Barriers and facilitators to implementation of the interoperable Survivorship Passport (SurPass) v2.0 in 6 European countries: a PanCareSurPass online survey study

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Abbreviations

CCS	Childhood cancer survivor
HCP	Healthcare professional
LTFU	Long-term follow-up
PCFU	PanCareFollowUp
PCSP	PanCareSurPass
SCP	Survivorship care plan
SurPass	Survivorship Passport
TS	Treatment summary

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SUMMARY

PURPOSE Long-term follow-up (LTFU) care for childhood cancer survivors (CCSs) is essential to improve and maintain their quality of life. The Survivorship Passport (SurPass) is a digital tool which can aid in the delivery of adequate LTFU care. During the European PanCareSurPass (PCSP) project, the SurPass v2.0 will be implemented and evaluated at six LTFU care clinics in Austria, Belgium, Germany, Italy, Lithuania and Spain. We aimed to identify barriers and facilitators to the implementation of the SurPass v2.0 with regard to the care process as well as ethical, legal, social, and economical aspects.

METHODS An online, semi-structured survey was distributed to 75 stakeholders (LTFU care providers, LTFU care program managers and CCSs) affiliated with one of the six centres. Barriers and facilitators identified in four centres or more were defined as main contextual factors influencing implementation of SurPass v2.0.

RESULTS 54 barriers and 50 facilitators were identified. Among main barriers were a lack of time and (financial) resources, gaps in knowledge concerning ethical and legal issues and a potential increase in health-related anxiety in CCSs upon receiving a SurPass. Main facilitators included institutions' access to electronic medical records, as well as previous experience with SurPass or similar tools.

CONCLUSIONS We provided an overview of contextual factors that may influence SurPass implementation. Solutions should be found to overcome barriers and ensure effective implementation of SurPass v2.0 into routine clinical care.

IMPLICATIONS FOR CANCER SURVIVORS These findings will be used to inform on an implementation strategy tailored for the six centres.

INTRODUCTION

Due to advances in therapeutic regimens and care, 5-year survival rates for childhood cancer have increased to over 80% in high income countries [1]. In fact, Europe currently counts over 500,000 childhood cancer survivors (CCSs) and this population is expanding by 8000-10,000 new CCSs each year [2]. Although crucial for survival, childhood cancer treatments can cause a wide variety of adverse effects. Most disappear soon after treatment ends, but some adverse effects persist or only develop many years later (late effects). Late effects may include physical health problems such as chronic fatigue, impaired fertility, neurological deficits, organ dysfunction and subsequent malignancies, yet CCSs' medical history can also gravely impact emotional well-being and even socio-economic status [3-12].

All in all, late effects of cancer treatment may cause quality of life of CCSs to be severely compromised. To improve quality of life, adequate long-term follow-up (LTFU) care that addresses CCSs' personal health needs is essential (13). According to expert opinion, high-quality LTFU care is person-centred and based on evidence-based guidelines for prevention, surveillance, and treatment of late effects. In addition, it has a strong focus on education of CCSs and their families to allow for more effective self-management, and thus further health promotion. Other important components of adequate LTFU care include a treatment summary (TS) and personalised survivorship care plan (SCP), which can increase knowledge on late effects in both healthcare professionals (HCPs) and CCSs and may support compliance with surveillance recommendations [14, 15].

Although the importance of LTFU care for CCSs has been repeatedly emphasised in scientific literature, well-organised LTFU programs are often lacking, resulting in big healthcare access disparities among CCSs, both within countries and across Europe [16]. To overcome these disparities and guide implementation of high-quality LTFU care, the Survivorship Passport (SurPass) was developed [17]. The SurPass tool includes all components needed for life-long LTFU care: 1) a TS, 2) a personalised SCP based on evidence-based guidelines and 3) comprehensive plain language information for CCSs and their families. Based on the medical information entered in the TS, built-in algorithms trigger relevant recommendations for follow-up care. These

recommendations form the basis of the personalised SCP, which HCPs can approve or modify according to CCSs' personal needs and circumstances.

To help guide paediatric cancer institutions in setting up comprehensive LTFU care programs, as well as to gain more knowledge on the feasibility and effectiveness of implementing person-centred survivorship care, the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare) (www.pancare.eu) established the Horizon 2020-funded PanCareFollowUp project (www.pancarefollowup.eu) [18]. As part of this ongoing project, the SurPass' potential to improve LTFU care for CCSs is being investigated in greater depth. So far, one important barrier for implementation of the SurPass (v1.2) in routine clinical care has been the manual entry of treatment data, which on average takes 1.5 hour for an individual CCS [17]. To overcome this barrier and significantly reduce preparation time, a new, interoperable version of the SurPass (v2.0) is being developed. This interoperable SurPass aims at semi-automated data input by connecting the SurPass to electronic health information systems and cancer registries using the Data Exchange Standard HL7 FHIR.

