castor

# **FAIRification at the source:** Transform ‘raw’ eCRF data into machine-readable data

Martijn Kersloot

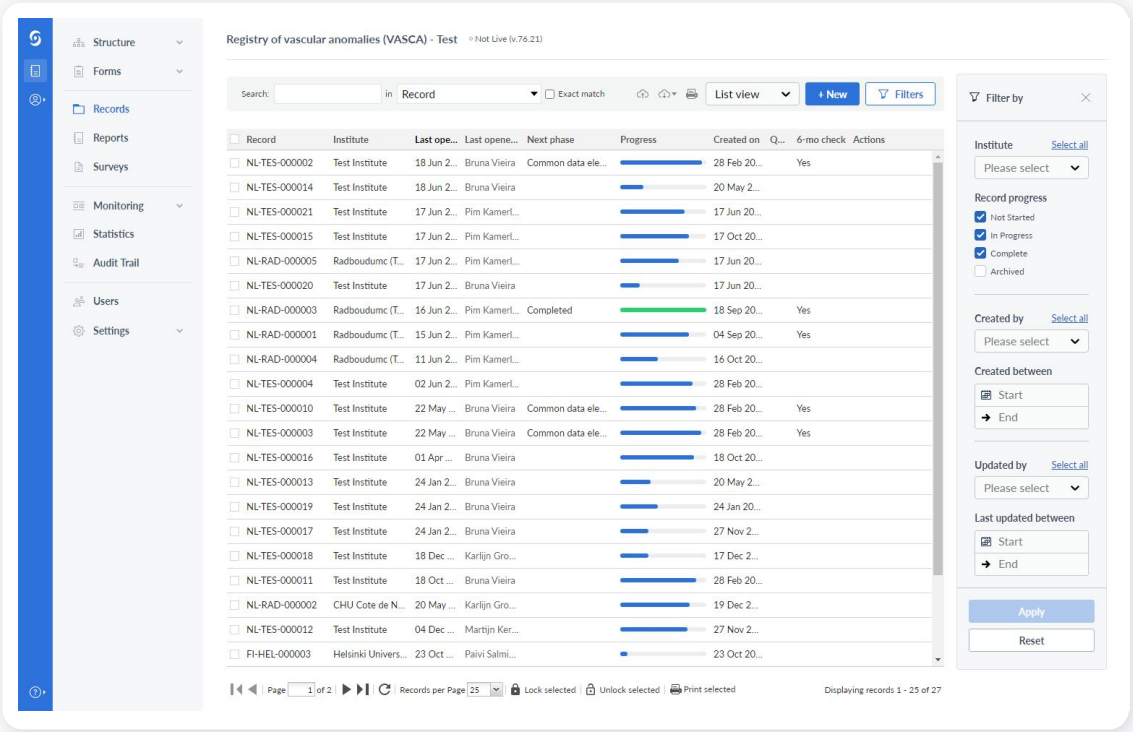
June 23, 2020

# Table of contents

# Castor

## Electronic Data Capture platform

Enabling researchers to easily capture and integrate clinical data from any source in real-time.



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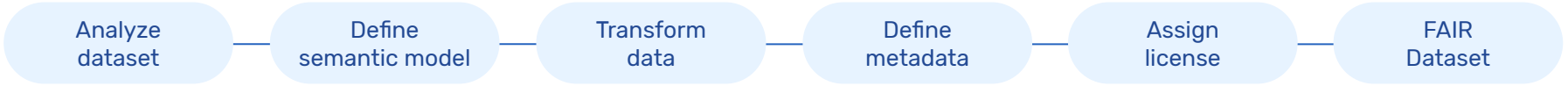


**Based on:** https://www.dtls.nl/fair-data/find-fair-data-tools/

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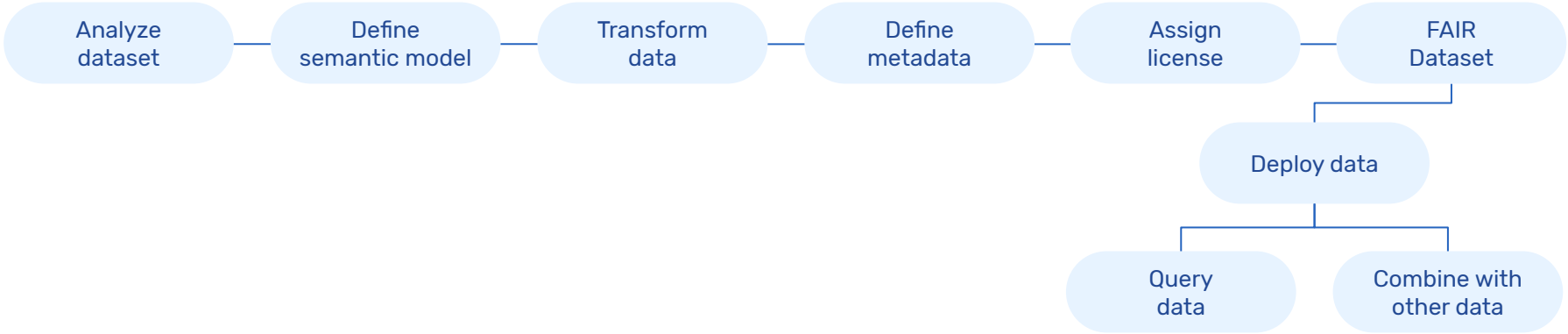


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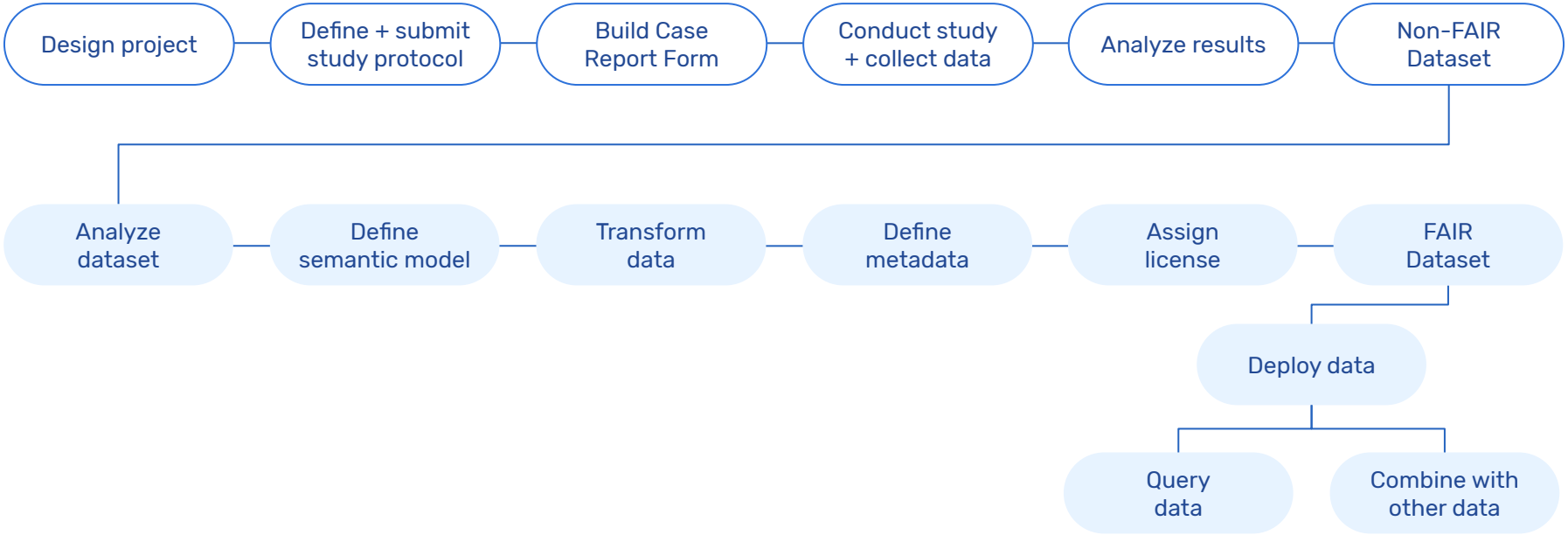


