

# **AMP patient opt out policy**

In most cases the GP practice will only share data with other health and social care providers for direct care purposes with implied or explicit consent. However the NHS has systems in place for sharing of data for direct care and other so called secondary uses that go beyond direct patient care. These systems have been designed as “opt-out systems”. That is all NHS patients in England are opted into these national and local schemes but then patients have to opt out if they do not want their data to be used in this way. The onus is on the practice to highlight such data sharing. We do this through our Privacy Notice and information on our billboards and website. The following sections describe our approach to data opt-outs and the information we give our patients on this issue.

## **Background**

### **Data Sharing for Direct care**

We share patients personal information on national (summary care record) and local (connect care) data sharing platforms to create care records that would allow healthcare professionals to see information on our patient’s medical history if needed in direct care clinical situations with the consent of the patient when possible. Even though these are direct care purposes, patients are able to opt out of such sharing.

### **Data Sharing for Secondary Uses**

Data is also shared with national organisations and data processors based on national guidelines and law. This is for purposes that go beyond direct medical care that GP surgeries and other healthcare organisations provide patients.. Secondary purposes include healthcare planning, audit, population analytics, research, and commissioning at a local, regional or national level. Often this will include patient identifiable data but sometimes may be anonymised aggregate data. Patients are able to opt out of secondary uses of their information.

## **Summary care Records**

The Summary Care Record (SCR) is an electronic record of important patient information, created from GP medical records. It can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care. This would normally be in a urgent or emergency clinical situation. Unlike connect care records which can only be viewed by health and social care professionals in South East London, this is a national care record, and can be accessed across England if the situation arose. Certain parts of patient medical records will be shared within the NHS to provide effective care to patients outside their GP practice. This will enable health care professionals to have quicker access to information about any medicines or allergies/bad reactions a patient may have had. The summary care record will contain Name, Date of Birth, NHS number, repeat medications and allergies. Information can only be accessed by an NHS professional that holds an NHS smart card with a chip and passcode. People accessing information can only see parts that are relevant to their job. Health care staff will ask for a patient's permission every time they need to look at the summary care record. If the patient is unable to be asked, i.e. they are unconscious, the health care professional may look into the record if it is for the good of the patient but a note will be places in the medical records to show this. The SCR is run by NHS Digital. NHS Digital is the secure haven for NHS patient data, a single secure repository where data collected from all branches of the NHS is processed. NHS Digital provides reports on the performance of the NHS, statistical information, audits and patient outcomes as well as patient level clinical IT platforms.

For more information about summary care records, visit <https://www.england.nhs.uk/learning-disabilities/improving-health/summary-care-records/>

If you wish to opt out of summary care records, fill out the form below and send to the GP practice.



Your emergency care summary

# OPT-OUT FORM

CONFIDENTIAL

## Request for my clinical information to be withheld from the Summary Care Record

If you **DO NOT** want a Summary Care Record please fill out the form and send it to your GP practice

### A. Please complete in BLOCK CAPITALS

Title ..... Surname / Family name .....

Forename(s) .....  
.....

Address .....  
.....

Postcode..... Phone No..... Date of birth .....

NHS Number (if known)..... Signature .....

B. If you are filling out this form on behalf of another person or a child, their GP practice will consider this request. Please ensure you fill out their details in section A and your details in section B

Your name ..... Your signature.....

Relationship to patient..... Date .....

### What does it mean if I ~~DO NOT~~ have a Summary Care Record?

NHS healthcare staff caring for you may not be aware of your current medications, allergies you suffer from

and any bad reactions to medicines you have had, in order to treat you safely in an emergency.

Your records will stay as they are now with information being shared by letter, email, fax or phone.

If you have any questions, or if you want to discuss your choices, please contact your GP practice.

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FOR NHS USE ONLY

Actioned by practice: yes / no

Date.....