During another, recently established, Horizon 2020-funded project named PanCareSurPass (PCSP) (www.pancaresurpass.eu), this new, interoperable version of the SurPass will be optimised, implemented and tested in paediatric cancer institutions from six European countries: Istituto Giannina Gaslini (IGG, Italy), St. Anna Kinderspital & St. Anna Kinderkrebsforschung (SAK-CCRI, Austria), Katholieke Universiteit Leuven (KU Leuven, Belgium), Universitaet zu Luebeck (UzL, Germany), Viesoji Istaiga Vilniaus Universiteto Ligonine Santaros Klinikos (VULSK, Lithuania) and Instituto de Investigación Sanitaria La Fe – Hospital Universitario y Politécnico La Fe (IISLaFe – HUyPLaFe, Spain). To inform on an implementation strategy for each of these institutions, an online, semi-structured survey study was designed. The aim of this survey study was to identify barriers and facilitators to the implementation of SurPass v2.0 in the aforementioned countries with regard to several action fields, namely the care process and its ethical, legal, social, and economical (ELSE) aspects (derived from Carroll's corporate social responsibility pyramid) [19].

METHODS

Survey design

In preparation of survey development, contextual factors that are known to influence implementation of LTFU care were investigated by extracting information from pre-existing literature, as well as from a recently updated systematic review [14, 20], and a consortium-wide focus group discussion. Subsequently, three comprehensive online surveys were developed addressing different stakeholder categories, namely HCPs, LTFU care program managers and CCSs (see Online Resource 1).

In each of the surveys, we first inquired about characteristics of the individual respondent, as well as the LTFU services offered at each institution to gain insight in their current comprehensiveness and complexity. Subsequent questions focused on identifying potential barriers and facilitators to implementation of the SurPass regarding the care process (e.g., staff involved in the delivery of LTFU care and time dedicated to each consultation) and ELSE aspects (e.g., data access by insurance providers and SurPass' cost-effectiveness). While HCPs were asked in more detail about the care process, the survey for LTFU care program managers had a strong focus on legal and economical barriers and facilitators to SurPass implementation. In the survey for CCSs, we mainly solicited their personal preferences and objections.

Survey procedures

From the six participating institutions, representatives informed on ethical requirements for survey research in their centre. Ethical review board or institutional approvals were required and obtained in Belgium, Italy, Germany and Spain. Institutional approval for pseudonymised data collection, analysis and storage was granted by the Princess Máxima Center, the Netherlands.

Survey participants from the three different stakeholder categories were identified and invited by centre representatives. For this online survey study, we decided to limit eligibility to stakeholders connected to the six participating institutions. PCSP consortium members fitting these eligibility criteria were invited to take part in this survey study.

Upon survey distribution and data collection, we made use of the cloud-based clinical data management platform Castor Electronic Data Capture (Castor EDC), an online survey tool which complies with all General

Data Protection Regulations. Participants with insufficient knowledge of the English language were offered language assistance on site. The surveys were launched on August 16, 2021 and responses were collected until October 4, 2021.

Data analysis

Pseudonymised survey data were exported from Castor EDC and processed and analysed using the statistical software SPSS (version 25.0. Armonk, NY: IBM Corporation). Data were analysed separately for each institution and stakeholder category. Responses describing LTFU program characteristics were verified by centre representatives within the PCSP consortium.

Primarily, data were analysed at the individual respondent level and results were entered into 18 comprehensive tables (six centres x three surveys). Subsequently, responses were analysed at stakeholder level, separately for each of the six institutions. When responses were contradictory (e.g., one manager answered that they had sufficient financial resources available, and two managers said otherwise), we decided in favor of the majority, namely that financial resources were lacking, which was then classified as a barrier. When tied, we decided the matter was still uncertain and also categorised this as a (knowledge) barrier. For a few questions, the responses from different stakeholder categories were compiled and analysed as a whole.

Making use of thematic analysis, a qualitative research technique, we arranged each of the identified barriers and facilitators according to their action field, grouped similar barriers and facilitators together and created subthemes [21]. Lastly, we created two figures that provide a quick overview of barriers and facilitating factors relevant to SurPass v2.0 implementation. Barriers and facilitators that were present in four centres or more were defined as main influencing factors.

RESULTS

In total, the surveys were disseminated to 75 stakeholders, including 29 HCPs, 18 LTFU care program managers and 28 CCSs. 54 stakeholders (20 HCPs, 13 managers and 21 CCSs) responded to the survey, resulting in an overall response rate of 72%. In each centre, at least one response for each stakeholder

category was collected. The number of invited and responding stakeholders and respective response rates per institution are shown in Supplementary Table 1 (Online Resource 2). From here onwards, individual centres (IGG (Italy), SAK-CCRI (Austria), KU Leuven (Belgium), UzL (Germany), VULSK (Lithuania) and IISLaFe – HUyPLaFe (Spain)) will be referred to by their country name.

Survey participants

The majority of responding HCPs were trained paediatric oncologists or haematologists (*n*=14) and their experience in LTFU care was rather diverse (Table 1). Among those fulfilling the role of LTFU care program manager were 9 care providers (paediatric oncologist or haematologist *n*=4, other care provider *n*=5), 2 assistant managers, 1 project manager, and 1 deputy medical director. 9/13 responding managers had over 10 years of experience in LTFU care management (Table 2). The CCSs participating in this study had been receiving LTFU care for less than 5 years (*n*=8), 5-10 years (*n*=4) and over 10 years (*n*=6). For four CCSs, it was unclear for how long they had received LTFU care prior to this study. Only 3/6 CCSs receiving LTFU care in Italy had ever received a SurPass before, namely the previous version of SurPass (v1.2) that was implemented during the PCFU project (Table 3).

