



EU Network of Youth Cancer Survivors (EU-CAYAS-NET)

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EU4Health Programme

Recommendations for Mental Health & Psychosocial Care after CAYA cancer - Standard, not luxury'¹

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PINTAIL LTD	PT	9	Beneficiary
SURVIVORS ÖSTERREICH - KINDER-KREBS-ÜBERLEBENDEN-INITIATIVE	SurvivorsAT	10	Associated Partner
Fondation d'Utilité Publique KickCancer	KickCancer	11	Associated Partner
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ASSOCIATION CHILDREN WITH ONCOHEMATOLOGIC DISEASES	ACOD	15	Associated Partner
Krijesnica - udruga za pomoc djeci i obiteljima suocenim s malignim bolestima	Krijesnica	16	Associated Partner
Spolecne k usmevu, z.s.	SKU	17	Associated Partner
FAKULTNI NEMOCNICE U SV. ANNY V BRNE	ICRC	18	Associated Partner

DEUTSCHE KINDERKREBSSTIFTUNG DER DEUTSCHE LEUKAMIE-FORSCHUNGSHILFE AKTION FÜR KREBSKRANKE KINDER E.V. STIFTUNG	DLFH/DKS	19	Associated Partner
NGO KARKINAKI AWARENESS FOR CHILDHOOD AND ADOLESCENT CANCER	KARKINAKI	20	Associated Partner
YouCan Cancer Support Network Ireland CLG	YouCan	21	Associated Partner
CanTeen Ireland	CanTeen Ireland	23	Associated Partner
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Asociatia Little People Romania	Little People	28	Associated Partner
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"Zvoncica" Childhood Cancer Parent Organization	ZVONCICA	30	Associated Partner
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Position paper ready for submission as open access publication in a journal (Mental Health & Psychosocial Care after CAYA cancer - Standard, not luxury)

-	1 Executive Summary	5
-	2 Introduction & Background	6
-	3 Approach	7
-	4 Results	9
-	5 Impact & Conclusion	10

- 1 Executive Summary

Background: With over 500,000 childhood, adolescent, and young adult (CAYA) cancer survivors in Europe, there is a growing need for comprehensive, long-term psychosocial support due to their higher risks of health and social issues. Mental health and psychosocial problems are often neglected, resulting in significant challenges like depression, anxiety, and lower educational and employment rates. The quality of care varies significantly across and within countries.

The EU-CAYAS-NET project aims to enhance the quality of life for CAYA cancer survivors. Focusing on Mental Health & Psychosocial Care among other topics, deliverable 3.1 addresses the challenges faced by this growing population. Through collaboration with over 40 organizations from 18 countries, the project seeks to raise awareness, assess gaps, and develop standards for mental health and psychosocial care. By providing resources and disseminating information through the platform www.beatcancer.eu, EU-CAYAS-NET aims to improve the well-being of young cancer survivors and support their potential, while also reducing the burden on healthcare systems and society as a whole.

Approach: Surveys were conducted, and consensus meetings were held to gather data and develop awareness material. A pocket card set was created addressing various psychosocial topics for education and policy work. A joint standard for psychosocial care will be developed incorporating stakeholder input and existing guidelines.

Results and recommendations:

- Inclusion in National Cancer Control Plans: Psychosocial follow-up care should be part of these plans
- Adherence to Clinical Guidelines: National systems should follow evidence-based, European guidelines to ensure a minimum standard of care.
- Integration into lifelong follow-up care programs: Psychosocial care should be core to follow-up programs, adapted to national contexts.
- Support through Joint Action Programs: Collaboration between the EU and national governments, with public funding and training, is essential for effective implementation.

Conclusion: The EU-CAYAS-NET project identified significant gaps in psychosocial care for young cancer survivors. Using a collaborative, multi-stakeholder approach, it developed practical materials for young people affected by cancer, accessible on the project's network platform. The recommendations based on the key outcomes of this deliverable build the basis to provide comprehensive, consistent support for young cancer survivors, improving their quality of life and reducing the burden on healthcare systems.

