LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

MIE 2014

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

Daniel NASSEH [a], Jutta ENGEL [a,b], Ulrich MANSMANN [a], Werner TRETTER [b] and Jürgen STAUSBERG [a]

a IBE, Ludwig-Maximilians-Universität München, Germany
b Munich Cancer Registry, Germany

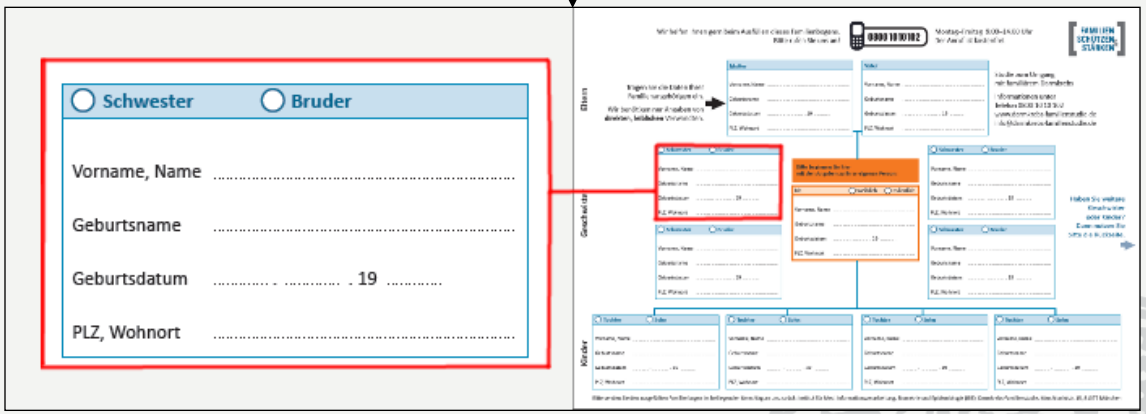
02.09.2014 - Istanbul

Study of family based colorectal cancer

Index-Patient
Newly diagnosed with colorectal cancer

Study of family based colorectal cancer

Index-Patient
Newly diagnosed with colorectal cancer

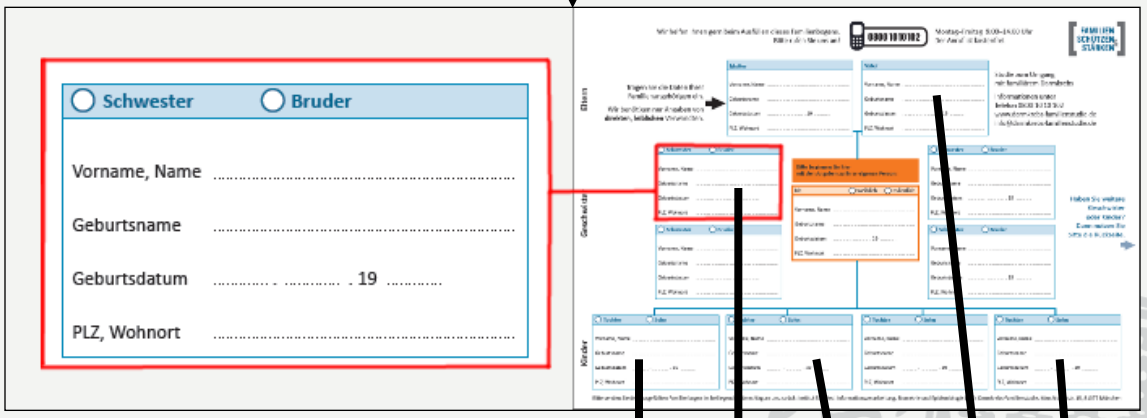


IDAT: Firstname, Lastname, Date of Birth, Adress …

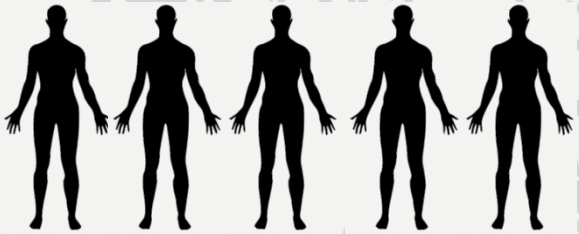
Mansmann U, Stausberg J, Engel J, Heussner P, Birkner B, Maar C. Familien schützen und stärken – Umgang mit familiärem Darmkrebs. *Gastroenterologe*. 2012; 161-162.

Study of family based colorectal cancer

Index-Patient
Newly diagnosed with colorectal cancer



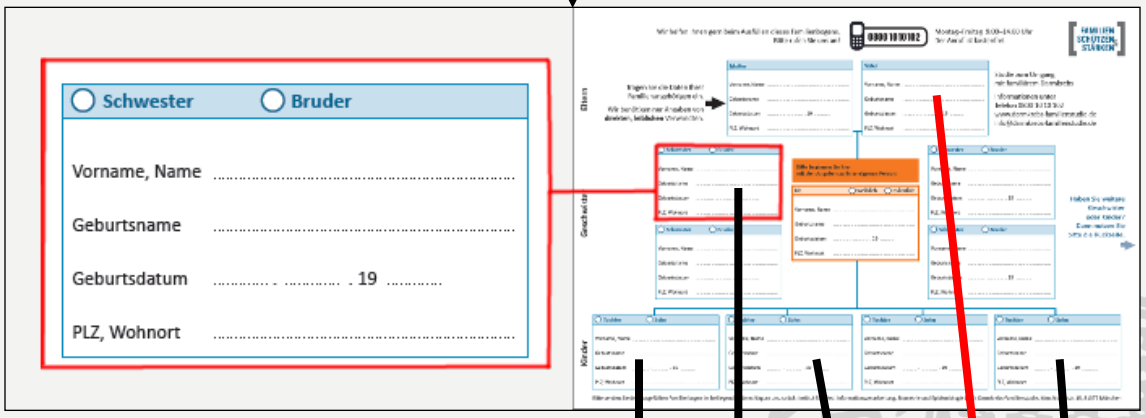
IDAT: Firstname, Lastname, Date of Birth, Adress …



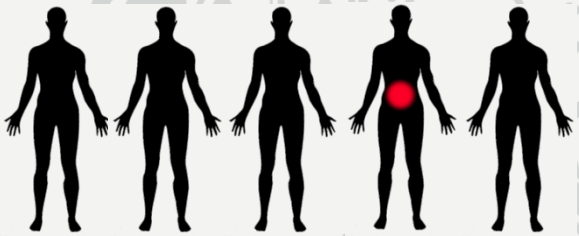
Mansmann U, Stausberg J, Engel J, Heussner P, Birkner B, Maar C. Familien schützen und stärken – Umgang mit familiärem Darmkrebs. *Gastroenterologe*. 2012; 161-162.

Study of family based colorectal cancer

Index-Patient
Newly diagnosed with colorectal cancer



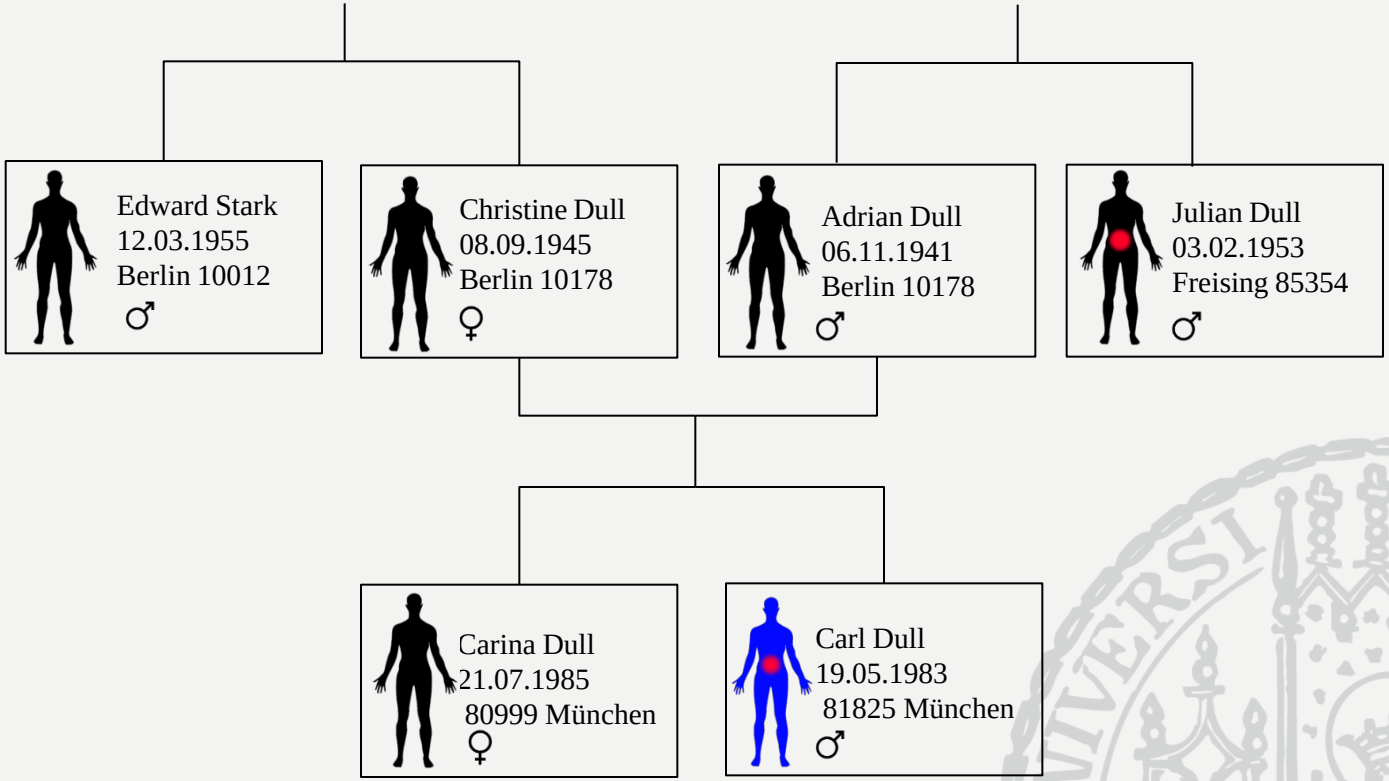
IDAT: Firstname, Lastname, Date of Birth, Adress …



