

# Childhood Cancer Survivorship Passport Challenges in the European Health Data Space

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# Introduction

Innovation in cancer therapy has increased childhood cancer survival rates.

Childhood cancer survivors (CCSs) are still at risk of developing late effects and are unaware of them.

The treating healthcare providers (HCPs) lack information about care required for CCS

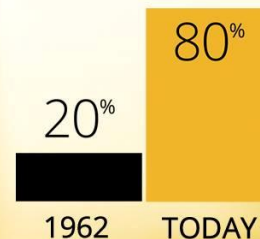
Survivorship Passport (SurPass): an innovative, digital tool to overcome knowledge gaps and to improve person-centred long-term follow-up (LTFU) care



SEPT

Childhood  
Cancer  
Awareness  
Month

Overall Childhood Cancer  
Survival Rates



# Introduction



SurPass (v1.2): manual entry of treatment data entry is time-demanding.



PanCareSurPass (PCSP) project (from 2021) to explore semi-automatic data entry by developing an interoperable version of SurPass (v2.0) and testing the integration with digital health infrastructures in 6 European countries using HL7 FHIR



# Introduction

## Pre-Implementation Study

**Implementation barrier:**  
consistency and  
interoperability lack among  
hospital EHR systems and  
digital health infrastructures

Motivated

**European Health Data Space  
(EHDS) + European EHR  
Exchange Format (EEHRxF):**  
new European digital health  
ecosystem to **facilitate the  
effective use of electronic  
health data for healthcare,  
research and innovation**

**Our study:** to analyse the  
potential impact of the EHDS  
regulation on the SurPass v2.0  
implementation strategy,  
using the Austrian  
implementation as an  
example



# SurPass Toolset



1

**Treatment Summary (TS)**: with description of demographics, cancer type and stage, chemo/radiotherapy cumulative treatment doses (CTD), and surgeries

2

**Survivorship Care Plan (SCP)**: with personalised surveillance recommendations automatically generated by built in algorithms linking the individual treatment history with risk factors identified by international guidelines for follow-up recommendations

3


**Follow-up event form**: allowing the registration of subsequent malignant and non-malignant events

# Methods

- SurPass pre-implementation study → produced general and country-specific recommendations and examples → Technical Implementation Strategy (TIS) for each participating country\*
- Partners are constantly progress monitor of the EHDS, eHealth Network guidelines, and initiatives supporting the EEHRxF, GDPR → IT technical specifications for SurPass v2.0 ensures interoperability, cybersecurity and guides the SurPass implementation in the 6 healthcare systems involved.

\*Countries: Austria, Belgium, Germany, Italy, Lithuania, and Spain

# Results: the PCSP FHIR IG

 **PanCareSurPass Project HL7 FHIR Implementation Guide**  
0.2.0 - CI Build 150

IG Home Table of Contents Functional Description Specifications Maturity Model Artifact Index Support

Table of Contents > PanCareSurPass FHIR IG - Home Page

PanCareSurPass Project HL7 FHIR Implementation Guide, published by PanCareSurPass Project. This guide is not an authorized publication; it is the continuous build for version 0.2.0 built by the FHIR (HL7® FHIR® Standard) CI Build. This version is based on the current content of <https://github.com/hl7-eu/pcsp/> and changes regularly. See the [Directory of published versions](#)

## 1 PanCareSurPass FHIR IG - Home Page

Official URL: <a href="http://hl7.eu/fhir/ig/pcsp/ImplementationGuide/hl7.eu.fhir.pcsp">http://hl7.eu/fhir/ig/pcsp/ImplementationGuide/hl7.eu.fhir.pcsp</a>	Version: <b>0.2.0</b>
Draft as of 2024-05-27	Computable Name: PCSPImplementationGuide

### 1.1 Scope

Specify **HL7 FHIR logical models** and **profiles** to be used within the European project **PanCareSurPass**. This project studies the scale-up and implementation of the digital Survivorship Passport to improve people-centred care for childhood cancer survivors.

