# Privacy-aware analytics on healthcare data

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HL7 Security Workgroup Meeting

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SEVENTH FRAMEWORK PROGRAMME

PORTAVITA Networked Health

AXLE

Amsterdam,
The Netherlands

Health IT supplier

European research projects:
- COMMODITY12
- **AXLE**

Chronic diseases:
- diabetes
- anticoagulation
- pulmonary diseases
...

Actively participating in
HL7, IHE, CIMI

PORTAVITA
Networked Health

10+ years experience in
SaaS / eHealth / Telemedicine

70 medical organizations

Treatment, Care and Prevention:
380.000 patients

Used daily by 6.000
medical professionals

Largest telemedicine provider
in Europe[1]: 65.000 on-line
self management patients

# The AXLE project

- European-funded innovation project
- **A**nalytics on e**X**tremely **L**arge **E**uropean data:

  Large-scale complex analytics on real-world datasets, while addressing the full requirements of real datasets (data quality, privacy, security and auditability)[2]
- Time frame: Nov 2012 – Nov 2015
- Portavita and four partners from academia and industry:

2ndQuadrant Professional PostgreSQL

BSC Barcelona Supercomputing Center Centro Nacional de Supercomputación

MANCHESTER 1824 The University of Manchester

University of Ljubljana Faculty of Computer and Information Science

PORTAVITA Networked Health

SEVENTH FRAMEWORK PROGRAMME

AXLE

# Health data as real-world dataset

Portavita provides:

- Synthetic CDA-based dataset generator
- Complex data models (HL7 RIM-based)
- Realistic use-cases of data use

Required granular access control to patient data

- Treatment of patient data is protected by law
- Patient's consent and organization policies

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**Can we use HCS[3] for data analytics purposes?**

# Outline

- Portavita use cases for data analytics
- Legal requirements
- Patient consent
- De-identification techniques
- HCS components in AXLE design

# Use Case 1: Public Health

In The Netherlands caregroups involve various care providers (e.g., GPs, dieticians, specialized doctors, etc.) for the treatment of chronic diseases

The *National Institute for Public Health and the Environment* (RIVM) wishes to monitor the process of treatment of chronic diseases

Examples of operations on the data:

- How frequently are the patients making regular check-ups
- The impact of such new process on the health of patients
- Comparison of the performance of various care groups
- ...

Portavita is required to export a de-identified dataset of patients data (EHRs)

Purpose of use: research for general interest

# Use case 2: Business Intelligence

The organizations (caregroups) wish to process patients' data for business intelligence purposes

Examples of operations on the data:

- Quality assessment across various care providers
- Monitoring, reporting of various treatments
- ...

Roles within the organizations:

- Super user: access all patients' data
- Research user:  access de-identified patients data

Purpose of use: internal research

# Legal background: EU directives

- Directive 95/46EC[4] & General Data Protection Regulation[5]
  - Patient data is personal data => sensitive => explicit consent is required for treatment of the data
  - Anonymous data fall outside the scope of the EU Directive => no consent required

# Legal background: Dutch law[6]

- Patient data can be used for health research without consent if one of the following two conditions is met:
  a) It is not reasonably possible to ask for consent and the privacy of the patient is not unnecessarily jeopardized
  b) Given the nature of research, asking for consent is not feasible and the data arrive at the researcher in such a way that re-identification is sufficiently prevented.
- In both instances three other conditions have to be met:
  1. The research serves a general interest
  2. The research cannot be carried out without those data
  3. The patient has not objected to such use of his/her data for research

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# Guidelines from legal analysis

- Patient consent:
  - Patients can opt-out from data treatment for research purposes

- Re-identification of patients should be sufficiently prevented
  - Safe pseudonymization of data subject
  - Suitable aggregation level of the research data related to the pseudonym

# Consent CDA[7]: Research opt-out

.....

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<act classCode=”ACT” moodCode=”DEF”>

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<!-- Information References: category, object id, sensitivity, related problem -->

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.....

