

Annex to the report “A vision of a Nordic secure digital infrastructure for health data: *The Nordic Commons*”

## Metadata Status for the Health Data Domain in Nordic Countries (August 2018)

In order to describe the national status for metadata of interest to health research and innovation according to a similar structure, the term *metadata domain* is used here to describe the *different types* of health metadata that *exist*, how this is *defined* and where it *resides* in the four Nordic countries; Denmark, Sweden, Finland and Norway.

### Domain Definitions

The purpose of the description under each sub-domain is to cover the status within the different subsets of data identified as the important parts forming the health data domain.

DK= Denmark

SE= Sweden

FI= Finland

NO= Norway

Metadata Domain per country	Definition
Biobanks	Biobank – “Collection of human biological material (such as cells or tissue, blood, urine, CSF (cerebrospinal fluid), saliva, cell lines, microorganisms), stored for one or more purposes (for example care and treatment, quality assurance, training, research and clinical trials), and information about this material.”
DK	Metadata about samples from the large majority of Danish biobanks (Statens Serum Institute, hospitals, research institutions etc. 24.5 mill. samples from 5.7 mill. individuals) is registered in the Danish Biobank Register. The samples are linked to data and metadata from the Civil Registration Registry, the National Patients Registry and the Pathology Registry.
SE	Biobank Sweden (former BBMRI.se and Nationellt biobanksråd/National Council of Biobanks) provides one entrance to metadata on the sample collection level. The biobanks and sample collections provide metadata both on the sample collection level and LIMS metadata on samples and sample handling in the Swedish Research Council national infrastructure RUT.

FI	Metadata about samples collected to the National THL Biobank are described on the THL Biobank's web page. THL Biobank samples are based on general population-based health examination studies. Finnish clinical biobanks have recently formed a joint operator (FinBB) to govern biobank collaboration and access to data. FinnBB does not yet have national level metadata on samples and related data, and the amount of metadata varies between the clinical biobanks.
NO	"The National Biobank Registry" of Norway provides metadata on sample collection level and links to all the major health surveys (reported surveys and biobanks) and population biobanks as well as the clinical biobanks in Norway, including collections of biological material as blood samples and biopsies. Structured metadata about samples are so far only provided by the HUNT Biobank belonging to the Nord-Trøndelag Health Study (HUNT). The samples are not linked to data or metadata from the National Patients Registry. Biobank Norway will have focus on further development of metadata from the biobanks through the project Biobank 3 (starting up in 2019)
Health Registers	Government registers collecting data with the purpose of monitoring, analysing and reporting regarding health and social conditions for the national population. (based on text <a href="http://www.socialstyrelsen.se/register/halsodataregister">http://www.socialstyrelsen.se/register/halsodataregister</a> ). Examples: patient register, pharmaceutical register, cancer register etc
DK	Health registries are consolidated under a single government organisation Sundhedsdatastyrelsen (Health Data Agency).
SE	Health register metadata are provided by the National Board of Health and Welfare in two ways, i.e. as variable lists and in a national infrastructure through cooperation with the Swedish Research Council.
FI	National health registers are mostly maintained by National Institute for Health and Welfare (THL). Some registers are maintained by the Social Insurance Institution (Kela) (medication registers) and by Statistics Finland (causes of death register). Registers are described in Finnish at Aineistokatalogi.fi metadata service. Descriptions are based on GSIM model.
NO	Health register (Sentrale helseregistre) metadata are consolidated under a single government repository (HealthTerm) and made searchable at Helsedata.no under the Directorate of eHealth. The interface to the repository will be based on open APIs. The health data programme run by the Directorate of eHealth will continue enriching, harmonising and standardising metadata based on the FAIR-principles throughout 2020.
Socio-economic Registers	National income, education, demographic (family...) registers relevant/linked for health data analysis.
DK	Socio-economic registries are consolidated under a single, government organisation: Statistics Denmark
SE	Metadata regarding socio-economic registers are provided by Statistics Sweden in two ways; on their website and in a national infrastructure through cooperation with the Swedish Research Council.

FI	Socio-economic registers are maintained by Statistics Finland. Some of the metadata are described on Statistics Finland's metadata service Taika.
NO	Socio-economic registers are consolidated under a single government organisation: Statistics Norway (microdata.no)
Laboratory Data	"Laboratory tests demonstrating the presence of physiologically significant substances in the blood, urine, tissue, and body fluids with application to the diagnosis or therapy of disease."(Mesh)
DK	Results from laboratory tests from hospitals and general practitioners are gathered in a national laboratory database. Researchers can access the data via the Danish Health Agency
SE	Laboratory test answers are being described with metadata and semantics through a lab service interface in the national service platform by Inera, an IT company jointly owned by the Swedish health care regions. The service interface will also provide access to lab answers after authentication and access control. The metadata and semantics will probably be harvested into the national infrastructure Register Utiliser Tool in the future.
FI	There are no national level metadata, whatsoever, on laboratory data in Finland.
NO	In Norway no national lab results database has been established thus far, but a project on this is in pipeline.
Registers of Clinical Quality	A national quality register collects data on problems, measures taken and results for individuals treated within health care and welfare and for a national population. (Translation based on definition on kvalitetsregister.se)
DK	The organisation The Danish Clinical Registries (RKKP) is responsible for all the databases of clinical quality. The Danish Health Agency has to authorise them. There are 72 authorised databases.
SE	The National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions (SKL) both provide high level metadata regarding national quality registers. The registries also provides variable level metadata as variable lists and are moving into the national infrastructure Register Utiliser Tool through cooperation with the Swedish Research Council.
FI	Currently, there are no official national clinical quality registers in Finland. The metadata of the local and regional registers cannot be found from open databases or web pages. The National Institute for Health and Welfare is leading a project on national health quality registers. The project period is from January 2018 to December 2019. During the project some quality register metadata will be described to national Aineistokatalogi.fi and to THL's National Code service.
NO	Metadata for registries of clinical quality (54) will be consolidated under the same government repository (HealthTerm) and provided by www.helsedata.no . The same solution as for the central health registries. The solutions are owned and run by the Directorate of eHealth. A pilot project took place in 2018, and a project run by SKDE (Nasjonalt Servicemiljø for medisinske kvalitetsregistre) will begin structuring, complementing and exporting metadata from the different IT-solutions (3) to HealthTerm in 2019. This includes both high level metadata on the register level and metadata on the variable level
Health Surveys/Cohort Studies	Health Surveys - "A systematic collection of factual data pertaining to health and disease in a human population within a given geographic area." (Mesh)

