



Citizen-centric data sharing: Getting Value

“People will be able to easily access and share their health data”

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13/02/2024  @ehtel_ehealth

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2030 Digital Compass: the European way for the Digital Decade

COM(2021) 118 final

- *“It is our proposed level of ambition that by 2030:*
 - 100% online provision of key public services available for European citizens and businesses
 - 100% of European citizens have access to medical records (e-records)
 - 80% of citizens will use a digital ID solution.”

➤ *Cooperation and coordination between Member States and EU-level is needed.*

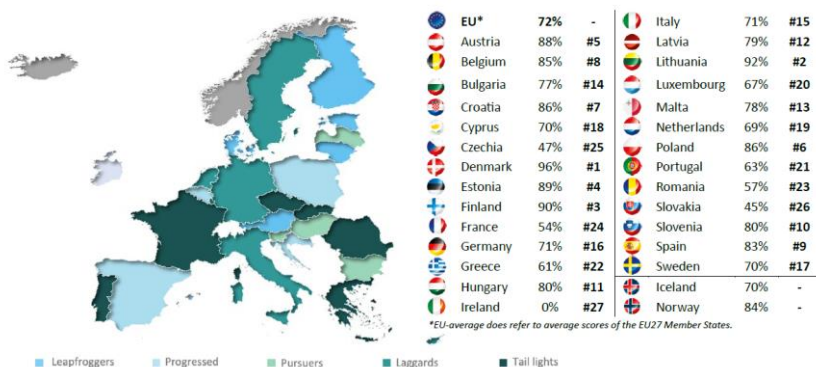


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2022 baseline: Citizens' access to their electronic health records

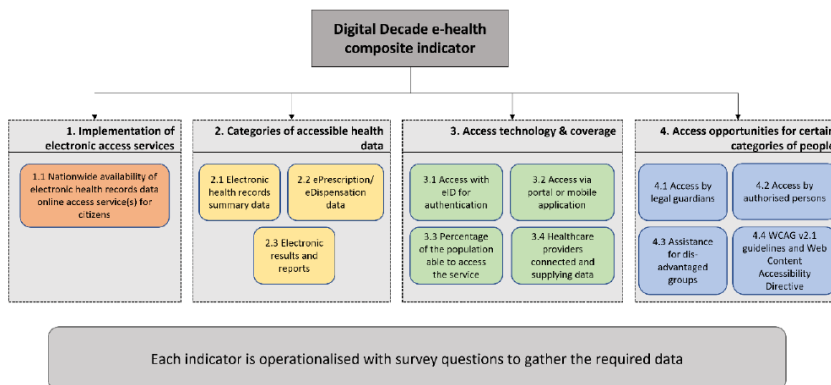
Figure 1. Citizens' access to their electronic health records in the EU, 2022
Overall performance of e-health composite scores by country groups



Source: Digital Decade e-Health Indicators Development – CNECT/LUX/2022/MVP/0027

Citizens' electronic access: Composite indicator

Figure 5. Digital Decade e-health composite indicator structure



Source: Digital Decade e-Health Indicators Development – CNECT/LUX/2022/MVP/0027

Categories of accessible data

Figure 10. Available and timely updated electronic health records summary data in the EU, 2022

Which of the following data is available to citizens through electronic health records data online access services in your country? For each item, is data generally updated in a timely way (e.g., within hours or a few days after the relevant healthcare session) following each care episode?

	AT	BE	BG	CY	CZ	DE	DK	EE	ES	FI	FR	GR	HR	HU	IE	IT	LT	LU	LV	MT	NL	PL	PT	RO	SE	SI	SK	IS	NO
Identification (e.g., national healthcare ID)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Personal information (e.g., name, date of birth, gender)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Allergies (e.g., description and type of allergy, severity, agent)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Current diagnoses (e.g., description and onset)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Medical devices and implants (e.g., Device ID, implant/explant date)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Procedures/operations (e.g., description, body site, date)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Current and relevant past medicines (e.g., reason, use, brand name, ingredients, dosage)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
No, not available to citizens.																													

