Vilnius Declaration

On Transition from Pediatric to Adult Cancer Care

Background information

There are over 500,000 young cancer survivors, aged 14-39 living in Europe[1] Thanks to advancements in medical treatments, the survival rate stands at an encouraging 85% in developed European countries. However, there are disparities between European countries, both in terms of survival rates and the way in which post-treatment care is organised.

As up to 75% of survivors experience one or more late effects of treatment, lifelong follow-up care is required to monitor their health. As children grow up and become adults, they should be prepared for the transition to the adult healthcare system.

The transition from paediatric to adult care often presents disruptions for survivors as there are no formal transition programs in place. The legal age of becoming an adult varies within the European Union Member States, ranging from 16 to 21 years of age. This gap leaves many survivors without appropriate support and continuity of care. The widespread lack of transition programs across Europe poses a challenge for patients, as it significantly affects their health-related quality of life.

Recognizing the critical need for improved survivorship care, a comprehensive evidence-based transition guidelines are developed as part of the EU-CAYAS-NET[2] project, which is co-funded by the European Commission and includes over 40 organisations from 18 countries. The guidelines aim to standardise and improve the transition process for young survivors to ensure consistent and effective support across the European Union.

Facilitating a smooth transition into adulthood empowers young survivors to make a valuable contribution to society. Providing them with the necessary support and resources they need not only prioritises their well-being, but also recognizes their potential to thrive and contribute meaningfully to their communities. Ultimately, investing in effective transition programs not only benefits individual survivors, but also strengthens civil society.

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[1] Challenges for children and adolescents with cancer in Europe: the SIOP-Europe agenda - PubMed (nih.gov)

[2] https://beatcancer.eu/about-us/

Methodology of the European guidelines

Within the EU-CAYAS-NET project, throughout 2023-2024 via comprehensive participation from all stakeholders a holistic approach was taken to identify existing best practices and understand the nuanced needs and preferences of young cancer survivors regarding the transition to adult healthcare. This involved organising three peer visits to renowned best practice centres: The Princess Maxima Center in Utrecht, the Netherlands; Sant Joan de Déu in Barcelona, Spain; and the Medical University of Vienna, Austria.

During these visits, the participants experienced the practices and environments of these institutions. Utilising peer observation forms, they documented their observations, noting both positive aspects and areas for improvement. This structured approach allowed for a detailed examination of the transition processes in place, providing valuable insights into what worked well and what could be enhanced and resulted in the drafting of the European recommendations.

All data collected from the peer visits, interactive sessions, and online workshop were analysed as part of the guidelines development process. By integrating these insights in the evidence-based clinical practice guidelines, comprehensive guidelines were created which reflect the real-world experiences and preferences of young cancer survivors. This approach ensures that the resulting guidelines are not only evidence-based, but is sensitive to the unique needs and circumstances of the individual cancer patients and their families.

Proposed set of actions

The below listed proposed set of actions addresses the critical gaps in transitional care for young cancer survivors, ensuring they receive the necessary support as they transition from paediatric to adult healthcare systems.

1. **A section on transition of care must be included in the National Cancer Control Plans as an integral part of life-long follow-up care of young cancer survivors.**

2. **National healthcare systems must adhere to the European evidence-based clinical practice guidelines to ensure a minimum standard of good transitional care.**[3]

[3] Transition guidelines: An important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork - European Journal of Cancer (ejcancer.com)

- The European guidelines is one of the major outputs of the EU-CAYAS-NET project, which is co-funded by the European Commission.
- The European guidelines serve as a blueprint for healthcare providers, outlining best practices and protocols for supporting young cancer survivors.
- Drawing on the latest research and expert consensus, the guidelines offer clear recommendations on the key elements of transitional care.

3. **Transition programs must be designed and implemented to provide tailored support to young cancer survivors.**
   - In order to comply with the latest European standards, these programs need to be designed in accordance with the transition guidelines recommendations, ensuring consistency and quality across different healthcare settings in the European Union.
   - Provision of comprehensive support services that addresses the diverse needs of young cancer survivors must be at the core of these programs.
   - National and cultural context must be considered during the implementation.

4. **The development and implementation of transition programs must be supported via joint action programs between the European Commission and national governments.**
   - State of the art transition programs offer comprehensive support services, including age-appropriate psychosocial support, education on managing long-term effects of cancer and its treatment, as well as guidance on navigating the adult healthcare system.
   - Public funding is a key-factor for implementing and running successful and effective transition programs. The lack of dedicated funding is a critical barrier in many European Union Member States resulting in lack of transition programs in place.
   - Training and upskilling of the healthcare providers to deliver standard of care transitional programs must be an integral part of funding.

By implementing these solutions, young cancer survivors will receive the support they need to navigate the transition from paediatric to adult healthcare systems successfully. This will improve their quality of life and will contribute to better health outcomes, long-term wellbeing, and a smoother reintegration to the society.

We, the Parties that are signatories, express our support for the proposed set of actions and commit to work together towards their implementation. EU-CAYAS-NET project partners, including Lithuanian Cancer Patient Coalition (POLA) undertakes to submit the proposed set

of actions to the European Commission with the aim of forming the European standards on transition from paediatric to adult cancer care.

Signed on 27 May, 2024 in the Parliament of the Republic of Lithuania by:

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