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FAIR Linked Health Data

WEBINAR REPORT

The role of SOLID technology in healthcare

UHASSELT

Content

Introduction

The digital transformation of healthcare is evolving rapidly, with data privacy, patient empowerment, and interoperability taking center stage. To explore these pressing topics, the **Research Group of Biomedical Data Sciences at Hasselt University** organized a webinar on **February 4, 2025**, focusing on the role of **SOLID** (Social Linked Data) technology in healthcare.

With **55 participants actively engaging in the meeting chat**, sharing insightful questions and personal thoughts, the event underscored the strong interest in decentralizing health data management. SOLID aims to shift data control from centralized institutions—such as hospitals and tech corporations—to individuals, offering exciting possibilities while also raising important questions about governance, data quality, interoperability, and real-world adoption.

With a diverse panel of speakers from academia, research institutions, and industry, the webinar facilitated a rich discussion on how SOLID can shape the future of health data management, research, and patient engagement.

This report provides a **detailed breakdown** of the event, including speaker presentations, panel discussions, key questions raised, and actionable insights. The **recording of the event** and the master slide deck used during the webinar are also available for those interested in a deeper dive.

Key takeaways

- **Empowering individuals:** SOLID technology decentralizes health data storage, separating data from applications to give citizens control over their personal health records and enhance transparency.
- **Trust & Governance:** A solid regulatory and governance framework is necessary to ensure ethical data management and applications, security, and compliance with legal frameworks (e.g., GDPR, EHDS).
- **Interoperability & Data standards:** Successful adoption requires alignment with existing health data models and standards, including FHIR, OMOP CDM, OpenEHR, SNOMED CT, LOINC, MedDRA, IDMP and EHDS frameworks (e.g., Health-DCAT-AP for metadata cataloging).
- **User-centered design:** Adoption depends on convenience such as user-friendly authentication, granular consent mechanisms, and integration with trusted identity solutions like Itsme.
- **Potential for preventive healthcare & research applications:** SOLID-based personal health records have significant potential to bridge primary and secondary data use, supporting preventive care, patient monitoring, and large-scale health research.

About SOLID

About the organizers

Research Group of Biomedical Data Sciences at Hasselt University

The Biomedical Data Sciences Research Group at **Hasselt University** is dedicated to enhancing healthcare through innovative data science methods. Affiliated with the **Biomedical Research Institute** (**BIOMED**), the **Data Science Institute** (**DSI**), and the **University MS Center** (***UMSC***), the group bridges the Biomedical Research Center and the Data Science Center to tackle complex challenges in health and care.

Our mission - #DataSavesLives

Our mission is rooted in the belief that data saves lives. We focus on real-world health data and operate in a multi-stakeholder environment to derive actionable insights. Our research investigates how we can reduce the time needed to answer urgent healthcare questions through data-driven insights while addressing both sociological and technical challenges.

What we do

We identify recurrent lessons learned through high-innovation use cases by:

- Working in real-world settings, integrating real-world health data from a multi-stakeholder perspective.
- Formulating use-case agnostic recommendations and frameworks, combining social and technical insights.
- Bridging research, education, and civic engagement, ensuring that our activities are not only innovative but also practical and impactful.

Collaboration and civic engagement

As a research group within Hasselt University, we serve three interconnected roles: we investigate, we serve, and we educate. We engage in:

- Collaborations with Flemish universities (KU Leuven, UGent, and UAntwerp e.g., within the Flemish AI Research Program) and international partners (e.g., OHDSI Europe community).
- Developing tools and strategies for real-world data management in multi-stakeholder ecosystems.
- Providing high-quality education in Biomedical Sciences, Bioinformatics, and Data Science in Health & Care.

About the organizers

Research Group of Biomedical Data Sciences at Hasselt University

Why this webinar?

Beyond research, we actively support the civic mission of our university by helping the health data ecosystem address major challenges related to real-world data. As part of this commitment, we are actively involved in initiatives such as:

- OHDSI Belgium – advancing health data harmonization and analytics.
- Remote Clinical Monitoring Center – developing remote monitoring solutions for chronic diseases (more info via inge.thijs@uhasselt.be).
- Health Campus Limburg DC – promoting innovation in digital health and personalized medicine in the region of Limburg.

Additionally, we act as 'trend-watchers', analyzing emerging trends in health data ecosystems. One such trend is SOLID technology, which motivated us to host this webinar. Together with our esteemed speakers, we explored:

- What is SOLID technology?
- How will SOLID influence (data) strategy in healthcare, particularly for remote monitoring, in the short and long term?