Figure 11. Available and timely updated ePrescription/eDispensation data in the EU, 2022

Which of the following data is available to citizens through electronic health data access services?

	AT	BE	BG	CY	CZ	DE	DK	EE	ES	FI	FR	GR	HR	HU	IE	IT	LT	LU	LV	MT	NL	PL	PT	RO	SE	SI	SK	IS	NO
ePrescription information (e.g., date of issuance, dosage, strength, administration, brand name)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
eDispensation information (e.g., date of dispensation, location, pharmacy)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
No, not available to citizens.																													

Figure 12. Available and timely updated electronic results and reports in the EU, 2022

Which of the following electronic report types are available to citizens through electronic health data access services?

	AT	BE	BG	CY	CZ	DE	DK	EE	ES	FI	FR	GR	HR	HU	IE	IT	LT	LU	LV	MT	NL	PL	PT	RO	SE	SI	SK	IS	NO
Laboratory test results	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Medical imaging reports (reports with summaries of diagnostic imaging procedures of any kind)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Medical images (made available to citizens in digital formats, e.g., png, jpeg or pdf)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Hospital discharge reports (reports with summaries of ward episodes or ambulatory care)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
No, not available to citizens.																													

Source: Digital Decade e-Health Indicators Development – CNECT/LUX/2022/MVP/0027

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Proposal for a Regulation on the European Health Data Space

- “The European Health Data Space will **empower** individuals across the EU to fully exercise their rights over their health data. People will be able to **easily access and share** these data while **retaining greater control**, fully in line with our overall EU approach to data protection.” Ioana-Maria Gligor (former Head of Unit in DG Santé)

EHDS Section 1

Access to and Transmission of Personal Electronic Health Data for Primary Use

- Article 3: Rights of natural persons in relation to the primary use of their personal electronic health data

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Proposal for a Regulation on the European Health Data Space

COM(2022) 197 final

Article 3

Rights of natural persons in relation to the primary use of their personal electronic health data

1. Natural persons shall have the **right to access** their personal electronic health data processed in the context of primary use of electronic health data, immediately, **free of charge and in an easily readable, consolidated and accessible form**.
2. Natural persons shall have the **right to receive an electronic copy**, in the European electronic health record exchange format referred to in Article 6, of at least their electronic health data in the priority categories referred to in Article 5.
3. ...
8. Natural persons shall have the **right to give access to or request** a data holder from the health or social security sector **to transmit** their electronic health data to a data recipient of their choice from the health or social security sector, immediately, free of charge and without hindrance from the data holder or from the manufacturers of the systems used by that holder.

European Parliament compromise of 13 December 2023

Article 3

Rights of natural persons in relation to the primary use of their personal electronic health data

1. [idem]...
2. Natural persons shall have the **right to receive an electronic copy**, in the European electronic health record exchange format referred to in Article 6, of at least their electronic health data, **or at the request of the natural person, a printed copy thereof, in accordance with Article 15(3) of Regulation (EU) 2016/679.**
- 2a. **The rights referred to in paragraphs 1 and 2 shall be deemed complementary to and be without prejudice to the rights and obligations established by Article 15 of Regulation (EU) 2016/679.**
3. ...
8. Natural persons shall have the **right to request** a **health** data holder from the health or social security sector or reimbursement services, **to transmit all or part of their electronic health data** to a health data recipient of their choice from the health or social security sector **or reimbursement services**, immediately, free of charge and without hindrance from the data holder or from the manufacturers of the systems used by that holder. **The health data recipient shall be clearly identified by the natural persons to the health data holder and their affiliation to the health or social security sector shall be demonstrated. Health data holders and their processors shall comply with the request and shall transmit the data in the format provided for in Article 5.**