	Cohorts – “Studies in which subsets of a defined population are identified. These groups may or may not be exposed to factors hypothesised to influence the probability of the occurrence of a particular disease or other outcome. Cohorts are defined populations which, as a whole, are followed in an attempt to determine distinguishing subgroup characteristics.” (Mesh)
DK	The datasets are typically owned and managed by the steering committee of the research projects. The greater part of the most important cohorts is transferred to the National Archive.
SE	The Swedish National Data Service provides a searchable resource for a subset of the cohorts based on data set/study level metadata. The Swedish Cohort Consortium (Cohorts.se) is making an effort to gather metadata in a common platform and adding cohorts successively. The Swedish Research Council will include cohorts in the national infrastructure Register Utiliser Tool.
FI	The major health surveys and cohort studies in Finland are conducted by National Institute for Health and Welfare. Such studies include National FinHealth (former Finriski and Health 2000/2011) health examination study and National FinSote Survey (former AVTK, EVTK, ATH Surveys). The metadata are described at THL’s Aineistokatalogi.fi, on THL’s webpages and on THL Biobank’s webpage. Part of this cohort data has been transmitted to THL Biobank.
NO	The Norwegian Institute of Public Health provides an overview and links to the national and regional health surveys. CONOR is a collection of health data and blood samples from several health studies. Unfortunately the website that displayed metadata to a certain extent on both survey level and question level has been shut down . Two of the main health surveys in Norway, Tromsundersøkelsen (TU) and Helseundersøkelsen i Nord-Trøndelag (HUNT) provide metadata on their own websites. So far there is no national strategy for further development of metadata on health surveys.
Electronic Health Records	Electronic health records (EHR) Media that facilitate transportability of pertinent information concerning patient's illness across varied providers and geographic locations. Some versions include direct linkages to online consumer health information that is relevant to the health conditions and treatments related to a specific patient. (Mesh)
DK	Health records are held in four different electronic health record systems with different metadata attributes. A subset of data from the health records is extracted to the national eJournal SUP. Region Nord is responsible for the database.
SE	The national service platform developed by Inera will implement national services to read data from electronic health records and publish metadata on service domains. There are several different EHR systems used with different metadata in Sweden.
FI	Right now there are more than 20 hospital districts in Finland organising specialised care and 311 municipalities organising primary care. Several EHR systems are used. There are three major clinical data lakes in Finland in the Helsinki and Uusimaa

	Hospital District (HUS), Southwest Finland Hospital District (VSSHP) and City of Kuopio, respectively. The variable level metadata of VSSHP clinical data lake is described at <a href="http://Aineistokatalogi.fi">Aineistokatalogi.fi</a> .
NO	Health records are held in eight different main EHR systems. Two in hospital, three in primary care and three for the Regular General Practitioners (RGPs). The EHR is not structured thus far, but there are ongoing initiatives connected to open EHR Archetypes (DIPS) and SNOMED CT (Epic). Terms used for administrative purposes are standardised and aligned with the variables in the National Patient Registry. For administrative code sets there are some metadata, among others they have an OID.
OMICS	The English-language neologism omics informally refers to a field of study in biology ending in -omics, such as genomics, proteomics or metabolomics. The related suffix -ome is used to address the objects of study of such fields, such as the genome, proteome or metabolome respectively. Omics aims at the collective characterisation and quantification of pools of biological molecules that translate into the structure, function, and dynamics of an organism or organisms. (Wikipedia)
DK	A law on establishing a Danish Genome Database was passed in 2018. The National Genome Centre will provide a national repository for genomics. Denmark is not a part of the European Genome-phenome Archive ( <a href="http://EGA">EGA</a> ). Hospitals and huge research consortiums - fx iPSYCH - have their own repositories at the HPC centres Computerome or GenomeDK.
SE	There is no national repository for rich metadata describing data sets today within the OMICS domain. Researchers often use international repositories, providing metadata and allocating identifiers based on requirements from publishers.
FI	An overhaul of the Biobank legislation is currently in process. It is possible that a national genome centre is going to be established and start functioning in connection with National Institute for Health and Welfare. Right now, however, no national omics database or metadatabase exists.
NO	There is no national repository for rich metadata describing data sets today within the OMICS domain, but the Norwegian Genomics Consortium (NGC), provides state-of-the-art high-throughput genomic analysis services.

## Alignment with the FAIR principles

We have used the FAIR<sup>ref</sup> principles as a compass when creating the overview of national resources handling metadata and semantics for the different types of health data. The principles have been applied from a general point of view and assessed in relation to what would be needed to support a Nordic Commons from a metadata and semantic point of view. In cases where there are multiple national resources we have included them in the text, but local and regional resources that do not have an ambition for national coverage have been excluded.

### FORCE11<sup>ref</sup> Criteria

#### TO BE FINDABLE:

- F1. (meta)data are assigned a globally unique and eternally persistent identifier.
- F2. data are described with rich metadata.
- F3. (meta)data are registered or indexed in a searchable resource.
- F4. metadata specify the data identifier.

#### TO BE ACCESSIBLE:

- A1 (meta)data are retrievable by their identifier using a standardised communications protocol.
  - A1.1 the protocol is open, free, and universally implementable.
  - A1.2 the protocol allows for an authentication and authorisation procedure, where necessary.
- A2 metadata are accessible, even when the data are no longer available.

#### TO BE INTEROPERABLE:

- I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
- I2. (meta)data use vocabularies that follow FAIR principles.
- I3. (meta)data include qualified references to other (meta)data.

#### TO BE RE-USABLE:

- R1. meta(data) have a plurality of accurate and relevant attributes.
  - R1.1. (meta)data are released with a clear and accessible data usage license.
  - R1.2. (meta)data are associated with their provenance.
  - R1.3. (meta)data meet domain-relevant community standards.

