

Matching study to registry data: maintaining data privacy in a study on family based colorectal cancer

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Study of family based colorectal cancer

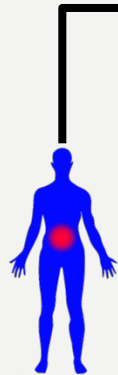
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Index-Patient
Newly diagnosed with
colorectal cancer



Study of family based colorectal cancer

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Index-Patient
Newly diagnosed with
colorectal cancer

*IDAT: Firstname, Lastname,
Date of Birth, Address ...*

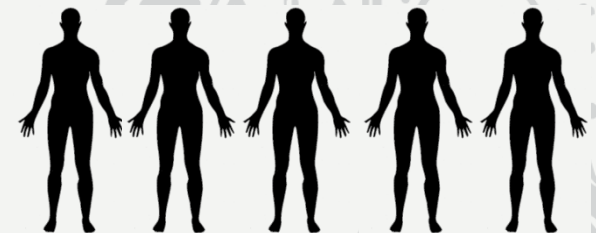
Study of family based colorectal cancer

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Study of family based colorectal cancer

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Index-Patient
Newly diagnosed with
colorectal cancer

☐ Schwester ☐ Bruder

Vorname, Name

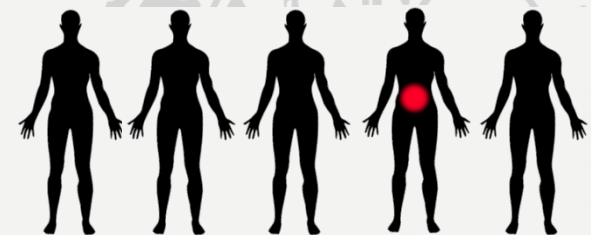
Geburtsname

Geburtsdatum 19

PLZ, Wohnort

Family member form fields include: Name, Geburtsdatum, PLZ, Wohnort, and various checkboxes for medical history.

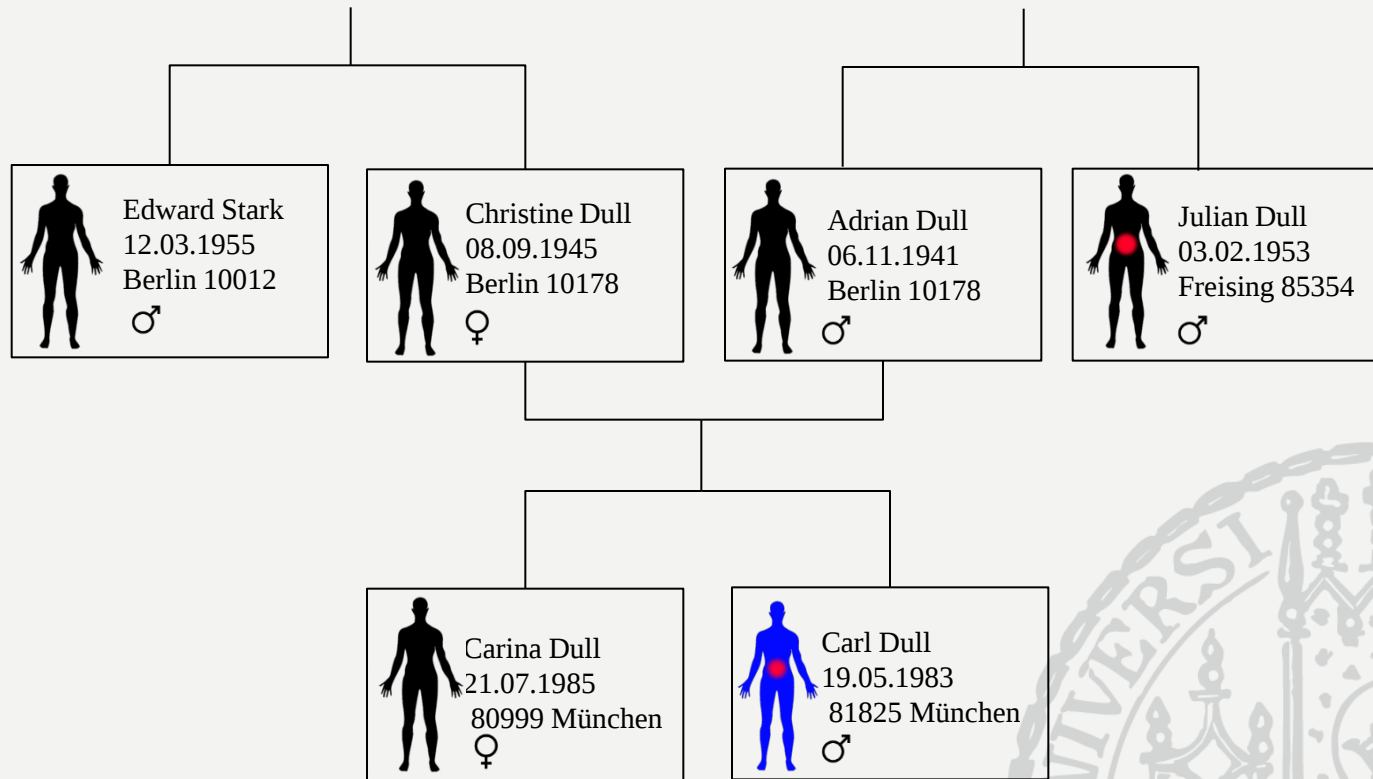
*IDAT: Firstname, Lastname,
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The task: Identifiing relatives who had a history of cancer in the past. If we find one, we also need the corresponding medical data.

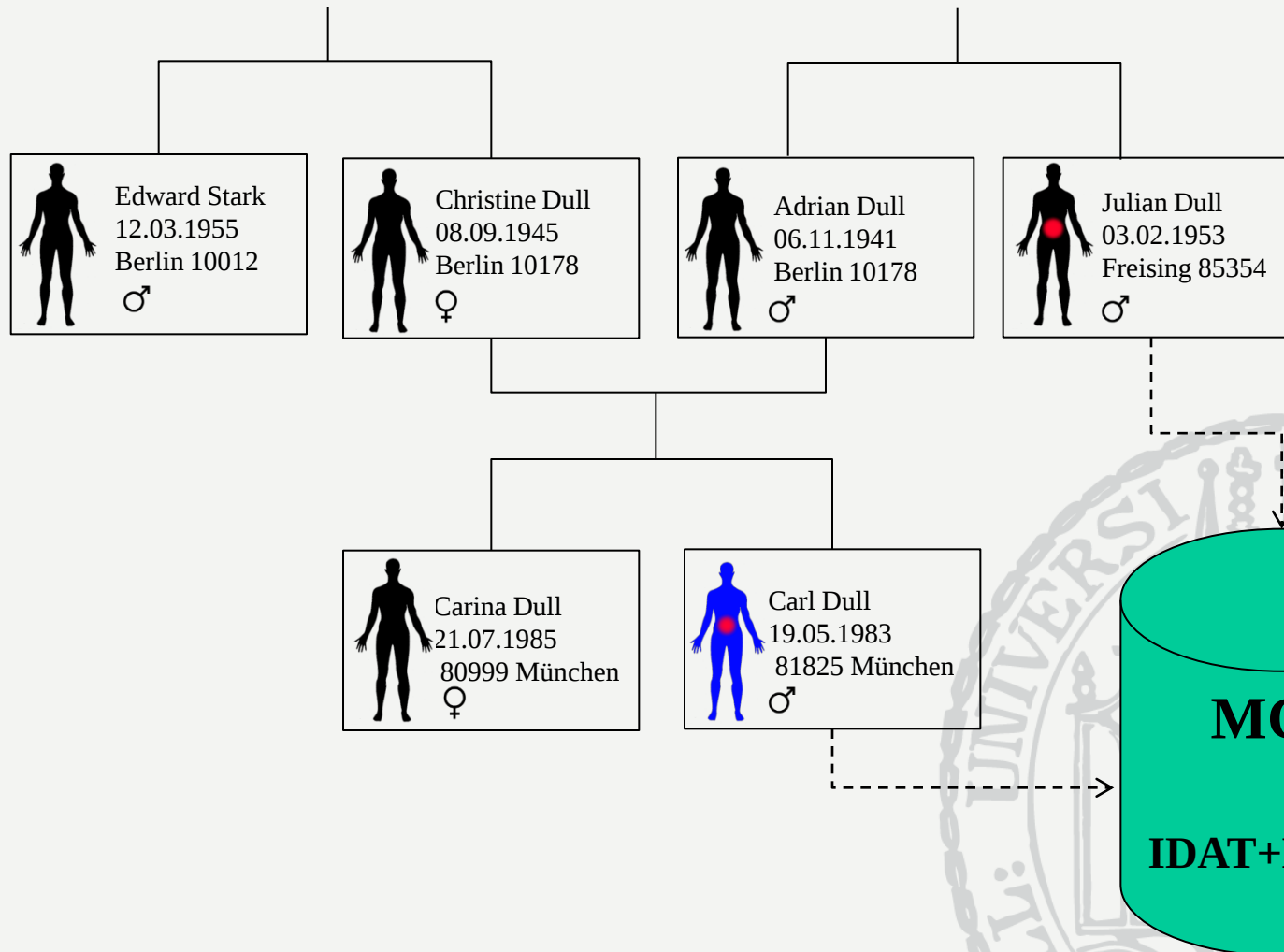
Identification: Matching study data to registry data (IDAT)