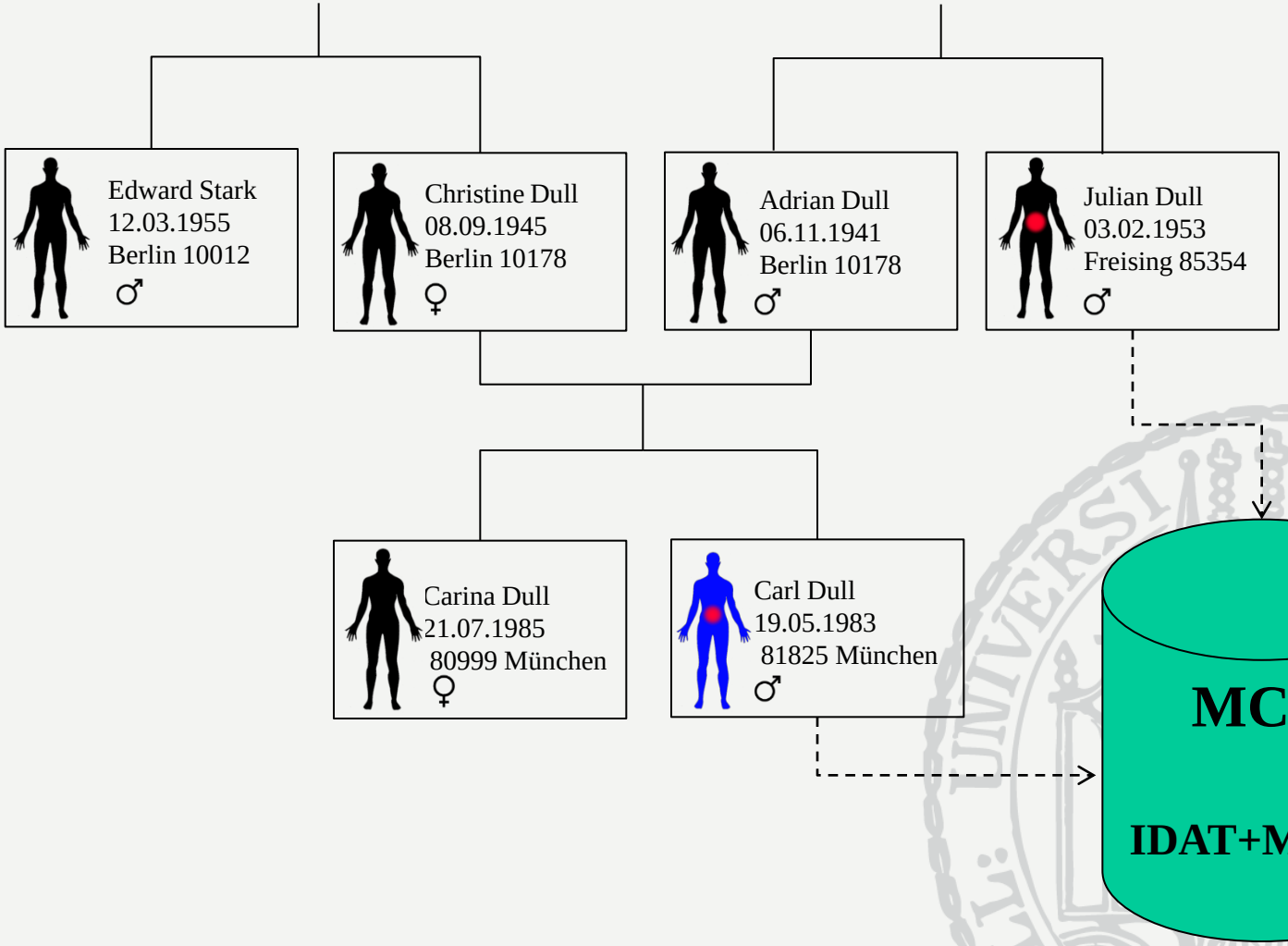
The task: Identifiing relatives who had a history of cancer in the past. If we find one, we also need the corresponding medical data.

Mansmann U, Stausberg J, Engel J, Heussner P, Birkner B, Maar C. Familien schützen und stärken – Umgang mit familiärem Darmkrebs. *Gastroenterologe*. 2012; 161-162.

Identification: Matching study data to registry data (IDAT)

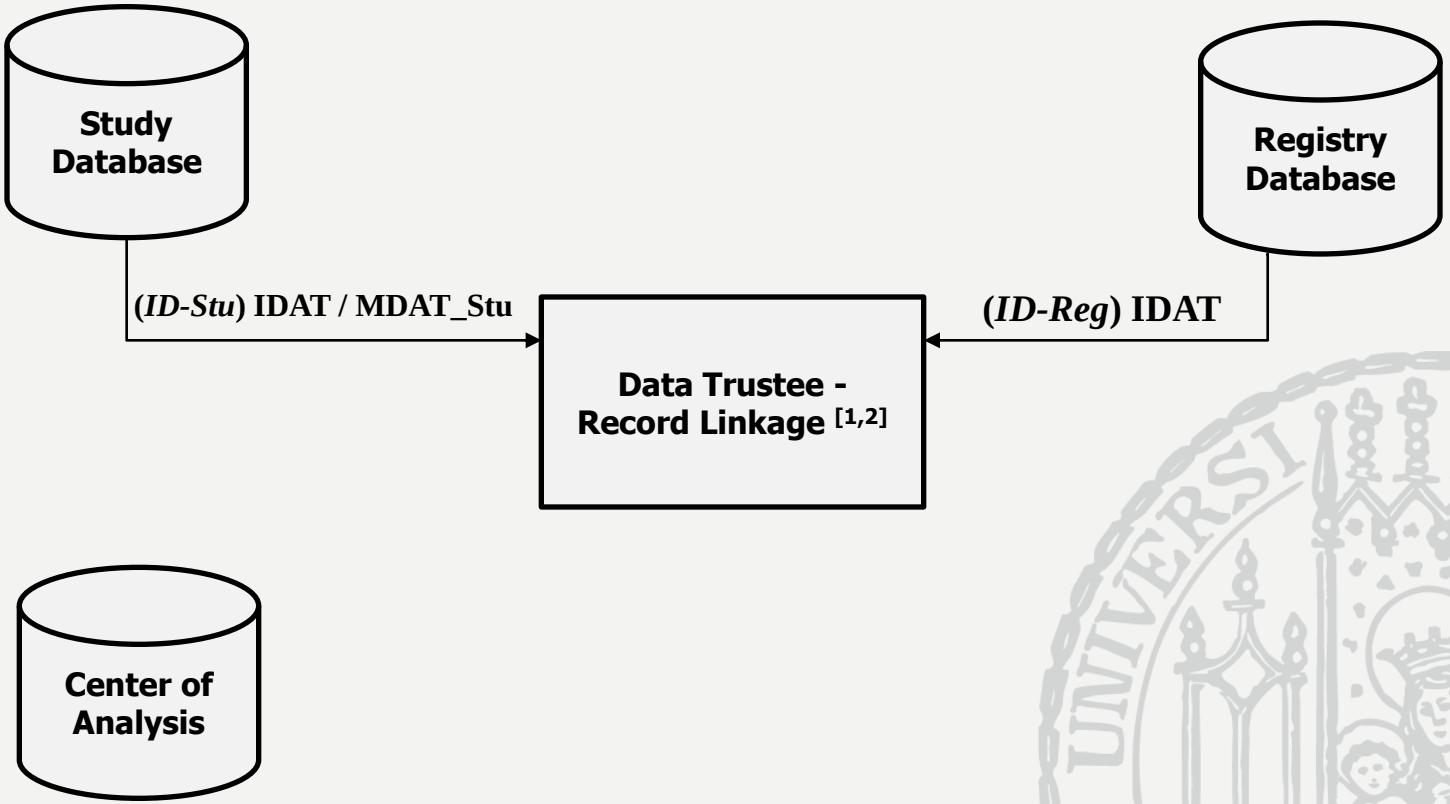


Identification: Matching study data to registry data (IDAT)



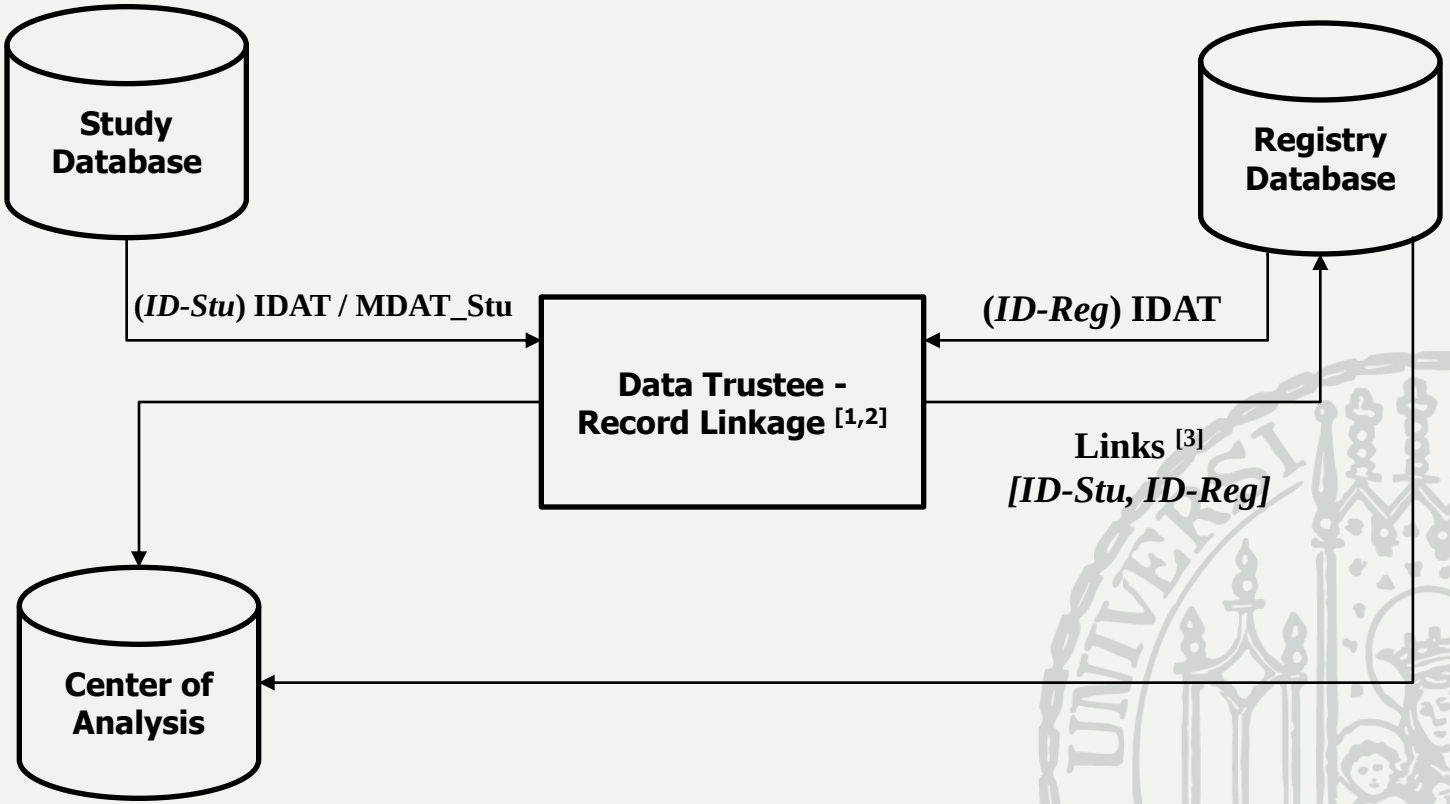
I. Institutional and organisational division of participating parties.

