

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**

Acknowledgements

This resource was co-designed with members of the community and healthcare workers from Black and South Asian backgrounds.

WHAT I CAN DO TO IMPROVE DATA PRACTICES

Everyone who works in healthcare can play a role in improving data quality. It is the small things that help to shift working culture.

We have included a few principles for you to keep in mind when holding conversations with patients and carers:



Remember that some people have legitimate concerns about the negative consequences that may arise if they share their data



Encourage patients to ask questions. Be open when you don't know the answer to a question and make the effort to find the answer



Ensure patients have the option to say no without being made to feel that they are being difficult or unreasonable



Allow people to take their time to come to a decision. You may find that some people may refuse, but when given the opportunity to think about the pros and cons they may decide to share their data

We have outlined a few things you can do depending upon your role to improve data practices, as a frontline worker:

- 01** Take the time to explain to patients why they are being asked to provide information and advise them on how it will be used and stored. Signpost them to other resources such as the [Understanding Patient Data](#) website
- 02** Make an effort to collect equalities monitoring data and remember this supports efforts to reduce health inequalities
- 03** Support patients to make an informed decision about whether they choose to share their data. Pages [7](#) and [8](#) of this guide provides some guidance to help you have meaningful conversations with service users
- 04** When colleagues present data or findings ask if they have analysed the data by ethnicity and other protected characteristics
- 05** Develop relationships with Black and South Asian VCSE organisations who can help to facilitate conversations with the community about the role of patient data
- 06** Provide timely access to interpretation and advocacy services to assist patients and carers to make informed decisions about how their data is collected and managed



BACKGROUND INFORMATION



01 Black, South Asian and (In)visible: Why patient data matters

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

02 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. patient feedback surveys, complaints etc.), protected characteristics (e.g. age, ethnicity, sex etc.), social/cultural information (e.g. employment status, religion)

03 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 to ensure that people from Black and South Asian backgrounds have equal opportunity to good health, access to high quality and safe services and live their lives to the full.

Collecting data accurately:

- Increases the likelihood that a patient's individual care needs will be met
- Enables the NHS to plan services that are designed to meet the needs of the populations they serve
- Improves methods and efficiency in diagnosing illnesses
- Helps services to provide good quality and safe healthcare
- Supports research into new and improved approaches to treat and prevent illness or disease
- Can be used to develop better policies which influence our access to healthcare
- Helps healthcare services to understand how factors outside of the health service (e.g. housing, debt, employment etc.) may impact the health outcomes of their patients

04 Concerns people may have about how their data is used

- Data may be shared with other agencies without their consent (e.g. Home Office)
- Risk of facing discrimination (personally or community)
- Data may be sold to commercial companies for profit
- Datasets have been compromised in the past, so identification of people may still be possible even if data security is promised

05 How is a patient's privacy protected?

NHS-specific guidelines are intended to ensure that confidential information is handled responsibly and in accordance with data protection laws. These guidelines specify that every organisation providing health and care services must make every effort to:

- Keep data secure
- Use data that cannot identify individual patients whenever possible
- Use data to benefit health and care
- Not use data for marketing or insurance purposes (unless this is requested by the patient)
- Make it clear why and how data is being used

06 Where is patient data stored?

A patient's data is collected during each contact with a health or social care service. This information may be stored as paper records or electronically.

07 Who has access to a patient's information? Once patient data has been anonymised or pseudonymised

The following organisations may have access to your data if they meet the criteria outlined in section 5:

- Non-profit research organisations (e.g. universities and charities)
- Commercial organisations (e.g. pharmaceutical companies researching and developing new drugs or treatment, and technology companies that provide software or data analysis services)
- National government departments (e.g. Department of Health and Social Care)
- Local Councils
- Primary care networks, which are local networks that include GPs and community, social care and mental health services, as well as pharmacies and voluntary services
- Integrated Care Systems are partnerships of organisations that work together to develop and provide coordinated health and care services to enhance the quality of life for local residents and the people who work in the area

08 What if a patient does not want to share their information?

Some information is needed to provide their care. However, they can opt out from providing data that is used for research or to plan services by accessing [NHS Digital's opt out service](#).