By hosting this discussion, we aim to stimulate cross-sector collaboration, helping different stakeholders learn from each other and build upon complementary expertise rather than working in isolation.

Agenda overview

1. **Welcome** - *Prof. dr. ir. Liesbet M. Peeters (UHasselt)*
2. **Introduction** - *dr. ir. Ilse Vermeulen (UHasselt)*
3. **Understanding SOLID: Principles & Applications** – *Prof. Jef Hooyberghs (UHasselt)*
4. **SOLID in Digital Health: Key Initiatives**
   - *We Are – dr. Elfi Goesaert (VITO)*
   - *Athumi – Ms. Dorien Bauwens*
   - *FAQIR Foundation – Prof. dr. ir. Filip Pattyn*
5. **Panel Discussion: SOLID's Role in Healthcare** - *all speakers, moderated by dr. ir. Ilse Vermeulen (UHasselt)*
6. **Closing Remarks & Next Steps** - *dr. ir. Ilse Vermeulen (UHasselt)*

Understanding SOLID - Principles & applications

Speaker: Prof. Jef Hooyberghs, UHasselt
(slides to be consulted via this link)

Prof. Hooyberghs provided a data-driven and process-oriented perspective on the principles of SOLID and its implications for health data governance. His presentation focused on the power shifts that accompany new technologies and how decentralization can help mitigate risks related to data ownership and accessibility.

Core principles of data governance in the digital era

1. **Benevolence** – Technology should benefit everyone, rather than consolidating power in a few centralized entities. A single identity provider controlling all health data is a risk that needs to be avoided.
2. **Decentralization** – The concentration of data in large entities (e.g., Google, Facebook, Amazon) leads to monopolization and potential abuse. Decentralization ensures greater control for individuals.
3. **Mutuality** – A collaborative governance model ensures that decentralization remains beneficial. Initiatives like MyData are working towards structuring personal data management in a responsible way.

The problem with the current data infrastructure

The existing API-based ecosystem allows for data exchange but is highly inefficient, often leading to the creation of data silos. While centralization improves efficiency, it compromises user control and security.

In today's internet landscape, platforms and services are tightly coupled (e.g., Facebook controlling both the platform and user data). This creates vendor lock-in, making it difficult for users to move their data freely.

How SOLID addresses these challenges

- **Enables free movement of data** across applications and services.
- **Decouples data from service providers**, allowing users to choose which applications can access their information.
- **Introduces personal data vaults or Personal Online Data stores (PODs)**, where individuals store copies of their own health data and selectively share them.

Understanding SOLID - Principles & applications

Speaker: Prof. Jef Hooyberghs, UHasselt
(slides to be consulted via this link)

The future of health data management

Prof. Hooyberghs outlined a three-layered framework (cfr. VITO's We Are initiative) for how SOLID could redefine health data governance:

1. **Core Data Storage Layer** – Personal data is stored in user-controlled vaults, ensuring transparency and accessibility.
2. **Functionality & Application Layer** – Digital services interact with personal data, but do not own or control it.
3. **Governance & Oversight Layer** – Government entities and other regulators empower individuals by establishing legal and technical safeguards for responsible data usage.

In this model, whenever data is accessed or used, a copy is stored in the user's POD, making the individual the natural crossroads of their own health and lifestyle data. This approach empowers individuals as central data hubs, enabling data-driven innovation while ensuring privacy and security.

Decentralization as a catalyst for innovation

Decentralization promotes greater synergy between stakeholders in the health ecosystem:

- **Open data & research** – Data produced for a specific purpose can be repurposed for R&D, provided users grant consent.
- **Privacy & legislation** – Users retain control over their information, ensuring compliance with evolving data protection laws.
- **Socioeconomic trends no longer conflic**t – Traditionally, business models, research goals, and patient privacy were at odds. SOLID enables a harmonized approach where these objectives can coexist.

Collaboration between sectors

For SOLID to succeed, cooperation across government, science, business, and civil society is crucial. Unlike the current fragmented system, a well-integrated SOLID ecosystem would:

- Ensure more equitable data access for researchers and public health initiatives, creating a level playing field.
- Strike a balance between commercial innovation and privacy protection.
- Empower citizens with a user-driven approach, allowing them to actively control how their data is used.

By shifting power from large central entities to individuals, SOLID introduces a fundamental change in how we think about data ownership, security, and accessibility.

SOLID in digital health - Key initiatives

We Are – Citizen-Centric Health Data Management
Speaker: dr. Elfi Goesaert, VITO
(slides to be consulted via this link)

Dr. Elfi Goesaert introduced the **We Are Initiative**, a collaborative effort focused on **transitioning healthcare from a reactive, disease-oriented model to a proactive, preventive, and citizen-empowered system**. The initiative aligns with the broader goal of **integrating personal health data into decision-making at both the individual and system levels**.

