

# Data Provision Notice

## Shielded Patient List - enhancement with cancer and rare diseases data v1.1

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Version: 1.1

Published: 23 November 2020



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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.

The data, as specified by NHS Digital in this published Data Provision Notice (**DPN**), 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 issued DPNs relating to the Shielded Patient List (SPL) data collection on 18 March 2020 (GPES data version 1), 09 April 2020 (GPES data version 2), 20 April 2020 (criminal justice data) and 18 September 2020 (GPES data version 3). These DPNs and this DPN cover data collections for the purpose of direct care in response to the spread of the COVID-19 (also known as coronavirus) in England for the following purposes identified in the COVID-19 Direction:

- 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 collections was to identify patients registered at GP practices or registered as part of the criminal justice secure and detained estate (Prisons) in England 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 extremely clinically vulnerable patients who were advised to take shielding measures to protect themselves. This list is the SPL (formerly known as the vulnerable patient list).

The patients on the SPL were contacted by the NHS on behalf of the Chief Medical Officer, Chris Whitty, to advise of the measures they could 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 and health and justice sites of their individual patients on the SPL, by flagging those patient records on GP patient record systems and the Health and Justice Information System (HJIS).

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

The objective of this collection, which collects cancer datasets and rare diseases datasets from Public Health England (PHE), is to improve the identification of patients who may be clinically extremely vulnerable if they contract the COVID-19 virus, by using more accurate clinical datasets linked with the existing data. It will allow NHS Digital to assess whether additional patients should be added to the SPL.

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<sup>1</sup> <https://digital.nhs.uk/>

A monthly collection, 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. The frequency of the data collection may change in response to demand.

## Purpose of the collection

The Secretary of State has directed NHS Digital to collect 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 objective of this collection is on an ongoing basis to identify cancer and rare diseases patients registered by the PHE National Disease Registration Service (NDRS) who may be clinically extremely vulnerable if they contract COVID-19. The data collected will be analysed and linked with other data NHS Digital holds 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>.

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/methodology>. The process for updating it is also set out here: <https://digital.nhs.uk/coronavirus/shielded-patient-list>. This will be updated to include the data collection through this DPN.

Patients added to the SPL will be contacted by post and/or SMS and/or email message 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>.

The SPL will also be used to inform GPs and healthcare clinicians of their individual patients on the SPL, by flagging those patient records on GP patient record systems and HJIS clinical 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>.

## Benefits of the collection

Patients facing the greatest risk if they contract COVID-19:

- 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.

It will enable the SPL to be updated monthly 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-notice/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.

This information is required by NHS Digital under section 259(1)(a) of the Health and Social Care Act 2012. In line with section 259(5) of the 2012 Act, all organisations in England that are within the scope of this Data Provision 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.

The cancer and rare diseases data held by PHE is exempt from the National Data Opt-Out. However, PHE does apply and maintain its own opt-out mechanism, details of which are published here:

<https://www.gov.uk/guidance/national-cancer-registration-and-analysis-service-ncras#opt-out-of-cancer-registration>

<https://www.gov.uk/government/publications/national-congenital-anomaly-and-rare-disease-registration-service-introductory-leaflet>

### 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 suppressed) 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
- 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 has various powers to disseminate data obtained under the COVID-19 Direction to appropriate organisations for COVID-19 purposes under section 261 of the Act. NHS Digital has also been served Notice by the Secretary of State under Regulation 3(4) of the Health Service (Control of Patient Information Regulations) 2002 (COPI) to disseminate confidential patient information to organisations permitted to process confidential patient information under Regulation 3(3) of COPI for the purposes set out in Regulation 3(1) of COPI to support the Secretary of State's response to COVID-19 (NHS Digital COPI Notice). NHS Digital will only share data with other organisations where this is necessary for a COVID-19 purpose and where those other organisations have a lawful basis to process the 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: <https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/when-does-a-national-data-opt-out-not-apply>

## Transparency

As NHS Digital is collecting personal data from Public Health England (PHE) through this collection it has a legal duty to provide transparency information under the [General Data Protection Regulation](#) (GDPR) about the data it is collecting under this notice.

