

## Press Release

# Survivorship Passport: For a better life after childhood cancer

(Wien, 7.7.2021) **EU funds research project to improve long-term follow-up care for childhood cancer survivors with 4 million euros.**

In Europe, 35,000 children and adolescents are diagnosed with cancer every year, about 300 of them in Austria. Thanks to successful therapies, in recent decades the survival rate has increased from 20 to 80 percent in European countries rich in resources. This results in about 500,000 survivors of childhood and adolescent cancer in Europe. However, 60 to 70 percent of all survivors worldwide struggle with late effects of the disease and its treatment. A particular challenge is the transition from pediatric to adult medical care, as relevant information to identify individual needs and to respond accordingly, is frequently lacking.

### All information in one passport

The Survivorship Passport is intended to close this supply gap throughout Europe and to improve long-term follow-up care. It will be available in both electronic and paper format and will provide survivors with a detailed and complete overview of their medical treatments. In addition, it provides evidence-based, personalized recommendations for long-term follow-up care thanks to integrated algorithms. These are based on a combination of the internationally recognized guidelines of the International Guideline Harmonization Group for Late Effects of Childhood Cancer (IGHG) and the PanCareFollowUp recommendations.

To ensure the best possible implementation of the European digital survivorship passport, the EU is funding the "PanCareSurPass" research project with four million euros. The document contains important medical information on diagnosis, treatment and the course of the disease, as well as personalized recommendations for the follow-up care of childhood and adolescent cancer survivors. Thus, the Survivorship Passport pursues a significant goal: the reduction of unawareness and uncertainty among patients and caring physicians regarding therapy and disease-associated complications.

Prof. Ruth Ladenstein, MD, MBA, cPM, head of the work package "Implementation Strategy Development" in the PanCareSurPass project and head of the Department of Studies and Statistics S<sup>2</sup>IRP at St. Anna Children's Cancer Research Institute in Vienna, comments: "The implementation of the Survivorship Passport at EU level is in many ways a success and a step towards overcoming the treatment inequalities of survivors in society. Based on this tool, adequate screening can be performed, and if necessary, appropriate therapies can be found with targeted diagnostic measures."

### Investigation and broad implementation

So far, the Survivorship Passport has not been implemented across the EU. Thanks to Prof. Ladenstein's intensive efforts and the support of Austria's "Onkologiebeirat", the concept of the Survivorship Passport has already been anchored as an important strategic goal in the Austrian Cancer Plan (Cancer Framework Program Austria, 6.2 Operational Goal: Implement a Survivorship Passport for Children and Adolescents, 2014, p. 46). In 2021, Prof. Ladenstein's participation in the Cancer Mission Board succeeded in anchoring the concept of the Survivorship Passport for all age groups in the Cancer Mission and in Europe's Beating Cancer Plan. There it can be found under the term SmartCard for patients with and after cancer (Better life for cancer patients initiative: Cancer Survivor Smart-Card and

European Cancer Patient Digital Centre. Europe's Beating Cancer Plan, 2021). At the same time, together with the Survivors Austria, the corresponding considerations for a connection with the ELGA electronic medical record have already been initiated at the federal level.

Based on the initiative of the Austrian Survivors Group, which called for such a tool, the strategic processing and the development steps have reached a high level of conceptual maturity after a preparatory period of now ten years in several EU-funded projects (ENCCA, PanCareSurFup, PanCareLIFE, ExPO-r-Net, PanCare FollowUp).

### **Current developments**

The new SurPass version is being tested at selected hospitals/cancer registries as part of a multi-national study in Austria, Belgium, Germany, Italy, Lithuania and Spain, paving the way for a broad implementation in these six countries. The current PanCareSurPass project has a duration of four years and is funded by the European Union's Horizon 2020 research and innovation program under grant agreement No. 899999 with four million euros. The vision for the future is to embed the Survivorship Passport as a tool in the respective electronic health records in Europe (ELGA in Austria), making it widely accessible to healthcare providers.

"One challenge in developing an implementation strategy is certainly the analysis and embedding of the relevant interoperability factors, as these relate to the various country-specific ethical, legal, social and economic aspects," comments Prof. Ladenstein.

The scientific teams involved are analyzing the Survivorship Passport and relevant electronic interfaces together with patient organizations, survivors and healthcare professionals. Such interfaces are found in the context of electronic health information systems, such as hospital medical records or national health records. The question of how to use available health data from different sources accurately and effectively is one aspect of the PanCareSurPass project. But health economic aspects of its implementation will also be highlighted. In addition, the researchers and patient representatives will develop replication materials, policy recommendations and models to support decision-makers in the healthcare system.