The need for a new healthcare paradigm

Traditional healthcare systems are **passive and reactive**, responding to diseases rather than preventing them. In contrast, the future of healthcare should be **preventive and citizen-driven**, with individuals at the **crossroads of their own data**. By combining **medical data, lifestyle choices, and mental health insights**, citizens can be better informed and empowered to **take control of their well-being**.

We Are - A collaborative ecosystem for data-driven health

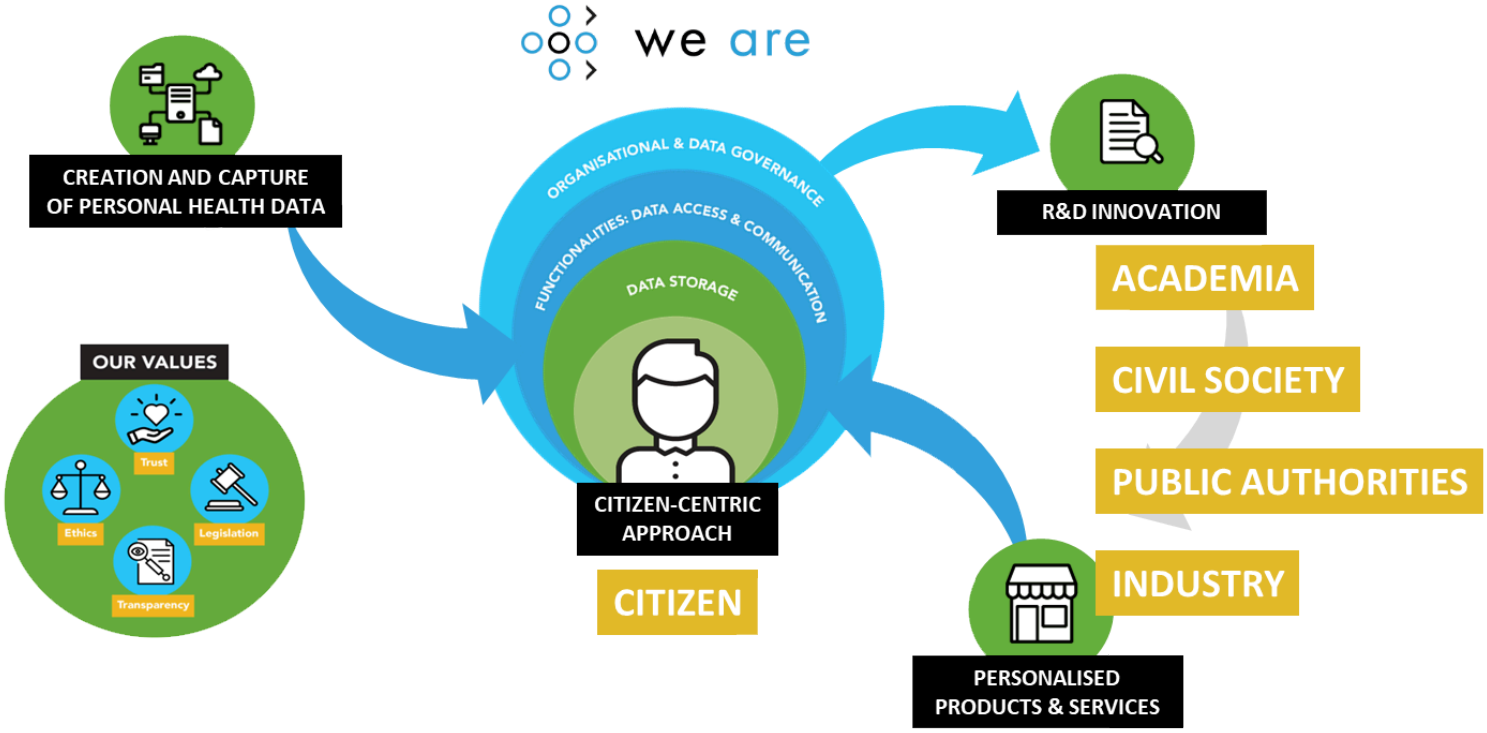
The **We Are Initiative** was founded in collaboration with **Domus Medica, Zorgnet Icuro, and the Flemish Patient Platform**, supported by **three Flemish government departments**. The initiative aims to **establish a technological and governance infrastructure** that enables citizens to securely manage and share their health data.