<sup>ref</sup> FORCE11 - <https://www.force11.org/group/fairgroup/fairprinciples> , <https://www.force11.org/node/6062>

## FAIR Metadata Status within the Health Data Domain

DK= Denmark

SE= Sweden

FI= Finland

NO= Norway

Domain	Country	Findable	Accessible	Interoperable	Re-useable
Biobanks					
	DK	Metadata about samples are findable in a single, national register	Metadata can be accessed at the homepage of the biobank register: <a href="http://biobanks.dk/">http://biobanks.dk/</a>	The biobank register is indexed with Civil Registration Number, ICD10 diagnosis codes, Sample type etc. Language is Danish and English	No user license is needed
	SE	Biobank Sweden (former BBMRI.se and Nationellt biobanksråd/National Council of Biobanks) provide one entrance with high level metadata based on MIABIS. <sup>1</sup> The Swedish Research Council infrastructure Register Utiliser Tool provides	Each hospital region has made its own decision on which solution and configuration to implement to handle pre-analytical metadata. Many regions store their pre-analytical metadata in a LIMS <sup>3</sup> but the content, that is the pre-analytical metadata stored,	National core concepts have been defined in a terminology <sup>5</sup> and was established by Biobank Sweden. A good semantic foundation to be used by the Biobanks for interoperability. The project "Gemensam Svensk	The samples that are stored in biobanks where the suggested GBIS information model has been implemented are based on ISO11179, the predecessor to GSIM <sup>7</sup> . Provenance metadata are handled by the researchers and there is

<sup>1</sup> <http://bbmriregister.meb.ki.se:8080/AwareIM/logonGuest.aw?domain=BBMRIRegister>

<sup>3</sup> Laboratory Information Management System

<sup>5</sup> "Landstingens gemensamma biobanksdokumentation.doc, Nationellt biobanksråd "

<sup>7</sup> <https://statswiki.unece.org/display/gsim/Generic+Statistical+Information+Model>

		<p>more detailed metadata harvested from LIMS, work on inclusion is ongoing. The new effort to create a national biobank infrastructure – Biobank Sverige – can be an important contribution to the sample findability in the future and in a recent official report of the Swedish Government the investigators propose a national register for stored biobank samples. The metadata proposed are limited but pre-analytical metadata regarding handling and preparation of samples should be included.<sup>2</sup></p>	<p>may differ between implementations. The national biobank infrastructure Biobank Sverige, (former BBMRI.se and Nationellt biobanksråd/National Council of Biobanks) was established in 2018.<sup>4</sup></p>	<p>Biobanksinfrastruktur (GSB)<sup>6</sup> went further and created an information standard for pre-analytical metadata (GBIS 1.0) based on the GSIM predecessor ISO11179. Implementation rests with the different biobanks and the degree of implementation differs widely. Extensions may be needed to meet local needs. In 2015 the national network of operative biobank facilities (today included in Biobank Sweden) agreed on a new version of GBIS, GBIS 2.0.</p>	<p>no national infrastructure for storing them at present. The Register Utiliser Tool infrastructure aims to develop such support in order to make provenance metadata nationally available. There are no general national guidelines for licences regarding the sample metadata today.</p>
	FI	<p>Currently there are eight clinical biobanks in Finland and one national population-based biobank (THL Biobank in National Institute for Health and Welfare). The THL Biobank has an open metadata</p>	<p>THL National Biobank metadata is public and published in the biobank webpage. Clinical/regional biobanks do not publish their metadata at present.</p>	<p>Biobanks take part in international collaborations such as BBMR-ERIC (BBMRI.fi) and ELIXIR. The BBMRI uses a common MIABIS framework for sample metadata management,</p>	<p>The metadata descriptions of the THL National Biobank have been mapped to and utilised in the GSIM/DDI-based Isaacus Metadata Model. The mapping did not contain the MIABIS-</p>

<sup>2</sup> [http://www.regeringen.se/490052/contentassets/e83f9a8d675440d5a8e215e0d960a554/sou-2018\\_4-framtidens-biobanker.pdf](http://www.regeringen.se/490052/contentassets/e83f9a8d675440d5a8e215e0d960a554/sou-2018_4-framtidens-biobanker.pdf)

<sup>4</sup> <http://biobanksverige.se/>

<sup>6</sup> <https://www.vr.se/download/18.7257118313b2995b0f29418/1360160789594/Gemensam+Svensk+Biobankstruktur+2013.pdf>

		<p>catalogue based on the MIABIS format. Additionally variable-level metadata is shared, but in non-standardised format. Clinical biobanks do not share their metadata in a public format. The National Supervisory Authority on Health and Welfare publishes a public Biobank Registry. However, this public registry does not contain metadata of the samples or variables of biobanks.</p> <p>Some national register classifications are described in the National Code Server maintained by THL and the National Insurance Institution.</p>	<p>The National Code Server has open API and some health register classifications can be reached from the server.</p>	<p>also in use in the THL National Biobank.</p>	<p>based sample metadata features.</p>
	NO	<p>There is so far no central entry point and register providing metadata on sample level for the Norwegian biobanks.</p> <p>The only biobank that provides metadata on sample level is the <b>HUNT Biobank</b> .</p>	<p>In almost all cases, the researcher must obtain an approval from the <b>Ethical Committees (REK)</b> to access data, and thereafter submit an application to each biobank and registry.</p>	<p>There is a very limited interoperability between data sources/registries/cohorts regarding data access, but a high degree of transparency through national networks, such as Biobank Norway.</p>	<p>For all the major health surveys and biobanks, generated data will be returned and stored in a “local” databank available for re-use by other researchers based on individual requests/applications.</p>

		<p>In the <b>National Biobank Registry</b> you can find information/metadata such as project title, responsible owner, manager of the biobank, description of the specimen, diagnoses about, and links to, all the major health surveys (reported surveys and biobanks) and population biobanks as well as the clinical biobanks in Norway, including collections of biological material such as blood samples and biopsies.</p> <p>All the biobanks has been given an unique number and a unique project ID (<b>CrisTIN</b>)</p> <p>More detailed information about all applications from 2009 is found in the project register of the <b>Regional Committees for Medical and Health</b></p>		<p><b>Biobank Norway</b> harmonises with the European Biobank Infrastructure BBMRI. BBMRI that uses the common MIABIS framework for sample metadata (minimal datasets) (MIABIS 2.0 core) management .</p>	
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		<p><b>Research Ethics (REK).</b></p> <p>There is an ongoing project within <b>Biobank Norway</b> to develop a Cohort Explorer.</p> <p>There are examples of metadata on biodata collected as a part of Tromsøundersøkelsen (TU), one of the largest health surveys in Norway, <a href="#">here</a></p>			
Health Registers					
	DK	<p>Rich metadata from all national health registries is indexed at the website eSundhed.dk. There is a dashboard where one can find aggregated data <a href="#">here</a>. There is no persistent identifier, but it is official governmental metadata.</p>	<p>Metadata can be accessed at the website eSundhed.dk, with definitions on registries, tables and variables. Attribute values can be downloaded as files <a href="#">here</a>.</p>	<p>The documentation is based on internally developed standards. Sundhedsdatastyrelsen is planning to implement the GSIM-based system Collectica Language is Danish only</p>	<p>No user license is needed Provenance metadata are provided at the <a href="#">website</a>.</p>
	SE	<p>Health register metadata are currently provided by the National Board of Health and Welfare (SoS)</p>	<p>Metadata are retrievable as variable lists, with varying degrees of richness, from SoS homepage but not by</p>	<p>Health register metadata provided by the SoS homepage do not in general include metadata</p>	<p>Metadata are not released with a clear licenses for usage but fall under the laws regulating</p>

