

## SPHN Semantic Interoperability Framework compliance and process for Data Transfer Requests (DTRs)

The National Data Streams (NDS) and Demonstrator Projects (DEM) are the first SPHN projects that will operate fully within the SPHN Semantic Interoperability Framework. The Project Schema creation and the process for Data Transfer Requests (DTRs) need to be done in a harmonized manner to ensure a smooth collaboration between the project teams, the central Data Coordination Center (DCC) teams, and the data-providing institutions. The following is a list of steps for the preparation of the project RDF Schema and external terminologies, de-identification rules as well as the workflow for the DTRs in SPHN projects elaborated together with representatives of the University Hospitals and SPHN projects.

Version 2, 15<sup>th</sup> November 2023

1. Preparatory steps

	Task	Responsibility	Comment
A	<b>Set up of <u>Git Group</u></b> (Git group for each project) Assign a maintainer to manage the project's Git group and user permission	NDS/DEM, (DCC)	
	Ensure that all necessary persons have access to the project's Git group (project members, DPs / UHs personnel, such as DP coordinators, data engineers, project coordinators, etc.)	NDS/DEM	
в	Project RDF Schema		
	Design semantic concepts and submit proposals to the DCC (PDF files using the <u>Templates</u> provided by DCC, following the <u>Guiding principles</u> )	NDS/DEM, (DP, RDF Support)	Can be an iterative process
	Receive feedback on concepts (Word files)	DCC	
	Implement feedback and resubmit to DCC until an agreement is reached	NDS/DEM, (RDF Support)	
	Integrate concepts into the project Dataset tem- plate (Template, User guide, Training)	NDS/DEM, (RDF Support)	
	Generate RDF (.ttl), SHACL, SPARQLs, and HTML using <u>Schema Forge</u> ; upload documents on project Git (Git group)	NDS/DEM, (RDF Support)	
	Folder structure and naming Group Project Name Repository*: "rdf-schema" (* Public) – Folder: "version-1"		A strict adherence to the folder struc- ture is necessary so that the SPHN Connector can di- rectly access the