Council Compromise of 31 October 2023

Article 8A

Right of natural persons to access their personal electronic health data

1. Natural persons shall have the right to access their personal electronic health data, **at a minimum data that belongs the priority categories in Article 5**, processed for the provision of healthcare through the electronic health data access services referred to in Article 8G. The access shall be provided immediately after the personal electronic health data has been registered in an EHR system, while adhering to technological practicability, **free of charge and in an easily readable, consolidated and accessible form**.
2. Natural persons shall have **the right to receive an electronic copy**, free of charge, through the electronic health data access services referred to in Article 8G, in the European electronic health record exchange format referred to in Article 6, of at least their personal electronic health data in the priority categories referred to in Article 5.
3. ...

Article 8D Right to data portability for natural persons


1. Natural persons shall have **the right to give access to or request a healthcare provider to transmit**, all or part of their electronic health data **that belongs to the priority categories as referred to in Article 5** to another provider of their choice from healthcare sector without delay, free of charge and without hindrance from the transmitting provider or from the manufacturers of the systems used by that provider, as appropriate.



Until this summer, I wasn't much concerned about my health data, but ...

- *Then, I became chronic patient and ... started to care about my health data*
- *Why?*
 - To be better prepared for my medical visit
 - To better synthesize what I learned during this visit
 - Because I am (a bit) anxious to know my lab results,
I don't have the skills to interpret all of them, but I can observe the evolution over time
 - Because I need now to manage my health condition, calibrate dietary restrictions ...







Connected as: **Marc Lange** - as Citizen | [Log out](#)

Are you willing to share your medical record?

Yes, but...

[Click here](#) and discover how to manage the access to your health data.

Overview consent

You have given your consent for the sharing of your data.

[My consent](#)

[My therapeutic relationships](#)

My health summary

Concise electronic summary of your current health status, created by the GP managing your Global Medical Record.

[🔗](#)

My Reports & Results

Overview of your health data available in a hospital or laboratory. Example: test results, examination results, hospital discharge report.

[🔗](#)

Links to other patient portals

Here you will find links to other patient portals offered by the 4 hospital networks in Belgium

[⌵](#)

My medicines

Information about your medication use. Example: medication schedule

[🔗](#)

My pending medication prescriptions

Prescriptions for medicines that you can book/pick up at the pharmacy.

My implants

Overview of medical devices implanted in you.

My vaccinations


Overview of the vaccinations you have received.

Health Insurance Funds

Access to the digital platform of your health insurance fund.

My handicap

Access to your allowance file. You can also apply for a handicap allowance.




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Réseau Santé Wallon - Espace Patient

[Accueil](#)
[Mes données](#)
[Mes autorisations d'accès](#)
[Mon historique des accès](#)
[Mon consentement](#)
[Mes services](#)
[Mes prescriptions](#)
[Ma mutuelle](#)
[Mon profil](#)

Documents

Vous trouverez ci-dessous la liste des documents qui ont été référencés par vos prestataires de soins sur le Réseau Santé Wallon. Ces documents ne sont accessibles qu'aux prestataires de soins autorisés (voir liste des prestataires de soins) et ce dans le cadre de votre prise en charge. Pour l'ajout ou l'exclusion d'un prestataire de soins autorisé à accéder à l'ensemble de vos documents, utilisez le menu « Autorisations d'accès ». Vous pouvez autoriser ou restreindre l'accès de certains documents médicaux en particulier en cliquant sur « gérer » dans la ligne concernant le document.

