Towards Dependable, Interoperable and Evolvable Personal Health Data Spaces Within the European Health Data Space

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Abstract: This paper examines the challenges and preliminary findings in developing a dependable, interoperable, and evolvable PHDS within the EHDS. The proposed architecture consolidates personal health data, including laboratory results, medical history, imaging, omic data, patient-reported outcomes, and wearable device data into an integrated master copy under individual control. It ensures seamless interoperability for primary use cases such as diagnosis and treatment and de-identified secondary uses such as research and AI, adhering to strict consent requirements. Dependability ensures data integrity, interoperability enables smooth data exchange, and evolvability allows adaptation to regulatory and technological changes. This framework enhances health data management, supports sustainable healthcare, and addresses key issues in ownership, security, and usability.

1 INTRODUCTION

The EHDS (European Commission, Directorate-General for Health and Food Safety, 2022) aims to harmonise health data management across Europe by enabling cross-border sharing, enhancing patient care, and driving innovation. However, achieving dependable, interoperable, and evolvable health data management remains difficult due to fragmentation, privacy concerns, and technological diversity. To clarify these challenges, we identify three key dilemmas in health data management (Klementi et al., 2024): a) *Accessibility*: Balancing broad health data access for societal benefits (e.g., research, AI, policymaking) with privacy protection remains challenging. Solutions must address these competing demands; b) *Comprehensiveness*: Fragmented health data across systems and devices leads to incomplete datasets, affecting decision-making and research. A unified, interoperable master copy is essential; c) *Ownership*: Health data control is mainly institutional rather than individual. Personal ownership can enhance data sharing, continuity of care, and sustainable healthcare.

Despite EHDS ambitions, challenges remain in achieving a unified health data ecosystem. Data fragmentation, restricted individual control, and balancing access with privacy hinder progress. Overcoming these issues is key to dependable, interoperable, and sustainable health data management that enhances care continuity and societal well-being.

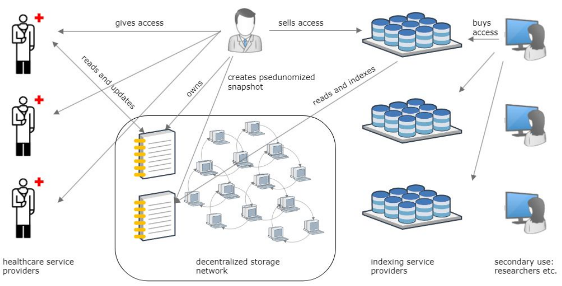

Figure 1: PHDS Architecture (Klementi et al., 2024).

This preliminary report proposes a PHDS architecture (Figure 1) aligned with EHDS objectives. By integrating semantic interoperability, secure decen-

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tralized storage (Swarm, 2022), and user-centric governance, we hypothesise that this approach ensures data dependability, interoperability, and evolvability while empowering individuals with ownership and control over their health data, complementing and innovatively enhancing existing healthcare IT infrastructure without replacing it.

The rest of the paper is structured as follows. The Methods section defines the PHDS concept, describes the tools used, and explains the Design Science methodology. The Results section presents the reference architecture, health data structure, and management principles. The Discussion section examines interoperability, dependability, and evolvability, analysing the architecture within the EHDS ecosystem and its impact on data quality, security, and stakeholder engagement. The paper concludes with future research.

2 METHODS

Our approach combines the principles of design science methodology with a case study analysis. A reference architecture for a PHDS was developed by leveraging semantic interoperability frameworks such as HL7 FHIR and archetype-based domain models (Piho, 2011). The proposed architecture ensures compliance with the GDPR and facilitates seamless integration into the EHDS ecosystem. Three key dimensions—dependability, interoperability, and evolvability (Piho et al., 2014)—were examined through real-world scenarios, including medical emergencies and cross-border healthcare provision.

