2.1 Discussion on new use cases including patient access to data

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Current scenario: HP access to data

20th eHN Meeting

Pilot project on enabling patient access to their health data

Call for grants to be published in the beginning of November 2021

Deadline for applications in the end of January 2022

Total amount: EUR 2 000 000

A consortium (one) of at least 3 Member States is acceptable.

At least 3 Member States in the consortium must go live with the service offering patient access to translated health data in production.

New feature: Patient access to translated data

Central terminology services

Country B

Health professional

Translated data (vax data, other PS parts, lab results, discharge letters..)

Viewing the data

App or portal A

Patient

Consent for the use of the app, if needed

Country A

NCP-A or a "pre-NCP" (e.g. EU Digital COVID Cert backend)

Data sources, national infrastructure

Consent for eHDSI services, if needed

Main enablers:

- Need to develop a patient portal or app
- Integration between NCP-A and the national/regional patient portal (or app)
- Access to Master Translation Catalogues of countries B, if possible (otherwise translation to English only)

Goals of the pilot project?

- Enable a few pioneer Member States to design and implement the Patient Access service logically linked to MyHealth@EU and launch it **in production**.
- The service has a translation element. The data will be translated at least into English, but translation to other languages is possible too.
- It will allow to explore and address challenges in terms of implementing this new service, making it easier to expand it to other Member States, and to build other similar services in the future.

Links to other developments

- EU Citizens' Vaccination Card
- European Digital Identity Wallets

But also consider:

- Standards for barcode representation of health data (EU DCC, Smart Health Cards, etc)
- Upcoming standards such as FHIR International Patient Access
- InteropEHRate and X-eHealth projects

Possible use cases

EU Citizens' Vaccination Card

- Citizens can access data on their vaccination status (not COVID-19 only) to be sure not to miss key vaccines for themselves or their children, in particular when moving between Member States.
- Citizens can also show their vaccination status to health professionals, in English or another official EU language.
- Vaccination entries may have a validation mechanism (EU DCC integrated in the same app or portal)
- Preferably app, but portal (which can generate a paper format) also possible

Possible use cases

Translated Patient Summary

- A citizen can access their Patient Summary and show it to a health professional in English or in another official EU language
- Potentially, export of parts of data in the form of credentials
- Preferably app, but portal also possible

Possible use cases

Authorisation to access data

- Streamlined access to Patient Summaries, ePrescriptions or other data in scope of MyHealth@EU
- The patient scans a QR code shown by the health professional's software using their app and confirms the right to provide access.
- Similar to current MyHealth@EU, but with right to access provided on the spot (instead of or in addition to consent given upfront), and avoiding the need to enter patient identifiers or other identity/document traits manually.
- App only

Combinations for later: New features and possible extensions, combined with current eHDSI services

Central terminology services

Country B

Health professional

Portal B or alternative system

Translated data (vax data, other PS parts, lab results, discharge letters..)

Transmitting the data

Authorization of access to data through eHDSI

App or portal A

Confirmation for accessing data

Patient

Consent for the use of the app, if needed

Country A

Translated data

NCP-A or a "pre-NCP" (e.g. EU Digital COVID Cert backend)

Data sources, national infrastructure

Consent for eHDSI services, if needed

Main enablers:

- Need to develop a patient portal or app
- Integration between NCP-A and the national/regional patient portal (or app)
- Access to Master Translation Catalogues of countries B, if possible (otherwise translation to English only)
- Implementation of further services as piloted by InteropEHRate

EU citizens' vaccination card

- Already before the COVID-19 pandemic, the European Commission commissioned a feasibility study on an EU citizens' vaccination card.
- The basis for launching this tender:
  - **Council Recommendation on strengthened cooperation against vaccine-preventable diseases from 2018.**
- The study, which will be completed in December 2021, is being carried out via a consortium called Vaccine-EU.
- During its work, Vaccine-EU has taken the work on the EU DCC and the experience gained with this initiative so far into account.

Three pillars of work

Minimalistic

- Easy to use
- Trusty
- Reassuring
- The least involving for the citizens
- The most involving for the health institutions
- Physical format: print out

Collaborative

- Useful
- Guided
- Shareable
- The best involvement of the citizens and of health professionals
- Physical format: leaflet

Autonomous

- Empowering
- Exhaustive
- Grants the citizens the best independence
- Physical format: card

Mapping of form and content of EU 27 (and other) electronic or paper VC

OUPUT: eVC template requirements for testing

Design & large scale testing of three dual templates (78 000 citizens)

OUTPUT: citizens' preferences

Feasibility assessment of an EU eVC (technical, operational, financial, legal dimensions)

OUTPUT: options and recommendations & path to implementation

19th eHealth Network

Reasoning behind the decentralised approach

Reuse existing assets

- Local/ regional Electronic Health Records (EHRs) used by health professionals in vaccination process
- IIS or national EHR deployed by some Member States

Reuse the national e-administration infrastructures and organisations:

- Accreditation and authentication of health professionals
- Authentication of data subjects (direct and indirect)
- Rendering of the information within pre-existing portals

Leverage the now familiar DCC

- Reuse the Digital Covid Certificate common components (DCC Gateway)

To encourage the creation of original offers

- Specific renderings (e.g. graphical timeline instead of events log)
- Population groups' specific repositories (soldiers, sea crew, oil platform personnel, etc.)
- Value added features, such as decision support systems

Proposed technical implementation

The vaccination card is a portable document managed by the data subject (direct for parents, indirect for minors), with three equivalent representations:

- Data at rest: a file in HL7/CDA format
- Activated data: HL7/FHIR Web resources exposed by an active repository
- Paper format: A QR Code reusing the COVID certificate technology

Trust chain for passive data

Reuse of backlog data

Activating the data

- Data are activated by uploading it to an active repository
- The citizen chooses the active repositories he wants to use
- The citizen retains controls on who can view his data through rendering servers
- Rendering servers adapt the presentation of the information for each specific purpose of use
- The presented information can be further personalized after merging with other data sources (such as medical and social characteristics)

Use of activated data

Health professional

Citizen

Service provider

Render to "users"

Purpose specific rendering servers

Interoperability framework

Policy specific clinical decision systems

Based on local vaccination policy
Adapt to individual characteristics

Territorial active repositories

Store and consolidate vaccine administration events
Exchange with systems (EHR, IIS)

Responsibilities

EU	Member States

• Defines the protocols for active repositories
• Creates and operates the pivot terminology server (to harmonize vaccines' representations)
• Extends the use for the DGC certificate gateway
  • Authorized signatures (certification authorities)
  • Serializers prefixes
• Provides compliance test tools (for portability and personal information security)
• Provides reference implementations
	• Offer at least one compliant solution (active repository + renderers)
	• Implement a serializer
	• Accredit their health professionals
	• Enforce compliance of any authorized solution
	
	The active repository could be a pre-existing IIS

Questions to the eHealth Network

- *What use cases the eHealth Network sees as most important for the Patient Access pilot?*
- *How the eHealth Network would like to organise its work in relation with the EU Vaccination Card?*

Questions?

Further information

eHealth Network
https://ec.europa.eu/health/ehealth/policy/network_en

All events
https://ec.europa.eu/health/ehealth/events_en#anchor0

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