



Descriptive Metadata Specification

Proposed Standard 2020

Purpose

The following document has been developed to refine and iterate the metadata needed for the Innovation Gateway.

The specification is initially focused on Descriptive and Administrative metadata (see proposed metadata levels in principles below).

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Document Control Information** | | | | | | | |
| **Version** | **Status** | **Author(s)** | **Date Created** | **Reviewer(s)** | **Date Reviewed** | **Approved** | **Notes** |
| **V2.0.0** | Release Candidate | A.Milward, D.Milward | 20/07/2020 | |  |  |  | | --- | --- | --- | | N.Sebire |  |  | | G.Reilly |  |  | | B.Gordon |  |  | | S.Varma |  |  | | | |  |
| **Minimum Retention Period** | | | Permanent | | | | |
| **Disposal Required** | | | Archive when new version created | | | | |
| **Classification** | | | PUBLIC | | | | |
| **Next Review due:** | | | 26/07/2020 | | | | |

Contents

[Purpose 2](#_Toc46998724)

[Contents 3](#_Toc46998725)

[Introduction 5](#_Toc46998726)

[**Layout:** 6](#_Toc46998727)

[Key terms: 7](#_Toc46998728)

[Descriptive Metadata 10](#_Toc46998729)

[Identifier 10](#_Toc46998730)

[Version 10](#_Toc46998731)

[Issued 10](#_Toc46998732)

[Modified 11](#_Toc46998733)

[Revisions 11](#_Toc46998734)

[Version 11](#_Toc46998735)

[Url 11](#_Toc46998736)

[Summary 11](#_Toc46998737)

[Title 12](#_Toc46998738)

[Abstract 12](#_Toc46998739)

[Contact Point 13](#_Toc46998740)

[Keywords 14](#_Toc46998741)

[DoiName 14](#_Toc46998742)

[Publisher 15](#_Toc46998743)

[Identifier 15](#_Toc46998744)

[Name 16](#_Toc46998745)

[Logo 16](#_Toc46998746)

[Description 17](#_Toc46998747)

[Contact Point 17](#_Toc46998748)

[Member Of 18](#_Toc46998749)

[Delivery Lead Time 19](#_Toc46998750)

[Access Rights 19](#_Toc46998751)

[Access Service 20](#_Toc46998752)

[Data Use Limitation 21](#_Toc46998753)

[Data Use Requirements 21](#_Toc46998754)

[Documentation 23](#_Toc46998755)

[Description 23](#_Toc46998756)

[Associated Media 23](#_Toc46998757)

[Is Part Of 24](#_Toc46998758)

[Coverage 24](#_Toc46998759)

[Spatial 24](#_Toc46998760)

[Typical Age Range 25](#_Toc46998761)

[Physical Sample Availability 26](#_Toc46998762)

[Followup 27](#_Toc46998763)

[Pathway 27](#_Toc46998764)

[Provenance 27](#_Toc46998765)

[Origin 27](#_Toc46998766)

[Purpose 27](#_Toc46998767)

[Source 28](#_Toc46998768)

[Collection Situation 28](#_Toc46998769)

[Temporal 29](#_Toc46998770)

[Accrual Periodicity 29](#_Toc46998771)

[Distribution Release Date 30](#_Toc46998772)

[Start Date 31](#_Toc46998773)

[End Date 32](#_Toc46998774)

[Time Lag 32](#_Toc46998775)

[Accessibility 33](#_Toc46998776)

[Usage 33](#_Toc46998777)

[Data Use Limitation 33](#_Toc46998778)

[Data Use Requirements 33](#_Toc46998779)

[Resource Creator 34](#_Toc46998780)

[Investigations 35](#_Toc46998781)

[Is Referenced By 35](#_Toc46998782)

[Access 36](#_Toc46998783)

[Access Rights 36](#_Toc46998784)

[Access Service 37](#_Toc46998785)

[Delivery Lead Time 37](#_Toc46998786)

[Jurisdiction 38](#_Toc46998787)

[Data Controller 39](#_Toc46998788)

[Data Processor 39](#_Toc46998789)

[Formats & Standards 40](#_Toc46998790)

[Vocabulary Encoding Scheme 40](#_Toc46998791)

[Conforms To 42](#_Toc46998792)

[Language 43](#_Toc46998793)

[Format 44](#_Toc46998794)

[Enrichment & Linkage 45](#_Toc46998795)

[Qualified Relation 45](#_Toc46998796)

[Derivation 46](#_Toc46998797)

[Tools 46](#_Toc46998798)

[Observations 47](#_Toc46998799)

[Observation 47](#_Toc46998800)

[Observed Node 48](#_Toc46998801)

[Measured Value 48](#_Toc46998802)

[Disambiguating Description 49](#_Toc46998803)

[Observation Date 49](#_Toc46998804)

[Measured Property 49](#_Toc46998805)

[Appendix 1: Change Log 51](#_Toc46998806)

Introduction

As part of the continued development of the Innovation Gateway Minimum Viable Product (MVP), Health Data Research UK (HDR UK) will continue to collect and improve the information about datasets that are available for research and innovation across their alliance member and their health data research hubs. This information must be human and machine-readable, allowing researchers to understand the data that is available, as well as allowing the Gateway to index the information and return relevant search results.

V2.0.0 builds on feedback from the initial specification (V1.1.7) and its implementation during the Innovation Gateway MVP phase. In addition, we’ve engaged academic, life science, industry and public sector data users and providers, as part of wider consultation that seeks to address which metadata attributes will allow users to evaluate the utility (“fit for purpose x”) of a dataset.

The following principles have governed the work and decisions made:

* Metadata should be based on a user need and a user story
* Metadata should be based on standard terminologies whenever possible including:
  + DCAT
  + Schema.org
  + Dublin Core
  + DDI
* If an identified need does not have an equivalent entry from the standards above, another relevant standard should be selected
* Only if no standard can be found should we create a new metadata entry
* Naming convention: Metadata "titles" will be lowercase, underscore separated (note that in the human readable specification we are using Capitalised for ease of reading)
* Where standard attributes have been used, we will use the name from that standard. However, we may ‘Label’ the attributes and provide guidance that makes the attribute more user friendly as many of our users will not be familiar with the more technical terminology.
* Prioritisation of Metadata should be based on Impact vs Effort (effort needs to consider potential for automation in the longer-term vs manual in nearer term).

As part of a wider scope of work we are seeking to work with the British Standards Institute, UK Data Standards Authority and the International Standards Organisation to gain wider adoption and increase metadata interoperability across organisations using this Healthcare Informatics Profile. A more generic iteration of this document may be created for these use cases.

This document only seeks to address Descriptive Metadata. A subsequent document will be published that seeks to address structural metadata within the wider context of Metadata Federation and Interoperable Data/Metadata catalogues.

**Layout:**

The document has been laid out in the following way:

Primitive data type

Metadata element name

**A screenshot of a cell phone

Description automatically generated**

Regular Expression (v3). Java.util.regex api

will be used to validate entries. See for more info.

Completion guidance for the Metadata

Some metadata elements may have enumerated values rather than regular expressions to constrain the values provided:

A picture containing bird

Description automatically generated

Constrained list of values

Key terms:

**Digital Innovation Hub**: Initially funded through the UK Research and Innovation [Industrial Strategy Challenge Fund](https://www.ukri.org/innovation/industrial-strategy-challenge-fund/) (ISCF) investment to kick-start the approach, these Hubs are formal collaborations between NHS, academic organisations, patients, charities and industry.  Each Hub will be set up to demonstrate and drive the utility of expert health data science, based on an area of expertise.  But this is not a research project – Hubs will be expected to provide data, curate the data and offer services for research and innovation. Please see <https://www.hdruk.ac.uk/infrastructure/the-hubs/>

for more information.

**Alliance**: The UK Health Data Research Alliance is an independent alliance of leading healthcare and research organisations united to establish best practice for the ethical use of UK health data for research at scale. Its members include organisations representing national organisations, NHS trusts, research institutes and charities. Please see <https://ukhealthdata.org/members/> for more information

**Innovation gateway MVP:** Created with input from patients and researchers, this first phase of the Gateway provides a library of information about over 400 health datasets that are held and managed by the NHS, research charities, research institutes and universities. Please see <https://healthdatagateway.org/> for more information.

**HDRUK onboarding platform (HOP**): Created to address the challenge of onboarding metadata from Alliance Members and Health Data Research Hubs the HOP provides utilities that allow organisations to submit metadata and for HDRUK to track submissions. Please see <https://hdruk.metadata.works/> for more information.

**Dataset**: We are using the schema.org definition of a dataset as a "body of structured information describing some topic(s) of interest". Each data published is asked to reasonably evaluate what they consider a discrete dataset within the context of research use and discovery.

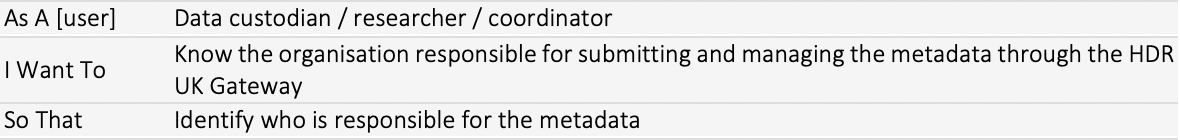
**Label**: In some cases, labels for attributes will be different from the underlying names used to store and interchange the information.

A screenshot of a cell phone

Description automatically generatedWhere possible, the name of the attribute is consistent with the underlying standard i.e. schema.org , whilst the label is representative of the user experience when they input the information.

Note that for a few attributes, we have reverted to the ‘standard’ name, but kept the label from previous versions.

**User Story**: Illustrates the purpose for collecting this metadata



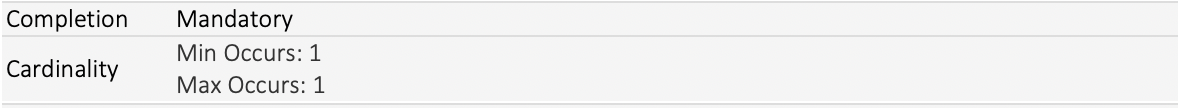
**Example**: Illustrative values that could be provided:



**Priority:** Indication of the priority of the metadata. Can be High, Medium or Low:



**Completion Guidance:** Metadata that has a min occurrence of >=1 or \* is mandatory (\* indicates many).If there is a min occurrence of 0 then the field is not mandatory. Some metadata may not be mandatory because it isn’t applicable to an organisation but completion is still be required, if it is relevant. Some metadata may not be mandatory but completion is recommended.



**Definition:** Formal definition for the metadata, usually referencing a standard.

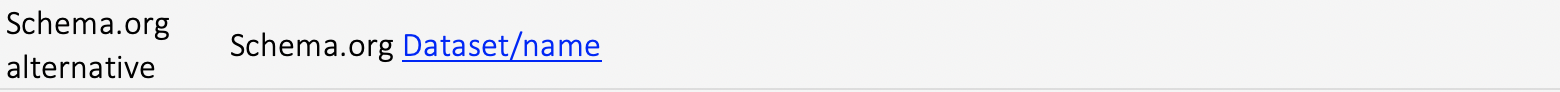


**Notes for HOP:** These are specific notes for the HDRUK Onboarding platform and Onboarding team. However, some of these notes are relevant to those submitting data so they have been included for reference.

A screenshot of a cell phone

Description automatically generated

**Schema.org alternative**: If available, a schema.org alternative has been identified. This will allow us to provide structured information for search engines. The HOP will publish the information in JSON-LD for ‘LIVE’ models.



**Survey metadata**: Alliance members and Hubs were surveyed and asked to evaluate the attributes collected as part of V1 of the metadata specification. We have included the results of the survey for each element to inform the consultation process for V2. Note that some elements were not part of V1 so these will not have survey results.

