

WHERE DO YOUR MEDICAL RECORDS GO?

Once data from your medical record has been extracted, the organisation that cares for you is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared or who has access to it.

Your NHS services across England are *required* to supply patients' personal and confidential medical information to part of the Department of Health – the Health & Social Care Information Centre, which trades as NHS Digital.

Medical staff treating you in GP surgeries, hospitals, A&E and out-of-hours centres will not use, or be able to use, the information held by NHS Digital. However, the uploaded data is likely to be made available to organisations outside of the NHS, such as universities and commercial organisations.

Details from your medical record are copied in a form that can identify you; these can include your NHS number, date of birth, postcode, gender and ethnicity, together with your medical diagnoses (including cancer and mental health), their complications, referrals to specialists, your prescriptions, your family history, details of your vaccinations and screening tests, your blood test results, your body mass index, and your smoking/alcohol habits.

Although care providers (such as hospitals or GPs) are required to copy the data, individual patients and their families have multiple rights and choices that can limit the transfer and what is done with their data.

These choices include the right to opt out of data leaving your GP practice, as well as the right to prevent your data being used for purposes beyond your direct care (the 'National Data Opt-out').

If you have children, Secretary of State Matt Hancock requires you to send documents to NHS officials who will decide whether you have proved to them that they are your children.

If you do nothing, i.e. if you do not opt out, then your and your children's medical information will be extracted and copied.

Once data is released, it does not get returned or deleted. So, while you can "change your mind at any time", your opt out will not cover any data that has already been copied.

Take action NOW

[Step 0: Check that your friends, family and colleagues know about this; it affects *everyone*.]

Step 1: To protect the most sensitive information held by your GP, simply fill in the form on the right. Cut out the form and post or drop it in to your GP practice, marked for the attention of your GP. If you wish to make a choice for your children or other members of your family for whom you are responsible at the same time, you can add their details on an additional sheet of paper.

Step 2: To express your wishes for the information held by care providers *other* than your GP, or for official bodies like NHS Digital, the official process to "Manage your choice" is described at:

<https://medconfidential.org/how-to-opt-out/>

Step 2.5: If you have dependents, NHS Digital requires you to send a form and (sometimes) documents about them.

Dear Doctor,

I am writing to give notice of my current wishes regarding the reuse of my medical records, and the records of those for whom I am responsible, for any purpose other than our direct medical care.

My wishes are as follows:

[Tick only the box relevant to your choice below]

'OPT OUT'

I DO NOT CONSENT to the reuse of my/our records for any purpose other than our medical care. Please ensure my dissent is recorded by whatever means possible, which includes adding the following codes to my/our records:

- GP data, or 'Dissent from secondary use of GP patient identifiable data' code (9Nu0 or SNOMED: **827241000000103**)
- Step 2 is no longer available via your GP*; NHS Digital requires you to complete a separate (possibly postal) process – see left.
- Turn sheet over and fill in details on reverse.

*To protect your *non-GP* data, you are now required to use the NHS Digital process explained here:

<https://medconfidential.org/how-to-opt-out/>

For your dependents, this may involve a paper form and several forms of ID documentation.

If you previously opted out, and you have changed your mind, and you do wish for your data to be used for purposes beyond your direct medical care, you must also use the NHS Digital process.

I am aware of the implications of this request, understand that it will not affect the care I receive and will notify you should I change my mind.

Signature: _____

Full name: _____

Address: _____

Postcode: _____

Date of birth: _____

NHS number (if known): _____

Additional patient(s) details:

Please take whatever steps necessary to ensure my choices about the following person's confidential personal information are respected, and record my choices on their behalf by whatever means possible.

Dependant's full name: _____

Address (if different): _____

Postcode: _____

Date of birth: _____

NHS number (if known): _____

Details of other family members whose choices I wish you to record are provided on a separate sheet, attached to this form.

Please note: this is not about the Summary Care Record (SCR), which is for the purpose of your direct care. Opting out of the SCR does not mean that you have automatically opted out of other data sharing.

Uses of patients' data for purposes beyond their direct care:

The National Data Opt-out covers data leaving:

- NHS Digital
- the Cancer Registry (the database of all cancer patients)
- other Disease Registries (date undecided)
- Clinical Practice Research Datalink (CPRD)
- by late 2021, hospitals and other care providers

The National Data Opt-out *does not* protect your data from:

- access by or copying to commercial organisations
- your and your family members' lifelong, linked medical histories being sold by NHS Digital
- onward release of data by non-DH Bodies

FIND OUT MORE

medConfidential recommends <http://nhsdatasharing.info> – a website by Dr Neil Bhatia, GP, which provides a more comprehensive overview of NHS data sharing.

Your data is shared by your CCG, NHS Digital and other parts of the Government, such as the MHRA and Public Health England. More information on this is provided at <https://www.nhs.uk/your-nhs-data-matters/> but it does not tell you how your medical records have been copied, for what reasons, or the outcomes of those actions.

Opting out will have no effect on your medical care. You can change your mind at any point, as new information is made available to you.

Copies of this leaflet for you to give to your friends and family can be downloaded from:

<https://medconfidential.org/how-to-opt-out/>

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**IMPORTANT INFORMATION
ABOUT YOUR MEDICAL RECORDS**

Please read – you may need to act