Three **key layers** define the We Are ecosystem:

1. **Data Storage:** Data is stored in personal data vaults using SOLID technology. Currently, this is the only SOLID environment that is production ready, the Athumi pod on the SOLID enterprise server.
2. **Interoperability, Data Models and consent management:** A standardized **R&D catalogue** and **semantic vocabularies** ensure that **health data can be effectively shared and reused**. Citizens can manage their consent preferences and monitor who accesses their data.
3. **Governance & Ethical Oversight:** A **data governance framework** ensures **ethical, legal, and participatory governance**, allowing citizens to be actively involved in decision-making.

SOLID in digital health - Key initiatives

We Are – Citizen-Centric Health Data Management
Speaker: dr. Elfi Goesaert, VITO
(slides to be consulted via this link)



We Are ecosystem

Connecting data to improve healthcare

By sharing data through **personalized applications**, individuals can benefit from:

- More accurate, personalized health recommendations.
- Improved integration of non-clinical and clinical data to support better treatment insights.
- Stronger patient empowerment, giving individuals the ability to self-manage their health information.

Applications and healthcare providers feed information back into personal data vaults, ensuring a dynamic and evolving health data ecosystem.

SOLID in digital health - Key initiatives

We Are – Citizen-Centric Health Data Management
Speaker: dr. Elfi Goesaert, VITO
(slides to be consulted via this link)

Case studies & practical implementations

Several tools and projects demonstrate the potential of We Are's citizen-centric approach:

- **BIPOPP Tool**: An evidence-based tool for assessing the risk of chronic diseases, and offering people tailored actions, integrated within a proto-SOLID framework.
- **Rare Disease Survey**: A specialized survey tailored to individuals with rare diseases, with the first example being TTP, a rare blood disease, facilitating improved care coordination and research. It went live in January, with data being collected in the Athumi pods.
- **Patient Survey hospital stay**: a survey assessing the quality of care patients received after a hospital stay. This was the first production test of data going into personal data vaults, the Athumi pods.
- **IDSA & WellData Projects**: We Are connects with larger data space ecosystems, integrating regional and interregional prevention data spaces.

Vision for the future - Expanding the health data ecosystem

The We Are Initiative envisions a seamless and interconnected health data ecosystem, where:

- All stakeholders —including citizens, healthcare providers, and researchers— collaborate in a trusted data-sharing environment.
- Personal health data is integrated across various platforms, ensuring that individuals can move freely between services without vendor lock-in.
- Prevention and quality of life become central tenets of healthcare policy and practice.

By bridging personal, clinical, and research data, We Are is laying the foundation for a healthcare system where citizens are active participants rather than passive recipients of care.

✅ *Key Components of "We Are":*

- **Personal Digital Vaults –** Citizens can store, manage, and share their health data.
- **Consent & Governance Layer –** Providing a structured approach to data sharing agreements.
- **Integration with Clinical & Non-Clinical Data –** Enabling more personalized healthcare solutions.

SOLID in digital health - Key initiatives

Athumi – Trusted Intermediary for access to Premium Data
Speaker: Ms. Dorien Bauwens, Athumi
(slides to be consulted via this link)

Ms. Dorien Bauwens provided insights into Athumi, an organization focused on enabling trusted data collaborations. Athumi plays a crucial role as a neutral intermediary, facilitating secure data exchange while ensuring that both citizens and organizations retain control over their data.

The challenge - Access to premium data

Access to high-value and sensitive data—whether organizational or personal—is often limited due to:

- **Lack of trust** between organizations, companies, and consumers.
- Concerns about **data privacy**, particularly with companies collecting and using personal information.
- **Regulatory complexities**, such as GDPR and the Data Governance Act, which allow for data sharing but impose significant compliance burdens.

Athumi aims to provide practical solutions to overcome these barriers by ensuring that legal, technical, and ethical requirements are met in data-sharing collaborations.

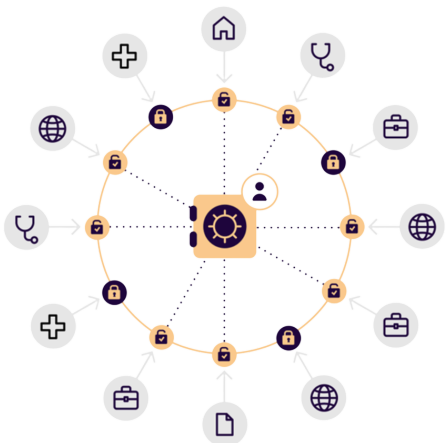
Athumi's role in data ecosystems

Athumi specializes in developing and managing new data ecosystems. It acts as a trusted intermediary, particularly in situations where:

- There is a lack of a neutral third party to facilitate data-sharing.
- Data-sharing requires transparency and governance mechanisms to foster trust among stakeholders.
- Secure and compliant data-sharing solutions are needed to streamline collaboration across sectors.

