Public attitudes toward the use of patient data

Aug 2021- Sept 2024

Understanding Patient Data

This deck lists the main research into UK public attitudes towards the use of health and patient data between August 2021 and September 2024.

Use this deck to find studies relevant to your work.

Let us know if there's something we should add by emailing hello@understandingpatientdata.org.uk.

Remember, care should be taken when generalising about people's views. People's attitudes are rarely fixed and do not apply equally across different groups, times and contexts.

Patient Perceptions on Data Sharing and Applying Artificial Intelligence to Health Care Data: Cross-sectional Survey

2021

What Happened?

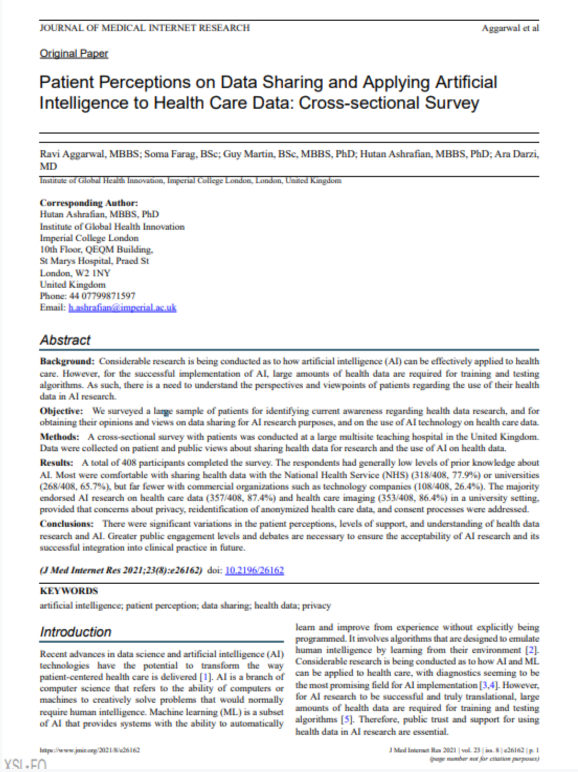
- Patients from across a multi-site UK hospital were surveyed about their views on the use of healthcare data for Artificial Intelligence (AI) research
- 408 respondents completed paper-based questionnaires

What were the main issues covered?

- Patients' views on their health data being used to support AI research
- Awareness of the use of health data by universities, the NHS and private companies
- Patients' views on anonymised health data sets for AI research purposes

Findings:

- Most respondents knew little about AI
- Most were comfortable with sharing their health data with the NHS and university researchers, but far fewer with commercial organisations
- Most supported health data being used for AI research by universities provided concerns about privacy, consent and reidentifications are addressed.
- The complete findings are [available online]



Original Paper

Patient Perceptions on Data Sharing and Applying Artificial Intelligence to Health Care Data: Cross-sectional Survey

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Abstract

Background: Considerable research is being conducted as to how artificial intelligence (AI) can be effectively applied to health care. However, for the successful implementation of AI, large amounts of health data are required for training and testing algorithms. As such, there is a need to understand the perspectives and viewpoints of patients regarding the use of their health data in AI research.

Objective: We surveyed a large sample of patients for identifying current awareness regarding health data research, and for obtaining their opinions and views on data sharing for AI research purposes, and on the use of AI technology on health care data.

Methods: A cross-sectional survey with patients was conducted at a large multisite teaching hospital in the United Kingdom. Data were collected on patient and public views about sharing health data for research and the use of AI on health data.

Results: A total of 408 participants completed the survey. The respondents had generally low levels of prior knowledge about AI. Most were comfortable with sharing health data with the National Health Service (NHS) (318/408, 77.9%) or universities (268/408, 65.7%), but far fewer with commercial organizations such as technology companies (108/408, 26.4%). The majority endorsed AI research on health care data (357/408, 87.4%) and health care imaging (353/408, 86.4%) in a university setting, provided that concerns about privacy, reidentification of anonymized health care data, and consent processes were addressed.

Conclusions: There were significant variations in the patient perceptions, levels of support, and understanding of health data research and AI. Greater public engagement levels and debates are necessary to ensure the acceptability of AI research and its successful integration into clinical practice in future.

(J Med Internet Res 2021;23(8):e26162) doi: 10.2196/26162

KEYWORDS

artificial intelligence; patient perception; data sharing; health data; privacy

Introduction

Recent advances in data science and artificial intelligence (AI) technologies have the potential to transform the way patient-centered health care is delivered [1]. AI is a branch of computer science that refers to the ability of computers or machines to creatively solve problems that would normally require human intelligence. Machine learning (ML) is a subset of AI that provides systems with the ability to automatically learn and improve from experience without explicitly being programmed. It involves algorithms that are designed to emulate human intelligence by learning from their environment [2]. Considerable research is being conducted as to how AI and ML can be applied to health care, with diagnostics seeming to be the most promising field for AI implementation [3,4]. However, for AI research to be successful and truly translational, large amounts of health data are required for training and testing algorithms [5]. Therefore, public trust and support for using health data in AI research are essential.

