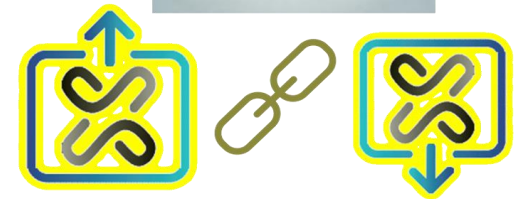


Health Data rights and the EEHRxF: An xShare Button Showcase





Catherine Chronaki

Scientific Coordinator, xShare Project

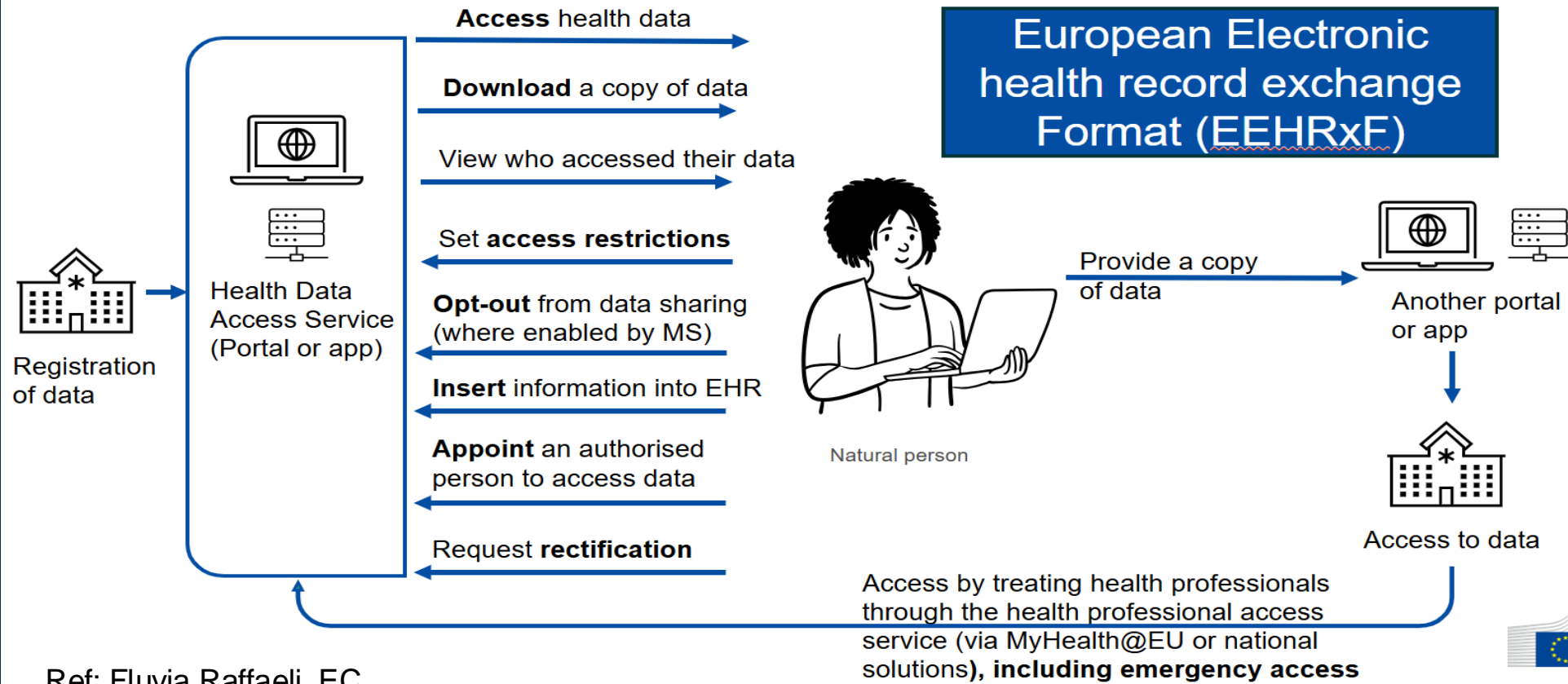
Secretary General, HL7 Europe



Outline

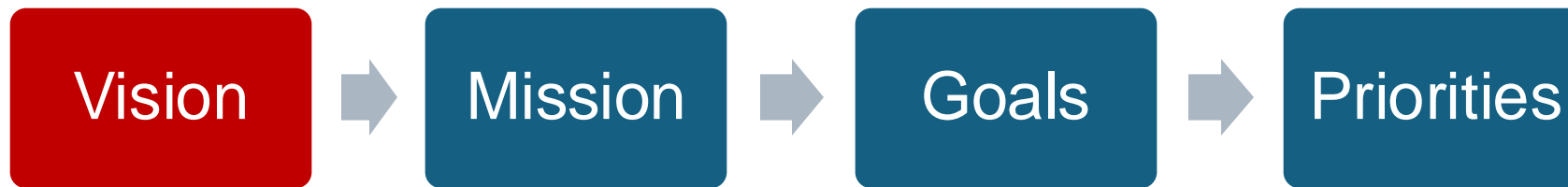
-  Health data rights: EHDS, format, and xShare
-  A year of xShare: paving the way for the format and the EHDS
 - Helicopter view of our achievements
 - Plans for the year ahead
-  Health data rights in the EHDS and the “yellow button”:
 - Trust and Flow
 - FAIRness and Quality
 - Digital Services and Literacy
-  An xShare button showcase from 6 EU states, regions, and hospitals
 - An emerging policy proposal to include QR code in medical documents

