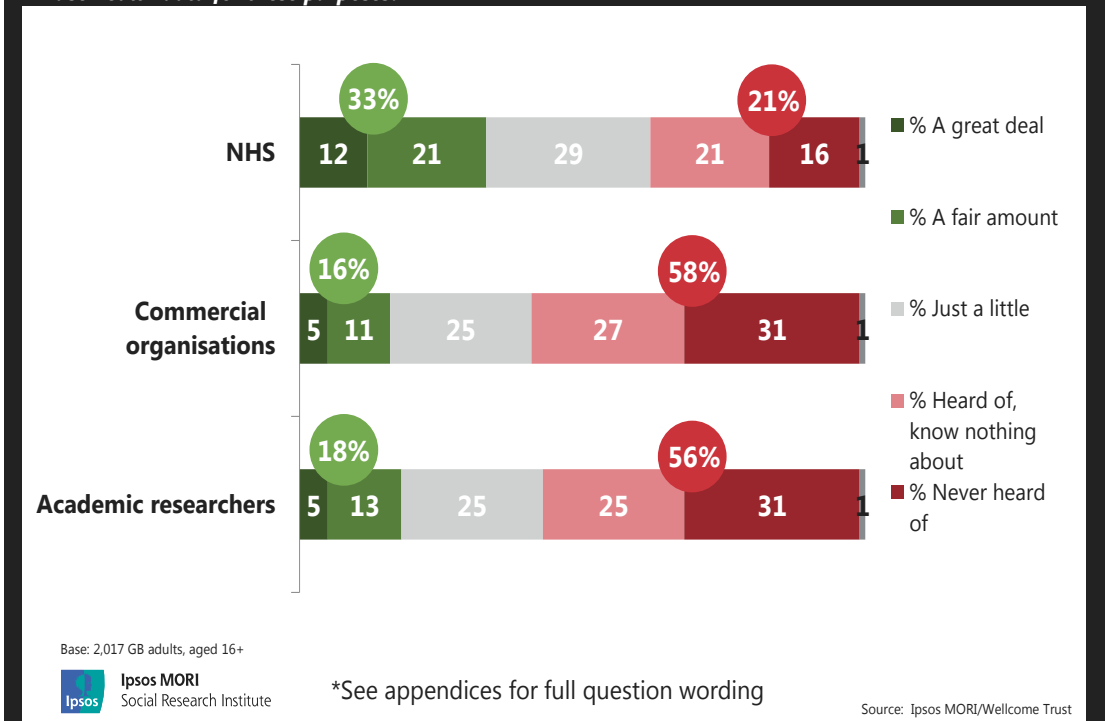
Revealed: Google AI has access to huge haul of NHS patient data