I. Institutional and organisational division of participating parties.



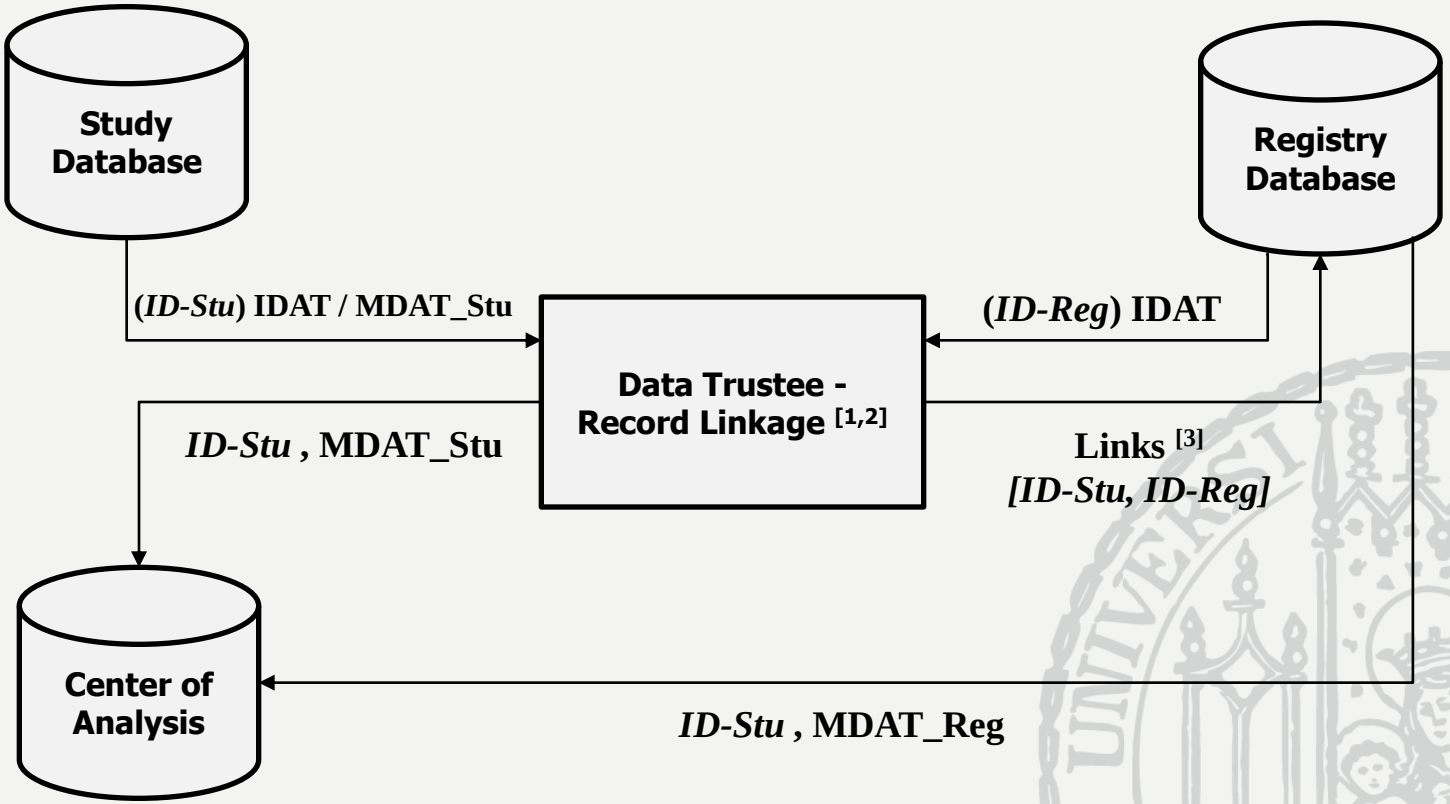
[1] Meyer M. Kontrollnummern und Record Linkage. Das Manual der epidemiologischen Krebsregistrierung. Hentschel S, Katalinie A, editor. Zuckschwerdt. 2011;57-68.
[2] Christen P. Data Matching – Concepts and Techniques for Record Linkage, Entity Resolution, and Duplicate Detection. Heidelberg: Springer; 2012.

I. Institutional and organisational division of participating parties.

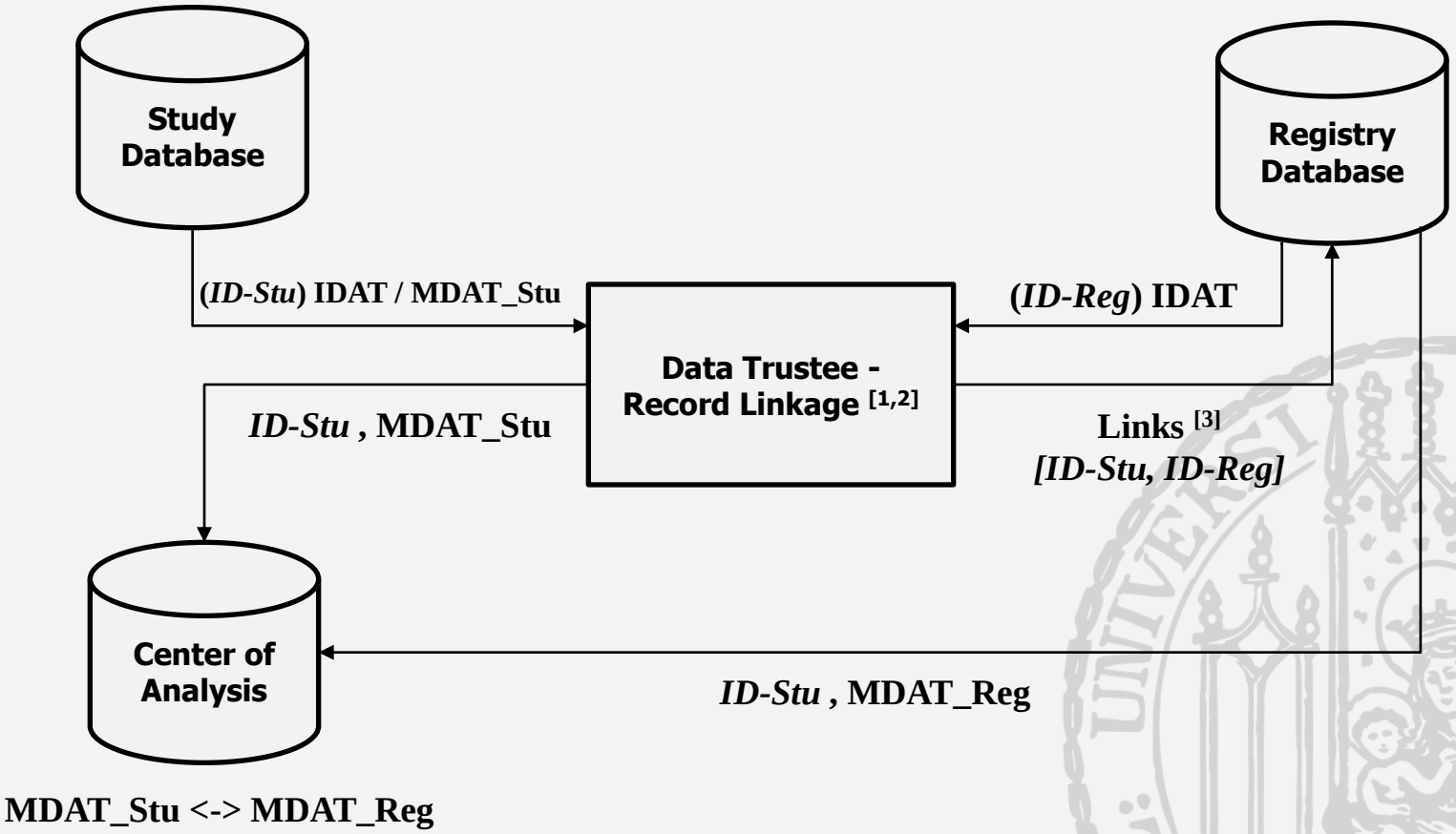


[3] Blakely T, Salmond C. Probabilistic record linkage and a method to calculate the positive predictive value. International Journal of Epidemiology. 2002 Dec; 31(6):1246-52.