Rights of natural persons in primary use

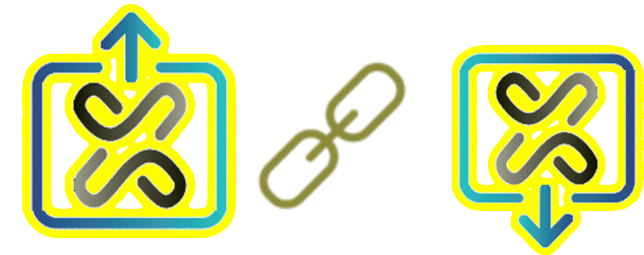


Ref: Fluvia Raffaelli, EC

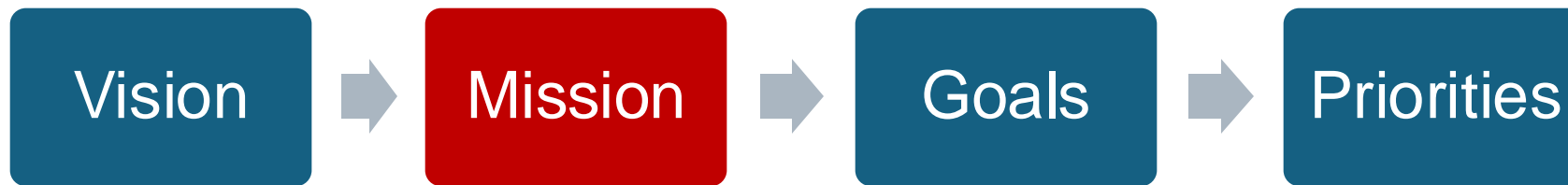
EHDS, the format, and xShare



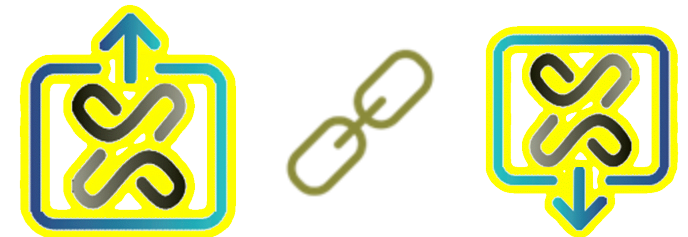
Our xShare Vision: Everyone can share their health data in EEHRx_F (the format) with a click-of-a-button in the European Health Data Space



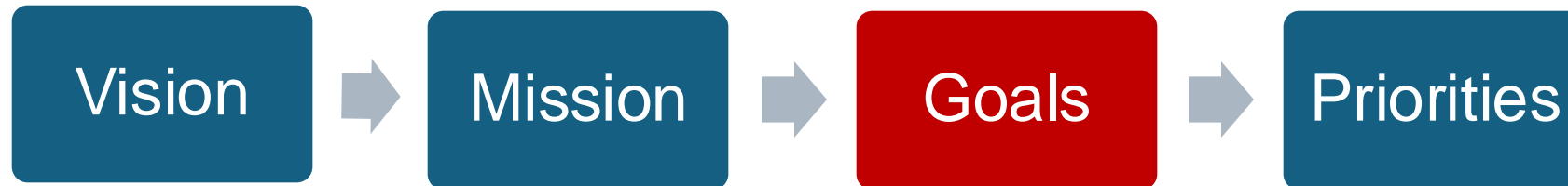
EHDS, the format, and xShare



xShare Mission: To experiment with evolving format specifications and identify future priority data categories, collaboratively preparing the digital health community for accelerated EHDS adoption.



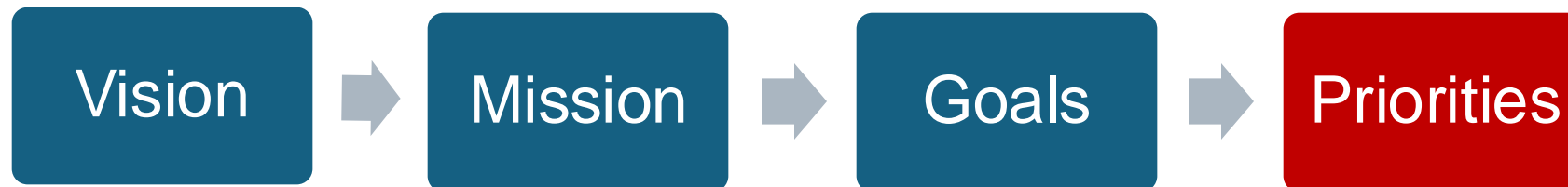
EHDS, the format, and xShare



- 🔥 The **Button and API** (the yellow button): featured in apps and websites
- 🔥 The **HUB** (the standards and policy HUB): brings global standards with industry and government to steward specifications and accelerate adoption
- 🔥 The **Label** (the industry label): demonstrates the commitment and capability of the industry to implement the format