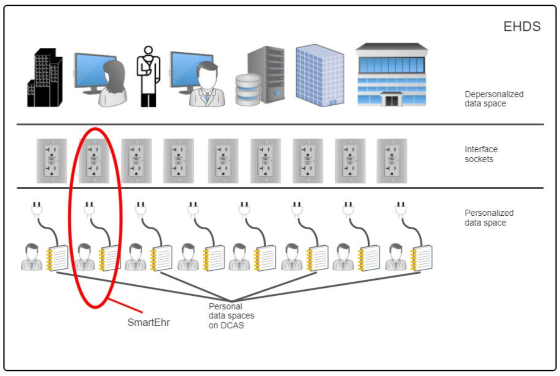

Figure 2: European Health Data Space (EHDS) (Klementi et al., 2024).

A **Personal Health Data Space (PHDS)** is a user-centric system allowing individuals to manage and control access to their health data from sources such as EHRs, wearable devices, and omic data. It aims to enhance personal data ownership while improving interoperability, dependability, and evolvability within healthcare systems.

The following key attributes of a PHDS can be specified: a) *Data Aggregation*: A PHDS consolidates health data from multiple sources, ensuring accessibility for care continuity; b) *User Empowerment and Control*: Individuals own and manage access, complying with GDPR and HIPAA; c) *Interoperability*: Standardized formats such as FHIR enable seamless data exchange across healthcare systems; d) *Data Security and Privacy*: Encryption, access controls, and de-identification reduce breach risks while ensuring compliance; e) *Evolvability*: A PHDS adapts dynamically to new technologies, standards and regulatory changes.

The following expected outcomes specify the benefits of implementing a PHDS in DCAS networks such as (Swarm, 2022): a) *Enhanced Patient Engagement*: A PHDS grants individuals full ownership and control of their health data, promoting active participation in health management, illness prevention, and continuity of care. It enables informed decision-making and better coordination across healthcare providers; b) *Improved Healthcare Coordination*: By consolidating a person's health data under their control within a decentralized content-addressable storage (DCAS) network, healthcare providers can always access complete information. This reduces reliance on centralized repositories, minimises breach risks, enhances treatment, and supports secure, consent-driven data reuse; c) *Facilitation of Research and Innovation*: With user consent, de-identified PHDS data in DCAS networks can support research, policymaking, and healthcare innovation, advancing medical science while ensuring privacy and ethical compliance.

However, there are no free lunches. The following challenges must be considered when implementing PHDS systems in DCAS networks: a) *Data Standardization*: Ensuring federated and evolvable interoperability is challenging due to inconsistent data entry, legacy systems, and evolving technologies; b) *User Engagement*: Motivating individuals to manage their health data requires intuitive interfaces, support systems, and incentives such as token rewards or reduced healthcare costs; c) *Regulatory Compliance*: PHDS implementations must align with regional and international data protection laws to safeguard user privacy and rights. In the EHDS context (Figure 2), PHDS integration enables seamless health data flow across borders, improving healthcare and fostering innovation. By tackling data fragmentation, accessibility, and ownership, a PHDS in a DCAS network advances a more efficient, patient-centred healthcare system.

A **Decentralized Content-Addressable Storage (DCAS)** network, such as (Swarm, 2022), distributes data across multiple nodes, ensuring redundancy, security, and accessibility. Unlike centralized systems, it uses content-based addressing, enhancing integrity and reducing tampering risks. As electronic shredders, DCAS networks break documents into tiny, meaningless fragments (Figure 3), distributing them across nodes. This prevents reconstruction without the proper permissions, significantly improving security and reducing unauthorized access risks.

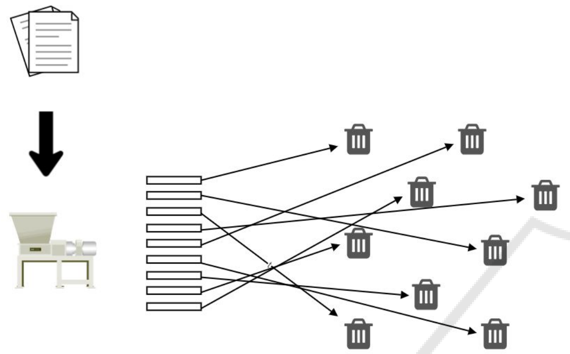

Figure 3: DCAS Network (Klementi et al., 2024).

