

Health Data Space Event 4 APRIL 2022

#4 Enabler Identity, Consent & Trust

Chapter 2a: Breakout Session



Chapter 2a: Breakout Use cases



• #4 Enabler Identity, Consent & Trust

Welcome and Opening



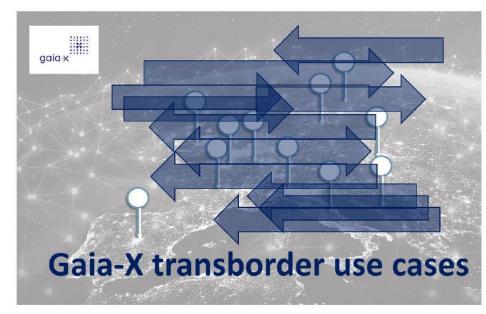
- Dr. Erwin Dijkstra, Distinguished Expert - Healthcare & Life Sciences, Atos
- Claire Unwin, Innovation Architect - Healthcare & Life Sciences, Atos

GAIA-X Health – use cases









Genomics and imaging data for cancer care and rare diseases: make this 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.

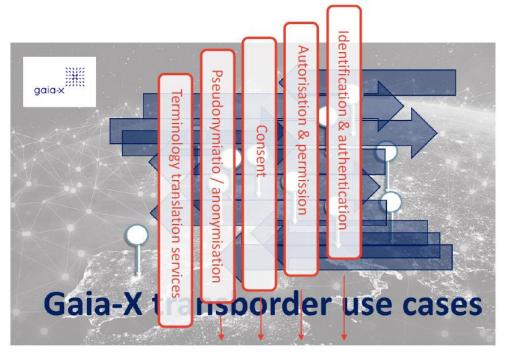
Medical record exploration: enable patients to get access to their medical records collected at different providers, and enable patients to provide access to their integral, longitudinal health record in a controlled manner to their doctor of choice or to a clinical study of choice.

GAIA-X Health -enablers

LUXEMBOURG INSTITUTE OF **HEALTH**







"enabler"-specific transversal working groups

In order for the trans-border use cases to further Gaia-X, they should be probed by working groups for specific, common enablers

- Each working group should be constituted by specialists around a given enabler
 - From the countries participating in the use case
 - From other member countries interested in the use case/subject
 - From AISBL «HQ» a specialist closest to the enabler
- Transversal working groups:
 - Identification & authentication management
 - Authorization & persmission management
 - Consent management
 - Pseudonymisation and anonymisation services
 - Terminology translation services
- Eventually, common solutions for enablers should be elaborated and proposed to AISBL

GAIA-X Health – this breakout



Welcome, opening, intro	Moderator	erwin.dijkstra@atos.net
Digital Responsibility Goals and Gaia-X	Jutta Meier	jj.meier@identityvalley.org
Data altruism and citizen trust	Joan Guanyabens	joan@guanyabens.com
Consent and agreement management	Lal Chandran	lal@igrant.io
eIDAS : Trusted Digital Identity	Domink Deimel	dominik.deimel@comuny.de
GAIA-X Trust Framework	Pierre Gronlier	Pierre.Gronlier@gaia-x.eu
Q&A with the audience	Moderator	
Polls on maturity & next step involvement	All participants	Claire.Unwin@atos.net
Next steps with the audience	Moderator	
Compile session summary	Moderator	

https://identityvalley.org/assets/download/IDV_Gaia-X-%20Analyse_Doppelseiten_220222.pdf

https://www.saluscoop.org/

https://igrant.io/

https://digital-strategy.ec.europa.eu/en/policies/eidas-regulation

https://sifted.eu/articles/estonia-digital-health/#:~:text=Estonia's%20health%20service%20has%20been,to%20look%20at%20those%20records.

https://www.gxfs.eu/

https://atos.net/en/industries/healthcare-life-sciences

Building blocks: identity, consent & trust. Digital Responsibility Goals & Gaia-X

gaia-x

Jutta Juliane Meier Founder & CEO Identity Valley

Digital Responsibility Gaas

Gaia-X Healthcare Data Space Event, April 4th 2022



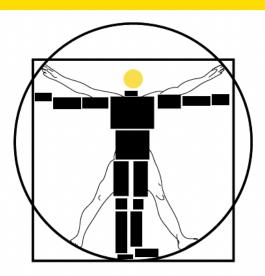
Identity Valley. Our credo.

#itsallabouttrust

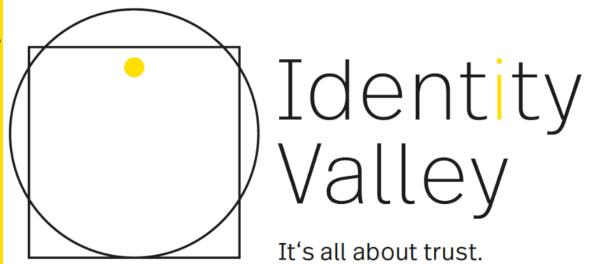
identityvalley.org



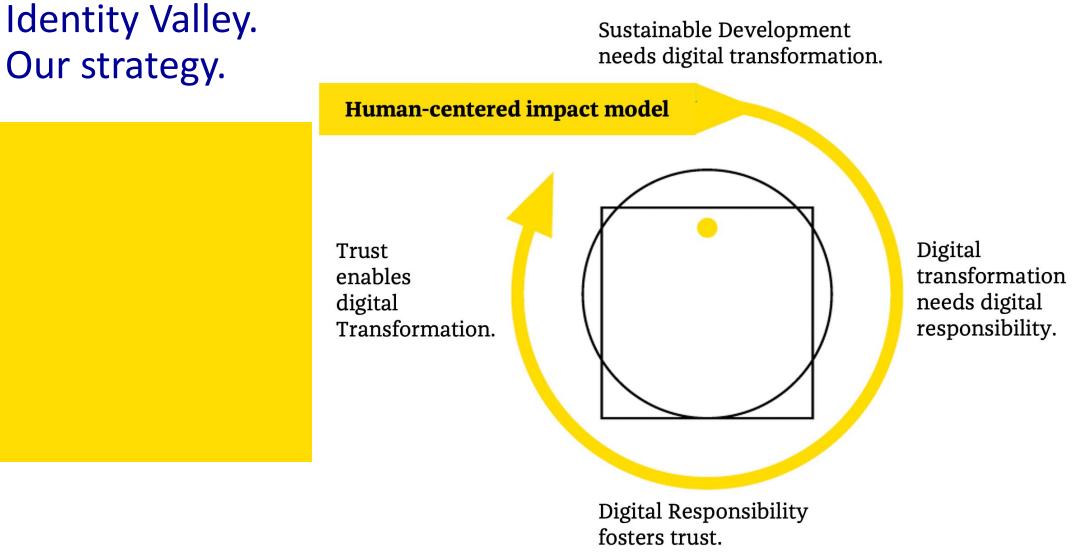
Identity Valley. Our purpose.



Inspired by da Vincis Vitruvian Man, the Identity Valley Logo tells a story of a human-centered science and evolution.







Climate Change &

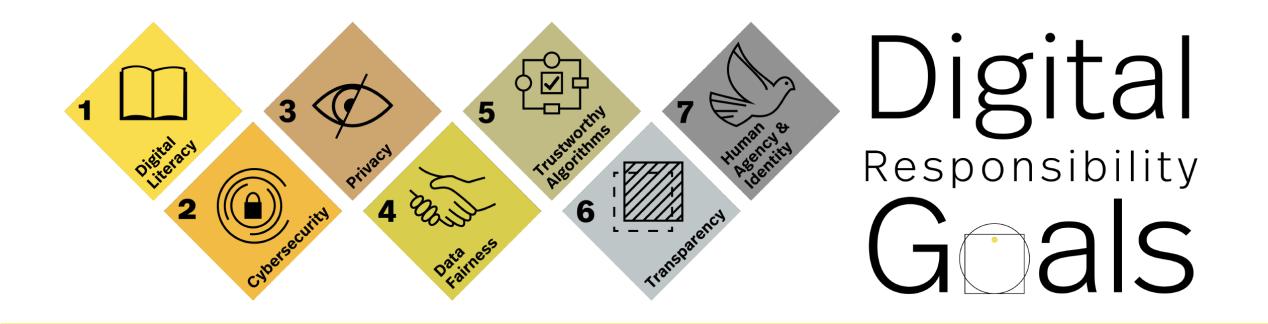
Digital Transformation.

