

NHS Digital Data Collection from the Practice

The NHS needs data about the patients it treats to plan and deliver its services and to ensure that care and treatment provided is safe and effective. The General Practice Data for Planning and Research data collection will help the NHS to improve health and care services for everyone by collecting patient data that can be used to do this. For example, patient data can help the NHS to:

- monitor the long-term safety and effectiveness of care
- plan how to deliver better health and care services
- prevent the spread of infectious diseases
- identify new treatments and medicines through health research

GP practices already share patient data for these purposes, but this new data collection will be more efficient and effective.

This means that GPs can get on with looking after their patients, and NHS Digital can provide controlled access to patient data to the NHS and other organisations who need to use it, to improve health and care for everyone.

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.

NHS Digital purposes for processing patient data

Patient data from GP medical records kept by GP practices in England is used every day to improve health, care and services through planning and research, helping to find better treatments and improve patient care. The NHS is introducing an improved way to share this information - called the General Practice Data for Planning and Research data collection.

NHS Digital will collect, analyse, publish, and share this patient data to improve health and care services for everyone. This includes:

- informing and developing health and social care policy
- planning and commissioning health and care services
- taking steps to protect public health (including managing and monitoring the coronavirus pandemic)
- in exceptional circumstances, providing you with individual care
- enabling healthcare and scientific research

Any data that NHS Digital collects will only be used for health and care purposes. It is never shared with marketing or insurance companies.

What patient data NHS Digital collect

Patient data will be collected from 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 the data collection started, and was previously registered at a GP practice in England when the data collection started

While 1 September has been seen by some as a cut-off date for opt-out, after which data extraction would begin, Government has stated this will not be the case and **data extraction will not commence until NHS Digital have met the tests.**

The NHS is introducing three changes to the opt-out system which mean that **patients will be able to change their opt-out status at any time:**

- **Patients do not need to register a Type 1 opt-out by 1 September** to ensure their GP data will not be uploaded
- NHS Digital will create the technical means to allow **GP data that has previously been uploaded to the system via the GPDPR collection to be deleted when someone registers a Type 1 opt-out**
- **The plan to retire Type 1 opt-outs** will be deferred for at least 12 months while we get the new arrangements up and running, and will not be implemented without consultation with the RCGP, the BMA and the National Data Guardian

We will not collect your name or where you live. Any other data that could directly identify you, for example NHS number, General Practice Local Patient Number, full postcode and date of birth, 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 no one will be able to directly identify you in the data. The diagram below helps to explain what this means. Using the terms in the diagram, the data we collect would be described as de-personalised.

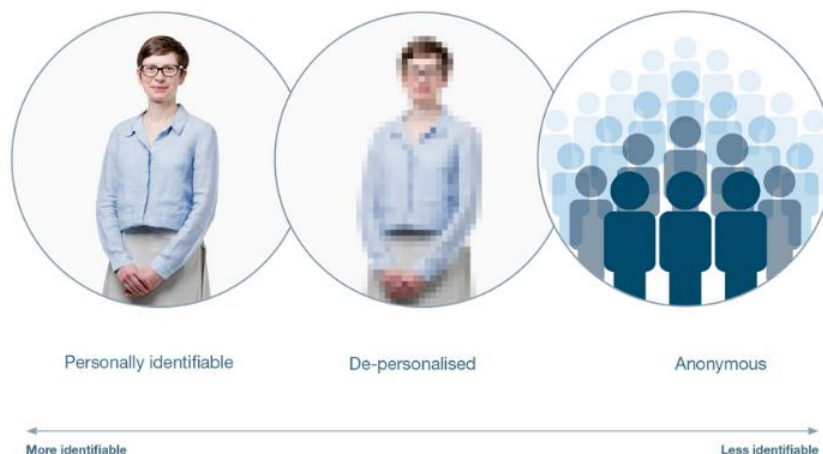


Image provided by Understanding Patient Data [under licence](#).

NHS Digital will be able to use the same software to convert the unique codes back to data that could directly identify you in certain circumstances, and where there is a valid legal reason. Only NHS Digital has the ability to do this. This would mean that the data became personally identifiable data in the diagram above. An example would be where you consent to your identifiable data being shared with a research project or clinical trial in which you are participating, as they need to know the data is about you.

More information about when we may be able to re-identify the data is in the [who we share your patient data with](#) section below.

The NHS Digital programme will be providing further information as the programme progresses. In the meantime, if you have any questions, you can contact the programme at enquiries@nhsdigital.nhs.uk.

The NHS Digital web pages also provide further information at <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research#additional-information-for-gp-practices>.

The Data NHD Digital collect

We will only collect structured and coded data from patient medical records that is needed for specific health and social care purposes explained above.

Data that directly identifies you as an individual patient, including your NHS number, General Practice Local Patient Number, full postcode, date of birth and if relevant date of death, is replaced with unique codes produced by de-identification software before it is sent to NHS Digital. This means that no one will be able to directly identify you in the data.