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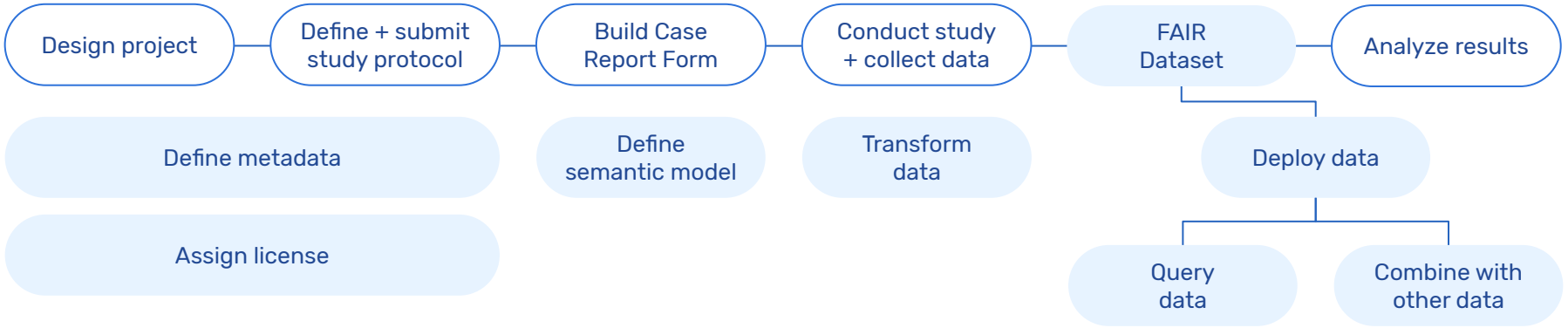


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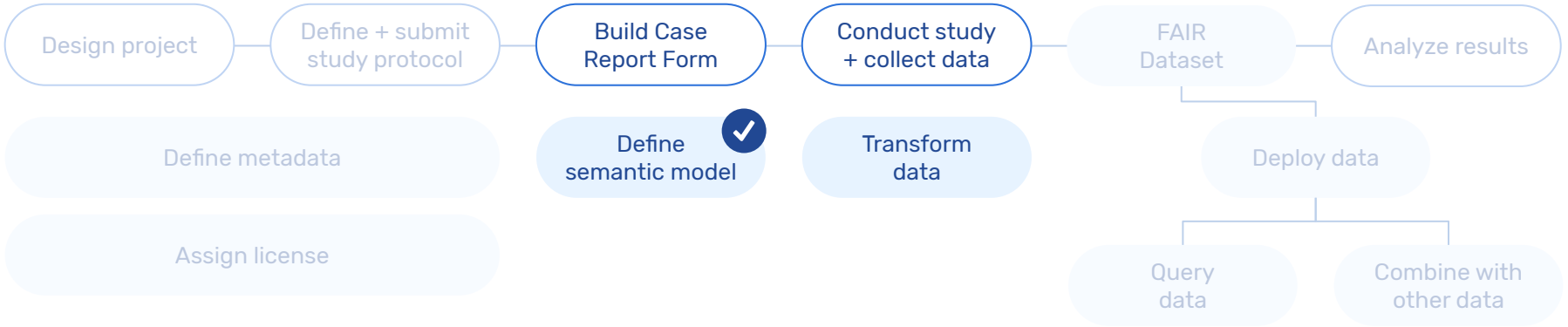


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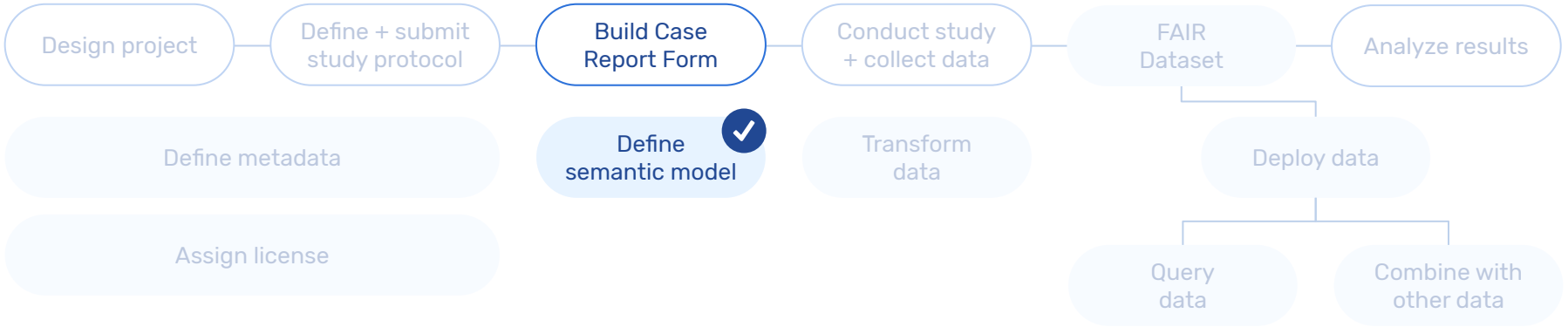



