

Health Data in Practice lecture series

Patient data and data-driven technologies in health care: patient and public perspectives

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24th November 2020



Learning Objectives

At the end of this lecture on patient data and data-driven technologies in health care you will be able to

- Understand why transparency and maintaining trustworthiness in use of patient data is important
- Define the ‘five safes’
- Understand the diversity of public and patient perspectives
- Summarise the key themes underlying these perspectives
- Summarise key principles underlying trusted use of patient data
- Know how to access resources when communicating to patients/public on use of patient data

“What we have not done is take the public with us in these discussions, and we really need their views...We need to have the public with us on it, otherwise they will ...be unwilling to share [data] with the people to whom they turn for care. That is the last thing we want to happen in our health service”

Dame Fiona Caldicott, National Data Guardian

Trust and Transparency

Andrew Morris, Director of HDRUK has highlighted that of the 5 big issues in using patient data for research

- **Transparency and earning trust**
– is the biggest challenge of all!

Others are

- Scale
- Data quality
- Digital maturity of health systems and data
- Managing the “tidal wave” of data



Trust is easily lost



NEWS

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Cambridge Analytica: Facebook data row academic says he is 'scapegoat'

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Trust is easily lost

Care.data: a media disaster



2014

NHS to scrap single database of patients' medical details

Care.data scheme to close after Fiona Caldicott review calls for tougher measures to keep information confidential



▲ The Caldicott review said patients must know what their data may be used for and how they can opt out if they do not want it shared. Photograph: AW/Alamy

2016

The government's scheme to store patients' medical information in a single database, which ran into massive problems over confidentiality, is to be scrapped, NHS England has said.

NEWS

Technology

Google DeepMind NHS app test broke UK privacy law

3 July 2017



A UK hospital did not do enough to protect the privacy of patients when it shared data with Google, the UK's Information Commission (ICO) has ruled.

The ICO censured the Royal Free NHS Foundation Trust about data handed over during tests of a novel way to detect kidney injuries.

2017

NHS hands over patient records to Home Office for immigration crackdown

Number of government requests to access confidential non-clinical details rises threefold since 2014 in drive to track down immigration offenders



▲ Patient medical record files. More than 8,000 people's records have been handed to the Home Office for immigration enforcement. Photograph: Murdo Macleod/The Guardian

The confidential patient records of more than 8,000 people have been handed over by the NHS to the Home Office in the past year as part of its drive to track down immigration offenders.

A memorandum of understanding, published for the first time on Tuesday, makes clear that NHS digital is required by law to hand over non-clinical patient details including last known addresses, dates of birth, GP's details and date registered with doctor.

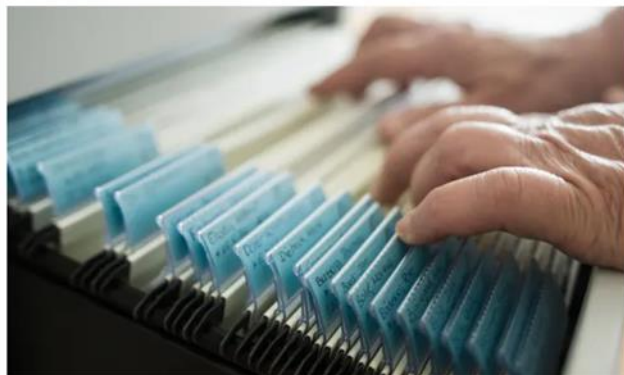
2017

Is the arm of the law long enough?

2018

Home Office scraps scheme that used NHS data to track migrants

Secret data-sharing deal dropped after legal action by Migrants' Rights Network



▲ The government agreed to suspend most of the data-sharing and limit use to tracing those involved who had committed serious crimes. Photograph: Alamy

The Home Office has abandoned a controversial “hostile environment” scheme using NHS data to track down patients believed to be breaching immigration rules.

In the face of a legal challenge brought by the Migrants' Rights Network, a memorandum of understanding between the Department of Health, NHS Digital and the Home Office is being scrapped.

2020

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Data protection

'Antiquated process': data regulator on obtaining Cambridge Analytica warrant

UK information commissioner calls for international approach to emerging threat

Alex Hern
@alexhern
Tue 24 Nov 2020 00.01 GMT

f t e 38

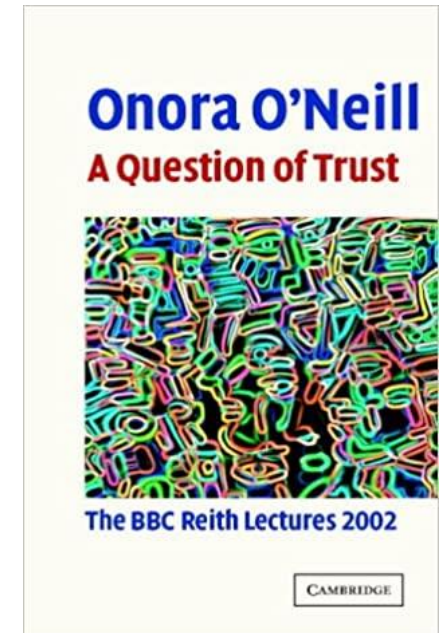
▲ Elizabeth Denham: 'At the end of three days and two different judges, I felt like I was in Hogwarts, going down the dark halls of the courthouse, looking for a seal for the warrant.' Photograph: Christopher Thomond/The Observer

The information commissioner has criticised the “antiquated process” that led to Facebook getting hold of Cambridge Analytica’s servers before the UK regulator itself, and renewed calls for an international approach to data privacy to tackle the emerging threat of data havens.