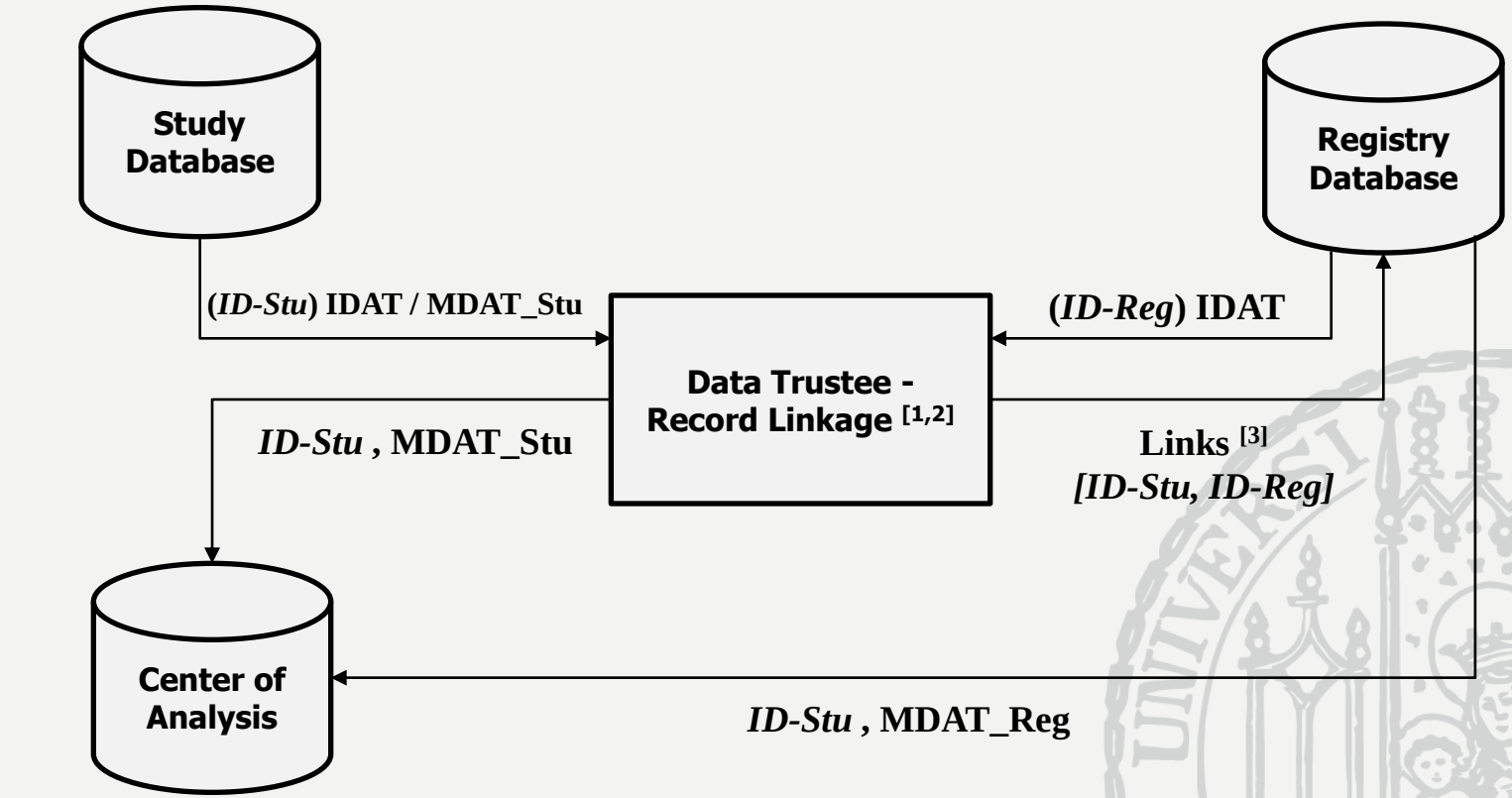
I. Institutional and organisational division of participating parties.



I. Institutional and organisational division of participating parties.



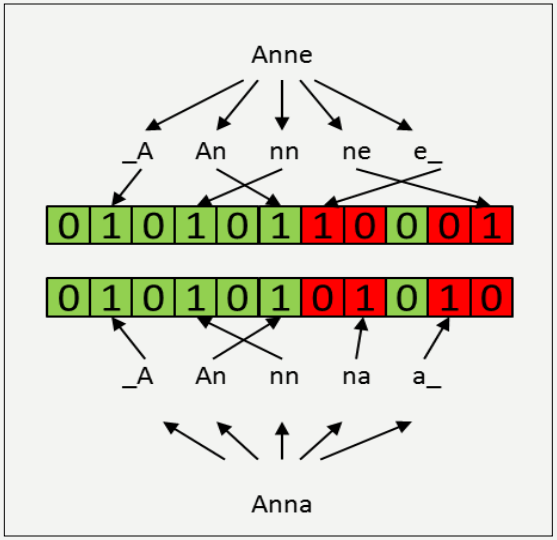
II. No transfer of identifiing data in human readable form



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

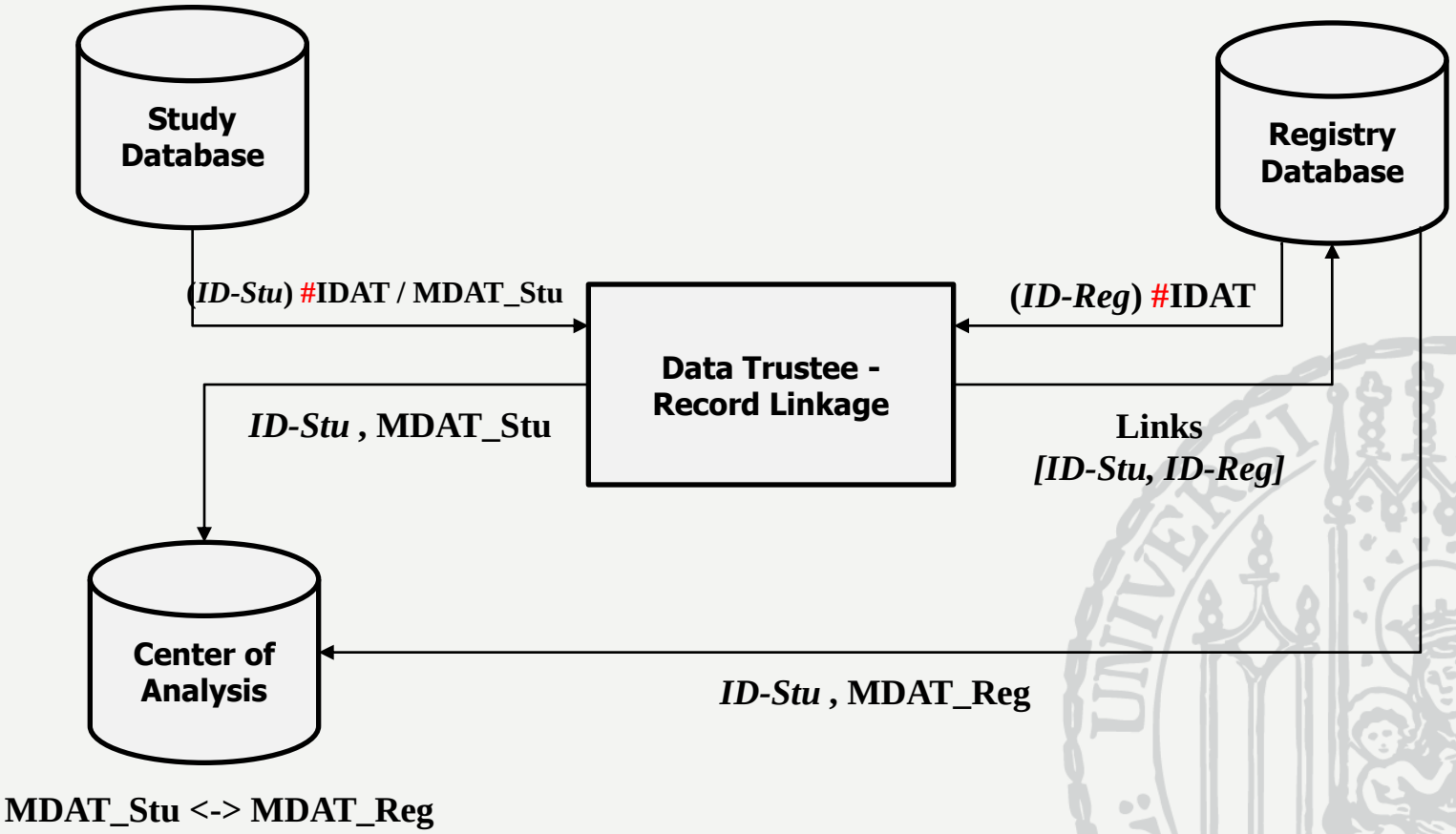
Cleartext	Hashvalue
Meier	05c2d2b4cad1a3f5bf547b484ac6f4a70893e944d5bd6fe0f28db40453bf3f3c
Meyer	876fdfa1d1152c1d024386a1f66e7725f292ef83404fc4d3be79c1b51cc81c45

Variant 2: Transform IDAT into Bloomfilters [2]