The key features of DCAS are as follows (Trón, 2021): *Content Addressing*: Data is identified by a cryptographic hash, ensuring integrity and version control; *Decentralisation*: Data is spread across nodes, eliminating single points of failure; *Data Redundancy*: Multiple copies ensure availability even if 70% of nodes go offline; *Scalability*: The distributed system efficiently handles large data volumes.

We may specify the following advantages of DCAS in the context of PHDS (Klementi et al., 2024): *Security and Privacy*: DCAS ensures strong security through cryptographic hashing and decentralization, reducing the risk of centralized attacks; *Data Ownership*: Patients control access to their health data and define usage terms; *Interoperability*: Aligning with HL7 FHIR, DCAS enables seamless data exchange while preserving integrity and eliminating duplication (Piho et al., 2012). Decentralized access reduces storage needs and operational costs, enhancing efficiency.

The **Design Science Methodology (DSM)** is a problem-solving approach for developing and evaluating innovative artefacts (Wieringa, 2014). We apply DSM to design the PHDS framework aligned with EHDS objectives: a) *Problem Identification and Analysis*: Using the Estonian Health Information System, we identified key challenges such as data fragmentation, limited individual control, and privacy-accessibility balance (Ross et al., 2023; Bertl et al., 2023a); b) *Defining Objectives*: Based on these challenges, we established goals for PHDS, focusing on dependability, interoperability, and evolvability (Klementi et al., 2022); c) *Design and Development*: The PHDS architecture integrates semantic interoperability, decentralized storage, and patient-centric governance (Klementi et al., 2024); d) *Demonstration and Evaluation*: Two research grants, 'Digital Health for a Whole and Healthy Society' (Estonian Research Council, 2028) and 'Medication Adherence and Treatment Efficacy' (Estonian Research Council, 2029), support five years of clinical evaluation, targeting TRL 6 and expanding our research team. By applying DSM principles, we aim to develop a scalable and adaptable PHDS architecture, addressing health data challenges while advancing EHDS goals.

3 RESULTS

3.1 Reference Architecture

The planned system adopts a decentralized, user-centric approach, giving individuals full control over their health records. Using a DCAS network, it ensures security, scalability, and privacy while complying with the GDPR and HIPAA. Its modular design enables interoperability, secure storage, and support for both primary (treatment, emergency care) and secondary (research, public health) use cases, prioritizing privacy and sustainability.

The *Core Application* (Figure 4) is central to managing personal health records (PHRs) in a DCAS network (Klementi et al., 2024; Klementi and Piho, 2024). Operating on the user's device, it ensures privacy, dependability, interoperability, and evolvability (Piho et al., 2014). The application presents health data through a user-friendly interface with annotation, search, and filtering features. Its abstraction layer enables independent communication with the DCAS network, ensuring adaptability without reliance on a single solution. *Root Hash Management:* The root hash uniquely identifies the user's health data, secured to prevent unauthorized access or loss. A mutable address space within the DCAS network encrypts and stores the hash, with recovery ensured using Shamir's Secret Sharing (Shamir, 2023; Klementi et al., 2024). *Storage Abstraction Layer (SAL):* SAL enables seamless data storage and retrieval, shielding the application from underlying storage protocols. *Content Handlers:* Modular handlers support various health data formats, ensuring compatibility with standards such as HL7 CDA, FHIR, ISO 13606, openEHR, and DICOM. *Interoperability Layers:* These layers en-

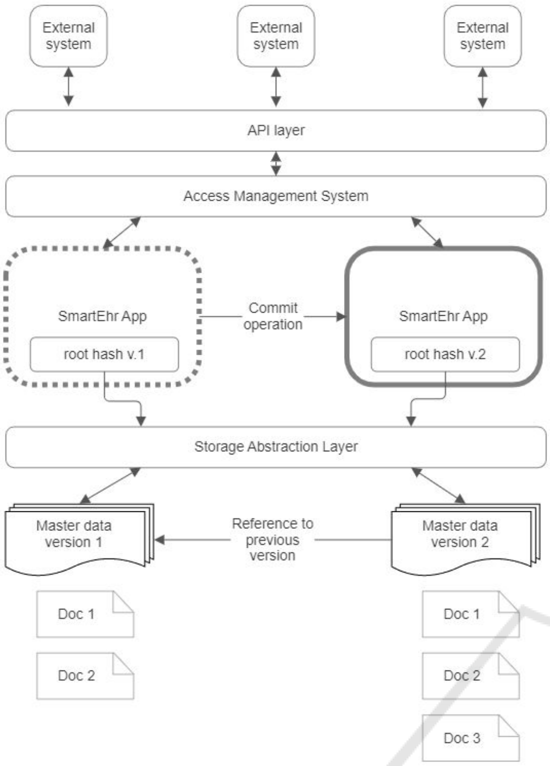

Figure 4: Core Application (Klementi et al., 2024).

