4 million euros awarded to EU project to improve long-term care for survivors of childhood and adolescent cancer by widely implementing the European digital Survivorship Passport

Thanks to better cancer treatments, more than 80% of children and adolescents in Europe who are treated for cancer will now survive more than 5 years. There are currently nearly 500,000 survivors of childhood and adolescent cancer across Europe, and this figure is growing every year. However, the cancer treatments are harsh and may cause long-term effects, so survivors require closer health monitoring over their lifetime than their peers who have not had cancer. At the moment only a minority of adult childhood cancer survivors receive appropriate care meaning there is still a long way to go in providing high quality long-term, person-centred follow-up care for survivors.

One of the challenges for long-term follow-up care is informing survivors about their personal risk of long-term effects and thereby empower them to manage their own needs for care and support, together with their healthcare professionals. The Survivorship Passport (SurPass, www.survivorshippassport.org developed by Cineca) was developed by a number of EU-funded projects including ENCCA (https://cordis.europa.eu/project/id/261474), PanCareSurFup (www.pancaresurfup.eu), ExPo-r-Net (https://www.expornet.eu/), and PanCareFollowUp (www.pancarefollowup.eu), and the PanCare Network (www.pancare.eu) as a tool to help overcome this challenge. The SurPass is available in electronic, as well in paper format, and provides survivors with a complete overview of their treatment and thanks to built-in algorithms gives personalised recommendations for follow-up care based on a combination of the internationally approved IGHG guidelines (www.ighg.org) and the PanCareFollowUp guidelines. However, the SurPass has not yet been widely implemented in Europe.

The EU-funded project PanCareSurPass (www.pancaresurpass.eu), which launched on 01 March 2021, will look at how to more widely implement the SurPass to improve survivorship care. 17 partners from 8 European countries (Austria, Belgium, Germany, Ireland, Italy, Lithuania, Netherlands, Spain) are joining forces to further develop the SurPass and create a strategy for European implementation. Part of the development work will include linking the SurPass to electronic health information systems (e.g. hospital medical record, national health records, where available) to improve the accuracy of health information available and reduce the time needed to generate the SurPass for each patient. The new SurPass version will be launched and tested in a multi-country study in Austria, Belgium, Germany, Italy, Lithuania and Spain. The study will look at how survivors and healthcare professionals view the SurPass, as well as the health economics of implementation. In addition, the project will gain insight into how health data from different sources can be used by adopting interoperability standards. To ensure the PanCareSurPass project is only the start of an even wider implementation of the SurPass across Europe, replication materials and policy recommendations, as well as a prediction model to help healthcare decision makers, will be developed.

“We are delighted that the survivors need for optimal long-term care is seen as well at the European Commission – we are thankful that they fund our project which is of high importance for Survivors of childhood cancer”, said Dr. Desiree Grabow (PanCareSurPass Project Coordinator, University Medical Centre, Germany).

Dr Riccardo Haupt (PanCareSurPass Research Manager, Istituto Giannina Gaslini, Italy) added “We are looking forward to this project which will allow a more efficient integration between high quality clinical care and late effects research. We hope that in the future the electronic Survivorship Passport will become a standard for care in all the European countries”.


Dr. Helena van der Pal (Past President of PanCare and Late Effects specialists) “PanCareSurPass will facilitate further implementation of survivorship care in Europe and therefore ensure equal access of care and improve quality of life for survivors of childhood cancer”.

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