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Data Harmonization in Organ Transplantation

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New Tools for Data Harmonization and Their Potential Applications in Organ Transplantation

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What is data harmonization?

- **Definition:** Data harmonization is the process of merging data from various sources and standardizing it into a single format.
- **Similar terms:**
  - **Record Linkage** : Integrating datasets using a **unique identifier**
  - **Data Warehousing** : Storing data from multiple sources in a **centralized location**
  - **Data Standardization** : Converting various units of data into a **common framework**
  - **Data Integration** : Combining data from different sources to provide a **unified view**
  - etc.
- **Prospective vs. Retrospective Harmonization:** Setting up studies for consistency vs. standardizing data after collection.

Introduction

Why do we need data harmonization?

- **Standardizing Data Across Regions and Systems:** To ensure that all parties use a standardized format for recording and sharing data.
- **Enhancing Decision-Making:** Standardized, high-quality data aids in informed decision-making for patient care, organ allocation, and transplant outcomes.
- **Facilitating Collaborative Research and Innovation:** Harmonized data enables comprehensive analyses, supporting research efforts to improve transplant protocols and long-term outcomes.

Global initiatives in data harmonization

- **Standardization Initiatives:** Various projects and tools exist to standardize terminology and integrate healthcare data globally.
  - ICD (**I**nternational **C**lassification of **D**iseases)
  - SNOMED CT (**S**ystematized **No**menclature of **Med**icine - **C**linical **T**erms)
  - LOINC (**L**ogical **O**bservation **I**dentifiers **N**ames and **C**odes) in the US
  - dm+d (**d**ictionary of **m**edicines and **d**evices) in UK
  - AMT (**A**ustralian **M**edicines **T**erminology) in Australia
- **Projects for Integrating Healthcare Data:** Examples include initiatives like **HMORN,** European platform of **EHR4CR, and i2b2-TranSMART**.
- **Common Data Models:** Initiatives like **OMOP** and **PCORNet** focus on standardizing healthcare data for broader usage.

Data Harmonization Initiatives in Organ Transplantation

- **Current Initiatives:** Registries and initiatives dedicated to harmonizing organ transplant data
  - **CTS** (Collaborative Transplant Study)
  - **SRTR** (Scientific Registry of Transplant Recipients)
  - **ANZDATA** (Australia and New Zealand Dialysis and Transplant Registry)
  - **OPTN** (Organ Procurement and Transplantation Network)

Harmonization Efforts for Registries

- **Transplantation Society's Global Data Harmonization Committee (TTS-GDHC):**
  - Development of **common data standards**
  - Standardization of **data elements and terminology**
  - Facilitation of **inter-registry data linkage**
  - Promotion of **data sharing policies**
  - Collaboration with **relevant organizations and stakeholders**

- **CDISC Therapeutic Area User Guide-Kidney Transplantation (TAUG-KT):**
  - Includes disease-specific metadata and guidance on implementing CDISC standards for various purposes such as data collection, analysis, and reporting

Challenges in Harmonizing Organ Transplant Data

I. Inadequate Representation of Transplantation-Specific Concepts

- **IRD** (Infectious Risk Donor)
- **KDRI** (Kidney Donor Risk Index)
- **KDPI** (Kidney Donor Profile Index)
- **ECD** (Expanded Criteria Donor)

- **HLA** (Human Leukocyte Antigen) **mismatch**
- **MELD** (Model for End-Stage Liver Disease)
- **LYFT** (Life Years from Transplant)
- etc.

- Visits at varying time points after transplant
- Frequently record free-text observations in different languages
- Rarely utilize structured data formats.