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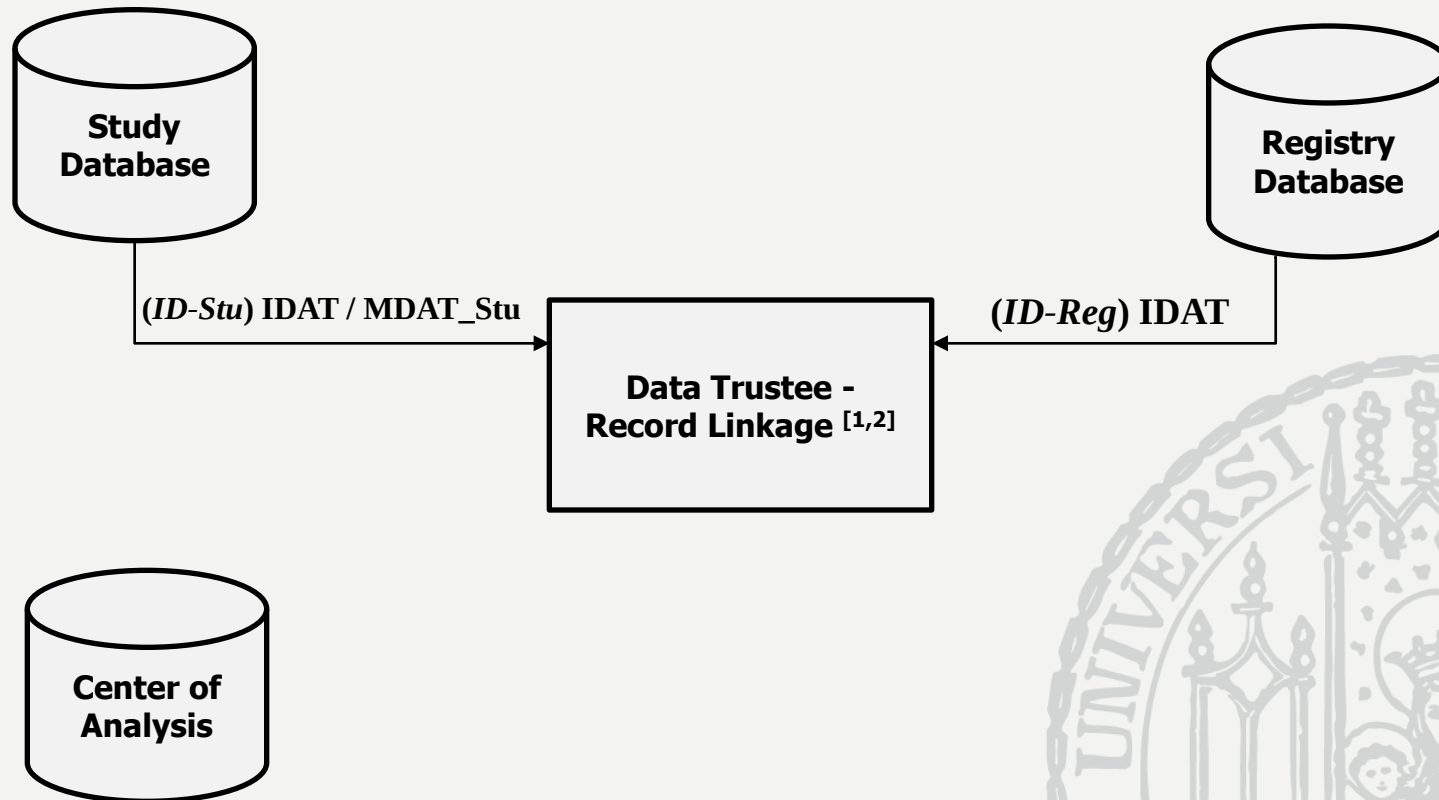


I. Institutional and organisational division of participating parties.

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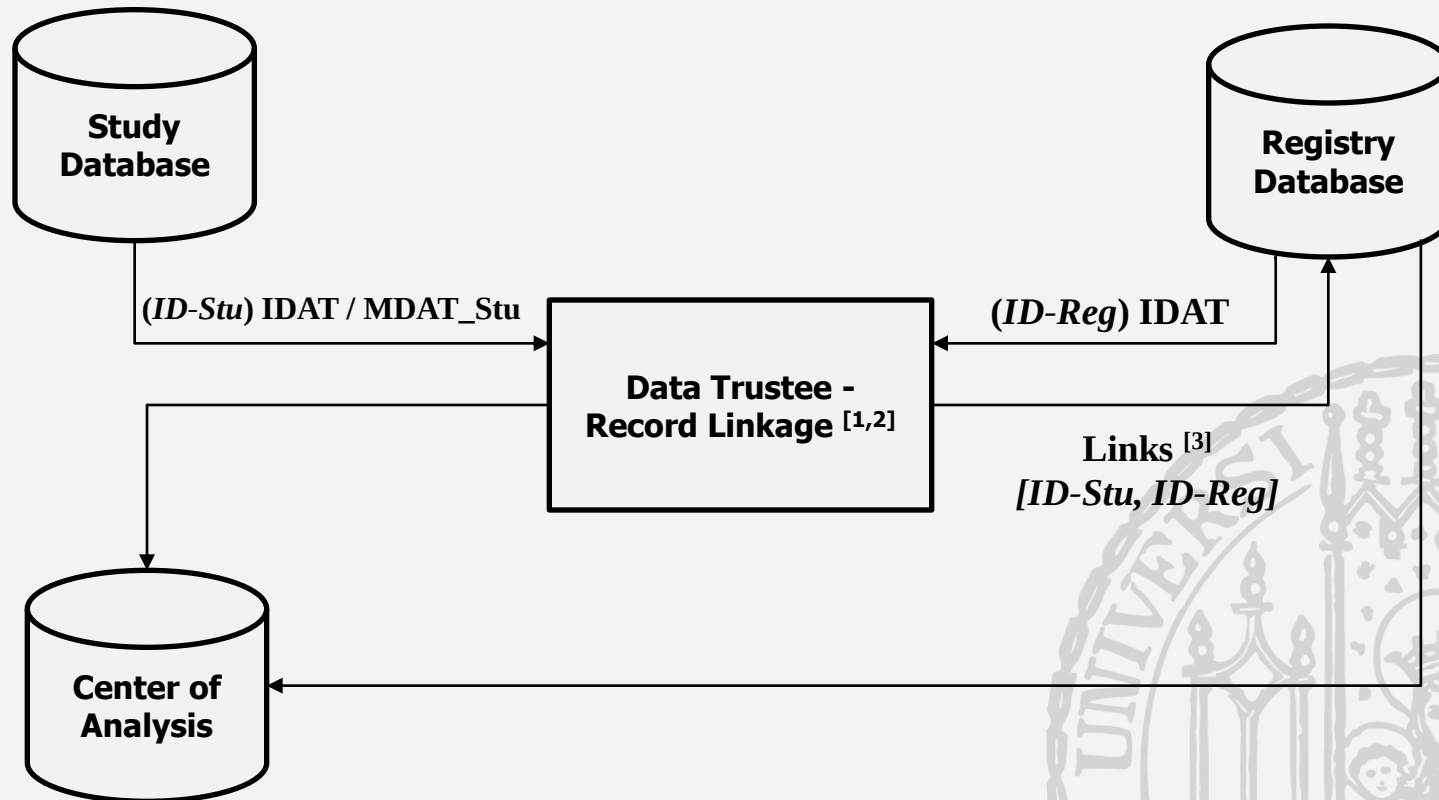
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[1] Meyer M. Kontrollnummern und Record Linkage. Das Manual der epidemiologischen Krebsregistrierung. Hentschel S, Katalinie A, editor. Zuckschwerdt. 2011;57-68.

[2] Christen P. Data Matching – Concepts and Techniques for Record Linkage, Entity Resolution, and Duplicate Detection. Heidelberg: Springer; 2012.