Descriptive Metadata

Describes a resource for purposes of discovery and identification.

|  |  |  |
| --- | --- | --- |
| Identifier | System dataset identifier  This is a repeating section that supports the addition of multiple identifiers, so any other identifiers that are available can be registered here. | urlOrUUIDv4  // value is decimal number x ==~ /^((([A-Za-z]{3,9}:(?:\/\/)?)(?:[-;:&=\+\$,\w]+@)?[A-Za-z0-9.-]+(:[0-9]+)?|(?:www.|[-;:&=\+\$,\w]+@)[A-Za-z0-9.-]+)((?:\/[\+~%\/.\w-\_]\*)?\??(?:[-\+=&;%@.\w\_]\*)#?(?:[\w]\*))?)|([a-fA-F0-9]{8}-[a-fA-F0-9]{4}-[a-fA-F0-9]{4}-[a-fA-F0-9]{4}-[a-fA-F0-9]{12})$/ |
| Label | Other Identifier | |
| Priority | Low | |
| Completion | Optional | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| Note: | The identifier might be used as part of the URI of the item, but still having it represented explicitly is useful. | |
| Definition | A unique identifier of the item.  RDF Property: [dct:identifier](http://purl.org/dc/terms/identifier)  Range: [rdfs:Literal](https://www.w3.org/2000/01/rdf-schema#Literal)  Source: [dcat:resource\_identifier](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_identifier)  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/) | |
| As A [user] | Researcher | |
| I Want To | Know the local identifier for the dataset | |
| So That | I can identify or refer to it | |
| Survey: Metadata Needed? (5 = Definitely Needed) | 4.38 | |
| Survey: Burden (5 = Easy) | 4.43 | |

|  |  |  |
| --- | --- | --- |
| Version | Dataset metadata version | semver  / x.x.x x ==~ /^([0-9]+)\.([0-9]+)\.([0-9]+)$/ |
| Example | 1.1.0 | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |

|  |  |  |
| --- | --- | --- |
| Issued | Dataset Metadata Creation Date | xs:dateTime |
| Title | Creation Date | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Vocabulary | Dcat:issued | |

|  |  |  |
| --- | --- | --- |
| Modified | Dataset Metadata Creation Date | xs:dateTime |
| Title | Modification Date | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Vocabulary | Dcat:modified | |

Revisions

Revisions of Dataset metadata.

|  |  |  |
| --- | --- | --- |
| Version | Dataset Metadata version | semver  / x.x.x x ==~ /^([0-9]+)\.([0-9]+)\.([0-9]+)$/ |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |

|  |  |  |
| --- | --- | --- |
| Url | URL endpoint to obtain the version | url  ///Regular expression (regex) to validate URL: x ==~ /((([A-Za-z]{3,9}:(?:\/\/)?)(?:[-;:&=\+\$,\w]+@)?[A-Za-z0-9.-]+(:[0-9]+)?|(?:www.|[-;:&=\+\$,\w]+@)[A-Za-z0-9.-]+)((?:\/[\+~%\/.\w-\_]\*)?\??(?:[-\+=&;%@.\w\_]\*)#?(?:[\w]\*))?)/ |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |

Summary

Summary metadata must be completed by Data Custodians onboarding metadata.

|  |  |  |
| --- | --- | --- |
| Title | Name of the dataset limited to 80 characters.  It should provide a short description of the dataset and be unique across the gateway. If your title is not unique, please add a prefix with your organisation name or identifier to differentiate it from other datasets within the Gateway. Please avoid acronyms wherever possible.  Good titles should summarise the content of the dataset and if relevant, the region the dataset covers.  **Notes**: if the dataset is a “linked dataset”, please indicate this using the prefix “Linked”. | 80characters  //Regular expression (regex) to validate and constrain title between 2 and 80 characters  x==~ /^.{2,80}$/ |

|  |  |
| --- | --- |
| Examples | North West London COVID-19 Patient Level Situation Report |
| Priority | High |
| Completion | Mandatory |
| Cardinality | Min Occurs: 1  Max Occurs: 1 |
| Definition | A name given to the item.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:title](http://purl.org/dc/terms/title)  Range: [rdfs:Literal](http://www.w3.org/2000/01/rdf-schema#Literal)  Source: [dcat:resource\_title](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_title) |
| As A [user] | Researcher |
| I Want To | Know the name of the dataset |
| So That | I can identify and find it |
| Schema.org alternative | Schema.org [Dataset/name](https://Schema.org/name) |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.75/5 |
| Survey: Burden (5 = Easy) | 4.71/5 |

|  |  |  |
| --- | --- | --- |
| Abstract | Provide a clear and brief descriptive signpost for researchers who are searching for data that may be relevant to their research. The abstract should allow the reader to determine the scope of the data collection and accurately summarise its content.  The optimal length is one paragraph (limited to 255 characters) and effective abstracts should avoid long sentences and abbreviations where possible.  **Note**: Researchers will view Titles and Abstracts when searching for datasets and choosing whether to explore their content further. Abstracts must be different from the full description for a dataset. | abstractText  //Regular expression (regex) to validate and constrain title between 5 and 255 characters  x==~ /^.{5,255}$/ |
| Example | CPRD Aurum contains primary care data contributed by General Practitioner (GP) practices using EMIS Web® including patient registration information and all care events that GPs have chosen to record as part of their usual medical practice. | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Definition | A summary of the resource.  Vocabulary: [DCMI Metadata Terms](https://hdronboard.metadata.works/specifications/dublin-core/dcmi-terms/)  RDF Type: [rdf:Property](http://www.w3.org/1999/02/22-rdf-syntax-ns#Property)  Refines: [dc:description](http://purl.org/dc/elements/1.1/description)  Source: [dct:abstract](http://purl.org/dc/terms/abstract) | |
| As A [user] | Researcher | |
| I Want To | read a plain English summary of the dataset | |
| So That | I can identify if it is of interest | |
| Schema.org alternative | Schema.org [Dataset/abstract](http://pending.Schema.org/abstract) | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.5/5 | |
| Survey: Burden (5 = Easy) | 4/5 | |

|  |  |  |
| --- | --- | --- |
| Contact Point | Please provide a valid email address that can be used to coordinate data access requests with the publisher.  Organisations are expected to provide a dedicated email address associated with the data access request process.  **Notes**: An employee’s email address can only be provided on a temporary basis and if one is provided an explicit consent must be obtained for this purpose. | email  //Regular expression (regex) to validate email addresses  x ==~/[^\s]+@[^\s]+\.[^\s]+/ |
| Default | Organisation contact point | |
| Examples | [SAILDatabank@swansea.ac.uk](mailto:SAILDatabank@swansea.ac.uk) | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Definition | Relevant contact information for the catalogued resource. Use of vCard is recommended [[VCARD-RDF]](https://www.w3.org/TR/vocab-dcat-2/#bib-vcard-rdf) .  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dcat:contactPoint](http://www.w3.org/ns/dcat#contactPoint)  Range: [vcard:Kind](https://www.w3.org/TR/vcard-rdf/#d4e1819)  Source: [dcat:resource\_contact\_point](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_contact_point) | |
| As A [user] | Researcher | |
| I Want To | Know the contact point | |
| So That | I can contact them about the dataset and request access | |
| Schema.org alternative | <https://schema.org/email> | |
| Notes for HOP | At registration organisations will have the opportunity to add a default contact point for their organisation. If users would like to change default values, they will be given the opportunity to do so by ‘un-checking’ a tick box next to the item. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.88/5 | |
| Survey: Burden (5 = Easy) | 4.14/5 | |

|  |  |  |
| --- | --- | --- |
| Keywords | Please provide relevant and specific keywords that can improve the SEO of your dataset as a comma separated list.  **Notes:** Onboarding portal will suggest keywords based on title, abstract and description. We are compiling a standardised list of keywords and synonyms across datasets to make filtering easier for users. These keywords will be split and stored as an array. | 80characters  x==~ /^.{2,80}$/ |
| Default | Health Data, Research | |
| Examples | SAIL, Primary care, GP | |
| Priority | Medium | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1 Max Occurs: \* | |
| Definition | A keyword or tag describing the resource.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dcat:keyword](http://www.w3.org/ns/dcat#keyword)  Range: [rdfs:Literal](http://www.w3.org/2000/01/rdf-schema#Literal)  Source: [dcat:resource\_keyword](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_keyword) | |
| As A [user] | Researcher | |
| I Want To | Identify the keywords associated with the data | |
| So That | I can index and search data, as well as look up similar datasets | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4/5 | |
| Survey: Burden (5 = Easy) | 3.57/5 | |

|  |  |  |  |
| --- | --- | --- | --- |
| DoiName | | All HDR UK registered datasets should either have a Digital Object Identifier (DOI) or be working towards obtaining one. If a DOI is available, please provide the DOI. You can either use the HDR UK Onboarding Portal (HOP) to mint a DOI for your dataset or your chosen alternative means.  **Note:** This is not the DOI of the publication(s) associated with the dataset. | doi  //Regular expression (regex) to validate DOI from https://www.crossref.org/blog/dois-and-matching-regular-expressions/  x==~ /^10.\d{4,9}/[-.\_;()/:A-Z0-9]+$/i |
| Priority | High | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Definition | Digital Object Identifier. Provides an actionable, interoperable, persistent link Actionable – through use of identifier syntax and network resolution mechanism (Handle System®) Persistent – through combination of supporting improved handle infrastructure (registry database, proxy support, etc) and social infrastructure (obligations by Registration Agencies) Interoperable – through use of a data model providing semantic interoperability and grouping mechanisms.  Vocabulary: [DOI Data Dictionary](https://www.doi.org/doi_handbook/schemas/dd/index.html)  Source: [DOI](https://www.doi.org/doi_handbook/schemas/dd/idd_DoiName.html) | | |
| As A [user] | Data custodian / researcher | | |
| I Want To | Provide a persistent interoperable identifier for a dataset | | |
| So That | I can uniquely identify it, globally, and provide a HTTP URI to navigate to metadata that describes it. | | |
| Notes for HOP | HOP will mint DOIs | | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.63 / 5 | | |
| Survey: Burden (5 = Easy) | 4.43/5 | | |

Publisher

**Completion Notes:** This is the organisation responsible for running or supporting the data access request process, as well as publishing and maintaining the metadata.

In most this will be the same as the HDR UK Organisation (Hub or Alliance Member).

However, in some cases this will be different i.e. Tissue Directory are an HDR UK Gateway organisation but coordinate activities across a number of data publishers i.e. Cambridge Blood and Stem Cell Biobank.

Information about each organisation onboarding and curating metadata for a given dataset must be provided, at registration, including:

|  |  |  |  |
| --- | --- | --- | --- |
| Identifier | | Please provide a Grid.ac identifier (see <https://www.grid.ac/institutes>) for your organisation  If your organisation does not have a Grid.ac identifier please use the “suggest and institute” function here:  [https://www.grid.ac/institutes#](https://www.grid.ac/institutes) | url  //Regular expression (regex) to validate URL:  x ==~ /((([A-Za-z]{3,9}:(?:\/\/)?)(?:[-;:&=\+\$,\w]+@)?[A-Za-z0-9.-]+(:[0-9]+)?|(?:www.|[-;:&=\+\$,\w]+@)[A-Za-z0-9.-]+)((?:\/[\+~%\/.\w-\_]\*)?\??(?:[-\+=&;%@.\w\_]\*)#?(?:[\w]\*))?)/ |
| Priority | Medium | | |
| Completion | Required | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Notes for HOP | |  |  | | --- | --- | | RGCP | <https://grid.ac/institutes/grid.451233.2> | | Genomics England | <https://grid.ac/institutes/grid.498322.6> | | DATA-CAN | None | | Gut Reaction | None | | INSIGHT | None | | DiscoverNOW | None | | Cystic Fibrosis Trust | <https://grid.ac/institutes/grid.453642.2> | | NIHR BioResource | Many sites. None for the central function. | | NSS Scotland | <https://www.grid.ac/institutes/grid.422655.2> | | Tissue Directory | None | | SAIL | None | | BREATHE | None | | NHS Digital | <https://www.grid.ac/institutes/grid.498467.0> | | Digitrial | None | | HQIP | <https://www.grid.ac/institutes/grid.484216.d> | | CPRD | <https://www.grid.ac/institutes/grid.477301.6> | | Barts Health NHS Trust | <https://www.grid.ac/institutes/grid.139534.9> | | University Hospitals Leicester NHS Trust | <https://www.grid.ac/institutes/grid.269014.8> | | Oxford | <https://www.grid.ac/institutes/grid.410556.3> | | PIONEER | None | | | |
| Definition: | Global Research Identifier Database URI | | |
| As A [user] | Data custodian / researcher / coordinator | | |
| I Want To | Access standardised metadata about the organisation | | |
| So That | I can understand the context of the organisation | | |

|  |  |  |  |
| --- | --- | --- | --- |
| Name | | Please provide the name of the Hub or Alliance member. | 80characters  //Regular expression to validate min, max character limit  x==~ /^.{2,80}$/ |
| As A [user] | Data custodian / researcher / coordinator | | |
| I Want To | Know the organisation responsible for submitting and managing the metadata through the HDR UK Gateway | | |
| So That | I can identify who is responsible for the metadata | | |
| Priority | High | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Definition | The name of the item.  Canonical URL: <http://schema.org/name>  Equivalent Property: dct:title | | |

