

GDPR Practice Data for Planning and Research (GPDPR)

Why NHS Digital collects general practice data

NHS Digital is the national custodian for health and care data in England and has responsibility for standardising, collecting, analysing, publishing and sharing data and information from across the health and social care system, including general practice.

NHS Digital collected patient data from general practices using a service called the General Practice Extraction Service (GPES), which has operated for over 10 years and now needs to be replaced. NHS Digital has engaged with doctors, patients, data and governance experts to design a new approach to collect data from general practice that:

- reduces burden on GP practices
- explains clearly how data is used
- supports processes that manage and enable lawful access to patient data to improve health and social care

What the data will be used for

Patient data collected from general practice is needed to support a wide variety of research and analysis to help run and improve health and care services. Whilst the data collected in other care settings such as hospitals is valuable in understanding and improving specific services, it is the patient data in general practice that helps us to understand whether the health and care system as a whole is working for patients.

In addition to replacing what GPES already does, the General Practice Data for Planning and Research service will also help to support the planning and commissioning of health and care services, the development of health and care policy, public health monitoring and interventions (including coronavirus (COVID-19) and enable many different areas of research, for example:

1. Research the long-term impact of coronavirus on the population

There is a lot about coronavirus that we do not know, including the long-term health impacts. Patient data from GP medical records will be very important in the coming months and years, as scientists analyse and understand the impact of the virus on human health.

2. Analyse healthcare inequalities

For example, to understand how people of different ethnicities access healthcare and how the outcomes of particular groups compare to the rest of the population. This will help the NHS to assess healthcare inequalities and make any necessary changes to its services.

3. Research and develop cures for serious illnesses

For example, patient data is being used by the [University of Oxford RECOVERY trial](#), which has found ways to improve the treatment for people with coronavirus.

What data is shared

This data will be shared from **1 September 2021**. Data may be shared from the GP medical records about:

- any living patient registered at a GP practice in England when the collection started - this includes children and adults
- any patient who died after 1 September 2021, and was previously registered at a GP practice in England when the data collection started

NHS Digital will not collect patients' names or addresses. Any other data that could directly identify patients (such as NHS Number, date of birth, full postcode) is replaced with unique codes which are produced by de-identification software before the data is shared with NHS Digital.

This process is called pseudonymisation and means that patients will not be identified directly in the data. NHS Digital will be able to use the software to convert the unique codes back to data that could directly identify patients in certain circumstances, and where there is a valid legal reason.

We will collect structured and coded data from patient medical records:

NHS Digital will collect	NHS Digital <u>does not</u> collect
Data about diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments, including information about physical, mental and sexual health	Name and address (except for postcode, protected in a unique coded form)
Data on sex, ethnicity and sexual orientation	Written notes (free text), such as the details of conversations with doctors and nurses
Data about staff who have treated patients	Images, letters and documents
	Coded data that is not needed due to its age - for example medication, referral and appointment data that is over 10 years old
	Coded data that GPs are not permitted to share by law - for example certain codes about IVF treatment, and certain information about gender re-assignment

Opting Out

If you don't want your identifiable patient data to be shared for purposes except for your own care, you can opt-out by registering a [Type 1 Opt-out](#) or a [National Data Opt-out](#), or both. These opt-outs are different and they are explained in more detail below. Your individual care will not be affected if you opt-out using either option.

Type 1 Opt-out (opting out of NHS Digital collecting your data)

We will not collect data from GP practices about patients who have registered a Type 1 Opt-out with their practice. More information about Type 1 Opt-outs is in our [GP Data for Planning and Research Transparency Notice](#), including a form that you can complete and send to your GP practice.

This collection will start on 1 September 2021.

If you register a Type 1 Opt-out after this collection has started, no more of your data will be shared with us. We will however still hold the patient data which was shared with us before you registered the Type 1 Opt-out.

If you do not want NHS Digital to share your identifiable patient data with anyone else for purposes beyond your own care, then you can also register a National Data Opt-out.

National Data Opt-out (opting out of NHS Digital sharing your data)

We will collect data from GP medical records about patients who have registered a National Data Opt-out. The National Data Opt-out applies to identifiable patient data about your health, which is called confidential patient information.

NHS Digital won't share any confidential patient information about you - this includes GP data, or other data we hold, such as hospital data - with other organisations, unless there is an exemption to this.

To find out more information and how to register a National Data Opt-Out, please read our [GP Data for Planning and Research Transparency Notice](#).

For more information, please visit: <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research#opting-out>

**Please ask a member of staff if you require this information
in a different format, eg. larger font.**

Thank you.