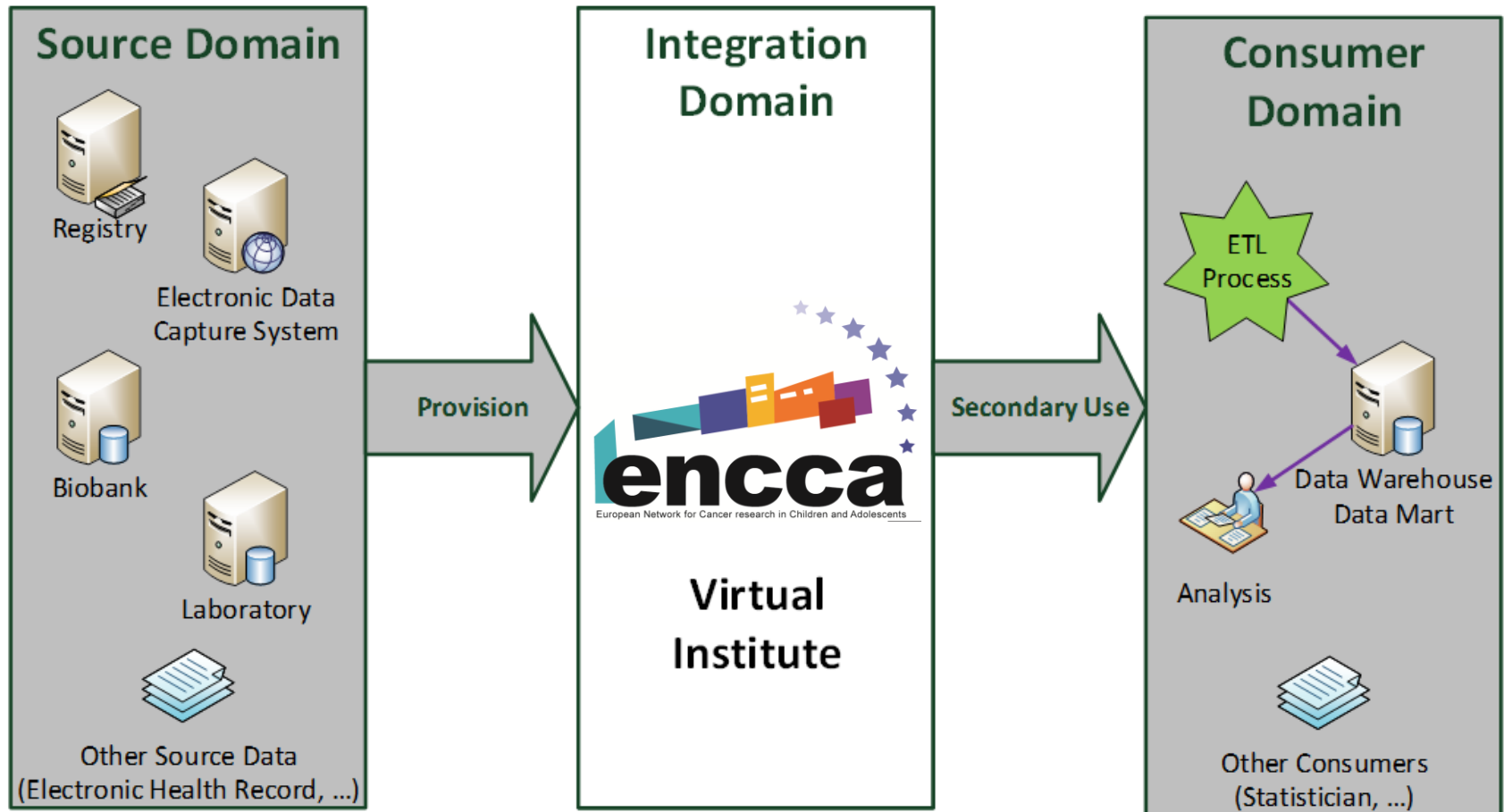


Patient Identity Management for Secondary Use of Biomedical Research Data in a Distributed Computing Environment

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Schema of the ENCCA (European Network for Cancer Research in Children and Adolescents) IT infrastructure for secondary use of biomedical research data



Methods

- The **requirements** for the **ENCCA Patient Identity Management** were collected in the context of
 - the explicit aims of the ENCCA project itself and
 - the implicit regulatory framework in which ENCCA is embedded.
- Based on the determined requirements an appropriate **concept** for **the ENCCA Patient Identity Management** was developed.

