

# GP Data for Planning and Research and Your Options

## What is this?

As part of running the health service, the Secretary of State can request that providers of services, such as your GP, must provide data to the centre. These are used for a wide variety of purposes including:

- Managing and planning demand for services such as how many people are being diagnosed with particular illnesses
- Analysing the outcomes of services to ensure the health service delivery is getting results
- Recently, managing the pandemic

These are requested from your GP by “Data Provision Notices” (DPNs) – which your GP is legally required to comply with. You can see all the current Data Provision Notices at:

<https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/data-provision-notice-dpns>,

The new extract service is now called “GP Data Service”, replacing the previous “GP Extraction Service”.

## What is the main change?

Currently these DPNs are mostly single purpose; for example, an extract of numbers of patients diagnosed with dementia. Because they are single purpose, commonly NHS Digital are taking the same data more than once, so an audit report a few years ago pointed out this was inefficient and needed consolidation.

## What is the “data grab” the press are talking about?

As part of work to consolidate the data provision notices (DPNs) NHS Digital have announced a new data provision called the “General Practice Data for Planning and Research”. A similar extract was already there for the pandemic purposes, but this will expire in September 2021 (unless extended). This is a general extract of “pseudonymised” data – that is, the data cannot directly identify you, but it is possible, with the assistance of NHS Digital, to identify you from data NHS Digital hold.

**No directly identifiable data is being shared with anyone outside your GP.**

The information being shared is “coded data” – this means things like particular conditions you have, basic details about you (age, area where you live), medications, some appointment data, vaccination status and so on.

Your GP notes are **not** shared – there are also a large number of excluded codes so it is not your “complete GP record” as some press reports state.

## Why might NHS Digital need to identify me from this data?

This is a very rare circumstance and the most common would commonly be for purposes of your safety. For example, suppose that research into the data showed that people with a particular condition treated with a particular drug had poor outcomes, it may be necessary to inform your GP that you fall into this

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group so treatment would be changed. There are other reasons for legally doing so, but these are far less common; it is an offence to re-identify data without a legal purpose.

## I don't want my data used like this. Can I opt out?

Yes.

Please fill in the form on the next pages and post/email to your GP. Your GP will apply the code which will stop your data being extracted.

The extract is now being delayed until September, so if you wish to opt out you need to do so before that date. If you apply the code later, your data will not be included in later extracts, but will be retained.

## I thought this was what the "National Data Opt-Out" was about?

The National Data Opt-Out (NDOP) applies to "confidential patient data" – that is, data that is identifiable. It appears that NHS Digital did not consider this data to be under that banner because it is pseudonymised. In law, pseudonymised data is still identifiable.

You can exercise the National Data Opt-Out by going to the web page below. There is a postal form available if you need it.

<https://www.nhs.uk/your-nhs-data-matters/>

It is unfortunate that this was done this way, because this is creating concern and putting load on GPs who are still dealing with the pandemic as your GP surgery has to apply the type 1 opt-out.

## Can I speak to the Practice DPO about this?

You always have the right to contact the practice DPO – however, the DPO is very clear that this is a legal extract and therefore patients can only exercise the opt-out.

Professional bodies have made representations to the Secretary of State for Health about this process and concerns. The DPO, along with other NHS DPOs has also made representations to NHS Digital expressing concern.

The DPO Contact details for North Central London Practices is Steve Durbin [dpo.ncl@nhs.net](mailto:dpo.ncl@nhs.net). You can also contact him by letter to your practice, or by phone to 020 8142 3936.

Please note that because this is legal, the DPOs advice is already clear – if you do not wish your data to be used in this way, you need to exercise the opt-out.

## Register your Type 1 opt-out

The data held in your GP medical records is shared with other healthcare professionals for the purposes of your individual care. It is also shared with other organisations to support health and care planning and research.

If you do not want your personally identifiable patient data to be shared outside of your GP practice for purposes except your own care, you can register an opt-out with your GP practice. This is known as a Type 1 Opt-out.

Type 1 Opt-outs may be discontinued in the future. If this happens then they may be turned into a National Data Opt-out. Your GP practice will tell you if this is going to happen and if you need to do anything. More information about the National Data Opt-out is here: <https://www.nhs.uk/your-nhs-data-matters/>

You can use this form to:

- register a Type 1 Opt-out, for yourself or for a dependent (if you are the parent or legal guardian of the patient) (to **Opt-out**)
- withdraw an existing Type 1 Opt-out, for yourself or a dependent (if you are the parent or legal guardian of the patient) if you have changed your preference (**Opt-in**)

This decision will not affect individual care and you can change your choice at any time, using this form. This form, once completed, should be sent to your GP practice by email or post.

### Details of the patient

<b>Title</b>											
<b>Forename(s)</b>											
<b>Surname</b>											
<b>Address</b>											
<b>Phone number</b>											
<b>Date of birth</b>											
<b>NHS Number (if known)</b>	<table border="1"><tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr></table>										

### Details of parent or legal guardian

If you are filling in this form on behalf of a dependent e.g. a child, the GP practice will first check that you have the authority to do so. Please complete the details below:

<b>Name</b>	
<b>Address</b>	
<b>Relationship to patient</b>	

## Register your Type 1 opt-out

### Your decision

**Opt-out**

I do not allow my identifiable patient data to be shared outside of the GP practice for purposes except my own care.

OR

I do not allow the patient above's identifiable patient data to be shared outside of the GP practice for purposes except their own care.

**Withdraw Opt-out (Opt-in)**

I do allow my identifiable patient data to be shared outside of the GP practice for purposes beyond my own care.

OR

I do allow the patient above's identifiable patient data to be shared outside of the GP practice for purposes beyond their own care.

### Your declaration

I confirm that:

- the information I have given in this form is correct
- I am the parent or legal guardian of the dependent person I am making a choice for set out above (if applicable)

**Signature**

**Date signed**

**When complete, please post or send by email to your GP practice**

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### **For GP Practice Use Only**

Date received		
Date applied		
Tick to select the codes applied	<b>Opt – Out - Dissent code:</b> 9Nu0 (827241000000103  Dissent from secondary use of general practitioner patient identifiable data (finding) )	
	<b>Opt – In - Dissent withdrawal code:</b> 9Nu1 (827261000000102  Dissent withdrawn for secondary use of general practitioner patient identifiable data (finding) )	