Trust and Trustworthiness

“Trust is valuable when placed in trustworthy agents and activities, but damaging or costly when (mis)placed in untrustworthy agents and activities. ... “

“...where we aim not to influence others, but to place and refuse trust intelligently we must link trust to trustworthiness, and must focus on evidence of honesty, competence and reliability”



Onora O'Neill (2018) *Linking Trust to Trustworthiness*, *International Journal of Philosophical Studies*, 26:2, 293-300, DOI: 10.1080/09672559.2018.1454637

“Say what you do, do what you say” What does transparency mean?

Transparency is

- important for creating trustworthy systems for data use.
- lets people understand what data you're holding or using, how it's managed, who is accountable for its protection and where they can find out more.
- a key principle of people's data rights under the GDPR/DPA 2018

In practice no common understanding of what transparency means

Understanding Patient Data highlight the following considerations in being transparent:

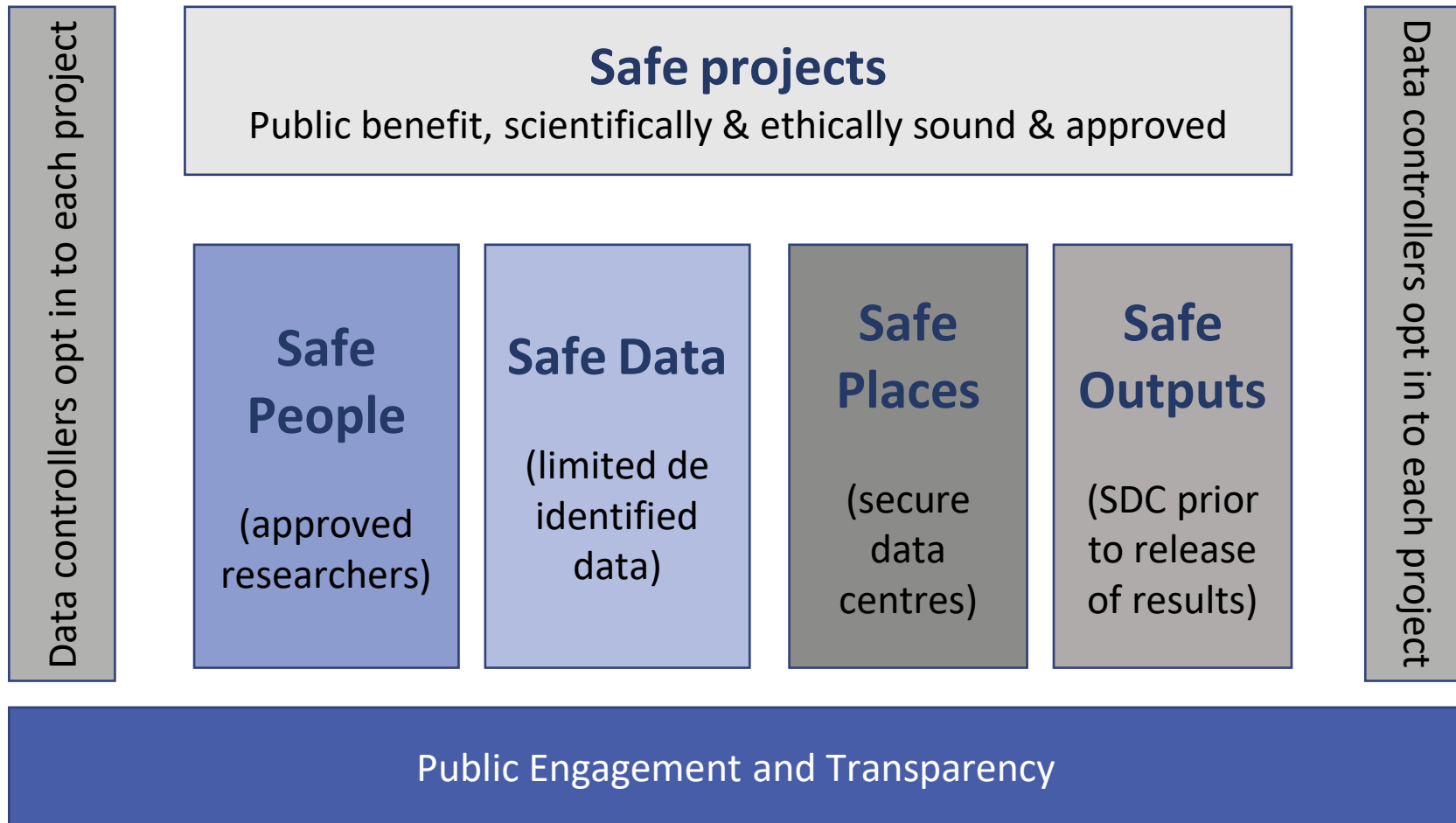
➤ **Content: What information should be provided?**

