Understanding Patient Data

Public attitudes to patient data use

A summary of existing research

July 2018

How to use this slide deck

This deck summarises published literature on UK public attitudes towards the use of health and patient data for research purposes (as at July 2018).

Please feel free to use any of the findings and statistics referenced, but do credit them appropriately. Links to all reports and papers are in the **Appendix**.

Note the study context, scale and methodology when citing statistics. Figures alone can be misleading, and it is important to be aware of the questions asked, sample sizes and any methodological limitations.

Be wary of 'cherry-picking' statistics: there is no such thing as 'the public' and care should be taken when generalising about people's views. People's attitudes are rarely fixed and do not always represent particular demographics, or apply equally across different contexts.

How to use this slide deck

This deck was put together for those working in healthcare institutions, research and charities. The focus is on attitudes to current health and care data use in the UK.

Understanding Patient Data has been set up to support conversations with the public, patients and healthcare professionals about how health and care data is used. We hope this resource is clear and useful.

If you are aware of literature that could contribute to this deck please let us know at hello@understandingpatientdata.org.uk.

Summary

- 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 of people 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**.

- Using **real examples**, **being transparent** and **encouraging genuine dialogue** (rather than purely transmitting information) are ways in which organisations can **increase** their **trustworthiness**.

Overview of Key Themes

1. Levels of awareness of how patient data is used
Key messages

- There is low awareness of how patient data is used beyond individual care.

- There is a low understanding of why companies need access to patient data.

- People find it difficult to come up with "spontaneous ideas" as to how patient data might be used. [6]

- A **"gulf"** exists between how people think the **NHS** is likely to use patient data and **reality**. [14]

1. Levels of awareness of how patient data is used
The big picture

- Only **33%** of people have heard *a great deal* or *fair amount* about how the NHS uses health care data. [23]

- Awareness is even lower for how academic researchers (**18%**) and commercial organisations (**16%**) use health care data.[23]

- Only **25%** of people are aware of the NHS Genomics programme. [12,13]

- Two surveys found **80** and **82%** of the general public polled had not heard of the national cancer registry.[19]

- **1/3** of people are unaware that health and care records are not "readily shared" between health and care professionals.[13]

- There is little **"spontaneous understanding"** of "how and why healthcare data might be used".[6]

- Only **20%** of people feel sufficiently informed about how their data will be used, with more than half fearing that they might regret giving permission.[12]

1. Levels of awareness of how patient data is used
Commercial use of data

- One paper reports a **lack of understanding** around why the NHS would want or need to allow **commercial access** to data, or how companies contribute to healthcare. [23]

- "Relatively few people know much about how commercial organisations use [patient] data". [27]

- However, one paper describes that in **qualitative and deliberative research** participants are often **more aware than assumed** of the **role of commercialisation** in research[2]

1. Levels of awareness of how patient data is used
How data is used

- People **underestimate** what **data is collected** and used in healthcare, and there is "confusion about the specifics of data and data science in general. (e.g. the difference between anonymised versus identifiable data, or definition of aggregate data)". [23]

- There is **low awareness** and **understanding** of **data linkage** and people have few spontaneous ideas on how health data might link to other sources of data. [22, 24]

- There is **little understanding** of the status-quo around data **safeguards**.[23]

2. Acceptability of using patient data
key messages

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

- There is some evidence that acceptability varies between groups of people.

- Some studies show people become more supportive and accepting of the principle of sharing data during **deliberative discussions** exploring **patient data uses**.

- Acceptability and support depends on the **specifics of data uses**.

- Only a few examples of literature were found relating to acceptability of sharing patient data for **groups with specific health conditions** (asthma[5], cancer[7]).

2. Acceptability of using patient data
the big picture

- **Public benefit** is the **key condition** for people accepting patient data sharing. [20, 23, 5, 1]

- Support is high for **sharing data for individual patient care (96%)**, but less for **medical research (77%[25] 74%[14])**
  - These views vary and levels of support depend on the **nature of the research** and **levels of trust**.