		<p>as variable lists on their homepage.<sup>8</sup> Through their cooperation with the Swedish Research Council they are also successively providing richer and more curated metadata in the national infrastructure RUT<sup>9</sup> which provides a searchable resource. Metadata In RUT are assigned URI-like identifiers. The plans are to assign DOIs to register and data set metadata in RUT.</p>	<p>identifier and not by a standardised protocol. No authentication or authorisation are needed. Health registers included in RUT are provided with an identifier and are retrievable after authentication and authorisation. The selection of protocols provided is under development.</p>	<p>regarding use of terminologies, vocabularies or ontologies and are not described according to a standardised metadata framework. Health register metadata curated and included in RUT uses both internationally standardised and government-specific terminologies, vocabularies, ontologies to describe the register concept systems. Metadata are specified according to GSIM<sup>10</sup>.</p>	<p>access to public information. Provenance information is sometimes provided by SoS in documents but the metadata in variable lists do not follow domain standards. Metadata provided in RUT meet the requirements of GSIM. Development of functions to provide rich provenance metadata both for registers and research data sets are ongoing.</p>
	FI	<p>Currently national health register metadata is provided on data set level in the Data Set Catalogue at the webpage of the National Institute for Health and Welfare. Some data set and variable level metadata have been described in the</p>	<p>Aineistoeditori's metadata is accessible online and published with open licence.</p>	<p>Aineistoeditori's metadata model is based on GSIM. The attributes have also been mapped to DDI 3.2 Lifecycle attributes. Some attributes follow Finnish Public Metadata Model: JHS RekMeta.</p>	<p>Aineistoeditori's variable level metadata is delivered through public API with open licence <a href="#">here</a>.</p>

<sup>8</sup> <http://www.socialstyrelsen.se/register>

<sup>9</sup> <http://rut.registerforskning.se/>

<sup>10</sup> <https://statswiki.unece.org/display/gsim/Generic+Statistical+Information+Model>

		Aineistoeditori editor. At the moment metadata is only available in Finnish.			
	NO	<p>Metadata, both on registry level and variable level, will be findable via <a href="http://www.helsedata.no">www.helsedata.no</a>. central registries.</p> <p>In HealthTerm<sup>11</sup> registers and variables (objects) will be assigned an unique ID.</p>	<p>The metadata will be accessible from</p> <ol style="list-style-type: none"> <li>1. <a href="http://www.helsedata.no">www.helsedata.no</a> through a “shopping cart” function and can be downloaded in in different common file formats.</li> <li>2. By an API-interface from the national repository “HealthTerm”.</li> </ol> <p><a href="#">HealthTerm</a> will contain both code lists, classifications, terminologies, registries and variables with associated metadata, and mappings between those.</p>	<p>The attributes are more or less aligned with the DDI-standard.</p> <p>During 2019, HDP will consider mapping the variables to GSIM (and perhaps HL7 FHIR)</p> <p>Some, but not all, variables are translated into English.</p> <p>The classifications used are both subsets of international classifications such as ICD-10 and ICPC-2, but are also based on internally develop code lists/value sets.</p> <p>Adopting the “FAIR-language” has been initiated.</p>	<p>There is no return of data to the central, national registries, but for some hospitals, validated diagnoses (ICD10-codes) are returned and stored by the research units (R&amp;D department) outside their patient register to be re-used for research purposes</p>

<sup>11</sup> <http://rut.registerforskning.se/>

Socio-economic Registers					
	DK	<p>Rich metadata from all national registers is searchable in the website <a href="#">here</a>.</p> <p>There is no persistent identifier, but it is official governmental metadata.</p>	<p>Metadata can be accessed on the <a href="#">website</a></p> <p>Attribute value lists are available for every variable.</p>	<p>Statistics Denmark has developed its own metadata system TIMES4. It uses both special Danish standards and Eurostat standards. They are planning to implement the GSIM-based system Collectica.</p> <p>Frequently used variables are described at a special high level in cooperation with Det Koordinerende Organ for Registerforskning. This relates to a self-developed documentation standard <a href="#">here</a>.</p> <p>The information is only available in Danish.</p>	<p>No user license is needed</p> <p>Provenance metadata are provided at the <a href="#">website</a>.</p>
	SE	<p>Socio-economic registers are provided by Statistics Sweden and they provide a national searchable resource for the metadata stored in their metadata repository (metaplus) and described with metadata according to the GSIM</p>	<p>The metadata provided by Statistics Sweden in metaplus is separated into a metadata repository and thus accessible separately from access to data. Access to metadata in metaplus does not require authentication and</p>	<p>Socio-economic register metadata provided by Statistics Sweden in metaplus do not include metadata regarding use of terminologies, vocabularies or ontologies. Concepts, and thus definitions, are not</p>	<p>Metadata are not released with a clear licenses for usage but fall under the laws regulating access to public information.</p> <p>Provenance metadata are provided in document form (SCBDOK) on the</p>

		<p>predecessor ISO11179<sup>12</sup> metadata standard.<sup>13</sup> Through their cooperation with SRC they are also successively providing richer metadata regarding semantics in the national infrastructure RUT according to GSIM<sup>14</sup> which provides a searchable resource. In RUT metadata are assigned URI-like identifiers. The plans are to assign DOIs to register and dataset metadata in RUT.</p>	<p>authorisation. Metadata provided through the RUT infrastructure is naturally also separated into a repository, access to RUT requires authentication and authorisation. The selection of protocols provided for access to metadata in RUT is under development.</p>	<p>separated from the variables. Metadata provided within RUT are curated and the semantics describing concepts and concept systems for the registers are using both standardised and government-specific terminologies. In general, availability to international terminologies/ontologies and also the work describing semantics are less developed within this domain than the others.</p>	<p>Statistic Sweden web.<sup>15</sup> The metadata meet relevant community standards both in metaplus (ISO11179) and in the modernised version of that standard provided in RUT (GSIM).</p>
	FI	<p>Statistics Finland has described its data set and instance variable level metadata using the COSSI metadata model. The COSSI model has been developed in Statistics Finland. Statistics Finland is studying the use of GSIM-based metadata</p>	<p>The most important databases are published on the taika.stat.fi webpage.</p>	<p>The COSSI model has been mapped to other metadata models, such as GSIM-based Aineistoeditori.fi model.</p>	<p>Statistics Finland's Classification server is planning to publish open API for public statistical classifications.</p> <p>Some variables may be published in the Aineistoeditori, which has an open API already</p>