|  |  |  |  |
| --- | --- | --- | --- |
| Logo | | Please provide a logo associated with the Gateway Organisation using a valid URL. The following formats will be accepted .jpg, .png or .svg.  **Note**: the image asset can be hosted by the organisation or uploaded using the onboarding portal. | url  //Regular expression (regex) to validate URL:  x==~ /https?:\/\/(www\.)?[-a-zA-Z0-9@:%.\_\+~#=]{1,256}\.[a-zA-Z0-9()]{1,6}\b([-a-zA-Z0-9()@:%\_\+.~#?&//=]\*)/ |
| Example | <https://www.hdruk.ac.uk/wp-content/themes/hdruk/assets/img/logo.svg> | | |
| Priority | High | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Definition | An associated logo.  Canonical URL: <http://schema.org/logo> | | |
| As A [user] | Data custodian / researcher / coordinator | | |
| I Want To | Know the organisation responsible for submitting and managing the metadata through the HDR UK Gateway | | |
| So That | I can identify who is responsible for the metadata | | |

|  |  |  |  |
| --- | --- | --- | --- |
| Description | | Please provide a URL that describes the organisation.  **Note**: Hubs can include a link to their HDR UK listing, Alliance members can include a link to their ukhealthdata.org page | url  //Regular expression (regex) to validate URL:  x ==~ /((([A-Za-z]{3,9}:(?:\/\/)?)(?:[-;:&=\+\$,\w]+@)?[A-Za-z0-9.-]+(:[0-9]+)?|(?:www.|[-;:&=\+\$,\w]+@)[A-Za-z0-9.-]+)((?:\/[\+~%\/.\w-\_]\*)?\??(?:[-\+=&;%@.\w\_]\*)#?(?:[\w]\*))?)/ |
| Examples | <https://www.hdruk.ac.uk/infrastructure/the-hubs/breathe/>  <https://ukhealthdata.org/members/barts-health-nhs-trust/>` | | |
| Priority | High | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Definition | A description of the organisation  Canonical URL: <http://schema.org/description> | | |
| As A [user] | Data custodian / researcher / coordinator | | |
| I Want To | Know more about the organisation responsible for submitting and managing the metadata through the HDR UK Gateway | | |
| So That | I can understand the context of the data and the submission | | |

|  |  |  |
| --- | --- | --- |
| Contact Point | Please provide a valid email address that can be used to coordinate data access requests with the publisher.  Organisations are expected to provide a dedicated email address associated with the data access request process for their organisation.  This will then be used as a default contact point for all datasets submitted by the organisation. However, there will be the opportunity to overwrite his value for each dataset.  **Notes**: An employee’s email address can only be provided on a temporary basis and if one is provided an explicit consent must be obtained for this purpose. | email  //Regular expression (regex) to validate email addresses  x ==~/[^\s]+@[^\s]+\.[^\s]+/ |
| Examples | [SAILDatabank@swansea.ac.uk](mailto:SAILDatabank@swansea.ac.uk) | |
| Priority | High | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Definition | Relevant contact information for the catalogued resource. Use of vCard is recommended [[VCARD-RDF]](https://www.w3.org/TR/vocab-dcat-2/#bib-vcard-rdf) .  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dcat:contactPoint](http://www.w3.org/ns/dcat#contactPoint)  Range: [vcard:Kind](https://www.w3.org/TR/vcard-rdf/#d4e1819)  Source: [dcat:resource\_contact\_point](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_contact_point) | |
| As A [user] | Researcher | |
| I Want To | Know the contact point | |
| So That | I can contact them about the dataset and request access | |
| Schema.org alternative | <https://schema.org/email> | |
| Notes for HOP | At registration organisations will have the opportunity to add a default contact point for their organisation. If users would like to change default values, they will be given the opportunity to do so by ‘un-checking’ a tick box next to the item. If the defaults are updated, then all datasets that have not been ‘un-checked’ will be overwritten with the new value. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.88/5 | |
| Survey: Burden (5 = Easy) | 4.14/5 | |

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Member Of | | Please indicate if the organisation is an Alliance Member or a Hub. | membership   |  |  | | --- | --- | | **HUB** | <https://www.hdruk.ac.uk/infrastructure/the-hubs/> | | **ALLIANCE** | <https://ukhealthdata.org/> | | **OTHER** | Other organisation affiliated with HDR UK | |
| Title | Organisation Membership | | |
| Priority | High | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Definition | An indicator of the organisations HDR UK membership | | |
| As A [user] | Data custodian / researcher / coordinator | | |
| I Want To | Know if the organisation is a Hub or an Alliance Member | | |
| So That | I can understand the context of the data and the submission | | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Delivery Lead Time | Please provide an indication of the typical processing times based on the types of requests typically received.  **Note:** This value will be used as default access request duration for all datasets submitted by the organisation. However, there will be the opportunity to overwrite his value for each dataset. | accessrequestDuration   |  |  | | --- | --- | | **LESS 1 WEEK** | Access request process typically processed in less than a week | | **1-2 WEEKS** | Access request process typically processed in one to two weeks | | **2-4 WEEKS** | Access request process typically processed in two to four weeks | | **1-2 MONTHS** | Access request process typically processed in one to two months | | **2-6 MONTHS** | Access request process typically processed in two to six months | | **MORE 6 MONTHS** | Access request process typically processed in more than six months | | **VARIABLE** | Access request lead time is variable | | **NOT APPLICABLE** | Access request process duration is not applicable | | **OTHER** | If the typical timeframe does not fit into the broad ranges i.e. lightweight application vs linked data application, please choose “Other” and indicate the typical timeframe within the description for the dataset. | |
| Label | Organisation Access Request Duration | |
| Priority | High | |
| Completion | Required | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | Indication of the typical duration of a data access request.  Source: Schema.org [Offer:deliveryLeadTime](http://Schema.org/deliveryLeadTime) | |
| As A [user] | Researcher | |
| I Want To | Know how much time it will take to process my data access request | |
| So That | I can plan and decide accordingly | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.75/5 | |
| Survey: Burden (5 = Easy) | 3/5 | |

|  |  |  |
| --- | --- | --- |
| Access Rights | The URL of a webpage where the data access request process and/or guidance is provided. If there is more than one access process i.e. industry vs academic please provide both.  If such a resource or the underlying process doesn’t exist, please provide “In Progress”, until both the process and the documentation are ready.  This will then be used as default access rights for all datasets submitted by the organisation. However, there will be the opportunity to overwrite his value for each dataset. | url  //Regular expression (regex) to validate URL:  x ==~ /((([A-Za-z]{3,9}:(?:\/\/)?)(?:[-;:&=\+\$,\w]+@)?[A-Za-z0-9.-]+(:[0-9]+)?|(?:www.|[-;:&=\+\$,\w]+@)[A-Za-z0-9.-]+)((?:\/[\+~%\/.\w-\_]\*)?\??(?:[-\+=&;%@.\w\_]\*)#?(?:[\w]\*))?)/ |
| Title | Organisation Access Rights | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: \* | |
| Definition | Information about who can access the resource or an indication of its security status.  Usage Note: Access Rights MAY include information regarding access or restrictions based on privacy, security, or other policies.  Vocabulary: Data Catalog Vocabulary (DCAT)  RDF Property: dct:access\_rights  Range: dct:RightsStatement  Source: dcat:distribution\_access\_rights | |
| As A [user] | Researcher | |
| I Want To | Know what I can do with the data | |
| So That | I can ensure that I have a legal and ethical basis for analysing it in my research | |
| Schema.org alternative | [Dataset/conditionsOfAccess](http://pending.Schema.org/conditionsOfAccess) | |
| Notes for HOP | At registration organisations will have the opportunity to add a default access rights for their organisation. If users would like to change default values, they will be given the opportunity to do so by ‘un-checking’ a tick box next to the item. If the defaults are updated, then all datasets that have not been ‘un-checked’ will be overwritten with the new value. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.5/5 | |
| Survey: Burden (5 = Easy) | 4.14/5 | |

|  |  |  |
| --- | --- | --- |
| Access Service | Please provide a brief description of the data access environment that is currently available to researchers.  If no environment is currently available, please indicate the current plans and timelines when the data will be made available through an access environment or process.  **Note:** This value will be used as default access environment for all datasets submitted by the organisation. However, there will be the opportunity to overwrite his value for each dataset. | longDescription  //Regular expression to validate min, max character limit, min 2, max 5000  X==~ /.{2,5000}/ |
| Title | Organisation Access Service | |
| Priority | High | |
| Completion | Required | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | |  | | --- | | Indication of the data access environment that will be made available to researchers | |  | |  | | |
| Vocabulary: DCAT | dcat:accessService | |
| As A [user] | Researcher | |
| I Want To | Know how I can access the data | |
| So That | I can plan and decide accordingly | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | NA | |
| Survey: Burden (5 = Easy) | NA | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Data Use Limitation | Please provide an indication of consent permissions for datasets and/or materials, and relates to the purposes for which datasets and/or material might be removed, stored or used.  **Notes**: where there are existing data-sharing arrangements such as the HDR UK HUB data sharing agreement or the NIHR HIC data sharing agreement this should be indicated within access rights.  This value will be used as terms for all datasets submitted by the organisation. However, there will be the opportunity to overwrite this value for each dataset. | datauseLimitation   |  |  | | --- | --- | | **GENERAL RESEARCH USE** | This data use limitation indicates that use is allowed for general research use for any research purpose | | **GENETIC STUDIES ONLY** | This data use limitation indicates that use is limited to genetic studies only (i.e., no phenotype-only research) | | **NO GENERAL METHODS RESEARCH** | This data use limitation indicates that use includes methods development research(e.g., development of software or algorithms) only within the bounds of other use limitations. | | **NO RESTRICTION** | This data use limitation indicates there is no restriction on use. | | **RESEARCH SPECIFIC RESTRICTIONS** | This data use limitation indicates that use is limited to studies of a certain research type. | | **RESEARCH USE ONLY** | This data use limitation indicates that use is limited to research purposes (e.g., does not include its use in clinical care). | | **NO LINKAGE** | This data use limitation indicates there is a restriction on linking to any other datasets | |
| Title | Organisation Data Use Limitation | |
| Priority | High | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| As A [user] | Researcher | |
| I Want To | Know the license that applies to the data | |
| So That | I Know the legal information that describes how the distribution is made available | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.13/5 (consulted on previous term - license) | |
| Survey: Burden (5 = Easy) | 3.14 (consulted on previous term - license) | |
| GA4GH | https://www.ebi.ac.uk/ols/ontologies/duo/terms?iri=http%3A%2F%2Fpurl.obolibrary.org%2Fobo%2FDUO\_0000001 | |
| GAG4H Definition | A data item that is used to indicate consent permissions for datasets and/or materials, and relates to the purposes for which datasets and/or material might be removed, stored or used. | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Data Use Requirements | Please indicate if there are any additional conditions set for use if any. Please ensure that these restrictions are documented in access rights information.  Note: this value will be used as terms for all datasets submitted by the organisation. However, there will be an opportunity to overwrite this value for each dataset. | datauseRequirements   |  |  | | --- | --- | | **COLLABORATION REQUIRED** | This requirement indicates that the requestor must agree to collaboration with the primary study investigator(s). | | **ETHICS APPROVAL REQUIRED** | This requirement indicates that the requestor must provide documentation of local IRB/ERB approval. | | **GEOGRAPHICAL RESTRICTIONS** | This requirement indicates that use is limited to within a specific geographic region. | | **INSTITUTION SPECIFIC RESTRICTIONS** | This requirement indicates that use is limited to use within an approved institution. | | **NOT FOR PROFIT USE** | This requirement indicates that use of the data is limited to not-for-profit organizations and not-for-profit use, non-commercial use. | | **PROJECT SPECIFIC RESTRICTIONS** | This requirement indicates that use is limited to use within an approved project. | | **PUBLICATION MORATORIUM** | This requirement indicates that requestor agrees not to publish results of studies until a specific date | | **PUBLICATION REQUIRED** | This requirement indicates that requestor agrees to make results of studies using the data available to the larger scientific community. | | **RETURN TO DATABASE OR RESOURCE** | This requirement indicates that the requestor must return derived/enriched data to the database/resource. | | **TIME LIMIT ON USE** | This requirement indicates that use is approved for a specific number of months. | | **USER SPECIFIC RESTRICTION** | This requirement indicates that use is limited to use by approved users. | |
| Title | Organisation Data Use Requirements | |
| Default | If such a legal basis does not exist e.g. the data set is being published for the first time, then please provide “In Progress”, until such time the legal terms and conditions are ready. | |
| Priority | High | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| As A [user] | Researcher | |
| I Want To | Know the license that applies to the data | |
| So That | I know the legal information that describes how the distribution is made available | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.13/5 (consulted on previous term - license) | |
| Survey: Burden (5 = Easy) | 3.14 (consulted on previous term - license) | |
| GA4GH | https://www.ebi.ac.uk/ols/ontologies/duo/terms?iri=http%3A%2F%2Fpurl.obolibrary.org%2Fobo%2FDUO\_0000001 | |
| GAG4H Definition | A data item that is used to indicate consent permissions for datasets and/or materials, and relates to the purposes for which datasets and/or material might be removed, stored or used. | |

