Collecting GP data - advice for the public

NHS Digital's improved collection of GP data will support vital health and care planning and research. Here we explain how and why your data is being used, and what to do if you don't want your data shared.

Redirected users

This page contains information for the public about the General Practice Data for Planning and Research (GPDPR) data collection. You may have been redirected from a different page, which focused on the national data opt-out.

Feedback

Why we need your data

Patient data is used every day to improve healthcare services through planning and research in England, helping to find better treatments and improve patient care.

It helps to decide what new health and care services are required in a local area, informs clinical guidance and policy, and supports researching and developing cures for serious illnesses, such as heart disease, diabetes, and cancer.

For example, GP data collected as part of the COVID response is being used by the University of Oxford RECOVERY trial, which is looking to find ways to improve the treatment for people with COVID-19.

Why we need a new system

Patient data is already being collected to improve health and care services. NHS Digital has collected patient data from general practices using a service called the General Practice Extraction

Service (GPES). This system is over 10 years old and now needs to be replaced.

NHS Digital has engaged with doctors, patients, data and governance experts to design a new and improved system to collect data from general practice that:

- reduces work for GPs so they have more time to focus on patient care
- explains clearly how data is used to help patients feel confident and informed
- means data is collected, stored and accessed in a secure and consistent way

How we keep your data secure

We take our responsibility to safeguard patient data extremely seriously. Data shared by NHS Digital is subject to strict rules around privacy, security and confidentiality and the new service has been designed to the highest standards.

We do not collect patients' names or exactly where they live. Any other data that could directly identify someone, for example their NHS number, full postcode and date of birth, is pseudonymised before it leaves their GP practice. This means that this data is replaced with unique codes so patients cannot be directly identified in the data which is shared with us. The data is also securely encrypted.

Feedback

We would only ever re-identify the data if there was a lawful reason to do so and it would need to be compliant with data protection law. For example, a patient may have agreed to take part in a research project or clinical trial and has already provided consent to their data being shared with the researchers for this purpose.

The law allows research projects which need to find volunteers for their research to contact patients directly about taking part in research or a clinical trial if the Health Research Authority has approved the request.

This would also need to be agreed through the Independent Group Advising on the Release of Data (IGARD) and the GP Professional Advisory Group (PAG), which is made up of representatives from the British Medical Association and the Royal College of General Practitioners.

You can opt out of sharing your data

If you do not want your GP to share your identifiable patient data for purposes except for your own care, you can opt-out by registering a Type 1 Opt-out. This prevents your data being shared with NHS Digital.

You can also register a National Data Opt-out, which will prevent NHS Digital from sharing your identifiable patient data for planning and research purposes. Your individual care will not be affected if you opt-out using either option.

Opt-outs (either type) that have been registered in the past will all be fully respected.

We have designed the collection with many safeguards in place to protect the privacy of patients, including removing all personal information that would directly identify patients before data is shared with NHS Digital.

By putting in place strict governance processes about who can access data and for what reasons, and being transparent about what data is shared and why, the programme aims to make patient data available safely and securely.

Making data available for research will lead to better:

- NHS services for patients
- treatments
- medicines

We make it clear how to opt-out

Although we have designed the collection with privacy protections in place, if patients do still want to opt out, they can. GPs already share data with other organisations for planning and research purposes in accordance with their own data sharing agreements and patients have had the opportunity to opt out of this type of data sharing for several years using the Type 1 Opt Out.

Feedback

We have provided support and materials to GPs so that they can also let their patients know about the collection. This contains detailed information about it, and the ways that patients can opt out.

In addition to materials for GPs to use, NHS Digital is promoting this new data collection through our website, engagement with media, through our stakeholders and patient groups and on social media channels. We want to raise awareness of the collection and its importance to help the NHS and research take place, but also to provide patients with a choice if they do not want their data to be used in this way.