**Based on:** https://www.dtls.nl/fair-data/find-fair-data-tools/

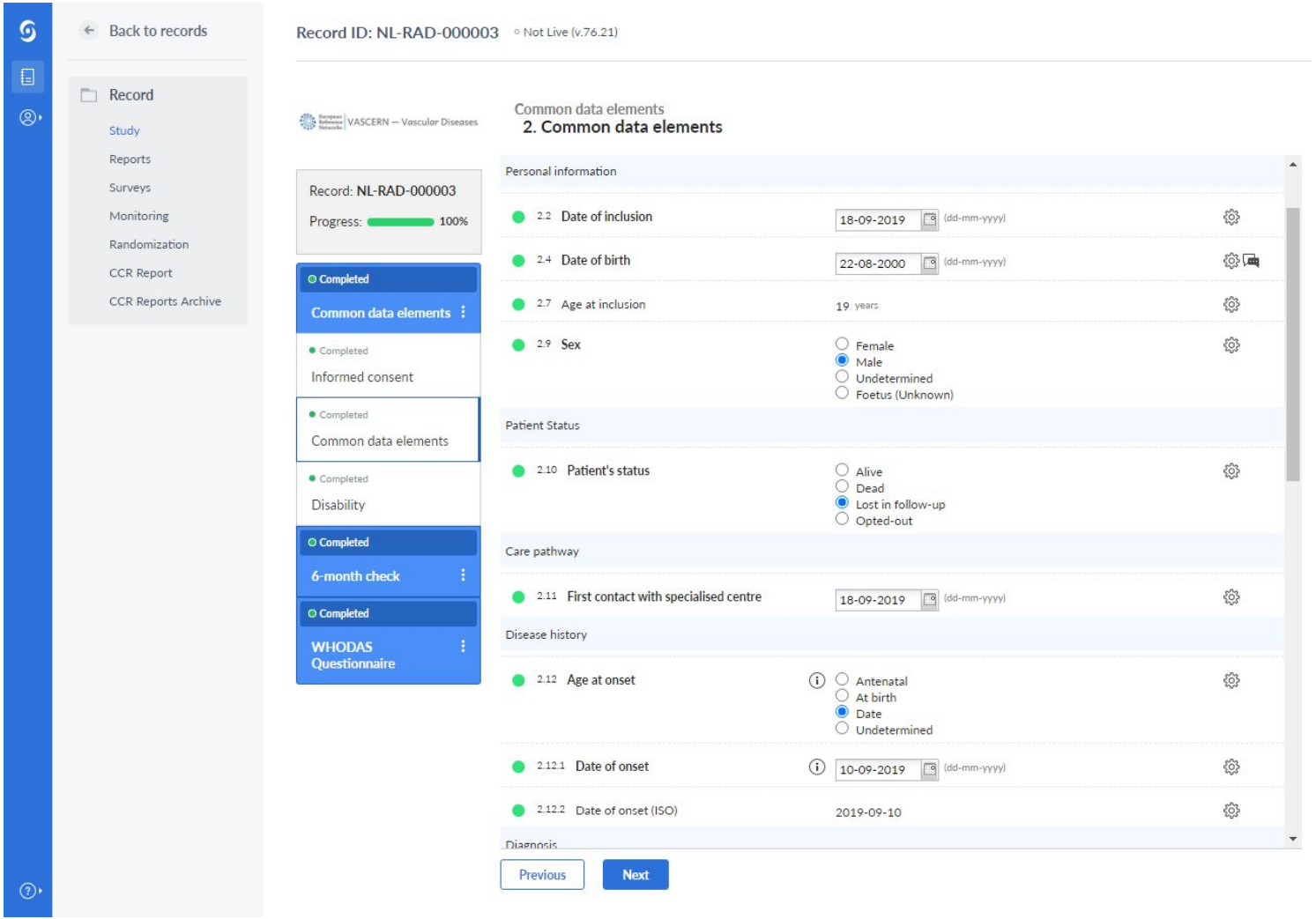
EUROPEAN COMMISSION
JOINT RESEARCH CENTRE
**Directorate F – Health, Consumers and Reference Materials**
**Unit F.1 – Health in Society**

## EUROPEAN PLATFORM ON RARE DISEASE REGISTRATION (EU RD Platform)

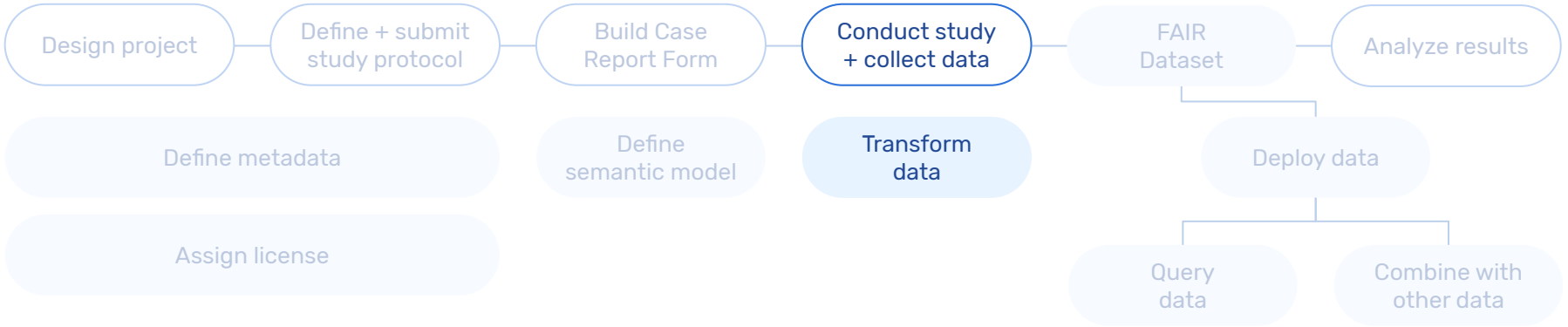
### SET OF COMMON DATA ELEMENTS FOR RARE DISEASES REGISTRATION

| GROUP | ELEMENT N° | ELEMENT NAME | ELEMENT DESCRIPTION | CODING | COMMENT |
|---|---|---|---|---|---|
| 1. Pseudonym | 1.1. | Pseudonym | Patient's pseudonym | • String | https://eu-rd-platform.jrc.ec.europa.eu/erdri/eupid-intro |
| 2. Personal information | 2.1. | Date of birth | Patient's date of birth | • Date (dd/mm/yyyy) | |
| | 2.2. | Sex | Patient's sex at birth | • Female<br>• Male<br>• Undetermined<br>• Foetus (Unknown) | |
| 3. Patient Status | 3.1. | Patient's status | Patient alive or dead | • Alive<br>• Dead<br>• Lost in follow-up<br>• Opted-out | If dead then answer question 3.2 |
| | 3.2. | Date of death | Patient's date of death | • Date (dd/mm/yyyy) | |
| 4. Care pathway | 4.1. | First contact with specialised centre | Date of first contact with specialised centre | • Date (dd/mm/yyyy) | |
| | | | e at which symptoms/signs st appeared | • Antenatal<br>• At birth<br>• Date (dd/mm/yyyy)<br>• Undetermined | |
| | | | e at which diagnosis was ade | • Antenatal<br>• At birth<br>• Date (dd/mm/yyyy)<br>• Undetermined | |
| | | | agnosis retained by the ecialised centre | Orpha code (strongly recommended – see link) / Alpha code/ ICD-9 code/ ICD-9-CM code / ICD-10 code | http://www.orphadata.org/cgi-bin/inc/product1.inc.php |
| | | | netic diagnosis retained by specialised centre | International classification of mutations (HGVS) (strongly recommended – see link) / HGNC / OMIM code | http://www.hgvs.org |
| | | | w the undiagnosed case is fined | • Phenotype (HPO)<br>• Genotype (HGVS) | |
| | | | tient's permission exists for ing contacted for research rposes | • YES<br>• NO | |
| | | | tient's consent exists for /her data to be reused for her research purposes | • YES<br>• NO | |
| | 7.3. | Biological sample | Patient's biological sample available for research | • YES<br>• NO | If YES answer question 7.4 |
| | 7.4. | Link to a biobank | Biological sample stored in a biobank | • YES (if appropriate use link)<br>• NO | https://directory.bbmri-eric.eu |
| | 8.1. | Classification of | Patient's disability profile | • Disability profile / Score | http://www.who.int/classifications |

