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Please click on the following link for further information:

<https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research>

Alternatively, watch the YouTube video for information about how the NHS uses your patient data:

<https://www.youtube.com/watch?v=YLi9gh7RyLA&t=91s>

General Practice Data for Planning and Research (GPDPR)

The data held in the GP medical records of patients is used every day to support health and care planning and research in England, helping to find better treatments and improve patient outcomes for everyone. NHS Digital has developed a new way to collect this data, called the General Practice Data for Planning and Research data collection.

The new data collection reduces burden on GP practices, allowing doctors and other staff to focus on patient care.

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 the NHS 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.

Researchers have previously used patient data from GP medical records to show that there was no association between the [measles, mumps and rubella vaccine and the development of autism](#); to confirm the [safety of the meningococcal group B vaccine](#); and to investigate whether certain [medications increase the risk of cancer](#).

Contributing to research projects will benefit us all as better and safer treatments are introduced more quickly and effectively without compromising your privacy and confidentiality.

NHS Digital has engaged with the [British Medical Association \(BMA\)](#), [Royal College of GPs \(RCGP\)](#) and the [National Data Guardian \(NDG\)](#) to ensure relevant safeguards are in place for patients and GP practices.

What data is being shared:

This data will be shared from 1 July 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 July 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.

NHS Digital will collect structured and coded data from patient medical records.

NHS Digital will collect:

- ✓ data about diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments, including information about physical, mental and sexual health,
- ✓ data on sex, ethnicity and sexual orientation,
- ✓ data about staff who have treated patients.

NHS Digital does not collect:

- ✗ name and address (except for postcode, protected in a unique coded form),
- ✗ written notes, such as the details of conversations with doctors and nurses,
- ✗ 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.

If you wish to opt-out of NHS Digital collecting and sharing your data then you must complete both Type 1 Opt-out form and the National Data Opt-Out.

The Type 1 Opt-out form can be found at reception and can be emailed to you on request.

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

If you do not want your identifiable patient data to be shared outside of the GP practice for purposes except your own care, you can register an opt-out with Burdwood. This is known as a Type 1 Opt-out. You can register a Type 1 Opt-out at any time. You can also change your mind at any time and withdraw a Type 1 Opt-out.

If you wish to register a Type 1 Opt-out with your GP practice before data sharing starts with NHS Digital, this should be done by the Type 1 Opt-out form which can be found at reception and can be emailed to you. You need to return this to us **by 23 June 2021**.

Type 1 Opt-outs were introduced in 2013 for data sharing from GP practices, but may be discontinued in the future as a new opt-out has since been introduced to cover the broader health and care system, called the [National Data Opt-out](#). If this happens, patients who have registered a Type 1 Opt-out will be informed.

NHS Digital will not collect any patient data for patients who have already registered a Type 1 Opt-in line with current policy. If this changes patients who have registered a Type 1 Opt-out will be informed.

If you register a Type 1 Opt-out after your patient data has already been shared with NHS Digital, no more of your data will be shared with NHS Digital. NHS Digital will however still hold the patient data which was shared with them before you registered the Type 1 Opt-out.

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

If you do not want NHS Digital to share your identifiable patient data, which is called [confidential patient information](#) with anyone else for purposes, except your own care (either GP data, or other data it holds, such as hospital data) then you can also register a [National Data Opt-out](#).

If you have registered a National Data Opt-out, NHS Digital won't share any confidential patient information about you with other organisations, unless there is an exemption to this, such as where there is a legal requirement or where it is in the public interest to do so, such as helping to manage contagious diseases like coronavirus. You can find out more about [exemptions on the NHS website](#).

From 1 October 2021, the National Data Opt-out will also apply to any confidential patient information shared by the GP practice with other organisations for purposes except your individual care. It won't apply to this data being shared by GP practices with NHS Digital, as it is a legal requirement for us to share this data with NHS Digital and the National Data Opt-out does not apply where there is a legal requirement to share data.

You can find out more about and register a National Data Opt-out, or change your choice on nhs.uk/your-nhs-data-matters or by calling 0300 3035678.