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NHS AI Lab Public Dialogue on Data Stewardship

2022

What Happened?

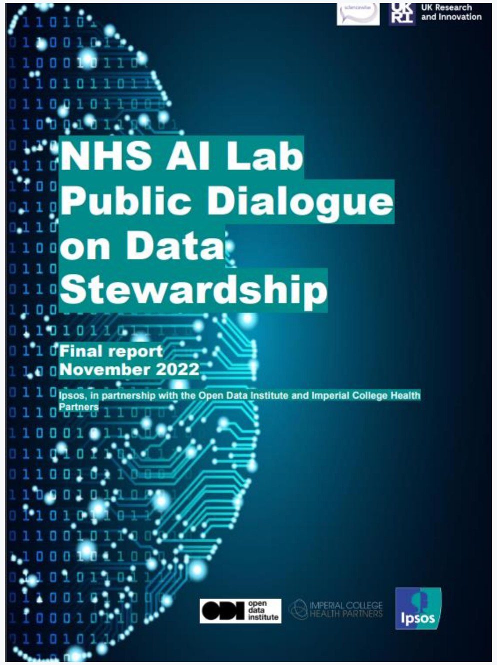
- The NHS AI Lab and the Sciencewise programme commissioned and co-funded a public dialogue regarding attitudes towards data stewardship concerning access to health data for AI research
- 47 participants from across the UK took part in 4 online workshops in July 2022, facilitates by Ipsos, along with Open Data Institute and Imperial College Health Partners

What were the main issues covered?

- Participants' views towards different data stewardship models, including delegated, collective, and individual decision-making mechanisms

Findings:

- Participants supported a combination or blend of complementary stewardship models as no single one is perfect
- Participants were generally supportive of giving individuals choice about their involvement, while also acknowledging the value of specialist expertise
- Participants emphasised the importance of any decision-making process being inclusive, representative and accessible to all
- Ultimately, participants wanted to see patients' and publics' best interests at the heart of decision-making
- The complete findings are available online



NHS AI Lab Public Dialogue on Data Stewardship

Final report
November 2022

Ipsos, in partnership with the Open Data Institute and Imperial College Health Partners

Public opinion on sharing data from health services for clinical and research purposes without explicit consent: an anonymous online survey in the UK

2022

What Happened?

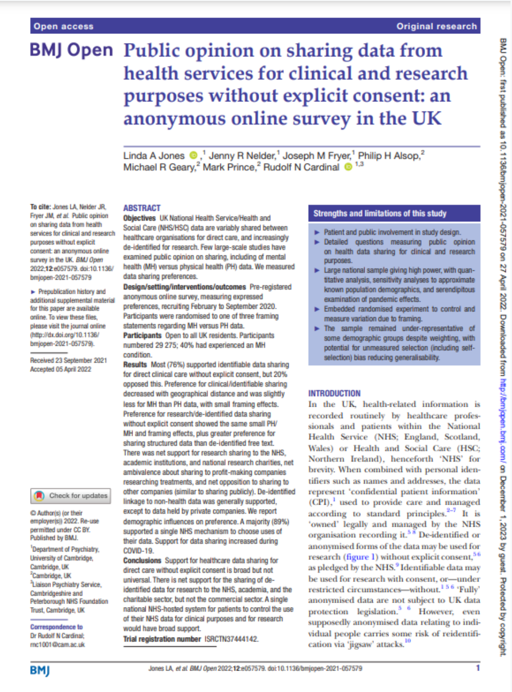
- Researchers at University of Cambridge conducted an online survey to examine public views on data sharing dependent on several different factors
- Approximately 29,000 UK residents took part in the survey

What were the main issues covered?

- Participants' views on identifiable data sharing without consent for individual clinical care
- The difference in attitudes surrounding mental health vs physical health data sharing
- Attitudes towards sharing data with public health bodies vs for academic research or commercial purposes

Findings:

- Around three-quarters of participants were in support of identifiable data sharing without consent for individual clinical care
- Net support for sharing with NHS, academic institutions, and research charities; net ambivalence for sharing with profit-making companies researching treatments; net opposition to sharing to other companies
- Nearly 90% of people supported a single NHS mechanism to choose uses of their data
- People were slightly less willing to share identifiable mental health data than physical health data for direct clinical care
- Support for data sharing increased during Covid-19
- The complete findings are available online



Open access Original research

BMJ Open

Public opinion on sharing data from health services for clinical and research purposes without explicit consent: an anonymous online survey in the UK

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► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2021-057579).

