Blue Button – Health data for sharing

TIC
Salut Social

Generalitat
de Catalunya

General information

/Salut

Good Practice implemented by: Catalan Ministry of Health (General Coordination of ICT)

Region: CATALONIA

Country: SPAIN

Total Region Population: 7.899.056 (1/1/2023)

Cooperation partners: CatSalut, Fundació TIC Salut Social.

Short Summary

The Catalan public healthcare system has introduced an innovative tool, **'Health Data for Sharing - Blue Button'**. This tool empowers users to securely download their clinical data for sharing with other healthcare systems or research endeavours.

What is the need / problem to be solved?

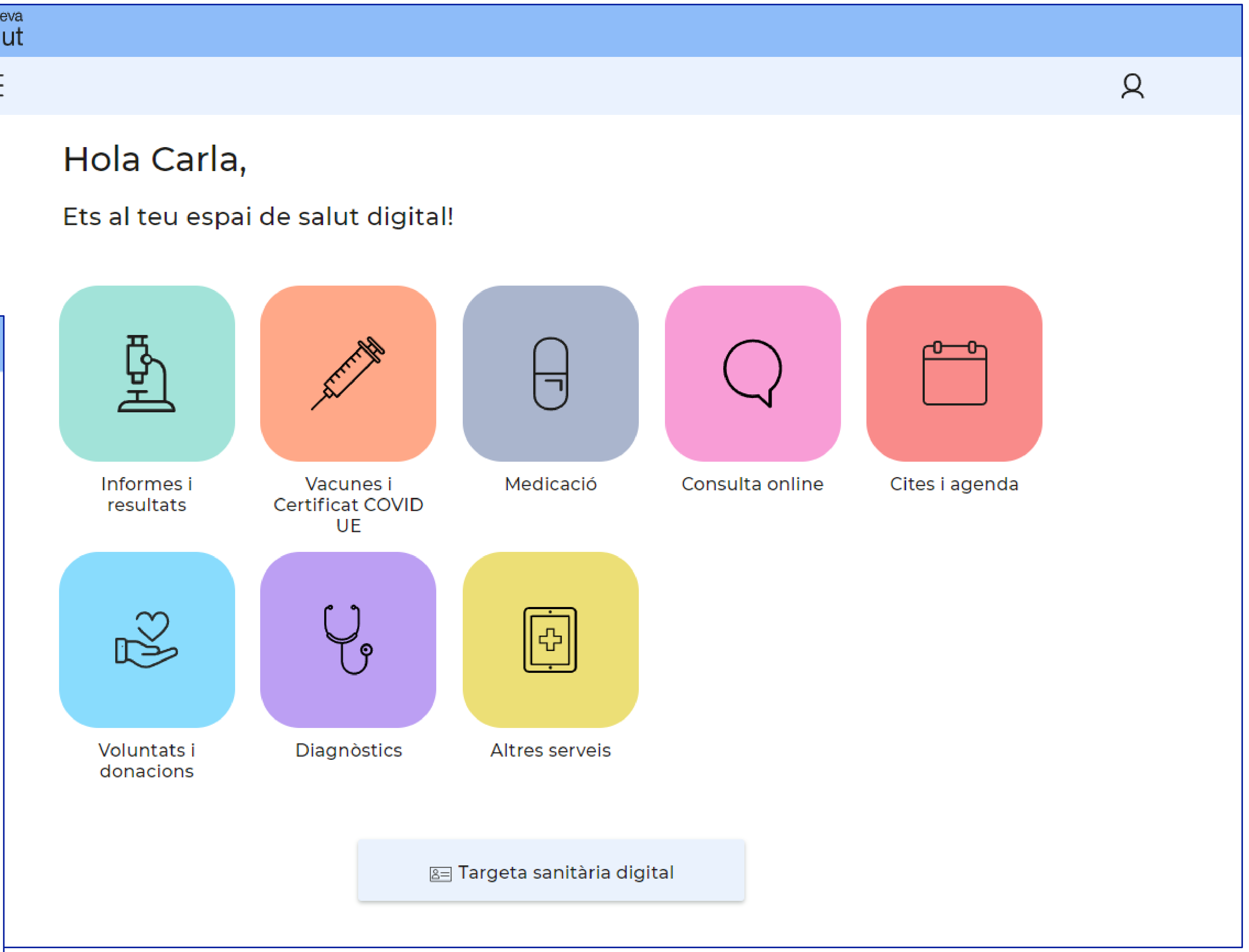
- Catalonia ➡ digitalization process for over 40 years.
- Needs to be solved:
  - Quality healthcare continuity: that my information be available to those who need to attend to me or wish to generate knowledge for the benefit of all.
  - Information from private sector available: personalization.
  - Creation of a new scenario: citizen empowerment, data portability

Context: La Meva Salut (My Health)

- LMS is a personal digital health space that allows the citizens of Catalonia to interact with the Catalan Health System in a non-face-to-face manner.
- La Meva Salut enables you to access your health information, consult with professionals, and perform procedures in an easy, secure, and confidential manner.
- Parents, legal guardians or responsible individuals can request access to LMS for their children under 18 years of age and those under their legal guardianship.
- La Meva Salut can be accessed through the web or by downloading the app .

Hola Carla

Ets al teu espai de salut digital.