- **80%** of people who were asked to imagine they had a health condition that affects their day-to-day life would *probably* or *definitely* like their **doctor to tell them about research** which would allow researchers confidential access to their medical records.[4]

2. Acceptability of using patient data *influences*

- In one study **17%** of people wouldn't want **commercial companies accessing** their health **data** for research at all

  - In the same study, sharing health data "for the **purposes** of **insurance** or **marketing** both face **significant resistance** from the public"

  - However, **61%** of people in the study would rather commercial companies access data than miss out on research benefits.[23]

- **94%** of people with **asthma** would **share anonymised data** with an **analytics company** to help develop tools for people at risk of an asthma attack.[5]

- When informed about the **cancer registry** and its uses **85%** of **people** with **cancer** and **72%** of the **general public** "believe the use of **cancer data** to improve services and treatments **outweighs** the **risk** to privacy and security".[7]

2. Acceptability of using patient data
How views may change

- Many members over the course of a **citizens' jury** became **more supportive** of information sharing for public benefit **in general,** even if they were less supportive about specific potential or planned uses of data that had been open to consideration.[8]

- During the course of **focus groups**, as participants became more informed, many found uses of data beyond individual care **more acceptable**, including commercial companies using patient data.[23]

- In two surveys of a similar size, **support** for health data being accessed by **commercial organisations** "undertaking health research" **dropped** between the survey published in 2016[23] and the survey published in 2018.[27]

3. Trust in those using patient data
key messages

- The **NHS** is **highly trusted** compared to other organisations.

- Generally, **GPs** and the **NHS** are trusted the most, followed by **academic researchers**.

- Across the literature questions about:
  - **who** has access,
  - for **what** purpose and **why**

  are uppermost in people's minds.

- **Commercial organisations** are **less trusted**.

- **94%** said whether or not they **trust** the organisation asking for their data is important in considering whether or not to share data. [28]

3. Trust in those using patient data
Who is trusted?

- **Trust** is **highest** in **GP surgeries** (where mentioned) and the **NHS**, followed by academic researchers.[18, 1, 16, 23]

- Most institutions are **trusted less with data** than they are trusted overall.[18]

- A systematic review shows **organisations** being **competent** (data security) and having the **right motivations** (public benefit) are both **key** to gain support for data sharing.[19]

- A review of published literature suggests that participants generally trust "**health care professionals** and **public sector researchers** with de-identified medical data" and **do not trust** "**government health agencies**" and "**commercial entities**". [10]

- In a European-wide survey, **24%** of UK respondents would **trust** medical **research charities** with **data** about them. [28]

4. Confidence in using patient data
Key messages

- Several surveys question **levels of confidence** around the **capability** of organisations to **safely manage data**.

- There are concerns around the **capability** of the **NHS** to **keep data secure**.

- There is some evidence of **differences in confidence** about data use across **different groups** of people.

- A **hacking scandal** can affect **confidence** in the ability of the NHS to handle data; but at the same time, there is **relatively high trust** in the ability of the NHS to **protect patient data**.

4. Confidence in using patient data
Data security

- **85%** of people in one survey knew about the Wannacry **hacking scandal** and **53%** said their **confidence** in the ability of the NHS to handle data was **negatively affected**.[12]

- In the same survey, **77%** said "they are **confident** in the ability of the **NHS** to **protect** their **patient data**."[12]

- **71.3%** share doubts the NHS can **guarantee security** of electronic health records (EHRs) whilst **53.5%** would still **support** development of national EHR.[19]

- **36%** are *very confident* and **44%** *fairly confident* that their data would be **secure** in health research their doctor suggests they take part in.[11]

5. Concerns in using patient data
Key messages

- People are **most concerned** about certain types of **sensitive patient data** (such as mental and sexual health data).

- Common concerns are around **security**, **misuse** and **causing harm**.

- There is **some evidence** that **some groups** of people **feel more powerless** than others in the face of concerns.