PHE uses its patient facing website for transparency purposes and have included the details of this collection under the heading *Linking datasets together to help COVID-19 analysis and research* at <https://www.ndrs.nhs.uk/national-disease-registration-service/patients/how-data-is-used/>

There is also a specific Transparency Notice for the SPL: <https://digital.nhs.uk/coronavirus/shielded-patient-list/shielded-patient-list-transparencynotice>

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<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.

NHS Digital will disclose in its Data Release Register<sup>3</sup>, the organisation to whom it disseminated the data obtained through this DPN and under the COVID-19 Direction and the purposes of the dissemination.

NHS Digital also discloses the organisations with whom it has shared the SPL on its website here: <https://digital.nhs.uk/coronavirus/shielded-patient-list/distribution>.

## Persons consulted

As part of the creation and ongoing maintenance of the SPL, 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
- The Data Coordination Board (DCB)<sup>4</sup>, 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.

Additionally, for the purposes of the cancer and rare diseases data, NHS Digital has consulted with the following persons:

- Public Health England (as Data Controllers of the NDRS data)
- University of Oxford
- Department of Health and Social Care.

## 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:

- Public Health 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.

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<sup>3</sup> <https://digital.nhs.uk/services/data-access-request-service-dars/register-of-approved-data-releases>

<sup>4</sup> 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.

## Form, manner, and period of the collection

The form for the collection will encompass cancer and rare diseases datasets held within the NDRS in PHE. The datasets will be collected via the NHS Digital Message Exchange for Social Care and Health (MESH) mechanism.

The manner for the collections is detailed in Appendix A for cancer data, rare diseases data and congenital anomalies data. Deceased patients will not be included.

The period for the collection will be:

Dataset	Period
Cancer Registry	Historic data (Fixed Annual snapshot) – One-off plus occasional ad-hoc transfer if patient opt-outs need to be applied Prospective data - monthly until further notice
RTDS	Historic data (Fixed Annual snapshot) – One-off plus occasional ad-hoc transfer if patient opt-outs need to be applied Prospective data – monthly until further notice
SACT	Historic data (Fixed Annual snapshot) – One-off plus occasional ad-hoc transfer if patient opt-outs need to be applied Prospective data – monthly until further notice
Proxy Cancer Registrations	Prospective data – monthly until further notice
Rare diseases datasets	One-off collection covering all available data (see Appendix A for specific dataset date ranges)
Congenital anomalies datasets	One-off collection covering all available data 2015 to 2018

## Burden of the collection

A burden assessment has not taken place for this collection. The urgent requirement for the data for the purpose of patient safety and direct care for at-risk patients outweighs the requirement for a burden assessment to take place.

This being the case, NHS Digital in seeking to minimise the burden of these collections has:

- continuously engaged with PHE to develop the minimum data collection
- developed and implemented operational processes for the collections which are proportionate and maintainable by PHE
- employed existing NHS Digital technical means, already employed by PHE, to collect the data
- utilised cancer datasets that are already being collected from PHE on a regular basis.

## Appendix A Specification

### Cancer datasets

Dataset	Patient identifiers (for linkage purposes)	Other fields
Subset of Cancer Registry dataset	For linkage purposes and patient matching in MPS:  NHS Number Gender Date of birth Forenames (given name(s)) Surname (family name) Address Postcode	TUMOURID PATIENTID STATUS OF REGISTRATION CTRY_CODE DIAGNOSISDATEBEST SITE_ICD10_02 SITE_ICD10_02_3CHAR MORPHOLOGY_ICD10_02_3CHAR BASIS OF DIAGNOSIS STAGE_BEST DIAG_TRUST CASCADE_INCI_FLAG DEDUP_FLAG BIRTHDATEBEST AGE SEX ETHNICITY FINAL_ROUTE CHRL_TOT_27_03
Radiotherapy Dataset (RTDS)	NHS Number Gender Date of birth Forenames (given name(s)) Surname (family name) Address Postcode	Complete dataset as made available to cancer researchers through the PHE Office for Data Release, see "Cancer registration data dictionary": <a href="https://www.gov.uk/government/publications/accessing-public-health-england-data">https://www.gov.uk/government/publications/accessing-public-health-england-data</a>