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ABSTRACT

Objectives UK National Health Service/Health and Social Care (NHS/HSC) data are variably shared between healthcare organisations for direct care, and increasingly de-identified for research. Few large-scale studies have examined public opinion on sharing, including of mental health (MH) versus physical health (PH) data. We measured data sharing preferences.

Design/setting/interventions/outcomes Pre-registered anonymous online survey, measuring expressed preferences, recruiting February to September 2020. Participants were randomised to one of three framing statements regarding MH versus PH data.

Participants Open to all UK residents. Participants numbered 29 275; 40% had experienced an MH condition.

Results Most (76%) supported identifiable data sharing for direct clinical care without explicit consent, but 20% opposed this. Preference for clinical/identifiable sharing decreased with geographical distance and was slightly less for MH than PH data, with small framing effects. Preference for research/de-identified data sharing without explicit consent showed the same small PH/MH and framing effects, plus greater preference for sharing structured data than de-identified free text. There was net support for research sharing to the NHS, academic institutions, and national research charities, net ambivalence about sharing to profit-making companies researching treatments, and net opposition to sharing to other companies (similar to sharing publicly). De-identified linkage to non-health data was generally supported, except to data held by private companies. We report demographic influences on preference. A majority (89%) supported a single NHS mechanism to choose uses of their data. Support for data sharing increased during COVID-19.

Conclusions Support for healthcare data sharing for direct care without explicit consent is broad but not universal. There is net support for the sharing of de-identified data for research to the NHS, academia, and the charitable sector, but not the commercial sector. A single national NHS-hosted system for patients to control the use of their NHS data for clinical purposes and for research would have broad support.

Trial registration number ISRCTN37444142.

Strengths and limitations of this study

- ► Patient and public involvement in study design.
- ► Detailed questions measuring public opinion on health data sharing for clinical and research purposes.
- ► Large national sample giving high power, with quantitative analysis, sensitivity analyses to approximate known population demographics, and serendipitous examination of pandemic effects.
- ► Embedded randomised experiment to control and measure variation due to framing.
- ► The sample remained under-representative of some demographic groups despite weighting, with potential for unmeasured selection (including self-selection) bias reducing generalisability.

INTRODUCTION

In the UK, health-related information is recorded routinely by healthcare professionals and patients within the National Health Service (NHS; England, Scotland, Wales) or Health and Social Care (HSC; Northern Ireland), henceforth 'NHS' for brevity. When combined with personal identifiers such as names and addresses, the data represent 'confidential patient information' (CPI),[1] used to provide care and managed according to standard principles.[2–7] It is 'owned' legally and managed by the NHS organisation recording it.[5 8] De-identified or anonymised forms of the data may be used for research (figure 1) without explicit consent,[5 6] as pledged by the NHS.[9] Identifiable data may be used for research with consent, or—under restricted circumstances—without.[1 5 6] 'Fully' anonymised data are not subject to UK data protection legislation.[5 6] However, even supposedly anonymised data relating to individual people carries some risk of reidentification via 'jigsaw' attacks.[10]

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BMJ Jones LA, *et al.* *BMJ Open* 2022;**12**:e057579. doi:10.1136/bmjopen-2021-057579 1

NHS Digital General Practice Data for Planning and Research (GPDPR) Research Report

2022

What Happened?

- NHS Digital commissioned an online and phone survey to assess public opinion on the GDPPR and wider data sharing preferences
- Just over 2,000 members of the public took part in the survey, mostly nationally representative with two small sub-samples to represent those less confident online

What were the main issues covered?

- Public awareness of key topics e.g. GPDPR, opt-out and anonymisation/ pseudonymisation
- Views on NHS data sharing and other usage of patient data
- Participants' preference and ability to opt-out of data sharing

NHS Digital

NHS Digital GPDPR

Research report April 2022

Presented by:
Research Works Limited

Findings:

- Awareness of GPDPR and opt-out is high but understanding of specific aspects and mechanisms is low
- Understanding of the different types of opt-out was low
- Most understood anonymised data but greater confusion around pseudonymised data
- Participants were generally supportive and trusting of the use of their data by the NHS, but were more sceptical of those outside the NHS having access
- Those who claimed to have opted-out reported reasons of privacy, security and sold data, with reassurance about security in particular most likely to influence future decisions about opt-out
- The complete findings are available online and informed the engagement phase for GPDPR

Building A Trustworthy National Data Research Infrastructure

2022

What Happened?

- Data and Analytics Research Environments UK (DARE) and Kohlrabi Consulting conducted a Public Dialogue with 44 members of the public through online workshops from January to February 2022
- The aim of the dialogue was to produce recommendations for ensuring the views captured are factored into the implementation of a more coordinated national data research infrastructure.

What were the main issues covered?