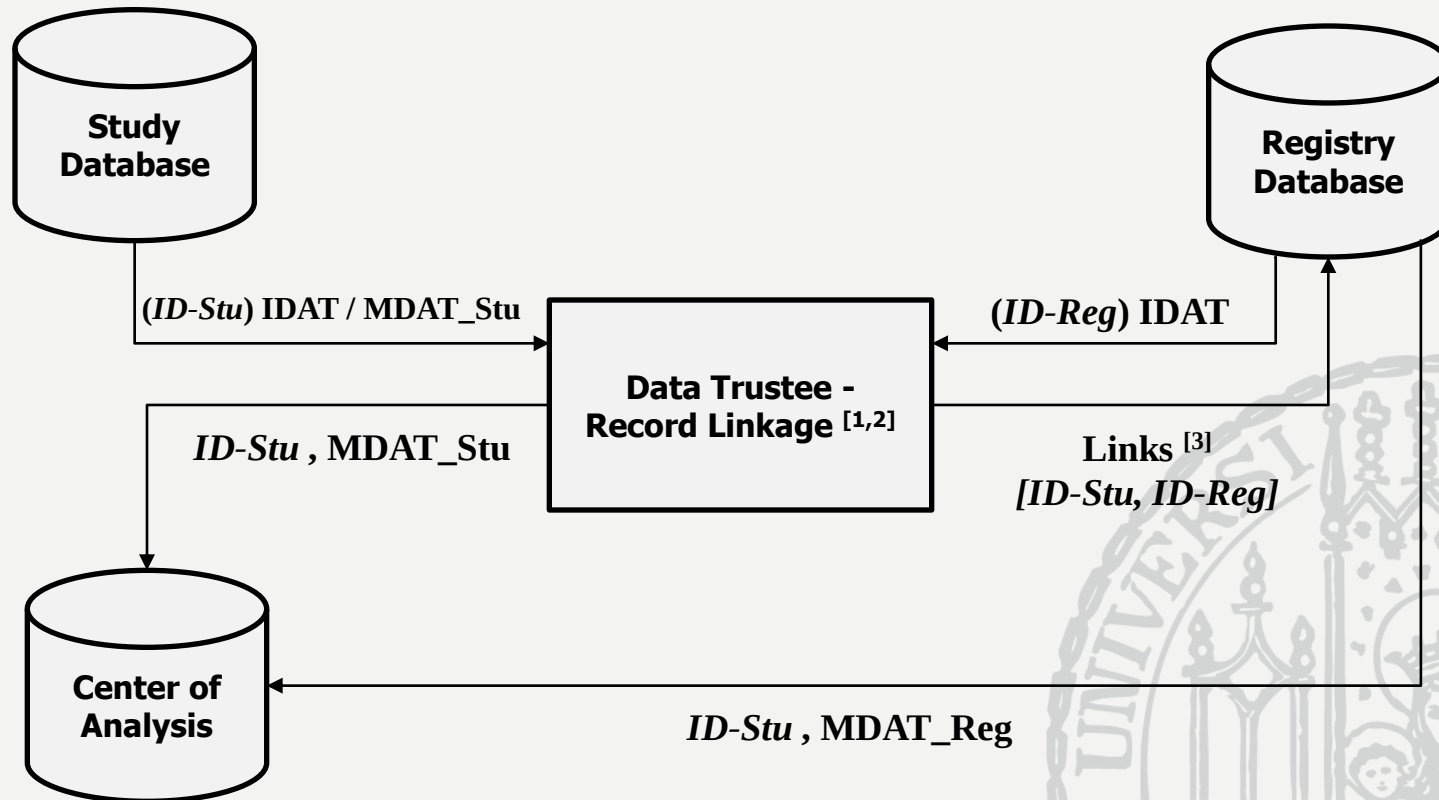
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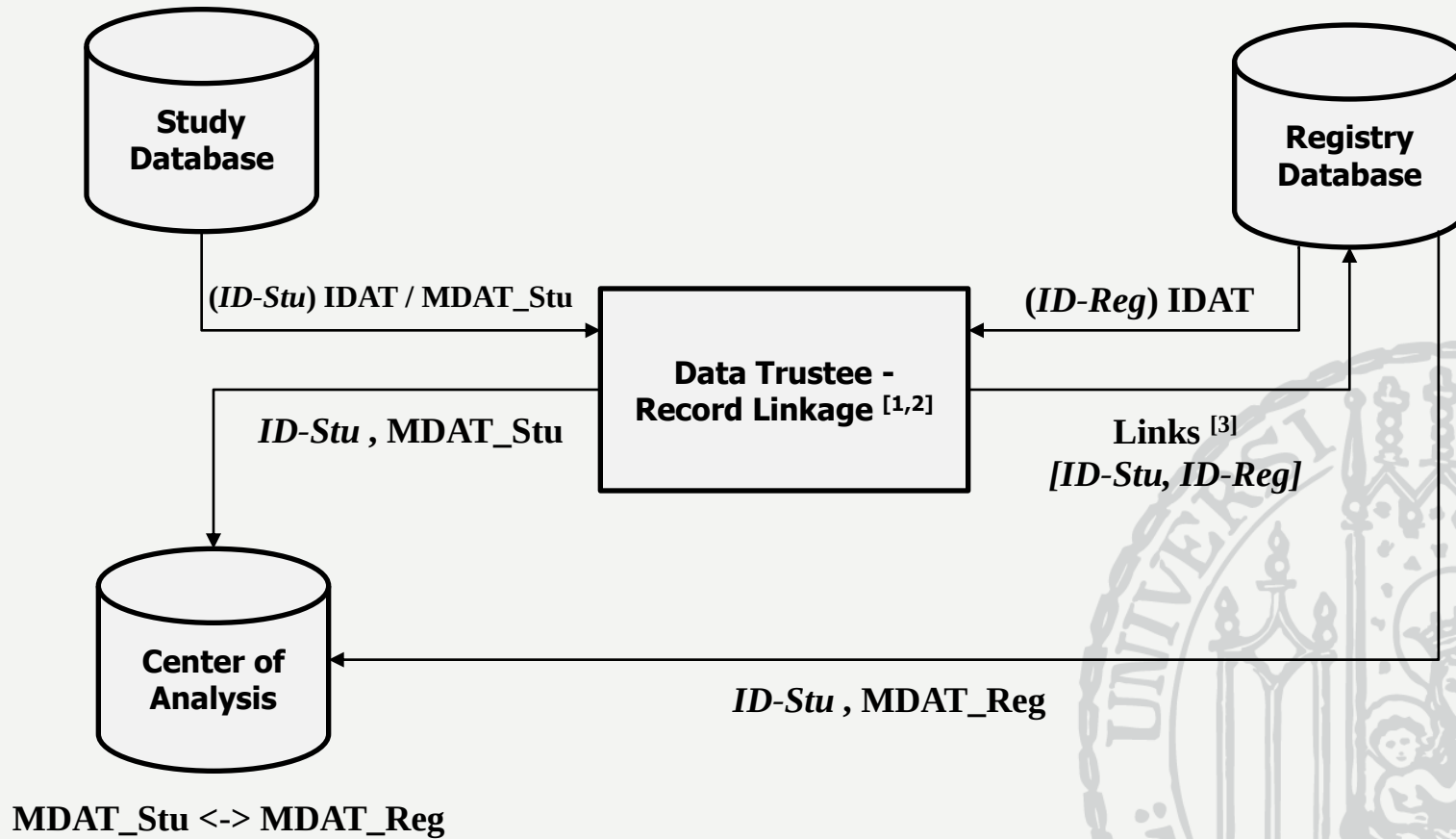
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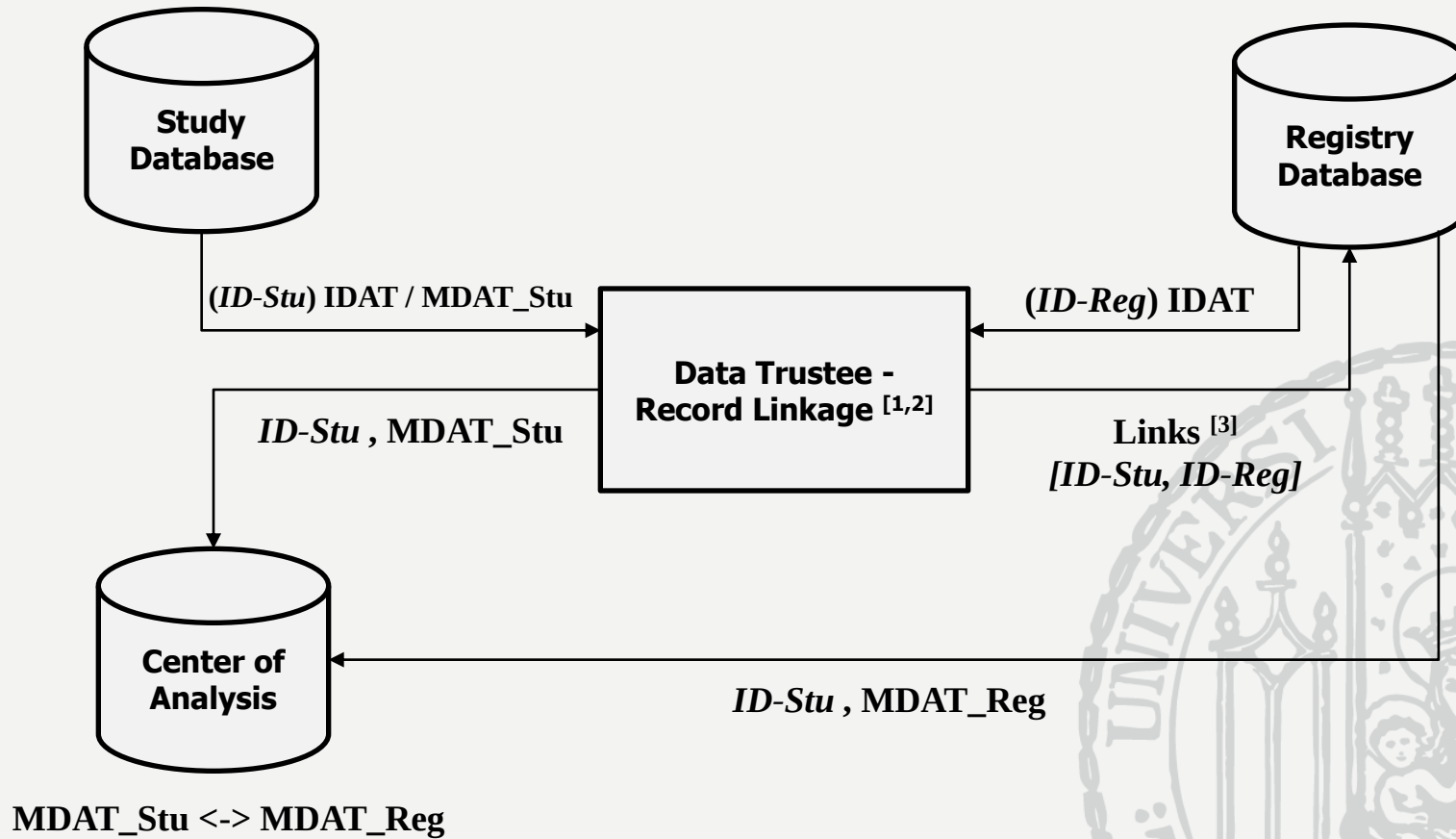