- Answer the right questions
- Be checkable, assessable
- Open, interoperable data

➤ **Context: How should information be conveyed?**

- Use the right language
- Provide accessible relevant information
- Embed this in organisational values and culture

The Five Safes



Diversity of Patient and Public Views and Understanding

- People do not have much spontaneous understanding about the range of ways patient data is used in health
- Most people support sharing patient data for individual care and a high proportion support sharing patient data for research where there is public benefit
- Key to support is knowing who has access to patient data and how it used
- People become more supportive of sharing patient data during the course of qualitative and deliberative studies
- The NHS is highly trusted compared to other organisations
- Support exists even though there are concerns
- Certain concerns are commonly held, some concerns differ between groups

Source: <https://understandingpatientdata.org.uk/how-do-people-feel-about-use-data>

Diversity of Patient and Public Views: some key themes

- Levels of **awareness** of how patient data is used
- **Acceptability** of using patient data
- **Trust** in those using patient data
- **Confidence** in using patient data
- **Concerns** about using patient data
- **Demographic differences** in attitudes
- Companies and patient data – **commercial uses**
- **Communicating** messages about the uses of patient data

Source: <https://understandingpatientdata.org.uk/how-do-people-feel-about-use-data>

Diversity of Patient and Public Views: key messages

1. Levels of awareness

- low awareness of how patient data is used beyond individual care
- low understanding of why companies need access to patient data
- a “gulf” exists between how people think the NHS is likely to use patient data and reality

2. Acceptability

- support for using patient data if it is for public benefit. This is key to the acceptability of using patient data beyond individual care

3. Trust

- The NHS is highly trusted compared to other organisations, commercial organisations least

4. Confidence

- There are concerns around the capability of the NHS to keep data secure but high trust in ability to protect patient data

5. Concerns

- The concerns people have include data security , accountability and data falling into “the wrong hands”

6. Demographic differences in attitudes

- Literature review found “no clear patterns by age, ethnicity, education level or SES emerged as to who was more favorable to data use” however some groups may be ‘seldom heard’

Source: <https://understandingpatientdata.org.uk/how-do-people-feel-about-use-data>

Diversity of Patient and Public Views: key messages

7. Communicating

- Communicating data linking “must explain the reasons for linking the data and the process of doing it very clearly” examples, visuals and diagrams are useful for understanding linkage.
- ... words used to describe patient data and its uses can be complex and confusing