The final version is available for download on the EU-CAYAS-NET Platform².

² LINK: [Enhancing Survivorship: EU-CAYAS-NET Quality of Life Initiatives - BeatCancer](#)

- 2 Introduction & Background

As EU-CAYAS-NET aims to improve the quality of life of childhood, adolescent and young adult (CAYA) cancer survivors, targeted actions and initiatives were carried out, covering areas which are of demonstrated benefit to the quality of life of young cancer survivors. This deliverable falls under the theme of *Quality of Life*, one of three themes identified by young survivors throughout Europe as most important for equitable, lifelong care (along with *Adolescent and Young Adult (AYA) care* and *Equity, Diversity and Inclusion (EDI)*).

D3.1 'Position paper ready for submission as open access publication in a journal (Mental Health & Psychosocial Care after CAYA cancer - Standard, not luxury)' is part of WP3 – Quality of Life, under the priority areas of Mental Health & Psychosocial Care (Task 3.2), alongside other areas in WP3 (Education & Career Support, Transition and Late Effects & Long-Term Follow-Up Care).

Background and aims

There are over 500,000 young cancer survivors, aged 14-39 living in Europe³. Thanks to advancements in medical treatments, the survival rate stands at an encouraging 85% in developed European countries. However, compared to their peers, survivors of CAYA cancer have a higher risk of health problems and other issues related to survivorship, therefore this growing population needs comprehensive long-term follow-up care and social support tailored to the age of diagnosis in order to enjoy optimal quality of life and healthy survivorship.

Mental health and psychosocial challenges are underestimated and often neglected aspects in CAYA cancer survivorship, even though it was shown that a significant proportion of survivors suffer from severe problems such as depression, anxiety, fatigue, neuropsychological impairments and suicidal thoughts^{4,5}. CAYA cancer survivors are also less likely to have higher education or full-time employment. In addition, the quality of psychosocial care can vary greatly - not only between countries, but also within countries, depending on the local hospitals⁶. This emphasises the high need to improve psychosocial support services that adequately address the mental health of CAYA cancer survivors, including educational and career support.

The EU-CAYAS-NET⁷ project, co-funded by the European Union and including over 40 organisations from 18 countries, therefore pursues the following objectives related to mental health and psychosocial care:

³ [Challenges for children and adolescents with cancer in Europe: the SIOP-Europe agenda - PubMed \(nih.gov\)](#)

⁴ H. Schröder et al., Psychosocial Care in Paediatric Oncology and Haematology, (https://www.awmf.org/fileadmin/user_upload/Leitlinien/025_Ges_fuer_Paediatriische_Onkologie_und_Haematologie/025-002eng_S3_Psychosocial-Care-Paediatric-Oncology-Haematology__2020-02.pdf).

⁵ L. Wiener, A. E. Kazak, R. B. Noll, A. F. Patenaude, M. J. Kupst, *Pediatr. Blood Cancer*. 62, S419–S424 (2015).

⁶

<https://ccieurope.eu/wp-content/uploads/2023/03/Implementation-of-psychosocial-Care-Survey-Summary-Report.pdf>

⁷ <https://beatcancer.eu/about-us/>

- 1) Raise awareness of the importance of mental health and psychosocial care for CAYA cancer survivors.
- 2) Better understand the current status and gaps in mental health and psychosocial care in Europe.
- 3) Develop a standard for mental health and psychosocial care for CAYA cancer survivors, including dissemination materials to support adoption of the standard into national health policy.

The outputs of these activities are made available on the network platform www.beatcancer.eu, with the network directing their contacts to relevant content.

Access to optimal psychosocial care improves the quality of life for every child, adolescent and young adult in Europe after their cancer treatment and supports them to reach their full potential.

Easily accessible psychoeducation about potential psychological and social consequences (late effects) of the disease and its treatment will in addition support the improvement health management of young people affected by cancer.