NHS Digital will be able to use the software to convert the unique codes back to data that could directly identify you in certain circumstances, and where there is a valid legal reason. This would mean that the data became personally identifiable in the diagram above. It will still be held securely and protected, including when it is shared by NHS Digital.

NHS Digital will collect

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

More detailed information about the patient data we collect is contained in the [Data Provision Notice issued to GP practices](#).

NHS Digital Does not collect.

- your name and address (except for your postcode in unique coded form)
- written notes (free text), 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 of NHS Digital collecting your data (Type 1 Opt-out)

If you do not want your identifiable patient data (personally identifiable data in the diagram above) to be shared outside of your GP practice for purposes except for 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 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 people who have registered a Type 1 Opt-out will be informed. More about National Data Opt-outs is in the section Who we share patient data with.

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

If you do not want your patient data shared with NHS Digital, you can register a Type 1 Opt-out with your GP practice. 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.

Data sharing with NHS Digital will start on 1 September 2021.

If you have already registered a Type 1 Opt-out with your GP practice your data will not be shared with NHS Digital.

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 returning this form to your GP practice. If you have previously registered a Type 1 Opt-out and you would like to withdraw this, you can also use the form to do this. You can send the form by post or email to your GP practice or call 0300 3035678 for a form to be sent out to you.

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 us before you registered the Type 1 Opt-out.

If you do not want NHS Digital to share your identifiable patient data (personally identifiable data in the diagram above) with anyone else for purposes beyond your own care, then you can also register a National Data Opt-out. There is more about National Data Opt-outs and when they apply in the National Data Opt-out section below.

NHS Digital legal basis for collecting, analysing, and sharing patient data.

When we collect, analyse, publish, and share patient data, there are strict laws in place that we must follow. Under the UK General Data Protection Regulation (GDPR), this includes explaining to you what legal provisions apply under GDPR that allows us to process patient data. The GDPR protects everyone's data.

NHS Digital has been directed by the Secretary of State for Health and Social Care under the [General Practice Data for Planning and Research Directions 2021](#) to collect and analyse data from GP practices for health and social care purposes including policy, planning, commissioning, public health and research purposes.

NHS Digital is the controller of the patient data collected and analysed under the GDPR jointly with the Secretary of State for Health and Social Care.

All GP practices in England are legally required to share data with NHS Digital for this purpose under the Health and Social Care Act 2012 (2012 Act). More information about this requirement is contained in the [Data Provision Notice](#) issued by NHS Digital to GP practices.

NHS Digital has various powers to publish anonymous statistical data and to share patient data under sections 260 and 261 of the 2012 Act. It also has powers to share data under other Acts, for example the Statistics and Registration Service Act 2007.

Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 (COPI) also allow confidential patient information to be used and shared appropriately and lawfully in a public health emergency. The Secretary of State has issued legal notices under COPI (COPI Notices) requiring NHS Digital, NHS England and Improvement, arm's-length bodies (such as Public Health England), local authorities, NHS trusts, Integrated Care Boards and GP practices to share confidential patient information to respond to the COVID-19 outbreak. Any information used or shared during the COVID-19 outbreak will be limited to the period of the outbreak unless there is another legal basis to use confidential patient information.

The legal basis under UKGDPR for General Practice Data for Planning and Research

How NHS Digital use patient data

NHS Digital will analyse and link the patient data we collect with other patient data we hold to create national data sets and for data quality purposes.

NHS Digital will be able to use the de-identification software to convert the unique codes back to data that could directly identify you in certain circumstances for these purposes, where this is necessary and where there is a valid legal reason. There are strict internal approvals which need to be in place before we can do this and this will be subject to independent scrutiny and oversight by the [Independent Group Advising on the Release of Data \(IGARD\)](#).

These national data sets are analysed and used by NHS Digital to produce national statistics and management information, including public dashboards about health and social care which are published. We never publish any patient data that could identify you. All data we publish is anonymous statistical data.

For more information about data, we publish see [Data and Information](#) and [Data Dashboards](#).

We may also carry out analysis on national data sets for data quality purposes and to support the work of others for the purposes set out in [Our purposes for processing patient data](#) section above.

Who NHS Digital share patient data with

All data which is shared by NHS Digital is subject to robust rules relating to privacy, security, and confidentiality and only the minimum amount of data necessary to achieve the relevant health and social care purpose will be shared.

All requests to access patient data from this collection, other than anonymous aggregate statistical data, will be assessed by NHS Digital's [Data Access Request Service](#), to make sure that organisations have a legal basis to use the data and that it will be used safely, securely and appropriately.

These requests for access to patient data will also be subject to independent scrutiny and oversight by the [Independent Group Advising on the Release of Data \(IGARD\)](#). Organisations approved to use this data will be required to enter into a data sharing agreement with NHS Digital regulating the use of the data.