<sup>12</sup> <https://www.iso.org/standard/61932.html>

<sup>13</sup> <https://www.h6.scb.se/metadata/sokning.aspx>

<sup>14</sup> <https://statswiki.unece.org/display/metis/Generic+Statistical+Information+Model>

<sup>15</sup> <http://www.scb.se/dokumentation/kvalitet-och-framtagning/>

		<p>description and some pilots are already in progress.</p> <p>The statistical classification database is in use as well, and is partly open for external users.</p>			enabling the re-use of data set and variable level metadata.
	NO	<p>Rich metadata from socio-economic registers, combined with the possibility to conduct <i>ad hoc</i> exploratory analysis, is searchable from an official website owned by Statistics Norway (SSB) and run by the Norwegian Centre for Research Data (NSD) <a href="#">here</a>.</p> <p>Every variable has a persistent identifier.</p>	<p>The metadata provided by SSB at microdata.no is separated into a metadata repository and thus accessible separately from access to data. Access to metadata at microdata.no does not require authentication and authorisation. Metadata from microdata.no will be provided at helsedata.no in 2019.</p>	<p>Through its <a href="#">RAIRD</a> project, NSD developed its own information called RIM (RAIRD Information Model). RIM is mainly based on GSIM. The Norwegian Agency for Public Management and eGovernment (Difi) has developed a standard for concept and metadata description, including which metadata elements/attributes are to be described when public institutions documents and publish data. The standard is based on recommendations in the Norwegian "Termlosen" which again is based on Dublin Cora and Nordterm's translation of NS-ISO 1087-1:2000 .</p>	<p>At <a href="https://data.norge.no/">https://data.norge.no/</a> DiFi provides access to open official data sets with associated API's. At microdata.no the researchers can store and/or download the query so that a data set can be recreated and shared.</p>

				<a href="http://www.difi.no/fagomrader-og-tjenester/digitalisering-og-samordning/standarder/standarder/standard-begrepsbeskrivelser">www.difi.no/fagomrader-og-tjenester/digitalisering-og-samordning/standarder/standarder/standard-begrepsbeskrivelser</a> The ongoing SKATE project, headed by the Agency for Public Management and eGovernment (Difi), , aims to strengthen the government's efforts to renew the Norwegian public sector and improve the organisation and efficiency of government administration. SKATE will focus on standards for metadata and API's, among other things.	
Laboratory Data					
	DK	One national database holds metadata on hospital laboratory analyses performed at departments of clinical biochemistry on blood	Metadata can be accessed at the Sundhedsdatastyrelsen since spring 2018.	CPR number, date and time of analysis, NPU code and/or analysis code and a result. The NPU terminology is an international classification	No user license is needed.

		samples, urine, cerebrospinal fluid and other bodily fluids. <a href="#">Here</a>		system for medical laboratory analyses. The terminology is designed to give information on a current state of a relevant biological system at a specified time point. The terminology does not describe processes or specific phases of analytical procedures. Available in Danish only.	
	SE	There is presently no national resource containing metadata for laboratory data but a lab service interface in the National Service Platform is being implemented by Inera. The service interface is built on rich common metadata in an information model and a common semantic model in a concept system.	There is no national resource for accessing laboratory metadata or data in place today, but the lab service interface that Inera is implementing in the National Service Platform will provide access to lab answers provided the user has the necessary access rights.	Today neither a national metadata standard nor terminology/terminologies have been implemented . The Inera project implementing the lab service interface is communicating guidelines and recommendations for usage of terminologies and code lists. For lab referrals NPU codes are used while lab answers are encoded using SnomedCT.	Presently neither a national metadata standard nor terminology/terminologies have been implemented, nor is there a common solution to provide provenance metadata. However, the Inera implementation aims to provide a rich set of metadata attributes to describe the lab results domain and the service interface. When possible, domain standards are used for describing semantic contents.
	FI	There is no national resource for laboratory metadata.	There is no national resource for accessing	There is no national metadata standard	There is no common solution to provide provenance to metadata.

		<p>However, some of the variable level hospital district laboratory metadata have been described in the Isaacus Metadata Editor.</p> <p>The National Institute for Health and Welfare has some data set level information on its laboratory contents partly published in Aineistoeditori.</p>	laboratory metadata or data.	implemented in the field of laboratory data.	
	NO	<p>Currently there is no national register for laboratory test results or standardised metadata.</p> <p>A concept evaluation and impact assessment of a national laboratory database was handed over from FHI to the Ministry of Health and Care Services on 29 September 2017.</p> <p>The paper recommends establishing a national laboratory database for, at</p>	<p>Scientists, health sector leaders, Government, business community, and citizens, have a need for data on laboratory test results. Today there is limited access to national statistics on lab test results. Scientists who would like to have data from multiple laboratories, must apply for disclosure of data from each individual laboratory, and data is usually encoded by different classifications in the local laboratory computer systems.</p>	<p>The exchange of standardised laboratory results between different actors in the health service today is based on ebXML messages and a nationally developed content standard (KITH).</p> <p>The Directorate of eHealth has recommended IHE XDS (Integrating the Health care Enterprise-Cross Enterprise Document Sharing) as the future standard for exchange of laboratory results.</p>	<p>In MSIS (Nasjonalt meldesystem for smittsomme sykdommer)) the entire test result is not saved <i>per se</i>, only the date of the test, and if necessary, date of diagnosis, procedure (sometimes based on local codes not similar to the ones used by the laboratories) and material (using local codes as well, and additional fields for information). For example, the MIC-values (Minimum Inhibitory</p>