# De-identification of patient data

# Identifying Patients Health Data[8]

- Direct identifiers:
  - Variables that directly identify an individual
  - Names, telephone numbers, Social Security Numbers etc.
  - Not useful for analytics
- Indirect identifiers (quasi-identifiers):
  - Gender, age, locations (e.g., postal code), profession etc.
  - Useful for analytics
- Health data
  - Diagnosis, medication,  dates
  - Useful for analytics
  - May re-identify patients

# Masking*

- Common techniques:
  - Suppression: removes fields
  - Randomization: replaces fields with random fake values
  - Shuffling: shuffles real values
  - Hashing: pseudonyms via one-way hashing
- Significantly reduces utility of the data
- Typically applied only to **direct identifiers**

* Not to be confused with Masking within the Security Labeling Service (SLS) module

# Safe Harbor

- HIPAA approved de-identification technique
- Masks 16 **direct identifiers** (e.g., names, email address, SSN etc.)
- Generalizes two **quasi-identifiers**:
  - First three digits of postal code when population size > 20 000, otherwise postal code is 000
  - Dates related to an individual (e.g., birth date, admission date, discharge date) represented only by year
- Pros:
  - Simple
  - The most common way to de-identify patient data
- Cons:
  - High risk of re-identification
  - Other fields, such as health data (e.g. diagnosis, number of visits etc.) and quasi-identifiers can be used to re-identify a patient

# De-identification: statistical method

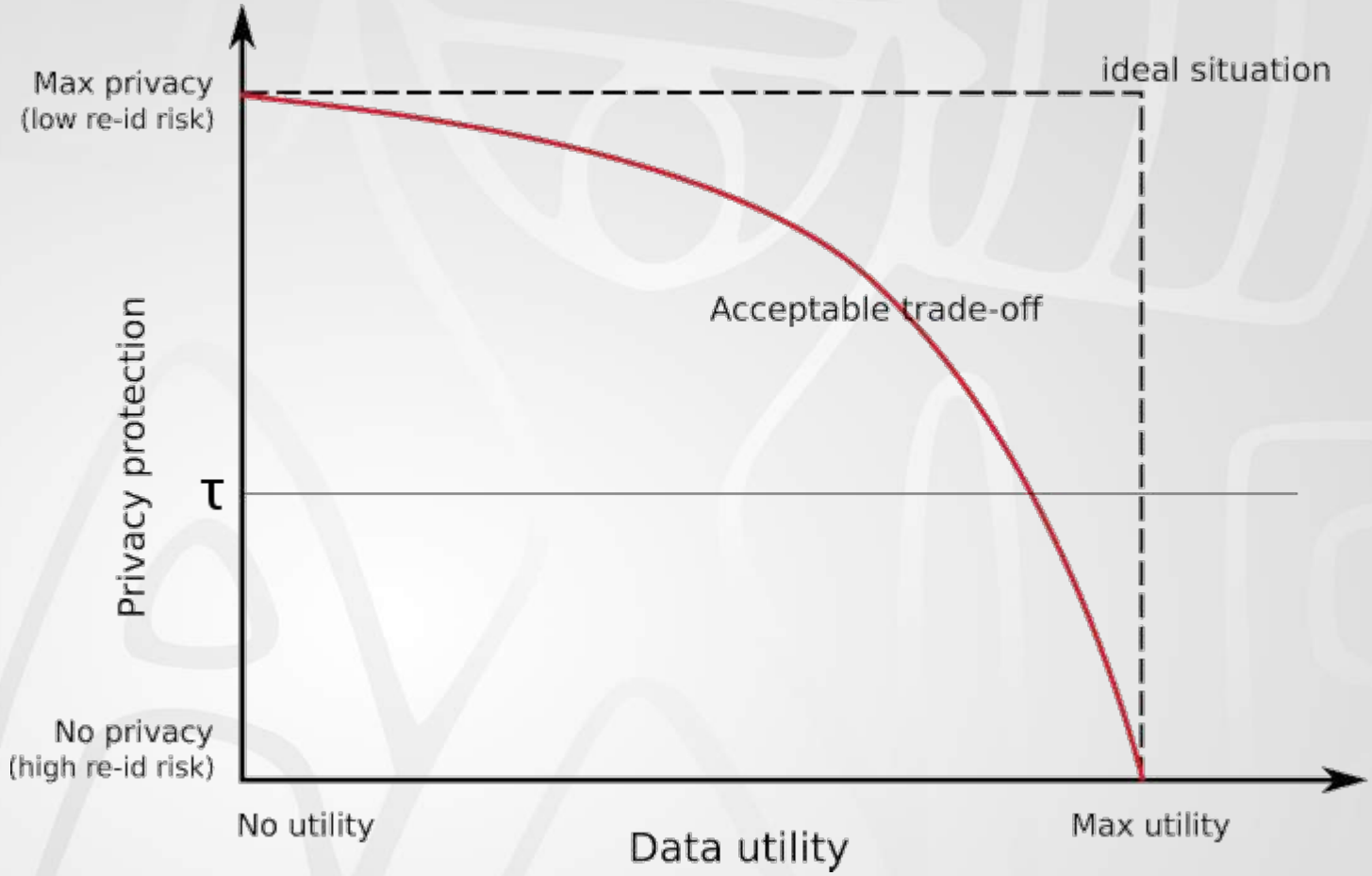
Maintain analytical value:

