

Proactive Q&A for stakeholders

Why is GP data being collected?

Patient data is used every day by NHS organisations and researchers to improve healthcare services, helping to find better treatments, plan new services and improve patient care.

Data from General Practice is used today and has been used for many years to support multiple planning and research needs.

GPES Data for Pandemic Planning and Research (COVID-19) is currently providing researchers with a vital source of GP data and is available to clinicians, researchers, academics and commissioners for COVID-19 planning and research purposes.

This information has been used by NHS organisations and researchers to help run and improve health and care services for patients throughout the pandemic, identify those most vulnerable to coronavirus, roll out vaccines, and for COVID-19 research. 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 COVID-19.

What is changing?

NHS Digital has been legally directed by the Secretary of State for Health and Social Care to establish a new, more efficient system to collect and provide access to as close to real-time data from GP Practices for planning, public health and research purposes.

The new system will improve and simplify the current processes and will replace multiple existing data collections into one collection updated seamlessly, reducing the burden on GPs and improving data security.

The case for change - why now?

The COVID-19 pandemic has caused so much suffering across the country. But in response, data has been used in new ways to care for people and help the NHS and social care to better understand and respond to the virus. 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 COVID-19.

GDPR is the replacement service for GPES and seeks to improve how data is collected from General Practice, reducing burden on GP practices, improving transparency for patients and reducing the amount of patient data being shared between organisations.

Do patients have a choice about how their data is used?

Patient data is used every day by NHS organisations and researchers to improve healthcare services, helping to find better treatments, plan new services and improve patient care.

If a patient does not want identifiable data to be shared outside their GP Practice except for their own care they can apply to opt-out with their GP Practice. This is known as a Type 1 opt-out. NHS Digital will not collect patient data for any patient who has registered a Type 1 opt-out with their GP.

The National Data opt-out will also be applied by NHS Digital in line with the National Data Opt-out policy.

For more information on the National Data Opt-Out exemptions, see [Section 6.2 of the National Data Opt-Out Operational Policy Guidance](#).

NHS Digital makes clear in its patient-facing communications, along with the communications to patients via the GP practice, that patients can choose to register a Type 1 opt out at their practice. GP professional representatives are aware of this signposting.

Who will get access to the data?

Data will only be shared with organisations who have a legal basis and meet strict criteria to use it for local, regional and national planning, policy development, commissioning, public health and research purposes. We will continue to publish the details of the data we share on our data release register.

Any requests for data will be assessed to ensure that there is an appropriate legal basis for us to share data, and independent advice will be sought from IGARD before any record level data is accessed. Requestors will only be able to access the minimum data required to meet their specific approved needs.

Increasingly, we will provide access to data within NHS Digital's [secure data access environment](#), reducing the need for record level data to be released. Where data is released we will check that requestors have all appropriate safeguards in place so that they store and handle the data safely and securely.

NHS Digital are legally prohibited from selling patient data and will never share data from this collection with anyone for reasons other than the above.

How are decisions made about accessing this data?

All requests for access to data held by NHS Digital go through the Data Access Request Service (DARS). This process assesses whether the requestor has the legal basis to access the data, checks that the purpose is for the benefit of health and care, assesses whether the amount and type of data requested is appropriate and proportionate to the purpose and determines the controls around the access to the data that will be required.

For record level and identifiable data requests, these are also reviewed by the Independent Group Advising on the Release of Data (IGARD) which includes independent GPs, lay members, IG experts as well as review by representatives of the GP profession to ensure that these data access requests are appropriately considered and dealt with. This process is thorough and if approved, results in a detailed and legally binding Data Sharing Agreement between NHS Digital and the requesting organisation.

NHS Digital also has powers to audit those with whom it shares patient data to ensure the organisation is complying with the terms of the Data Sharing Agreement. Any serious breach would result in the data access being withdrawn and be reported to the Information Commissioners Office (ICO) for investigation and sanctions.

How will you protect sensitive data included within the collection?

NHS Digital has a responsibility to protect and provide secure and legal access to patient data for health and care purposes. We respect and protect all personal and special category data to the same high standards that we apply to all data we collect.

For GP data, we have applied additional protection. Any data which directly identifies an individual will be pseudonymised and then encrypted before it leaves the GP practice to protect patient privacy.

Any organisation seeking access to data that could be considered sensitive will be scrutinised through the DARS process.

How are we ensuring patients are aware of this new collection?

Data from General Practice is shared every day to help run and improve the health service. Currently this data is shared by each GP practice to many different organisations, including NHS Digital.

NHS Digital remains committed to being transparent with patients and the public about the collection and use of data and has worked with the GP profession, patient groups and those who require access to this data to improve how the data is collected and made available. A key part of this is to reduce the amount of patient data being shared and to improve transparency for patients over the use of their data along with the choices they can make about this use.

NHS Digital has and will continue to work with patients and patient groups to review its approach and materials to ensure they are clear and meaningful.

In 2017 and 2018 the National Data Opt-out ran a public information campaign to raise awareness of patient data use and to advise of patient choices regarding this use for planning and research purposes. 'Your NHS data matters' is still an active public communication channel reminding the public that their data is used and that they can opt out.

Over and above transparency, NHS Digital and its stakeholders will actively promote the new service to raise awareness with patients. As GP practices start to be visited more and more, materials will be made available to practices to use in their waiting areas to raise patient awareness.

How can patients find out what data about them is being collected and used?

Patients expect that the NHS is well informed and prepared to deliver the best care for patients and their loved ones. The data NHS Digital will collect is data that has been recorded by the GP practice and is already being shared with many other organisations for a variety of planning and research requirements. A patient can request that either the GP practice or NHS Digital shares what data it holds about them and where that has been shared.

We are committed to work with stakeholders to review and improve the service and transparency of data use over time. This is the start of the conversation not the end.