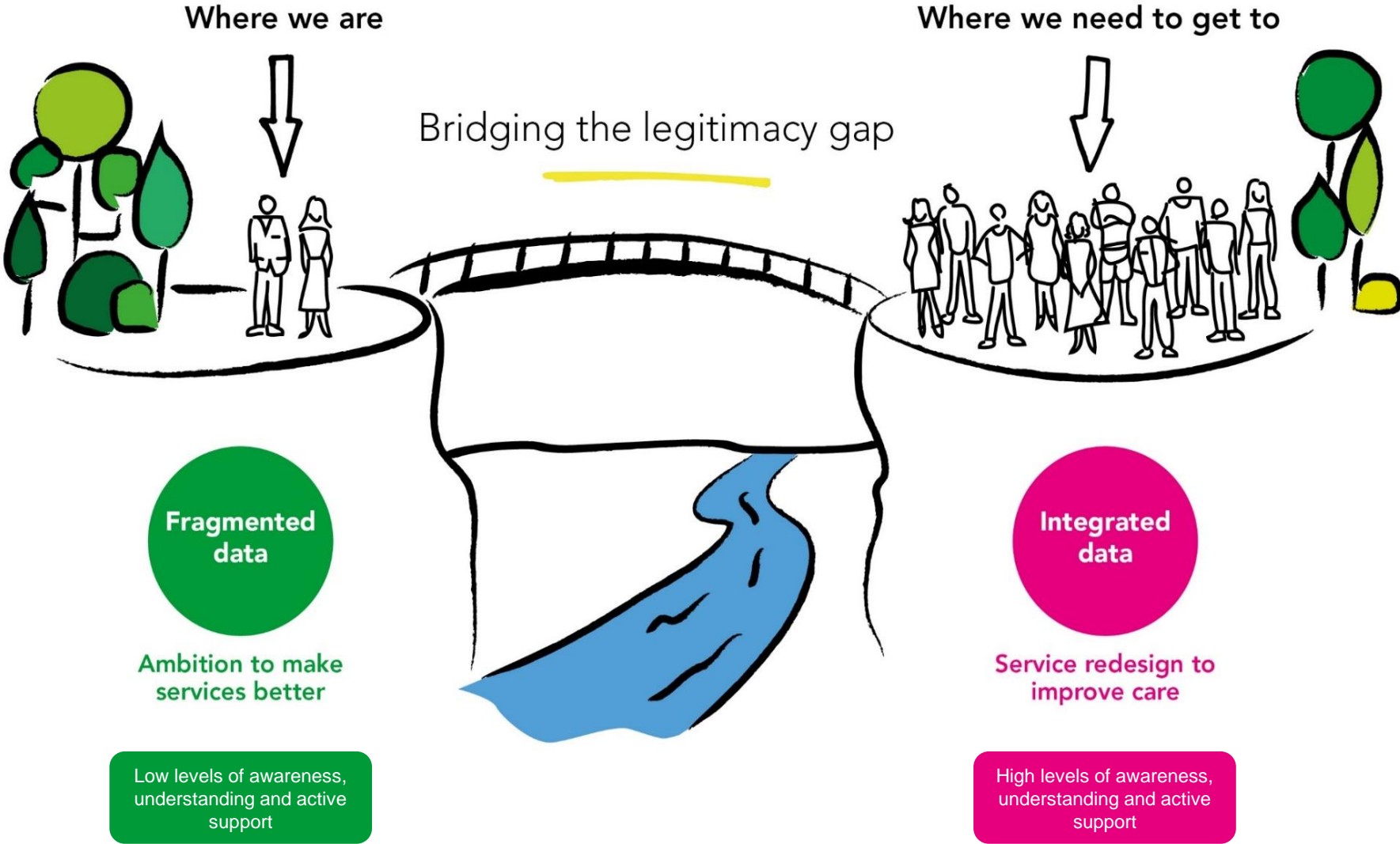
8. Commercial uses

- In many surveys, participants express concerns about companies using patient data
- If there is a public benefit people are more likely to accept access to patient data by companies
- Conditions people would like in place before companies can have access to patient data include:
 - strict rules so data cannot be passed to third parties (53%)
 - removing identifying information from data before it is accessed (52%)
 - sanctions and fines if companies misuse data (47%)
 - secure storage for data (47%).
- 17% of people in the one study¹ don't want companies accessing patient data for research **under any circumstances**. Their reasons focus on ideas around: harm to them or to their family; negative impacts to society

¹Wellcome The One Way Mirror: Public attitudes to commercial access to health data (2016)

BUILDING PUBLIC TRUST

In all cases though, we must take the public with us ... *and avoid a complacency about the desire for digital and information sharing*

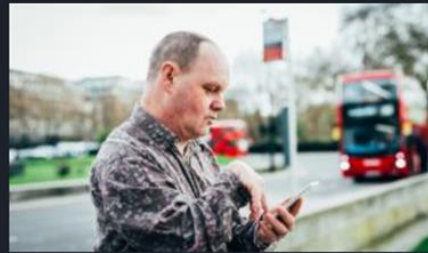




What's this all about?



What's happening now?



What are Londoners already saying?



ONE LONDON

Joining up Londoners' health and care

Citizens' Summit



Why is this important?

Do you have any questions?



Phase 1: Stakeholder Engagement & Co-design

Phase 2: Conversation and Deliberation

Phase 3: Awareness Campaign

Insights

1



Staff and stakeholder views



Use cases and patient stories



Public & professional reps co-design outcomes framework and design principles

2



Far reaching and inclusive dialogue to further explore issues and test assumptions. Mixed methodology – face to face and online engagement. Focus on both public and professional audiences

3



Deliberative process e.g. citizen assembly



Recommendations

Awareness campaign across public and professional audiences

Feb – Jul 2019

Aug 2019 - Mar 2020

Mar – Dec 2020

169 Londoners engaged, including heavy health and social care users, young people, migrants, homeless people, gypsy and traveller community, non-English speakers and those suffering domestic abuse

Cross cutting themes

Views corroborated with existing evidence:

- Assumption that data already linked
- Perceived social benefits of data use
- Limited understanding of secondary uses
- Concerns around commercial use of data

Views differed by attitudes about data, rather than by group or background characteristics:

- Data fundamentalists
- Data unconcerned
- Data pragmatists

Raised a range of concerns:

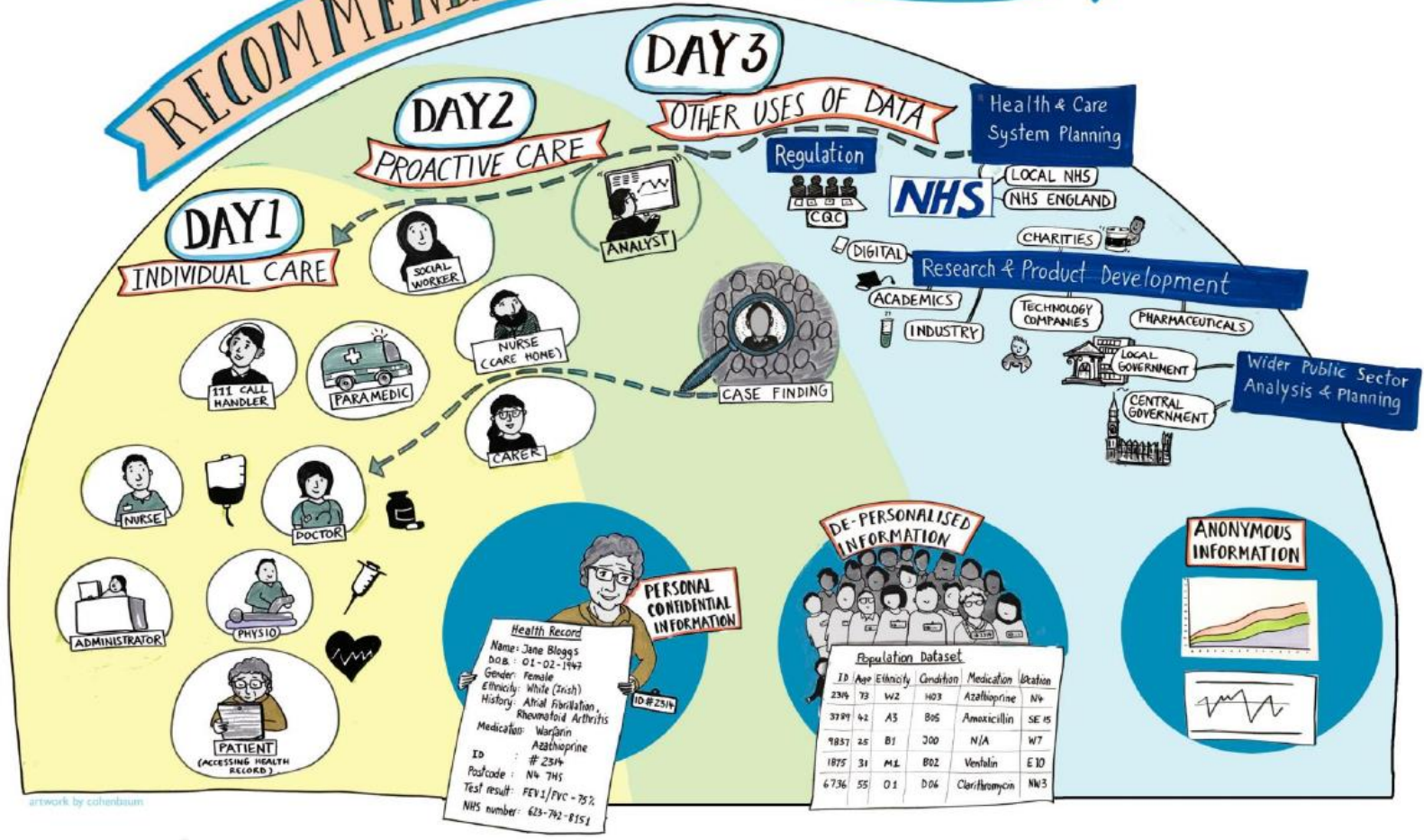
- Data access (for staff and patients)
- Consent and patient rights
- Feasibility of changes to how data is used

<https://onelondon.online/citizenssummit/>
<https://www.onelondon.online/wp-content/uploads/2020/07/Public-deliberation-in-the-use-of-health-and-care-data.pdf>



RECOMMENDATION FORMING

DAY 4



artwork by cohenissan



March 2016

The One-Way Mirror: Public attitudes to commercial access to health data

Report prepared for the Wellcome Trust

wellcome trust

April 2017

Public views of Machine Learning

Findings from public research and engagement
conducted on behalf of the Royal Society

Ipsos MORI

THE
ROYAL
SOCIETY



ETHICAL, SOCIAL, AND POLITICAL CHALLENGES OF ARTIFICIAL INTELLIGENCE IN HEALTH

A report with





Our data-driven future in healthcare

People and partnerships at the heart of health related technologies

Process

- A **programme of dialogue** by Ipsos MORI with patients, the public and healthcare professionals - to explore their views, hopes and concerns about use of data-driven technologies in the NHS.
- A **policy implications workshop** which discussed the findings of the dialogue programme amongst key stakeholders including NHS representatives, data controllers, funders, regulators, industry, and patient representatives.
- A **Steering Group** representing a breadth of expertise to review the evidence and develop the principles.
- Referring to **previous work and reports** by other organisations and aligning with ongoing work (e.g. DHSC Code of Conduct for data-driven technologies).
- **Stakeholder engagement** to ensure that the range of views of those involved in designing, deploying and using patient data and data-driven technologies are considered.

