

Data for Science and Health at Wellcome





Health data: engaging with patients and the public

Emily Jesper-Mir,. Partnerships
and engagement Manager
(job-share with Rebecca Asher)



Wellcome funds data science methods and digital tools to change the future of scientific research and help solve urgent health challenges



Trustworthy data science to help solve urgent health challenges

The trustworthiness of datasets and digital technologies is determined by how they are conceived, built, used and evolved

The importance of trustworthy data science

When data is not used properly, the negative outcomes can be serious, far-reaching and have long-term impacts. For example:

- Systems apparently based on non-biased data can worsen inequalities if the analysis is based on wrong assumptions
- In the USA, a [healthcare algorithm was found](#) to be under-allocating resources to Black patients due to racial bias
- The algorithm identified higher-risk groups partly by analysing much money was spent on their past healthcare. However, less money tended to be spent on Black patients.
- Consequently, Black patients were rated as less sick than White patients, even if they had the same health conditions

Datasets for machine learning to improve health across the globe

Machine learning could be used to improve health – but there's also a risk it increases health inequalities, as datasets for machine learning tend to be concentrated in high-income settings and exclude certain communities.

To help efforts to address this, Wellcome has contributed to a call for machine learning-ready datasets, run by the [Lacuna fund](#). Teams are investigating the potential of AI to help improve health across the globe.

To include:

- Reducing racial disparities in chronic pain in the United States, through machine learning on data about real patient outcomes

This funding call was also supported by The Rockefeller Foundation, Google.org, and the Gordon and Betty Moore Foundation.



Engagement projects

- **Closing gaps in patient data for Black and South Asian communities:** a nationally representative survey, community research and engagement
- **A public guide to large datasets:** cocreated with experts and members of the public
- **An easy-read guide to NHS data:** cocreated with adults with learning disabilities



HOW TO REDUCE THE RISK OF CAUSING HARM

8

Data is not neutral and contributes to the systemic injustices we see in healthcare and wider society. It plays an important role in what we know about human existence. It shapes the judgements and decisions we make in our daily lives, influences our behaviours and affects how we navigate the world. In the context of healthcare, data shapes who is seen and who is invisible, whose needs are met, overlooked or ignored.

(Creary et al, 2022)



What it means to be seen

Closing gaps in patient data for Black and South Asian communities

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The LK Team



Natalie Creary (she/her)
Nat-a-lee Cr-ear-ree

Project & Research Lead

A Community Development specialist, academic, racial justice advocate, Diversity, Equity and Inclusion advisor, and founder of Liberating Knowledge Ltd.

LiberatingKnowledge@outlook.com



Daphne Amevenu (she/her)
Daff-nee Am-ee-ve-nu

Project & Research Lead

Director of Amevenu Ventures LTD. A management consultant with expertise in spreading innovative approaches in health and care, establishing and delivering national health programmes, project and programme management expertise and diversity and inclusion advisor.



Jess Shivji (she/her)
Jess-i-ka Shiv-gee

Communications & Engagement Lead

Communications specialist with experience across marketing, PR, stakeholder and community engagement.