**Source:** https://eu-rd-platform.jrc.ec.europa.eu/set-of-common-data-elements_en


Back to records
Record
Study
Reports
Surveys
Monitoring
Randomization
CCR Report
CCR Reports Archive
Record ID: NL-RAD-000003
Not Live (v.76.21)
VASCERN — Vascular Diseases
Record: NL-RAD-000003
Progress: 100%
Completed
Common data elements
Completed
Informed consent
Completed
Common data elements
Completed
Disability
Completed
6-month check
Completed
WHODAS Questionnaire
Common data elements
2. Common data elements
Personal information
2.2 Date of inclusion
18-09-2019
(dd-mm-yyyy)
2.4 Date of birth
22-08-2000
(dd-mm-yyyy)
2.7 Age at inclusion
19 years
2.9 Sex
Female
Male
Undetermined
Foetus (Unknown)
Patient Status
2.10 Patient's status
Alive
Dead
Lost in follow-up
Opted-out
Care pathway
2.11 First contact with specialised centre
18-09-2019
(dd-mm-yyyy)
Disease history
2.12 Age at onset
Antenatal
At birth
Date
Undetermined
2.12.1 Date of onset
10-09-2019
(dd-mm-yyyy)
2.12.2 Date of onset (ISO)
2019-09-10
Diagnosis
Previous
Next

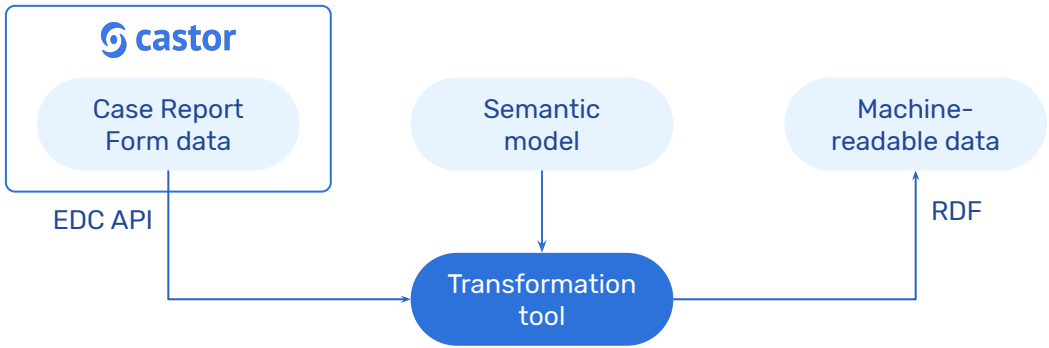
# “FAIR at the source”



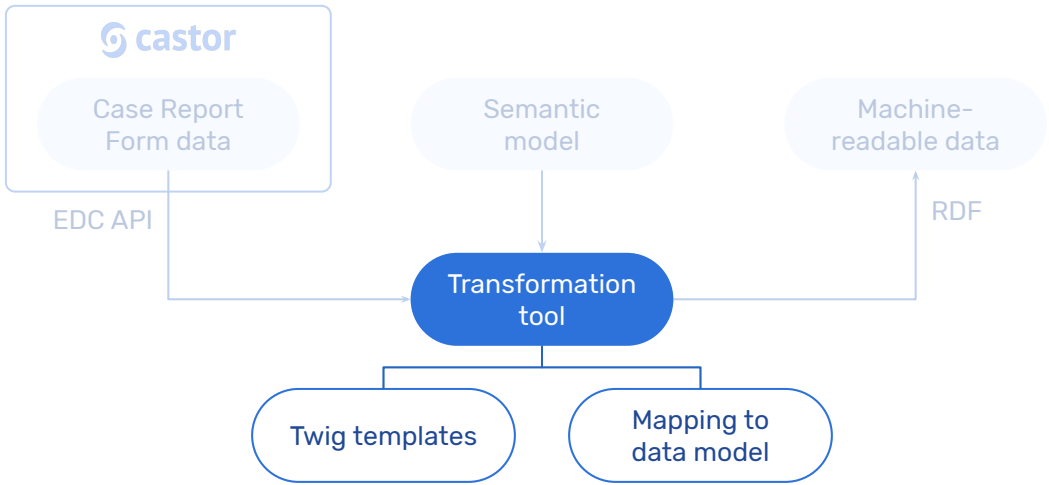

**Based on:** https://www.dtls.nl/fair-data/find-fair-data-tools/

# Transformation of the data

# Transformation of the data



# Transformation of the data



# Transformation tool: Twig templates

- Pilot approach
- Twig: Templating language
    - Algorithm replaces placeholders in document with data

# Transformation tool: Twig templates

```
Hi, my name is {{Name}}
```

```
Name: Martijn
```

```
Hi, my name is Martijn
```

# Transformation tool: Twig templates

- Pilot approach
- Twig: Templating language
    - Algorithm replaces placeholders in document with data
- Example Turtle file filled with placeholders for identifiers and data
- Script fetches data from the eCRF and fills the placeholders for every record

# Transformation tool: Twig templates

```
<…/{{Record.Id}}#person> ero:0001966
<…/{{Record.Id}}#gender> .

<…/{{Record.Id}}#gender> a ncit:C28421;
      sio:000300 {{Record.Data.Sex.Concept}} .
```

```
Record: [
   Id: NL-RAD-00001
   Data: [
      Sex: [
         Concept: snomedct:703117000,
         Value: 1,
         Label: “Male”
      ]
   ]
]
```

```
<…/ NL-RAD-00001 #person> ero:0001966
<…/ NL-RAD-00001 #gender> .

<…/ NL-RAD-00001 #gender> a ncit:C28421;
      sio:000300 snomedct:703117000 .
```

# Transformation tool: Twig templates

- Pilot approach
- Twig: Templating language
    - Algorithm replaces placeholders in document with data
- Example Turtle file filled with placeholders for identifiers and data
- Script fetches data from the eCRF and fills the placeholders for every record

