NHS Digital

Data Provision Notice

COVID-19 Related Cancer Research

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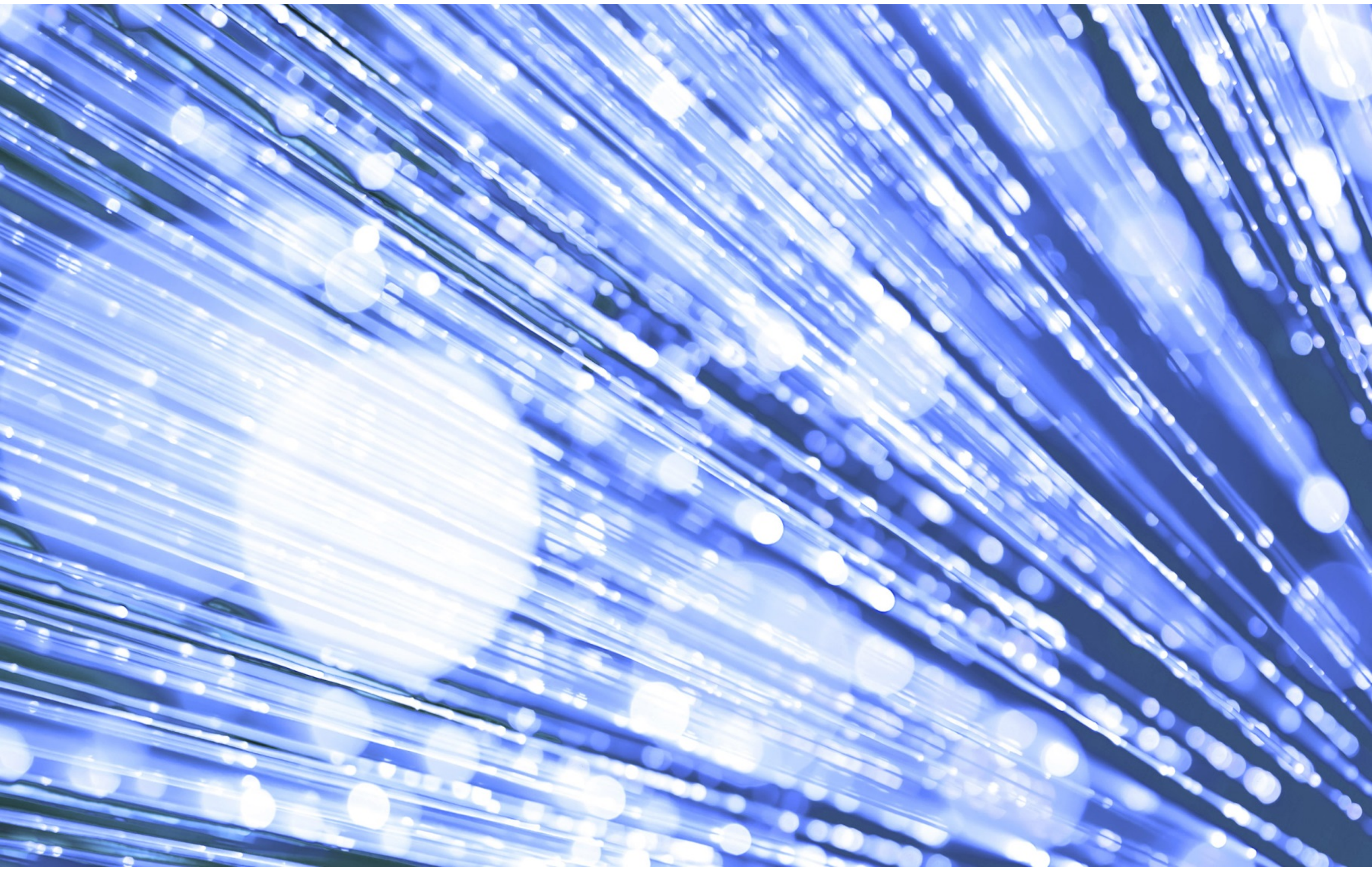

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Background

The Health and Social Care Act 2012 (the 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 or NHS England.