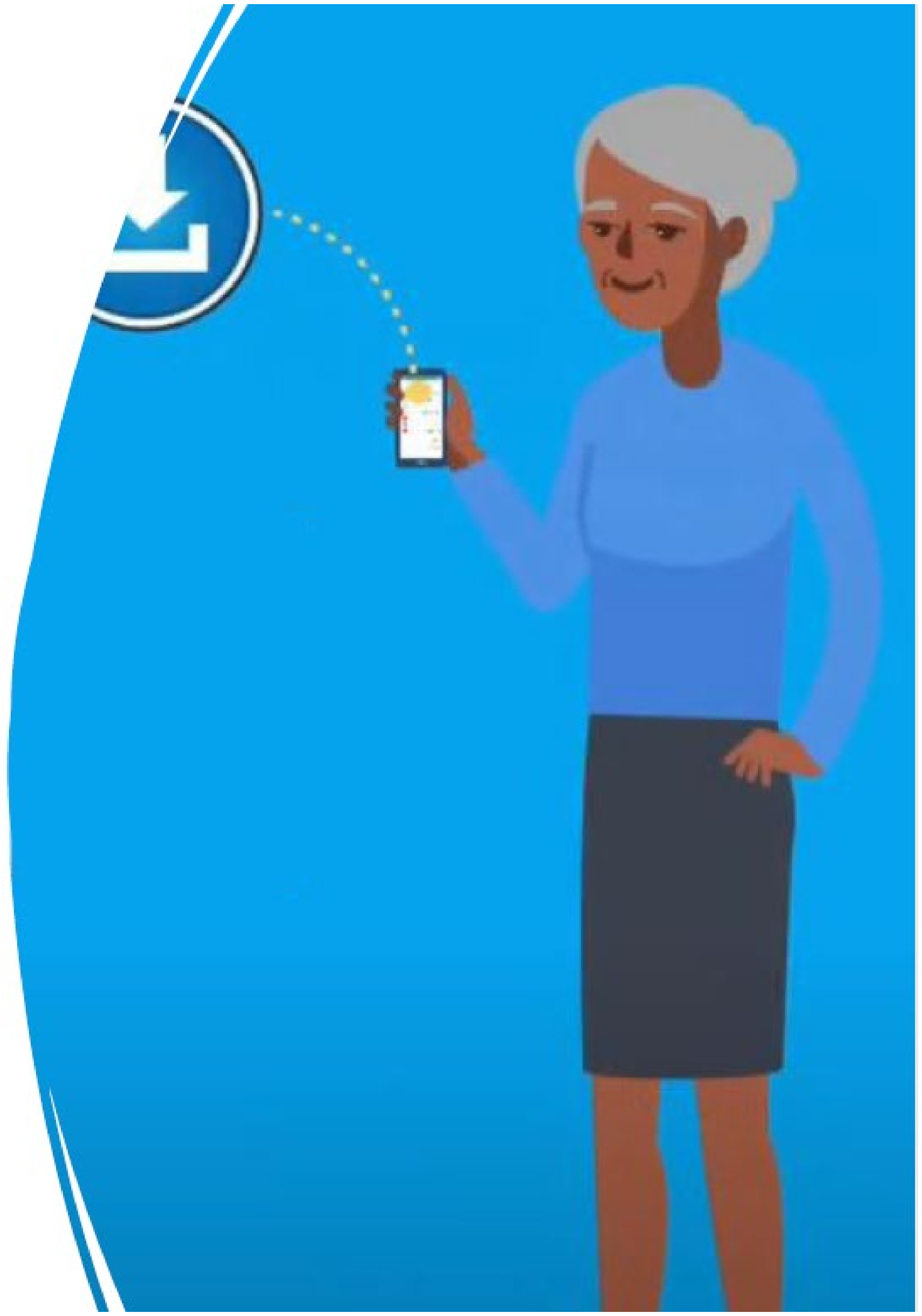
Hola Carla,

Ets al teu espai de salut digital!

Blue button (I)

In this context, the Catalan MoH has developed and added a functionality called “Blue button” to LMS that…

- Affords users the ability to securely download their clinical data for sharing purposes with other healthcare systems or research entities.
- Allows the empowerment of the citizen by allowing the digital portability of their data in compliance with the GDPR.
- Citizens can retrieve their International Patient Summary – a standardized document that contains essential patient health information, designed to facilitate the exchange of a patient information across borders. Also hospital discharge reports.
- IPS contains information about diagnoses, treatments, vaccinations, test result and allergies. This service is set to facilitate the determination of the most suitable course of action, mitigate allergy-related risks and overcome language barriers.



International Patient Summary (IPS)

IPS (International Patient Summary) defined at an international level (Guidelines on Patient Summary, europa.eu), and being adopted at both European, Spanish, and Catalan levels.

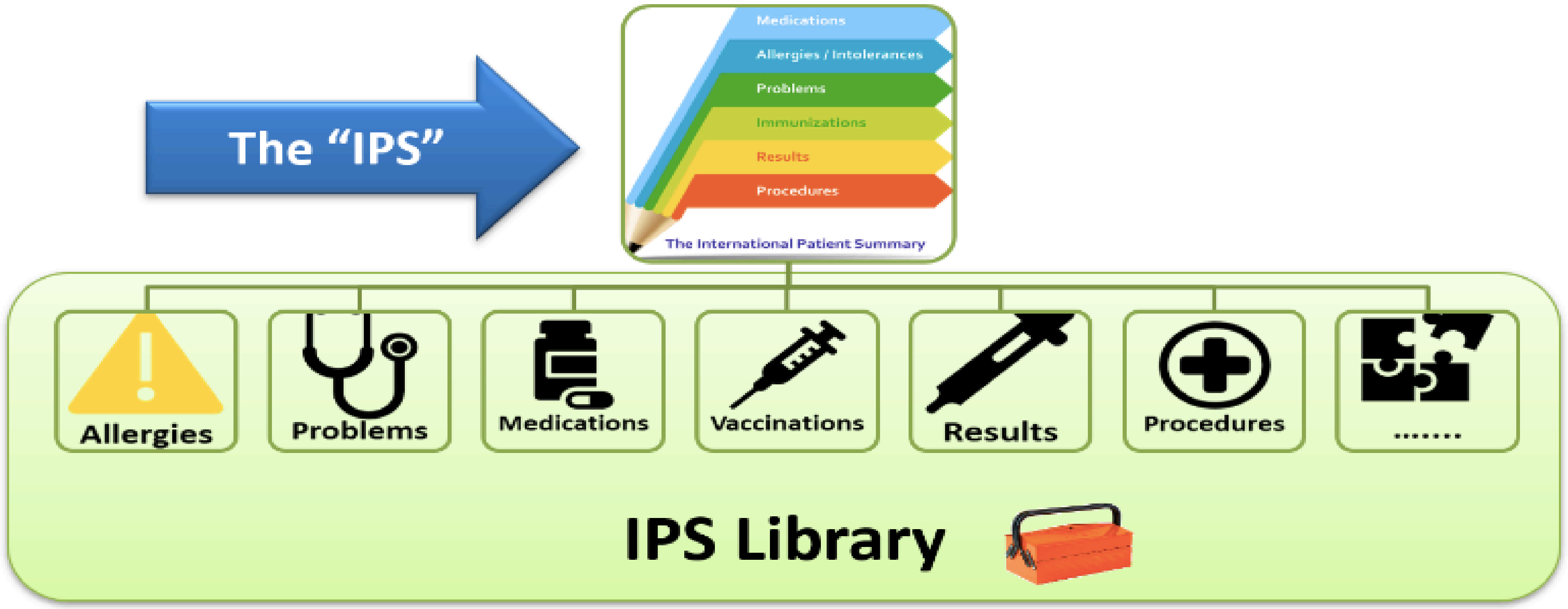
It is an extract from an electronic medical record containing essential health information about a citizen, as specified in EN 17269 and ISO 27269 standards.