able secure data exchange with healthcare systems using federated interoperability and standardized APIs (Sõerd et al., 2023; Randmaa et al., 2022). *Extension Modules:* Downloadable plug-ins enhance functionality, integrating wearable devices and advanced health analytics.

This architecture gives users full control over PHRs while ensuring secure, efficient data sharing for primary and secondary use. Its modular design adapts to evolving healthcare and technology needs.

3.2 Domain Model

A key aspect of ensuring sustainable semantic interoperability and second-order data evolvability is using a suitable healthcare domain model (Piho, 2011). This model standardises data meaning across systems, allowing adaptation to new standards and use cases. It supports primary uses such as treatment and diagnostics while enabling de-identified data for secondary purposes, including research, public health, and AI.

The internal healthcare domain model (Figure 5) follows the Zachman Framework (ZF), covering key healthcare architecture aspects and aligning with ZF's six interrogatives (Piho et al., 2010b). It includes sub-models for products, services, involved parties, roles, processes, events, money, and rules. Using Peter Coad's item-description model (Coad, 1992), each entity (e.g., 'product', 'service', 'organisation') has a corresponding type, ensuring consistency and adaptability over time (Oei et al., 1994).

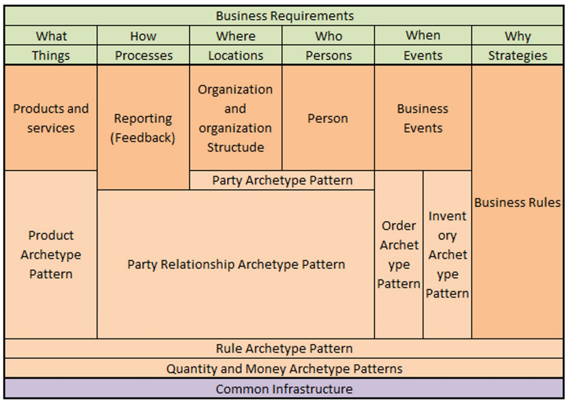

Figure 5: Zachman Framework-based domain model.

Products and Services: The 'What' dimension includes all healthcare assets, such as medical devices, records, clinical documents, services, and samples. Entities are modelled with relationships, classifications, and properties for comprehensive representation.

Persons, Organizations and Roles: The 'Who' dimension defines key stakeholders—patients, providers, payers, regulators, and staff—along with their roles, rights, and responsibilities. Roles refine this further, e.g., 'provider' includes physicians, nurses, and lab technicians, enabling role-based access control (RBAC) and precise task allocation.

Processes: The 'How' dimension defines healthcare workflows, including admissions, diagnostics, treatments, and billing, ensuring efficiency, compliance, and interoperability. Each process consists of threads, tasks, and activities, with outcomes recorded in system registries. Following Peter Coad's item-description pattern, every element (process, thread, task, activity, outcome) has a corresponding type. Plans are modelled as anticipated processes and outcomes, aligning with healthcare ontology standards such as ISO 13940 (ContSys) (Sõerd et al., 2023).

Locations: The 'Where' dimension models locations as organisations and organization units rather than states, cities, streets and houses, linking events to specific hospital departments (e.g., admissions, emergency). This domain-driven approach improves resource tracking, staff responsibilities, and data de-identification by referencing departments instead of exact locations. It enhances patient flow management, compliance, and resource allocation while ensuring interoperability across healthcare networks.