Principles

The project has developed five key principles. Each has a 'mission statement' and then further information underneath to guide the development, evaluation and use of data-driven technologies in line with the perspectives of patients, the public and healthcare professionals.



A. Purpose and value



B. Privacy and rights



C. Public engagement and partnership



D. NHS stewardship



E. Evaluation and regulation

Principles - what do they say?

There are five key principles. Each has a 'mission statement' and then more detailed principles underneath.

A. Purpose, value and benefits

Data-driven technologies should be designed and used for clearly defined purposes that uphold the social values of the NHS and benefit individuals, the NHS, or society.



B. Privacy, rights and choice

Data-driven technologies should be designed and used in ways and settings that respect and protect the privacy, rights and choices of patients and the public.



C. Public engagement and partnership

Those determining the purpose and uses of data-driven technologies should include patients and the public as active partners.



D. NHS data stewardship and responsibilities

The NHS, and those acting on its behalf, should demonstrate their continued trustworthiness by ensuring responsible and effective stewardship of patient data and data-driven technologies in the NHS.



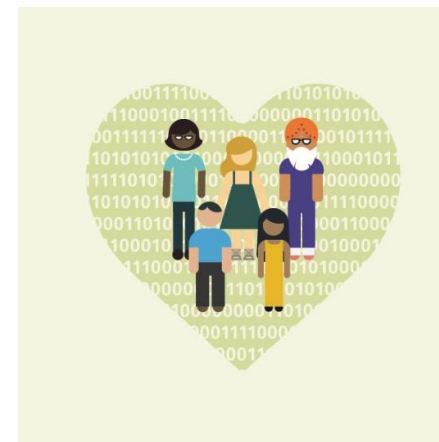
E. Evaluation and regulation

Data-driven technologies should be evaluated and regulated in ways that build understanding, confidence and trust, and guide their use in the NHS.



Our responsibilities

- Involving and actively partnering with patients and the public.
- Effective and accountable stewardship of patient data and data-driven technologies in the NHS
- Establishing robust processes for the evaluation, regulation and continued oversight of the use of patient data and data-driven technologies





March 2016

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A report with



UK Government code of conduct for data-driven health and care technology

Principle 1: Understand users, their needs and the context

Principle 2: Define the outcome and how the technology will contribute to it

Principle 3: Use data that is in line with appropriate guidelines for the purpose for which it is being used

Principle 4: Be fair, transparent and accountable about what data is being used

Principle 5: Make use of open standards

Principle 6: Be transparent about the limitations of the data used

Principle 7: Show what type of algorithm is being developed or deployed, the ethical examination of how the data is used, how its performance will be validated and how it will be integrated into health and care provision

Principle 8: Generate evidence of effectiveness for the intended use and value for money

Principle 9: Make security integral to the design

Principle 10: Define the commercial strategy

Source: <https://www.gov.uk/government/publications/code-of-conduct-for-data-driven-health-and-care-technology/initial-code-of-conduct-for-data-driven-health-and-care-technology>

Foundations of Fairness

- The research involved discussions with patient advocacy groups, three citizens' juries and a nationally representative survey of over 2,000 people.
- Headline survey results (*Based on nationally representative survey of 2095 people*)
 - 82% of people expect the NHS to publish information about data access partnerships
 - 74% of people believe the public should be involved in decisions about how NHS data is used
 - 81% of people believe benefits that come from partnerships should be distributed across the NHS
 - 63% of people are unaware that the NHS gives third parties access to data



Foundations of Fairness

- The research involved discussions with patient advocacy groups, three citizens' juries and a nationally representative survey of over 2,000 people.
- Accountability, transparency and public participation must be established for third-party use of NHS data
- The findings show that the public will only support third parties using NHS-held health data when there is benefit to patients across the UK, rather than short-term financial gain for the NHS.
- Benefits to patients includes things like improving disease detection or developing new medicines and treatments.
- While people recognise the potential benefits of health data being used by researchers, charities and industry, they have concerns about accountability and potential exploitation of the NHS by private companies.
- The majority (74%) want the public to be involved in decisions on how health data is used, and 82% want the NHS to publish information on who it is sharing data with.

Foundations of Fairness

Where next for NHS health data partnerships?

March 2020

 Understanding Patient Data

 Ada Lovelace Institute

Foundations of Fairness

Key findings

- All partnerships between NHS and third parties that include access to NHS data, must aim to improve health and care for everyone.
- Improvements to health must be prioritised over financial incentives, and should be distributed across the country, to prevent making health inequality worse.
- NHS bodies need support and guidance to negotiate fair terms for agreements with third parties.
- The public is concerned the NHS will be exploited by private companies. A single point of guidance and oversight should be established to set consistent rules across the NHS for third-party access to data.
- Public accountability, good governance and transparency are critical to maintain public confidence.
- People care about NHS data and should be able to find out how it is used.
- Decisions on third party access to NHS data should go through a transparent process and be subject to external oversight.
- The public should have a say in how NHS data is used.
- People should be involved in decisions about third party access to NHS data, because it is generated by their interactions with the health service.