EHDS, the format, and xShare

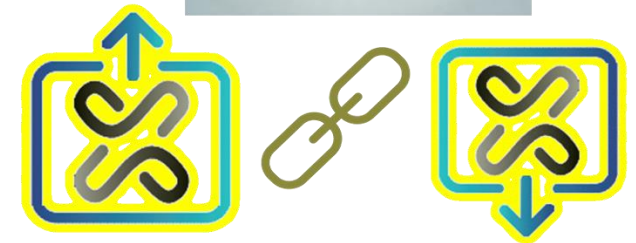


- 🔥 Demonstrate the **xShare impact** across continuity of care, clinical research, and population health.
- 🔥 Start with **9 adoption sites** – select 25+ ecosystem partners to accelerate adoption across Europe.
- 🔥 Demonstrate safe, trusted, low-cost **sharing** of high-quality structured coded health data.
- 🔥 Facilitate movement of **digital health services** across Europe and globally through standards.
- 🔥 Drive Europe's **competitive advantage** for R&I in EHDS in the era of AI and big data.
- 🔥 Hub as an **accelerator** contributing to adoption of global standards with the EEHRxF format.



A year in the life of xShare

- Minimum data set towards IPS-R
- EHRxF in a nutshell and xShare campaign
- Industry forum and Regulators forum
- European EHRxF website to serve the Hub
- Organized 4 X-Bundle retreats,
 - 4th Thessaloniki 21-24 Oct 2024
 - xShare Button showcase



Attendees:

Hans, Gille, Pier Angelo Sottile, Mario Fregonara Medici (CEN-BH); Derek Ritz, Sofia Fraconi (r) (IHE-Europe); Giorgio Cangioli, Luc-Chaty Rhonda Facile, Kai U Heitmann, Catherine Chronaki, (HL7 Europe); Evangelos Markatos (FORTH); Fábio Januário, Vasco Delgado-Gomes, (UNINOVA); George Dafoulas (IDIKA); Grégoire Rigoulot-Michel (TTSA); Morten Bruun-Rasmussen (MEDIQ); Nathan da Silva Carvalho (DIGITALEUROPE); Nenad Živković, Argiris Gkogkidis, (GNOMON INFORMATICS SA) Panayiotis Savva, (NEHA); Sara Alabart Martinez, Shulei Huang (Fundació TIC Salut Social); Stefano Dalmiani (FTGM), Lucie Keunen (Andaman7)

X-Bundle Retreat for the xShare Button, Thessaloniki 21-24 October, 2024



- ✂ X-Bundle for the xShare Button review
- ✂ Collaborative work with xt-EHR, XpanDH
- ✂ xShare Button IG development with HL7 FHIR
 - HL7 FHIR v1.0.0 as working version for IPS
 - SmartHealthLinks or Qrcode (paper+)
- ✂ Working with the xShare Button
 - European Infrastructures: e.g. myHealth@EU
 - Hospitals, Regions, Countries infrastructures
 - Consumer apps (Andaman7)
- ✂ Review toolbox for xShare Button
 - Need for CDA2FHIR conversion, recommend interoperability in the source
 - Synthetic data and visualization <https://vi7eti.net>
 - 200 synthetic lab reports: <https://vi7eti.net/?focus=eulab>
- ✂ Preparing future retreats for IPS+R and Care Plans
- ✂ xShare, XpanDH, xt-EHR, Potential



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Status of EEHRxF (format) specifications



HL7 FHIR IGs overview

	Patient Summary	Laboratory Results	Hospital Discharge report	ePrescription	Medical Imaging and reports	BASE
Global Standard						
European Standard						
European Specialized						
European X-border						



Towards xShare Button X-Bundle



X-Bundles Registry



HOME

X-BUNDLES












ABOUT

LEGEND

CREDITS

xShare Yellow Button

The xShare button functionality enables the patient to download and share their health data with a click of a button.

-  **Business Specifications** 
-  **Application Specifications** 
-  **Content Specifications**
-  **Technical Specifications** 
-  **Tools**
-  **Supporting material** 
-  **Labeling Specifications**



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xShare Button specs based on HL7 FHIR



Share EHR Xchange Format X-Bundles Registry XpanDH

HOME X-BUNDLES ABOUT LEGEND CREDITS

 Content specification 







xShare Yellow Button - content

xShare Yellow Button: content

Status: draft Date: 2024-10-30 Version: 0.0.1

Used By [Show/Hide](#)

Uses [Show/Hide](#)

	Laboratory Report
	Patient Summary
	Digital Imaging Report
	Hospital Discharge Report
	Medicine Prescription and Dispense
	MyHealth@EU Laboratory Report