- **Pros:** Easy and fast way to pilot, many implementations available
- **Cons:** Hard to maintain, hard to read, sensitive to errors, not scalable

```
# Module 0: Person
<{{url}}/{{record.id}}#person> a ncbit:9606 ;
      ro:0000087 <{{url}}/{{record.id}}#role> .

<{{url}}/{{record.id}}#role> a obi:0000093 .

# Module 1: Pseudonym
<{{url}}/{{record.id}}#person> iao:0000219 <{{url}}/{{record.id}}#identifier> .

<{{url}}/{{record.id}}#identifier> a rdc-meta:23d2f73b_6bb4_4c8f_af98_a3bb4a1f8e30;
      dct:identifier "{{record.id}}";

# Module 2: Personal information
```

```
{% if record.data.study.FieldResultByVariableName('sex').value != null %}
      <{{url}}/{{record.id}}#person> ero:0001966 <{{url}}/{{record.id}}#gender> .
      <{{url}}/{{record.id}}#gender> a ncit:C28421;
            sio:000300 <{{record.data.study.FieldResultByVariableName('sex').metadata}}> ;
            dct:modified "{{record.data.study.FieldResultByVariableName('sex').updatedOn|date('Y-m-d H:i:s')}}" .
{% endif %}
```

```
{% if record.data.study.FieldResultByVariableName('year_of_birth').value != null %}
      <{{url}}/{{record.id}}#person> sio:000008 <{{url}}/{{record.id}}#birthdate> .
      <{{url}}/{{record.id}}#birthdate> a ncit:C68615;
            sio:000300 {{record.data.study.FieldResultByVariableName('year_of_birth').value}} ;
            dct:modified "{{record.data.study.FieldResultByVariableName('year_of_birth').updatedOn|date('Y-m-d H:i:s')}}" .
{% endif %}
```

```
# Module 3: Patient status
```

```
{% if record.data.study.FieldResultByVariableName('status').value != null %}
      <{{url}}/{{record.id}}#person> sio:000008 <{{url}}/{{record.id}}#status> .
      <{{url}}/{{record.id}}#status> a ncit:C25688 ;
            sio:000300 <{{record.data.study.FieldResultByVariableName('status').metadata}}> ;
            dct:modified "{{record.data.study.FieldResultByVariableName('status').updatedOn|date('Y-m-d H:i:s')}}" .

        {% if record.data.study.FieldResultByVariableName('status').label == 'Dead'
           and record.data.study.FieldResultByVariableName('date_of_death').value != null %}
            <{{url}}/{{record.id}}#status> sio:000008 <{{url}}/{{record.id}}#deathdate> .
            <{{url}}/{{record.id}}#deathdate> a ncit:C70810 ;
                  sio:000008 {{record.data.study.FieldResultByVariableName('date_of_death').value}} ;
                  dct:modified "{{record.data.study.FieldResultByVariableName('date_of_death').updatedOn|date('Y-m-d
            H:i:s')}}" .
        {% endif %}

{% endif %}
```

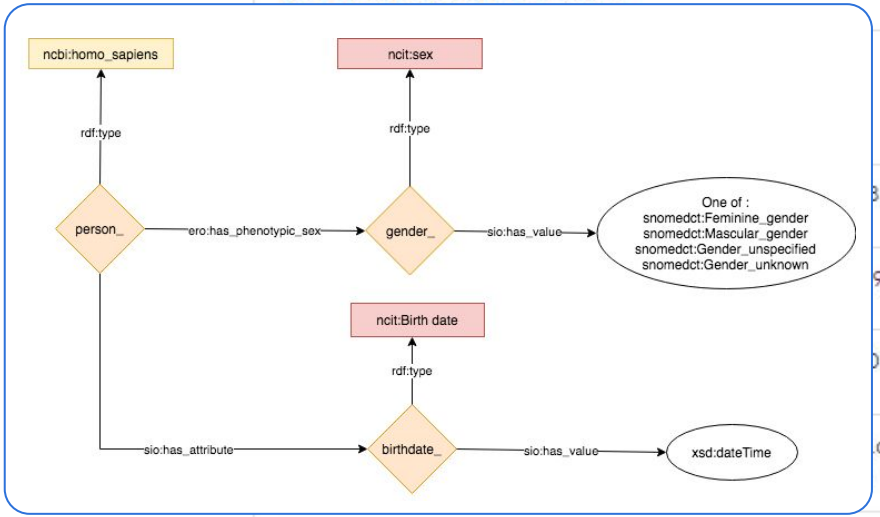
# Transformation tool: Mapping to model

- Current approach
- Import or recreate data model in transformation tool
    - Mark specific ‘value nodes’ in data model that should be filled with a value from the eCRF

## Module 3. Personal information

Edit module | + Add triple

| Subject | Predicate | Object |
| --- | --- | --- |
| Record | sio:SIO_000008 | Birth date /birthdate |
| | obo:ERO_0001966 | Gender /gender |
| Birth date /birthdate | sio:SIO_000300 | Date of birth Plain value (date) |
| | http://www.w3.org/1999/02/22-rdf-syntax-ns#type | Birth date obo:NCIT_C68615 |
| Gender /gender | sio:SIO_000300 | Gender Annotated value |
| | http://www.w3.org/1999/02/22-rdf-syntax-ns#type | Sex obo:NCIT_C28421 |




Module 3. Personal information

Edit module

+ Add triple

Object

Birth date
/birthdate

966

Gender
/gender

Date of birth
Plain value (date)