### 1.2 The PancareSurPass Project

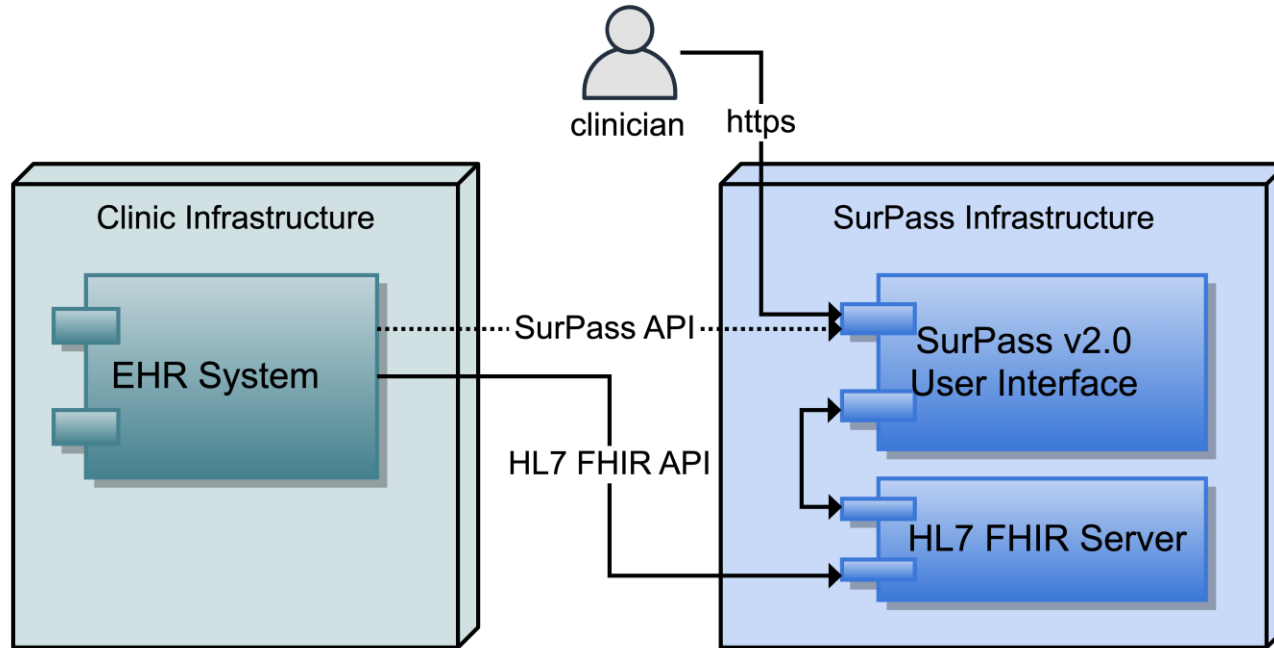
#### 1.2.1 Overview

- Scope
- The PancareSurPass Project
- Dependencies
- Cross Version Analysis
- Global Profiles
- IP statements
- Authors and Contributors

- Key SurPass 2.0 TIS element → guided the implementation incorporating feedback (also from HCPs) → instrument to scale-up adoption of SurPass v2.0 across Europe.

<https://build.fhir.org/ig/hl7-eu/pcsp/>

# Results: the SurPass infrastructure



- The integration of SurPass platform and the EHR system was done to facilitate national/regional capabilities and policies for each state



# Discussion and conclusions

- European context:
  - **Fragmented healthcare systems** with different organization models and implementation speeds
  - EHDS and EEHRxF are emerging to develop a new ecosystem for health data use
- PCSP is addressing how **implementation can be optimized** in different countries.
- Austria's EHR "ELGA" case study for SurPass 2.0 and EHDS implementation
  - **Implementation challenging**: map from CDA format to the FHIR profiles → The PCSP FHIR IG can accelerate SurPass v2.0 adoption across Europe
  - SUPA Bioregistry integration:
    - a model for other member states towards a European-scale late effects registry
    - use case to pioneer efficient transition between primary and secondary use of health data in the EHDS.