- Mask direct identifiers
- Generalize other fields
  - when risk of re-identification greater than a certain threshold

Re-identification risk threshold depends on the risk of exposure

- Public vs internal use of the dataset

# Privacy vs. data utility




Source: K. El Emam and L. Arbuckle. “Anonymizing Health Data”. O'Reilly Media. December 2013.

# Assessing re-dentification risk: example

| Patient gender | Handedness |
|---|---|
| M | L |
| F | R |
| F | L |
| M | L |
| F | R |
| M | L |
| M | R |
| F | R |
| M | R |
| F | L |

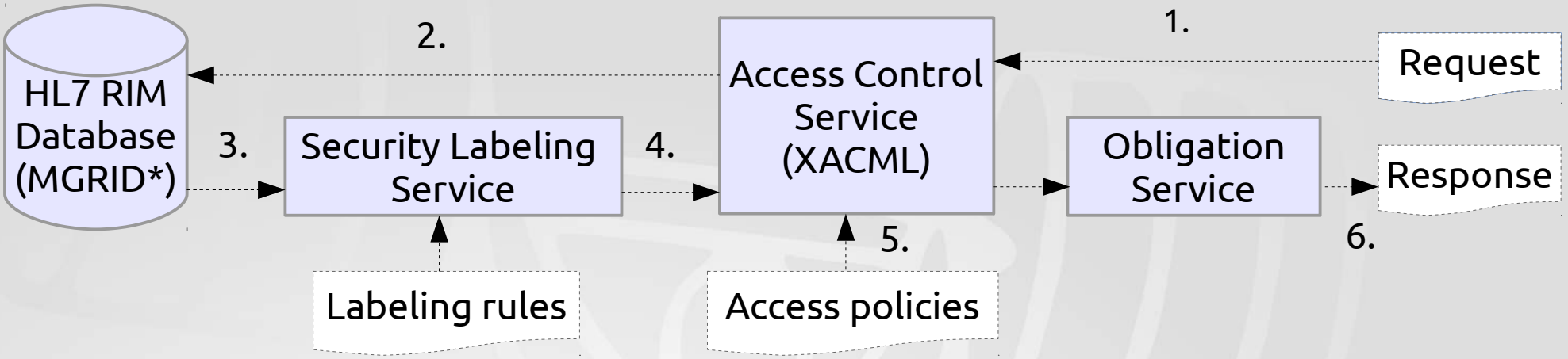
- Equivalence classes (similar records)

| Class | # of records | Re-identification risk |
|---|---|---|
| F-L | 2 records | .5 |
| M-L | 3 records | .33 |
| F-R | 3 records | .33 |
| M-R | 2 records | .5 |

