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:

- General Practice Data for Planning and Research (GPDPR) extraction
- Risk stratification schemes
- National clinical audits (such as the National Diabetes Audit)
- 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 NHS Digital 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 from accessing your medical record if and when appropriate, and with your explicit consent.

Secondary uses are not about information sharing between healthcare professionals.

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.

It will have no effect on the way that any hospital is paid by the NHS for treating you.

It will have absolutely no effect whatsoever on any of the following:

- The Electronic Prescription Service
- E-Referrals
- The Summary Care Record
- EMIS Web data streaming
- 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).
- It will in no way affect any medical care you need for COVID-19
- It will in no way affect your eligibility for, or your ability to receive, your COVID-19 vaccinations

- It will in no way affect your ability to hold, or show, a "COVID-19 vaccination passport"
- It will in no way affect your ability to contribute to research about COVID-19, if you are asked for your explicit permission first