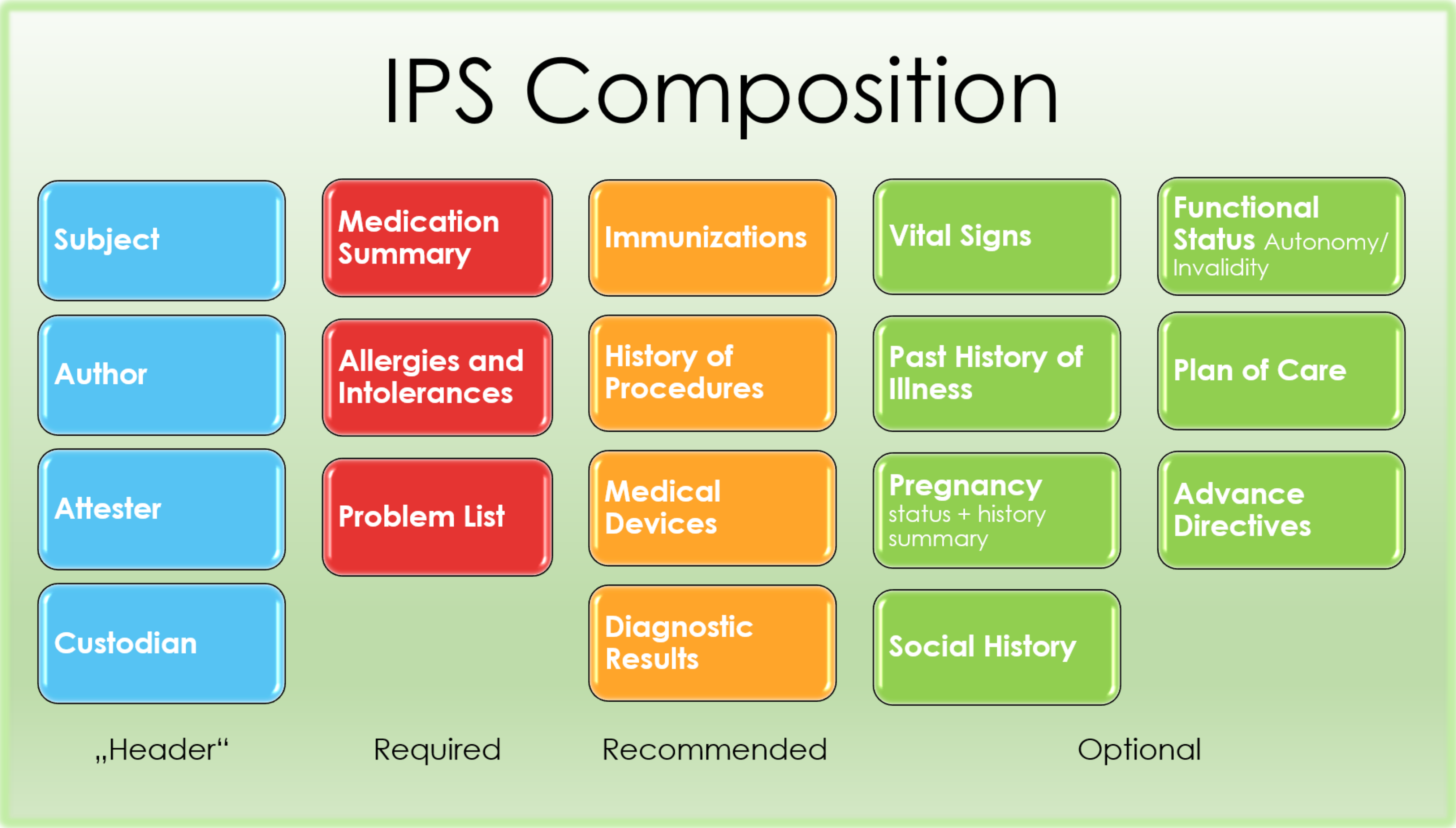
The IPS dataset is minimal and non-exhaustive, independent of specialty and health conditions, yet clinically relevant.

The IPS document consists of a set of robust, well-defined, and potentially reusable basic data elements:

- **Patient**: Patient demographic data
- **Organization**: Data specific to the entity generating the IPS
- **Medication**: Summary of the patient's regular medication
- **Allergies and intolerances**: List of patient allergies, adverse reactions, or intolerances
- **Immunizations**: Vaccines administered to the patient
- **Diagnostic history**: List of health problems the patient has had in the past
- **List of procedures**: Procedures performed on the patient, with a focus on surgical ones
- **Active problems**: List of current health problems of the patient

International Patient Summary (IPS)





IPS Composition

„Header“	Required	Recommended	Optional	
Subject	Medication Summary	Immunizations	Vital Signs	Functional Status Autonomy/ Invalidity
Author	Allergies and Intolerances	History of Procedures	Past History of Illness	Plan of Care
Attester	Problem List	Medical Devices	Pregnancy status + history summary	Advance Directives
Custodian		Diagnostic Results	Social History	

Blue button (II)

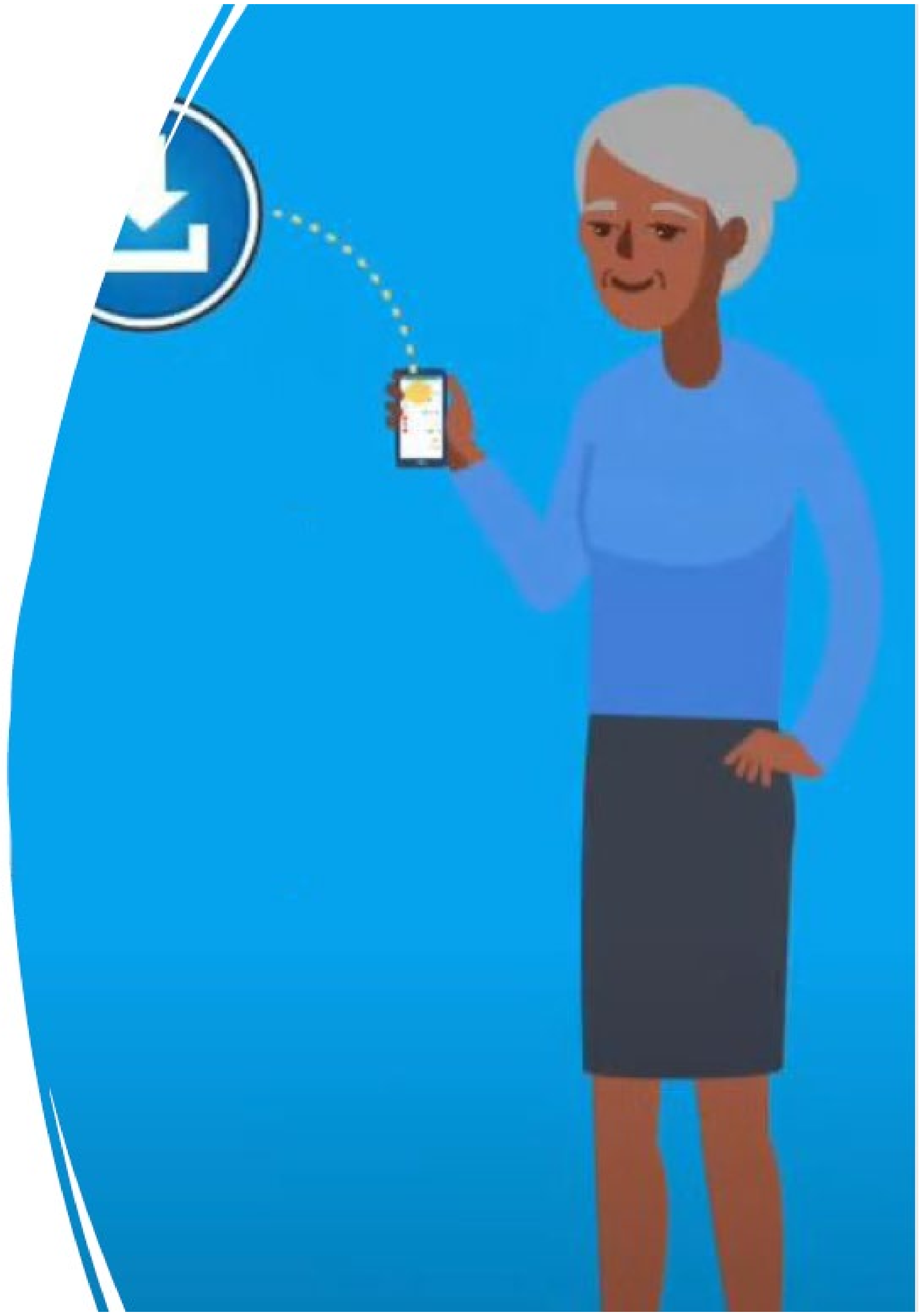
- For the moment the *blue button* functionality has only been implemented in the US healthcare system and in the Catalan public health system.