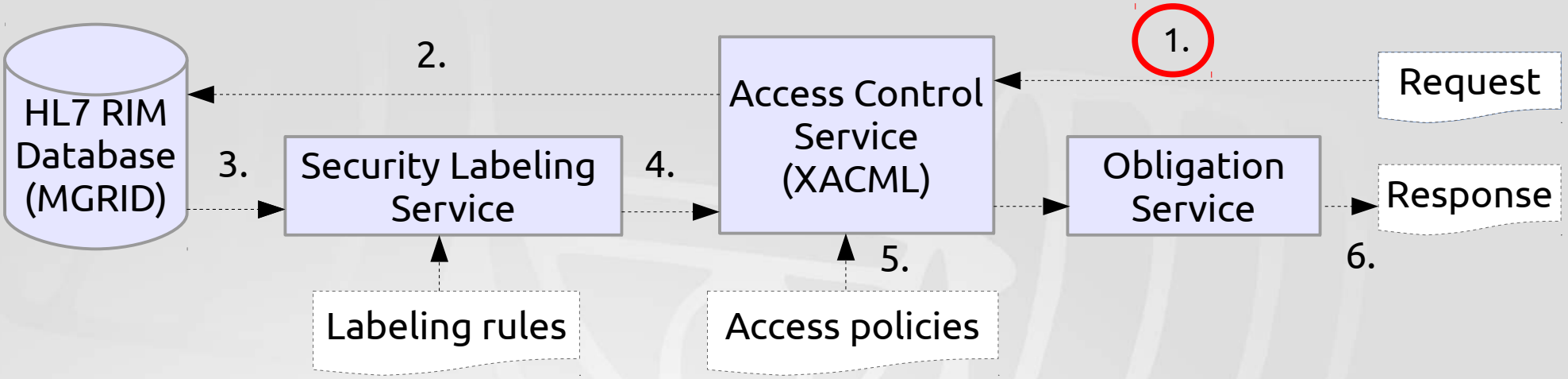
- Threshold: $\tau = .4$
- Above threshold: 2 (F-L) + 2 (M-R) = 4 records
- Conslusion:

  40% of all records has a re-identification risk above threshold

# HCS for analytics on healthcare data




*) www.mgrid.net

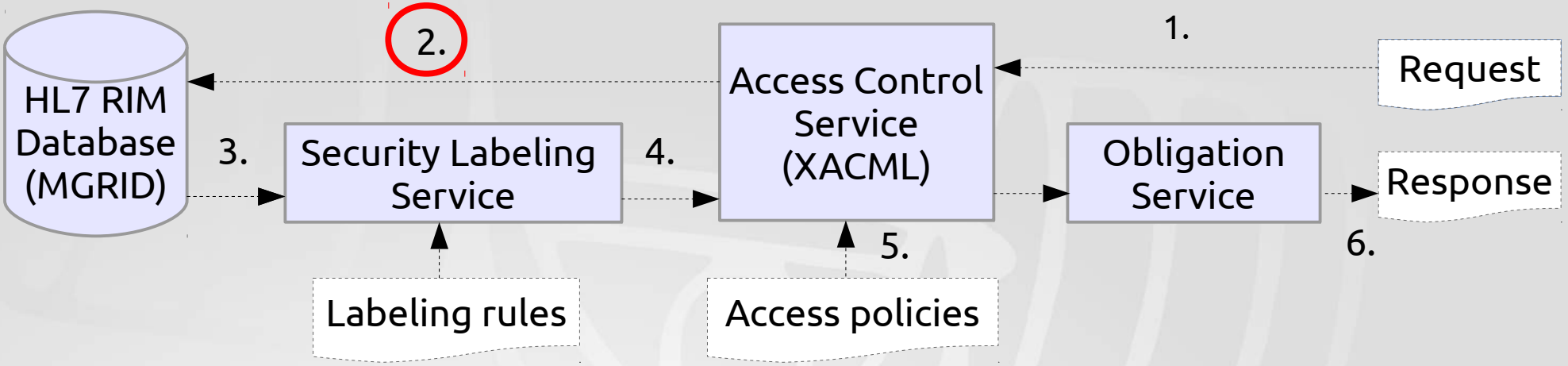



1: Request:

