

Data Provision Notice

GPES Data for Consented Research

Information Asset Owner: Michael Chapman

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Background

The Health and Social Care Act 2012 (the **2012 Act**) gives NHS England statutory powers, under section 259(1)(a), to require data from health or social care bodies, or organisations that provide publicly funded health or adult social care in England, where it has been directed to establish an information system by the Secretary of State for Health and Social Care.

Data is required, as specified by NHS England in this published Data Provision Notice (**Notice**) below, to enable NHS England to comply with the [GPES Data for Consented Research Directions 2026 \(Directions\)](#) and the accompanying [Directions Requirement Specification \(Requirements Specification\)](#) issued by the Secretary of State for Health and Social Care to NHS England. Therefore, organisations that are in scope of the Notice (as identified below) are legally required, under section 259(5) of the 2012 Act, to comply with the requirement to provide the data in the form, manner and in accordance with the timing requirements specified below.

Purpose of the Directions

Millions of people resident in England participate in research studies relating to their health or where health is a relevant factor. These studies may be interventional, where what happens to at least some of the participants is changed because of their participation, or observational, where groups of individuals are followed up over time without any specific intervention.

Many of these studies have the explicit consent of participants to use routinely collected healthcare data to follow up the participants in an efficient and cost-effective fashion. Many studies are also able to include participants who lack capacity to consent in their research studies, where this complies with the requirements of the Mental Capacity Act 2005 (**2005 Act**) and regard has been given to Chapter 11 of the Mental Capacity Act Code of Practice (Code of Practice)¹.

NHS England routinely provides participant data to research studies through its Data Access Request Service (**DARS**) where this is consistent with the explicit consent given by or on behalf of participants and the information provided to consultees who have advised that a participant without capacity to consent should take part in the research study.

The coded patient data held in the General Practice (**GP**) records is a rich source of information about health. For some conditions it may be the only place where a diagnosis or risk factor is recorded. In other cases, it can complement other sources of healthcare data to give a more complete picture and avoid biases.²

However, many patients' permissions for their GP record to be shared are currently unmet. Current studies must establish individual agreements with GP practices to access data held about their participants. This is burdensome for both research studies and GPs, who are not

¹ [Mental Capacity Act Code of Practice](#)

² See Sudlow, CLM (2024). Uniting the UK's Health Data: A Huge Opportunity for Society. <https://doi.org/10.5281/zenodo.13353747>, sections 3.1.2 and 4.1.

resourced to conduct the detailed review needed to ensure that requests from individual studies are appropriate.

To address these issues, the Secretary of State has therefore directed NHS England under the Directions to establish and operate an information system for the collection of certain information held in GP health records.

The data to be collected is however already collected from GP health records by NHS England (the **Existing Data Collection**) under the [COVID-19 Public Health Directions 2020 - NHS England \(COVID-19 Direction\)](#) for COVID-19 Purposes (as described in the COVID-19 Direction). In order to minimise costs and reduce burden on GP Practices and their GP system suppliers, no new physical data collection by NHS England is therefore required as the Directions require the Existing Data Collection to be used.

The data already being collected in the Existing Data Collection will enable NHS England to operate a service (the **Service**) to share data with specific research studies approved to access their participant data (**Approved Research Studies**) for certain patients where:

- explicit consent has been provided by or on behalf of the patient to their data being shared with that Approved Research Study for health research; or
- someone, such as a family member (called a consultee) says a patient who lacks capacity should, and in their view would wish to, take part in the research. This is permitted under the Mental Capacity Act 2005³.

For a research study to be approved to access their participant data under these Directions, they are required to meet certain defined and published criteria (**Access Criteria**) including the criteria set out in the [Requirements Specification](#) and other access criteria published by NHS England.

Approved Research Studies will be approved by the Department of Health and Social Care and NHS England and details of Approved Research Studies will be published by NHS England on its [website](#).