# Discussion and conclusions

- PCSP is in-line with the core elements of the provisional agreement on EHDS
  - e.g. informed consent, restricted information access, different measures governing access to sensitive data, data access bodies and trusted data holders
- Economic considerations:
  - implementation costs dependent on the digitization level of the hospital information system
  - standards usage plays a key role to reduce cost and effort
  - The cheapest option in the short term: data not transferred automatically but typed in manually
    - However, a higher digitization level will reduce costs and efforts in the long run

# SurPass Health Data + the Yellow Button

Cross Project Synergies

# SurPass Health Data + the Yellow Button

- The PanCareSurPass digital tool (SurPass) helps childhood cancer survivors manage their long-term care.
  - SurPass (version 2.0) is **interoperability** with Electronic Health Information Systems (EHISs) and Electronic Health Records (EHRs) using **HL7 FHIR**.
- The xSHARE Yellow Button could be a potential **mechanism for individuals using the SurPass system to share their survivorship care plans and treatment summaries with other healthcare providers** or even for their own access through patient portals that have implemented the Yellow Button.

Perfect alignment with the goals of the xSHARE project in **empowering individuals to share their health data easily and securely across different systems in Europe.**

# The Yellow Button



- **Imagine** - Everyone can share their health data in EEHRxF (the format) with a click-of-a-button in the European Health Data Space (EHDS).
- **The xShare button** - The xSHARE button is envisioned as a **simple, one-click solution** to **empower individuals to share their health data** securely and easily across different healthcare systems and services within Europe.
  - AIMS: Make exercising **data portability rights** under **GDPR** straightforward **for citizens**.



# The Yellow Button: One Click to Connected Care



- Through EHDS, “Marco” (patient) shares his digital Survivorship Passport with “Elena” (HCP) —instantly, using the Yellow Button.
- “Elena” reviews his complete treatment history
- Adjusts his follow-up plan based on risk
- Receives alerts for overdue screenings
- Collaborates with other oncologists on complex cases



# The Impact: Better Outcomes – for All



- The Yellow Button empowers clinicians and patients alike.
- Doctors access timely, accurate data
- Patients get coordinated, personalized care
- Improved collaboration across borders
- Elena now delivers care with confidence and support



# Yellow Button Adoption Kits

- We have the technology and are testing it now.
- The question is **How do we ensure these (and other) technologies are actually used?**
  - consistently, securely, and across all corners of Europe?
- That's where **adoption kits** and training come in
- Adoption kits are critical for the **uptake of the technology**





# Adoption Kits – What are they?

Adoption Kits are simple **tutorials** on how to adopt/use the technology each tailored 3 stakeholder groups:

- Patients:
  - **What do they gain** from the European Health Data Space?
  - How they can use the format/data to do things not possible up to now?
  - How can they use the EHDS to **lead healthier lives**?
  - How can they **become empowered** by the EHDS?
- Health Care Professionals:
  - How does this **benefit their patients**?
  - How does this **benefit themselves**?
- IT developers:
  - How can they implement the technologies easily?
  - What **recourses** exist out there?

# 2nd Adoption Kit: for Healthcare Providers

- **Under development now! We need your help!**
- **Click and xShare:**
  - Transforming Health Data Access for Healthcare providers
  - The Yellow Button experience within the European Health Data Space
- It covers:
  - The **European Health Data Space**
  - The **European Electronic Health Record Exchange Format**
  - **How can healthcare providers benefit?**
  - **Practical Use cases**
  - Empowerment stories
  - How to utilize the Yellow Button (#xShareYellowButton)

# Let's Collaborate!

- Contribute to the development of the Adoption Kit for Healthcare providers
  - SurPass (the Survivorship Passport) could be an early adopter or beneficiary of the xSHARE Yellow Button implementation within relevant healthcare interfaces.
    - Data: Treatment Summary, post-treatment data, and other types of key data
  - Review Persona development – ensure real-world relevance
  - Potentially participate in Advisory Council?

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## PanCareSurPass

is an EU-funded project looking at how to more widely implement the SurPass to improve survivorship care for survivors of childhood and adolescent cancer in Europe.

### Late Effects Clinics & Registries



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MAINZ

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### Stakeholder Representatives



PanCare  
SurPass

Scan to see what  
PanCareSurPass  
is about



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# Thanks for your attention!