

The Survivorship Passport

a digital tool for better health and homogeneous long-term care for childhood cancer survivors



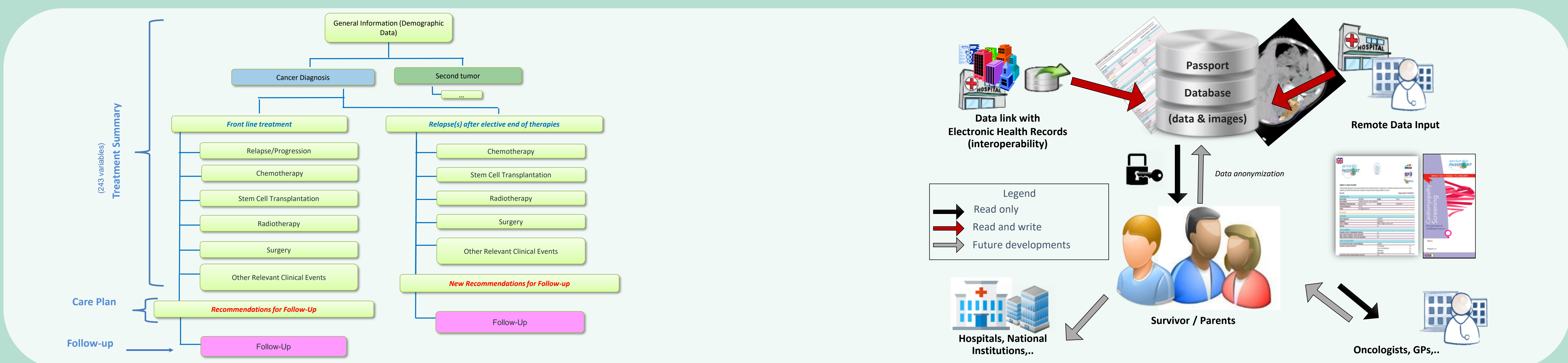
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BACKGROUND

There are >500,000 childhood cancer survivors (CCS) living now in Europe and about 8,000 add on each year. 3 out of 4 CCS are affected by chronic conditions related to the original cancer or to the treatments used for its cure. These conditions may occur even several years after cancer diagnosis and treatment. It is important to keep treatment information of CCS, in particular for the critical transition period from paediatric to adult care. Many CCS, as well healthcare professionals, lack information about possible late effects, personal risk profiles and the need of long-term follow-up care. Most have poor or no access to their clinical and treatment data as well as to a survivorship care plan. The PanCare Network was funded in 2008 in collaboration with CCS.