- User/requester
- Purpose of use
- Query

Example:

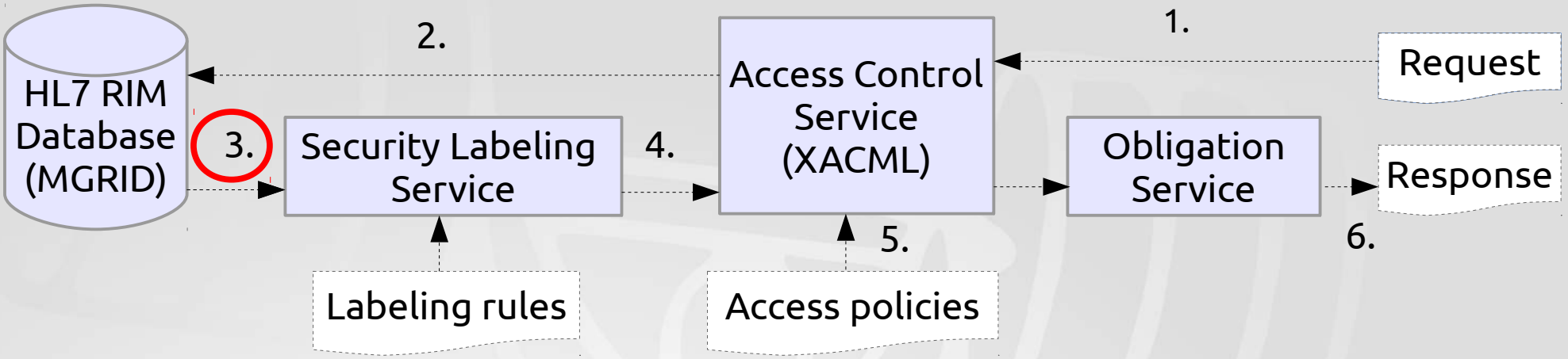
- *John Smith wants to do research and asks for demographic data of all female diabetes patients*




2: Query

Example:

- *demographic data of all female diabetes patients*

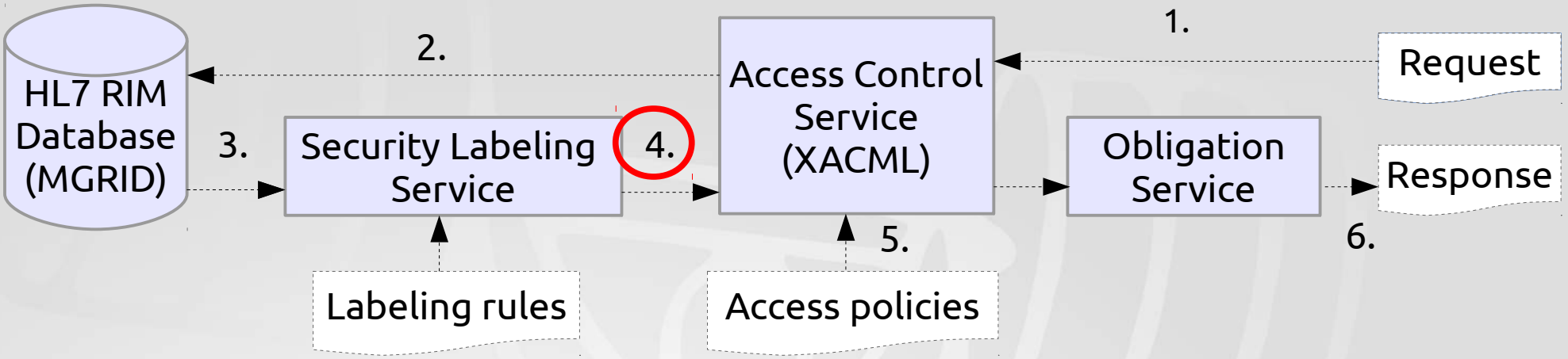



3: Query result:

