dHealth 2022
G. Schreier et al. (Eds.)

doi:10.3233/SHTI220363

Factors Influencing Implementation of the Survivorship Passport: The IT Perspective

Catherine CHRONAKI[a,1], Eliana CHARALAMBOUS[a,b], Giorgio CANGIOLI[a], Günter SCHREIER[c], Selina van den OEVER[d], Helena van der PAL[d], Leontien KREMER[d], Anne UYTTEBROECK[e], Bart VAN DEN BOSCH[e], Justas TRINKUNAS[f], Jelena RASCON[f], Ruth LADENSTEIN[g,m], Vanessa DÜSTER[g], Edit BARDI[m,n], Diana WALZ[h], Anna-Liesa FILBERD[i], Desiree GRABOW[i], Thorsten LANGER[j], Adela Cañete NIETO[k], Antonio J. Orduña GALÁN[k], Marisa CORRECHER PALAU[k], Giacomo CAVALCA[l] and Riccardo HAUPT[l]

[a]HL7 Europe, Brussels, Belgium; [b]Venizeleio General Hospital of Heraklion, Heraklion, Greece; [c]AIT Austrian Institute of Technology, Graz, Austria; [d]Princess Maxima Center for Paediatric Oncology, Utrecht, The Netherland; [e]University Hospitals Leuven, Leuven, Belgium; [f]Vilnius University Hospital Santaros Klinikos, Vilnius, Lithuania; [g]Children's Cancer Research Institute, Vienna, Austria; [h]Division Medical Documentation, IMBEI, University Medical Center Mainz, Mainz, Germany; [i]German Childhood Cancer Registry, University Medical Center of the Johannes Gutenberg University Mainz, Mainz, Germany; [j]University of Lübeck, Lübeck, Germany; [k]Fundacion para la Investigacion del Hospital Universitario La Fe De La Comunidad Valenciana, Valencia, Spain; [l]IRCCS, Istituto Giannina Gaslini, Genova, Italy; [m]St Anna Children's Hospital, Vienna, Austria; [n]Department of Paediatrics and Adolescent Medicine, Johannes Kepler University Linz, Kepler University Hospital, Linz, Austria

Abstract. Compared to the general population, childhood cancer survivors represent a vulnerable population as they are at increased risk of developing health problems, known as late effects, resulting in excess morbidity and mortality. The Survivorship Passport aims to capture key health data about the survivors and their treatment, as well as personalized recommendations and a care plan with the aim to support long-term survivorship care. The PanCareSurPass (PCSP) project building on the experience gained in an earlier implementation in Giannina Gaslini Institute, Italy, will implement and rigorously assess an integrated, HL7 FHIR based, implementation of the Survivorship Passport. The six implementation countries, namely Austria, Belgium, Germany, Italy, Lithuania, and Spain, are supported by different national or regional digital health infrastructures and Electronic Medical Record (EMR) systems. Semi structured interviews were carried out to explore potential factors affecting implementation, identify use cases, and coded data that can be semi-automatically transferred from the EMR to SurPass. This paper reflects on findings of these interviews and confirms the need for a multidisciplinary and multi-professional approach towards a sustainable and integrated large-scale implementation of the Survivorship Passport across Europe.

Keywords. International Patient Summary, Paediatric Oncology, Cancer Survivors, Survivorship Passport, Childhood Cancer, Electronic Medical Records, HL7 FHIR.

[1] Corresponding Author Catherine Chronaki, 38-40 Square de Meeus, Brussels, 1000, Belgium, chronaki@HL7europe.org

1 Introduction

The Survivorship Passport (SurPass) is a digital tool based on international clinical guidelines that provides childhood cancer survivors (CCS) and health care professionals (HCPs) with the information needed for long-term follow-up survivorship care, better health promotion, improved late effects management and secondary cancer prevention. The SurPass provides an overview of all relevant personal health data related to the cancer treatment of CCS (e.g., demographics, cancer diagnosis, therapeutic management etc.) in a Treatment Summary together with a personalized Survivorship Care Plan, based on international evidence-based clinical guidelines [1,2,3,4]. PanCareSurPass (https://www.pancaresurpass.eu/) aims to develop and deploy a new version of SurPass (v2.0), which allows for semi-automated data entry by integrating SurPass to EMRs at treatment facilities, regional or national Electronic Health Records (EHRs), and cancer registries. The main SurPass use cases considered are: (a) creation of SurPass from EMR; (b) creation of SurPass from a national cancer registry or from a specific national SurPass Registry; (c) update of SurPass; (d) generation of Care Plan; (e) link SurPass to EMR; (f) publish SurPass to the national/regional EHR.