Events: The 'When' dimension tracks healthcare

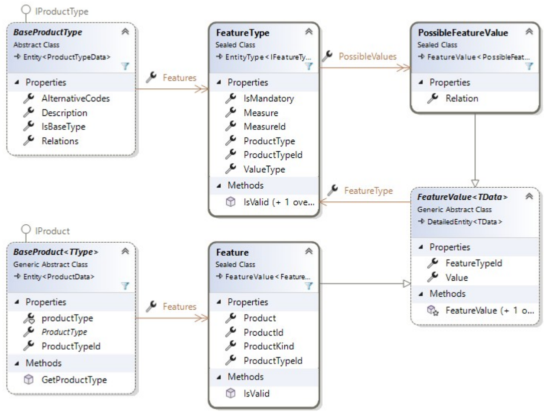

Figure 6: Peter Coad's item-description pattern example.

events through structured registries. Inventory ledgers record acquisitions and disposals, general ledgers log financial transactions, and personnel records track employment periods. Clinical outcomes are documented in EHRs, EMRs, PHRs, or Patient Summaries. This approach ensures precise event tracking, accountability, and semantic interoperability across healthcare systems.

Rules: The 'Why' dimension defines healthcare rules, distinguishing rule types (Rule) from applicable data (Rule Context) using Peter Coad's item-description pattern. Rules consist of logical operations (AND, NOT, OR, XOR) and relations (Equals, IsGreater, IsLess). They define role requirements and process sequences or interpret clinical results, ensuring precise and flexible rule implementation across scenarios.

Money and Quantities: These models define monetary values and measurements with units, ensuring consistency across the healthcare domain. Standardized units enable calculations, comparisons, and aggregations, enhancing accuracy in financial transactions, resource allocation, and data analysis. Integrating these patterns supports data integrity and the seamless handling of complex financial and quantitative requirements.

First-order evolvability (Oei et al., 1994) allows CRUD operations on a database. By adding fields such as RecordId, DomainId, ValidFrom, and RecordedBy (Piho et al., 2010a; Piho, 2011), changes can be logged and audit-trailed. Each entity has a unique DomainId, while every transaction is tracked with a unique RecordId (Piho et al., 2014).

To achieve second-order evolvability (Oei et al., 1994), we apply Peter Coad's item-description pattern (Coad, 1992), reducing second-order to first-order evolvability for entity type records. By adding property types to entity types and properties to entities (Figure 6), we enable dynamic modifications of 'tables and columns' or 'classes and properties'. This ensures adaptability, where items represent core entities (e.g., medical devices, patient records) and descriptions store metadata for flexible model updates.

The proposed domain model aligns with the Object Management Group's (OMG) Meta-Object Facility (MOF) standard, supporting hierarchical abstraction: a) *M3 Level*: A universal domain model (Single Underlying Model (Meier et al., 2019)) with archetypes guiding system architecture and defining M2 Level concepts; b) *M2 Level*: Domain ontologies such as ContSys (ISO 13940) define standardized healthcare concepts, serving as an interoperability layer (Sõerd et al., 2023); c) *M1 Level*: Standards and terminologies (HL7 CDA, FHIR, openEHR, SNOMED, LOINC, ICD, DICOM) specified by M2 Level; d) *M0 Level*: Practical implementations of M1 Level standards.

This hierarchical alignment ensures the domain model remains extensible, interoperable, and compatible with evolving healthcare standards, supporting backward and forward interoperability (Bossenko et al., 2022). Structured with the item-description pattern and based on the ZF, the model provides a robust foundation for healthcare data, information and knowledge management. Integration with OMG MOF enhances interoperability, scalability, and adaptability, enabling efficient healthcare delivery and secure personal health data management a within DCAS-based PHDS.

3.3 Big Health Picture

To unify an individual's health data under personal ownership and control, we introduce the Big Health Picture, inspired by the Big Blood Picture in laboratory informatics. It securely stores all health-related data, including EHRs, EMRs, lab results, omics data, medical images, and user-collected data from wearables and home devices. This approach enhances privacy, interoperability, and integration across healthcare platforms. By adopting the Big Health Picture, individuals gain greater control over their data while healthcare providers access accurate, up-to-date information. Integrating AI and ML ensures well-reasoned, evidence-based recommendations while preserving human decision-making (Bertl et al., 2023c; Bertl et al., 2023b).