Climate Change





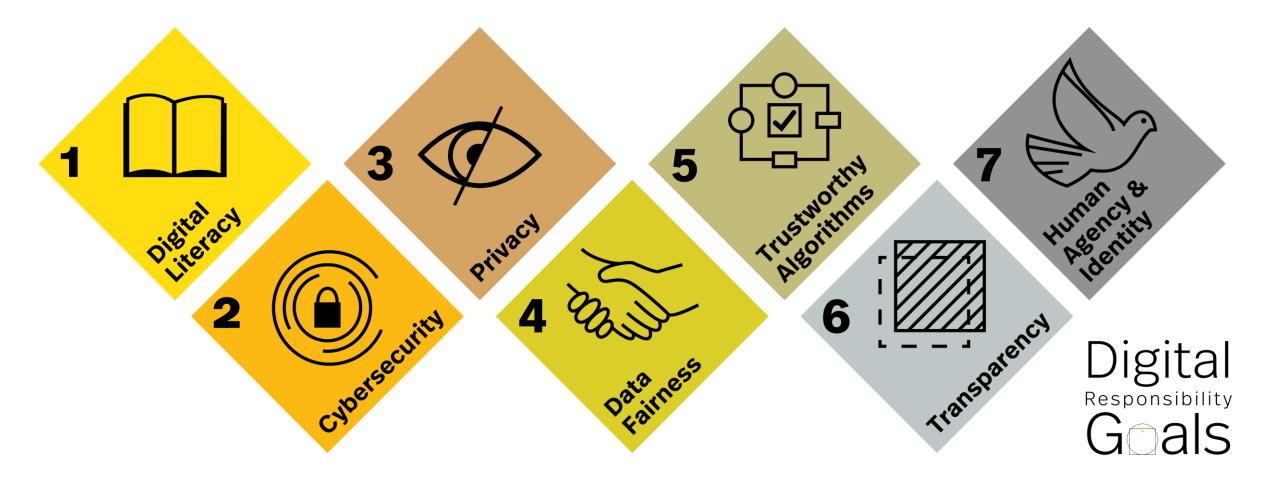
Digital Transformation.



Digital Transformation.



The 7 Digital Responsibility Goals - providing guidance on the path to greater trust and a human-centered digital transformation.





"Europe can, and should, create rules for living, working and communicating in the digital space that our citizens can rely on. The Digital Responsibility Goals are a valuable benchmark for this."*



European Parliament

Prof. Dr. Angelika Niebler Member of the European Parliament

*June 23rd 2021 – First Public Launch of the Digital Responsibility Goals – virtually @ European Parliament





"We need to be more courageous to shape the digital space in a way that it serves humanity and strengthens democracies. The Digital Responsibility Goals offer such a framework and should become a norm in Europe."*

Ilsabe von Campenhausen Executive BMW Foundation Herbert Quandt **BMW Foundation** Herbert Quandt

*June 23rd 2021 – First Public Launch of the Digital Responsibility Goals – virtually @ European Parliament





"Collaboration with our industrial automation customers can only remain successful if we ensure that the exchange of information is based on trust. That's why Identity Valley's Digital Responsibility Goals are so important."*

Curt–Michael Stoll Vice-Chairman of the Supervisory Board FESTO SE & CO. KG



*June 23rd 2021 – First Public Launch of the Digital Responsibility Goals – virtually @ European Parliament





"People will only trust machines and algorithms if they can be confident that their identity and that of others will be protected. With the Digital Responsibility Goals Identity Valley works towards responsible action and therefore promotes the building of this trust as the basis for Digital Transformation."*

ir Innovation und Wettbewerb

Dietmar Harhoff

Director

Max Planck Institute for Innovation and Competition

*June 23rd 2021 – First Public Launch of the Digital Responsibility Goals – virtually @ European Parliament



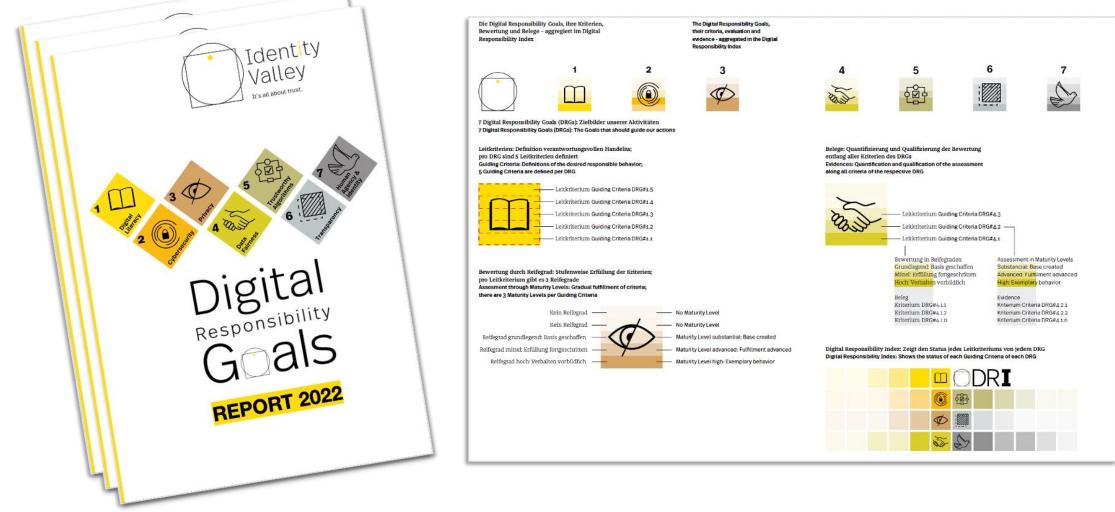


How can we be sure? Through Monitoring and measuring.



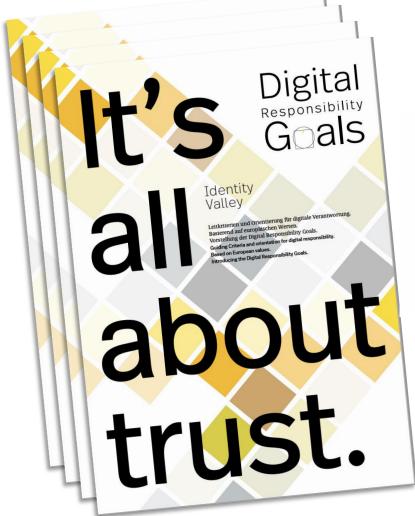


Making progress visible. Through Digital Responsibility Reports.





Our first strategy paper. Published on February 22nd at eco HQ.



"

Developing the Digital Responsibility Goals was started by a consortium - consisting of academics, NGOs, and industry experts and will be further refined continuously in a multi-stakeholder approach.

Download: https://www.gxfs.eu/panel-discussion-on-digital-responsibility-and-gaia-x/

Our very first analysis. Digital Responsibility Goals and Gaia-X.

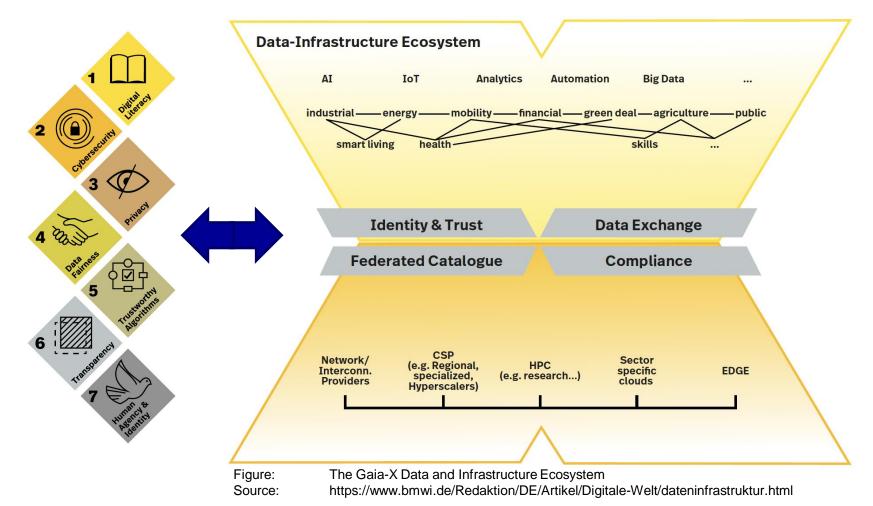


"

One of the key initiatives to establish digital eco systems is Gaia-X with its firm promise to be open, transparent, sovereign, fair, independent, inclusive, free, federated, innovative and evolutionary.