- Participants’ attitudes towards different methods of data access
- What people consider trustworthy use of data for research
- Perceived risks and benefits of data research
- Desired level of public involvement in data research

DARE UK

Building a trustworthy national data research infrastructure: A UK-wide public dialogue

May 2022

Findings:

- Participants had little existing knowledge about data research and wanted more transparency and proactive messaging about how data is handled
- People wanted the public engagement process to be more open and accessible
- Most people were reassured by existing security measures, but many were concerned about possible data breaches
- People were most comfortable with researchers accessing personal data on a Secure Data Environment in a secure room, as opposed to remote personal access
- The complete findings and recommendations are available online

Exploring public attitudes towards the use of digital health technologies and data

2023

What Happened?

- The Health Foundation commissioned a survey asking people about their data sharing preferences and views on technology use in healthcare
- Over 7,000 nationally representative members of the public took part in an online survey in March 2023

What were the main issues covered?

- Whether technologies improve healthcare and which types should be used
- How participants felt about their health data being used by a variety of organisations and for different purposes
- What the participants knew about the way the NHS uses data

Findings:

- Most people are supportive of technologies to improve healthcare, but more so those that empower people to manage their health better and connect them with NHS rather than those that come between them such as chatbots
- Women and those on low/no income were less positive about healthcare technology, highlighting the need for wide and representative public engagement
- The public is generally happy with a range of ways data can be used outside of individual care, but there is still work to be done to grow trust in health data use
- Generally the public trusts NHS organisations more with health data than government or commercial organisations, though this varies by age
- The complete findings are [available online]

Exploring public attitudes towards the use of digital health technologies and data

Nell Thornton, Tim Horton, Tom Hardie, Charly Coxon

The Health Foundation

Understanding Public Attitudes and Willingness to Share Commercial Data for Health Research: Survey Study in the United Kingdom

2023

What Happened?

- A survey study was commissioned to investigate the public's willingness to share different types of commercial data for health research purposes with varying types of organisations, and identify relevant socio-demographic determinants
- 1,534 participants took part in the study via Survey Monkey in August 2020, funded by a Cancer Research UK Early Detection and Diagnosis project grant, with support from the Peter Sowerby Foundation

What were the main issues covered?

- Participants' awareness of GDPR
- Participants' attitudes towards sharing commercial data with public bodies vs private companies

Findings:

- Most people surveyed were aware of GDPR
- Increasing age was correlated with less willingness to share all kinds of data
- More people were happy to share their data with government and academic bodies than with private companies
- The complete findings are [available online]()

JMIR PUBLIC HEALTH AND SURVEILLANCE Hirst et al

Original Paper

Understanding Public Attitudes and Willingness to Share Commercial Data for Health Research: Survey Study in the United Kingdom

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Abstract

Background: Health research using commercial data is increasing. The evidence on public acceptability and sociodemographic characteristics of individuals willing to share commercial data for health research is scarce.

Objective: This survey study investigates the willingness to share commercial data for health research in the United Kingdom with 3 different organizations (government, private, and academic institutions), 5 different data types (internet, shopping, wearable devices, smartphones, and social media), and 10 different invitation methods to recruit participants for research studies with a focus on sociodemographic characteristics and psychological predictors.

Methods: We conducted a web-based survey using quota sampling based on age distribution in the United Kingdom in July 2020 (N=1534). Chi-squared tests tested differences by sociodemographic characteristics, and adjusted ordered logistic regressions tested associations with trust, perceived importance of privacy, worry about data misuse and perceived risks, and perceived benefits of data sharing. The results are shown as percentages, adjusted odds ratios, and 95% CIs.

Results: Overall, 61.1% (937/1534) of participants were willing to share their data with the government and 61% (936/1534) of participants were willing to share their data with academic research institutions compared with 43.1% (661/1534) who were willing to share their data with private organizations. The willingness to share varied between specific types of data—51.8% (794/1534) for loyalty cards, 35.2% (540/1534) for internet search history, 32% (491/1534) for smartphone data, 31.8% (488/1534) for wearable device data, and 30.4% (467/1534) for social media data. Increasing age was consistently and negatively associated with all the outcomes. Trust was positively associated with willingness to share commercial data, whereas worry about data misuse and the perceived importance of privacy were negatively associated with willingness to share commercial data. The perceived risk of sharing data was positively associated with willingness to share when the participants considered all the specific data types but not with the organizations. The participants favored postal research invitations over digital research invitations.

Conclusions: This UK-based survey study shows that willingness to share commercial data for health research varies; however, researchers should focus on effectively communicating their data practices to minimize concerns about data misuse and improve public trust in data science. The results of this study can be further used as a guide to consider methods to improve recruitment strategies in health-related research and to improve response rates and participant retention.

https://publichealth.jmir.org/2023/1/e40814 JMIR Public Health Surveill 2023 | vol. 9 | e40814 | p. 1
(page number not for citation purposes)

XSL•FO

Towards a Healthier, Wealthier UK: Unlocking the Value of Healthcare Data

2023

What Happened?