Dataset	Patient identifiers (for linkage purposes)	Other fields	
Systemic Anti-Cancer Therapy (SACT) dataset	NHS Number Gender Date of birth Forenames (given name(s)) Surname (family name) Address Postcode	Complete dataset as made available to cancer researchers through the PHE Office for Data Release, see "Cancer registration data dictionary": <a href="https://www.gov.uk/government/publications/accessing-public-health-england-data">https://www.gov.uk/government/publications/accessing-public-health-england-data</a>	
Proxy Cancer Registration dataset	NHS Number Gender Date of birth Forenames (given name(s)) Surname (family name) Address Postcode	RAPID_TUMOUR table:  Individualid Patientid Nhsnumber Tumour_avpid Diagnosisdate Tumour_site Birthdatebest Sex Postcode Ethniccategory Stage Quintile_2019 Chrl_tot_27_03 Morphology Route to diagnosis	RAPID_PATHWAY Table:  Individualid Patientid Nhsnumber Avpid Event_type Event_property_1 Event_property_2 Event_property_3 Event_date Event_end Received_date Trust_code Source_table Source_id

## Rare diseases and congenital anomalies datasets

Rare diseases data:

PHE has permission to collect information about patients who have a confirmed or suspected rare disease with an Orphanet classification and a prevalence of less than one in 2000. The following datasets are held and will be collected:

Dataset	Patient identifiers (for linkage purposes)	Other fields	PHE Legal basis	Background	Time period from	Uncertainties
Sickle cell and thalassaemia newborn outcomes	NHS Number Forename Surname Date of birth Sex Postcode	Confirmed diagnosis	s251	NCARDRS holds data on babies diagnosed with sickle cell and thalassaemia through the Newborn Outcomes Dataset (NBO) from approximately 2010 onwards.	2010	
Inherited metabolic disease specialised services	NHS Number Forename Surname Date of birth Postcode	Diagnosis Treatment holiday Treatment switch Drug	s251	NCARDRS is working in partnership with the Inherited Metabolic Disease Clinical Reference Group (CRG) to register all patients seen in the IMD specialist centres. NCARDRS currently holds information on around 9000 IMD patients. We are also working with the CRG to identify conditions likely to be at increased risk either to infection or decompensation and to record treatment holiday information from specialised centres.	All metabolic activity	Not national coverage - awaiting submissions
Newborn screening	NHS Number Forename Surname Date of birth	Disorder	s251	NCARDRS is collecting newborn screening data on those diagnosed with inherited metabolic conditions from 2012.	2012 until present	Not national coverage - awaiting submissions

Dataset	Patient identifiers (for linkage purposes)	Other fields	PHE Legal basis	Background	Time period from	Uncertainties
Rare autoimmune rheumatic diseases	NHS Number Forename Surname Date of birth Sex Postcode	Rare disease	s251	Surveillance of the effect of COVID-19 on people with rare autoimmune rheumatic diseases, including ANCA-associated vasculitis, Takayasu's arteritis, Giant cell arteritis, Behcet's disease, Systemic lupus erythematosus, Scleroderma, Dermatolysisitis and polymyositis. HES records queried and a proportion validated using remote access into hospital systems.	2003/04 to 2019/20	
Rare diabetes	NHS Number Forename Surname Date of birth Postcode	Diagnosis	s251	Clinic case lists about cases of Alstrom, Bardet biedl and Wolfram syndromes.	Clinician case list	Not national coverage - awaiting submissions
Multiple systems atrophy	NHS Number Forename Surname Date of birth Postcode	Rare disease	Charity and outsourced charity study. Data sharing with NCARDS has been written into consent documents.	Self-reported patients via patient charity and outsourced charity study.	Patients reporting in 2019 and 2020	Data self-reported by patients, diagnoses not confirmed
Wilson's disease - case confirmation and known cases	NHS Number Forename Surname Date of birth Postcode	Diagnosis Drug therapy Liver transplant	s251	Case validation of HES identified cases of Wilson's disease and notification of known cases.	All known cases	Not national coverage - awaiting submissions