[Ajouter une note dans le journal](#)

[Ajouter un résumé de santé](#)

Rapports | SumEHR | Medication | Journal | Laboratoire | Vaccination | Imagerie | Notes patient | Infos patient

Filtrer par dates: ☐

Date	Type	Auteur	Profil	Service	Site	Disponibilité
23/08/2023 (13:43)	Résultat de laboratoire (LAB)	MINON JEAN-MARC	Médecin	Laboratoire	CHR DE LA CITADELLE	Accessible
10/09/2023 (14:55)	Résultat de laboratoire (LAB)	MINON JEAN-MARC	Médecin	Laboratoire	CHR DE LA CITADELLE	Accessible
05/08/2023 (09:45)	Résultat de laboratoire (LAB)	MINON JEAN-MARC	Médecin	Laboratoire	CHR DE LA CITADELLE	Accessible
05/09/2023 (09:42)	Rapport de consultation (CHR) (GÉNÉRALE Prescription de soins affimées)	BRUVIER LOUISE	Médecin	Chirurgie abdominale, digestive et vésiculaire	CHR DE LA CITADELLE	Accessible
04/09/2023 (10:10)	Résultat de laboratoire (LAB)	MINON JEAN-MARC	Médecin	Laboratoire	CHR DE LA CITADELLE	Accessible
03/08/2023 (12:27)	Rapport d'histopathologie (URSO, GIGHE, 01 - HC205 - Lettre de sortie F32)	TROISFONTAINES ERIC	Médecin	Urologie	CHR DE LA CITADELLE	Accessible
03/08/2023 (00:00)	Résultat (Protocole d'anatomie pathologique)	PATER OLIVIER	Médecin	Anatomopathologie	Centre Hospitalier Universitaire de Liège Librabre par le méde	
02/09/2023 (15:02)	Résultat de laboratoire (LAB)	MINON JEAN-MARC	Médecin	Laboratoire	CHR DE LA CITADELLE	Accessible
25/07/2023 (16:20)	Résultat de laboratoire (LAB)	MINON JEAN-MARC	Médecin	Laboratoire	CHR DE LA CITADELLE	Accessible
25/07/2023 (16:20)	Résultat de laboratoire (LAB)	MINON JEAN-MARC	Médecin	Laboratoire	CHR DE LA CITADELLE	Accessible

Liste de prestataires de soins ayant l'autorisation d'accéder à mes documents médicaux

Vous trouverez ci-dessous la liste des prestataires de soins qui ont le droit d'accéder à vos documents médicaux. Vous pouvez en ajouter et vous pouvez également en exclure. Attention, l'exclusion concerne l'accès à l'ensemble de vos documents médicaux. Vous pouvez également restreindre l'accès de certains documents en particulier à partir de la liste des documents.

[Ajouter une autorisation d'accès](#)

[Ajouter une exclusion](#)


Afficher : Tous | En cours | Expirés

Médecin	Inami	Date début	Date de fin	
TROISFONTAINES Eric	16605008450	8/08/2023	7/09/2024	🔗
Aventin Bernard	16670439004	31/05/2023	30/08/2024	🔗
Delhaugne Vincent	16683505730	6/10/2022	6/01/2024	🔗

Autres prises en charge

Prestataire de soins	Inami	Type	Date début	Date de fin	
MASSET Catherine	16764479590	Prise en charge hospitalière	10/09/2023	8/11/2023	🔗
BRUVIER Louise	10269907045	Prise en charge hospitalière	26/07/2023	24/10/2023	🔗
SALIBA Sandra	10263076010	Prise en charge ambulatoire	25/07/2023	23/10/2023	🔗
VAN DYCK Babette	10024558045	Prise en charge ambulatoire	25/07/2023	23/10/2023	🔗