Athumi already operates a mature service platform, enabling seamless and secure access to data for various applications.

athumi



SOLID in digital health - Key initiatives

Athumi – Trusted Intermediary for access to Premium Data
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The Athumi POD Platform: Building practical use cases

Athumi has developed a SOLID-based POD platform that is currently being used for impactful use cases, such as:

- Sharing government data, such as diplomas and student certificates, securely and efficiently.
- Building hyper-personalised media services.
- Athumi's pods are a core component of the WeAre Health platform.
- Ensuring compliance with privacy regulations while improving access to personal and organizational data.

Athumi is also investing heavily in **user experience**, collaborating closely with Itsme to enhance authentication and authorization processes. The focus is on making **data-sharing intuitive and accessible** while ensuring users remain in control of their personal information.

Why Athumi?

Athumi's approach is designed to provide structured, compliant, and privacy-first data-sharing solutions that benefit multiple stakeholders:

- **Businesses and organizations** gain secure access to high-quality data for operational and analytical use.
- **Citizens** retain control over their personal data and can decide how, when, and with whom it is shared.
- **Regulatory bodies** are assured that all data-sharing processes meet legal and ethical standards.

By supporting trusted data collaborations, Athumi is creating new opportunities for businesses, research institutions, and government agencies to engage in data-driven innovation without compromising privacy, security, or compliance.

✅ *Athumi's key offerings:*

- **Secure Data Exchange Solutions –** Connecting different stakeholders in a legally compliant manner.
- **User-Friendly Data Sharing Processes –** Simplifying data consent and citizen onboarding.
- **Solid PODs for Personal Data Storage, Governance and Digital Identity –** Already being used for student diplomas & healthcare data.

SOLID in digital health - Key initiatives

FAQIR Foundation – Patient-Centric Data Vaults & Interoperability
Speaker: Prof. dr. ir. Filip Pattyn, FAQIR Foundation & FAQIR Institute
(slides to be consulted via this link)

The final speaker, dr. Filip Pattyn, presented the **PACSOI (Patient-Centric SOLID) Initiative**, a project aimed at breaking data silos, improving patient care, and enabling secondary data use through health data vaults. The initiative builds on SOLID technology and additional frameworks to address the specific needs of healthcare.

The shift towards patient-centric data management

The traditional healthcare system is fragmented, with patient data stored across different institutions and systems. This makes it difficult for individuals to access, manage, and reuse their own health information. The PACSOI initiative proposes a personalized, structured approach, where data is:

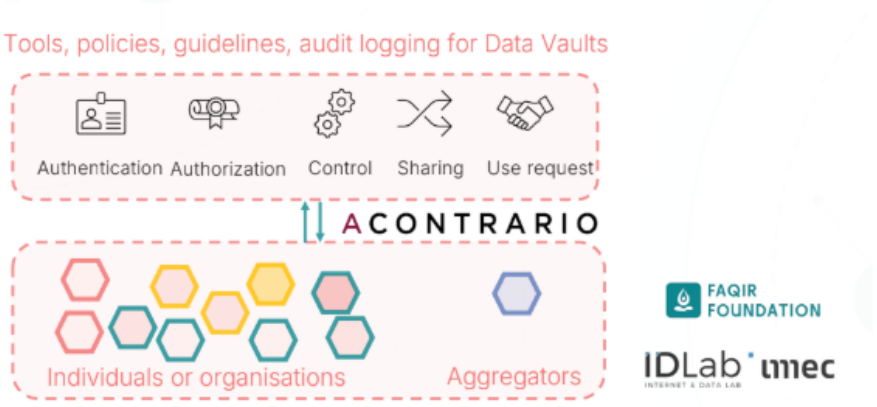
- Moved **closer to the patient**, reducing fragmentation.
- Stored in a **personal health data vault** or made easily accessible in a structured way.
- **Integrated** across healthcare and research environments, supporting both primary and secondary use.

While SOLID technology provides a foundation for decentralizing data, PACSOI aims to make it:

- **More scalable**, allowing for widespread adoption.
- **More trustworthy and secure**, ensuring data protection and compliance.
- **Optimized for data reuse**, enabling seamless secondary use for healthcare, research and policy-making.

To achieve this, PACSOI is developing a network of data vaults for both individuals and institutions. These vaults will be governed by:

- Data governance frameworks (in collaboration with Acontrario Law and IDLab).
- Standardized data models to ensure interoperability and reusability.
- Secure authentication and authorization layers for controlled access.