- Tagged data

Example:

| Name | Date of birth |
|---|---|
| Anna Anderson | 1966-12-11 |
| Barbara Brown | 1939-11-15 |
| Carol Clark | 1965-02-02 |
| Dorothy Davids | 1954-05-04 |
| Elizabeth Evans | 1948-11-02 |



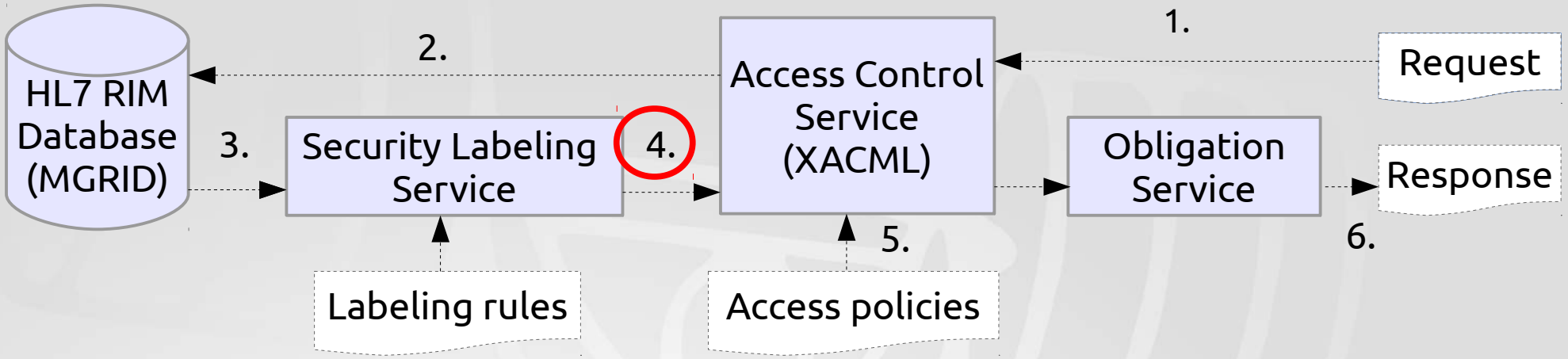

4: Labeled result:

- Tagged data
- Security label: sensitivity, obligations, purpose of use, etc.

Example:

| Name | Date of birth |
|---|---|
| Anna Anderson | 1966-12-11 |
| Barbara Brown | 1939-11-15 |
| ... | |

Sensitivity: low
Purpose of use: treatment, research
Obligation: de-identify




**Transformations applied by SLS (vs Obligation Service)**

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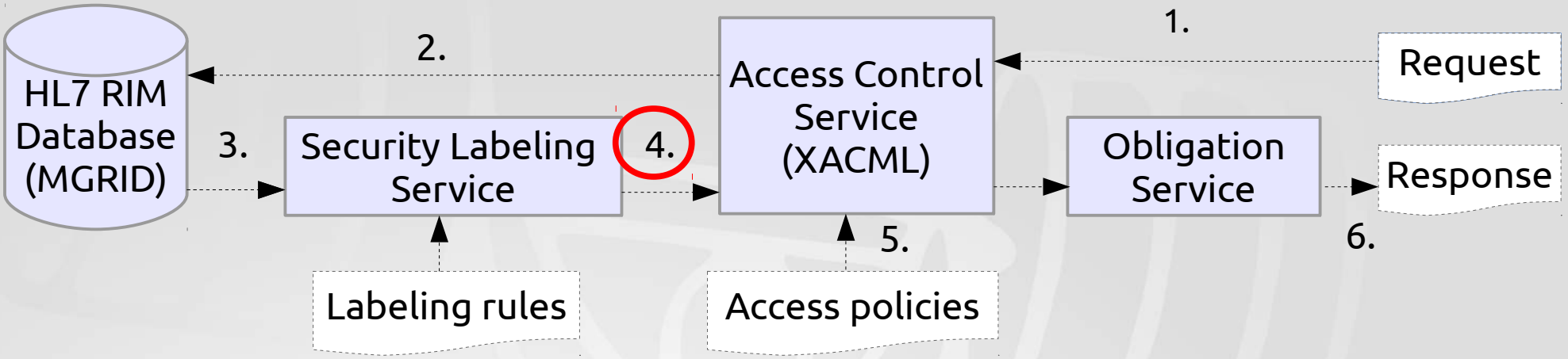