Qualitative research: Engagement with healthcare workers

LK worked with UPD to understand the root causes of patient data inequalities

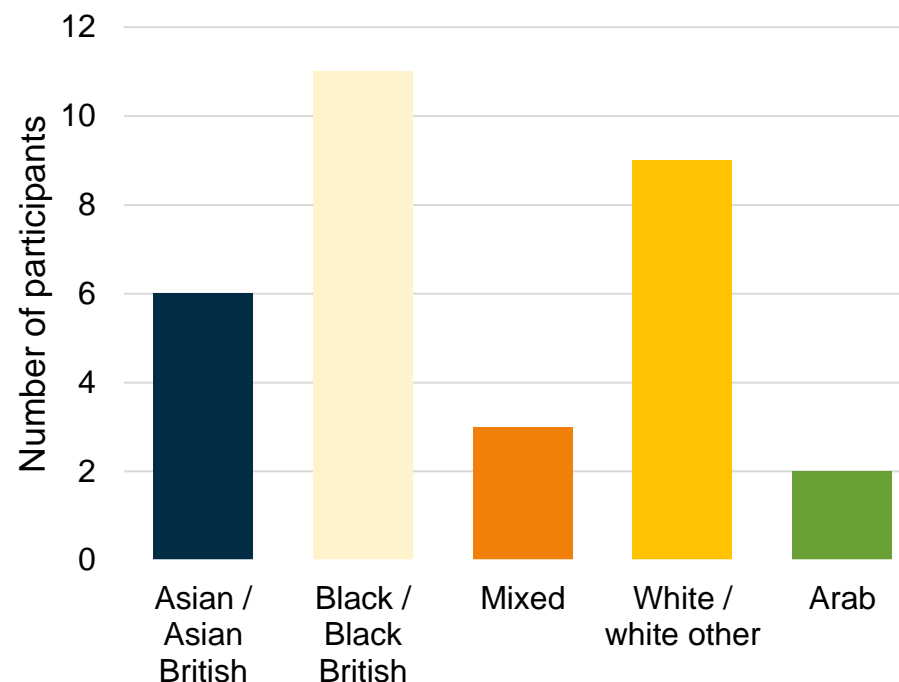
Liberating Knowledge worked with Understanding Patient Data to build on insights generated from previous work conducted by ClearView Research

- **Qualitative research** explored the perspectives of healthcare workers on the following:
 - why patient data is less complete for patients from Black and/or South Asian backgrounds
 - barriers that hinder good data practice and possible solutions that would make it easier for the workforce to collect and use data more effectively
 - suggestions for how the NHS could use data to improve service provision and the health outcomes of Black and South Asian communities.
- **Quantitative research** aimed to survey a representative sample, exploring the key themes that emerged from ClearView Research's work to measure the extent to which the views that surfaced were shared among Black and South Asian communities.

We spoke with a diverse group of healthcare professionals

- We used a purposive sampling approach to engage a heterogeneous sample
- Healthcare workers were recruited through social media and professional contacts
- We conducted 5 online focus groups (1.5 – 1.75 hrs) and 8 interviews (0.5 – 1.5 hrs)
- 37 participants were recruited in total

28 female, 8 male



There are several barriers for staff to equitably collect and analyse data

Healthcare professionals highlighted a range of barriers that may contribute to inequalities in data collection. These included:

- a lack of awareness among staff about how the NHS uses patient data
- difficulties in managing time and resource pressures
- lack of access to technological solutions that could improve data collection and use

'Data is hugely important. However, if it's an add-on to ten other things I need to do, unfortunately, it's going to be at bottom of the pile.'

Concerns about the lack of diversity in leadership and a culture tolerating racism

- Some professionals shared concerns about the absence of people in leadership roles committed to addressing inequalities
- They also shared experiences and frustrations pointing to organisational hierarchy and work culture that tolerates bullying and institutional racism
- Some staff expressed concerns about being perceived as racist which led them to avoid collecting patient data
- There were also issues with staff of all background allowing stereotypes to limit what information they request from patients

'I think that there is a big thing about not being perceived as racist. People aren't letting the patient fill [the equalities forms] . People are guessing and not asking or communicating with them or completing it correctly.'
Matron, White British, Female

'Maybe those that are making the decisions aren't necessarily directly impacted. So, maybe the answers to the questions don't really matter to them.'

'As a trainee, if I would say something and my White peer would say something, he would be listened to, even though we said the same thing. He could be even junior to me.'

Anaesthetist, South Asian British, Female

Levels of awareness of the consequences of gaps in patient data were mixed

- Most people understood that data was needed to provide individual-level care
- Healthcare workers were less aware of how data is used in service planning and research
- People from racially minoritised backgrounds were more likely to highlight the importance of being represented in datasets to reduce inequalities
- Some healthcare workers appear to interpret the inequalities experienced by racially minoritised groups to have some form of biological basis rather than situating health inequalities in the context of wider structural issues

'I think one of the key advantages with collecting data is that you make sure that service provision is equitable.'