5. Concerns in using patient data
The big picture

- The concerns people have include **data security**, **accountability** and data falling into **"the wrong hands"**.[21]
- **Concerns** around (general) personal data collection/use include:
  - that personal data **inaccuracies** may be **hard to correct**
  - the risk that the NHS may use data to **discriminate** by **prioritising** some patients for treatment over others either now or in the future.[24]
- **Perceived risks** to sharing **EHR** data include:
  - **security** (hacking, leaking, loss, unauthorised access)
  - **misuse** (identity theft, financial gain)
  - **harm** (insurance costs, disadvantaging groups, re-identification, 'social discomfort and community embarrassment').[19]
- **Concerns** about sharing anonymised medical records and genetic data include:
  - **trust,**
  - the **nature of the research**,
  - **not knowing enough** about research (especially for genetic information).[25]

5. Concerns in using patient data
The big picture

- **53%** of people are **more aware** of **data security** issues than they were three years ago and **57%** of people are **more concerned** with **how** their **data** is being **used** in general.[12]

- Sharing **sensitive data** (mental health, sexual health, sexuality, religion) holds **greater concern** than for other types of data.[3]

- **Young people** are **more aware** of data security issues, yet **55%** of those aged 18-34 compared to **62%** of those aged 55 and older are **concerned**.[12]

- People who are concerned about privatisation often conflate it with using patient data beyond individual care. **Older people** tend to be **more concerned** about **privatisation** than other age groups.[6]

6. Demographic differences in attitudes
key messages

- **Certain concerns** about patient data are **commonly held,** some concerns **differ** between **groups**.

- Perceptions of the benefits of sharing patient data, and confidence in sharing patient data, may differ between groups.

- Some examples show demographic differences in attitudes within studies

- Despite this, a literature review on using data from Electronic Health Records (EHR) found "**no clear patterns** by age, ethnicity, education level or SES emerged as to who was more favourable to data use."[10]

6. Demographic differences in attitudes
awareness and acceptability

- **Younger people** are more **"familiar"** with **'Big Data'** and could more easily **think of benefits** to using healthcare data.[6]

- **Young people** are more **supportive** of access to **electronic patient records** to improve health service **administration** and for **research** (for medicines and improved health) than for other reasons.[21]

- **36%** of people are *very confident* and **44%** *fairly confident* that their data would be **secure** in **health research** their **doctor** suggests they take part in, however:
  - Confidence is **highest** in the age range **15-34** and decreases with age
  - **26%** of people from **ethnic minority** groups were **very confident**, compared to **37%** of **white people**.[11]

- People grouped by social grade as **ABC1** are more likely than people grouped as **C2DE** to consider that **health data** offers potential **benefits** to **society**.[24]

6. Demographic differences in attitudes

concerns

- People grouped by social grade as **C2DE** were seen to feel **more powerless** to deal with **consequences** of **personal data harms** than people in other socio-economic groups;[24]

- In the same study, people were resistant to the idea of **message targeting** at the **individual level** due to data linking, and to the **risk** of being **blamed** or **"told off"**. The study said **lower socio-economic groups** "can feel particularly defensive". [24]

- For **young people**, the **acceptability** of **Electronic Patient Records** relates to:

- **who has access** to their record

- *having a say* in who else has access

- **privacy** from certain groups (e.g. parents)

- **being kept up to date** on the system, security and safety

- **knowing who is accessing their record**, why and what this might mean.[21]

7. Public attitudes to Electronic Health Records (EHRs)
Key messages

- A systematic review found **conflicting findings** between studies by **age range**, **education level** and **ethnicity group**. It was not possible to conclude if specific groups had "an **overall negative** or **positive attitude** towards the **sharing** of **EHRs** for secondary purposes such as **research**".[19]

- In the same study **71.3%** share **doubts** the NHS can guarantee security of EHRs whilst **53.5%** would still **support development** of national EHR.[19]

- It also shows reported **public support** for **EHRs** varied between qualitative studies, with different studies reporting levels of support at **62.5%**, **62.47%** and **81%**. [19]

8. Attitudes to accessing one's own patient data
Key messages

- In one report, **80%** of patients polled would like to **view** their **medical records online**.

  - When only **2%** of the population report "any digitally enabled transactions with the NHS".

