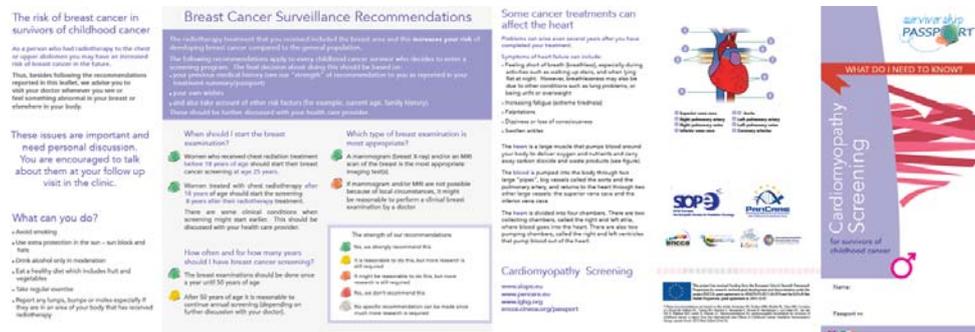


## The Survivorship Passport: Be the Expert of Your Own Health



**Childhood cancers are rare, but survivors are not.** More and more children and adolescents survive cancer, and it is estimated that approx. 300,000 childhood cancer survivors currently live on our continent (in 2020, their number will reach nearly half a million). Many survive well past their 50<sup>th</sup> birthday, and this encouraging development is due to the major progresses made by researchers within the European clinical trial groups specialised in paediatric malignancies.

Although this is certainly a cause for rejoicing, many survivors suffer from **side effects** (chronic conditions, second malignant tumours, fertility issues, etc.) on the long term, that are severe enough to affect their daily lives. Another problem is the general lack of information – both on the side of survivors and of healthcare professionals – on the clinical history of the former patient and on the possible late effects stemming from having a tumour in the paediatric age. This missing knowledge becomes particularly critical in the transition from paediatric to adult care and when survivors move to another country, and can generate incorrect diagnosis and treatments.

Our Society is looking for solutions to improving the quality of life for survivors, and this very important topic has been indeed included as one of the 7 objectives in the [SIOPE Strategic Plan](#).

One way of providing survivors with optimal long-term care is the creation of a '**Survivorship Passport**' for each child and adolescent cured of a cancer, a useful tool providing instant access to the medical history of patients who ended a cancer therapy, making survivors and healthcare professionals aware of the potential risks or late effects stemming from the previous disease and treatment received. This self-generating document contains all details of the survivor's disease and treatment, and a database for storing the clinical data and hence facilitate monitoring and research. Information is provided in an easily understandable way, and includes recommendations for an adequate follow-up, depending on individual risk factors. Both doctors and survivors will have the possibility to access this information via a dedicated secured website and a mobile app.

This initiative also involves extensive coordination across Europe, as the aim is to integrate the Passport in the **National Cancer Plans** of the main EU member states, in the section dedicated to paediatric cancers. This was already the case of Austria last year, and integration into the national, institutional and clinical trial databases will prove essential to make all stakeholders aware of the existence of this tool and to make it sustainable long term.

SIOPE is actively collaborating with Dr Riccardo Haupt (Italy), the coordinator of this initiative, in the framework of our three main EU projects: [ENCCA](#), [PanCareSurFup](#) and [ExPO-r-Net](#). Our Society is currently working on the design of the **recommendations and guidelines** (e.g. on gonadal toxicity, hearing disabilities, etc.), foreseen to accompany the Passport as soon as the text and its translations are approved by the international project team. The first two nicely designed brochures on cardiomyopathy and breast cancer (in English and German) have been already finalised and presented to the Austrian Ministry of Health on the occasion of the European Cancer Congress last September. SIOPE also designed a very nice **folder** to collect all documents (the Survivorship Passport, the brochures and the codes to access the online tools) which will be useful to serve the survivor's needs.

### More information:

- [ICCCPO page on the Survivorship Passport](#)
- [Article on CancerWorld #59](#)