Foundations of Fairness

Where next for NHS health data partnerships?

March 2020

 Understanding Patient Data

 Ada Lovelace Institute

www.understandingpatientdata.org.uk

 @Patient_Data



Understanding Patient Data



Using patient data could
help save lives



Patient data should be
kept safe and secure, to
protect privacy

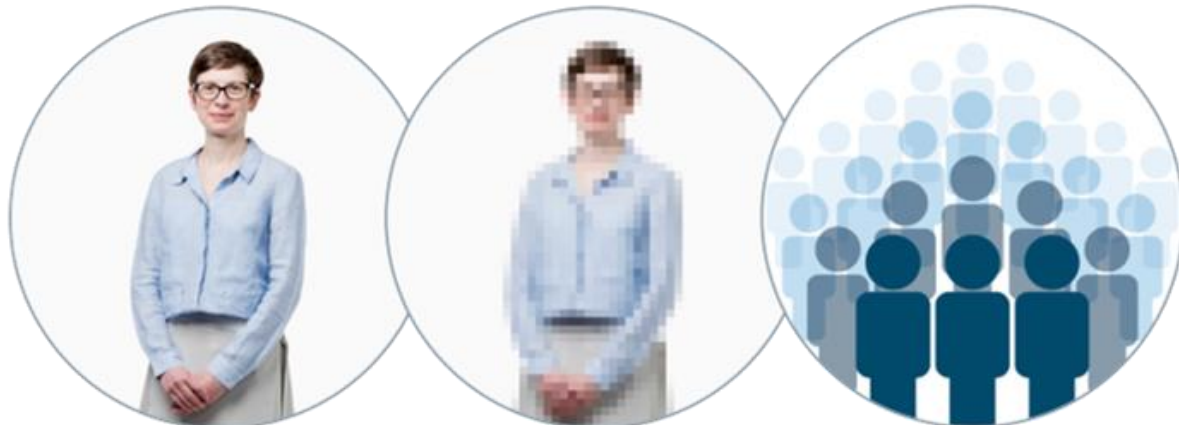
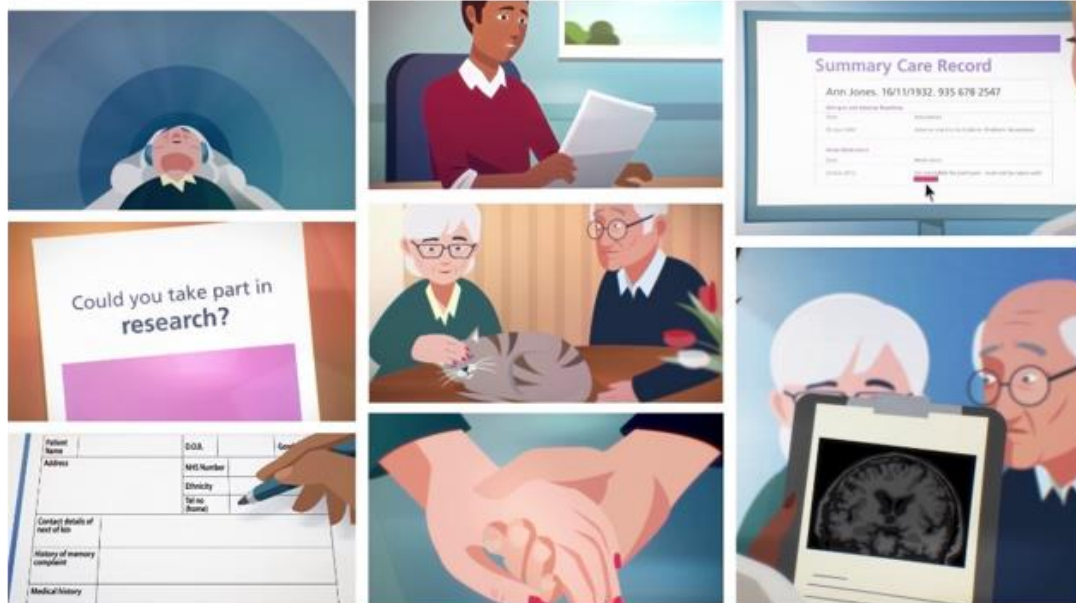