org/1999/02/22-rdf-

Birth date
obo:NCIT_C68615

Gender
/gender

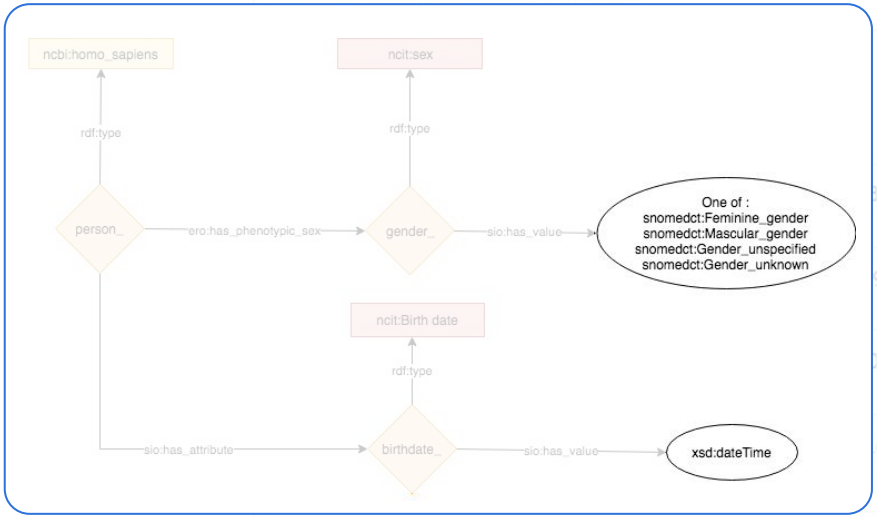
sio:SIO_000300

Gender
Annotated value

http://www.w3.org/1999/02/22-rdf-syntax-ns#type

Sex
obo:NCIT_C28421

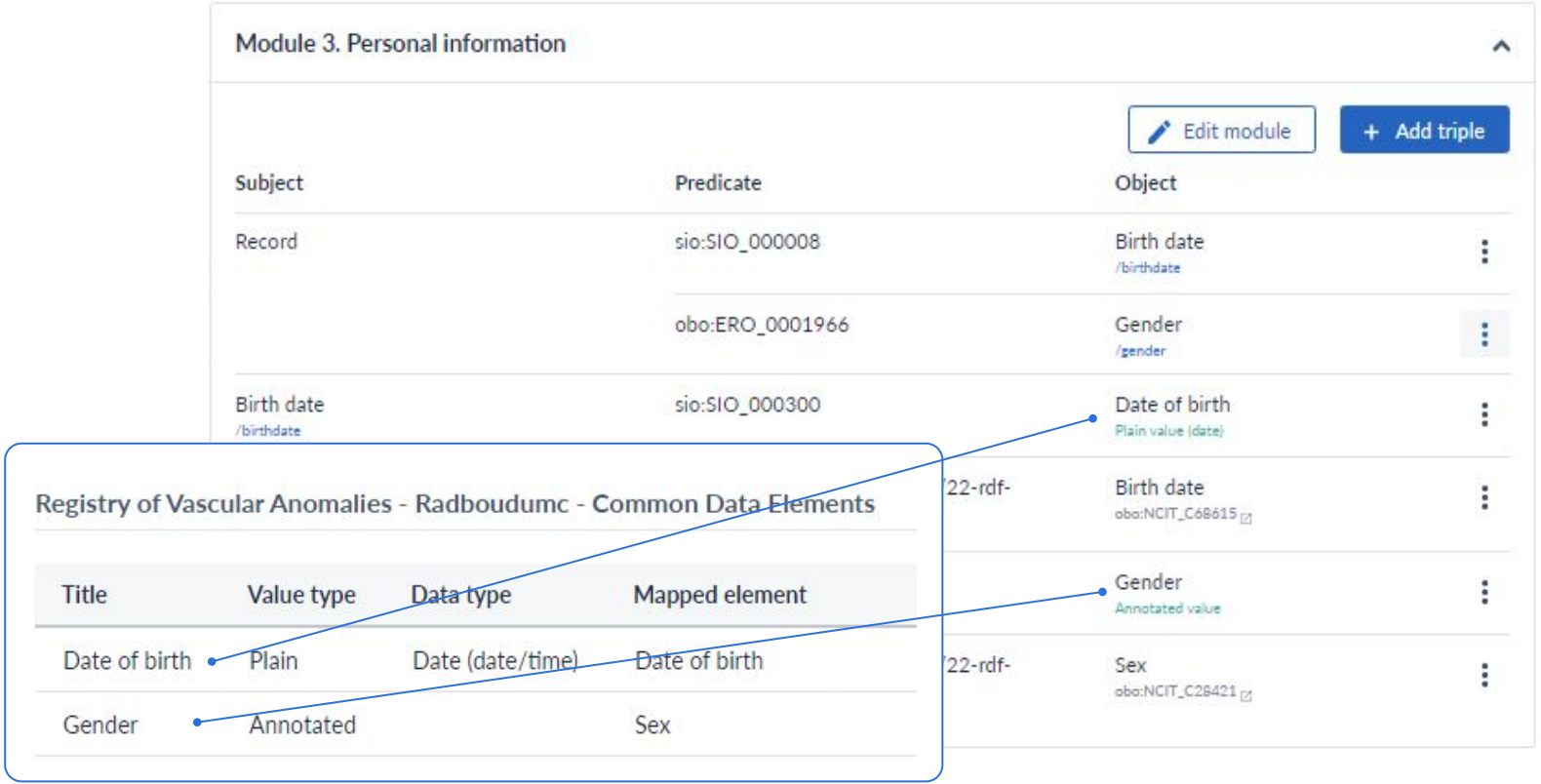
**Source:** https://github.com/ejp-rd-vp/ERN-common-data-elements/wiki/Personal-information

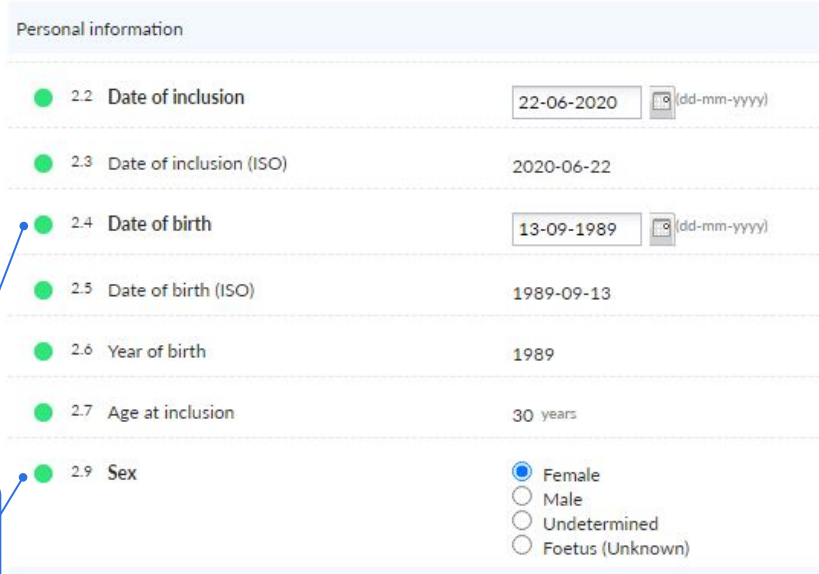



Source: https://github.com/ejp-rd-vp/ERN-common-data-elements/wiki/Personal-information

# Transformation tool: Mapping to model

- Current approach
- Import or recreate data model in transformation tool
    - Mark specific ‘value nodes’ in data model that should be filled with a value from the eCRF
- Map question on eCRF to node in data model


Module 3. Personal information
Edit module
+ Add triple
Subject
Predicate
Object
Record
sio:SIO_000008
Birth date
/birthdate
obo:ERO_0001966
Gender
/gender
Birth date
/birthdate
sio:SIO_000300
Date of birth
Plain value (date)
Birth date
obo:NCIT_C68615
Gender
Annotated value
Sex
obo:NCIT_C28421
Registry of Vascular Anomalies - Radboudumc - Common Data Elements
Title
Value type
Data type
Mapped element
Date of birth
Plain
Date (date/time)
Date of birth
Gender
Annotated
Sex




## Registry of Vascular Anomalies - Radboudumc - Common Data Elements

| Title | Value type | Data type | Mapped element |
|---|---|---|---|
| Date of birth | Plain | Date (date/time) | Date of birth |
| Gender | Annotated | | Sex |

ERN Common Data Elements

## Full data model

```
@prefix obo: <http://purl.obolibrary.org/obo/> .
@prefix sio: <http://semanticscience.org/resource/> .

</Record ID>
  obo:RO_0000087 </Record ID/role> ;
  a obo:NCBITaxon_9606 ;
  obo:ERO_0001966 </Record ID/gender> ;
  sio:SIO_000008 </Record ID/birthdate> .

</Record ID/role> a obo:RO_0000093 .
</Record ID/birthdate> sio:SIO_000300 "Plain value of Date of birth (dateTime)" .
</Record ID/gender> sio:SIO_000300 <Annotated value of Gender> .
```

