Protecting Patients' Rights in Medical Research Networks

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Integrate Health Care and Medical Research

To advance diagnostic and therapeutic knowledge.
Keep data and biomaterials for future research

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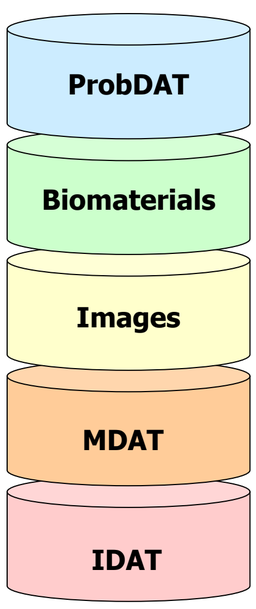
Protect Patients' Data and Biomaterials

According to rules of ethics and professional discretion as well as national and international data protection laws.

Separate Informational Powers



Data from analyses

Biomaterials, associated data

Images and associated data

Medical data

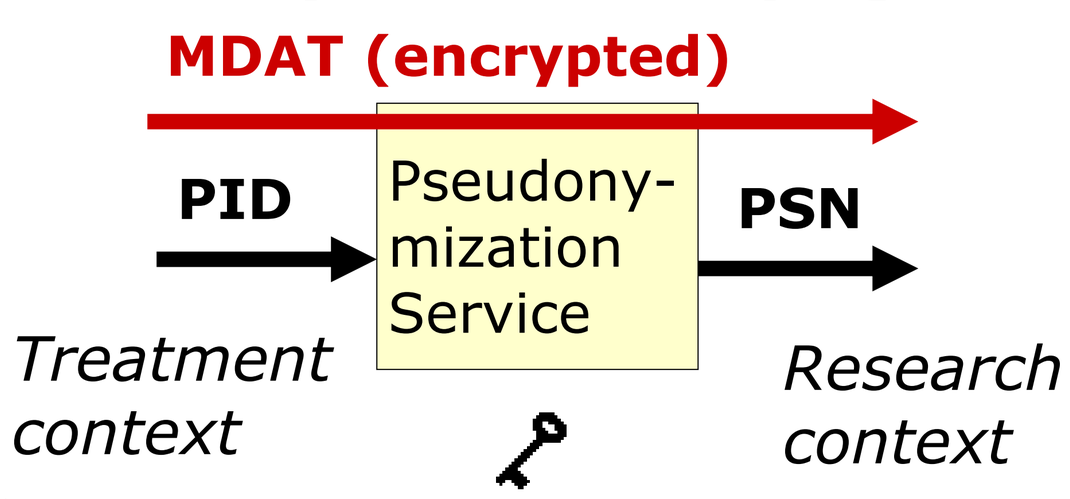
Identifying data

Keep information at distinct locations with independent supervision.
Let Trusted Third Parties control data flows.

Use distinct pseudonyms for MDAT, Biomaterials, Images

Additional safeguards compensate for
- **vaguely specified purpose**
- **unlimited storage time**

Pseudonymize Identifying Data



A pseudonym (PSN) is an encrypted unique Patient Identifier (PID).

The TMF Concept

A "generic" model with variants for the processing of information in research networks and biobanks.
Methods: *Separation of Informational Powers* and *Pseudonymization* together with carefully formulated *Informed Consent Templates* and *Standard Operating Procedures*.
Several networks followed this approach. Others will follow.
The German Data Protection Commissioners approved this concept.

The TMF Concept enables long time medical research data bases and biobanks, fulfils the privacy requirements, and gives freedom for medical research while protecting patients' rights.

TMF, Telematikplattform für Medizinische Forschungsnetze e. V.

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