Liens d'exclusions
aucun résultat




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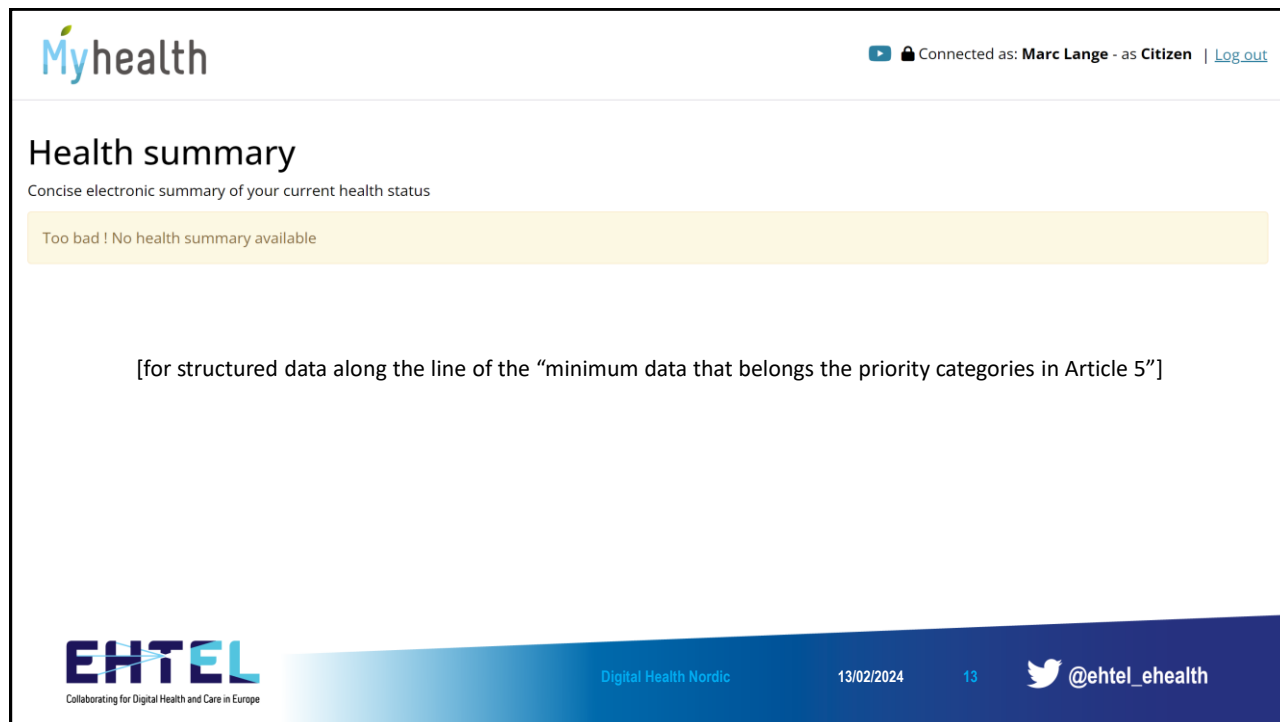
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Health summary