I. Institutional and organisational division of participating parties.

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II. No transfer of identifying data in human readable form



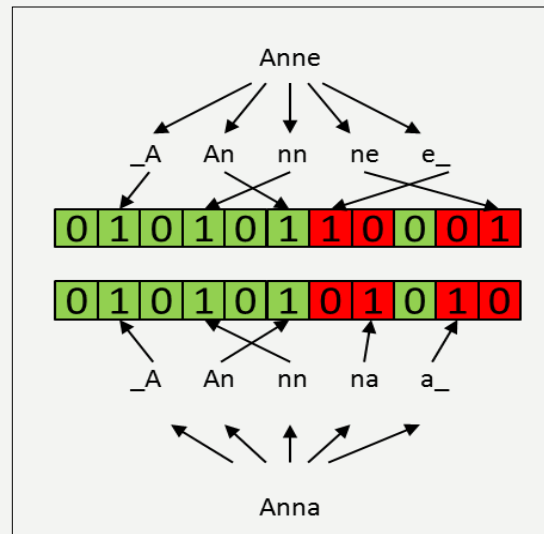
II. No transfer of identifying data in human readable form

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Variant 1: Apply Hashfunctions (e.g. SHA-2^[1]) on IDAT

Cleartext	Hashvalue
Meier	05c2d2b4cad1a3f5bf547b484ac6f4a70893e944d5bd6fe0f28db40453bf3f3c
Meyer	876fdfa1d1152c1d024386a1f66e7725f292ef83404fc4d3be79c1b51cc81c45

Variant 2: Transform IDAT into Bloomfilters^[2]

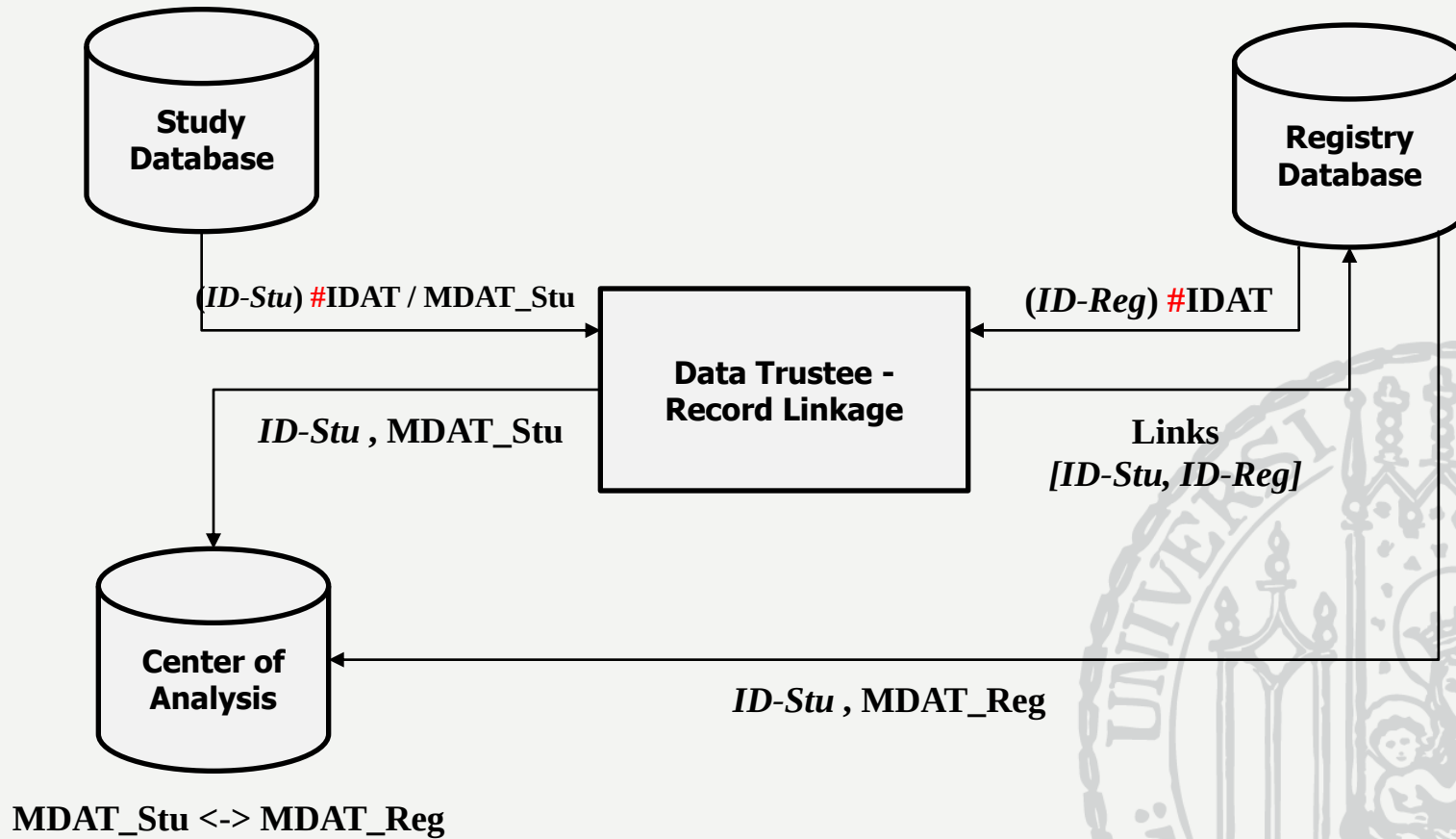


[1] Gilbert H, Handschuh H. Security Analysis of SHA-256 and Sisters. Selected Areas in Cryptography. 2003; 175–193

[2] Schnell R, Bachteler T, Reiher J. Privacy-preserving record linkage using Bloom filters. BMC Medical Informatics and Decision Making. 2009; 9:41