Participating institutions

The average reported number of CCSs having an in-person consultation at the LTFU care clinic each year varied per institution with 500 CCSs seen in Italy, 130 in Austria, 350 in Belgium, 125 in Germany, 100 in Lithuania and 120 in Spain (Table 4). At each of the six paediatric cancer institutions, one or more HCPs confirmed to deliver survivorship care to all CCSs, independent of their cancer diagnosis and treatment. In Italy, Austria, Belgium and Germany, LTFU care was reported to be available throughout CCSs' entire lifespan, whereas in Lithuania LTFU care was only offered until 5 years after diagnosis. In Spain, LTFU care was provided for a certain time period since cancer diagnosis and/or treatment, or until the CCS reaches a certain age. Here, the exact duration for which LTFU care was available differed per HCP. When LTFU care was no longer provided, CCSs treated in Lithuania and Spain were able to receive care from their local general practitioner.

The array of (medical) specialties involved in the delivery of LTFU care can be used as an indicator of a LTFU care program's complexity. In addition to this, having integrated components such as surveillance and/or treatment of late effects, education of CCSs and the use of a TS and SCP adds to the comprehensiveness of LTFU care. Based on these criteria, LTFU care programs in Italy, Austria, Germany and Spain were reported to be most advanced, which may in turn facilitate more efficient and effective implementation of the SurPass at these institutions.

Contextual factors impacting SurPass v2.0 implementation

Perceived barriers and facilitators to the implementation of the SurPass v2.0 identified by this online survey are shown in Figures 1A and 1B. More detailed overviews of stakeholders' responses per institution are shown in Supplementary Table 2 (Online Resource 2).

The care process

Within our first action field of interest, namely the care process, lack of time was identified as a potential barrier to implementation of the SurPass into routine clinical care. When inquired about the amount of time that will be needed to get the SurPass v2.0 fully up and running, LTFU care program managers from 4/6 centres were unable to make a good estimation. In Lithuania, managers estimated that the implementation process will take 5-6 months or longer. Moreover, after implementation of the interoperable tool has been completed, an ongoing time investment will be required from LTFU care staff, in particular to prepare and update the SurPass for each CCS individually. In Belgium, Germany and Lithuania, ≥50% of HCPs were willing to invest up to 30 minutes preparing a SurPass for an individual CCS. To update an existing SurPass, ≥50% of HCPs from Italy, Austria, Belgium and Germany were prepared to spend a maximum of 15 minutes. On the other hand, LTFU care program managers from 5/6 institutions were, all staff combined, willing to invest 60 minutes or more to prepare for each individual consultation. In addition, HCPs from each of the six institutions reported to have sufficient time (≥30 minutes) allocated for the actual consultation, during which the SurPass can be explained and discussed with the CCS.

Other contextual factors that will likely facilitate SurPass implementation included 5/6 institutions having a wide array of medical specialties involved in the delivery of LTFU care, as well as the vast majority (80%) of stakeholders being convinced of SurPass' added value. Likewise, CCSs from each of the six centres expected to feel more informed about late effects and LTFU care upon receiving a SurPass. Interoperability between the SurPass and existing health records will be facilitated by each of the institutions having access to electronic health records and one or more childhood cancer registries. In addition, 4/6 institutions reported the presence of a national or regional LTFU care program and all confirmed active collaboration with (a) patient organisation(s). HCPs from Austria, Belgium, Germany and Spain confirmed previous experience with tools similar to SurPass (e.g., locally defined treatment summaries and survivorship care plans) while an earlier version (SurPass v1.2) had already been implemented in Italy. Components of LTFU care such as screening for relapse and subsequent malignancies, as well as late effects surveillance and treatment had already been integrated to some extent at each of the participating institutions, although not in a uniform way.

Ethical and legal aspects

1/3 CCSs who had already received an earlier version of the SurPass in Italy reported a moderate increase in anxiety upon receiving the survivorship care plan. From the remaining CCSs participating in this study, 11/25 (44%) expressed that receiving a SurPass might make them feel (≥slightly) more anxious about their health. That said, HCPs and LTFU care program managers from 3/6 participating institutions failed to mention proper anxiety mitigation strategies when inquired about this topic. In addition to this potential ethical barrier, a number of knowledge gaps were identified within the ethical and legal action fields. For example, when asked about the personnel who will gain access to SurPass data upon implementation, HCPs from the same centre responded inconsistently naming different types of staff members. Simultaneously, stakeholders from 4/6 centres were uncertain whether healthcare and/or life risk insurance providers are allowed to access SurPass data, thereby gaining information that could potentially influence CCSs' insurance coverage. Moreover, while CCSs from Germany, Lithuania and Spain reported to object to receiving a SurPass if they cannot decide for themselves what information is shared in their SurPass, HCPs and/or LTFU care program managers from

these institutions were unsure about the feasibility of letting each individual CCS have a say. Other knowledge gaps that surfaced concerned the minimum storage time of SurPass data, whether storage of patient data on the SurPass platform, hosted in the Cineca data centre in Italy, is legally allowed, and which parties should provide their consent upon implementation of the interoperable SurPass tool at the respective outpatient clinics.

