Supplementary Table 1. All barriers and facilitators for the implementation of SurPass.

Action Fields	Themes	Barriers	Facilitators
Care		• There are too many guidelines for LTFU care for CCSs [a]	• Importance of psychosocial aspects to be discussed with the psychologist/social worker [a]
		• Lack of good guidance on child-adult care transition [b]	
		• Lack of monitoring LTFU attendance [b]	• CCSs should be introduced to SurPass at the end of treatment [b]
		• Uncertainty about how CCSs will be contacted to introduce SurPass [b]	• Standardised and centralised LTFU care [b,c,d,e,f]
		• Management of diseases takes much time and resources for CCSs and their relatives [c]	• CCSs trying to manage the LTFU care (e.g. medication and consults) themselves experience difficulty regarding documentation [c]
		• Lack of LTFU care and network cooperation [b,c,e,f]	• Less complicated requirements to obtain LTFU care documents [c]
		• GP should be linked to LTFU care HCPs [c]	• SurPass should be included in transition towards adult care [c,d]
		• Lack of interdisciplinary contact points for CCSs for psychological late effects [c]	• Delivery of SurPass through LTFU clinic [c]
	Organisational context	• Lack of LTFU care after 5 years post-treatment in Germany [c]	• Clinic needs to support informing the CCSs or relatives and hand over a SurPass [c]
		• Lack of a standard way of how paediatric oncologists work [c]	• Provide care structures [c]
		• Uncertainty if a single centre for LTFU care is feasible [c]	• Health insurance companies should be involved [c]
		• Lack of checklist/guideline on how to best communicate late effects [c]	• Psychological late effects should be standardised [c]
			• Transition from paediatric to adult care should be interdisciplinary [c]
		• Requirement of a referral for a medical specialist is needed [e]	
		• Referrals should be clearer [e]	• HCPs should prepare SurPass [c]
		• Lack of monitoring of health conditions [e]	• Contact person for late effects should be included [c]
		• Lack of single functioning centre for LTFU care [e]	• Communication with GPs should be improved [c]
		• Lack of shared care institutions [e]	• There should be ownership in the management of information and LTFU care [c]
		• Lack of follow-up visits for late effect screening only [f]	
		• Too little CCSs for each quota of primary care doctors [f]	• Involvement of case managers in LTFU care [c]
		• LTFU care included in research instead of health system [f]	• Implementation of adult LTFU care centres [c]

		• Lack of coordinators between HCPs [f] • Lack of recommendations/LTFU care for patients with chronic diseases [f] • Lack of psychological follow-up of CCSs [f]	• Use of video consultations in LTFU care [c] • Coordination within in LTFU care [c] • Uncertainty about what should be done to improve LTFU care until SurPass is implemented [c] • Creation of a data base of HCPs in LTFU care [c] • Building strong local teams with HCPs who feel locally connected and are in close exchange with the LTFU outpatient clinic [c] • Importance of the transition of paediatric care to adult care [d] • LTFU should be included nationally and in the cancer plan of each community [f] • Knowledge sharing within primary healthcare [f] • LTFU consultation in each community in the portfolio of care services [f] • Creation of protocols by the regional ministries to increase resources and obligate LTFU care [f] • Notifications within digital health systems [f]
	Time	• Workload too high when the HCPs has to validate the correctness of data sent in FHIR format to CINECA [d]	• Clear timeline of when to include which information in the SurPass [c]
	Involved staff	• Lack of a contact point for young adult CCSs [c] • Doctors for adult CCSs need to be involved in monitoring [e] • Concerns about increase of workload of HCPs [f]	• Late effects specialists should take the lead in LTFU care [b] • Involvement of a contact person for further questions regarding SurPass [b,c] • Nationwide list of HCPs for LTFU care should be developed [c] • Private practice HCPs should be included in LTFU care [c] • Involvement of the family physician is of great importance [f] • Hiring data managers for cases prior to EHR [f]