The data, as specified by NHS Digital in this published Data Provision Notice, is required to support the COVID-19 Public Health Directions 2020 from NHS England to NHS Digital. Therefore, organisations that are in scope of the notice are legally required, under section 259(5) of the Act, to provide the data in the form and manner specified below.

Purpose of the collection

NHS England 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 (NHS England) 2020, 17 March 2020 (as amended) (COVID-19 Direction)

The Cancer data assets are required by NHS Digital to support COVID-19 requests for linkage and analysis. These requests are often urgent and in support of direct care and service monitoring, planning and research. These are all functions that NHS Digital has been asked to deliver as a national resource in response to COVID-19, through the COVID-19 Directions.

COVID-19 Related Research

The cancer data assets are necessary to enable research into the effects of COVID-19 on cancer referrals, services, diagnosis, pathways, treatments, and outcomes using the Trusted Research Environment (TRE), hosted by NHS Digital.

The high level purposes relate directly to the following COVID-19 Purposes as outlined in the COVID-19 Directions:

Purpose 1: 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;

Purpose 2: understanding information about patient access to health services and adult social care services and the need for wider care of patients and vulnerable groups as a direct or indirect result of COVID-19 and the availability and capacity of those services or that care;

Purpose 3: 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;

Purpose 4: research and planning in relation to COVID-19

The TRE as a service, provides researchers with support on data access requests, provision of data using the secure Data Processing Service (DPS) and help with analysis work. Approved research projects will help to guide national decision making and recommend potential interventions to reduce the severity of COVID-19 outcomes.

Benefits of the collection

The collection of the PHE cancer data for use in the Trusted Research Environment (TRE) will enable a range of researchers and analysts from cancer stakeholder organisations to:

- Provide a clear picture of the number of cancer patients diagnosed with COVID-19 which will support capacity planning and the recovery of the NHS
- Aid the monitoring and managing of the response to COVID-19 by health and social care bodies and the Government, related to patients with suspected and confirmed cancer
- Assist in the provision of information to the public about COVID-19 and cancer
- Undertake detailed analyses of cancer pathways (referral, diagnosis, treatment and outcomes) in cancer and COVID-19 patients
- Enable the data to be linked to other data obtained by NHS Digital as part of its statutory functions, including demographic information, hospital activity and civil registration information to enable better analysis, research and insights in relation to COVID-19, including its causes and treatments

Access to the Cancer datasets via the TRE will provide rapid, safe, and trustworthy access to data in a transparent way that accelerates the pace of quality research, playing a leading role in the UK's COVID-19 response for cancer services.

Legal basis for the collection, analysis, publication and dissemination

Collection and Analysis

NHS Digital has been directed by NHS England under section 254 of the Health and Social Care Act 2012; to establish and operate a system for the collection and analysis of the information specified for this service. A copy of the Direction is published here https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/nhs-england-directions/covid-19-public-health-nhs-england-directions-2020.

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 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 Data Provision Notice.

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

The data held by PHE in support of the National Cancer Programme (National Cancer Registration Data Set, Radiotherapy Dataset (RTDS), Systemic Anti-Cancer Therapy (SACT) dataset and Rapid Cancer Registration Data Set) is exempt from the national data opt-out, but 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. Rapid Diagnostic Centre (RDC) minimum dataset is not exempt from the national data opt-out and as such will follow the standard processes at NHS Digital to remove patients who have chosen to opt-out.

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.

Access to the data collected under this DPN will be via the TRE unless NHS Digital has a legal obligation to release this data and would reasonably need to do so by other means than through the TRE.

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 DPN, 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 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 in accordance with the Code of Practice for Statistics.