One important ethical and legal facilitating factor was proper SurPass data protection; HCPs from Italy, Austria and Spain and managers from Austria, Germany and Spain were confident in saying that this can be guaranteed at their institution. In addition, provided that the CCS gives informed consent, secondary use of SurPass data for research purposes is allowed in each of the six centres.

Social aspects

Few social issues were identified that could hamper SurPass implementation at the six participating institutions, yet our results rendered some social facilitating factors. At time of evaluation, 76% of responding CCSs did not feel discriminated or disadvantaged due to their childhood cancer history and none expected that receiving a SurPass would change this. In addition, the vast majority of managers expressed reluctance to ask CCSs to pay an extra monetary contribution. Consequently, the SurPass is likely to become equally accessible to all CCSs regardless of their financial status.

Economical aspects

A lack of financial resource availability in each of the six centres could hinder effective implementation and continued use of the interoperable SurPass tool. LTFU care program managers from Italy, Austria, Lithuania and Spain expressed that their institution will likely need additional financial resources, while managers from Belgium and Germany were still uncertain whether the funds available will be sufficient. Despite a foreseen lack of financial resources, LTFU care program managers from Austria, Belgium, Germany, Lithuania and Spain responded that they are unlikely to receive additional funding from external parties.

Where other, non-monetary resources are concerned, managers from Italy, Germany and Lithuania replied that they have sufficient staff, time and knowledge available to successfully implement the interoperable

SurPass at their institution. Even though a lack of funds could impact effective implementation of SurPass, LTFU care program managers from Italy, Austria and Spain were positive that, in the long run, implementation of the digital tool could be (at least somewhat) cost-effective. Managers from Belgium, Germany and Lithuania remained unsure whether SurPass' benefits will turn out to outweigh the costs.

DISCUSSION

By means of an online survey distributed to HCPs, LTFU care program managers and CCSs, we identified and assessed contextual factors that may hamper or facilitate the implementation of the interoperable SurPass at each of the six centres participating in the PCSP project. Main barriers included a lack of time of HCPs and (financial) resources, as well as a (potential) increase in anxiety in CCSs upon receiving their individual SurPass. In addition, important knowledge gaps were identified within ethical and legal action fields, such as which parties will gain access to SurPass data and whether data storage on the SurPass platform maintained in Italy is legally allowed. Main contextual factors that will likely facilitate SurPass implementation included each institution having access to electronic medical records, stakeholders' convictions of SurPass' added value to LTFU care programs and previous experience with SurPass or other treatment summaries and SCPs.

Primarily, the amount of time needed to prepare and update the SurPass v2.0 will depend on the level of interconnection that can be established between the SurPass and existing databases and Electronic Health Record systems, as well as the electronic availability of relevant medical records. Each of the participating institutions' electronic availability of medical data, their computing infrastructure and the level of interoperability that can be achieved has been assessed by de Beijer et al. [22].

For previous versions of the SurPass, where diagnosis and treatment data had to be entered manually, the preparation time for one individual SurPass averaged 1.5 hour [17]. Based on earlier pilot testing of interoperability between databases of already closed leukemia protocols and the SurPass, the preparation time for a standard risk leukaemia survivor is estimated to be 30 minutes [17]. Yet for some CCSs, in particular those with a more complex medical history or paper-based medical records, creating a SurPass will remain more time consuming. In Belgium, Germany and Lithuania, ≥50% of HCPs that participated in this survey

study were willing (or able) to spend up to 30 minutes preparing the SurPass, meaning that HCPs' lack of time could hamper implementation and continued use of SurPass v2.0 at these institutions.

In accordance with our own findings, pre-existing literature describes the lack of time and resources as a recurrent challenge affecting SCP implementation. In 2013, Dulko and colleagues evaluated the process of SCP completion and surveyed oncology staff and primary care physicians about the barriers to implementing SCPs. These included the amount of time required by oncology staff to obtain the information for SCPs, as well as insufficient knowledge of cancer survivorship [23]. Thereafter, more studies corroborated the preparation of SCPs to be labour intensive, with the estimated amount of time invested by medical staff ranging from 1-4 hours [24-27]. To overcome these barriers and increase feasibility and cost-effectiveness of the SurPass, a significant reduction of the time investment required by medical staff is crucial. While aiming to achieve the highest possible level of interoperability at each of the six participating institutions, outsourcing SurPass data management (e.g., retrieving missing treatment data) to experienced data managers may be an additional solution to alleviate HCPs' workload.

Naturally, in order to hire additional staff, sufficient monetary resources are a prerequisite. Yet the results from this online survey show that there is a need for financial support to implement the interoperable SurPass. LTFU care program managers from each of the PCSP centres were in agreement that CCSs should not be asked to pay a monetary contribution upon receiving a SurPass, which might inadvertently worsen LTFU care access disparities. Nonetheless, they also deemed it unlikely that they would receive financial support from external parties such as patient organisations. Accordingly, possible reimbursement options for CCSs or other ways to acquire additional funding should be further investigated.