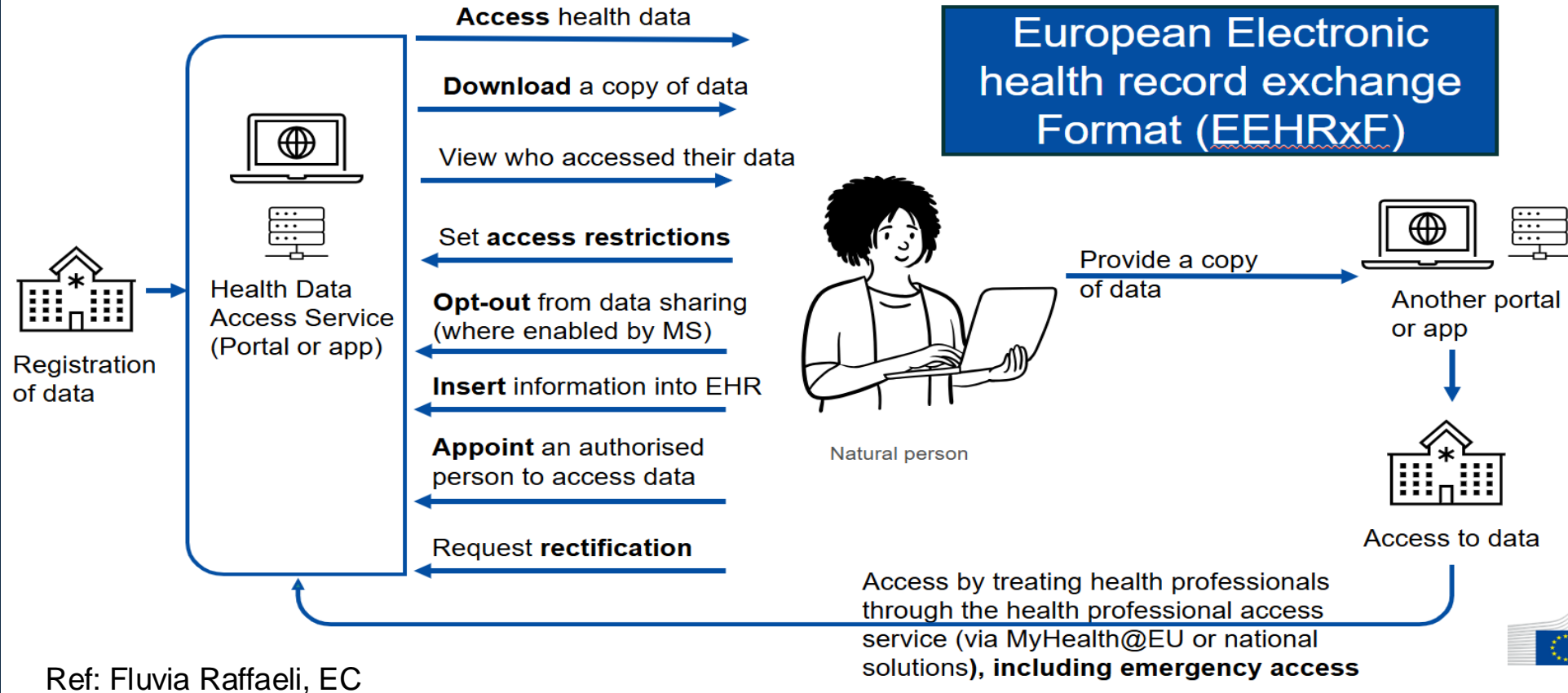
Stay tuned for the xShare Button IG 1.0!








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Rights of natural persons in primary use



xShare Button Showcase

-  Yellow Button: the format in action.
-  Showcase digital health service focused on natural persons
 -  Get my data in the format: Data portability - myHealth@EU infrastructure
 - **Download / upload my data with the format: 3 primary data categories: IPS,HRD, Lab**
 - **Insert** / rectify via health profession in televisit
 -  **Access** and Receive my IPS data in a safe and trusted way:
 - find a clinical trial: Pre-eligibility test for Clinical Trials
 - use the IPS to receive tailored ePI on Medicines I take (collaboration Gravitare-Health)
 -  **Access, Receive and Use** my health data in transitions of care:
 - Translation of my health data (ANS in France)
 - Transitions of care using IPS, HDR, LAB in HL7 FHIR and SHL
 - in and across border

xShare Toolbox: experimenting with synthetic data and open source tools

- Realistic synthetic data in the evolving format
- CDA to FHIR conversion
- Stylesheets and visualization tools



vi7eti.net/index.php





Welcome to Visualize HL7 Example and Test Instances (vi7eti)

Purpose of this site

This site exists to show and demonstrate Visualization of Example and Test Instances with HL7 CDA or FHIR specifications (implementation guides) as a base.

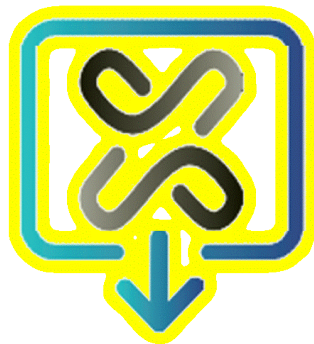
Disclaimer: These web pages are not intended to be used as a source of information for real patient care, medicines etc.

VIZUALIZATION FOR TEST AND EXAMPLE PURPOSES ONLY!