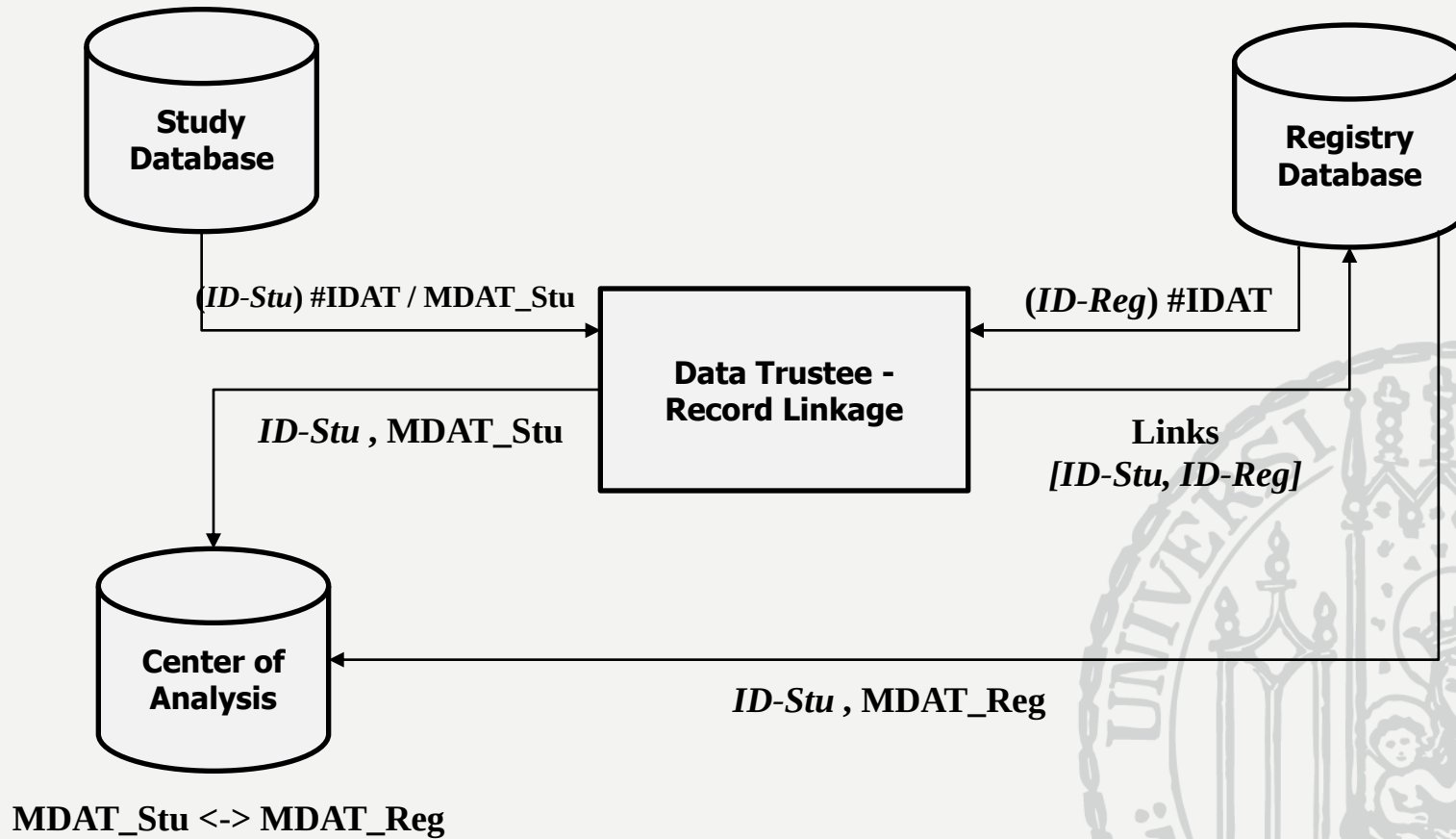
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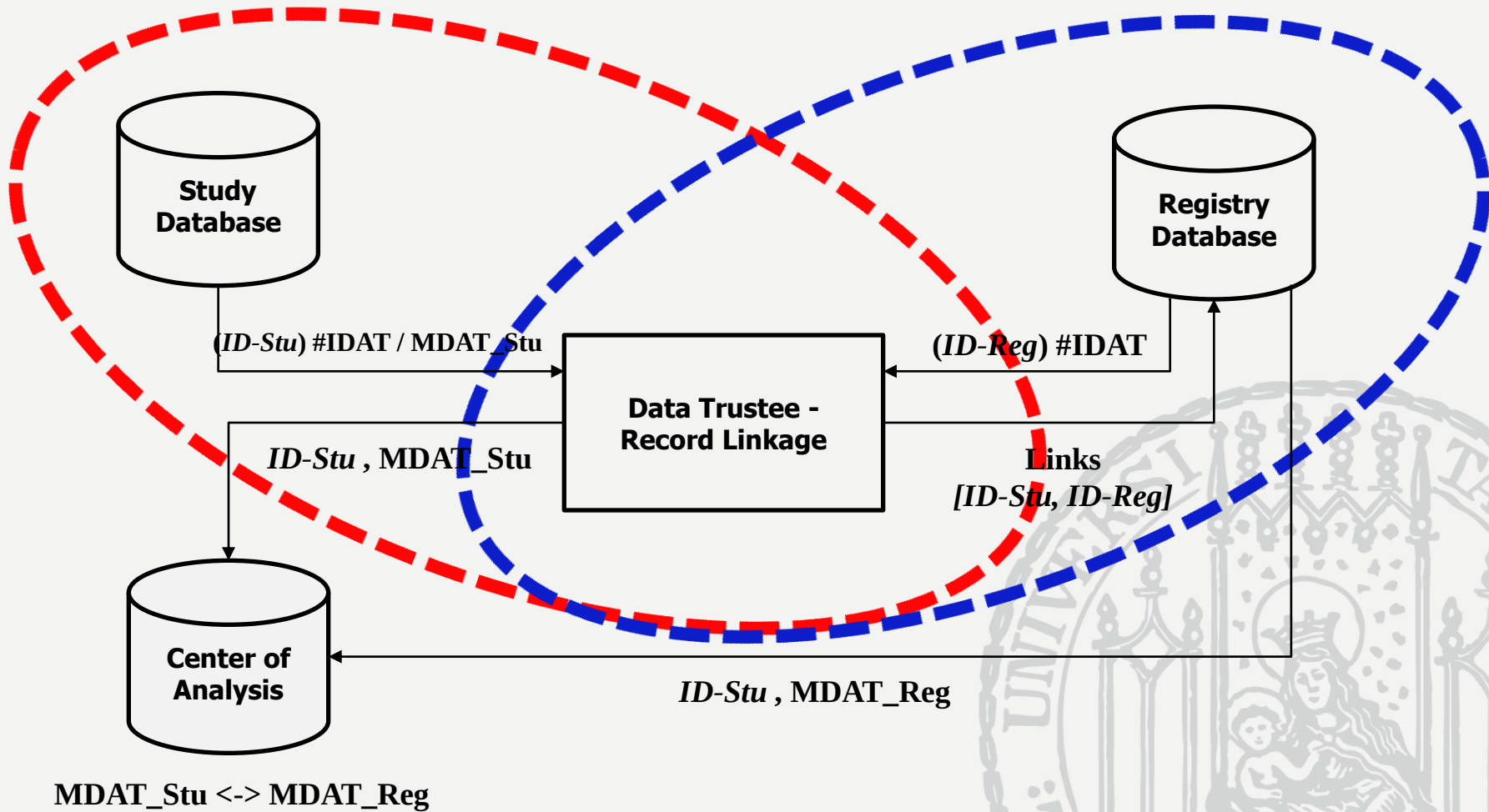
III. Registry-ID and study-ID may only be shared with the data-trustee