Documentation

Documentation can include a rich text description of the dataset or links to media such as documents, images, presentations, videos or links to data dictionaries, profiles or dashboards. Organisations are required to confirm that they have permission to distribute any additional media.

|  |  |  |
| --- | --- | --- |
| Description | An HTML account of the data that provides context and scope of the data, limited to 3000 characters (1 Page), and/or a resolvable URL that describes the dataset. Additional information can be recorded and included using media.  **Notes:** A WYSIWYG editor will be available through the onboarding portal. | description  //Regular expression to validate min, max character limit : min 2, max 3000  X==~ /.{2,3000}/ |
| Priority | High | |
| Completion | Required | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | A free-text account of the record.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dc:description](http://purl.org/dc/terms/description)  Range: [rdfs:Literal](http://www.w3.org/2000/01/rdf-schema#Literal)  Source: [dcat:record\_description](https://www.w3.org/TR/vocab-dcat-2/#Property:record_description)  See Schema.org [Dataset:description](https://Schema.org/description) | |
| As A [user] | Researcher | |
| I Want To | Know the description | |
| So That | I can understand information about the dataset | |
| HOP Notes | A WYSIWYG editor will be available through the onboarding portal. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.5/5 | |
| Survey: Burden (5 = Easy) | 4/5 | |

|  |  |  |
| --- | --- | --- |
| Associated Media | Please provide any media associated with the Gateway Organisation using a valid URI for the content. This is an opportunity to provide additional context that could be useful for researchers wanting to understand more about the dataset and its relevance to their research question. The following formats will be accepted .jpg, .png or .svg, .pdf, .xslx or .docx.  **Note:** media asset can be hosted by the organisation or uploaded using the onboarding portal. | url  //Regular expression (regex) to validate URL:  x==~ /https?:\/\/(www\.)?[-a-zA-Z0-9@:%.\_\+~#=]{1,256}\.[a-zA-Z0-9()]{1,6}\b([-a-zA-Z0-9()@:%\_\+.~#?&//=]\*)/ |
| Example | This could be a PDF Document that describes methodology or further detail about the datasets, or a graph or charts that provides further context about the dataset. | |
| Priority | Low | |
| Completion | Optional | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| Definition | A media object that encodes this CreativeWork. This property is a synonym for encoding.  Vocabulary: <https://schema.org/associatedMedia> | |
| As A [user] | Researcher | |
| I Want To | Know the description | |
| So That | I can understand information about the dataset | |
| HOP Notes | Users must confirm that they have permission to publish any media | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | NA | |
| Survey: Burden (5 = Easy) | NA | |

|  |  |  |
| --- | --- | --- |
| Is Part Of | Please complete only if the dataset is part of a group or family of datasets i.e. Hospital Episode Statistics has several constituents.  **Note:** Schema will support url, 80 characters or "NOT APPLICABLE" | xs:string |
| Examples | Hospital Episodes Statistics datasets (A&E, APC, OP, AC MSDS). | |
| Default | If no such group exists please provide “Not Applicable”. | |
| Priority | Medium | |
| Completion | Required | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | Indicates an item or CreativeWork that this item, or CreativeWork (in some sense), is part of.  Inverse-property: hasPart. | |
| As A [user] | Researcher | |
| I Want To | Know whether the dataset is part of a wider group | |
| So That | I can find other datasets of the group | |
| HOP Notes | Default of “ Not Applicable ” will be provided, unless edited by the user. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.43/5 | |
| Survey: Burden (5 = Easy) | 3.57/5 | |

Coverage

This information includes attributes for geographical and temporal coverage, cohort details etc. to enable a deeper understanding of the dataset content so that researchers can make decisions about the relevance of the underlying data.

|  |  |  |
| --- | --- | --- |
| Spatial | The geographical area covered by the dataset.  **Notes:** It is recommended that links are to entries in a well-maintained gazetteer such as <https://www.geonames.org/> | url  //Regular expression (regex) to validate URL:  x==~ /https?:\/\/(www\.)?[-a-zA-Z0-9@:%.\_\+~#=]{1,256}\.[a-zA-Z0-9()]{1,6}\b([-a-zA-Z0-9()@:%\_\+.~#?&//=]\*)/ |
| Example | <https://www.geonames.org/11609043/north-yorkshire.html> | |
| Label | Geographic Coverage | |
| Priority | Medium | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | Usage Note: The spatial coverage of a dataset may be encoded as an instance of dct:Location or may be indicated using a URI reference (link) to a resource describing a location.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:spatial](http://purl.org/dc/terms/spatial)  Range: [dct:Location](http://purl.org/dc/terms/Location) (A spatial region or named place)  Source: [dcat:dataset\_spatial](https://www.w3.org/TR/vocab-dcat-2/#Property:dataset_spatialhttps://www.w3.org/TR/vocab-dcat-2/)  See also: Schema.org [Dataset/spatialCoverage](https://Schema.org/spatialCoverage) | |
| Notes | https://what3words.com/daring.lion.race | |
| As A [user] | Researcher | |
| I Want To | Know the geographic are covered by the dataset | |
| So That | I can contextualise my research | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4/5 | |
| Survey: Burden (5 = Easy) | 3.86/5 | |

|  |  |  |
| --- | --- | --- |
| Typical Age Range | **Guidance:** Please indicate the age range in whole years of participants in the dataset. Please provide range in the following format ‘[min age] – [max age]’ where both the minimum and maximum are whole numbers (integers). | ageRange  //Regular Expression (regex) to validate age range according to format: x ==~ /(150|1[0-4][0-9]|[0-9]|[1-8][0-9]|9[0-9])-(150|1[0-4][0-9]|[0-9]|[1-8][0-9]|9[0-9])/ |
| Example | ‘0-18’, ‘11-90‘ | |
| Label | Age Range | |
| Priority | High | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | The typical age range of participants in the dataset  Vocabulary: [Schema.org](https://www.w3.org/TR/vocab-dcat-2/)  <https://schema.org/typicalAgeRange> | |
| As A [user] | Researcher | |
| I Want To | Know the age range of individuals included within data | |
| So That | I can understand whether data is suitable for my needs | |
| Gateway Notes | Gateway will derive filters based on grouping the information provided however, the onboarding portal will collect the granular information, if this is available. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.25/5 | |
| Survey: Burden (5 = Easy) | 3.71/5 | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Physical Sample Availability | Availability of physical samples associated with the dataset.  If samples are available, please indicate the types of samples that are available. More than one type may be provided.  If sample are not yet available, please provide “AVAILABILITY TO BE CONFIRMED”.  If samples are not available, then please provide “NOT AVAILABLE”. | physicalsampleAvailability   |  |  | | --- | --- | |  |  | | NOT AVAILABLE | Samples associated with the dataset are not available | | BONE MARROW | Bone marrow samples associated with the data are available | | CANCER CELL LINES | Cancer cell line samples associated with the data are available | | CORE BIOPSY | Core biopsy samples associated with the data are available | | CDNA/MRNA | CDNA/MRNA samples associated with the data are available | | DNA | DNA samples associated with the data are available | | FAECES | Faeces samples associated with the data are available | | IMMORTALIZED CELL LINES | Immortalized cell line samples associated with the data are available | | MICRORNA | MicroRNA samples associated with the data are available | | PERIPHERAL BLOOD CELLS | Peripheral blood cell samples associated with the data are available | | PLASMA | Plasma samples associated with the data are available | | PM TISSUE | PM Tissue samples associated with the data are available | | PRIMARY CELLS | Primary cell samples associated with the data are available | | RNA | RNA samples associated with the data are available | | SALIVA | Saliva samples associated with the data are available | | SERUM | Serum samples associated with the data are available | | SWABS | Swab samples associated with the data are available | | TISSUE | Tissue samples associated with the data are available | | URINE | Urine samples associated with the data are available | | WHOLE BLOOD | Whole blood samples associated with the data are available | | AVAILABILITY TO BE CONFIRMED | Availability of samples is currently being confirmed | | OTHER | Other types of sample available |   Kindly provided by the Tissue Directory Coordinating Centre | |
| Default | NOT AVAILABLE | |
| Priority | High | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| As A [user] | Researcher | |
| I Want To | Know if there are any samples associated with the data available | |
| So That | I can request access to samples for my research | |
| Survey: Metadata Needed? | 3.38/5 (5 = Definitely Needed) | |
| Survey: Burden | 3.43/5 (5 = Easy) | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Followup | If known, what is the typical time span that a patient appears in the dataset (follow up period). | followup   |  |  | | --- | --- | | **0 - 6 MONTHS** | Data typically available for a patient over a 0-6 month period | | **6 - 12 MONTHS** | Data typically available for a patient over a 6-12 month period | | **1 - 10 YEARS** | Data typically available for a patient over a 1-10 year period | | **> 10 YEARS** | Data typically available for a patient for over a 10 year period | | **UNKNOWN** | Timespan is Unknown | | **OTHER** | Data available for a patient over another time period | |
|  |  | |

|  |  |  |
| --- | --- | --- |
| Pathway | Please indicate if the dataset is representative of the patient pathway and any limitations the dataset may have with respect to pathway coverage. This could include if the dataset is from a single speciality or area, a single tier of care, linked across two tiers (e.g. primary and secondary care), or an integrated care record covering the whole patient pathway. | description  //Regular expression to validate min, max character limit : min 2, max 3000  X==~ /.{2,3000$/ |
|  |  | |

Provenance

Provenance information allows researchers to understand data within the context of its origins and can be an indicator of quality, authenticity and timeliness.

Origin

Indicators of the origin of the data.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Purpose | Please indicate the purpose(s) that the dataset was collected. | purpose   |  |  | | --- | --- | | **STUDY** | Data collected for a specific research study. | | **DISEASE REGISTRY** | Data collected as part of a disease registry. | | **TRIAL** | Data collected for as part of a clinical trial. | | **CARE** | Data collected as part of routine clinical care. | | **AUDIT** | Data collected as part of an audit programme | | **ADMINISTRATIVE** | Data collected for administrative and management information purposes | | **FINANCIAL** | Data collected either for payments or for billing | | **OTHER** | Data collected for other purpose | |
| Priority | High | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| As A [user] | Researcher | |
| I Want To | Know the why the data was collected | |
| So That | I can understand if it is relevant to my use cases | |
| Definition | The purpose of the ResourcePackage, why the ResourcePackage took place. This should include detailed information on the investigator's primary ResourcePackage questions or hypotheses as well as information on any legal basis for the data collection, such as laws requiring the collection of census data for apportionment purposes. Legal or other authorization should be provided in detail within AuthorizationSource. Supports multiple language versions of the same content as well as optional formatting of the content.  Vocabulary:  DDI: https://ddialliance.org/Specification/DDI-Lifecycle/3.3/XMLSchema/FieldLevelDocumentation/ | |
| HOP Notes | Multiple checkbox | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Source | | Please indicate the source of the data extraction. | source   |  |  | | --- | --- | | **EPR** | Data Extracted from Electronic Patient Record | | **ELECTRONIC SURVEY** | Data has been extracted from electronic surveys | | **LIMS** | Data has been extracted from a laboratory information management system | | **PAPER BASED** | Data has been extracted from paper forms | | **FREETEXT NLP** | Data has been extracted from unstructured freetext using natural language processing | | **MACHINE GENERATED** | Data has been machine generated i.e. imaging | | **OTHER** | Data has been extracted by another bespoke process | |
| Priority | High | | |
| Completion | Required | | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | | |
| Definition | A related resource from which the described resource is derived. | | |
| As A [user] | Researcher | | |
| I Want To | Know the source of the data | | |
| So That | I can understand the quality of the data source | | |
| Vocabulary | https://dublincore.org/specifications/dublin-core/dcmi-terms/#source | | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Collection Situation | | Pleases indicate the setting(s) where data was collected. Multiple settings may be provided | setting   |  |  | | --- | --- | | **CLINIC** | Specific clinic such as antenatal clinic | | **PRIMARY CARE** | General Medical Practitioner Practice | | **ACCIDENT AN EMERGENCY** | Accident emergency department | | **OUTPATIENTS** | Outpatient care | | **IN-PATIENTS** | In-patient care | | **SERVICES** | Services such as drug misuse or blood transfusion | | **COMMUNITY** | Community settings | | **HOME** | Home setting | | **PRIVATE** | Private Medical Clinic | | **PHARMACY** | Pharmacy | | **OTHER** | Other setting | |
| Priority | High | | |
| Completion | Required | | |
| Label | Setting | | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | | |
| Definition | A brief textual description or classification of the collection situation. Supports the use of an external controlled vocabulary  Vocabulary:  DDI: <https://ddialliance.org/Specification/DDI-Lifecycle/3.2/XMLSchema/FieldLevelDocumentation/schemas/datacollection_xsd/elements/CollectionSituation.html> | | |
| As A [user] | Researcher | | |
| I Want To | Know the source of the data | | |
| So That | I can understand the quality and provenance of the data | | |