- +  Electronic Medicinal Product Information (ePI)
- +  European Laboratory Report
- +  International Patient Summary (IPS)
- +  European Hospital Discharge Letter (HDR)

© dr Kai Heitmann, HL7 Europe • LGPL-3.0 license • Background Information on Visualize HL7 Example and Test Instances (vi7eti) follows
Powered by [Synthea](#) Copyright © 2024 The MITRE Corporation • MIT License Copyright (c) [OpenAI](#) • [ART-DECOR](#) Expert Group and ART-DECOR Open Tools GmbH

xShare Button Download



myHealth@EU and teleconsultation

Updating IPS in myhealth@EU

Meet Yiannis



Actors: GNOMON



Kostis Kaggelides
CEO
gnomon
INFORMATICS



Kostas Karkaletsis
CTO
gnomon
INFORMATICS



Alexander Berler
Director Consulting Services
gnomon
INFORMATICS



Argiris Gkogkidis
Project Manager
gnomon
INFORMATICS



Antiopi Panou
HAIKA



George Dafoulas
HAIKA



Co-funded by the European Union



An Athens resident who uses the eHealthPass mobile app to manage his personal health records seamlessly.

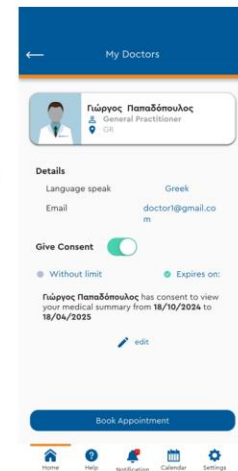


Dr. George

There is missing information in your IPS

I had an allergy

Remote Visit



Download IPS



NCPeH infrastructure

CDA 2 FHIR conversion



Dr. George: I have it added: download again



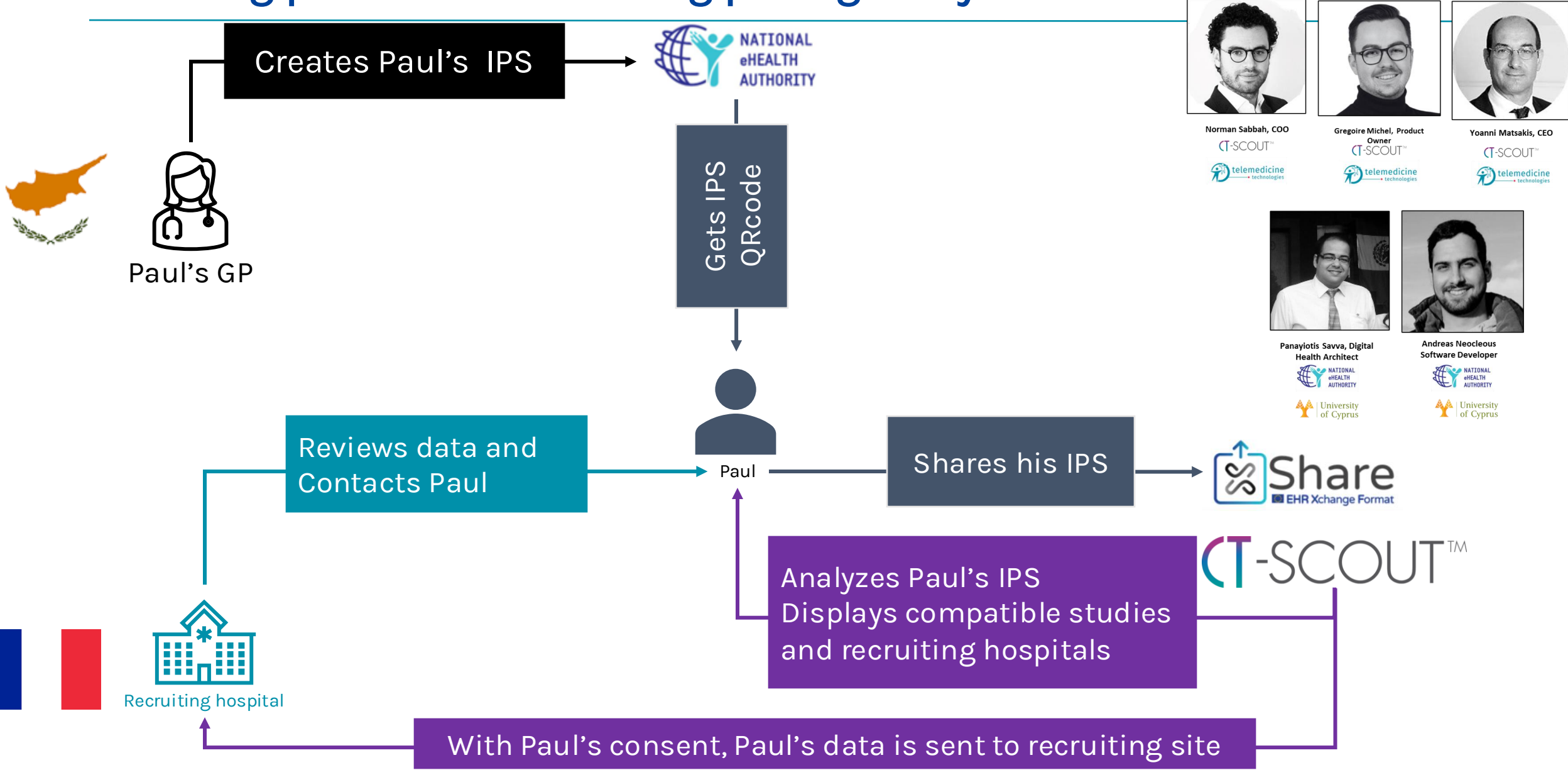


MyHealth@EU and teleconsultation

Greek adoption site



Enhancing patient care enabling preeligibility check for clinical trials



Paul's GP



Norman Sabbah, COO
CT-SCOUT™
telemedicine technologies



Gregoire Michel, Product Owner
CT-SCOUT™
telemedicine technologies



Yoanni Matsakis, CEO
CT-SCOUT™
telemedicine technologies



Panayiotis Savva, Digital Health Architect
NATIONAL eHEALTH AUTHORITY
University of Cyprus