Organisations consulted

Under section 258 of the Health and Social Care Act 2012, NHS England must consult with stakeholders before establishing a new information system. The following stakeholders have been consulted during the development of this Service:

- The GP profession as represented by the British Medical Association (BMA) and Royal College of General Practitioners (RCGP), both through the Joint GP IT Committee and separate engagement.
- Major consented research studies: Genomics England, Our Future Health, and UK Biobank.
- Department of Health and Social Care.

³ Under sections 30 to 33 of the Mental Capacity Act 2005 and chapter 11 of the of the Mental Capacity Act Code of Practice

- The Association of Medical Research Charities.
- Health Data Research UK.
- Patient representative groups: useMYdata, Patients Association and National Voices.
- medConfidential.
- The Information Commissioner’s Office.
- The National Data Guardian for Health & Social Care.
- The Health Research Authority.
- The Confidentiality Advisory Group.

Legal basis for collection

NHS England has been directed by the Secretary of State for Health and Social Care under the Directions to establish and operate an information system for the Service. The Directions and accompanying Requirements Specification are published on the NHS England [website](#).

Organisations within the scope of this Data Provision Notice

Under section 259(1)(a) of the 2012 Act, this Notice is served (in accordance with the [procedure](#) published as part of the NHS England duty under section 259(8) of the 2012 Act) on **all General Practices in England who are using TPP and EMIS GP health record systems**.

Under section 259(5) of the 2012 Act, General Practices within this scope must provide the data identified below as the Required Data, in the form and manner and in accordance with the timing requirements specified below for the period of the collection set out below.

Scope of the Collection

All patients currently registered with a General Practice or with a date of death on or after 1 November 2019 whose record contains certain coded information. For each patient, NHS England requires the following personal data:

- NHS Number
- Postcode
- Address
- Surname and forename
- Sex
- Ethnicity
- Date of birth
- Date of death.

Data will be collected for the associated SNOMED code(s) and date(s) for GP record entries including:

- Diagnoses and findings
- Medications and other prescribed items
- Investigations, tests and results
- Treatments and outcomes
- Vaccinations and immunisations.

Type 1 Objections

Type 1 objections are applied to data prior to collection by NHS England and those records are excluded from the Data Specification. Therefore, the data for those participants who have registered a Type 1 objection with their GP will not be collected and will not be available to share with an Approved Research Study, even if explicit consent has been provided by or on behalf of those participants, for so long as a Type 1 objection is in place.

Required Data and the Form, Manner and Timing of the Data to be Collected

Required Data

The data set to be collected (the **Required Data**) is set out in the [GPES Data for Pandemic Planning and Research \(GDPPR\) data specification](#) (the **Data Specification**).

Form, Manner and Timing for collection of the Required Data

In order to minimise costs and reduce burden on GP Practices and their GP system suppliers, NHS England will use the Existing Data Collection. The Required Data will therefore be collected by NHS England once for the purposes of operating the information system required under the COVID-19 Directions and also for establishing and operating the information system established under these Directions. Data will be collected from General Practitioners in England, via their GP system suppliers. A [Data Provision Notice](#) was issued previously in relation to the collection of the Existing Data Collection under the COVID-19 Directions, which has been updated to reflect that the data is also required by NHS England and being collected and used under these Directions.

Collection of data is via a monthly extract. This means that all activity which happens in the preceding month is collected every month. The collection is anticipated to continue until the expiry of the Directions.

As no new physical data collection by NHS England is required for GP practices to comply with this Notice, GP practices are not required to take any action in response to it.

Burden of the collection

Steps taken by NHS England to minimise the burden of collection

NHS England has a statutory duty under section 253(2) of the 2012 Act to seek to minimise the burden it imposes on others. In seeking to meet these obligations in relation to these Directions, the Service has been designed to reduce the burden, responsibility, and risks on the General Practice of individually administering multiple requests for access to data for research, through NHS England operating the Service.

As the Existing Data Collection will be used by NHS England to operate the Service and no new data collection needs to be established, there is no additional burden on General Practices as a result of these Directions.