Temporal

Information indicative of temporal provenance.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Accrual Periodicity | | Please indicate the frequency of publishing. If a dataset is published regularly please choose a publishing periodicity from the constrained list and indicate the next release date. When the release date becomes historical, a new release date will be calculated based on the publishing periodicity.  If a dataset has been published and will remain static please indicate that it is static and indicated when it was released.  If a dataset is released on an irregular basis or “on-demand” please indicate that it is Irregular and leave release date as null.  If a dataset can be published in real-time or near-real-time please indicate that it is continuous and leave release date as null. Notes: see <https://www.dublincore.org/specifications/dublin-core/collection-description/frequency/> | periodicity   |  |  | | --- | --- | | **STATIC** | Dataset published once. | | **IRREGULAR** | Dataset published at uneven intervals. | | **CONTINUOUS** | Dataset published without interruption. | | **BIENNIAL** | Dataset published every two years. | | **ANNUAL** | Dataset published occurs once a year. | | **BIANNUAL** | Dataset published twice a year | | **QUARTERLY** | Dataset published every three months. | | **BIMONTHLY** | Dataset published every two months. | | **MONTHLY** | Dataset published once a month. | | **BIWEEKLY** | Dataset published every two weeks. | | **WEEKLY** | Dataset published once a week. | | **SEMIWEEKLY** | Dataset published twice a week. | | **DAILY** | Dataset published once a day. | | **OTHER** | Dataset published using other interval | |
| Priority | High | | |
| Label | Periodicity | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Definition | The frequency at which dataset is published.  Usage Note: The value of [dct:accrualPeriodicity](http://purl.org/dc/terms/accrualPeriodicity) gives the rate at which the dataset-as-a-whole is updated. This may be complemented by [dcat:temporalResolution](https://www.w3.org/TR/vocab-dcat-2/#Property:dataset_temporal_resolution) to give the time between collected data points in a time series.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:accrualPeriodicity](http://purl.org/dc/terms/accrualPeriodicity)  Range: [dct:Frequency](http://purl.org/dc/terms/Frequency) (A rate at which something recurs)  Source: [dcat:dataset\_frequency](https://www.w3.org/TR/vocab-dcat-2/#Property:dataset_frequency)  See also: Schema.org [Dataset/temporalCoverage](https://Schema.org/temporalCoverage) | | |
| As A [user] | Researcher | | |
| I Want To | Know the frequency of the dataset update | | |
| So That | I know the timeliness of the data | | |
| HOP Notes | For periodic releases we should notify the user to automatically create a new version of the dataset. | | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.25/5 | | |
| Survey: Burden (5 = Easy) | 4.29/5 | | |

|  |  |  |
| --- | --- | --- |
| Distribution Release Date | Date of the latest release of the dataset.  If this is a regular release i.e. quarterly, or this is a static dataset please complete this alongside [Periodicity](https://hdronboard.metadata.works/#/122894/dataElement/122907).  If this is Irregular or Continuously released please leave this blank.  **Notes**: Periodicity and release date will be used to determine when the next release is expected. i.e. the next release date can then be calculated automatically. E.g. if the release date is documented as 01/01/2020 and it is now 20/04/2020 and there is a quarterly release schedule, the latest release will be calculated as 01/04/2020. | xs:dateTime |
| Priority | High | |
| Label | Release Date | |
| Completion | Required (if applicable) | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | Date and Time compliant string [DATETIME] and typed using the appropriate XML Schema datatype [XMLSCHEMA11-2] ([xsd:gYear](https://www.w3.org/TR/xmlschema11-2/" \l "gYear) , [xsd:gYearMonth](https://www.w3.org/TR/xmlschema11-2/" \l "gYearMonth) , [xsd:date](https://www.w3.org/TR/xmlschema11-2/" \l "date) , or [xsd:dateTime](https://www.w3.org/TR/xmlschema11-2/" \l "dateTime) ).  Usage Note: This property SHOULD be set using the first Known date of issuance.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:issued](http://purl.org/dc/terms/issued)  Range: [rdfs:Literal](http://www.w3.org/2000/01/rdf-schema#Literal)  Source: [dcat:distribution\_release\_date](https://www.w3.org/TR/vocab-dcat-2/#Property:distribution_release_date)  See Schema.org [Dataset/datePublished](https://Schema.org/datePublished) | |
| As A [user] | Researcher | |
| I Want To | Know the publication date | |
| So That | I Know how recent, relevant and timely the dataset is | |
| HOP Notes | Validation should be included to ensure that release date is completed if periodicity is regular | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4/5 | |
| Survey: Burden (5 = Easy) | 3.43/5 | |

|  |  |  |
| --- | --- | --- |
| Start Date | The start of the time period that the dataset provides coverage for.  If there are multiple cohorts in the dataset with varying start dates, please provide the earliest date and use the description or the media attribute to provide more information. | xs:dateTime |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Definition | The start of the period.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dcat:startDate](http://www.w3.org/ns/dcat#startDate)  Domain: [dcat:PeriodOfTime](https://www.w3.org/TR/vocab-dcat-2/#Class:Period_of_Time)  Range: [rdfs:Literal](https://www.w3.org/TR/rdf-schema/#ch_literal) encoded using the relevant ISO 8601 Date and Time compliant string [DATETIME] and typed using the appropriate XML Schema datatype [XMLSCHEMA11-2] ([xsd:gYear](https://www.w3.org/TR/xmlschema11-2/" \l "gYear) , [xsd:gYearMonth](https://www.w3.org/TR/xmlschema11-2/" \l "gYearMonth) , [xsd:date](https://www.w3.org/TR/xmlschema11-2/" \l "date) , or [xsd:dateTime](https://www.w3.org/TR/xmlschema11-2/" \l "dateTime) ).  Source: [dcat:period\_start\_date](https://www.w3.org/TR/vocab-dcat-2/#Property:period_start_date)  See also: Schema.org [Dataset/temporalCoverage](https://Schema.org/temporalCoverage) | |
| As A [user] | Researcher | |
| I Want To | Know the time period from when data is available | |
| So That | I can use data that is within the time period I am interested and understand if there is enough history | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.13/5 | |
| Survey: Burden (5 = Easy) | 4.14/5 | |

|  |  |  |
| --- | --- | --- |
| End Date | The end of the time period that the dataset provides coverage for.  If the dataset is “Continuous” and has no known end date, please leave blank.  If there are multiple cohorts in the dataset with varying end dates, please provide the latest date. | endDate  // value is dateTime or date or NOT APPLICABLE x ==~ /(\d{4}-[01]\d-[0-3]\dT[0-2]\d:[0-5]\d:[0-5]\d(?:\.\d+)?Z?)|(\d{4}-[01]\d-[0-3]\d)|(NOT APPLICABLE)/ |
| Priority | High | |
| Completion | Required (if applicable) | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | The end of the period.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dcat:endDate](http://www.w3.org/ns/dcat#endDate)  Domain: [dcat:PeriodOfTime](https://www.w3.org/TR/vocab-dcat-2/#Class:Period_of_Time)  Source: [dcat:period\_end\_date](https://www.w3.org/TR/vocab-dcat-2/#Property:period_end_date)  Range: [rdfs:Literal](https://www.w3.org/TR/rdf-schema/#ch_literal) encoded using the relevant ISO 8601 Date and Time compliant string [DATETIME] and typed using the appropriate XML Schema datatype [XMLSCHEMA11-2] ([xsd:gYear](https://www.w3.org/TR/xmlschema11-2/" \l "gYear) , [xsd:gYearMonth](https://www.w3.org/TR/xmlschema11-2/" \l "gYearMonth) , [xsd:date](https://www.w3.org/TR/xmlschema11-2/" \l "date) , or [xsd:dateTime](https://www.w3.org/TR/xmlschema11-2/" \l "dateTime) ).  Source : Schema.org [Dataset/temporalCoverage](https://Schema.org/temporalCoverage) | |
| As A [user] | Researcher | |
| I Want To | Know the time period until when data is available | |
| So That | I can use data that is within the time period I am interested in and understand if there is enough history. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.13/5 | |
| Survey: Burden (5 = Easy) | 3.86/5 | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Time Lag | | Please indicate the typical time-lag between an event and the data for that event appearing in the dataset. | timeLag   |  |  | | --- | --- | | **LESS 1 WEEK** | Typical time lag of less than a week | | **1-2 WEEKS** | Typical time lag of one to two weeks | | **2-4 WEEKS** | Typical time lag of two to four weeks | | **1-2 MONTHS** | Typical time lag of one to two months | | **2-6 MONTHS** | Typical time lag of two to six months | | **6 MONTHS PLUS** | Typical time lag of more than six months | | **VARIABLE** | Variable time lag | | **NOT APPLICABLE** | Not Applicable i.e. static dataset | | **OTHER** | Other time lag | |
| Default | VARIABLE | | |
| Priority | High | | |
| Label | Periodicity | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |

Accessibility

Accessibility information allows researchers to understand access, usage, limitations, formats, standards and linkage or interoperability with toolsets.

Usage

This section includes information about how the data can be used and how it is currently being used.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Data Use Limitation | Please provide an indication of consent permissions for datasets and/or materials, and relates to the purposes for which datasets and/or material might be removed, stored or used.  NOTE: we have extended the DUO to include a value for NO LINKAGE | dataUseLimitation   |  |  | | --- | --- | | **GENERAL RESEARCH USE** | This data use limitation indicates that use is allowed for general research use for any research purpose | | **GENETIC STUDIES ONLY** | This data use limitation indicates that use is limited to genetic studies only (i.e., no phenotype-only research) | | **NO GENERAL METHODS RESEARCH** | This data use limitation indicates that use includes methods development research(e.g., development of software or algorithms) only within the bounds of other use limitations. | | **NO RESTRICTION** | This data use limitation indicates there is no restriction on use. | | **RESEARCH SPECIFIC RESTRICTIONS** | This data use limitation indicates that use is limited to studies of a certain research type. | | **RESEARCH USE ONLY** | This data use limitation indicates that use is limited to research purposes (e.g., does not include its use in clinical care). | | **NO LINKAGE** | This data use limitation indicates there is a restriction on linking to any other datasets | |
| Title | Organisation Data Use Limitation | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| As A [user] | Researcher | |
| I Want To | Know the license that applies to the data | |
| So That | I Know the legal information that describes how the distribution is made available | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.13/5 (consulted on previous term - license) | |
| Survey: Burden (5 = Easy) | 3.14 (consulted on previous term - license) | |
| GA4GH | https://www.ebi.ac.uk/ols/ontologies/duo/terms?iri=http%3A%2F%2Fpurl.obolibrary.org%2Fobo%2FDUO\_0000001 | |
| GAG4H Definition | A data item that is used to indicate consent permissions for datasets and/or materials, and relates to the purposes for which datasets and/or material might be removed, stored or used. | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Data Use Requirements | Please indicate if there are any additional conditions set for use if any, multiple requirements may be provided.  Please ensure that these restrictions are documented in access rights information. | datauseRequirements   |  |  | | --- | --- | | **COLLABORATION REQUIRED** | This requirement indicates that the requestor must agree to collaboration with the primary study investigator(s). | | **ETHICS APPROVAL REQUIRED** | This requirement indicates that the requestor must provide documentation of local IRB/ERB approval. | | **GEOGRAPHICAL RESTRICTIONS** | This requirement indicates that use is limited to within a specific geographic region. | | **INSTITUTION SPECIFIC RESTRICTIONS** | This requirement indicates that use is limited to use within an approved institution. | | **NOT FOR PROFIT USE** | This requirement indicates that use of the data is limited to not-for-profit organizations and not-for-profit use, non-commercial use. | | **PROJECT SPECIFIC RESTRICTIONS** | This requirement indicates that use is limited to use within an approved project. | | **PUBLICATION MORATORIUM** | This requirement indicates that requestor agrees not to publish results of studies until a specific date | | **PUBLICATION REQUIRED** | This requirement indicates that requestor agrees to make results of studies using the data available to the larger scientific community. | | **RETURN TO DATABASE OR RESOURCE** | This requirement indicates that the requestor must return derived/enriched data to the database/resource. | | **TIME LIMIT ON USE** | This requirement indicates that use is approved for a specific number of months. | | **USER SPECIFIC RESTRICTION** | This requirement indicates that use is limited to use by approved users. | |
| **GA4GH** | https://www.ebi.ac.uk/ols/ontologies/duo/terms?iri=http%3A%2F%2Fpurl.obolibrary.org%2Fobo%2FDUO\_0000001 | |
| **GA4GH Definition** | A data item that is used to indicate consent permissions for datasets and/or materials, and relates to the purposes for which datasets and/or material might be removed, stored or used. | |