## Module 1. Person

## Module 2. Pseudonym

## Module 3. Personal information

# Transformation tool: Mapping to model

- Current approach
- Import or recreate data model in transformation tool
    - Mark specific ‘value nodes’ in data model that should be filled with a value from the eCRF
- Map question on eCRF to node in data model
- Script fetches data from the eCRF, creates RDF using model and adds ‘value nodes’ for eCRF data

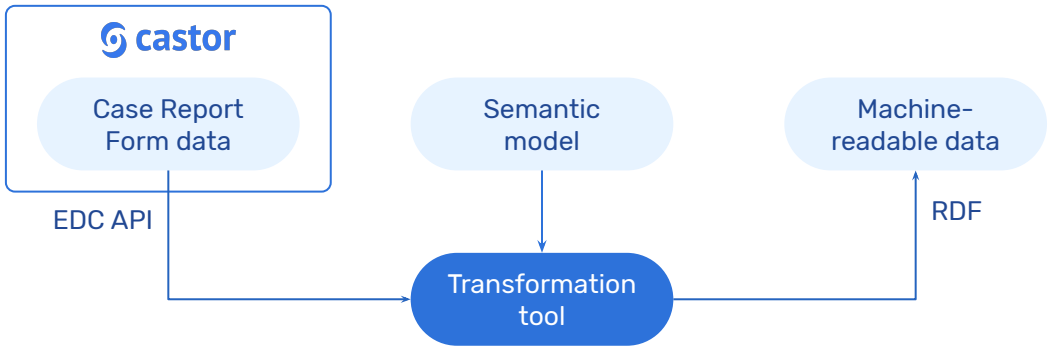
```
@prefix rdf: <http://www.w3.org/1999/02/22-rdf-syntax-ns#> .
@prefix obo: <http://purl.obolibrary.org/obo/> .
@prefix sio: <http://semanticscience.org/resource/> .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/BE-STL-000001> obo:RO_0000087 <https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/BE-STL-000001/role> ;
                                                                                                  rdf:type obo:NCBITaxon_9606 ;
                                                                                                  obo:ERO_0001966 <https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/BE-STL-000001/gender> ;
                                                                                                  sio:SIO_000008 <https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/BE-STL-000001/birthdate> .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/BE-STL-000001/role> rdf:type obo:RO_0000093 .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/BE-STL-000001/birthdate> sio:SIO_000300 "2015-07-21T00:00:00"^^<http://www.w3.org/2001/XMLSchema#dateTime> ;
                                                                                                            rdf:type obo:NCIT_C68615 .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/BE-STL-000001/gender> sio:SIO_000300 <http://purl.bioontology.org/ontology/SNOMEDCT/703118005> ;
                                                                                                       rdf:type obo:NCIT_C28421 .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/ES-HCP-000001> obo:RO_0000087 <https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/ES-HCP-000001/role> ;
                                                                                                  rdf:type obo:NCBITaxon_9606 ;
                                                                                                  obo:ERO_0001966 <https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/ES-HCP-000001/gender> ;
                                                                                                  sio:SIO_000008 <https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/ES-HCP-000001/birthdate> .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/ES-HCP-000001/role> rdf:type obo:RO_0000093 .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/ES-HCP-000001/birthdate> sio:SIO_000300 "1992-08-27T00:00:00"^^<http://www.w3.org/2001/XMLSchema#dateTime> ;
                                                                                                            rdf:type obo:NCIT_C68615 .

<https://fdp.castoredc.com/fdp/dataset/radboudumc/distribution/radboudumc-cde/rdf/ES-HCP-000001/gender> rdf:type obo:NCIT_C28421 .
```

# Transformation tool: Mapping to model

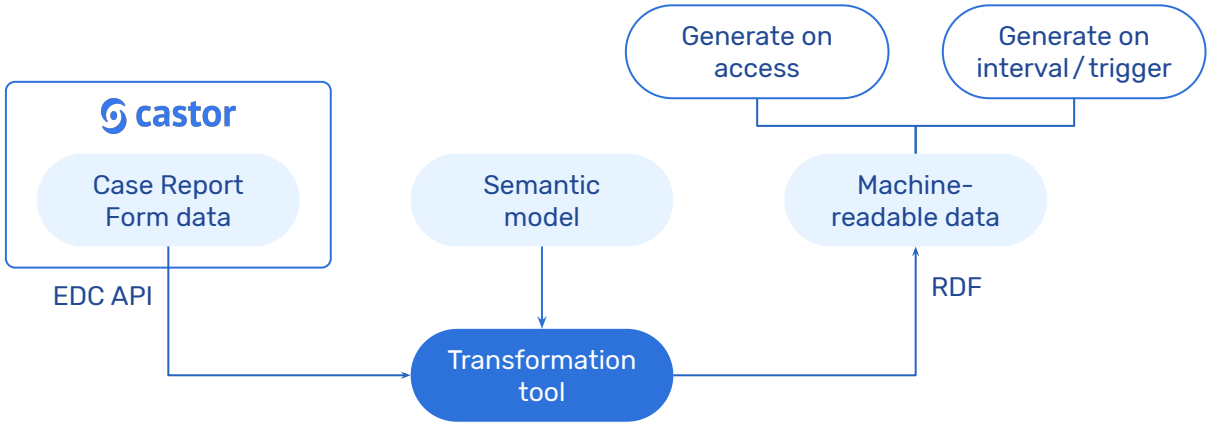
- Current approach
- Import or recreate data model in transformation tool
    - Mark specific ‘value nodes’ in data model that should be filled with a value from the eCRF
- Map question on eCRF to node in data model
- Script fetches data from the eCRF, creates RDF using model and adds ‘value nodes’ for eCRF data

- **Pros:** Scalable, clear overview of triples, easy to maintain, RDF validation on generation
- **Cons:** Initially harder to set up