Download: https://www.gxfs.eu/panel-discussion-on-digital-responsibility-and-gaia-x/

Our very first analysis. Digital Responsibility Goals and Gaia-X.



Digital Responsibility Goals and Gaia-X. Our initial assessment.

X X is not 1 1 X explicitly Digital mentioned Literacy is mentioned. 1 \checkmark / \checkmark but not fully according to Cybersecurity **DRG** guiding criteria 6 is mentioned 1 V / / in the full scope of the Privacy **DRG** guiding criteria - CO- \checkmark \checkmark / 1 Data Fairness Х X 1 1 Trustworthy Algorithms 1 1 / / Transparency Х Х Х Х Humai Agency &

Status: January 2022 Panel-Discussion and Download of full papers: https://www.gxfs.eu/panel-discussion-on-digitalresponsibility-and-gaia-x/



"Digital responsibility is a complex topic and we at eco are pleased that Identity Valley wants to take on the challenge and make digital responsibility measurable. Gaia-X is on the right track and already addresses important elements of digital responsibility, but there is also still room for improvement."*

Andreas Weiss

Member of the Executive Board & Lead for Digital Business Models eco Association of the Internet Industry

*February 22nd 2022 – Public Launch of the Digital Responsibility Goals strategy paper & A first analysis of Gaia-X – virtually @ eco HQ Cologne





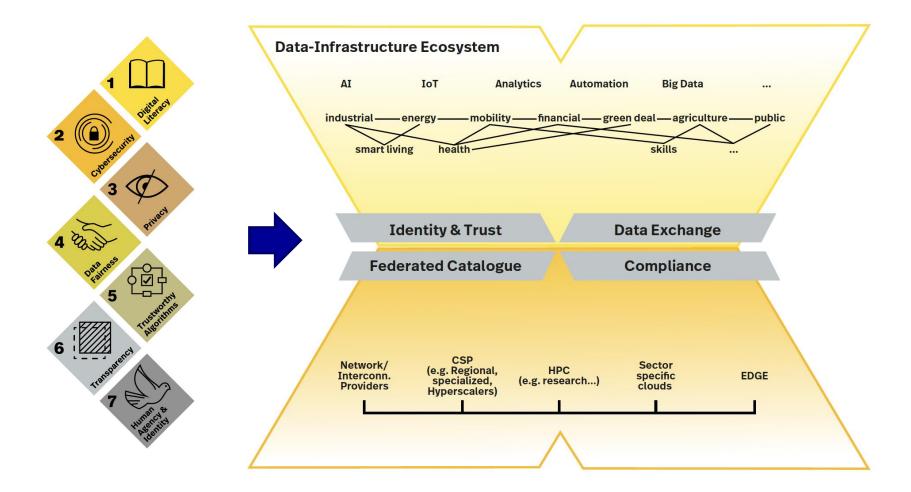


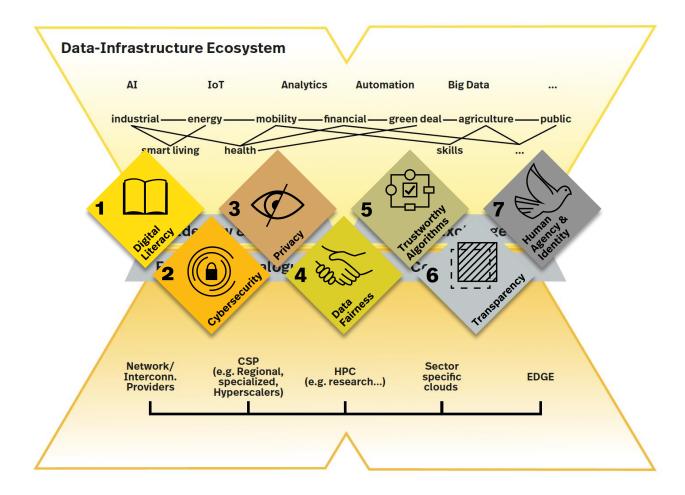
..."When I read this research I found it extremely interesting because it's the translation of the social responsibility into digital responsibility where our world is transitioning from a physical ecosystem into a digital or augmented ecosystem. So it makes perfect sense."...

Francesco Bonfiglio CEO

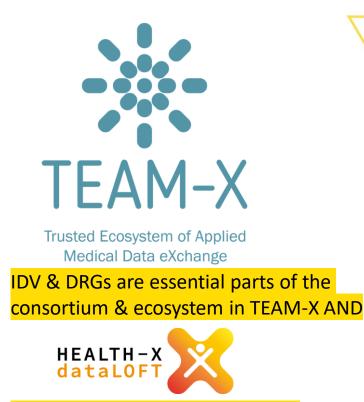
Gaia-X

*February 22nd 2022 – Public Launch of the Digital Responsibility Goals strategy paper & A first analysis of Gaia-X – virtually @ eco HQ Cologne

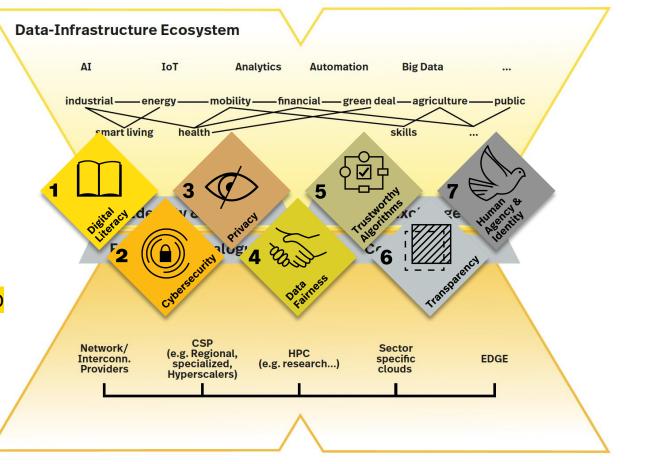




Digital Responsibility Goals & Gaia-X. Current research project(s).



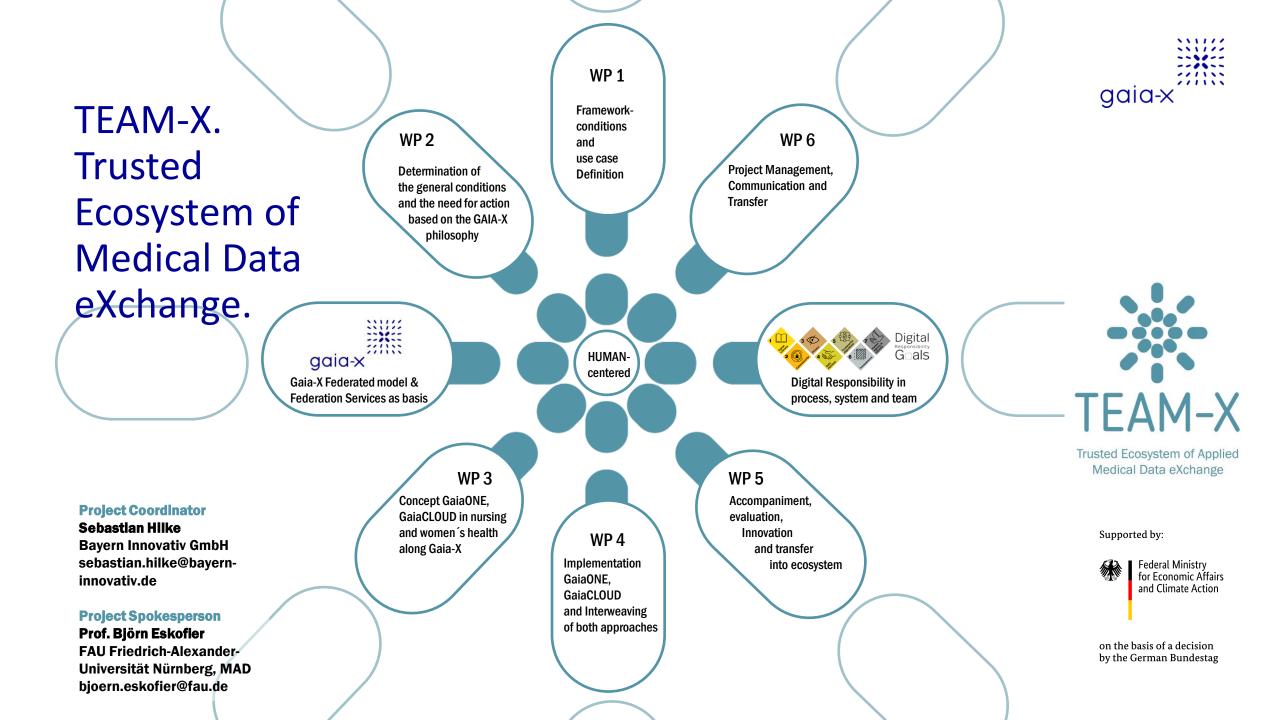
honorary contributors within the Patient Advisory Board of HEALTH-X



Supported by:



on the basis of a decision by the German Bundestag



DRGs and TEAM-X. Changing Perspectives.