Transparency

NHS Digital is collecting personal data from Public Health England (PHE) through this collection. NHS Digital have a legal duty to provide transparency information under GDPR about the data collected under this data provision notice. Requests for data dissemination, via the TRE will be evaluated based on purpose, legal basis, cyber security, and other considerations set out in the transparency notice. NHS Digital may also seek advice from the Independent Group Advising on the Release of Data (IGARD).

Transparency notice: https://digital.nhs.uk/coronavirus/coronavirus-covid-19-response-information-governance-hub/coronavirus-covid-19-response-transparency-notice#our-legal-basis-under-gdpr

PHE use their 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/

Parties consulted

For the TRE, NHS Digital has consulted with the following parties through the PHE Cancer Stakeholder Coordination Group which includes:

- Association of the British Pharmaceutical Industry (ABPI)
- Cancer Alliances
- Cancer Research UK (CRUK)
- Care Quality Commission (CQC)
- Clinical Practice Research Datalink (CPRD)
- Genomics England
- Getting It Right First Time (GIRFT)
- Health Data Research UK and DATA-CAN (not members of the PHE group)
- Healthcare Quality Improvement Partnership (HQIP)
- Macmillan Cancer Support
- National Cancer Programme
- National Cancer Research Institute (NCRI)
- National Disease Registration Service (NDRS)
- National Institute for Health and Care Excellence (NICE)
- NHS Digital
- NHS England and NHS Improvement Cancer Team
- NHS England Specialised Commissioning
- Patient representatives
- Public Health England (PHE)
- Rarer and less common cancers (Cancer52).

In addition, three representatives from the PHE Cancer Stakeholder Coordination Group and one representative from HDR-UK are members of the NHS Digital Cancer TRE Client Group, which has provided senior direction to the development of the Cancer TRE.

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 organisations:

- Public Health England

Under section 259(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, manner, and period of the collection

The form for the collection will encompass data held within the PHE controlled National Cancer Registration, Radiotherapy (RTDS), Systemic Anti-Cancer Therapy (SACT), Rapid Cancer Registration datasets and Rapid Diagnostic Centre (RDC) minimum dataset. The datasets will be collected via the NHS Digital Secure Electronic File Transfer (SEFT) mechanism, and Message Exchange for Social Care and Health (MESH).

The manner for the collections will be:

Dataset	**Purpose**	**Patient identifiers** (for linkage purposes)	**Other fields**
National Cancer Registration Data Set	Purpose 1 -4	For linkage purposes and patient matching in MPS: NHS Number Gender Date of birth Date of Death Forenames (given name(s)) Surname (family name) Address Postcode	To ensure integrity of the data, all data contained in the following tables in the NDRS Cancer Analysis System relating to finalised, de-duplicated cancers, will be transferred: ANALYSISNCR.AT_TUMOUR_ENGLAND ANALYSISNCR.AT_PATIENT_ENGLAND ANALYSISNCR.AT_TREATMENT_ENGLAND ANALYSISNCR.AT_PATHWAY_COHORT ANALYSISNCR.AT_PATHWAY_INDIVIDUALS ANALYSISNCR.AT_PATHWAY ANALYSISNCR.AT_GEOGRAPHY_ENGLAND For the most recent data YEAR available LSOA11_INCOME_QUINTILES LSOA01_INCOME_QUINTILES RTD[YEAR] CHARLSON_2006TO[YEAR] TREATMENT_TABLE_13[YEAR] – *NB this table is currently under-going an update to include more recent data so may not be available immediately*