4. Labeled result:
- Tagged data
- Security label: sensitivity

**Expression of conditional obligations**
E.g. only de-identify when purpose of use is 'research'

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| Name | Date of birth |
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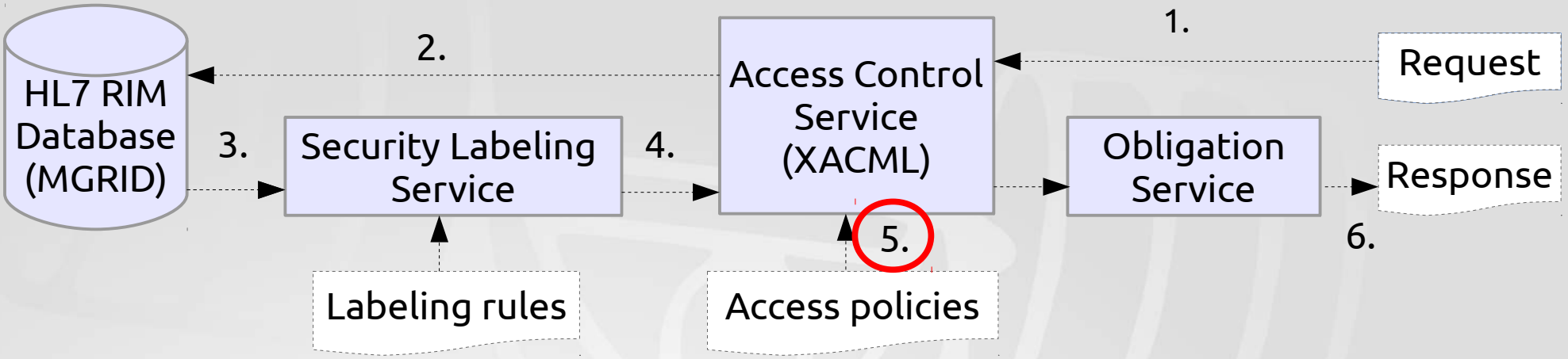
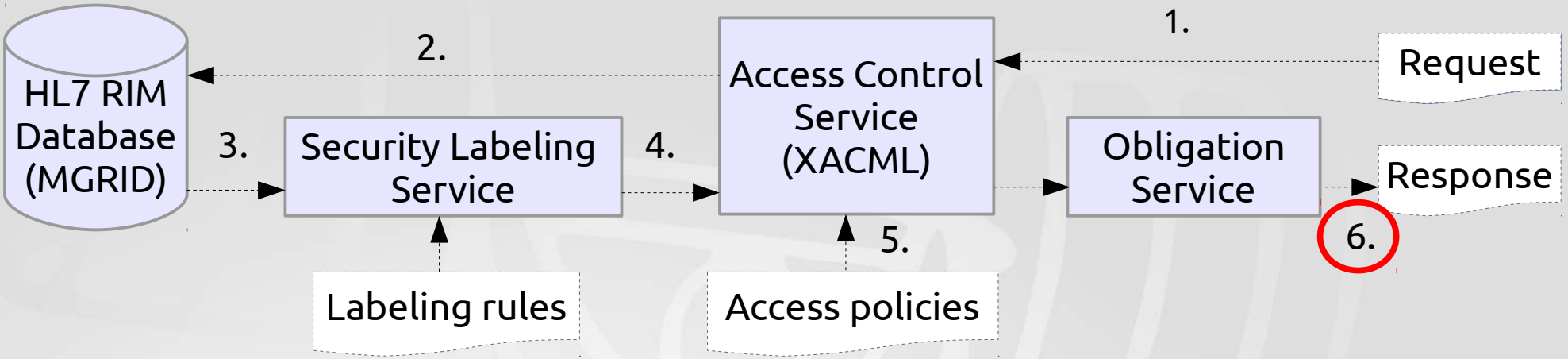