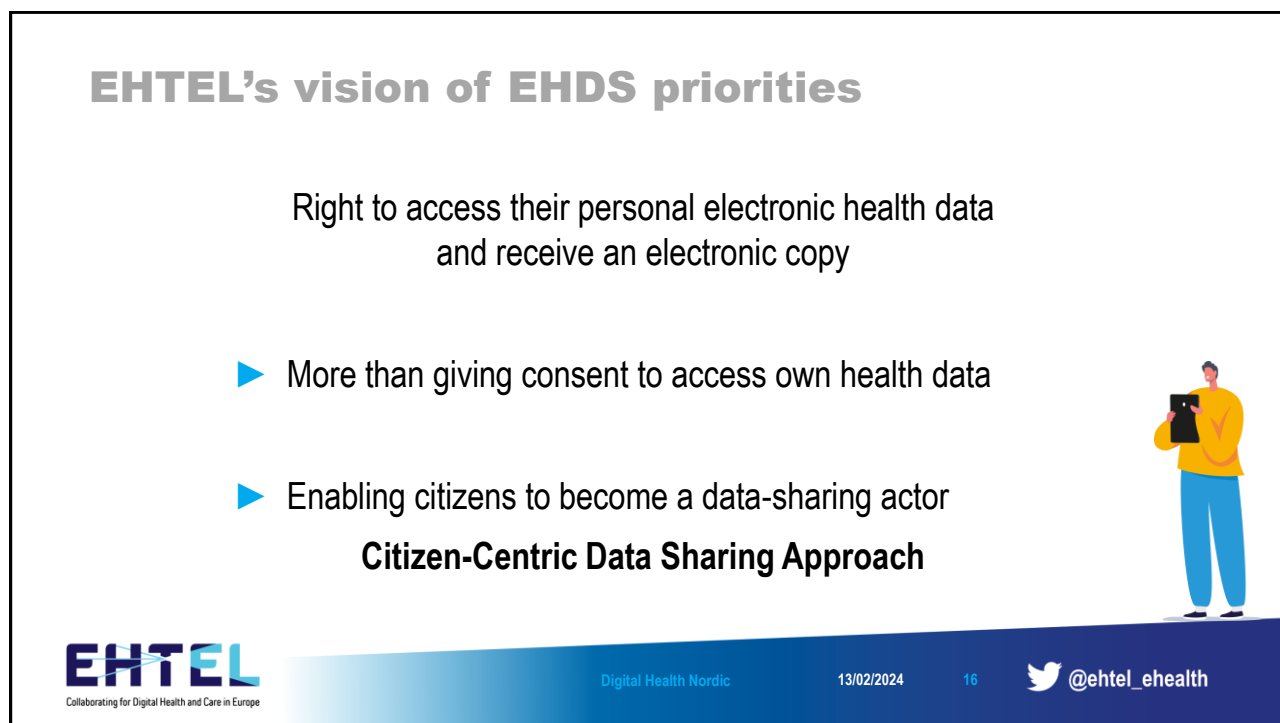
Concise electronic summary of your current health status

Too bad ! No health summary available

[for structured data along the line of the "minimum data that belongs the priority categories in Article 5"]

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EHTEL's vision of EHDS priorities


Right to access their personal electronic health data
and receive an electronic copy

- ▶ More than giving consent to access own health data
- ▶ Enabling citizens to become a data-sharing actor


Citizen-Centric Data Sharing Approach

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U.S. Department of Veterans Affairs



**Blue Button
Download
My Data**

VA Blue Button Learn About Blue Button Use VA Blue Button

HealthIT.gov

Official Website of The Office of the National Coordinator for Health Information Technology (ONC)

TOPICS ▾ BLOG NEWS ▾ DATA ABOUT ONC ▾


HealthIT.gov > How Do It? > For Individuals

For Individuals


Protecting Your Privacy & Security

How do I? Answers to Individuals' Common Questions


Access my health information?




Use my health data?




Protect my privacy and keep my information secure?




Find resources and tools for consumers?



Connect with my state health IT stakeholders?







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La meva Salut
gencat
La meva salut


Blue Button – Health Data for sharing

Objectives

In summary, the objectives of the BB tool are:


- To empower the citizens by providing them access to their personal health records in an immediate, easy and free way.
- To grant the citizens full access to their data in order to share their information whenever, wherever and whoever they want.
- Provide data in an electronic, structured and reusable format.
- To contribute towards the new European Health Data Space regulation. The BB initiative aligns with the principles of the EHDS by providing immediate access to health data, adhering to international standards and promoting cross-border data sharing.






TIC Salut Social

Innovation and digital transformation




Generalitat de Catalunya



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

- *Objective #2 : Demonstrate the benefit and value of the xSHARE Button supporting the right of individuals to data portability under GDPR data in continuity of care use cases*