- The information is downloaded in accordance with HL7 C-CDA and Blue Button 2.0 standards and specifications, and also in compliance with the EU implementation guides from IHE.

- The IPS is downloaded in an structured XML format. These documents are intended for use by professionals who have a reading system or a compatible device that allow viewing this files in this format.

- This first version of the *blue button* functionality is currently available for citizens.

- Iphone users can view their XML file through the HEALTH app



Blue button (III)

Justificant d'alta al registre central de persones acreditades del CatSalut (RCA)

Descarregar

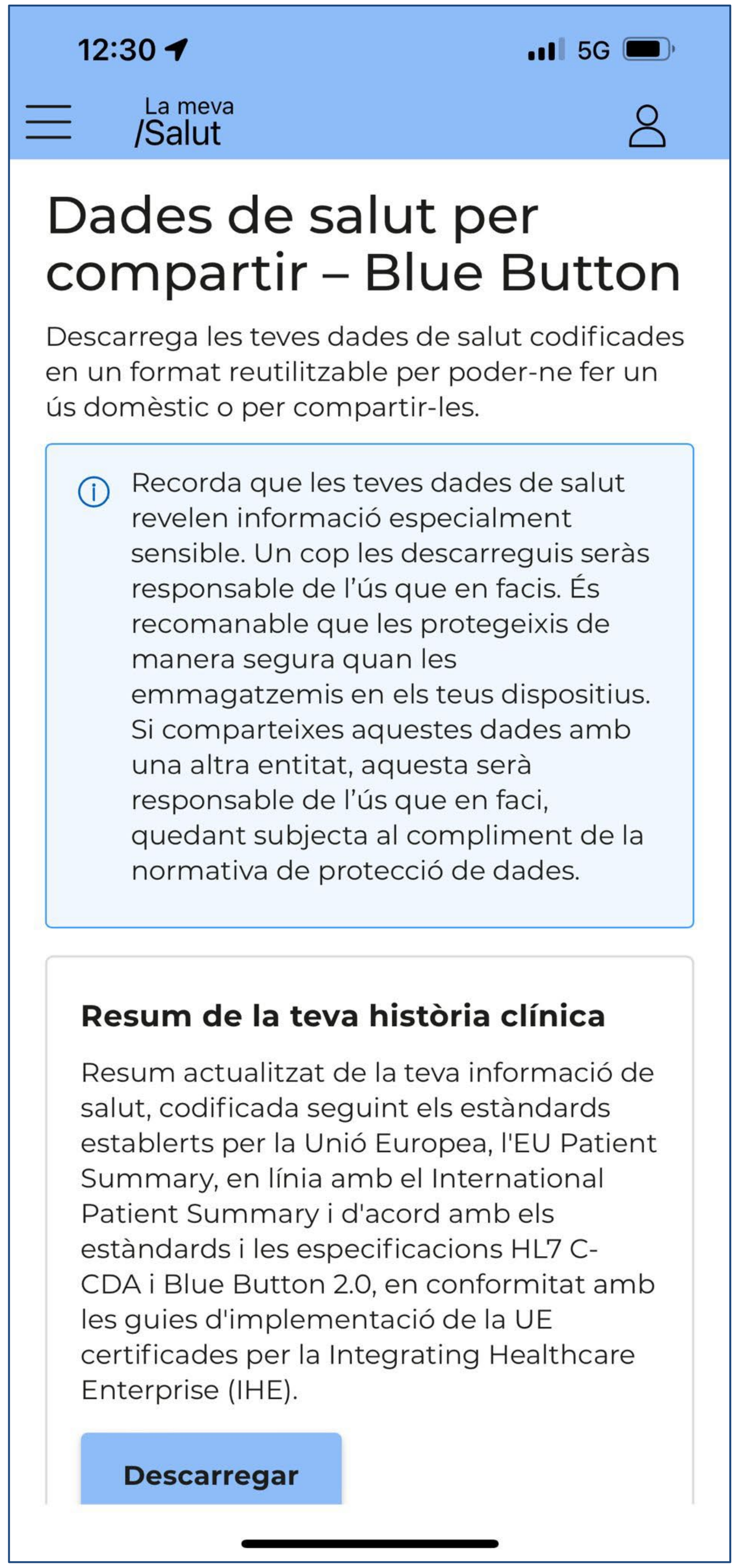
Document que justifica que et trobes en situació d'alta al registre central de persones acreditades del CatSalut. Aquest justificant és assimilable al document de fe de vida.

Dades de salut per compartir – Blue Button

Descarregar

Descarrega la teva informació de salut codificada per poder-la compartir amb altres professionals d'acord amb els estàndards i les especificacions HL7 C-CDA i Blue Button 2.0. Es descarrega en format XML, format que permet l'intercanvi d'informació entre diferents plataformes.

Consulta els accessos realitzats a les teves dades.



