A guide to the national data opt-out for carers

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Introduction

‘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 for their confidential patient information to be used only for their individual care and treatment or also used for research and planning purposes. If you would like to find out about how data saves lives a series of animations is available at www.patientdata.org.uk.

This additional guidance has been created to help carers through the process of supporting someone they care for to make the decision, or to make a decision on their behalf if necessary. This document assumes that the reader already understands the purpose of the national data opt-out. To find out about the national data opt-out visit nhs.uk/your-nhs-data-matters.

Helping the person you care for to make a decision

If the person you care for is able to make their own decision but requires some support to understand the information, you might want to access easy-read information, audio and other accessible materials to make this easier. These are available online at https://digital.nhs.uk/services/national-data-opt-out-programme/supporting-patients-information-and-resources.

You may also want to consider:

- communicating in a way that suits the person best, e.g. at a time(s) of the day when the person’s understanding is better than perhaps at other times or in a place/ setting where they feel more at ease
- breaking down difficult information into smaller points that are easier to understand and allowing people time to consider and understand each point before continuing
- explaining succinctly what the risks and benefits are to opting out, describing any foreseeable consequences of making the decision, and explaining the effects the decision might have on the person
- it may be necessary to repeat information or go back over a point several times.

If after doing this the person you care for wishes to register a national data opt-out, you can help them to do this using the online service at nhs.uk/your-nhs-data-matters. Alternatively you can contact the national data opt-out helpline on 0300 303 5678. They will guide you through the process or send you an opt-out form to complete and return by post.

You are encouraged to do as much as you can to help the person you care for to decide for themselves, using the materials listed above.

When the person you care for cannot decide whether to opt out for themselves

If the person you care for cannot make the decision about whether to set a national data opt-out themselves, you will need to follow the steps below to act in their best interests and register the choice you feel they would want to make.

Step 1:

Do you have a formal legal relationship with the patient allowing you to make decisions on their behalf? Examples would be parental responsibility for a child; legal power of attorney or court appointed deputy.

If the answer is yes, then follow step 2.

If the answer is no, then you cannot register a national data opt-out on their behalf, but you might be able to help the person to make a decision and support them through the process.

Step 2:

Do you feel that the person you care for would wish to opt out?

You should try to decide what the person would want if they could decide themselves about whether to set a national data opt-out. You might consider their past thoughts about information sharing and you may want to consult with people who know them.

If you think the person you care for is happy for their information to be shared you don't need to do anything further.

If you think that the person you care for would wish to register a national data opt-out, or you are satisfied that registering a national data opt-out is in that person's best interest then follow step 3.

Step 3:

Registering a national data opt-out

You will need to know the name, date of birth and NHS number of the person you care for. Our website explains how to find the NHS number.

You will need to have a photocopy of documentary evidence to demonstrate you have a formal legal relationship with the patient.

If you don't have the NHS number of the person you care for you will need a photocopy of an identity document for them instead. This is so that we can ensure that the opt-out is registered for the right person.

You will need to download a form which you will send in with the above documents to register a national data opt-out. The return address is on the form. The form can be found at https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/other-ways-to-manage-your-choice/.

Alternatively you can contact the national data opt-out helpline on 0300 303 5678. They will send you an opt-out form that you can complete and return. They will process the opt-out and let you know when it has been done.

Things to consider when making a decision on behalf of the person you care for

If you are caring for someone who is not able to make a decision, even with an easy-read version or other alternative formats, you will need to make the decision on that person's behalf.

We know that carers will want to make the right decision on behalf of the person they care for. To help you, here are some things you might want to consider if you are making this decision on behalf of someone else:

• you are likely to know the person you care for very well, so make a decision based on what you think their wishes would be

• what you decide to do with your own data should not influence what you decide on behalf of the person with care and support needs. You might decide that they would come to a different decision to you and that's completely fine

• try not to worry about the decision. If you make a decision that you think is best for the person you care for and best reflects their wishes, that is the most important thing

• remember you can only do the best you can when making the decision, it may not be possible to know what the person you care for would have wanted, but you can make a decision that you think is best for them.

• you can change your mind, on behalf of the person you care for, either to opt back in or opt out at a later date. To do this you should contact the national data opt-out helpline on 0300 303 5678.

Accessible information and further support

If you feel the person you care for can make a decision but needs some support to do this you can request an easy-read version of the information leaflet. Information is also available in Braille, large print, audio, British Sign Language and a selection of language translations.

The easy-read version of the leaflet and other formats can be found at https://digital.nhs.uk/services/national-data-opt-out-programme/supporting-patients-information-and-resources or you can request a copy by emailing enquiries@nhs.net. Alternatively you can call the national data opt-out helpline on 0300 303 5678.

To call the helpline using the Next Generation Text Service (NGTS) dial 18001 followed by 0300 303 5678.

There will be staff available via the national data opt-out helpline on 0300 303 5678 who will be able to answer your questions including those you may have as a carer.

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


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