Moreover, investing in effective long-term psychosocial care not only benefits the individual survivor but will also minimise the burden on the national healthcare system and society as a whole by making more efficient use of resources and placing lower pressure on social funds.

- 3 Approach

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 mental health & psychosocial care.

Project Beneficiary MUV was the main responsible party for the execution of the tasks, with regular strategic planning, continuous feedback and support from CCI-E.

Task 3.2.1 **Develop awareness materials**

Descriptions of common mental/psychosocial late effects and challenges have been created according to current literature, taking into account existing awareness materials and, most importantly, peer experience. Via several online consensus meetings with cancer survivor representatives and health care professionals from across Europe, a highly participative approach throughout the development process was put in place, ensuring that the topics selected for the later awareness materials truly reflect the real-life challenges faced by young people affected by cancer.

List of consensus meetings and numbers of participants:

The first consensus meeting took place on 11.06.2024 with 16 participants from 7 countries. The second consensus meeting took place on 21.06.2024 with 10 participants from 5 countries. Both groups consisted of HCP and cancer survivor representative/patient advocates.

Before the consensus meetings there was also a Delphi round where cancer survivor representatives and HCPs were asked for feedback. 22 people filled in the delphi, with 15 finishing it.

Based on qualitative analysis of the consensus meetings, content has been developed and then reviewed again by the consensus group. The authors and designers of the individual pocket cards were also always teams of HCP and cancer survivor representatives.

Task 3.2.2 Better understand the current status and gaps

An online survey for CAYA cancer survivors on the current status and gaps in mental support and psychosocial care services, with a special focus on mental health support and psychosocial care in long-term follow-up care, has been performed. In order to ensure relevance of the outcomes to the survivor community, the research objectives have been identified by CAYA cancer survivor representatives in an online consensus group meeting, backed up by current literature and psychosocial care guidelines. The development, conduction and analysis of the survey was carried out by MUV in a cooperative approach together with the other WP3 teams PanCare & PMC and reviewed by CCI Europe. After a pilot phase to test the questionnaire, the final survey consisted of 41 questions on personal experiences, needs and visions regarding psychosocial follow-up care. The survey was accessible online between 6.11.23-21.4.24, the average time for completion was 20 minutes. The data collected were analysed using basic statistical tools such as Microsoft Excel, or, if applicable with more advanced tools for detailed analysis (e.g. IBM SPSS, AMOS, R). Data were analysed descriptively, as well as inductively.

This survey has been co-developed with the survey from Task 3.5.1 (Identify best practices and lack of LTFU care) in order to optimally use synergies between the topics and to avoid duplication of efforts.

Task 3.2.4 Develop joint standard of mental health & psychosocial care after CAYA cancer for Europe

A workgroup consisting of CAYA cancer survivor representatives, mental and psychosocial as well as other health care professionals extensively reviewed existing psychosocial care guidelines and standards. In two consensus meetings, the importance of the individual existing standard was voted on, but necessary changes and missing topics were also discussed. Based on this and taking into account recent scientific literature and also the results of the survey (T3.2.2), the workgroup drafted a joint standard for psychosocial care in CAYA cancer survivorship. The draft will be further discussed and validated by the consensus group.

The aim was to prepare a position paper for open access publication in a journal (Mental Health & Psychosocial Care after CAYA cancer – Standard, not luxury). In the course of the project, more and more interconnections between the tasks became evident. As mental health and psychosocial care should have a high priority during and beyond cancer, and especially in long-term follow-up care and transition to adult care, it was therefore decided to produce a joint three-part publication on the topics of Mental Health & Psychosocial Care, Long-Term Follow-Up and Transition from Childhood to Adulthood (joint publication of D3.1, D3.3 and D3.4). One third of the publication will reflect the findings of task 3.2. and highlight prospective solutions for better access to mental health support and psychosocial care after CAYA cancer. The joint paper will be submitted to an international peer-reviewed journal in fall 2024, and made openly accessible upon publication.