SOLID in digital health - Key initiatives

FAQIR Foundation – Patient-Centric Data Vaults & Interoperability
Speaker: Prof. dr. ir. Filip Pattyn, FAQIR Foundation & FAQIR Institute
(slides to be consulted via this link)

Bridging the gap between primary and secondary use

PACSOI differentiates between two key data use scenarios:

1. **Primary Use**: Data is directly used by individuals and healthcare providers for personalized treatments, care coordination, and monitoring.
2. **Secondary Use**: Anonymized or pseudonymized data is utilized for research, regulatory reporting, and healthcare innovation.

By structuring personal health records (PHRs) in a standardized format, PACSOI ensures that:

- Individuals remain in control of their health data.
- Healthcare professionals gain structured insights, improving care delivery.
- Researchers and policymakers can access anonymized data, facilitating evidence-based decision-making.

Interoperability & Standards - Making data work across systems

To ensure broad usability, PACSOI aligns with established health data standards, including:

- **HL7-FHIR** – As a digital envelope for data exchange.
- **OMOP Common Data Model (CDM)** – To structure secondary-use data in a research-friendly format.
- **OpenEHR** and Interoperability Frameworks – To create a person-centric ontology that integrates clinical and self-generated health data.

This structured approach avoids inconsistencies in data storage, ensuring that every application can efficiently access and use patient data.

SOLID in digital health - Key initiatives

FAQIR Foundation – Patient-Centric Data Vaults & Interoperability
Speaker: Prof. dr. ir. Filip Pattyn, FAQIR Foundation & FAQIR Institute
(slides to be consulted via this link)

A new perspective on the patient journey

PACSOI envisions a **holistic, patient-driven model**, where:

- Patients actively track and manage their health evolution, improving self-care and motivation.
- Care teams access real-time data insights, leading to better decision-making.
- Health professionals utilize aggregated patient data dashboards, enhancing care coordination and early intervention.
- Real-world data (RWD) can be leveraged for innovation, including drug repurposing, biomarker discovery, and health economic research.

Initial findings suggest that up to 80% of patients are willing to share their data for secondary use, provided their privacy is protected and data is used ethically.

Future directions - Expanding the health data ecosystem

PACSOI is focused on:

- **Connecting with larger European health data spaces**, ensuring alignment with EHDS.
- **Developing user-friendly tools** that encourage patient engagement in data sharing.
- **Refining governance structures** to ensure legal, ethical & societal acceptability.

By bridging patient data with clinical and research frameworks, PACSOI aims to create a sustainable, patient-centric health data ecosystem, ultimately improving healthcare delivery, medical research, and personalized treatments.

✅ *FAQIR's core focus areas:*

- **Interoperability with Health Standards** (HL7-FHIR, OMOP CDM, , SNOMED CT, LOINC, OpenEHR).
- **Person-Controlled Health Data Vaults** – Aligning with PHRs (Personal Health Records).
- **Enabling Secondary Data Use for Research, Innovation and Policy-Making** while respecting privacy regulations.

*"Up to 80% of patients are willing to share their health data for re-use, provided it's done **ethically and securely**."*

Panel discussion - Addressing key challenges

Consent & user control - The need for granularity

A key discussion point was how to improve the balance between the granularity and usability of consent mechanisms. To simplify data-sharing decisions, users should have the option to share data with specific institutions or research projects in a single step, while still retaining the flexibility to review and refine their consent settings. Recognizing that individuals have different preferences, solutions should incorporate both simplified and detailed consent management options. Additionally, vulnerable populations require support networks and accessible assistance centers to help manage their data-sharing preferences responsibly.

Building trust in health data sharing

Trust is a fundamental requirement for the adoption of SOLID-based health data sharing. This trust is built through:

- **Ensuring data quality**: Metadata must be accurate and clinically relevant to make shared health data useful.
- **Transparency in data use**: Clearly defining how and when data is shared, whether through automated processes or user-driven approvals.
- **Legal and ethical considerations**: For certain health data use cases, such as within the context of population health management - e.g., vaccination records - default settings should be defined without opt-out options available, to serve the bigger good.
- **Personalized data sharing**: Users should be able to selectively share health information without being overwhelmed by excessive complexity.

Promoting user-friendly adoption

Embedding data-sharing features into familiar applications can enhance user trust and encourage adoption. A stepwise approach that introduces users to the process gradually, rather than overwhelming them with information at the outset, is preferred. Widely adopted digital identity solutions, such as Itsme, can serve as entry points to SOLID-based data management. Additionally, leveraging existing administrative processes—such as digital diplomas and tax filings—can help introduce users to secure digital identity-linked data vaults in a practical and familiar way.