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Ref:4705

## **Appendix Two- Patient Information Leaflet – Secondary Uses**

# **THE NATIONAL DATA OPT OUT (NDOO)**

### **Introduction**

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 that 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 are 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.

However you are able to opt out of such uses of your data. A Type 1 opt out stops data from your GP records going to NHS Digital for secondary uses. The NDOO (previously known as the Type 2 opt out) stops any other data held by other health and social care providers going to NHS digital. You may opt of either or both. However, if you want to maximise that chance of your data not being in anyway way apart from direct medical care you should do a Type 1 and NDOO opt out.

For further information see- <https://digital.nhs.uk/services/national-data-opt-out-programme>

## **Type 1 opt-outs**

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

## **NDOO (previously called Type 2 Opt)**

The national data opt-out enables patients to set or update their choice regarding how their confidential patient information is used for purposes of planning and research, except for certain circumstances.

The opt-out choice is set directly by the patient, either online or via a supported national telephone service without the involvement of the General Practice.

All type 2 objections will be converted to national data opt-outs from 25 May 2018 and any patient wanting to opt-out after this date should be directed to the national data opt-out.

Once an individual registers a national data opt-out, their confidential patient information may not be used for the purposes of planning and research. Until a patient registers a national data opt-out their confidential patient information may be used for purposes of planning and research providing there is a legal basis to do so unless they have a type 1 objection in place in which case their GP data will not be used

A national data opt-out will not apply retrospectively, meaning it does not need to be applied to data that has already been processed. At the point a particular dataset has been used or released, all patients who have opted out at that time will be removed. Data does not need to be recalled once released or otherwise processed. A patient may choose to change their opt-out decision at any time and their current choice will be respected at any given time, replacing any previous choices made. If a patient has previously opted-out, but then subsequently withdraws their opt-out, their confidential patient information (including any historic data) will become available for use beyond their individual care once again. This is true even where the data relates to a period where the patient had previously opted-out.

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

- 1)** If you wish to opt out of Secondary uses (NDOO) of information from health providers you can do so at 'Your NHS Data matters' website ([www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters)) where you can find out more about data sharing and set a national data opt-outs

**2)** Make sure you have a secondary uses, **Type 1** (9Nu0) objection in force on your GP record as well – do this via the receptionists.

If you have Type 1 opt out at the GP surgery and have a NDOO with NHS Digital –

- 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 I set, or keep, my Type 1/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 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 surgery 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 surgery
- They will **in no way** prevent you from registering for secure online access to your GP record (Patient Online).
- They will **in no way** affect situations where the surgery, 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.
- They will **in no way** stop information being *provided* to the National Disease/Cancer Registries (run by Public Health England).
- They will **in no way** affect situations where the surgery, 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.
- They will in no way effect the ways GP practices and hospitals are paid for the work they do,.
- The NDOO will **not stop**:
  - Commercial sales of hospital data (HES) by NHS Digital
  - Lifelong linked medical histories being disseminated by NHS Digital
  - Onwards release of data by non-NHS bodies (once they have been provided with your information by NHS Digital)

## **What about Research/Blood and Organ Donation?**

The NDOO/Type 1 objections will **in no way** prevent you from [taking part in accredited medical research](#), blood or organ donation 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 for permission*).

## **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 surgery, then this will have automatically have set your NDOO status to “*do not allow*”. You will receive a letter from NHS Digital, confirming this, in due course. Any children aged 13yrs or over will receive their own letter as well.

Anyone aged 13yrs or over can set their NDOO status via an online service at [www.nhs.uk/your-nhs-data-matters](http://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](#).

# **OPT OUT FORM – MEDICAL RECORDS**

Dear TMA,

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.

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Name:

Signature:

DOB:

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

## **National data opt-out (Type 2 Objection)**

If you wish to opt out of, **Type 2 / national data opt out** you can do so at 'Your NHs Data matters' website (<https://www.nhs.uk/your-nhs-data-matters/>) where you can find out more about data sharing and set a national data opt-outs