
# Enable the future of healthcare: federated, citizen-centric and insight-driven!

Event Report– April 4th, 2022

## Event scope

Digitalisation is fundamentally changing the way we manage health. Citizens get in control of their sensitive health data, and they get to say who may use it, for how long and for which purpose. Care providers get connected digitally with their patients and their peers, to give them a comprehensive and longitudinal view that allows them to provide the best care each time.

Governmental organisations get access to selections of health data that enable them to optimise health policies and to act in the event of crises. Scientists and industry get access to selections of health data to accelerate the development of medications and medical devices that are proven safe and effective.

All these stakeholders need access to health data, at the right time and place, beyond European borders, in a trustable manner, without harming the individual's privacy rights and preferences. The future healthcare system will be decentralised, citizen-centric and insight-driven. Data sharing is key to enable personalised, optimised and value-based health and care.

***How is Gaia-X contributing towards a trustable, scalable, and efficient health data space in Europe?***

During the half day summit on April 4, 2022, multi-disciplinary keynote speakers and panels addressed this key question and equally explored next concrete steps during the breakout sessions.

## Our monumental goal

Based upon the common thread across all event presentations, we may distill the following fundamental ambition for a **Gaia-X powered health data space**:

> *The European health domain is highly fragmented. Gaia-X aims to make health data accessible to enable the e creation of health insights; improve the prevention and care of each citizen; improve the dialogue between citizens and healthcare professionals, and accelerate the progress made on*

*health policy and medical innovation. Access to health data will be balanced with the privacy of this sensitive personal data, such that citizens control them entirely*

*The Gaia-X framework enables health data spaces that are citizen centric, sovereign and federated and that can be deployed with trust and at scale. These data spaces integrate existing data initiatives in a federated structure and invite new initiatives to join the federation, to progress medicine, reduce costs and improve health for all.*

Health Data Space TODAY


Health Data Space in the FUTURE


## Session highlights

From the keynote presentations as well as from the breakout sessions, we could summarise the following common themes and requirements:

- Start from the citizen's perspective. Always keep control with the citizen, except when the data is used for the public good according to European or national legislation. Effective and user-friendly consent management is therefore crucial.
- For the data infrastructure, we need solutions that support both primary and secondary use cases. Throughout the event we saw that use cases are frequently intertwined.
- Implement clear governance and incentives for the use of data on personal, regional, national, and European level and for delivery of care, for research, for commercial and governmental use.
- Provide a framework to implement Health Data Spaces at scale, in a compliant, secure, and trustable manner. The Gaia-X trust framework is an excellent foundation for this.
- Enable the storage and access of personal and non-personal health information in trusted and collaborative cloud infrastructures, with elasticity to scale and with a proper legal basis.
- Enable a broad and seamless match of demand and offer of healthcare services, directly accessible by citizens. The pan-European digital health application programs, with quality and reimbursement guarantees, are an opportunity to accelerate in this field.
- Accelerate research and development in healthcare (prevention, diagnosis, treatment, etc.) through the connection of R&D, hospitals, patients, pharma, medical devices in a homogeneous ecosystem. This allows to level the playing field for all market stakeholders.

- Enable the transition from traditional medicine to PPP medicine (Predictive, Precision, Personalised) thanks to the creation of large data spaces of genomic, imaging, clinical and real-world data. We saw many promising solutions in the various use case breakout sessions.
- There was a lot of recognition for the common building blocks, critical to the health domain and essential to create breakthroughs at scale.

## Next steps

The following actions are now in progress and for the interested audience to consider:

- Publish a more extensive summary of the event in the Gaia-X Magazine: check out the first release by the end of April.
- Join Gaia-X as a member: https://www.gaia-x.eu/how-to-join. More information may be checked here: https://gaia-x.eu/sites/default/files/2021-10/Gaia-X%20Membership.pdf
- Join the Gaia-X Health community, an open working group for interested stakeholders in the health domain (Gaia-X membership not required): by sending a request by Email to joingaiaxhealth@lih.lu. Here we will continue the match-making process between health data space initiatives of interest to adopt the Gaia-X trust framework. We will continue to explore opportunities within these three prioritised use case themes:
    - **Genomics, imaging and clinical data for cancer care and rare diseases**: make this combined data available at a large, cross-country scale, for study, and for improving diagnosis and treatment. And make the data-driven findings available at the point of care, in applications useful for the treating physician as well as to the patient.
    - **Patient driven measurements and outcomes:** bring the infrastructure in place to learn from patient centric observations at a massive scale, and to deploy smart patient applications using that data using this same infrastructure.
    - **Longitudinal patient records exploration:** enable patients to get access to their medical records collected at different providers, and enable patients to provide access to their integral, longitudinal health record in a controlled manner to their doctor of choice or to a clinical study of choice.

- Join one of the three open working groups who will deepen the common building blocks by sending your request of interest to join by email to joingaiaxhealth@lih.lu.
    - **Identity, consent, and trust:** each data space initiative needs to resolve the most basic requirements to ensure trust and to allow sovereign control. They require a trust framework, federated identity management and consent management. In this working group, we will investigate how Gaia-X framework and common building blocks can be utilized, and where we need to add health-specific requirements to close remaining gaps.
    - **Data standardisation:** standardisation of health data has come a long way. Still several standards are competing to achieve the required level of semantic interoperability. Many of the existing standards still struggle with the adoption by professional users. In this working group, we will discuss the required convergence of standards, the struggles with adoption and the common components to enable semantic interoperability.
    - **Trusted AI:** artificial intelligence (AI) plays an increasingly important role in decision making. The ability to trust AI and its output is therefore crucial for its adoption and reaching full potential, especially in such sensitive sectors as health. Trusted AI encompasses concepts for reliability, privacy, security, fairness, transparency,

robustness, inclusiveness, accountability, and explanation. In this working group we will discuss approaches to the required principles for a successful implementation.