|  |  |  |
| --- | --- | --- |
| [Resource](https://hdronboard.metadata.works/#/122894/dataElement/122934) Creator | Please provide the text that you would like included as part of any citation that credits this dataset. This is typically just the name of the publisher. No employee details should be provided. | shortDescription  // value is between 2 and 1000 characters x ==~ /^.{2,1000}$/ |
| Label | Citation Requirements | |
| Example | National Services Scotland | |
| Default | Name of the publisher | |
| Priority | Medium | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | The entity responsible for producing the resource.  Usage Note: Resources of type foaf:Agent are recommended as values for this property.  See also: § 6.11 Class: Organization/Person  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:creator](http://purl.org/dc/terms/creator)  Range: [foaf:term\_Agent](http://xmlns.com/foaf/spec/#term_Agent)  Source: [dcat:resource\_creator](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_creator) | |
| As A [user] | Researcher | |
| I want to | Know the creator | |
| So That | I can understand the context and means for attribution | |
| Survey: Metadata Needed? (5 = Definitely Needed) | 3.38/5 | |
| Survey: Burden (5 = Easy) | 3.57/5 | |

|  |  |  |
| --- | --- | --- |
| Investigations | Please provide a link to any active projects that are using the dataset. | url  //Regular expression (regex) to validate URL: x==~ /(http(s)?:\/\/.)?(www\.)?[-a-zA-Z0-9@:%.\_\+~#=]{2,256}\.[a-z]{2,6}\b([-a-zA-Z0-9@:%\_\+.~#?&//=]\*) |(In Progress)/ |
| Cardinality | MinOccurs: 0  Max Occurs: \* | |

|  |  |  |
| --- | --- | --- |
| Is Referenced By | Please provide the keystone paper associated with the dataset. Also include a list of known citations, if available and should be links to existing resources where the dataset has been used or referenced. Please provide multiple entries, or if you are using a csv upload please provide them as a tab separated list.  [Author] ([Year]) [Title] . [DOI] . [Source] | doi  // value is doi x ==~ /10.\d{4,9}\/[\-\.\\_\;\(\)\/\:a-z0-9A-Z]+/ |
| Label | Citations | |
| Example | de Lusignan S, Correa A, Smith GE, Yonova I, Pebody R, Ferreira F, Elliot AJ, Fleming DM. RCGP Research and Surveillance Centre: 50 years’ surveillance of influenza, infections, and respiratory conditions. BJGP 2017; 67 (663): 440-441. DOI: https://doi.org/10.3399/bjgp17X692645. | |
| Priority | Medium | |
| Completion | Recommended (if applicable) | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| Definition | A related resource, such as a publication, that references, cites, or otherwise points to the catalogued resource.  Usage Note: In relation to the use case of data citation, when the catalogued resource is a dataset, the dct:isReferencedBy property allows to relate the dataset to the resources (such as scholarly publications) that cite or point to the dataset. Multiple dct:isReferencedBy properties can be used to indicate the dataset has been referenced by multiple publications, or other resources. Usage Note: This property is used to associate a resource with the resource (of type dcat:Resource) in question. For other relations to resources not covered with this property, the more generic property [dcat:qualifiedRelation](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_qualified_relation) can be used.  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:isReferencedBy](http://purl.org/dc/terms/isReferencedBy)  Source: [dcat:resource\_is\_referenced\_by](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_is_referenced_by) | |
| As A [user] | Researcher | |
| I Want To | Know how to cite the asset | |
| So That | I can appropriately cite the resource in my research publications | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.38/5 | |
| Survey: Burden (5 = Easy) | 2.71/5 | |

Access

This section includes information about data access.

|  |  |  |
| --- | --- | --- |
| Access Rights | The URL of a webpage where the data access request process and/or guidance is provided. If there is more than one access process i.e. industry vs academic please provide both.  If such a resource or the underlying process doesn’t exist, please provide “In Progress”, until both the process and the documentation are ready. | url  //Regular expression (regex) to validate URL:  x==~ /(http(s)?:\/\/.)?(www\.)?[-a-zA-Z0-9@:%.\_\+~#=]{2,256}\.[a-z]{2,6}\b([-a-zA-Z0-9@:%\_\+.~#?&//=]\*) |(In Progress)/ |
| Default | Organisation Access Rights | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: \* | |
| Definition | Information about who can access the resource or an indication of its security status.  Usage Note: Access Rights MAY include information regarding access or restrictions based on privacy, security, or other policies.  Vocabulary: Data Catalog Vocabulary (DCAT)  RDF Property: dct:access\_rights  Range: dct:RightsStatement  Source: dcat:distribution\_access\_rights | |
| As A [user] | Researcher | |
| I Want To | Know what I can do with the data | |
| So That | I can ensure that I have a legal and ethical basis for analysing it in my research | |
| Schema.org alternative | [Dataset/conditionsOfAccess](http://pending.Schema.org/conditionsOfAccess) | |
| Notes for HOP | At registration organisations will have the opportunity to add a default access rights for their organisation. If users would like to change default values, they will be given the opportunity to do so by ‘un-checking’ a tick box next to the item. If the defaults are updated, then all datasets that have not been ‘un-checked’ will be overwritten with the new value. | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.5/5 | |
| Survey: Burden (5 = Easy) | 4.14/5 | |

|  |  |  |
| --- | --- | --- |
| Access Service | Please provide a brief description of the data access environment that is currently available to researchers.  If no environment is currently available, please indicate the current plans and timelines when the data will be made available through an access environment or process.  **Note:** This value will be used as default access environment for all datasets submitted by the organisation. However, there will be the opportunity to overwrite this value for each dataset. | longDescription  //Regular expression to validate min, max character limit, min 2, max 5000  X==~ /.{2,5000}/ |
| Label | Research Environment / Service | |
| Priority | High | |
| Completion | Required | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | A data service that gives access to the distribution of the dataset  Vocabulary: Data Catalog Vocabulary (DCAT RDF Property: dcat:accessService  Usage Notes: cat:accessService SHOULD be used to link to a description of a dcat:DataService that can provide access to this distribution. | |
| As A [user] | Researcher | |
| I Want To | Know how I can access the data | |
| So That | I can plan and decide accordingly | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | NA | |
| Survey: Burden (5 = Easy) | NA | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Delivery Lead Time | Please provide an indication of the typical processing times based on the types of requests typically received. | accessRequestDuration   |  |  | | --- | --- | | **LESS 1 WEEK** | Access request process typically processed in less than a week | | **1-2 WEEKS** | Access request process typically processed in one to two weeks | | **2-4 WEEKS** | Access request process typically processed in two to four weeks | | **1-2 MONTHS** | Access request process typically processed in one to two months | | **2-6 MONTHS** | Access request process typically processed in two to six months | | **MORE 6 MONTHS** | Access request process typically processed in more than six months | | **VARIABLE** | Access request lead time is variable | | **NOT APPLICABLE** | Access request process duration is not applicable | | **OTHER** | If the typical timeframe does not fit into the broad ranges i.e. lightweight application vs linked data application, please choose “Other” and indicate the typical timeframe within the description for the dataset. | |
| Label | Access Request Duration | |
| Priority | High | |
| Completion | Required | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | Indication of the typical duration of a data access request.  Source: https://schema.org/deliveryLeadTime | |
| As A [user] | Researcher | |
| I Want To | Know how much time it will take to process my data access request | |
| So That | I can plan and decide accordingly | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.75/5 | |
| Survey: Burden (5 = Easy) | 3/5 | |

|  |  |  |
| --- | --- | --- |
| Jurisdiction | Please use country code from [ISO 3166-1](https://en.wikipedia.org/wiki/ISO_3166-1) country codes and the associated [ISO 3166-2](https://www.iso.org/standard/63546.html) for regions, cities, states etc. for the country/state under whose laws the data subjects’ data is collected, processed and stored. Multiple Jurisdications may be provided (if applicable). | isocountryCode  // value is decimal number x ==~ /^[A-Z]{2}(-[A-Z]{2,3})?$/ |
| Default | GB-ENG | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: \* | |
| Definition | A named and identified geospatial area with defined borders which is used for exercising the action of the Rule. An IRI MUST be used to represent this value.  Note: A code value for the area and source of the code must be presented in the Right Operand. Example: the [iso3166] Country Codes or the Getty Thesaurus of Geographic Names. Narrower terms: spatialCoordinates.  Vocabulary: Dublin Core  Source: <http://purl.org/dc/terms/Jurisdiction> | |
| Notes for HOP | Multi-select needed | |
| As A [user] | Researcher | |
| I Want To | Know about potential constraints on the data due to jurisdiction | |
| So That | I can tailor my request and research accordingly (or realise the data isn’t suitable) | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.5/5 | |
| Survey: Burden (5 = Easy) | 3.71/5 | |

|  |  |  |
| --- | --- | --- |
| Data Controller | Data Controller means a person/entity who (either alone or jointly or in common with other persons/entities) determines the purposes for which and the way any Data Subject data, specifically personal data or are to be processed.  **Notes**: For most organisations this will be the same as the publisher of the dataset. If this is not the case, please indicate that there is a different controller.  If there is a different controller please complete the Data Processor attribute to indicate that the publisher is a Processor rather than the data controller. | longDescription  //Regular expression to validate min, max character limit : min 2, max 5000  X==~ /^.{2,5000}$/ |
| Examples | In some cases, there may be multiple data controllers i.e. GP data. If this is the case please indicate the fact in a free-text field and describe the data sharing arrangement or a link to it, so that this can be understood by research users. | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Definition | Source: [ICO Key Terms: Controllers and Processors](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/controllers-and-processors/) , [Article 4.7 of GDPR](https://eur-lex.europa.eu/eli/reg/2016/679/art_4/par_7/pnt_g/oj)  Vocabulary: [Data Privacy Vocabulary](https://www.w3.org/ns/dpv)  Source: [dpv:DataController](https://www.w3.org/ns/dpv#dpv:DataController) | |
| As A [user] | Processor | |
| I Want To | Know who has ultimate responsibility for the dataset (if not the publisher) | |
| So That | I can continue to process their data | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.75/5 | |
| Survey: Burden (5 = Easy) | 3.86/5 | |

|  |  |  |
| --- | --- | --- |
| Data Processor | A Data Processor, in relation to any Data Subject data, specifically personal data, means any person/entity (other than an employee of the data controller) who processes the data on behalf of the data controller.  **Notes**: Required to complete if the Publisher is the Data Processor rather than the data controller. | longDescription  //Regular expression to validate min, max character limit : min 2, max 5000  X==~ /^.{2,5000}$/ |
| Default | If the Publisher is also the Data Controller please provide “Not Applicable”. | |
| Priority | High | |
| Completion | Required (if applicable) | |
| Cardinality | Min Occurs: 0  Max Occurs:1 | |
| Definition | Source: [ICO Key Terms: Controllers and Processors](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/controllers-and-processors/) , [Article 4.7 of GDPR](https://eur-lex.europa.eu/eli/reg/2016/679/art_4/par_7/pnt_g/oj)  Vocabulary: [Data Privacy Vocabulary](https://www.w3.org/ns/dpv)  Source: [dpv:DataProcessor](https://www.w3.org/ns/dpv#dpv:DataProcessor) | |
| As A [user] | Administrator | |
| I Want To | Know who the data processor is | |
| So That | I that can understand the legal basis for processing | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.75/5 | |
| Survey: Burden (5 = Easy) | 3.43/5 | |

