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)

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.

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.

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

- *Will have no effect* on anonymised or aggregate (numbers) information 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 at your GP surgery/local hospital/other health organisation, where you have given your explicit consent to be involved (i.e. you have been asked *first*).

It will **in no way** prevent 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
- Contributing to UK Biobank
- Joining the 100K Genomes project
- Taking part in clinical drug trials
- Donating your body to medical science after your death
- Giving money (in a tax-efficient way) to a medical charity
- Being contacted by your GP to invite you to take part in any research

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
- Information being *provided* to the National Disease/Cancer Registries (run by Public Health England).
- Uploading of aggregated information via The Quality and Outcomes Framework
- Uploading of aggregated information via QSurveillance

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 National Data opt-out as well (see separate factsheet), and with *both* the Type 1 and National Data opt-outs in force:

- 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

Information about the "*National Data Opt Out*", can be found in this factsheet.

OPT OUT FORM – MEDICAL RECORDS

Dear GP Surgery,

I do not wish to allow my medical records to be used for any purpose other than my medical care.

Please ensure my dissent to secondary uses is recorded by whatever means possible, which includes adding the following codes to my GP record:

☐   Uploading information from my GP record

Type 1 objection: 9Nu0/XaZ89

I understand that I can opt back in to any or all of these at any time in the future

Name:

Signature:

DOB:

Your name/signature & relationship if applying on behalf of another person (e.g. parent/legal guardian):