List of consensus meetings and numbers of participants:

D3.1 Recommendations for Mental Health & Psychosocial Care after CAYA cancer - Standard, not luxury

15 participants attended the first consensus group meeting (26.01.2024) and 12 participants attended the second consensus group meeting (26.04.2024) for a total of 27 participants in attendance at the meetings. Both groups consisted of HCP and youth cancer representatives/patient advocates. Additionally other people are participating in feedback rounds via review of online documentation which will enhance the quality of the finalised standard of care. Overall, this will lead to more than 40 participants involved in the consensus process, via meetings and other means of feed on the joint standard of care.

Task 3.2.5 **Prepare webinar for community and identify multipliers**

The webinars are available on the EU-CAYAS-NET YouTube channel:

(<https://www.youtube.com/@youthcancersurvivors>).

In the webinar on mental health and psychosocial care, the content and speakers were jointly agreed on by survivor representatives and HCPs. Care was taken to ensure that the topic was not only considered in a pathological way, but that psycho-social topics were highlighted that determine the everyday lives of many young persons living with or beyond cancer. All EU-CAYAS-NET webinars were promoted extensively via WP6.

- **4 Results**

Better understanding the current status and gaps: A Europe-wide survey on mental health and psychosocial care among CAYA cancer survivors with the aim to gain knowledge about current existing LTFU, with a special focus on mental health and psycho-social care was filled in by 195 survivors from 24 countries. The results showed that there is a lack of information and surveillance on mental health issues in our target group. Additionally, there is a big gap in the needs of survivors regarding psychosocial problems (e.g. financial issues, social relations/friendships, anxiety, fatigue or neuropsychological issues) compared to the support they receive. The survivors reported a lack of attention to psycho-social late effects in LTFU care. Some of the barriers to receiving psychosocial care that were most commonly described are financial constraints/affordability and a lack of LTFU institutions offering psychosocial support.

The survey for health care professionals was answered by 11 (teams of) HCP from 7 countries. A common theme described as a barrier in the results is the stigma concerning mental health and psychosocial issues, but also a lack of information about available support services which can make it harder for young survivors to seek help. They wish for low-threshold accessibility to psychosocial care services so that every survivor can receive the help they need.

Awareness materials:

The pocket card set consists of 9 finished cards and one in preparation and can be expanded with additional topics if needed. Currently, the set provides information and recommendations about the following psychosocial topics and challenges:

- 10 Keypoints on Mental Health
- Talking about serious matters
- Do's and Don'ts in communication
- Social dimension
- Education support
- Career Support
- Neuropsychology (in preparation)
- Fear and hope
- Grief and depression
- My right to grieve

The pocket card set is aimed at young people living with and beyond cancer, as well as carers, health care professionals, patient representatives/organisations and everyone involved in the process, like teachers, peers and friends. They can be used for psychoeducation purposes, as a basis for dialogue and as a tangible tool for policy work.

Each card focuses on a different topic stating the issue, what is needed and what needs to be done about it, specific recommendations for action, as well as keypoints and tips to keep in mind. Additionally each card contains a contact field which can be filled in to direct someone to a specialist or organisation, an explanation of technical terms (e.g. treatment methods) and a link to the website (beatcancer.eu) to find more information regarding a specific topic.

Availability:

- Online: [Pocket Cards for Mental Health Awareness and Guidance for Cancer Patients and Beyond - BeatCancer](#),
- Print

Later they will be translated into at least 8 different European languages.

Development and dissemination of a joint standard for psychosocial care after CAYA cancer for Europe: All data collected throughout WP 3.2 were analysed to get extensive insight in the needs and preferences as well as barriers and facilitators in organising and implementing psychosocial care. The results, together with existing knowledge from previous initiatives, were integrated into a joint standard for psychosocial care after CAYA cancer for Europe and will be made on the platform upon finalisation of the project. Our approach ensured insight into needs and preferences from the perspective of multiple stakeholders and a broad overview of the European situation, taking into account the unique needs and circumstances of the individual survivors and psychosocial care services across Europe.