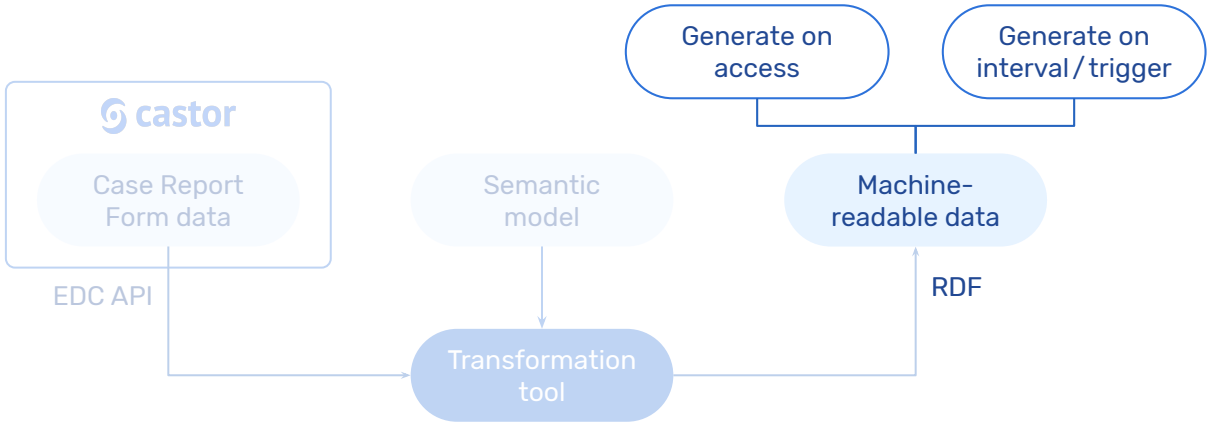
# Transformation of the data



# Transformation of the data



# Transformation of the data



# Storage approaches: Generate on access

- Generate RDF when end-user tries to access the data
- **Pros:**
  - Secure: data is stored in the EDC platform only
  - No need for additional access control: EDC platform handles authorization
  - Easier to maintain: no additional servers or services needed
- **Cons:**
  - Not possible to query: data is not stored in a Triple store
    - Data has to be imported into local Triple store before it can be queried
  - Slow: Data from all patients has to be loaded from the EDC platform

# Storage approaches: Store and generate on interval/trigger

- Generate RDF with interval (every X min. / …) or trigger (manual / data is updated / …)
- **Pros:**
  - Fast: Data is ‘cached’ and can be accessed immediately
  - Data can be loaded selectively: only import EDC records when data is changed
  - Possible to query the data
- **Cons:**
  - Security: data is stored in the EDC and in the triple store
    - Tool needs access to the data (API user)
    - Access control implementation needed (own / let EDC handle access control)
  - Additional servers or services needed

```
RDF Generator
============
Last import:     2020-06-20T14:06:19+00:00
URI:             https://fdp.castoredc.com/fdp/dataset/vasca-test-5ee8c8b9145a2/distribution/testcde2/rdf
API user:        <martijn+fdp@castoredc.com>
RDF Store:       current
Records found:   3 record(s)

- Record 110001 is not changed since last import
- Record 110002 is not changed since last import
- Record 110003 is changed since last import
    - Removing old render for record 110003
    - Rendering record 110003
    - Saving record to <https://fdp.castoredc.com/fdp/dataset/vasca-test-5ee8c8b9145a2/distribution/testcde2/rdf/g/110003>

Import finished
- 1 record(s) imported
- 2 record(s) skipped
```

# Demo

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# Query Registry of Vascular Anomalies - Radboudumc - Common Data Elements



```
PREFIX xsd: <http://www.w3.org/2001/XMLSchema#>
PREFIX rdf: <http://www.w3.org/1999/02/22-rdf-syntax-ns#>
PREFIX rdfs: <http://www.w3.org/2000/01/rdf-schema#>
PREFIX sio: <http://semanticscience.org/resource/>
PREFIX obo: <http://purl.obolibrary.org/obo/>

SELECT ?patient ?birthdate ?gender WHERE {
  ?patient a obo:NCBITaxon_9606 ;
  sio:SIO_000008 ?birthdate_node ;
  obo:ERO_0001966 ?gender_node .

  ?birthdate_node a obo:NCIT_C68615 ;
           sio:SIO_000300 ?birthdate .

  ?gender_node a obo:NCIT_C28421 ;
           sio:SIO_000300 ?gender .

  FILTER (?birthdate < "2000"^^xsd:gYear)
}
```

9 results in 0.10 seconds

Hide query editor

Run query

| patient | birthdate | gender |
|---|---|---|
| :FI-HEL-000002 | 1998-10-15T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-RAD-000001 | 1988-08-17T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000004 | 1984-06-25T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000010 | 1960-12-14T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000011 | 1998-08-18T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000015 | 1985-11-13T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000016 | 1990-10-18T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000019 | 1994-01-11T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000021 | 1997-09-15T00:00:00 ^^xsd:dateTime | snomedct:703117000 |

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# Query Registry of Vascular Anomalies - Radboudumc - Common Data Elements



```
PREFIX xsd: <http://www.w3.org/2001/XMLSchema#>
PREFIX rdf: <http://www.w3.org/1999/02/22-rdf-syntax-ns#>
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PREFIX sio: <http://semanticscience.org/resource/>
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SELECT ?patient ?birthdate ?gender WHERE {
  ?patient a obo:NCBITaxon_9606 ;
  sio:SIO_000008 ?birthdate_node ;
  obo:ERO_0001966 ?gender_node .

  ?birthdate_node a obo:NCIT_C68615 ;
           sio:SIO_000300 ?birthdate .

  ?gender_node a obo:NCIT_C28421 ;
           sio:SIO_000300 ?gender .

  # FILTER (?birthdate < "2000"^^xsd:gYear)
}
```

16 results in 0.17 seconds

Hide query editor

Run query

| patient | birthdate | gender |
|---|---|---|
| :BE-STL-000001 | 2015-07-21T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :FI-HEL-000002 | 1998-10-15T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-RAD-000001 | 1988-08-17T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-RAD-000002 | 2000-05-19T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-RAD-000003 | 2000-08-22T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-RAD-000005 | 2002-01-09T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000002 | 2019-05-20T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000003 | 2005-02-04T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000004 | 1984-06-25T00:00:00 ^^xsd:dateTime | snomedct:703117000 |

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# Query Registry of Vascular Anomalies - Radboudumc - Common Data Elements



**16** results in **0.17** seconds

Show query editor

Run query

| patient | birthdate | gender |
|---|---|---|
| :BE-STL-000001 | 2015-07-21T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :FI-HEL-000002 | 1998-10-15T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-RAD-000001 | 1988-08-17T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-RAD-000002 | 2000-05-19T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-RAD-000003 | 2000-08-22T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-RAD-000005 | 2002-01-09T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000002 | 2019-05-20T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000003 | 2005-02-04T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000004 | 1984-06-25T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000010 | 1960-12-14T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000011 | 1998-08-18T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000012 | 2005-02-16T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000015 | 1985-11-13T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000016 | 1990-10-18T00:00:00 ^^xsd:dateTime | snomedct:703118005 |
| :NL-TES-000019 | 1994-01-11T00:00:00 ^^xsd:dateTime | snomedct:703117000 |
| :NL-TES-000021 | 1997-09-15T00:00:00 ^^xsd:dateTime | snomedct:703117000 |

# Next steps

- Improve the mapping interface and algorithm
  - Repeated data
- Open up the mapping tool to end users

# Summary

- “FAIR at the source” should be incorporated in the research process / process of setting up a registry
- Castor has worked with the Registry of Vascular Anomalies to generate FAIR Data at the source (the eCRF)
    - Conversion approaches: Twig templates and Data model mapping
    - Storage approaches: Generate on access (none) and Generate on interval (store)
- The FAIR eCRF data can be accessed and queried using a FAIR Data Point
- Taking next steps to make this broadly available

# castor

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