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Key Research Areas for Building and Deploying a Common Data Model for an Intensive Medicine Data Space in Europe and Beyond

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Abstract. Key Research Areas (KRAs) were identified to establish a semantic interoperability framework for intensive medicine data in Europe. These include assessing common data model value, ensuring smooth data interoperability, supporting data standardization for efficient dataset use, and defining anonymization requirements to balance data protection and innovation.

Keywords. Common Data Model, Data Space, Standardization, Interoperability, Artificial Intelligence, Clinical Decision Support, Intensive Care

1. Introduction and Methods

Intensive Care Unit (ICU) is a data-rich environment - generating huge amounts of data - but there is a notable absence of secure cross-border data access, sharing, and processing framework. This is a crucial issue because developing effective AI systems relies on high-quality, representative, reliable, trustworthy, and large datasets. From September to November 2023, dedicated meetings were held to identify Key Research Areas (KRAs) and associated challenges for defining and deploying Common Data Models (CDMs) in an Intensive Medicine Data Space. The methodology involved experts in medical informatics, data standardization, data science, artificial intelligence, and intensive care. The advantages of an architecture based on the Data Spaces Blueprint by the Digital Space Support Centre [1] and Gaia-X were considered.

2. Results, Discussion and Conclusions

This work outlines a roadmap for deploying a data space in ICU settings to develop AI, share clinical best practices, and support personalized medicine, benchmarking, and disaster preparedness. Key Research Areas (KRAs) include defining flexible Common Data Models through HL7 FHIR [2] and OMOP-CDM [3] (KRA One), establishing standards for semantics and interoperability (KRA Two), supporting data providers and users (KRA Three), and ensuring secure data sharing through anonymization and pseudonymization (KRA Four). A set of 4 KRAs to contribute to defining CDMs for an Intensive Medicine Data Space in Europe and Beyond has been identified. KRAs need to be addressed and expanded to contribute to the objectives of this work.

The identified KRAs aim to tackle challenges in EU ICUs hindering data-driven clinical decision-making and innovations. They will select CDMs and standardize data elements, outline requirements for seamless data interoperability, and develop secure platforms for aggregating ICU datasets for secondary analysis and treatment-specific tools.

References

[1] Doe J. Data Spaces Blueprint | Version 0.5. Digital Single Market. September 2023. https://dssc.eu/space/BPE/179175433/

 Organización para la Investigación y el Desarrollo de Estándares de Información en Salud (OHDSI). Data Standardization. OHDSI; 2024. <u>https://www.ohdsi.org/data-standardization/</u>

^[2] Health Level Seven International. Fast Healthcare Interoperability Resources (FHIR). Health Level Seven International; 2024. <u>https://hl7.org/fhir/</u>