Dataset	**Purpose**	**Patient identifiers** (for linkage purposes)	**Other fields**
Radiotherapy Dataset (RTDS)	Purpose 1 -4	NHS Number Gender Date of birth Date of Death Forenames (given name(s)) Surname (family name) Address Postcode	To ensure integrity of the data, all data contained in the following tables in the NDRS Cancer Analysis System will be transferred: RTDS.AT_EPISODES_ENGLAND RTDS.AT_EXPOSURES_ENGLAND RTDS.AT_OPCDS_ENGLAND RTDS.AT_PATIENT_ENGLAND RTDS.AT_PRESCRIPTIONS_ENGLAND RTDS2016.OPCDS_CAS1712_LINKAGE (NATCANCSAT) RTDS2016.OPCDS_PROCEDURES (NATCANCSAT) RTDS2016.OPCDS_ ANONYMISED (NATCANSAT) RTDS2016.RTDS_EPISODES (NATCANCSAT) RTDS2016.RTDS_EXPOSURES (NATCANCSAT) RTDS2016.RTDS_PRESCRIPTIONS (NATCANCSAT)
Systemic Anti-Cancer Therapy (SACT) dataset	Purpose 1-4	NHS Number Gender Date of birth Date of Death Forenames (given name(s)) Surname (family name) Address Postcode	To ensure integrity of the data, all data contained in the following tables in the NDRS Cancer Analysis System will be transferred: SACT.AT_CYCLE_ENGLAND SACT.AT_DRUG_DETAIL_ENGLAND SACT.AT_TUMOUR_ENGLAND SACT.AT_PATIENT_ENGLAND SACT.AT_REGIMEN_ENGLAND SACT.AT_OUTCOME_ENGLAND SACT_LEGACY.CYCLE (SACT LEGACY) SACT_LEGACY.DRUG_DETAIL (SACT LEGACY) SACT_LEGACY.TUMOUR (SACT LEGACY) SACT_LEGACY.PATIENT (SACT LEGACY) SACT_LEGACY.SACT_LEGACY_CAS2001_LINK (SACT_LEGACY) SACT_LEGACY.REGIMEN (SACT LEGACY) SACT_LEGACY.OUTCOME (SACT LEGACY)
Rapid Cancer Registration Data Set	Purpose 1 -4	NHS number Gender Date of birth Date of Death Forenames (given name(s)) Surname (family name) Address Postcode	To ensure integrity of the data, all data contained in the following tables in the NDRS Cancer Analysis System will be transferred: ANALYSISNCR.AT_RAPID_TUMOUR ANALYSISNCR.AT_RAPID_PATHWAY

Dataset	**Purpose**	**Patient identifiers** (for linkage purposes)	**Other fields**
Rapid Diagnostic Centre (RDC) minimum dataset, two components – site specific and non site specific pathways	Purpose 1 -4	NHS number Date of birth	Site Specific Data 'providercode' 'fasterdiagnosis_enddate' 'dateofreferral' 'canceralliancecode' 'consultationsbeforereferral' 'finaldiagnosisstatus' 'historyofalcoholconsumption' 'performancestatus_adult' 'referralresult' 'smokingstatus' 'symptoms_other' 'dateoffirstsymptoms' 'dateofonwardreferralordischarge' 'dateoftriage' 'comorbidities' 'filterfunctiontests' 'symptoms' 'test' 'test_date' 'other_test' 'other_test_date' [NB ‘other test’ and ‘other_test_date’ is a repeating item and can contain data for up to six tests/dates] Non Site Specific Data 'providercode' 'fasterdiagnosis_enddate' 'dateofreferral' 'canceralliancecode' 'sitespecificreferralpathway”

The period for the collection will be:

Dataset	**Period**
National Cancer Registration Data Set	Historic data– One-off plus occasional ad-hoc transfer if patient opt-outs need to be applied Prospective data - dataset specific, monthly or annual until further notice
Radiotherapy Data Set	Historic data– One-off plus occasional ad-hoc transfer if patient opt-outs need to be applied Prospective data (dataset specific) – monthly until further notice
Systemic Anti-Cancer Therapy Data Set	Historic data– One-off plus occasional ad-hoc transfer if patient opt-outs need to be applied Prospective data (dataset specific) – monthly until further notice
Rapid Cancer Registration Data Set	Prospective data – monthly until further notice
Rapid Diagnostic Centre (RDC) minimum dataset	Initial collection of the RDC minimum dataset (all data collected to date) plus ongoing monthly collection

Burden of the collection

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

This process is carried out by the Data Standards Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching Data Alliance Partnership (DAPB) approval process. The DAPB, acting under authority of the Secretary of State, oversees the assurance, approval and publication of information standards and data collections for the health and social care system in England.

