

The National Data Opt Out

a factsheet

NHS Digital has launched the National Data Opt Out on 25th May 2018, to coincide with the EU GDPR. www.nhs.uk/your-nhs-data-matters

What is the National Data Opt Out (NDOO)?

The NDOO is a mechanism by which individuals in England can control, to a limited degree, certain aspects of their confidential medical information and, in particular, what NHS Digital can do with it once in their possession.

The NDOO only applies to confidential information, which is medical information that can identify you, for example by containing your name, DOB, address, NHS number etc. The NDOO is not limited to electronic data and so includes paper records.

And the NDOO only applies to uses of your confidential medical information for secondary purposes, that is unrelated to, and beyond, the direct medical care that GP surgeries and other healthcare organisations provide you with when you are unwell, or to keep you well. Secondary purposes include healthcare planning, audit, population analytics, “risk stratification”, research, “commissioning”, commercial and even political uses.

Nearly always, you are not asked for your permission before your information is used in this way. It simply replaces the Type 2 (9Nu4) opt-out that has been in force for some years, and which you were able to express, together with the Type 1 (9Nu0) objection, via your GP Practice.

It is, therefore, nothing new.

If I set, or keep, my NDOO status at “do not allow”, what will this mean?

- Confidential medical information obtained by NHS Digital from GP surgeries, hospital trusts, mental health providers and social care, will not be released or disseminated by them in a format that can identify you.
- In due course, the NDOO will prohibit certain data extractions from your GP record, where this involves confidential medical information, and where your permission or consent would not be sought before your data was released (so-called section 251 approval).
- The NDOO will, eventually, prevent confidential medical information leaving the Cancer Registry, certain other disease registries, the Clinical Practice Research Datalink (CPRD); and
- By 2020, all hospitals and other healthcare providers.

What will the NDOO/Type 1 objection NOT do?

- They will **in no way** affect the sharing of information for the purposes of your medical care and treatment, e.g. where information is shared between a GP Practice and a hospital. It will not stop your GP using the Electronic Referral Service (eRS), the Electronic Prescription Service (EPS), or GP2GP transfers of medical records.

- They will **in no way** affect the National Summary Care Record (SCR). You can opt-out of the SCR via the Practice or our website.
 - The NDOO will **in no way** affect any local shared care record project or scheme
 - They will **in no way** affect SystmOne data streaming. You can opt-out of SystmOne data streaming via the Practice or our website.
 - They will **in no way** prevent you from registering for secure online access to your GP record (Patient Online). You can find more information about that on our website.
 - They will in no way affect situations where the Practice, or other healthcare organisation, is legally required to share your information (such as a court order or when mandated under section 259 of the Health and Social Care Act – but see later).
 - They will **in no way** affect you being invited, when appropriate, for any of the National Screening Programmes, such as cervical/breast/bowel/abdominal aortic aneurysm/diabetic eye screening. You can opt-out of these separately, if you wish.
 - They will **in no way** stop information being provided to the National Disease/Cancer Registries (run by Public Health England). You can opt-out of this separately, if you wish.
 - They will **in no way** affect situations where the Practice, or any other healthcare organisation, shares data in an anonymised or aggregate (numbers only) format, in other words where that data cannot identify an individual. Such as “open data”.
- The NDOO **will not stop**:
 - o Commercial sales of hospital data (HES) by NHS Digital
 - o Lifelong linked medical histories being disseminated by NHS Digital
 - o Onwards release of data by non-NHS bodies (once they have been provided with your information by NHS Digital)

What about Research?

The NDOO/Type 1 objection will **in no way** prevent you from taking part in accredited medical research, at your GP Practice/local hospital/other health organisation, where you have given your explicit consent to be involved (i.e. you have been asked first for permission).

They 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 – with your permission
- “Donating your Data” for medical research - with your permission
- Contributing to UK Biobank - with your permission
- Joining the 100K Genomes project - with your permission
- Taking part in clinical drug trials
- Joining dementia research
- “Crowdsourc” cancer research via games and apps
- Donating your body to medical science after your death
- Donating your brain to medical science after your death
- Making a living donation (e.g. kidney, liver or bone)

- Donating your hair (to make a wig for children and young adults)
- 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
- Granting researchers access to your medical records, or information extracted from your medical records - with your permission

Will the NDOO stop my confidential GP information being uploaded to NHS Digital in the first place?

No. NHS Digital does not rely upon section 251 approval (anymore) for data gathering, preferring instead to make such data collections compulsory under section 259 of the Health and Social Care Act.

However, the existing secondary uses, Type 1 (9Nu0), opt-out that many people have in force on their GP record **will** prohibit data (confidential and, in some cases, de-identified) from being extracted and uploaded from your GP record to NHS Digital. In addition, the Type 1 opt-out will also prohibit section 251 approved data extractions, for example for “risk stratification”, as well as the mandatory section 259 extractions.

So how do I maximally limit secondary uses of my medical records, beyond my direct medical care, should I wish to?

- 1) Set your NDOO status to “do not allow”, see later for how to do this, **and**
- 2) Make sure you have a secondary uses, Type 1 (9Nu0) objection in force on your GP record – do this via the Practice or our website

What about preventing NHS Digital releasing or disseminating anonymised and pseudonymised data about me?

You cannot – directly. And you have no control over why they are doing this, for what purpose(s), and to which organisation they are releasing your information to.

But you can limit how much information NHS Digital gathers about you from healthcare organisations, if you want, by maximally limiting the secondary uses of your medical records, as described above.

So how do I set, check, or update my National Data Opt Out status?

If you had previously requested a Type 2 objection to be in force, via the Practice, then this will automatically have set your NDOO status to “do not allow”. You should have received a letter from NHS Digital, confirming this. Any children aged 13yrs or over will have received their own letter as well.

It is no longer possible to directly view, set or change your NDOO status at your GP Practice.

Anyone aged 13yrs or over can set their NDOO status via an online service at www.nhs.uk/your-nhs-data-matters

Anyone aged 12yrs or younger, or acting on behalf of another individual (i.e. as a proxy, perhaps with lasting power of attorney authority), cannot do this online but will have to ring 0300 303 5678, or by printing off a form and posting it.

More information about NHS data sharing, opting-out and objecting, and the NHS databases can be found on our website or at www.nhsdatasharing.info