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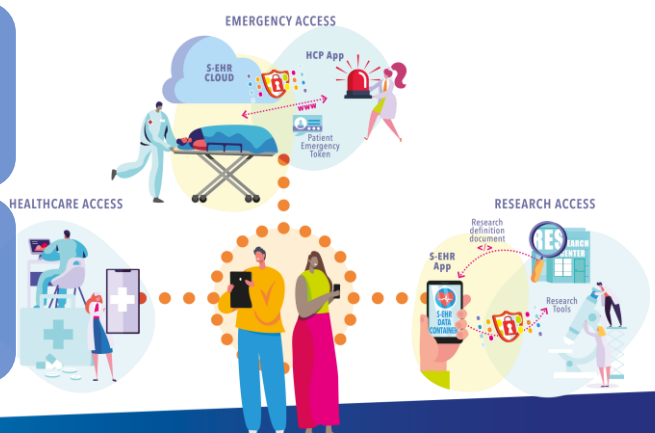
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How can we action citizen-centric data sharing?



InteropEHRate has developed protocols to allow citizens to access their own data with their mobile and share it with others.

InteropEHRate has also developed solutions to facilitate data sharing for research purposes.



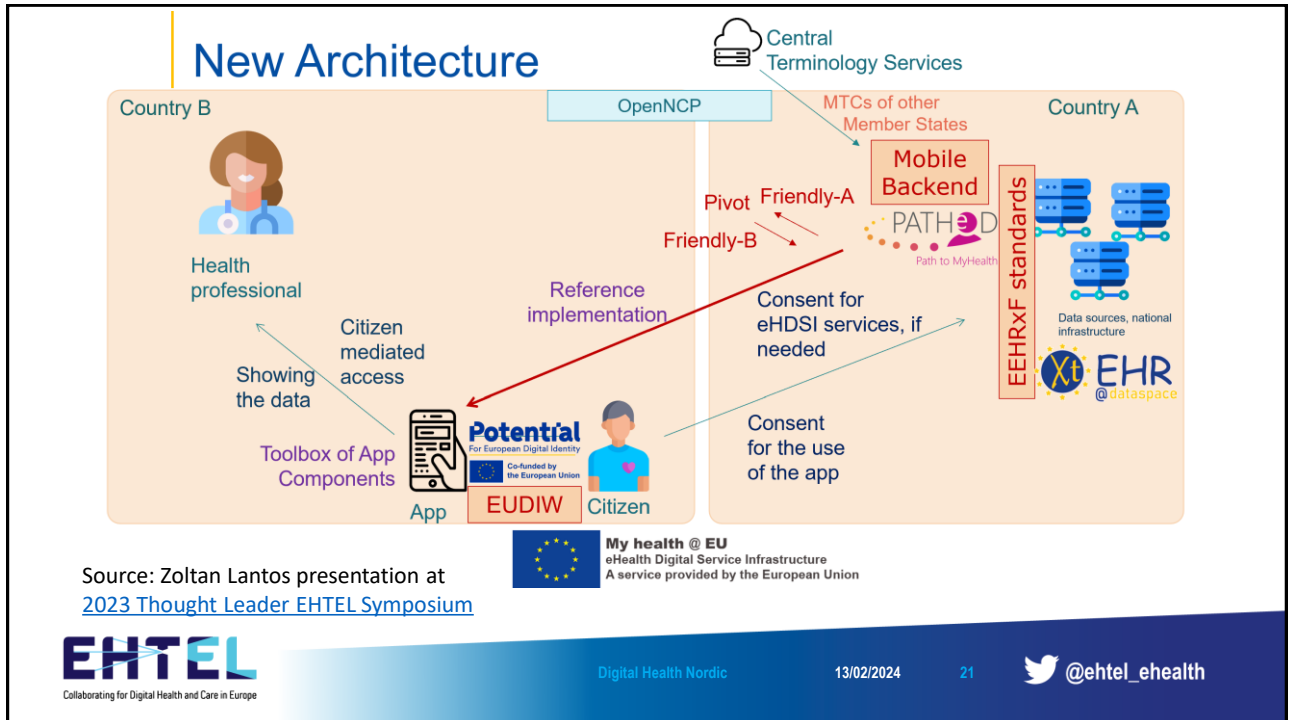
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