There are several organisations who are likely to need access to different elements of patient data from the General Practice Data for Planning and Research collection. These include but may not be limited to:

- the Department of Health and Social Care and its executive agencies, including Public Health England and other government departments
- NHS England and NHS Improvement
- primary care networks (PCNs), Integrated Care Boards (ICBs) and integrated care organisations (ICOs)

- local authorities
- research organisations, including universities, charities, clinical research organisations that run clinical trials and pharmaceutical companies

If the request is approved, the data will either be made available within a secure data access environment within NHS Digital infrastructure, or where the needs of the recipient cannot be met this way, as a direct dissemination of data. We plan to reduce the amount of data being processed outside central, secure data environments and increase the data we make available to be accessed via our secure data access environment. For more information read about improved data access in [improving our data processing services](#).

Data will always be shared in the uniquely coded form (de-personalised data in the diagram above) unless in the circumstances of any specific request it is necessary for it to be provided in an identifiable form (personally identifiable data in the diagram above). For example, when express patient consent has been given to a researcher to link patient data from the General Practice for Planning and Research collection to data the researcher has already obtained from the patient.

It is therefore possible for NHS Digital to convert the unique codes back to data that could directly identify you in certain circumstances, and where there is a valid legal reason which permits this without breaching the common law duty of confidentiality. This would include:

- where the data was needed by a health professional for your own care and treatment
- where you have expressly consented to this, for example to participate in a clinical trial
- where there is a legal obligation, for example where the COPI Notices apply - see [Our legal basis for collecting, analysing and sharing patient data](#) above for more information on this
- where approval has been provided by the [Health Research Authority](#) or the Secretary of State with support from the [Confidentiality Advisory Group \(CAG\)](#) under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 (COPI) - this is sometimes known as a 'section 251 approval'

This would mean that the data was personally identifiable in the diagram above. Re-identification of the data would only take place following approval of the specific request through the Data Access Request Service, and subject to independent assurance by IGARD and consultation with the Professional Advisory Group, which is made up of representatives from the BMA and the RCGP. If you have registered a National Data Opt-out, this would be applied in accordance with the National Data Opt-out policy before any identifiable patient data (personally identifiable data in the diagram above) about you was shared. More about the National Data Opt-out is in the section below.

Details of who we have shared data with, in what form and for what purposes are published on our [data release register](#).

The practice is one of many organisations working in the health and care system to improve care for patients and the public.

Whenever you use a health or care service, such as attending Accident & Emergency or using Community Care services, important information about you is collected in a patient record for that service. Collecting this information helps to ensure you get the best possible care and treatment.

The information collected about you when you use these services can also be used and provided to other organisations for purposes beyond your individual care, for instance to help with:

- improving the quality and standards of care provided
- research into the development of new treatments
- preventing illness and diseases
- monitoring safety
- planning services

This may only take place when there is a clear legal basis to use this information. All these uses help to provide better health and care for you, your family and future generations. Confidential patient information about your health and care is **only used** like this where allowed by law.

Most of the time, anonymised data is used for research and planning so that you cannot be identified in which case your confidential patient information isn't needed.

You have a choice about whether you want your confidential patient information to be used in this way. If you are happy with this use of information you do not need to do anything. If you do choose to opt out your confidential patient information will still be used to support your individual care.

To find out more or to register your choice to opt out, please visit www.nhs.uk/your-nhs-data-matters.

On this web page you will:

- See what is meant by confidential patient information
- Find examples of when confidential patient information is used for individual care and examples of when it is used for purposes beyond individual care
- Find out more about the benefits of sharing data
- Understand more about who uses the data
- Find out how your data is protected
- Be able to access the system to view, set or change your opt-out setting
- Find the contact telephone number if you want to know any more or to set/change your opt-out by phone
- See the situations where the opt-out will not apply

You can also find out more about how patient information is used at:

<https://www.hra.nhs.uk/information-about-patients/> (which covers health and care research); and

<https://understandingpatientdata.org.uk/what-you-need-know> (which covers how and why patient information is used, the safeguards and how decisions are made)

You can change your mind about your choice at any time.

Data being used or shared for purposes beyond individual care does not include your data being shared with insurance companies or used for marketing purposes and data would only be used in this way with your specific agreement.

Health and care organisations have until 2020 to put systems and processes in place so they can be compliant with the national data opt-out and apply your choice to any confidential patient information they use or share for purposes beyond your individual care. Our organisation 'is / is not currently' compliant with the national data opt-out policy.

Where do we store your information electronically?

All the personal data we process is processed by our staff in the UK however for the purposes of IT hosting and maintenance this information may be located on servers within the European Union.

No 3rd parties have access to your personal data unless the law allows them to do so and appropriate safeguards have been put in place such as a Data Processor as above). We have a Data Protection regime in place to oversee the effective and secure processing of your personal and or special category (sensitive, confidential) data.