NHS Digital

Data Provision Notice

COVID-19 at-risk Patients data collection version 3

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Information and technology
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Contents

Background

The Health and Social Care Act 2012 (the **2012 Act**) gives the Health and Social Care Information Centre, now known as NHS Digital 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 & 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.

NHS Digital have consulted the General Practitioners Committee (GPC England) of the British Medical Association (BMA) and the Royal College of General Practitioners (RCGP) and they have given full support to these data collections.

"*The RCGP and BMA are supportive of this data extraction which will enable practices to support their most vulnerable patients. Given the nature of the COVID crisis and the need to move quickly to support those patients at greatest need, we are content that NHS Digital's proposals to collect data from the GP system suppliers for the uses indicated in this Data Provision Notice are proportionate.*"

NHS Digital issued version one of this DPN on 18 March 2020. This outlined an initial one-off data collection for the purpose of direct care in response to the spread of the COVID-19 (also known as coronavirus) in the UK for the following purposes identified in the COVID-19 Directions:

- identifying and understanding information about patients or potential patients with or at risk of COVID-19
- the management of patients with or at risk of COVID-19 including locating, contacting, screening, flagging, and monitoring such patients.

The objective of the initial collection was to identify patients registered at General Practices who may have been clinically extremely vulnerable if they contracted the COVID-19 virus. The data collected was analysed and linked with other data held by NHS Digital to identify a list of clinically extremely vulnerable patients who were advised to take shielding measures to protect themselves. This list is the Shielded Patient List (formerly known as the vulnerable patient list).

The patients on the Shielded Patient List (SPL) were contacted by post and/or SMS message by the NHS behalf of the Chief Medical Officer, Chris Whitty, to advise of the measures they can take to reduce their risk of contracting the virus and sign-post them to the Extremely Vulnerable Persons service operated by gov.uk at: https://www.gov.uk/coronavirus-extremely-vulnerable. The SPL was also used to inform GPs of their individual patients on the SPL, by flagging those patient records on GP patient record systems.

NHS Digital has been requested by the Chief Medical Officer to maintain the SPL and has published information about how it will update the SPL on its website: https://digital.nhs.uk/coronavirus/shielded-patient-list.

The initial one-off extract of data, used to create the SPL, was based on an existing specification for flu vaccination eligibility. The outputs from this first data collection were reviewed following the work to produce the SPL resulting in changes to minimise and improve the collection. A weekly extraction of the revised specification has taken place since April 2020.

The weekly extract collects data about patients that GPs have identified as clinically extremely vulnerable to COVID-19 who should be added to the SPL. Information about patients who are on the SPL are provided back to GPs by NHS Digital through identifying those patient records with a flag on GP systems.

The SPL was developed early in the COVID-19 outbreak when evidence about the groups of patients most at risk was based on what was known about risk factors with other known respiratory viral infections. The SPL is intended to be a dynamic list that will adapt as knowledge of the disease improves and more clinical evidence becomes available.

In August 2020, the NHS announced that the seasonal national flu immunisation programme criteria for 2020 - 2021 will be expanded to include patients on the SPL. Therefore, to provide information that will support the identification of patients at moderate or high risk of complications from flu, a revision to the weekly extract of data has taken place.

This, version three of the extract for the purpose of maintaining and updating the SPL, will 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.

The table below shows the data included in the weekly versions of the data extractions:

Data collection extracted on a weekly basis week commencing 13 April 2020	Revised weekly data collection. The first collection is due week commencing 28 September 2020
All patients with defined long-term medical conditions which pose a COVID-19 risk, identified as clinically extremely vulnerable to that risk and/or on certain drug treatments as below:	All patients with defined long-term medical conditions which pose a COVID-19 risk, identified as clinically extremely vulnerable/potentially clinically vulnerable to that risk and/or on certain drug treatments as below:
Medical conditions that provide information on clinically extremely vulnerable patients • Severe asthma and dust related lung disease with relevant treatment in the last 12 months (asthma treatment & prednisolone OR high dose corticosteroid safety card) • COPD emphysema, and associated lung diseases with relevant treatment in the last 12 months (COPD drugs OR high dose corticosteroid safety card)	**Medical conditions that provide information on clinically extremely vulnerable patients** • Severe asthma and dust related lung disease with relevant treatment in the last 12 months (asthma treatment & prednisolone OR high dose corticosteroid safety card) • COPD emphysema, and associated lung diseases with relevant treatment in the last 12 months (COPD drugs OR high dose corticosteroid safety card)

