

Pseudonymisation: Applications in Medical Research

ULD - ENISA Workshop: Pseudonymisation and relevant security technologies

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Based on slides from S.C. Semler, J. Drepper, I. Schlünder

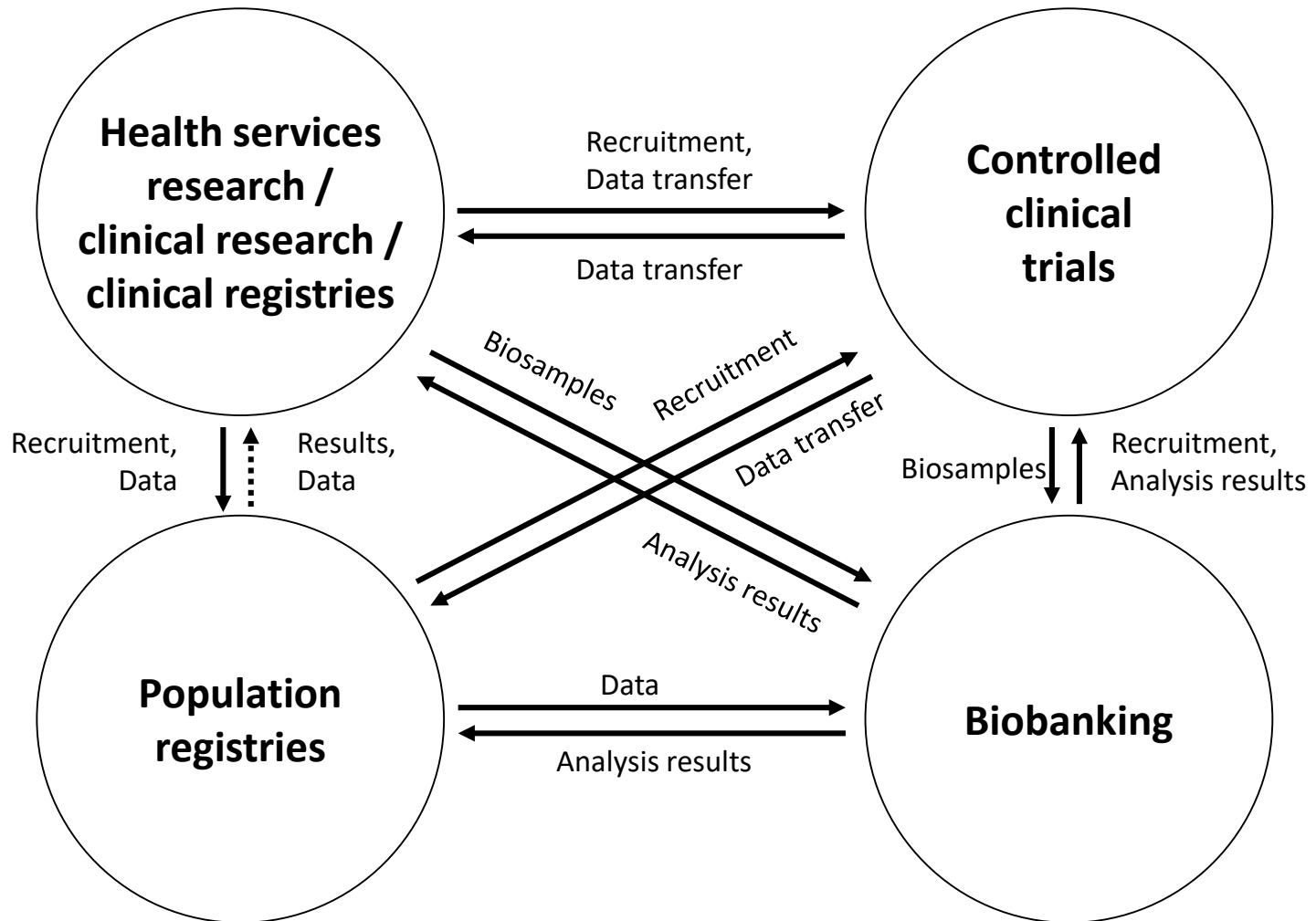
Introducing TMF



- ▶ Non-profit umbrella organisation for networked medical research in Germany
- ▶ 64 members with more than 100 sites
- ▶ Funding
 - ▶ indirect funding from BMBF, DFG, BMEL, etc.
 - Membership eligible for funding
 - ▶ Third-party funding projects



