

Controlling your medical records – Type 1 opt-outs

You have the right to control how medical information about you is shared, disseminated or sold, for purposes other than your direct medical care – so called *secondary uses (or purposes)*.

Secondary uses include projects involved in risk stratification, “population health management”, national clinical audits, research, healthcare planning, commissioning of healthcare services by CCGs, commercial and even political uses.

You can control your personal confidential information by expressing an objection, or *opt-out*, to your GP surgery, who will then add a special read-code, or electronic flag, to your GP record.

One such opt-out is known as a *Type 1 opt-out* (sometimes referred to as a *9Nu0* opt-out, after the flag added when expressed).

A Type 1 opt-out, when present in your GP record, should prevent identifiable information about you being extracted from your GP record, and uploaded to *any* other organisation, for purposes other than your direct care.

A Type 1 opt-out should then prohibit extraction and uploading for all of the following secondary uses:

- Risk stratification schemes (often run by your local CCG)
- National clinical audits (such as the National Diabetes Audit)
- The Clinical Practice Research Datalink (CPRD)
- Extraction of de-identified information about you concerning any eMed3 Statement of Fitness to Work reports (i.e. sick notes), uploaded to NHS Digital, and subsequently passed by the HSCIC to the Department of Work and Pensions
- All extractions and uploading of identifiable information about you to NHS Digital, for any secondary purpose (so-called GPES extractions)

It is therefore, a single, unitary, secondary uses, opt-out.

Unfortunately, the Type 1 opt-out is not 100% effective in prohibiting *all* of the above secondary uses. Some of those schemes, most notably some of the risk stratification schemes processing information for secondary purposes blatantly ignore the Type 1 opt-out.

However, the opt-out form on www.nhsdatasharing.info will ensure that no such secondary processing takes place, should that be your wish.

A Type 1 secondary use objection will *in no way affect* how healthcare professionals provide you with direct medical care, or prevent them accessing your medical record if and when appropriate, and with your explicit consent.

Secondary uses are not about information sharing between healthcare professionals.

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Be reassured - a Type 1, secondary uses opt-out:

- *Will have no effect* on aggregate information about you being shared within the NHS to help medical research
- *In no way* prevents you from agreeing - with your *explicit consent* - to partake in high-quality medical research based at your GP surgery, particularly if your surgery is a [Research Ready accredited practice](#)
- *Will not* prohibit your GP from writing to you to invite you to take part in such research, should you wish to
- *Will not* prohibit you from explicitly consenting to have your DNA sequenced under the [100K project](#), should you be eligible
- Will not prohibit the extraction of your data by [UK Biobank](#), if you have signed up, and explicitly consent, to this project

It *will not* stop you from:

- [Giving blood](#)
- [Joining the NHS Organ Donor Register](#)
- [Signing up to the Anthony Nolan register](#) to donate your blood stem cells or bone marrow
- [Donating your DNA for medical research](#)
- [Taking part in clinical drug trials](#)
- [Donating your body to medical science](#) after your death
- Giving money ([in a tax-efficient way](#)) to any medical charity of your choosing

It will have *no effect* on the medical care that you receive either from your GP surgery or from anywhere else within the NHS or private sector.

It will have *no effect* on your GP surgery and the way that it is paid by the NHS or on the services that it provides (e.g. via [CQRS](#)).

It will have *no effect* on the way that any hospital is paid by the NHS for treating you (e.g. [Payment by Results](#)).

It will have [*absolutely no effect whatsoever*](#) on any of the following:

- *The Electronic Prescription Service*
- *Choose & Book/E-Referrals*
- *The Summary Care Record*
- [GP2GP](#) transfers
- *The NHS Cervical Screening programme*
- *The NHS Bowel Cancer Screening programme*
- *The NHS Breast Screening programme*
- *The NHS Abdominal Aortic Aneurysm Screening programme*
- *NHS Diabetic Retinopathy Screening*
- *Uploading of aggregated information via [The Quality and Outcomes Framework](#)*

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The Type 1 / 9Nu0 secondary uses opt-out is a very useful flag to request your GP to add to your surgery record. For many of the secondary uses schemes:

- Your GP surgery will not be the data controller for the uploaded information
- You may never find out that your information is being used in these ways
- You may never find out how your information is, or will be, used in these ways
- You have little or no control over which organisation receives your personal confidential information
- You have little or no control over how your information is used by those organisations
- You cannot prevent those organisations from passing your information on to other organisations

You will lose control of your information once extracted and uploaded - unless you opt-out.

You can express a Type 2 opt-out as well (see separate factsheet), and with *both* the Type 1 and Type 2 opt-outs in force, and marked in your GP record:

- No record-level information whatsoever will be uploaded from your GP record to NHS Digital
- NHS Digital will have *no* information from your GP record to release or sell, in any format, to any organisation, for any purpose
- NHS Digital will only continue to hold information extracted from your hospital records, as well as aggregate information (i.e. numbers) from your GP practice
- NHS Digital will not be able to release or sell any information that clearly identifies you from the information extracted from your hospital records

If you wish to opt-out of secondary uses, do so now.

Following the publication of the Caldicott 3 data sharing proposals, it may well be that the Department of Health will withdraw the right of citizens to prevent the extraction and uploading of their personal confidential information to NHS Digital.

After a certain date, it may be that you will no longer be able to request such an opt-out from your GP surgery. You can opt back in to secondary uses at any time in the future.

A Type 1 opt-out, for as long as it is available, *might* well stop the extraction of your GP medical information to the Single National GP Dataset, the replacement to the now decommissioned care.data project.

You can find out more about secondary uses, the effects of the 9Nu0 opt-out, the NHS Databases, and NHS data sharing in general, as well as a suitable opt-out form, at:

www.nhsdatasharing.info