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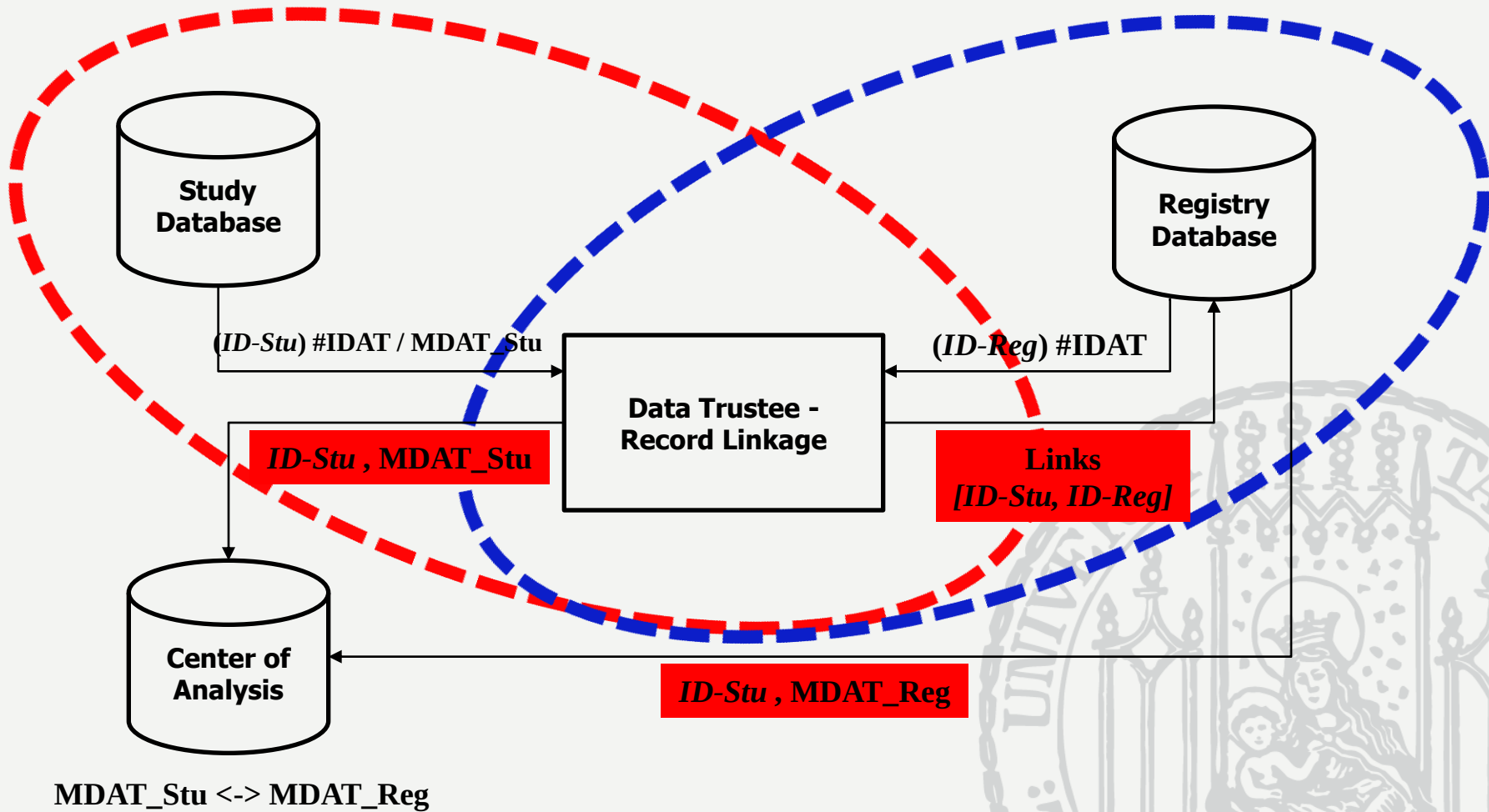
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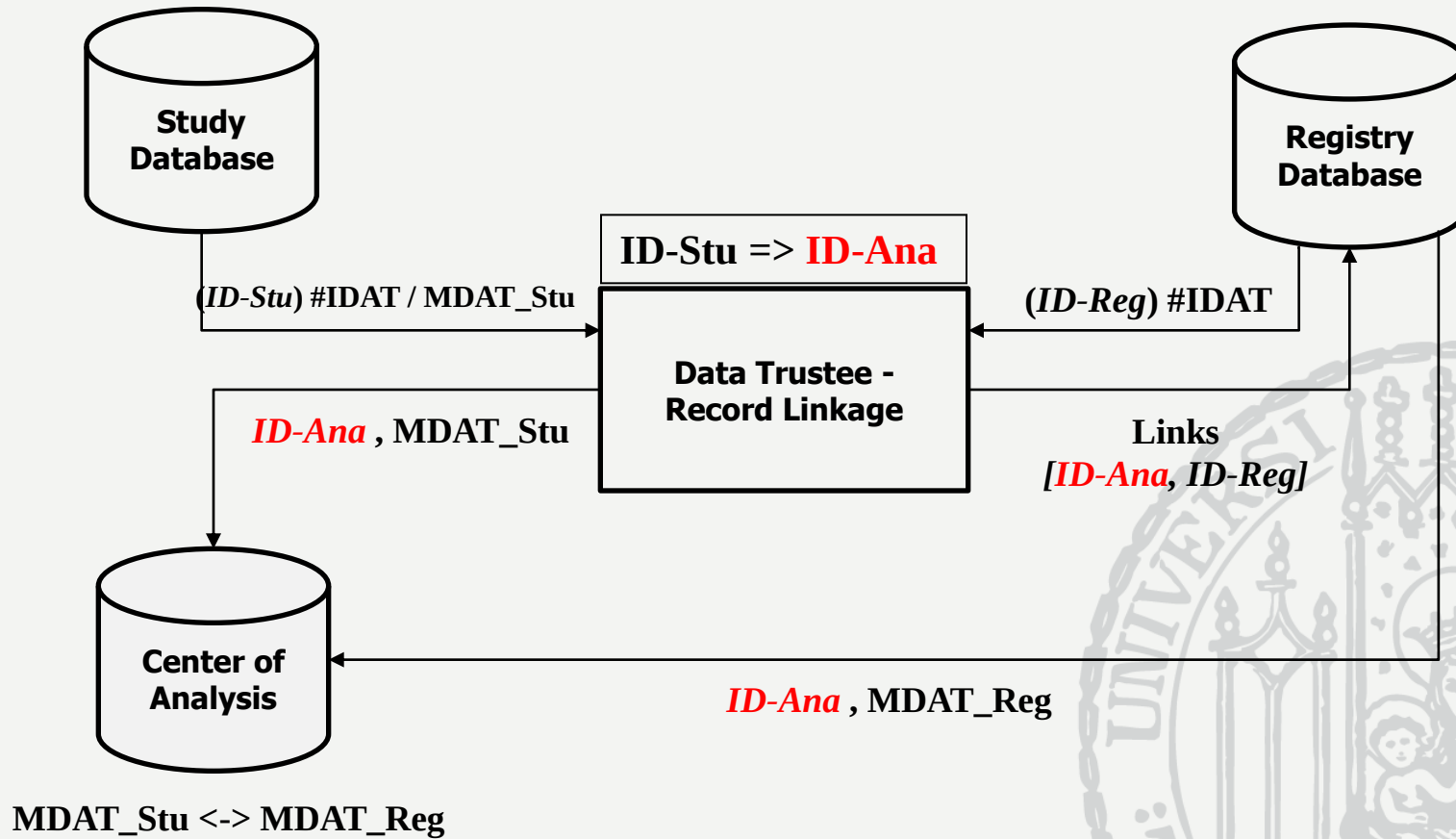
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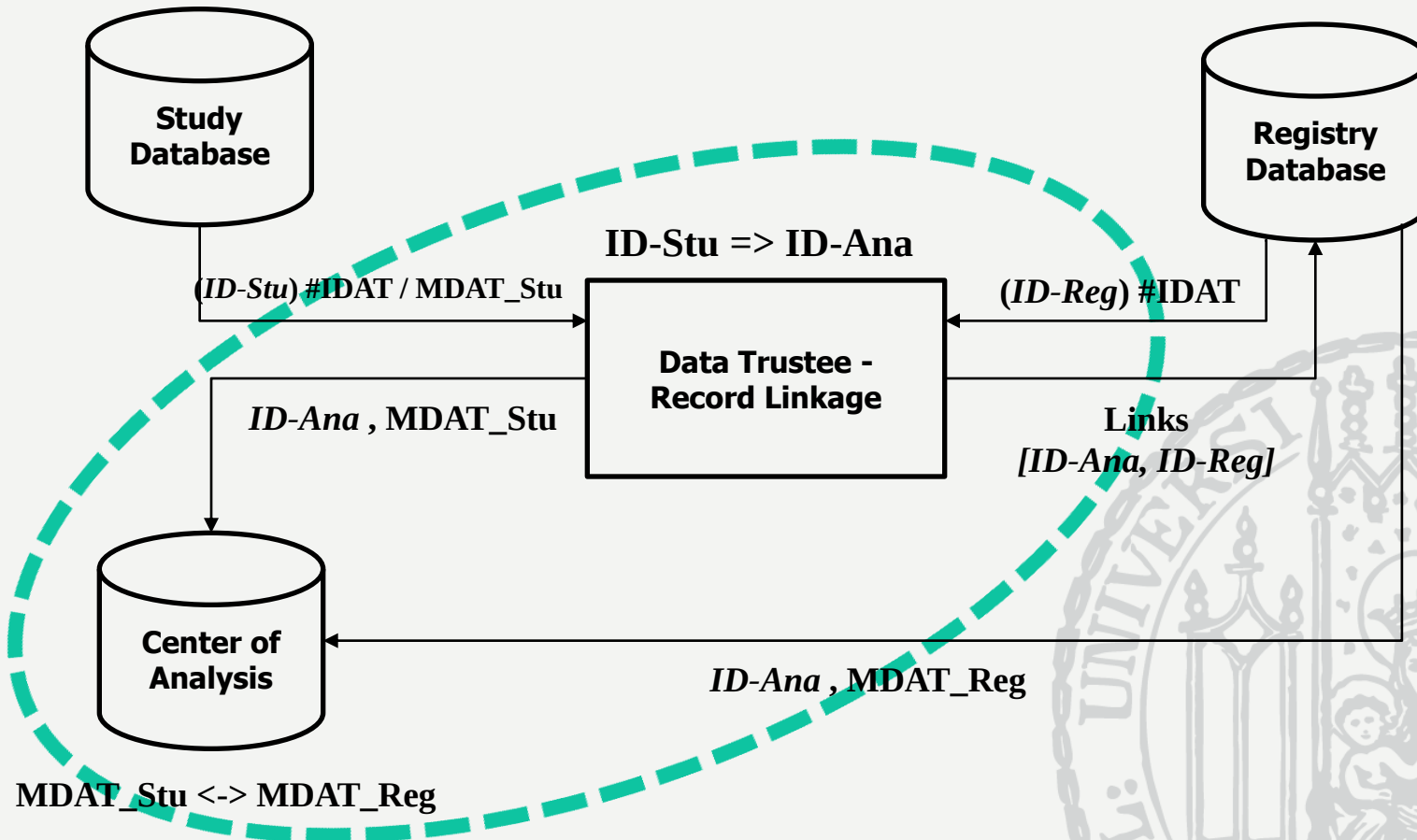
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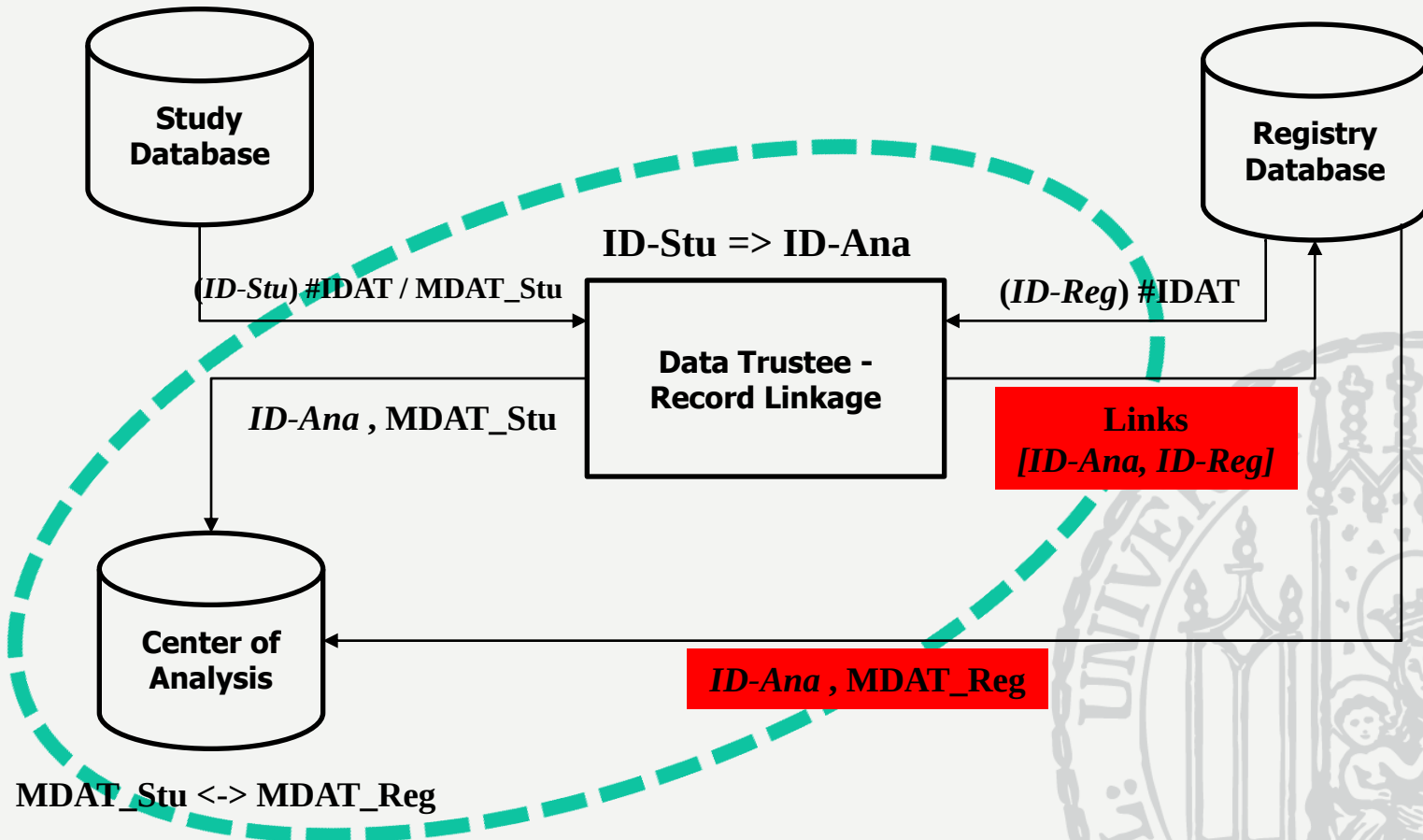
IV. Analysis-ID may only be shared between the Data Trustee and the Center of Analysis