If lots of people opt out the data becomes less useful

If a large number of people choose to opt out then the data becomes less useful for planning services and conducting research. This is a particular problem if people from certain areas or groups are more likely to opt out. If that happens then services may not reflect the needs of those groups or areas and research may reach misleading conclusions.

Understanding Patient Data have provided more information on this topic, including specific examples on their website.

Why we need to collect sensitive data about things like domestic violence and STIs

We need to collect sensitive data to help plan and design services, and research conditions to better support the people affected. For example, we need to collect data about domestic violence to ensure the right local support services are in place. Victims of physical and sexual violence are also more likely to suffer from mental health problems. But without data about these sensitive events and conditions it is much more difficult to conduct research to provide better services and support.

We respect and protect all the data we collect to the same high standards, but we have also added additional protections as we know how important it is to protect this sensitive data.

This includes going through our Data Access Request Service (DARS) process which means the Independent Group Advising on the Release of Data (IGARD) and a GP Professional Advisory Group (PAG), with representatives from the British Medical Association and the Royal College of General Practitioners, can scrutinise it to ensure the use of that data is absolutely necessary and is legal and appropriate.

Feedback

We are not going to sell your data

NHS Digital does not sell data. It does however charge those who want to access its data for the costs of making the data available to them. This is because we are not funded centrally to do this. Charges only cover the cost of running the service and means that those organisations who need access to the data bear the costs of this, rather than NHS Digital. We do not make profits from the service.

The data will only be used for health and care planning and research purposes by organisations who have a legal basis and legitimate need to use the data. We publish the details of the data we share on our data release register so we can be held to account.

We do not allow data to be used solely for commercial purposes.

NHS Digital will not approve requests for data to be used for:

- insurance or marketing purposes
- promoting or selling products or services
- market research
- advertising

How we ensure people use the data as promised

Once data is shared, we carry out independent audits and, where necessary, post audit reviews to check organisations are using the data for the purposes they said they would, in accordance with the terms and conditions of their data sharing agreements.

Where our data is accessed directly by organisations in our secure research environments, we also carry out audits of who has accessed the data from the organisation to make sure they are authorised users and check how the data has been used in the environment.

This helps to ensure that organisations abide by the terms and conditions set by NHS Digital and data is kept safe and secure.

Any serious breach of our terms and conditions of use would result in the data access being withdrawn and we may report the breach to the Information Commissioners Office (ICO) for investigation.

This is not care.data

Feedback

There have been conversations online that have drawn parallels between this programme and something called ‘care.data’ in 2014. This is not an extension to, or evolution of, that programme.

Patient data is already being collected and used to improve health and care services. This is a new system, designed over the last three years, to improve how data from your GP is shared with organisations involved in the planning of the health and care system, and clinical researchers.

Our processes for accessing data are now very different to those seven years ago when ‘care.data’ was developed. We uphold the Caldicott Principles for ethical data sharing and are also bound by data protection laws such as the General Data Protection Regulation (GDPR).

There is also oversight from independent experts on data sharing. This includes the Independent Group Advising on the Release of Data (IGARD) and a GP Professional Advisory Group (PAG), with representatives from the British Medical Association and the Royal College of General Practitioners.

We have completed a data protection impact assessment

We have carried out a very rigorous and full data protection impact assessment (DPIA) as this is required under the UK General Data Protection Regulation (GDPR) rules.

This is currently going through a final review and assurance process and we will publish the baseline version of it shortly. However, a DPIA is not a static assessment and, therefore, will be reviewed and updated regularly to reflect changes and developments in the service. We will publish updated versions of it from time to time.

Data we will not collect

We will not collect your entire GP record.

We will not collect:

- patient names and full addresses
- written notes (free text) of any consultations or interactions between patients and clinicians
- images, letters, videos, or documents
- medicines, appointment, or referral data over ten years old
- legally restricted data such as IVF treatment or gender reassignment

We will collect most of the structured and coded elements of the GP record. Find more information on what structured and coded data means.

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