

Controlling your medical records – Type 2 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 2 opt-out* (sometimes referred to as a *9Nu4* opt-out, after the flag added when expressed).

The Type 2 opt-out acts to control information about you as held by the NHS Digital (formerly the HSCIC).

NHS Digital holds information about you obtained from a variety of sources, such as hospital trusts, mental health services, maternity records, community records, collectively known as Hospital Episode Statistics (HES). It also holds some information from your GP record.

NHS Digital, and its predecessor the NHSIC, have been giving, and selling, HES data for years and years, to hundreds and hundreds of organisations, a fact only commonly realised since the (now discontinued) *care.data* project was proposed.

A Type 2 opt-out, when present in your GP record, should prevent identifiable information about you being disseminated, shared or sold, by NHS Digital, for purposes other than your direct care.

It will not prevent NHS Digital disseminating, sharing, or selling, information about you that is either effectively anonymised (i.e. cannot identify you), or aggregated (i.e. just numbers).

More information about Type 2 opt-outs can be found at <http://content.digital.nhs.uk/article/7072/Applying-Type-2-Opt-Outs>

A Type 2 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.

With a Type 2 opt-out in force, you will still be invited to cervical screening, breast screening, bowel cancer screening, diabetic retinopathy screening, abdominal aortic aneurysm screening, and any other current or future national screening programmes, if you are eligible - the Type 1 and Type 2 opt-outs do not prevent these programmes in any way.

Controlling your medical records – Type 2 opt-outs

The 9Nu4 opt-out is a very useful flag to request your GP to add to your surgery record. When it comes to how NHS Digital disseminates or sells personal confidential information that it holds about you:

- You will not be asked before your data is released or sold by NHS Digital
- You will not be informed when your data has been released or sold by NHS Digital
- You cannot approve or select the organisations that NHS Digital gives or sells your information to
- You cannot prohibit the release or sale of your information to organisations based outside of the UK
- You cannot prohibit the release or sale of your information to non-NHS organisations, such as commercial or insurance companies
- You cannot select what information about you is released or sold, and what is not
- You cannot specify that information about you is only used or sold for research purposes
- You cannot object to your information being provided or sold to particular organisations, or for particular research, that you find ethically unacceptable
- You cannot object to your information being provided or sold in ways that might contribute to the closure of local NHS services (such as your local A&E department or hospital trust)
- You cannot object to your information being provided or sold to organisations who might already hold other information about you
- You cannot track your data once sold - you will *not* be able to trace where your data went, or whether it was sold on under a commercial re-use license, to whom, and for what further purpose

You can express a Type 1 opt-out as well (see separate factsheet).

With *both* the Type 1 and Type 2 opt-outs in force, and marked in your GP record:

- No 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
- NHS Digital will not be able to release or sell any information that clearly identifies you from the information extracted from your hospital records

You can find out more about secondary uses, the effects of the 9Nu4 opt-out, the NHS Databases, and NHS data sharing in general, as well as a suitable opt-out form, at:

www.nhsdatasharing.info