Dades de salut per compartir – Blue Button

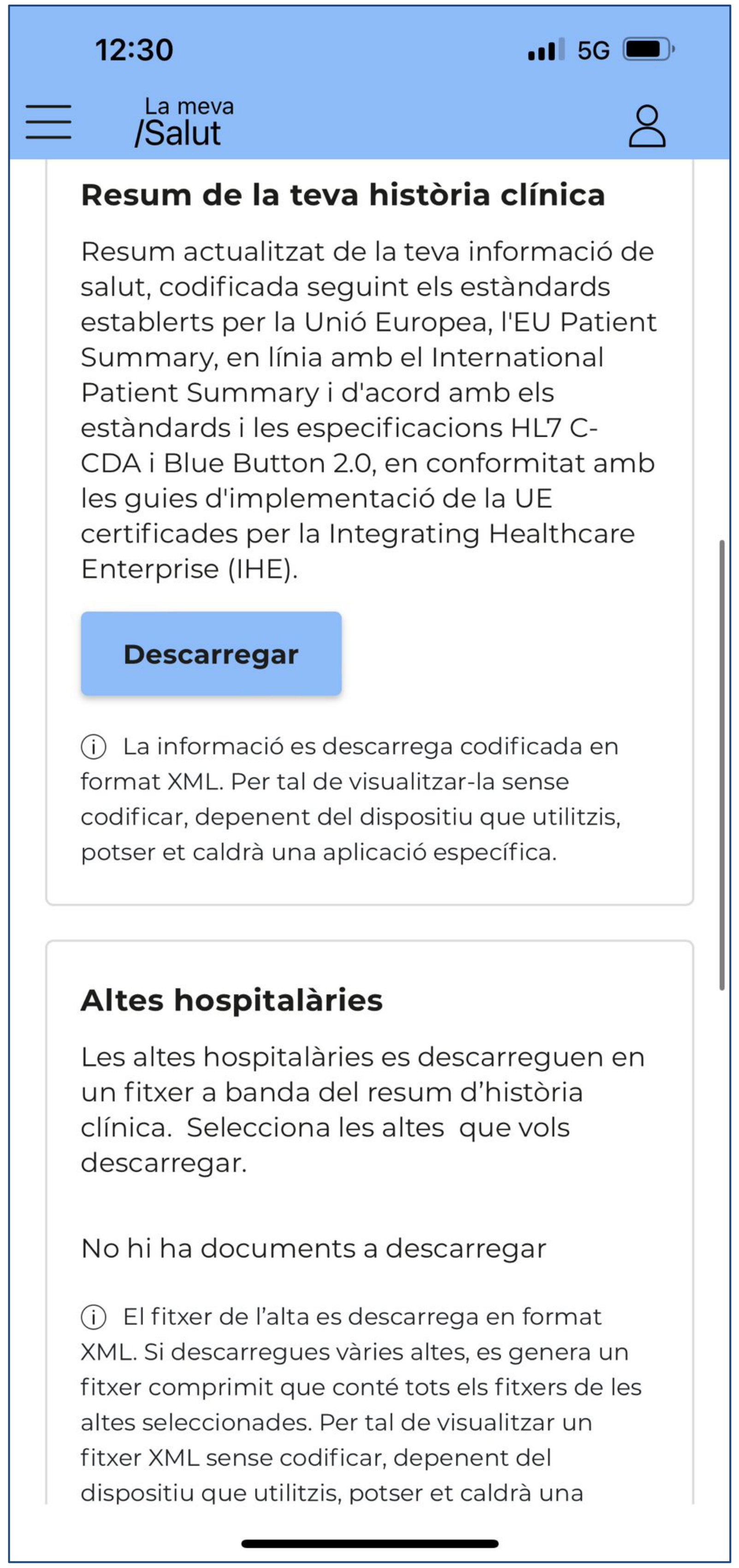
Descarrega les teves dades de salut codificades en un format reutilitzable per poder-ne fer un ús domèstic o per compartir-les.

Recorda que les teves dades de salut revelen informació especialment sensible. Un cop les descarreguis seràs responsable de l'ús que en facis. És recomanable que les protegeixis de manera segura quan les emmagatzemis en els teus dispositius. Si comparteixes aquestes dades amb una altra entitat, aquesta serà responsable de l'ús que en faci, quedant subjecta al compliment de la normativa de protecció de dades.

Resum de la teva història clínica

Resum actualitzat de la teva informació de salut, codificada seguint els estàndards establerts per la Unió Europea, l'EU Patient Summary, en línia amb el International Patient Summary i d'acord amb els estàndards i les especificacions HL7 C-CDA i Blue Button 2.0, en conformitat amb les guies d'implementació de la UE certificades per la Integrating Healthcare Enterprise (IHE).

Descarregar



Resum de la teva història clínica

Resum actualitzat de la teva informació de salut, codificada seguint els estàndards establerts per la Unió Europea, l'EU Patient Summary, en línia amb el International Patient Summary i d'acord amb els estàndards i les especificacions HL7 C-CDA i Blue Button 2.0, en conformitat amb les guies d'implementació de la UE certificades per la Integrating Healthcare Enterprise (IHE).

Descarregar

La informació es descarrega codificada en format XML. Per tal de visualitzar-la sense codificar, depenent del dispositiu que utilitzis, potser et caldrà una aplicació específica.

Altes hospitalàries

Les altes hospitalàries es descarreguen en un fitxer a banda del resum d'història clínica. Selecciona les altes que vols descarregar.

No hi ha documents a descarregar

El fitxer de l'alta es descarrega en format XML. Si descarregues vàries altes, es genera un fitxer comprimit que conté tots els fitxers de les altes seleccionades. Per tal de visualitzar un fitxer XML sense codificar, depenent del dispositiu que utilitzis, potser et caldrà una