Although SCPs aim to increase health-related quality of life of CCSs and their families, we should also consider their potential negative impact on emotional wellbeing. Indeed, about half of the CCSs that participated in this study related a potential increase in anxiety upon receiving a SCP. This is not unthinkable, as a SCP informs CCSs on the (often various) health problems they may face due to their childhood cancer history. Findings from earlier studies confirm that SCPs can have a substantial emotional impact in (adult) cancer survivors, although a meta-analysis on SCPs and (adult) cancer survivors' patient-reported anxiety showed no significant net effect [28-30]. Possibly, while a SCP increases anxiety in some CCSs, it may also relieve it in

others. Still, as CCSs are often more susceptible to health-related anxiety, the SurPass needs to be adequately explained and discussed during the LTFU care consultation. In addition, SurPass v2.0 should be embedded in a robust psychological support program.

While this study corroborates some known barriers to SCP implementation, we also present novel findings, in particular a wide array of potential ethical and legal concerns. Most noteworthy, one of the proposed PCSP implementation approaches, where medical data needs to be shared with the SurPass platform, hosted in the Cineca data centre in Italy, may not be legally justified. Alternative strategies could be to make use of the future European Health Data Space, of which development was initiated by the European Commission in May 2022 to facilitate cross-border exchange of electronic health data, or to create on-premise clouds owned by the institutes, where a duplicate of the SurPass platform can be hosted and managed by the institutions' IT-departments [31]. Nevertheless, while on-premise clouds offer the highest degree of data security, there are also disadvantages, such as a higher commitment of local IT-specialists to maintain and upgrade the hardware and software. Most importantly, institutions need to make clear and deliberate decisions about SurPass data access, storage and protection. Subsequently, these decisions – and their consequences – need to be communicated towards CCSs and their families, so that they can make an informed decision about whether they would like to receive a SurPass.

A major strength of this study is the centre-specific approach by which barriers and facilitators to adoption of the SurPass care model were assessed. Namely, contextual factors that exist in one paediatric cancer institution do not necessarily exist in another, even when situated within the same country. Another strength is the involvement of different types of stakeholders, namely HCPs, management staff and CCSs, thereby creating a more complete and comprehensive overview of remaining knowledge gaps and concerns. Engaging these stakeholders in the pre-implementation phase will likely also expedite the actual implementation process. In addition, with an overall response rate of 72% and response rates for the individual stakeholder categories ranging from 69-75%, we believe this survey study to be representative of HCPs and management staff that will be involved in the implementation of the SurPass v2.0 into their LTFU care programs. Nevertheless, since the total CCS population is in fact much larger than the sample included

in our study, we are aware that CCSs might be underrepresented. Therefore, CCSs' views on potential barriers and facilitators for SurPass v2.0 implementation will be investigated in more depth in a future study.

This study also has limitations. Most importantly, as the explorative character of survey research is somewhat limited, it is possible that we missed some hampering and facilitating factors that are relevant to SurPass v2.0 implementation. In addition, although our study provides insight into the most prevalent contextual factors that are likely to influence SurPass implementation, our findings cannot be directly extrapolated to other centres outside the PCSP project. To help guide other paediatric cancer institutions and share the knowledge and experience obtained from SurPass v2.0 implementation, a replication manual will be developed and freely disseminated after the PCSP project ends.

In this paper, we presented findings from an online survey study that assessed barriers and facilitators to SurPass v2.0 implementation at the six institutions participating in the European PCSP project. These findings will be used to inform the implementation strategy for each of these institutions, thereby ensuring more effective implementation of the interoperable SurPass tool.

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Statements and declarations

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Competing interests

The authors have no competing interests to disclose.

Author contributions

All authors contributed to the conception and design of this study and design of the surveys. Ethical approvals were obtained and data were collected by authors affiliated with the six participating institutions. Data were analysed by Selina R. van den Oever, Ismay A. E. de Beijer, Leontien C. M. Kremer, Helena J. H. van der Pal and Saskia M. F. Pluijm and results were interpreted by all authors. The manuscript was drafted by Selina R. van den Oever and critically revised by all authors. All authors approved the final version of this manuscript.

Data availability

Study participants did not consent to data sharing outside the PanCareSurPass project. Access to participant data is therefore limited to national and international supervisory authorities. Upon request, the study protocol can be made available (please send an email to s.r.vandenoever-2@prinsesmaximacentrum.nl).

Ethics approval

Ethical review board or institutional approvals were required and obtained in Belgium (Ethics Committee Research UZ Leuven), Italy (Comitato Etico Regionale della Liguria), Germany (Ethik-Komission Universität zu Lübeck) and Spain (Comité de Ética de la Investigación con medicamentos). Institutional approval for pseudonymised data collection, analysis and storage was granted by the Princess Máxima Center, the Netherlands (Clinical Research Committee Princess Máxima Centrum). This study was performed in line with the principles of the Declaration of Helsinki.