	Knowledge (about care)	• Lack of knowledge of long-term effects among HCPs [c, f] • Screening- and LTFU care recommendations unknown [c, f] • Uncertainty about what the psychological late effects are [c] • Uncertainty about what tools exist for LTFU care [c] • Uncertainty about when to inform CCSs about late effects [c] • Lack of health education for families [f] • Lack of training for different HCPs [f] • Lack of knowledge in insurance companies regarding late effects [f]	• CCSs should be updated about relevant novel research findings [b] • Education about LTFU care for CCSs [c] • Sharing information about late effects as soon as possible [c] • Oncology education for medical student [c] • LTFU care education for oncological paediatricians [c] • Information events about LTFU care for GPs [c] • Providing informative material/educational options for CCSs about late effects [c] • Awareness about LTFU care should be raised by the GPs [d] • Semi-annual debriefing meetings between specialists to share information [e] • Importance of disease knowledge in children < 16 years [f]
	Experience		• SurPass is seen as a tool to be aware of wellness and check-ups for CCSs [d]
	Perceived added value	• Uncertainty among centres outside St. Anna if SurPass will add any extra value to LTFU care [a] • Uncertainty which stakeholders will benefit from SurPass [a]	• University Hospital Graz would like to have SurPass implemented [a] • Relief of future possible illnesses – SurPass helps to remember following consultations etc. [b] • Digital SurPass could be useful when centralised with no additional administrative burden [b] • Digital SurPass useful for young CCSs because they will not be dependent on parents [b] • SurPass can inform CCSs about the risks, long-term effects and screenings [b] • SurPass is expected to be a helpful tool in the transition towards adult care [c]

			• SurPass is perceived to be helpful to reduce the need to explain late effects [d]
			• Surpass could act as a referral to specialist [e]
			• Convenient for doctors to see aggregated information in SurPass for further treatment decisions [e]
			• Useful to have information concentrated in SurPass [e]
			• SurPass considered useful for research to improve treatment [e]
	Satisfaction with Surpass		• SurPass implementation would benefit from a sound evaluation [a]
	SurPass content	• Uncertainty on what psychosocial information is needed or wanted in SurPass [a] • SurPass is only focused on health risks instead of prevention [b] • Lack of information about minor ailments in SurPass [b] • Lack of information about how CCSs can improve their lives themselves (e.g. exercise or lifestyle) [b] • Uncertainty about when information is entered into SurPass [b] • Uncertainty about how to determine which information should be included in SurPass [c] • Uncertainty about the need for oncological and other medical information [f]	• Simple but detailed info in SurPass can stop the "catastrophising" [b] • Information in SurPass is formulated differently for CCSs and HCPs [b] • Preventive screening for possible serious illnesses: automatically planned & arranged by SurPass [b] • HCPs easily accessible for CCSs via single point of contact in SurPass [b] • SurPass should include positive messages/experiences from more experienced CCSs [b] • SurPass should include a mentorship option for CCSs [b] • LTFU care should include medical as well as psychological components [b] • SurPass could involve a prevention component [b] • Important to include psychosocial care aspects in LTFU care [b] • SurPass could include guidelines for psychosocial topics [b]

- Psychosocial components in SurPass should be optional to activate (not standard) [b, c]
- Nuance is important in SurPass [b]
- Contact option for psychosocial care within SurPass would be helpful [b,c]
- Standardised medication plan in the SurPass is desirable [c]
- SurPass should be a dynamic document linked (and updated) to the development of the child [c]
- New findings must also be recorded in the SurPass after 30 years [c]
- SurPass should include a psychological component [a,b,c,d]
- SurPass should include plain language information for young/cognitive impaired CCSs [c]
- SurPass should be positively oriented [b,c]
- A structure in which all information on the course of the disease and LTFU care is brought together and can be found again without difficulty is seen as desirable [c]
- Importance to distinguish what kind of data and relation to the cancer phase should be entered in SurPass [c]
- SurPass should include the invisible disabilities and overall welfare of CCSs [d]
- Updates of recommendations based on individual information is needed [e]
- Special function within SurPass for continuously monitoring health complications [e]
- Complete treatment summery converted directly into SurPass would be useful [e]

			• Notifications for reaching patient milestones or appointments [f]
			• Notifications notifying hospitals to call the CCSS for appointments [f]
Ethical	SurPass access	• Uncertainty about who should be able to access SurPass (e.g. parents, HCPs and insurance companies) [a,b,c,f] • Uncertainty about who receives SurPass [b] • Uncertainty about how impaired CCSs can access SurPass [b,c] • Uncertainty about who has access to add data into SurPass [f]	• SurPass should not be accessible for insurance providers [b, f] • Informal care should have access to SurPass [b] • Counsellors for CCSs with limited autonomy should have access to SurPass [b] • SurPass access rights must be granted by the patient [b,c,e] • SurPass is issued at the "5-year follow-up" and then handed over to CCSs or relatives [c] • Accessibility of SurPass should be well prepared and implemented [c] • Visibility of Surpass for all doctors is permitted by CCSs [e]
	Data protection	• Uncertainty what will happen to the data in SurPass [a] • Information can only be registered via the GDA (health authority) - only the GDA is allowed to register in ELGA [a] • Uncertainty if CCSs allow SurPass data that benefits others to be shared [a] • Data protection of European citizens differs outside the European Union [b] • Uncertainty about data retention [b] • Validation of data cannot be done automatically [d] • Importance of data security and data protection [f] • Importance of the geographical location of the data and related security measures [f]	• Informed consent by CCSs is needed to add sensitive information in SurPass [b] • SurPass should have an option for CCSs to view and conceal sensitive information [a,b,c,e] • Need of a control authority to ensure the patient has been informed and that the SurPass has been handed over [c] • The patients' consent form could include an option to agree with transferring Surpass to ESPBI [e] • Data should be codified [f]