Psychologist, Black British (Caribbean), Male

Healthcare professionals' had big ambitions for how the NHS routinely collects and uses patient data

Healthcare professionals mentioned that greater attention needed to be placed on reassuring patients of the benefits of sharing their data

Others were keen for the NHS to take advantage of technology to improve the standardisation of data collection

Some staff felt the NHS could be more radical in redistributing power to patients to give them more control over their data and for their communities to benefit directly from the resources and insights generated through research and private partnerships

Staff welcomed the opportunity to learn from other sectors and within the NHS who are already collecting and using data effectively

'It's important to ensure that the patient understands fully why you're collecting that data. They would be more likely to cooperate, and give you all the data that you require.'

Doctor, Black, Male

'We must lean on the people in the communities who are well respected, and who people do listen to.'

*Clinician/Researcher, White
Other, Female*

Key findings from engagement with healthcare workers

We conducted a mix of **focus groups and interviews with 37 healthcare workers** to explore their perspectives of the barriers and enablers to data collection in Black and South Asian communities. We gathered the following insights:



Challenges in how **confident staff feel** describing the purpose and use of data they are not required to use in their role



A **lack of people in leadership roles** who are committed to tackling bullying, institutional racism and health inequalities and who are from Black and South Asian communities was identified as a barrier to reducing inequalities



A concern from Black and South Asian communities, including healthcare workers, about **whether they can trust the NHS** given past harms



Quantitative research: survey with the public

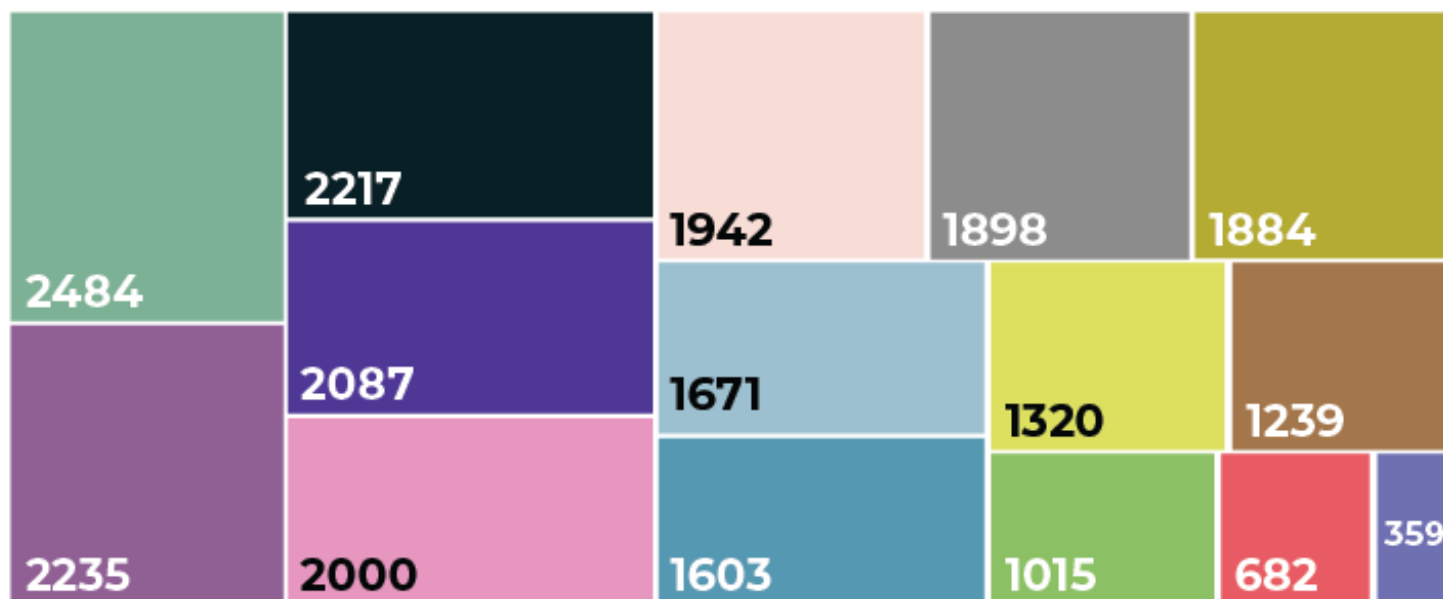
Respondents across all ethnicities are willing to share data