  - And only **4%** of GP practices offer online health care record access to their patients, when over **96%** of GP practices have installed "digital clinical record systems". [26]

- **92%** of **adults** and **97%** of **young people** supported patient access to their own records.[14]

9. Communicating messages about the uses of patient data
Key messages

- Research and researchers are more likely to be **"perceived as trustworthy"** if **transparent**, **open dialogue** is held with the public, rather than just dissemination of information.[2]

- **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.[22]

- Research commissioned by UPD found the **words** used to **describe patient data** and its uses can be **complex** and **confusing**. Guidance on words to use which are accurate, meaningful and accessible can be found on our [website]. [29]

Appendix

1. Administrative Data Research Centre Northern Ireland, Access Research Knowledge (ARK), *Public attitudes to data linkage and sharing* (2017)

Aim: "To capture a baseline of public attitudes in Northern Ireland towards data linkage and sharing which can then be reassessed at intervals to measure changes in public trust and understanding."

Sample/method: A survey of 1,200 people (Northern Ireland Life and Times survey - subset on data sharing), interviews

URL: https://ijpds.org/article/view/320; http://www.ark.ac.uk/publications/updates/update108.pdf; http://www.ark.ac.uk/events/datasharingsep16.pdf

2. Aitken. M, Cunningham-Burley. S, Pagliari. C, *Moving from trust to trustworthiness: Experiences of public engagement in the Scottish Health Informatics Programme* (2016)

Aim: "to explore perceptions of the role, relevance and functions of trust (or trustworthiness) in relation to research practices."

Sample/method: Eight focus groups and a stakeholder workshop

URL: https://doi.org/10.1093/scipol/scv075

3.   Aitken. M, St.Jorre. J, Pagliari. C, Jepson. R, Cunningham-Burley. S, *Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies* (2016)

Aim: "[to bring together] a timely review of current evidence"

Sample/method: systematic review

URL: https://doi.org/10.1186/s12910-016-0153-x

4.   Association of Medical Research Charities, *Public support for research in the NHS* (2011)

Aim: To investigate public support for research in the NHS.

Sample/method: 990 interviews

URL: https://www.ipsos.com/ipsos-mori/en-uk/public-support-research-nhs

5.   Asthma UK, *Data sharing and technology: Exploring the attitudes of people with asthma* (2018)

Aim: to ask people with asthma about their attitudes to sharing their patient data for research and service improvement, and about the use of new technology and data in their asthma care.

Sample/method: A survey of 3,000 people

URL: https://www.asthma.org.uk/datareport

6. British Medical Association, *Secondary Uses of Healthcare Data Public Workshop Debrief* (2015)

Aim: "to know more about public awareness and understanding of secondary uses of healthcare data, and what concerns the public have over the sharing of healthcare data for secondary purposes."

Sample/method: Three workshops (one public, two BMA members)

URL: https://www.bma.org.uk/collective-voice/policy-and-research/ethics/secondary-uses-of-data/public-workshop

7. Cancer Research UK and Macmillan Cancer Support *Improving awareness of the English cancer registry amongst patients, health professionals and the public* (2016)

Aim: "to specifically consider how people with cancer can best be informed about cancer registration"

Sample/method: Two surveys of over 2,000 people (1,400 people with cancer, 1,000 general public, 340 health professionals) and 20 cancer charities, nine engagement events

URL: https://www.macmillan.org.uk/documents/policy/improving-awareness-of-the-english-cancer-registry.pdf

8.   Connected Health Cities *Connected Health Cities Citizens' Juries Report* (2017)

Aim: "to understand better how the public balances [the] competing goals [of improved care and health services and protecting individual's privacy]" around planned and potential uses of data.