Andreas Neocleous, Software Developer
NATIONAL eHEALTH AUTHORITY
University of Cyprus

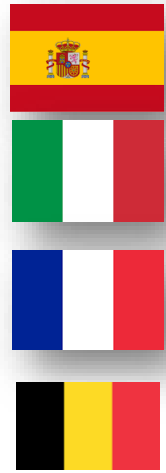


Enhancing patient care enabling preeligibility check for clinical trials

Let's go for a demo !



Collecting my data: TicSalut Social to Andaman7



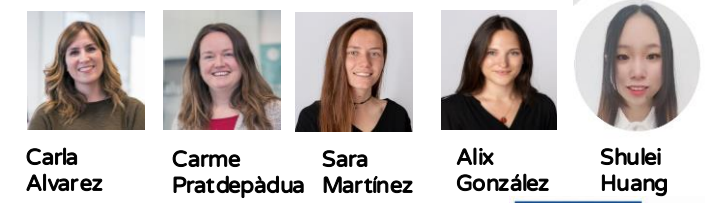
Scenario:

- Access Andaman7 App and Login to "La Meva Salut"
- Download the IPS in CDA Format
- Visualize the IPS within the Andaman7 Patient Record
- Automatic Conversion from CDA to FHIR
- Inclusion of FHIR IPS

Actors: Andaman7



Actors: Fundació TIC Salut Social



Citizen-centered data collection

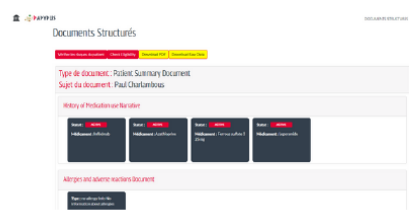
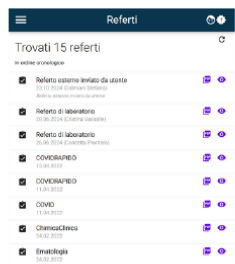
- 📋 Demo video outline
 - The citizen gathers their health data, in the **EEHRxF***, from multiple sources
 - Monasterio – Hospitals in Tuscany (Italy)
 - La Meva Salut – Health portal for Catalonia (Spain)
 - Any other health institution that implemented the **Yellow Button**
 - Data is aggregated in a single record, in Andaman7, the **citizen's mobile PHR**
 - The citizen enriches the data set
 - Wearables / Connected devices
 - Medications (OTC, supplements,...) and adherence data
 - Problems, symptoms, vital signs,...
 - The PHR in the hands of the citizen is the baseline for many use cases
 - **Care**: cross border, national, home setting, tele-care,...
 - **Research**: trials recruitment and participation (DTC, RWE,...)
 - **Prevention**

Citizen-centered data collection/aggregation,
powered by the **EEHRx_F** * and the
xShare yellow button

https://drive.google.com/file/d/14dHTSd2L3HaN6O8UsJbFMck1rgysY4Qe/view?usp=drive_link

Patient Data translation

DEMO



Scenario :

- Monasterio provides a QR code of an Italian document
- Citizen downloads an image (PDF) of the QR code and stores locally in A7 for further display
- Citizen shows the picture (from the stored image of the QR code in A7) to ECN
- Document is read from the QR code in Papyrus
- Terminology server in France translates the document in French



Actors : Monasterio



Stefano Dalmiani
CTO



Paolo Marcheschi
CIO



Actors : Papyrus



Luc Chatty
CEO



Wylem Bars
Architect



Actors : National Terminology service



Thierry Dart
Interoperability director



Abdelali Boussadi
French national FHIR Terminology
Service Product manager



Actors : Andaman7



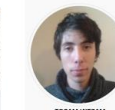
Vincent Keunen
CEO



Sebastien Hannay
Software Engineer - CTO



Lucie Keunen
CMIO



Tosam Mitram
cto@andaman7.com





Patient Data translation



Patient Data exchange in France

DEMO

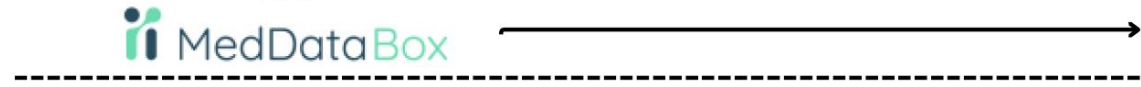
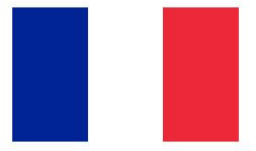


CENTRE HOSPITALIER CHALON SUR SAONE
William Morey

Documents Structurés
Type de document: Patient Summary Document
Sujet du document: Paul Chouabouis