We asked survey participants how much they agreed with the statement '*I am willing to share my personal data with the NHS*' and to specify this for different types of data

Across all demographic variables, most respondents agreed or strongly agreed that they were willing to share their data with the NHS

Respondents are less comfortable sharing information about their financial situation

Respondents were asked to select the type of information they were willing to share with the NHS. They were most comfortable sharing their date of birth, ethnicity name and gender. Across all ethnicities respondents indicated that they were least comfortable sharing information about debt or their income.



Participants could select multiple types of information

- | | |
|-----------------------------------|-----------------------|
| Address | Lifestyle information |
| Citizenship or immigration status | Location data |
| Date of birth | Mental health |
| Debt | Name |
| Ethnicity | Relationship status |
| Gender or gender expression | Religion |
| Housing | Sexual orientation |
| Income | |

There is a positive correlation between trust in institutions and willingness to share personal health data

There is a stronger correlation between engagement in health information and trust in public organisations as compared to private companies

The only group who did not reflect this trend were those with long term conditions

Generally, with age there was increasing trust in institutions as engagement in health information increased until age 60

Survey with the general public

Only one in five respondents had a conversation with a healthcare worker about how their data is used

Overall, 19% of respondents had a conversation with a healthcare worker about how their data is used

This proportion varies when looking at the different demographics

25.6% of Black respondents have had a conversation compared to 13.2% of White respondents

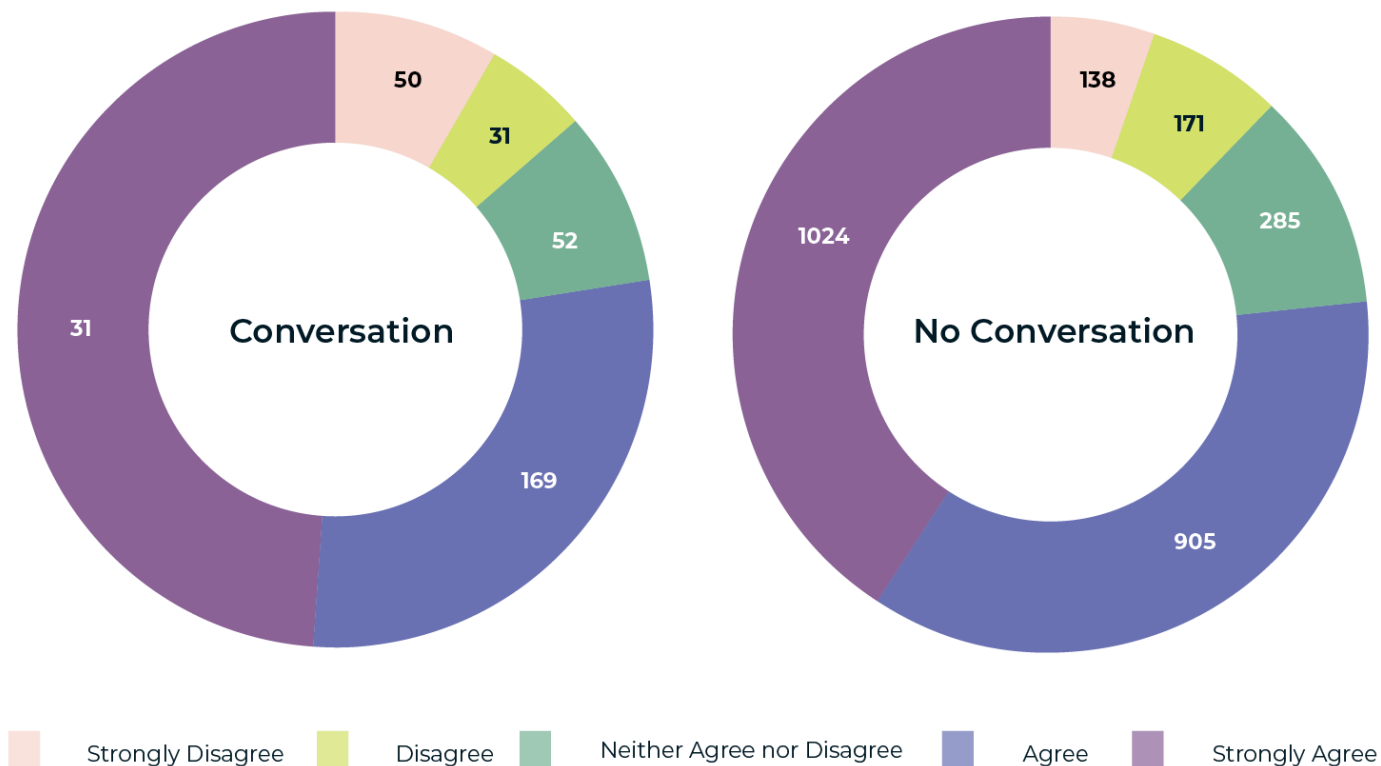
Younger people are more likely compared to older people to have had a conversation