Sample/method: 36 people in two citizens juries

URL: https://www.connectedhealthcities.org/what-is-a-chc/public-engagment/citizens-juries-chc/citizens-juries/

9.   Economic and Social Research Council and Office for National Statistics *Dialogue on data: Exploring the public's views on using administrative data for research purposes* (2014)

Aim: "to explore public understanding and views of administrative data and data linking"

Sample/method: 136 people including 20 experts in seven sets of workshops

URL: https://esrc.ukri.org/files/public-engagement/public-dialogues/dialogue-on-data-exploring-the-public-s-views-on-using-linked-administrative-data-for-research-purposes/

10.   Ford. E, Stockdale. J, Jackson. R, Cassell. J *For the greater good? Patient and public attitudes to use of medical free text data in research* (2017)

Aim: "a review of the literature on patient and public understanding and attitudes towards the use of patients' medical data for research, particularly seeking views on free text".

Sample/method: Systematic search

URL: https://doi.org/10.23889/ijpds.v1i1.249

11. Health Research Authority and National Institute for Health Research *Survey of the general public: attitudes towards health research* (2017)

Aim: "to understand the range of opinions held by the public about health research"

Sample/method: Over 1,000 interviews

URL: https://www.hra.nhs.uk/about-us/news-updates/blog-what-public-thinks-research-and-why-it-matters/

12. Healthwatch England *How do people feel about their data being shared by the NHS?* (2018)

Aim: "to understand more about people's attitudes towards how their data is used"

Sample/method: A survey of 2,000 people

URL: https://www.healthwatch.co.uk/news/how-do-people-feel-about-their-data-being-shared-nhs

13. Healthwatch Surrey (2015) *If I've told you once …. People's views on record sharing between the health and care professionals involved in their care in Surrey*

Aim: "[to investigate] the views of people in Surrey around sharing of health and care records between the health and care professionals involved in their care"

Sample/method: A survey of 577 people

URL: https://www.healthwatchsurrey.co.uk/wp-content/uploads/2017/06/If-Ive-told-you-once-Peoples-views-on-record-sharing-between-health-and-social-care-professionals-FULL-REPORT.pdf

14. New Economics Foundation *Who Sees What: Exploring public views on personal electronic health records* (2010)

Aim: "how [people] understand the Health Service's obligation to safeguard their privacy"

Sample/method: 6,000 people consulted through deliberative events, public consultation stalls, classroom activities

URL: https://neweconomics.org/uploads/files/2cb17ab59382fe7c67_bfm6bdoas.pdf

15. NHS Digital *NHS Digital poll on patient data and confidentiality* (2018)

Aim: to poll views on sharing NHS patient address data for the investigation of crime.

Sample/method: 2,000 telephone interviews

URL: https://digital.nhs.uk/news-and-events/latest-news/nhs-digital-statement-on-health-select-committees-report-into-patient-data-sharing

16. Open Data Institute *Attitudes towards data sharing* (2018)

Aim: "revealing current attitudes of British adults online towards sharing personal data"
Sample/method: A survey of 2,000 people

URL: https://theodi.org/article/odi-survey-reveals-british-consumer-attitudes-to-sharing-personal-data/

17. RAND Europe *Privacy of health records Europeans' preferences on electronic health data storage and sharing* (2015)

Aim: "to quantify citizens' views on privacy and security issues in three real-life scenarios: travelling by train or metro, choosing an internet service provider and storing personal health data"

Sample/method: A survey of 26,000 EU27 citizens

URL: https://www.rand.org/pubs/research_briefs/RB9843z3.html

18. Royal Statistical Society *Public attitudes to the use and sharing of their data* (2014)

Aim: "to get a snapshot of public trust in institutions handling their data, and attitudes toward data linkage and data privacy"

Sample/method: 2,019 people polled

URL: https://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons-for-policymakers
http://www.statslife.org.uk/images/pdf/rss-data-trust-data-sharing-attitudes-research-note.pdf
https://www.statslife.org.uk/files/perceptions_of_data_privacy_charts_slides.pdf

19. Stockdale. J, Cassell. J and Ford. E, *"Giving something back": A systematic review and ethical enquiry of public opinions on the use of patient data for research in the United Kingdom and the Republic of Ireland* (2018)

Aim: "[we] aimed to systematically review the literature on UK and Irish public opinions of medical data use in research"

Sample/method: systematic review

URL: https://wellcomeopenresearch.org/articles/3-6/v2

20. Tully. MP, Bozentko. K, Clement. S, Hunn. A, Hassan. L, Norris. R, Oswald. M, Peek. N *Investigating the Extent to Which Patients Should Control Access to Patient Records for Research* (2018)

Aim: "The aim of this project was to extend knowledge about what control informed citizens would seek over the use of health records for research after participating in a deliberative process using citizens' juries."