Panel discussion - Addressing key challenges

Ensuring data quality & interoperability

Ensuring data quality and interoperability is essential for the success of SOLID-based health data sharing. Existing health data communication protocols and standards, such as HL7-FHIR, OpenEHR, and OMOP CDM, should be leveraged to maintain consistency and reliability. Metadata annotation is particularly important to ensure that secondary data use remains meaningful. However, while open standards offer a foundation for interoperability, they do not automatically guarantee high-quality data. Additional validation frameworks must be incorporated to enhance harmonization efforts.

Challenges exist in implementing standard data models within SOLID. Since SOLID does not impose a fixed data structure, achieving interoperability across different systems can be complex. FHIR serves as an exchange format rather than a storage format, meaning additional implementation layers are needed to integrate with personal health vaults.

Similarly, OMOP is optimized for structured secondary data use but is not inherently designed for personal health data storage. The focus should be on ensuring that personal health records are linkable and structured, allowing for meaningful integration across systems.

Preventing lock-in & enhancing data portability

A key consideration in developing SOLID-based health data solutions is preventing vendor lock-in and ensuring data portability. In principle, users should have the flexibility to move their health data seamlessly across different providers, services, and applications. Tech providers must prioritize interoperability over proprietary solutions that restrict data mobility, while governance structures should reinforce seamless data migration to maintain individual control over personal health information.

However, in Belgium, there is currently only one provider for production-level SOLID data (Athumi). While SOLID is designed as an open standard that allows switching between pod providers, this remains hypothetical at this stage due to the lack of alternative production-level providers. A broader ecosystem of SOLID-compatible providers would be necessary to fully realize the potential for interoperability and user choice. That said, even with only one SOLID-POD provider, vendor lock-in can still be mitigated at the application level, ensuring that users are not restricted to a single ecosystem for accessing and managing their health data.

Personal data vaults play an essential role in this ecosystem, but true interoperability requires collaboration among all stakeholders to uphold ethical data governance principles. Data-sharing frameworks should not only ensure security but also maintain the usability and actionability of personal health data.

Panel discussion - Addressing key challenges

Onboarding & driving adoption

A user-friendly onboarding process is essential to encourage adoption. Simplified registration and consent processes will make it easier for individuals to begin using SOLID-based data vaults. Sandbox environments, where users can experiment with SOLID vaults before committing, are currently being explored as an introductory tool. Practical use cases—such as employment certificates, student attestations, and tax data integration—can serve as low-risk entry points for broader health data sharing.

SOLID's role in the European Health Data Space (EHDS)

The potential of SOLID to support the European Health Data Space was also discussed. While traditional data spaces typically focus on large institutional networks, SOLID offers an individual-centric approach that complements these frameworks. For SOLID to be effectively integrated into EHDS, its metadata structures and data models must align with EHDS standards to ensure smooth interoperability.

Personal health vaults powered by SOLID could serve as intermediary layers, enabling individuals to engage with large-scale EHDS datasets while maintaining personalized control over their data. One possible improvement in health data accessibility is the development of automated summary records (SumEHRs) that ensure personal health data remains accurate, up-to-date, and easily shareable when needed.

Unanswered questions & future considerations

To remain within the scheduled timeframe of the webinar, several insightful questions from the chat - big shout out to the highly engaged participants! - remained (partially) unanswered. These questions serve as food for thought for experts working in the field and could be explored further in future discussions—or perhaps in a follow-up webinar?

Key unanswered questions

- **Incentivizing data sharing**: What are effective strategies to drive traffic and incentivize patients and care providers to share their data?
- **Use cases & data sources**: What specific use cases are being targeted? Does this include EHR data and direct connections to hospitals?
- **Default consent settings**: Can SOLID technology provide default sharing settings for citizens who may struggle to manage their own data?
- **Avoiding data silos**: Since SOLID is open science technology, does allowing everyone to set up their own SOLID POD create new data silos?
- **Onboarding process**: What onboarding process is in place for new users? What does the onboarding package include, and how easy is it for citizens to set up a profile? (*this question was mainly tackled from the data user's standpoint, not from the citizen's perspective)
- **Preventive vs. reactive healthcare**: How can SOLID technology be integrated into daily healthy living, rather than being seen as something only relevant in illness?
- **Trust between unfamiliar systems**: How can trust be established when an app provider does not know the SOLID POD provider and vice versa (e.g., cross-border healthcare scenarios)?
- **Ensuring data quality**: How can data quality be guaranteed if individuals control how their data is stored in their personal SOLID PODs? (e.g., validated data from health care records vs. remote monitoring/PROMS)
- **Data models in SOLID PODs**: Since different data models (document-based, graph-based) can be used, how can consistency be ensured across PODs?
- **Preventing multiple PODs per user**: How can duplication be avoided when a single individual may have multiple SOLID PODs with different providers? Are there agreements in place to ensure interoperability? Could this potentially introduce bias in large-scale research using aggregated data from multiple PODs?
- **Scalability of SOLID**: Is SOLID industry-proof, and can it scale for widespread healthcare adoption?