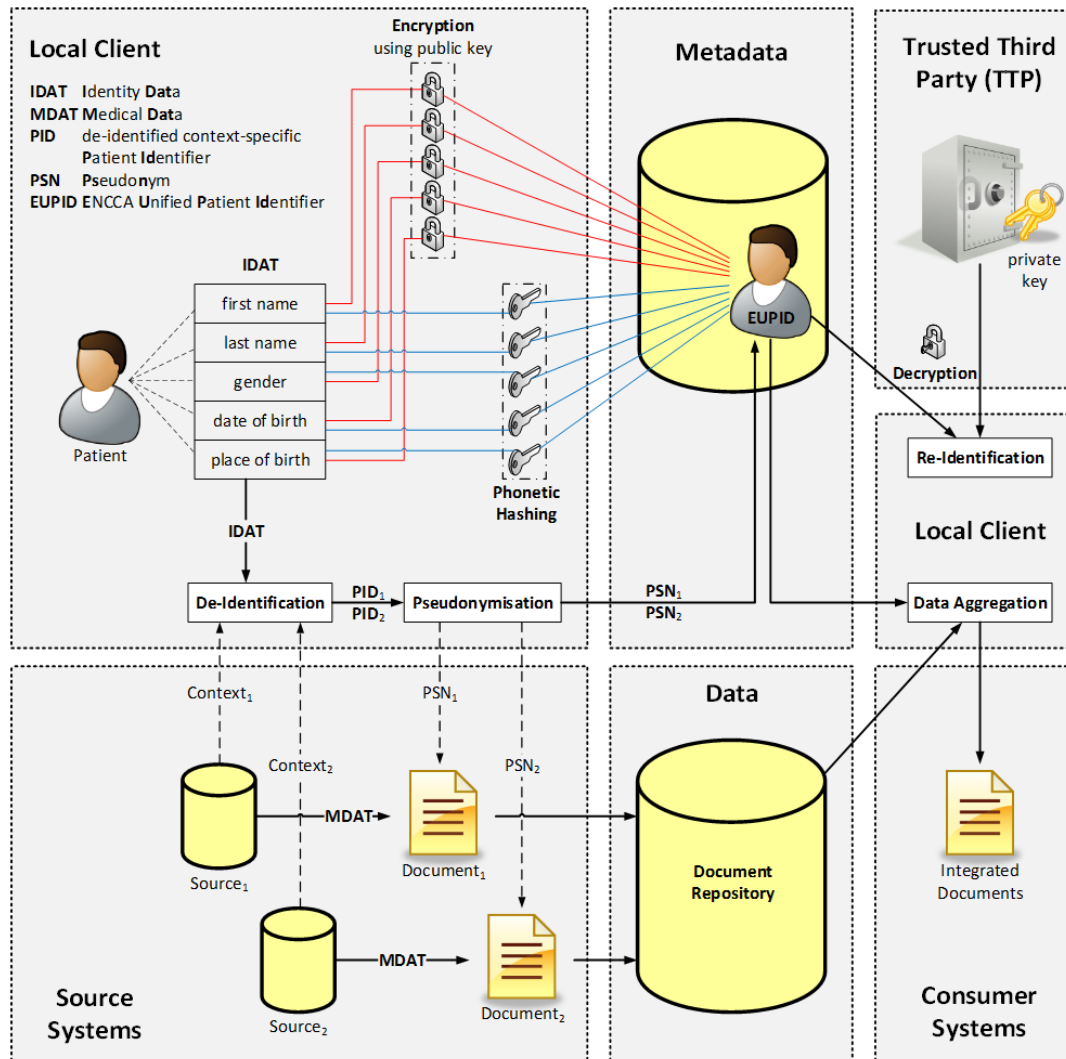
Results (1)

Requirements for the Patient Identity Management

- R1 prevent a **duplicate registration** of one and the same patient
- R2 **different pseudonyms** for one and the same patient **for different contexts**, identification of patients should be rendered (almost) impossible for another context
- R3 **re-identification** of patients
- R4 **avoid** transparent **universal patient IDs**
- R5 feasible in a **distributed computing environment**

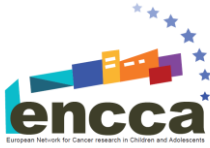
Results (2)

Concept for the PIM for secondary use of biomedical research data



Discussion and Conclusion

- Data aggregation according to later needs – **late data binding**
- **Separation of MDAT and metadata reduces** the hazards of **unintended re-identification** and **increases data security**
- **Support of distributed computing environments** makes concept also **suitable for approaches using cloud technologies**
- **Concept presented** to the ENCCA board and **cleared for implementation**



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