

## **Data Provision Notice**

# GPES Data for Pandemic Planning & Research (COVID-19)

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## Information and technology for better health and care

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## **Background**

The Health and Social Care Act 2012 (the 2012 Act) gives the Health and Social Care Information Centre, now known as NHS Digital<sup>1</sup> and hereafter referred to by this name, 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 (Secretary of State) or NHS England and NHS Improvement (NHS England).

The data, as specified by NHS Digital in this published Data Provision Notice (DPN or Notice), is required to support a Direction from the Secretary of State to NHS Digital. Therefore, organisations that are in scope of the Notice are legally required, under sections 259(1)(a) and 259(5) of the 2012 Act, to provide the data in the form and manner specified below.

The England General Practitioners Committee (GPC England), of the British Medical Association (BMA) and the Royal College of General Practitioners (RCGP) have also requested that NHS Digital collect clinically relevant data centrally for the purposes outlined later in the DPN and they have requested support from General Practitioners for these data collections. They have made the following statement:

'The RCGP and BMA support this initiative. The collection set out in this DPN was designed by NHS Digital, with the support of NHSX in response to concerns raised by representatives of the GP profession regarding the current pressure on General Practice to respond to multiple requests to release data in support of COVID-19 planning and research.

NHS Digital as the data controller for nationally extracted data will ensure that due diligence is carried out regarding any applications made to NHS Digital for access to the data that is being collected. NHSX will be responsible for a single point of contact (SPOC) COVID-19 request process that will triage and prioritise those applications that are applicable to this data set and pass those applications to NHS Digital who will be responsible for assessing and fulfilling the applications; these applications will only be successful if they pass the appropriate ethical, legal and Information Governance requirements to ensure that data is only shared where it is secure, lawful and appropriate to do so. NHS Digital will do this through the Data Access Request Service (DARS) with advice on requests for data from this collection from the Independent Group Advising on the Release of Data (IGARD) along with consultation with profession representatives at RCGP and the BMA.

Once this data collection has been established, all organisations, including CCGs and Integrated Care Services, are to be re-directed when requesting data from your GP practice for any COVID-19 non-direct care purposes, into the NHSX SPOC for COVID-19 requests process, thereby reducing your workload'.

The only but important and legally binding responsibility for general practice is to comply with this DPN by registering your participation on CQRS in the normal way. We are asking you as a matter of urgency to complete this task at the earliest opportunity and would be grateful if you could achieve this by 27 May 2020 so that the benefits of this initiative can start as quickly as possible.'

<sup>&</sup>lt;sup>1</sup> https://digital.nhs.uk/

## **Purpose of the collection**

The Secretary of State has directed NHS Digital to collect, process and analyse data in connection with COVID-19 to support the Secretary of State's response to COVID-19 and support various COVID-19 purposes set out in the COVID-19 Public Health Directions 2020, 17 March 2020 (as amended) (COVID-19 Direction) and below. This enables NHS Digital to collect data and analyse and link the data for COVID-19 purposes with other data held by NHS Digital.

The purpose of the data collection is also to respond to the intense demand for General Practice data to be shared in support of vital planning and research for COVID-19 purposes, including under the general legal notice issued by the Secretary of State under Regulation 3(4) of the Health Service (Control of Patient Information) Regulations 2002 (COPI).

NHS Digital has therefore been requested by the joint co-chairs of the Joint GP IT Committee (JGPITC) (the BMA and RCGP) to provide a tactical solution during the period of the COVID-19 pandemic to meet this demand and to relieve the growing burden and responsibility on General Practices. On 15 April 2020 the BMA and RCGP therefore gave their support via JGPITC to NHS Digital's proposal to use the General Practice Extraction Service (GPES) to deliver a data collection from General Practices, at scale and pace, as a tactical solution to support the COVID-19 response in the pandemic emergency period.

It is a requirement of the JGPITC that all requests by organisations to access and use this data will need to be made via the NHSX SPOC COVID-19 request process, that will triage and prioritise these requests and refer appropriate requests on to the NHS Digital Data Access Request Service (DARS).

NHS Digital will consult with representatives of the BMA and the RCGP on all requests for access to the data. An outline of the process for this agreed with the BMA and the RCGP is published here. Requests by organisations to access record level data from this collection will also be subject to Independent Group Advising on the Release of Data (IGARD) consideration. Data applicants will need to demonstrate they have a lawful basis to access the data for COVID-19 purposes.

