

# 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:

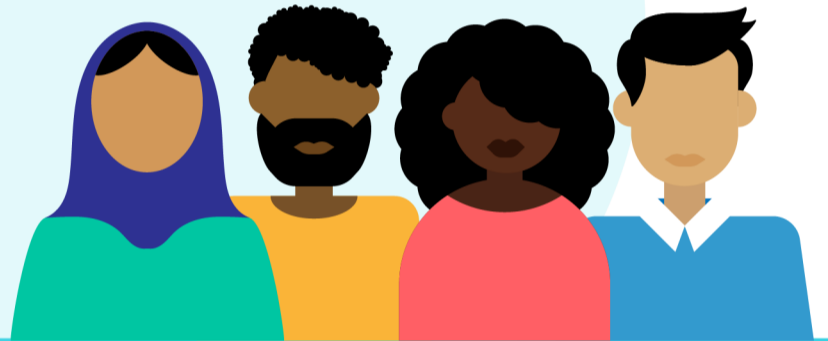


- **Clinical data** (Blood pressure, results from tests)
- **Feedback on services** (e.g. surveys, complaints etc.)
- **Protected characteristics** (e.g. age, ethnicity etc.)
- **Social/cultural information** (e.g. employment status, religion)

### **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



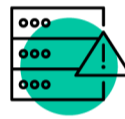
Sharing data with other agencies



Discrimination



Selling data to private companies

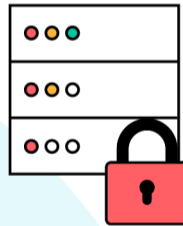


Data breaches

### **5** 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 organisations 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.



### **6** 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.



### **7** 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

### **8** 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