Conversation with a healthcare worker by ethnicity



The power of the conversation

There is an increased willingness to share patient data with 47.9% who are strongly willing to do so after having a conversation with a healthcare worker about their data versus 40% who have not had a conversation



Key findings from survey

A survey of 3,273 respondents found:

- **High levels of engagement in health-related information** amongst survey participants
- Survey respondents across all backgrounds **trust the NHS with their personal data**
- **People from all ethnicities** have similar levels of engagement with health information and **have a willingness to share personal data**
- **Only one in five respondents** had a conversation with a healthcare worker about how their data is used
- **Black and South Asian respondents have both greater concern about the impact of discrimination** against them and their communities when sharing their data as well as **greater hope** that sharing data can reduce likelihood of discrimination
- Conversations with NHS staff **increased willingness to share personal data** and a broader understanding of its use
- Most respondents want to **learn about how health data is used** ahead of health consultations; written formats preferred



Key reflections

Black and South Asian communities are not more reluctant to share their personal data

- There were similar levels of comfort in sharing most types of data with the NHS across all ethnicities
- Across all ethnicities there were high levels of engagement in health information indicating there isn't an issue regarding interest and engagement within Black and South Asian communities
- The findings support the insights surfaced documented in ClearView Research's Diverse Voices in Data report which found that Black and South Asian communities are willing and interested in sharing their patient data
- Hiding behind the narrative that some communities are 'hard to reach' perpetuates the assumption that the responsibility to take action rests with minoritised groups rather than the NHS

The NHS needs to reflect on its trustworthiness rather than whether communities trust it

- Lack of trust is often cited as a reason for supposed lack of willingness by Black and South Asian communities in sharing data. However, our findings suggest that these communities report high levels of trust in the NHS and a willingness to share their data
- We encourage NHS organisations to think more critically about how they can make themselves trustworthy organisations for all communities
- This should be their focus rather than relying on narratives that inequalities in patient data being a consequence of Black and South Asian communities lacking trust in institutions
- This may potentially lead to building more equitable relationships with such communities and opportunities to work collaboratively to tackle health inequalities effectively

There's a greater burden of tackling health inequalities for communities who experience inequality

- We found challenges in engaging White healthcare workers in this research with significant time required to recruit healthcare workers to the focus groups
- Insights from the survey suggested less concern for potential discrimination for minoritised ethnic communities by White respondents
- Healthcare workers shared they saw less engagement in tackling health inequalities among senior leaders who were not from a minoritised background
- To make progress in tackling health inequalities addressing gaps in patient data is one way to support these efforts. It is imperative that all staff recognise they have a role and responsibility to reduce health inequalities. This is particularly important for influential and senior decision makers