Developing a comprehensive *Big Health Picture* requires integrating a robust domain model, such as the one based on the ZF, with practical serialization formats for storing PHRs in PHDS within a DCAS network. HL7 FHIR supports suitable formats: a) *JSON*: Lightweight, human-readable, and

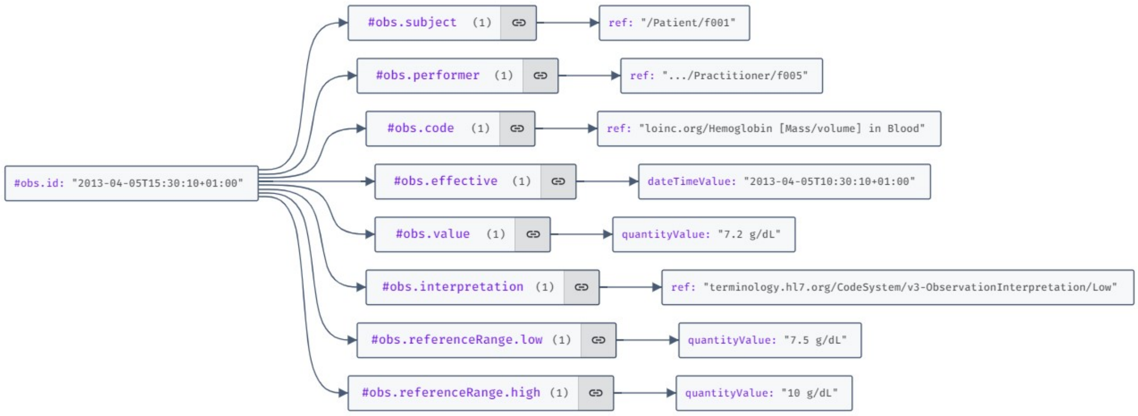

Figure 7: FHIR Observation (Klementi et al., 2024).

Hash	When	Why	How	What	Who	Where
...						
$hash_{i-2}$						
$hash_{i-1}$						
$hash_i$	28/10/1999	Routine appointent	Harry Potters's height in cm, measured by a doctor Miriam Strout	174.6	Dr Miriam Strout, healer	St. Mungo's Hospital for Magical Maladies and Injuries
$hash_{i+1}$						
$hash_{i+2}$						
...						
...						

Figure 8: One possible representation of records in Big Health Picture.

widely used for web-based data exchange; b) *Turtle*: RDF-based syntax (Figure 7) enabling rich semantic relationships and knowledge graphs; c) *FHIR Shorthand (FSH)*: A domain-specific language for efficiently defining FHIR artefacts and extensions; *Balancing Semantics with Syntax*: The domain model defines semantics, while serialization must effectively capture data types, including text, images, and omics, ensuring provenance and modification history.

Constructing the Big Health Picture: Representing health data as an interconnected knowledge graph enhances analytics, clinical decision-making, and personalized medicine. The structured approach of the ZF ensures systematic organization beyond simple RDF triples, advocating for richer data structures (Vinay K. Chaudhri, 2021). While RDF triples offer flexibility, they may lack the efficiency needed for dependability, interoperability, and evolvability. As shown in Figure 8, a more advanced internal structure provides a more precise and functional representation of personal health data in a PHDS. Integrating a semantically robust domain model with a suitable serialization format is pivotal in constructing a comprehensive *Big Health Picture*. By adhering to the ZF-based domain model and selecting appropriate data representation methods, we try to ensure that PHRs are stored, managed, and utilized to support interoperability, scalability, and comprehensive personal health data management.

3.4 On-the-Fly Data Transformation

The practical implementation of a *Big Health Picture* requires a flexible approach to transforming health data across formats, enabling seamless integration with its domain model while ensuring usability for primary and secondary purposes. *Federated Semantic Interoperability*: This approach (Sõerd et al., 2023; Randmaa et al., 2022) enables collaboration with existing healthcare IT without uniform formats or central repositories. It supports transitioning from legacy standards such as HL7 CDA to modern ones such as HL7 FHIR, preserving historical data integrity while ensuring real-time usability through dynamic conversions.