### Benefits of the collection

Organisations, including the Government, health and social care organisations and researchers need access to this vital data for a range of COVID-19 purposes, to help plan, monitor and manage the national response to the COVID-19 pandemic, which will help save lives. COVID-19 purposes for which this data may be analysed and used may include:

- understanding COVID-19 and risks to public health, trends in COVID-19 and such risks, and controlling and preventing the spread of COVID-19 and such risks
- identifying and understanding information about patients or potential patients with, or at risk of COVID-19, information about incidents of patient exposure to COVID-19 and the management of patients with or at risk of COVID-19 including: locating, contacting, screening, flagging and monitoring such patients and collecting information about and providing services in relation to testing, diagnosis, self-isolation,

fitness to work, treatment, medical and social interventions and recovery from COVID-

- understanding information about patient access to health services and adult social care services as a direct or indirect result of COVID-19, and the availability and capacity of those services
- monitoring and managing the response to COVID-19 by health and social care bodies and the Government including providing information to the public about COVID-19 and its effectiveness and information about capacity, medicines, equipment, supplies, services and the workforce within the health services and adult social care services
- delivering services to patients, clinicians, the health services and adult social care services workforce and the public about and in connection with COVID-19, including the provision of information, fit notes and the provision of health care and adult social care services; and
- research and planning in relation to COVID-19.

Data may be analysed and linked to other data held by NHS Digital, or held by other organisations to which access to the data is granted for COVID-19 purposes, through the process described above.

Data will be collected nationally from all GP Practices by NHS Digital every fortnight. All requests to access this data will be triaged through the NHSX SPOC COVID-19 request process and assessed and fulfilled by NHS Digital through DARS. This will significantly reduce the burden on General Practice at a time when demand on resources is high, enabling General Practice to focus on delivering health care and support to patients. It will also reduce compliance burden and risk for General Practice associated with sharing data and complying with the terms of the general legal notice issued under COPI, which applies to General Practices.

## Legal basis for the collection, analysis, publication and dissemination

### Collection and Analysis

NHS Digital has been directed by the Secretary of State under section 254 of the 2012 Act under the COVID-19 Direction to establish and operate a system for the collection and analysis of the information specified for this service: GPES Data for Pandemic Planning and Research (COVID-19). A copy of the COVID-19 Direction is published here: https://digital.nhs.uk//about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/covid-19-public-health-directions-2020.

Details of the information to be collected can be found in Appendix A – Specification of this DPN. Type 1 objections will be upheld in collecting this data from General Practices and therefore the data for those patients who have registered a Type 1 objection with their GP will not be collected. The Type 1 objection prevents an individual's personal identifiable confidential information from being shared outside of their GP Practice except when it is being used for the purposes of their direct care. The National Data Opt-Out will not apply to the collection of the data, as this is a collection which is required by law.

This information is required by NHS Digital under section 259(1)(a) of the 2012 Act to comply with the COVID-19 Direction. In line with section 259(5) of the 2012 Act, all organisations in England that are within the scope of this Notice, as identified below under Health and Social Care Bodies within the scope of the collection, must comply with the requirement and provide information to NHS Digital in the form, manner and for the period specified in this Notice.

This Notice is issued in accordance with the procedure published as part of NHS Digital's duty under section 259(8) of the 2012 Act.

#### **Publication**

NHS Digital has been directed not to publish any information it obtains under the COVID-19 Direction, which includes the data collected under this Notice, except for the publication of anonymous statistical data (with small numbers supressed) where:

- this is either agreed by the Secretary of State; or
- NHS Digital reasonably believes:
  - it to be in the public interest to publish the data following consultation with relevant parties. This would include consulting for example NHSX, the Department of Health and Social Care, NHS England and NHS Improvement, Public Health England and professional bodies. In the case of this collection, this would include the BMA, the RCGP and the JGIPTC; and
  - this does not to any significant extent interfere with the performance by NHS Digital of its other functions in response to COVID-19 or its other functions more generally.

Any information that is published will be fully anonymised in accordance with the Information Commissioner's Office Anonymisation Code of Practice<sup>2</sup> and be in accordance with the Code of Practice for Statistics.

#### Dissemination

NHS Digital retains responsibility and accountability at all times for the dissemination of data from the collection as the Controller under the General Data Protection Regulation 2016 (GDPR). It will do so through ensuring that requests for data are necessary, proportionate, that the minimum amount of data necessary for the purpose only is shared and that the transfer and use of the data shared will be secure and lawful.