		• Using patient identifiers for information use outside SurPass (e.g. SIP and DNI) [f]	
	CCSs' rights	• Uncertainty about what happens when parents do not inform their child about SurPass [c]	• Co-design/co-creation involving CCSs is necessary [a] • CCSs' requests should be included into SurPass [a] • Autonomy of younger CCSs should be considered [b] • CCSs would like to see what ESPBI documents look like [e]
	Anxiety in CCSs	• SurPass could cause stress/anxiety/fear [b,c] • SurPass could lead to over-concern [b,c] • SurPass could lead to "catastrophising" (every minor thing could be seen as a serious illness) [b,c] • Anxiety can cause people not to use SurPass [b] • Uncertainty about when it is the right time to mention late effects [c] • Anxiety caused by the lack of appropriate LTFU care [f]	• Dose and repeat the information about late effects to prevent the feeling of being overwhelmed [c]
	CCSs' responsibilities	• The need for CCSs to know they have to take responsibility for SurPass [f]	• Care program should be positively oriented and controllable by CCSs themselves [b] • SurPass will bring empowerment to CCSs because of their own coordination of care [c] • Advice for CCSs on taking responsibility [c]
Legal	Legal requirements	• Importance of site hosting server regarding legal issues [b] • Communication tailored to CCSs instead of parents when legal age is reached [b] • Lack of obligation to inform CCSs about late effects [c] • Uncertainty about how to agree on the exchange of information [f]	• Informed consent is included into ELGA and should be in SurPass [a] • SurPass should become accessible when CCSs transfer to adult care [c]

		• CCSs should have reached the legal age or age 16 to receive SurPass [f]	
	Secondary use of data		• Importance of distinction between collecting data for treatment or research objectives [b,c,f] • Synchronisation of care and research data [c,f]
	National regulations	• Strict law regulation- tracking only up to 18 years [e]	• SurPass should be a recognised document at the national level [d]
Social	Standard of care	• Need for a clearly defined psychosocial list developed by CCSs at European level [a] • Uncertainty about how to involve young adults with cancer [c]	• CCSs would like to receive e-mails regarding LTFU care from the clinic [c] • Creation of LTFU care units with minimum standards [f]
	Involvement of societal organisations	• Lack of involvement of political institutions [f]	• Importance of the Parents' Federation to create pressure on LTFU care [f] • Availability of parents' association as an intermediary between CCSs and HCPs [f] • Involve global/European organisations to defend insurance equity of CCSs [f]
	Discrimination towards CCSs	• The name "SurPass" could lead to stigmatisation [b] • Difficulties and differences in insurance for CCSs [f] • The need for CCSs to be able to opt for the same insurance policies as other citizens [f]	
Economic	Institutional resources	• Further financial support is needed for implementation of SurPass in Austria [a] • Concerns about the budget to be able to finalise SurPass project [f]	
	External resources	• Health insurance funds must finance SurPass implementation (Innsbruck) [a]	