METHODS

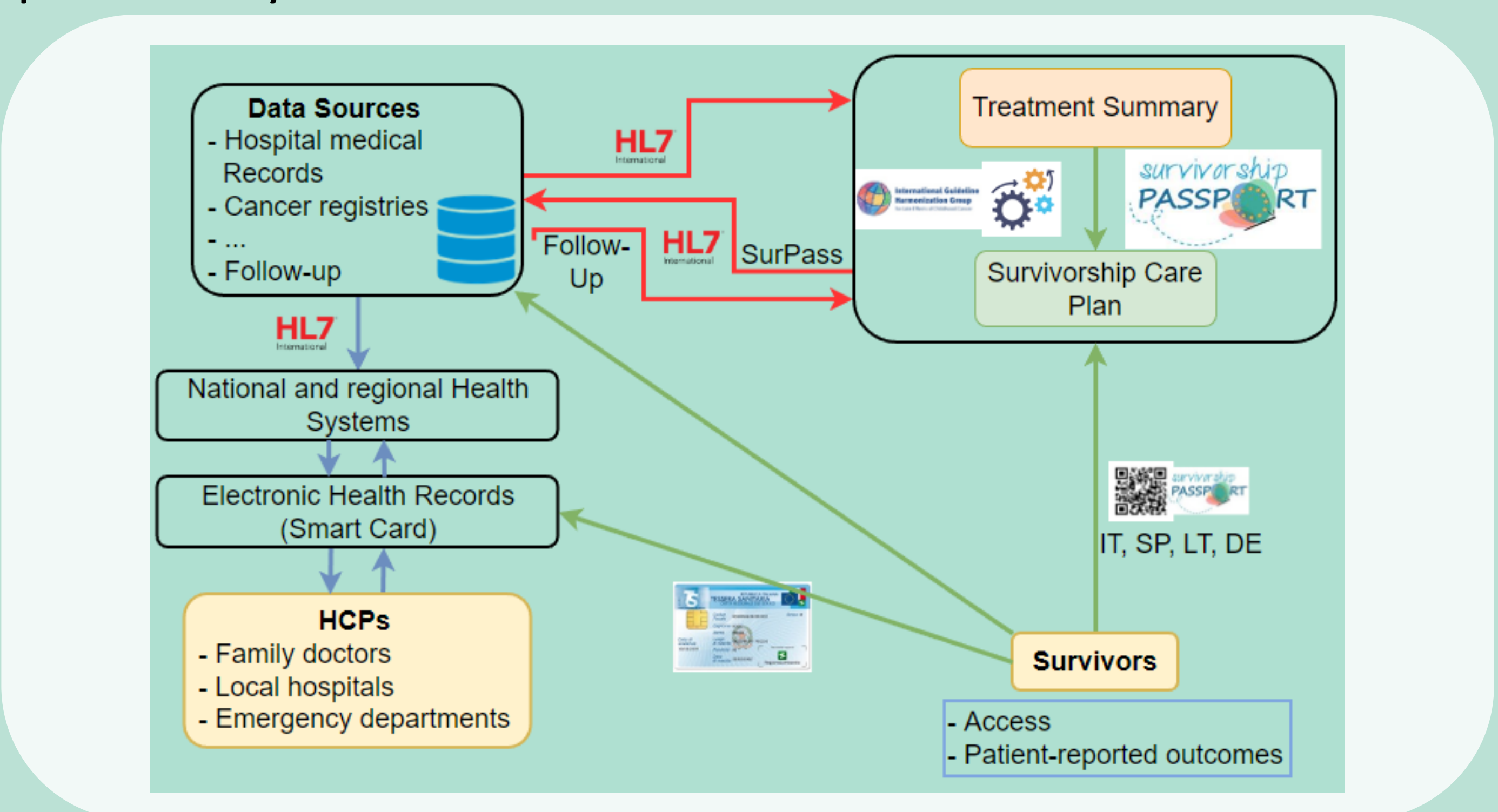
The Survivorship Passport (SurPass) is an innovative, digital tool developed by the PanCare community thanks to several EU-funded projects with the aim of improving quality of life and health status of CCS. The SurPass structure is based on two main sections: the treatment summary and the personalized care plan, plus a follow-up form.



Evidence Based guidelines to monitor for possible organ-specific complications have been developed by the International Guidelines Harmonization Group (IGHG) and the PanCare Guidelines Group. Guidelines are and will be regularly updated. Built-in algorithms link the treatment history of each CCS to a personalized Care Plan based on risk factors identified by the IGHG/PanCare network. The SurPass web-based platform is GDPR compliant. Health care providers as well the CCS can access it through a secure authentication. The SurPass is applying for Medical Device EU certification.

RESULTS

To allow SurPass integration into health systems, the PanCareSurPass project is now developing and testing in six European countries interoperability procedures to enable bilateral semi-automated data transfer between the electronic health information systems and the SurPass platform by means of HL7 Fhir.



CONCLUSIONS

Similar to Europe's vision of a 'Cancer Survivor Smart Card', the SurPass tool is a proof of concept on how to link the individual treatment history to best personalized follow-up care for CCS. Within the newly funded smartCARE project coordinated by ECO, experiences of the PanCare community with SurPass will be shared.