Organisations which may seek access to the data for planning purposes may include the Department of Health and Social Care and other Government Departments involved in the COVID-19 response, NHS England and NHS Improvement, Public Health England, NHS Trusts and Clinical Commissioning Groups (CCGs). Research organisations, including Universities, NHS Trusts and private research companies may seek access to the data for the purposes of carrying out vital COVID-19 research. Examples of current Urgent Public Health Nationally Prioritised COVID-19 research studies and those organisations carrying out that research are available on the National Institute of Health Research Portal.

<sup>&</sup>lt;sup>2</sup> https://ico.org.uk/media/for-organisations/documents/1061/anonymisation-code.pdf or any subsequent document on the same topic published by the ICO

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The Health and Social Care Information Centre is a non-departmental body created by statute, also known as NHS Digital.

NHS Digital has various legal powers to disseminate the data for COVID-19 purposes, including under section 261 of the 2012 Act and under the NHS Digital COPI Notice. Data applicants will need to demonstrate though the NHSX SPOC COVID-19 request process and the DARS assessment process that they have a lawful basis to access and process the data for COVID-19 purposes. Where identifiable data is requested, the data applicant would need a legal basis to process this data without breaching the common law duty of confidence. This may include express patient consent for example in the case of certain research and clinical trials, or Regulation 3 or Regulation 5 of COPI may apply. Use of data for research purpose will also require a Research Ethics Committee approval.

NHS Digital will consult with the BMA and the RCGP on all requests for access to this data which are received by DARS. An outline of the process for this agreed with the BMA and the RCGP is here. Requests by organisations to access record level (pseudonymised or identifiable) data from this collection will also be subject to IGARD consideration and advice.

Requests will be assessed by DARS and IGARD against specific criteria underpinned by information governance assessment standards. These standards include additional scrutiny when there is involvement of any organisation where the public may have particular concerns about their involvement in health and social care. The DARS process is robust and well-established, and consists of enquiry, triage, review, independent oversight through IGARD, approval, access, audit and destruction phases. All data approved for release through DARS and IGARD are subject to robust data sharing agreements between NHS Digital and the Controller requesting the data. More detail on the DARS process, standards and the data sharing agreements used are available here. Details on the IGARD review process is here. For more information including about IGARD's constitution and its assurance and oversight role, please see its Terms of Reference.

In the unlikely event that IGARD did not recommend approval of a request for access to this data and NHS Digital disagreed with that recommendation, NHS Digital would seek guidance from the National Data Guardian or where appropriate, advice from the Confidentiality Advisory Group under section 262A of the Health and Social Care Act 2012 before disseminating any data.

The application of the National Data Opt-Out will be considered on a case by case basis for each dissemination and may or may not apply depending on the specific COVID-19 purposes for which the data is to be used. This is because during this period of emergency, the National Data Opt-Out will not generally apply where data is used to support the coronavirus outbreak, due to the public interest in and legal requirements to share information. For more information on the National Data Opt-Out and its application during the COVID-19 period see Section 6.2 of the National Data Opt-Out Operational Policy Guidance.

#### **Transparency**

As NHS Digital is collecting personal data from General Practices through this collection, General Practices have a legal duty to be transparent and to provide patients with transparency information under GDPR about the data they are sharing with NHS Digital.

General Practices therefore need to update their own Transparency Notices on their websites to include details of this collection. NHS Digital has produced a template General Practice Transparency Notice which GPs can use to do this here.

NHS Digital has also produced its own transparency notice, the GPES Data for Pandemic Planning and Research Supplementary Transparency Notice. This provides more information about how NHS Digital will process the data collected from General Practice. The template General Practice Transparency Notice contains a link to this NHS Digital transparency notice so that if patients would like more information, they can click through to the NHS Digital notice.

NHS Digital continues to work closely with the Information Commissioner's Office (ICO) to ensure a high level of transparency for patients during this period and the ICO has reviewed these Transparency Notices.

NHS Digital will disclose in its Data Release Register, the organisations to whom it disseminates the data obtained through this DPN and the purposes of the dissemination. It will also publish examples of how the data from this collection has been used, to inform the public and the profession of the benefits from the use of the data.

Minutes of IGARD meetings are published weekly here and provide details of the advice IGARD has provided on each request it has considered together with its recommendations.