Consent to participate

Written informed consent was obtained from all participants included in this study.

Consent to publish

All responses to the survey were pseudonymised. Participants were informed that by participating in this study, they consent to publication of their pseudonymised responses.

Appendix A. PanCareSurPass Consortium

Universitaetsmedizin der Johannes Gutenberg-Universitaet Mainz (UMC-Mainz) Desiree Grabow, Anna-Liesa Filbert, Dorothea Niehoff, Diana Walz, Friederike Erdmann (until month 22), Claudia Spix.

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St. Anna Kinderkrebsforschung (CCRI) Ruth Ladenstein, Edit Bardi, Vanessa Düster (until month 22).

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HL7 International Fondation (HL7 Europe) Catherine Chronaki, Giorgio Cangioli, Eliana Charalambous.

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Pintail LTD (PT) Not applicable.

Table 1. Characteristics of individual survey participants – HCPs.

HCPs	Italy	Austria	Belgium	Germany	Lithuania	Spain
Professional background						
Paediatric oncologist or haematologist (*n*)	2	3	1	-	1	7
Radiation oncologist (*n*)	-	-	1	-	-	-
Paediatric doctor (*n*)	1	-	-	-	-	-
Paediatric endocrinologist (*n*)	1	-	-	-	-	-
Clinical nurse specialist/senior nurse (*n*)	-	-	-	1	1	-
Study nurse (*n*)	-	-	-	1	-	-
Experience in LTFU care						
<5 years (*n*)	2	-	1	1	2	1
5-10 years (*n*)	1	-	1	1	-	2
>10 years (*n*)	1	3	-	-	-	4

Abbreviations: HCPs, healthcare professionals, LTFU, long-term follow-up.

Table 2. Characteristics of individual survey participants – LTFU care program managers.

LTFU care program managers	Italy	Austria	Belgium	Germany	Lithuania	Spain
Professional background						
Deputy medical director (*n*)	-	-	-	-	-	1
Project manager (*n*)	-	-	1	-	-	-
Assistant/support manager (*n*)	-	-	1	-	-	1
Paediatric oncologist or haematologist (*n*)	-	2	-	1	1	-
Other care provider (*n*)	1	1	-	2	1	-
Experience in LTFU care management						
<5 years (*n*)	-	-	-	1	-	2
5-10 years (*n*)	-	-	1	1	-	-
>10 years (*n*)	1	3	1	1	2	-

Abbreviation: LTFU, long-term follow-up.

Table 3. Characteristics of individual survey participants – CCSs.

CCSs	Italy	Austria	Belgium	Germany	Lithuania	Spain
Received LTFU care for						
<5 years (*n*)	1	2	-	3	-	2
5-10 years (*n*)	2	-	-	-	1	-
>10 years (*n*)	1	3	1	-	-	1
Other (*n*) [a]	2	-	-	-	1	1
Frequency of consultation with LTFU care provider						
Once a year or more often (*n*)	2	4	-	3	-	2
Once every 2-4 years (*n*)	2	1	1	-	-	-
Once every 5 years or less often (*n*)	-	-	-	-	-	-
Other (*n*)	2[b,c]	-	-	-	2[c]	2[c]
Received a SurPass before						
Yes (*n*)	3	-	-	-	-	-
No (*n*)	3	5	1	3	2	4

Abbreviations: LTFU, long-term follow-up, CCSs, childhood cancer survivors. [a] Missing or unclear. [b] Whenever necessary. [c] Currently not receiving LTFU care.

Table 4. Characteristics and comprehensiveness of LTFU care provided at the participating institutions.

	Italy	Austria	Belgium	Germany	Lithuania	Spain
Average number of CCSs seen per year (n)	500	130	350	125	100	120
LTFU care available for CCSs[a]						
Independent of diagnosis and treatment	X	X	X	X	X	X
With specific cancer subtypes only		X				
With specific cancer treatments only			X			X
Start of LTFU care[a]						
Directly after cancer treatment		X	X		X	X
Two years after end of cancer treatment	X					
Five years after end of cancer treatment				X		X
Five years after diagnosis			X		X	
Duration of LTFU care[a]						
For life	X	X	X	X		
Until the CCS reaches a certain age		X	X			X
Until a certain time since cancer diagnosis					X	X
Until a certain time since cancer treatment		X				X
Specialities involved in LTFU care						
Late effects specialist	X	X		X		X
Paediatric oncologist or haematologist	X	X	X	X	X	X
Medical oncologist	*	*		X		*
Radiation oncologist	*		X	X		X
Cardiologist	X	X	*	X	*	X
Endocrinologist	X	X	*	X	*	X
Gynaecologist	X	*		X		*
Internist	X	*	*	X		
Opthalmologist	X				*	
Otorhinolaryngologist	X				*	
(Neuro)psychologist	X	X	X	X	X	X
General practitioner		*		X	X	X
Clinical nurse specialist/senior nurse	X	X		X	X	X
Advanced practice provider	*	X		X	X	X
Social worker		X		X	X	X
Physical therapist		X	X	X	*	*
Occupational therapist		X				*
Nutritionist	X	X			*	*
Research doctor	X					
Data manager	X	X		X	X	
LTFU care program manager	X	X		X		
Teacher		X				
Specialties directly involved/consulted (n)	18	18	7	16	13	15
Components of LTFU care						
Screening for relapse	√	√	√	√	√	√
Screening for subsequent malignancies	√	√	√	√	√	√
Screening for late effects	√	√	√	√	√	√
Treatment of late effects	√	√	√	√	√	√
Education of CCS	√	√		√	√	√
SurPass v1.2	√[b]					
Treatment summary	√	√	√	√		√
Survivorship care plan	√	√	√	√		√
Plain language information for CCSs	√	√		√		√
Shared decision making	√	√	√	√		√
Best-practice guidelines	√	√	√	√		√