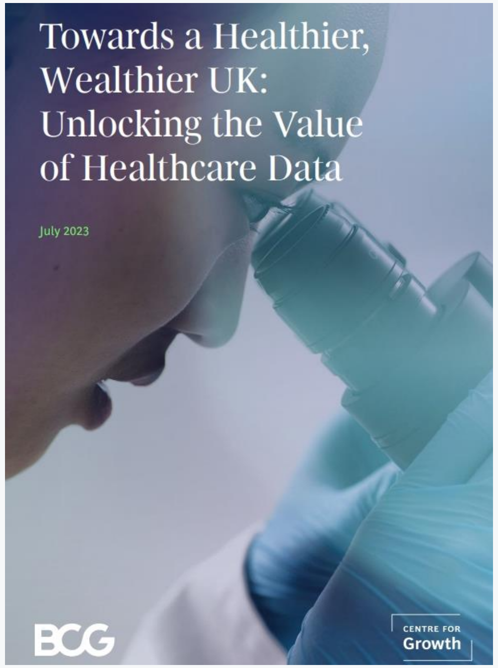
- Boston Consulting Group carried out a representative survey of the public in England to examine public perceptions around access and use of healthcare data
- 2,030 adults in England were polled in an online survey, provided by J.L Partners in May 2023

What were the main issues covered?

- Participants' support for data sharing with the NHS
- Preferences relating to data sharing vs data access
- Attitudes towards COVID-style COPI (Control of Patient Information) notices
- Public and personal engagement about data use

Findings:

- People were generally open to sharing their healthcare data – 90% were willing to share with the NHS for any purpose; there is more support than opposition for private companies (except for tech companies)
- People were more comfortable with data access than data sharing, and broadly support the ongoing use of COPI notices for research on serious diseases and to improve efficiencies to reduce patient backlogs
- Participants wanted to be more proactively told about how their data is being used or be able to request the information when they wanted, so transparency about how, where and why data is accessed is vital
- 2/3rds of people were comfortable with the idea of value or profit being generated from healthcare data providing some if reinvested into the health system or where there is wider public benefit
- The complete findings are [available online]



Towards a Healthier, Wealthier UK: Unlocking the Value of Healthcare Data

July 2023

BCG

CENTRE FOR Growth

@Patient_Data

Understanding the attitudes and experiences of people living with potentially stigmatised long-term health conditions with respect to collecting and sharing health and lifestyle data

2023

What Happened?

- 14 individuals living with potentially stigmatised long term health conditions (LTHC) in England were interviewed and carried out card-sorting tasks to understand their preferences towards sharing health and lifestyle data

What were the main issues covered?

- Participants' preferences for collecting health and lifestyle data
- Attitudes and experiences of sharing this information with healthcare professionals, as well as charities support groups, family, friends and work
- Feelings about this data being shared with pharmaceutical companies, academic researchers, health charities or other commercial organisations

Findings:

- Participants were generally receptive to sharing their data, for the public benefit, mainly with public health bodies and for academic research
- Anonymity was considered a key enabler of data sharing, especially with pharmaceutical companies, advertising firms and other commercial organisations
- The complete findings are available online

Original research

DIGITAL HEALTH

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SAGE

Understanding the attitudes and experiences of people living with potentially stigmatised long-term health conditions with respect to collecting and sharing health and lifestyle data

Richard Brown[1], Elizabeth Sillence[1], Lynne Coventry[1],
Emma Simpson[2], Jo Gibbs[3], Shema Tariq[3], Abigail C. Durrant[4]
and Karen Lloyd[3]

Abstract

Background: The emerging landscape of patient-generated data (PGData) provides an opportunity to collect large quantities of information that can be used to develop our understanding of different health conditions and potentially improve the quality of life for those living with long-term health condition (LTHCs). If the potential benefits of PGData are to be realised, we need a better understanding of the psychological barriers and facilitators to the collection and beneficial sharing of health and lifestyle data. Due to the understudied role that stigma plays in sharing PGData, we explore the attitudes and experiences of those living with potentially stigmatised LTHCs with respect to collecting and sharing health and lifestyle data.

Methods: This study used semi-structured interviews and a card sorting task to explore the attitudes and experiences of people living with potentially stigmatised LTHCs. Fourteen adult participants who reported having a range of conditions were recruited in England. Template analysis was used to analyse interview transcripts and descriptive statistics were used for the card sorting task.

Results: The findings present four overarching themes: Preferences for collecting health and lifestyle data, Importance of anonymity, Expected use of data, and Sources of emotional support. Participants illustrated a general willingness to share health and lifestyle data; however, there were some notable differences in sharing experiences, varying both by information type and recipient group. Overall, participants did not identify health-related stigma as a barrier to collecting or sharing their personal health and lifestyle data.

Conclusions: We outline a number of preferences that participants feel would encourage them to collect and share data more readily, which may be considered when developing data sharing tools for the future.