Formats & Standards

Section includes technical attributes for language vocabularies, sizes etc. and gives researchers facts about and processing the underlying data in the dataset.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Vocabulary Encoding Scheme | Listany relevantterminologies / ontologies / controlled vocabularies, such as ICD 10 Codes, NHS Data Dictionary National Codes or SNOMED CT International, that are being used by the dataset.  If the controlled vocabularies are local standards, please make that explicit.  If you are using a standard that has not been included in the list, please use “other” and contact support desk to ask for an addition.  **Notes**: More than one vocabulary may be provided. | controlledVocabulary   |  |  | | --- | --- | | **LOCAL** | Local Coding Standard | | **OPCS4** | https://www.datadictionary.nhs.uk/web\_site\_content/supporting\_information/clinical\_coding/opcs\_classification\_of\_interventions\_and\_procedures.asp | | **READ** | https://digital.nhs.uk/services/terminology-and-classifications/read-codes | | **SNOMED CT** | http://www.snomed.org/ | | **SNOMED RT** | https://confluence.ihtsdotools.org/display/DOCGLOSS/SNOMED+RT | | **DM+D** | https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci0052-dictionary-of-medicines-and-devices-dm-d | | **NHS NATIONAL CODES** | https://www.datadictionary.nhs.uk/ | | **NHS SCOTLAND NATIONAL CODES** | https://www.ndc.scot.nhs.uk/Data-Dictionary/ | | **NHS WALES NATIONAL CODES** | http://www.datadictionary.wales.nhs.uk/ | | **ODS** | https://digital.nhs.uk/services/organisation-data-service | | **LOINC** | https://loinc.org/ | | **ICD10** | https://www.who.int/classifications/icd/icdonlineversions/en/ | | **ICD10CM** | https://www.cdc.gov/nchs/icd/icd10cm.htm | | **ICD10PCS** | https://ec.europa.eu/eip/ageing/standards/healthcare/e-health/icd-10-pcs\_en | | **ICD9CM** | https://www.cdc.gov/nchs/icd/icd9cm.htm | | **ICD9** | https://www.cdc.gov/nchs/icd/icd9.htm | | **ICDO3** | https://www.who.int/classifications/icd/adaptations/oncology/en/ | | **AMT** | https://www.digitalhealth.gov.au/about-the-agency/tenders-and-offers/community-pharmacy-software-industry-partnership-offer/Webinar%20-%20Australian%20Medicines%20Terminology%20(AMT)%20and%20Implementation%20Options%2001032017.pdf | | **APC** | https://www.acep.org/administration/reimbursement/reimbursement-faqs/apc-ambulatory-payment-classifications-faq/ | | **ATC** | https://www.whocc.no/atc\_ddd\_index/ | | **CIEL** | https://github.com/OpenConceptLab/ocl\_web/wiki/CIEL | | **HPO** | https://hpo.jax.org/app/ | | **CPT4** | https://www.cms.gov/Regulations-and-Guidance/Legislation/CLIA/Downloads/SubjecttoCLIA.pdf | | **DPD** | https://health-products.canada.ca/dpd-bdpp/index-eng.jsp | | **DRG** | http://www.euro.who.int/\_\_data/assets/pdf\_file/0004/162265/e96538.pdf | | **HEMONC** | https://hemonc.org/wiki/Main\_Page | | **JMDC** | https://www.jmdc.co.jp/en/ | | **KCD7** | https://forums.ohdsi.org/t/adding-kcd7-code-korean-icd-10-to-the-omop-vocabulary/7576 | | **MULTUM** | https://www.cerner.com/solutions/drug-database | | **NAACCR** | https://www.naaccr.org/ | | **NDC** | https://www.fda.gov/drugs/drug-approvals-and-databases/national-drug-code-directory | | **NDFRT** | https://www.nlm.nih.gov/research/umls/sourcereleasedocs/current/NDFRT/index.html | | **OXMIS** | https://oxrisk.com/oxmis/ | | **RXNORM** | https://www.nlm.nih.gov/research/umls/rxnorm/index.html | | **RXNORM EXTENSION** | https://www.nlm.nih.gov/research/umls/rxnorm/index.html | | **SPL** | <https://www.fda.gov/industry/fda-resources-data-standards/structured-product-labeling-resources> | | **OTHER** | Please indicate if there is another standard that you are using. This will trigger a support ticket where you can request the addition of the terminology to the HOP. | |
| Label | Controlled Vocabulary | |
| Default | LOCAL | |
| Priority | Medium | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1 Max Occurs: \* | |
| Definition | An enumerated set of resources.  Vocabulary: Dublin Core  https://www.dublincore.org/specifications/dublin-core/dcmi-terms/#http://purl.org/dc/dcam/VocabularyEncodingScheme | |
| As A [user] | Researcher | |
| I Want To | Know which vocabulary does the dataset use or provide | |
| So That | I can use it to link to other datasets that use the same vocabularies | |
| HOP Notes | If Other selected this should trigger a support ticket | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.75/5 | |
| Survey: Burden (5 = Easy) | 3/5 | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Conforms To | List standardiseddata models that the **dataset** has been **stored in** or **transformed to,** such as OMOP or FHIR. If the data is only available in a local format, please make that explicit.  If you are using a standard that has not been included in the list, please use “other” and contact support desk to ask for an addition. | standardisedDataModels   |  |  | | --- | --- | | **HL7 FHIR** | <https://www.hl7.org/fhir/> | | **HL7 V2** | <https://www.hl7.org/implement/standards/product_section.cfm?section=13> | | **HL7 CDA** | <https://www.hl7.org/implement/standards/product_section.cfm?section=10> | | **HL7 CCOW** | <https://www.hl7.org/implement/standards/product_section.cfm?section=16> | | **LOINC** | <https://loinc.org/> | | **DICOM** | <https://www.dicomstandard.org/> | | **I2B2** | <https://www.i2b2.org/> | | **IHE** | <https://www.ihe.net/resources/profiles/> | | **OMOP** | <https://www.ohdsi.org/data-standardization/the-common-data-model/> | | **OPENEHR** | <https://www.openehr.org/> | | **SENTINEL** | <https://www.sentinelinitiative.org/sentinel/data/distributed-database-common-data-model> | | **PCORNET** | <https://pcornet.org/data-driven-common-model/> | | **CDISC** | <https://www.cdisc.org/standards/data-exchange/odm> | | **LOCAL** | In-house developed data model | | **OTHER** | Other standardised data model | |
| Default | LOCAL | | |
| Priority | Medium | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | | |
| Definition | An established standard to which the described resource conforms.  “A basis for comparison; a reference point against which other things can be evaluated." [DCTERMS])  Usage Note: This property SHOULD be used to indicate the model, schema, ontology, view or profile that the catalogued resource content conforms to.”  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:conformsTo](http://purl.org/dc/terms/conformsTo)  Range: [dct:Standard](http://purl.org/dc/terms/Standard)  Source: [dcat:resource\_conforms\_to](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_conforms_to) | | |
| As A [user] | Researcher | | |
| I Want To | Know which standards the data set conforms to | | |
| So That | I can apply models, pipelines and analysis from | | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.13/5 | | |
| Survey: Burden (5 = Easy) | 2.86/5 | | |

|  |  |  |
| --- | --- | --- |
| Language | This should list all the languages in which the dataset metadata and underlying data is made available. | xs:language |
| Default | en | |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: \* | |
| Definition | A language of the item. This refers to the natural language used for textual metadata (i.e. titles, descriptions, etc) of a catalogued resource (i.e. dataset or service) or the textual values of a dataset distribution.  Usage Note: Resources defined by the Library of Congress (ISO 639-1, ISO 639-2) SHOULD be used. If an ISO 639-1 (two-letter) code is defined for language, then its corresponding IRI SHOULD be used; if no ISO 639-1 code is defined, then IRI corresponding to the ISO 639-2 (three-letter) code SHOULD be used. Repeat this property if the resource is available in multiple languages. If representations of a dataset are available for each language separately, define an instance of dcat:Distribution for each language and describe the specific language of each distribution using dcat:language (i.e. the dataset will have multiple dcat:language values and each distribution will have just one as the value of its dcat:language property).  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dct:language](http://purl.org/dc/terms/language)  Range: [dct:LinguisticSystem](http://purl.org/dc/terms/LinguisticSystem)  Source: [dcat:language](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_language) | |
| As A [user] | Researcher | |
| I Want To | Know the language of the dataset | |
| So That | I understand the contents using that language | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 4.25/5 | |
| Survey: Burden (5 = Easy) | 4.57/5 | |

|  |  |  |
| --- | --- | --- |
| Format | If multiple formats are available please specify.  See application, audio, image, message, model, multipart, text, video, <https://www.iana.org/assignments/media-types/media-types.xhtml>  **Note**: If your file format is not included in the current list of formats, please indicate other. If you are using the HOP you will be directed to a service desk page where you can request your additional format. If not please go to:  <https://metadata.atlassian.net/servicedesk/customer/portal/4> to request your format. | format  Application:    Text:    Image:    Video:    Audio: |
| Example | text/tab-separated-values, application/sql, text/csv, image/diacom-rle | | |
| Priority | High | | |
| Completion | Mandatory | | |
| Cardinality | Min Occurs: 1  Max Occurs: \* | | |
| Definition | The file format of the distribution.  Usage Note: dcat:mediaType SHOULD be used if the type of the distribution is defined by IANA [IANA-MEDIA-TYPES].  RDF Property: http://purl.org/dc/terms/format  Range: <https://dublincore.org/specifications/dublin-core/dcmi-terms/#MediaTypeOrExtent>  Source: https://www.w3.org/TR/vocab-dcat-2/#Property:distribution\_format | | |
| As A [user] | Researcher | | |
| I Want To | Know the format | | |
| So That | I Know how to process it | | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.88/5 | | |
| Survey: Burden (5 = Easy) | 4.57/5 | | |

Enrichment & Linkage

This section includes information about related datasets that may have previously been linked, as well as indicating if there is the opportunity to link to other datasets in the future. If a dataset has been enriched and/or derivations, scores and existing tools are available this section allows providers to indicate this to researchers.

|  |  |  |
| --- | --- | --- |
| Qualified Relation | If applicable, please provide the DOI of other datasets that have previously been linked to this dataset and their availability.  If no DOI is available, please provide the title of the datasets that can be linked, where possible using the same title of a dataset previously onboarded to the HOP.  **Note**: If all the datasets from Gateway organisation can be linked please indicate “ALL” and the onboarding portal will automate linkage across the datasets submitted. | linkedDatasets  //Regular expression (regex) to validate URL: x ==~ /((([A-Za-z]{3,9}:(?:\/\/)?)(?:[-;:&=\+\$,\w]+@)?[A-Za-z0-9.-]+(:[0-9]+)?|(?:www.|[-;:&=\+\$,\w]+@)[A-Za-z0-9.-]+)((?:\/[\+~%\/.\w-\_]\*)?\??(?:[-\+=&;%@.\w\_]\*)#?(?:[\w]\*))?)|ALL|NA/ |
| Label | Linked Dataset | |
| Priority | Medium | |
| Completion | Recommended (if applicable) | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| Definition | Link to a description of a relationship with another resource.  Usage Note: Used to link to another resource where the nature of the relationship is Known but does not match one of the standard [DCTERMS] properties (dct:hasPart, dct:isPartOf, dct:conformsTo, dct:isFormatOf, dct:hasFormat, dct:isVersionOf, dct:hasVersion, dct:replaces, dct:isReplacedBy, dct:references, dct:isReferencedBy, dct:requires, dct:isRequiredBy) or [PROV-O] properties (prov:wasDerivedFrom, prov:wasInfluencedBy, prov:wasQuotedFrom, prov:wasRevisionOf, prov:hadPrimarySource, prov:alternateOf, prov:specializationOf).  Vocabulary: [Data Catalog Vocabulary (DCAT)](https://www.w3.org/TR/vocab-dcat-2/)  RDF Property: [dcat:qualifiedRelation](http://www.w3.org/ns/dcat#qualifiedRelation)  Sub-property of: [prov:qualifiedInfluence](https://www.w3.org/TR/prov-o/#qualifiedInfluence)  Domain: [dcat:Resource](https://www.w3.org/TR/vocab-dcat-2/#Class:Resource)  Range: [dcat:Class:Relationship](https://www.w3.org/TR/vocab-dcat-2/#Class:Relationship)  Source: [dcat:resource\_qualified\_relation](https://www.w3.org/TR/vocab-dcat-2/#Property:resource_qualified_relation) | |
| As A [user] | Researcher | |
| I Want To | Know if there are any datasets that have already been linked | |
| So That | I can use more pre-processed data in my research | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.63/5 | |
| Survey: Burden (5 = Easy) | 3.57/5 | |

|  |  |  |
| --- | --- | --- |
| Derivation | Indicate if derived datasets or predefined extracts are available and the type of derivation available.  **Notes:** Single or multiple dimensions can be provided as a derived extract alongside the dataset. | abstractText  //Regular expression (regex) to validate and constrain title between 5 and 255 characters  x==~ /^.{5,255}$/ |
| Label | Derived Dataset | |
| Default | If such derivations are not known by the Publisher, then please provide “Not Known”.  If there are no derivations calculated, please indicate “Not Available”. | |
| Examples | The Royal College of GPs derives scores such Charlson Comorbidity Score as part of their standard outputs. | |
| Priority | Medium | |
| Completion | Recommended (if applicable) | |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |
| Definition | A derivation is a transformation of an entity into another, an update of an entity resulting in a new one, or the construction of a new entity based on a pre-existing entity. If this is Entity:e, then it can qualify how it was derived using prov:qualifiedDerivation [a prov:Derivation; prov:entity :e; :foo :bar ].  Vocabulary: [PROV-O: The PROV Ontology](https://www.w3.org/TR/prov-o/)  RDF Property: [prov:qualifiedDerivation](https://www.w3.org/TR/prov-o/#qualifiedDerivation)  Sub-property of: [prov:qualifiedInfluence](https://www.w3.org/TR/prov-o/#qualifiedInfluence)  Domain: [prov:Entity](https://www.w3.org/TR/prov-o/#Entity)  Range: [prov:Derivation](https://www.w3.org/TR/prov-o/#Derivation)  PROV-DM term: [prov:wasDerivedFrom](https://www.w3.org/TR/prov-o/#wasDerivedFrom)  See also: Schema.org [Dataset/isBasedOn](https://Schema.org/isBasedOn) | |
| As A [user] | Researcher | |
| I Want To | Know if there are any derivations | |
| So That | I can reuse pre-processed information | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.57/5 | |
| Survey: Burden (5 = Easy) | 3.57/5 | |

|  |  |  |
| --- | --- | --- |
| Tools | Please provide the URL of any analysis tools or models that have been created for this dataset and are available for further use. Multiple tools may be provided.  **Note:** We encourage users to adopt a model along the lines of https://www.ga4gh.org/news/tool-registry-service-api-enabling-an-interoperable-library-of-genomics-analysis-tools/ | url  //Regular expression (regex) to validate URL:  x==~ /https?:\/\/(www\.)?[-a-zA-Z0-9@:%.\_\+~#=]{1,256}\.[a-zA-Z0-9()]{1,6}\b([-a-zA-Z0-9()@:%\_\+.~#?&//=]\*)/ |
| Cardinality | Min Occurs: 0  Max Occurs: \* | |

Observations

Based on schema.org observation model and used to specify series of observations about a dataset, such as number of persons, events or findings.