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

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?*



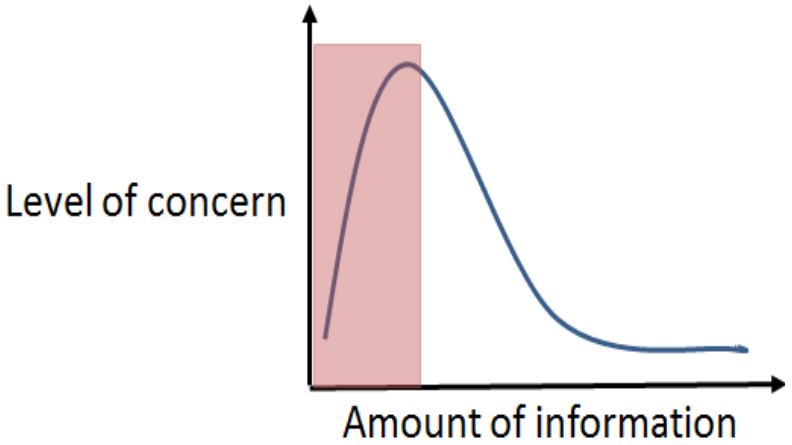
Base: 2,017 GB adults, aged 16+

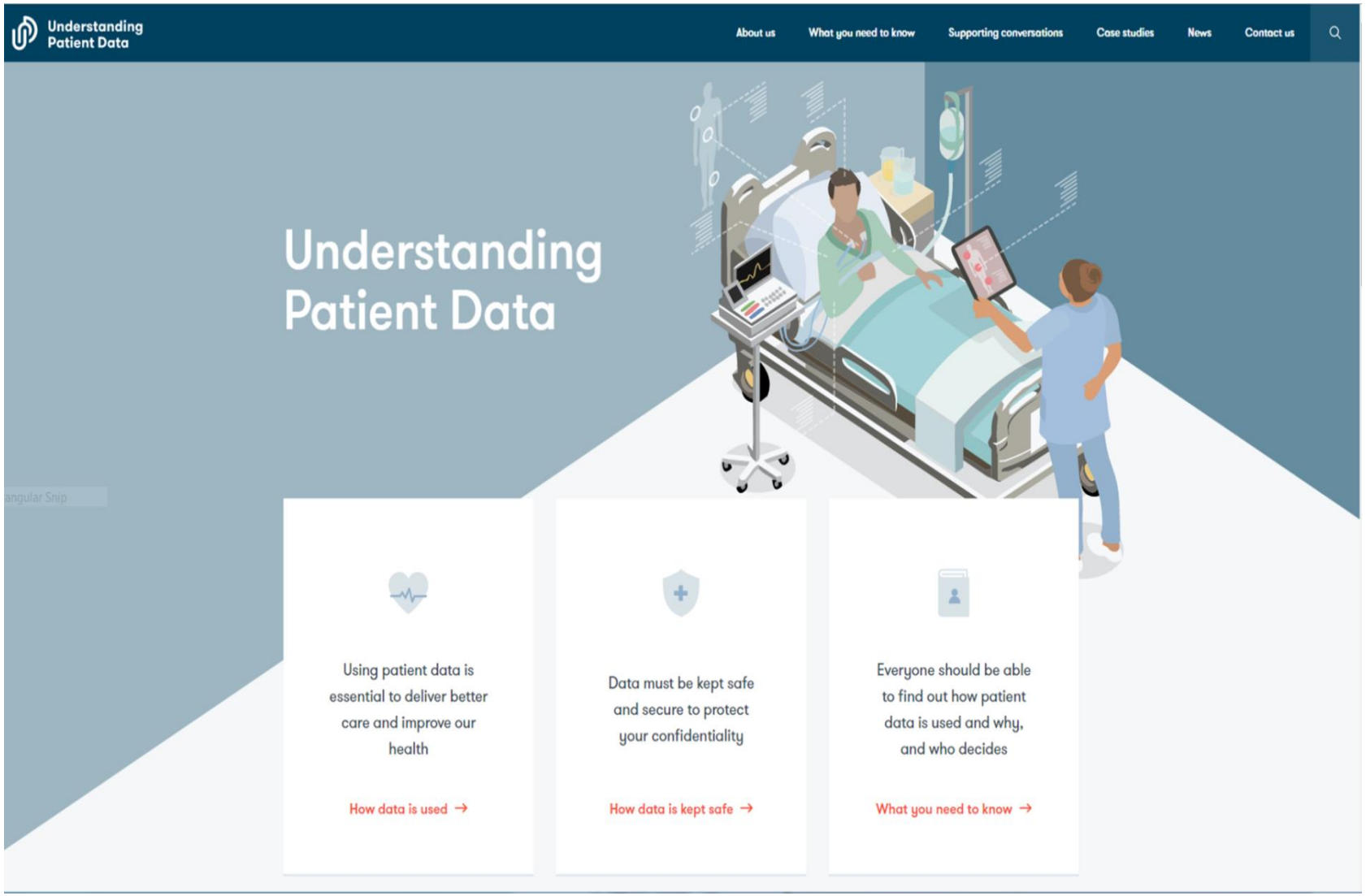
Ipsos MORI Social Research Institute

*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.





www.understandingpatientdata.org.uk

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

Data must be kept safe and secure to protect your confidentiality

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

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

wellcome
MRC Medical Research Council
Department of Health
E·S·R·C Economic & Social Research Council
Public Health England

Supporters

amrc Association of Medical Research Charities
Arthritis Research UK
British Heart Foundation
Information Governance Alliance IGA
INVOLVE
Cancer Research UK
cancer52 the common voice for less common cancers
Connected Health Cities
MQ Transforming mental health through research
We are Macmillan. Cancer Support
National Data Guardian
CPRD
Farr The Farr Institute of Health Informatics Research
NHS National Institute for Health Research
The Richmond Group of Charities
UK Clinical Research Collaboration igniting our potential
Genomics england
NHS Health Research Authority
use MY data

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.