Now is the time to ensure staff are equipped to close the gap in patient data

- NHS staff need to be supported to understand why it's important to have complete data and the potential of using data to tackle health inequalities and improve services for all
- Given the positive impact of having a conversation between healthcare workers and patients about data usage, and yet the low frequency of this happening, there needs to be more space created for these conversations
- It is important to share with communities how data collected from them is used in planning and research. This would avoid an extractive relationship where information is shared but no benefit is seen



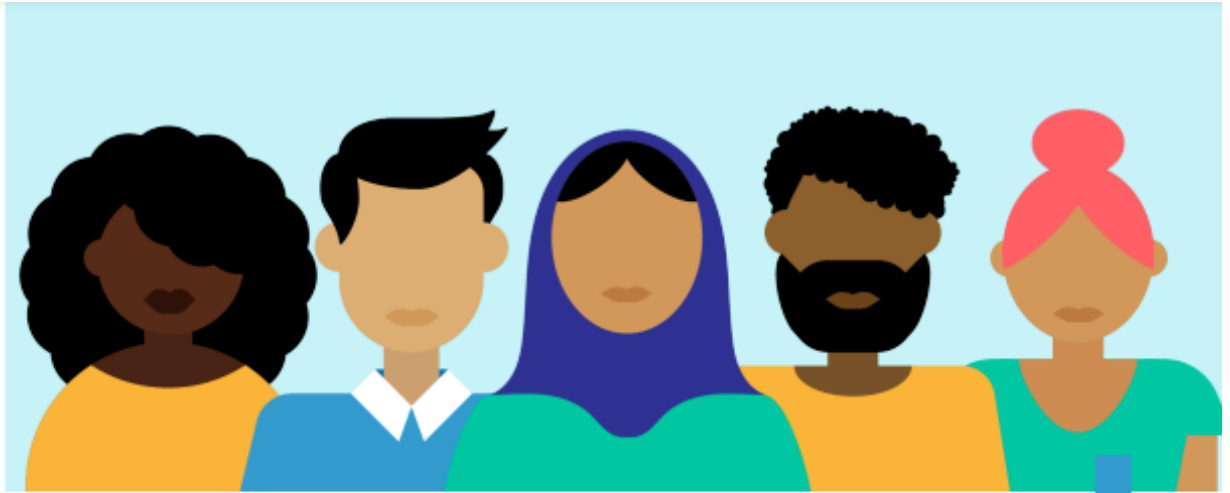
Recommendations

Recommendations

1. **Create the conditions for systemic change** to enable the following recommendations to be delivered by accelerating efforts to eradicate racism within the NHS
2. Consider **developing a race equity framework for physical health services** that draws on Patient and Carer Race Equality Framework in Mental Health services
3. **Secure the support and commitment of senior leaders** to improve data practices, embed inequalities work and create space for staff to innovate within the NHS
4. Actively **challenge 'hard to reach' narratives**
5. Equip healthcare workers with **tools to hold meaningful conversations about data**
6. **Regularly share the learning from equalities work** with the community, healthcare workers and the wider professional and scientific community

Recommendations

7. Maximise opportunities to **meaningfully engage and resource Black and Asian-led VCSE organisations** to involve local communities
8. **Develop system wide protocols to routinely collect equalities data**, disaggregate it by protected characteristics and use an intersectional approach to analysis
9. Work with racially minoritised communities and the Unified Information Standard for Protected Characteristics teams to **expand the ethnicity categories used by the NHS**
10. Invest in **research that takes an intersectional approach** to explore the health experiences of Black and South Asian communities
11. Embed an **antiracist approach** to data collection, analysis, dissemination and use



CLOSING THE GAP IN PATIENT DATA FOR BLACK AND SOUTH ASIAN COMMUNITIES:

A guide for healthcare workers

This guide provides an introduction to the inequalities in patient health data for Black and South Asian communities. It shares practical solutions, co-designed by healthcare workers and communities, to support people who work for the NHS to play their role in reducing health inequalities by improving their data practices.