## Recordings and presentations

All sessions of the event were recorded, both the presentations and recordings may be accessed through the Gaia-X dedicated event agenda.

**Chapter 1 General session:**

- Citizen perspective, compilation of quotations
- Needs from clinical/academic world, Emmanuel Bacry, French Health Data Hub
- Needs from the industry, Cecilia Bonefeld-Dahl, DIGITALEUROPE
- Health domain challenges and trends, Cristina Bescos, EIT Health
- Needs from EU university hospitals, Martin Hirsch, AP-HP
- From today – To the future of health, Bert Verdonck, Philips, Gaia-X
- A future, virtual hospital perspective, Jeroen Tas, Philips, Gaia-X and Maurice vd Bosch, CEO of OLVG Hospital Amsterdam
- Legislative perspective: Data* Acts and EHDS, Thomas Hellebrand, DIGITALEUROPE
- Legislative perspective: TEHDAS: status of investigations, Tapani Piha, Sitra
- Gaia-X Infrastructure & Data ecosystem: the trust framework, Pierre Gronlier, Gaia-X

**Chapter 2 Breakout sessions:**

- **Use cases #1:** Genomics, Imaging and Clinical Data for Cancer Care and Rare Diseases,
  *Moderator: Andrea Derix, Bayer*
  - Beyond 1M genome project, Juan Arenas Marquez, ELIXIR
  - Clinical genomics cloud use cases, Dr. Patrick Kemmeren, Princess Maxima Center for pediatric oncology
  - AI applications in omics studies: what we need, Jean Marc Christille, Astronomic Observatory of Val D'Aosta
  - Carecol – gastric cancer data collaborative, Andrea Pescino, Stratejai and Elena Bonfiglio, Microsoft
  - de.NBI Cloud: not a data space (yet), Harald Wagener, Berlin institute of health, Charite

- **Use cases #2:** Patient Driven Measurements and Outcomes,
  *Moderator: Jasmin Schulz, Luxembourg institute of health*
  - A common health data space: HEALTH-X dataLOFT, Roland Eils, Berlin institute of health, Charite
  - TEAM-X: trusted ecosystem of applied medical data exchange, Jochen Bauer, Friedrich-Alexander University, Erlangen-Nurnberg
  - Clinnova – cross-border health innovation, Jasmin Schulz, Luxembourg institute of health
  - Digital health applications, Ronald Gräfe, kaia health
  - Secur-e-Health: privacy preserving, cross-organizational analytics, Sarah Van Drumpt, TNO

- **Use cases #3:** Longitudinal Patient Records Exploration
  *Moderators: Jeroen Tas, Philips & Francesco Bonfiglio, Gaia-X*
  - Remote patient monitoring for heart disease patients and early treatment for stroke patients, Michale Mossal, NTT and Jacques Federspiel, Hopitaux Robert Schuman
  - Interoperable and citizen controlled cross-border sharing of diabetes data, Mikael Rinnetmaki, sensotrend
  - Connecting clinical data warehouses to computing resources in the cloud, Romain Bey, AP-HP
  - A data space for blended care, Nico van Rooijen, Philips
  - Using AI in transplant optimization, Dr Ignacio Revuelta,
  - C4Yourself project, Jildau Bouwman, TNO

- **Common building blocks #1:** identity, consent & trust management
  *Moderators: Erwin Dijkstra & Claire Unwin, Atos*
  - Digital responsibility goals and Gaia-X, Jutta Meier, Identity Valley
  - Data altruism and citizen trust, Joan Guanyabens, SalusCoop
  - Consent and agreement management, Lal Chandran, iGrant.io
  - eIDAS: trusted digital identity, Dr. Dominik Deimel, comuny
  - Gaia-X trust framework, Pierre Gronlier, Gaia-X

- **Common building blocks #2:** Data standards
  *Moderators: Enrique Bernal & Carlos Telleria*
  - The international patient summary, Stephen Kay,
  - EHDEN, OMOP and common data models, Sebastiaan van Sandijk, Odysseus data services
  - Data standardisation – Harmony alliance, Ruben Villoria, Health evidence
  - health RI and clinical data standards, Jan-Willem Boiten, health RI
  - Rare disease data in health data spaces, Tala Haddad, Orphanet Inserm US-14
  - HL7 interoperability – lessons learned, Lloyd McKenzie, Accenture

- **Common building blocks #3:** Trusted AI
  *Moderators: Ulf Nehrbass, Christian Schorr, and Philipp Slusallek*
  - AI in healthcare – the transborder Clinnova initiative, Ulf Nehrbass
  - Strategic discussion on trusted AI, Prof. Philipp Slusallek and Dr. Christian Schorr, DFKI
  - How advanced anonymization can improve federated architectures, Tuomo Pertikäinen, VEIL.AI
  - Expert.ai natural language understanding, Gianluca Sensidoni, Expert.ai
  - AI-based risk prediction and treatment effect estimation, Prof. Dr. Thomas Zahn, Risikoanalytik
  - Trusted AI for data interoperability, Dermot Doyle, Dynaccurate