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# A guide to the national data opt-out for the voluntary sector

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## What is changing?

'Your Data Matters to the NHS' is a campaign which informs the public that the strict rules about how data can and cannot be used were strengthened from May 2018. Individuals can choose whether their confidential patient information is used for research and planning.

The NHS is developing a new system to give patients more control over how their confidential patient information is used. The system will offer patients and the public the opportunity to make an informed choice about whether they wish their confidential patient information to be used for their individual care and treatment or also to be used for research and planning purposes.

Patients who decide they do not want their confidential patient information used for planning and research purposes can choose to set a national data opt-out.

## What is this guide for?

This guide is designed to inform voluntary and community sector partners about the national data opt-out.

We know that local patient groups, voluntary sector organisations, faith groups and other local forums are well placed to have conversations with their members and networks, including about sharing of health and care information.

We hope this document gives you the information you need to respond to queries and so you can support your members and networks to make an informed choice about what happens to their data.

We are grateful for, and thank you for, your support of engagement about the national data opt-out.

## How has this guide been developed?

This guide has been developed with the voluntary sector, who have supported us in understanding the needs of different groups, testing our communication materials and our approach to accessibility. We have heard from stakeholders that conversation guides would be a key resource for advocates or other community based staff.

## How can you get copies?

You can download a copy of this guide from 25 May 2018 using the national data opt-out website

<https://digital.nhs.uk/services/national-data-opt-out-programme/guidance-for-health-and-care-staff#guidance-for-voluntary-sector-staff>

## Background

### What is confidential patient information?

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

### How is 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 confidential patient information is used for research and planning

Research using confidential patient information 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 who might be at risk of heart disease.

Research using confidential patient information revealed that Black African women in England are nearly twice as likely to be diagnosed with late stage breast cancer as White women in England. This means researchers can now find out why there is this difference so diagnosis rates can be improved for Black African women.

To read more about these examples visit [www.patientdata.org.uk](http://www.patientdata.org.uk)

### About the national data opt-out

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

If they do opt out, there are some specific situations where their data may still be used beyond their individual care: for example, during an epidemic, where there might be a risk to their or to other people's health. See [nhs.uk/your-nhs-data-matters/manage-your-choice/where-opt-outs-dont-apply/](https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/where-opt-outs-dont-apply/) for more information on where opt-outs don't apply.

## How to register a preference

Members of the public may use the online or telephone service to request that their confidential patient information is not used beyond their own individual care. They can also set or change their preference at any time. If someone does not wish to opt out, they don't have to do anything at all.

Someone's decision will not affect their own individual care in any way. They can also change their mind in the future, if they wish to do so.

To opt out online people should go to [nhs.uk/your-nhs-data-matters](https://nhs.uk/your-nhs-data-matters).

## Before starting

An individual must have an email address or mobile phone number registered with an NHS service to continue online. They can ask their GP practice for help if they need to confirm their contact information is up-to-date.

They will also need:

- access to their email or mobile phone
- their NHS number.

## Where can people find their NHS number?

An NHS number is a 10 digit number, like 485 777 3456.

Patients can find their NHS number on any document sent to them by the NHS. This may include:

- prescriptions
- test results
- hospital referral letters
- appointment letters
- their NHS medical card.

Patients can ask their GP practice for help if they can't find their NHS number.

## Other ways for people to set their preference

Someone who wants support to opt out online can call the national data opt-out helpline at 0300 303 5678.

Alternatively they can set an opt-out through a paper-based process via the national data opt-out helpline. A form can be requested via the helpline. This will enable patients who have neither a mobile phone nor an email address to register their preference. It will still require some verification of identity.

A formal proxy, a person with legal powers to make decisions on behalf of someone else e.g. those with parental responsibility or lasting power of attorney, can register an opt-out on behalf of another person. This will be done through the paper-based route described above. For more information read the resource for carers at <https://digital.nhs.uk/services/national-data-opt-out-programme/supporting-patients-information-and-resources>.

## What can voluntary sector organisations do?

Some possible activities are listed below:

- put an item on the agenda for one of your regular meetings with members or networks
- hold a special meeting or a drop-in information session to discuss
- have conversations with individuals about the choice they are able to make
- include an update in one of your regular bulletins (see Appendix 1) or on your website
- display posters in your premises which can be downloaded at <https://digital.nhs.uk/services/national-data-opt-out-programme/supporting-patients-information-and-resources>
- share messages via social media. We are developing a pack of tweets that could be used
- make people aware that accessible materials, including easy-read materials, different languages and large print versions, are available on our website or via the helpline
- advise your members and networks where they can get more information
- provide feedback to the programme if you find the messages are not being understood or if there are specific barriers for any of the groups you engage with.

## Where can someone be signposted to for more information?

If people would like more information about the national data opt-out, then please direct them to [nhs.uk/your-nhs-data-matters](https://nhs.uk/your-nhs-data-matters) or the national data opt-out helpline on 0300 303 5678. To call us using the Next Generation Text service, 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:

- **Patient handout**
- **Easy-read handout**
- **Large print handout**
- **Audio of handout**
- **Braille handout**
- **BSL version of handout**
- **Language translations**

These can also be requested by contacting the national data opt-out helpline on 0300 303 5678.

Tailored resources have also been developed for groups that may have additional concerns or questions:

<https://digital.nhs.uk/services/national-data-opt-out-programme/supporting-patients-information-and-resources>:

- **Young People**
- **Carers**
- **BME Groups**
- **Gypsy Travellers (still in development)**

If people would like more information about their data rights they can visit the Your Data Matters campaign at [ico.org.uk](https://ico.org.uk).

## Our approach to engagement

Over the coming months there will be a wider communication about data sharing with new data protection legislation having been introduced in May 2018. This will include describing to the public the benefits of using data and how data is kept safe. The National Data Opt-out Programme will be responsible for communicating about the national data opt-out within this wider context so that people are aware of their choices. Our planned communications include:

- workforce engagement - this includes collaboration with the Royal College of General Practitioners to ensure that GP practices have the resources they require to support patients. It also includes a robust plan to communicate regionally and locally to the workforce via a range of networks and bulletins
- a layered public-facing information campaign - this will include posters/leaflets in public areas across the health and care system; information on nhs.uk; information in privacy notices; and targeted approaches, e.g. through specialist groups, community networks and the voluntary sector
- targeted engagement for groups who may miss the mainstream communication campaign. This will be done through existing voluntary sector networks working with groups such as the elderly, Gypsy, Roma and Traveller communities and people who are homeless
- engagement with patient participation groups who will be well placed to share information with their patients.

## Appendix 1: Sample bulletin content

### Your Data Matters to the NHS

Information about your health and care helps us to improve your individual care, speed up diagnosis, plan your 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 how it is used.

You can choose whether your confidential patient information is used for research and planning. Find out more at [nhs.uk/your-nhs-data-matters](https://nhs.uk/your-nhs-data-matters)

