

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, also known 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 can limit the transfer of their data, i.e. **you have the right to opt out**. There are various options, including a “National Data Opt-out” introduced in May 2018.

If you do nothing, i.e. if you do not opt out, then your 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 already copied.

To express your wishes, simply fill in your details and tick the correct box(es) on the form to the right of this page. **CAUTION: tick only the box(es) that express your consent choice – the top two tickboxes opt you out, the bottom tickbox opts you in.** 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 opt out – or opt in – your children or other members of your family for whom you are responsible, you can add their details on an additional sheet of paper.

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.

Further information is available online – details overleaf.

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(es) 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
(Read v2: 9Nu0 or CVT3: XaZ89)
- National Data Opt-out programme**, or 'Dissent from disclosure of personal confidential data by NHS Digital' code
(Read v2: 9Nu4 or CTV3: XaaVL)
- Turn sheet over and fill in details on reverse.*

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, then use the tickbox below:

I CONSENT to the reuse of my records for purposes other than my medical care. Please ensure my withdrawal of dissent is recorded by adding the following code to my record:

'Dissent withdrawn from disclosure of personal confidential data by NHS Digital'
(Read v2: 9Nu5 or CTV3: XaaVM)

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.

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

The National Data Opt-out covers data leaving:

- NHS Digital
- the Cancer Registry (by October 2018)
- other Disease Registries (date undecided)
- CPRD
- by 2020, hospitals and other care providers

The National Data Opt-out *does not* cover:

- commercial sale of HES by NHS Digital
- lifelong linked medical histories being disseminated by NHS Digital
- onward release of data by non-NHS Bodies

FIND OUT MORE

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

Your data is shared by your CCG, NHS Digital and other parts of the Government, such as MHRA and Public Health England – the latter affecting every patient who has had cancer in the last 20 years, which collects data on an ongoing basis. 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, why, or the outcomes from 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 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