
A guide to the national data opt-out for BME communities

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We want to make sure you and your family have the best care now and in the future.

To do this we may use your confidential patient information to make care better and safer for everyone. It may be used in two different ways – to improve your individual care, and for research and planning.

What is confidential patient information?

Confidential patient information (CPI) identifies you and says something about your health care or treatment. You would expect this information to be kept private. Information that only identifies you like your name and address is not CPI and may still be used. For example to contact you if your GP practice is merging with another.

How is your confidential patient information used for research and planning?

This information can help to research new treatments, speed up diagnosis and improve health and care.

It is used by the NHS, local authorities, university and hospital researchers, medical colleges, and pharmaceutical companies researching new treatments.

Examples of how information is used for research and planning

Research using confidential patient information from hospital and GP records has shown that 50 per cent of people with South Asian, African and African-Caribbean origins will develop diabetes by the time they are 80. This kind of information is invaluable in planning how to prevent or diagnose diabetes early in these groups.

To read more about this and other important examples of where patient data has been used for research and planning visit www.patientdata.org.uk

You do not need to do anything if you are happy about how your confidential patient information is used.

If you do not want your confidential patient information to be used for research and planning you can choose to opt out securely online or through a telephone service.

You can make your choice about opting out from 25 May 2018. There is no deadline and you can change your choice at any time.

To find out more about the use of information or to choose to opt-out, visit our website nhs.uk/your-nhs-data-matters or call 0300 303 5678. To use the Next Generation Text Service (NGTS) dial 18001 followed by 0300 303 5678.

Will choosing this opt-out affect your care and treatment?

No, your confidential patient information will still be used for your individual care. Choosing to opt out will not affect your care and treatment. You will still be invited for screening services, such as that for bowel cancer.

Where do you have a choice?

If you choose to opt out, your confidential patient information will no longer be used for research and planning. There may still be times when your confidential patient information is used: for example, during an epidemic, where there might be a risk to you or to other people's health. You can also still give consent to share your data in a specific research project.