Understanding
Patient Data



Black, South Asian and (In)visible:

Why patient data matters

1

Patient data for Black and South Asian communities is more likely to be missing or recorded incorrectly



2

What is patient data?

The NHS collects a lot of different types of data here are a few:



- **Clinical data** (Blood pressure, results from tests)
- **Feedback on services** (e.g. surveys, complaints etc.)
- **Protected characteristics** (e.g. age, ethnicity etc.)
- **Social/cultural information** (e.g. employment status, religion)

3

Why does it matter if data is collected from Black and South Asian communities?

Collecting patient data and using it well is a crucial step. It will ensure that people from these communities have equal opportunity to have good health, access to high quality and safe services and live full lives.



Better able to meet a patient's care needs



Helps to provide good quality and safe healthcare



Delivers services designed to meet the needs of the local population



Supports the development of new and improved approaches to treat and prevent illness or disease



Supports better policies which influence our access to healthcare



Helps services to understand how factors outside of the health service affect our health (e.g. debt, housing etc.)



Improves methods and efficiency in diagnosing illnesses



4

Concerns people may have about how their data is used



Sharing data with other agencies



Discrimination



Selling data to private companies



Data breaches





CLOSING THE GAP IN PATIENT DATA FOR BLACK AND SOUTH ASIAN COMMUNITIES:

A guide for NHS leaders and policy professionals

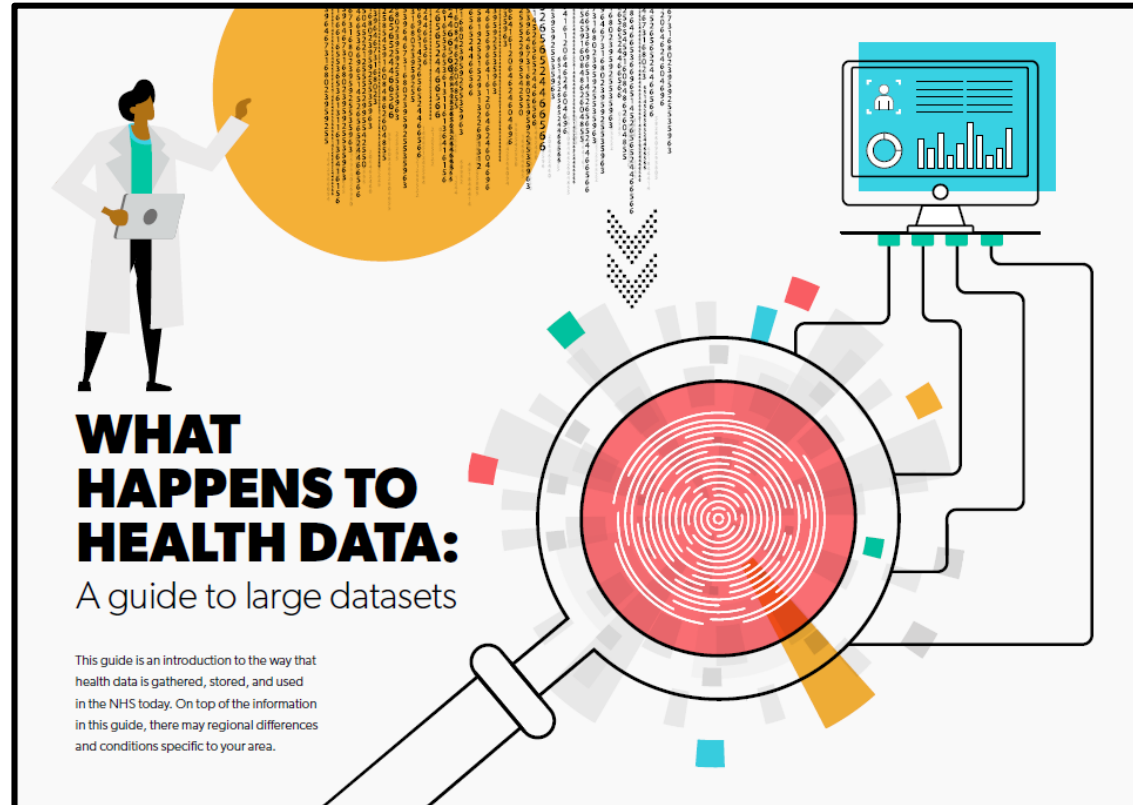
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Understanding
Patient Data