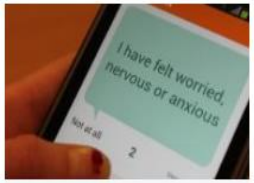
IMPACT OF WORK

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

DISEASE TYPE OR POPULATION GROUP

- Asthma (6)
- Autism (1)
- Cancer (6)
- Cardiovascular disease (6)
- 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

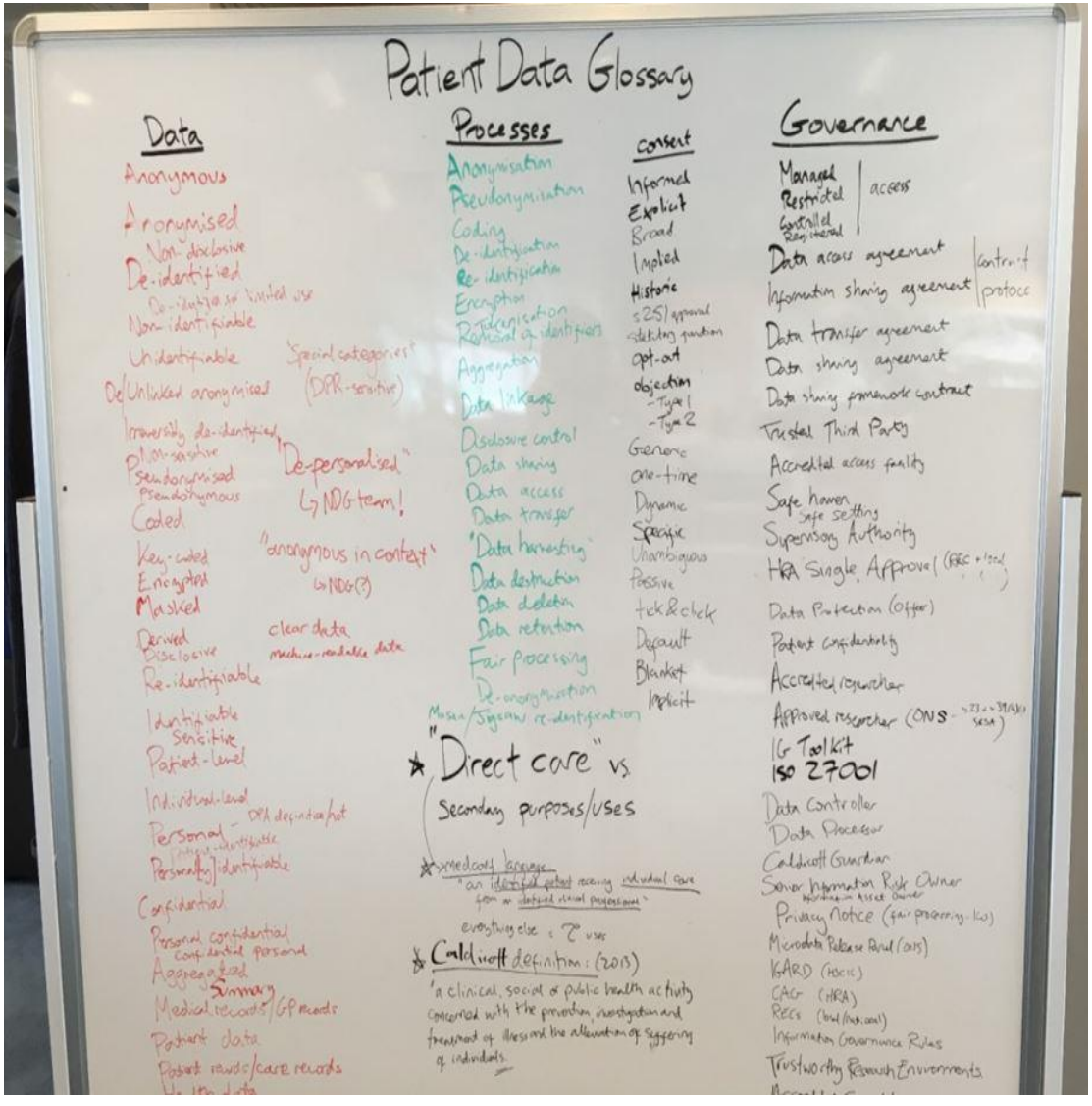
Evaluating the effectiveness of a treatment through online forum data