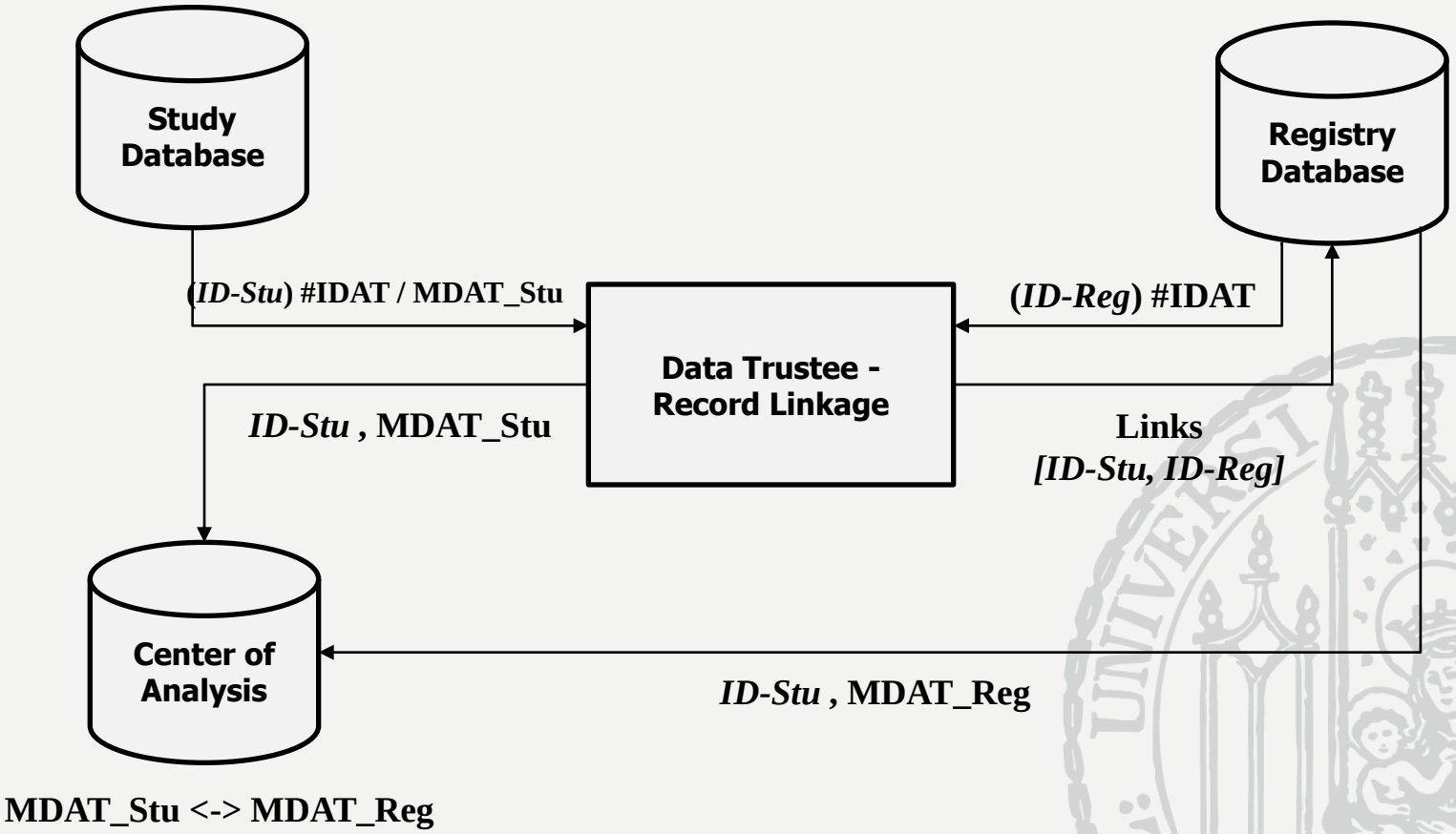


[1] Gilbert H, Handschuh H. Security Analysis of SHA-256 and Sisters. Selected Areas in Cryptography. 2003; 175–193
[2] Schnell R, Bachteler T, Reiher J. Privacy-preserving record linkage using Bloom filters. *BMC Medical Informatics and Decision Making*. 2009; 9:41

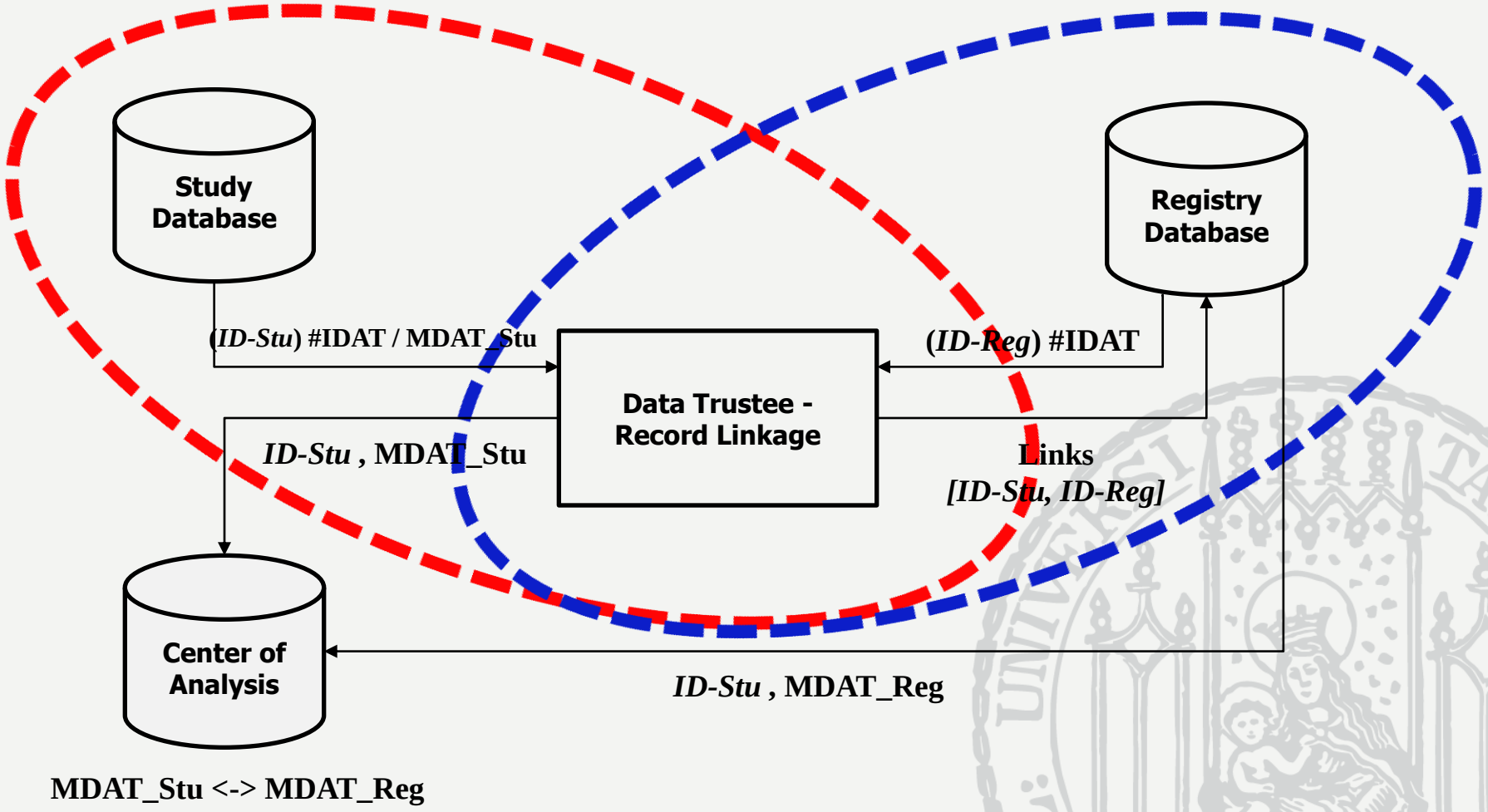
II. No transfer of identifiing data in human readable form



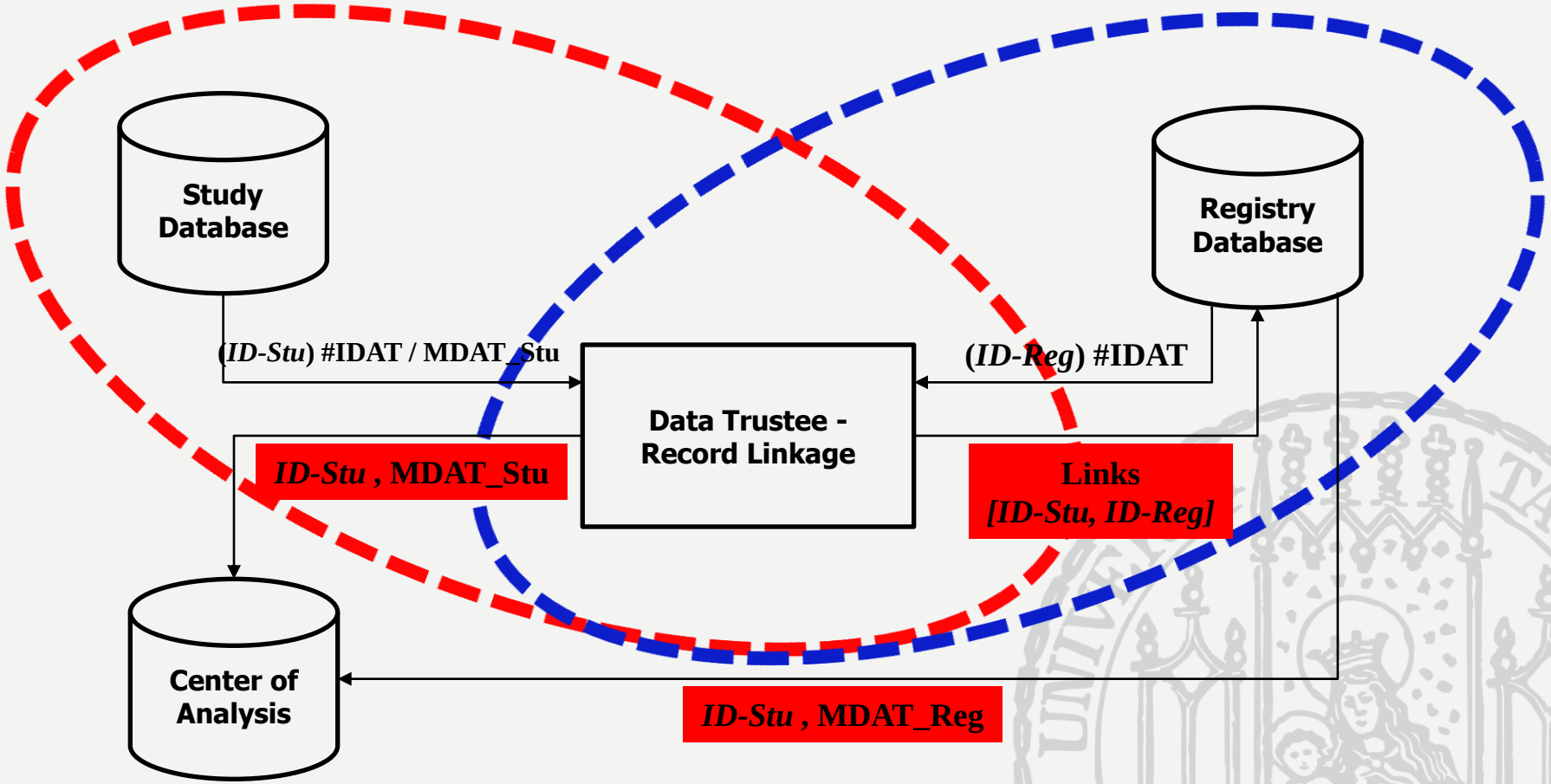
III. Registry-ID and study-ID may only be shared with the data-trustee