Abbreviations: LTFU, long-term follow-up, CCSs, childhood cancer survivors, TS, treatment summary, SCP, survivorship care plan. X = yes, mentioned by at least one respondent. * = not directly involved but regularly consulted, mentioned by at least one respondent. √ = yes, verified by centre representatives. [a] May differ per HCP, therefore several answers possible. [b] SurPass v1.2 already includes use of shared decision making, best-practice guidelines, a treatment summary and survivorship care plan.

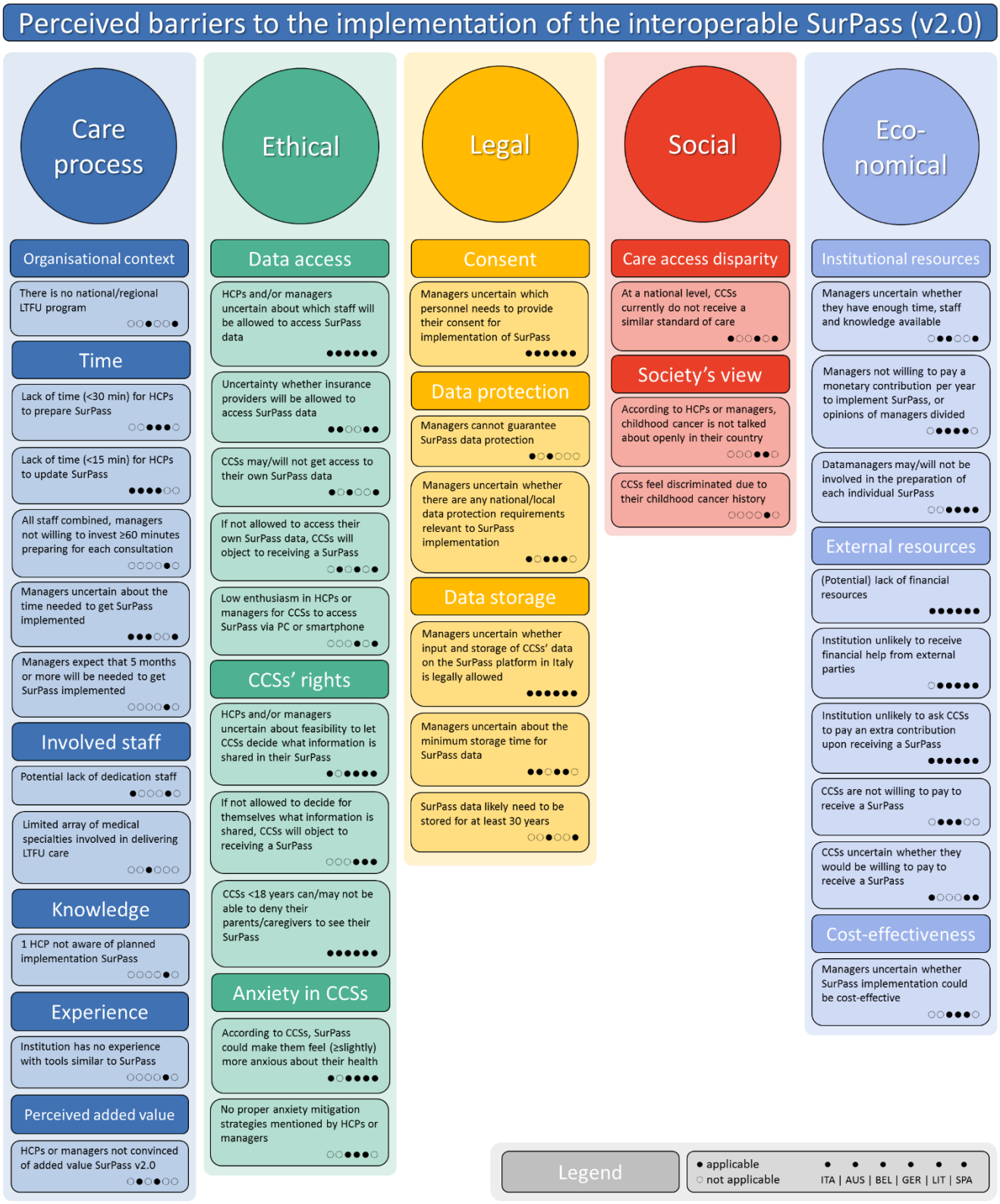

Figure 1A. Perceived barriers to the implementation of the interoperable SurPass (v2.0), arranged by action field and subtheme. For each identified barrier, to which institution(s) it applied is shown in the bottom right corner with open (not applicable) and filled (applicable) circles, with this order from left to right: Italy – Austria – Belgium – Germany – Lithuania – Spain. Barriers that applied to the majority of the participating institutions included lack of time and (financial) resources. In each of the six centres, knowledge gaps existed where most ethical and legal issues are concerned. Few social barriers were identified. Abbreviations: HCPs, healthcare professionals, LTFU, long-term follow-up, CCSs, childhood cancer survivors.