5: Policies

- Legal policies
- Organizational policies
- …
- Patient consent

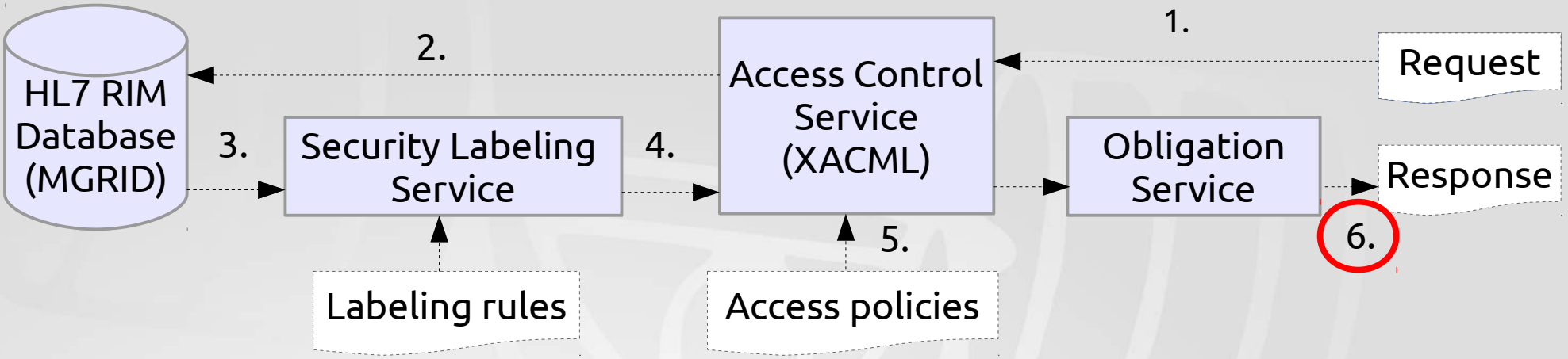



6: Response

- Tagged data: de-identified

Example:

| Name | Date of birth |
|---|---|
| ******** | 1966 |
| ******** | 1939 |
| ... | |




6: Response

- Tagged data: de-identified

Example:

| Name | Date of birth |
|---|---|
| ******** | 1966 |
| ******** | 1939 |
| ... | |

**Taking into account risk of exposure**

# Conclusions and future work

HCS seems adequate for our data analytics use cases

- Access control for primary and secondary use
- Security label vocabulary
- Consent CDA

Next steps:

- Design and implement our SLS
- Access control mechanism

# References


1. FIEEC, ASIP Sante'. “Lessons learned from the FIEEC/ASIP study on telemedicine and telehealth”, March 2011.
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4. Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. October 1995.
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6. Act on the Treatment Contract (art. 7.458 BW) and the Data Protection Act (art. 23.2) combined.
7. Implementation guide for CDA Release 2.0: Privacy Consent Directives Release 1. May 2013.
8. K. El Emam. “Guide to the De-Identification of Personal Health Information”. CRC Press. May 2013.
9. K. El Emam and L. Arbuckle. “Anonymizing Health Data”. O'Reilly Media. December 2013.