

Why a new data collection 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.

How your data is kept secure

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 the GP practice. Your data is replaced with unique codes so you cannot be directly identified. The data is also securely encrypted.

NHS Digital is 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 NHS Digital is not funded centrally to do this. The organisations using this service will be published on the register.

What systems will ensure safe use of data as promised?

Independent audits and, where necessary, post audit reviews to check organisations will be undertaken. Any serious breach of terms and conditions of use would result in the data access being withdrawn and a report of the breach made to the Information Commissioners Office (ICO) for investigation.

This is not *care.data*

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. This is a new system, designed over the last three years. Processes for accessing data are now very different to those seven years ago

when '*care.data*' was developed.

NHS Digital conforms with 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.

A data protection impact assessment

A very rigorous and full data protection impact assessment (DPIA) has been undertaken, as this is required under the UK General Data Protection Regulation (GDPR) rules.

This is currently going through a final review and assurance process. However, a DPIA is not a static assessment and, therefore, will be reviewed and updated regularly to reflect changes and developments in the service.

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.

Why sensitive data about things like domestic violence and STIs needs to be collected

NHS Digital collects 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. However, without data about these sensitive events and conditions, it is much more difficult to conduct research to provide better services and support.

NHS Digital respects and protects all the data that is collected to the same high standards, but there are also additional protections to protect this sensitive data.

Opt out options

Type 1 Opt-Out	Type2 National Opt-Out
Stops all your medical data from your GP being shared by NHS Digital (apart from your Direct Care)	Stops all your other medical data being shared by NHS Digital (apart from for your Direct Care)
This includes all treatments managed within the Practice.	This includes hospital or clinic treatments, being used for purposes other than your direct care (e.g. for research and planning)
How to opt out You must register a Type1 Opt-Out with the Peninsula Practice by Tuesday 17 August, 2021 . A form can be accessed online at the website or from one of the Practice sites. S:\Website\practiceleaflet_files\type-1-opt-out-form.pdf This form can be used for all family members who wish to opt out (including children and adult dependents)	How to opt out This can be done on line for yourself. (There is no deadline) https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/ or you can ring 0300 303 5678 - Monday to Friday, 9am to 5pm (exc. bank holidays). If you have children under 13, you need to fill in this form and e-mail or post it back to NHS Digital - this form works for both you and your children. https://assets.nhs.uk/nhsuk-cms/documents/Make_and_manage_your_choice_or_your_childs_choice_PDF_224kb.pdf If you have an adult dependent for whom you have legal responsibility, you must use another form and send it back to NHS Digital . https://assets.nhs.uk/nhsuk-cms/documents/Make_and_manage_a_choice_for_someone_else_PDF_154kb.pdf

Data will not be used solely for commercial purposes. NHS Digital will not approve requests for

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

NHS Digital will not

- **patient names and full**
- **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**

Statement by the ICO 8 June 2021

“Data Protection law enables organisations to share data safely and, when it comes to using health information there are particular safeguards that must be put in place to protect people’s privacy. This ensures people’s data isn’t used or shared in ways they wouldn’t expect. “The success of any project will rely on people trusting and having confidence in how their personal data will be used. It is crucial that, from the start, thought is given to how this can be explained clearly to people. “We recognise the concerns people have with the GP Data for Planning and Research programme and, while we have already engaged with NHS Digital regarding their data protection obligations, we continue to work with them and others about next steps.”