SurPass v2.0 will be implemented in six European countries (Austria, Belgium, Germany, Italy, Lithuania & Spain) to establish a prediction model for the costs involved. These countries call for different SurPass configurations due to differences in EMR systems and overall health infrastructure organization. To prepare and validate the IT section of the pre-implementation survey, 10 questions were used as the basis of semi-structured interviews that involved both Health and IT professionals in each site.

This paper presents the findings of these interviews, provides a preliminary analysis of barriers and facilitators from an IT perspective, and proposes recommendations for the implementation strategy targeting at the large-scale deployment of the SurPass.

2 Methodology

A questionnaire comprising 10 questions was developed to perform a first exploration of IT barriers and facilitators in the integration of SurPass in the IT infrastructure and clinical practice of each of the six centers. The integration of SurPass in the IT infrastructure involves capturing information from the EHR or respective cancer registry that is necessary to complete the treatment summary section or generate the care plan. Results were obtained through semi structured interviews carried out through teleconferencing. In each interview both IT and health professionals were present.

The interview comprised of three parts: (a) a free flow discussion of SurPass, CCS care, and late effects management, (b) presentation of possible IT solutions, and (c) completion of the IT questionnaire by the interviewers with assistance from the participants. After the interview, the minutes were sent back to the participants for validation. The questions of the interviews addressed topics related to IT support to Late Effects Management and the availability of data sources, the degree to which the relevant data are structured and coded, as well as the terminologies employed. The data elements explicitly mentioned, comprised the CCS's Medical History, Cancer Diagnosis -including laboratory results, imaging and histology reports-, and Therapeutic Management -including chemo-, radio-, immunotherapy, hormonal therapy and/or stem cell/bone marrow transplantation. Additional questions addressed availability of regional and national EHR services, issues of data security and privacy as well as data retention.

3 Results

The discussion during the interviews and the responses obtained about the foreseen way of implementing SurPass in each of the six countries, paints a colorful picture across Europe, characterized by similarities but also differences, as shown Table 1., where we summarize the results from each center interviewed, focusing on the type of information available and coding system in use.

Table 1: Childhood Cancer survivors (CCS), late-effects care, and coding of key elements in the EMR deployed in each of the six centers implementing SurPass in PCSP.

	IGG Italy	CCRI Austria	UZ Leuven Belgium	UzL Germany	VULSK Lithuania	Hu La Fe Spain
EMR Adoption	2015	2010	2008	2009	2015	2012
Average number of CC patients diagnosed per year	120	120	100	30	50	100
Average number of CCS seen per year	350	300	250	100	100	140
Coding						
Comorbidities /Hereditary Syndromes	ICD-9-CM	ICD-10	SNOMED-CT	ICD-10	ICD-10	CIE (ICD-10)
Allergies	Own coding		Own coding			Own coding
Cancer Diagnosis	ICD-9	ICD-10 ICCC-3 ICD-O-3	ICD-10	ICD-10, ICCC-3, ICD-O-3	ICD-10 ICD-O-3	CIE (ICD-10)
Histology	ICD-O-3	ICCC-3 ICD-O-3	CODAP2017	ICD-10, ICCC-3, ICD-O-3	ICD-O-3	SNOMED-CT
Surgical Procedures	ICD-9-CM		Own coding		DRG	CIE (ICD-10)
Medication	ATC	ATC & Austria Codex	ATC		ATC	Own coding

3.1 CCRI, Austria

The Elektronische Gesundheitsakte (ELGA), the National eHealth Infrastructure in Austria, has not finalized implementation of the standardized Patient Summary in HL7 CDA (Clinical Document Architecture) yet. However, the upload/download of respective hospital reports into ELGA is possible. Reporting to the National Cancer registry, operated by Statistik Austria, is a legal requirement and captures information necessary in ICDO-3 and ICCC-3 coding. Lab results and radiology reports may be retrieved partially from health care providers. ICD-10 coding is used for cancer diagnosis and treatment complications, while ICDO-3 and ICCC-3 are used for reporting to Statistik Austria. The Austria Codex is used to reference for Medication. However, automated computation of specific elements of the SurPass, like the cumulative dose of chemotherapy agents, would require considerable resources, given the complexity of the architecture of the whole system. Hence, cumulative dose needs to be calculated manually. The CCRI hosts the unit for Studies and Statistics and Integrated Projects

(S²IRP), which acts as national coordinating clinical trial unit for all childhood and adolescent cancer entities except for brain tumors, which are under the responsibility of two other university sites in Austria. Here is a potential resource to retrieve descriptive core data from clinical trial data bases. In addition, S²IRP acts as a reporter to Statistik Austria on behalf of the St. Anna Children's Hospital. Figure 1 below shows an early design of SUPA (Survivorship Passport in Austria), the implementation architecture for SurPass in Austria with its connection to ELGA, and the forthcoming SUPA Bioregistry.