PROCESS

PERSPECTIVE

SYSTEM

PERSPECTIVE



COMBINED SYSTEM & PROCESS PERSPECTIVE UMAN Digital Responsibility Index HUMAN-TEAM PERSPECTIVE

The Digital Responsibility Goals not only combine the systems- and processperspective within TEAM-X, but also... ... add the human dimension through a human centered perspective. This is how the DRG Index will be generated in an overall holistic approach along all DRG Criteria.



DRGs and TEAM-X. New ways of governance, tools and responsible leaders mindsets.

Governance in process

- Digital Responsibility Guiding Criteria
- Digital Responsibility Community
- Impact Assessment Committee
- Sector-specific further development of guiding criteria: DRG4Health
- Digital Responsibility Report
- Code of Conduct based on:
 - Innovation
 - Collaboration
 - ✤ Openness

Tools in the system

- Integration in Issue Tracker
- Integration in templates
- Development of a Digital Responsibility Canvas
- Database with examples of digital responsibility along the use cases

Mindset & Skills from the Team

- Expansion of digital literacy in the team
- Expansion of digital literacy among users and in the ecosystem as a whole
- Digital responsibility dialogues at state,
 national and European level
- Responsible leadership training
- Building an interdisciplinary digital responsibility community
- Understanding and implementing digital responsibility as a competitive advantage



DRGs and TEAM-X. Accompanying Ms. Schulze (diagnosed with breast cancer).

HUMAN

centered

Palliative Care

Women 's Clinic

6

DRG# 6 Transparency: The use (i.e. digital and personal processing) of the data by the corresponding actors is presented to Ms. Schulze in TEAM- X in a comprehensible way using examples and simulations; she receives information about who uses the information > increasing her DRG#1 Digital Literacy. DRG#1 Digital Literacy: (a) Ensuring a laymanunderstandable presentation and (b) system - intrinsic functions to support digital literacy.

Digital Responsibility in process, system and team

DRG#2–Cybersecurity: ensures data secure storage and sharing

DRG# 3 Privacy:

Ms. Schulze is sufficiently informed about the significance and implications of the data she selects, she wishes to forward to her family doctor, the women's clinic and palliative care aaia-x



one more thing... Digital Responsibility Goals & European Digital Rights and Principles.

..."It is with great interest that we read about your initiative aiming to establish a sustainable digital agenda based on human rights and values. Your project is very timely, in particular in light of the Commission's work on a Declaration on Digital Rights and Principles."...

Margrethe Vestager Executive Vice-President European Commission



*January 12th 2022 – Personal letter to Ms Meier, responding on a letter of several initiatives calling the EC to have a look at the DRGs



gaia-x

Let's get in touch:

Thank you!

Identity Valley. It's all about trust.



Jutta Juliane Meier

jj.meier@identityvalley.org https://www.linkedin.com/in/juttajulianemeier



Data Altruism and Citizen Trust



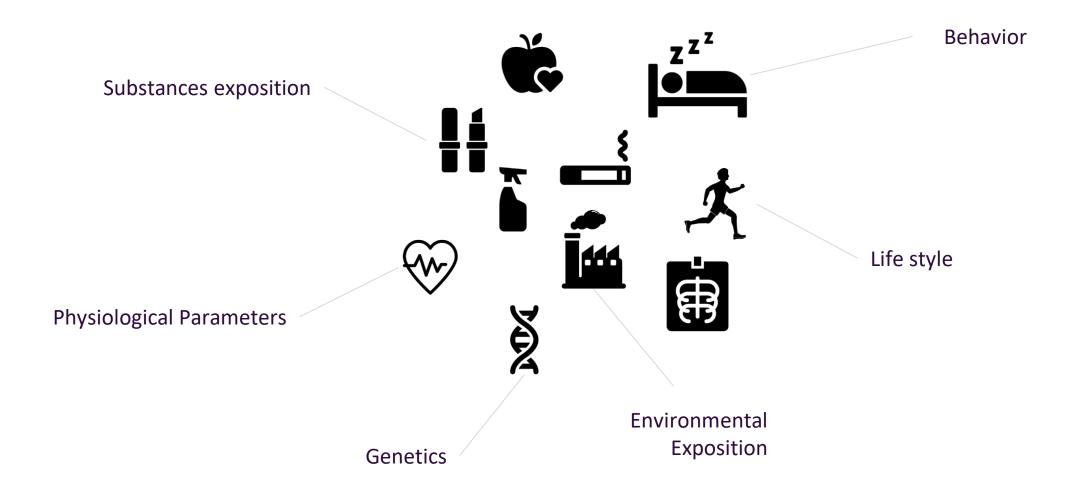
Joan Guanyabens, Founder SALUSCOOP





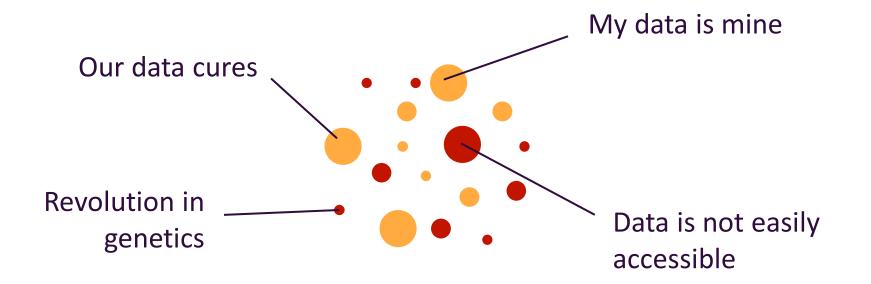


Understand Diseases



Our vision





Changes in the capacity of citizens and social demands Data-driven innovations in technological developments & research

Economic pressure on public health systems

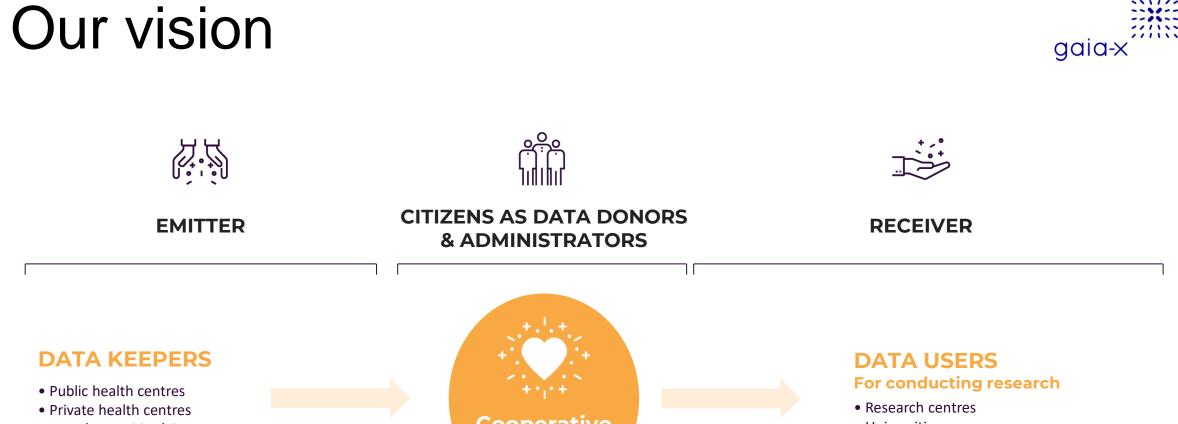


SALUS.COOP

Citizen Initiative New data Institution Citizen data cooperative for health research Data Donors for common good

1- Accelerate research with projects aimed at improving quality of life of all.