Challenges in Harmonizing Organ Transplant Data

II. Institutional and Administrative Barriers

- Conflicting institutional policies
- Varying data privacy rules

- Variability in health system operations over time due to technological advancements
- Diversity in treatment and allocation policies across regions

- **At the international level:**
- Differences in countries' approaches to health data security and patient privacy further complicate harmonization efforts

Challenges in Harmonizing Organ Transplant Data

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III. Inconsistent and Insufficient Granularity

Aspect	Noting General Information	Noting Specific Details
Age Recording	Age range (45-55 years old)	Birthdate or specific age (48 years old)
Organ Rejection	Binary outcome (yes/no)	Severity score (e.g., mild, moderate, severe)
Medication Usage	Absence/Presence	Dosage (e.g., 100 mg), frequency (e.g., twice daily), duration (e.g., 6 months)
Post-Transplant Complications	Absence/Presence	Severity scale (e.g., mild, moderate, severe), Impact on patient outcomes (e.g., hospital readmission, prolonged recovery)
Transplant Outcomes	Successful or failed	Graft function (e.g., creatinine levels, eGFR), Patient-reported outcomes (e.g., quality of life, satisfaction with transplant outcome)

Future Perspectives

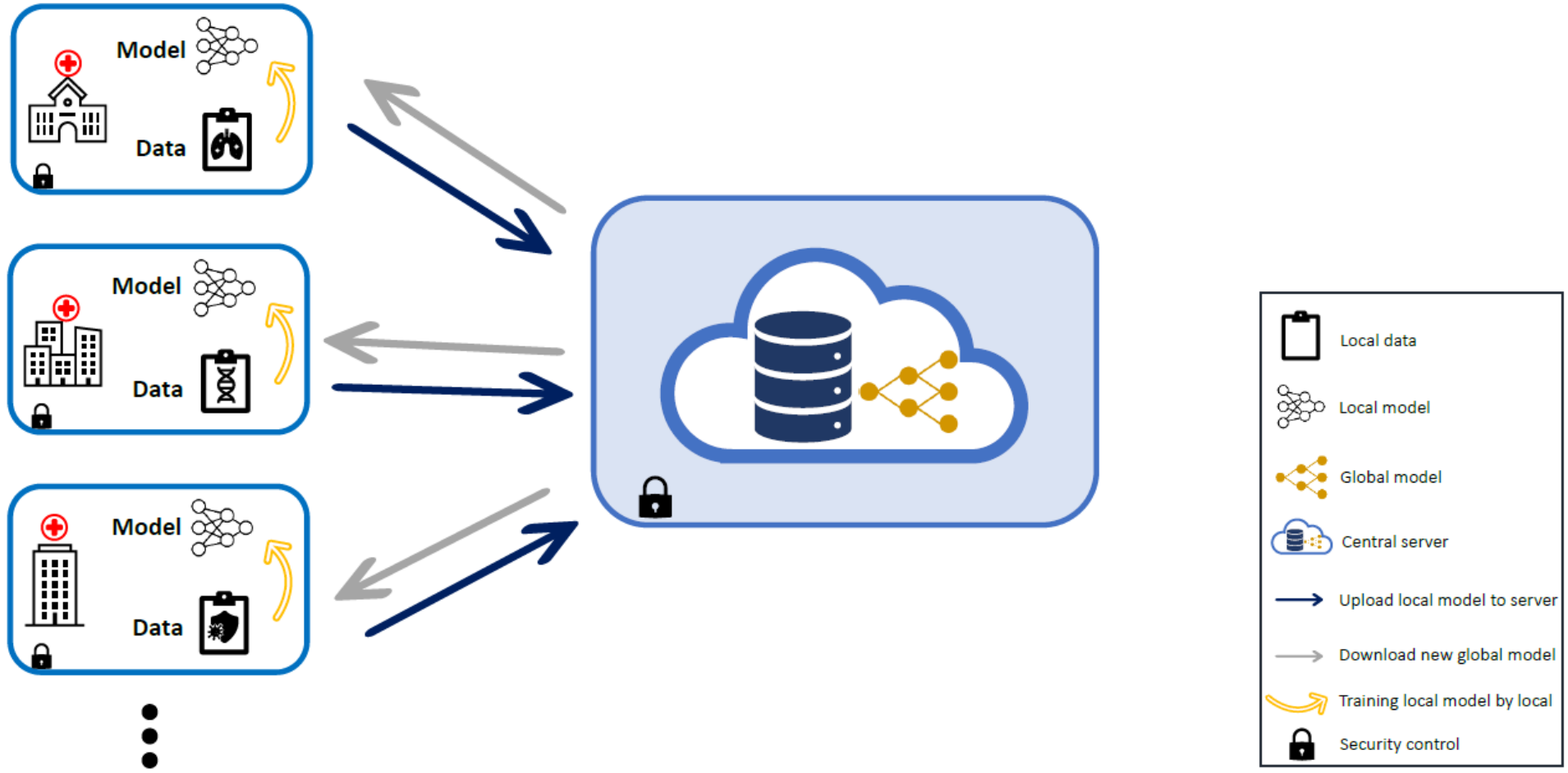
Implementation of Privacy Preserving Frameworks