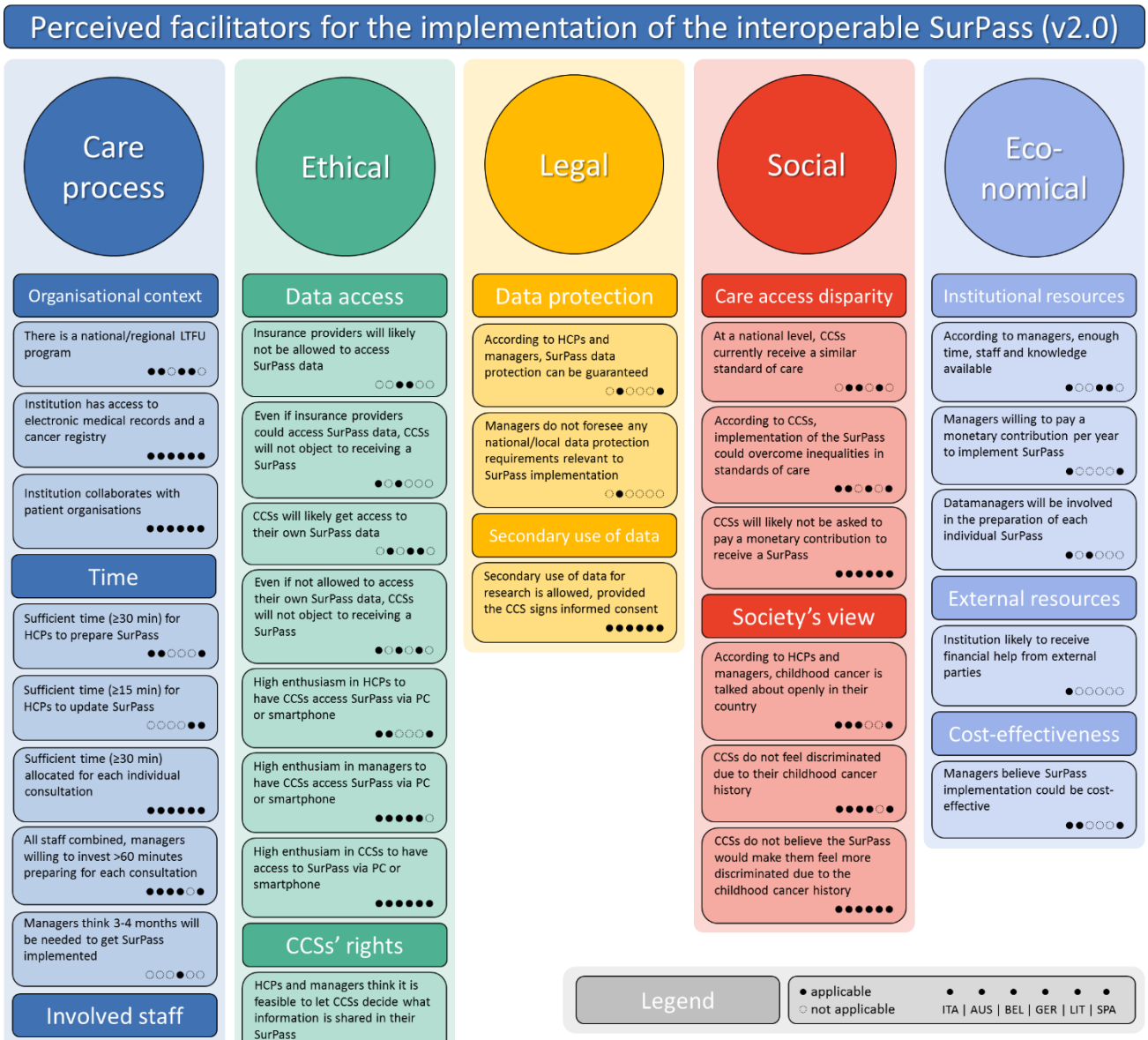

Figure 1B. Perceived facilitators for the implementation of the interoperable SurPass (v2.0), arranged by action field and subtheme. For each identified facilitator, to which institution(s) it applied is shown in the bottom right corner with open (not applicable) and filled (applicable) circles, with this order from left to right: Italy – Austria – Belgium – Germany – Lithuania – Spain. Facilitators that applied to the majority of the participating institutions included access to electronic medical records, the perceived added value, previous experience with (tools similar to) SurPass and CCSs not having to pay a monetary contribution. Abbreviations: HCPs, healthcare professionals, LTFU, long-term follow-up, CCSs, childhood cancer survivors.