documents describing the concepts)       Future         - Subfolder "shact" (optional, only needed if SHACLs are manually adapted)       Future         - Subfolder "spargl" (optional)       NDS/DEM         - Subfolder "sourcestore       NDS/DEM         - Subfolder "sourcestore       NDS/DEM         - Folder: "version-2"       NDS/DEM         Add tag "Release-candidate-schema- <project- name&gt;-syear&gt;-version&gt;" to the repository       NDS/DEM         Review of the documents       DCC         Add tag "DCC-approved-schema-<project- name&gt;-syear&gt;-version&gt;"       DCC         Group Project to SPHN compliant RDF (User quide. Training)       DCC         Upload in RDF files (.ttl) on project Git (Git proup)       NDS/DEM, (RDF Support)         Group Project Name Repository: "external-terminologies"       NDS/DEM, (RDF Support)         Provide feedback       DCC       Can be an iterativ process         De-identification rules       NDS/DEM       NDS/DEM&lt;</project- </project- </project- </project- </project- </project- </project- 				
name>- <year>-<year>-       Can be an iterative process         Notify the DCC once the schema is ready for review (email to dcc@sib.swiss)       NDS/DEM       Can be an iterative process         Review of the documents       DCC       DCC         Add tag "DCC-approved-schema-<project-name>-<year>-<year>-<year>-<year>-<year>-<year>-       DCC       DCC         Publish the HTML documentation of the schema on the biomedit.ch website       DCC       DCC         C       External Terminologies       NDS/DEM, (RDF Support)       Image: the project to SPHN compliant RDF         Upload in RDF files (.ttl) on project Git (Git group)       NDS/DEM, (RDF Support)       Image: the project Name         Repository: "external-terminologies"       DCC       Can be an iterative process         Provide feedback       DCC       Can be an iterative process         Incorporate feedback       NDS/DEM, (RDF Support)       Process         De-identification rules       NDS/DEM, (RDF Support)       Process         Fill in the document highlighting the required deidentification rules using the template provided deident where the project deriveates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       Sroup Project Name       NDS/DEM         Group Project Name       Repository: "de-identification-rules"       NDS/DEM         U</year></year></year></year></year></year></project-name></year></year>		<ul> <li>documents describing the concepts)</li> <li>Subfolder "schema" (.ttl file of the Project RDF Schema)</li> <li>Subfolder "shacl" (optional, only needed if SHACLs are manually adapted)</li> <li>Subfolder "sparql" (optional)</li> <li>Subfolder "doc" (HTMLfor website docu- mentation of the schema)</li> </ul>		required files in the future
Notify the DCC once the schema is ready for review (email to doc@sib.swiss)       NDS/DEM       Can be an iterative process         Review of the documents       DCC         Add tag "DCC-approved-schema- <project-name>-<pre>-<pre>-<pre>-<pre>-</pre>-</pre>        name&gt;-<pre>-<pre>-<pre>-</pre>        Publish the HTML documentation of the schema on the biomedit.ch website       DCC         C       External Terminologies       DCC         FAIRify and translate external terminologies used in the project to SPHN compliant RDF (User quide, Training)       NDS/DEM, (RDF Support)         Upload in RDF files (.ttl) on project Git (Git group)       NDS/DEM, (RDF Support)         Group Project Name       DCC         Repository: "external-terminologies"       NDS/DEM, (RDF Support)         De-identification rules       NDS/DEM, (RDF Support)         Fill in the document highlighting the required de-identification rules using the template provided by the DCC. For all rules where the project derivates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM       NDS/DEM         Group Project Name       Repository: "de-identification-rules"       NDS/DEM         Provide feedback       DCC       Can be an iterative process         Upload the filled template on project Git (Git group)       NDS/DEM       NDS/DEM         Provide feedback</pre></pre></pre></pre></project-name>			NDS/DEM	
Add tag "DCC-approved-schema- <project- name&gt;-<year>-<version>"       DCC         Publish the HTML documentation of the schema on the biomedit.ch website       DCC         C       External Terminologies         FAIRify and translate external terminologies used in the project to SPHN compliant RDF (User guide, Training)       NDS/DEM, (RDF Support)         Upload in RDF files (.ttl) on project Git (Git group)       NDS/DEM, (RDF Support)         Group Project Name Repository: "external-terminologies"       DCC         Provide feedback       DCC         Incorporate feedback       DCC         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM         Group Project Name Repository: "de-identification-rules"       NDS/DEM         Provide feedback       DCC         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM         Provide feedback       DCC       Can be an iterative process         Provide feedback       DCC       Can be an iterative p</version></year></project- 		Notify the DCC once the schema is ready for re-	NDS/DEM	Can be an iterative process
name>- <year>-<version>"       DCC         Publish the HTML documentation of the schema on the biomedit.ch website       DCC         C       External Terminologies       NDS/DEM, (RDF Support)         used in the project to SPHN compliant RDF (User guide, Training)       NDS/DEM, (RDF Support)         Upload in RDF files (.ttl) on project Git (Git group)       NDS/DEM, (RDF Support)         Group Project Name Repository: "external-terminologies"       DCC         Provide feedback       DCC         Incorporate feedback       DCC         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM         Group Project Name Repository: "de-identification-rules"       NDS/DEM         Provide feedback       DCC         C. For all rules where the project Git (Git group)       NDS/DEM         Group Project Name Repository: "de-identification-rules"       NDS/DEM         Provide feedback       DCC       Can be an iterativ process         Provide feedback       DCC       Can be an iterativ process         In case any rules are deviating from the default, DCC       DCC   </version></year>		Review of the documents	DCC	