We will be supporting the schema.org observation model (https://schema.org/Observation). Users will be encouraged to provide their own statistißcal populations as the project progresses however, initially we will encourage users to provide observations on the number of persons, number of events and number of findings included in the dataset.

Example:

Statistical Population 1   
type: StatisticalPopulation   
populationType: Persons   
numConstraints: 0

Statistical Population 2   
type: StatisticalPopulation   
populationType: Events   
numConstraints: 0

Statistical Population 3   
type: StatisticalPopulation   
populationType: Findings   
numConstraints: 0

typeOf: Observation   
observedNode: Statistical Population 1   
measuredProperty: count   
measuredValue: 32937   
observationDate: “2017”

Observation

Multiple observations about the dataset may be provided and users are expected to provide at least one observation (1..\*). We will be supporting the schema.org observation model (https://schema.org/Observation) with default values. Users will be encouraged to provide their own statistical populations as the project progresses.

Example:

***Statistical Population 1***   
type: StatisticalPopulation   
populationType: Persons   
numConstraints: 0

Statistical Population 2   
type: StatisticalPopulation   
populationType: Events   
numConstraints: 0

Statistical Population 3   
type: StatisticalPopulation   
populationType: Findings   
numConstraints: 0

typeOf: Observation   
observedNode: ***Statistical Population 1***  
measuredProperty: count   
measuredValue: 32937   
observationDate: “2017”

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Observed Node | Please select one of the following statistical populations for your observation. | statisticalPopulationContrained   |  |  | | --- | --- | | Persons | Unique persons recorded in the dataset | | Events | Unique events such as procedures and prescriptions within the dataset | | Findings | Unique findings included in the dataset such as diagnoses, test results, images or specimens | |
| Label | Statistical Population | |
| Definition | The observedNode of an Observation, often a StatisticalPopulation.  Vocabulary: Schema.org <https://schema.org/observedNode> | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |

|  |  |  |
| --- | --- | --- |
| Measured Value | Please provide the population size associated with the population type the dataset i.e. 1000 people in a study, or 87 images (MRI) of Knee  **Usage Note:** Used with Statistical Population, which specifies the type of the population in the dataset. | xs:positiveInteger |
| Priority | High | |
| Completion | Mandatory | |
| Cardinality | Min Occurs: 1  Max Occurs: 1 | |
| Definition | Source: Schema.org <https://schema.org/measuredValue> | |
| As A [user] | Researcher | |
| I Want To | Know the population size and type within data | |
| So That | I can understand whether data amount is suitable for my needs | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | 3.25/5 | |
| Survey: Burden (5 = Easy) | 3/5 | |

|  |  |  |
| --- | --- | --- |
| Disambiguating Description | If SNOMED CT term does not provide sufficient detail, please provide a description that disambiguates the population type. | abstractText  //Regular expression (regex) to validate and constrain title between 5 and 255 characters  x==~ /^.{5,255}$/ |
| Priority | High | |
| Completion | Recommended | |
| Cardinality | Min Occurs: 0  Max Occurs: 1 | |
| Definition | A short description of the item used to disambiguate from other, similar items. Information from other properties (in particular, name) may be necessary for the description to be useful for disambiguation.  Source: Schema.org <https://schema.org/disambiguatingDescription> | |
| As A [user] | Researcher | |
| I Want To | Know the population size and type within data | |
| So That | I can understand whether data amount is suitable for my need | |
| Survey: Metadata Needed?  (5 = Definitely Needed) | NA | |
| Survey: Burden (5 = Easy) | NA | |

|  |  |  |
| --- | --- | --- |
| Observation Date | Please provide the date of the observation. | xs:dateTime |
| **Vocabulary: Schema.org** | https://schema.org/observationDate | |
| **Definition** | The observationDate of an Observation. | |
| **Default to** | Release Date | |
| **Cardinality** | Min Occurs: 1  Max Occurs: 1 | |

|  |  |  |
| --- | --- | --- |
| Measured Property | Initially this will be defaulted to "Count". | xs:string |
| **Priority** | Medium | |
| **Completion** | Mandatory | |
| **Cardinality** | Min Occurs: 1  Max Occurs: 1 | |
| **Vocabulary** | Schema.org: The measuredProperty of an Observation, either a schema.org property, a property from other RDF-compatible systems e.g. W3C RDF Data Cube, or schema.org extensions such as GS1's.  https://schema.org/measuredProperty | |
| **As A [user]** | Researcher | |
| **I Want To** | Know the population type within the data | |
| **So That** | I can understand whether data subject is suitable for my need | |
| **HOP Notes** | Initially we will want a “search” on a subset of SNOMED CT terms. | |
| **Survey: Metadata Needed? (5 = Definitely Needed)** | 4.13/5 | |
| **Survey: Burden (5 = Easy)** | 4/5 | |

Appendix 1: Change Log

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **HDR UK Descriptive Metadata Specifications v2** |  |  |  | **HOP Descriptive Metadata Specifications v1** | |
| **Descriptive Attribute Hierarchy** | | | **Description** | **Level** | **Attribute Name** |
| Identifier |  |  | System dataset identifier. | Summary | Identifier |
| Version |  |  | Dataset metadata version. | Summary | Version |
| Revisions | URL |  | Revisions of Dataset metadata: Identifier. |  |  |
| Revisions | Version |  | Revisions of Dataset metadata: Version. |  |  |
| Issued |  |  | Dataset descriptive metadata creation date. | Business | Release Date |
| Modified |  |  | Dataset descriptive metadata modification date. |  |  |
| Summary | Title |  | Title of the dataset. It should provide a short description. | Summary | Title |
| Summary | Abstract |  | The abstract should allow the reader to determine the scope of the data collection. and accurately summarise its content. | Summary | Abstract |
| Summary | Publisher | Member Of | Please indicate if the organisation is an Alliance Member or a Hub. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Access Rights | Organisation default access rights. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Delivery Lead Time | Organisation default lead time. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Data Use Limitation | Organisation default data use limitation. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Data Use Requirements | Organisation default data use requirements. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Access Service | Organisation default data access environment. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Name | Organisation name. | Summary | Publisher |
| Summary | Publisher | Logo | Organisation logo. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Description | Organisation description. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Publisher | Contact Point | Organisation default contact point. | *not part of Metadata Specs v1* | Publisher Default Attributes |
| Summary | Contact Point |  | Dataset contact point. | Summary | Contact Point |
| Summary | Keywords |  | Relevant and specific keywords that improve the SEO of the dataset. | Coverage | Keywords |
| Summary | Alternate Identifiers |  | Alternate dataset identifiers or local identifiers. | *not part of Metadata Specs v1* |  |
| Summary | DOI |  | Unique Digital Object Identifier. | Attribution | DOI |
| Documentation | Description |  | A free-text description of the dataset. | Business | Description |
| Documentation | Associated Media |  | Additional context that could be useful for researchers wanting to understand more about the dataset. | *not part of Metadata Specs v1* |  |
| Documentation | Is Part Of |  | Please complete only if the dataset is part of a group or family. | Summary | Group |
| Coverage | Spatial |  | The geographical area covered by the dataset. | Coverage | Geographic Coverage |
| Coverage | Typical Age Range |  | Please indicate the age range in whole years of participants in the dataset. | Coverage | Age Band |
| Coverage | Physical Sample Availability |  | If samples are available, please indicate the types of samples that are available. | Coverage | Physical Sample Availability |
| Coverage | Follow-Up |  | If known, what is the typical time span that a patient appears in the dataset (follow up period). | *not part of Metadata Specs v1* |  |
| Coverage | Pathway |  | Please indicate if the dataset is representative of the patient pathway. | *not part of Metadata Specs v1* |  |
| Provenance | Origin | Purpose | Pleases indicate the purpose(s) that the dataset was collected. | *not part of Metadata Specs v1* |  |
| Provenance | Origin | Source | Pleases indicate the source of the data extraction. | *not part of Metadata Specs v1* |  |
| Provenance | Origin | Collection Situation | Pleases indicate the setting(s) where data was collected. | *not part of Metadata Specs v1* |  |
| Provenance | Temporal | Accrual Periodicity | Please indicate the frequency of publishing. | Coverage | Periodicity |
| Provenance | Temporal | Distribution Release Date | Date of the latest release of the dataset. | Business | Release Date |
| Provenance | Temporal | End Date | The end of the time period that the dataset provides coverage for. | Coverage | Dataset End Date |
| Provenance | Temporal | Time Lag | Please indicate the typical time-lag between an event and the data for that event appearing in the dataset. | *not part of Metadata Specs v1* |  |
| Provenance | Temporal | Start Date | The start of the time period that the dataset provides coverage for. | Coverage | Dataset Start Date |
| Accessibility | Access | Access Rights | Description and guidance of the data access request process. | Summary | Access Rights |
| Accessibility | Access | Access Service | Brief description of the data access environment that is currently available to researchers. | *not part of Metadata Specs v1* |  |
| Accessibility | Access | Delivery Lead Time | Indication of the typical processing data access request processing time. | Business | Access Request Duration |
| Accessibility | Access | Jurisdiction | Country/state under whose laws the data subjects’ data is collected, processed and stored. | Coverage | Jurisdiction |
| Accessibility | Access | Data Controller | The person/entity who determines the purposes for which and the way any data, specifically personal data, are to be processed. | Business | Data Controller |
| Accessibility | Access | Data Processor | Any person/entity who processes the data on behalf of the data controller. | Business | Data Processor |
| Accessibility | Usage | Data Use Limitation | Please provide an indication of consent permissions for the dataset. | *not part of Metadata Specs v1* |  |
| Accessibility | Usage | Data Use Requirements | Please document restrictions and additional conditions for the use of the dataset. | *not part of Metadata Specs v1* |  |
| Accessibility | Usage | Resource Creator | Text to be included as part of citations of credit for the dataset. | Attribution | Creator |
| Accessibility | Usage | Investigations |  | *not part of Metadata Specs v1* |  |
| Accessibility | Usage | Is Referenced By | Please provide the keystone paper associated with the dataset. | Attribution | Citations |
| Accessibility | Formats and Standards | Vocabulary Encoding Scheme | Relevant terminologies / ontologies / controlled vocabularies that are being used by the dataset. | Structure | Controlled Vocabulary |
| Accessibility | Formats and Standards | Conforms To | Standardised data models that the dataset has been stored in or transformed to. | Structure | Conforms To |
| Accessibility | Formats and Standards | Language | Language in which dataset metadata and underlying data is made available. | Structure | Language |
| Accessibility | Formats and Standards | Format | File format of the dataset. | Structure | Format |
| Accessibility | Enrichment and Linkage | Qualified Relation | DOI of other datasets that have previously been linked to this dataset and their availability. | Business | Linked Datasets |
| Accessibility | Enrichment and Linkage | Derivation | Derived datasets and the type of derivation available or predefined extracts. | Business | Derived Datasets |
| Observations | Observed Node |  | The statistical populations for this observation. | *not part of Metadata Specs v1* |  |
| Observations | Measured Value |  | The population size associated with the population type the dataset. | *not part of Metadata Specs v1* |  |
| Observations | Observation Date |  | Date of the observation. | *not part of Metadata Specs v1* |  |
| Observations | Disambiguating Description |  | Please provide a description that disambiguates the population type. | *not part of Metadata Specs v1* |  |
| Observations | Measured Property |  | The measured property. | *not part of Metadata Specs v1* |  |
|  |  |  | *not part of Metadata Specs v2* | *Business* | Access Request Cost |
|  |  |  | *refer to Data Use Limitations and Data Use Requirements* | *Business* | License |
|  |  |  | *see Observations* | *Coverage* | Statistical Population |
|  |  |  | *not part of Metadata Specs v2* | *Structure* | File Size |