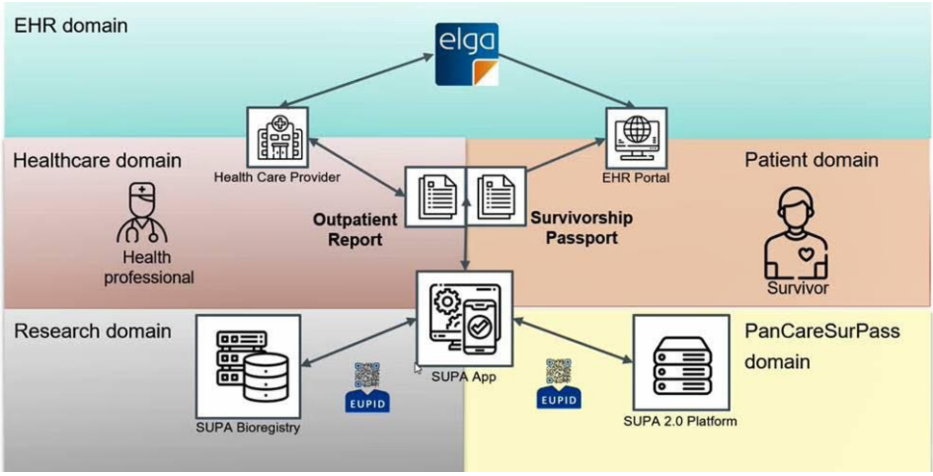

Figure 1: Embedding SurPass in the Austrian environment demonstrates crossovers of the healthcare and research domains facilitated by EUPID [5].

3.2 University Hospitals Leuven, UZ Leuven, Belgium

The EMR system at the University Hospitals Leuven (UZ Leuven) is quite advanced and is the only one of the six centers interviewed that can provide the cumulative dose of antineoplasmatic agents automatically for CCS diagnosed. Radiotherapy type (fraction and site) and cumulative dose are electronically available. The EMR system is also connected to the Belgian National eHealth Network which connects all hospitals in Belgium. The Academic center of KU Leuven is part of a hospital network and detailed clinical data can be shared among member hospitals. Lab results, radiology reports and medical/nursing data are all available, even if retrieving detailed information may be difficult. Hereditary syndromes are coded in Systemized Nomenclature of Medicine Clinical Terms (SNOMED-CT). Cancer diagnosis is encoded using the WHO International Classification of Diseases release 10 (ICD-10) terminology. Internal coding is used for surgical procedures.

3.3 Giannina Gaslini Institute, Italy

An earlier version of SurPass (v1.2) has been deployed, assessed, and validated as part of a clinical trial in Gaslini. However, SurPass v1.2 was not integrated to the hospital EMR and creating SurPass is time consuming. There are plans to interconnect Gaslini with the Regional eHealth network as part of PCSP. Although SurPass v1.2 uses the International Classification of Diseases for Oncology (ICD-O-3) for cancer diagnosis and histological diagnoses, the EHR of the hospital uses ICD-9 for codification of cancer

diagnosis and surgical procedures. For the cancer laboratory tests, their own codifications are used. For medications, they use WHO's Anatomical Therapeutic Chemical (ATC) Coding.

3.4 Hu La Fe, Spain

The Spanish health system is organized based on autonomous regions, with regional governments that have developed their system. Hu La Fe belongs to the region of Valencia and all Hospital EMRs in the region are connected. The coding of childhood cancer diagnoses and procedures uses ICD-10. For histology reports the SNOMED-CT terminology is used, and the other information systems of Pharmaceuticals, Laboratories and Radiology are coded with their own custom systems. Clinical data can be shared/visualized with primary care centers and other hospitals in the region.

3.5 Vilnius University Hospital Santaros Klinikos (VULSK), Lithuania

VULSK are the major hospitals for paediatric cancer in Lithuania. The in-house developed hospital information system (SANTA-HIS) at VULSK is supported by more than 30 IT specialists and integrates EMR, laboratory, picture archiving and communication system (PACS), staff and resource management, document management, quality management system, adverse events system and many other systems that are necessary for effective health care services. SANTA-HIS system is integrated with Lithuanian national health information which electronically stores medical records of each resident of Lithuania and integrates all internal information systems of healthcare institutions into a single unified system. Most of the data elements required to assemble SurPass are readily available: cancer diagnosis and lab results use well-known terminologies. Diagnostic imaging reports and treatment summary for CCS are also available. The coding system in use for cancer diagnosis and hereditary syndromes is the ICD-10. ICD-O-3 is used for histology reports. For surgical procedures, the Australian Diagnostic Related Groups (DRGs) System based on ICD-10 is used. At VULSK, while drug order, delivery, shipment, out-patient prescription are all electronic, on the ward patient prescriptions are still in paper. Thus, cumulative doses of chemotherapy agents need to be calculated manually.

