**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](https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/transparency-notice#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 July 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](https://nhs-prod.global.ssl.fastly.net/binaries/content/assets/website-assets/data-and-information/data-collections/general-practice-data-for-planning-and-research/type-1-opt-out-form.docx) to your GP practice by **23 June 2021** to allow time for processing it. 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](https://www.nhs.uk/your-nhs-data-matters/). There is more about National Data Opt-outs and when they apply in the [National Data Opt-out section](https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/transparency-notice#national-data-opt-out-opting-out-of-nhs-digital-sharing-your-data-) below.

**Our 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](https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/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](https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/data-provision-notices-dpns/general-practice-data-for-planning-and-research) 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, clinical commissioning groups 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 GDPR for General Practice Data for Planning and Research

**How we 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)](https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/independent-group-advising-on-the-release-of-data).

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](https://digital.nhs.uk/data) and [Data Dashboards](https://digital.nhs.uk/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](https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/transparency-notice#our-purposes-for-processing-patient-data) section above.

**Who we 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](https://digital.nhs.uk/services/data-access-request-service-dars), 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)](https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/independent-group-advising-on-the-release-of-data). 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 a number of 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), clinical commissioning groups (CCGs) 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](https://digital.nhs.uk/data-and-information/data-insights-and-statistics/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](https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/transparency-notice#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](https://www.hra.nhs.uk/) or the Secretary of State with support from the [Confidentiality Advisory Group (CAG)](https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/) 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](https://digital.nhs.uk/services/data-access-request-service-dars/register-of-approved-data-releases).

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

This applies to identifiable patient data about your health (personally identifiable data in the diagram above), which is called [confidential patient information](https://www.nhs.uk/your-nhs-data-matters/). If you don’t want your confidential patient information to be shared by NHS Digital for purposes except your own care - either GP data, or other data we hold, such as hospital data - you can register a [National Data Opt-out](https://www.nhs.uk/your-nhs-data-matters/).

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](https://www.nhs.uk/your-nhs-data-matters/where-your-choice-does-not-apply/).

From 1 October 2021, the National Data Opt-out will also apply to any confidential patient information shared by your 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 GP practices 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](https://www.nhs.uk/your-nhs-data-matters/) or by calling 0300 3035678.

**How long we keep patient data for**

We will keep your patient data for as long as is necessary for the purposes outlined above in accordance with the [Records Management Code of Practice for Health and Social Care 2016](https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/codes-of-practice-for-handling-information-in-health-and-care/records-management-code-of-practice-for-health-and-social-care-2016) and [NHS Digital's Records Management Policy](http://nhs-acct.global.ssl.fastly.net/binaries/content/assets/website-assets/corporate-information/corporate-information-and-documents/nhs-digital-records-management-policy.pdf).

Other organisations with whom we share your personal data must only keep it for as long as is necessary and as set out in the Data Sharing Agreement with that organisation. Information about this will be provided in their privacy notices on their websites.

**Where we store patient data**

NHS Digital only stores and processes patient data for this data collection within the United Kingdom (UK).

Fully anonymous data (that does not allow you to be directly or indirectly identified), for example statistical data that is published, may be stored and processed outside of the UK. Some of our processors may process patient data outside of the UK. If they do, we will always ensure that the transfer outside of the UK complies with data protection laws.

**Your rights over your patient data**

You can read more about the health and care information collected by NHS Digital, our legal basis for collecting it and your choices and rights in:

* [How we look after your health and care information](https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information)
* [NHS Digital Transparency Notice](https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/gdpr/gdpr-register)
* [NHS Digital COVID-19 Response Transparency Notice](https://digital.nhs.uk/coronavirus/coronavirus-covid-19-response-information-governance-hub/coronavirus-covid-19-response-transparency-notice)

**Changes to this notice**

We may make changes to this Transparency Notice. If we do, the 'last edited' date on this page will also change. Any changes to this notice will apply immediately from the date of any change.

Last edited: 26 May 2021 12:07 pm