Areas of medical research: overview



Areas of medical research: properties

- ▶ Different areas of medical research
 - ▶ are subject to different legal frameworks
 - ▶ that vary from area to area

- ▶ As a consequence, different medical research projects require different data protection concepts

- ▶ Often, data must be identifiable
 - ▶ necessary for consultative participation (study leaders, experts)
 - ▶ for correct assignment of data and quality management

TMF's generic data protection concept



- ▶ Combines the experience of TMF's Working Group on Data Protection from over 15 years of consulting medical research projects
- ▶ Recommended by the Conference of Federal and State Data Protection Commissioners
- ▶ Data pseudonymisation as a core protection measure

TMF data protection concept: approach

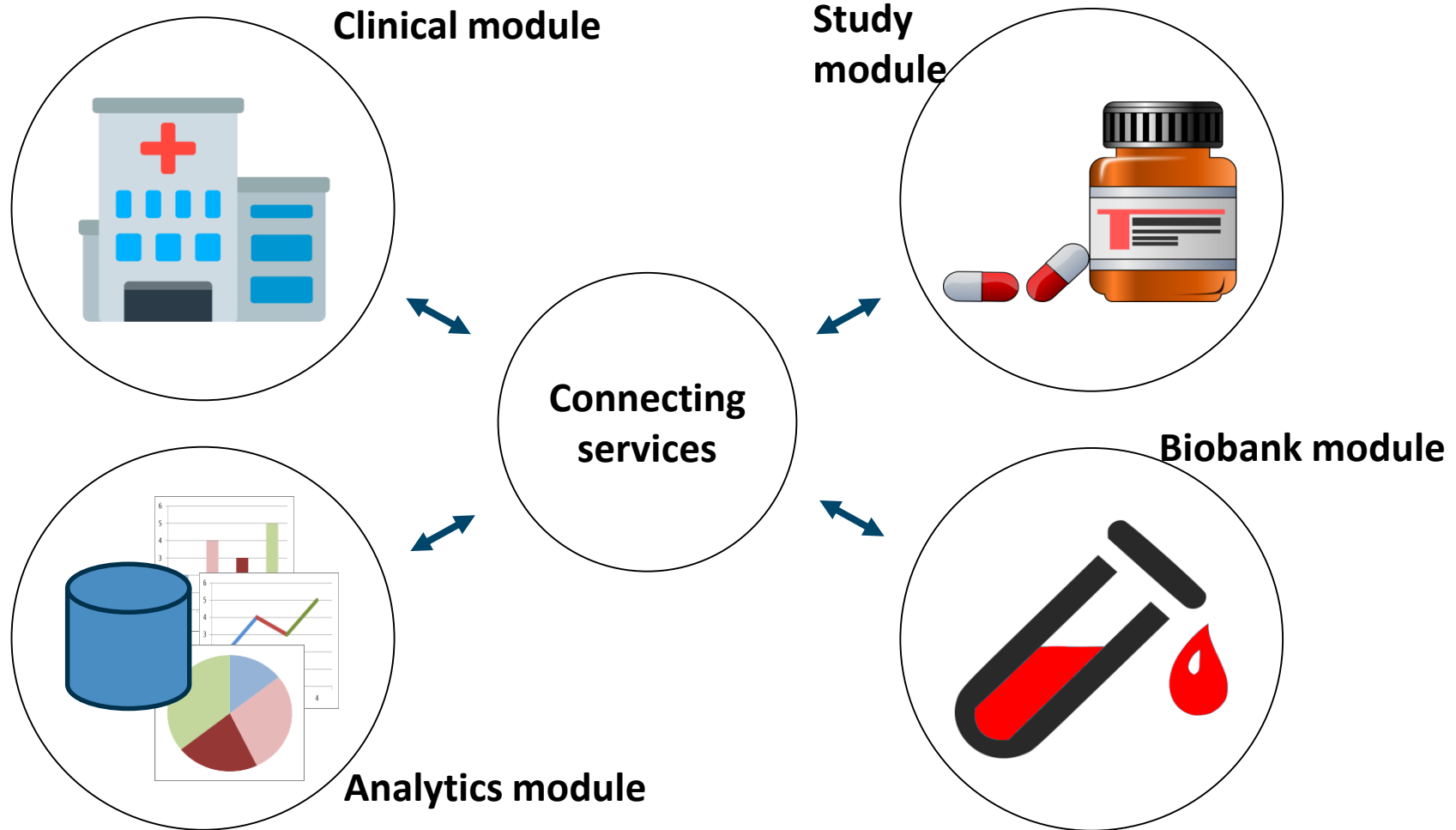
Modular, scalable architecture with the goal of flexibility and ease of implementation