In Austria, the association Survivors Austria – Children's Cancer Survivors Initiative will support the implementation of the PanCareSurPass project – both in terms of content and health policy. "Within the framework of our close cooperation with St. Anna Children's Cancer Research Institute and CCI Europe, the European umbrella organization for children's cancer aid organizations, we will actively shape the project – through our specialist expertise as well as our knowledge gained from 18 years of experience working with survivors of childhood oncological diseases. In this way, we want to ensure that the final result actually meets the needs of those affected," says Hannah Gsell, chairwoman of the Survivors Austria association and project manager at Childhood Cancer International (CCI) Europe.

### **Personalized aftercare could cushion late effects**

In order to be able to recognize late effects earlier and treat them more successfully, it is important to be able to offer survivors high-quality, person-centered long-term aftercare. To this end, an adequate follow-up infrastructure and intensive monitoring of health status are key. The health status of survivors should therefore be monitored closely and more intensively than that of their healthy peers - and always based on their particular medical history. This could also make it easier for former patients to enter professional life and maintain a job.

### **Survivors: "Now we need the support of politics."**

Implementing the Survivorship Passport not only brings more empowerment to survivors of pediatric oncology diseases by making them experts in their own health, allowing them to take care of their own

health management and receive adequate medical care, but also makes it easier to change doctors if necessary, "without having to tell the same story again and again."

Asked from her point of view as a patient representative, Carina Schneider, a psychologist and member of the board of Survivors Austria and CCI Europe, says: "Early information about the possible late effects of cancer in childhood, adolescence and young adulthood is essential for one's own health management and for preventive health care. If you don't know what can or probably will happen to you, you can't know what you should pay special attention to in terms of prevention and early detection in order to maintain the best possible state of health. In Europe, it currently makes little difference whether you live in a rich or a poor country: there are de facto hardly any adequate care structures for the long-term follow-up of adult survivors of pediatric oncological diseases. We are impatient! For so many years, we have been working together with children's cancer aid organizations and experts throughout Austria and Europe to develop the Survivorship Passport. Now we need the support of our politicians and our healthcare system to implement it, so that survivors get the long-term care they need."

### **International Voices: PanCareSurPass to become standard of care**

Dr. Desiree Grabow, PanCareSurPass Project Coordinator, University Medical Center Mainz, Germany, states: "We are pleased that survivors' need for optimal long-term follow-up care is also seen by the European Commission - we are grateful that they are funding our project, which is of great importance for survivors of childhood cancer."

Dr. Riccardo Haupt, PanCareSurPass Research Manager, Istituto Giannina Gaslini, Italy, comments: "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 the electronic Survivorship Passport will become a standard of care in all European countries."

Dr. Helena van der Pal, member of the PanCare leadership team and late effects specialist, says, "PanCareSurPass will facilitate the further implementation of survivorship care in Europe and therefore ensure equal access to care and improving quality of life for survivors of childhood cancer."

### **Contacts and project responsibilities in Austria**

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Lead Work Package 2 (WP2): Implementation Strategy Development

In WP2, under the leadership of Prof. Ladenstein the country-specific ethical, legal, social and economic aspects for the implementation strategy will be identified in order to generate specific recommendations on this basis.

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Head of Work Package 5 (WP5): Development of predictive models

In close cooperation with the development of the Implementation Strategy Development and based on the findings of the country-specific conditions, cost-benefit analyses will be carried out in WP5 under the

leadership of an interdisciplinary GÖG team. In addition, decision criteria will be analyzed and published in the form of a decision support tool for infrastructure developments.

### Further information can be found online at:

Projekt PanCareSurPass [www.pancaresurpass.eu](http://www.pancaresurpass.eu)

Survivors Österreich [www.survivors.at](http://www.survivors.at)

ZONE / IONA <https://www.survivors.at/nachsorge1/zone/>, <https://www.survivors.at/iona/>

ERN PaedCan <https://paedcan.ern-net.eu/>

SurPass: [www.survivorshippassport.org](http://www.survivorshippassport.org)

ENCCA <https://cordis.europa.eu/project/id/261474>

PanCareSurFup [www.pancaresurfup.eu](http://www.pancaresurfup.eu)

ExPo-r-Net <https://www.expornet.eu/>

PanCareFollowUp [www.pancarefollowup.eu](http://www.pancarefollowup.eu)

IGHG-Leitlinien [www.ighg.org](http://www.ighg.org)

CCI Europe <https://ccieurope.eu/>

CHILDHOOD CANCER #RaiseYourHands4Survivors #CCAM #SURVIVORS:  
<https://www.youtube.com/watch?v=dK8pmnx8iJY>



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