Dataset	Patient identifiers (for linkage purposes)	Other fields	PHE Legal basis	Background	Time period from	Uncertainties
Wilson's disease - CROWD study	NHS Number	Rare disease	Data sharing with NCARDRS has been written into consent documents for this study.	The CROWD study aims to discover why some people with Wilson's disease develop neurological or psychiatric problems but others develop liver problems.	2018	Consenting study participants only
Wilson's disease - prospective data collection	NHS Number Forename Surname Date of birth Sex Postcode	Rare disease	s251	Notifications of cases of Wilson's disease from SAS trace element labs.	2019	Not national coverage
Wilson's disease - molecular data	NHS Number Forename Surname Date of birth Postcode	Rare disease Headline result	s251	Molecular data to support Wilson's disease case ascertainment work.	2019	Not national coverage - pilot data from one lab
Haemophagocytic lymphohistiocytosis (HLH)	NHS Number Forename Surname Date of birth Sex Postcode	Diagnosis	s251	Case validation of HES identified cases of HLH and notification of known cases.	Clinician case list	Not national coverage

## Congenital anomalies datasets:

Dataset	Content	Patient identifiers	Other fields
CARA (2015 onwards)	Q code anomalies, Also includes	For linkage purposes and patient matching: NHS Number Gender Date of birth Forename (given name) Surname (at birth) Surname (current) Postcode of delivery	patientid gestationallength Birthweight icd anomalydescription status teststatus karyotypearrayresult rapidniptresult
WANDA (babies born from 1994-2015)		For linkage purposes and patient matching: NHS Number Gender Date of birth Forename (given name) * Surname (family name) * Surname (current) * Postcode of delivery	Numloc (patient identifier) Weight (birth weight) Gestlength (gestational length) Syndrome (ICD-10 code) Malfo1 -Malfo8 (ICD -10 code) SP_malfo1-sp_malfo8 (anomaly description) Sp_karyo (karyotype description) Sp_syndrome (syndrome description)
NoRCAS Babies born from (1984 -2014)		For linkage purposes and patient matching: NHS Number Gender Date of birth Forename (given name) * Surname (family name) * Postcode of delivery	Numloc Weight Gestlength Syndrome Malfo1 -Malfo8 SP_malfo1-sp_malfo8 Sp_karyo Sp_syndrome
SWCAR (2002-2015)		For linkage purposes and patient matching: NHS Number Gender Date of birth Forename (given name) * Surname (family name) * Postcode of delivery	Numloc Weight Gestlength Syndrome Malfo1 -Malfo8 SP_malfo1-sp_malfo8 karyo Sp_karyo Sp_syndrome

Dataset	Content	Patient identifiers	Other fields
CAROB (2005-2015)		For linkage purposes and patient matching: NHS Number Gender Date of birth Forename (given name) * Surname (family name) * Postcode of delivery	Numloc Weight Gestlength Syndrome Malfo1 -Malfo8 SP_malfo1-sp_malfo8 Sp_karyo Sp_syndrome
EMSYCAR (1998-2012)		For linkage purposes and patient matching: NHS Number Gender Date of birth Forename (given name) * Surname (family name) * Postcode of delivery	Numloc Weight Gestlength Syndrome Malfo1 -Malfo8 SP_malfo1-sp_malfo8 Sp_karyo Sp_syndrome

\* not always available

**For further information**

**[www.digital.nhs.uk](http://www.digital.nhs.uk)**

**0300 303 5678**

**[enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk)**

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