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

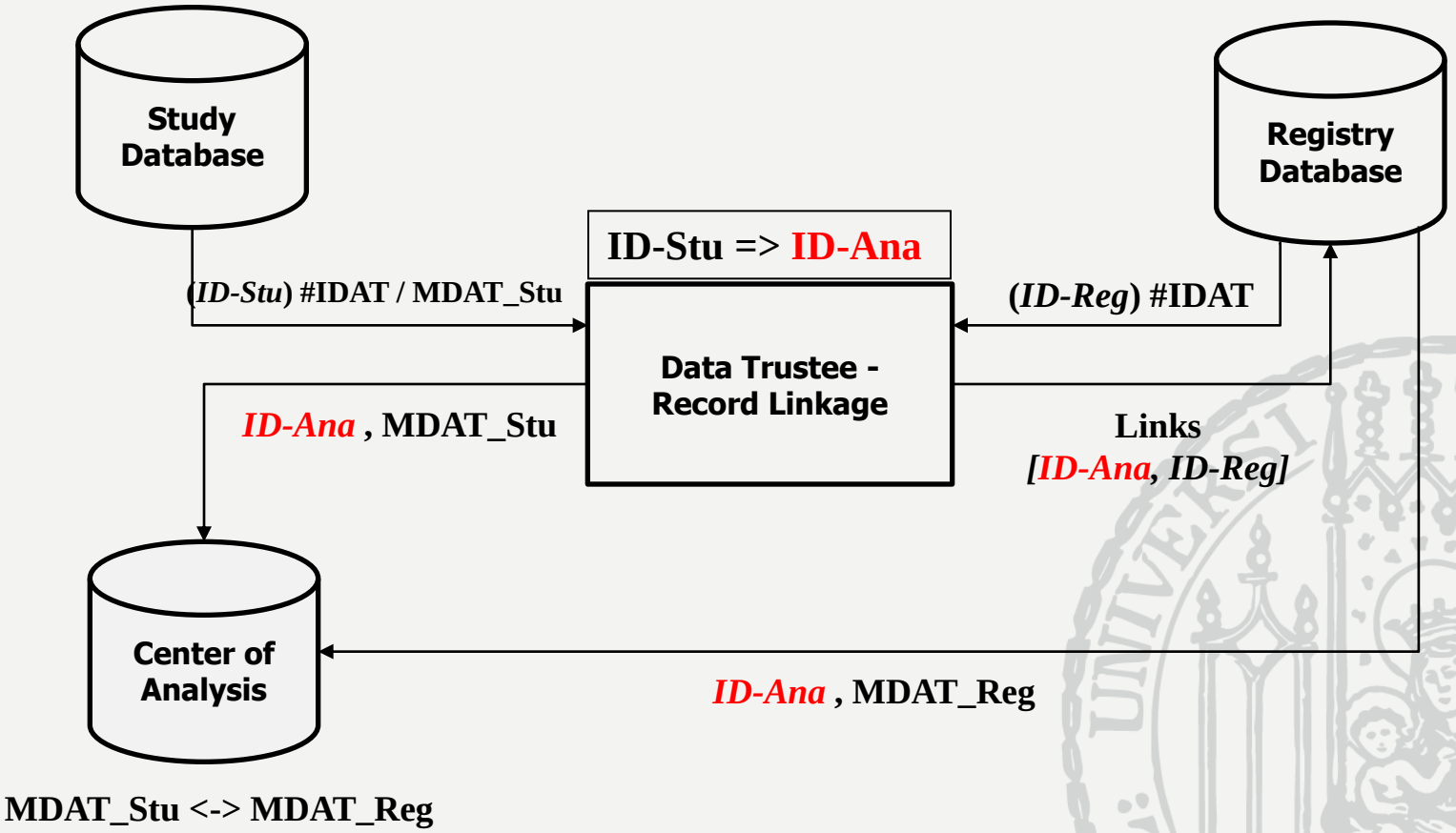


III. Registry-ID and study-ID may only be shared with the data-trustee

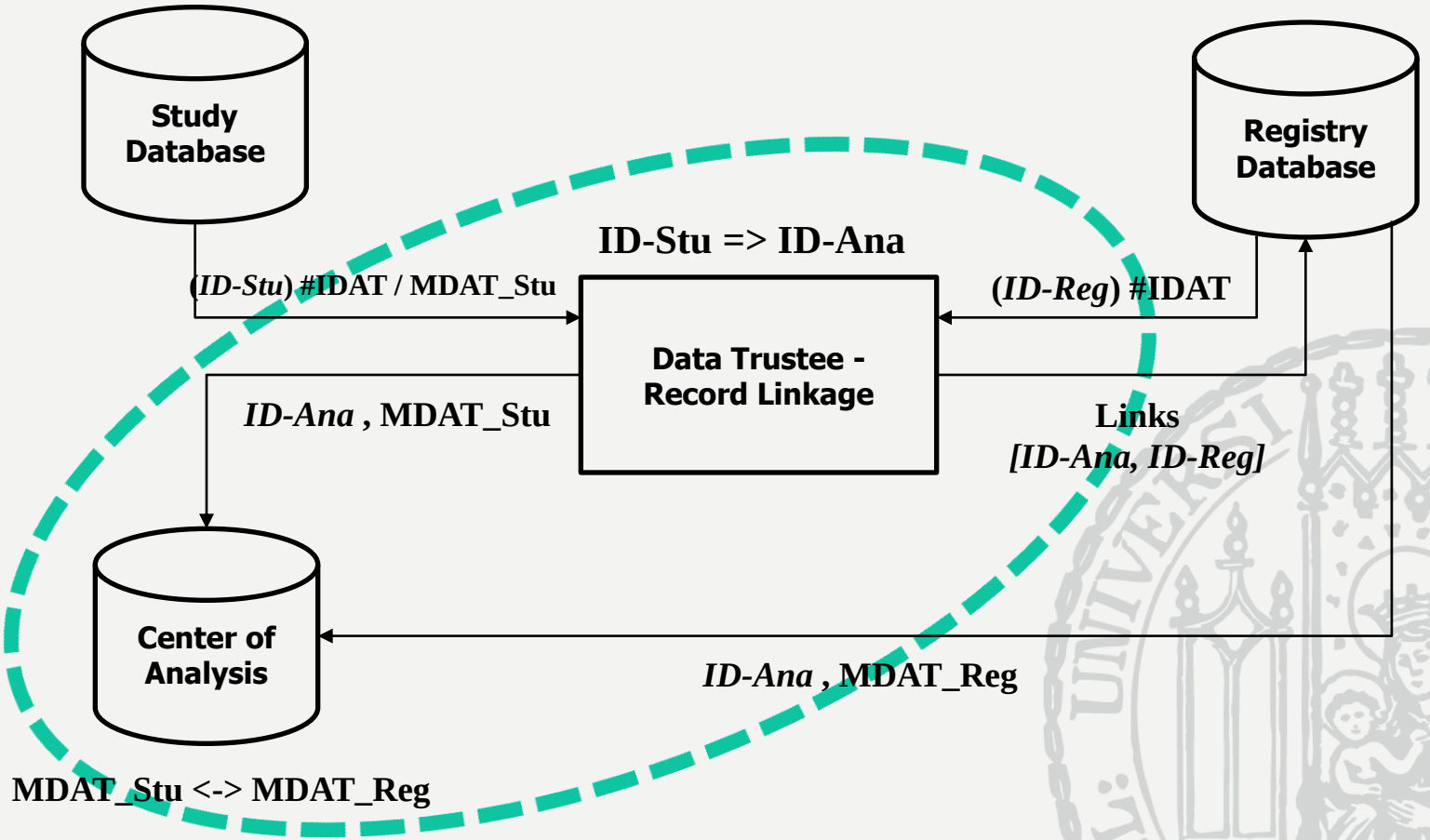


MDAT_Stu <-> MDAT_Reg

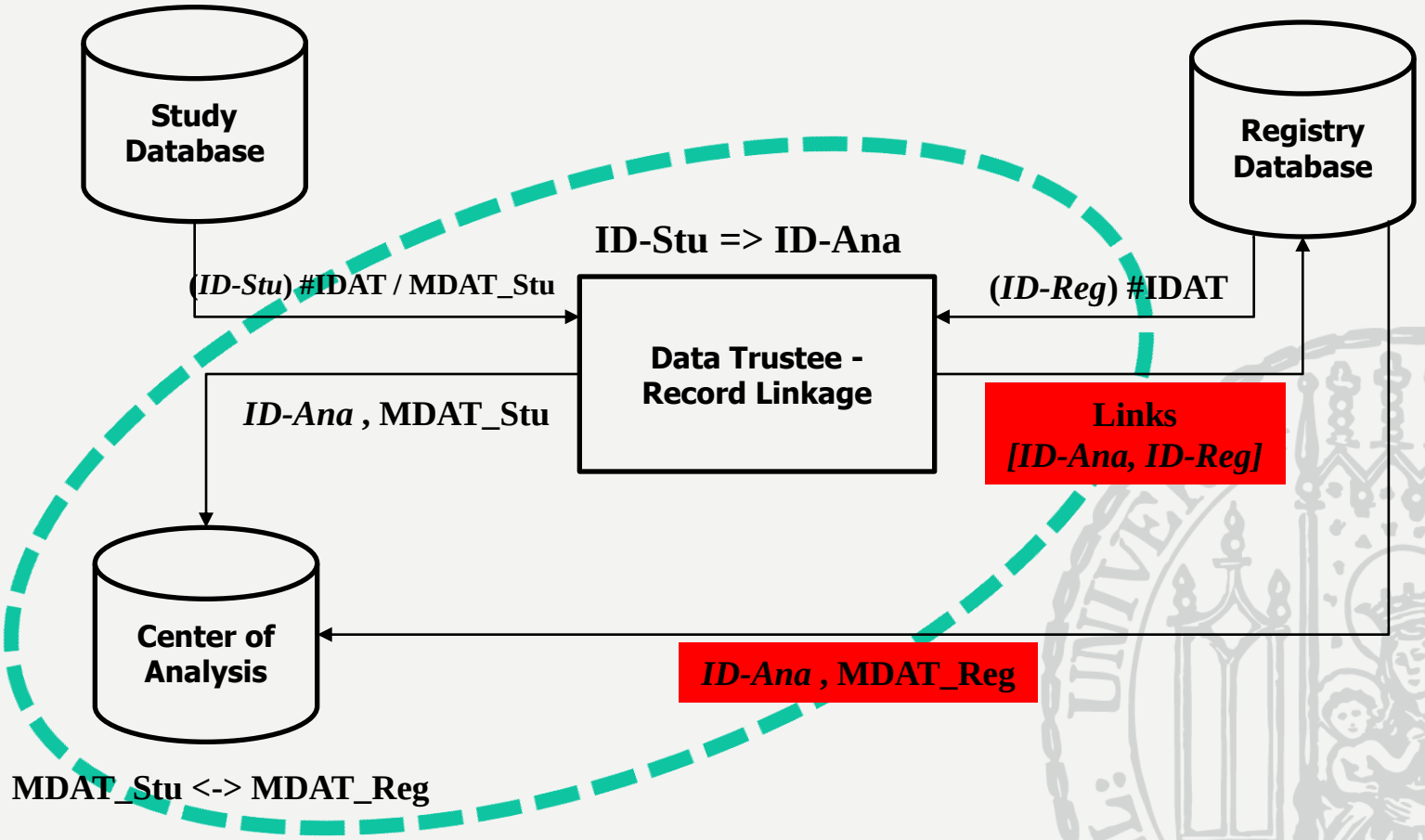
III. Registry-ID and study-ID may only be shared with the data-trustee