3.6 National German Childhood Cancer Registry, Mainz, and University Hospital Schleswig-Holstein, UKSH Lübeck

All incident childhood and adolescent cancer cases below the age of 18 years at diagnosis are centrally registered at the German Childhood Cancer Registry (GCCR) at University Medical Center Mainz (UMC-Mainz). The Cancer Diagnosis is encoded using ICD-10, ICD-O-3, ICCC-3. By centrally contacting the former patients, the GCCR established a structure for long-term surveillance in Germany. The UKSH, Campus Lübeck, under the lead of Prof. Dr. T. Langer, assembled about 10 interdisciplinary working late-effects clinics, which aim at establishing late-effects care for survivors following international guidelines and recommendations. UKSH, Campus Lübeck works closely with the German Childhood Cancer Registry at UMC-Mainz.

The aim of this interdisciplinary network of late effects clinics and the GCCR is to improve patient-centered care and linking national and international late effects data and standards of care. The central implementation of the SurPass will be at UMC-Mainz. In

this way, potential linkage with clinical data coming from treating clinics, long-term care clinics, and clinical trials paves the way towards providing SurPass to all CCS.

4 Discussion

The interviews identified recurrent themes that point to several barriers and facilitators to scaling-up implementation of SurPass v2.0 in each of the participating countries.

4.1 Awareness of the SurPass Platform and its functionality

Among the six countries, only Gaslini Institute in Genova, Italy had experience from implementing a previous version of the SurPass, SurPass v1.2 [1]. However, SurPass v1.2 was not integrated to the hospital EMR, and its creation was quite time-consuming. Cancer specialists in some of the other centers had experience with the survivorship passport as a paper booklet piloted in the University Hospitals Leuven (Belgium) [4], or as an end of treatment report in MS Word i.e., HULAFE (Spain), or as a report in the EMR system of the hospital, i.e., VULSK (Lithuania). However, IT-specialists in the IT departments, e.g., Gaslini, were mostly unaware what the SurPass requirements for integration to the EMR were. They also did not know how SurPass supports the CCS care pathway. In fact, this was a recurrent theme, as the interviews conveyed that in most cases IT professionals at the hospital sites were not aware what implementing SurPass or connecting it to the national / regional eHealth infrastructure meant for health professionals and patients.

4.2 Access to Clinical Information Sources, CCS registries, and National EHRs

The semi-automated creation of SurPass in its digital form, requires pulling data from multiple clinical information sources and making it available as part of regional, national, and eventually European EHR infrastructures. However, in most centers, IT-specialists were not aware of the process required to interconnect local systems to national or regional health records. This was the case of Gaslini (Italy). In CCRI (Austria) there is the possibility to upload documents to ELGA, but the process of generating these documents may be time consuming. In contrast, Germany, where the implementation involves the national German Childhood Cancer Registry, connection appears easier. For example, only University Hospitals Leuven (Belgium) are able to retrieve data to automatically compute the cumulative dose of chemotherapy agents and this is possible only for CCS diagnosed after 2008. In some countries it is possible to publish reports from the EMR system to the National or regional eHealth infrastructure e.g., Fascicolo Sanitario Electronico, in Italy or ELGA in Austria. However, the process of publishing new types of reports is typically very long, resource intensive and bureaucratic with numerous stakeholders being involved.

4.3 Health data reconciliation and overall integration

Moreover, in the end, to support late-effects care coordination and reconciliation among multiple institutions that store medical information concerning CCS is necessary. For example, in the case of Germany, the German Childhood Cancer Registry and the Academic late -effects Database in Lübeck provide partly overlapping information on

CCS of relevance to SurPass. This means that data need to be reconciled. A problem arises because of different disease, surgical procedure or imaging diagnosis coding systems employed in centers within and across countries (see Table 1). This is, actually a problem that may exist in centers within the country, region, and even in departments of the same center. Respondents from all institutions highlighted the need for more resources, i.e., funding, personnel, IT knowledge among HCPs and IT support to scale-up SurPass, lowering the amount of time required to create and/or update SurPass.