- 2- Promote digital heritage awareness as a form of collective empowerment.
- 3- Empowering ourselves as citizens through research projects to make us feel: Deciding with whom we share data. In what terms do we do it.



- Apps/ wearables/ devices
- Personal

Cooperative of citizens

- Universities
- Research units in companies





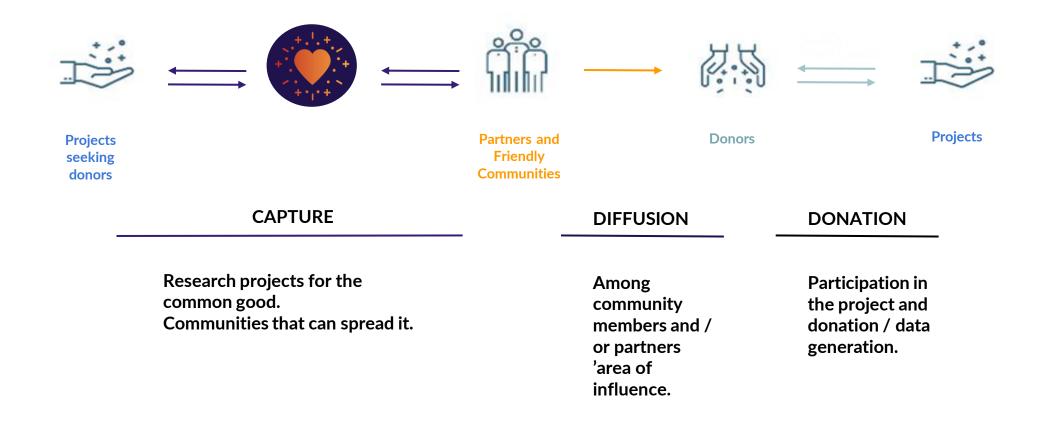
SALUS CG LICENSE

Salus Common Good Data License for Health Research

Only health: your data will only be used for research of chronic and rare illnesses.

- **2** Non-commercial: research projects will be promoted by entities who support general interest such as public institutions, universities and foundations.
- **Shared results:** results of the research will be accessible at no cost.
 - Maximum privacy: all data will be anonymized prior to use.
- **Complete control:** you will be able to cancel or change the conditions under which your data can be accessed at any time.

How SalusCoop works?



SalusCoop: App & Web Application (back office)



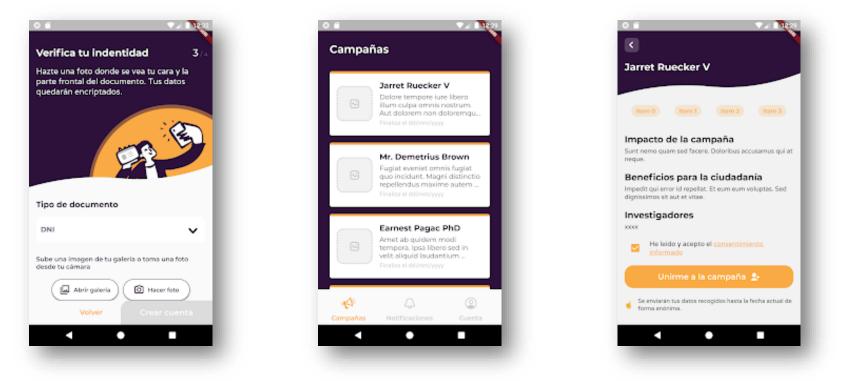




We use technology, blockchain, to ensure security, transparency, data immutability and auditability, all within a trusted distributed environment that guaranties:

- the identity of the participants
- no intermediary has access to the shared content
- privacy and access control to captured data

App for Donors



Registration and identity verification of volunteers (KYC), generating a tokenized (anonymized) identity.

Transparently captures data from surveys and habits data from Google Fit (Android) and Apple Health (IOs) devices

Volunteer subscribes to research campaigns to which they give their data

Web Application (back office) for Researchers

				+ /	Añadir campaña			
	Show 10 + entries		Buscar en la tabla:					
	Nombre îj Investigador principal	î	\uparrow_{\downarrow} Fecha de creación	\uparrow_{\downarrow} Estado \uparrow_{\downarrow} Accion	res \uparrow_\downarrow			
	CitieS-Health Researcher Example	del 01/11/2021 al 31/12/2022	09/11/2021	Activa (1) 🖉 🖉 [9 û			
Datos generales Datos de investigación	Sujetos y datos del estudio Consentimiento	del 08/11/2021 al 30/11/2021	08/11 CitieS-Health Activa del 01/11/2021 al 31/12	/2022				
		del 10/10/2021 al 31/12/2021	influencias varían según la evol	contaminación atmosférica o el uso de espacios verde Jción de la pandemia de COVID-19 y según cómo hay	va afectado la pandemia a cada persona. Los pa	no, estrés y calidad del sueño articipantes contestarán un ci	, y si esas uestionario	
		del 01/11/2021 al 30/11/2023	diario breve (menos de 5 minut 17/09 https://www.ctieshealthbon.eu/ 67	os) durante 2 semanas y los datos se cruzarán con ma	ipas de contaminación y espacios verdes.			
Nombre de la campaña *	Palabras claves *		3	12382				
CitieS-Health	× covid × saludmental × contaminación × estrés		usuarios unidos	pasos				
Imagen de la campaña	Máx. 5		Datos recopilados					
Seleccionar archivo Ningún archivo seleccionado	Impacto de la campaña *							
	La relación entre variables ambientales y		Usuario ID		Localidad usuario	Pasos	Distance	Fecha
Ver fichero actual	diferentes parámetros de salud mental se ha estudiado poco y la evidencia disponible				Barcelona	3940	1824 m	01/11/202
	es todavía limitada. El presente proyecto contribuirá a aportar nueva información		-		Barcelona	7923	4853 m	02/11/202
Página web del proyecto *	sobre la posible asociación entre Máx. 100 palabras		-		Barcelona	10548	6636 m	03/11/202
https://www.citieshealthbcn.eu/					Barcelona	5752	3523 m	04/11/202

Research centers:

Generates and manage research campaigns and view and export all anonymized data collected by volunteers who have subscribed to the research campaign

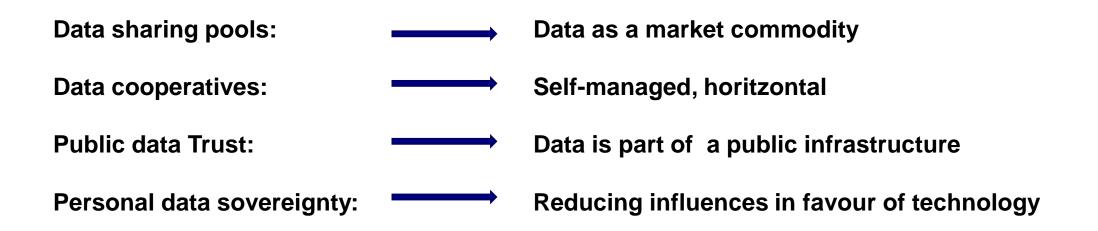
Governance Personal Data



The question is who owns data ? Sovereignty: control and use.