Where can I find more information about health data?

Understanding Patient Data has produced a number of guides including:

- [Why is it important to use patient data?](#)
- [What happens to Health Data: A guide to large datasets](#)

To learn more about how the NHS uses data visit [NHS Digital](#)

Ada Lovelace Institute focuses on research to ensure data and Artificial Intelligence works for everyone.

<https://www.adalovelaceinstitute.org/about/>

The NHS Race & Health Observatory works to identify and tackle ethnic inequalities in health and care <https://www.nhsrho.org/>

The Algorithmic Justice League is an organisation established in the USA who use art and research to highlight the social implications and harms of artificial intelligence <https://www.ajl.org/about>

Health Data Research UK is a national institute that aims to pull together the UK's health data to enable discoveries that improve people's lives. <https://www.hdruk.ac.uk>



To get the most from this guide, we encourage you to consider your own audiences and how best to provide the information they'd want. UPD resources are a starting point to edit and adapt to your own specific needs. Excluding reports, UPD resources are freely available on a CC-BY license.

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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



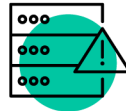
Sharing data with other agencies



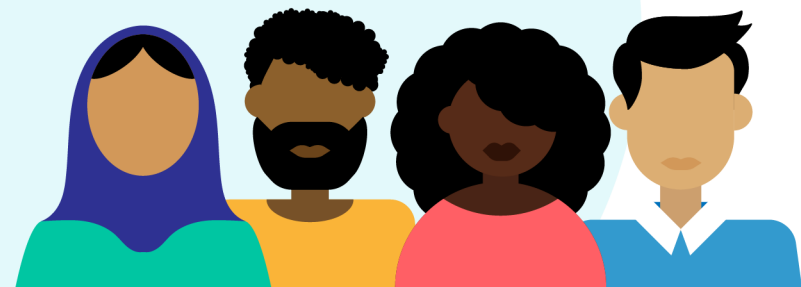
Discrimination



Selling data to private companies



Data breaches

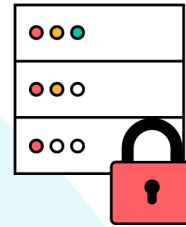


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How is a patient's privacy protected?

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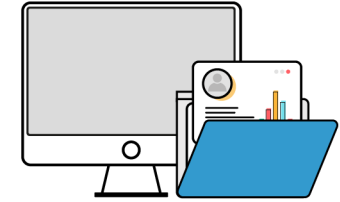
Keep data secure; Use data that cannot identify individual patients whenever possible; Use data to benefit health and care; Not use data for marketing or insurance purposes (unless this is requested by the patient); Make it clear why and how data is being used.



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Where is patient data stored?

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Who has access to a patient's information? Once patient data has been anonymised or pseudonymised and provided criteria in box 5 have been met



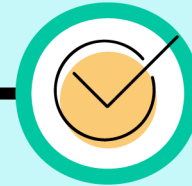
Non-profit research organisations



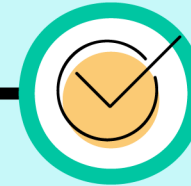
Commercial organisations



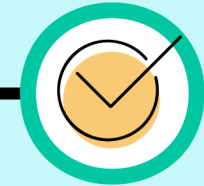
Government departments



Local Councils



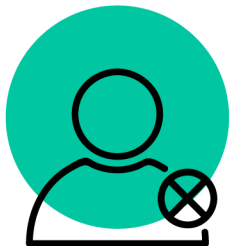
Primary Care Networks



Integrated Care Systems

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What if a patient does not want to share their information?



Some information is needed to provide their care. However, they can opt out from providing data that is used for research or to plan services by accessing NHS Digital's opt out service.



For more information



About patient data



NHS Digital Opt out service



Your right of access



Complain about data breaches