		<p>first, microbiological test results.</p> <p>The “project” was not given priority in 2018 among others because the National Health Analytics Platform will not be up and running before mid-2019.</p> <p>Study of the need for structured, standardised and rich metadata entered was not a part of the evaluation.</p>	<p>IA standardised XML message is used for exchanging lab results between health care actors. This message may use codes according to the Norwegian Lab Classification (NLK)</p> <p>The two support tables for trial material and anatomic location, however, are not mandatory.</p> <p>Establishing a national laboratory database in the National Health Analytics Platform (HAP) will make it possible to search for laboratory data based on a common classification and make the data semantically compatible.</p>	<p>In the long term the HL7 FHIR probably will take over.</p> <p>The Norwegian Directorate of e-Health is working towards implementation of the NPU terminology as a national standard for laboratories in communicating requisitions and examination results.</p> <p>NLK (Norsk Laboratoriekodverk) content consists of both a selection of NPU codes and national extensions that is named NOR codes, approximately 9500 total.</p>	<p>Concentration) are not saved, nor is information when something is intermediary resistance/sensitive. MSIS also does not have the ability to store e.g."titer"-changes in the lab answers (important for interpretation of measles for example). MSIS has only one lab result per case.</p>
Registers of Clinical Quality					
	DK	<p>All the databases can be found on the same <a href="#">webpage</a>.</p>	<p>Metadata can be accessed at the website <a href="http://rkkp.dk">rkkp.dk</a></p>	<p>There is a self-developed standard called “Generisk Model”. There is a common online template with: Purpose, Population,</p>	<p>No user license is needed</p> <p>There is a <a href="#">standardised data model</a> for transfer of data to the Regions’ BI-systems</p>

				Algorithms, Data sources and Variables with documentation. All databases are documented in the template. The information is mostly in Danish.	<a href="http://www.rkkp.dk/afrapportering/lobende-afrapportering/">http://www.rkkp.dk/afrapportering/lobende-afrapportering/</a>
	SE	<p>The National Board of Health and Welfare (SoS) and the Swedish Association of Local Authorities and Regions (SALAR) both provides high level metadata from national quality registers on their respective websites.</p> <p>Rich curated metadata are searchable in the national infrastructure Register Utiliser Tool (RUT) for the included quality registers. The curation process for inclusion in RUT is ongoing and at the moment research intensive registers have priority.</p>	<p>Metadata is retrievable as variable lists, with varying degrees of richness, from the quality registers' websites but not by identifier and not by a standardised protocol. Health registers included in RUT are provided with an identifier and are retrievable after authentication and authorisation. The selection of protocols provided are under development.</p>	<p>SALAR and SoS have an ongoing project for data collection<sup>16</sup> that enhances interoperability together with the national quality registers by mapping the register variables to "Nationellt Fackspråk", that consists of, for instance, SoS termbank and SnomedCT. The OID identifier is used to identify terminologies and code lists.</p> <p>SRC uses this mapping when creating concept systems in RUT. RUT uses both internationally standardised and government-specific terminologies, vocabularies, ontologies to describe the register</p>	<p>Metadata are not released with a clear licenses for usage but fall under the laws regulating access to public information. Provenance information documented by the quality registers greatly varies.</p> <p>Metadata for registers that are curated and included in RUT meet the requirements of GSIM. Development of functions to provide rich provenance metadata both for registers and research data sets are ongoing.</p>

<sup>16</sup> <http://kvalitetsregister.se/forbattravarden/projekt/nationellaprogrammetfordatainsamling/datinsamlingstrategi.1975.html>

				concept systems. Metadata are specified according to GSIM. <sup>17</sup>	
	FI	Currently there are only a few national quality registers in Finland. Their metadata have not yet been described.	The metadata cannot be found in public format.	There is no standard for describing national clinical quality registries. However, the Isaacus Metadata model, which is based on GSIM, can be utilised, as the THL has recently initiated a national pilot programme for clinical quality registries.	There are no national resources containing metadata for clinical quality registries.
	NO <sup>18</sup>	In Norway there are 53 quality registries with national status. In addition to these there are assumed to be more than 150 without national status.  The Regional Health Authorities (RHF)(4) owns the quality registries.	Metadata are retrievable as variable lists, with varying degrees of richness, from the quality registers' homepages but not by a national identifier and not by a standardised protocol. No authentication or authorisation are needed.  In cooperation between SKDE and HRR, one register (Ryggkirurgiregsiteret) is reporting structured and standardised metadata to	In the National Directorate of eHealth, there is an ongoing pilot project on mapping the register variables to SnomedCT and other common standard and/or national code lists.  A national OID on registries, variables and standardised metadata elements will not be established until HealthTerm is up and running.	Metadata are not released with a clear licenses for usage but fall under the laws regulating access to public information. Provenance information documented by the quality registers varies widely. Metadata for registers that are curated and included in EUTRO meet the requirements of an internally developed

<sup>17</sup> <https://statswiki.unece.org/display/gsim/Generic+Statistical+Information+Model>

<sup>18</sup> Note: The initiatives and “tools” described under Health Registries includes Registers of Clinical Quality as well

		<p>“Nasjonalt servicemiljø for medisinske kvalitetsregistre” (SKDE) offers services for new and existing registries. SKDE has an overview over all the national quality registries on its website, with links to their sub-registries, forms for reporting, variables and value sets. This is called “Variabelbiblioteket” <a href="https://www.kvalitetsregistre.no/artikkel/velkommen-til-variabelbiblioteket">https://www.kvalitetsregistre.no/artikkel/velkommen-til-variabelbiblioteket</a></p> <p>There are few metadats In “Variabelbiblioteket”. It was updated in 2017. There is no plan for further updating or development. The information is modelled in the same tool as that being used by the regional health authorities to model their clinical archetypes. “Clinical Knowledge Manager” by OpeneHR.</p>	<p>the existing national repository EUTRO as a pilot effort. The metadata will soon be retrievable on website <a href="http://hrr.uit.no/hrr/">http://hrr.uit.no/hrr/</a>.</p> <p>Funding has been granted in 2018 and 2019 to harvest metadata from more of the registries. It a lot of manual work structuring and exporting/importing the metadata the first time, and it will take some years to involve all the 54 national quality registries.</p> <p>About 30% of the national quality registries are managed either by “The Cancer Registry” or “The National Heart and Cardio Registry”.</p>	<p>The established OIDs in the national repository for classification, code lists and terms, are referred to as common metadata across variables with a similar meaning. This will build a good starting point for further harmonisation and standardisation of variables.</p> <p>In HealthTerm this could be used for mapping the variables to internationally standardised and government-specific terminologies, vocabularies and ontologies.</p> <p>So far the metadata are not specified according to an international standard, but there are ongoing initiatives to map existing standards to GSIM.</p>	<p>standard.</p> <p>Development of functions to provide rich provenance metadata both for registers and research data sets are ongoing initiatives in Helsedataprogrammet.</p>
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Health Surveys/Cohort Studies					
	DK	Metadata from many surveys and cohorts is	Metadata is structured due to the DDI-L standard.	The information is available in Danish	No user license is needed