NHS Digital will also produce a number of reports on the data shared from this collection including:

- KPI reports to the NHS Digital Executive Management Team, on the dissemination of the data;
- a monthly report to the NDG and the BMA and RCGP on the dissemination of the data; and
- a report to the NHS Digital Public Board via its KPI pack, which will be published with the Public Board papers in accordance with the current process here.

### **Persons consulted**

NHS Digital has, as required under section 258 of the 2012 Act, consulted with the following organisations:

- The British Medical Association (BMA)
- The Royal College of General Practitioners (RCGP)
- The Department of Health and Social Care, as directing organisation
- NHSX
- NHS England and NHS Improvement
- The National Data Guardian
- Research bodies for the purpose of research in relation to COVID-19.

## Health and Social Care Bodies within the scope of the collection

Under section 259(1)(a) of the Health and Social Care Act 2012, this Notice is served in accordance with the procedure published as part of the NHS Digital duty under section 259(8) on the following persons:

General Practices in England.

Under section 259(1)(a) and (5) of the Health and Social Care Act 2012 the organisation types specified in the above Scope must comply with the Form, Manner and Period requirements below.

#### Form of the collection

The GPES data extraction will identify all patients currently registered with a General Practice or with a date of death on or after 1 November 2019 whose record contain coded information relevant to pandemic planning and research.

For each patient above, NHS Digital will require the following personal data:

- NHS Number
- postcode
- address
- surname and forename
- sex
- ethnicity
- date of birth
- date of death.

Data will be extracted for the associated SNOMED<sup>3</sup> 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.

The Specification at Appendix A provides details of each data item to be extracted.

<sup>&</sup>lt;sup>3</sup> https://digital.nhs.uk/services/terminology-and-classifications/snomed-ct

#### Manner of the collection

General Practices will be sent an invitation to participate via the Calculating Quality Reporting Service (CQRS). This invitation must be accepted as there is a Direction in place for this data collection and it is a legal requirement for General Practices to provide this data under section 259(1)(a). All General Practices are therefore mandated to comply with this invitation and approve the collection.

The required data will be collected from General Practices' clinical IT systems via the General Practice Extraction Service (GPES). The NHS Digital GP Collections webpage<sup>4</sup> provides further information on this service.

The CQRS participation window will run in parallel with the technical development of the extract. General Practices must therefore accept the invitation by **27 May 2020** to be included in the initial extract. Given the importance of this collection to supporting vital COVID-19 planning and research and to reduce burden for General Practice, General Practices are encouraged to approve the collection as soon as possible.

Once collected, the data will be stored in the NHS Digital secure Data Access Environment (DAE) used by NHS Digital in line with the COVID-19 Direction and shared only with those organisations which have a legal basis to process the data and where necessary in order to achieve the COVID-19 purposes, in accordance with the process set out above.

#### Period of the collection

This General Practice Extraction Service (GPES) data will be extracted as a snapshot in time extract on the initial collection. A subsequent fortnightly extraction will then continue until the expiry of the COVID-19 Direction. This is currently 31 March 2022 but will be reviewed in September 2020 and every six months thereafter. The frequency of the data collection may change in response to demand.

### **Burden of the collection**

## Steps taken by NHS Digital to minimise the burden of collection

A burden assessment has not taken place for this collection. The urgent requirement for the data for the purpose of responding to COVID-19 outweighs the requirement for a burden assessment to take place.

However, one of the purposes of this collection is to reduce burden for General Practice as GPES COVID-19 data will be collected nationally and disseminated by NHS Digital, therefore reducing the burden on General Practices at a time when demand on resources is high. This will enable General Practice to focus on delivering health care and support to patients. It will also reduce compliance burden and risk for General Practice associated with sharing data and complying with the terms of the general legal notice issued under COPI, which applies to General Practice.

<sup>&</sup>lt;sup>4</sup> https://digital.nhs.uk/services/general-practice-gp-collections

NHS Digital has also sought to minimise the burden on General Practices by using existing data extract technology, rather than requesting information in another format which may be more burdensome to process.

In seeking to minimise the burden it imposes on others, in line with sections 253(2)(a) and 265(3) of the 2012 Act, NHS Digital has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

## Appendix A - Specification

The patient/record data that will be included in the GPES Data for Pandemic Planning & Research data collection may be found on the Business Rules page on NHS Digital's website:

https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/quality-and-outcomes-framework-qof#other-extracts

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