Burden assessments have not taken place for this collection. The urgent requirement for the data to support the nationwide response of the NHS to COVID-19 outweighs the requirement for such assessments at this time.

That 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.

Annex – Previous Data Provision Notice (For information only)

This document is an uplift of the original published DPN. The original DPN covered the Cancer Pathways analysis as a key purpose. This purpose is no longer current, and the work has been completed. To maintain transparency the original information from the DPN is included below.

Purpose of the collection

The National Cancer Programme identified a requirement for expert analyses to support policy setting, service planning and recovery modelling as well as quantifying the longer term implications, understanding the direct and indirect impact of the COVID-19 pandemic on the NHS and cancer patient outcomes.

It recognised that existing Public Health England (PHE) data does not allow for the real-time monitoring of cancer services and the cancer pathway required by the National Cancer Programme in managing its response to COVID-19.

However, the event-based registration model employed by PHE is flexible enough to accommodate additional data feeds e.g. from NHS Digital, which can be linked to provide a rich resource and a fuller and more timely response to help to these key questions.

To this end PHE and NHS Digital collaborated with other stakeholders across the cancer system to coordinate better data linkage, tracking and analysis across the patient pathway from primary through to secondary care and outcome.

The overarching collaboration will answer questions against the following themes:

- How is cancer management being modified in response to the pandemic?
- What are the reasons for changes in the management of individual patients?
- What effect will these changes have on patient outcomes?
- What are the risks of COVID-19 infection and death for patients having cancer treatment during the pandemic?

There are two high level purposes for this collection, Cancer Pathways Analysis and COVID-19 Related Research.

Cancer Pathways Analysis

Two projects were undertaken using the event-based cancer pathway that was created by linking PHE and NHSD data. The outputs of these projects are internal co-badged PHE/NHSD reports that describe and quantify the impact of COVID-19 on patients diagnosed with cancer.

Benefits of the collection

The purpose of the collection and the resulting analysis is to understand how the flow of patients through the cancer system has changed as a result of the COVID-19 pandemic by:

- creating an event-based cancer pathway that captures relevant activity from PHE and NHS Digital data

- calculating key metrics to describe duration between and frequency of events along the patient pathway during the pandemic and compared to the same period last year
- assessing the impact of having COVID-19 on patients with cancer.

This will ultimately benefit the entire cancer system by providing answers to the immediate challenge of COVID-19 and service planning, as well as the longer term need to understand its impact on cancer services and patient outcomes.

Legal basis for the collection, analysis, publication and dissemination

As noted in the full body of the DPN.

Parties consulted

Following receipt of a direction to establish a system to collect the Cancer Pathways Analysis, NHS Digital has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following parties:

- National Cancer Programme including the National Clinical Director
- Public Health England
- NHS England and NHS Improvement
- Cancer Research UK
- Macmillan Cancer Support
- National Cancer Research Institute
- Cancer Alliance Data, Evidence and Analysis Service (CADEAS)
- East of England Cancer Alliance.

The Cancer Data and Analytics Advisory Group (CDAAG), which reports to the National Cancer Board, will oversee delivery, and agree any new priorities for the Cancer Pathways Analysis. CDAAG brings together the relevant experts from across the NHS, Arms' Length Bodies and Third Sector to advise the National Cancer Board on cancer data and analytical work related to the delivery of the cancer ambitions and commitments in the NHS Long Term Plan and other national strategic plans relating to cancer. They are responsible for the coordination of analytical requests relating to cancer and COVID-19, advising on which organisations are best placed to address them and ensuring results and resources are shared between members. Coordination will take place through CDAAG to avoid duplication and minimise burden.

Scope of the collection

As noted in the full body of the DPN.

Form, manner, and period of the collection

As noted in the full body of the DPN.

Burden of the collection

As noted in the full body of the DPN.

For further information

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