Tools such as TermX (Bossenko et al., 2024a) use visual editors and declarative languages such as FHIR Mapping Language (FML) to enable low-code/no-code transformations, allowing domain experts to create rules without technical expertise. This simplifies data transformation, improving accuracy and speed. Bossenko et al. (Bossenko et al., 2024b) highlight the value of reusable transformation components, organizing them hierarchically from data types to document structures. Modular libraries streamline development, enhance consistency, and reduce maintenance effort.

Integration into DCAS Networks: In a PHDS within a DCAS network, transformation engines must enable on-the-fly data conversion, dynamically transforming data upon access rather than storing preconverted copies. This approach supports federated interoperability, reducing extensive migrations and duplications while ensuring cost-effectiveness and efficiency. By leveraging reusable components and tools such as TermX, real-time transformations bridge legacy and modern health data formats. Integrating these capabilities within DCAS networks ensures interoperability, preserves historical data, and supports both primary care and research, making the *Big Health Picture* vision achievable and sustainable.

4 DISCUSSIONS

The proposed PHDS architecture embodies the critical attributes of dependability, interoperability, and evolvability, which are vital for addressing the complexities of modern health data management.

Dependability in a PHDS is ensured through DCAS networks, blockchain audit trails, and encryption. Content-addressable storage maintains integrity, preventing unauthorized changes. *Decentralized Storage:* DCAS distributes health data across nodes, reducing failures and enhancing availability. *Data Integrity:* Blockchain audit trails (Kask et al., 2023b; Kask et al., 2023a) ensure transparency and traceable transactions. *Security and Privacy:* Encryption, user governance, and data de-identification protect information. Explicit consent ensures GDPR and HIPAA compliance.

The architecture's interoperability bridges fragmented healthcare systems, supporting global mobility. Using semantic interoperability frameworks (Section 3), the PHDS model enables seamless data exchange across formats such as HL7 FHIR, HL7 CDA, and openEHR. *Standardized Data Exchange:* TermX ensures compatibility with various formats, including HL7 FHIR, HL7 CDA, openEHR, and OMOP CDA. *Federated Interoperability:* A PHDS allows providers and third parties to access data in the preferred formats while maintaining semantic integrity. *Unified Health Data Management:* A single, interoperable master copy eliminates redundancies and improves efficiency. The solution's validation for primary medical use is detailed in (Klementi et al., 2024) and the Methods section.

The evolvability of the PHDS domain model ensures adaptability to regulatory and technological changes. *Modular Design:* Its modularity enables the seamless integration of new functionalities and data types, such as genomic data and advanced analytics. *Regulatory Alignment:* Compliance with GDPR and HIPAA allows adaptation to evolving privacy, security, and data governance policies. *Long-Term Viability:* The item-description pattern ensures second-order evolvability, supporting both immediate and future healthcare and research needs.

The PHDS in DCAS network architecture tackles key challenges, including privacy, accessibility, data fragmentation, and ownership. *Privacy vs. Accessibility*: The system balances research and public health benefits with strict privacy controls (Klementi et al., 2024). A secure DCAS network enforces encrypted access and requires explicit user consent for data sharing. *Resolving Data Fragmentation*: By unifying diverse data sources under individual control, PHDS eliminates silos and enhances healthcare delivery. Semantic interoperability ensures meaningful data use across systems. *Empowering Ownership*: A PHDS places individuals at the centre of health data governance, fostering trust and transparency in data sharing.

With dependability, interoperability, and evolvability, a PHDS offers a transformative solution for modern health data challenges, paving the way for a secure, efficient, and adaptable healthcare ecosystem.

5 CONCLUSIONS

A PHDS offers a transformative approach to health data management, addressing critical dependability, interoperability, and evolvability challenges. By empowering individuals with ownership and control, a PHDS, based on Decentralized Content-Addressable Storage (DCAS) networks, aligns with the EHDS objectives and supports societal benefits through enhanced healthcare delivery and advanced research opportunities. Currently at approximately Technology Readiness Level 3, the system has received two research grants (Estonian Research Council, 2028; Estonian Research Council, 2029) to validate its applicability in relevant clinical settings within the Estonian e-health ecosystem.

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