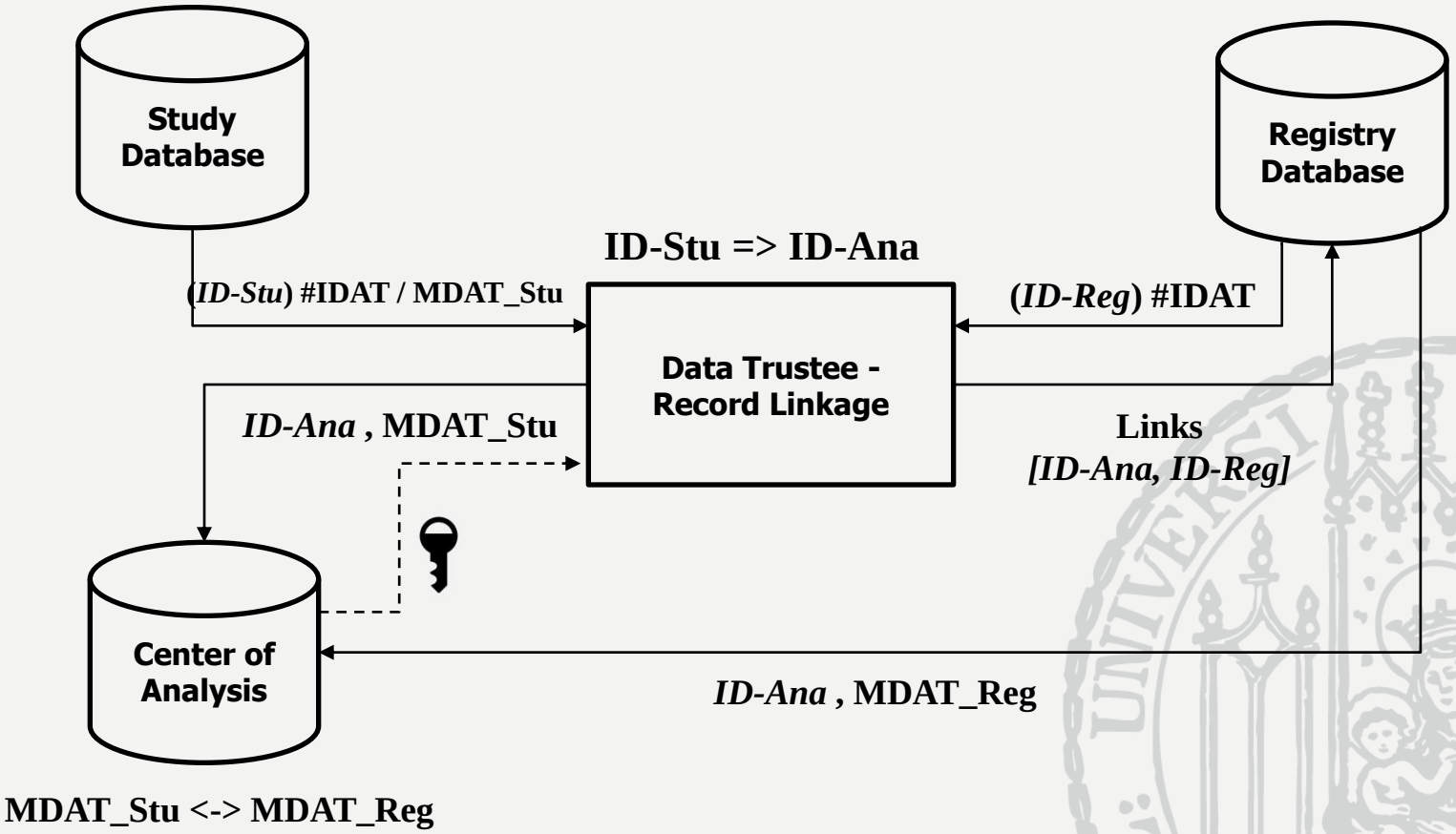
IV. Analysis-ID may only be shared between the Data Trustee and the Center of Analysis



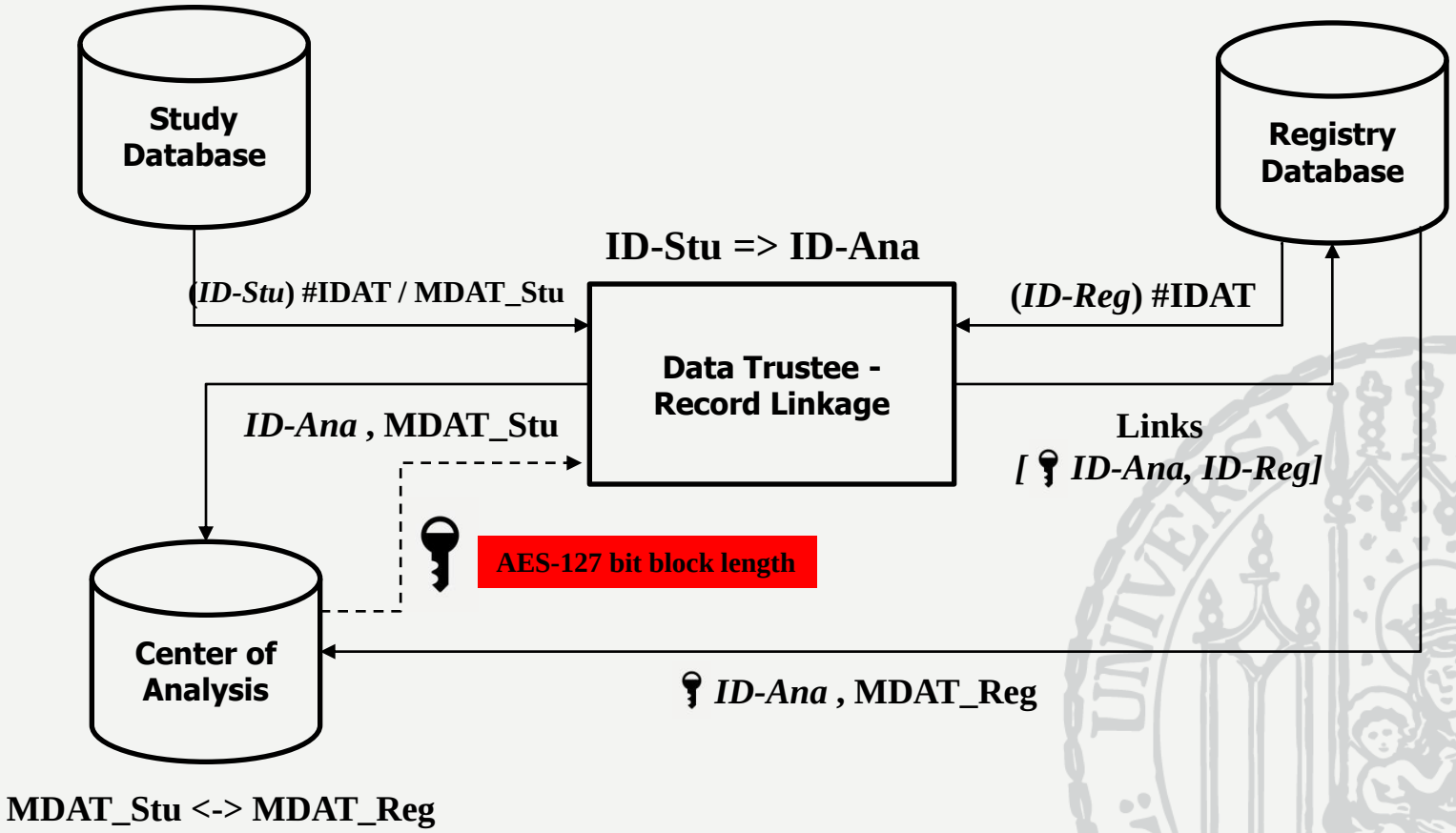
IV. Analysis-ID may only be shared between the Data Trustee and the Center of Analysis