Publish the HTML documentation of the schema on the biomedit.ch website       DCC         C       External Terminologies       NDS/DEM, (RDF Support)         Sector and the project to SPHN compliant RDF (User quide, Training)       NDS/DEM, (RDF Support)         Upload in RDF files (.ttl) on project Git (Git group)       NDS/DEM, (RDF Support)         Group Project Name Repository: "external-terminologies"       DCC         Provide feedback       DCC       Can be an iterative process         Incorporate feedback       DCC       Can be an iterative process         D       De-identification rules       NDS/DEM         Fill in the document highlighting the required deridentification rules using the template provided by the DCC. For all rules where the project derivates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM       NDS/DEM         Group Project Name Repository: "de-identification-rules"       NDS/DEM       NDS/DEM			DCC	
FAIRify and translate external terminologies used in the project to SPHN compliant RDF (User guide, Training)       NDS/DEM, (RDF Support)         Upload in RDF files (.ttl) on project Git (Git group)       NDS/DEM, (RDF Support)         Group Project Name Repository: "external-terminologies"       NDS/DEM, (RDF Support)         Provide feedback       DCC       Can be an iterative process         D De-identification rules       NDS/DEM, (RDF Support)         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM       NDS/DEM         Group Project Name Repository: "de-identification-rules"       NDS/DEM       NDS/DEM         Provide feedback       DCC       Can be an iterative process         Upload the filled template on project Git (Git group)       NDS/DEM       NDS/DEM         Provide feedback       DCC       Can be an iterative process         Provide feedback       DCC       Can be an iterative process         Incorporate feedback       NDS/DEM       process			DCC	
FAIRify and translate external terminologies used in the project to SPHN compliant RDF (User guide, Training)       NDS/DEM, (RDF Support)         Upload in RDF files (.ttl) on project Git (Git group)       NDS/DEM, (RDF Support)         Group Project Name Repository: "external-terminologies"       NDS/DEM, (RDF Support)         Provide feedback       DCC       Can be an iterative process         D De-identification rules       NDS/DEM, (RDF Support)         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM       NDS/DEM         Group Project Name Repository: "de-identification-rules"       NDS/DEM       NDS/DEM         Provide feedback       DCC       Can be an iterative process         Upload the filled template on project Git (Git group)       NDS/DEM       NDS/DEM         Provide feedback       DCC       Can be an iterative process         Provide feedback       DCC       Can be an iterative process         Incorporate feedback       NDS/DEM       process	C	External Terminologies		
group)       Group Project Name         Repository: "external-terminologies"       DCC         Provide feedback       DCC         Incorporate feedback       NDS/DEM, (RDF Support)         process       Provide feedback         De-identification rules       NDS/DEM, (RDF Support)         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM         Group Project Name       Repository: "de-identification-rules"         Provide feedback       DCC       Can be an iterative process         Incorporate feedback       DCC       Can be an iterative process         Incorporate feedback       DCC       Can be an iterative process         In case any rules are deviating from the default,       DCC       Can be an iterative process		FAIRify and translate external terminologies used in the project to SPHN compliant RDF ( <u>User guide, Training</u> )	NDS/DEM, (RDF Support)	
Incorporate feedback       NDS/DEM, (RDF Support)       process         D       De-identification rules       NDS/DEM       Process         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM       Image: Complex of the template on project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM       Image: Complex of template on project deri- vates from the default rules, provide a reason       NDS/DEM         Upload the filled template on project Git (Git group)       Group Project Name Repository: "de-identification-rules"       NDS/DEM       Image: Complex of template on project feedback         Incorporate feedback       DCC       Can be an iterative process         In case any rules are deviating from the default, In case any rules are deviating from the default,       DCC		group) Group Project Name		
D       De-identification rules       NDS/DEM, (RDF Support)         Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.       NDS/DEM         Upload the filled template on project Git (Git group)       NDS/DEM         Group Project Name Repository: "de-identification-rules"       DCC       Can be an iterative process         Incorporate feedback       NDS/DEM       process		Provide feedback	DCC	Can be an iterative
Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.NDS/DEMUpload the filled template on project Git (Git group)NDS/DEMNDS/DEMGroup Project Name Repository: "de-identification-rules"DCCCan be an iterative processIncorporate feedbackNDS/DEMProvides an iterative processIn case any rules are deviating from the default,DCCCan be an iterative		Incorporate feedback	NDS/DEM, (RDF Support)	process
Fill in the document highlighting the required de- identification rules using the template provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason why this is needed.NDS/DEMUpload the filled template on project Git (Git group)NDS/DEMNDS/DEMGroup Project Name Repository: "de-identification-rules"DCCCan be an iterative processIncorporate feedbackNDS/DEMProvides an iterative processIn case any rules are deviating from the default,DCCCan be an iterative	D	De-identification rules		
group)       Group Project Name         Repository: "de-identification-rules"         Provide feedback       DCC         Incorporate feedback       NDS/DEM         In case any rules are deviating from the default,       DCC		identification rules using the <u>template</u> provided by the DCC. For all rules where the project deri- vates from the default rules, provide a reason	NDS/DEM	
Repository: "de-identification-rules"       DCC       Can be an iterative process         Incorporate feedback       NDS/DEM       process         In case any rules are deviating from the default,       DCC       Con be an iterative process			NDS/DEM	
Incorporate feedback     NDS/DEM     process       In case any rules are deviating from the default,     DCC     In case				
In case any rules are deviating from the default, DCC		Provide feedback	DCC	Can be an iterative
		Incorporate feedback	NDS/DEM	process
UHs via HIT-STAG		approval of hospitals is needed. DCC to contact	DCC	