Keywords

data sharing, patient-generated data, long-term health conditions, trust, identity, privacy, security, stigma

Submission date: 24 December 2020; Acceptance date: 16 February 2022

Introduction

Recent decades have seen a steady increase in life expectancy in many high-income countries across the world.[1] Most of the rise in life expectancy has been attributed to declining rates of mortality amongst older adults as a result of improvements in healthcare.[2] In the coming

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Examining public views on decentralised health data sharing

2023

What Happened?

- 30 participants in England took place in five online focus groups to examine public views and concerns about new models of health data sharing in the UK

What were the main issues covered?

- Public attitudes towards the prospective use of DLT (blockchain) technology in health data sharing
- Perceived benefits vs drawbacks of decentralised data sharing
- Governance of new models of data sharing

Findings:

- Participants were broadly in favour of a shift towards new decentralised models of data sharing
- Participants were optimistic about the opportunity and enhanced transparency provided by blockchain methods to monitor access to their data, but had concerns about the potential to exacerbate health and digital inequalities not only amongst patients but also healthcare professionals
- Participants were unsure of the feasibility of utilising these technologies in the NHS given already poorly-functioning IT systems and interoperability issues
- The complete findings are [available online]

PLOS ONE

RESEARCH ARTICLE

Examining public views on decentralised health data sharing

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Competing interests: The authors have declared that no competing interests exist.

Abstract

In recent years, researchers have begun to explore the use of Distributed Ledger Technologies (DLT), also known as blockchain, in health data sharing contexts. However, there is a significant lack of research that examines public attitudes towards the use of this technology. In this paper, we begin to address this issue and present results from a series of focus groups which explored public views and concerns about engaging with new models of personal health data sharing in the UK. We found that participants were broadly in favour of a shift towards new decentralised models of data sharing. Retaining 'proof' of health information stored about patients and the capacity to provide permanent audit trails, enabled by immutable and transparent properties of DLT, were regarded as particularly valuable for our participants and prospective data custodians. Participants also identified other potential benefits such as supporting people to become more health data literate and enabling patients to make informed decisions about how their data was shared and with whom. However, participants also voiced concerns about the potential to further exacerbate existing health and digital inequalities. Participants were also apprehensive about the removal of intermediaries in the design of personal health informatics systems.

Introduction

Traditional patient health data management services have followed a highly centralised model with public and private health providers acting as data custodians on behalf of patients and as intermediaries for third-party data consumers such as pharmaceutical organisations. More recently, researchers have begun to explore the possibilities of using Distributed Ledger Technologies (DLT), also known as blockchain as an alternative, decentralised form of personal health data management, which can support individuals to have more direct control over their health data. The capacity of DLTs to facilitate more secure data sharing and offer verification between disparate healthcare information systems such as personal electronic health records

@Patient_Data

Centre for Data Ethics and Innovation Public Attitudes to Data and AI Tracker Surveys

2023

What Happened?

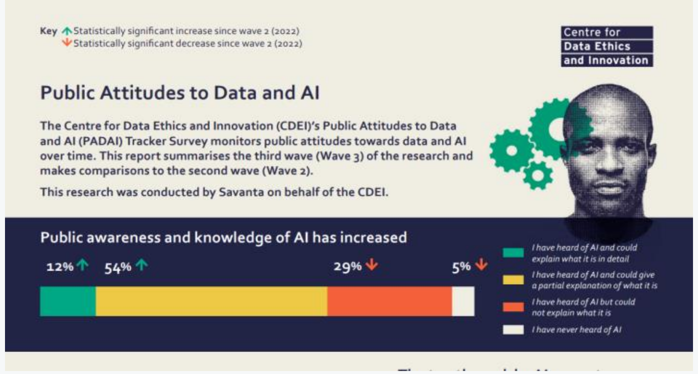
- The Centre for Data Ethics and Innovation commissioned a tracker survey to monitor public attitudes towards using data and AI over time, including in relation to health
- The surveys took place in three waves between 2021 and 2023, where 4,000 people took part in online surveys, plus 200 phone interviews to involve digitally excluded people

What were the main issues covered?

- Public views on value, risks, benefits and concerns and preferences about AI and data use

Findings:

- Public awareness and knowledge of AI has increased over time, with the perception that the impact of it will be overall neutral, though the perception that it will be negative is growing
- Health is considered as one of the top three areas where data use presents the greatest opportunities for improvement
- There has been an overall shift in the public's beliefs about data use
- People are consistently concerned with data security and generally do not want identifiable data used
- The NHS inspires the highest public trust to use data to benefit society, followed by university researchers and pharmaceutical companies, with reduced trust in government and large tech companies
- The complete findings [are available online]



Key ↑ Statistically significant increase since wave 2 (2022)
↓ Statistically significant decrease since wave 2 (2022)

Centre for
Data Ethics
and Innovation

Public Attitudes to Data and AI

The Centre for Data Ethics and Innovation (CDEI)'s Public Attitudes to Data and AI (PADAI) Tracker Survey monitors public attitudes towards data and AI over time. This report summarises the third wave (Wave 3) of the research and makes comparisons to the second wave (Wave 2).