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www.understandingpatientdata.org.uk

What questions might you have about large datasets?



What is health data and why is it collected?



What are the potential benefits of large health datasets?



What are the potential harms?



How is my privacy is protected?



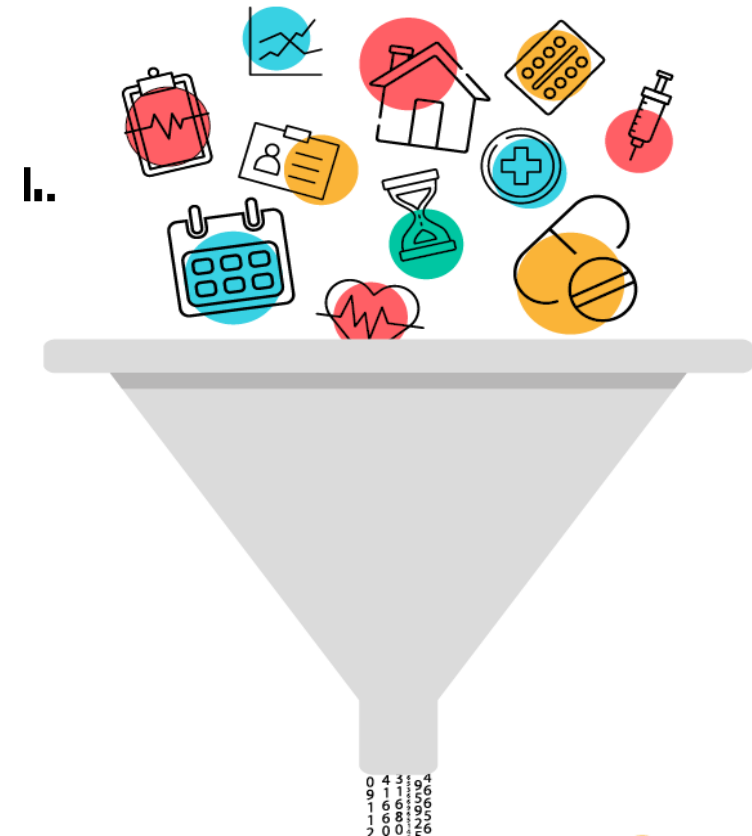
Who can and who can't access health data?



For data analysis to be useful, the data must be collected from a large and representative group of people

If not, then using the data could make inequalities worse.

For example, inaccurate information could cause resources to be withheld from groups who are already disadvantaged



The potential harms of large datasets include:



Privacy breaches

The potential for unauthorised intrusions into a patient's personal or private information



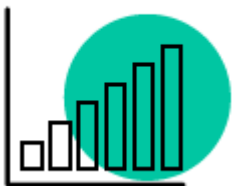
Discrimination and stigma

The use of data to characterise people in ways that create – or add to – disadvantages



Disenfranchisement and disempowerment

Patients not being given enough control over health data, or education about how it is used



Exploitation

Lack of benefit to the NHS and its patients when health data is used commercially



How the NHS uses our personal health information

An easy-read guide



Co-producing accessible information to support health literacy

A Guide



Thank you

[Linkedin.com/Emily-Jesper-Mir](https://www.linkedin.com/in/Emily-Jesper-Mir)
emilyandrebecca-dsh@wellcome.ac.uk