Acteurs : Hopital de Chalon sur Saone



Documents Structurés
Type de document: Patient Summary Document
Sujet du document: Paul Chouabouis



Scenario :

- Chalon shows the patient in their Hopsiia platform
- Chalon generates the patient IPS (hidden)
- Document is displayed in Chalon's Papyrus Application
- Document is downloaded and sent to the patient through MSS santé
- Document is sent to the Mayenne practitioner through MSS santé
- Doctor in Mayenne connects to Healthshare, no patient info
- Doctor in Mayenne connects to Papyrus in Healthshare, import file
- Doctor in Mayenne imports the data => it's visible in Healthshare



CENTRE HOSPITALIER LAVAL

Acteurs : GHT Mayenne

Acteurs : National registry

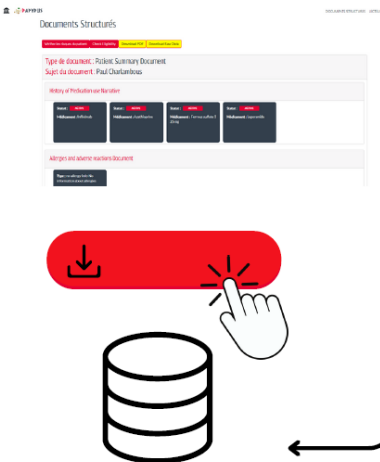
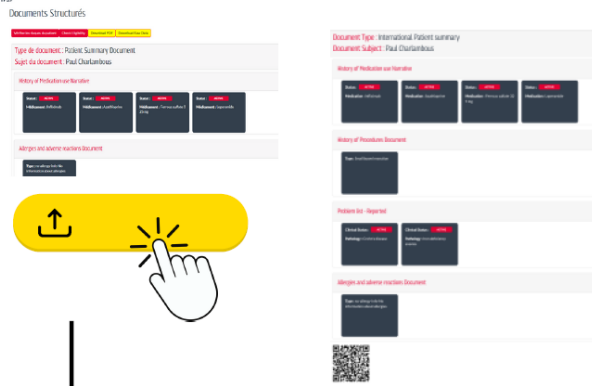
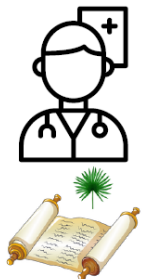
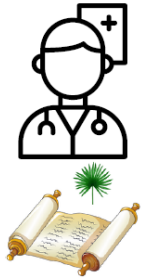




Patient Data exchange in one country



Patient Data hospital exchange across borders



DEMO



Scenario :

- Charleroi provides the QR code
- Citizen downloads the QR code image into Andaman7
- Citizen shows the picture to ECN (from his mobile app)
- Data is imported in Mayenne through QR code reading

Actors : Hopital de Charleroi



Marie Detrait
CMIO
GRAND HOPITAL DE CHARLEROI



Luc Chatty
CEO
FYRSTAIN



Wylem Bars
Architect
FYRSTAIN

Actors : Andaman7



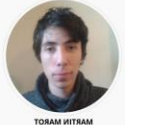
Vincent Keunen
CEO
Andaman7



SEBASTIEN HANNAY
Software Engineer - CTO
Andaman7



Lucie Keunen
CMIO
Andaman7



TORAN HITRAM
Andaman7

Actors : GHT Mayenne



Vincent Errera
Vice Director
CENTRE HOSPITALIER LAVAL



Florence Cureau
Sales Engineer
InterSystems Creative data technology



Erion Dasho
Clinical Advisor
InterSystems Creative data technology

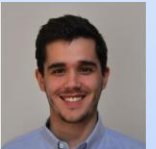
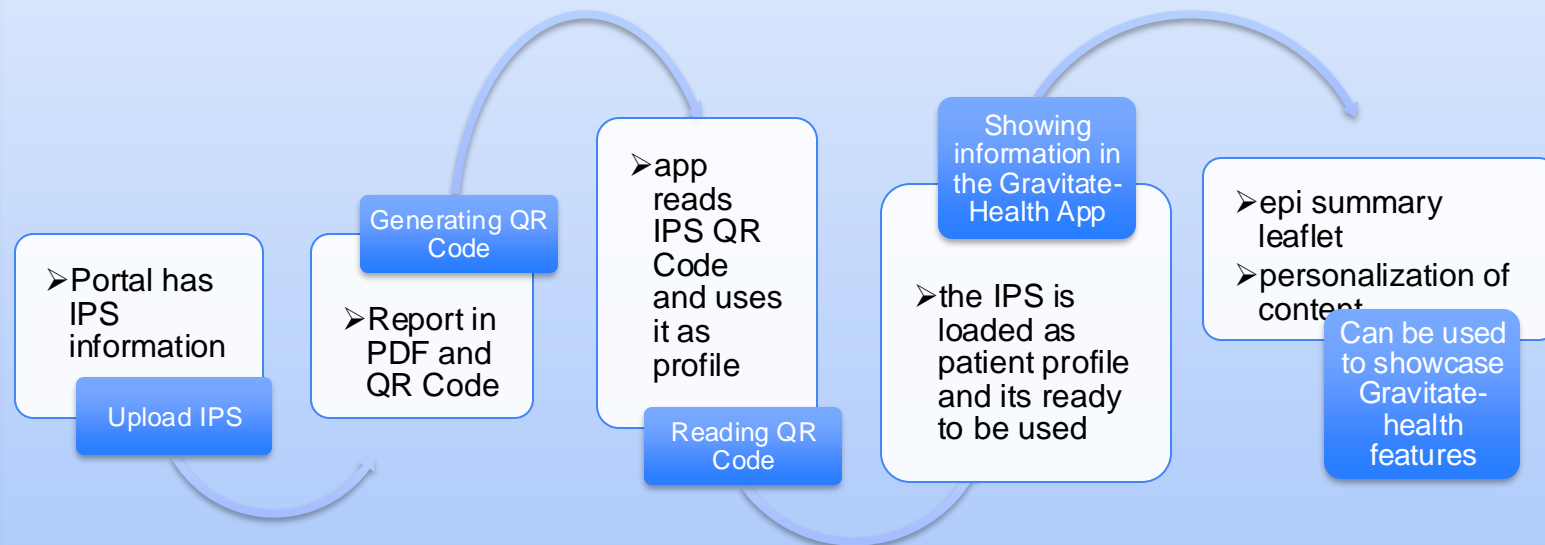