Blue Button – Health Data for sharing

```
<?xml version="1.0" encoding="UTF-8" standalone="yes"?>
<ClinicalDocument xmlns="urn:hl7-org:v3" xmlns:ns2="urn:hl7-
org:sdtc">
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   <templateId root="1.3.6.1.4.1.19376.1.5.3.1.1.1"/>
   <templateId root="1.3.6.1.4.1.19376.1.5.3.1.1.2"/>
   <templateId root="2.16.840.1.113883.10.20.1"/>
   <templateId root="2.16.840.1.113883.10.20.3"/>
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   <templateId root="1.3.6.1.4.1.19376.1.5.3.1.1.5"/>
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extension="10764701704972290861"/>
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codeSystemName="LOINC" displayName="Summary of Episode
Note"/>
   <title>European Patient Summary</title>
   <effectiveTime value="20240111122450+0100"/>
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codeSystemName="Confidentiality" displayName="Normal"/>
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>
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streetName>
            <city>Barcelona</city>
            <state>ES</state>
            <postalCode>08010</postalCode>
         </addr>
         <telecom nullFlavor="NI"/>
         <patient>
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               <given>Carla</given>
               <family>Alvarez</family>
               <family>Costa</family>
```
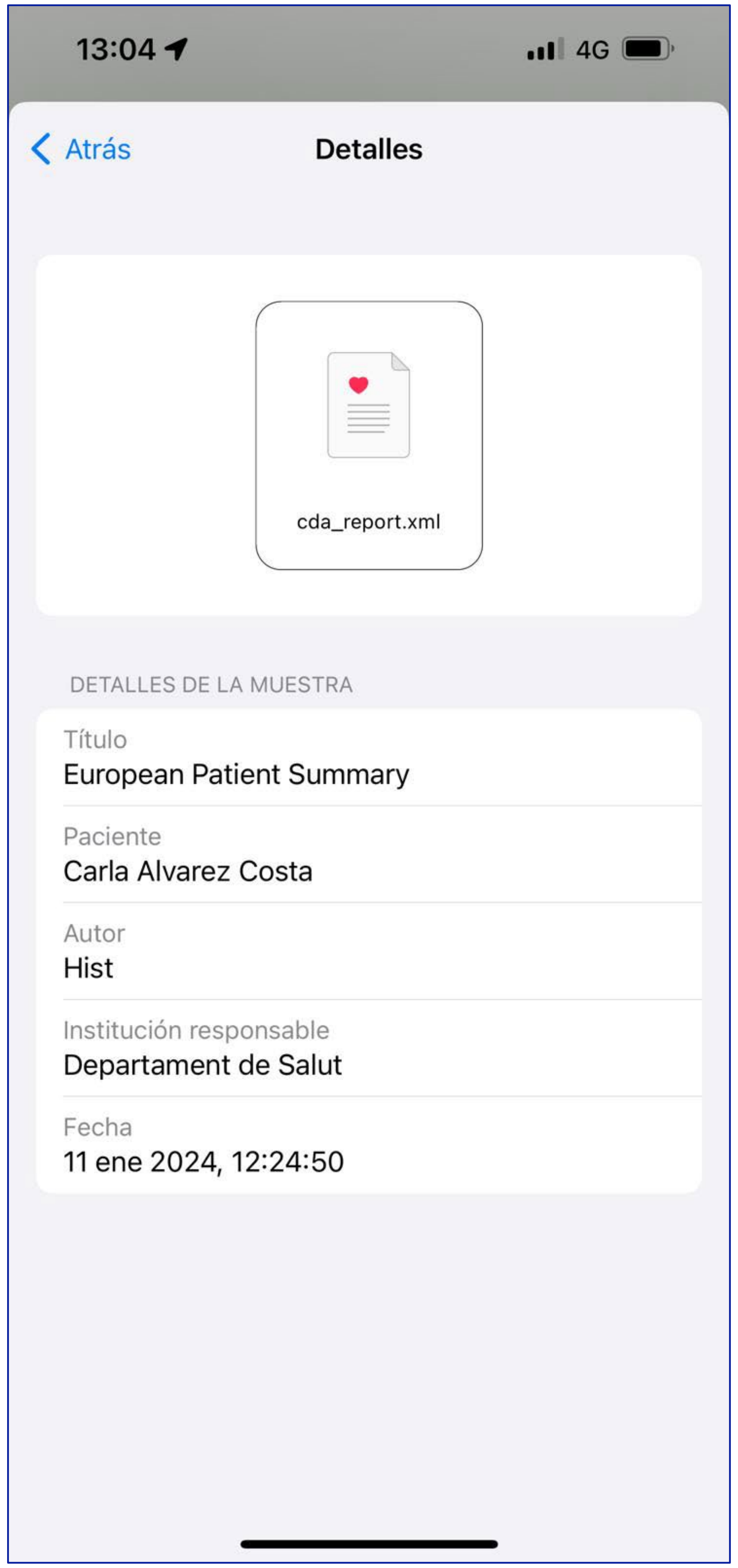