- Pseudonymization and separate storage of directly identifying data and medical data
- Areas with differing legal frameworks covered in corresponding modules
- Modules are connected via central services, e.g. for (de-) pseudonymization

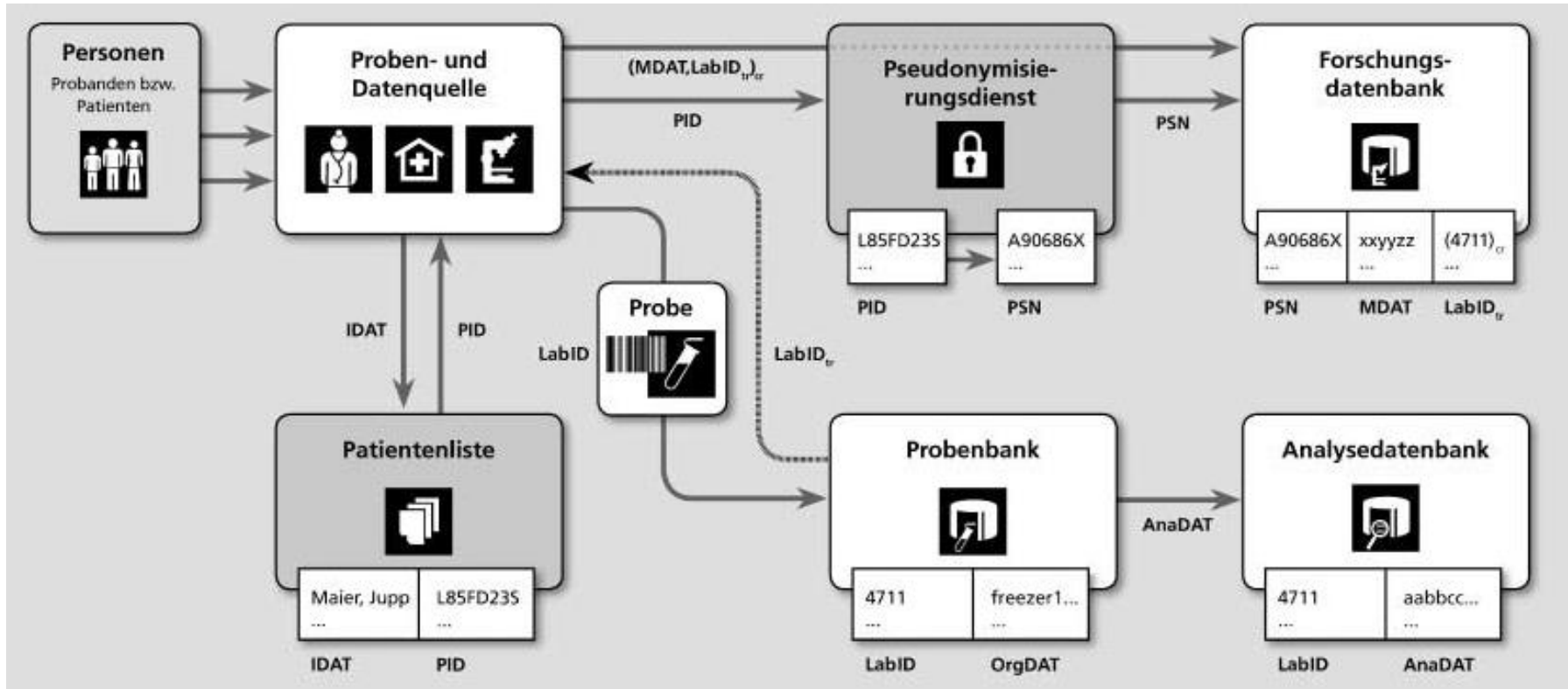
Structure

- Data protection concepts for the individual areas ("modules")
- Data protection concept for the overall architecture ("maximum model")