Everyone should be able
to find out about how
patient data is used

Toolkit: what people want to know



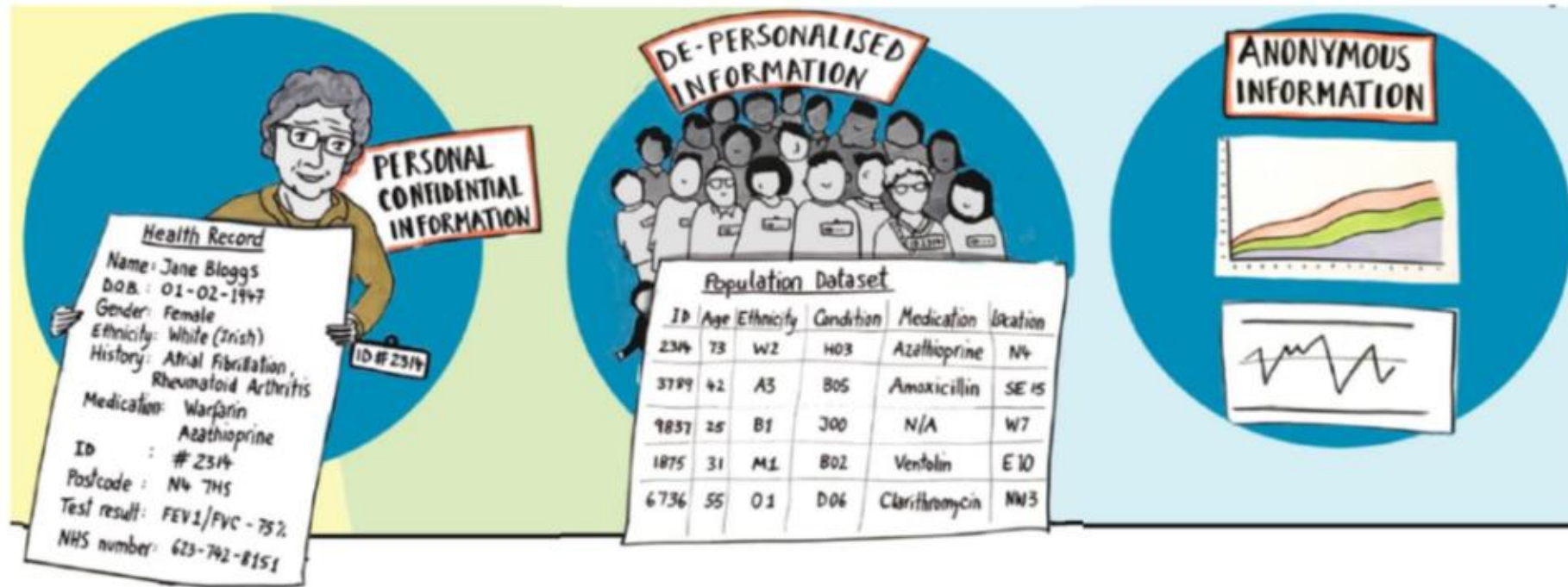
Resources



Understanding Patient Data

This work uses data provided by patients and collected by the NHS as part of their care and support.

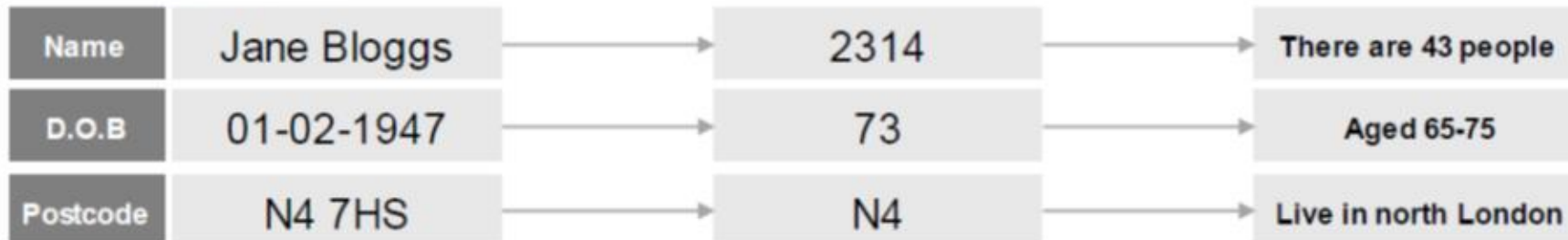
#datasaveslives



Health Record
 Name: Jane Bloggs
 DOB: 01-02-1947
 Gender: Female
 Ethnicity: White (Irish)
 History: Atrial Fibrillation, Rheumatoid Arthritis
 Medication: Warfarin, Azathioprine
 ID: # 2314
 Postcode: N4 7HS
 Test result: FEV1/FVC - 75%
 NHS number: 623-742-8151

Population Dataset

ID	Age	Ethnicity	Condition	Medication	Location
2314	73	W2	H03	Azathioprine	N4
3789	42	A3	B05	Amoxicillin	SE 15
9837	25	B1	J00	N/A	W7
1875	31	M1	B02	Ventolin	E 10
6736	55	O1	D06	Clarithromycin	NW3



What are you most excited about for health data in next 5 years?



Further reading

- Posted on QMPlus
- Slides will be available on QMPlus
- No assignment this week due to Turing Conference
- Next week's lecture on CoProduction will be given by Dr Meredith Hawking and will have an associated assignment