

Towards dynamic consent and transparent access tracking for decentralized health records using the SOLID framework

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Abstract

Managing health data in decentralized systems is challenging due to the need for fine-grained consent and transparent access workflows. Based on RDF/OWL technologies, the SOLID framework offers a unique approach to addressing these challenges by enabling individuals to store and control their data independently. This paper presents a conceptual design that integrates dynamic consent management and transparent access tracking into a decentralized health record infrastructure. By exploring RDF's semantic capabilities, we aim to enhance interoperability and enable advanced reasoning over consent rules and data sharing, laying the foundation for future prototypes and implementations in patient-centric health data ecosystems.

Keywords

Dynamic consent, decentralized health records, RDF/OWL, SOLID

1. Introduction

Transitioning from centralized to decentralized health data systems is essential for empowering patients. However, managing consent and ensuring data transparency remain significant challenges [1]. The SOLID framework, which decouples data from applications and utilizes RDF for semantic processing [2, 3], offers a promising basis for addressing these issues. This paper proposes a conceptual design to integrate dynamic consent and transparent access tracking into a decentralized health data system, aiming to foster a patient-centric approach to health data management.

2. Conceptual framework

Our work envisions a system with three key components. First, dynamic consent management allows patients to define consent rules stored as RDF triples in their SOLID pods. These rules can include conditions like time-bound data sharing or data-type-specific sharing, with the RDF format facilitating semantic reasoning that allows the system to process and enforce consent dynamically. Second, transparent access tracking enables patients to monitor data access activities. This tracking system includes a timeline displaying access requests from third parties, decisions on these requests and a detailed log of data access events, all driven by the patient's consent rules. Finally, emergency access protocols allow trusted parties, such as doctors, to temporarily bypass standard consent mechanisms in critical situations, with all actions explicitly logged to ensure transparency and traceability. In this framework, third-party applications query the patient's SOLID pod for access to their data, with the queries dynamically evaluated against the stored consent rules. Unlike generic SOLID implementations, our design incorporates semantic enhancements using RDF/OWL, enabling reasoning over consent conditions and data access patterns. This allows the system to support nuanced and flexible consent management while ensuring patient oversight through real-time tracking of all data interactions.

SWAT4HCLS 2025: 16th International Conference on Semantic Web Applications and Tools for Health Care and Life Sciences 2025

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3. Preliminary feasibility and challenges

This system offers benefits such as empowering patients with granular control, enhancing trust through real-time audit trails and ensuring safety with emergency protocols. However, challenges include creating user-friendly interfaces for non-technical patients, ensuring performance with large datasets, and aligning with existing standards that facilitate interoperability and data harmonization, like FHIR, HL7, and SNOMED CT. RDF/OWL's semantic richness introduces complexity, requiring efficient reasoning mechanisms to maintain performance.

4. Towards implementation

Initial steps include building a proof-of-concept system using the SOLID SDK and integrating semantic processing libraries. This prototype will be tested with simulated patient data and realworld scenarios, such as managing data from commercial sensors and smart devices. Feedback from patients and providers will guide refinements, focusing on usability and relevance. Iterative improvements will bring the system closer to deployment, ensuring interoperability and patient empowerment.

5. Conclusion

This work outlines a conceptual approach to integrating dynamic consent and transparent access tracking into decentralized health record systems using the SOLID framework. We aim to inspire further research and development in patient-centric health data management. Future work will focus on prototyping, usability testing, and ensuring interoperability with existing health data standards.

Declaration on Generative AI

The authors have not employed any Generative AI tools.

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