TMF data protection concept: modules



TMF data protection concept: details



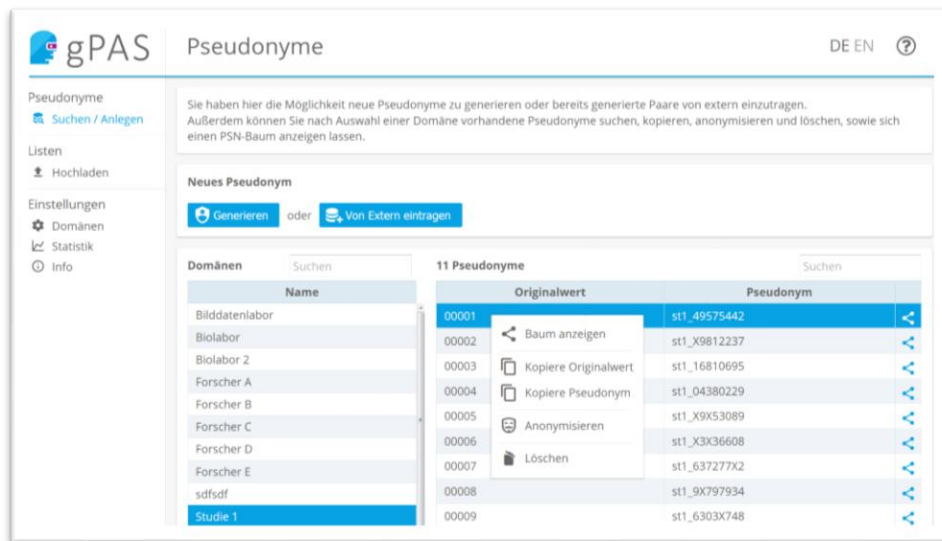
Source: K. Pommerening, "Das Datenschutzkonzept der TMF für Biomaterialbanken", it - Inf. Technol., vol. 49, no. 6, pp. 352–359, 2007

Connecting services and tools

Provided by the community, developed with third-party funding

Take domain specifics into account, e.g. pseudonyms must be human-readable and are often printed on barcodes

Example:



The screenshot shows the gPAS Pseudonyme interface. On the left, there is a sidebar with navigation options: Suchen / Anlegen, Listen, Hochladen, Einstellungen, Domänen, Statistik, and Info. The main content area has a header with the gPAS logo, the title 'Pseudonyme', and language options 'DE EN'. Below the header, there is a text block explaining the functionality: 'Sie haben hier die Möglichkeit neue Pseudonyme zu generieren oder bereits generierte Paare von extern einzutragen. Außerdem können Sie nach Auswahl einer Domäne vorhandene Pseudonyme suchen, kopieren, anonymisieren und löschen, sowie sich einen PSN-Baum anzeigen lassen.' Below this, there are two buttons: 'Generieren' and 'Von Extern eintragen'. The main part of the interface is a table with two columns: 'Domänen' and '11 Pseudonyme'. The 'Domänen' column lists various domains like 'Bilddatenlabor', 'Biolabor', 'Forscher A', etc. The '11 Pseudonyme' column shows a table with 'Originalwert' and 'Pseudonym' columns. A context menu is open over the first row of the pseudonym table, showing options like 'Baum anzeigen', 'Kopiere Originalwert', 'Kopiere Pseudonym', 'Anonymisieren', and 'Löschen'.

Domänen	Suchen	Originalwert	Pseudonym
Bilddatenlabor	00001		st1_49575442
Biolabor	00002		st1_X9812237
Biolabor 2	00003		st1_16810695
Forscher A	00004		st1_04380229
Forscher B	00005		st1_X9X53089
Forscher C	00006		st1_X3X36608
Forscher D	00007		st1_637277X2
Forscher E	00008		st1_9X797934
sdfsdf	00009		st1_6303X748

Source: <https://www.ths-greifswald.de/forscher/gpas/>

Thank you for your attention!



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