This research was conducted by Savanta on behalf of the CDEI.

Public awareness and knowledge of AI has increased

Patient empowerment: what is the role of technology in transforming care?

2023

What Happened?

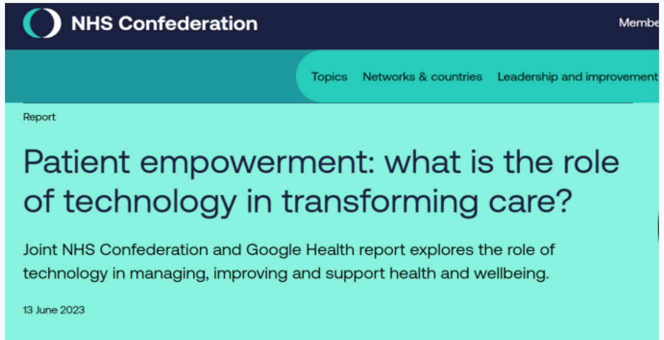
- The NHS Confederation, in partnership with Google Health, commissioned Ipsos to explore people's behaviours, attitudes, and beliefs about responsibility and control when it comes to their health and the role that health technologies play in this
- They surveyed more than 1,000 UK adults, and interviewed 7 individuals with long-term health conditions and have frequent interaction with the health system

What were the main issues covered?

- Public understanding, attitudes and beliefs about responsibility and control over their health
- Impact of health technologies and citizen expectations, needs and ambitions
- Attitudes and future needs with respect to health data and privacy

Findings:

- 82% of surveyed GPs believe that the use of wearable and connected devices will enable patients to proactively manage their own health while also providing greater ownership of their personal health information
- 53% of individuals with long-term conditions are using the NHS app to access personal health information compared to 33% of the general population
- Using technology such as wearables or apps to monitor and support health is seen by the majority as having real personal value
- Approximately 7 out of 10 people would be happy to share information and data from health technologies with their doctor
- The complete findings are available online



Report

Patient empowerment: what is the role of technology in transforming care?

Joint NHS Confederation and Google Health report explores the role of technology in managing, improving and support health and wellbeing.

13 June 2023

Public attitudes to data in the NHS and social care

2024

What Happened?

- In anticipation of NHS England's large scale programme of public engagement on data, they conducted a survey of over 22,000 people and held focus groups and interviews to understand public attitudes to health and social care data

What were the main issues covered?

- Understanding of health and social care data, general concerns, and trust in the NHS
- Different attitudes that people have toward health and social care data
- Identification of different segments of the public across the population

Findings:

- 83% of people said they trusted the NHS to keep their data secure
- The most common concern regarding data security was cyber attacks
- There is good knowledge, understanding and comfort in how data is used in health and care
- Six attitudinal segments were identified: confident data enthusiasts (21%), neutral followers (20%), cautious data sharers (14%), unfamiliar and unsure (11%), disengaged and health data protective (23%), and NHS and privacy sceptics (10%)
- The complete findings are available online

Public attitudes to data in the NHS and social care

Date Published: 9 May 2024

AI in health care: what do the public and NHS staff think?

2024

What Happened?

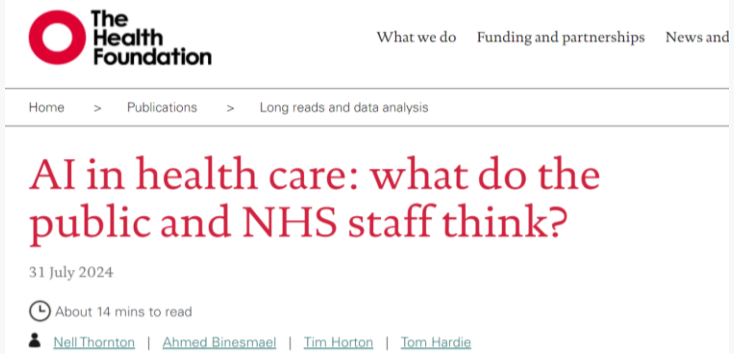
- The Health Foundation commissioned a survey conducted in June/July 2024 of over 7,200 nationally representative members of the public and over 1,200 NHS staff members to learn more about attitudes towards AI

What were the main issues covered?