"We have lost control over our personal data" Sir Tim Berners-Lee

ALTERNATIVE MODELS



Governance personal data - Conclusions



With emerging data, **social science and a citizen perspective** on data governance are needed to balance and reduce power asymmetries. A single model is not the solution but **civil and public society must be there**

Europe as the world leader in a fair and competitive digital economy for an open, democratic and sustainable society

Political-technical agreements to redistribute the value generated from the data

Consent Management and Data Agreements

• Lal Chandran, Co-Founder and CTO, iGrant.io (Sweden)



Contents

- What is consent? Characteristics of consent
- What drives the need for consent? What are data agreements?
- Role of data intermediaries in data agreement handling
- Data Agreement lifecycle
- Key actors and use cases
- Universal agreement workflow (e.g. with consent as a legal basis)
- Health sector use case examples

What is consent? Characteristics of consent

is a **voluntary** declaration of intent, from which a person is **free** to **withdraw** at any time

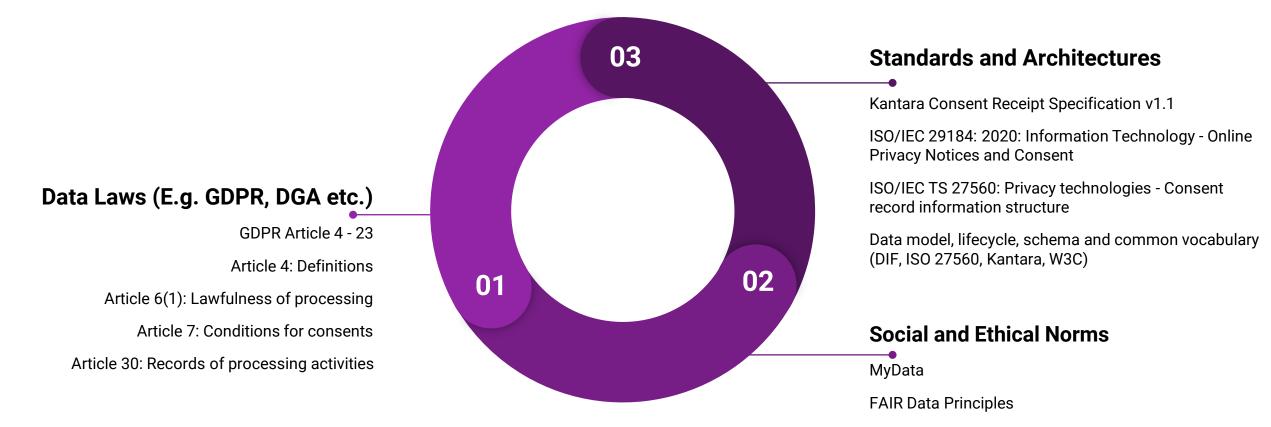
For individuals:

- freely given, informed and unambiguous
- can **opt-in** anytime through various medium
- can view and **opt-out** anytime

For Organisations:

- Consent is **specific**. Provisions of consent is clearly distinguishable from terms and conditions
- **Demonstrating consent** is on the data controller
- Withdrawal of consent shall be as easy as granting of consent
- Consent may not be conditional on unnecessary processing → A consent is tied to a usage purpose that the data subject can opt out

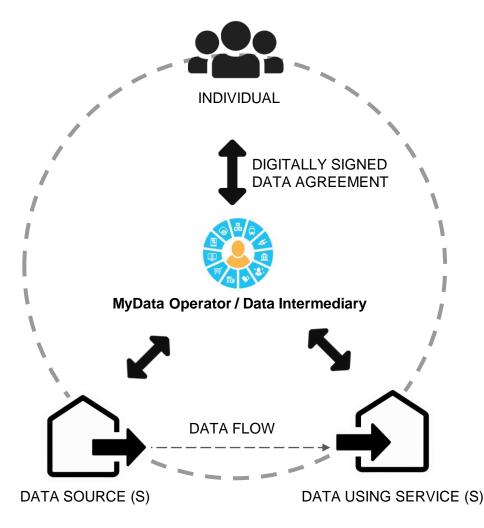
What drives the need for consent?



Trust frameworks



Role of Data Intermediaries in data agreement handling



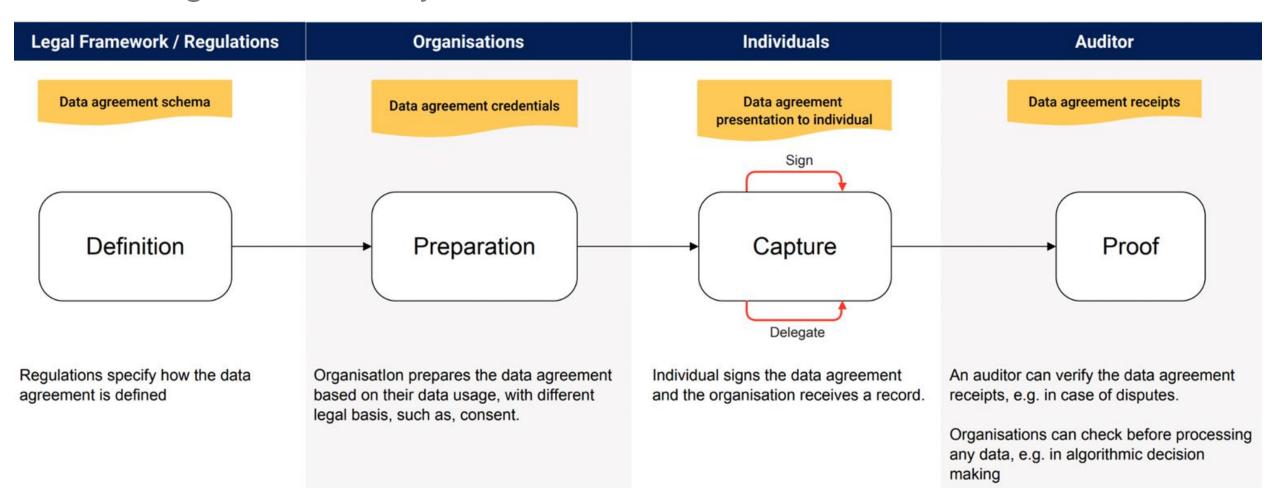
MyData Operator or a Data intermediary manages

- Permissions / Consents /Data Agreements
- Personal Data Transfer

Individual agrees to sharing data \rightarrow a personal data wallet (in real-time) or via other mechanisms

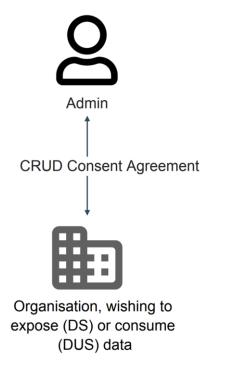
Credentials could be stored for e.g. in a decentralised data wallet app (dApp) or it can be based on centralised identifiers

Data agreement lifecycle



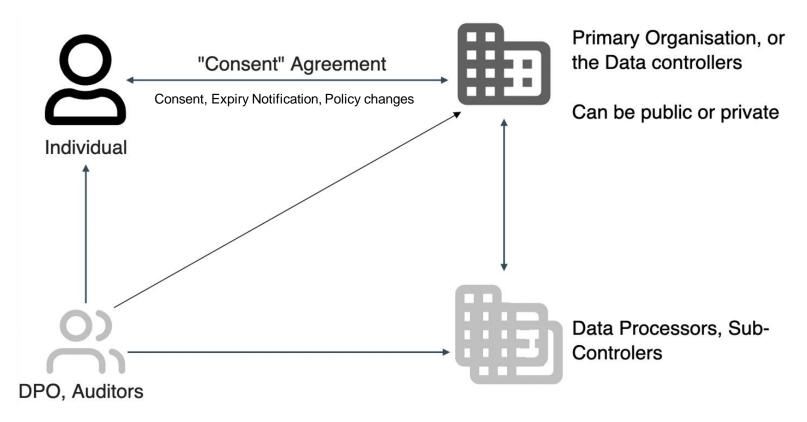
Key actors and use cases

Organisation Administrator



*CRUD = Create/Read/Update/Delete

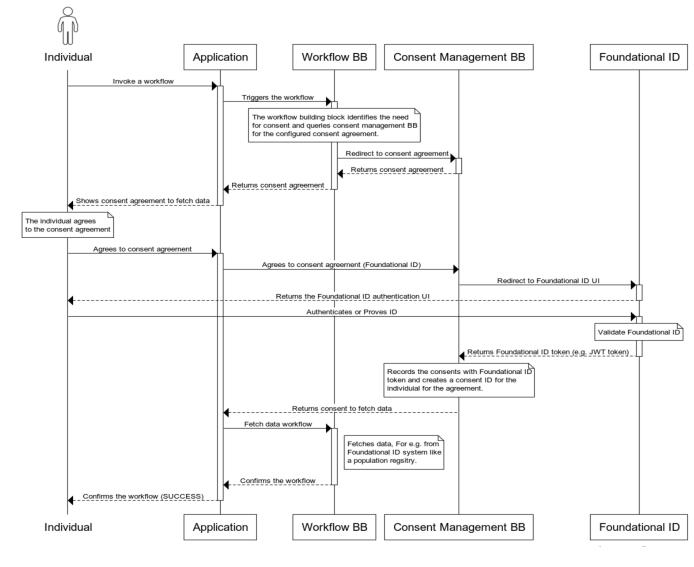
Individuals and Auditors



Universal agreement workflow



(e.g. with consent as a legal basis)



Key considerations

- Applies to the processing of personal data during a digital transaction
 - Internal processing
 - Data sharing during registration
 - Data sharing post-registration
- Can be plugged into any workflow
- Rights-based approach
- Supports centralised (OAuth based) and decentralised architectures like SSI with data wallets

Health sector use case examples gaia-x Personalised care Aggregation for self-care Data sharing for registration Consents for e.g. research

gaia-x

Thank you!