DETALLES DE LA MUESTRA

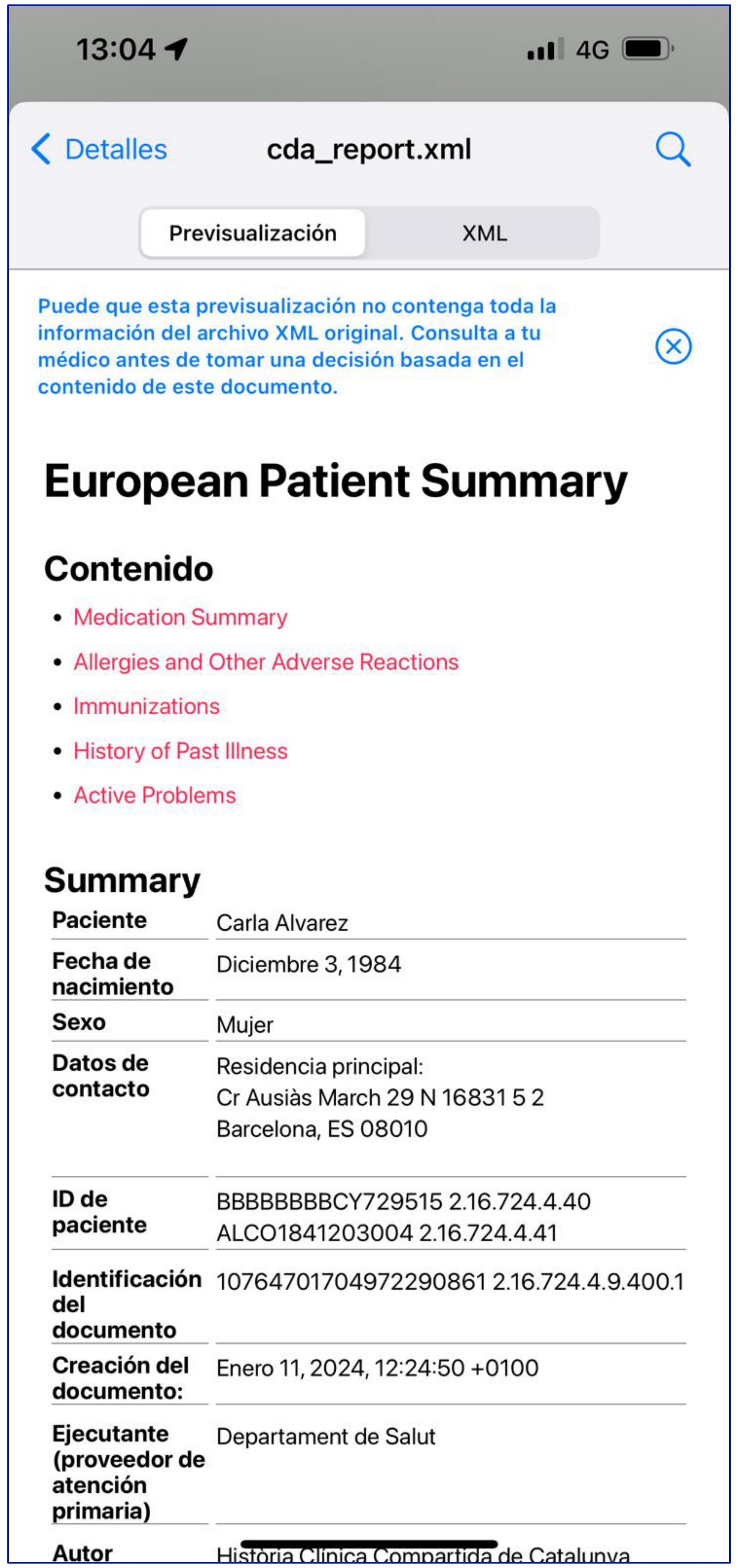
Título
European Patient Summary

Paciente
Carla Alvarez Costa

Autor
Hist

Institución responsable
Departament de Salut

Fecha
11 ene 2024, 12:24:50



Puede que esta previsualización no contenga toda la información del archivo XML original. Consulta a tu médico antes de tomar una decisión basada en el contenido de este documento.

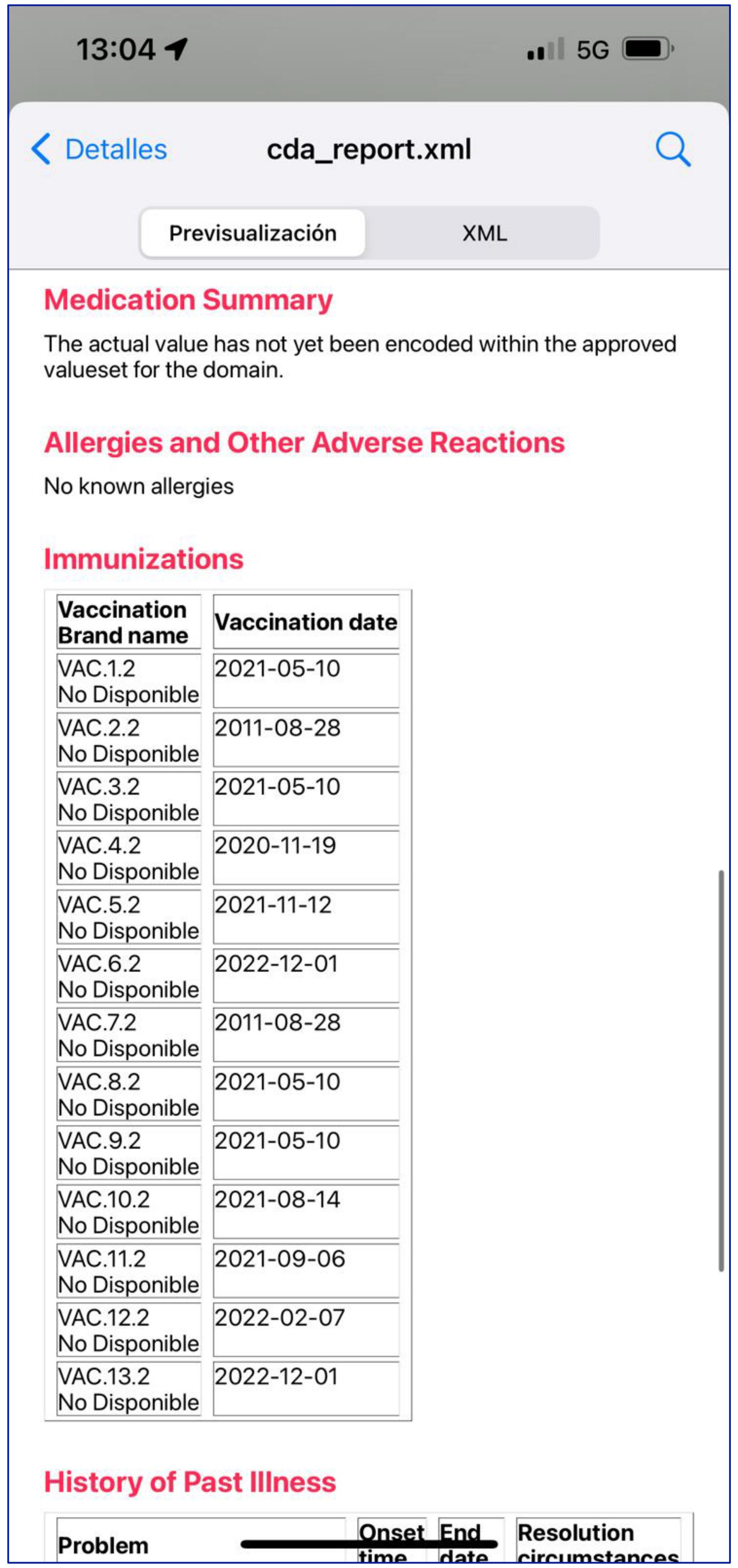
European Patient Summary

Contenido

- Medication Summary
- Allergies and Other Adverse Reactions
- Immunizations
- History of Past Illness
- Active Problems

Summary

Paciente	Carla Alvarez
Fecha de nacimiento	Diciembre 3, 1984
Sexo	Mujer
Datos de contacto	Residencia principal: Cr Ausiàs March 29 N 16831 5 2 Barcelona, ES 08010
ID de paciente	BBBBBBBBCY729515 2.16.724.4.40 ALCO1841203004 2.16.724.4.41
Identificación del documento	10764701704972290861 2.16.724.4.9.400.1
Creación del documento:	Enero 11, 2024, 12:24:50 +0100
Ejecutante (proveedor de atención primaria)	Departament de Salut
Autor	Història Clínica Compartida de Catalunya



Medication Summary

The actual value has not yet been encoded within the approved valueset for the domain.

Allergies and Other Adverse Reactions

No known allergies

Immunizations

Vaccination Brand name	Vaccination date
VAC.1.2 No Disponible	2021-05-10
VAC.2.2 No Disponible	2011-08-28
VAC.3.2 No Disponible	2021-05-10
VAC.4.2 No Disponible	2020-11-19
VAC.5.2 No Disponible	2021-11-12
VAC.6.2 No Disponible	2022-12-01
VAC.7.2 No Disponible	2011-08-28
VAC.8.2 No Disponible	2021-05-10
VAC.9.2 No Disponible	2021-05-10
VAC.10.2 No Disponible	2021-08-14
VAC.11.2 No Disponible	2021-09-06
VAC.12.2 No Disponible	2022-02-07
VAC.13.2 No Disponible	2022-12-01

History of Past Illness

Problem	Onset time	End date	Resolution circumstances

Involvement of the private sector

- Agreements with ACES
- Support in the adoption of the Patient Summary: Creation of specific IPS according to EU compliances and interoperability guidelines
- Support in the implementation of the Blue Button in health insurance apps/portals
- 2 pilots in a population of 500,000 people

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.