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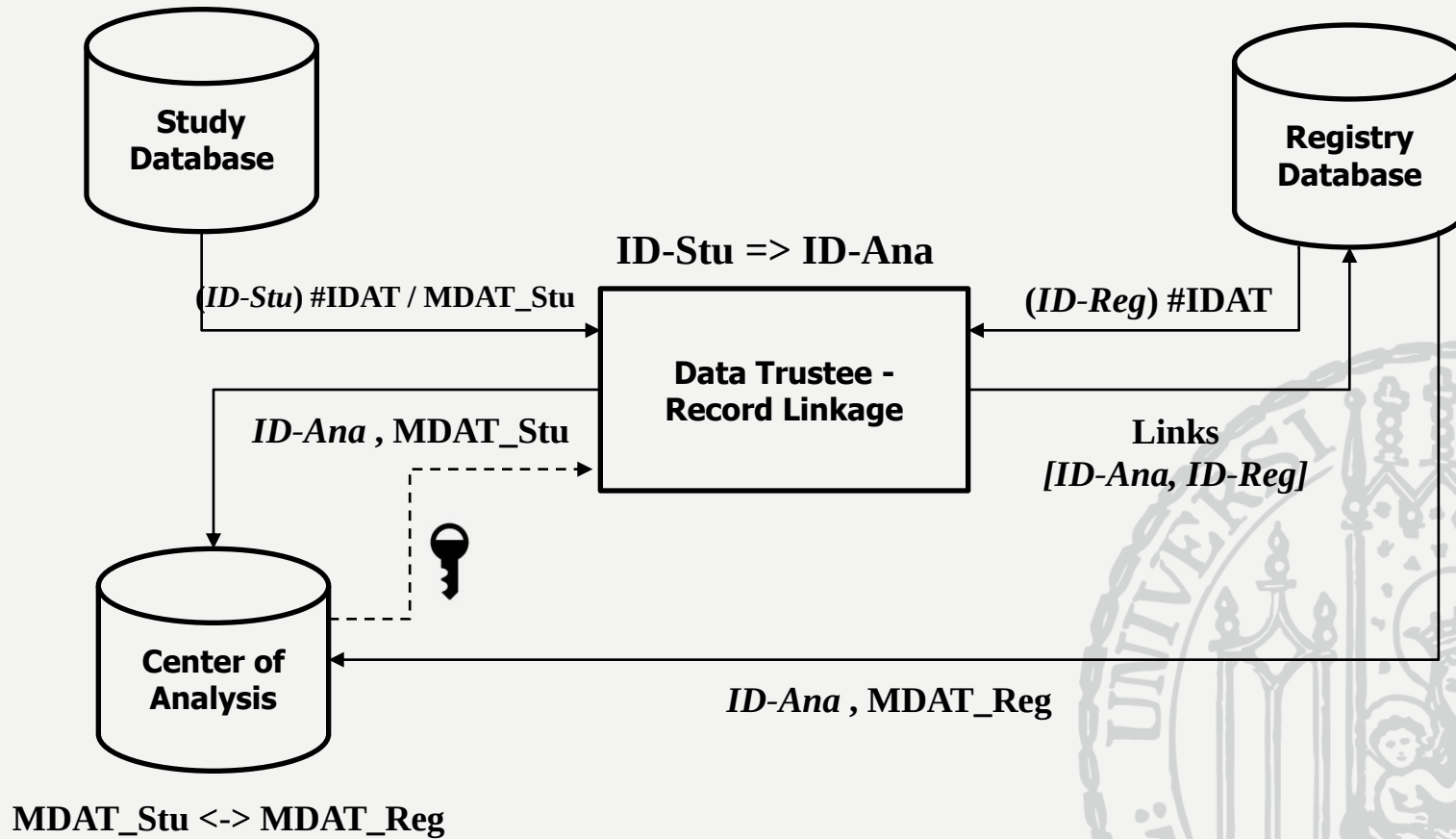