4.4 Use of standard interfaces, structured data, and terminology

Well-defined structured data in the clinical information system sources, coupled with the use of standard terminologies i.e., LOINC and standard Application Programming Interfaces (API) interfaces, such as HL7 FHIR, can be facilitators in the implementation of SurPass. IT-specialists in Spain and Belgium reported as a barrier to the efficient and effective implementation of SurPass v2.0, the absence of API to access, enter or update information, or to access the appointment scheduling system, as well as the absence of interconnection to imaging or laboratory departments. The European EHRxF and the HL7 FHIR International Patient Summary are expected to provide standard interoperable and reusable components to reduce the cost of scaling up implementation of SurPass in its digital form. Table 2 below, shows standards and interoperability frameworks in each country that can be support the implementation of SurPass v2.0.

Table 2: Standards and Interoperability Frameworks available in each country or center.

Standards	IGG Italy	CCRI/SAK Austria	UZ Leuven Belgium	UzL & GCCR Germany	VULSK Lithuania	HULAFE Spain
HL7 version 2	X	X	X	X		X
HL7 version 3	X		X			
HL7 FHIR	X		X	X	X	
HL7 CDA	X	X	X			
IHE profiles	X	X				
KMEHR (Belgian EHR Exchange)			X			

4.5 Recommendations

Even though knowledge of interoperability standards, and HL7 FHIR in particular, is high among the people interviewed, deployment of SurPass is not straightforward. Some concrete recommendations to the follow-up actions of the project in the context of its implementation strategy and more focused pre-implementation actions are as follows:

Recommendation #1: IT-Specialists in the target institutions and of National Health Systems need to familiarize themselves with the concept of the SurPass and the implementation options for their center, discussing details and observing workflows.

Recommendation #2: IT-Specialists responsible for the health information systems in the hospital receive training in connecting to national/regional health infrastructures, services offered, and associated standards.

Recommendation #3: The PCSP consortium should invest in promoting awareness of the impact of the SurPass in the long-term wellbeing of CCS among HCP, hospital management, patient and IT-specialist community of each center and beyond. This could

create incentives for the HCPs to get involved in the implementation of SurPass and for the managers to be willing to find the resources needed.

These recommendations apply not only to the large-scale implementation of SurPass, but also can help make digital health interventions available as part of the daily medical practice. We expect that these recommendations will be further explored in the Open Space meetings planned in the project early in 2022.

5 Conclusions

These semi-structured interviews provide insights into the local contexts for implementing the SurPass v2.0 in Austria, Belgium, Germany, Italy, Lithuania and Spain. Findings from the interviews have been integrated into barrier and facilitators assessments in the pre-implementation survey and the Open Space meetings to follow in each of the partner clinics. Ultimately, the results of the follow-up online survey study and the future results of the Open Space meetings will be used to develop a report with country-specific overviews to elaborate the SurPass Implementation Strategy.

Acknowledgements

PanCareSurPass has received funding from EU's Horizon 2020 R&I programme under GA No 899999. The material presented and views expressed here are the responsibilities of the author(s) only. The European Commission takes no responsibility for any use made of the information set out. We would like to thank all the members of the PanCareSurPass consortium for their contribution and commitment to the vision of SurPass. We thank Kylie O'Brien from Pintail Services Limited, for her pivotal management and coordination work throughout the entire PanCareSurPass project.

References

[1] Haupt, Riccardo, Essiaf, Samira, Dellacasa, Chiara, et al (2018). The 'Survivorship Passport' for childhood cancer survivors. *Eur J Cancer. 102. 69-81. 10.1016/j.ejca.2018.07.006.*

[2] Michel G, Mulder RL, van der Pal H, et al. (2019) Evidence-based recommendations for the organization of long-term follow-up care for childhood and adolescent cancer survivors: a report from the PanCareSurFup Guidelines Working Group. *J of Cancer Survivorship (2019) 13:759–772*

[3] Kremer LC, Mulder RL, Oeffinger KC et al. (2013). A worldwide collaboration to harmonize guidelines for the long-term follow-up of childhood and young adult cancer survivors: a report from the International Late Effects of Childhood Cancer GHWG. *Paediatric blood & cancer. 2013;60(4):543-9.*

[4] van Kalsbeek RJ, van der Pal H, Kremer LC et al. (2021). European PanCareFollowUp recommendation for surveillance of late effects of childhood, adolescent, young adult cancer. *Eur J Cancer 2021 Sep;154:316-328.*

[5] Nitzlnader M and Schreier G. Patient Identity Management for Secondary Use of Biomedical Research Data in a Distributed Computing Environment, eHealth2014: Health Informatics Meets eHealth, 211-9.