- How people think AI will impact on health care
- How staff think it will impact on work
- What the advantages and disadvantages of AI in health care might be

Findings:

- 54% of the UK public and 76% of NHS staff surveyed said they support the use of AI for patient care, with 61% of the public and 81% of NHS staff surveyed saying they support the use of AI for administrative purposes
- A significant minority are not supportive, though - 1 in 6 members of the public and 1 in 10 of the staff members said they think that AI will make care quality worse, a perception more common amongst young people and women
- 53% of the public and 65% of staff members surveyed felt AI may increase the feeling of distance between patients and healthcare staff
- 30% of the public had concerns about the decision-making accuracy of AI and the clinical consequences of that
- Support varied by role, e.g., medical and dental staff were more supportive than healthcare assistants and support workers
- The complete findings are available online



AI in health care: what do the public and NHS staff think?

31 July 2024

About 14 mins to read

Nell Thornton | Ahmed Binesmael | Tim Horton | Tom Hardie

@Patient_Data

Public attitudes towards patient data for planning and population health

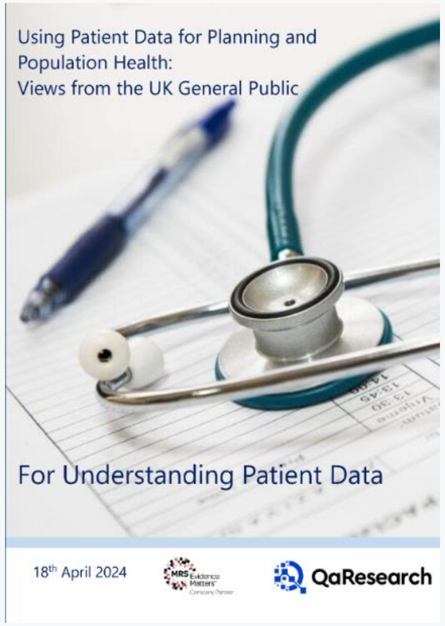
2024

What Happened?

- We (UPD) commissioned QA Research to conduct research into public attitudes towards patient data for planning and population health
- A nationally representative sample of 1,000 people were surveyed, followed by four guided workshops with representation from across the UK

What were the main issues covered?

- Awareness of data use for planning and population health compared to individual care and research
- Levels of support for specific examples of data use for planning and population health
- Perceived benefits and risks of using data for planning and population health and how this drives support
- Views on identifiability and choice



Using Patient Data for Planning and Population Health:
Views from the UK General Public

For Understanding Patient Data

18th April 2024

QaResearch

Findings:

- People are less familiar with the use of data for planning and population health than for individual care or research
- People are overwhelmingly supportive of the use of data for planning and population health
- Willingness to share data was most positively impacted by the potential to speed up access to treatment and reduce waiting lists, and most negatively by the fear of data breaches
- Most believe the NHS should have automatic access to data for planning and population health
- People generally prefer the use of de-identified data over identifiable data for planning and population health
- There were some differences in views between nations in the UK
- The complete findings are available online

@Patient_Data

More to browse...

Developing a data pact: the relationships between the public, their data, and the health and care system

This 2023 report by Patients Association, with the support of Department of Health and Social Care, explores findings from focus groups examining attitudes towards data sharing generally, as well for specific uses of data, before focusing on the implications and expectations of a data pact

NHS national data opt-outs: trends and potential consequences for health data research

This 2024 research analysed trends in NHS national data opt-outs in England and considered the consequences for health research and policy

Who cares what the public think? UK public attitudes to regulating data and data-driven technologies

This 2022 report from Ada Lovelace draws together evidence from nearly 40 studies about UK public attitudes to data conducted in recent years

Data sharing and linkage for the public good: follow-up report

This 2024 follow-up report from the Office for Statistics Regulation assesses the progress that has been made towards the recommendations from its 2023 report on enabling greater data sharing and linkage for research and statistics for the public good, including in relation to public engagement and attitudes

A deliberation on London's health and care data

This 2022 report from Ipsos and Imperial College Health Partners builds upon the 2020 OneLondon Citizens' Summit, involving deliberative engagement with 59 Londoner's across 4 workshops to ask them how the NHS should move forward in terms of either keeping locally controlled data environments or moving towards a more pan-London approach

Citizens' Jury on QCovid: report on the jury's conclusions and key findings

This 2022 report from Ipsos Scotland summarises key findings from six workshops with 25 people across Scotland to explore the question "what are the risks and benefits of using public health data to predict people's risk of dying from Covid-19?" particularly in relation to the risk prediction model QCovid

Public perspectives on the use of health data in research and innovation

This 2022 report from Ipsos Scotland, commissioned by DataLoch, sets out the findings from survey research with 595 people in Scotland to measure public perceptions of the use of potentially sensitive health data for various uses

Public dialogue on the use of data by the public sector in Scotland

This 2024 report from Ipsos Scotland summarizes key findings from six workshops with 25 people across Scotland to explore the question "What guidelines should the public sector follow when using citizens data?" and the subsequent ethical guidelines for data use formulated by the participants.

Think there’s something we should add?

Email us at hello@understandingpatientdata.org.uk

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Patient Data