In addition, the following recommendations/ set of actions, shown in chapter 5, have been developed, based on the outputs of the activities above. They will be included in a Position Paper covering Mental Health & Psychosocial Care, Transition and LTFU which will be submitted to a peer-reviewed journal.

- 5 Impact & Conclusion

Within the scope of EU-CAYAS-NET, we were able to identify significant shortcomings, barriers and facilitators related to the provision and accessibility of psychosocial care. Moreover, in a highly participative, multi-stakeholder approach co-led by patient advocates and health care professionals, we developed tangible and ready-to-use materials of high practical relevance to young people affected by cancer, which will be openly accessible on the network platform.

In addition to these psychoeducational and care-related outputs, the shortcomings identified in our results were translated into an action set to advocate for at national level, which was piloted as “Declaration of Vienna” in one of the three national policy events of EU-CAYAS-NET. Our set of actions addresses the critical gaps in psychosocial care for young cancer survivors to ensure that they have access to adequate support across Europe, adapted to the specific national and healthcare settings:

- 1. A section on psychosocial follow-up care must be included in the National Cancer Control Plans as an integral part of person-centred life-long follow-up care of young cancer survivors.**
- 2. National healthcare systems must adhere to existing European evidence-based clinical practice guidelines to ensure a minimum standard of psychosocial screening and follow-up care.**^{8,9,10,11,12}
 - The existing guidelines give guidance to e.g. the monitoring and management of late effects related to mental health, education and vocational status, fatigue as well as psychosocial impacts of physical long-term side effects of the cancer and its treatment.
 - The EU-CAYAS-NET European Joint Standard of Care serves as a blueprint for healthcare providers, outlining best practices and integrating evidence- and consensus-based analysis of needs and preferences to young cancer survivors.
 - The jointly developed awareness materials provide additional orientation to various psychosocial challenges. They shall improve access to state-of-the-art psychosocial care and help facilitate implementation in clinical practice.
- 3. Psychosocial care must be implemented as an integral part of life-long follow-up care programs to ensure holistic support to young cancer survivors.**

⁸ <https://www.ighg.org/guidelines/topics/mental-health-problems/>

⁹ <https://www.ighg.org/guidelines/topics/fatigue/>

¹⁰ <https://www.ighg.org/guidelines/topics/psychosocial-problems/>

¹¹ <https://www.ighg.org/guidelines/topics/fertility-preservation/recommendations/>

¹² <https://register.awmf.org/de/leitlinien/detail/025-002>

- In order to comply with the latest European standards, these programs need to be designed in accordance with the EU-CAYAS-NET European Joint Standard of Care, 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.
- A survivorship care plan including regular screening of psychosocial wellbeing is recommended to be used.

4. The development and implementation of psychosocial follow-up care must be supported via joint action programs between the European Commission and national governments.

- State of the art psychosocial follow-up care programs offer comprehensive support services, including age-appropriate and person-centred social, psychological, educational and vocational support.
- Public funding is a key-factor for implementing and sustaining successful and effective psychosocial follow-up care. The lack of dedicated funding is a critical barrier in many European Union Member States resulting in the lack of mental health and psychosocial care and support services in place.
- Training and upskilling of the healthcare providers to deliver state-of-the-art psychosocial care must be an integral part of funding.

Implementing the solutions based on the outcomes of the EU-CAYAS-NET project on mental health & psychosocial care for young cancer survivors conducted in WP3 – Quality of Life will ensure that young cancer survivors will have access to potentially life-saving long-term follow-up care services. This will improve their quality of life and will contribute to better health outcomes, long-term wellbeing, and a smoother reintegration to the society.

In order to ensure that at least no language barrier stands in the way of implementing the recommendations, these recommendations were translated into 8 other European languages (Italian, French, BCS, Spanish, German, Dutch, Lithuanian, Romanian) in addition to the original English version. These are available on the platform at <https://beatcancer.eu/resources/quality-of-life/article/quality-of-life-project-outputs/>.