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

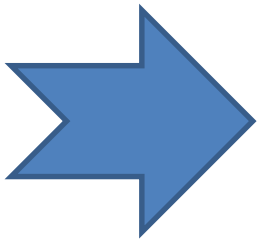


Our first project question and focus

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

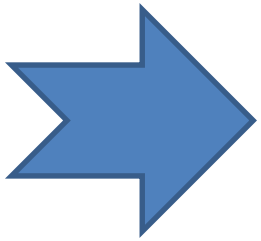
Talking about uses of data

“Primary” uses



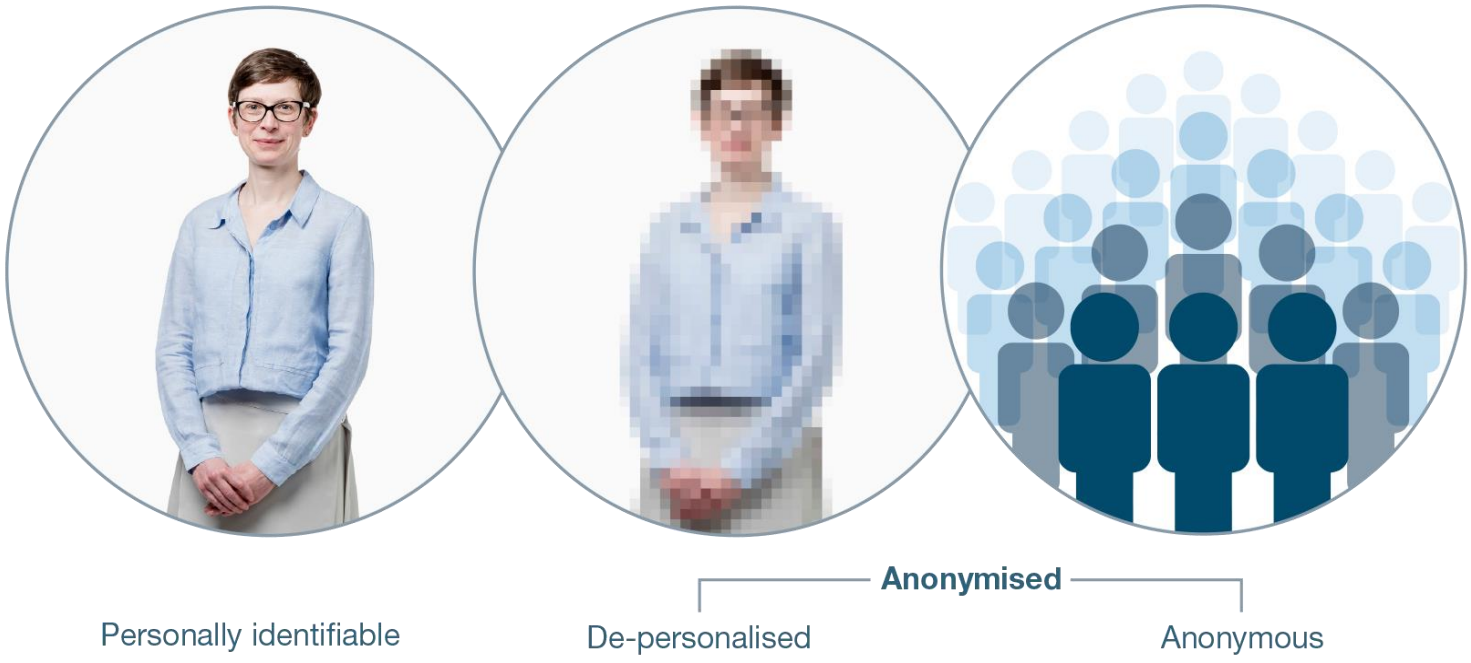
Individual care

“Secondary” uses



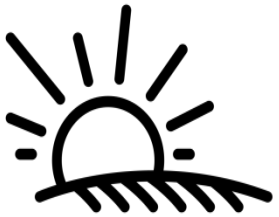
Improving health, care and services through research and planning

Spectrum of identifiability



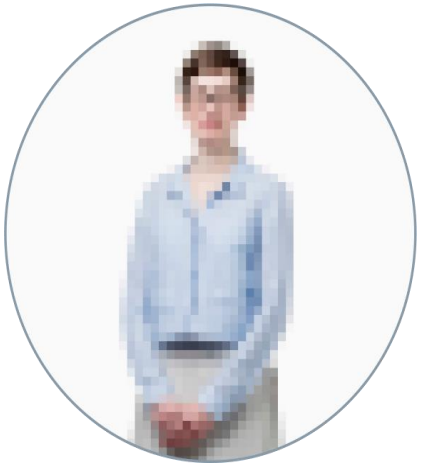
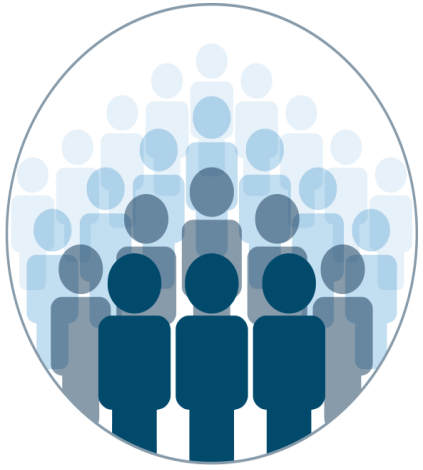
What's on the horizon for patient data?

- 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

hello@understandingpatientdata.org.uk

@Patient_Data