- Twitter: @lalchandran
- Email: <u>lal@igrant.io</u>
- Mobile: +46725298991
- iGrant.io, Sweden



Lal Chandran Co-Founder, CTO and Board Member at iGrant.io | Self-Sovereign Identity (SSI) |...



eIDAS : Trusted Digital Identity



Dr. Dominik Deimel,

CEO / Founder comuny GmbH

Member of MyData global Initiator MyData German hub



Significance of digital identity for citizens





Roadmap Identity Management







eIDAS 1.0 - 2014

POLICY AND LEGISLATION | Publication 02 September 2014

Publication of the Regulation on electronic identification and trust services for electronic transactions in the internal market

elDAS 2.0 – coming now

Press release | 3 June 2021 | Brussels

Commission proposes a trusted and secure Digital Identity for all Europeans

10 principles of self sovereign identity management



Existence Control Access **Transparency** Persistence **Portability** Interoperability Consent Minimilization **Protection**

CONCEPCE



Quelle: http://www.lifewithalacrity.com/2016/04/the-path-to-self-soverereign-identity.html

Mobile phone replaces electronic health card

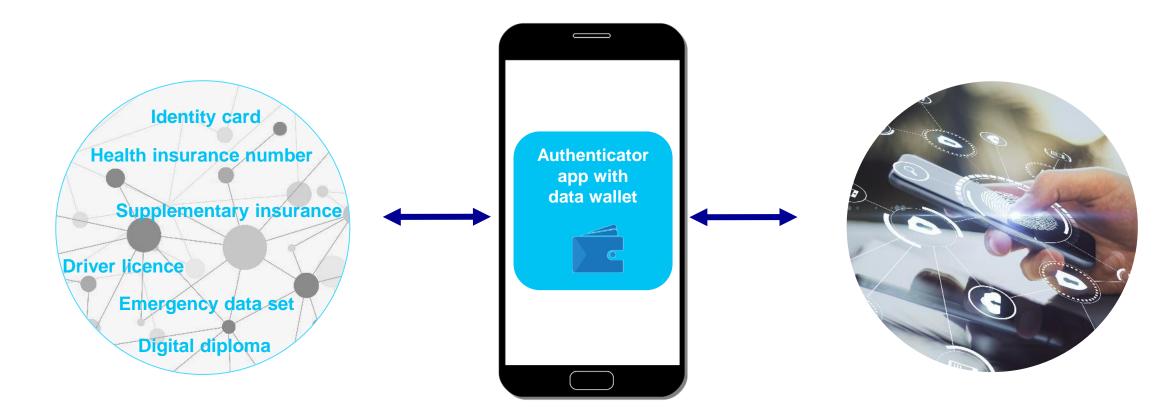






eIDAS 2.0 supports data management via mobile device



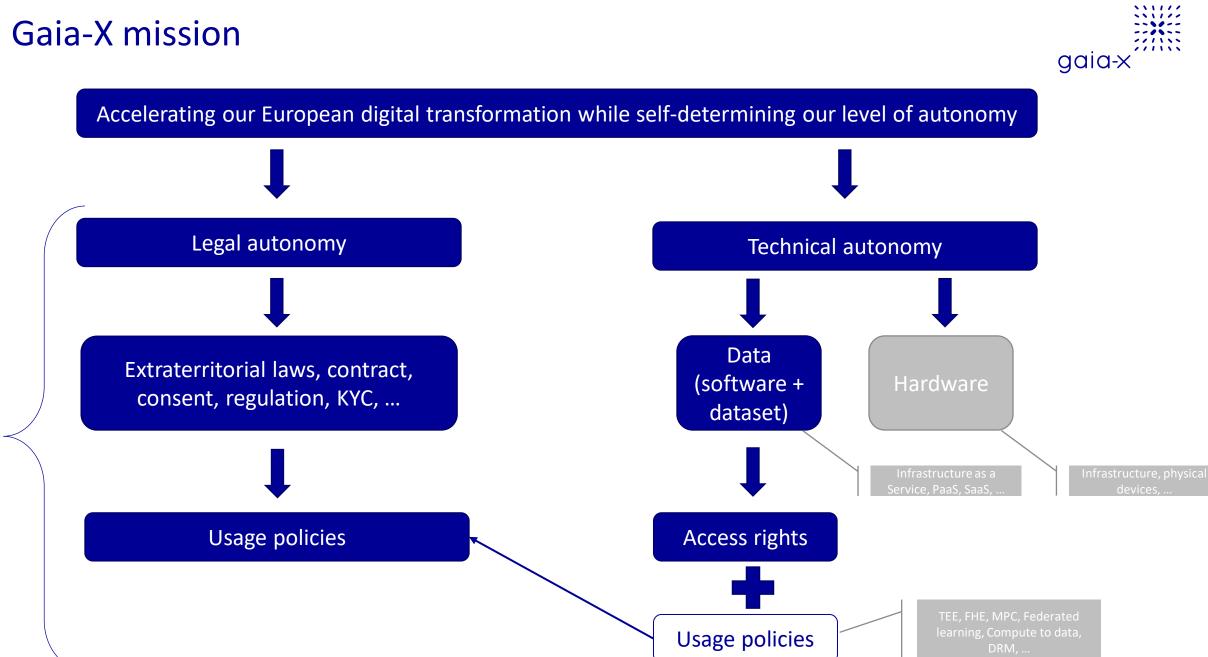


Attributes **Issuer** (government, insurance company, university a.o.) Data **Owner** with transfer via mobile device Attribute **Verifier** (consumer) (ePrescribing , electonich health reord, car sharing a.o.)

Gaia-X Trust Framework



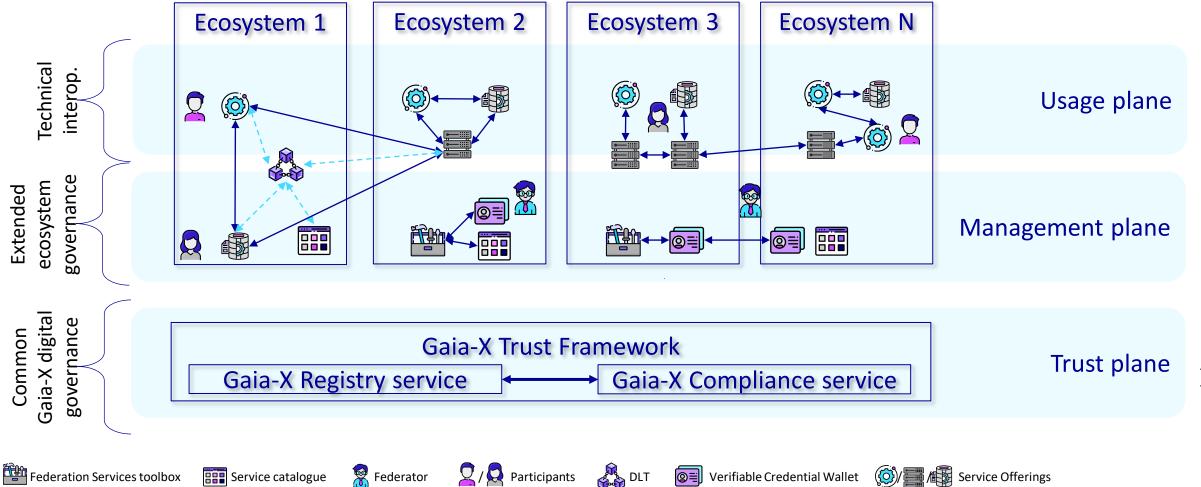
• **Pierre Gronlier,** CTO, Gaia-X



Common digital governance

One Gaia-X Ecosystem, federating interoperable autonomous ecosystems.