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

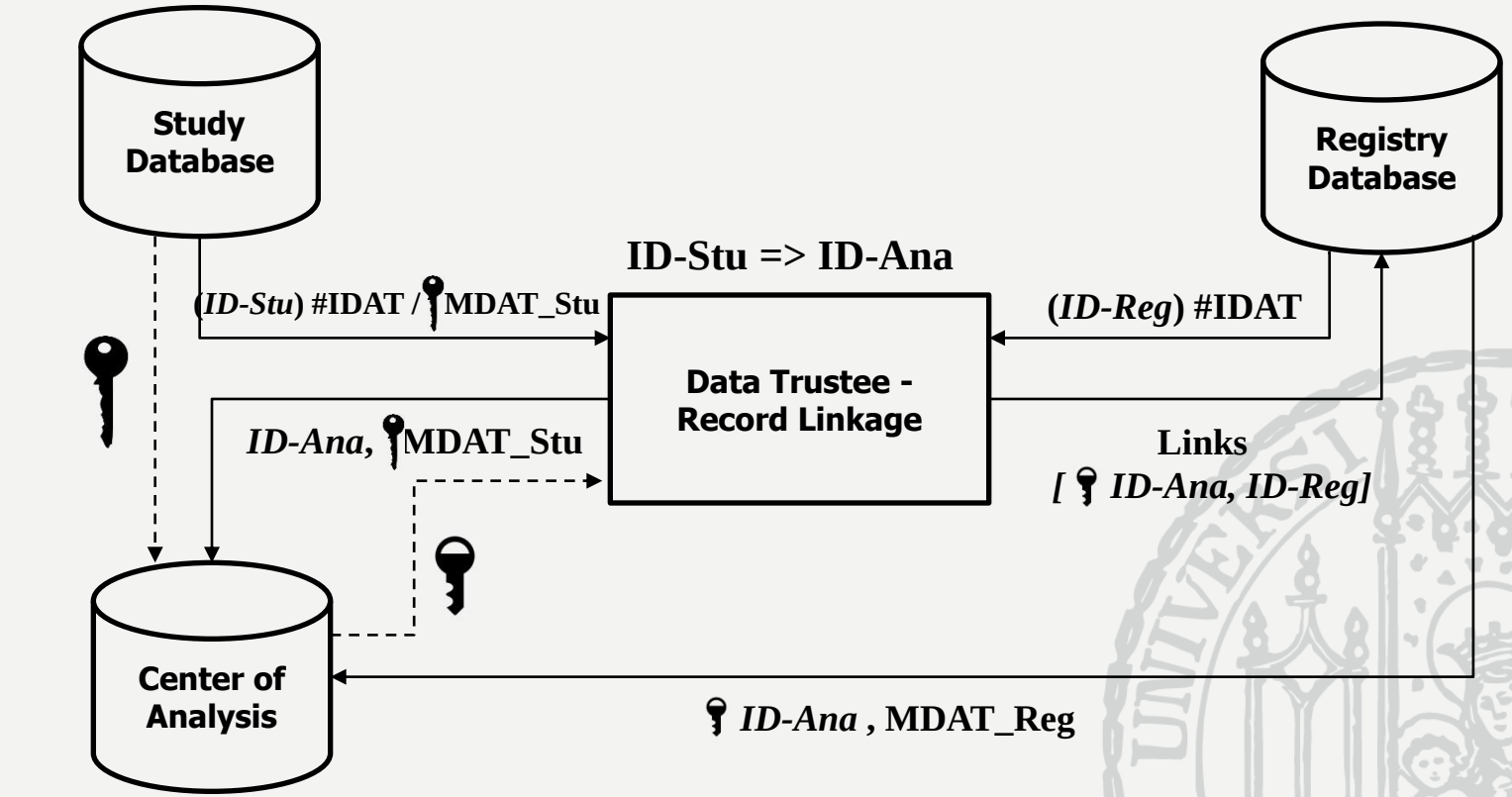


IV. Analysis-ID may only be shared between the Data Trustee and the Center of Analysis

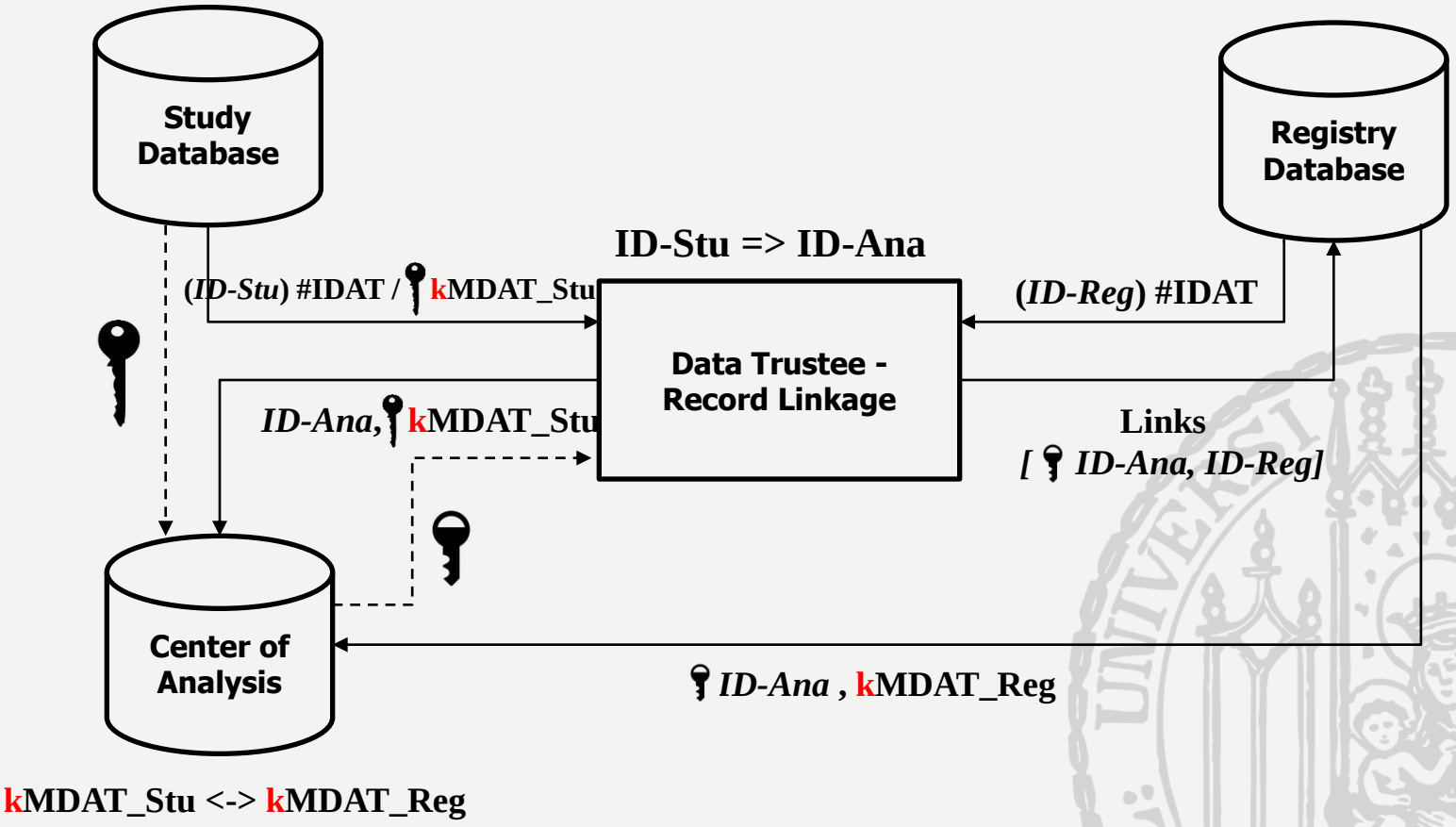


[1] BSI - Technische Richtlinie, Kryptographische Verfahren: Empfehlungen und Schlüssellängen, BSI TR-02102. 2013;
[2] Daemen J, Rijmen V. AES Proposal: Rijndael. 1999;

V. MDAT should only be readable for designated institutions

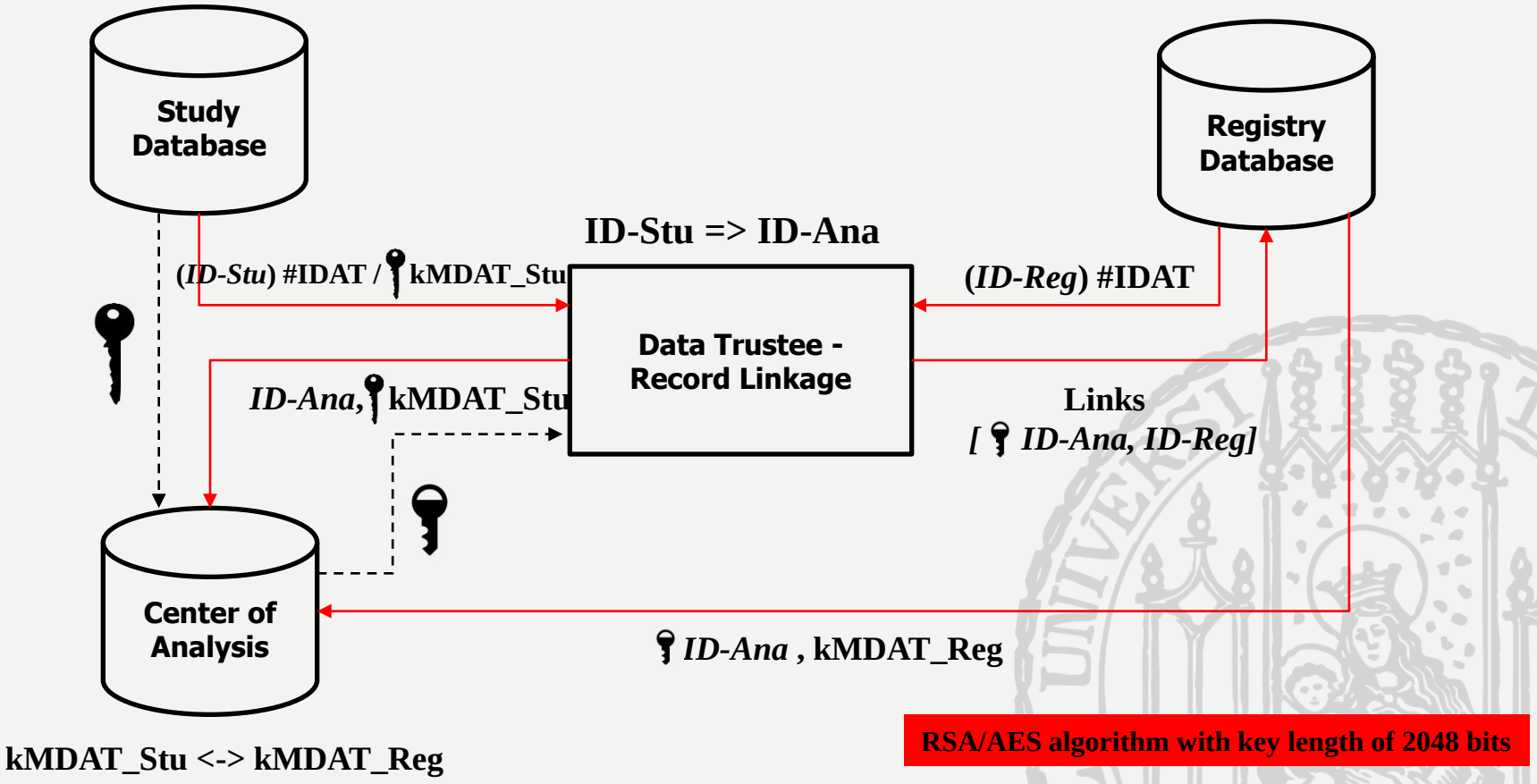


VI. Prevention of reidentification by k-Anonymisation



L Sweeney. K-anonymity: A model for protecting privacy. *International journal of uncertainity, fuzziness and knowledge-based systems*. 2002; 10(5).

VII. Additional Layer of assymetrical transport encryption



Palanisamy V, Jeneba M. Hybrid cryptography by the implementation of RSA and AES. *International Journal of Current Research.* April 2011;33(4): 241-44.

LMU LUDWIG-MAXIMILIANS-UNIVERSITÄT MÜNCHEN

Any questions?

MIE 2014