		available at the Danish Data Archive (The National Archives). Some cohorts can only be found on their respective websites. metadata at the National Archives has a persistent identifier.			
	SE	<p>Many of the Swedish cohorts are today findable in common national infrastructures.</p> <p>Swedish National Data Service (SND) provides a searchable resource for a subset of the cohorts based on data set/study level metadata.<sup>19</sup> SND also includes data set level metadata for cohorts that are a member of cohorts.se (se below)</p> <p>As an example, the Swedish Cohort</p>	<p>SND provides access to metadata regarding many of the Swedish cohorts on a data set/study level. Among these cohorts from the consortium Cohorts.se. DOI is used.<sup>21</sup></p> <p>Cohort Metadata described by the Swedish Cohort Consortium are successively accessible on a variable level through the maelstrom platform but differ when it comes to metadata content.<sup>22</sup> Cohort metadata in RUT are presently being curated</p>	<p>Cohort Metadata described by SND uses the metadata standard DDI and standardised terminologies and code lists/classifications.<sup>23</sup></p> <p>Cohort Metadata described by the Swedish Cohort Consortium is not using a metadata standard and is not using standardised vocabularies/terminologies. The harmonisation logic used in the event the variable is a part of a harmonisation</p>	<p>SND provides access to metadata regarding many of the Swedish cohorts on a data set/study level but is not providing metadata on a variable level. In SND2.0 the aim is to provide more granular metadata on a variable level. Provenance metadata could be further developed to increase re-usability. Licenses are clearly delineated.</p> <p>The Swedish Cohort Consortium is not using a metadata standard and is</p>

<sup>19</sup> <https://snd.gu.se/sv>

<sup>21</sup> <https://snd.gu.se/sv>

<sup>22</sup> <https://www.maelstrom-research.org/mica/network/cohorts.se>

<sup>23</sup> <https://snd.gu.se/sv>

		<p>Consortium (Cohorts.se) is making an effort to gather metadata in a common platform and adding cohorts successively.<sup>20</sup> From a FAIR criteria point of view, though, they are not using a common metadata standard so the richness of the metadata varies between cohorts.</p> <p>The Register Utiliser Tool (RUT) digital infrastructure aims to include cohorts curated into the GSIM metadata standard framework and on a variable level. At the moment this is with URI-like PIDs but there are plans to allocate DOIs.</p>	and not yet uploaded.	<p>process is displayed.<sup>24</sup></p> <p>RUT uses both internationally standardised and government-specific terminologies, vocabularies, ontologies to describe the register concept systems. Metadata are specified according to GSIM.<sup>25</sup></p>	<p>not using standardised vocabularies/terminologies on the variable level.</p> <p>On the data set/study level this is provided within the SND solution.</p> <p>Provenance metadata are not provided.</p>
	FI	Health surveys and cohorts of THL have been described in multiple places.	Aineistoeditori's metadata are accessible in the internet and published with open licence.	Aineistoeditori's metadata model is based on GSIM. The attributes have also been mapped to DDI Lifecycle attributes. Some attributes follow Finnish	Aineistoeditori's variable level metadata is delivered through public API with open licence.

<sup>20</sup> <http://cohorts.se/>

<sup>24</sup> <https://www.maelstrom-research.org/mica/network/cohorts.se>

<sup>25</sup> <http://rut.registerforskning.se/>

		<p>Some of the health survey data can be accessed from THL Biobank and the metadata descriptions can be found there.</p> <p>Some health survey and health examination study metadata can be found from Aineistoeditori.</p>		Public Metadata Model: JHS RekMeta.	
	NO	<p>The Norwegian Institute of Public Health (FHI) provides an overview with metadata on survey level data from most of the regional health surveys from 1974 to 2009.</p> <p>CONOR previously offered access to metadata via the website <a href="http://conor.uit.no/conor/">http://conor.uit.no/conor/</a> Metadata on variables from CONOR surveys conducted between 1994 and 2008 that were available on the website have not been accessible since 2018.</p>	<p>Metadata from the HUNT (Helseundersøkelsen i Nord Trøndelag) can be accessed online via <a href="https://hunt-db.medisin.ntnu.no/hunt-db/#/studypart/1">https://hunt-db.medisin.ntnu.no/hunt-db/#/studypart/1</a></p> <p><b>TU (Tromsundersøkelsen)</b> is ready for exporting standardised metadata to the new national metadata repository HealthTerm. Variables from the two of the questionnaires (Q1 and Q2) , some analysis and some clinical examinations are published in NESSTAR. <a href="http://tromsundersokelsen.uit.no/tromso/">http://tromsundersokelsen.uit.no/tromso/</a></p>	The interoperability between the surveys is poor.	For all the major health surveys and biobanks, generated data will be returned and stored in a "local" databank available for reuse by other researchers based on individual requests/applications.

Electronic Health Records					
	DK	Metadata for the e-Journal SUP data model can only be found on the website of the organisation, which no longer holds the database. <a href="https://www.medcom.dk/standarder/e-journalstandarder">https://www.medcom.dk/standarder/e-journalstandarder</a>	Metadata is accessible as labels in web forms for citizens and health personnel at <a href="http://sundhed.dk">sundhed.dk</a>	XML-forms for the database can be downloaded at <a href="https://www.medcom.dk/standarder/e-journalstandarder">https://www.medcom.dk/standarder/e-journalstandarder</a>	Information is in Danish only. Metadata is shown in html-forms at <a href="http://sundhed.dk">sundhed.dk</a>
	SE	Metadata describing contents of the Swedish EHRs are not generally available on a national level today. The National Service Platform that is implementing national services to read data from EHRs publishes metadata on the service domains <sup>26</sup> and contracts <sup>27</sup> and code lists <sup>28</sup> used, but there is no national metadata repository to provide good	Metadata describing service contracts and code lists are available but implementation of the contracts is not nationwide. OID identifiers are provided to identify code lists and local identifiers. <sup>30</sup>	The national information structure and the national technical/domain language <sup>31</sup> provides a basic national semantic platform for interoperability. Implementation in the regional systems differ. The project "Gemensamt ramverk av standard för interoperabilitet" in which the Swedish Association of Local Authorities, the Swedish eHealth Agency,	Metadata and data accessible through the national service-based platform meet domain specific standards but coverage is not national. Provenance information would need to be further developed in order to support re-usability better.

