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**

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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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