- Utilizing methods, such as **SMPC** (Secure Multi-Party Computation) and **cryptographic protocols**, to perform analyses on **encrypted or aggregated data**
- **DataSHIELD**
- **Differential Privacy**
- **TEEs** (Trusted Execution Environment)
- **Secure Data Enclaves**

Future Perspectives

Implementation of AI-Based Federated Learning

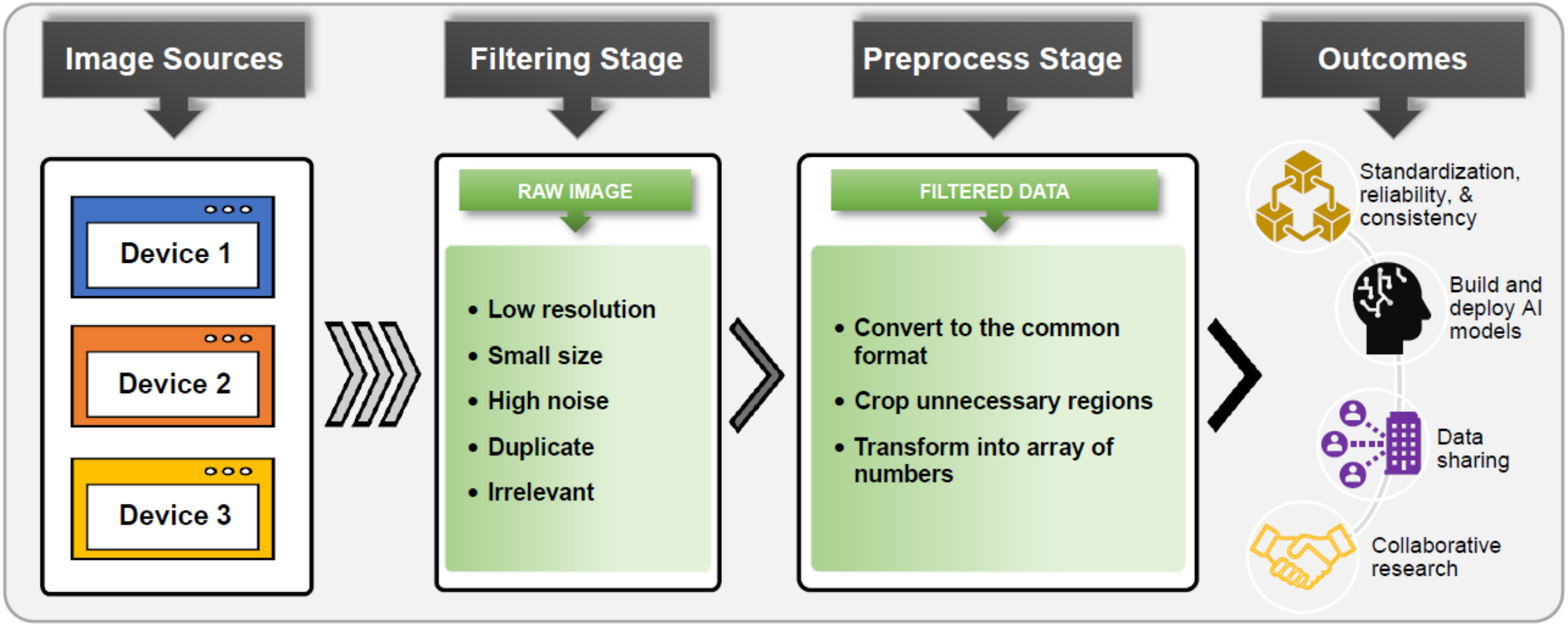
Federated learning enables training of machine learning **models** on decentralized data sources



Future Perspectives

Development of a Common Image Data Model (CIDM)

To define consistent image formats, metadata standards, and quality control measures



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