	CCSs' financial burden	• CCSs' fear that insurers' knowledge of their situation will lead to a higher financial burden [f]	
Information & IT	Knowledge IT specialists	• Uncertainty on how the FSE can be kept updated [d] • Uncertainty about how to possibly revise the electronic medical record structure [d]	
	Data system accessibility	• Uncertainty about how it is ensured that different file formats stay readable and accessible [c] • No restriction of visibility of some or part of medical documents in ESPBI system [e]	• Data access from GP/paediatrician needed [c] • Possibility to make the patient information in VULSK ELI system "sensitive" [e]
	Patient data availability	• Uncertainty about when data will be put in SurPass [c] • Incompleteness of data due to missing key attributes [d]	• Including medication in SurPass is perceived to have no technical difficulties [a] • Fixed date for creation and delivery is needed [c]
	SurPass usability	• Uncertainty if CCSs who have been opted out of ELGA also receive SurPass [a] • Uncertainty if CCSs can add data into SurPass themselves [a] • Uncertainty about how to lower the threshold to use SurPass [b,c] • Administrative tasks for CCSs could lead to not using SurPass [b] • Uncertainty about what should be done if CCSs refuse the SurPass [c] • Uncertainty on how to update SurPass regarding psychological late effects [c] • Uncertainty about how SurPass data can be used in other countries [b,c,f] • Uncertainty if SurPass applies to young adult CCSs [c] • Doubts regarding the need for internet to access SurPass [f]	• Cooperation of software producers, technical hospital team and developers is necessary [a] • Pilot implementation of SurPass is planned for St. Anna [a] • Implement a SurPass pilot in every PCSP centre [a] • SurPass should address young CCSs and parents together [b] • Usability of SurPass abroad [c,d] • Joint meetings between IT and HCPs in order to test the coding of the live data [d] • After discharge CCSs should still have access to SurPass [f] • Traceability of what is written in SurPass and by whom [f]

System integration	• Different HIS systems in Austria - adaptations necessary for each centre [a] • COZO, KUL differs from EPD [b] • Uncertainty about the integration of different data formats [c, f] • Uncertainty about how, when and by whom data is entered in SurPass [c] • Data format not standardised across HIS [c] • Uncertainty on how to integrate the SurPass with the FSE (which is a document of the PNNR) [d] • Documents from the hospital can only be sent to the ESF by PDF format [d] • Current development of the ESF in the PNRR which currently provides for the CDA2 format, while the project provides for FHIR [d] • Uncertainty about how the SurPass is updated [c,d,f] • Uncertainty about system integration between national and European health systems [b,c,d,f]	• Pilot for linking all HIS in Austria [a] • Every hospital needs to set up a CDA to have common basis for linking all HIS [a] • Austria is working on implementation of a common CDA to finish within 1-2 years [a] • Linking SurPass and Cancer Registries could avoid duplication [b] • The possibility of combining SurPass with the Health Card [c] • Automatic filing of SurPass from HIS [a,b,c,d,e,f] • Automatic transfer of data from SurPass to HIS [a,b,c,d,e,f] • FHIR for data exchange and networking of clinics has to be used [c] • HL7 FHIR offers possibility to generate data to GP [c] • In the future documents of the citizen will be visible to the health professionals in Liguria (EHR) [d] • The application formats the standardised documents in CDA2 [d] • Development of software to make PDF files available to the ESF [d] • Integration of multiple platforms to use SurPass [f] • Integration with EHR [f] • Standardisation of data [f] • Facilitating the software and data collection correctly [f]
Knowledge about SurPass	• Uncertainty about who should be contacted about SurPass use (CCSs/parents?) [b] • Uncertainty on how SurPass will be understandable for young children [c]	• Importance of disclosure regarding SurPass information to various HCPs [b] • Consultation about SurPass should be provided [b] • Send information about and together with SurPass [c]

		• Promotion material should provide information about SurPass in simple language [b,c,d,f]
		• Information brochures to explain SurPass for older CCSs [c]
		• Pixie-books for younger CCSs to explain SurPass [c]
		• Education for HCPs about SurPass and its importance to CCSs [e]
		• Learning how to use SurPass for HCPs and CCSs [f]
SurPass format	• Uncertainty about how blind CCSs can access the data [c] • Uncertainty about what language should be used in SurPass for migrated CCSs [c] • Uncertainty about a suitable target medium (folder, stick, PDF) [c] • Uncertainty about the (time) structure of information which enters SurPass [c] • Uncertainty about who will make SurPass digital [d]	• The name SurPass could be changed to "care program" [b] • Data should be available as a PDF document rather than in paper [c] • Storing SurPass electronically as a PDF document is seen as positive [c] • SurPass should include all common languages to choose from [c, d, f] • SurPass could use a multilingual approach (national language vs English) [c] • SurPass should also still be available on paper [c] • Bilingual double SurPass [c] • Surpass should be an official document [d] • SurPass should include the possibility to use the QR code/ link directly with a PDF that CCSs can open to consult the legislation [d]

authority, GPs; general practitioners, HCPs; healthcare professional, HIS; Hospital Information Systems, KUL; Katholieke Universiteit België, LTFU; long-term follow-up, PNNR; Piano Nazionale di Ripresa e Resilienza (National Recovery and Resilience Plan), SIP; Session Initiation Protocol, St. Anna; St. Anna Kinderkrebsforschung, SurPass; Survivorship Passport.