Sample/method: Two three-day citizens juries

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URL: http://www.jmir.org/2018/3/e112/

21. The Royal Academy of Engineering *Privacy and prejudice: Young people's views on the development and use of Electronic Patient Records* (2010)

Aim: "to gather the views and disseminate the findings to the relevant stakeholders and policy makers to give young people a voice regarding the development of…the EPR system."

Sample/method: National public engagement programme 'Breathing Country' about Electronic Patient Records and their use in medical research. Electronic polling, focus groups, a two-day deliberative conference and a community researchers activity.

URL: https://www.raeng.org.uk/publications/reports/privacy-and-prejudice-views

22. UCL *Public attitudes to data linkage* (2018)

Aim: "to explore people's understanding and perceptions of data linkage, particularly linkage between health examination survey data and administrative records."

Sample/method: Three deliberative discussion groups

URL: http://www.natcen.ac.uk/our-research/research/public-attitudes-to-data-linkage/

23. Wellcome *The One-Way Mirror: Public attitudes to commercial access to health data* (2015)

Aim: "to understand how attitudes towards commercial access to health data are formed and influenced, among a cross-section of the British general public and with specific audiences such as healthcare professionals, patients, and members of cohort studies."

Sample/method: 16 workshops with 246 people, including general public, GP's and hospital doctors and people with a long term condition

URL: https://wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf

24. Wellcome *Summary Report of Qualitative Research into Public Attitudes to Personal Data and Linking Personal Data* (2013)

Aim: "to understand the general public's attitudes to different types of personal data and data linking."

Sample/method: Six 90 minute focus groups and six 45 minute telephone interviews including 50 people from socio-economic groups ABC1 and C2DE

URL: https://wellcome.ac.uk/sites/default/files/wtp053205_0.pdf

25. Wellcome *Wellcome Trust Monitor Report Wave 3* Chapter 6 (2015)

Aim: "[examines public] willingness to allow their medical records, and genetic information, to be used in medical research studies, and what concerns they may have about this."

Sample/method: 1,524 interviews

URL: https://wellcome.ac.uk/sites/default/files/monitor-wave3-full-wellcome-apr16.pdf

26. Nuffield Trust *Delivering the benefits of digital healthcare* (2016)

Aim: "set out the possibilities to transform health care offered by digital technologies"

Sample/method: Literature and evidence review, 40 interviews, survey of a panel of NHS leaders

URL: https://www.nuffieldtrust.org.uk/files/2017-01/delivering-the-benefits-of-digital-technology-web-final.pdf

27. The Health Foundation, the Institute for Fiscal Studies, The King's Fund and the Nuffield Trust (2018) *What will new technology mean for the NHS and its patients?*

Aim: "[to] question how the NHS should prepare for… technological advances"

URL: https://www.kingsfund.org.uk/sites/default/files/2018-06/NHS_at_70_what_will_new_technology_mean_for_the_NHS_0.pdf

28. Open Data Institute (2018) *Who do we trust with personal data?*

Aim: Investigate attitudes to data sharing (Europe-wide)

Sample/method: A survey of 2,000 people

URL: https://theodi.org/article/who-do-we-trust-with-personal-data-odi-commissioned-survey-reveals-most-and-least-trusted-sectors-across-europe/

29. Understanding Patient Data (2017) *Patient Data: Finding the best set of words to use*

Aim: "To come up with a set of words [to describe patient data] …which are simple, clear and accurate to help build trust and understanding"

Sample/method: Workshop, expert review, 12 focus groups with the public and health professionals

URL: http://understandingpatientdata.org.uk/sites/default/files/2017-04/Data%20vocabulary_Good%20Business%20report%20March%202017_0.pdf