- Non-asthma and non-COPD chronic respiratory disease - Cancer (haem and others) - Congenital heart disease - Genetic, metabolic or autoimmune disease - Immunosuppression drugs in the last 12 months - Flu-like symptoms or respiratory tract infections from 1 November 2019 - Transplants with severe Immunosuppression drug treatment in the last 12 months - Pregnant in last 9 months	- Non-asthma and non-COPD chronic respiratory disease - Cancer (haem and others) - Congenital heart disease - Genetic, metabolic or autoimmune disease - Immunosuppression drugs in the last 12 months - Flu-like symptoms or respiratory tract infections from 1 November 2019 - Transplants with severe Immunosuppression drug treatment in the last 12 months - Pregnant in last 9 months *(no change)*
Patients designated separately as at risk from COVID-19 using high/medium/low risk SNOMED CT codes, for example	Patients designated separately as at risk from COVID-19 using high/medium/low risk SNOMED CT codes, for example *(no change)*
Patients with a COVID-19 activity code	Patients with a COVID-19 activity code *(no change)*
	Clinically vulnerable patients (eligible for seasonal flu vaccination) - Chronic respiratory disease - Unresolved asthma with recent asthma drug treatment (in the last 12 months) or has ever had an emergency hospital admission due to asthma - Chronic heart disease - Unresolved chronic kidney disease stage 3, 4 and 5 - Unresolved diabetes mellitus - Unresolved immunosuppression diagnosis - Immunosuppression procedure in the last 12 months - Chronic liver disease - Chronic neurological disease - Pregnant in the last 9 months (different cluster to clinically extremely vulnerable group) - In patients aged 16 and over: BMI of 40+ in the last 12 months - In patients aged 16 and over: Latest BMI in the last 3 years was 40+ - Learning disability (including Down's) - Has a 'requires flu vaccination' code - Identified as a healthcare worker in the last 12 months - Household contact of an immunocompromised individual

	Other potentially clinically vulnerable patients
	- Unresolved hypertension - Pulmonary hypertension - Dementia - Systemic lupus - Discoid and non-systemic lupus - Psoriasis - Rheumatoid arthritis and associated disorders
	Additional data items for patients from the above groups - Latest ethnic category code (all groups) - Earliest code indicating that the patient has died (all groups) - Latest smoking status (all groups) - Blood pressure from the last 2 years (all groups) - In patients aged 16 and over: all BMI and weight in the last 5 years plus latest height (all groups) - IFCC-HbA1c in the last 2 years (for diabetic patients in the flu group only) - Latest COPD resolved and admission codes (for COPD patients in the clinically extremely vulnerable group only) - ACE inhibitors, ARBs and non-steroidal anti-inflammatory drugs in the last 12 months (all groups) - Latest asthma emergency admission codes (for asthma patients in the flu group only) - Asthma-related drug treatments in the last 12 months (for asthma patients in the flu group only)

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 (COVID-19 Direction) (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 rationale for changing the data extraction is that the initial data collection was based on an existing specification for flu vaccination eligibility. This data extraction was then refined in order to more accurately reflect the patients who are clinically extremely vulnerable to COVID-19 and also to minimise the data we are collecting. A further refinement of the data extraction has taken place leading to the inclusion of new data being extracted. This will provide information to inform vaccination programmes. This General Practice Extraction

Service (GPES) data will be extracted weekly and be used to assist in producing a weekly update of the SPL.

The objective of this collection is on an ongoing basis to identify patients registered at General Practices who may be:

- clinically extremely vulnerable if they contract COVID-19
- at moderate or high risk of complications from flu or COVID-19.

The data collected will be analysed and linked with other data NHS Digital or other organisations hold to identify:

- a list of clinically extremely vulnerable patients who will be advised to take shielding measures to protect themselves. Advice given to these patients has been published by Public Health England and is available here: https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19#what-do-we-mean-by-extremely-vulnerable
- a list of patients at moderate or high risk of complications from flu to inform the flu call/recall vaccination programme. Further information on the flu programme can be found here: https://www.england.nhs.uk/wp-content/uploads/2020/05/Letter_AnnualFlu_2020-21_20200805.pdf

The extract may also be used for future direct care purposes relating to the COVID-19 outbreak.

The methodology NHS Digital has used to produce the SPL is explained in detail and is published on the NHS Digital SPL website page here: https://digital.nhs.uk/coronavirus/shielded-patient-list

Patients added to the SPL will be contacted by post, email (and/or SMS message where this is necessary) by the NHS on behalf of the Chief Medical Officer, Chris Whitty, to:

- advise of the measures they can take to reduce their risk of contracting the virus and sign-post them to the Extremely Vulnerable Persons service operated by gov.uk at https://www.gov.uk/coronavirus-extremely-vulnerable
- offer a flu vaccination or to contact non-responders who remain unvaccinated (as per NHS England specifications for the service).