HIT-STAG representatives are responsible to check hospital internally according to the hospital internal processes.	DP	
In case hospitals do not agree with the de-identi- fication rules, adapt accordingly	NDS/DEM	

## 2. Data Transfer Requests (DTRs)

Step	Task	Respon- sibility	Comment
1	Create the technical Data Transfer Requests in the <u>BioMedIT Por-</u> tal ( <u>Work instruction</u> , one per data providing institution)	NDS/DEM	Attention: New pro- cess! The individ- ual DTRs should not be approved by the DP until step 8 of this DTR work- flow is com- pleted
2	Evaluate the legal situation (is the DTUA signed?), approval of DTR	DCC (ELSI- Helpdesk)	
3	<ul> <li>Prepare the following documents and upload them on the Git (Git group for all projects):</li> <li>Data transfer specification (see template below)</li> <li>Cohort specification (e.g., use Excel template file from Project submission plus additional information if needed)</li> <li>Reused SPHN concepts (csv extracted from the <u>Confluence</u>, include only concepts you want to request in this DTR, including additional information e.g., Scores or Lab tests, additional comments like e.g., mandatory for the project, specific subsets of code to be delivered)</li> <li>Requested project concepts (csv; optional; include only concepts you want to request in this DTR, since your schema may contain concepts not relevant for all data providers, e.g., omics concepts or cohort concepts may not be requested from a UH)</li> <li>Folder structure and naming</li> <li>Group Project Name</li> <li>Repository: "data-transfer"</li> <li>Folder: "data-transfer specification</li> <li>Technical DTR IDs from the BioMedIT Portal:</li> <li>Status (in preparation/active/on hold/ stopped)</li> <li>Frequency of data transfers:</li> <li>Timeline:</li> <li>Providers:</li> </ul>	NDS/DEM	A common structure of this folder makes life easier for DP and DCC teams

Swiss Personalized Health Network

**SPHN** 

	<ul> <li>Cohort specification: <i>link to document on Git</i></li> <li>De-identification rules: <i>link to the document on Git</i></li> <li>RDF Schema: <i>link to schema on Git e.g., <u>SPHN</u> <u>2023.2 or LUCID 2023.1</u></i></li> <li>Reused SPHN concepts: <i>link to csv on Git</i></li> <li>Requested project concepts: <i>link to csv on Git</i></li> <li>Comments:</li> </ul> Subfolder: "cohort-specification" Subfolder: "reused-sphn-concepts" <ul> <li>Subfolder: "requested-project-concepts"</li> </ul>		
4	Notify the DCC once the documents are final and ready for evalua-	NDS/DEM	
-	tion: Email to <u>dcc@sib.swiss</u> with reference [NDS/DEM Name and DTR Nr.], containing the link to the GitLab repository.	NDO/DEM	
5	Evaluate the documents	DCC	Can be an it- erative pro- cess together with the NDS/DEM with consul- tancy of HIT- STAG if nec- essary
6	Final approval and notification of NDS/DEM, add tag "DCC-ap- proved-dtr- <number>-<project>"</project></number>	DCC	
7	Communicate to UHs that the current DTR is approved and docu- ments can be accessed on the Git (DP Coordinator, UH-specific project coordinators, NDS/DEM PIs and DM, cc HIT-STAG repre- sentatives)	DCC	
8	Trigger of UH internal (governance) processes, if needed	DP	
9	Approval of the technical DTRs in the BioMedIT Portal by data pro- viders (DP) indicating that DP are ready	DP	This should only be done once all of the above criteria/steps have been met
10	Start of the data transfers	DP	
11	In case a data transfer request is stopped or discontinued change the status in the README. Inform DCC by email dcc@sib.swiss Each change in the specification results in a new Data transfer re- guest on the Git.	NDS/DEM	
	Inform all involved DPs by email	NDS/DEM	

Swiss Personalized Health Network

SPHN



NDS/DEM=National Data Streams/Demonstrator Projects; DP=Data Provider; RDF Support=Data Management / RDF support on the BioMedIT nodes; DCC=Data Coordination Center, DTUA= Data Transfer and Use Agreement, DTR= Data Transfer Requests, UH= University Hospitals.

Example: A full example of a dummy project can be found on the Git (here)