The Survivorship Passport: an innovative solution for follow-up

An outstanding achievement of ENCCA has been the partnership between professionals, survivors and IT experts to create a “Survivorship Passport”. As 80% of young people with cancer are now surviving, it is essential that health systems are able to deal with this ever-impressing figure by informing all relevant stakeholders on possible risks or late effects of the cancer treatment received.

Treatments for children and adolescents with cancer are very complex: they may involve different types of treatment (e.g. surgery, chemotherapy, radiotherapy) and may lead to late effects and risks that will strongly impact the quality-of-life of the young patients once they reach adulthood. The current lack of information on many patients’ medical history becomes particularly critical as children become adults or as they move to another country.

The Survivorship Passport can provide a solution to this problematic situation. This innovative tool provides relevant information on the medical history of patients who ended a cancer therapy, making survivors, GPs and healthcare professionals aware of the potential risks or late effects stemming from the previous disease and treatment received. Developed by the Italian Interuniversity Consortium Cineca, in collaboration with survivors representatives (ICCCPO), and clinicians coordinated by the Gaslini Institute the passport is one of the main deliverables of the EU-funded project ENCCA, and it has been designed in close collaboration with the PanCareSurFup project.

The information on the document is written in a simple and understandable way, and – on the basis of the personal data collected – the passport includes recommendations for a tailored follow-up based on up-to-date clinical guidelines (developed with PanCareSurFup) to facilitate the prevention, early detection and treatment of potential late effects or relapses. The passport is generated through a secured web-based platform which is patient oriented, accessible in multiple languages by all type of users (patients, clinicians, etc.) and can be integrated with national/hospital databases and clinical trials databases.

The Survivorship Passport aims to harmonise the follow up on former cancer patients across Europe, by promoting homogeneous criteria and evidence-based guidelines from clinical practice for prevention, early detection and treatment of physical and psychosocial late adverse effects. In the age of personalised medicine, this simple and accessible tool can enhance an age-appropriate healthcare and address individual patient issues specific of paediatric cancer survivors, possibly leading to important breakthroughs in the monitoring and cure of childhood cancer survivors on the long-term.