Impact & Outcomes

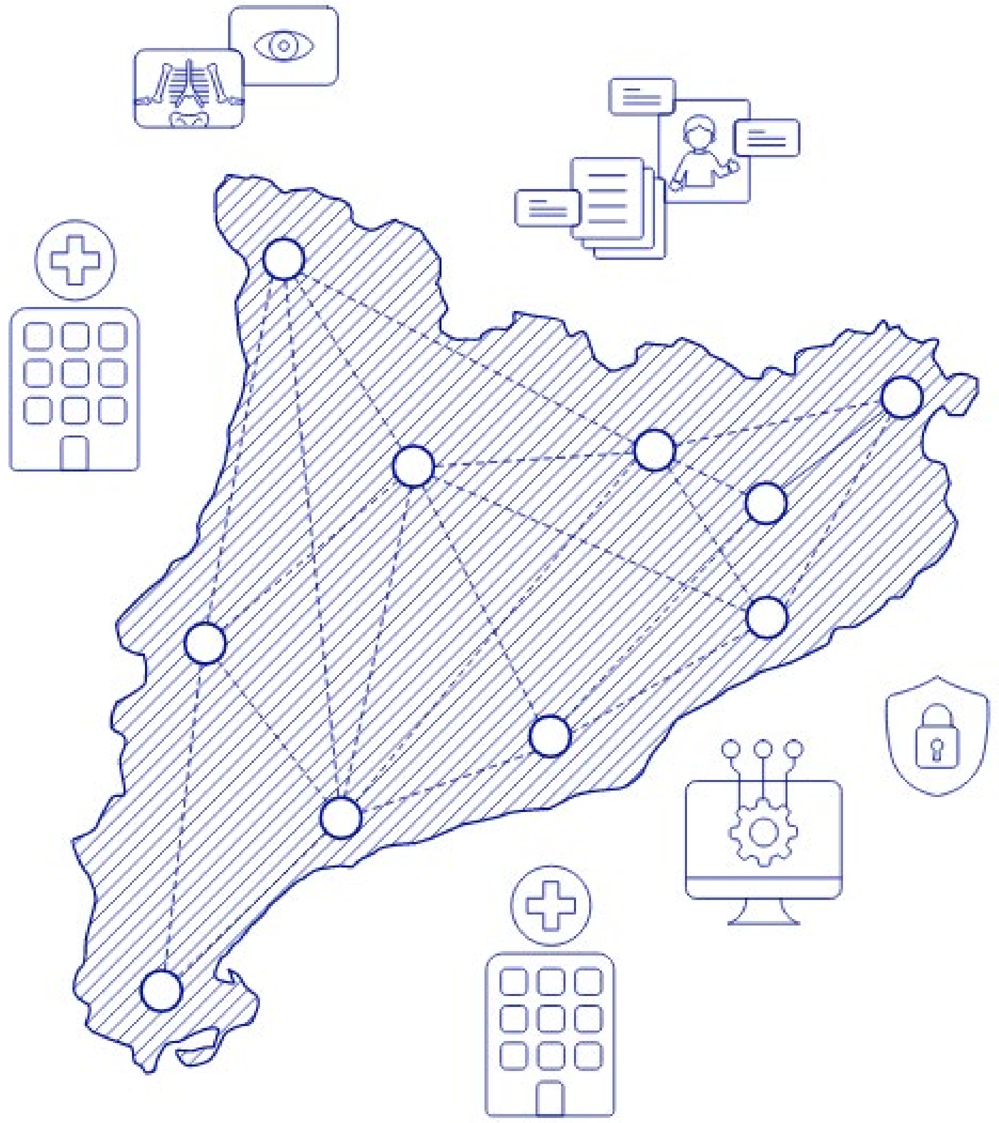
- **Enhanced Patient Empowerment**: Citizens now have immediate, easy, and electronic access to their health data, granting them unprecedented control over their medical information.
- **Improved Healthcare Delivery**: The exchange of International Patient Summaries (IPS) enables healthcare professionals to make informed decisions, especially when treating patients from different countries, thereby enhancing the quality and continuity of care.
- **Mitigated Allergy-Related Risks**: With access to critical medical data, including allergies, the risk of allergic reactions during treatment is significantly reduced.
- **Language Barrier Overcome**: The tool addresses language barriers by providing standardized patient health information for healthcare professionals.
- **International Collaboration**: The 'European Patient Summary' collaboration with other European countries, and plans for future expansion, demonstrates Catalonia's commitment to pioneering cross-border healthcare data sharing.
- **Legal and Ethical Compliance**: The initiative adheres to the General Data Protection Regulation (GDPR) and aligns with the European Health Data Space (EHDS) standards and specifications, ensuring ethical and legal compliance.

Current challenges:

Short-term challenges

- To be able to extend the information currently contained on the IPS to the domains defined on the x-eHealth project: medical imaging, lab results, discharge reports and rare diseases.

- To be able to share this information with other public health systems but also with private healthcare centres is a significant challenge in Catalonia's Public Health System.



Long term challenges

- To include a document viewer tool to visualize the IPS report downloaded by the citizen.
- To include the "upload" functionality on LMS and apps from private sector

Next Steps – xShare project

HORIZON-HLTH-2023-IND-06-02: EXPANDING THE EUROPEAN ELECTRONIC HEALTH RECORD EXCHANGE FORMAT TO IMPROVE INTEROPERABILITY WITHIN THE EUROPEAN HEALTH DATA SPACE

- *36 month project*
- *40 European partners*
- *8 million €*
- *8 pilot sites*

X SHARE: EXPANDING THE EUROPEAN EHRxF TO SHARE AND EFFECTIVELY USE HEALTH DATA WITHIN THE EHDS

The xShare project aims to enable the sharing of citizens' data in the EEHRxF through a button. This xShare button will be available on health portals and patient apps, allowing European citizens to port their data in compliance with GDPR. Furthermore, xShare will contribute to research and innovation within the EHDS. xShare will develop:

1. Harmonized and common requirements and specifications, including FHIR implementation guides, tools, datasets, and educational support for the key domains of EEHRxF.
2. A set of common elements within the health information domains of EEHRxF applicable to EHDS, public/population, and clinical research.
3. A harmonized extension of IPS specifications to include ealth plans, making them usable for research purposes.
4. Adoption of the xShare button in 8 regions, with a special emphasis on three use cases: Data portability, EEHRxF in public health and cross-border threats, and data access for research and the private sector.

Thank you for your attention

Carla Alvarez Costa
Head of Public Funding Programs
calvarez@ticsalutsocial.cat

TIC Salut Social Generalitat de Catalunya