Co-funded by the European Union

Patient Data exchange crossborder



Use my IPS to receive tailored Information on Medicines I take.







Product Owner,
Gravitate Health



Co-funded by
the European Union

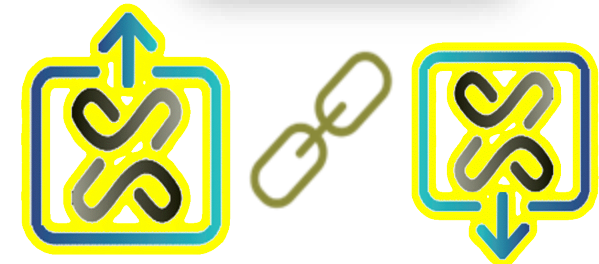
DEMO

Lessons learned from the showcase

-  SmartHealthLinks work: a bridge to EUDDI
-  QR codes on clinical documents (pdf) giving patients access to their data in computable form (paper+)
-  Work on merging IPS or Diagn. Results, Disch. Reports.
 - Provenance in key.
-  Need to invest on innovating with the format (EEHRxF)
 - Digital health services that make sense and empower
 - Trust and Flow of health data under citizen control
 - FAIRness and Quality to advance clinical research

Looking forward to xShare year 2

- ✚ Establish the EHRxF Standards and Policy Hub as a legal entity
 - EEHRxF Website launch
 - Scaleup partnership with xt-EHR, TEHDAS2, and others
 - Grow the community of practice and product/service registry
- Explore feasibility xShare Industry Label as add on
- ✚ Launch the calls for 25+ business actors in the EU ecosystem adopting EEHRxF
- ✚ Release xShare Button IG 1.0
- ✚ Organize xShare retreat on EEHRxF for IPS+R and care plays
- ✚ Launch EEHRxF adoption monitor dashboard and second “yellow button” campaign



Thank you!



xShare: Expanding the European EHRxF to share and effectively use health data within the EHDS



Project page
<https://www.linkedin.com/company/xshare-project>

LinkedIn group

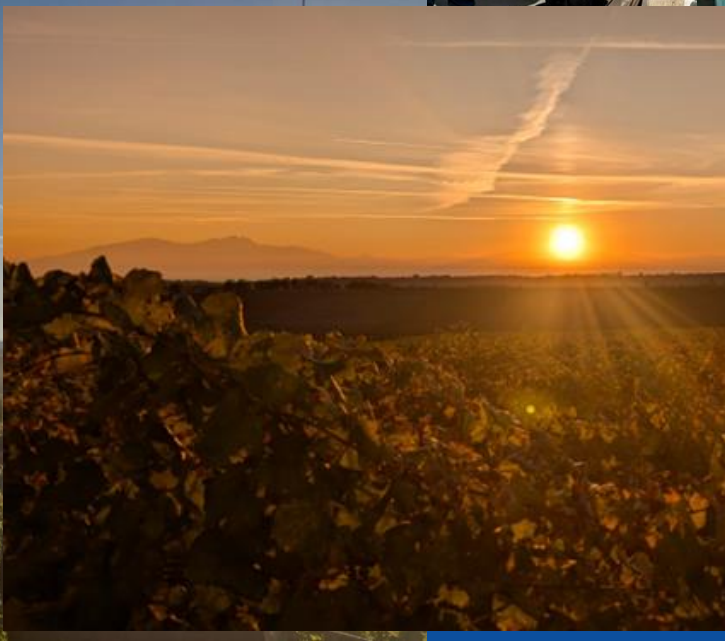
<https://www.linkedin.com/groups/14353596/>



Project account
https://twitter.com/xShare_project

Interested to be involved?
Contact us!
Info@xshare-project.eu





Join the community of excellence!



Are you ready for the **Button**?

xShare envisions everyone sharing their health data in European Electronic Health Record Exchange Format (EEHRxF) with a click-of-a-button – the **xShare Yellow Button**!

#xShareYellowButton



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