 Gaia-X Ecosystem: the virtual set of Participants, Service Offerings, Resources fulfilling the requirements of the Gaia-X Trust Framework.



gaia-x

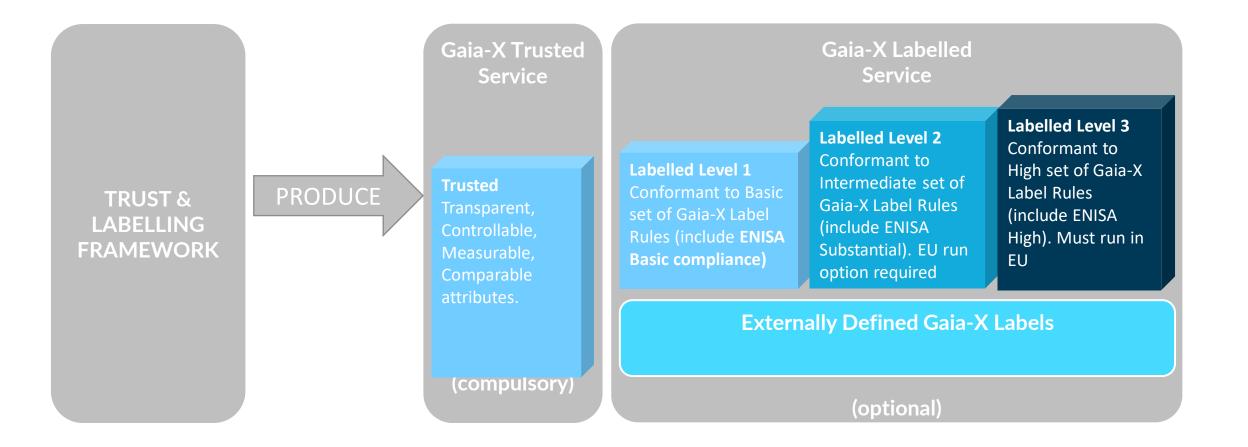
Today's status



gaia-x

Gaia-X Trust & Labelling Framework





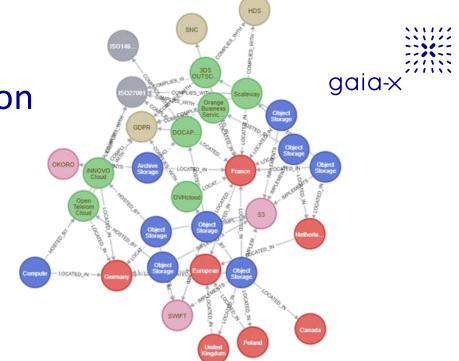
Gaia-X Trust Framework 1/2 from fragmented market to service composition

Enable the creation of more complex composite

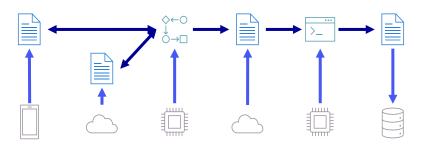
services from atomic or elementary services as well as complex services.

- Ensuring composability and hence substitution
- Creates **Transparency** with portability across

providers and hosting platform



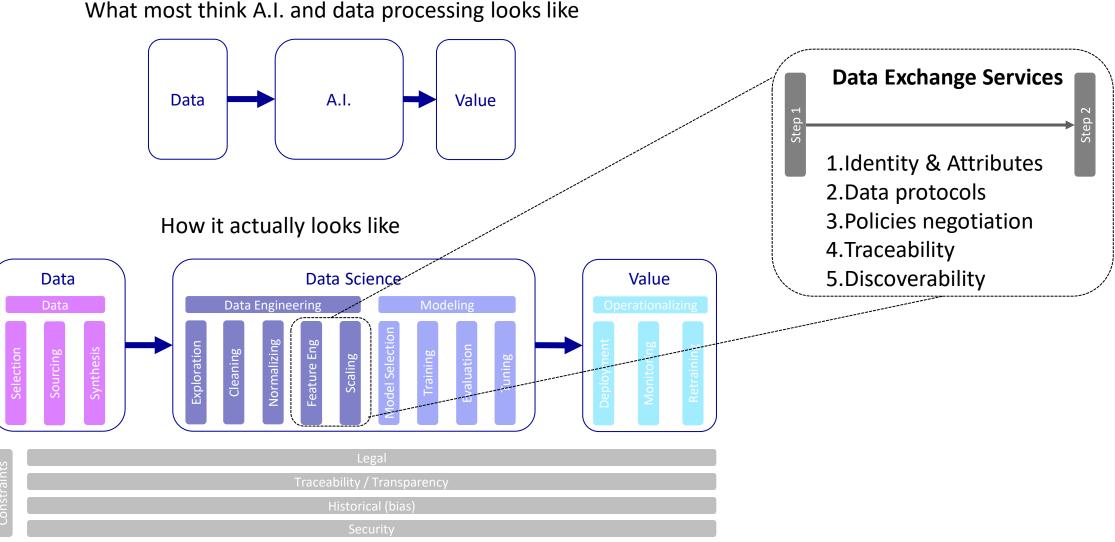
Knowledge graph of verifiable and composable signed claims (Catalogue demonstrator - March 2020)



Data pipeline example, from edge (mobile) to cloud

Data Exchange services



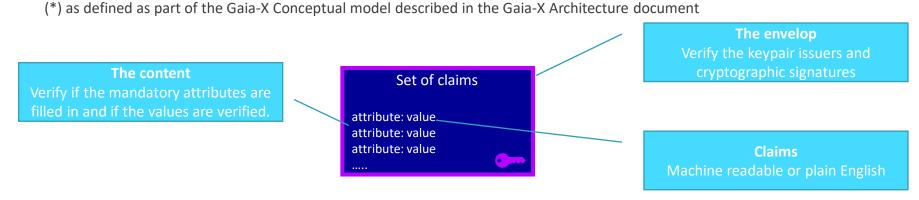


What most think A.I. and data processing looks like

Gaia-X Trust Framework 2/2

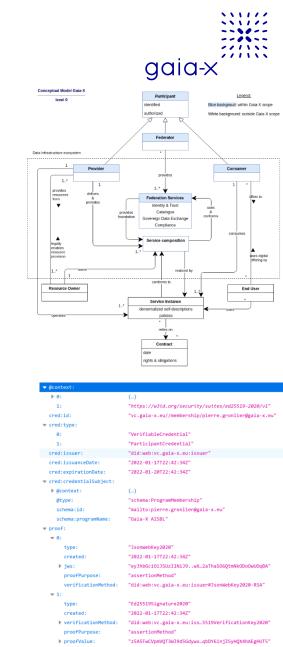
To ensure **Trust** the Gaia-X Trust Framework is:

- Automated by Gaia-X specific components part of decentralized technology framework
- Versioned, i.e. bound to a specific version in time of the Compliance rules set
- Applied to the self-description file of all entities implied in the Gaia-X conceptual model (*)
- Aimed to verify the existence and veracity of the attributes and not judging their value



- Trust Framework example:
 - All cars must have a color
 - All Datasets must have a location
 - All Services must identify their provider with its legal country of jurisdiction.

- Label examples:
 - cars level 1 are red, cars level 2 are blue, ...
 - My dataset must be located in EU
 - My services must be non-subject/immune to non-EU laws



Gaia-X Trust Framework summary

- Measurable & Comparable Gaia-X Trust Index as a function of service composition and signature's identity.
- Doesn't take decision for the user 2nd order rule
- Enforce transparency
- Enable **portability** service composition
- Enable traceability consent aggregation and policies attenuation
- Automatable machine readable
- Secure Zero-Knowledge-Proof principle
- Scalable Web semantics
- Cost efficient SMEs included
- Include **Remediation** / Penalties







Question?

https://www.gaia-x.eu https://members.gaia-x.eu

Q&A





Polls on maturity & next step involvement

gaia-x

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Maturity Q1: 25 sec Q2: 25 sec Q3: 25 sec Involvement / follow-up Q4: 25 sec Q5: 25 sec Q6: 50 sec

The poll will automatically go to the next question after 25/50 sec.

You will find the link to the poll in the CHAT

Session Summary



