A guide to the national data opt-out for helplines

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nhs.uk/your-nhs-data-matters

Introduction

This guide is about the choice patients and the public have about how their confidential patient information is used.

Information about patients' health and care helps us to improve individual care, speed up diagnosis, plan local services and research new treatments. In May 2018, the strict rules about how this data can and cannot be used were strengthened.

The NHS is committed to keeping patient information safe and always being clear about the purposes that it is used for. Members of the public can now choose whether their confidential patient information is used for research and planning. To find out more visit: nhs.uk/your-nhs-data-matters.

Helplines are highly effective at engaging with and providing support to people who may find it challenging to access mainstream healthcare provision. As these changes roll out, some of the people who contact your helpline may wish to discuss these changes with you, perhaps within a wider conversation.

This guide explains the national data opt-out in more detail, and provides information for call handlers on where to signpost callers for more information.

What are the changes?

Confidential patient information is used in two different ways:

Individual care

Health and care professionals may use confidential patient information to help patients with treatment or care.

For example, if someone visits a hospital, the doctor they see may access their GP records for important information about their health.

Research and planning

Confidential patient information is also used to:

- plan and improve health and care services
- research and develop cures for serious illnesses.

Most of the time, we use anonymised data for research and planning. So confidential patient information isn't always needed.

Confidential patient information will still be used to support individual care. Any preference a person sets using this service will not change this.

However, if someone doesn't agree with their confidential patient information being used for research and planning, they can opt out of this. If someone opts out, there are some specific situations where data may still be used. Data that does not identify a person may still also be used.

Examples of how information is used for research and planning

Research using GP data has improved the understanding of the link between diabetes and heart disease. This information can now be used to help plan healthcare services and support doctors and patients to have a better understanding of who might be at risk of heart disease.

To read more about this example and find others visit
www.patientdata.org.uk

How will information be used?

The NHS collects health and care data from all NHS trusts and local authorities. Data is also collected from private organisations, such as private hospitals providing NHS funded care. Research bodies and organisations can request access to this data.

Research bodies and organisations include:

- university researchers
- hospital researchers
- medical colleges
- pharmaceutical companies researching new treatments.

Who can’t use this data?

Confidential patient information is used to support the delivery of health and social care services. Access to identifiable health and care information will not be given to:

- marketing companies
- insurance companies

  (unless you specifically request this).

Patients and the public have a choice about how their information is used

Patients and the public who decide they do not want their confidential patient information used for planning and research purposes will be able to register their national data opt-out from 25 May 2018.

Patients and the public may use the online service to set or change their preference at any time. Alternatively they can phone the helpline to support them to opt out online or request a form to opt out via post. If someone is happy for their data to be shared for research and planning purposes then they do not need to do anything at all.

Why might callers be asking a helpline about this?

Patients and the public may hear about the national data opt-out through a range of methods, for example a handout in a community centre or a poster in a GP practice. It is possible that a caller may discuss the information that they have seen as part of a wider conversation with your helpline, or be seeking support to make a choice on whether or not to opt out.

This may be more likely to happen if your helpline:

- provides support on medical issues
- supports callers who are particularly vulnerable, such as being elderly, being a carer, having a disability, encountering a mental health problem or not having English as a first language
- supports callers in areas where confidentiality is a concern.

Where can a caller be signposted to for more information?

If members of the public would like more information about the national data opt-out, then please direct them to nhs.uk/your-nhs-data-matters or the national data opt-out helpline on 0300 303 5678. To use the Next Generation Text Service (NGTS) dial 18001 followed by 0300 303 5678.

Handouts are available from https://digital.nhs.uk/services/national-data-opt-out-programme/supporting-patients-information-and-resources in a range of accessible formats. These can also be requested by contacting the national data opt-out helpline on 0300 303 5678.

For more information about your data rights please visit the Your Data Matters campaign at [ico.org.uk](ico.org.uk).

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