Unanswered questions & future considerations

Key unanswered questions *(continued)*

- **Metadata and EHDS**: In the EHDS, metadata is crucial for data cataloging. How will this work if SOLID PODs were to be used in European Data Spaces? Will the SOLID POD provider be responsible for the metadata catalogue of an individual's POD?
- **Lessons from other industries**: What lessons can be learned from other sectors where sensitive data sharing has been successfully implemented (e.g., finance, telecommunications)?
- **Hybrid care & data storage**: How does the organization of hybrid care models (e.g., remote monitoring for chronic care) depend on whether data is stored in a regular platform vs. a SOLID POD? *(*this question was already briefly touched upon, but might need some more elaboration)*
- **Future synergies**: How can collaboration between different initiatives and projects be strengthened to ensure seamless integration and knowledge sharing?
- **Limitations of SOLID**: What are the current limitations of SOLID technology, and what additional ecosystem players are needed to complement its functionalities?

These questions highlight ongoing challenges and opportunities within SOLID-based healthcare data management. Addressing them in future discussions could help refine solutions and accelerate adoption.

Conclusion - Opportunities & challenges in the evolving health data ecosystem

The healthcare sector is indeed undergoing rapid digital transformation, with e.g., SOLID technology and upcoming EHDS regulations presenting both new opportunities and critical challenges.

Opportunities SOLID technology

- **Empowered individuals**: By decentralizing data storage, SOLID offers citizens control over their health data, potentially leading to more personalized healthcare and greater patient engagement.
- **Improved interoperability**: Aligning SOLID with HL7-FHIR, OMOP CDM, and EHDS frameworks can create a more connected and efficient healthcare ecosystem.
- **Advancing preventive care**: SOLID-based personal health records have the potential to shift focus from reactive to preventive healthcare, enabling earlier interventions and better long-term outcomes.
- **Scalability & adaptability**: SOLID is an open standard, meaning it can evolve and adapt to different healthcare systems and digital health policies.
- **Trust & governance**: Transparent data-sharing mechanisms with strong governance structures can enhance trust among stakeholders, ensuring ethical and responsible health data usage.

Remaining challenges

- **Complex health ecosystem:** The healthcare landscape is already under severe pressure due to aging populations, digital illiteracy, and health inequity. Implementing new digital frameworks must not exacerbate these issues.
- **Interoperability gaps:** Despite alignment efforts, technical and procedural challenges persist in ensuring seamless data exchange across hospitals, care providers, digital health applications, and patient-controlled PODs.
- **Data literacy & digital divide:** Many citizens—particularly older adults and vulnerable populations—may struggle to manage, share, or interpret their own health data, increasing risks of misuse or exclusion.
- **Regulatory uncertainty:** While the EHDS aims to provide a structured data governance framework, the exact implementation process and regulatory impact on decentralized models like SOLID remains uncertain.
- **Data quality & trust issues:** Without clear validation mechanisms, data stored in SOLID PODs could vary in quality, leading to challenges in clinical decision-making and research reliability.
- **Adoption & incentivization:** Encouraging both patients and healthcare providers to actively use and trust SOLID-based platforms requires long-term education, incentives, and robust support systems.

Final thoughts

While SOLID technology represents significant progress towards **more open, transparent, and citizen/patient-centered health data ecosystems**, there remain substantial challenges that must be strategically addressed.

To ensure that digital health solutions truly serve patients, healthcare providers, and policymakers, **collaboration is key**. Efforts to improve **interoperability**, **regulatory alignment**, and **user experience** should not take place in isolation. Instead of reinventing the wheel within silos, stakeholders—including governments, research institutions, technology developers, and patient advocacy groups—must work together to build **cohesive** and **sustainable solutions**.

Ensuring **inclusive access**, building user-friendly interfaces, establishing strong governance models, and **aligning with existing healthcare workflows** will be crucial in determining the long-term success of these initiatives.

Only through **collaboration and knowledge exchange** can we create a **fair, accessible, and efficient health data ecosystem** that benefits all. This discussion is just beginning—perhaps a follow-up webinar could help assess progress and explore new synergies?

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