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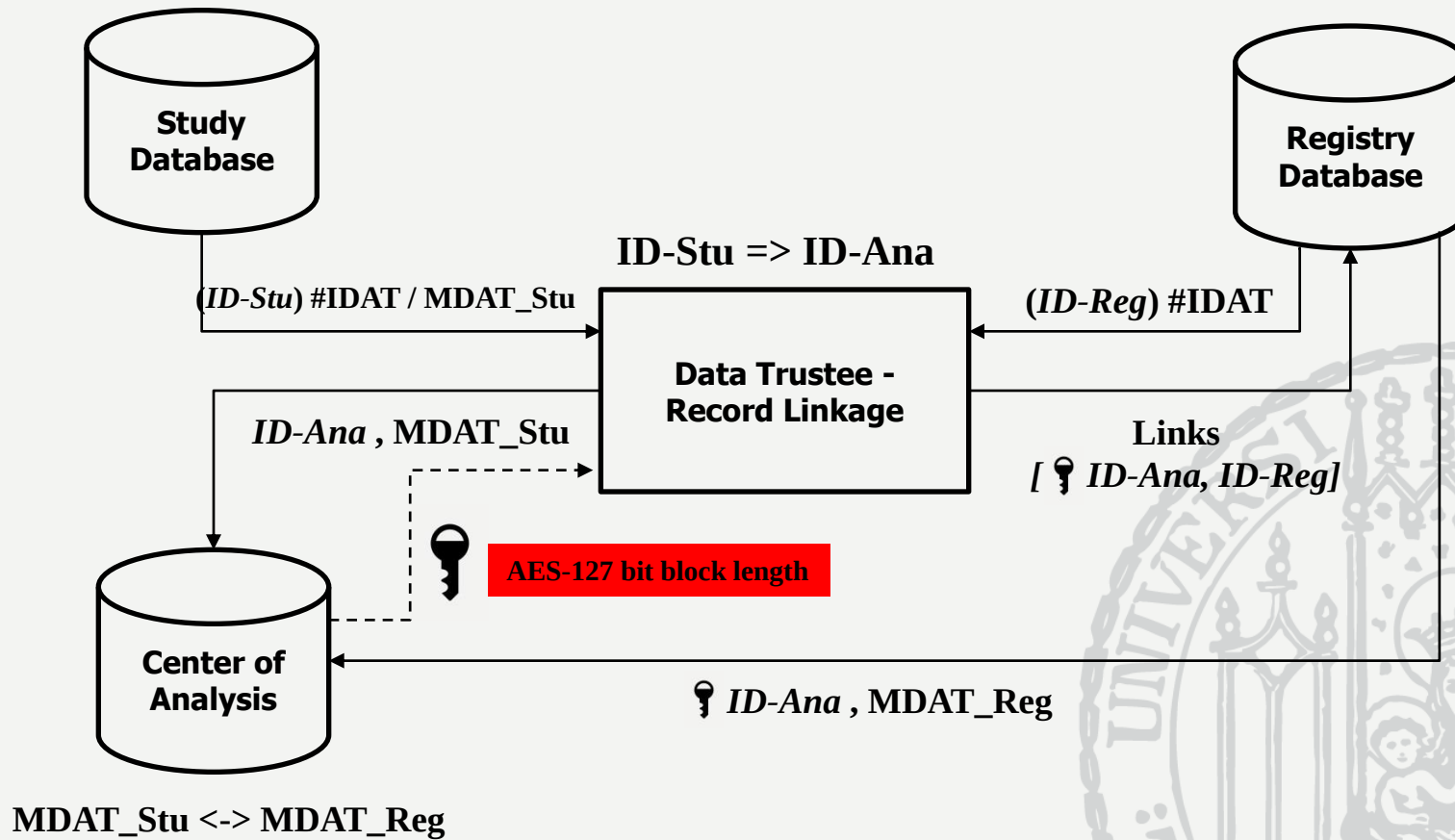
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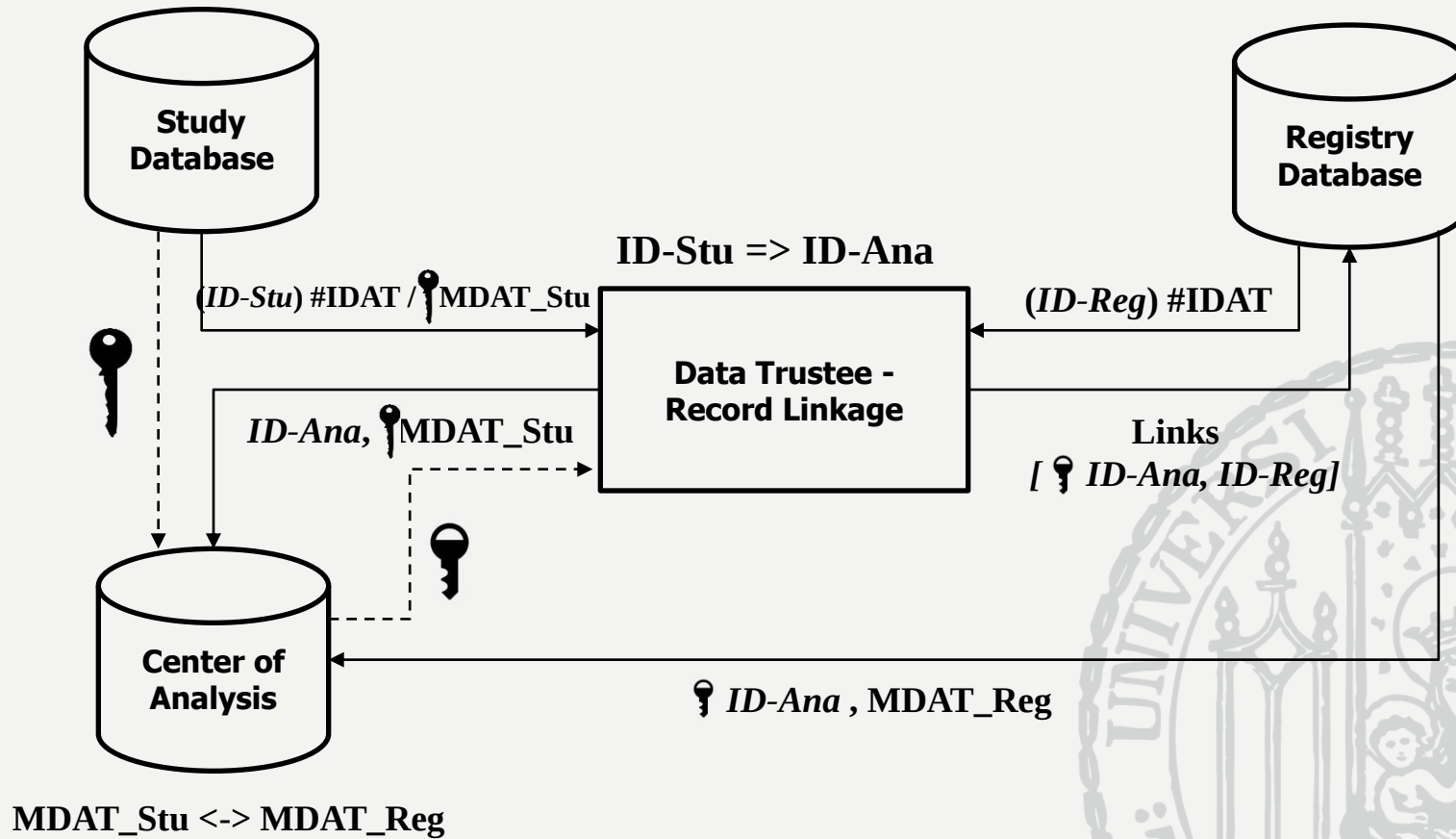


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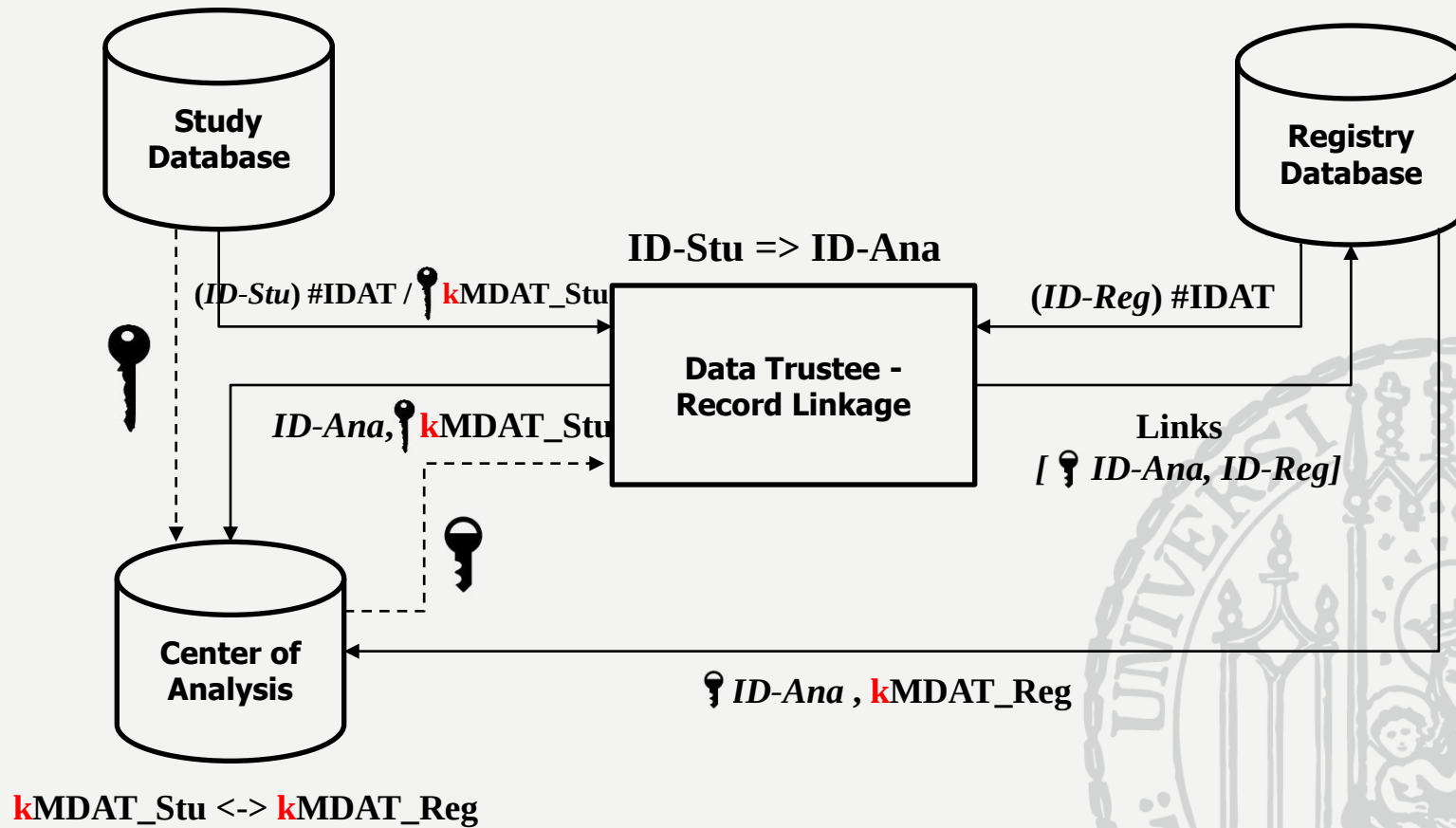
V. MDAT should only be readable for designated institutions

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VI. Prevention of reidentification by *k*-Anonymisation

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VII. Additional Layer of assymetrical transport encryption

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