<sup>26</sup> <http://rivta.se/domains/>

<sup>27</sup> [http://rivta.se/domains/interaction\\_index.html](http://rivta.se/domains/interaction_index.html)

<sup>28</sup> <https://riv-ta.atlassian.net/wiki/spaces/KINT/pages/270532953/Kodverk+i+nationella+tj+nstaplattformen>

<sup>30</sup> <https://www.inera.se/kundservice/dokument-och-lankar/arkitektur--regelverk/verksamhet--informatik/>

<sup>31</sup> <http://www.socialstyrelsen.se/nationellehalsa/nationellinformationsstruktur>

		findability for metadata describing each EHR system's content in itself or mapped to the harmonised national metadata. <sup>29</sup> The implementation of the service contracts are not made on a national level for all regions and journal systems.		representatives from the industry and the regions participated, provided a report containing recommendations for increased interoperability within Swedish health care, and called for proof-of-concept work to be done in 2017. <sup>32</sup> Among the recommendations was how to work with terminologies/ vocabularies on a national level and how to evaluate and use domain metadata standards.	
	FI	Currently there is no standard or national catalogue for EHR metadata. Some hospital districts (specialised care) have developed Data Lakes in order to help the utilisation of the clinical data. Some datasets and variable descriptions have	Most of the metadata is not public.	Aineistoeditori's metadata model is based on GSIM. The attributes have also been mapped to DDI Lifecycle attributes. Some attributes follow Finnish Public Metadata Model: JHS RekMeta.	Aineistoeditori's variable level metadata is delivered through public API with open licence: <a href="https://aineistokatalogi.fi/swagger-ui.html">https://aineistokatalogi.fi/swagger-ui.html</a>

<sup>29</sup> <http://www.socialstyrelsen.se/nationellehalsa/nationellinformationsstruktur>

<sup>32</sup> <https://www.inera.se/Fordjupning/arkitektur-och-regelverk/standarderforinteroperabilitet/> "Gemensamt ramverk av standard för interoperabilitet, 2017"

		been described in the Isaacus Aineistoeditori.			
	NO	<p>There are no searchable common resources with rich and standardised metadata on the variables used in the different EHR systems.</p> <p>Health records are held in 8 different <u>main</u> HER systems. 2 for hospitals, 3 in primary care and 3 for the RGP.</p> <p>A subset of data and metadata from all systems is extracted to the national "Kjernejournal".  <a href="https://helsenorge.no/kjernejournal">https://helsenorge.no/kjernejournal</a></p>	<p>Structured and standardised metadata about the variables reported to the National Patient Registry (NPR), mainly administrative, are accessible from NESSTAR.  <a href="http://hrr.uit.no/hrr/">http://hrr.uit.no/hrr/</a></p> <p>There is an ongoing project that is testing SNOMED CT as a common reference terminology across/on top of existing clinical classifications, and clinical variables used registries.</p> <p>Both clinical and administrative classifications and coding systems, with metadata are available at  <a href="http://volven.no/">http://volven.no/</a> and  <a href="https://finnkode.ehelse.no/">https://finnkode.ehelse.no/</a></p>	<p>National interoperability (more technical standards are accessible at  <a href="https://sarepta.ehelse.no/">https://sarepta.ehelse.no/</a></p> <p>Detailed clinical information model for primary use in the DIPS EHR systems are accessible at  <a href="http://arketyper.no/ckm/">http://arketyper.no/ckm/</a></p> <p>The models are based on Open EHR Archetypes. There are metadata on the models.  So far this is not an approved national standard.</p>	<p>The reusability of the EHR's are poor because because little of the clinical information is structured and standardized. Administrative information is reusable through the National Patient Registries and other National Health Registries.</p>
OMICS	DK				

	SE	<p>There is no national repository for rich metadata describing data sets today within the OMICS domain. The use of globally administered persistent identifiers varies widely within the domain and also between studies.</p> <p>Researchers are instead using international repositories, providing metadata and allocating identifiers based on requirements from publishers. The metadata standards and ontologies used are often administered by the international repositories.</p> <p>Data sets not related to publications, that are not subject to the publishers' requirements are often not sent to the repositories.</p> <p>The Swedish National Data Service (SND) is planning implementation of a</p>	<p>Metadata describing data sets related to publications are often accessible through international repositories but not via a national infrastructure.</p> <p>Since there are many domains and subdomains (proteomics, metabolomics, genomics etc) specific repositories are complemented with repositories that can provide a common entrance for access to the metadata.</p> <p>Metadata not related to publications are not always easily accessible.</p> <p>The SND repository will increase accessibility when implemented.</p>	<p>There is no national infrastructure that supports knowledge representation and semantics.</p> <p>Knowledge representation is quite developed within the domain but in international repositories rather than on a national level. That said there are variations between subdomains.</p> <p>Standardised ontologies are often used by the international repositories where data related to publications are often uploaded.</p> <p>When ontologies are not covering the data sets and/or content the knowledge representation is not as well developed.</p> <p>Data sets not related to publications vary more when it comes to semantic</p>	<p>Clear licenses for the data and metadata are often not provided.</p> <p>Provenance metadata are often required by the international repositories but the richness of the provenance metadata provided varies a lot between data sets and repositories.</p> <p>Standards are often used quite flexibly when it comes to required content.</p>
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		national repository which may improve findability on a national level.		descriptions.	
	FI	<p>The legislation regulating the Finnish Genome Center (“Genomikeskus”) is under preparation (situation in September 2019).</p> <p>The Finnish Genome Center will be an independent unit in contact with National Institute for Health and Welfare (THL).</p> <p>Currently no public omics metadata have been released, but possibilities for the standardised description and release will rapidly increase after the Finnish Genome Center is established. The referral period was until July 2019.</p>	<p>Currently no public metadata.</p> <p>Possibilities for the description and release of omics metadata will rapidly increase when the Finnish Genome Center is established.</p>	<p>Currently no public metadata.</p> <p>Possibilities for the description and release of omics metadata will rapidly increase when the Finnish Genome Center is established.</p>	<p>Currently no public metadata.</p> <p>Possibilities for the description and release of omics metadata will rapidly increase when the Finnish Genome Center is established.</p>
	NO				