The SPL will also be used to inform GPs of their individual patients on the SPL, by flagging those patient records on GP patient record systems. The SPL will be shared with a variety of other organisations involved in the care and support of those patients and for planning, commissioning and research purposes associated with COVID-19. Full details of those with whom information has been shared can be found on the NHS Digital SPL website here: https://digital.nhs.uk/coronavirus/shielded-patient-list/distribution.

Requests by organisations to access record level data from this collection will 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 Government, health and social care organisations need to access 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-19.

Data will 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 General Practices by NHS Digital every week. All requests to access this data will be through Data Access Request Service (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 the National Health Service (Control of Patient Information Regulations) 2002 (COPI), which applies to General Practices

Patients facing the greatest risk if they contract COVID-19 and/or are in the moderate to high risk of complications from flu:

- will be identified and known to health organisations

- will have a greater awareness of the recommended preventative shielding measures

- will be able to follow clear advice

- will be able to ask for help and support, including social care support and essential food supplies, through the Extremely Vulnerable Persons service operated by gov.uk.

It will enable the SPL to be updated weekly to identify new patients and changes to patients on the List and will enable support provisions to be more dynamic and responsive to both social and clinical need. It will also enable vital planning, commissioning, and research to be carried out for COVID-19 purposes.

If patients facing the greatest risk follow advice, it is hoped that this will contribute to the delay and mitigation of the spread of COVID-19 and save lives.

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: COVID-19 at-risk patients. A copy of the 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 not be applied 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 in 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 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; 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[1] and be in accordance with the Code of Practice for Statistics.

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[1] https://ico.org.uk/media/for-organisations/documents/1061/anonymisation-code.pdf or any subsequent document on the same topic published by the ICO

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.

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.

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.

Therefore, General Practices need to update their own Transparency Notices on their websites to include details of this collection. NHS Digital has produced a COVID-19 response transparency notice which GPs can use to do this here: https://digital.nhs.uk/coronavirus/coronavirus-covid-19-response-information-governance-hub

There is also specific Transparency Notice for SPL: https://digital.nhs.uk/coronavirus/shielded-patient-list/shielded-patient-list-transparency-notice

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)

- Department of Health and Social Care, as directing organisation

- Public Health England (PHE)

- NHS England and NHS Improvement

- NHSX

- NHS Digital Information Governance team

- The Data Coordination Board (**DCB**)[2], which includes representatives from the Department of Health and Social Care (**DHSC**), the National Institute for Health and Care Excellence (**NICE)**, NHS England and NHS Improvement (NHSE/I), PHE, Care Quality Commission (**CQC**), Local Government Association (**LGA**), Health Education England (**HEE**), Health Research Authority (HRA), Association of Directors of Adult Social Services (**ADASS**) and NHS Digital.

- Chief Medical Officers of England, Scotland, Wales and Northern Ireland.

Health and Social Care Bodies within the scope of the collection

Under section 259(1)(a) and (5) of the 2012 Act, 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) and (5) of the 2012 Act 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 who fall under the cohort count and 70 code clusters specified in the business rules. These are outlined in Appendix A – Specification.

For each patient above, NHS Digital will require the following personal data, as well as the General Practice that individuals are registered with:

- NHS Number

- surname and forename

- date of birth

- date of death

- address

- ethnic category

- sex.

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[2] The Data Coordination Board (DCB) – a sub board of the system-wide Digital Delivery Board (DDB), the DCB acts with delegated authority from the DDB and directly from the Secretary of State as the main governance route through which all data collection requirements are agreed, and priorities assigned.

Where a patient's record contains a defined long-term medical condition, which poses a COVID-19 risk and/or a condition/code which identifies a patient as being of moderate or high risk of complications from flu/COVID-19, data will be extracted for:

- the associated SNOMED[3] CT code(s) and date(s) for the:
    - medical condition
    - recorded activity for COVID-19 in the patient's medical record
    - drug treatment(s)
- any values such as scores or prescriptions associated with the SNOMED CT code(s).

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

Manner of the collection

General Practices will be automatically enrolled into the data extract and will not be required to participate. This will reduce burden on GPs as there will be no offer of participation on Calculating Quality Reporting Service (CQRS).

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[4] provides further information on this service.

Once collected, the data will be stored appropriately by the NHS Digital Data Management Service (DMS) in line with the COVID-19 Direction and shared only with those organisations who 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

The GPES data will be extracted on a weekly basis with the revised data collection due week commencing 28 September 2020. The 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

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, the burden will be minimal as General Practices are not required to accept an offer of participation in the data collection.

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

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[3] https://digital.nhs.uk/services/terminology-and-classifications/snomed-ct
[4] https://digital.nhs.uk/services/general-practice-gp-collections

Appendix A – Specification

The patient/record data that will be included in the COVID-19 Clinical Risk Extract version 3.0, or the latest amended version as agreed by NHS England and NHS Improvement, 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.

For further information

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